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FACTORS INFLUENCING COMMUNITY REINTEGRATION OF PERSONS WITH SPINAL CORD INJURY WHO RECEIVED PRIVATE IN-PATIENT REHABILITATION IN GAUTENG

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of

Master of Science in Occupational Therapy

Johannesburg, 2018

DECLARATION

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ABSTRACT

Persons with spinal cord injury (SCI) continue to face numerous contextual barriers to community reintegration, despite receiving rehabilitation. To ascertain the perceived factors influencing community reintegration of persons with SCI, who received private in-patient rehabilitation, a quantitative descriptive approach was used. Fifty-four persons participated in this study by completing a cross-sectional online self-administered survey, including; a sociodemographic profile, the Reintegrated into Normal Living Index (RNLI) and the Craig Hospital Inventory of Environmental Factors – Short Form (CHIEF–SF). Data was analysed using STATISTICA 13.2. Majority (63.5%) of participants were male, living with incomplete paraplegia (75%;) and 52% were employed. Eighty percent of participants experienced moderate to severe restrictions to participation, with low satisfaction in community reintegration. Help at work/school, business policies, help at home, attitudes at work/school and the natural environment were the greatest environmental barriers, while social support and access to private transport were the greatest facilitators to community reintegration.

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ABBREVIATIONS

AD	Autonomic Dysreflexia
ADL	Activities of Daily Living
AIDS	Auto Immune Deficiency Syndrome
CHART	Craig Handicap Assessment and Reporting Technique
CHIEF	Craig Hospital Inventory of Environmental Factors
CHIEF–SF	Craig Hospital Inventory of Environmental Factors – Short Form
CIM	Community participation measure
CIQ	Community Integration Questionnaire
COPM	Canadian Occupational Performance Model
GBS	Guillain Barre Syndrome
GI	Gastrointestinal
HIV	Human Immunodeficiency Virus
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, Disability and Health
IPAQ	Impact on Participation and Autonomy Questionnaire
INDS	Integrated National Disability Strategy
ISCOS	International Spinal Cord Society
LIFE-H	Assessment of Life Habits
LHS	London Handicap Scale
MND	Motor Neuron Disease
MVA	Motor Vehicle Accident
NRP	National Rehabilitation Policy
NTSCI	Non-traumatic spinal cord injury
OT	Occupational Therapy/therapist
PARTS/M	Participation Survey/Mobility
PEO	Person-Environment-Occupation
QASA	QuadPara Association of South Africa
RNLI	Reintegration into Normal Living Index
RTA	Road Traffic Accident
RTI	Respiratory Tract Infection
SASCA	South African Spinal Cord Association

SCI	Spinal Cord Injury
SCI RE	Spinal Cord Injury Research Evidence
TB	Tuberculosis
TSCI	Traumatic Spinal Cord Injury
UBPL	Upper Bound Poverty Line
UK	United Kingdom
UNCRDP	United Nations Convention for the Rights of Persons with Disabilities
US	United States
USA	United States of America
UTI	Urinary Tract Infection
WFOT	World Federation of Occupational Therapy
WHO	World Health Organisation
WPRPD	White Paper on the Rights of Persons with Disability

OPERATIONAL DEFINITIONS

Activity	The execution of a task or action by an individual (WHO 2001)
Community participation	Active engagement in non-domestic, social activities outside of the home (Chang et al. 2013)
Community reintegration	The acquiring or resuming of age-/gender-/culture-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 the natural community settings (Dijkers 1998)
Disability	Disability is imposed by society when a person with a physical, psychosocial, intellectual, neurological and/or sensory impairment is denied access to full participation in all aspects of life, and when society fails to uphold the rights and specific needs of individuals with impairments (RSA 2016)
Environmental factors	The physical, social and attitudinal environment in which people live and conduct their lives (WHO 2001)
Incidence of SCI	The number of new cases of persons who have become spinal-cord injured in a population over a specified period (WHO & ISCOS 2013)
Occupational deprivation	The inability to engage in occupations because of some external restriction (Watson & Fourie 2004)
Occupational imbalance	Occurs when a person is under-occupied, over-occupied or unoccupied (Stadnyk et al. 2010)
Occupational injustice	Socially structured or formed conditions that give rise to stressful occupational experiences (Stadnyk et al. 2010)
Occupational marginalization	Discriminated against individuals or groups of people due to their gender, race or ability (Stadnyk et al. 2010)

Occupational performance	The dynamic experience of a person engaged in purposeful activities and tasks within an environment (Law et al. 1996)
Paraplegia	Injury to the thoracic, lumbar and sacral segments of the spinal cord, depicted by varying degrees of sensory and/or motor impairment in the lower extremities and truncal region, with upper extremity function preserved (Maynard et al. 1997)
Participation	Involvement in a life situation (WHO 2001)
Participation restrictions	Problems an individual may experience in involvement in life situations (WHO 2001)
Personal factors	The background of an individual's life and living, comprising features of the individual that are not part of a health condition or health states (WHO 2001)
Prevalence of SCI	The number of people in the population living with SCI at a given point in time (WHO & ISCOS 2013)
Rehabilitation	Process aimed at enabling persons with disability to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels to become participating members of society, with access to all the benefits and opportunities of that society (WHO 2001)
Spinal cord injury	Damage to the spinal cord, including cauda equina and conus medullaris, leading to motor and/or sensory deficits, and/or autonomic dysfunction lasting more than three days post-injury (Sommer 2010).
Quadriplegia	Motor and/or sensory impairment/loss in all four limbs and trunk resulting from injury to the cervical segments (C1-C8/T1) of the spinal cord (Maynard et al. 1997; Nas et al. 2015)

CHAPTER 1: INTRODUCTION

1.1 Introduction Orientation

Spinal cord injury (SCI) is a common neurological disorder, often resulting in severe and long-term disability that has profound consequences at a personal, familial and societal level (WHO & ISCOS 2013). A key factor in life satisfaction following an acquired disability is being able to make connections with others and redefine oneself as an active, contributing member of society (Whiteneck, Meade, Dijkers et al. 2004; Whiteneck 2006). This is achieved through participation in meaningful occupations and social interaction outside of the home environment (Whiteneck 2006), and is essential for health and wellbeing (Wilcock 1998; Law 2002). For this reason, community reintegration post SCI is a key focus of the rehabilitation process and an indication of effective intervention (Magasi, Heinemann & Whiteneck 2008). Community reintegration post impairment or disability involves resuming appropriate roles, statuses and activities, with family, friends, and others with the community (Dijkers 1998). The rehabilitation of persons with SCI plays a key role in reintegrating persons with disability back into society. A person living with a disability such as SCI requires a level of functioning that exceeds what they had before the injury to compensate for their impairment and successfully reintegration into the community. Occupational therapists aim to assist in this regard by equipping their patients and their families with the skills and resources required for living in the community post injury (Jang, Wang & Wang 2005). Despite this, upon returning to normal living, persons with SCI continue to be faced with numerous contextual barriers to community reintegration (Dijkers 1997; Whiteneck, Harrison-Felix, Mellick, Charlifue & Gerhart 2004). Overcoming these barriers to achieve a satisfying level of community reintegration is one of their greatest challenges (Whiteneck, Meade, Dijkers, Tate, Bushnik & Forchheimer 2004).

The relationship between participation in the community and quality of life is one of the main reasons that community reintegration is a highly regarded rehabilitative outcome for individuals with disability (Whiteneck 2006; Magasi et al. 2008; Hammel, Magasi, Heinmann, Whiteneck, Bogner & Rodriguez 2008). Despite this focus in

clinical practice and the extensive legislation providing for the rights of persons with disability, including South Africa's White paper on an Integrated National Disability Strategy (INDS) and the United Nations Convention for the Rights of Persons with Disabilities (UNCRPD), disabled persons continue to encounter various obstacles regarding access and equity within their physical, social and/or political contexts in both developed and developing countries (WHO & ISCOS 2013). This research report surveys the perceived level of and the factors influencing community reintegration post SCI of a diverse group of individuals discharged from a private rehabilitative hospital in Johannesburg, Gauteng, South Africa.

This chapter describes the background to and justification for the study. It explains the purpose of the study and informs the reader of the research question. Thereafter, it lists the aim and objectives of the study followed by the potential significance of the study.

1.2 Background to the Study

1.2.1 Living with a disability in South Africa

South Africa is a unique context, a country of extremes with regard to accessibility of resources as a result of the apartheid system. "The consequences of centuries of governance that stripped South Africa of all but hope has left a legacy of underdevelopment and dependence that is extremely difficult to reverse" (Watson & Fourie 2004:42). Racial discrimination during the apartheid era denied persons of colour free access to occupations (occupational restriction) and is a clear example of how legislation leads to occupational deprivation and occupational marginalisation, outcomes of occupational injustice (Stadnyk, Townsend & Wilcock 2010; Watson & Fourie 2004). Occupational injustices are socially structured or formed conditions that give rise to stressful occupational experiences (Stadnyk et al. 2010). Occupational deprivation is an outcome of occupational injustice and is described as "the inability to engage in occupations because of some external restriction" (Watson & Fourie 2004:56). Further, occupational marginalisation occurs when individuals or groups of people are discriminated against due to their gender, race or ability (Stadnyk et al. 2010).

South Africa continues to have a very high unemployment rate (25.3%) and according to the 2015 Poverty Trends in South Africa report, 30.3 million (55.5%) people in South Africa live below the poverty line, with 64.2% of all black Africans below the upper-bound poverty line (UBPL) (Statistics South Africa 2017). Individuals at the UBPL (earning at least R992 per person per month) can purchase both adequate levels of food and non-food items (Statistics South Africa 2017). Persons living below this line or even at the UBPL struggle to make day-to-day ends meet. Extensive medical expenses associated with disability such as caregivers, medical supplies, assistive devices and equipment acts as an additional financial burden. The effects of living with a disability in South Africa are thus compounded by factors such as poverty. These factors together place persons living with disability at greater risk of experiencing occupational injustice. It is important for therapists to realise that many of their patients in South Africa, even before becoming disabled, lived in conditions that restricted choice, autonomy and opportunity for occupational engagement (Fourie, Galvaan & Beeton 2004).

According to Nelson Mandela (1995), “The new South Africa should be accessible and open to everyone. We must see that we remove the obstacles. Only then will the rights of disabled persons to equal opportunities become a reality” (RSA 2016:49). To facilitate the removal of barriers to healthcare, education, employment and other domains of life for persons with disability, in 1997 former President Mbeki sanctioned the INDS. The INDS aims to achieve “a Society for all... encompassing human diversity and the development of all human potential”. Despite having this strategy in place, there continues to be evident social and economic gaps which compound the restrictions of disability and other marginalised groups, preventing full participation or inclusion of those with severe disability (Watson & Fourie 2004; Fourie et al. 2004).

As a result of the continued socioeconomic discrepancies of those marginalised and vulnerable, violence “associated with low-income, disadvantaged communities” (Fourie et al. 2004:79), remains one of the main causes of disability (including SCI) in South Africa, with violence-induced injuries being the second leading cause of death in South Africa (Joseph, Delcarme, Vlok, Wahman, Phillips & Wikmar 2015; Hart 1994; Fourie et al. 2004). The violence in South Africa is not only a predominant cause of disability and death, but together with gangsterism and theft contributes to

poor community reintegration, as it limits access to occupations outside the home environment and in communities (Fourie et al. 2004). The interconnectedness of disability and poverty is emphasised in the National Development Plan for 2030 adopted in 2012. The plan states that "[d]isability and poverty operate in a vicious circle. Disability often leads to poverty and poverty, in turn, often results in disability. People with disabilities face multiple discriminatory barriers. Disability must be integrated into all facets of planning, recognising that there is no one-size-fits-all approach" (National Planning Commission 2011:52).

In 2007, The South African government sanctioned the UNCRPD with the vision of providing comprehensive habilitation and rehabilitation to ensure the full and effective participation of persons with disability in society. An analysis of the first country report highlighted significant gaps in the quality of information provided regarding its implementation (RSA 2013). It was reported that the lack of implementation was due to a dearth of effective monitoring and evaluation systems in place to track implementation of the UNCRPD in South Africa (RSA 2013). It remains evident that although there is comprehensive South African and international legislation providing for the rights of persons with disability, these persons continue to be faced with attitudinal and political discrepancies and to be engaged in a struggle for barrier-free environments. This report argues that the legislation intended to address the issues faced by persons with disability in terms of accessibility has, to date, not been implemented or is not adequate. The revised White Paper on the Rights of Persons with Disability (WPRPD) reiterates the importance of removing barriers to access and participation as a strategic pillar to realising the rights of persons with disability (RSA 2016).

1.2.2 Spinal cord injury rehabilitation in South Africa

The World Health Organization (WHO) emphasises that rehabilitation is instrumental in enabling people with disabilities to be reintegrated into their home or community, live independently and participate in education, the open labour market and civic life (WHO 2017). Access to rehabilitation can decrease the consequences of injury, improve health and wellbeing, optimise quality of life and reduce the burden of care and the use of health services (WHO 2017). The World Health Organisation (WHO

2017) reiterates that, although there is limited data on the need for rehabilitation, the type and quality of measures provided and estimates of unmet needs, there remain large gaps in the provision of and access to rehabilitation services in low-income and middle-income countries such as South Africa.

Within South Africa, patients receive medical treatment and rehabilitation within either the public or private sector depending on their access to funding. There are 18 rehabilitation centres with facilities for spinal cord rehabilitation in South Africa, which are equally distributed between the private and public health sectors. Ten of these units are in Gauteng province, four in the Tshwane Metropolitan Area (Medi-clinic Muelmed, Life Eugene Marais, Tshwane Rehabilitation Hospital and Dr George Mukhari Hospital) and six in the Ekurhuleni Metropolitan Area (Edenvale Hospital, Netcare Rehabilitation Hospital, Life New Kensington Clinic, Life Riverfield Lodge, Thelle Mogoerane Regional Hospital and South Rand Hospital).

It is believed by many that the private sector only caters for those on medical aid or who can privately afford the high medical costs. However, Netcare Rehabilitation Hospital, where this study was based, provides for patients funded by medical aid, private funds, the Workman's Compensation Association (WCA), Rand Mutual Assurance (RMA), and the Road Accident Fund (RAF). Thus, it uniquely provides rehabilitation for persons of all socioeconomic strata within South Africa and neighbouring countries.

The therapy division at Netcare Rehabilitation Hospital uses the principles of Landrum, Schmidt & McLean (1995) outcome-based rehabilitation to guide therapeutic intervention. Outcome-based rehabilitation emphasises five outcome levels: Physiology Stability, Physiological Maintenance, Residential Reintegration, Community Reintegration and Productivity (Landrum et al. 1995). Upon discharge, a patient should ideally have achieved Outcome Level Four (Community Reintegration) or be able to access parts of their community, either independently or with assistance. This achievement theoretically ensures a safe and appropriate level of functioning within the community upon discharge, which will be refined on an out-patient basis. However, this is not always possible, as it is highly dependent on the unique personal (level of injury, motivation, co-morbidities) and contextual factors

that either facilitate or hinder the individual's participation in the community. Achievement of community reintegration is further impacted by the authorised length of stay at the rehabilitation facility. To date, there is no reported consensus concerning the optimal length or intensity (dose) of rehabilitation for persons with SCI (Lamontagne, Gagnon, Allaire & Noreau, 2013). Length of stay at Netcare Rehabilitation Hospital is thus, recommended by a multidisciplinary team (physiotherapist, occupational therapist, rehabilitation case manager, social worker and doctor) post assessment, based on their discretion. However, this does not guarantee that the funder with authorise the full duration. There is a current trend of decreasing length of stay of medical aid patients, while patients funded by WCA tend to stay longer than recommended due to delayed authorisation and issuing of equipment.

1.2.3 The role of occupational therapy in community reintegration post spinal cord injury

The American Occupational Therapy Association (AOTA) (2014:S2) states that the occupational therapist's overarching goal is to achieve "health, well-being, and participation in life through engagement in occupation". The role of the occupational therapist in the rehabilitation of persons with disability (including SCI) is to optimize function and, ultimately, participation in occupations including: activities of daily living (ADL), instrumental activities of daily living (IADL), work, education, rest and sleep, play, leisure and social participation (AOTA 2014). This process is required to facilitate the reintegration of persons with SCI into their home and community environments with or without assistance and to eventually achieve participation as productive members of society. To optimise this process and enable engagement in meaningful activities within the community, an occupational therapist needs to consider the individual needs of his or her client and fully understand the context to which their clients will be returning. In doing so, occupational therapists need to consider the complex interplay between the health condition, personal factors and environment that act to either facilitate or prevent functioning. Occupational therapists are key role players in advocating for the needs of persons with disability, including those with SCI, and in empowering their patients to take charge of their rehabilitation process in hospital and in their home/community environment. The

WPRPD reiterates that to create environments that are accessible to all, law and policy makers, service providers, regulatory bodies, the public and the private sectors as well as the organisations of and for persons with disability need to work in collaboration (RSA 2016).

1.3 Statement of the Problem

1.3.1 Community reintegration issues identified by the researcher

The researcher, an occupational therapist working in the in-patient spinal unit and in collaboration with the out-patient department at Netcare Rehabilitation Hospital, noted that there is often a discrepancy between the level of functioning described in the discharge report and the actual or patient-perceived level of reintegration into the community. This may be attributed to the fact that the patient was able to fulfil some aspects of Outcome Level 4 (Community Reintegration) within the supportive environment of the hospital but does not necessarily have the support and resources available to perform the same activities within the context in which he or she resides upon discharge. One could thus argue that the jump from an in-patient facility to the home environment may be too large in some cases, and thus the patients may find themselves regressing due to lack of support, contextual barriers and medical complications. This is supported by a study in New Zealand which concluded “that the spinal unit may not adequately equip the recovering person with SCI for life in the real world” (Nunnerley, Hay-Smith & Dean 2013:1164). This is further indicated by a trend of decreasing length of stay in rehabilitation facilities – patients are being discharged with unmet needs, fewer skills for community reintegration, and at higher risk of secondary complications (Nunnerley et al. 2013; Joseph, Scriba, Wilson, Mothabeng & Theron 2017).

This raises the following questions regarding current practice in SCI rehabilitation:

1) Are patients adequately prepared to return to normal living in their own context following discharge?
2) Is the current approach to community reintegration in therapy appropriate for all strata of the South African population?
3) Are the individual challenges experienced by patients being identified and addressed during in-patient rehabilitation?

These questions highlight areas of potential research within this area of occupational therapy to guide client-centred practice in private rehabilitation in Johannesburg, Gauteng. This would ensure that the areas of community reintegration addressed in therapy are relevant to each person's unique sociodemographic and environmental factors, optimising reintegration into their own context. These questions formed the foundation from which this study developed.

1.3.2. Limited Spinal Cord Injury rehabilitation research in South Africa

Even though community reintegration is rapidly becoming a significant area of clinical, policy and research concern, research into reintegration post SCI within developing countries continues to be sparse, while international literature focusing on the outcomes of rehabilitation post SCI within developed countries has grown rapidly over the past few years. However, the majority of researchers continue to focus on impairments and activity limitations rather than participation (Barclay, McDonald, Lentin & Bourke-Taylor 2016). More research on the role of environmental factors in the lives of people with SCI will be beneficial (Whiteneck, Meade, Dijkers et al. 2004; Barclay et al. 2016) as this can be a contributing factor in limiting community reintegration. Research within this topic has been conducted in developing countries such as India (Sekaran, Vijayakumari, Hariharan, Zachariah, Joseph & Senthil Kumar 2010; Kamalesh Kumar, Kumar & Praveenraj 2012) and the Middle East (Rahimi-Movaghar, Kazen Sayyah, Akbari, Khorramirouz, Rasouli, Moradi-Lakeh, Shokraneh & Vaccaro 2013). However, there are still a limited number of studies that investigate aspects of community reintegration of persons with SCI within South Africa. Two studies were identified that considered the concept of community reintegration or the perceived barriers to participation, namely;

1. Mothabeng (2011) in her PhD thesis used a mixed methodology to investigate community participation of people living with SCI in the Tshwane Metropolitan Area.
2. Joseph, Wahman, Phillips & Nilsson Wikmar (2016) conducted a qualitative study to explore the experiences of reclaiming participation post traumatic SCI in the metropolitan area of Cape Town, South Africa

Although set in different contexts to the current study, these studies provide insight into the needs of and challenges faced by persons with SCI in South Africa. According to Whalley-Hammell (2010:20), “barriers to participation need to be identified and addressed not only at the level of the individual but also in the communities in which people live”. Thus, the level of community reintegration and the effects of various factors on community reintegration after SCI need to be understood within their unique contexts (Sekaran et al. 2010). In this way, therapists can work collaboratively with their patients to address contextual issues and prepare each patient for the specific environment into which he or she needs to reintegrate, as well as facilitate the development of environments that aid successful participation. This is particularly important within the South African context due to the varying environments that patients come from – from abject poverty, overcrowding and poor infrastructure to wealthy urban dwellers with abundant resources.

Successful reintegration into society is a measure of overall recovery from disability and an indication of effective rehabilitation (Whiteneck 2016). However, due to poor follow-up post discharge in South Africa (at both private and government level) and limited local literature, the actual outcome of persons with SCI in South Africa is unknown. Additionally, as supported by Mothabeng (2011), "fully rehabilitated” persons with SCI living in the community are physically deteriorating post discharge due to unclear or unaddressed sociodemographic and environmental barriers preventing optimal participation and community reintegration. Although the available local SCI literature descries the sociodemographic profiles of their sample population, limited information is available pertaining to the sociodemographic factors of persons with SCI who have received rehabilitation in private rehabilitation facilities.

1.4 Justification

Community reintegration post SCI continues to be hindered by numerous contextual barriers, including transportation, natural and built environments, technology and equipment as well as social support/other people (Barclay, McDonald & Lentin 2015). This is exacerbated in a developing country such as South Africa, where poverty is rife and infrastructure is unfavourable to wheelchair users. Despite this

knowledge, as well as the emphasis placed on participation within the International Classification of Functioning (ICF), clinical practice and by stakeholders (such as disability policy makers and disability advocacy organisations), little research exploring community reintegration post SCI in South Africa is available. This may be due to the lack of focus on SCI research within academic institutions, the lack of publications by clinicians and Master's or PhD students, and lack of resources such as time and funds for research, and could contribute to the poorly coordinated systems of care in South Africa. Community reintegration is a highly-valued rehabilitation outcome for persons with SCI as it relates to a person's ability to be an active and productive member of society as well as to his or her overall quality of life (Magasi et al. 2008; Whiteneck, Meade, Dijkers et al. 2004; Whiteneck 2006). Consequently, therapeutic intervention should be aimed at optimising a person's potential to achieve this outcome (a satisfying level of community reintegration).

To optimise community reintegration post SCI, barriers to participation need to be minimised or patients empowered to overcome these barriers (Whiteneck, Meade, Dijkers et al. 2004). According to Barclay et al. (2016), persons with SCI want more support from health professionals in terms of community participation. Occupational therapists need to provide their patients with strategies to deal with the barriers to community participation, both physical, emotional and societal, in order to optimise reintegration into the community and potential employment (Barclay et al. 2016). For this to be achieved, therapists need to gain insight into the current level of community participation of persons with SCI and evidence of the unique barriers to participation being experienced within different contexts. In doing so, rehabilitation professionals can ensure sound outcome-based, client-centred and contextually relevant rehabilitation is provided to their patients. This knowledge will also allow occupational therapists to promote and create opportunities for social and community participation within communities (Barclay et al. 2015).

Within the South African context, a patient is expected to return to his or her home environment post in-patient rehabilitation, whether it be an urban or rural, formal or informal settlement with poor infrastructure and negative attitudes, or an accessible, accommodating middle- to upper-class environment. Home adaptations, equipment and assistive devices are only available to those with appropriate funding, and not to

all as part of a government provision or regulation (such as the disabled facilities grant offered in the United Kingdom (UK)). It is thus important to gain an understanding of how these sociodemographic and specific environmental factors impact the reintegration of persons with disability into normal life. This information is vital to guide rehabilitation and to optimise the reintegration of persons with SCI from all socioeconomic strata back into society within the South African context. Due to South Africa's unique situation, it cannot be assumed that international findings, especially from developed countries, can be applied to the South Africa population. This necessitates further investigation into the level of perceived community reintegration post SCI and the barriers that persons living with SCI in South Africa continue to face.

1.5 Purpose of this Study

Based on the benefits of community reintegration post SCI shown in international literature, it is important to gain an understanding of the perceived level of and contributing factors to community reintegration of persons with SCI. The purpose of this study is to extend the research on community reintegration of persons with SCI in the South African context. This study considers the concept of community reintegration holistically and includes the perceived barriers to participation experienced by persons with SCI from resourced and under-resourced areas within South Africa. The results of the study may inform rehabilitation practice to ensure that facilitating factors are enhanced and where possible, barriers are minimised to promote successful community reintegration of persons with SCI.

1.6 Research Question

How do persons with SCI, who received private in-patient rehabilitation in Gauteng, rate their level of community reintegration, and which sociodemographic and environmental factors are ~~are barriers~~ impacting on their level of community reintegration?

1.7 Aim

To determine the sociodemographic and environmental factors that influence the perceived level of community reintegration among persons with SCI who received private in-patient rehabilitation in Gauteng.

1.8 Objectives

1.8.1 Establish the sociodemographic factors of the participants that influences their perceived level of community reintegration

1.8.2 Determine the level of community reintegration of the participants using the Reintegration into Normal Living Index (RNLI).

1.8.3 Identify the environmental barriers to community participation by the participants using the Craig Hospital Inventory of Environmental Factors – Short Form (CHIEF–SF).

1.9 Significance of the Study

1.9.1 The Department of Health

This study provides valuable insights into the perceived level of reintegration post SCI and the barriers that continue to prevent persons with SCI from reintegrating into the community and potentially contributing as productive members of society. This study identified critical areas of concern with regard to participation post SCI. These findings, along with other evidence documented in recent SCI research in South Africa, are crucial to guiding future policy development, policy revision and/or implementation within the South African context. Policies should not be generalised, but should be based on the specific needs of a population. The needs of a population can only be identified through follow-up and/or research. Research in South Africa on community reintegration post SCI and the barriers experienced to full participation is limited, and thus the results of this study will be made available to the Department of Health to aid in making or revising informed polices. Through this, policies for persons with disability can be revised, optimised and hopefully implemented to ensure equality and equity for all in accordance with the WPHRPD, INDS and UNCRPD.

1.9.2 Private rehabilitation facilities

Since this study was based at a private hospital, the results will give private rehabilitation facilities within Gauteng valuable insight into the experiences of persons with SCI post discharge regarding community reintegration. With this knowledge, rehabilitation facilities can revisit their programmes and potentially make the necessary changes to optimise their in-patient and out-patient services, which will aid persons with SCI transition from hospital to community.

1.9.3 The occupational therapy profession and other allied health professions

The overarching goal of occupational therapy is to achieve “health, well-being and participation in life through engagement in occupation” (AOTA 2014:S2). Thus, “enabling engagement in meaningful activities in the community must be at the forefront of occupational therapy intervention, both at an individual level and through advocacy and policy involvement, to improve the quality of life of people with SCI living in the community” (Barclay et al. 2016:27). The knowledge garnered from this research will be made available to occupational therapists and other allied health professions working in rehabilitation to provide them with up-to-date insights into the contextual (personal and environmental) challenges faced by persons with SCI of various sociodemographic profiles in the South African context. This information has the potential to act as a platform for the development or revision of therapy programmes to ensure that the focus of treatment is client-centred, meeting the needs of the individuals within their complex social contexts of everyday life. Additionally, therapists can use this information to identify ways to improve participation both immediately after injury and over the longer term. This will help the occupational therapy profession not only to offer services focused on self-care activities and the ability to return home, but also to expand acute rehabilitation to address full participation in work, family and community life.

1.9.4 People living with spinal cord injury

It is essential for rehabilitation therapists to work in conjunction with persons with disability to advocate for the rights these people and ensure optimal development and implementation of policy. This study identifies key factors that impact participation and reintegration into the community. This knowledge will guide future

rehabilitation to ensure individuals with SCI are sufficiently resilient and prepared to optimally reintegrate into their community and engage as productively in society post injury as would one who is able-bodied.

1.10 Summary of the Introduction

This chapter provided relevant background information and the justification for the study. It explained the purpose of the study and informed the reader of the research question, aim and objectives of the study. Lastly, the potential significance of the study to the Department of Health, the Occupational Therapy profession and persons with SCI was considered. In the next chapter, the literature relating to community reintegration and the environmental barriers experienced by persons post SCI is reviewed.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction to the Literature Review

An extensive search of the available literature was conducted to gain insight into the current knowledge of the epidemiology of SCI in South Africa and the barriers to community reintegration post SCI, locally and internationally. The following databases were searched for literature: EBSCO, PubMed, PMC, CINAHL, Cochrane Library, SAGE publications and Google Scholar. The following keywords were used in the search: Spinal cord injury, SCI, Non-traumatic SCI, Traumatic SCI, community integration, reintegration, community participation, social participation, participation, occupational therapy, rehabilitation, barriers, secondary complications, epidemiology, South Africa, RNLI, CHIEF, return to work, quadriplegia and paraplegia. The information garnered served as a background for the development of the study and a platform on which to compare and discuss results.

