

**COMMUNITY PARTICIPATION FOR
PEOPLE LIVING WITH SPINAL CORD INJURY
IN THE TSHWANE METROPOLITAN AREA**

A thesis submitted to the physiotherapy department at the University of Pretoria
in partial fulfilment of the requirements for the degree PhD Physiotherapy



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DEDICATION

This thesis is dedicated to my late farther, Mr Matthews Mabudushane Moswane, who always encouraged his children to work hard and reach for the stars.

*'Thanks dad, for all your support and encouragement
– I so wish you were here to see this in person.
You are and will always be PAPA NUMBER ONE!'*



DECLARATION

I declare that “An Assessment Of Factors Influencing Community Participation For People Living With Spinal Cord Injury In The Tshwane Metropolitan Area” is my own work, and that it has not been submitted for any degree or examination in any other university. All the sources I have used or quoted have been indicated and acknowledged by means of complete references.

DJ Mothabeng

Signature November 2010

Dr. CA Eksteen

Witness.....

STUDY PUBLICATIONS

The following publications emanated in preparation for and during the course of the study:

Published:

Mothabeng DJ, Malinga CP, Van der Merwe CB, Qhomane PT, Motjotji SN (2007): The views of patients with Spinal cord injuries on their rehabilitation experience. *South African Journal of Physiotherapy 63 (3): 22 – 25*

Mothabeng DJ (2007): A perspective on Disability and Rehabilitation. *South African Journal of Physiotherapy 63 (1): 32 – 34*

Submitted for publication:

Mothabeng DJ Factors influencing the participation of people living with Spinal cord injuries in physical activity. *Submitted to: South African Journal of Physiotherapy*

Mothabeng DJ, Measurement in Rehabilitation – a perspective. *Submitted to: Journal of Community and Health Sciences*

Mothabeng DJ, Eksteen CE and Westaway M. Psychometric validation of the Return to Normal Living Index as a measure of participation for people living with spinal cord injury in South Africa. *Submitted to the Journal of Physiotherapy Science.*

Mothabeng DJ, Eksteen CE and Westaway M. Socio-demographic correlates of community participation in people living with spinal cord injury in South Africa. *Submitted to the Disability and Society Journal*

Abstract

Background and Purpose:

People living with SCI (PLWSCI) have to cope with various challenges when they return home after institutionalized rehabilitation, especially with integrating back into and participating in their communities. To date no study has been conducted in South Africa to empirically measure community integration or to evaluate factors affecting the community integration of PLWSCI. The purpose of the study was to investigate factors influencing the community participation of PLWSCI after rehabilitation.

Methodology:

A cross-sectional, analytical research design employing both qualitative and quantitative approaches was used.

Data collection

Phase one: Participants were identified from the databases of two rehabilitation centers, and the snow balling technique. Data were collected by implementing: the socio-demographic and injury profile (SDIP), the Return to Normal Living Index (RNLI), the Spinal Cord Injury Measure – version II (SCIM II) and the Craig Hospital Inventory of Environmental Factors – short form (CHIEF-SF).

Phase two: In-depth face to face interviews were conducted with a purposely selected sample group from participants of phase one of the study to determine how participants perceive their community participation.

Data Analysis:

Phase one: Data were analyzed using version 17 of the Statistical Package for the Social Sciences (SPSS 17). Descriptive statistics, T- tests, Pearson product-moment correlation coefficients and one way analysis of variance (ANOVA), with Bonferroni adjustments for multiple comparisons, was done to examine demographic characteristics and participants' community participation.

Data from Phase 2 was subjected to data-reducing procedures using qualitative techniques.

Results – Phase One

One hundred and sixty PLWSCI (134 males and 26 females) from the Tshwane metropolitan area participated in this phase of the study. The participants were predominantly young, male, unemployed and single and their major cause of SCI was road traffic accidents, which accounted for 71% of the injuries.

The participants' satisfaction with their community participation was generally low, only 20% expressed satisfaction with their community participation. Satisfaction with community participation was significantly associated with the participants' race, level of education, employment, educational qualifications, years of living with SCI, level of SCI, health complications, perceived health status, functional ability and perceived environmental factors such as physical (structural and geographic) barriers and lack of transport.

Results – Phase 2

Fifteen PLWSCI participated in interviews. Two themes influencing participation were identified from the interview transcripts: Personal factors (coping skills, rehabilitation experience, future aspirations, personal needs, psycho-emotional issues and meaningful use of time) and Environmental factors (attitudes of others, social support and accessibility issues).

Conclusion

The results of the two phases revealed that community participation of PLWSCI was mainly related to three major categories of factors: personal factors, disability-related factors and environmental factors. Satisfaction with community participation was greater in participants who had been living with SCI for longer periods, had more years of basic education, were not black Africans, lived in

suburbs, and were employed. A positive outlook on life and engagement in creative activities during free time enhanced community participation.

Disability-related factors included level of SCI, functional ability and perceived general health influenced satisfaction with community participation.

Community participation was greater in participants who experienced fewer environmental barriers. “Attitudes of members of society”, “accessibility of the environment” and “social support” influenced the participants’ satisfaction with community participation.

A framework for facilitating community participation of PLWSCI was developed. Strategies to be implemented by various multi-sectoral stakeholders to enhance community participation are proposed.

Keywords: spinal cord injury, community participation, environmental factors, personal factors, socio-demographic factors

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May the Almighty God *who is able to do exceedingly abundantly above all that you can think or imagine* (Ephesians 3:20) bless you all.



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PREFACE TO THE THESIS

The preface to this thesis is an anecdotal case study based on a true story. The name and other identifying features of the individual have been changed to protect the individual, in keeping with ethical principles. This preface is intended to highlight the plight of people living with disabilities, specifically those living with spinal cord injuries, thus illuminating the rationale behind this study.

Melita is a 34 – year old single mother who used to live in a two – roomed rented shack in Mamelodi, a predominantly black township in the North-Eastern part of the Tshwane metropolitan area. She has two daughters aged eight and 12 years respectively, living with her mother in a semi-rural village 100km north of Tshwane. She was involved in a car accident a year ago, when the overloaded taxi she had boarded to work overturned and she sustained injuries to her cervical spine resulting in complete C6 Quadriplegia. Prior to her accident, she was a casual labourer, working as a domestic worker in the suburbs near her township twice a week, on Tuesday and Thursdays. The rest of the week she sold vegetables in the street of her township as a means of income generation. These two ‘jobs’ sustained her family for three years prior to her injury.

After the accident, Melita was admitted to a local hospital where her injuries were stabilized. Two weeks later she was referred to a spinal unit where she underwent rehabilitation. She was fully rehabilitated and after six months in the rehabilitation unit, she discharged home in a wheelchair. She did not qualify for compensation through the Road Accident Fund because the taxi she was injured in was involved in a ‘single-vehicle’ accident.



Because she was not working for two months, she could not afford to pay the rent for her shack anymore and had to go and live with her children and her mother in the village. She has applied for a disability grant, and is waiting for the outcome – she can barely make ends meet. The question is: (1) was her family and the community at large ready to receive and live with her in her condition and (2) was she physically, mentally and otherwise prepared to face life out in the community? Was the community Prepared in terms of accessibility to accommodate PLWSCI such as Melita?

Melita's wish was 'to work for my children and educate them so they can have a better future'. But what kind of work can an unskilled and uneducated tetraplegic woman expect to find in the rural village? In the deep rural villages, people with severe disabilities are looked down upon as they are seen as a curse. Her aging mother could not look after her, so Melita spent most of the time in bed in her mother's house. Melita was kept indoors while her little girls were fortunately being looked after by relatives. Within two months after going to the village, Melita was re-admitted to hospital with severe pressure ulcers and major depression. She did not make it..... how many others out there are like her?

Melita's story is but one of many, with different causes and trajectories. The psychosocial consequences of a serious disability like SCI which include losing employment are too enormous. Even if Melita had lived long enough to receive the disability grant of R1050 per month, how far would it have stretched to sustain her? One wonders who is failing who in these cases. Are the health professionals not adequately equipping

PLWSC for life outside the hospital during rehabilitation, or are the social circumstances just impossible to survive with a serious SCI?

Melita's life story also poses a number of questions for rehabilitation policy and practice. Was her fate dictated by society's non-preparedness to receive her? Was she adequately prepared for life in the community? If she was completely rehabilitated, why did she not cope with participating in normal life roles in the community? This thesis takes us through a journey that attempts to unravel these questions systematically in an attempt to provide solutions for similar and other situations.

In this study, the community participation of PLWSC after rehabilitation is investigated. It is hoped that this study will provide an understanding of the community participation challenges experienced by people living with spinal cord injury. It also envisaged that the study will highlight the resources and services needed to improve community participation for these people with specific reference to barriers and facilitators. The information gained from this study is anticipated to facilitate the planning, implementation and evaluation of programs to guide rehabilitation professionals, planners and policymakers in addressing the issues raised by the study.

CHAPTER 1

INTRODUCTION

1.1 INTRODUCTORY ORIENTATION

A spinal cord injury (SCI) is a devastating condition with results in enormous personal and psychosocial consequences. People living with SCI (PLWSCI) have to cope with various challenges, of which adapting to community life is one of the greatest. The main challenge for PLWSCI starts when they return home after institutionalised rehabilitation and they have to reintegrate into and participate in their communities again. Community participation requires being able to fulfil their roles as members of their households, participants in their communities, and citizens of their world. Such participation in the community is the ultimate outcome of rehabilitation for people with disabilities, including spinal cord injury (SCI). This thesis explores factors related to the community participation of people living with spinal cord injury (PLWSCI) resident in the Tshwane metropolitan area of the Gauteng province of South Africa.

In this chapter, the difficulties faced by people with disabilities, especially PLWSCI, are briefly discussed to provide the background to the aims and objectives of the study and to indicate the need for the involvement of rehabilitation professionals in ameliorating these challenges. The chapter further elucidates the need for disability research in South Africa with specific reference to SCI rehabilitation outcomes research.

1.2 BACKGROUND TO THE STUDY

1.2.1 Disability and Spinal Cord Injury

Over the past three decades, people living with disabilities (PWD) have been engaged in a struggle to remove the barriers which have denied them opportunities to integrate into their communities and participate as citizens equal to their able-bodied counterparts. To this end, PWD have worked together with rehabilitation professionals and engaged governments and progress has been made, especially when it comes to legislation acknowledging the rights of PWD, including those living with SCI. This progress is manifest in important policy documents like the South African Integrated National Disability Strategy (Mbeki, 1997) and the United Nations Convention on the Rights of People with Disabilities (2008).

The passage of the Integrated National Disability Strategy (INDS) (Mbeki, 1997) brought about expectations that this policy would facilitate the removal of barriers to healthcare, education, employment and other important domains of life for PWD. Fifteen years into the democratic dispensation, however, PWD, including PLWSCI, still face challenges in terms of equity and access to basic services. PWD living in poor socioeconomic environments face even greater challenges in terms of community participation owing to limited resources and lack of infrastructure (Hagglund & Clay, 1997; Rouland & Lyons, 1989). This study therefore argues that the INDS and other legislation and policies intended to redress disability issues have not adequately addressed the needs of PWD, including people living with spinal cord injury (PLWSCI).

Disability is, however, a broad topic with multiple facets, including policy issues, different types of disability, and causes of disability, to mention but a few. This study focuses on SCI as a disability issue for the following reasons:

- The researcher has a special interest in SCI and disability issues. She has been lecturing on SCI for more than eight years; first at the former Medical University of Southern Africa (now University of Limpopo – MEDUNSA campus) and now at the University of Pretoria.
- During her years as a spinal rehabilitation clinician, the researcher observed a large number of PLWSCI being readmitted to hospital mere months after discharge with serious complications including pressure ulcers, urinary tract infections and septicaemia.
- The researcher has also observed that there is a lack of SCI outcome rehabilitation research in South Africa, and aims to contribute towards improving the situation through this study.

In order to further illuminate the rationale behind this study, the challenges of SCI rehabilitation are discussed in the following sections, in terms of the different stages/levels of rehabilitation and the specific challenges in the South African context.

1.2.2 The rehabilitation of people living with spinal cord injury

SCI presents a number of challenges to the injured person, the rehabilitation team, the family and society at large. For a person who has sustained PLWSCI and who has sustained a complete high lesion (i.e. cervical), the challenge becomes even greater because this person loses functioning of all four limbs; hence the extent of “disability” becomes greater. It is even worse when the person is from an economically disadvantaged area, where the physical surroundings may not be suitable for wheelchairs, and where members of the community regard “crippled people” as cursed (Rouland & Lyons, 1989). The challenge for the rehabilitation team in the case of a person with such a high lesion relates to prolonged rehabilitation periods and the management of health complications. These complications are discussed in detail in chapter 2. The challenges for the family of a person with a high lesion are mainly related

to the fact that such a person is more dependent on others for basic functions and family members have to change their roles to accommodate this individual.

The medical and rehabilitative management of people who have sustained SCI has progressed dramatically over the centuries. The first medical records of SCI management are reported to have been documented in the Edwin Smith Papyrus by Imhotep, the father of Egyptian medicine (Hughes, 1988). According to Lifshutz and Colohan (2004), Imhotep is reported to have documented the following regarding the first ever medical record of a SCI:

If thou examinest a man having a dislocation of his neck, shouldst thou find him unconscious of his two arms (and) his two legs on account of it while his phallus is erected on account of it, (and) urine drops from his member without his knowing it; his flesh has received wind: his two eyes are blood-shot; it is a dislocation of a vertebra of his neck extending to his backbone which causes him to be unconscious of his two arms . . . Thou shouldst say concerning him . . . an ailment not to be treated.

This nihilistic approach to SCI management persisted until the 1940s, during World War II. Post war advances in the emergency care and rehabilitation services under the leadership of Sir Ludwig Guttman in England and Donald Monroe in the USA enabled people to survive SCI (Lifshutz & Colohan, 2004). In 1944, Guttman established the first spinal unit in Stoke Mandeville, United Kingdom.

During the past three decades, further substantial improvements have been witnessed worldwide in the medical, technological, pharmacological and rehabilitative management of spinal cord injury (SCI) (Magasi, Heinemann & Whiteneck, 2008). As a result of these improvements, people with SCI are now living longer and achieving greater functional independence. Because of this increased lifespan, the focus of medical management and rehabilitation for

people with SCI has shifted from medical management of the acute condition to issues that affect quality of life and community participation.

Participation is a highly valued rehabilitation outcome for people with SCI, their caregivers and society at large, because it is related to a person's ability to be an active and contributing member of society (Whiteneck, 2006). Participation is also important for disability and rehabilitation policy, and is the hallmark of legislative initiatives like the Integrated National Disability Strategy of South African (Mbeki, 1997), the American with Disabilities Act of 1990 and the United Nations Standard for the Equalisation of Opportunities for PWD (WHO, 2001b). Given the importance of participation in rehabilitation policy and practice and the participation challenges observed by the researcher in clinical practice, it is imperative that rehabilitation practitioners give priority to participation in both research and practice.

1.2.3 Stages/levels of rehabilitation

Spinal rehabilitation programmes aim to enhance the residual functional abilities of people who have an acquired disabling impairment because of SCI, to optimise their functional ability and to promote participation in everyday living in a manner that fosters optimal quality of life for the individual. In order to achieve this aim, PLWSCI undergo a number of rehabilitation stages/levels. Landrum, Schmidt and McLean (1995) describe rehabilitation as taking place on six levels, while the Rehabilitation Document of the South African Society of Physiotherapy (SASP, 2004) describes it as taking place on three levels. The two descriptions are complementary, as indicated in Table 1.1.

Table 1.1 Stages and levels of rehabilitation

Stage of Rehabilitation (SASP, 2004)	Level of Rehabilitation (Landrum et al., 1995)	Descriptive title of Level according to Landrum et al., 1995
Early stage	LEVEL 0	Physiological instability
	LEVEL 1	Physiological stability
Mid stage	LEVEL 2	Physiological maintenance
	LEVEL 3	Home or residential integration
Late stage	LEVEL 4	Community reintegration
	LEVEL 5	Productive activity

It must be noted that the rehabilitation process is not always as linear as discussed in this paper, with one stage leading in a natural progression to the next. Entry into the rehabilitation process may occur at any of the stages, depending on the condition of the PLWSCI, and on progression or regression (due to complications or disease process). Once a PLWSCI has entered the rehabilitation process, he or she may move between the different stages in a flexible manner as dictated by individual needs in terms of progression, stabilisation or regression (SASP, 2004). Rehabilitation is therefore a dynamic process, tailored to meet the needs of the PLWSCI.

1.2.3.1 Early stage rehabilitation

Early stage rehabilitation means that the individual is in the initial stages of the injury or illness or is acutely unwell or dysfunctional owing to neglect and/or underlying systemic conditions. This stage covers the following two levels as described by Landrum et al. (1995):

Level 0: Physiological instability

PLWSCI are classified at Level 0 when they have just sustained a SCI through injury or disease and are admitted to an acute care facility. At this level, acute medical and physiological conditions have not yet been completely assessed, diagnosed or managed.

Level 1: Physiological stability

PLWSCI are classified at Level 1 when they receive care in an acute setting, e.g. hospital, ICU or acute medical/surgical ward. The aim of this stage is to stabilise the PWLSCI medically before they start actively engaging in a rehabilitation programme. The goals of Level 1 are achieved when all major medical and physiological problems have been addressed and are appropriately managed.

A major challenge affecting the “early stage rehabilitation” stems from the shortage of specialised spinal rehabilitation units mentioned earlier (in section 1.2.2). Because there are few units, most people who sustain SCI spend long periods at the initial admitting hospital, waiting to be referred to a rehabilitation unit. During this waiting period, many complications such as pressure ulcers and urinary tract infections can develop. These complications cause further delays in the rehabilitation process, because most specialised spinal rehabilitation units do not admit people who have pressure ulcers or other complications.

1.2.3.2 Mid stage rehabilitation

Once a PLWSCI is medically stable and admitted to a rehabilitation unit and/or centre, he or she spends between six weeks and three months participating in an intensive, structured multidisciplinary rehabilitation programme, appropriate to the level and severity of the lesion. The “mid stage of rehabilitation”, commonly known as “in-patient rehabilitation”, is an important stepping stone towards regaining and learning new skills for achieving and maintaining independent living. This stage covers rehabilitation Levels 2 and 3 of Landrum et al. (1995).

Level 2: Physiological maintenance

This level is necessary to preserve the physiological health of the patient. The goal of rehabilitation at Level 2 is to achieve basic rehabilitation outcomes

which include functional independence in self-care, mobility, safety, communication, cognition and behaviour.

Level 3: Home or residential reintegration

This level focuses on achieving a contextually acceptable level of functioning matching the site of a long-term residence to which the PLWSCI will be discharged (e.g. own home, Old Age Home or shelter). The goals for Level 3 include assisting the PLWSCI in reaching an optimum level of functional independence in self-care, mobility, safety, communication and basic home management appropriate to the client's capacity and environmental conditions. Moderate levels of assistance and supervision may be required, depending on the level of the SCI. Skills transference to the PLWSCI and care-givers is essential to maintain physiological stability.

The main aim of “mid stage rehabilitation” is to prepare the PLWSCI for community living by educating them about their condition and training them to perform activities of daily living to ensure maximum functional independence according to their level of SCI. Most rehabilitation units make PLWSCI visit the places they will reside in post discharge for at least two weekends during “mid stage rehabilitation”, to ensure that they will cope with community living after discharge. Whether the PLWSCI are adequately prepared for community living is the major focus of this thesis.

1.2.3.3 Late stage rehabilitation

This stage represents a transition in the life of a PLWSCI, from a safe environment of rehabilitation in the specialised rehabilitation unit, to independent living in the community. This stage covers Levels 4 and 5 of Landrum et al. (1995):

Level 4: Community reintegration

Level 4 focuses on the achievement of a maximal level of functioning in terms of self-management, social competencies, community mobility, financial management, self-directed health monitoring, participation in sport, recreation and other community activities. These advanced rehabilitation outcomes are necessary to achieve an appropriate level of functioning for the PLWSCI within the community.

PLWSCI may require a minimal level of assistance and/or supervision to achieve the aims at this level, depending on the level and completeness of their SCI. The availability of assistance to perform activities, as well as environmental resources and barriers that may facilitate or hinder the individual, are important factors in determining whether the individual will experience activity limitations or participation restrictions (Landrum et al., 1995).

Level 5: Productive activity

At this level, the focus of rehabilitation is on full integration into productive activities that are appropriate to the PLWSCI's condition within the limitations of that person's functional capacity, interests and stage of life. *"The level of productive activity achieved is dependent on the person's activity limitations and participation restrictions, as well as environmental barriers and resources"* (Landrum et al., 1995).

It is during the "late stage rehabilitation" that the preparation of the PLWSCI for independent life in the community is tested. Ideally, rehabilitation should continue at community level and PLWSCI should also be regularly followed up to determine whether they are coping with life in the community after discharge from institutionalised rehabilitation. Regarding community rehabilitation, the South African National Department of Health instituted a system of compulsory community service for health professionals to make sure that health services,

including rehabilitation services, are accessible to all South Africans. The continuing occurrence of cases like the one presented in the preface suggests that this system may not be achieving all its goals.

The post-discharge follow up of PLWSCI in South Africa presents a challenge. Rehabilitation professionals are not always able to follow up PLWSCI after discharge from hospital to determine whether successful integration, including participation in the community, has been achieved. Some institutions (e.g. Rand Mutual Assurance) do follow their patients up; however, the results of these follow ups have not been published. Therefore the post-discharge outcome of PLWSCI in South Africa remains unknown. Carpenter (1994) argues that because of the lack of follow up, the rehabilitation team is unable to evaluate the impact of its interventions beyond the hospital and/or rehabilitation facility.

The causes of limited follow up of patients are multi-faceted. Based on the author's observations, they include factors such as the shortage of human resources, limited financial resources and the high crime rate in South Africa. The latter will deter professionals who may be willing to make follow-up visits to PLWSCI residing in areas that are deemed unsafe (e.g. townships and squatter areas) or difficult to access. For the remote rural patient, the lack of physical address or (mobile) telephone makes follow up particularly challenging. Geographic constraints, lack of social support systems and infrastructure problems (inaccessibility owing to poor road conditions) exacerbate the situation even further (Hagglund, 1997).

All South African citizens have a constitutional right to the access to basic, affordable healthcare including rehabilitation, irrespective of their socio-economic status or the area in which they reside. The previously discussed compulsory community service (CCS) for all health professionals was implemented in 2003 in order to address inequitable distribution of health

personnel in the country and to ensure quality health care for all citizens (Government notice R498 of 19 May 2000). A major objective of the CCS is to improve access to health care (including rehabilitation follow up), especially for previously disadvantaged communities, including those residing in socio-economically disadvantaged areas. Whether CCS has achieved its intended goals, especially in terms of benefit to people living with disabilities caused by SCI, remains to be evaluated.

1.2.4 Spinal cord injury rehabilitation in South Africa

South Africa is classified as a low to middle income African nation, with a small GDP (relative to its population), and a lower life expectancy compared to highly developed nations (World Bank Group, 2009).

The rehabilitation of PLWSCI takes place in both public and private hospitals in South Africa. There are two organisations involved with issues of SCI in South Africa, one for professionals and one for PLWSCI. The Southern African Spinal Cord Association (SASCA) is a multidisciplinary body, responsible for the support of health professionals involved in the rehabilitation of PLWSCI. On the other hand, the needs of PLWSCI are addressed through the Quad-Para Association of Southern Africa (QASA). These two organisations work together to ensure a better quality of life for PLWSCI. Despite the presence of these two strong organisations, SCI rehabilitation still faces a number of challenges in South Africa. The following sections discuss these difficulties facing SCI rehabilitation in South Africa.

1.2.2.1 Rehabilitation units available to people with SCI

The environment in which rehabilitation takes place has changed considerably in recent years, since Guttman established the first spinal unit in Stoke Mandeville, United Kingdom, in 1944 (Lifshutz & Colohan, 2004). The effectiveness of specialist rehabilitation units for SCI has become well

established (Inman, 1999; Kennedy, 2007; Trieschmann, 1988). Given the current emphasis on cost containment and reductions in length of stay after admission, community reintegration and participation have become important goals of rehabilitation in the spinal units (Hammell, 2006; Kennedy, 2007).

In South Africa, most health and rehabilitation facilities are centred in urban and socio-economically advantaged areas, whereas the highest numbers of people with disabilities, including PLWSCI, live in the rural and socio-economically disadvantaged areas (Booyens, 2003; SAHRC, 2002). There are only 23 rehabilitation facilities in South Africa, including 17 spinal rehabilitation units (<http://www.sasca.org.za/resources.html>). These 17 spinal units are equally distributed between the public and the private sector (eight in each sector, and one public-private enterprise in the Western Cape). Eight of the 17 spinal units are in the Gauteng province, with four in the Tshwane metropolitan area (two public and two private).

The national distribution of rehabilitation facilities between the public and the private sector is an issue of serious concern, and one which cannot be discussed without considering the historical and cultural context of South Africa. Fifteen years after democracy, the oppression and inequities of the past continue to cast a shadow over the provision of rehabilitation services.

Eighty percent (80%) of the population is dependent on the government for healthcare, while 20% makes use of private healthcare (Department of Health, 2003). Both of these groups have access to eight rehabilitation facilities respectively, as indicated above. It goes without saying that the government facilities are not adequate in coping with the number of people requiring services. As a result, there is delayed rehabilitation owing to waiting lists, inadequate rehabilitation due to early discharge and/or both (Department of Health, 2003).

1.3 PROBLEM STATEMENT

1.3.1 The challenges faced by PLWSCI observed by the researcher

People living with SCI have to cope with various challenges when they return home after institutionalised rehabilitation (Charlifue, 2004; Dijkers, 1996, 1998). These challenges include mobility in places that are not adequately accessible, taking responsibility for their own health as well as participation in community activities.

The researcher has observed with concern that PLWSCI are re-admitted to hospital for a number of health complications (as in the case of Melita in the preface) fairly soon after they have been discharged. Such observations suggest that the PLWSCI are not coping with living with SCI in the community, and specifically with healthy living. Experiences of PLWSCI such as Melita's have led the researcher to question why supposedly 'fully rehabilitated' PLWSCI deteriorate in terms of their physical condition once they are living in their communities. If the PLWSCI are adequately prepared for community living during institutionalised rehabilitation, why are they developing serious secondary complications that at times result in death soon after they have been discharged from rehabilitation? What is happening to the PLWSCI in the community that their lives are so negatively affected? These questions prompted the researcher to investigate factors influencing the community participation of PLWSCI.

13.2 Limited research on SCI rehabilitation in RSA

Of further concern to the researcher was the limited local literature on the participation of PLWSCI in community life. The literature on the outcomes of rehabilitation following SCI from international studies has been growing rapidly

over the past three decades; however, very little research has been conducted in South Africa in this field.

Only a limited number of studies related to the topic of community participation have been conducted on SCI in South Africa. These studies include a survey on the needs of PLWSCI in Soweto by Cock (1989), an evaluation of the health promotion needs of youth living with SCI in the Western Cape by Njoki et al. (2004), an exploration of the experiences of people living with SCI in the Eastern Cape by Magenuka (2006), the impact of SCI on South African youth by Njoki et al. (2007), a survey of the problems encountered by black tetraplegic patients once discharged from hospital by Monageng (2007) and an evaluation of the functioning of primary school children living with paraplegia in the Western Cape by Vosloo (2009). Although all the above studies investigated some aspects related to community participation, none considered the concept holistically. However, these studies do provide some insights into the problem of community participation and form a useful foundation upon which the current study will be built.

1.4 JUSTIFICATION OF THE STUDY

1.4.1 The importance of research on participation

Participation is a highly valued rehabilitation outcome for people with SCI, their caregivers and society at large, because it is related to a person's ability to be an active and contributing member of society (Whiteneck, 2006). Participation is also important for disability and rehabilitation policy, and it is the hallmark of legislative initiatives such as the Integrated National Disability Strategy of South African (Mbeki, 1997), the American with Disabilities Act of 1990 and the United Nations Standard for the Equalisation of Opportunities for PWD (WHO, 2001b). Given the importance of participation for rehabilitation policy and practice and the participation challenges observed by the researcher in clinical

practice, it is imperative that rehabilitation practitioners give priority to participation in both research and practice.

1.4.2 The unique context of PLWSCI in South Africa

South Africa is a country with a unique history that is directly related to the well-being of PWD, including PLWSCI. The transition of South Africa from constitutional racial segregation and exploitation to a non-racial democracy came about through a protracted struggle characterised by political violence (Bradshaw et al., 2003). This violence was a cause of many disabilities in the pre-democratic era. Although political oppression has diminished, interpersonal violence as a result of urbanisation and ongoing socio-economic discrepancies still exists, creating a new dispensation of trauma as a cause of disability, including SCI. The unique epidemiology of SCI which affects outcomes for PLWSCI in South Africa highlights the need for SCI outcomes research in this country. It cannot be assumed that the findings of studies on SCI outcomes performed in other countries will be applicable to PLWSCI in South Africa.

1.5 RESEARCH QUESTIONS

Based on the discussion above, this study sought to answer the following questions in order to devise practical guidelines for facilitating the participation of PLWSCI in their communities:

- What are the personal demographic, biological and socio-economic factors that influence the community participation of people living with SCI?
- How do PLWSCI experience their community participation?
- What strategies do PLWSCI use to successfully integrate into their communities?
- What measures should be put in place to optimise their community participation?

1.6 RESEARCH FRAMEWORK

In order to arrive at answers to the questions posed in section 1.5, a conceptual framework was designed. The aim of the conceptual framework is to express clearly the logic underpinning the design and evaluation of the study, so that it is clear to both the researcher and the reader (Burns & Grove, 2003). A conceptual framework “sets the stage” for presentation of the specific research question that drives the investigation and helps to identify research variables and to clarify relationships among the variables (McGaghie, Bordage & Shea, 2001).

The World Health Organisation’s (WHO) model of disablement, the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), is selected as the disablement model underpinning the conceptual framework which informs the design and evaluation of this study. Disablement models offer the necessary frameworks for conducting outcomes research, which forms the necessary foundation of evidence based practice (Snyder, Parsons, Valovich McLeod, Bay, Michener & Sauers, 2008). This study investigates rehabilitation outcomes in the community, hence the relevance of the model.

The United Nations Standard rules (WHO, 2001b) define rehabilitation as:

a process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing her or him with the tools to change her or his own life. Rehabilitation involves measures intended to compensate for a loss of function or a functional limitation (for example, by technical aids) and other measures intended to facilitate social adjustments or readjustment.

Three main outcomes of rehabilitation which fit in the ICF model can be derived from the United Nations definition, further highlighting the relevance of the ICF to this study. The outcomes are:

- to optimise health (ICF Body Structure and Function level),
- to improve functioning (ICF Activities level), and
- to facilitate community integration and restore quality of life (ICF Participation level).

Since the focus of this study is community participation, and participation is a core concept and one of the ICF domains, the ICF is thus relevant to the conceptual framework of this study. The ICF disablement model is illustrated in Figure 1.1 below:

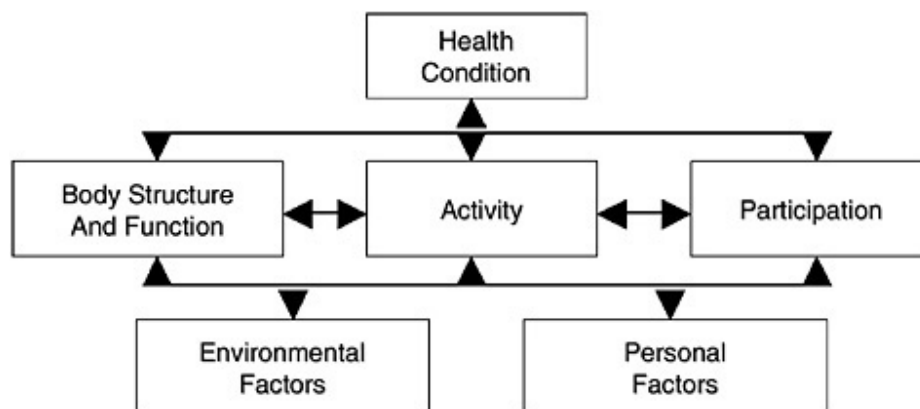


Figure 1.1 The WHO model - ICF (Source: WHO, 2002)

From the model of the ICF, the factors influencing participation are derived as illustrated in Figure 1.2. Figure 1.2 was reorganised to depict the conceptual framework of this study which is based on the ICF model (Figure 1.3).