2.2 Spinal Cord Injury

An SCI is a chronic neurological condition that occurs when a traumatic injury or disease process leads to compression, bruising, laceration or severing of the spinal cord (Sommer 2010). Typical characteristics resulting from the damage include motor (paralysis) and/or sensory deficits, and/or autonomic dysfunction lasting more than three days (Sommer 2010). The characteristics vary depending on the level, cause and extent of injury. Spinal Cord Injuries can be broadly classified into two categories based on the aetiology: traumatic SCI (TSCI) and non-traumatic SCI (NTSCI), and then further sub-classified by the level of injury as quadriplegia and paraplegia. Quadriplegia results from injury to the cervical segments (C1-C8/T1) of the spinal cord and presents with some degree of motor and/or sensory impairment/loss in all four limbs and trunk (Maynard, Bracken, Creasey, Ditunno, Donovan, Ducker, Garber, Marino, Stover, Tator, Waters, Wilberger & Young 1997; Nas, Yazmalar, Sah, Aydin & Önes 2015). Paraplegia is caused by injury to the thoracic, lumbar and sacral segments of the spinal cord (including cauda equine and conus medullaris) and is characterised by varying degrees of sensory and/or motor impairment in the lower extremities and (depending on the level) truncal region, with

upper extremity function preserved (Maynard et al. 1997). Another important classification criterion of an SCI is the completeness or extent of the lesion (Maynard et al. 1997). The completeness of the lesion is ultimately determined by sacral sparing (Maynard et al. 1997) and is used as a measure of impairment and a crude prognostic indicator for functional recovery. In attempts to standardise the classification of SCI, the American Spinal Injury Association (ASIA) impairment scale was proposed (Maynard et al. 1997) and has since been adopted by practitioners worldwide.

2.3 Consequences Post Spinal Cord Injury

An SCI results in chronic neurological fallout and, depending on the severity of the injury, can cause a significant decrease in one's level of functioning with consequent limitations on activity and participation at home and in the community. Immediately post SCI a person loses control of his or her body (variable loss of sensation, paralysis and automatic dysfunction) below the level of the lesion. Depending on the level, severity and completeness of the lesion, the person may become completely debilitated and helpless, dependent on those around them to meet their basic needs, or alternatively may require specialised equipment and assistive devices to return to previous activities. In addition to the primary impairments resulting from the injury, secondary complications such as pain, fatigue, infections, pressure ulcers, bowel and bladder dysfunction and psychological conditions may develop which impact recovery, exacerbate the level of disability experienced and affect the potential outcome (Sommer 2010; Callaway, Barclay, McDonald, Farnworth & Casey 2015). This level of disability is known to have devastating consequences at an individual, familial and, potentially, societal level due to the high cost of ongoing medical treatment and the lifelong burden of care (WHO 2013). If a person is unable to regain control over their entire body or aspects thereof, their ability to function in IADL is diminished and their potential to reintegrate into society as productive members is significantly reduced.

There is an ever-growing rate of survival and increased life expectancy in persons with SCI due to ongoing advances in medical technology (Barclay et al. 2016). These advances have led to improvements in SCI recognition, evaluation, acute

management and general clinical and rehabilitative services, which have resulted in not only longer life expectancy but decreased mortality from secondary complications (Barclay et al. 2016; WHO & ISCOS 2013). To reduce the burden of care on families and the implications for the state, it is essential that persons with SCI are facilitated to reach their optimum level of functioning, reintegrate into the community and become productive members of society in one way or another. Individuals and groups of persons with disability need to be able to do what is meaningful and useful to them, their families, their community and society (Stadnyk et al. 2010). To achieve this occupational therapists, along with the patients themselves, their family and other members of the medical team, need to optimise the complex interplay between the person (with SCI), the environment (in which they live) and the occupation (that must be achieved).

2.4 Epidemiology of Spinal Cord Injury

To date, limited epidemiological data on SCI in South Africa is available, due to the lack of a national database, inconsistent data reporting, poor record keeping and lack of epidemiological research. The WHO and the International Spinal Cord Society (ISCOS) emphasise the need for an international database of SCI epidemiology (McCaughey, Purcell, McLean, Fraser, Bewick, Borotkanics & Allan 2016; WHO & ISCOS 2013). All SCI centres in the United States of America (USA) are expected to provide all relevant epidemiological information to the National Spinal Cord Injury Statistical Centre for research purposes (McCaughey et al. 2016). Epidemiological information is key to assessing intervention outcome, developing prevention strategies and planning for the provision of resources and care (McCaughey et al. 2016).

Four studies that report on the epidemiology of SCI in South Africa were identified (Joseph et al. 2015; Hart 1994; Sothmann, Stander, Kruger & Dunn 2015; Godlwana, Gounden, Ngubo, Nsibane, Nyawo & Puckree 2008). These studies each looked at a specific province, region or hospital in South Africa, thus their results are not representative of the entire country. Three of the four studies report predominantly on TSCI, providing little insight into the incidence and aetiology of NTSCI (Joseph et al. 2015; Hart 1994; Sothmann et al. 2015). Godlwana et al.

(2008) discuss the incidence and profile of SCI post spinal tuberculosis (TB) at a single public hospital in KwaZulu-Natal (KZN). The WHO & ISCOS (2013) report that historically, the majority (90%) of SCIs were traumatic; however most recent literature demonstrates a significant rise in NTSCI.

2.4.1 Incidence of spinal cord injury

Joseph et al. (2015) report on the incidence, aetiology and injury characteristics of TSCI in the city of Cape Town. The estimated incidence of TSCI in Cape Town was 75.6 per million persons (Joseph et al. 2015). This is significantly higher than the estimated global incidence of SCI (23 per million persons) (Fitzharris Cripps & Lee 2014; Lee, Cripps, Fitzharris & Wing 2014) and the estimated incidence of SCI within developing countries as 25 per million per year (Rahimi-Movaghar et al. 2013). This demonstrates the staggeringly high incidence of TSCI in South Africa, which is among the highest in the world (Joseph et al. 2015). Further, in line with international data (Wyndaele & Wyndaele 2006; WHO & ISCOS 2013), Joseph et al. (2015) found that males tend to be at higher risk of TSCI. This trend was also noted in Sothmann et al.'s (2015) research at Groote Schuur Hospital (Cape Town) and Enicker, Gonya & Hardcastle's (2015) research at Albert Luthuli Central Hospital (KZN), where 84% and 88% of patients with SCI respectively were males in their late twenties/early thirties.

Despite the incidence of NTSCI potentially being greater than that of TSCI (New & Marshall 2014), limited data are available on the incidence of NTSCI worldwide. According to Draulans, Kiekens, Roels & Peers (2011), this can be attributed to the complex nature and progressive onset of NTSCI. The only data available on the overall incidence of NTSCI in South Africa is a study by Hart (1994), which reports that only 11% of SCIs were non-traumatic. This figure cannot be generalised, as this article reports on a single hospital-based study conducted over two decades ago. A literature review conducted by New, Cripps & Bonne Lee (2014) reports an anticipated rise in the incidence of NTSCI in both developed and developing countries due to the increasing age of the population and the rise in opportunistic diseases because of Human Immunodeficiency virus (HIV) and autoimmune deficiency Syndrome (AIDS). This is in line with the WHO & ISCOS (2013), which

report that although historically a majority (90%) of SCIs were traumatic, the most recent literature demonstrates a significant rise in NTSCI. The disease process involved in NTSCI places patients at higher risk of complications, impacting the treatment, rehabilitation process and outcome of a patient and thus, due to the rise in incidence worldwide, should be a focus of future research (New et al. 2014).

Wyndaele and Wyndaele (2006) conclude that persons with SCI tend to be young males in their early thirties, with paraplegia due to a traumatic cause. This has serious social implications, as men of this age are in their prime and should be productive, contributing members of society supporting themselves and, potentially, their families. Despite the National SCI Statistical Centre (NSCI SC) (2016) noting that the average age of SCI has climbed from 29 years during the 1970s to 42 years at present, SCI will continue to have detrimental socioeconomic implications for society. It is estimated that the lifetime cost of a 25-year-old living with quadriplegia in a developed country is $5.4 million (the current exchange rate is R13,02 to the US dollar) (McCaughey et al. 2016). This includes costs associated with hospitalisation, out-patient care, equipment and home modifications and caregivers (McCaughey et al. 2016).

With regard to the prevalence and mortality of TSCI and NTSCI in South Africa, no reliable data are available. However, according to the QuadPara Association of South Africa (QASA) it was estimated in 2009 that there were approximately 50 000 persons with SCI currently living in South Africa (Sereilis 2009). This information is based on data collected through the “Bags of Hope” initiative, aimed at building and managing a database for persons with SCI in South Africa, which was begun in 2003 by QASA together with Coloplast. Barclay et al. (2016) report that the significant advances in medical and rehabilitative care over the last few decades have led to improved life expectancy post SCI worldwide; however, concern for long-term health and wellbeing remain. Spinal Cord Injury (SCI) mortality rates (calculated as death in the first year after injury) differ significantly between countries and within countries; they range from 4.0% (North America) to 84.0% (West Africa) (Sothmann et al 2015) In low-income countries, people living with SCI continue to die from preventable secondary conditions such as urological complications and pressure sores (WHO & ISCOS 2013). In contrast, a shift to causes similar to those in the general population

(for example pneumonia and influenza) as the principal cause of death of persons with SCI in high-resourced (developed) countries has been demonstrated (WHO & ISCOS 2013). No reports documenting the mortality rate for South Africa were found.

2.4.2 Aetiology of spinal cord injury

The main cause of TSCI in South Africa was found to be violence (Joseph et al. 2015; Hart 1994). Approximately 60% of all TSCIs reported in Cape Town were due to assault, followed by motor vehicle accidents (MVAs) (26%) and falls from heights (12%) (Joseph et al. 2015). This is in line with the findings of a study in the Johannesburg area two decades earlier, with approximately 56% of TSCIs resulting from gunshot and stab wounds, with MVAs and falls from heights accounting for 25% and 2.4% respectively (Hart 1994). A recent study in KZN further reported that in 31% of all patients admitted with SCIs, the injuries were caused by stab wounds (Enicker et al. 2015). In contrast to the above, a study by Sothmann et al. (2015) based at a government hospital in Cape Town identified MVAs (44.6%) as the most prevalent cause of injury, followed by violence (27.2%) and then falls (15.5%). Mothabeng (2011), in agreement with Sothmann et al. (2015), reports that 71% of SCIs were caused by RTAs with only 19.5% of SCIs the result of violence. This is in line with Cripps et al. (2011) and WHO & ISCOS (2013), who report RTAs as the most common cause of TSCIs worldwide, with nearly 70% of cases in the African region being attributed to transport. Although the third leading cause of TSCI in South Africa, falls are less prominent in South Africa than the rest of the world, with WHO & ISCOS (2013) reporting that falls are the second leading cause of TSCI worldwide, ranging between 27% and 40%.

With regard to NTSCI in South Africa, limited data on the aetiology is available. A literature review conducted by New et al. (2014) identified a high rate of TB and HIV-related NTSCI in the sub-Saharan African countries of Ethiopia, Kenya, Malawi, Zimbabwe, Ghana and Nigeria. Other causes of NTSCI reported included tumours/malignancies, transverse myelopathy and myelitis. A local study conducted at the King George V Hospital in KZN provides insight into the incidence of SCI resulting from spinal TB (Godlwana et al. 2008). Of 525 patients treated over a one-year period (2015–2016), 20% presented with TB spine, of whom all had a history of

pulmonary TB and 28% were known to be HIV-positive (Godlwana et al. 2008). The WHO (2011) reports that the HIV–TB co-infection rate in South Africa is high. While trauma continues to be the greatest cause of SCI, a growing number of persons in South Africa are sustaining spinal cord affliction as a result of HIV-related diseases such as TB spine (Mothabeng 2011). The rise in NTSCI resulting from HIV-related diseases poses new challenges to SCI rehabilitation. Persons with NTSCI resulting from HIV-related diseases, as well as those patients with TSCI who are co-infected with HIV, have been shown to take longer to recover post SCI due to the complexity of the disease process (New et al. 2014). Furthermore, they are more prone to complications due to their susceptibility to opportunistic infections, and have higher levels of fatigue than those persons with SCI who are HIV-negative (New et al. 2014). Interestingly and contradictory to the findings of TSCI, 58% of those with spinal TB in this study were female (Godlwana et al. 2008).

2.5 International Classification of Functioning, Disability and Health

The ICF was formally endorsed by the WHO in May 2001 as a framework to structure and guide rehabilitation (WHO 2001) (Figure 2.1). It provides health professionals worldwide with a common language and a framework in which to understand health, health-related conditions and the complex interactions that occur between the person and the context of that person (WHO 2001).

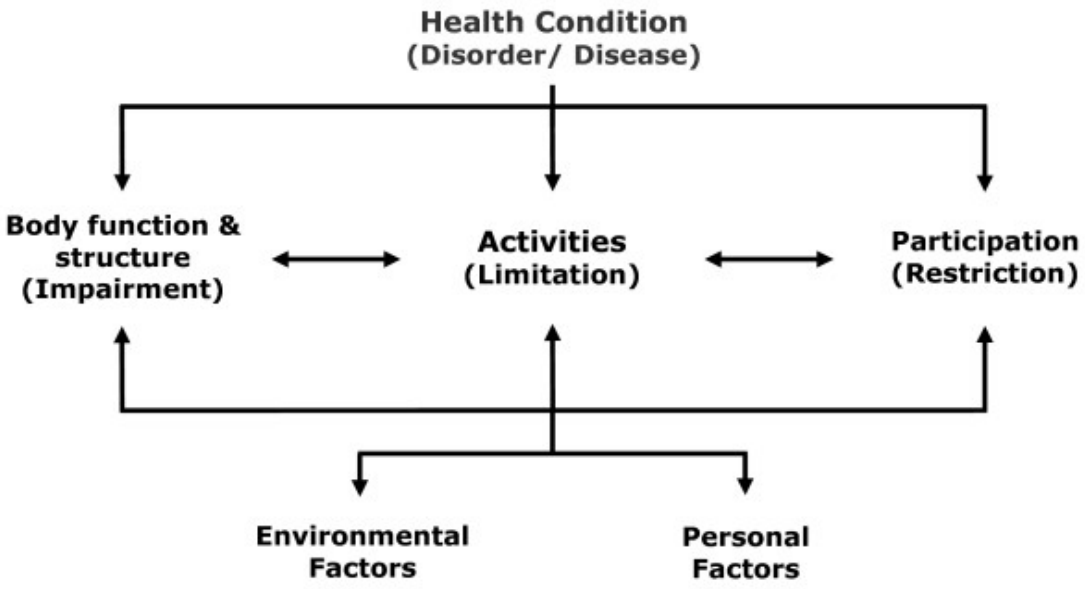

Figure 2.1 ICF Domains of Function (WHO 2001)

The ICF framework portrays the impact of health conditions on individuals' lives and places, functioning and disability in a context that includes both environmental and personal factors (Whiteneck 2006). The ICF has two parts: i) Functioning and Disability and ii) Contextual Factors (WHO 2001). Each part is further divided into two components. Functioning and Disability encompasses "body function" and "structures, activities and participation" while contextual factors include "personal factors" and "environmental factors" (physical, social and attitudinal) that facilitate or hinder functioning (WHO 2001). Within this model an individual's level of functioning is the result of the complex interaction between their health condition and contextual factors. Thus, disability is not seen as a feature of the person but rather a result of the dynamic interplay between the health condition, personal factors and the environment (WHO 2001).

2.6 Participation

With the introduction of the concept of "Participation" into the ICF as a separate construct from "Activity", participation in itself became a key rehabilitative outcome (Hammel et al. 2008). The ICF defines participation as "a person's involvement in a situation" and activity as "the execution of a task or action by an individual" (WHO 2001:35). Much debate has occurred over the vagueness of the terms. Hammel et

al. (2008) clarify that participation differs from “activity”, which is one’s capacity to engage in or execute a task, as it links to the observable performance within life situations. He highlights that true participation includes more than one’s active engagement in life situations; it embodies the personal meaning and satisfaction experienced from the engagement with others (Hammel et al. 2008). Thus, a social or interpersonal element is usually attached to the concept of participation (a social connectedness to others), but it also includes a personal component that is attached to meaning and satisfaction (Hammel et al. 2008). Due to this ambiguity of terms, much literature has moved away from using the term “participation” as defined in the ICF and prefers to talk of “community participation” or “social participation”, which are used interchangeably (Barclay et al. 2015). Levasseur, Richard, Gauvin & Raymond (2010:2147) define “social participation” as “a person’s involvement in activities that provide interaction with others in society or the community”. Chang, Coster & Helfrich (2013:772) define community participation as the “active involvement in activities that are intrinsically social and occur outside the home or are part of a non-domestic role”. It is however a common trend that to achieve a satisfying level of “participation”, opportunities for active engagement in activities within society need to be available and accessible (Hammel et al. 2008).

This brings us to the ICF concept of “participation restrictions” – the “problems an individual may experience in involvement in life situations” (WHO 2001:8). These restrictions to participation are the result of the complex interplay of a person’s functional impairments and the activity limitations, as well as the interactive influence of the contextual factors (WHO 2001). This is in line with occupational therapists’ belief that participation is either supported or restricted by the individual’s (physical, affective or cognitive) abilities, the task or occupation itself, or the environment (physical, social, cultural, attitudinal and legislative) (WFOT 2011). An occupational therapist thus needs to work collaboratively with the patient/client to facilitate successful participation at home and in the community by enabling individuals to change aspects of their person, their occupation, the environment, or some combination of these (WFOT 2011). If a person is unable to participate within their community (whether because of the individual’s ability, the occupation they wish to follow or the influence of the environment) they will not be able to integrate into society and a satisfying level of community reintegration will not be achieved.

This is in line with the principles of the Person-Environment-Occupation (PEO) Model, an occupational therapy conceptual framework designed by Law, Cooper, Strong, Stewart, Rigby & Letts (1996) aimed at providing a foundation for application to practice. The model assumes that "occupational performance results from the dynamic relationship between people, their occupations and roles and the environments in which they live, work" (Law et al. 1996:219). Occupational performance is defined as "the dynamic experience of a person engaged in purposeful activities and tasks within an environment" (Law et al. 1996:226). Figure 2.2 depicts the three components of the PEO model, the occupation, environment and person, as inter-related circles (Law et al. 1996). The overlap of the circles represents the influence of the three elements on occupational performance (Law et al. 1996).

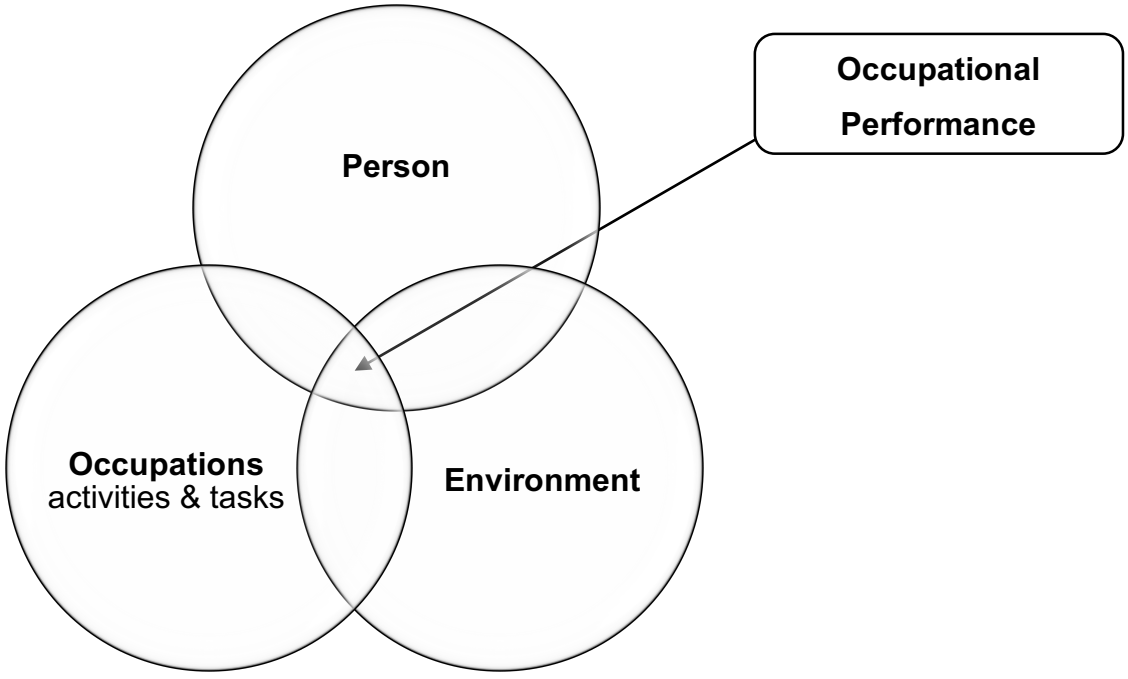

Figure 2.2 The Person-Environment-Occupation (PEO) Model (Law et al. 1996)

The PEO model encourages occupational therapists to treat holistically, considering the person, their occupations, activities and tasks as well as the environment in which these take place (Law et al. 1996). This provides the therapist with multiple avenues to elicit change (Law et al. 1996); for example, focusing on adapting the

environment (implementing intervention at various levels of the environment) rather than treating the person as a single entity within an institution or at home (Law et al. 1996). Often, the environment is more amendable to change than the person (Law et al. 1996). This is particularly true for persons living with irreversible physical disabilities such as SCI. The environment in which persons find themselves can aid or impede human occupational performance (Law et al. 1996). For example, a gymnasium without a ramp or an elevator will restrict a wheelchair-bound person's participation in their desired occupation and limit social participation (minimising occupational performance). The overarching goal of occupational therapy within this model is to maximise the fit between the person, the environment and the desired occupation to maximise occupation performance (or participation) (Law et al. 1996).

2.7 Community Reintegration

Community (re)integration is a similar construct to participation as defined by the ICF, however, it "extends beyond the person: it promotes his/her fullest inclusion and participation within the physical and psychosocial environment" (Stiens, Kirshblum, Groah, McKinley & Gittler 2002:S72). Community reintegration provides one with a sense of competence, purpose and meaning and is vital for the psychosocial wellbeing of an individual (Kamalesh Kumar et al. 2012). Furthermore, community reintegration facilitates the establishment of roles and responsibilities, enhances knowledge and promotes overall skill development (Kamalesh Kumar et al. 2012). Dijkers (1998:5) defines "community (re)integration (after/with (physical) impairment or disability" as "acquiring/resuming age-/gender-/culture-appropriate roles/statuses/activities, including independence/ interdependence in decision making, and productive behaviours performed as part of multi-varied relationships with family, friends, and others in natural community settings". Thus, for persons with disability, community reintegration requires the ability to restore old roles, responsibilities and relations as well as develop new ones (Dijkers 1997). This can be challenging, as the ability to participate in meaningful activities outside the home environment depends not only on the person's capability, but on the opportunities for employment, leisure or socialisation available as well as the accessibility of the environment (Whiteneck, Meade, Dijkers et al. 2004). Within South Africa, the ability of persons with a disability (such as SCI) to participate in the community is not only

dependent on their current ability, but also influenced by premorbid and compounding morbid occupational injustices inflicted by the apartheid regime and engrained social discrepancies resulting in occupational imbalance, occupational deprivation or occupational marginalisation (Stadnyk et al. 2010).

2.8 Community Reintegration Post Spinal Cord Injury

Although many persons with SCI are able to reintegrate into society in some way or another, the majority experience difficulties in this regard (Craig, Nicolson Perry, Guest, Tran & Middleton 2015). Joseph et al. (2016:1376) identify "journey dominated by obstacles" as an emerging theme, with "obstacles" being explained as changes in one's body function within unconducive environments, thus preventing participation. These unconducive environments, riddled with barriers to participation, have been shown to have a greater impact on community reintegration than impairment of body functions (Joseph et al. 2016). Barclay et al. (2015) demonstrate that many persons with SCI are socially isolated in terms of community, social and civic life due to contextual barriers, such as lack of accessible transport, limited social support, poor infrastructure or inaccessible environments, hindering participation. "Humans are social beings whose lives are embedded in social values, rules, constraints, cultures and communities" (Stadnyk et al. 2010:335). It is crucial that barriers to community reintegration are identified and negotiated to facilitate reclaiming participation, as poor participation in the community has been closely associated with poor quality of life (Whiteneck, Meade et al. 2004; Lund, Nordlund, Bernspang & Lexell 2007; Kamalesh Kumar et al. 2012), greater levels of unemployment (Krause, Saunders & Acuna 2012; Anderson, Dumont, Azzaria, Le Bourdais & Noreau 2007), and a higher mortality rate (Krause et al. 2012; Krause, DeVivo & Jackson 2004; Cao, Krause & DiPiro 2013). Additionally, perceived levels of participation and problems with participation are determinants of life satisfaction in people with SCI (Dijkers 1997). Lund et al. (2007) emphasise the importance of focusing on problems with participation and community reintegration during the rehabilitation process to optimise life satisfaction after SCI.

2.9 Factors Influencing Community Reintegration Post Spinal Cord Injury

Factors are either features that inhibit participation (barriers) or features that enhance ability to participate (facilitators). According to the ICF and in line with the PEO model, one's ability to reintegrate into the community is influenced by environmental factors (environment), personal characteristics, impairments (person) and activity limitations (occupation) (WHO 2001; Law et al. 1996). Due to the complex interplay between the person and environment, one not only assesses the person's ability to engage in the activity or life situation but should include the role of the environment (Hammel et al. 2008). Environmental factors can aid or impede human occupational performance (Law et al. 1996).

According to Whalley-Hammell (2010), persons with SCI who perceive no barriers to participation experience levels of life satisfaction that are similar to a those in a healthy population. Life satisfaction may be associated with the degree of environmental barriers and inequity of opportunity encountered, rather than the physical impairment itself (Whalley-Hammell 2010; Dijkers 1997). Hammell et al. (2008) and the WHO (2013) suggest that environmental factors, including attitudes, policies, accessibility and resources, tend to be the primary barriers to social and community participation of many persons with SCI impacting reintegration. Moreover, inequitable community access may contribute to secondary conditions, which further limit one's ability to actively participate in the community (Whalley-Hammell 2010). In line with the ICF framework, Barclay et al. (2015) reiterate three common trends influencing participation post SCI: health issues affect social participation, resources and environmental accessibility impact social participation and other people influence community engagement. Barclay et al. (2016) conclude that the physical environment, unsupportive social attitudes and mental health issues have been identified as the greatest barriers to community participation.

2.9.1 Personal factors

Personal factors include features such as age, gender, culture, level of education, financial resources and level of motivation (WHO 2001). These factors have the potential to positively or negatively impact a person's functional recovery and ultimately their potential to integrate back into their community and resume

productive lifestyles (WHO 2001). SCI tends to be most common in males of working age, which has critical social and economic implications on an individual, familial and societal level (Lysack et al. 2007; Wyndaele & Wyndaele 2006; Joseph et al. 2015; Anderson et al. 2007). Anderson et al. (2007) emphasise that economic self-sufficiency and work-related occupations are highly disrupted post SCI, often leading to financial insecurity. It has been shown that those who are younger at the onset of SCI participate more actively in the rehabilitation process, with a greater chance of reintegrating into their social roles and returning to productivity (Craig et al. 2015; Whiteneck, Tate & Charlifue 1999). Furthermore, being female has been associated with a greater level of occupational community reintegration (Whiteneck et al 1999). Mothabeng (2011) concludes that race is significantly associated with participation – black African participants scored lower than the non-black participants, with Caucasians being the most satisfied with their level of reintegration. Culture in South Africa has been shown to directly influence the rehabilitation and acceptance of the person living with disability into the home and community environment (Mothabeng 2011). A recent South African study by Visagie, Eide, Dyrstad, Mannan, Swartz, Schnieder, Mji, Manthali, Khogali, Rooy, Hem & Maclachlan (2017) reports that level of education was not associated with environmental barriers. However, those with a higher level of education are more likely to have access to the information required and have shown a greater potential to return to work (Mothabeng 2011), with employment post injury being a strong indicator of higher levels of satisfaction in terms of participation (Mothabeng 2011). Carpenter, Forewell, Jongbloed & Backman (2007) found that persons with higher household incomes perceived greater life satisfaction. Those of a higher socioeconomic status have access to resources (such as assistive devices, adapted and special equipment, technology and caregivers) that can aid function and independence at home and in the community (Barclay et al. 2016). Sufficient help at home, private transportation, adapted and special equipment (such as power wheelchairs or adapted golf carts) have been identified as facilitators to community reintegration and associated with increased life satisfaction (carpenter, 2007). On the contrary, Barclay et al. (2016), further reported that excessive financial resources have also been associated with demotivation and laziness which can act as a barrier to active participation in the community. Lastly, a person's innate level of motivation is an important indicator of

functional recovery (Geyh, Nick, Stirnimann, Michel, Peter & Lude 2012; Guest, Craig, Tran & Middleton 2015). Although there are factors (such as youth and motivation) that have been shown to facilitate functional recovery and community participation, variance in community reintegration is still evident and cannot be explained by personal factors alone. It thus needs to be considered as one part of a complex interplay of the person, environment and occupation (Whiteneck et al. 1999).