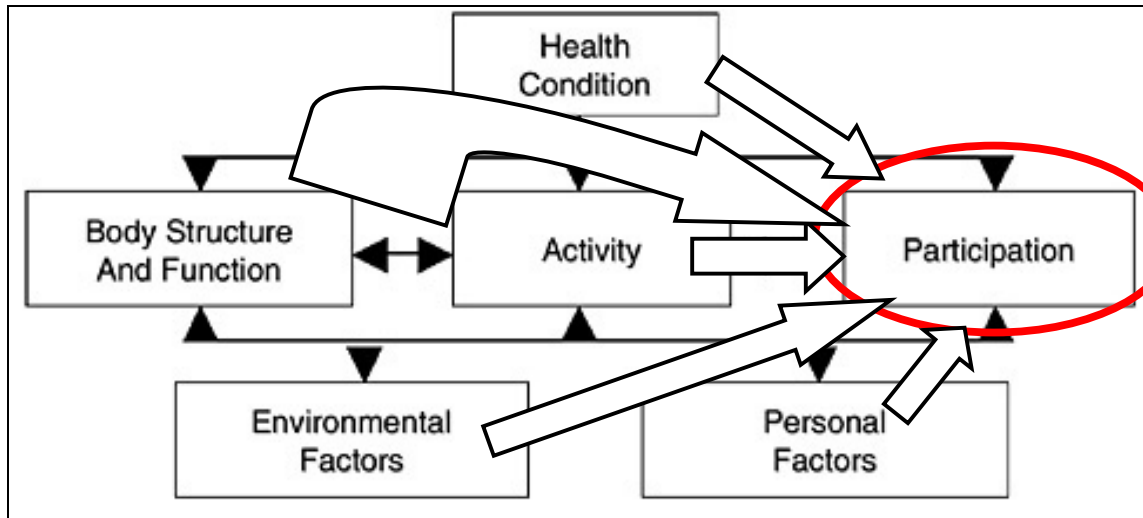


Figure 1.2 Factors influencing participation in the ICF framework

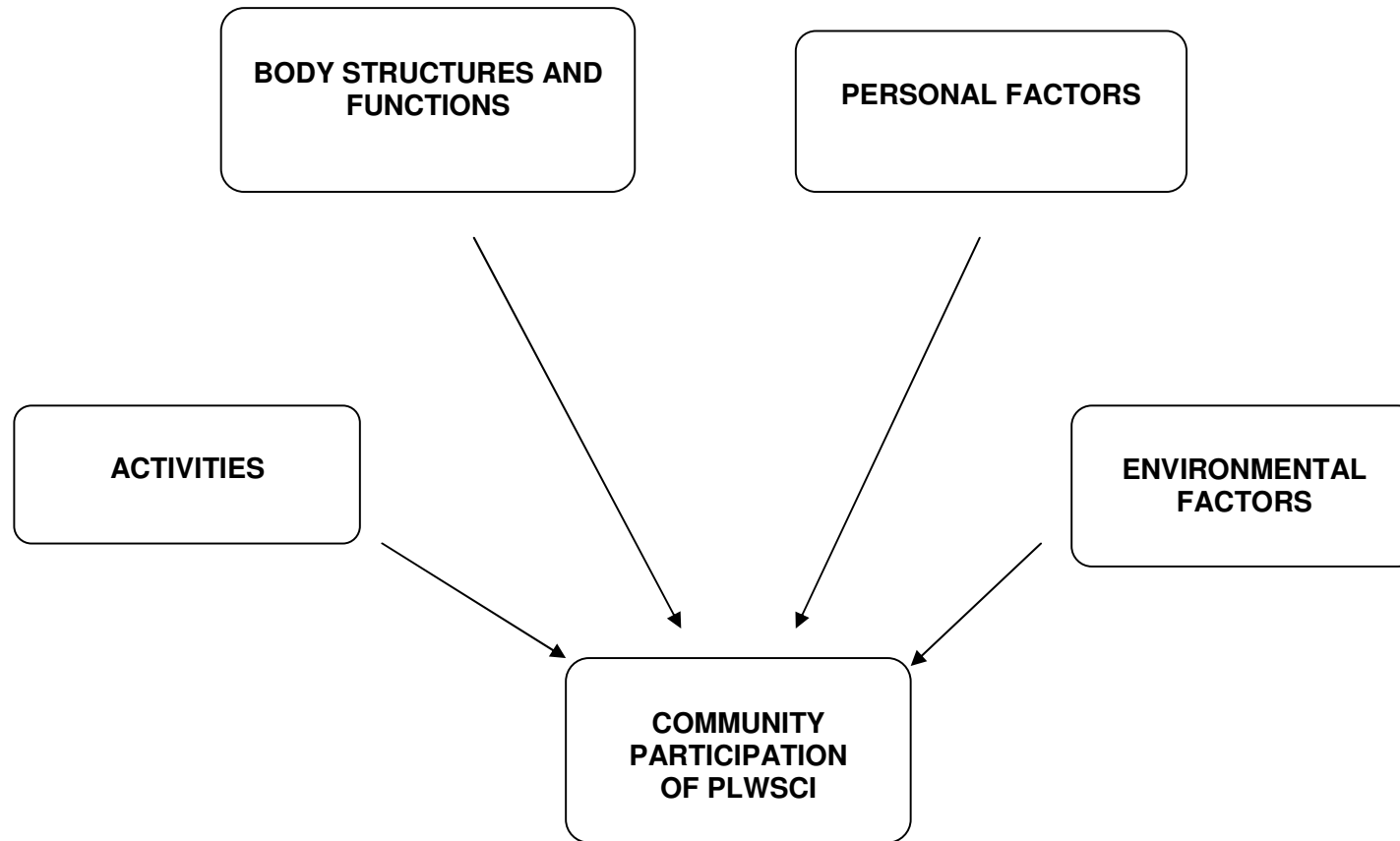


Figure 1.3: Conceptual framework for the study

1.7 AIMS AND OBJECTIVES

The aim of this study is to investigate the factors affecting the community participation of people living with SCI in the Tshwane metropolitan area, in order to develop a framework for community participation. Information from this study will be used to make recommendations to relevant stakeholders regarding measures to facilitate the community participation of people living with SCI.

1.7.1 OBJECTIVES OF THE STUDY

The objectives of this study are:

- 1.7.1.1 To determine the demographic and injury profile of the participants.
- 1.7.1.2 To determine the participants' level of satisfaction with their community participation.
- 1.7.1.3 To determine the functional activity level of the participants.
- 1.7.1.4 To determine the impact of environmental factors on community participation.
- 1.7.1.5 To determine the influence of demographic and injury factors on the community participation of PLWSCI.
- 1.7.1.6 To determine the influence of environmental factors on the community participation of these PLWSCI.
- 1.7.1.7 To explore the perceptions of PLWSCI regarding factors that influence their community participation.
- 1.7.1.8 To develop a framework of community participation for PLWSCI and to make recommendations to relevant stakeholders (i.e. rehabilitation practitioners and policy makers) regarding measures to facilitate community participation by PLWSCI.

In order to address the abovementioned objectives, this study was undertaken and conducted in two phases. Phase 1 entailed the collection of predominantly quantitative data to answer the first six objectives (1.7.1.1 – 1.7.1.6). In addressing objectives 1.7.1.7, a deeper perspective was required; a qualitative approach was thus followed in Phase 2. The findings of phase one and two were used to address objective 1.7.1.8.

1.8 STUDY METHODOLOGY

1.8.1 Research approach

A mixed methodology approach was deemed appropriate to evaluate participation outcomes in this study. A combination of approaches was chosen, and the study was therefore conducted in two phases, a quantitative phase to capture the objective dimension of factors influencing community participation and a qualitative phase to capture the subjective dimension based on the perceptions of PLWSCI.

1.8.2 Research setting

The research was conducted at the homes of PLWSCI who reside in the Tshwane metropolitan area in the Gauteng province of South Africa.

1.8.3 Participant selection

Participants for this study were PLWSCI, resident in the research setting for a minimum of two years. For Phase 1 of the study, a non-probability convenience sampling method was used by the researcher to recruit participants for this study. Potential participants were identified from the databases of the QuadPara Association of South Africa, spinal rehabilitation centres, and through word of mouth referral by other participants. A total of 160 people living

with spinal cord injury in the Tshwane metropolitan area participated in the study.

Potential participants for Phase 2 of the study were key informants selected by the researcher during Phase 1, using purposive sampling. The selected key informants possessed the most characteristic, representative or typical attributes of the study population (De Vos, 2002a).

1.8.4 Data collection

In Phase 1 of the study, data was collected by the researcher using a battery of instruments to obtain information on participants' demographic and injury characteristics, their satisfaction with community integration, their functional activities and the impact of the environment on their community participation. In Phase 2, in-depth interviews were conducted with a purposive sample to determine how participants perceived their community participation with specific reference to barriers and facilitators.

1.8.5 Data analysis

Phase 1 data was captured on a Microsoft Excel spreadsheet and analysed using version 17 of the Statistical Package for Social Scientists (SPSS 17). Descriptive statistics were the first step in analysis of the questionnaire data. The data was then subjected to psychometric testing to determine the validity and reliability of the data gathering instruments for use in a South African context. The relationships between the variables measured by the different instruments were determined using correlation coefficient and p-values. Phase 2 data was analysed using qualitative data analysis techniques of thematic generation using summarising, coding, finding themes, clustering and writing. Thick, rich descriptions were used to present the observational data. A graphic representation of the methodology is presented in Figure 1.4.

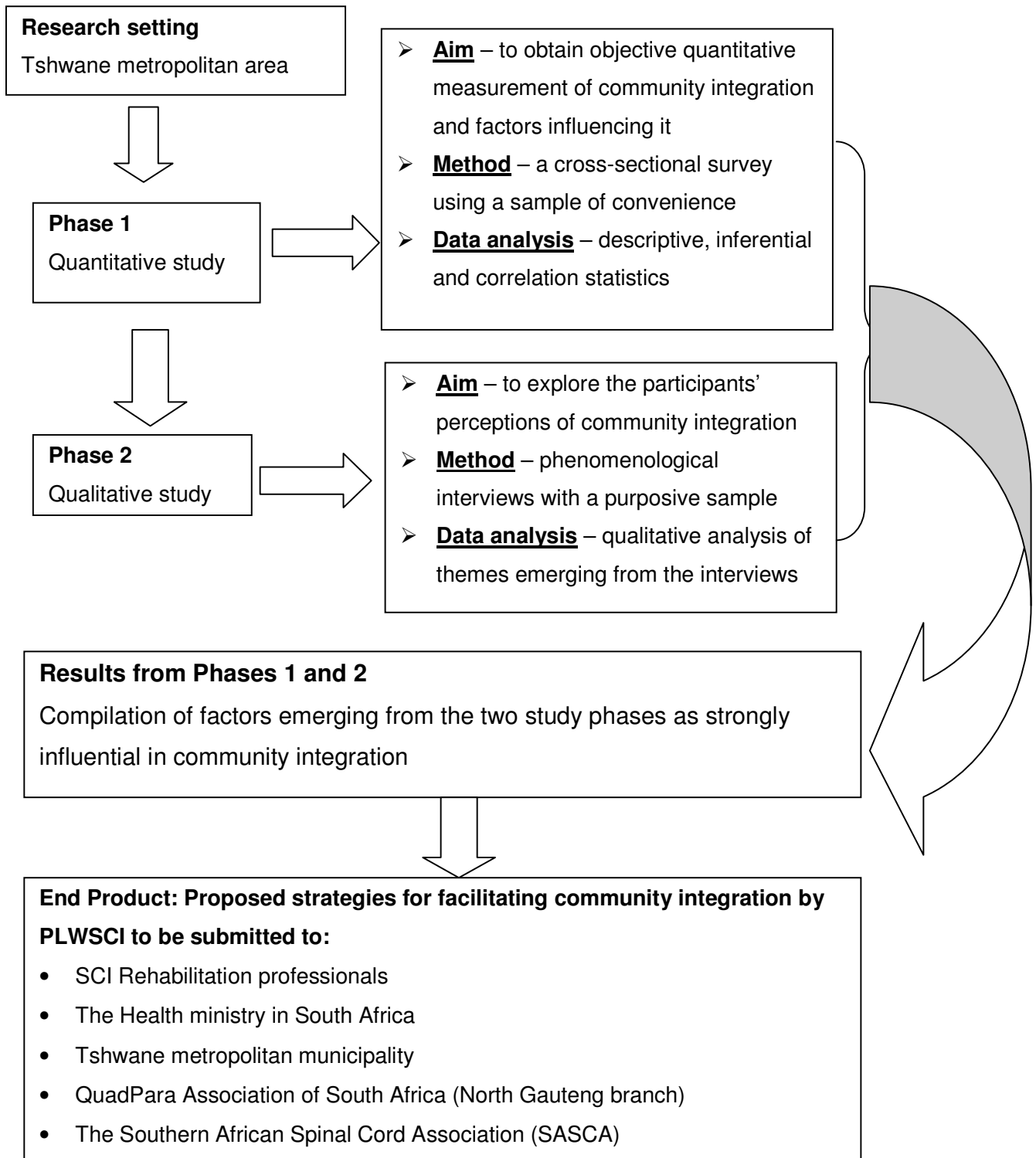


Figure 1.4: Overview of the methodology

1.9 SIGNIFICANCE OF THE STUDY

The following main stakeholders stand to benefit from this study:

1.9.1 The physiotherapy profession

As members of the rehabilitation team, physiotherapists are mainly responsible for the physical rehabilitation of PLWSCI. The origins of physiotherapy are rooted in physical rehabilitation; hence the management of physical disability from any cause including SCI is the primary concern of physiotherapists (Rothstein, 1994).

The role of physiotherapy is to provide PLWSCI with opportunities to achieve maximum functional independence at bodily, personal and societal level. It is at the level of society/community that the person with a disability is faced with the ultimate test of functional ability (i.e. whether he or she is fully integrated into the community or not). The rehabilitation efforts of physiotherapists and other members of the rehabilitation team would be in vain if the PLWSCI were unable to utilise the physical gains of body and personal function to fully reintegrate into their society. It is therefore important for physiotherapists and other rehabilitation team members to follow up the patients post discharge and determine whether the goals achieved during institutional rehabilitation have been maintained in the community.

The National Rehabilitation Policy (SA Department of Health, 2002) identifies patient follow up and evaluation as one of the strategies for preventing further disability and facilitating the participation of PWD in their communities. As indicated in the problem statement, lack of follow up is a major problem following the rehabilitation of PLWSCI. By following PLWSCI up in their communities after rehabilitation and evaluating them, clinicians can obtain valuable information which, according to Carpenter (2004), can be used to:

- Indicate whether the PLWSCI can integrate improved functional abilities into his/her community environment,
- Evaluate whether the rehabilitation efforts have adequately prepared the PWSCI for living in the community or not.

An evaluation of the rehabilitation outcome of former patients of spinal rehabilitation units will thus provide the physiotherapists and other members of the rehabilitation team with a better understanding of the appropriateness of the rehabilitation interventions and inputs, and how PLWSCI cope with participation in their communities.

It is envisaged that this study will identify and describe the realities that people disabled by SCI face after discharge from hospital or rehabilitation unit. Rehabilitation professionals strive to restore the constellation of conditions that will help an individual to lead a normal or as near-normal a life as possible. It is therefore important for rehabilitation professionals to identify those factors that could contribute to improved community participation as soon after injury as possible. Such information will help physiotherapists and other rehabilitation team members to form a better understanding of the needs of PLWSCI regarding community participation, so that appropriate interventions (e.g. treatment, counselling, referral, education or advocacy, as applicable) may be instituted and integrated into a comprehensive rehabilitation process.

1.9.2 The South African Department of Health

Currently, very little disability or rehabilitation research information exists to inform relevant authorities on policy development and/or implementation. This study is anticipated to generate guidelines for addressing specific issues identified as influencing the community. The long term solution to barriers to community participation requires the advocacy action of rehabilitation professionals in the health and social policy arena. The researcher will

therefore disseminate the results of this study to policy decision makers in the Department of Health to make them aware of the issues that affect the community participation by PLWSCI. Such information could assist the Health Department in generating policies to ensure that the burden of disability is reduced and that the quality of life of the PLWSCI is improved in accordance with the national rehabilitation policy (SA Department of Health, 2002) and the INDS (Mbeki, 1997).

1.9.3 People living with Spinal Cord Injury

People living with disabilities, including SCI, are still amongst the most marginalised groups in the country, despite efforts by disability movements and government policy (Mbeki, 1997). The researcher intends to disseminate the results of this study to policy makers and other relevant authorities to raise their awareness of the needs of clients with SCI, with specific reference to community participation. It is envisaged that this study will have an influence on the National Disability Policy as outlined in the National Disability Strategy (Mbeki, 1997).