2.9.2 Health-related factors

Health-related factors are those factors linked to the ICF category of "Body Structure and Function" (WHO 2001). These include the nature, level and completeness of the SCI as well as the secondary medical complications that can develop (WHO 2001).

2.9.2.1 Nature, level and completeness of spinal cord injury

The level of SCI, its nature and completeness directly affects one's mobility and functional ability to engage in meaningful activities in and out of the home environment (Sommer 2010). As described above, injury to the spinal cord will result in some form of motor and/or sensory fallout with potential autonomic dysfunction (T6 and above) (Sommer 2010; Grigorean, Sandu, Popescu, Lacobini, Stoian, Neascu & Popa, 2009). The level of neurological injury provides an indication of motor loss and the potential medical and functional consequences involved (Sommer 2010). For example, a person with paraplegia will lose his or her ability to walk as well as bowel and bladder control; however he or she will preserve the ability to use the upper extremities (Sommer 2010; Maynard et al. 1997). A person with quadriplegia, on the other hand, will lose the innervation of the muscles below the level of the injury (C1–C8/T1) – thus losing the function of their upper limbs and that of their lower limbs and trunk (Sommer 2010; Maynard et al. 1997). Injury to neurological segment C4 and above further causes loss of control of the diaphragm, and thus requires assistive coughing and/or ventilation (Sommer 2010). The level of neurological injury dictates the number of muscles innervated and the severity of the impairment. Persons with quadriplegia tend be less functional or require more effort and assistance to achieve a satisfactory level of independence and community reintegration than persons with paraplegia (Sommer 2010). However, prognosis post

SCI is further influenced by the completeness of the injury (Whiteneck et al. 1999; Sommer 2010). Completeness of an SCI is usually classified using the ASIA scale and is ultimately determined by sacral sparing (Sommer 2010). If a lesion is incomplete the potential for neurological recovery is greater (Sommer 2010) and therefore the patient's potential for functional recovery is significantly enhanced. Mothabeng (2011) concludes that type of injury was significantly related to functional ability, with higher functional scores being associated with greater levels of perceived reintegration. Mothabeng (2011) reiterates the importance of rehabilitation in facilitating a person's greatest level of function to enhance participation and community reintegration. Although the level of injury and completeness are good indicators of functional recovery, neither adequately predicts or explains variance in community reintegration post SCI (Whiteneck et al. 1999).

2.9.2.2 Secondary complications

The development of secondary complications continues to be a challenge faced by health professionals, policy makers and the individuals living with SCI themselves (Callaway et al. 2015; Whalley-Hammell 2010). Complications such as pressure ulcers, urinary tract infections (UTI), autonomic dysreflexia (AD), respiratory infections/dysfunction and gastrointestinal (GI) issues can result in rehospitalisation and potentially death (Callaway et al. 2015). Other complications such as pain, fatigue, depression and high levels of anxiety, although non-life-threatening, have the potential to lead to altered occupational participation, social isolation, further psychological morbidity and decreased life satisfaction (Callaway et al. 2015). Secondary health complications impede a person's independence in ADLs, IADLs and mobility as well as their capacity to engage actively in the community and contribute as productive members of society (Callaway et al. 2015). These complication are serious and their complexities have the potential to exacerbate the degree of disability experienced by persons with SCI, negatively impacting their long-term participation, productivity, emotional status and overall quality of life (Callaway et al. 2015).

i. Pain

Pain is a subjective sensation and can be visceral, neuropathic or musculoskeletal in nature, often requiring pharmocotherapy or psychological intervention (Nair, Taly,

Maheshwarappa, Kumar, Murali, Rao. 2005). Pain has been reported as one of the most common secondary complications experienced by persons with SCI and is believed to be one of the greatest barriers to role participation, with a negative impact on quality of life (Donnelly & Eng 2005; Nair et al. 2005; Callaway et al. 2015). Poor pain management and spasms directly influence engagement in meaningful occupations, social participation and ultimately, community reintegration (Callaway et al. 2015). Donnelly & Eng (2005) and Tonack, Hetzig, Craven, Campbell, Boschen & McGillivray (2008) found that those persons with SCI who report chronic pain scored lower on the RNLI – indicating that they perceived lower levels of satisfaction with community participation. Persons with quadriplegia have a high prevalence of shoulder pain, which negatively impacts the functional use of their upper limbs and their abilty to engage independently in the home and community environments (Salisbury, Nitz & Souvlis 2006). Silvestri (2017) concludes that chronic shoulder pain is a serious complication post SCI, limiting occupational engagement, functional independence and quality of life of those affected. Donnelly & Eng (2005) emphasise that pain should be managed in the rehabilitation phase post SCI as well as during the transition into the community to optimise reintegration.

ii. Musculoskeletal complications

Spasticity, presenting as spasms, is the most common medical complication involving the musculoskeletal system post SCI (Nair et al. 2005). Spasticity tends to be more common in TSCI, with 60 to 70% of persons with TSCI and only 14.9 to 21.1% of those with NTSCI presenting with spasms (Nair et al. 2005). There is often a delayed onset of spasticity, with many patients only developing the condition post discharge (Nair et al. 2005). Spasms are a significant contributor to pain and can affect functional ability, thus requiring pharmaceutical intervention, for example Baclofen or Botox. Contractures are common post SCI, resulting in reduced joint range of motion such as decreased hip extension from sitting in the chair (Nair et al. 2005). Contractures can lead to pain and potentially to pressure ulcers and interfere with motor performance (Nair et al. 2005). Early implementation of a positioning programme and stretching regime is vital to the maintenance of the integrity of the joints post SCI (Nair et al. 2005). Lastly, immobility post SCI can lead to deep vein thrombosis which increases the risk of pulmonary embolism – a preventable cause of death post SCI (Nair et al. 2005).

iii. Bladder and bowel dysfunction

UTIs and other bladder-related complications tend to be a recurrent issue and pose an additional health burden post SCI (Monaliza, Samriti & Salunke 2017). Post SCI, the neurological pathways that control the bladder (storing and voiding) processes are interrupted or damaged, leading to bladder dysfunction – known as "neurogenic bladder" (Monaliza et al. 2017). This dysfunction leads to urine retention or incontinence, which together with the need for a catheter (indwelling or intermittent self-catheters) increase the risk of UTIs (Monaliza et al. 2017).

In addition to bladder dysfunction, bowel incontinence (neurogenic bowel) and associated gastrointestinal (GI) complications are common post SCI (Lynch, Antony, Dobbs & Frizelle 2001) and have been shown to decrease quality of life (Callaway et al. 2015). A review by Amsters, Schuurs, Pershouse, Power, Harestad, Kendall & Kuipers (2016) reported that bladder and bowel dysfunction are the most common "body structure and function" factors that impede participation in social situations outside of the home environment. Bowel dysfunction has been associated with major physical and psychological difficulty and consequently an increased level of dependency post SCI (Lynch et al. 2001). Therefore, a person who has bowel issues will tend to avoid public exposure in case of embarrassment (Callaway et al. 2015).

iv. Pressure ulcers

Another common and serious complication post SCI is the development of pressure ulcers (Callaway et al. 2015). Pressure ulcers arise from prolonged pressure at an area of a bony prominence, for example at the sacral region. This is due to the lack of sensory input, reduced blood circulation and poor pressure care education (Sommer 2010). The only way to heal a pressure sore is to remove all pressure from that area (Sommer 2010). For this reason, a person with a sacral pressure sore is unable to sit in his or her wheelchair (i.e. is bedridden) and loses opportunities to reintegrate into the community. Thus, pressure ulcers have the potential to further limit functional ability and community participation, exacerbate social isolation and decrease quality of life. If the pressure ulcer persists and worsens, the person will be admitted to hospital and/or numerous complications may develop such as infection, AD (in those with a neurological lesion at T6 or above) and potentially death (Callaway et al. 2015).

v. Autonomic dysfunction

AD causes an imbalanced reflex sympathetic discharge, leading to potentially life-threatening hypertensive bouts with compensatory bradycardia (Grigorean et al. 2009; Sommer 2010) This is usually triggered by a noxious stimulant below the level of the lesion, for example UTIs, blocked catheter, distended bladder or bowel, pressure ulcer, or ingrown toenail (Grigorean et al. 2009; Sommer 2010). In the case of SCI, the stimulus impulses travelling in the spinal cord toward the brain are blocked and the body does not respond as it would normally. A reflex is activated that increases the activity of the sympathetic portion of the autonomic nervous system. This results in a narrowing of the blood vessels, which causes a rise in blood pressure. It is considered a medical emergency and must be recognised immediately. If left untreated, AD can cause seizures, retinal haemorrhage, pulmonary oedema, renal insufficiency, myocardial infarction, cerebral haemorrhage and ultimately death (Grigorean et al. 2009).

vi. Respiratory infections

Persons with SCI, especially those with cervical injuries (quadriplegia), are at high risk of developing respiratory-related complications (such as pneumonia) (Callaway et al. 2015). The use of a trachea, ventilator and/or assisted coughing due to muscle weakness, increases the risk of mucus build-up and leaves the respiratory system susceptible to bacteria (Callaway et al. 2015). Respiratory infections are serious, as they can trigger AD and become life-threatening unless treated medically and in time. In addition to increased chances of recurring infection, if a person is unable to breathe independently (requiring assisted coughing or a ventilator) their chances of reintegration are significantly reduced (Callaway et al. 2015).

vii. Psychosocial

Developing a comorbid psychological condition post injury is common and can have devastating consequences. A longitudinal study by Lim, Shiue, Ho, Yu, Kao, Wang & Kuo (2017) concluded that persons with TSCI have a significantly higher risk of new-onset depression or anxiety when compared to the healthy population. It is suggested that the loss of function post SCI negatively impacts one's expectations of the future, leading to psychological impairment (Lim et al. 2017). This is often exacerbated by SCI-related pain (Lim et al. 2017). Barclay et al. (2016) identify that

early after discharge, mental health issues tend to be greater barriers to community reintegration than physical health complications. Tonack et al. (2008) report that the presence of psychological issues post SCI is associated with lower levels of reintegration and diminished life satisfaction. Recent studies have also shown mood disorders and perceived level of stress to be significantly lower in persons with SCI who maintain good physical health, in comparison to those who develop secondary complications (such as UTIs, pressure ulcers, respiratory tract Infections (RTI)) (Callaway et al. 2015). There is a strong correlation between psychosocial functioning and life satisfaction, with poor psychosocial functioning post SCI decreasing one's overall life satisfaction and perceived level of participation (Tonack et al. 2008). Dijkers' (1997) meta-analysis implies that participation is a greater predictor of quality of life than either impairment or disability.

viii. Fatigue

Intervention post SCI should address the cognitive and emotional impairments as well as the physical body functions and structures (Callaway et al. 2015). Fatigue post SCI is another prevalent, serious complication and a significant contributor to diminished or altered life role participation (Callaway et al. 2015). Fatigue results from a complex interplay between cognitive, emotional and physical factors (Callaway et al. 2015; Whalley-Hammell 2010). According to Wijesuriya, Tran, Middleton & Craig (2010), fatigue is greater amongst the SCI population and is associated with a poorer quality of life. It has been demonstrated that persons living with SCI with low levels of fatigue, have similar life satisfaction to able bodied persons of similar age (Wijesuriya et al 2010). Fatigue is greater in those persons living with spinal cord injury whose injury was fewer than nine years ago – indicating that time since injury is related to the level of fatigue (Wijesuriya et al 2010). Further, North (1999) reports, that fatigue along with decreased vigour are common side effects of Baclofen – a common medication used in the treatment of spasm post SCI – which may contribute to adverse psychological effects, increased self-neglect and lead to a reduction in participation in activities at home and in the community.

2.9.3 Environmental factors

The ICF divides environmental factors into five categories: products and technology; natural and built environment; support and relations; attitudes; and services,

systems, and policies (WHO 2001). These factors dynamically interact with the other components of the ICF (namely body functions and structures, activities and participation) to promote or hinder function. Law et al. (1996) emphasise that environmental factors are not static and can have enabling or constraining effects on human occupational performance. An environment that facilitates participation in society can improve one's experience of disability, while barriers (or an environment without facilitators) will restrict an individual's reintegration, potentially increasing the degree of disability experienced and decreasing their life satisfaction (Barclay et al. 2016; Carpenter et al. 2007; WHO 2001; WHO 2011). South African literature demonstrates that individuals with and without disability experience environmental barriers; however, the barriers are exacerbated for persons with disability (Visagie et al. 2017), with transportation, the natural environment and access to health services being the most common and severe barriers to reintegration (Visagie et al. 2017).

2.9.3.1 Physical environment

The physical environment encompasses the natural and built environment, transportation and products and technology. Restricted access to environments or appropriate equipment is associated with a delayed return to productivity, a higher burden of care and a greater cost to the state (WHO 2001).

i. Natural and the built environment

Unrestricted access to shopping malls, workplaces, recreation and vacation travel is crucial to community reintegration and life satisfaction (Wehman, Wilson & Targett 1999). Many persons with disability are prevented from engaging in activities within the community due to the inaccessibility of the natural or built environment (Barclay et al. 2016). The natural environment includes weather (for example rain, wind), geographic (for example urban or rural) and topographic (for example hills, ground cover) features of the environment. The built environment includes those features of the environment that are man-made, including architectural structures and land development (for example paving, roads, walkways, entrances) as well as features such as noise, light, air quality, accessibility (cognitive, physical, communicative etc.) and safety or security. Barclay et al. (2016) recently reported that the inability to access other people's homes and/or restaurants was specifically identified as a barrier to social participation. The National Building Regulations and Building

Standards Act (Act 103 of 1977) states that all people with disabilities should be able to safely enter buildings (ramps) and safely use all the facilities within (Keuter 2008). Surprisingly, even new buildings and public spaces are not always designed to accommodate persons with disability, despite legislation in place to cater for their needs (Barclay et al. 2016).

With regard to South African literature, Joseph et al. (2016) report that persons living with SCI were concerned about the physical environment, highlighting that many public spaces, including government buildings, are not wheelchair-accessible and if they are, amenities such as toilets are inaccessible. Mothabeng (2011) reports that persons with SCI in the Tshwane metropolitan district were moderately satisfied with accessibility aspects (access around the home and in the community) that influenced their participation in society. The participants said that community access is made difficult by the geographical landscape, topographical features and roads – including steep slopes up which they are unable to independently self-propel their wheelchair and untarred, gravel roads in the townships which are difficult to manage in a wheelchair (Mothabeng 2011). Although not recorded in the literature, South Africa's roads and walkways, especially in rural areas and townships, are not of a high standard – cracked, uneven pavements, steep ramps and waterlogged roads make moving around the community frustrating and dangerous for persons in wheelchairs. According to WHO (2011), the basic features of access in new construction should include: ramps on pavements, safe street crossings, accessible entries/exits, accessible path of travel to all spaces and access to public amenities.

ii. Transportation

Transportation enables independent access to employment, education, recreational and social activities as well as health care facilities (WHO 2011). Barclay et al. (2016) identified that the availability and accessibility of transport (public and private) and transport-related infrastructure (for example disabled parking bays) play an important role in community participation and overall reintegration. Transport issues have been shown to significantly impact a person's ability to access meaningful employment, education and health care and to limit their participation in recreational and social activities (Wehman et al. 1999). Within Tshwane, South Africa (in line with international literature) transportation barriers have been shown to have the greatest

impact on persons with SCI as identified using the CHIEF (Mothabeng 2011). Persons with disability in South Africa who rely on public transport to access the community have expressed numerous challenges in terms of availability, accessibility and affordability – for example, minibus taxis are reluctant to provide services to persons in a wheelchair and if they do, they charge them double (the wheelchair takes up an extra space) (Venter 2011; Mothabeng 2011; Joseph et al. 2016). This extra cost makes going out into the community (such as going to gym, shopping centres, grant pay-out points or health facilities) very expensive. Many persons with disability cannot afford these costs – there is a strong link between disability and poverty in developing countries, with the two constructs being mutually reinforcing and enduring – which is a major barrier to mobility (Venter 2011) and hence to community reintegration. Furthermore, transportation problems are exacerbated for those persons who reside in displaced urban townships or deep rural locations (Venter 2011). Visagie et al. (2017) recently emphasised that the natural environment (including lack of infrastructure, poor roads, challenging terrains and extreme heat) feeds into the transportation problems and is naturally more problematic in poorer communities. The lack of affordable and accessible transportation in South Africa restricts persons with disability from participating in activities outside the home environment (Joseph et al. 2016). This finding is in line with international literature, which states that transportation issues are common barriers to participation and lead to social isolation (Wehman et al. 1999). Mothabeng (2011) reports that public transport in South Africa poorly accommodates persons who use wheelchairs and states that driving your own car in South Africa enhances one's participation in the community and perceived level of community reintegration. This is in line with Carpenter et al. (2007), who conclude that the ability to drive one's own car acts as a facilitator for social activity and community participation.

iii. Products and technology

Access to products (including adapted and special equipment and assistive devices) has been associated with greater community participation (Carpenter et al. 2007). Advances in technology have enabled persons with SCI, especially those with cervical injuries, to connect with "the outside world" – including social networks and communities outside their home environments (Barclay et al. 2016). Technology has

become a great facilitator of community reintegration by providing persons with SCI greater opportunities to participate in hobbies, leisure and social and productive (study and work) activities on a community level (Barclay et al. 2016). Technology has additionally increased access to information: for example persons with disability can access information regarding accessibility of restaurants, work spaces, schools, support groups etc. or look for and apply for work online (Barclay et al. 2016). In 2008, an online platform was developed – "Disabled Travel in South Africa" by wikitravel– that provides persons with disability in South Africa vital information regarding accessibility. For example, they provide information on car rental companies that stock cars with hand controls and hotels and popular tourist destinations that are wheelchair accessible.

Accessibility to products and technology is, however, dependent on socioeconomic status, being less readily available to lower-income homes (Carpenter et al. 2007) and rural areas (Visagie et al. 2017). Environmental barriers (including those related to technology, transportation and accessibility) have been found to increase with reduced socioeconomic status in South Africa (Visagie et al. 2017). No research was found that considered the availability of products and technology to persons with disability of differing socioeconomic statuses in South Africa and the effects thereof.

2.9.3.2 Social support and societal attitudes

Social support has been shown to facilitate community reintegration (Barclay et al. 2015; Barclay et al. 2016) and be a key predictor of outcome post SCI (Putzke, Elliot & Scott-Richards 2001). Barclay et al. (2015) emphasise the enabling role that close friends and family play during the transition back home and back into the community. Putzke et al. (2001) highlight that strong social support is associated with higher rates of employment, fewer psychological symptoms, decreased secondary complications and an overall increase in quality of life. Carpenter et al (2007), noted that many persons living with SCI who live alone report the lack of someone to rely on for help/assistance and further identified that help and support from family and friends at home as an important facilitator to participation in chosen activities at home and in the community. A survey by Whiteneck, Meade, Dijkers et al. (2004), established 'help at home' as one of the top three environmental barriers to participation. It is recommended that close family and friends be included as part of

the rehabilitation process to aid the achievement of community reintegration (Barclay et al. 2015). With regard to local literature and social support, Mothabeng (2011) concludes that “social support” strongly influences the satisfaction of a person with disability with community participation. She also documents that supportive family helped participants cope with the challenges they faced in terms of participation in the community (Mothabeng 2011). Engaging in social participation or relationships (spending time with others) has been linked to increased quality of life (Barclay et al. 2015). However, participants say that the challenges in the environment (such as poor accessibility in the natural or built environment) make it difficult to go out and meet people (socialise) (Mothabeng 2011). Furthermore, persons with SCI who are married tend to report higher levels of life satisfaction than those that are not (Putzke et al. 2001). One’s marital relationship (or partnership) post SCI is an important source of social support. However, an increase in divorce rate post SCI has been noted (Putzke et al. 2001).

“Harmful and negative attitudes and stereotypes associated with disability continue to segregate persons with disabilities from mainstream social and economic life” (RSA 2016:51). Recently Joseph et al. (2016) reiterate how cultural beliefs and attitudes continue to devalue persons living with disability. According to, Maja, Mann, Sign, Steyn & Naidoo (2011), “cultural myths and misconceptions” play in role in excluding persons with disability from society – some African cultures view disabled family members as a “social and economic curse”. Such negative attitudes act as invisible barriers to participation (at home, school, work and in the community), which contributing to poor community reintegration (Offergeld 2012). Mothabeng (2011:215) concludes that “attitudes of members in society” influence satisfaction with community reintegration. The attitudes of other people have been shown to influence one’s ability to participate and the quality of one’s engagement in society (Barclay et al. 2016). Research has revealed that negative attitudes relating to disability is resultant from ignorance and that intervention is shifting from reasonable accommodation to “time and effort spent trying to change the attitudes towards” persons living with disability (Maja 2011:27).

2.9.3.3 Services, systems and policies

In 2007, South Africa adopted the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), agreeing to ensure that persons with disability have "access, on an equal basis with others, to the physical environment, transportation, to information and communications, including information and communications technologies and systems" both in urban and in rural areas" (United Nations General Assembly 2007:8). It is however evident that there are still limitations on accessibility due to the physical environment in South Africa. Although South Africa has adopted policies providing for the rights of persons with disability, implementation of these is not evident. Experience has elicited that voluntary efforts are not successful in overcoming environmental barriers (WHO 2011). The WHO (2011) suggests mandatory minimum standards be developed, as they have been demonstrated to be most effective in achieving accessibility and encouraging accessibility audits. Further, it is noted that majority of businesses have legislation pertaining to equal opportunity but few have specific strategies or policies in place for recruiting and employing persons with disability (Maja 2011). Occupational therapists and other health professionals, together with persons with disability, play a key role in influencing the development of such policies that reduce further disability and exclusion by addressing barriers in the physical and social/attitudinal environment, increasing awareness of disability and creating opportunities for employment as well as identifying the effects of their implementation or lack thereof (Barclay et al. 2016).

2.10 Measuring Community Reintegration and the Influencing Factors Post Spinal Cord Injury

Community reintegration post SCI is closely linked with life satisfaction and is an important goal of rehabilitation, with the level of reintegration post SCI being a good indication of effective intervention. Section 2.9 highlighted the various personal and environmental factors affecting community reintegration post SCI. This section outlines the available instrumentation for measuring community reintegration and the barriers perceived to guide selection for the current study's methodology.

2.10.1 Measure of personal and health-related factors

As described above, personal factors include sociodemographic features such as age, gender, culture, level of education, financial resources and level of motivation, while health-related factors include the nature, level and completeness of the SCI as well as the secondary medical complications that can develop (WHO 2001). No standardised or non-standardised assessment was identified, with most studies using self-developed profiles. Similarly, the researcher developed a self-reporting sociodemographic profile that consisted of 42 questions pertaining to the personal and health-related factors relevant to this study.

2.10.2 Measure of participation and community reintegration

The resumption of normal patterns of living post disability or disease (such as SCI) is crucial to achieving a satisfying level of community reintegration and optimising health, wellbeing and quality of life (Hitzig, Escobar, Noreau & Craven2012). The acknowledgment that persons with disability are faced with numerous challenges to participation in life situations (Hitzig et al. 2012; WHO 2001; Hammel et al. 2008) has led to participation becoming a key rehabilitative outcome and overall community reintegration an indication of successful rehabilitation. True participation includes more than one's active engagement in life situations; it embodies the personal meaning and satisfaction experienced from engagement in life activities with others (Hammel et al. 2008). This concept has evolved to encompass both a societal (objective) and personal (subjective) perspective (Hitzig et al. 2012). Recently, Chang et al. (2013) described community participation as an active engagement in non-domestic, social activities outside of the home. Due to the importance of community reintegration, much research has been conducted over the past few decades to understand the possible disruptions of participation post disease or injury and how one can effectively measure the concept. Many instruments have been developed to assess participation and participation limitation; however few are specifically designed for the SCI population. As there is no gold standard for measuring participation or community reintegration, the responsibility is placed on the researcher to establish the best tool(s) to meet the objectives of the study.

The following measures of community participation and reintegration emerged in the literature: the Craig Handicap Assessment and Reporting technique (CHART), community participation measure (CIM), Community Integration Questionnaire (CIQ), Canadian Occupational Performance Model (COPM), Impact on Participation and Autonomy Questionnaire (IPAQ), the Assessment of Life Habits (LIFE-H), the London Handicap Scale (LHS), Participation Survey/Mobility (PARTS/M) and the RNLI. Most of these measures are aimed at measuring participation are based on an objective perspective, with few assessing participation post injury from a subjective point of view (Hitzig et al. 2012). Of those that assess the concept of participation subjectively (IPA, LIFE-H, PARTS/M and RNLI), only the RNLI has been adopted both in the research and clinical setting and used within the SCI population (Hitzig et al. 2012). Although the CHART is a valid and reliable measure and is used frequently in research with SCI, it has been criticised due to its objective perspective and because it assesses “handicap” (loss or limitation of opportunities to participate) and not “participation” as described above (Hitzig et al. 2012).

The RNLI by Wood-Dauphinee, Opzoomer, Williams, Marchand & Spitzer (1998) was designed to measure personal satisfaction with the performance of everyday activities by persons living with disabilities (Stark, Edwards, Hollingsworth & Gray 2005). The tool assesses a person’s perceived satisfaction about performance in life activities within the following categories: mobility, self-care, daily activity, social and recreational activity and family roles (Hitzig et al. 2012; Stark et al. 2005). The measure covers involvement in and satisfaction with the occupational performance areas of personal management, recreation, social activity, functional mobility and work as well as performance patterns, including comfort with their roles in relationships and coping skills (Hitzig et al. 2012). This tool has a low administrative burden and has the potential for routine use in a clinical setting (Hitzig et al. 2012). Hitzig et al. (2012) demonstrate that the RNLI is sensitive to factors (such as health issues, mobility status, social network) that are likely to influence participation post SCI in the community. These results were consistent with previous studies and Hitzig et al. (2012) conclude that the RNLI is a reliable and valid tool for use with the SCI population. The RNLI has further demonstrated acceptable measurement properties for use within the SCI population in South Africa (Mothabeng, Eksteen & Westaway 2012) and provides an overall score of satisfaction with community reintegration.

2.10.3 Measures of environmental factors

Persons with disability experience many restrictions to participation as a result of the complex interplay of a person's functional impairments and activity limitations and the interactive influence of contextual factors (WHO 2001). Participation and reintegration into the community are either supported or restricted by the individual's abilities, the occupation itself, or the environment (WFOT 2011). In 1997, the Institute of Medicine in the USA emphasised the role of environmental factors in the lives of persons with disability (Brandt & Pope 1997). "Environmental factors" was subsequently added to the revised model of disablement in 1999 (WHO 2001). This led to the conceptualisation of a measurement instrument that could assess the nature and extent of environmental (physical, social and political) barriers experienced by persons with disability (Whiteneck 2001). The CHIEF (Appendix D) was the first (and only) measure developed that considered the degree to which the social, physical and political environments acted as barriers or facilitators to participation for people with disability (Whiteneck, Meade, Dijkers et al. 2004). A shortened version of the CHIEF is available, known as the CHIEF–SF (Craig Hospital Research Department, 2001).

2.11 Summary of the Literature Review

This chapter provided the reader with an overview of the international and local literature available regarding community reintegration post SCI. There is limited literature regarding community reintegration post SCI in South Africa, which underlines the importance of research in this area within the South African context. The chapter was outlined using the ICF model, which guides the flow of information and helps explain key concepts such as participation and community reintegration. Factors (barriers and facilitators) found to influence these concepts were further identified within different contexts. The instruments for measuring community reintegration and environmental barriers were then explored to guide selection for this study.

This literature review identified that community reintegration post SCI is a global challenge. Despite the focus of rehabilitation and legislation, persons with disability continue to be faced with numerous barriers to optimal reintegration into society.

Much research on the topic is emerging from developed countries (for example the USA and Australia); however, literature from developing countries is scarce, with little contextually relevant literature available. Findings from American or Australian (for example) literature cannot be generalised to a unique context such as South Africa; however; the findings can be used as a platform from which studies in different contexts (such as this study) can develop. For therapists to optimally prepare their patients for life in the community and to aid in the creation of opportunities for social and community participation post SCI, factors influencing participation and reintegration must be established at both an individual and a community level (Barclay et al. 2015) within the specific contexts in which they reside.

The evidence garnered will guide practice and ensure that intervention is client-centred and meets the needs of individuals within their specific, unique contexts, optimising outcome. Enabling engagement in meaningful activities within the community must be at the forefront of occupational therapy intervention to improve the quality of life of persons with SCI. This should be achieved not only at an individual level but by addressing societal barriers and creating new opportunities for participation to optimize community reintegration (Barclay et al. 2016).

The next chapter discusses the methodology used in the study to determine the sociodemographic and environmental factors that influence the level of community reintegration among persons with SCI who received private rehabilitation in Gauteng.

CHAPTER 3: METHODOLOGY

3.1 Introduction to Methodology

This chapter provides a thorough description of the methodology used in this study to address the aim and objectives. It outlines the research design used and describes the study population, sample size and sampling strategy. This is followed by a description of the study instrument, its validity and reliability, and a summary of the pilot study. Next this chapter explains the data collection process and how the data were managed and analysed using REDcap, Excel and STATISTICA 13.2. Lastly, the chapter outlines ethical considerations and discusses the limitations of the study.

3.2 Summary of Research Design

A descriptive, cross-sectional survey design was used to gather demographic information, describe the perceived level of reintegration and identify barriers to community participation faced by persons with SCI in Gauteng. This design enabled the researcher to gain information pertaining to community reintegration of a select group at a specific point in time (Fink 2003).

An online, self-administered, cross-sectional survey comprising a demographic profile and two standardised questionnaires was administered to gain information on the variables of interest. A survey design has been shown to retrieve pertinent information relating to population characteristics by studying a sample of that population (Cresswell 2013). Thus, the data collected provides a description of the sample that could potentially be generalised to the whole population (Mathison 2012). Cross-sectional surveys are effective in describing perceptions and knowledge of different populations in a South African context at a single point in time (Fink 2003). For the above reasons, the nature of this study design was appropriate to meet the objectives of the study.

3.3 Population

Any person with a spinal cord dysfunction who received in-patient rehabilitation at Netcare Rehabilitation Hospital in 2014 and 2015 and is now living in the community was eligible to take part in the study. Netcare Rehabilitation Hospital has an established SCI unit that offers a specialised therapy programme aimed at promoting optimal rehabilitative outcomes. Although this is a private facility, the medical and rehabilitation costs of patients are funded by: WCA, RMA, the RAF, medical aids or private funds. Patients admitted to this hospital are thus representative of all socioeconomic strata within South Africa.

The actual population size of persons with SCI admitted to the Netcare Rehabilitation Spinal Unit in 2014 and 2015 was established using Rita Henn and Partners' therapist statistics as well as hospital records stored online as part of the South African Database for Functional Medicine (SADFM). The surname of each patient treated was then inserted into SADFM to identify their specific diagnosis according to ICD 10 coding and a medical doctor's description upon admission.

Inclusion criteria:

- Persons who suffered a TSCI or NTSCI resulting in complete or incomplete quadriplegia or paraplegia (ICD-10 code classification G82.1, G82.2, G83.3, G82.4, G82.5)
- Persons who were admitted to a Netcare Rehabilitative Hospital post injury for at least two weeks in 2014 or 2015
- Persons 18 years or older
- Persons who were 12 months' (minimum) post discharge from the rehabilitation hospital
- Persons who have lived in South Africa since discharge
- Persons who gave consent to participate in the study

Exclusion criteria:

Persons who presented with a verbal communicative disorder and co-morbidity, i.e. traumatic brain injury (TBI), stroke or dementia, that rendered them unable to answer the questions independently and subjectively, were excluded from the study. This

information was gained when the researcher telephonically contacted perspective participants to provide study information and request participation.

3.4 Sampling

The entire study population of 166 patients was considered for this study. It was established that a returned sample size of 116 participants was predetermined as the required minimum to be representative of the population (Bartlett II, Kotrlik & Higgins 2001). This is based on Cochrane's Formula, with a margin of error of 0.5 around a 95% confidence level. To ensure that the characteristics of the sample approximate the broad characteristics of the total sample population, a stratified random selection of subjects was used.

3.5 Instrumentation

3.5.1. Survey instruments

The selection of instruments used in the survey was based on the appropriateness of the tool to the research question, evidence of validity and reliability with the SCI population (discussed in Chapter 2) and the practicality of administration. The self-administered survey included: 1) a sociodemographic profile, 2) the RNLI and 3) the CHIEF–SF. The survey in its entirety takes 20 to 35 minutes to complete online depending on hand function, internet speed and computer literacy.

i. Sociodemographic profile (Appendix B)

As described in Chapter 2, no comprehensive standardised sociodemographic questionnaire pertaining to SCI was found, and thus the sociodemographic profile was developed for this study. This section of the survey consisted of 42 questions pertaining to the participant's demographics (age, gender etc.), injury (type, level, age at onset etc.), functional independence (need for a caregiver, mobility, living arrangements etc.) and aspects of community (re)integration pre- and post injury (employment, recreation and form of community mobility). The questions for the sociodemographic profile were informed by available international and local literature on SCI as outlined in Chapter 2. The sociodemographic questionnaire takes 10–15 minutes to self-administer.

ii. Reintegration into Normal Living Index (RNLI) (Appendix C)

The RNLI is a 11-item self-report measure of community participation designed to assess a person's satisfaction with their performance in the following life activities: mobility, self-care, daily activity, social and recreational activity and family roles (Hitzig et al. 2012). This tool has demonstrated good internal consistency and validity (construct/concurrent) in research with the SCI population internationally (Hitzig et al. 2012). Further, Mothabeng et al. (2012) established an excellent reliability coefficient (Cronbach's alpha = 0.97) for the use of the RNLI with persons living with SCI in South Africa.

There are three alternative scoring systems available to determine the extent to which each statement describes the situation: 1) a three-point scoring system, 2) a visual analogue scale (VAS) and 3) a four-point scoring system. For the purposes of this study, a four-point scoring system was used to prevent the participant response bias – choosing the middle choice as default. Each item is rated by using a four-point scale: 1 = Does not describe my situation (score 1); 2 = Sometimes describes me or my situation (score 2); 3 = Mostly describes me or my situation (score 3) or 4 = Fully describes me or my situation (score 4). The RNLI is easy to understand and takes five minutes to self-administer. The RNLI is scored by tallying the 11 scores for each participant. The maximum score for the RNLI is 44. Higher scores represent higher levels of perceived reintegration – a score of 44 thus indicates that the participant is fully satisfied with their perceived level of community reintegration. To establish the level of satisfaction with community participation for each participant, scores were converted into percentages and categorised as follows (Pang, Eng & Miller 2007).

100%	Fully satisfied with their community participation
80–99%	Perception of mild restrictions in community participation
60–79%	Perception of moderate restrictions in community participation
<60%	Severe restrictions in self-perceived community participation

The following are the reasons for selecting the RNLI used in this study:

1. The RNLI is freely available online; no training and no permission are required for utilisation.
2. The RNLI is a self-administered tool.
3. The RNLI is short (11 items) and quick to complete with a low administrative burden.
4. The RNLI assesses participation as defined by the ICF from a subjective perspective.
5. The RNLI is valid and reliable with the SCI population in South Africa.

iii. Craig Hospital Inventory of Environmental Factors – Short Form (CHIEF–SF) (Appendix D)

For this study the CHIEF–SF (a 12-item instrument) was used. The CHIEF–SF is made up of items within the original five domains of the CHIEF (outlined in Chapter 2) with the greatest discriminant validity and conceptual clarity (Craig Hospital Research Department 2001). The CHIEF–SF has demonstrated good construct validity as well as acceptable internal consistency (Cronbach's alpha =0.75) within the SCI population internationally (Whiteneck, Harrison-Felix, Mellick et al. 2004). The CHIEF–SF has been used in South Africa with the SCI population (Mothabeng 2011); however no psychometric properties were reported, as "the CHIEF–SF data were not appropriate for factor analysis" (Mothabeng 2011:140).

The CHIEF–SF is made up of the 12 items within the original five domains with the greatest discriminant validity and conceptual clarity (Craig Hospital Research Department 2001). The participants rate the frequency and magnitude of each of the 12 items as in the CHIEF as described above. The CHIEF–SF takes approximately six to eight minutes to self-administer. Scoring of each CHIEF–SF item is then calculated by establishing the product of the frequency score (from 0=never to 4=daily) and the magnitude of impact score (1= little problem and 2= big problem) to produce an overall product score that ranges from 0–8. The higher the product score, the greater the frequency and/or magnitude of environmental barriers. The total CHIEF score was calculated by adding up the 11-item product scores.

Permission to use this tool was granted by Gail Whiteneck from the Craig Hospital Research Department via email (Appendix E).

3.5.2 Ensuring validity and reliability

3.5.2.1 Ensuring validity

Validity is the degree to which a test measures what is meant to – implying that one must ensure that the tools used measure the construct(s) intended to be measured (Cozby 2009). This provides a level of confidence from which one can draw conclusions (Cozby 2009). Construct validity is the degree to which a tool measures what it intends to measure, upon which inferences can be made (Cozby 2009). Construct validity was ensured by identifying common trends related to personal and injury-related factors, participation and environmental barriers experienced post SCI through an in-depth literature review. Research demonstrates strong construct validity for both the RNLI (Hirtzig et al. 2012; Mothabeng et al. 2012) and the CHIEF-SF for the SCI population (Whiteneck, Harrison-Felix, Mellick et al. 2004). Content validity is concerned with the content covered by the instrumentation used (Cozby 2009). Both the RNLI and CHIEF–SF have good content validity in terms of community reintegration (Mothabeng et al. 2012) and participation limitations (Whiteneck 2001), and are in line with the objectives of the study. The content for the sociodemographic questionnaire was based on the evidence found in the literature review for personal and injury-related factors influencing participation post SCI. Face validity is a weak form of validity, involving the appropriateness, readability and clarity of the questions (Cozby 2009). Both content and face validity were enhanced by input from supervisor(s), a thorough review of the literature and by the pilot study conducted with persons with SCI prior to beginning the study.

3.5.2.2 Ensuring reliability

A measurement tool is reliable if it reveals similar results on different occasions (Cozby 2009). Reliability is thus the degree of consistency with which a tool measures what it is supposed to measure. There are three types of reliability: test-re-test, inter-rater reliability and internal consistency (Cozby 2009). The study is cross-sectional and self-administered, thus test-re-test or inter-rater reliability are not applicable. Both the RNLI and CHIEF–SF have demonstrated strong internal

consistency for the use of the SCI population (Whiteneck, Meade, Dijkers et al. 2004), with the RNLI demonstrating excellent internal consistency (Cronbach's alpha = 0.97) for use within the SCI population, as mentioned above.

3.6 Pilot Study

A pilot study was conducted over a two-week period in December 2016 to test the administrative procedure of the study and to identify and correct any instrumentation errors. Piloting a study is useful to gain information about the appropriateness of the design, method and procedure as well as to identify errors prior to commencing the larger study (Van Teijlingen & Hundley 2001).

Eight persons with SCI of varied gender, age, education and culture, rehabilitated in the private sector in Gauteng and discharged prior to January 2014, were identified via word of mouth and contacted personally by the researcher. The researcher explained the purpose of the pilot study in relation to the larger study and requested voluntary participation. The participants were given the option to receive and complete the questionnaire via email or to use the facilities at Netcare Rehabilitation Hospital to complete the study online. Six of the eight surveys were emailed and the other two were completed online at the hospital with the aid of a research assistant for language translation and assistance for typing due to poor hand function. In this way, both administration techniques were trialled. The research assistant, who was fluent in both isiZulu and Sesotho, was trained prior to the pilot study to ensure the content or meaning of the questions did not change when translated, to maintain objectivity and to prevent bias. Informed consent was implied when the participants completed the survey online or agreed to complete the survey as part of the pilot study at Netcare Rehabilitation Hospital.

Once the survey was completed, the participants were asked several questions either by email or face-to-face with the researcher. The questions pertained to the content and clarity of the questions, the appropriateness of the language used and the effectiveness of the translator, the level of comprehension and the format of the questionnaire, the time taken to complete the survey and lastly, the accessibility of the questionnaire via the REDcap link.

Overall, the main concerns identified by the participants pertained to the ambiguity of certain words and sentences due to poor phrasing and/or grammatical error. All grammatical errors identified were rectified. Question 4a in the CHIEF was of concern to five of the participants, who wanted to know what “information” the question referred to. As the CHIEF is a standardised questionnaire the question could not be altered. Thus, a memorandum was developed to provide examples of what “information” this could refer to, for example accessibility of public areas, disability rights etc. In this way, the researcher’s or research assistant’s responses to this question were uniform. In addition to the above, two participants suggested that questions relating to equipment accessibility and physical/structural barriers to community participation are included. Four additional questions regarding equipment accessibility and the physical accessibility of buildings/places in the community were added to the sociodemographic questionnaire. No questions were deemed inappropriate by the participants. Two questions that were deemed repetitive were removed by the researcher. At this stage, the sociodemographic questionnaire consisted of 42 questions. The time taken to complete the survey in its entirety ranged between 20 minutes to 35 minutes by persons with paraplegia and quadriplegia respectively.

3.7 Ethical Considerations

Before the data collection process commenced, ethical approval was obtained from the Human Research Ethics Committee (HREC) at the University of the Witwatersrand (clearance certificate no. M160851) (Appendix F) and written permission was obtained from the Netcare Ethics Committee (approval number UNIV-2016-0063) (Appendix G) and Rita Henn & Partners, who are responsible for the rehabilitative services at Netcare Rehabilitation Hospital (Appendix H). Information regarding the study was first described telephonically to each potential participant. Once the participant agreed to take part in the study, he or she was provided with an information sheet (Appendix I) via email, fax or collection, detailing the study and the process of informed consent. Consent was implied when the participant completed the survey online. It was clearly explained that participation in the study was voluntary and that participants had the right to withdraw from the study at any given time as a way of respecting their autonomy. Confidentiality was

ensured, as no personal details (for example name, contact number or email address) were required to complete the survey and each participant was coded automatically by REDcap. In this way, no names or other identifying information appeared on any data sheet or could be used in the write-up of the study. This was to protect the participant's identity and to ensure anonymity. All completed questionnaires were stored in a password-protected folder on the researcher's private laptop to which only the researcher and research supervisor had access. All data will be destroyed after six years as per the HPCSA guidelines. Participants or participants' family members (especially those where a family member was deceased) who demonstrated signs of emotional instability were referred to the social worker at Netcare Rehabilitation Hospital for counselling (for their own account).

3.8 Data Collection

The data collection process commenced on 01 March 2017. The names and file numbers of persons with SCI admitted to Netcare Rehabilitation Hospital in 2014 and 2015 were identified using the therapist's monthly statistics and then diagnoses were verified using the SADFM database. The researcher, together with a research assistant, used the patient numbers to locate patient contact details through Rita Henn and Partners' online file scans. At least one contact number (either belonging to the patient, a family member or their employer) was identified for each of the 166 patients.

Recruitment to the study entailed contacting each potential participant via telephone, informing them about the study and inviting them to participate. The telephone calls ranged from 3 to 42 minutes per call depending on the amount of information requested by the potential participant. Potential participants could make an informed, independent decision as to whether they agree to or decline participation. It was explained to the participant that there would be no negative consequences for not taking part in the survey and no participant was forced to participate. Once verbal consent had been obtained telephonically, potential participants were offered four options to complete the survey: via email and complete it online; receive printable copies of the survey; receive the survey via fax; or alternatively come to Netcare

Rehabilitation Hospital to complete the three self-administered questionnaires. An information sheet was attached to the survey outlining all the details of the survey, ethical considerations and consent information (Appendix I). Participant consent was implied when the participants choose to participate and completed the survey online. Participants were reimbursed for all costs incurred as part of the study (time and transport). An independent translator was made available to assist participants who did not understand or read English at Netcare Rehabilitation Hospital; however this service was not utilised. Data collection continued until the population was exhausted.

A total of 135 and 107 SCI patients were treated on an in-patient basis in 2014 and 2015 respectively. The surname of each patient treated was then inserted into SADFM to identify their specific diagnosis according to ICD 10 coding and medical doctor's description upon admission. Forty-six persons from 2014 and 30 persons from 2015 were excluded immediately from the population because their diagnostic classification was not that of SCI/dysfunction (G82, G82.1; G82.2, G82.3, G82.4 or G82.5). The 76 persons excluded from the study were treated in the spinal unit for any of the following diagnoses: Gillian-Barré Syndrome (GBS), Motor Neuron Disease (MND), orthopaedic injury, TBI or stroke. The potential reason for their different diagnoses is that the spinal therapists may have screened those persons with TBI or stroke and then referred them to the appropriate unit. Additionally, persons with GBS and MND are treated in the spinal unit. Thus, the total number of patients with SCI/dysfunction treated in the spinal unit in 2014 and 2015 was 166, of which 89 were from 2014 and 77 from 2015. Of the 166 potential participants, 14 were deceased and 26 did not live in the Republic of South Africa and thus were excluded from the study. This left the researcher with 126 potential participants (making the adjusted minimum required sample size 74 to be representative of the population) (Figure 4.1).

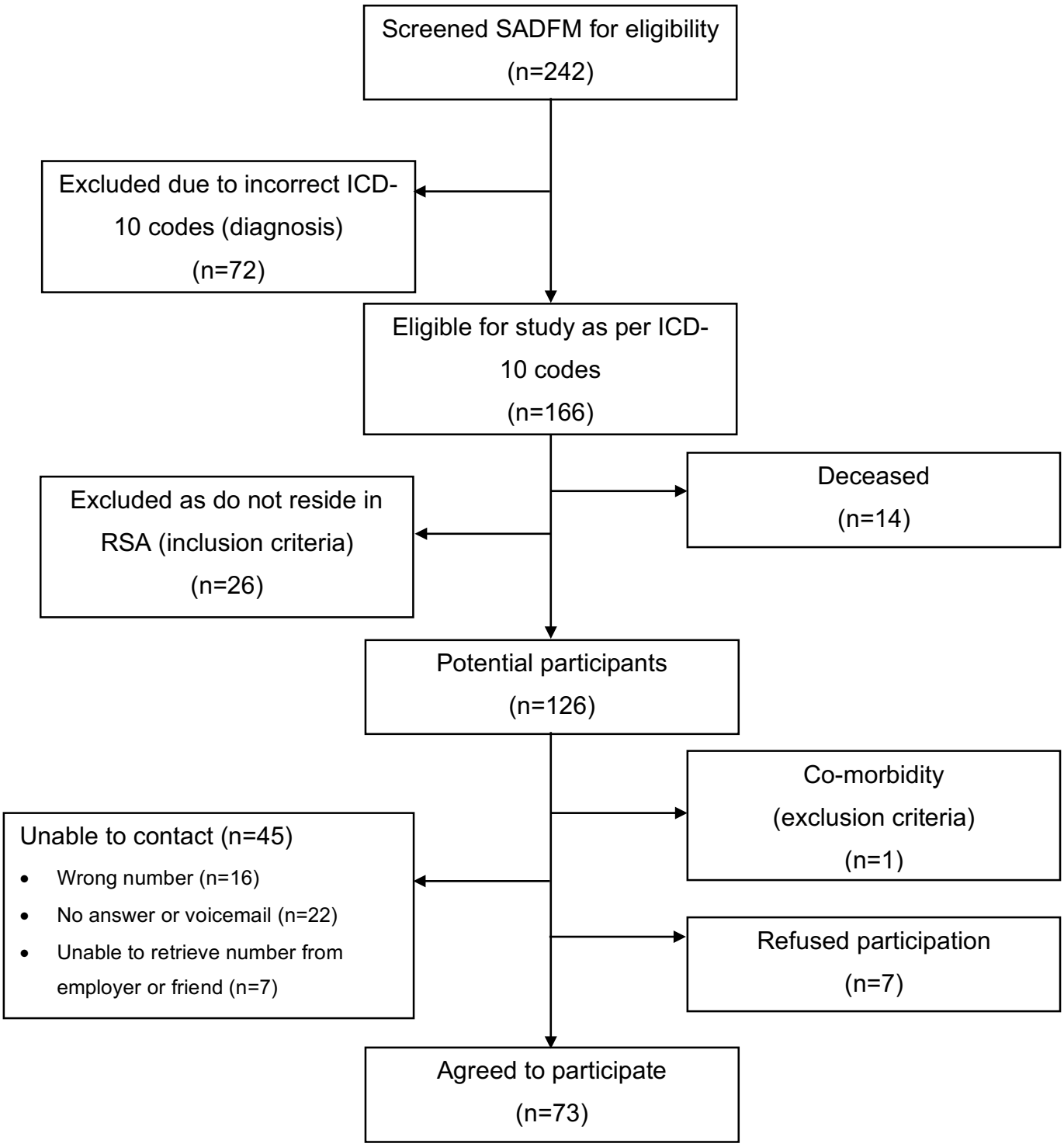

Figure 3.1 Consort Flow Diagram of Participants Part 1

Of the 126 potential participants, the researcher was unable to contact 45 for the following reasons: “wrong numbers” or “numbers that do not exist” (n=16), “no answer” or “voicemail” (n=22) (called on six occasions over a four-month period) or

the contact numbers belonged to an employer or friend who could not give the researcher the direct contact number for the person (n=7). Seven persons refused participation. Seventy-three people agreed to participate (Figure 3.1).

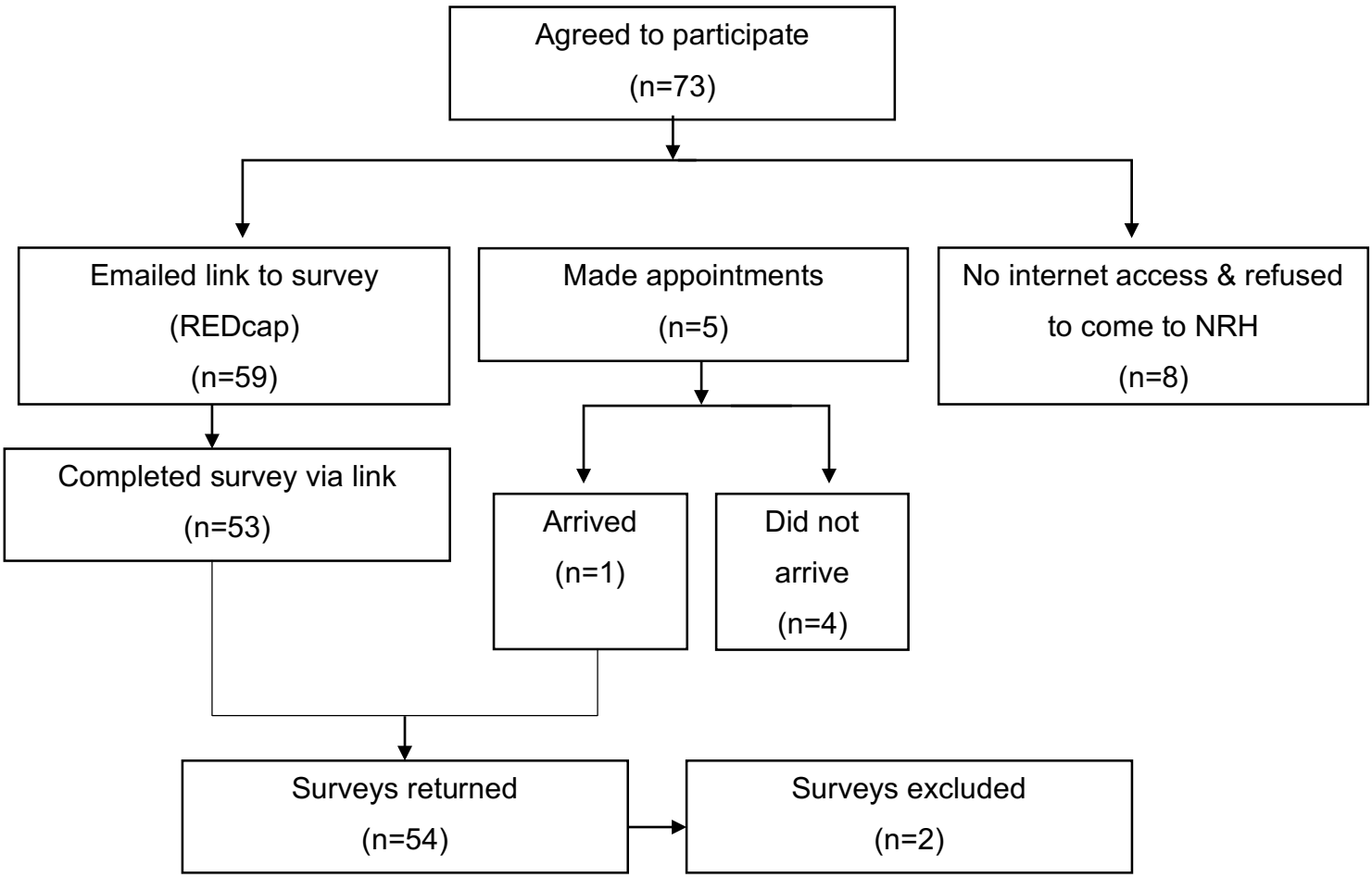

Figure 3.2 Consort Flow Diagram of Participants Part 2

Of the 73 people who agreed to participate, eight had no internet access and were unable to come to Netcare Rehabilitation Hospital due to transport and accessibility issues. One participant had co-morbid dementia and was excluded from the study. Overall, 65 persons agreed to participate. Of those who agreed to participate, 59 were emailed the survey link, one was sent a fax and five made appointments to come to Netcare Rehabilitation Hospital. Of the five who made appointments, only one arrived. In total 54 surveys were completed by 31 July 2017 (Figure 3.2).

Of the 54 surveys, only 30 completed all three questionnaires, one completed the first two questionnaires and 23 completed only the sociodemographic profile. Two surveys were excluded as only the first question of the sociodemographic profile was answered.

3.9 Data management

Information collected via REDcap was exported into a password-protected Excel spreadsheet in preparation for data analysis. Each survey was coded automatically and no identifying information was available. Only the researcher and Wits supervisor(s) had access to the information extracted. The information gathered was solely used to meet the purposes of this study.

3.10 Data analysis

To meet the objectives of the study, descriptive analysis was done. The sociodemographic information, level of participation (RNLI) and the environmental barriers (CHIEF–SF) experienced by the participants were analysed using STATISTICA 13.2, using frequencies as well as means and medians for the demographic and environmental variables assessed. The open-ended questions in the sociodemographic section (questions 41 and 42) were analysed by content analysis in Excel using frequencies.

Secondary to the descriptive analysis, inferential statistics were explored to identify possible correlations or relationships between sociodemographic variables (such as type of injury, gender) and the RNLI and CHIEF–SF scores - distribution free tests, the Mann-Whitney U-test and Kruskal Wallis test, were used. Significance was set at 0.05 or less.

3.11 Summary of Methodology

Chapter 3 provides the reader with an in-depth understanding of the research methodology used to conduct the study to meet the objectives. In summary, the study was descriptive in nature and utilised a cross-sectional, online, self-administered survey. The survey consisted of three questionnaires: 1) a

sociodemographic profile, 2) the RNLI and 3) the CHIEF–SF. The whole population (consisting of 166 persons with SCI rehabilitated at Netcare Rehabilitation Hospital in 2014 and 2015) was considered for the study. A returned sample size of 116 participants was predetermined as the required minimum to be representative of the population. The data collection process only commenced once ethical approval had been granted from the HREC of the University of the Witwatersrand (Appendix F) and by the Netcare Ethics Committee (Appendix G). Recruitment to the study entailed contacting each potential participant via telephone, informing them about the study and inviting them to participate. Once verbal consent was gained, the researcher emailed an information sheet and the link to the survey that was loaded onto REDcap. Information collected via REDcap was exported into a password-protected Excel spreadsheet in preparation for data analysis. Each survey was coded automatically in REDcap and no identifying information was available to ensure anonymity. Descriptive analysis was done to meet the objectives of the study using STATISTICA 13.2. The open-ended questions in the sociodemographic section were analysed through content analysis in Excel using frequencies and described. Secondary to the descriptive analysis, inferential statistics were explored to identify possible correlations or relationships between sociodemographic variables (such as type of injury, gender) and the RNLI and CHIEF–SF scores using STASTICA 13.2. Chapter 4 discusses the results yielded by the study.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter gives the findings of the study carried out as per the methodology described in Chapter 3. Of the persons with SCI discharged from Netcare Rehabilitation Hospital in 2014 and 2015 (166), 126 (75.9%) were contacted and 65 (39.2%) agreed to take part in the study. Fifty-four surveys were returned. Two participants did not go further than the first question of the demographic questionnaire and were thus removed from the data prior to analysis. Therefore, the reported results are based on 52 participants.

4.2 Sociodemographic Information

The first objective of the study was to establish the sociodemographic profile of the participants that influence their level of community reintegration. To do so, it was necessary to establish the sociodemographic information of the participants with SCI who were rehabilitated at Netcare Rehabilitation Hospital. Fifty-two participants completed the sociodemographic profile (Appendix B) (n=52).

4.2.1 Demographic profile

4.2.1.1 Personal demographics

The majority (63.5%; 33/52) of the participants were male with a median age of 39 years. The participants, at the time of the study, ranged from 19 to 88 years of age, with 77% (40/55) of the participants between the ages of 18 and 49. Most participants (42.3%; 22/52) spoke an African language (Table 4.1).

Table 4.1 Demographic Characteristics of the Participants (n=52)

Sociodemographic profile questions	n	Cumul. count	%	Cumul. %
Question 2: Gender				
Male	33	33	63.5	63.5
Female	19	52	36.5	100
Question 1: Current age				
18–29	11	11	21.1	21.1
30–39	15	26	28.8	49.9
40–49	14	40	27	76.9
50–59	8	48	15.4	92.3
>60	4	52	7.7	100
Question 4: Marital status				
Single	23	23	44.2	44.2
Married	19	42	36.5	80.7
Divorced	2	44	3.9	84.6
Widowed	5	49	9.6	94.2
Partnered	3	52	5.8	100
Question 3: Home language				
English	16	16	30.8	30.8
Afrikaans	14	30	26.9	57.7
isiZulu	2	32	3.9	61.6
isiXhosa	3	35	5.7	67.3
Sesotho	5	40	9.6	76.9
Sepedi	4	44	7.7	84.6
Setswana	6	50	11.5	96.1
Tshivenda	2	52	3.9	100

4.2.1.2 Level of education

More than half (55.8%, 29/52) of the participants had received tertiary education, of whom 75.9% (22/29) had at least one diploma and 24.1% (7/29) had at least one degree. The remaining 42.2% (22/52) had received some level of secondary education, with a majority (30.7%; 16/52) having completed matric (Grade 12) with no further education.