This study is also envisaged to highlight rehabilitation related issues that affect the community participation of PLWSCI. Such information “increases our understanding from the perspective of PLWSCI, and is essential in the implementation of client centred rehabilitation that targets their needs” (Larsson-Lund, Nordlund, Nyga, Lexell & Bernspa, 2005). Physiotherapists and other health professionals will, it is hoped, use the results of this study to ensure that rehabilitation efforts are relevant to the needs of PLWSCI, to prepare them to cope with the challenges of life in the community.

1.10 SCOPE OF THE STUDY

This study focuses on PLWSCI resident in the Tshwane metropolitan area. The area was chosen for the study because it encompasses a variety of residential types including suburbs, townships, informal settlements and semi-rural areas. These various residential areas provide different socio-geographic environments with different types of barriers that may pose a challenge to community participation. The researcher anticipates that PLWSCI from socio-economically disadvantaged areas in the Tshwane metropolitan area will experience greater challenges to community participation than their counterparts from socio-economically advantaged areas.

A second reason for conducting this study in and around Tshwane is that PLWSCI from these areas are rehabilitated at public and private spinal rehabilitation units associated with the Physiotherapy Department at the Faculty of Health Sciences of the University of Pretoria. This study is therefore part of the university's community engagement in these institutions in terms of providing them with information regarding rehabilitation outcomes of PLWSCI discharged from these institutions.

The researcher also resides and works in the study area. The area is therefore accessible for data collection purposes and for the implementation of any practical recommendations that might emanate from the research, making the research sustainable.

1.11 TERMINOLOGY

1.11.1 Disability

Disability refers to any restriction or lack of the ability to perform an activity in the manner or within the range considered typical for a human being, as a result of impairment (Chase, Cornille & English, 2000). According to the ICF (World Health Organization, 2001), disability is used as an umbrella term for bodily impairments, personal activity limitations and societal participation restrictions.

1.11.2 Spinal Cord injury

The spinal cord is that part of the central nervous system consisting of nerve cells and bundles of nerves that connect the brain with all parts of the body. The spinal cord is thus a link between the brain and the rest of the body, conveying both motor and sensory messages to and from the brain and body (Concise Oxford Dictionary, 1995). Damage to the spinal cord through trauma or disease process therefore results in impairments of sensation and motor function in the body.

A spinal cord injury (SCI) is a temporary or permanent deficit in sensory motor and bladder and bowel function which occurs as a result of a pathology, or a traumatic lesion of neural elements in the spinal canal (Dorsett, 2001; Nielsen, 2003). SCI causes varying degrees of loss of motor sensory function below the level of the spinal cord, depending on the extent of the lesion. Tetraplegia (also known as quadriplegia) results from lesions in the cervical region, whereby the trunk and all four extremities are affected. Paraplegia occurs when the trunk and lower limbs are affected from the level of the second thoracic nerve root, depending on the level of injury (Hampton & Marshall, 2000; O'Hare & Hall, 1997).

1.11.3 People Living with Spinal Cord Injury (PLWSCI)

For the purposes of this study, the abbreviation PLWSCI is used to refer to a **person or people** living with spinal cord injury (paraplegic or quadriplegic and complete or incomplete), who were once patients with spinal cord injury at rehabilitation units of public and/or private hospitals, and have since been discharged to their various homes/socio-economic environments. In instances where reference is made to PLWSCI still in hospital or a rehabilitation institution, the term **patient** is used. The noun patient refers to an individual waiting for or under medical treatment (Harris, 2007).

1.11.4 Community participation

Community participation as used in this study combines two terms, namely community integration and participation. Community integration refers to being part of the mainstream of family and community life, resuming normal roles and responsibilities as appropriate to the PLWSCI's age, gender and culture and being an active and contributing member of society (Dijkers, 1998). Participation is defined as involvement in everyday life situations and participation restriction is defined as problems that an individual may experience while involved in life situations, preventing him or her from full involvement in these life situations (WHO, 2001). Community participation therefore requires that PLWSCI should overcome the many barriers imposed by their disability and the surrounding environment.

1.11.5 Rehabilitation

The following two definitions of rehabilitation are relevant in this study. The first definition is from WHO (2001a) which states that

Rehabilitation is a progressive, dynamic, goal-oriented and often time-limited process, which enables an individual with an impairment to identify

and reach his/her optimal mental, physical, cognitive and social functional level (WHO, 2001).

The second definition by the United Nations Standard Roles (WHO 2001b) states that rehabilitation is

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

From these two definitions, a definition is derived for this study which states that rehabilitation is *the empowerment of people with disabilities to live functionally independent and productive lives as members of their communities (society).*

1.12 OUTLINE OF THESIS CHAPTERS

Chapter 1 presented the background to the current study. The problem statement, conceptual framework, aims and objectives of the study, justification for and significance of the study were discussed. The chapter concluded with the definition of terms used in the study.

Chapter 2 reviews the literature which is pertinent to this study. It highlights the epidemiology of SCI and elaborates on the conceptual framework for this study. The rehabilitation of PLWSCI is discussed, with specific reference to challenges in the South African context and the functional impact of SCI. The conceptual framework is used to guide the review of factors influencing the community participation by PLWSCI, including the role of rehabilitation. The

various instruments used to measure community participation and related factors are also presented using the conceptual framework.

Chapter 3 presents the methodology used in this study. The main study and a pilot study conducted to validate the planned methodology are presented. The research setting, study design and study population for each phase are described. Data collection methods and measures to ensure the reliability and validity of the data gathering instruments are discussed. The main study methodology, following modifications made after the pilot study, is presented in two major phases – a quantitative phase and a qualitative phase.

In Chapter 4, the results of phase 1 are presented, and these are discussed in Chapter 5. Chapter 6 presents and discusses the results of phase 2. The findings from both phases of the study are integrated in Chapter 7, where a final conceptual framework of participation is presented, strategies for facilitating participation are proposed, the thesis is concluded, strengths and limitations of the study are highlighted and recommendations for future research are made.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In Chapter 1, the background and problem, purpose, objectives, research approach and significance of the study were described. As part of the discussion of the background to the problem, the researcher referred to literature regarding the rehabilitation of PLWSC, the impact of disability as a result of SCI and the challenging reality of reintegrating PLWSCI into their communities. In this chapter the literature on community participation by PLWSCI is reviewed in order to provide an overview of factors influencing the process of renewed participation.

An electronic and manual literature search was conducted to identify the literature available on the various facets of the topic and to select relevant resources for the review. The search was performed using various electronic databases: Medline, Cinahl, Science direct, PEDro, and Pubmed. The Google scholar search engine was also utilised. Keywords used included spinal cord injury, rehabilitation outcome, community participation, functional outcome, disability and outcomes research. The search was limited to resources in the English language and was conducted over the period January 1988 to July 2009. The researcher also searched the reference lists of relevant articles, and particular resources were subsequently found on-line, through an inter-library loan and/or in the archives of the health science library of the University of Pretoria. The search strategy is illustrated in Table 2.1.

Table 2.1: Literature search strategy

Database(s)	Keywords	Cut-off date of articles included in the search	Limitation (e.g. language, human)
- Science Direct - Ovid - PubMed - Medline, - Cinahl, - PEDro, - Google Scholar	- spinal cord injury, - rehabilitation outcome, - community participation, - functional outcome, - disability and - outcomes	January 1988 to July 2009	- English language - Human subject

This literature review begins with an overview of the epidemiology of SCI, indicating the global nature of the problem. The overview is followed by a discussion of the International Classification of Functioning Disability and Health (ICF) (WHO, 2001a) as the disablement model underpinning the conceptual framework of this study. Factors influencing community participation are discussed within the theoretical framework and the various tools used for measuring community participation are presented using the same framework. The literature review is presented according to the following non-exhaustive sub-topics that are derived from the research objectives, and which encapsulate the essence of the study:

- Epidemiology of SCI
- Background to the conceptual framework of this study
- Factors influencing the community participation by PLWSCI
- A review of the measures of community participation following SCI.

The outline of the literature review is presented schematically in Figure 2.1.

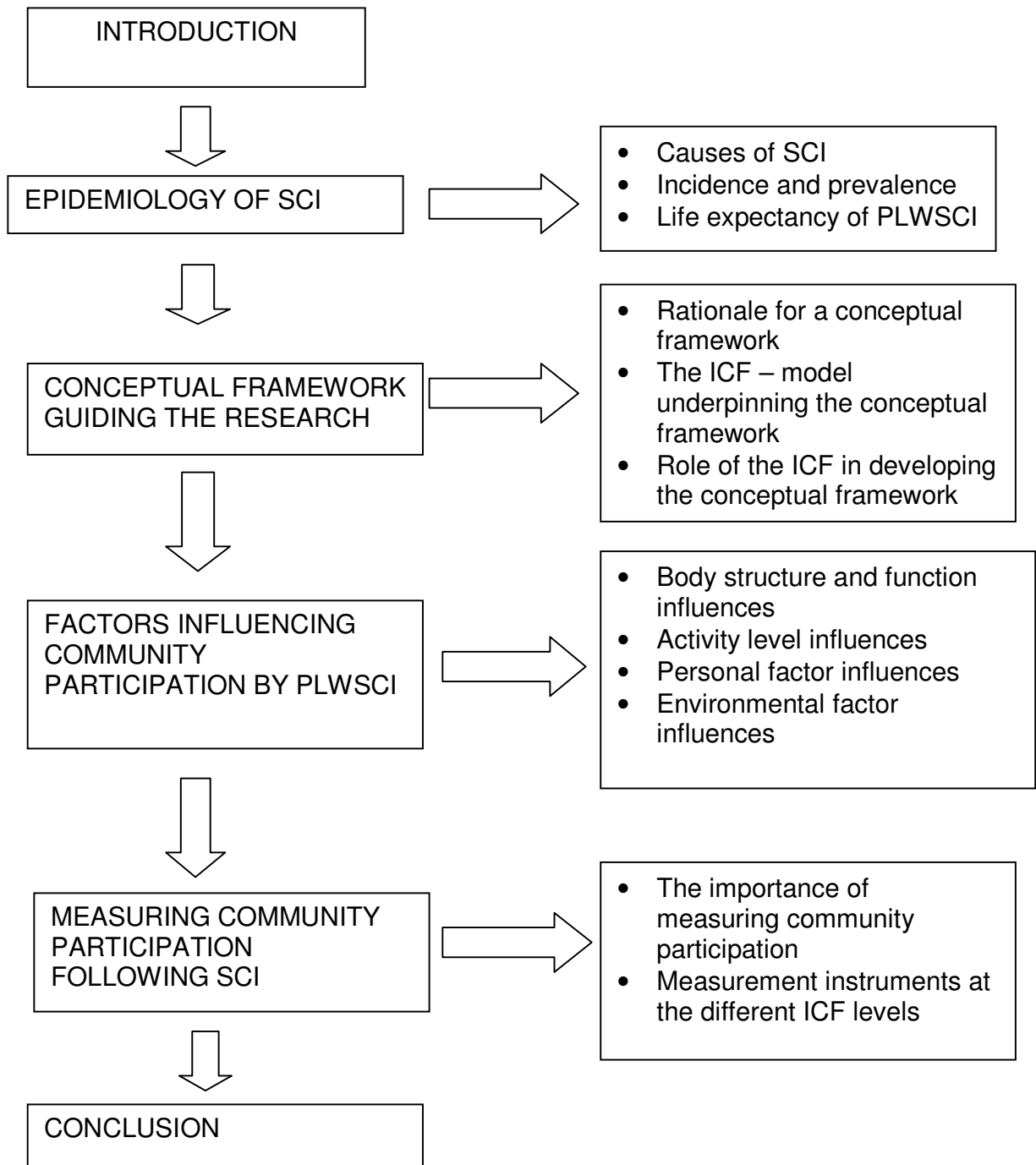


Figure 2.1: Outline of aspects of the literature review

2.2 EPIDEMIOLOGY OF SPINAL CORD INJURY

A spinal cord injury has been reported as a low-incidence type of injury, yet it is a high cost, disabling condition that results in tremendous change a person's life (Yarkony, Formal & Cawley, 1997). SCI causes high personal and bio-psychological impacts and significant socio-economic consequences, making it important to establish its incidence and prevalence. Incidence rates are important because they reflect the level of control of the various causes of SCI and the need for improved prevention strategies. Equally important are prevalence rates, because high prevalence rates have a huge impact on healthcare and on social resources (Wyndaele & Wyndaele, 2006), and eventually affect the tax payer.

2.2.1 Incidence and prevalence of SCI

There are no official statistics on the incidence or prevalence of SCI in South Africa. However, a report by the Department of Health estimated that about 2000 patients per annum are treated for SCI in public and private hospitals nationally. This estimated number implies an incidence of fifty people per million members of the population (Department of Health, 2003). On the other hand, the QuadPara Association of South Africa suggests that about 650 people sustain SCIs in the country annually and that there are over 50 000 PLWSCI in South Africa (Sereilis, 2009). QASA's figures are an underestimation compared to the estimates provided by the Department of Health. This discrepancy highlights the need for better epidemiological information, something which could be achieved by keeping a national SCI database.

A recent review of the global literature on the prevalence of SCI by Wyndaele and Wyndaele (2006) yielded surprisingly few articles on the topic. The review revealed that in the USA, an estimated 250 000 persons were living with SCI in

2005, converting to a prevalence of about 755 per million of the population. Other countries reviewed included Sweden with 223/million, Finland with a prevalence of 280/million and Australia with a prevalence of 681/million (op. cit.). However, the prevalence reported in these countries is a reflection of the prevalence of SCI in developed countries, and may not be applicable to developing countries. Countries that have centralised healthcare and record keeping systems like the United States with their National Model Spinal Cord Injury Systems Database, have population-based estimates of the incidence and prevalence of SCI (Eastwood et Al., 1999). Unfortunately, such systems have not yet been developed in South Africa, hence the lack of reliable data. This further highlights the need for improved reporting and publishing of SCI and the need for publication of SCI research findings in both developing and some developed countries.

2.2.2 Aetiology of Spinal Cord Injury

The aetiology of SCI varies throughout the world. A review of the literature on SCI epidemiology by Ackery, Tator and Krassioukov (2004) indicated that countries with similar market economies display similar aetiological trends, age distributions and male-to-female ratios for SCI. The age of individuals at the time of SCI was found to be higher in developed countries, possibly because of longer life expectancies in those countries. The male-to-female ratio was found to be higher in less developed countries, and this is possibly because of the predominant manual labour and risk-taking behaviour characteristic of men in these countries (Tator & Krassioukov, 2004).

The causes of SCI include trauma, disease and congenital defects (Hulsebosch, 2002). In most cases, an SCI occurs suddenly due to trauma and as such mainly affects young males in the prime of their lives (Hampton & Marshall, 2000; Morris & Marshall, 1997). The most common traumatic causes of spinal cord injury globally are motor vehicle accidents (MVA), falls, sports-

related injuries and violence related injuries including gunshot wounds and stab wounds (Hulsebosch, 2002; QASA, 2009). In South Africa, both gunshot injuries and motor vehicle accidents (MVA) have been reported as the leading causes of the injury (Hart & Williams, 1994; Mothabeng, 1999). Geographic location and the time of the year play a role in the aetiology of SCI in South Africa. More violence related injuries (gunshots) are seen in the major cities, and many of the MVA-related injuries occur during festive periods around Easter and Christmas time (Bradshaw et al., 2003; Magenuka, 2007).

However, over the past two decades, a significant new feature in the epidemiology of SCI in South Africa has been observed. While traumatic causes remain the major cause of SCI, a new picture in the gallery of causes is emerging. A number of people sustain SCI as a result of HIV-related diseases like tuberculosis of the spine (TB Spine) while other patients with traumatic SCI only discover that they have HIV after sustaining the spinal injury (Mothabeng, 2006).

2.2.3 Life expectancy of people living with Spinal Cord Injury

The management of spinal cord injuries (SCI) has progressed dramatically from the days of the ancient Egyptians, where it is documented in the Edwin Smith papyrus that an SCI “was an ailment not to be treated” (Hughes, 1988). Until the late 20th century, the life of a PLWSCI was cut short as a result of this nihilistic approach to patient care and by various medical complications that went mismanaged. Due to advances in healthcare and assistive technologies, the life expectancy of persons with SCI has increased, unlike a few decades ago when death was certain, due to secondary complications after injury (Chan, Lee & Lieh-Mak, 2000; Norrbrink, Budh & O’Steraker, 2007; Post et al., 2005).