4.2.1.3 Vocational status

With regard to work, 78.8% (41/52) of the participants were employed before their injury. Of the participants, 65.4% (34/52) returned to work after their injury, of whom only half (17/34) returned to the same job as they held before the injury. Of the participants who returned to work post injury, 53% (18/34) returned within six months, 29.4% (10/34) returned within one year, 8.8% (3/34) took more than one

year and 8.8% (3/34) took two years or more. At the time of the study, 52% (27/52) of the participants were still working, of whom 7.4% (2/27) were self-employed (Table 4.2). Those who were not employed (48.1%; 25/52) included two who were retired (and received a pension) and two who were studying at a university. Four participants received South African Social Security Agency (SASSA) grants (government disability grant) and 19.2% (10/52) of the participants received no form of income. Five participants reported receiving income via disability insurance.

Table 4.2 Vocational Status of the Participants (n=52)

Sociodemographic profile questions	**n**	**Cumul. count**	**%**	**Cumul. %**
Question 27a: Did you work before the injury?				
Yes	41	41	78.8	78.8
No	11	52	21.2	100
Question 28a: Did you return to work after your injury?				
Yes	34	34	65.4	65.4
No	15	49	28.8	94.3
Missing	3	52	5.8	100
Question 28c: How long after the injury did you return to work?				
Within six months	18	18	53	53
Within one year	10	28	29.4	82.4
More than one year	3	31	8.8	91.2
More than two years	3	34	8.8	100
Question 29a: Are you still working?				
Yes	27	27	52	52
No	19	46	36.5	88.5
Missing	6	52	11.5	100
Question 29b: if yes, are you employed or self-employed? (n=27)				
Employed	25	25	92.6	92.6
Self-employed	2	27	7.4	100

4.2.2 Medical history

4.2.2.1 Level, nature and cause of injury

As depicted in Table 4.3, the majority of participants were between the ages of 18 and 49 years and presented with paraplegia (75%; 39/52) at the time of injury. All injuries that occurred after the age of 60 years were reported in women, where the injuries were attributed to falls in the home. All injuries that occurred under the age of 18 years were males and attributed to MVAs. More than half of the participants (57.7%; 30/52) presented with injury of the thoracic region and 17.3% (9/52) with injury to the lumbar region of the spinal cord, of which 35.9% (14/39) were complete.

Of those participants with quadriplegia (25%; 13/52), 77% (10/13) were incomplete and 23% (3/13) were complete. The majority (73.1%; 38/52) of participant injuries were traumatic in nature. Motor vehicle/bike accidents were the most common cause of injury (44.2%; 23/52), followed by acts of violence (including gunshot wounds) (13.4%; 7/52) and falls (7.7%; 4/52). The remaining 26.9% (14/52) of injuries were non-traumatic in nature, resulting from one of the following medical conditions: tumours, TB spine, transverse myelitis, viral infection, meningitis, spinal arachnoid cysts and bacterial infection. NTSCI was more common in females (47.4%; 9/19) than males (12.1%; 4/33).

Table 4.3 Health-Related Factors of the Participants (n=52)

Sociodemographic profile questions	**n**	**Cumul. count**	**%**	**Cumul. %**
Question 11: Level of injury				
Cervical	13	13	25	25
Thoracic	30	43	57.7	82.7
Lumbar	9	52	17.3	100
Question 10: Type of Injury				
Complete quadriplegia	3	3	5.8	5.8
Incomplete quadriplegia	10	13	19.2	25
Complete paraplegia	14	27	26.9	51.9
Incomplete paraplegia	25	52	48.1	100
Question 13: Age at onset of injury				
Less than 18 years	4	4	7.7	7.7
18 – 29 years	12	16	23.1	30.8
30 – 39 years	12	28	23.1	53.9
40 – 49 years	15	43	28.8	82.7
50 – 59 years	6	49	11.5	94.2
older than 60 years	3	52	5.8	100
Question 14a: What was the cause of your injury?				
Gunshot wound	6	6	11.5	11.5
Violence	1	7	1.9	13.4
Motor vehicle accident	23	30	44.2	57.6
Falls	4	34	7.7	65.3
Mining accident	1	35	1.9	67.2
Tumour	3	38	5.8	73
Sport-related	2	40	3.9	76.9
Work-related	1	41	1.9	78.8
Other	11	52	21.2	100

4.2.2.2 Length of hospital stay and funding

The majority of the participants (57.7%; 30/52) spent 6 to 12 weeks in hospital, with 12 weeks being the most common length of stay (19.2%; 10/52) (Figure 4.1).

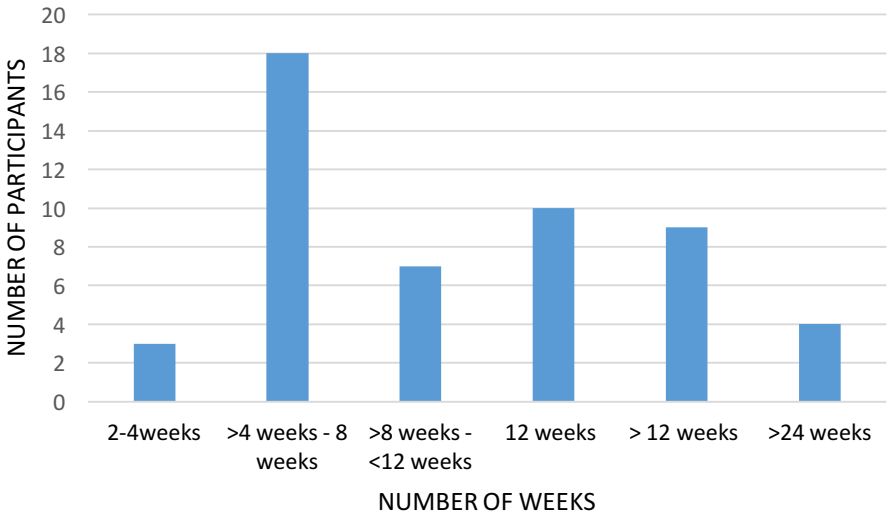

Figure 4.1 Length of Stay at Netcare Rehabilitation Hospital (n=52)

The four participants with the longest stay were funded by the WCA. The majority of the participants (88.5%; 46/52) were funded by a medical aid (Figure 4.2).

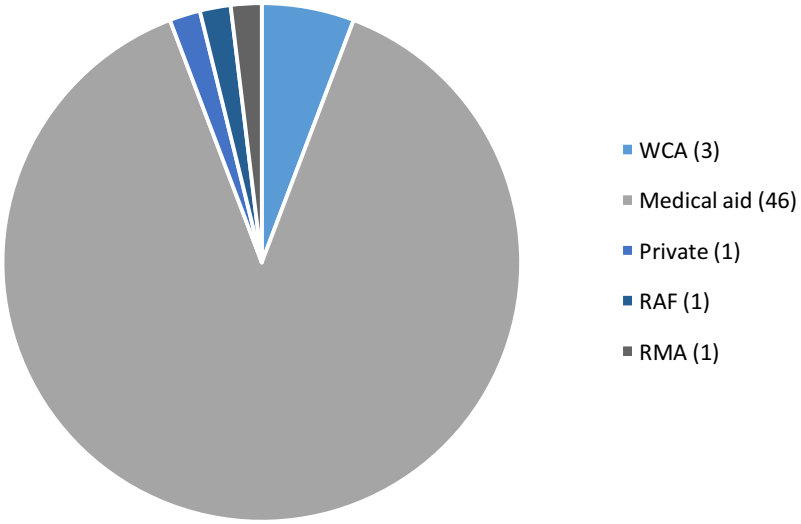

Figure 4.2 Funding for In-patient Rehabilitation (n=52)

4.2.2.3 Out-patient therapy

Less than one-third (28.8%, 15/52) of the participants were attending out-patient therapy at the time of the study. Their reasons included: learning to walk again, for maintenance therapy, for improved fine motor dexterity, for overall strengthening, for vocational rehabilitation and lastly, to aid with secondary complications. Of those participants (71.2%; 37/52) who were not attending out-patient therapy, 35.1% (13/37) reported that this was due to the cost of therapy and/or insufficient funding. One participant reported that he was unable to attend out-patient therapy due to a pressure ulcer. Four participants (10.8%; 4/37) reported that they did not attend out-patient therapy solely because of a lack of transport.

4.2.2.4 Complications

More than a third (36.5%; 19/52) of the participants reported that they had been readmitted to hospital at least once subsequent to their discharge from Netcare Rehabilitation Hospital, due to a secondary complication. UTIs were the most common complication (71.1%; 37/52), followed by pressure ulcers (23.1%; 12/52) and RTIs (9.6; 5/52).

4.2.3 Personal factors

4.2.3.1 Mobility

Wheelchairs were used by 67.3% (35/52) of the participants. The majority required a manual wheelchair for indoor (61.5% 32/52) and outdoor (59.6% 31/52) mobility. A power wheelchair was used indoors by 5.8% (3/52) and outdoors by 7.7% (4/52) of participants, all of whom were persons with quadriplegia. Only 15.4% (8/52) of the participants walked indoors and outdoors without assistive devices such as a walking frame, crutch or an ankle and foot orthosis (Table 4.4).

Table 4.4 Means of Mobility (n=52)

Mean of Mobility	**n**	**Cumul. count**	**%**	**Cumul. %**
Indoor Mobility				
Manual wheelchair	32	32	61.5	61.5
Power wheelchair	3	35	5.8	67.3
Walker with assistive device	5	40	9.6	76.9
Walker without assistive device	9	49	17.3	94.2
Missing	3	52	5.8	100
Indoor Mobility				
Manual wheelchair	31	31	59.6	59.6
Power wheelchair	4	35	7.7	67.3
Walker with assistive device	6	41	11.5	78.8
Walker without assistive device	8	49	15.4	94.2
Missing	3	52	5.8	100

4.2.3.2 Assistance and caregivers

The majority (57.7%; 30/52) of participants reported that they required a caregiver, though only 44.2% (23/52) of participants had a caregiver. The remaining participants (13.4% 7/52) reported that they could not afford one. Of those who had a caregiver (44.2%; 23/52), 43.4% (10/23) were quadriplegic, 78.3% (18/23) required care seven days a week and 39% (9/23) had more than one caregiver. A family member was the primary caregiver in 69.6% (16/23) of the cases. Only 13% (3/23) had employed a caregiver from a private company. Assistance for personal management was required by 63.4% (33/52), with 59.6% (31/52) of the participants requiring assistance specific to bowel and bladder management (Table 4.5).

Table 4.5 Assistance for Personal Management and Transfers (n=52)

Assistance	n	Cumul. count	%	Cumul. %
Question 19: Do you require assistance for bowel and bladder management?				
Yes	20	20	38.4	38.4
Sometimes	11	31	21.2	59.6
No	20	51	38.5	98.1
Missing	1	52	1.9	100
Question 20: Do you require assistance to meet other personal needs?	21	21	40.4	40.4
Yes	12	33	23.1	63.5
Sometimes	18	51	34.6	98.1
No	1	52	1.9	100
Missing				
Transfers				
Independent	32	32	61.6	61.6
Independent with transfer board	4	36	7.7	69.3
Assistance of one person	6	42	11.5	80.8
Assistance of two people	6	48	11.5	92.3
Other	1	49	1.9	94.2
Missing	3	52	5.8	100

4.2.3.3 Equipment

More than a third of the participants (34.6%; 18/52) reported that there was equipment that they need/want which they did not have, including self-care assistive devices, vehicle adaptations, standing frame, commode, motorised wheelchairs and callipers for walking. Lack of funding was the main reason for not having the equipment (55.6%; 10/18). Of the participants, 50% (9/18) reported that not having access to this equipment negatively impacted their community participation.

4.2.4 Social factors

4.2.4.1 Living arrangements

The majority of the participants (76.9% 40/52) lived in brick houses, 1,9% (1/52) resided in an RDP house, 11.5% (11.5/52) lived in apartments and 9.6% (5/52) did not specify. A majority of the participants (46.2%; 24/52) owned their houses, 38.9% (15/52) were renting and 21.2% (11/52) neither owned nor rented. A change in living arrangements after the SCI was reported by 67.3% (35/52) of the participants. Of

those who made changes to their living arrangements; 54.3% (19/35) made adaptations to the outside of their existing house, 60% (21/35) made adaptations to the inside of their existing house, 14.3% (5/35) moved to a new house, 22.9% (8/35) made adaptations to the outside of a new house and 11.4% (4/35) made adaptations to the inside of a new house (Figure 4.3).

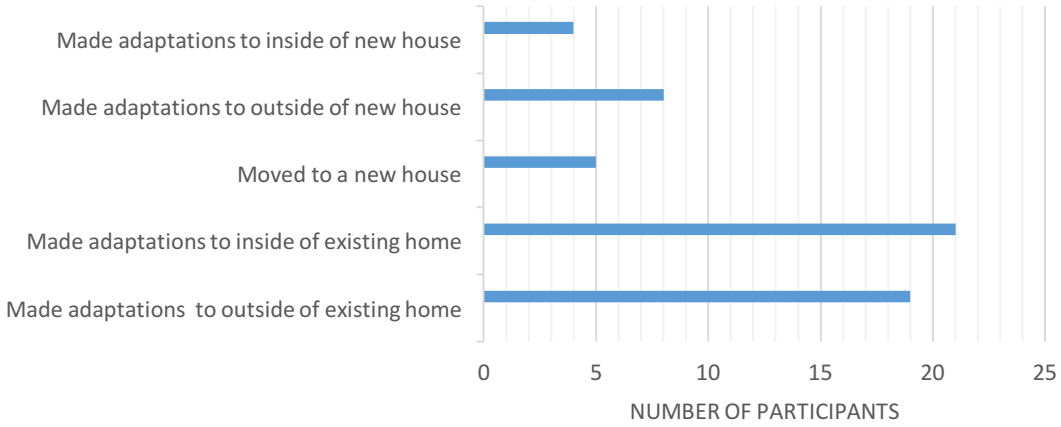

Figure 4.3 Change in Living Arrangements/Home Adaptations (n=35)

As demonstrated in Figure 4.4, the majority (48.1%; 25/52) of the participants lived with their spouse/partner. Participants who lived with at least one child made up 44.2% (23/52) of the sample and 32.7% (17/52) lived with their parent(s). No participants lived with a friend or caregiver only. Only 13.5% (7/52) of the participants reported living alone.

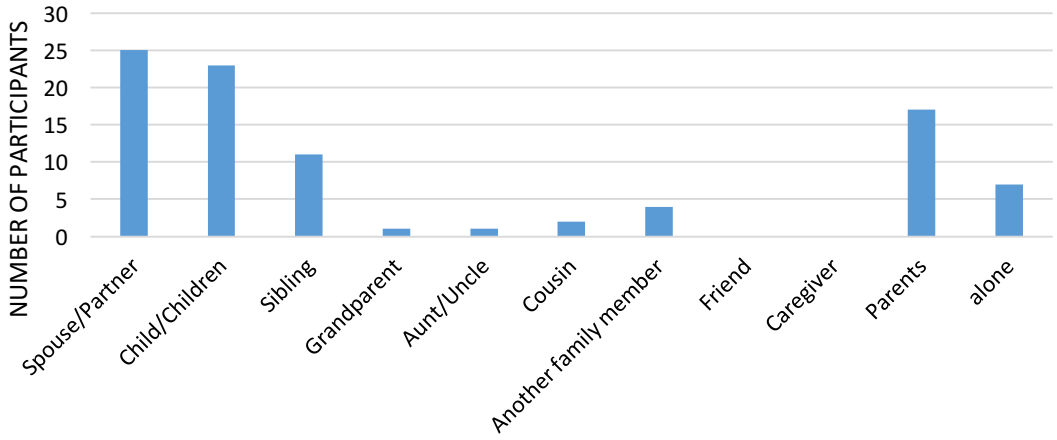

Figure 4.4 "With whom do you live?" (n=52)

4.2.4.2 Transportation

As demonstrated in Figure 4.5, the majority (42.3%; 22/52) of the participants drove their own private car (with or without adaptations). More than one-third (38.5%; 20/52) relied on friends and family for transportation needs. Two participants reported that their caregiver drove their private cars. Two participants (3.8%; 2/52) used taxis and Uber services. No participants reported using or knowing of any transport resources available to persons with disability.

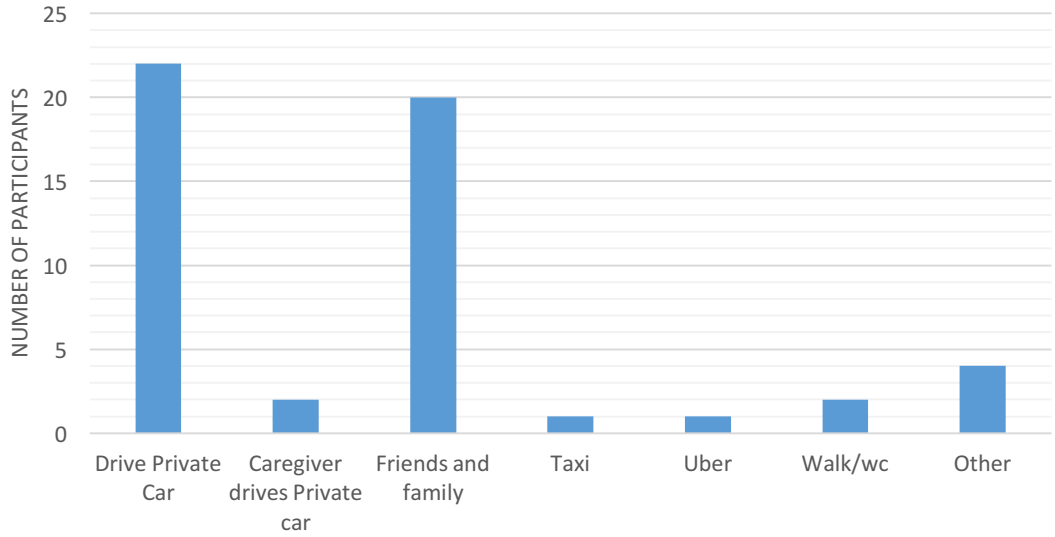

Figure 4.5 Means of Transportation (n=52)

4.2.5 Comments made by the participants regarding community participation

The last two questions (Questions 41 and 42) of the sociodemographic profile were open-ended questions, asking the participants: "*What do you think is your greatest barrier to community participation?*" (Question 41) and "*What do you think is your greatest facilitator to community participation?*" (Question 42) prior to the administration of the RNLI (appendix C) and the CHIEF–SF (Appendix D). More than a third (36.17%; 19/52) indicated that wheelchair accessibility in public places was the greatest barrier to community participation, with one person mentioning that "wheelchair access is limited – ramps are in short supply, uneven, unmaintained pavements and walkways make it difficult" and another commenting on the "lack of ramps on pavements". This is a relatively low percentage, as when asked if the design and layout of buildings and places used in the community made it difficult for them to do what they needed to do (Question 35), approximately two-thirds (63.5%; 33/52) of participants said "yes". Wheelchair accessibility was followed by 13.5%

(7/52) of participants reporting that people's attitudes were their greatest barrier, with comments such as "there is a huge lack of awareness about disability", "people stare", "people think I'm stupid" and "people saying ah shame". Transport was reported as a barrier by 11.5% (6/52) of participants, with one particularly mentioning the lack of disabled parking bays. Bowel accidents, the need for assistance, limited funds, pain and lack of information about what resources are available were other identified barriers.

With regard to facilitators, 28.8% (15/52) of the participants reported that their social support from friends and family was their greatest support for community participation. This was followed by 26.9% (14/52) indicating that their motivation and positive attitude was their greatest facilitator. Other facilitators identified included therapy, other people's attitudes, their ability to communicate, their independence, their caregivers and friendly taxi drivers. However, 17.3% (9/52) said "nothing" facilitates their community reintegration.

4.3 Community Reintegration

The second objective of the study was to determine the participants' level of community reintegration. The RNLI (Appendix C) was used to establish the participant's satisfaction with their community participation. As described in Chapter 3, the RNLI is made up of 11 items and each item was scored by the participant using a four-point scale. The higher the score, the better the patient's perceived reintegration, reflecting greater satisfaction with community participation with regards to that item. A score of above two indicates mostly or fully reintegrated within that area of participation. Thirty-one participants completed the RNLI.

4.3.1 Reintegration according to the Reintegration into Normal Living Index

Table 4.6 Mean Scores and Standard Deviation (SD) of the Reintegration into Normal Living Index Items (n=31)

No.	RNLI item	Mean	SD
1	I move around my living quarters as I feel necessary.	2.64	1.25
2	I move around my community as I feel necessary.	2.25	1.15
3	I am able to take trips out of town as I feel necessary.	2.55	1.12
4	I am comfortable with how my self-care needs are met.	2.94	1.03
5	I spend most of my days occupied in work activity that is necessary or important to me.	2.45	1.18
6	I am able to participate in recreational activities as I want to.	2.48	1.06
7	I participate in social activities with friends/family and/or business acquaintances as is necessary or desirable to me.	2.61	1.02
8	I assume a role in my family which meets my needs and those of other family members.	2.65	1.11
9	In general I am comfortable with my personal relationships.	3.09	0.98
10	In general I am comfortable with myself when I am in the company of others.	2.71	1.10
11	I feel that I can deal with life events as they happen.	2.90	1.04

The mean scores of the individual items ranged between 2.25 and 3.09, with a standard deviation (SD) of 0.98–1.25 (Table 4.6). The high SDs indicate variation between participants' responses and thus the individual items required further analysis to determine the actual level of satisfaction of the participants. The highest mean score (3.09) was for Item 9: "In general I am comfortable with my personal relationships", with two-thirds of the participants scoring 3 (Mostly describes me or my situation) or 4 (fully describes me or my situation). Indicating, participants were mostly satisfied within their relationships.

The participants were least satisfied with Item 2: "I move around my community as I feel necessary" (lowest mean score 2.25 with a standard deviation SD of 1.15), followed by Item 5: "I spend most of my days occupied in work activity that is necessary or important to me", Item 6: "I am able to participate in recreational activities as I want to", Item 3: "I am able to take trips out of town as I feel necessary" and Item 7: "I participate in social activities with friends/family and/or business acquaintances as is necessary or desirable to me".

With regard to Item 2, although the mean score was 2.25, 35.5% of the participants scored 1 (does not describe my situation) and 58.1% of the participants combined scored 1 or 2. Only 19.3% reported that they moved around their community as they felt necessary (Figure 4.6). Indicating that more than half of the participants were not satisfied in terms of community mobility.

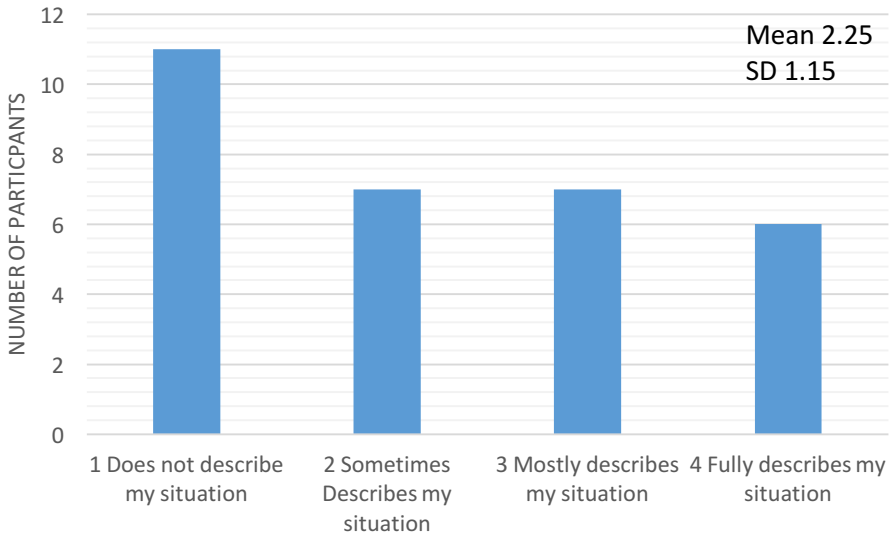

Figure 4.6 Item 2 "I move around my community as I feel necessary" (n=31)

Similarly, with regards to Item 5: "I spend most of my days occupied in work activity that is necessary or important to me", although the mean score was 2.45 (Table 4.6) more than half of the participants scored either a 1 (does not describe my situation) (29%) or a 2 (sometimes describes my situation) (23%).

4.3.2 Overall perceived satisfaction with community participation

The scores for the 11 individual items were added to establish a total RNLI score (maximum 44) per participant. The scores were then adjusted to a score out of 100. The adjusted total RNLI mean score was 66.6 (SD± 20.6 and range 25–100). These scores were used to establish the participants' overall perceived satisfaction with their community participation (Figure 4.7). A majority (48%) of the participants scored between 60–79, indicating perceptions of moderate restrictions to community participation. Severe restrictions in self-perceived community participation (score >60) were seen in 32% of the participants. Thirteen per cent perceived mild

restrictions to community participation and only 7% were fully satisfied with their community participation.

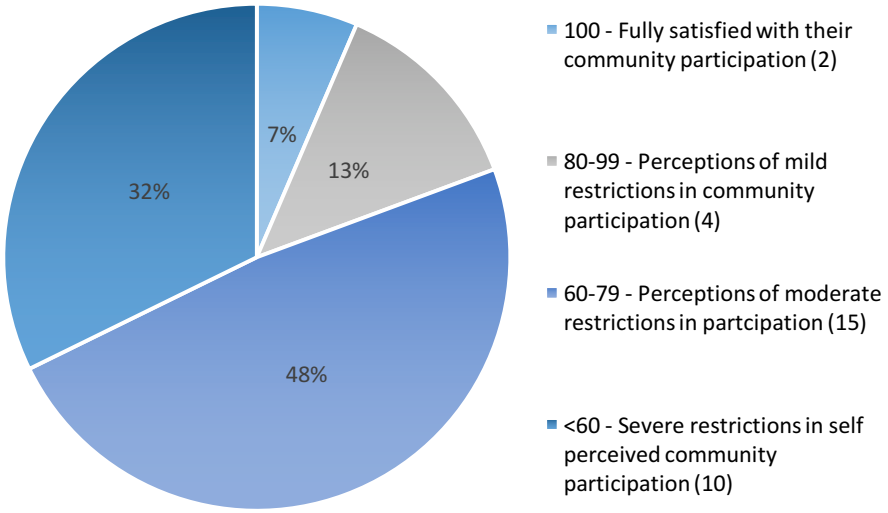

Figure 4.7 Percentage Distribution of Participants' Overall Perceived Satisfaction with Community Participation (n=31)

4.3.3 Sociodemographic factors that influence community reintegration

To establish the sociodemographic factors of the participants that influence the perceived level of community reintegration, distribution free tests - the Mann-Whitney U-test and the Kruskal Wallis test - were used to determine the equality of "two" or "three or more" independent sample medians respectively. A significant difference within the RNLI scores was seen in the following sample groups: type of injury, amount of assistance, community mobility and employment.

4.3.3.1 Type of injury

As demonstrated in Table 4.7, the RNLI total scores were significantly different ($p<0.05$) across the different types of injury: complete paraplegia, incomplete paraplegia, complete quadriplegia and incomplete quadriplegia. The median scores were calculated for each type of injury to establish which type had the highest score and which had the lowest score on the RNLI. Incomplete paraplegia had 35.00 and complete quadriplegia had 23.50. The higher the score, the better the patient's perceived reintegration, reflecting that the persons with incomplete paraplegia

perceived greater satisfaction with community participation and those with complete quadriplegia were the least satisfied with their level of community participation.

Table 4.7 Reintegration into Normal Living Index Scores and Type of Injury

Type of Injury	Median	Lower and Upper Quartile	p value (significant p<0.05)
Incomplete paraplegia	35.00	30.00 - 42.00	0.044
Complete paraplegia	30.00	15.00 - 33.00	
Incomplete quadriplegia	25.00	23.00 - 29.00	
Complete quadriplegia	23.50	19.00 - 28.00	

4.3.3.2 Assistance required

The RNLI scores differed significantly (p=0.010) among those participants that receive assistance, those that did not receive assistance and those that received occasional assistance to meet their needs (Table 4.8). The participants that did not require assistance had the highest median (40.00) scores, indicating that they perceived greater satisfaction with community participation than those who received occasional assistance and those who were dependent on others.

Table 4.8 Reintegration into Normal Living Index Scores and Assistance Required

Do you require assistance?	Median	Lower and Upper Quartile	p value (significant p<0.05)
No	40.00	32.50 – 43.50	0.010
Sometimes	33.00	28.00 – 34.00	
Yes	26.00	21.00 – 30.00	

4.3.3.3 Transportation

Significant differences (p=0.035) between the RNLI scores were noted between the five groups of community accessibility: drives private car, relies on friends and family for transport, uses taxis, accesses the community by walking/wheelchair and other means of transport.

Table 4.9 Reintegration into Normal Living Index Scores and Community Mobility

Community mobility	Median	Lower and Upper Quartile	p value (significant p<0.05)
Walk/wheelchair use	41.00	41.00 – 41.00	0.035
Drives car	33.50	30.00 – 39.00	
Taxi	32.00	32.00 – 32.00	
Friends and family	23.00	19.00 – 29.00	
Other	23.00	21.00 – 25.00	

The participants who either walk or use their wheelchair to access the community had the highest median score (Table 4.9), indicating the greatest perceived level of reintegration. However, this data is skewed as only one participant who accessed their community via walking or wheelchair use completed the RNLI. The data that is more representative is that those who drive themselves to access the community or use taxis are more satisfied with their level of community reintegration than those who rely on family/friends or other means of transport.

4.3.3.4 Employment

A significant difference in RNLI scores was established between those who were currently working and those who were not. The participants who were working at the time of the study had the highest median (33.00) scores, indicating that they perceived greater satisfaction with community participation than those who were not working (Table 4.10).

Table 4.10 Reintegration into Normal Living Index Scores and Employment

Are you currently working?	Median	Lower and Upper Quartile	p value (significant p<0.05)
Yes	33.00	32.00 – 41.00	0.028
No	28.00	23.00 – 30.00	

4.4 Environmental Barriers

The third objective of the study was to identify the environmental barriers to community participation by the participants using the CHIEF–SF (Appendix D). Thirty participants completed the CHIEF–SF.

4.4.1 Opportunities for community participation post spinal cord injury

As part of the CHIEF–SF participants were asked if they felt that they had had the same opportunities as other people to participate in and take advantage of 1) education, 2) employment and 3) recreation/leisure. As demonstrated in Table 4.11, the majority of participants indicated that following their SCI, they do not have the same opportunities as other people to participate in and take advantage of employment (65.4%; 34/52) or recreation (63.5%; 33/52). Opportunity for education appears to be less of an issue, with 53.8% of participants indicating that they have the same opportunity as other people in this regard.

Table 4.11 Opportunity for Participation in Employment, Education and Recreation

Following your SCI, do you think you have had the same opportunity for:	Percentage (n)	
	Yes	**No**
Education	53.8 (28)	44.2 (23)
Employment	30.7 (16)	65.4 (34)
Recreation/leisure	36.5 (19)	63.5 (33)

4.4.2 Environmental barriers reported by the participants

Figure 4.8 graphs the frequency, magnitude and product scores of each of the 12 items (environmental barriers) of the CHIEF–SF in descending order of product scores. The product score indicates the overall impact of the barrier. Thus, the greater the product score, the greater the impact of the barrier. A mean product item score between 1 and 2 implies that on average, each of the 12 items is confronted "monthly" and each item causes a "little problem", or alternatively is confronted less often but causes a "big problem". The top five environmental barriers reported by the participants overall are help at work/school (1.96), business policies (1.83), help at home (1.77), attitudes at work/school (1.42) and the natural environment (1.37).

When considering solely the frequency of the barriers experienced, barriers in business and government policies rank first (1.3), followed by help at home (1.27), help at work/school (1.21), barriers in the natural environment (1.17) and then attitudes at work or school (1.08). On the other hand, discrimination, health care and information ranked higher on the magnitude scale (0.77) than on the frequency scale (0.57). This indicates that barriers resulting from these items were relatively more problematic, though infrequent. At least one person reported maximum impact (score 8) for each environmental barrier.

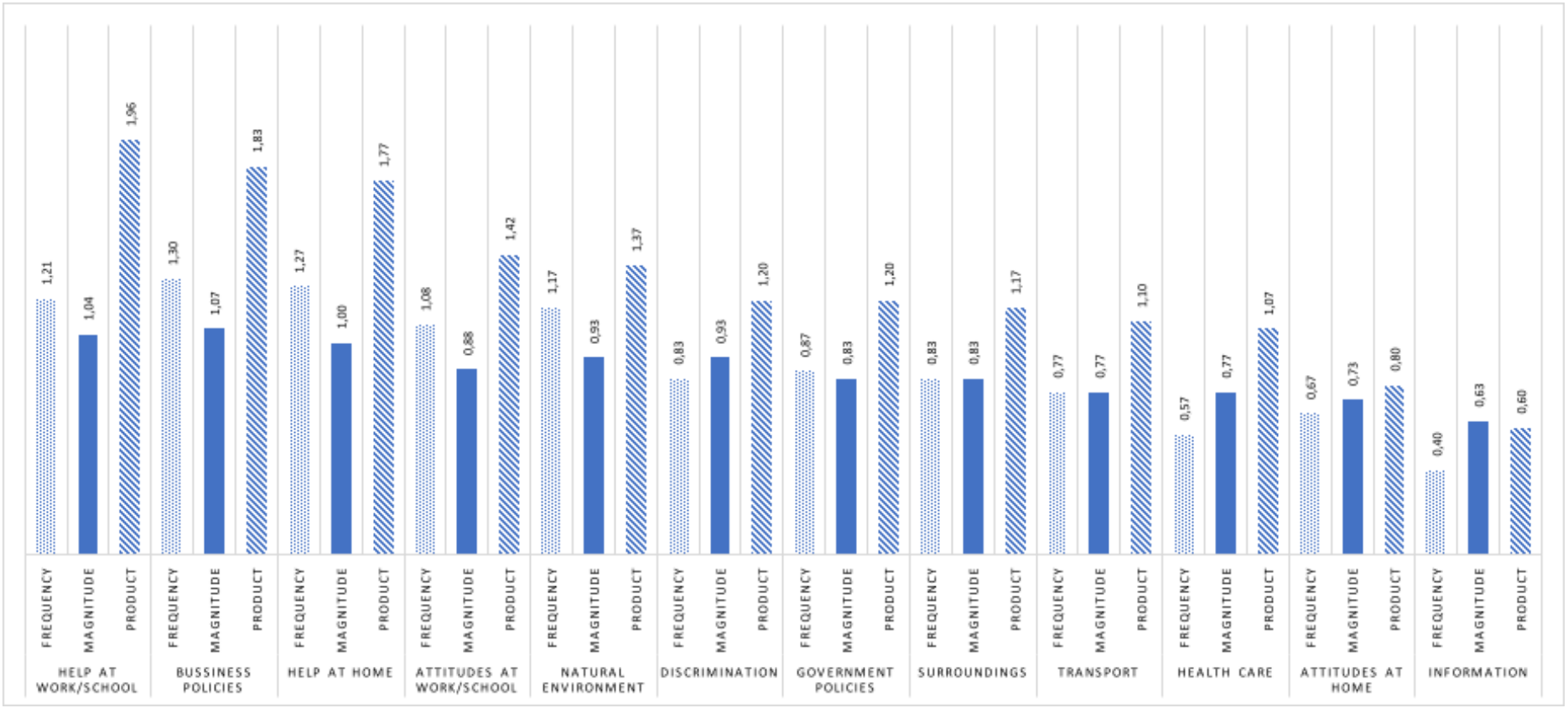

Figure 4.8 Craig Hospital Inventory of Environmental Factors-Short Form Item Average Frequency, Magnitude, and Product Scores in Descending Product Score Order

4.4.3 Average sub-scale scores

Figure 4.9 graphs the mean sub-scale scores of the perceived impact of environmental factors on CHIEF–SF. The participants reported that help and attitudes at work (the work/school sub-scale) were the most problematic (1.69), followed by barriers in business and government policy (the policies sub-scale) (1.52), barriers in transportation, help at home, health care and information availability (which make up the service/assistance sub-scale) (1.13), barriers in the natural environment and surroundings (the physical/structural sub-scale) (1.10), and attitudes at home and discrimination (the attitude/support sub-scale) (1.00).

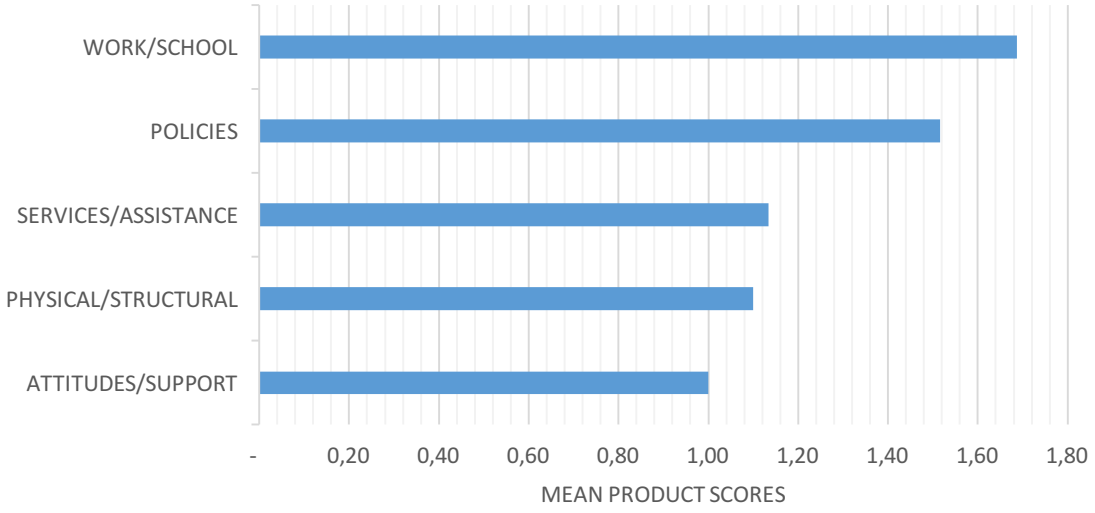

Figure 4.9 Craig Hospital Inventory of Environmental Factors–Short Form Sub-Scale Scores in Descending Product Score Order

4.4.4 Frequency distribution of Craig Hospital Inventory of Environmental Factors–Short Form total scores

Figure 4.10 shows the frequency distribution of the CHIEF–SF total scores of the sample (n=30). The total CHIEF–SF is the mean of up to 12 product (impact) scores. Only 6.7% of participants experienced no barriers (score of 0). Fifty per cent of the participants reported experiencing infrequent small barriers (scored 0-1). The remaining 42.3% scored more than one. Only one participant (3.35%) scored in the seven to eight range (7.67) – denoting great impact of all barriers of the CHIEF–SF.

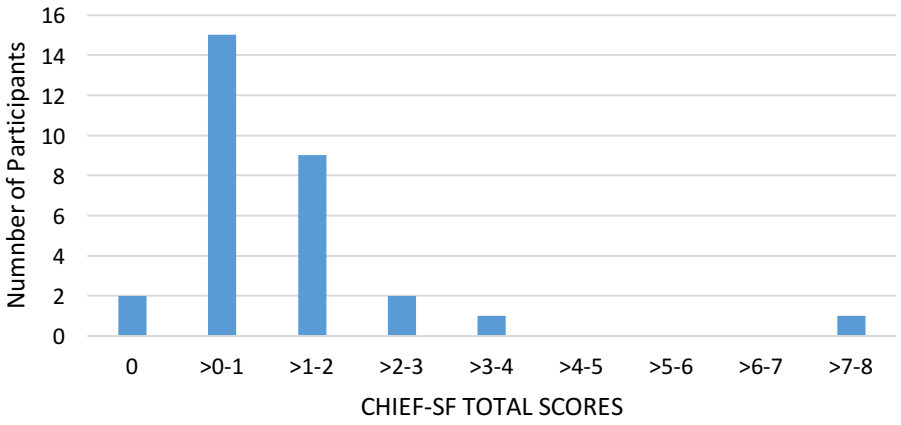

Figure 4.10 Distribution of Craig Hospital Inventory of Environmental Factors–Short Form Total Scores

4.4.5 Sociodemographic factors that influence environmental barriers

Significant difference within the CHIEF–SF scores was observed when using the Mann-Whitney U-test (two independent variables) for gender (p=0.043). No other variables elicited significant p-values. The median scores were calculated to establish which gender had the highest score and which had the lowest score on the CHIEF–SF – males scored higher than females (Table 4.12). On the CHIEF–SF, the higher the score the greater the impact of the barriers experienced, reflecting that males experienced greater barriers to community reintegration than female participants.

Table 4.12 Inferential Statistics: Gender

Gender	**Median**	**Lower and Upper Quartile**	**p value (significant p<0.05)**
Male	14.00	6.00 – 24.00	0.043
Female	3.50	1.00 – 14.00	

4.5 Summary of Results

This chapter used descriptive statistics to describe the findings of the study garnered from the sociodemographic profile, RNLI and CHIEF–SF to meet the objectives of the study.

The sociodemographic questionnaire was completed by 51 participants. The majority of the participants were male and in their thirties. All participants had received secondary or tertiary education. More than half of the participants were currently working, of whom 7.4% were self-employed. Paraplegia accounted for three-quarters of the participants. Motor vehicle/bike accidents were the most common cause of injury, followed by acts of violence (including gunshot wounds) and then falls. NTSCI accounted for approximately one-third of the participants. The majority of patients spent 6 to 12 weeks in hospital, with 12 weeks being the most common length of stay. The majority of patients were funded by a medical aid. Approximately one-third of the participants were receiving out-patient therapy. For those not receiving out-patient therapy, the most common reasons are lack of funding or transportation issues. More than a third of the participants had been readmitted to hospital post discharge due to complications. UTIs are the most common secondary complication. The majority of the participants required a wheelchair for indoor and outdoor mobility. More than half of the participants required a caregiver. Due to cost and lack of availability, only 44.2% had a caregiver. A family member was the primary caregiver in most of the cases. More than a third of participants required assistance with bowel and bladder and other personal needs. Lack of access to equipment was reported to negatively impact community participation. A change in living arrangements after the SCI was reported by most (67.3%) of the participants. The majority of participants lived with their spouse and/or children. Only a small majority (13.5%) of the participants lived alone. The majority of participants drove their own private car, while 38.5% of participants relied on their family or friends for transport.

With regard to the RNLI, the participants were most satisfied with their personal relationships and least satisfied with their community mobility. The majority of the participants scored between 60 to 79, indicating perceptions of moderate restrictions to community participation. Severe restrictions in self-perceived community

participation (score >60) were seen in 32% of the participants. Thirteen per cent perceived mild restrictions to community participation. Only 7% of the participants were fully satisfied with their community participation. Lastly, significant differences were seen in the RNLI scores in the following sample groups: type of injury, assistance required and community mobility.

The CHIEF–SF was used to identify the environmental barriers experienced by the participants. The five environmental barriers identified as having the greatest overall impact were: help at work/school, business policies, help at home, attitudes at work/school and the natural environment. The CHIEF-SF scores differed significantly between males and females, with males experiencing greater barriers to community reintegration.

The following chapter discusses the results presented in this chapter by linking the findings to local and international literature.

CHAPTER 5: DISCUSSION

5.1 Introduction

The aim of this study was to determine the sociodemographic and environmental factors that influence the level of community reintegration of persons with SCI who received private rehabilitation in Gauteng. This chapter discusses the key results of the study in relation to the objectives of the study and the available local and international literature related to the topic.

5.2 Sociodemographic Factors

The sociodemographic profile of the participants was established using a sociodemographic questionnaire (Appendix B). There is a large body of literature considering the sociodemographic profile of SCI globally; however, knowledge of the sociodemographic of SCI within South Africa to date is sparse despite efforts of the QASA to develop a national database through the “Bags of Hope” initiative in collaboration with Coloplast.

5.2.1 Personal Factors

5.2.1.1 Gender

The majority (63.5%) of the study participants were male (Table 4.1), which is in line with local (Hart 1994; Mothabeng 2011; Joseph et al. 2015; Sothmann et al. 2015; Enicker et al. 2015) and international literature (Wyndaele & Wyndaele 2006; Nunnerley et al. 2013; McCaughey et al. 2016; Rahimi-Movaghar et al. 2013). The gender distribution ration of 1.74:1 (male: female) is, however, much lower than that which has been previously reported, suggesting that the male population (although much greater than the female population) may be under-represented in this sample (Hart 1994; Mothabeng 2011; Sothmann et al. 2015) or represent a changing demographic profile given the increase in NTSCI.

5.2.1.2 Age

The mean age at injury was 38.2 years (SD= ±14,66), ranging between 15 and 85 years, with 53.9% and 5.7% of the cohort in the 18–39 and >65 age categories

respectively (Table 4.1). Although the mean age established in this study is slightly higher than that in other local literature – 33.5 (Joseph et al. 2015), 34 (Sothmann et al. 2015) and 29.19 years (Mothabeng 2011) – the NSCI SC (2016) reveals that the average age of SCI has increased from 29 years during the 1970s to 42 years currently. It is speculated that this is because people are living more active lifestyles way into their middle age. This could be further attributed to the increase of NTSCI, particularly associated with HIV/AIDS in South Africa. In line with local (Hart 1994; Mothabeng 2011; Sothmann et al. 2015) and international literature (McCaughey et al. 2016) the majority (75%) of participants were between the ages of 18 and 49 years – an age category typically characterised by economically active individuals.

5.2.1.3 Marital status

The marital status (Table 4.1) of the participants of the current study is representative of that described by the NSCI SC (2016). According to the NSCI SC (2016) more than half of persons with SCI in the USA are either single or never married, approximately 32.8% are married and 9.5% divorced at the time of the injury. As stated in Chapter 4, this study revealed that the majority (53.8%) of the participants were single, 36.5% married and 3.8% divorced. When compared to local literature, the percentage of persons with SCI who were single at the time of the injury is lower than that previously recorded (Mothabeng 2011). This may be explained by the fact that the age group of this sample is slightly older than that previously recorded. Results from previous studies in the USA have shown that the impact of disability in terms of social integration is greater, with lower life satisfaction, in persons with SCI who are single (Putzke et al. 2001). Putzke et al. (2001) further suggest that “being married” lessens the risk of social isolation and enhances adjustment post SCI.

5.2.1.4 Language and race

A majority of the participants in this study reported an African language (jsiZulu, isiXhosa, Sesotho, Sepedi, Setswana, Tshivenda or Tswana) as their home language, followed by English (30.8%) and Afrikaans (26.9%) (Table 4.1). It can be inferred that language is linked to race. According to the 2011 census, black Africans made up 64.21% of the Johannesburg population and 77.36% of the Gauteng population. This sample may therefore not be representative of the population, which

may be attributed to the fact that the research was based at a private medical facility with 88.5% of participants' in-patient stay at the hospital funded by a private medical aid (Statistics South Africa 2011). Data published by the Institute of Race Relations demonstrates that the majority of South Africans do not have medical aid, with only 10.5% of black Africans being covered compared to 72.7% of white people (Statistics South Africa 2016). This is linked to the socioeconomic crisis in South Africa, with 30.3 million persons living below the UBPL (R992 per month per person), of whom 64.2% are black Africans.

5.2.1.5 Level of education

None of the participants in the current study received no education, which was in line with Mothabeng's (2011) findings. However, the standard of education in the current study was higher, with the minimum level of education being Grade 8 and more than half of the participants reporting some form of tertiary education (Diploma 42.3%; Degree 13.5%). The higher level of education represented by the sample in this study may be indicative of the higher socioeconomic status of the participants in Mothabeng's (2011) study. The average number of years of schooling for adults in South Africa is currently 6.1, despite all South Africans having the right to a basic education with the nine compulsory years of schooling (Statistics South Africa 2017). A literature review by Anderson et al. (2007) emphasises the importance of education as a facilitator of returning to work post SCI, with less than 12 years of education placing one at a disadvantage for employment. Two of the participants in the study who form part of the "unemployed" group are enrolled at university. Anderson et al. (2017) highlights that engaging in educational activities post SCI has been associated with an increased likelihood of employment. This being said, return to school or university post SCI should be encouraged and/or facilitated during the rehabilitation process – an important role of the occupational therapist.

5.2.1.6 Employment and return to work

Anderson et al. (2007) report that the unemployment rate post SCI remains high, which has huge financial implications for the individual, their family and society. The current study has a high incidence (78.8%) (Table 4.2) of participants who were employed before their injury when compared to previous local literature (Mothabeng 2011), which is more than likely due to the setting of the study and the

socioeconomic status of the participants (for example, they have higher levels of education). A high percentage (82.9%) of those participants in the study who were previously employed returned to work post injury, which is almost double the number of those who returned to work in a previous study (Mothabeng 2011). A higher level of education has been associated with a higher socioeconomic status and greater opportunities for employment. Increased educational attainment favours engagement in professional, administrative and managerial jobs, which are more accessible post SCI than manual labour (Anderson et al. 2007). The employment rate at the time of the study, however, dropped to 65.9% (52% of the total sample population). Anderson et al. (2007) highlight the trend that many persons with SCI who are re-employed post injury terminate their employment at a later stage.

Research demonstrates that persons with SCI who are unemployed would like to go back to work, but perceive fewer opportunities and are faced with greater barriers to employment (for example transportation, societal attitudes and accessibility) (Anderson et al. 2007). In the current study, 65.4% of the population reported that they did not have the same opportunities as other people to participate in and take advantage of employment. Research has further demonstrated that those previously unemployed struggle to gain meaningful employment post injury (Anderson et al. 2007). Mothabeng (2011) established a significant association between employment before and after injury: it is not clear from the current study if any participant who was not working before the injury gained employment thereafter. A contributing factor to the reduced rate of employment post injury (especially with regards to those who were not previously working) may be owing to the fact that many companies lack or have poorly implemented internal policies targeted at recruiting and employing persons living with disability (Maja 2011). Other determinants of employment post SCI include: injury-related factors (severity of injury, time since injury, medical status and psychological state); personal factors (age, gender, marital status, race); environmental factors; and access to vocational rehabilitation (Anderson et al. 2007).

As described above, the majority of persons who sustain SCIs are of working age. Therefore the high incidence of unemployment post SCI, in conjunction with the cost of medical care (particularly pertaining to quadriplegia) post SCI, can have

detrimental socioeconomic effects on households and society as a whole (McCaughey et al. 2016). Re-employment has been linked to better adaptation post injury (Anderson et al. 2007). This is seen in the study findings, as the participants who were working at the time of the study perceived greater satisfaction with community reintegration than those who were not working. Due to the positive impact of employment on community reintegration, occupational therapists need to ensure that the return to work process is prioritised, addressed and facilitated during the rehabilitation process. The clinician not only needs to gain a sound understanding of the client, his/her motivation to return to work and abilities, he/she needs to identify the physical (structural and environmental) and social/attitudinal barriers to re-employment. A building may be accessible and the nature of the task may be administrative, but the employer may have negative attitudes towards persons with disabilities and make the work environment unfriendly or unconducive.

It is interesting to note that only four participants received government disability grants from SASSA. A disability grant is a social grant issued to persons between 18 and 59 years who are medically unfit for work due to a mental or physical disability (RSA 2017). The maximum value of the disability grant is R1 600.00 per month and is based on a means test (value of assets and income). Almost 20% of the participants reported having no form of income. Their eligibility for a grant is unknown to the researcher. It is essential for the rehabilitation team, usually the social worker or the vocational therapist, to empower individuals living with a disability to know their rights and provide them with the information or the ability to access information such as that for a SASSA grant.

5.2.2 Injury- and medical-related factors

5.2.2.1 Aetiology

The causes of injury (Table 4.3) in this current study were both traumatic and non-traumatic, with traumatic accounting for the greatest percentage (73.1%), which is in line with local (Mothabeng 2011; Hart 1994; Draulans et al. 2011) and international literature (Wyndaele & Wyndaele 2006; WHO & ISCOS 2013). The percentage of NTSCI in the present study is greater than that previously recorded in South Africa – 19.4% (Mothabeng 2011) and 11% (Hart 1994). The variances in figures may be due

to the different study locations or may potentially represent a steady incline in NTSCI. As mentioned in Chapter 2, a rise in the incidence of NTSCI is anticipated in both developed and developing countries due to the increasing age of the population and the rise in opportunistic diseases due to HIV/AIDS (New et al. 2014; WHO & ISCOS 2013).

The main cause of TSCI in the current study was MVAs (44.2%). This is in line with Sothmann et al. 2015, Mothabeng 2011 and Draulans et al. 2011, who conclude that MVA/RTAs were the most common cause of TSCI in South Africa, as well as Cripps et al. (2011) and WHO & ISCOS (2013) who reported RTAs to be the most common cause of TSCIs worldwide. According to the Automobile Association, 2016 saw 14 071 people die on South Africa's roads with Gauteng having the highest percentage of road fatalities (Road Traffic Management Corporation (RTMC) 2016). The RTMC (2016) reports that human factors account for 77.5% of road crashes and fatalities, while vehicle factors and road and environmental factors only account for 6% and 16.5% respectively. The human factors that lead to road accidents include jaywalking pedestrians (38.8%), hit-and-run crashes (18.5%), high speed (14.1%), overtaking in the face of oncoming traffic (6.9%), drunk driving or driving while on drugs (3.6%) and driver fatigue (2.2%) (RTMC 2016). Draulans et al. (2011) previously reported that the high number of RTAs in Southern Africa (including South Africa) can be attributed to the increasing number of vehicles without infrastructure accommodation, vehicles not equipped with safety belts or safety belts not being used and transporting people in open bakkies or lorries.

In the current study, acts of violence only accounted for 13.4% of injuries, which is significantly lower than that reported by Joseph et al. (2015), Enicker et al. (2015) and Hart (1994) – all of whom found violence as the greatest cause of injury. Joseph et al. (2015) report that approximately 60% of all TSCIs reported in the city of Cape Town were due to assault, followed by MVAs (26%). Lee et al. (2014) report that South Africa has the highest incidence of gunshot wounds in the world, and according to Joseph et al. (2015) violence-induced injuries are the second leading cause of death in South Africa. The differing results may be because the hospital in this study was based on a private facility, while the studies of Joseph et al. (2015) and Enicker et al. (2015) were based on government facilities. Much violence occurs

in underdeveloped, overpopulated and empoverished areas such as townships, and thus persons of lower socioeconomic status who do not have medical aid are at higher risk of injury resulting from violence. It can be speculated that government medical facilities treat many more injuries resulting from violence than do private facilities.

According to the WHO & ISCOS (2013), falls are the second leading course of TSCI worldwide. Falls only accounted for 7.7% of injuries in the current study, which is in line with WHO & ISCOS (2013) who report that African regions have the lowest percentage of falls. According to Nair (2005), TSCI is more common in men than women. This finding was supported in the current study, with 87.9% of males and 52.6% of females presenting with TSCI. McCaughey et al. (2016), however, report a higher incidence of SCI due to falls in women over 65 years of age. This is in line with the current study's findings, where all injuries in people over 65 years were in women and attributed to falling in the home. WHO and ISCOS (2013) found that low falls become the most common cause of SCI after the age of 60 years.

With regard to NTSCI, the aetiology is highly varied. The current study's findings are in line with Nair (2005), Godlwana et al. (2008) and Mothabeng (2011), with the most frequent causes of NTSCI being TB spine, transverse myelitis and tumours. Research in sub-Saharan Africa by New et al. (2014) reported high rates of TB and HIV-related NTSCI. The WHO (2011) report that the HIV–TB co-infection rate in South Africa is high, and a growing number of persons in South Africa are sustaining SCIs as a result of HIV-related diseases such as TB spine – posing new challenges to SCI rehabilitation, as those persons with NTSCI tend to be more susceptible to secondary complications such as bladder infection and are associated with a longer hospital stay (New et al. 2014). Nair et al. (2005) report that the ratio of men to women is more equal in NTSCI than TSCI; furthermore, Draulans et al. (2011) report that it occurs more in men than women.

Neither of these findings were represented in the current study, with a gender distribution ratio of 1:3.92 (male: female) for NTSCI. This finding was more in line with Godlwana et al. (2008), where 58% of those with spinal TB were female. Draulans et al. (2011) further report that the average age in the USA for TSCI (38.6 years) was significantly lower than NTSCI (61.2 years). Within the current study,

although the average age (38.6 years) for TSCI was representative, it was not much greater than that of NTSCI (36.8 years). This may suggest a rise in HIV-related infections causing SCI in a younger South African population.

As mentioned in Chapter 2, SCI mortality rates (calculated as death in the first year after injury) differ significantly between countries and within countries, ranging from 4.0% (North America) to 84.0% (West Africa) (ISCOS 2010). No reports documenting the mortality rate for South Africa were found. Within the current study 8.4% (14 persons) of the total population (166 persons) had died within the first year of discharge. This percentage may be lower than the actual mortality rate, as the researcher was unable to contact 48 of the participants. Of the deaths three were due to suicide, one to cancer and one to a pressure ulcer. The remaining nine causes of death are unknown to the researcher. Dijkers (2004) reports that the rate of suicide in the SCI population is greater than in the population at large, with the causes varying from a rational decision to depression.

5.2.2.2 Level and nature of injury

Paraplegia outnumbers quadriplegia in both the TCSI and NTSCI cohorts, with the majority of injuries sustained by the participants in this study being incomplete (Table 4.3). This is representative of the international literature, in which it was found that paraplegia accounts for 55% to 75% of all SCIs, with the majority being incomplete (Draulans et al. 2011; Wyndaele & Wyndaele 2006). To the contrary, a study in Cape Town (Joseph et al 2015) found assault (59.3%) to be the main cause of injury reported and that spinal injury to the cervical region of the spinal cord was the most common (53.1%). Interestingly, despite the high number of incomplete injuries (with research indicating greater potential for recovery) in the current study, 71.5% of the participants were still dependent on wheelchairs for indoor and outdoor mobility.