The survival rate of PLWSCI is highest among persons in their teens and twenties (Norrbrink et al., 2007). In the USA, the rate of surviving an SCI has improved to approximately 88% in the first twelve years following an injury, with even better survival rates among young adults (De Vivo, Richards, Stover & Go, 1991). In Australia, O'Connor (2005) reported a survival rate of 86% at 10 years post injury. There are no published statistics on the survival rate for PLWSCI in South Africa. The only available statistics on the African continent are from Zimbabwe: Levy, Makarawo, Madzivire and Bhebhe (1998) reported a one-year survival rate of at least 51% based on a study they conducted over three years. This lack of statistics on the survival of PLWSCI further supports the previously indicated need for more research in South Africa and Africa, as well as globally.

2.3 BACKGROUND TO THE CONCEPTUAL FRAMEWORK

Having outlined the global impact of SCI in terms of its epidemiology, this section discusses the background to the framework within which the community participation of PLWSCI is to be studied.

In Chapter 1 (section 1. 6) it was pointed out that the ICF (WHO, 2001) is the selected disablement model of choice underpinning the conceptual framework for this study. Disablement models provide a framework for understanding the effects of injury and/disease on human functioning (Snyder et al., 2008) and are therefore a foundation for outcomes assessment.

The first disablement model was proposed by Nagi (1961), a sociologist employed by the United States Social Security Agency. Numerous other models have been developed since, including but not limited to the World Health Organisation's International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO 1980), the National Centre for Medical Rehabilitation Research (NCMRR) (1992), the Disability Creation Process (Fougeyrollas, 1998) and the World Health Organisation's International

Classification of Functioning Disability and Health (ICF) (WHO, 2001). In this section, the historical evolution and theoretical background of the ICF as the model underpinning the conceptual framework of this study is presented.

2.3.1 Evolution of the World Health Organisation's model - International Classification of Functioning Disability and Health (ICF)

The first disablement model of the World Health Organisation, the International Classification of Impairments, Disabilities and Handicaps (ICIDH), was developed by Dr Philip Wood in the UK in the early 1970s. In 1972, the World Health Organisation recognised the need for better methods to evaluate healthcare, and commissioned an investigation into a model that could describe the consequences of injury and/or diseases, particularly chronic and progressive or irreversible disorders, for human functioning. A manual of classification relating to the consequences of disease, the International Classification of Impairments, Disabilities and Handicaps (ICIDH) was published in 1980 and has undergone several revisions since.

Secondary to numerous revisions of the ICIDH, a new model incorporating all factors that impact on disability and affect functioning, namely the International Classification of Functioning Disability and Health (ICF), was adopted in 2001. One major change in the ICF was to remove the negative connotations associated with disability by using more positive terms to describe its characteristics. For instance, reference is made to a patient's "functional abilities" rather than "handicaps".

The development of the ICF started as a revision of the ICIDH, to correct inappropriate terminology and to reflect the interactive nature of the components by moving away from a linear model. One of the criticisms levelled against the ICIDH was its lack of explicit recognition of the role of the

environment in the disablement process. However, the ICIDH does refer to the environment by stating that “handicaps reflect interaction with and adaptation to the individual’s surroundings” (Whiteneck, 2005).

The evolution of the WHO model from ICIDH to ICF is illustrated in Figure 2.2 below:

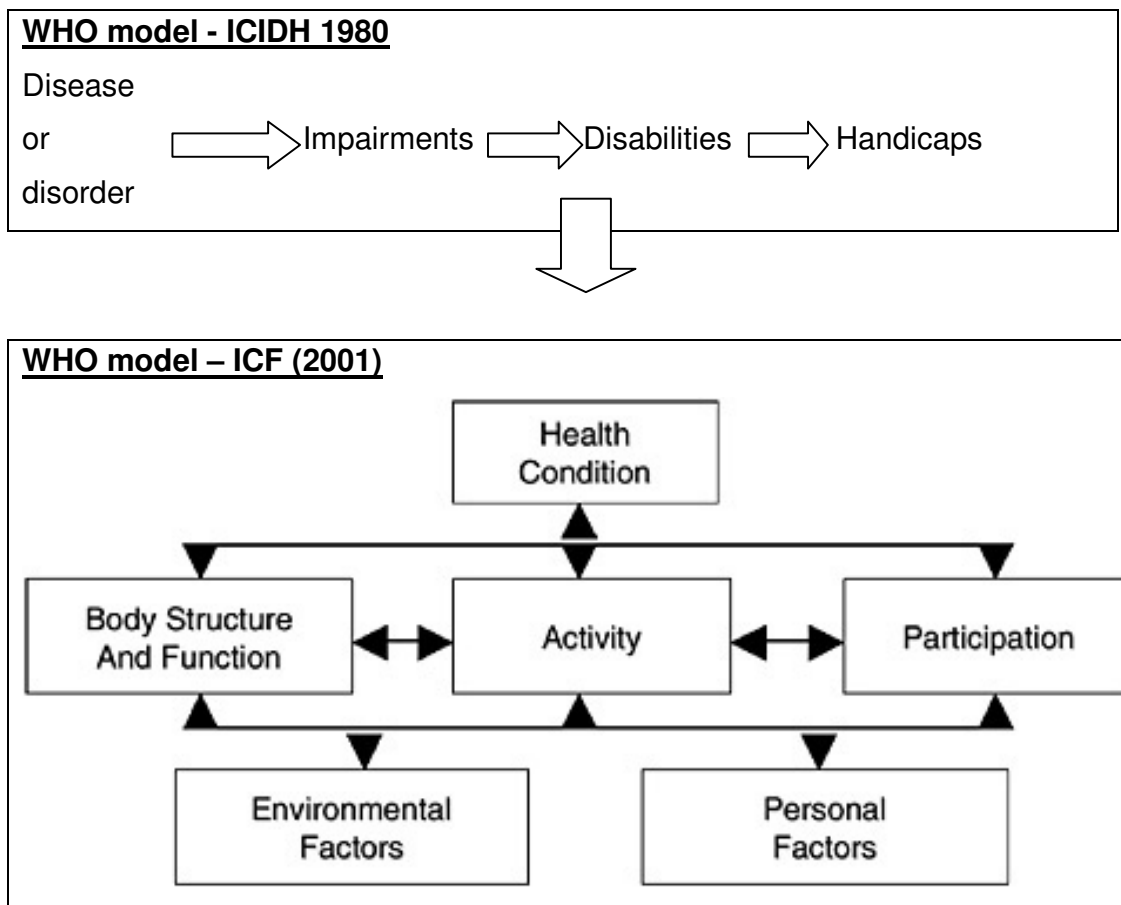


Figure 2.2: Evolution of the WHO model – from ICIDH to ICF

The ICF is a disablement model used to describe functioning and disability in relation to a health condition. Based on a bio-psychological model, the ICF integrates elements of both the medical and social models of disability. The ICF places the functioning of a person living with a disability in a context that acknowledges the interactions between a person's health, the environment, and social and personal factors. According to Jette (2005), the ICF looks

beyond mortality and disease to focus on how people live with their conditions. The ICF is thus a very useful framework for assessing how health conditions affect the functioning of individuals (Schneider, Hurst, Miller & Ustun, 2003; World Health Organization, 2001).

2.3.2 Components of the ICF

As illustrated in Figure 2.2, the ICF conceptualises disability as having a medical or health condition as one of its core components. The health condition in the case of this study is a spinal cord injury (SCI), which occurs as a result of either trauma or disease. In the ICF disablement model, disability occurs when a health condition leads to dysfunction at the domain levels (body functions and structures and activities and participation) resulting in impairments of body functions and structures, activity limitations or participation restrictions as mediated by both environmental and personal contextual factors.

The ICF is arranged in two parts. Part 1 of the ICF is termed Functioning and Disability while part 2 is Contextual Factors (WHO, 2001a).

2.3.2.1 Part 1 of the ICF: Functioning and Disability

This part of the ICF encompasses three levels of human functioning, namely body functions and structures, activities and participation (Boerman, 2004; WHO, 2001). The following sections discuss the application of the ICF to PLWSCI.

a) Body structure and function component level

The body functions and structures level of the ICF includes both mental and physical aspects of health. Body functions refer the physiological functions of the body and body structures entail the anatomical parts (i.e., sensory organs, limbs). Changes or deviations from normal function at this level are referred to

as impairments. Impairments due to SCI include loss of muscle strength and sensation below the lesion, and incontinence of bladder and bowel function.

b) Activities level

The activities level of the ICF entails personal functional activities such as walking, communication, learning, playing and interacting with others (Bornman, 2004; WHO, 2001). When a PLWSCI has difficulty performing one or more functional activities, as determined through a physical evaluation or observation by a rehabilitation professional, or as reported by the PLWSCI him or herself, this problem is called an activity limitation. Depending on the level and completeness of the SCI, a PLWSCI may present with limitations to activities of daily living, mobility and self-care.

c) Participation level

The participation level refers to involvement in life situations; including being autonomous and able to control one's own life, even if one is not actually doing things oneself. The presence of one or more activity limitations places a PLWSCI at risk of being excluded from participating in a range of life situations. The extent to which a PLWSCI is able or unable to participate in certain situations (e.g. work, school, social events etc.) will contribute to the extent and type of disadvantage he or she experiences. For example, a young PLWSCI who does not participate in learning will experience a disadvantage on the level of educational attainment whilst another who does not participate in social events or activities will experience the disadvantage of social exclusion.

2.3.2.2 Part 2 of the ICF model - Contextual Factors

Contextual factors are those factors that represent the background of an individual's life and living (Bornman, 2004). Contextual factors are particularly important because they address the significant effect of environmental as well as personal factors on the person's overall level of functioning. Contextual

factors are divided into two components in the ICF, namely environmental factors and personal factors, discussed in the following sections:

a) Environmental Factors

Environmental factors include those in the physical environment (including buildings and roads), the social environment (including family and friends) and the attitudinal environment (including the attitudes of people in the community). The impact of environmental factors is critical to the participation of PLWSCI in their communities. The environment may be either on that facilitates or presents obstacles to participation.

If the environment is facilitating, a PLWSCI may, despite significant activity limitations, still be able participate in daily life situations and activities such as going to work or enjoying quality time with family and friends. For example, a PLWSCI who is unable to walk may be able to move around effectively in a wheelchair if the physical environment is accessible for wheelchair users. Another person may be totally dependent on others for function but if family and friends are supportive this person may experience few of the disadvantages of exclusion. However, if the environment presents many obstacles, the same two PLWSCI could face significant disadvantages because of an inaccessible physical environment or a stressful and unsupportive social network.

b) Personal Factors

Personal factors include features of an individual that are not part of a health condition, such as age, motivation, educational level and experience of living with the health condition (Bornman, 2004). Personal factors can also act as barriers to or facilitators of community participation. For example, a very motivated PLWSCI may have a high lesion with limited physical abilities, but may achieve a better participation level than someone with a low lesion who is not motivated. On the other hand, a young and educated PLWSCI may find it

easier to reintegrate into society and to participate in various meaningful activities than an older, uneducated person.

2.3.3 Summary – background to the conceptual framework

In this section, the historical background of the ICF, which underpins the conceptual framework of this study, was presented. From this background, four main elements which influence community participation, namely body structures and function, functional activities, personal factors and environmental factors, were identified (as illustrated in the conceptual framework in figure 1.4). In the next section, the review of literature illustrating the influence of these factors on participation is presented.

2.4 FACTORS INFLUENCING THE COMMUNITY PARTICIPATION OF PEOPLE LIVING WITH SPINAL CORD INJURY

Despite the intensive efforts of rehabilitation through education and functional skills training, PLWSCI experience a range of physical and psychosocial difficulties once they return to the community (Kendall, Ungerer & Dorsett, 2003). Even those individuals who make significant gains in rehabilitation may experience difficulties when attempting to participate in various roles as members of their communities. An SCI impacts on many facets of an individual's life, including social roles, personal goals and future life expectations (Conroy & McKenna, 1999; Wood-Dauphinee et al., 2002). The ensuing sections discuss the literature on factors affecting participation as outlined in the framework in section 2.3.4.

2.4.1 The influence of factors in the 'body structure and function' component on community participation

An injury to the spinal cord as a result of trauma or disease causes a circumscribed spinal cord lesion resulting in functional deficits owing to the disconnection of efferent motor and afferent sensory pathways between that part of the body and brain centres (Curt, Bruehlmeier, Leenders, Roelke, Dietz, 2002). The injured person presents with paralysis and loss of sensory function below the level of the injury, as well as loss of bowel and bladder control (Dorsett, 2001). Voluntary movement above the lesion is maintained although changed due to inevitable adaptation of the body's balance mechanisms and loss of spontaneous whole body movement.

Following an SCI, the patient can present with one of two main injury levels, namely paraplegia or quadriplegia (also known as tetraplegia). Quadriplegia is the result of an injury above the first thoracic vertebra and is characterised by paralysis of the trunk and lower limbs, and partial paralysis of the upper limbs (total paralysis of the upper limbs occurs in injuries above the fourth cervical vertebra, C4). A lesion above the C4 neurological level results in paralysis of the diaphragm. In addition to upper and lower limb paralysis, the muscles of the thorax and trunk are also paralysed to an extent that is determined by the level of the lesion. This results in respiratory problems that include low tidal volume and the inability to cough effectively and clear the chest of secretions.

In the case of paraplegia, the injury occurs below the first thoracic spinal nerve, resulting in loss of sensation or motor function in the lower limbs and lower part of the thorax or trunk (Dorsett, 2001). The PLWSCI loses bladder and bowel function and the ability to walk. The influence of body structure and function impairments on the participation of PLWSCI in the community is determined by the neurological level of the injury (NLOI), the completeness of the injury, the

presence of medical complications and the psychological status of the individual (Marino, et al., 2003).

2.4.1.1 Type and level of the lesion

Depending on the nature and level of the lesion incurred, injuries to the spinal cord usually result in some degree of cord-related motor and sensory impairment that may be complete or incomplete, temporary or permanent. Many individuals are left with serious residual disability which often leads to severe body changes and the inability to perform functional activities, including mobility and activities of daily living (Wood-Dauphinee & Exner, 2002).

The NLOI is defined as the most caudal (i.e. lowest) level of the spinal cord that has normal motor and sensory functions (Ditunno, Young, Donovan & Greasey, 1994). Motor function is determined by manually testing key muscle groups on both sides of the body. These muscle groups represent neurological levels, and findings are graded 0-5. Sensory function is determined by examining 28 key sensory points on both sides of the body.

The completeness of the SCI is determined using the American Spinal Injury Association (ASIA) Impairment Scale (American Spinal Injury Association, 2002). The ASIA scale classifies the completeness of SCI on a scale from A to E, as follows:

- *A - Complete = No sacral motor or sensory sensation in segments S4-5.*
- *B - Sensory incomplete = Preservation of sensation below the level of injury extending through sacral segments S4-5.*
- *C - Motor incomplete = Voluntary anal sphincter contraction or sensory sacral sparing with sparing of motor function below the motor level of injury, with the majority of key muscles having a strength grade of less than 3.*
- *D - Motor incomplete = Voluntary anal sphincter contraction or sensory sacral sparing with sparing of motor function below the motor level of injury, with the majority of key muscles having a strength grade of 3 or greater.*

- *E - Normal = Normal motor and sensory recovery.*

The neurological level and completeness of the injury are important factors that assist in predicting functional outcomes after SCI (American Spinal Injury Association 2002; Ditunno et al., 1994; Eastwood et al., 1999). The main factor that determines functional activity is the motor level of the lesion. A patient with a complete and high SCI level (i.e. tetraplegia) will have fewer innervated muscles with which to perform physical functions than a PLWSCI with a low level injury (e.g. low paraplegia). On the other hand, if the lesion is incomplete, the potential for neurological recovery is greater, and it will be easier to perform physical functional activities and to reintegrate into society.

2.4.1.2 Health-related complications

A variety of complications can occur during both the acute and chronic stages of the SCI despite advances in prevention and treatment of spinal cord injuries (SCI) (Chen, Apple, Hudson, & Bode, 1999). The presence of medical complications has a direct impact on a person's functional ability, feeling of well-being and ultimately on his or her participation in society. The three most common complications that affect PLWSCI are pressure ulcers (PU), urinary tract infections, and respiratory infections.

a) Pressure sores

Pressure ulcers are the most serious of secondary complications that a patient with SCI can develop, with potentially fatal consequences. They usually occur over bony prominences and are classified in stages by the degree of tissue damage observed. Pressure ulcers are defined as lesions caused by unrelieved pressure, resulting in damage to the underlying tissue (Garber & Rintala, 2003). Pressure sores occur in 25%-85% of permanent wheelchair users and are the cause of 8% of deaths amongst PLWSCI (Basson et al., 2006). PLWSCI have a higher risk of developing PU than other people living with a disability because of their impaired sensation and immobility. The

presence of pressure ulcers will confine a PLWSCI to bed, thus limiting the postures and activities that s/he will be able to adopt and/or perform. These limited activities will also limit or prevent the PLWSCI from participating in the community.