5.2.2.3 Length of stay

Most of the patients were admitted to the spinal unit at Netcare Rehabilitation Hospital for a period of 6 to 12 weeks (Figure 4.1). A decline in rehabilitation length of stay has been noted in the USA – from 98 days in the 1970s to 36 days currently (NSCI SC 2016). The researcher was unable to find local literature regarding the average length of stay of persons with SCI in private in-patient rehabilitation facilities.

The only data available regarding length of stay post spinal cord injury in South Africa was in a study at Groote Schuur Hospital Acute Spinal Cord Injury Unit, Cape Town (Sothmann at al 2015). The average length of stay was 28 days with a majority (64.2%) of the patients staying for more than one month, 21.9% for one to two months, 6.1% for two to three months and 7.5% for greater than three months (Sothmann at al 2015). These stats however are gained from a Government hospital and not characteristic of the current study population and setting. As there is no consensus concerning the optimal length or intensity of rehabilitation for persons with SCI, the decision is placed on the treating clinicians and can vary significantly between clinicians and facilities (Lamontagne et al 2013). As per the researcher's experience working in the spinal unit at Netcare Rehabilitation Hospital, 12 weeks and 24 weeks of intensive in-patient rehabilitation is typically recommended for paraplegia and quadriplegia respectively, bar any significant medical complication. Patients funded by WCA tend to receive the recommended length of stay. The lengths of stay persons with medical aid vary drastically dependent on the patients' medical aid scheme/plan and or rate of recovery reflected in weekly reports. Although not available in local literature, a decrease in medical aid patients' length of stay has been noted by health practitioners. In this way, patients are often discharged home to inaccessible environments, with poor levels of independence and often without equipment due to delayed authorisation or limited funds.

5.2.3.4 Secondary complications

In the current study, more than a third of the participants had been readmitted to hospital at least once subsequent to their discharge from rehabilitation, due to a secondary complication. Medical complications and hospital readmission have been shown to interfere with re-employment post injury, are associated with lower levels of life satisfaction (Anderson et al. 2007; Tonack et al. 2008) and lower scores on the RNLI (indicating less satisfaction with community participation) (Hitzig et al. 2012; Tonack et al. 2008). In line with recent international literature (Monaliza et al. 2017), UTIs were the most common complication. This was followed by pressure ulcers in the current study, which were the most common complication in the study by Mothabeng (2011). Neither the severity nor the effects of secondary complications on participation were explored in this study (i.e. whether those who had had a pressure ulcer perceived lower levels of satisfaction with community participation).

These factors should be considered for future research within the South African context.

5.3 Community Reintegration Post Spinal Cord Injury

The level of community reintegration of the participants was determined using the RNLI (Appendix C). Research has indicated that levels of perceived satisfaction with social and community participation are strong determinants of quality of life post SCI (Dijkers 1997). This chapter further discussed the sociodemographic factors that influenced the level of community reintegration of the participants.

Within the current study, the majority of the participants perceived moderate to severe restrictions in community participation as per their overall mean RNLI scores (Figure 4.7), indicating a relatively poor overall satisfaction with their level of reintegration. The findings revealed that the participants were most satisfied with their personal relationships/friendships (m=3.09) and least satisfied with their community mobility (m=2.25), followed by work/productive activity (m=2.45), recreational activity (m=2.48), travel/taking trips (m=2.55) and social participation (m=2.61) respectively. The two participants of the sample population who were fully satisfied (100/100) with their community reintegration were female, incomplete paraplegics who are walking, drive a private car and have returned to work since the injury. This result speaks to the findings that paraplegics (particularly incomplete paraplegics) (Mothabeng 2011) and re-employment post injury have been linked to better adaptation post injury (Anderson et al. 2007) and that women tend to be more satisfied with their level of community reintegration post SCI than men (Whiteneck et al. 1999). In practice however, this is not always the case as often persons living with SCI do not regain such high levels of mobility (such as walking) due the level and extent of their injury. Further, although not reflected in this study, most patients or persons living with SCI in SA cannot afford a private car and the public transportation services (such as mini taxis) are not easily accessible for persons in wheelchairs and costly for persons who are mostly unemployed.

Four sociodemographic factors were found to be significantly associated with community reintegration in this study: type of injury (p=0.044) (Table 4.7), level of independence (assistance) (p=0.010) (Table 4.8), transportation (p=0.035) (Table

4.9) and employment (0.028) (Table 4.10). Persons with paraplegia were more satisfied with their level of community reintegration than persons with quadriplegia, persons with incomplete paraplegia being the most satisfied and persons with complete quadriplegia the least satisfied. Mothebeng (2011) found that the level of injury was significantly related to RNLI scores, with persons with lumbar injuries scoring higher on the RNLI than those with thoracic and cervical injuries respectively. It appears that persons with paraplegia experience greater levels of satisfaction with perceived community participation and overall reintegration. The fact that persons with complete quadriplegia experience lower levels of community participation post injury may relate to Anderson et al.'s (2007) finding that persons with complete cervical lesions are less likely to return to work post injury. Return to work post injury has been associated with greater satisfaction with community reintegration (Anderson et al. 2007). Although not explored in this study, persons with paraplegia tend to have better functional outcomes than those with quadriplegia (Mothabeng 2011) and satisfaction with community participation is perceived as lower in those experiencing functional decline (Tonack et al. 2008). Although Tonack et al. (2008) do not discuss type of injury as a factor contributing to community participation, they identified injury duration as a contributing factor with "increased time since injury" positively related to the RNLI. This was not explored in the current study.

With regard to the level of independence (Table 4.8), the participants who were independent perceived greater satisfaction with community participation than those who received occasional assistance and those who were dependent on others, respectively. This could relate to the finding by Tonack et al. (2008) that satisfaction with community participation increases with functional independence. This being said, the high levels of dissatisfaction with community reintegration in the current study (the majority of participants experiencing moderate restrictions as per the total scores on the RNLI) could be exacerbated by the large number of participants being dependent on a caregiver or requiring some level of assistance for personal management (decreased functional independence), meaning one is dependent on another for personal management, particularly bowel and bladder management. As mentioned in Chapter 2, bladder and bowel dysfunction is a common factor that impedes community or social participation (Amsters et al. 2016). It often results in persons with SCI avoiding public exposure or engagement in recreational activities

(such as going to the gym or movies) in case of embarrassment (Callaway et al. 2015). Lack of independence in terms of bowel and bladder becomes problematic when considering the return to work process and may hinder successful reintegration into the workplace. Furthermore, many of the participants who required assistance from a caregiver reported that they could not afford one. The cost of a caregiver in South Africa ranges from approximately R50 to R120 per hour for a weekday. The high cost of care (especially if one is reliant on the R1 600 SASSA grant) results in many of the participants relying on a family member for assistance. This places a huge emotional burden on family members and can affect life roles; for example, a wife becoming a carer may alter the way in which she views her husband. “When a partner or family member takes on caregiver duties for the person with SCI, this has been suggested as potentially deleterious to some relationships” (Amsters et al 2016:6).

With regard to transportation, the ability to drive one’s own car acts as a facilitator for social activity and community participation (Carpenter et al. 2007). Participants in the current study who accessed the community via private car were more satisfied with their level of community reintegration than those who relied on family/friends or other means of transport (Table 4.9). This is supported by Putzke et al. (2001), who found that satisfaction with transportation was enhanced by owning a car. Most participants in the current study were reliant on friends, family or public transport to access the community. This links with the fact that the participants were least satisfied with community mobility, and may contribute to the dissatisfaction with travel (taking trips) out of town. Mothabeng (2011) reported that public transport in South Africa poorly accommodates persons who use wheelchairs and states that driving your own car in South Africa enhances community participation and perceived level of community reintegration. With this being said, occupational therapists should focus on community mobility post SCI within a person’s unique environment and prioritise return to driving when appropriate to reduce the effects of ‘transportation’ as a barrier to reintegration. Further, occupational therapists need to work together with persons with disability to advocate for reasonable accommodations to make public transport more accessible and affordable for persons with disability, particularly persons using wheelchairs.

Lastly, the participants who were employed at the time of the study scored higher on the RNLI, indicating that they perceived a greater level of community reintegration (Table 4.10). This supports Mothabeng's (2011) finding that employed participants are more likely to be satisfied with their level of participation in the community than the unemployed participants. Similarly, Tonack et al. (2008) found employment status to be a significant contributor to satisfaction with community participation and level of reintegration. Anderson et al. (2007), identify time since injury as an important employability factor post SCI. This links with the finding by Tonack et al. (2008) stated above – that satisfaction with community participation is directly correlated with time since injury. Although not explored in the current study, Tonack et al. (2008) further found psychological complications and perceived health as significant contributors to community reintegration and to life satisfaction.

5.4 Environmental Barriers to Participation

Joseph et al. (2016:1375) identified "journey dominated by obstacles" as an emerging theme in a qualitative study in the city of Cape Town, with "obstacles" being explained as changes in one's body function within unconducive environments preventing participation. These environments, riddled with barriers to participation, have been demonstrated to have greater impact on community participation than impairments of body function (Joseph et al. 2016). This section discusses the environmental barriers to community participation of the participants using the CHIEF–SF.

The top five environmental barriers (as per the product score of individual items) were, in descending order, help at work/school, business policies, help at home, attitudes at work/school and the natural environment (Figure 4.8). Relatively less frequent were barriers posed by access to information, access to health care, attitudes at home, transportation and the surroundings. Infrequent access to information, discrimination and heath care scored higher on the magnitude scores, indicating that when they do occur (although not frequent) they are relatively more problematic.

The barriers identified in this study differ somewhat from the SCI literature – particularly pertaining to the natural environment and transportation. Whiteneck,

Harrison-Felix, Mellick et al. (2004) identify attitudes at work/school, natural environment, policies of businesses, information and help at work/school to be the greatest barriers. Whiteneck, Meade, Dijkers et al. (2004) identify barriers in the natural environment, transportation, help at home, health care, and government policy as having the greatest impact, while Lysack et al. (2007) report that the greatest barriers identified were the natural environment, government policies, transportation, access to health services and attitudes at home. With regard to local literature, Mothabeng (2011) and Visagie et al. (2017) – more in line with international literature than the current study – establish transportation and the natural environment as two of the greatest barriers in South Africa.

When considering the mean product score (0.06 to 1.96) of each item compared with the possible scale range of 0 to 8, it appears that these levels of barriers identified in the current study are low. However, it must be noted that most of these scores are greater than those previously reported in local literature (Mothabeng 2011) and although not conducted in this study much greater than those of persons without physical disability (Whiteneck, Meade, Dijkers et al. 2004). Although Mothabeng (2011) reports a mean product score of 2.06 for transportation, transportation was much less of a barrier in the current study (mean score of 1.10). This may be attributed to the fact that the current study population is of a higher socioeconomic status and fewer participants relied on public transport. More than 50% of the participants that completed the CHIEF-SF indicated on the sociodemographic profile that they drive their own car to access the community. As stated above, participants who accessed the community via private car were overall more satisfied with their level of community reintegration than those who relied on family/friends or other means of transport (Table 4.9). Mothabeng (2011) reports discrimination as having the second-greatest impact (mean product score of 1.32), which is more representative of that identified in the current study (mean product score of 1.2 which ranked sixth). The remaining items' mean product score in the study by Mothabeng (2011) ranged between 0.13 and 0.73, which is relatively low in comparison to those of the current study in which the barrier with the least impact ('Information') has a mean product score of 0.6. The level of impact of barriers demonstrated in the current study is representative of that identified in international literature by Lysack et al. (2007), whose mean product scores ranged between 0.61 and 2.75. However, the

greatest barriers identified by Lysack et al. (2007) differ, as mentioned above. The mean product scores of the current study were also much greater than those reported by Whiteneck, Harrison-Felix, Mellick et al. (2004) and Whiteneck, Meade, Dijkers et al. (2004). In addition, Whiteneck, Harrison-Felix, Mellick et al. (2004) found that 20% of their sample experienced no barriers (score of 0) and 75% of the participants scored less than one, indicating that three-quarters of their sample experienced infrequent small barriers. In contrast, in our sample 6.7% scored 0 and 50% of the participants scored less than one, with the remaining 43.3% scoring more than one (indicating a greater impact of barriers on a greater percentage of the current sample population).

Similarly, to transportation, barriers to the natural environment ranked in the top two in local and top five in international literature and only placed 5th according to the CHIEF-SF results in the current study. These differences are potentially attributed to the higher socioeconomic status of the participants of the current study. Due to the environment in which the current participants reside (more affluent areas), they may not be as affected by the natural environment such as 'rough terrain and weather conditions'. The differing results within these different contexts emphasise the importance of identifying the unique environmental barriers within different contexts – one should not simply generalise results from one context to another. This is of clinical relevance to practitioners working in both private and public sectors as one needs to fully understand the environment in which their patients reside to ensure adequate skill attainment and the issuing of suitable equipment, to optimise reintegration.

The trend that many persons with SCI who are re-employed post injury terminate their employment at a later stage (as mentioned in 5.2.1.6), potentially speaks to the finding that help at work, business policies and attitudes at work are three of the top five environmental barriers (Figure 4.8) – similar findings by Whiteneck, Harrison-Felix, Mellick et al. (2004) as indicated above. Persons living with SCI may not be able to keep up with the physical demands and rules at the workplace (including getting to work on time, sitting for prolonged periods, typing or writing speed, deadlines etc.) and/or work at a slower pace than their colleagues. Many persons continue to rely on assistance form a caregiver or a family member at home and thus

returning to work on an independent basis becomes difficult. Persons living with SCI (particularly quadriplegia) may continue to require assistance with transferring into and out of a car, accessing elevators, pushing up and down ramps and over longer distance, toileting and making tea/lunch. This help may not be readily available at work and is dependent on the person's relationships with colleagues and the capacity for others to aid. Relationships post injury may shift – according to Amsters et al (2016), some friends (or colleagues) "simply cannot cope with the changes associated with maintaining a relationship with a person with SCI". Another potential reason for termination of employment may be that the persons living with SCI, may have to downgrade their job (due to physical ability or reasonable accommodation agreements) at the workplace and may feel less valued and/or be dissatisfied from an intellectual point of view of the new/adjusted role. With regards to attitudes at work – people without disabilities often view people with disabilities as inferior (Maja et al 2011). These negative impressions can foster discrimination in the workplace and contribute to poor working conditions and ultimately resignation (Maja et al 2011). For these reasons business legislation and policies are vital in overcoming segregation and discrimination of persons living with disability at work. However, although these policies and guidelines are in place they are often poorly implemented (Maja 2011).

An interesting finding is that the participants identified "social support" (help at work/school and help at home) or lack thereof as the greatest barrier, as well as the greatest facilitator to community participation. This is in line with Carpenter et al. (2007), who state that help and support from family members and friends facilitates participation at home and in the community. "Given the challenges of living with an SCI, isolation from family and lack of supportive relationships clearly makes it difficult for these people to fully engage in community participation" (Carpenter et al 2007:431). Carpenter et al (2007), noted that those people living alone were less satisfied with their perceived level of support from others. They expressed the lack of people to share their joys and achievements with, aid in decision making and to ask for assistance when need (Carpenter et al 2007). Similarly, Putzke et al. (2001) indicate that persons with SCI who report greater support, for example at home/work or school, that provides increased social integration have lower levels of depression. Lower levels of psychological issues are positively associated with higher levels of

community reintegration, and social support is an important predictor of physical and mental health as well as quality of life post SCI (Geyh et al. 2012).

With regards to the built environment, although not included in the CHIEF-SF, 63.5% of participants reported on the sociodemographic profile (Appendix B) that the design and layout of buildings and public places in the community make it difficult for them to do what they need to do. More than a third of participants reported that wheelchair accessibility in public places was the greatest barrier to community participation. This supports that, despite adequate legislation in place such as The National Building Regulations and Building Standards Act (Act 103 of 1977), many buildings and public spaces continue to be inaccessible to persons with disability. This highlights the fact that intervention needs to extend beyond the physical and immediate needs of clients - clinicians need to play a role in the advocacy of the rights of persons living with disability and the implementation of policy.

Lastly, Gender was the only sociodemographic variable significantly associated with the CHIEF–SF in this sample and no injury-related factors were significantly associated. The current research demonstrates that males experience greater barriers to community reintegration than female participants. This is in line with international research, which indicates that women perceive greater levels of community reintegration post SCI (Whiteneck et al. 1999). This result may owe to the fact that male and female occupations and roles tend to differ. Although, gendered occupational roles are shifting, traditionally, males leave the house to fulfil their roles (i.e. employment) and females stay at home to care for the children and/or manage the home. According to Whiteneck et al (1999:1490), post injury “females are more likely to return to homemaking roles, while males are less likely to return to salaried employment”. Thus, females may be more content or satisfied not fully reintegrating into the community (i.e. not returning to work) or may achieve a premorbid level of community participation sooner than males. Males may only be content once independent and back at work due to their premorbid roles and expectation – often associated with being the bread winner. It is important for clinicians to acknowledge the occupational differences between male and females in the rehabilitation process. This can be done through establishing a sound premorbid occupational profile of the clients to ensure that therapy is targeting the client’s specific needs and desires. In

contrast, Lysack et al (2007) found none of the sociodemographic or injury variables to be significantly associated with the CHIEF however, they reported that women and African-Americans experience greater environmental barriers. Although not studied in the current study - Mothabeng (2011) concludes that black African participants scored lower than the non-black participants, with Caucasians being the most satisfied with their level of reintegration. In South Africa, this may still be attributed to the dire effects of apartheid with 64.2% of all black Africans living below the upper-bound poverty line (UBPL).

5.5 Implications of the Research for Practice

Despite community reintegration becoming a significant area of clinical, policy and research concern, literature regarding this continues to be sparse, particularly in developing countries, with the majority of the literature focusing on impairments and activity limitations rather than participation (Barclay et al. 2016). The leaders in this field state that more research on the role of environmental factors in the lives of people with SCI would be beneficial, aid successful intervention and guide policy revision and potentially implementation (Whiteneck, Meade, Dijkers et al. 2004; Barclay et al. 2016). According to the researcher's knowledge, only two studies of the SCI population incorporating the concept of community reintegration or the perceived barriers to participation in South Africa have been conducted – both of which were in different contexts to the current study (Mothabeng 2011; Joseph et al. 2016).

This study provides insight into the level of community reintegration perceived by the participants post SCI and identifies key environmental barriers to community participation in Gauteng – which differ from those previously emphasised in South Africa. A greater emphasis on social support and the attitudes of others at work/school and home, as well as business policies, was noted (more so than before). Although the natural and built environment features as one of the top five barriers to participation, it was not as prevalent as previously recorded. Furthermore, transportation was reported as having less of an impact than one would assume. This may be due to the current study's population which is possibly a sample of persons with a higher economic status.

These findings highlight the importance of identifying and understanding barriers to participation within the unique contexts in which they exist and dealing with them accordingly (Hammell 2010; Sekaran et al. 2010). The results of this research, as well as that of Mothabeng (2011) and Joseph et al. (2016) could act as a platform on which future research can build to better understand the factors influencing reintegration back into the community of persons with SCI. This understanding will guide clinical practice to ensure intervention adequately prepares individuals for the transition from the hospital to "real life" and will assist in identifying shortfalls in terms of policy implementation. It will also aid in identifying areas of most concern that need to be address at a political level. Persons with disability should be able to participate freely, without limitation, within the community. "The new South Africa should be accessible and open to everyone. We must see that we remove the obstacles. Only then will the rights of disabled persons to equal opportunities become a reality" (RSA 2016:49). It is the role of occupational therapists and other health professionals to empower persons with disability and work collaboratively in creating barrier-free, facilitating environments to optimise the reintegration of all persons with impairment or disability.

5.6 Dissemination of Results

The results of this study will be shared with the Department of Health, rehabilitation facilities, occupational therapists and other allied health professionals, as well as persons living with SCI, through reports and conferences (for example the South African Spinal Cord Association posters or presentations).

5.7 Study Limitations

Although the findings garnered by this study highlight significant restrictions to community participation post SCI, the findings represent a small sample from one rehabilitation centre in Gauteng and thus cannot be generalised to the SCI population in Gauteng, South Africa. As the minimum sample size for the study's population was not met, the sample (54) is not even a representative sample of individuals rehabilitated at the participating centre. The study sample was significantly diminished by the number of people who were uncontactable due to incorrect numbers and phones on voicemail or who no longer lived in South Africa.

The findings may be skewed, since only those with a telephone and access to the internet could complete the survey. Thus, it was more likely that persons of high socioeconomic status or who are employed (52%) completed the survey. For this reason, the study's findings should be interpreted with caution.

Another limitation to the study was the survey design on REDcap. Participants only completed one of three questionnaires that comprised the survey. Many persons did not complete the RNLI or and CHIEF–SF, further decreasing the generalisability of the results of these two instruments. A way to overcome this would have been to allow all the questions of each of the three questionnaires to follow on from one another.

Furthermore, as the researcher was a clinician at the hospital used in this study, some of the participants may have had a relationship with her (as their occupational therapist), which may have influenced responses to the questions.

Lastly, the CHIEF–SF and RNLI instruments are brief numerical scales and cannot be expected to fully describe participation and environmental barriers experienced. They can, however, be used as a starting point at which comprehensive evaluation can occur. Furthermore, although in line with the objectives of this study, the CHIEF–SF only considers the environmental factors as barriers and does not identify those factors that act as facilitators to participation. To enhance community participation post SCI, one can aim to remove barriers but should also create environments that facilitate participation. Lastly, both instruments were developed internationally and little literature regarding their sensitivity to the South African context is available, specifically with regard to the CHIEF–SF.

5.8 Summary of Discussion

This chapter discussed the findings of this study as set out in Chapter 4 (Results) in terms of the sociodemographic factors of the participants, their perceived level of community reintegration as per the RNLI and the environmental barriers to participation they experienced as per the CHIEF-SF by linking to local and international literature related to the topic. In line with local and international literature, the sociodemographic profile revealed that the participants of the current

study were predominantly male between the age of 18 and 49 years – an age category typically characterised by economically active individuals which has profound consequences at a personal, familial and societal level. Traumatic SCIs were more common than NTSCIs, with RTAs being the most prominent aetiology. Most of the participants were incomplete paraplegics and just more than half were currently employed. The education level and employment rate was higher than that previously recorded in SA literature and may be representative of a higher socioeconomic status of participants. A trend that many persons with SCI who are re-employed post injury terminate their employment at a later stage was noted and may be resultant of a lack of help at work (ranked 1st in terms of magnitude of barrier), business policies (rules and regulations) (ranked 2nd) and the attitudes of others at work (ranked 4th) – which were identified as three of the top five environmental barriers to community reintegrating. The other two environmental barriers identified by the CHIEF-SF were help at home (ranked 3rd) and the natural environment (ranked 5th). Gender was the only sociodemographic factor that was found to influence perceived environmental barriers – with females reporting less barriers to participation than males. This is potentially owing to gendered specific occupational roles – with females more likely to return to homemaking roles, while males are less likely to return to salaried employment. Overall, according to the total RNLI scores, the participants experienced moderate restrictions to community reintegration. The sociodemographic variables that demonstrated significant relationship with the RNLI scores were: type of injury, employment status, means of transportation and independence. Those living with incomplete paraplegia who were employed, drive a private car and were independent at the time of the study, perceived greater satisfaction with community participation.

This chapter further discussed the implications of this study for future practice, particularly pertaining to the importance of identifying and understanding the influencing factors to participation within the unique contexts in which they exist and dealing with them accordingly to optimize community reintegration post injury. Lastly, the limitations pertaining to the current study were highlighted.

The next chapter concludes the study and provides recommendations for clinical practice and future research.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

This chapter summarises the previous chapters, highlighting the key findings and conclusions of the study. It further suggests recommendations for clinical practice and future research.

6.2 Conclusion

Due to the profound consequences of SCI at a personal, familial and societal level (WHO & ISCOS, 2013), community reintegration post injury has emerged as a highly regarded focus of the rehabilitation process and is often used as an indication of effective intervention (Magasi et al. 2008; Hammel et al. 2008). Research has indicated that following an acquired disability, life satisfaction is enhanced through participation in meaningful occupations and social interaction outside the home environment (Wilcock 1998; Law 2002; Whiteneck 2006). It is the role of occupational therapists and other health professionals to assist successful reintegration by equipping persons with disability and their families with the skills and resources required for living in the community post injury (Jang et al. 2005). Despite this focus in clinical practice and the extensive legislation providing for the rights of persons with disability (including South Africa's INDS and UNCRPD), disabled persons continue to encounter various obstacles to access and equity within their physical, social and/or political contexts in both developed and developing countries (WHO & ISCOS 2013). These barriers to community participation result in poor reintegration, which is detrimental to health and wellbeing (Dijkers, 1997; Whiteneck, Harrison-Felix, Mellick et al. 2004).

There is a vast literature regarding community reintegration post SCI emerging internationally, but research into the South African SCI population is scarce. South Africa is a unique context and international literature cannot be generalised to the South African population. Further, due to the stark socioeconomically differences resulting from the apartheid government – findings or statistics related to the

government sector cannot be inferred onto the private health sector and vice versa. The current study hopes to add valuable insights to the pool of available South African literature regarding SCI and community reintegration within the private sector. The participants of the current study were predominantly male between the age of 18 and 49 years. Traumatic SCIs were more common than NTSCIs, with RTAs being the most prominent aetiology. Most of the participants were incomplete paraplegics and just more than half were currently employed. The participants experienced moderate restrictions to participation as per the total RNLI scores. The variables that demonstrated significant relationship with the RNLI scores were: type of injury, employment status, means of transportation and independence. Those living with incomplete paraplegia who were employed, drive a private car and were independent at the time of the study, perceived greater satisfaction with community participation and overall reintegration.

The environmental barriers identified from the CHIEF–SF differed from those previously reported in the literature, with less emphasis on transportation and the natural environment. The greatest environmental barriers identified by the participants were, in descending order: help at work/school, business policies, help at home, attitudes at work/school and the natural environment. More emphasis was placed on the role of social factors and attitudes of people at work, school and home than previously reported. This was supported by many of the participants identifying social support from friends, family and colleagues as one of the greatest facilitators to community participation. Gender was the only variable that demonstrated a significant relationship with the CHIEF–SF scores, with males experiencing more barriers than females. This may be attributed to premorbid gendered occupational roles and emphasises the importance of gaining a sound premorbid occupational profile to guide rehabilitation goals and optimize community reintegration.

In conclusion, the study reveals that persons with SCI living in the community within Gauteng, South Africa, continue to face numerous contextual (personal and environmental) barriers to community participation despite legislation in place for an equal and accessible South Africa. The results demonstrated that persons who have incomplete paraplegia, are employed, drive a private car and are independent, perceive greater satisfaction with their perceived level of community reintegration.

6.3 Recommendations

6.3.1 The occupational therapy profession

The findings of this report suggest that the transition from rehabilitation to the “real world” is not always a smooth one. Persons with SCI experience numerous barriers and limitations to community participation, leaving them with low levels of perceived satisfaction with community reintegration. From this, it appears that more could be done by the rehabilitation facilities to assist people with SCI to reintegrate into the community. To do so, occupational therapists need to gain a thorough understanding of their clients’ unique context. In so doing the occupational therapist will be better equipped to work collaboratively with the client to establish a means of overcoming barriers from an individual to a societal/political level.

It is important to acknowledge that rehabilitation occurs during an unwelcome phase in a life disrupted by a severe debilitating injury and is a time of profound uncertainty and struggle (Hammell 2007). With this in mind, many persons in the acute phase of their rehabilitation are often oblivious to the barriers they might face (post discharge) and thus struggle to understand why such aspects of rehabilitation are important. It is recommended that the occupational therapist discuss these potential challenges with their patients from an early stage, but ideally deal with them on an out-patient basis when the client is moving back into their environment. Furthermore, it is recommended that patients return three to six months post discharge for a reassessment and that tools such as the CHIEF or CHIEF–SF and RNLI be used to guide the assessment.

As part of an occupational therapist’s social responsibility it is further recommended that more occupational therapists empower their clients to stand up for their rights and together play an active role in empowering changes to the current legislation, as well as enforcing their implementation, to create environments that are accessible to those persons living not only with SCI but with disability in general in South Africa.

6.3.2 Future research

- It is recommended that a qualitative study be conducted in response to this study to explore the environmental barriers established in the current study. Enhancing participation in activities in and out of the home post injury is the overarching goal of occupational therapy. Occupational therapists need to gain a deeper understanding of barriers and the causes thereof to optimise their potential, to address them or aid their clients to overcome them.

- It was highlighted in the study that although there are environmental barriers to participation, there are also factors that facilitate participation. A study exploring these factors would be beneficial. To optimise participation, one could either aim to remove barriers (which may be at a political or societal level) or assist in identifying facilitators. It may be more realistic for occupational therapists working in rehabilitation centres (who have little control over the existing barriers to participation), to equip their clients with skills or provide information that facilitates participation, such as the strength to ramp up a curb to access the sidewalk or information regarding available resources or support networks in the community.

- It is recommended that a national longitudinal study be conducted to determine the epidemiology of SCI in South Africa and establish a national database. This will require the collaboration of the spinal units within the private and public sector in each of the nine provinces.

- It is recommended that a notational longitudinal (and/or retrospective) study be conducted to establish the average length of stay in hospital (acute, sub-acute and rehabilitation) post SCI for both the private and public health sectors in South Africa. This information can be used to compare to international statistics and be used to assist clinicians in determining a patient recommended length of stay post injury for optimal rehabilitation.

- It is recommended that a standardised sociodemographic profile relevant to the South African population be developed that can be used in all studies of SCI in South Africa.

6.4 Summary of Conclusion and Recommendations

This chapter concluded the study and provided valuable recommendations for the occupational therapy profession and future research on community reintegration post SCI in South Africa.

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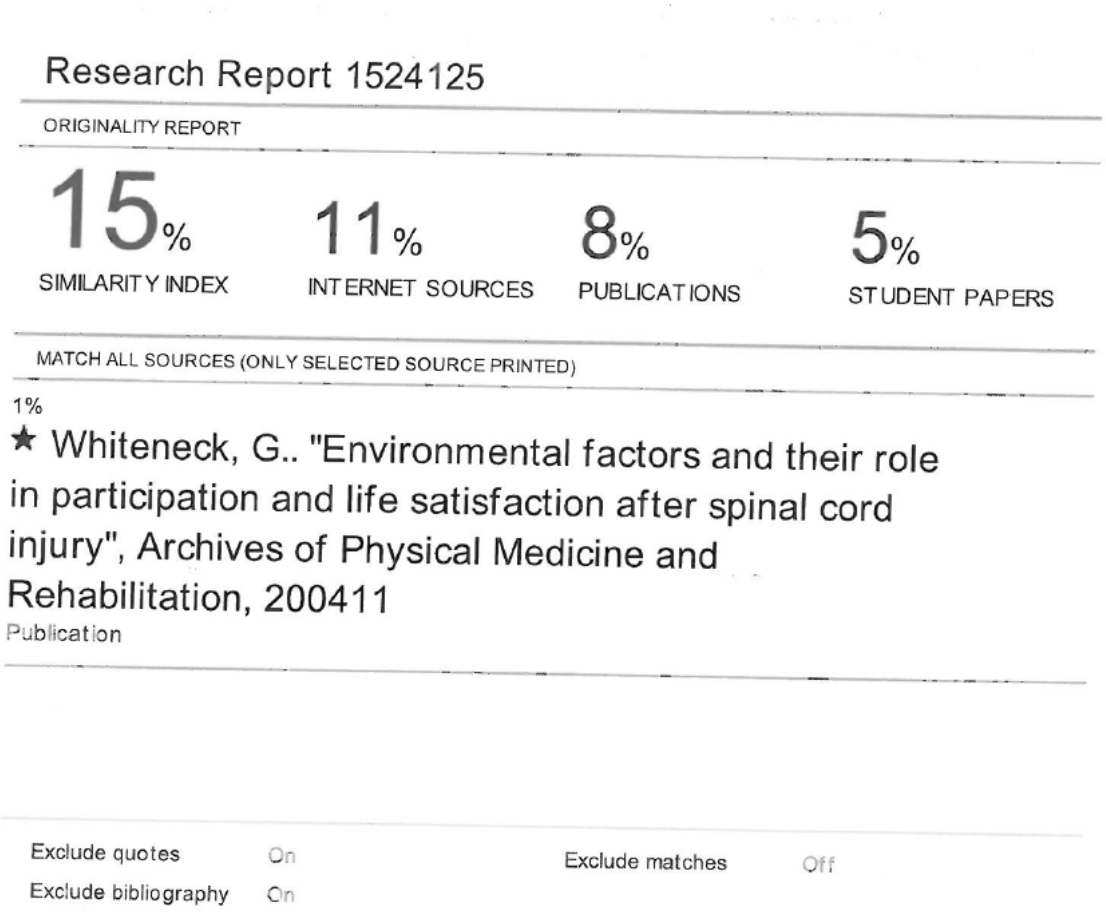
Appendix A: Turn it in Report



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Appendix B: Sociodemographic Profile

Confidential

Demographic Questionnaire

This study will require you to answer questions related to your spinal cord injury, demographics, socio economic status, level of functioning, level of reintegration into your community and environmental barriers that you have faced following your spinal cord injury. If you agree to participate, the questions will take approximately 20-25 minutes to complete.

This survey is made up of three questionnaires:

A Demographic Questionnaire

The Craig Hospital Inventory of Environmental Barriers

The Reintegration into Normal Living Index

Please note that all information you provide will be confidential and will only be used for the purpose of this academic study. All the information you provide will be kept recorded on a form and stored in a secure, password protected folder that only the researcher can access.

By completing the below questionnaires you agree to take part in this study and consent to the following:

I understand the purpose of the study

I understand that I may withdraw from the study at any time and will not be penalised or prejudiced in any way

I understand that I do not have to share any information that I am not comfortable sharing when I answer the questions.

I understand that participating in the research will not harm me or affect me negatively in any way

I understand that my personal details will remain unknown and that all my information and answers to the survey will remain confidential.

Once you have answered all the questions of the Demographic Questionnaire, click SUBMIT and move onto the second questionnaire (The Craig Hospital Inventory of Environmental Barriers)

Thank you for your time!

1 What is your date of birth?

_____

2 What gender are you?

◯ Female ◯ Male

3 What is your home language?

_____

4 Please indicate your marital Status

◯ Single ◯ Married ◯ Divorced ◯ Widow ◯ Partner

5 What is your highest level of education?

_____

6a What type of residence do you stay in?

◯ Brick house
◯ RDP house
◯ Shack
◯ Prefabricated
◯ Flat/apartment
◯ Other

6b If you selected other, please comment on the type of residence

_____

6c Are you renting or do you own your residence?

◯ Renting
◯ Owner
◯ Neither

7 What area does your residence fall?

_____

8a With whom do you live? (you can chose more than one)

☐ Spouse/partner
☐ Child/children
☐ Sibling
☐ Grand parent
☐ Aunt/Uncle
☐ Cousin
☐ Another family member
☐ Friend
☐ Carer
☐ Parents
☐ Alone

8b If none of the above are applicable, please indicate with whom do you live

_____

9a Did your living arrangements change after your spinal cord injury?

◯ Yes ◯ No

9b If yes, how did they change? (you can select more than one)

☐ Made adaptations to the outside of existing home
☐ Made adaptations to the inside of existing home
☐ Moved house
☐ Made adaptations to inside of new home
☐ Made adaptations to the outside of new home

10 Please indicate your type of injury

◯ Complete paraplegia
◯ Incomplete paraplegia
◯ Complete quadriplegia
◯ Incomplete quadriplegia

11 Please indicate your level of injury

◯ Cervical (C1 - C7/8)
◯ Thoracic (T1 - 12)
◯ Lumbar (L1 - L5)
◯ Sacral

12 What date did your injury occur?

_____

13 What was your age at the onset of injury?

_____

14a What was the cause of your spinal cord injury?

◯ Gunshot wound
◯ Act of violence (e.g. stab wound)
◯ Motor vehicle accident
◯ Fall from height
◯ Mining accident
◯ Tumor
◯ Sport related injury
◯ Work related injury
◯ Other

14b If you selected other, please indicate the cause in the text box below

_____

15a What was the duration of stay at Nectare Rehabilitation Hospital following your SCI? (please indicate in weeks)

_____

15bi How was your stay at Netcare Rehabilitation funded?

◯ Workmans Compensation Assurance (WCA)
◯ Medical aid
◯ Private
◯ Road Accident Fund (RAF)
◯ Rand Mutual Assurance (RMA)
◯ Federated Employers Mutual Assurance Company (FEMA)
◯ Other

15biiIf you selected other, please indicate your source of funding for your inpatient stay

_____

16a Are you currently receiving out-patient therapy?

◯ Yes ◯ No

16b If you selected yes, what is the reason you are attending out-patient therapy?

_____

16c If you selected no to attending therapy, why not?

_____

17a Have you had any of the following complications? (you can choose more than 1)

☐ Pressure ulcer
☐ Urinary tract infection
☐ Respiratory tract infection
☐ Other

17b If you selected other, please indicate what complication.

18 Have you been re-admitted to hospital for any of the above complications?

◯ Yes ◯ No

19 Do you require assistance for your bladder and bowel management?

◯ Yes ◯ No ◯ Sometimes

20 Do you require assistance to meet your OTHER personal needs?

◯ Yes ◯ No ◯ Sometimes

21a Do you have a caregiver?

◯ Yes, I have one care giver
◯ Yes, I have more than one care givers
◯ No, I do not need a caregiver
◯ No, I can not afford a caregiver

21b If you selected yes, indicate whether your caregiver is a (you can select more than one)

☐ family member
☐ paid family member
☐ friend
☐ paid friend
☐ private hired caregiver
☐ other

21c If you selected yes, how many days per week do you require care/assistance?

◯ 1
◯ 2
◯ 3
◯ 4
◯ 5
◯ 6
◯ 7

22 How do you move around indoors?

◯ Manual wheelchair
◯ Power chair - hand operated
◯ Power chair - mouth operated
◯ Walker - with assistance
◯ Walker - without assistance

23 How do you move around outdoors?

◯ Manual wheelchair
◯ power chair - hand operated
◯ Power chair - mouth operated
◯ Walker - with assistance
◯ Walker - without assistance

24 Do you use any other equipment or assistive devices, other than your wheelchair?

_____

25a Is there any specific equipment or assistive devices you want or need that you do not have?

◯ Yes ◯ No

25b If you selected yes, what is the reason you do not have this equipment?

25c If you selected yes, does this impact your community participation? (for example, going to the shops, attending church, playing sport etc.)

◯ Yes ◯ No

26a Specify your independence in terms of tranfers:

◯ Independent
◯ Independent with transfer board
◯ Require assistance of 1 person
◯ Require assistance of 2 persons
◯ Require a Hoist
◯ Other

26b If you selected other, please comment below

_____

27a Did you work before the injury?

◯ Yes ◯ No

27b If yes, what was your occupation?

_____

28a Did you return to work after your injury?

◯ Yes ◯ No

28b If yes, did you return to the same job?

◯ Yes
◯ No

28c How long after the injury did you return to work (if applicable)?

◯ 1 month
◯ 2 months
◯ 3 months
◯ 4 months
◯ 5 months
◯ 6 months
◯ 7 months
◯ 8 months
◯ 9 months
◯ 10 months
◯ 11 months
◯ 1 year
◯ More than 1 year
◯ More that 18 months
◯ More than 2 years

29a Are you still working?

◯ Yes
◯ No

29b If yes, are you employed or self employed?

_____

29c If no, why are you not working?

29d If you are not working, would you like to return to work?

◯ Yes ◯ No

30a If you are not working, do you receive any form of income?

◯ Yes ◯ No

30b If you selected yes, please indicate the source of your income (you can select more than one option)

☐ Government disability grant
☐ Disability insurance payment
☐ Income protection insurance
☐ Salary - full
☐ A percentage of your salary from previous employer
☐ Other

30c If you selected other, please indicate your source of income

_____

31a Did you receive any support during rehabilitation to return to work?

◯ Yes ◯ No

31b Was the support you received sufficient?

◯ Yes
◯ No

31c If no, what additional assistance did you want?

_____

32 What activities did you regularly engage in before the spinal cord injury? these could include things such as hobbies, going to work, taking care of your home, being involved with your family and friends in social, recreational and civic activities in the community.

33a Do you still engage in these activities?

◯ Yes, all of them
◯ Yes, some of them
◯ No

33b If you selected no, please state the reason

_____

34a Do you engage in the same activities that you regularly engaged in before the spinal cord injury? (these could include things such as hobbies, going to work, taking care of your home, being involved with your family and friends in social, recreational and civic activities in the community)

◯ Yes
◯ No

34b If yes, do you do the above mentioned activities independently or with assistance?

◯ Independently
◯ Require occasional assistance
◯ Require assistance

34c if no, what activities would you like to do but can't since the spinal cord injury and why?

35 Has the design and layout of buildings and places you use in the community made it difficult for you to do what you want or need to do?

◯ Yes
◯ No

36a How do you get around the community?

◯ I drive my own car
◯ My caregiver drives my car
◯ I rely on family/friends to drive me around
◯ Taxi
◯ Uber
◯ Bus
◯ Train
◯ Walk/Wheelchair use
◯ Use transport for persons with disability
◯ Other

36b If you selected other, please indicate how you get around the community

_____

37a With regards to transport, do you know of or make use of any resources available to persons with disability in your community?

◯ Yes ◯ No

37b If you do use such community resources for transport, please indicate which ones

_____

38 Following your spinal cord injury, do you think you have the same opportunities as other people to participate in and take advantage of education?

◯ Yes
◯ No

39 Following your spinal cord injury, do you think you have the same opportunities as other people to participate in and take advantage of employment?

◯ Yes
◯ No

40 Following your spinal cord injury, do you think you have the same opportunities as other people to participate in and take advantage of recreation/leisure?

◯ Yes
◯ No

41 What do you think is your biggest barrier to community participation?

42 What do you think has helped you with regards to community participation?

Appendix C: Reintegration into Normal Living Index (RNLI)

Confidential

Reintegration To Normal Living Index (RNLI)

The RNLI is a 11-item self-report community reintegration questionnaire that is designed to measure community participation by assessing a person's satisfaction of performance in life activities including; mobility, self care, daily activity, social and recreational activity as well as family roles. You will be required to indicate whether each statement: does not describes your situation, sometimes describes your situation, mostly describes your situation or fully describes your situation

On completion of this questionnaire you would have finished the survey.

Thank you for your participation!

1 I move around my living quarters as I feel necessary.

◯ Does not describe my situation
◯ Sometimes describes me or my situation
◯ Mostly describes me or my situation
◯ Fully describes me or my situation

2 I move around my community as I feel necessary.

◯ Does not describe my situation
◯ Sometimes describes me or my situation
◯ Mostly describes me or my situation
◯ Fully describes me or my situation

3 I am able to take trips out of town as I feel are necessary.

◯ Does not describe my situation
◯ Sometimes describes me or my situation
◯ Mostly describes me or my situation
◯ Fully describes me or my situation

4 I am comfortable with how my self-care needs (dressing, feeding, toileting, bathing) are met.

◯ Does not describe my situation
◯ Sometimes describes me or my situation
◯ Mostly describes me or my situation
◯ Fully describes me or my situation

5 I spend most of my days occupied in work activity that is necessary or important to me.

◯ Does not describe my situation
◯ Sometimes describes me or my situation
◯ Mostly describes me or my situation
◯ Fully describes me or my situation

6 I am able to participate in recreational activities (hobbies, crafts, sports, reading, television, games, computers, etc.) as I want to.

◯ Does not describe my situation
◯ Sometimes describes me or my situation
◯ Mostly describes me or my situation
◯ Fully describes me or my situation

7 I participate in social activities with family friends and/or business acquaintances as is necessary or desirable to me.

◯ Does not describe my situation
◯ Sometimes describes me or my situation
◯ Mostly describes me or my situation
◯ Fully describes me or my situation

8 I assume a role in my family which meets my needs and those of other family members.

◯ Does not describe my situation
◯ Sometimes describes me or my situation
◯ Mostly describes me or my situation
◯ Fully describes me or my situation

9 In general I am comfortable with my personal relationships.

◯ Does not describe my situation
◯ Sometimes describes me or my situation
◯ Mostly describes me or my situation
◯ Fully describes me or my situation

10 In general I am comfortable with myself when I am in the company of others.

◯ Does not describe my situation
◯ Sometimes describes me or my situation
◯ Mostly describes me or my situation
◯ Fully describes me or my situation

11 I feel that I can deal with life events as they happen.

◯ Does not describe my situation
◯ Sometimes describes me or my situation
◯ Mostly describes me or my situation
◯ Fully describes me or my situation

Wood-Dauphinee S Williams JI. Reintegration to normal living as a proxy to quality of life. J Chron Dis. 1987; 40:

491-499. (Figure 2 page 495).

Wood-Daughinee SL Opzoomer A et al. Assessment of global function: The Reintegration to Normal Living Index.

Arch Phys Med Rehabil. 1988; 69: 583-590.

Appendix D: Craig Hospital Inventory of Environmental Factors - Short Form (CHIEF-SF)

Confidential

Craig Hospital Inventory of Environmental Factors (CHIEF-SF)

The following 12 questions that make up the CHIEF-SF will ask about the environmental factors that may or may not have affected your participation in the community in the past 12 months.

Please indicate how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year and tell me whether each item on the list below has been a problem daily, weekly, monthly, less than monthly or never. If the item occurs, then answer the question with reagrds to how big a problem the item is with regard to your participation in the activities that matter to you.

(Note: if a question asks specifically about school or work and you neither work nor attend school, check not applicable)

Once you have completed the 12 questions, please click SUBMIT and move onto the final questionnaire (The Reintegration into Normal living Index)

Thank you!

1a In the past 12 months, how often has the availability of transportation been a problem for you?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than monthly
◯ Never
◯ Not applicable

1b When this problem (1a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

2a In the past 12 months, how often has the natural environment - temperature, terrain, climate - made it difficult to do what you want or need to do?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than monthly
◯ Never
◯ Not applicable

2b When this problem (2a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

3a In the past 12 months, how often have other aspects of your surroundings - lighting, noise, crowds, etc - made it difficult to do what you want or need to do?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than monthly
◯ Never
◯ Not applicable

3b When this problem (3a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

4a In the past 12 months, how often has the information you wanted or needed not been available in a format you can use or understand?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than Monthly
◯ Never
◯ Not applicable

4b When this problem (4a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

5a In the past 12 months, how often has the availability of health care services and medical care been a problem for you?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than Monthly
◯ Never
◯ Not applicable

5b When this problem (5a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

6a In the past 12 months, how often did you need someone else's help in your home and could not get it easily?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than Monthly
◯ Never
◯ Not applicable

6b When this problem (6a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

7a In the past 12 months, how often did you need someone else's help at school or work and could not get it easily?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than Monthly
◯ Never
◯ Not applicable

7b When this problem (7a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

8a In the past 12 months, how often have other people's attitudes toward you been a problem at home?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than Monthly
◯ Never
◯ Not applicable

8b When this problem (8a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

9a In the past 12 months, how often have other people's attitudes toward you been a problem at school or work?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than Monthly
◯ Never
◯ Not applicable

9b When this problem (9a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

10a In the past 12 months, how often did you experience prejudice or discrimination?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than Monthly
◯ Never
◯ Not applicable

10b When this problem (10a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

11a In the past 12 months, how often did the policies and rules of businesses and organizations make problems for you?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than Monthly
◯ Never
◯ Not applicable

11b When this problem (11a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

12a In the past 12 months, how often did government programs and policies make it difficult for you to do what you want or need to do?

◯ Daily
◯ Weekly
◯ Monthly
◯ Less than Monthly
◯ Never
◯ Not applicable

12b When this problem (12a) occurs has it been a big problem or a little problem?

◯ Big problem ◯ Little problem

Appendix E: Permission to use the Craig Hospital Inventory of Environmental Factors –Short Form (CHIEF-SF) (e-mail correspondence)

Dale,

You have permission to use the CHIEF in your research. It is in the public domain and available to anyone. The CHIEF manual is available at https://craighospital.org/uploads/CraigHospital.ChiefManual.pdf and the initial CHIEF article is attached. These should provide you with background and information about use of CHIEF. No further training is required as this is a simple instrument to administer as an interview or a questionnaire. Let me know if you have further questions and good luck with your research – gale

Gale Whiteneck, PhD, FACRM
Principal Investigator
Craig Hospital
3425 S Clarkson St
Englewood, CO 80113
303-789-8204

Appendix F: Ethical Approval Letter from Human Research Ethics Committee

R14/49 Miss Dale van der Veen

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160851

NAME: (Principal Investigator)	Miss Dale van der Veen
DEPARTMENT:	Occupational Therapy Netcare Rehabilitation Hospital
PROJECT TITLE:	Factors Influencing Community Reintegration of Persons with Spinal Cord Injury who Received Private Inpatient Rehabilitation in Gauteng
DATE CONSIDERED:	26/08/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Eileen Du Plooy
APPROVED BY:	Professor P Cleaton-Jones,Chairperson, HREC (Medical)
DATE OF APPROVAL:	26/10/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004, 10th floor, Senate House/3rd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in August and will therefore be due in the month of August each year.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix G: Written Permission from Netcare Ethics Committee

Netcare Hospitals (Pty) Ltd

Tel: + 27 (0)11 301 0000
Fax: Corporate +27 (0)11 301 0499
76 Maude Street, Corner West Street, Sandton, South Africa
Private Bag X34, Benmore, 2010, South Africa
www.netcare.co.za

RESEARCH OPERATIONS COMMITTEE FINAL APPROVAL OF RESEARCH

Approval number: UNIV-2016-0063

Ms Dale van der Veen

E mail: dalevdv.ot@gmail.com

Dear Ms Van der Veen

RE: FACTORS INFLUENCING COMMUNITY REINTEGRATION OF PERSONS WITH SPINAL CORD INJURY WHO RECEIVED PRIVATE INPATIENT REHABILITATION IN GAUTENG

The above-mentioned research was reviewed by the Research Operations Committee's delegated members and it is with pleasure that we inform you that your application to conduct this research at Netcare Rehabilitation Hospital, has been approved, subject to the following:

i) Research may now commence with this FINAL APPROVAL from the Netcare Research Operations Committee.

ii) All information regarding Netcare will be treated as legally privileged and confidential.

iii) Netcare's name will not be mentioned without written consent from the Netcare Research Operations Committee.

iv) All legal requirements regarding patient / participant's rights and confidentiality will be complied with.

v) The research will be conducted in compliance with the GUIDELINES FOR GOOD PRACTICE IN THE CONDUCT OF CLINICAL TRIALS IN HUMAN PARTICIPANTS IN SOUTH AFRICA (2006)

vi) Netcare must be furnished with a STATUS REPORT on the progress of the study at least annually on 30th September irrespective of the date of approval from the Netcare Research Operations Committee as well as a FINAL REPORT with reference to intention to publish and probable journals for publication, on completion of the study.

Directors: J du Plessis, S Chetty, R H Friedland, K N Gibson

Company Secretary: L Bagwandeen

Reg. No. 1996/006591/07

vii) A copy of the research report will be provided to the Netcare Research Operations Committee once it is finally approved by the relevant primary party or tertiary institution, or once complete or if discontinued for any reason whatsoever prior to the expected completion date.

viii) Netcare has the right to implement any recommendations from the research.

ix) Netcare reserves the right to withdraw the approval for research at any time during the process, should the research prove to be detrimental to the subjects/Netcare or should the researcher not comply with the conditions of approval.

x) APPROVAL IS VALID FOR A PERIOD OF 36 MONTHS FROM DATE OF THIS LETTER OR COMPLETION OR DISCONTINUATION OF THE TRIAL, WHICHEVER IS THE FIRST.

We wish you success in your research.

Yours faithfully

20/10/16.

Prof Dion du Plessis
Full member: Netcare Research Operations Committee & Medical Practitioner evaluating research applications as per Management and Governance Policy

Shannon Nell
Chairperson: Netcare Research Operations Committee
Netcare Hospitals (Pty) Ltd
Date: 24/10/2016

Directors: J du Plessis, S Chetty, R H Friedland, K N Gibson

Company Secretary: L Bagwandeen

Reg. No. 1996/006591/07

Appendix H: Permission to access SCI therapy files from Rita Henn & Partners

Reg.no. 2003/024744/2
Pr.no. 050 000 0206822
Vat no.4040209365

PostNet Suite 224, Private bag X 9
Melville, Johannesburg
2109

RITA HENN & PARTNERS INC
PHYSICAL REHABILITATION THERAPISTS
Affiliated with SummitRehab

Tel: +27(0)11 489 1226
Fax: 086 545 5557
info@physicalrehab.co.za

Netcare Rehabilitation Hospital
Cnr Canary & Bunting road
Auckland Park, 2006

01/06/2016

To Whom It May Concern

Re: Research conducted by Dale Van Der Veen at RITA HENN & PARTNERS INCORPORATED

Regarding your letter requesting approval and permission to conduct this study at Netcare Rehabilitation Hospital we are extremely willing and grant permission for this study to be conducted. Please note that while you are busy with any activities with the patients that you are completely liable for any incidences that may arise. Please ensure that at no time the research study interferes with patient's therapy sessions. Please always lease with relevant staff and patients where necessary. Separate permission is required from Hospital Management the group of Netcare Hospitals.

Yours Truly



Megan Knox
PhD (Physiotherapy) Wits
The Partners of Rita Henn and Partners Inc.

Directors of Rita Henn & Partners Inc
Rita Henn • Megan Knox • Hilary Tiernay • Mariette Marx • Luschka Dearle
Sheldene Reynolds • Sarah Quinlan • Almari Smit • Rae Tovell-Holdt • Lauren Paikin

Appendix I: Information Letter and Consent information

Faculty of Health Sciences, Postgraduate Office
Phillip V Tobias Building, 2nd Floor
Cnr York & Princess of Wales Terrace, Parktown 2193
Tel: (011) 717 2745 | Fax: (011) 717 2119
Email: Mathoto.senamela@wits.ac.za

Information Letter

To whom this may concern,

As part of a Masters degree, I am conducting a research study to determine the things that prevent or promote people with spinal cord injury to reintegrate into the community and return to normal living. The title of the study is *"Factors* influencing *community reintegration of persons with spinal cord injury who received private inpatient rehabilitation in Gauteng, South Africa".*

You have been identified as a potential participant as you were rehabilitated for a spinal cord injury at Netcare Rehabilitation Hospital in Gauteng in either 2014 or 2015. Thus, I would like to invite you to participate in this research study. Participation is voluntary and you have the option to decline should you not be interested in participating.

The study will require you to answer questions related to your spinal cord injury, demographics, socio economics, level of functioning, level of reintegration into your community and environmental barriers that you have been faced with following your spinal cord injury.

All information you provide will be confidential and will only be used for the purpose of this academic study. All the information you provide will be kept recorded on a form and stored in a secure, password protected folder.

Please note the following:

- There are no risks involved in participating in this study and if you feel uncomfortable with some of the questions asked, you are not obliged to answer those questions
- You are able to withdraw your participation at any time
- Should you wish not to participate in the study your health care will not be affected in any way
- There are no costs involved
- There is no direct benefit to you in participating however, the information gained will be used by health professionals to inform rehabilitation in order to improve community reintegration for people with spinal cord injury

By completing the survey, you agree to take part in this study and consent to the following:

- I understand the purpose of the study
- I understand that I may withdraw from the study at any time and will not be penalized or prejudiced in any way
- I understand that I do not have to share any information that I am not comfortable sharing when I answer the questions.
- I understand that participating in the research will not harm me or affect me negatively in any way
- I understand that my personal details will remain unknown and that all my information and answers to the survey will remain confidential.

If you agree to partake in the study, please click on the following link **http://j.mp/2kIKoWx.** The survey will take approximately 15 to 25 minutes to complete.

If you have any questions or concerns about the interview or study, please contact:

1. The researcher, **Ms Dale van der Veen** on 084 222 1192 or email on dalevdv.ot@gmail.com
2. The study supervisor, Mrs Eileen Du Plooy at the Occupational Therapy Department at the University of Witwatersrand on 011 7173701 or eileen.duplooy@wits.ac.za
3. Representative from the Human Research Ethic Committee: Prof P Cleaton Jones, 011 717 2301, peter.cleaton-jones1@wits.ac.za; Ms Z Ndlovu, zanele.ndlovu@wits.ac.za, Mr Rhulani Mkans, Rhulani.mkansi@wits.ac.zai or Mr Lebo Moeng, Lebo.moeng@wits.ac.za

Thank you for your time.

Kind regards

Dale van der Veen

Appendix J: Approval of Title

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

13 September 2016
Person No: 1524125
PAG

Miss DA Van Der Veen
Po Box 751 758
Gardenview
2047
South Africa

Dear Miss Van Der Veen

Master of Science in Occupational Therapy: Approval of Title

We have pleasure in advising that your proposal entitled *Factors influencing community reintegration of persons with spinal cord injury who received private inpatient rehabilitation in Gauteng* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

Appendix K: Declaration Letter by Language Editor

Jill Bishop
Language Practitioner

109 De Velde
De Beers Road
Somerset West

P O Box 85
Somerset Mall
Somerset West
7137

e-mail: jill.bishop@absamail.co.za
Full member: Professional Editors' Group
Cell: 083 989 4655
LinkedIn: http://lnkdn/zJhF2Z

Certificate

14 February 2018

TO WHOM IT MAY CONCERN

Dissertation/thesis title: *Factors influencing community reintegration of persons with spinal cord injury who received private in-patient rehabilitation in Gauteng*

Author: Dale van der Veen

I certify that I copy-edited the above document for layout (including numbering, pagination and heading format), grammar, spelling and punctuation. Citations in the text were reconciled with the accompanying Reference List. The writer was provided with corrections/amendments/suggestions which required action.

It is the author's prerogative to accept or reject the suggested changes. The final copy submitted for examination purposes is the responsibility of the author.

JM Bishop MA

Full member of the Professional Editors' Guild

Jillian Margaret Bishop ID 5111230057085 DoB 23 – 11 – 1951
Tax no. 018236645