The aetiology of the pressure sore is multi-dimensional. Pressure, sheer friction and poor nutrition contribute directly to the physiological aetiology of pressure sores (Garber & Rintala, 2003). Other factors associated with the development of these sores include immobility and psychosocial factors such as inadequate personal and financial resources as well as non-compliance with preventative behaviour (Garber & Rintala, 2003). Krause (1998) explored correlations between secondary conditions including pressure sores and subjective well-being and found that pressure sores were most highly related to emotional distress, decreased financial well-being and poor living circumstances. The various factors contributing to development of PS are reflected in Figure 2.3 (Britz et al., 2007).

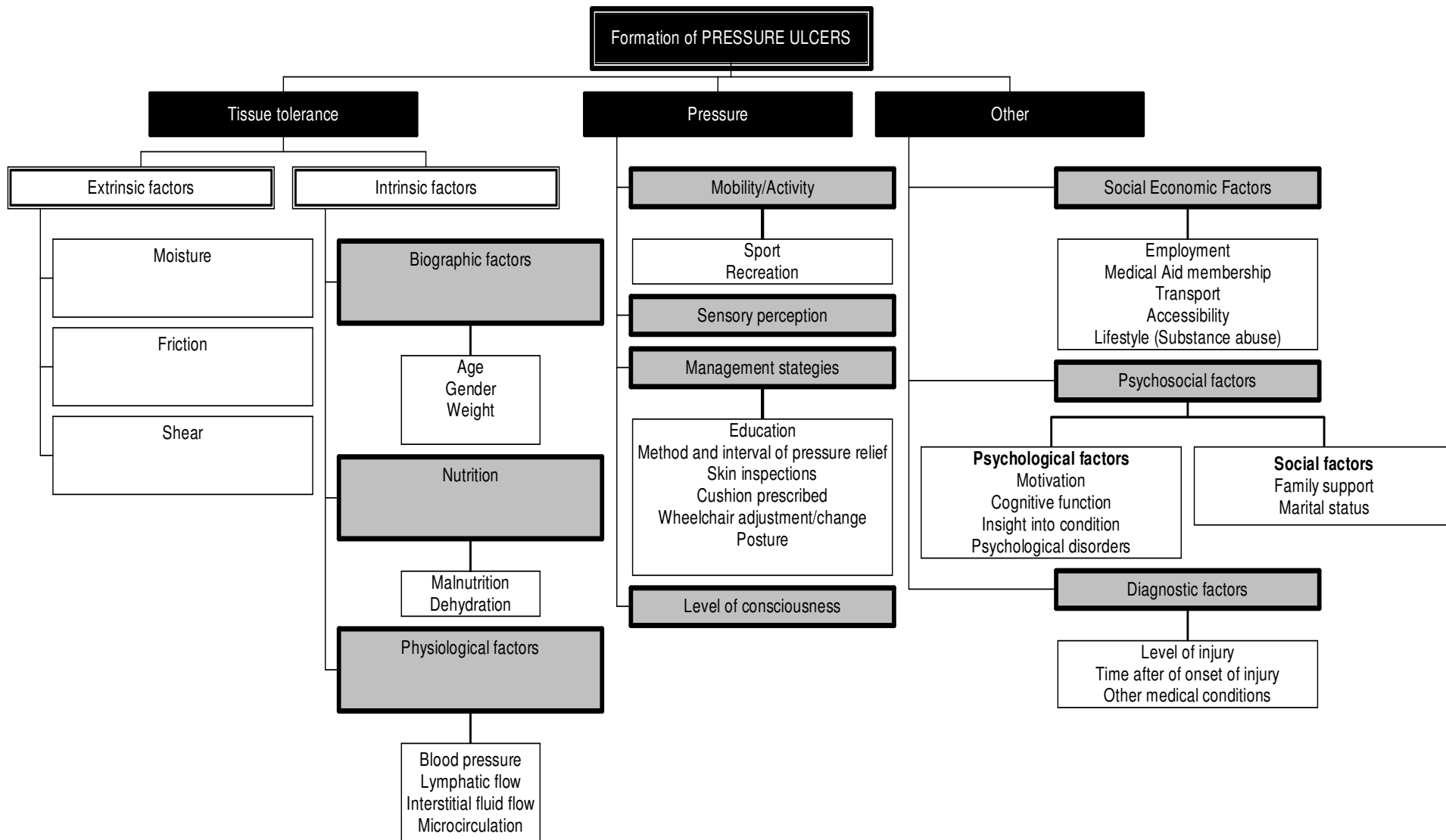


Figure 2.3 Risk factors for pressure ulcer development

b) Urinary tract infection (UTI)

Asymptomatic bacteruria is common among SCI patients who use self-catheterisation, with urinary tract infection (UTI) being the most frequent complication (Montegomerie, 1997). The factors increasing the risk of infection include over-distension of the bladder, vesico-ureteric reflux, high pressure voiding, large post-void residuals and stones in the urinary tract (Salomon, Denys, Merle, Chartier-Kastler, Perronne, Gaillard & Bernard, 2006). Savic, Short, Weitzenkamp, Charlifue and Gardner (2000) postulate that urinary and skin complications are the principle reasons for readmission of individuals with spinal cord injury after being discharged.

c) Respiratory infections

Respiratory complications are the leading cause of morbidity and mortality following SCI (Cardozo, 2007; Smith, Evans, Kurich, Jibby, Waever, Nayna Patel & Burns, 2007; Werhagen, 2008). Respiratory infections occur as a result of reduced inspiration and expiration ability, decreased tidal volumes and an inability to cough out secretions (Soden, Walsh, Middleton, Craven, Ruthkowski & Yeo, 2000).

Davies and McColl (2002) conducted a study on the incidence of lifestyle risks for three disease outcomes, namely cardiovascular disease, respiratory infection and urinary tract infections, in PLWSCI. These authors found that people with tetraplegia were at greater risk of developing respiratory infections than those with paraplegia. This was attributed to their impaired ability to clear the respiratory tract of secretions by coughing, leading to retention of respiratory tract secretions and respiratory infections. The authors further found that the number of cigarettes smoked per day increased the risk of respiratory infection.

d) Gastrointestinal complications

Spinal cord injury (SCI) has an impact on multiple organs in PLWSCI, including bowel function (Hass, Geng, Evers & Knecht, 2005). Signs and symptoms of bowel dysfunction as well as complications reported in the literature include prolonged colonic transit time, faecal impaction, abdominal distension and colonic dilatation (Haas et al., 2005). Changes in bowel motility, sphincter control, and decreased gross motor dexterity interact to make bowel management a major lifestyle problem and one which limits quality of life (Lynch et al., 200; 1Ayas, Leblebici, Sozay, Bayramoglu & Niron, 2006).

Bowel dysfunction following spinal cord injury (SCI) is increasingly recognised as an area of major physical and psychological discomfort for PLWSCI (Lynch, Antony, Dobbs & Frizelle, 2001). Problems of bowel dysfunction also increase the level of dependency among PLWSCI (Kanisto & Rintala, 1995; Ayas et al., 2006).

Bowel dysfunction is more common in people with higher injuries (tetraplegia) than in those with lower injuries (paraplegia) and it has a major impact on the lifestyle of PLWSCI. Ayas et al. (2006) also found that the majority of male paraplegics (80%) and tetraplegics (46%) ranked bladder and bowel dysfunction as their greatest functional loss, second only to loss of mobility. The more complete the SCI, the greater the effect on bowel function as a result of the greater difficulty associated with toileting and the need for assistance (Stone, Nino-Murcia, Wolfe & Perlash, 1990). The biggest problem associated with bowel dysfunction is “*having a bowel accident*”, which is socially unacceptable to a PLWSCI. This leads to problems of social isolation, as the PLWSCI chooses to stay away from the public for fear of embarrassment.

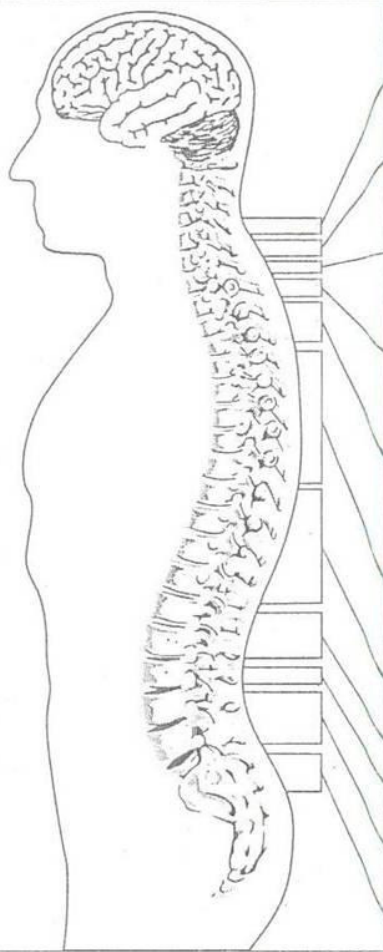
e) Psychological status

The psychosocial consequences of SCI stem mainly from the resultant marked changes in body image after a spinal cord injury (Brown, Bell, Maynard, Richardson, & Wagner, 1999; North, 1999). Adapting to these changes can be a significant psychological challenge for some individuals, leading to depression and anxiety. Other psychological challenges include fear of rejection by partners or peers, poor coping skills and a struggle with self-identity (Carpenter, 1994; Brown, et al., 1999; Craig et al., 1999; Levins et al., 2004). The ability of the PLWSCI to adapt their socio-emotional behaviour to their changed functional ability in all spheres of life is also crucial to successful community participation.

2.4.2 The influence of functional activities on community participation

Activity as defined in the International Classification of Function, Health and Disability (WHO 2001) is the execution of a task or action. Activities of daily living and mobility are the functional outcomes expected from people with SCI (Catz et al., 1997). Skills of self-care and mobility are basic to higher levels of functioning, and improvement in these abilities is likely to have considerable impact on the ability of the PLWSCI to participate in community life, and eventually on his/her quality of life (Catz et al., 1997). A study on the functional outcome of patients with SCI found that the ability of patients to perform functional activities was closely associated with the neurological level of the lesion and the presence of medical complications (Vogel, Klaas, Lubicky & Anderson, 1998). Depending on the level and completeness of the injury, a PLWSCI may not be able to perform certain basic functions as illustrated in Table 2.2.

Table 2.2 Functional abilities of PLWSCI



LEVEL	MUSCLE FUNCTION	ABILITIES
C3	None to little diaphragm Neck control.	Special adapted wheelchair, portable ventilating system. Mouth-stick communication.
C4	Neck control, Some shoulder function.	Can manipulate electric wheelchair with special devices. Mouth-Stick communication.
C5	Partial shoulder control. Partial elbow flexion.	Able to eat with special devices. Can propel a wheelchair with assistive devices. Can swim and bowl with adaptive equipment.
C6	Shoulder control, elbow flexion and can move wrist.	Can dress independently with special equipment. Can transfer in bed or car independently. Can drive with adaptive equipment.
C7-8	Shoulder control, elbow extension, some hand function.	Can completely dress with special equipment. Able to shower. Able to work in a building free from architectural barriers.
T1-5	Normal upper extremity muscle function.	Total wheelchair independence. Can move from wheelchair to floor and back. Can stand with assistance. Can compete in all wheelchair sports. Has fine motor coordination in fingers.
T6-10	Partial trunk stability.	Can walk with long braces and crutches in the home.
T11-L1	Trunk stability.	Can possibly walk to do some household activities.
L2	Hip flexion.	Can walk within the confines of the house.
L3-4	Knee extension.	Can walk in the community with leg braces and crutches or cane.
L5-S2	Leg and ankle control.	Can possibly walk without any special devices.

Eareckson Tada et al (Joni and Friends) : 1980, p.21

2.4.3 The influence of personal factors on community participation

Personal factors include features of an individual that are not part of a health condition such as age, motivation, educational level, experience of living with the health condition, to mention but a few. The presence of certain personal characteristics has been found to have either a negative or a positive influence on community participation. In the following sections, the influence of the demographic characteristics and rehabilitation experience of the PLWSCI are discussed.

2.4.3.1 Demographic influences on participation

The age, ethnicity and level of education of PLWSCI have been reported as having an influence on community participation (Krause 1996, 1997; Krause, Sternberg, Lottes & Maides, 1997). These authors found that PLWSCI who were younger, of Caucasian ethnicity and with better education participated more actively in society and demonstrated higher levels of participation in their communities. Similar findings were reported by Whiteneck, Tate and Charlifue (1999) in a study to identify factors predicting community participation after SCI. These authors found that gender was also related to community participation, with males participating better than females. A study on the quality of life of African Americans with SCI found that the male gender had a positive influence on community participation (Charlifue & Gehart, 2004). Regarding the number of years post injury, the reviewed literature suggests that the longer the period post injury, the better the community participation (Charlifue & Gehart, 2004; Pentland et al., 1995).

All the above personal factors have been built into the methodology of this study, as they are important in a developing country like South Africa, where demographic issues (especially gender) still influence the socioeconomic status of individuals (Bradshaw et al., 2004). The influence of some of the demographic factors is illustrated in Table 2.4 below.

Table 2.3 The effects of demographic factors on community participation

Demographic factor	Impact (positive or negative)	Reference
Male gender	Positive Positive Negative	Tomassen et al. 2000 Krause 2003 Ville & Ravaud 1996 Anderson & Vogel 2002
High level of injury (Cervical or tetraplegia)	Negative Negative Negative Negative Negative Negative Negative	Krause 2003 Krause 1996 Anderson & Vogel 2002 Krause & Anson 1996 Noreau et al. 1999 Young & Murphy 2002 Castle 1994 Tate et al. 1993
Years of injury	Positive (more yrs) Positive (more yrs)	Meade et al. 2004 Crewe & Krause 1990
Employment	Positive	Mackenzie et al. 1986
Age at time of injury	Positive (younger) Positive	Noreau et al. 1999 Ville & Ravaud 1996
Higher education pre-injury	Positive Positive Positive Positive Positive Positive Positive	Tomassen et al. 2000 Krause 2003 Krause & Anson 1996 MacKenzie et al. 1986 Goldberg & Freed 1982 Ville & Ravaud 1996 Noreau et al. 1999 Castle 1994
Education & training post injury	Positive +	Tomassen et al. 2000 Krause 2003
Private insurance	Positive	Tate et al. 1993
Racial & ethnic minorities	Negative	Meade et al. 2004

2.4.3.2 The influence of rehabilitation on community participation

The focus of rehabilitation for chronic disabling conditions like SCI has shifted from a biomedical to a bio-psychosocial model, with increasing emphasis on a client-centred approach to rehabilitation (Cardol et al., 2002; Kennedy 2007; Pimentel 2008). Rehabilitation programmes aim to enhance the adjustment to life following spinal cord injury by equipping the individual with the skills and resources required for community participation (Conroy & McKenna, 1999). The objectives of rehabilitation are to maximise functional independence, prevent secondary complications, optimise physical functioning and facilitate renewed participation in the community (Ada, Mackery, Heard & Adams, 1999; Chappell et al., 2003; Rimmer, 1999). After the inpatient rehabilitation phase has been completed, the PLWSCI is discharged into the community to resume his/her social life roles. It is during this period that PLWSCI face obstacles associated with their return into the community

The experience of PLWSCI during institutionalised rehabilitation has a bearing on their outcome following discharge. Cott (2004) interviewed people with long-term physical disabilities, including SCI, on the role of rehabilitation in preparing them for community living. Participants in their study reported that they felt ill prepared for community living with respect to practical skills and dealing with the emotional challenges of living with a chronic disabling condition. Similar findings were reported by Magenuka (2006) in a study of the experience of South Africans living with SCI in rural areas. In both studies, participants felt that rehabilitation professionals only addressed impairments and activity limitations, and not participation in social relationships, home life, education, work and economic life. Therefore the transition from being a rehabilitation “patient” to becoming a community-dwelling person with a disability was particularly challenging for the participants once they were discharged from rehabilitation (op. cit.).

These findings were confirmed by Cott, Wiles and Devitt (2007) in their review of the literature on preparing clients for life in the community after their rehabilitation. A key finding from this review was that clients “*found discharge from rehabilitation services distressing in that they feel they have received inadequate information about their expected outcome, ill-prepared for life in the community and unable to participate in life in the ways that they find fulfilling*”. Rehabilitation needs to address bio-medical needs, as well as the psycho-social and environmental contexts of PLWSCI. That is why this study asks whether our rehabilitation programmes have effectively prepared PLWSCI for life in the community.

Nolan (2008) conducted a literature review of patients’ experiences of rehabilitation in order to gain an understanding of these experiences and to outline implications for the practice of rehabilitation. The review revealed that the attitude of rehabilitation staff is a very strong and significant factor influencing the experience of PLWSCI. Similar findings were reported by Mothabeng, Malinga, Van der Merwe, Qhomane and Motjotji (2007) in their study on the views patients with spinal cord injuries had about their rehabilitation experiences. Hammell (2007) concurred that rehabilitation staff “*hold the power to facilitate or to thwart the process of reconstructing life*” owing to their intimate involvement in the early stages when a PLWSCI forms a new identity as a PWD. The attitude of rehabilitation staff can therefore be a facilitator or an obstacle to the preparation of community participation by the PLWSCI.

2.4.4 The influence of environmental factors on community participation

Environmental factors are part of contextual factors, those factors that represent the background of an individual’s life and living (Bornman, 2004). Environmental factors include the cultural (e.g. attitudes, beliefs), physical (e.g. architecture) and social (e.g. family and friends) aspects that surround the

individual (Law et al., 1997). The environment is therefore the situational context that shapes what PLWSCI can do by either supporting or constraining them in their performance of activities and thus affecting community participation.

Environmental factors can act as impediments or facilitators of community participation.

2.4.4.1 The physical environment

The physical environment can also act as an impediment to or facilitator of participation of PLWSCI in society. The physical factors include geographic, architectural and transportation issues and have been identified as accessibility problems that spinal cord injured individuals encounter once back in the community (Anderson & Vogel, 2002; Levins, Redenbach & Dyck, 2004). These factors may cause the social isolation of the person living with SCI, limiting the extent to which the individual is able to integrate fully into and participate in society.

The geographic area around the home of the PLWSCI can be a barrier if it is not conducive to wheelchair use. This may mean that the PLWSCI is unable to leave the house, limiting his/her participation in society. Examples of architectural barriers are inaccessible buildings and community centres where there may be stairs but no lifts or ramps for wheelchair users. Transportation issues include the lack of affordable and disability-friendly public transport.

Whiteneck, Meade, Dijkers, Tate, Bushnik and Forchheimer (2004) conducted a survey of the role of environmental factors on the participation of 2762 PLWSCI in the USA, who had been living with SCI for between one and 25 years. The results of the survey revealed that the perceived top five environmental barriers were those in the natural environment, transportation, help at home, healthcare and government policy, as reported using the Craig Hospital Inventory of Environmental Factors (CHIEF) instrument. Significant

predictors of higher CHIEF total scores (i.e. more perceived environmental barriers) were mid-age range at time of injury, female, minority ethnicity, more recent injury, more severe injury, and higher degree of activity limitations (all at $p < 0.05$).

2.4.4.2 The social environment

Social support is an important factor in enhancing the participation of PLWSCI in rehabilitation (Larson Lund et al., 2005), and eventually in their communities. Larson Lund et al. (2005) suggest that it is important to focus on factors related to social support during rehabilitation, as this will facilitate positive community participation. This is why it is common practice in spinal rehabilitation facilities for PLWSCI to have weekend passes and to experience the realities of the social environment by interacting with family, friends and the community in the natural environment in preparation of participation after discharge from the rehabilitation facility. Hampton (2001) found social support from family and friends to have a positive influence on the quality of life of young Chinese adults living with SCI.

Social support from peers with SCI is another important resource for PLWSCI. Peer support is crucial in helping a new PLWSCI to “accept his/her condition”, as a source of motivation and encouragement. Support groups have been reported to have a positive influence on self-reliance and group participation in a South African case study of people with physical disabilities, including PLWSCI (Stewart & Bhagwanjee, 1999). Similarly, an investigation of the social support needs of PLWSCI in Virginia by Mead et al. (2006) found that the greatest need was to network with other people with SCI in a support group.

2.4.5 Summary – factors influencing community participation

From the discussion in the preceding sections, it emerges that the ability of PLWSCI to participate in their communities depends on their personal characteristics and experiences, the accessibility of the physical environment and the support in the social environment. As indicated in the justification of the study in chapter 1, there is very limited research on community participation by PLWSCI in South Africa. In the next section, a brief review of what South African literature there is on the topic is presented.

2.5 SOUTH AFRICAN RESEARCH ON THE COMMUNITY PARTICIPATION OF PLWSCI

The existing literature on community participation has been growing in the past two decades; however, limited research has been conducted on this topic in the South African context. As indicated in chapter 1, very few articles on the topic have been published in this context. The few South African studies that do exist lend support to the international literature as far as the personal and environmental factors influencing community participation are concerned. Table 2.5 below reflects South African studies related to the participation of PLWSCI (personal and environmental factors in italics and underlined).

Table 2.4 South African studies on the community participation of PLWSCI

Publication	Aim of study	Main findings
Cock (1989) (Disability and Society Journal)	To determine the needs of PLWSCI in Soweto	Lives of PLWSCI in Soweto are characterised by <u>poverty and isolation</u>
Leshilo (2005) (MA Social Work thesis, University of Pretoria)	The feelings of people with physical disabilities regarding discrimination in Tembisa	PWD feel <u>isolated, rejected, marginalised and stigmatised</u> in their own community
Magenuka (2006) (PhD Nursing (rehabilitation) thesis, University of South Africa)	To explore the experiences of people living with SCI in the Eastern Cape	PLWSCI live in <u>isolation</u> and have a limited social life. They feel <u>ill-prepared for life in the community</u> and are poorly integrated into the community
Njoki et al. (2007) (South African Journal of Physiotherapy)	The impact of SCI on South African youth in the Western Cape	<u>Social identity, intra and interpersonal factors, social support and employment</u> are major challenges for youth with SCI once back in the community.
Monageng (2007) (MA Social Work thesis, University of Pretoria)	Psychosocial problems encountered by black tetraplegics once discharged from hospital	Psycho-social challenges included <u>disturbed family relations, negative self esteem, lack of self confidence, lack of transport and stigmatisation</u> by the community.
Vosloo (2009) (Disability and Rehabilitation Journal)	To evaluate the functioning of primary school children living with paraplegia in the Western Cape	The children were restricted in cognitive independence and mobility. Physical and educational <u>resources, social support and equity</u> are needed to facilitate the inclusion of these children

2.6 MEASURING COMMUNITY PARTICIPATION FOLLOWING SCI

Community participation is an important outcome to evaluate following the rehabilitation of persons with disabilities, including those with spinal cord injury (SCI), because participation is closely related to quality of life (Dijkers, 1997). Section 2.5 presented the various factors affecting the community participation of PLWSCI. In this section, the literature on instruments for measuring community participation and related factors is reviewed in order to select instruments for implementation in this study (Chapter 3).

There are very few instruments specifically developed for measuring community participation by PLWSCI. Most instruments used with this population are generic and have been developed for use with the general population living with physical disabilities. As indicated in the framework in chapter 1, the community participation of PLWSCI is influenced by factors related to body structure and functions, activities, personal and environmental factors. All these factors must be taken into cognisance when measuring participation. Therefore the description of instruments in this section includes all factors, and is not limited to instruments that measure participation only.

2.6.1 Measurement instruments at body structure and function level

Problems of body structure and function are called impairments (Bornman, 2004). The major impairments following SCI are motor and sensory loss, and these are used to determine the Neurological Level of Injury (NLOI). The NLOI is determined using the International Standards for Neurological and Functional Classification of Spinal Cord Injury (ISCS-CI-92), initially published by the American Spinal Injury Association (ASIA) in 1982, and adopted by the International Spinal Cord Association (ISCOS) in 1992. The international standard (hereafter referred to as the ASIA scale) tests the NLOI using motor and sensory testing.

The ASIA scale will not be used as a measuring instrument in this study, as it is not the intention to diagnose the participants by determining the level of their lesions. The study participants are all living with chronic SCI (for more than two years), and therefore their diagnoses are well established. During the study, the level of the lesion will be established by asking the participants questions using the socio-demographic and injury profile (SDIP) (Appendix H) designed by the researcher.

The socio-demographic and injury profile (SDIP) will be used to collect information on participants' personal data, and SCI and general health data: injury data, including the cause of the SCI, **level of the SCI**, date of injury, **completeness of injury**, current **complications of the SCI and any related health problems**. By the time PLWSCI are discharged from rehabilitation, they are educated regarding the level and completeness of their lesion, and whether their injury is complete or not. The researcher will also be able to verify the participants' responses by checking the recorded level and completeness on the database.

2.6.2 Measurement instruments at activity level

A number of instruments exist for measuring the functional activities of PLWSCI. These include instruments for measuring activities of daily living and/or mobility. Some measurement instruments have been specifically developed for PLWSCI, while others are generic for use with all people with disabilities. Table 2.6 provides a summary of the instruments measuring the activity levels applicable to PLWSCI.

Table 2.5 Instruments for measuring the activity level outcomes for PLWSCI

Instrument and reference	Purpose of instrument	Validity and reliability	Comments
Barthel Index (BI) (Mahoney and Barthel, 1955)	To assess the severity of disability or independence in personal care and mobility	Good validity and reliability	Oldest measure of functional ability. Has been used on PLWSCI but has floor and ceiling effects. Not sensitive to changes in function of PLWSCI.
Functional Independence Measure (FIM) (Granger et al., 1986)	To assess the functional ability of PWD in terms of physical and cognitive disability	Excellent validity and reliability	The FIM is considered a gold standard routinely used in most rehabilitation institutions for assessing ADL, in PWD, and has been used in PLWSCI. A major limitation is lack of sensitivity to small functional changes in PLWSCI.
Quadriplegic Index of Function (QIF) (Gresham et al., 1986)	To measure functional improvements in people with quadriplegia during rehabilitation	Excellent validity and reliability	Designed to measure functional activity in PLWSCI who are still in rehabilitation. Specifically designed for people with quadriplegia.
Spinal Cord Independence Measure (SCIM) (Catz et al., 1997)	To measure functional ability of PLWSCI in terms of self-care, respiration, sphincter management and mobility	Excellent reliability and validity. Validated in a multicentre trial in 13 countries.	Developed specifically for PLWSCI, to counter the shortcomings of sensitivity in other tools.

From the instruments presented in Table 2.6, the SCIM was selected as the instrument of choice for measuring the functional abilities of PLWSCI for the following reasons:

- The SCIM is the only instrument designed specifically to measure functional ability in PLWSCI. The SCIM was developed in Israel by Katz and Itzkovich (1997) because previous measures of functional ability were found not to be sensitive to changes in the functional status of people with SCI (Allan et al., 2000). The SCIM was revised by the developers in 2001, and SCIM II was developed. The SCIM II (Appendix J) is the validated version which was used in this study.
- The validity of the SCIM II is supported by several studies including a recent multi-centre study of 13 centres in six countries. The results suggest strong validity and reliability (Katz et al., 2007) and better sensitivity to change, compared to the Functional Independence Measure (Katz et al., 1997). The SCIM is widely used as a preferred research instrument in SCI rehabilitation (Grijalva et al., 2003; Itzkovich et al., 2002, 2006; Katz et al., 1997; Katz et al., 2001b; Katz et al., 2002; Katz et al., 2004; Katz et al., 2006; McKinley et al., 2001; Morganti et al., 2005; Popovic et al., 2006; Ronen et al., 2004; Scivoletto et al., 2003).
- The SCIM II has been used before on South African patients with spinal cord injury, but the psychometric properties of the instrument were not reported (Mothabeng et al., 2005). This study will therefore establish its psychometric properties.

2.7.3 Measurement instruments at participation level

There has been tremendous progress over the past three decades in understanding how individuals resume participating in life activities following a health condition. The interest of rehabilitation professionals in measuring participation has evolved in line with the development of disablement models.

The measurement of participation is the most meaningful outcome of rehabilitation, as it measures outcomes in relation to real life issues in the community (Cicerone, 2004). There are many factors that contribute to a person's level of participation, making it the most challenging variable to measure.

Community participation is “the experience of being a part of the community, being accepted, and not being unduly disadvantaged because of the disability” (McColl, 2001, 215). Participation is important to people with disabilities, disability policy, rehabilitation research, and clinical practice, because it is the real life outcome of SCI rehabilitation. Therefore, it is imperative that clinicians and researchers interested in community participation have access to instruments that accurately measure participation in ways that are both conceptually and psychometrically sound (Magasi, Heinemann & Whiteneck, 2008).

Three main ideas are encompassed in the definition of participation, namely, having activities to fill one's time, being independent in one's living situation and having relationships with other people (Dijkers, 1998). The measurement of community participation should therefore address these three categories of role functioning. Table 2.7 presents a comparison of the various measures of participation as summarised by The Participation Team (2005).

Table 2.6 The Participation Team's comparison of participation measures (Source: Participation Team, 2005)

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
CHART (Craig Handicap Assessment and Reporting Technique)	Measure handicap in the community of persons with SCI (used with other populations, e.g. TBI, stroke, MS, amputations, burns)	Self or interview-administered	27 items Dimensions: physical independence, mobility, occupation, social participation, economic self-sufficiency	30	Yes Observer test-retest	Yes Content construct criterion	Gives similar weights in occupation subscale (i.e. hours worked on job and hours worked in household); does not attempt to measure disability (activity) and handicap (participation) together	Norms developed based on small sample and primarily working young adults from middle class background; ceiling effects with skewed distributions; therefore, recommend not using total score, but base analyses on sub-scores	Walker et al. (2003) Hall et al. (1998) O'Neill et al. (1998) Whiteneck et al. (1992)

Table 2.6 The Participation Team's comparison of the participation measures (cont.)

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
CIM (Community Participation Measure)	Measure community participation of persons with TBI (used with other populations)	Self or interview-administered (phone or face-to-face)	10 items (qualitative statements) measured on 5 point scale from always agree to always disagree e.g. "I can be independent in this community"	5	Yes Internal consistency	Yes Content construct criterion/discriminate	Domains empirically derived; uses client centred language; brief; used in practice with broad range of disabilities	Not widely used; further psychometric development and testing required	McColl et al. (1998) McColl et al. (1997)
CIQ (Community Integration Questionnaire)	Measure handicap as a function of community participation of persons with TBI (used with other)	Self or interview-administered (phone or face-to-face)	15 items Dimensions: home participation, social participation, productivity	10	Yes Internal consistency test-retest	Yes Content construct construct	Widely used; brief; developed specifically for TBI population; based on ICIDH	Variation in inter-rater agreement; ceiling effects (home & social participation); using composite total	Dijkers (1997) Willer et al. (1993)



	populations)							score is questionable; gender effects; scoring system awards more points for certain activities for doing them alone than with others	
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Table 2.6 The Participation Team's comparison of the participation measures (cont.)

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
COPM (Canadian Occupational Performance Measure)	Measure changes in self-perception of occupational performance across a variety of disabilities and developmental stages	In-person interview (semi-structured)	2 (10 point scales) with 3 dimensions Dimensions: performance and satisfaction in occupational performance (self-care, productivity and leisure)	30-40	Yes Internal consistency test-retest	Yes Content criterion construct responsiveness	Considers importance and satisfaction with performance; measures client identified problems; problems are weighted by client in terms of importance; used with broad spectrum of disabilities and age ranges	May be challenging for persons with cognitive impairment to complete semi-structured interview; can extend beyond 40 minutes	McColl et al. (2000) Law et al. (1998)
IPAQ (Impact on Participation and Autonomy Questionnaire)	Measure autonomy and participation of people with chronic disorders	Self-administered	33 items Domains: autonomy indoors, family role, autonomy outdoors, social relations, and work and educational opportunities	30	Yes Internal-consistency test-retest	Yes Content construct convergent discriminate	Focuses on autonomy and participation rather than ability and capacity;	Responsiveness requires further study; does not address productivity other than paid work	Cardol et al. (2001) Cardol et al. (1999)

Table 2.6 (cont.) The Participation Team's comparison of the participation measures

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
LIFE-H (v 3.0) (Assessment of Life Habits)	Measure quality of social participation	Self-administered or external administrator	240 (long) and 69 (short) version items Dimensions: nutrition, fitness, personal care, communication, responsibility, interpersonal relationships, community, education, residence, mobility, employment, recreation	30-60 (short) and 20-120 (long)	Yes Internal consistency test-retest	Yes Content convergent	Measures level of difficulty, type of assistance, and satisfaction with life habit; documents the impact of assistive technology provision; short form available for more general screening; version available for children (5-13 years of age)	Responsiveness requires further study; lengthy to complete	Noreau et al. (2004) Noreau et al. (2002) Fougeyrollas et al. (1998)

Table 2.7 (cont.) The Participation Team's comparison of the different participation measures

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
LHS (London Handicap Scale)	Measure degree of handicap of persons with disability	Self or interview-administered	6 items Dimensions: mobility, orientation, occupation, physical independence, social participation, economic self-sufficiency	10-15	Yes Test-retest internal consistency	Yes Content construct/convergent responsiveness	Takes into account aids and environmental modification available; based on ICDH dimension of handicap; brief; easily understood; simplified scoring system revised in 2000	Includes concept of orientation and physical independence which have been criticised for not being dimensions of handicap or participation	Jenkinson et al. (2000) Harwood et al. (1994)
RNL (Reparticipation to Normal Living Index)	Measure resumption of normal patterns of living after disability or disease (e.g. stroke, SCI)	Self or interview-administered	11 items with 10cm visual analogue scale response format Dimensions: disability, role performance, interpersonal relationships	5-10	Yes Internal consistency observer	Yes Content criterion construct	Easy to score and interpret; brief; used in numerous research studies and practice domains; empirically derived	Visual analogue scale may pose difficulties for persons with cognitive deficits; combines domains of disability (activity) and handicap (participation)	Wood-Dauphinee et al. (1988)



Table 2.6 (cont.) The Participation Team's comparison of the participation measures

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
SPRS (Sydney Psychosocial Participation Scale)	Measure specific types of psychosocial disabilities and handicaps that occur after TBI	Interview (structured and/or semi structured) or independent rating by clinician who is familiar with client	12 statements (with 4 items in each of the 3 dimensions) Dimensions: occupational activities, interpersonal relationships, independent living skills	15	Yes Inter-rater internal consistency	Yes Content construct / convergent responsiveness	Developed based on ICIDH; compares person against their own pre-morbid level of functioning; sensitive enough to detect change over time	Some items do not apply to all individuals (e.g. people not currently in a relationship); difficulties with 7 point rating scale (distinguishing between levels); relatively new assessment; not used widely in research to date	Tate et al. (1999)

Of the instruments described in Table 2.7 above, the Reintegration to Normal Living Index (RNLI) was selected as the instrument of choice to measure community participation in this study. The RNLI (Appendix I) developed by Wood-Dauphinee et al. (1988) is an 11-item instrument that evaluates how people living with chronic and disabling conditions (like SCI) perceive their involvement in community participation activities such as self-care, recreational and social activities.

The reasons for selecting the RNLI were the following:

- The RNLI is short (11 items), easy to understand and quick to complete (May & Warren, 2002). A copy of the RNLI is freely available on the internet and it does not require any licensing or special training to administer or score.
- The RNLI reflects the concept of person-perceived participation by assessing an individual's satisfaction with performance in life activities including mobility, self-care, daily activity, recreational activity, and family roles (May & Warren, 2002).
- The RNLI has been widely studied in different countries among different patient population groups (Bourdeau, Desrosiers & Gosselin, 2008; Carter, Buckley & Ferraro et al., 2000; Daneski, Coshall, Tillingand & Wolfe, 2003; Pang, Eng & Miller, 2007) and is recommended as a participation measure (Participation Team, 2005; Willkie, Peat, Thomas & Croft, 2004).
- The RNLI has been validated as a measure of participation. A recent study by Stark, Edwards, Hollingsworth and Gray (2005) to establish the validity and reliability of the RNLI in a population of community-dwelling adults with mobility limitations (including PLWSCI) found the RNLI to have a Cronbach alpha value of 0.91, which is excellent reliability (Arias & de Vos, 1996; George & Mallery, 2003; Nunnally, 1978). In their review of conceptual and methodological issues related to the construct of participation as defined by the ICF, the Participation Team (2005) identified the RNLI as the participation measure of choice for client centred rehabilitation. Similarly, a review of 27 participation instruments by Willkie, Peat, Thomas and Croft (2004) found the RNLI to be the most relevant

measuring instrument of participation restrictions with the largest proportion of participation items when compared with other instruments.

2.6.4 Instruments for measuring personal factors

Personal factors refer to the bio-psychosocial aspects of the individual, which are not part of their injury (Bornman, 2004). These are typically assessed using a checklist, and include age, gender, marital status and socio-economic status (Westaway, 2007). The socio-demographic part of the previously mentioned SDIP (2.6.1) was selected for measuring personal factors in this study.

2.6.5 Instruments for measuring environmental factors

Very few instruments have been designed for measuring the impact of environmental factors on people with disabilities (including PLWSCI). The Craig Hospital Inventory of Environmental Factors is practically the first instrument specifically designed for this purpose; therefore there was no real choice of instruments in this regard. The CHIEF is “*a broad-based measure of the environment that quantifies the degree to which elements of the physical, social, and political environments act as barriers or facilitators to full participation for people with disabilities*” (Whiteneck, 2001, 14). For the above reason, the CHIEF short form (Appendix K: CHIEF-SF) was selected to evaluate the impact of perceived environmental barriers to community participation as reported by individuals with SCI. The CHIEF has also been used in South Africa (Vosloo, 2009), but the psychometric properties of the instrument were not reported.

The CHIEF is a 25-item instrument designed to measure accessibility, accommodation, resource availability, social support and equality. The CHIEF items ask participants questions about frequency and magnitude of environmental barriers experienced over the past year. For example, CHIEF item 2 reads: “In the past 12 months, how often has the natural environment – temperature, terrain, and climate – made it difficult to do what you want or need to do?” Each question is graded

according to the frequency of the problem, the magnitude of the problem and then added to measure the overall impact of the perceived barrier/facilitator, as described in section 3.2.5.5.1(c) on the scoring of the CHIEF instrument.

The CHIEF total score has high test-retest reliability (Intraclass correlation coefficients [ICC] = 0.93) and high internal consistency (Cronbach alpha = 0.93) (Whiteneck, Harrison-Felix, Mellick, Brooks, Charlifue, & Gerhart, 2004).

The short version of the CHIEF, CHIEF-SF, was selected for use in this study. The CHIEF-SF utilises only 12 items of the original CHIEF without compromising the validity and reliability of the instrument. Psychometric properties of the CHIEF-SF were evaluated using a sample of convenience of 409 individuals with disability, including 124 participants with SCI (Whiteneck, Harrison-Felix, Mellick, Brooks, Charlifue & Gerhart, 2004). The CHIEF-SF has a high correlation of subscale and total scores, suggesting good construct validity. The internal consistency of the CHIEF-SF was found to be acceptable with a Cronbach alpha of 0.75 (Whiteneck et al., 2004).

It takes about 10 minutes to administer the CHIEF as a self-report measure, and up to 15 minutes if administered by an interviewer. The CHIEF-SF takes about seven to eight minutes to administer.

2.7 SUMMARY OF THE LITERATURE REVIEW

This chapter has provided a review of the literature with regard to the research relevant to this study. Owing to limited research on the subject in South Africa, most of the literature reviewed focussed on international studies. The chapter discussed the background of the ICF as the model underpinning the conceptual framework of this study. Factors influencing participation and the various instruments for measuring community participation and related factors following SCI were also discussed within the conceptual framework.

The reviewed literature indicated that the participation of PLWSCI in various societal roles is a global challenge, and that there is a dearth of contextually relevant and local literature on the topic. Most studies reviewed were conducted in developed countries, and their findings may not necessarily apply to developing contexts like South Africa. There is thus a knowledge gap to be addressed in this study.

Based on the literature review, the following instruments were selected for use in the methodology:

- The Socio-Demographic and Injury Profile was selected to describe the SCI and personal profile of the participants.
- The Reintegration to Normal Living Index (RNLI) was selected as a measure of the participants' level of satisfaction with their community participation.
- The Spinal Cord Independence Measure (SCIM) was selected as a measure of participants' functional abilities in terms of activities of daily living, respiration and bladder management and mobility.
- The Craig Hospital Inventory of Environmental Factors – short form (CHIEF-SF) was selected as a measure of the participants' perceived barriers to community participation.

The next chapter discusses the methodology of this study, as informed by this literature review.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

In Chapter 1, the background, rationale, aims and objectives of this study were presented. Chapter 2 reviewed the literature pertaining to community participation with specific reference to factors influencing participation and measurement instruments. A number of instruments for measuring community participation and related factors were also identified and selected for use in this research study.

The research methodology that is described in this chapter includes the originally planned methodology as well as an indication of how this was altered after the pilot study. The originally planned methodology is described, followed by the pilot study and the adapted methodology based on the findings of the pilot study. The methodology is therefore presented in three sections in order to indicate systematically how the study evolved.

- Section A describes the methodology in three phases as it was originally planned during the conceptualisation of the study. The section is therefore presented in the future tense. In each phase, the objectives, data gathering techniques, participant selection procedures, data collection procedures and methods of data analysis are described.
- Section B describes the pilot study that was conducted to validate the research methodology and data gathering instruments prior to the main study. The findings of each phase of the pilot study are presented. Based on the results, suggestions are made on how to adapt the methodology.
- Finally, Section C describes how the main study methodology was implemented based on the pilot study results.

The chapter ends with a description of the ethical considerations applied in this study, and a brief summary of the chapter.

3.2 SECTION A: METHODOLOGY AS ORIGINALLY PLANNED

3.2.1 Introduction

The rehabilitation of PLWSCI is a continuous journey from the onset of the SCI to community reintegration. Due to pressures of cost containment and the need for rehabilitation beds for new patients, PLWSCI are sometimes discharged before they are fully rehabilitated. They therefore need continuing care and support to reach optimal recovery. However, in South Africa little is known about the needs and problems of PLWSCI once they are discharged and sent back to their respective communities. The researcher observed that a number of PLWSCI returned to hospital for management or treatment of complications such as contractures and pressure ulcers after being discharged, suggesting that PLWSCI have difficulty coping with living with a SCI in the community. There is also a dearth of South African literature on the post rehabilitation outcomes of PLWSCI, especially regarding community participation. These problems prompted the researcher to investigate the factors that could be influencing the integration and participation of PLWSCI in their respective communities. When the data gathering instruments that were considered as the most appropriate for this study were identified from the literature review, the researcher realised that none of these instruments had been validated among PLWSCI in a South African context. It was therefore necessary to validate these instruments as part of the current study.

3.2.2 Research aim

The aim of this study is to explore factors that influence the community participation of PLWSCI resident in the Tshwane metropolitan area. This community participation will be explored by implementing objective measurements as well as ascertaining the

perspective of the PLWSCI through in-depth interviews. The envisaged end-product of the study is a framework of community participation, and proposed strategies to be implemented by various stakeholders in the facilitation of community participation for PLWSCI.

3.2.3 Research Approach

The exploratory nature of this research necessitates that a combination of objective measurements of community participation and related factors, and an in-depth discussion of the participants' perceptions of community participation be used. Therefore a mixed method approach which incorporates both quantitative and qualitative research methodologies was chosen. This mixed method research approach will allow the researcher to adopt "between methods triangulation" (Neuman, 2000) which will make the study findings more informative and comprehensive. This triangulation will be achieved by combining quantitative assessments of community participation and related factors measured with a researcher-administered battery of instruments, the participants' perceptions and experiences measured using semi-structured interviews and the researcher's observations.

3.2.4 Research Setting

The setting for the study and both phases of the main study will be the homes of the participants who reside in the Tshwane metropolitan area and surrounding areas. It was decided to conduct the research in participants' homes so that the researcher could observe the environment and social relationships in which the participants were involved.

The Tshwane metropolitan area (formerly the Greater Pretoria metropolitan area) lies in the smallest of South Africa's nine provinces, Gauteng. Tshwane covers an area of 2 198 km² (approximately 65 x 50 km) and it includes Pretoria, Centurion, Laudium,

Eersterust, Akasia, Soshanguve, Atteridgeville, Crocodile River, Ga-Rankuwa, Mabopane, Winterveld, Hammanskraal, Temba, and Mamelodi (see Figure 3.1, Map of Tshwane). The city has about ten inhabitants per hectare, with an estimated population of nearly two million people (<http://www.tshwane.gov.za/cityprofile>). The home language profile of Tshwane indicates that the most widely used home language is Sepedi (Northern Sotho), followed by Afrikaans, Setswana, Xitsonga, IsiZulu and English (<http://www.tshwane.gov.za/cityprofile>). These six languages account for about 85% of the population, and the researcher is conversant in all these languages.

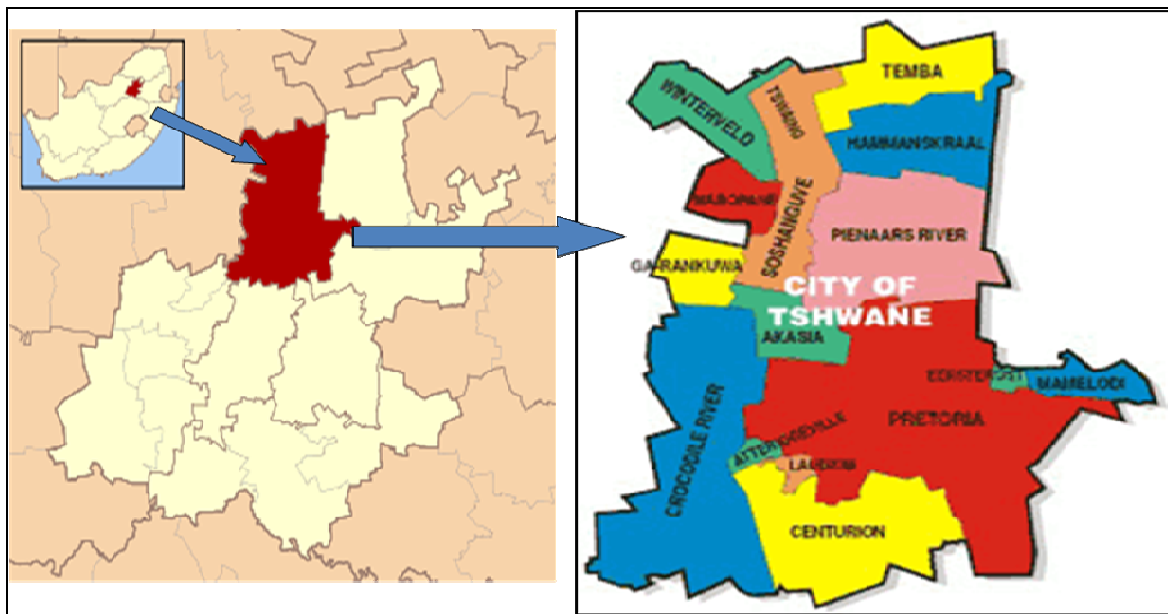


Figure 3.1 Map of the Tshwane Metropolitan area in South Africa

3.2.5 Study Population

The target population for this study is all PLWSCI in the Tshwane Metropolitan area. The accessible population were those PLWSCI registered in the databases used in the study (namely the electronic database of Just at Meulmed Rehabilitation Centre, and the admissions book of the Tshwane Rehabilitation Centre). Two methods of participant recruitment were implemented in this phase of the study to identify a

sample of convenience. Firstly, participants were recruited using the databases of the rehabilitation units from which they were discharged. The second method of participant recruitment was by word of mouth.

PLWSCI who have telephone numbers listed on the database will be contacted by phone and invited to participate after the aim of the study and what it entails has been explained to them. PLWSCI who have no telephone numbers will be personally visited in their homes so they can be given a detailed explanation of the study, and be invited to participate.

3.2.6 Phase 1 of the methodology as planned

3.2.6.1 Objectives of the planned Phase 1

The objectives of this phase were to:

- Ascertain the socio-demographic and SCI profile of the participants
- Measure the participants' level of satisfaction with their community participation
- Measure the functional abilities of the participants
- Determine the impact of environmental factors as perceived by the participants
- Test the psychometric properties of the measuring instruments on a South African population of PLWSCI
- Determine relationships between community participation and other variables measured in this study.

3.2.6.2 Research design

An exploratory, cross-sectional design will be adopted in this phase of the study, in order to address the general aim of this phase which is to obtain point in time measurements of community participation and related factors. A cross-sectional survey was chosen because, according to Whiteneck and Gerhart (2001), surveys are valuable for describing population characteristics (e.g. nature and extent of disability) and for studying rehabilitation outcomes in a selected sample. Survey

research is important to rehabilitation research, and is commonly used in studies to obtain data which can be used to influence rehabilitation policy (op.cit.).

3.2.6.3 Participant selection

To qualify for inclusion in all phases of the study, participants had to satisfy the following criteria:

- be 18 years of age and older
- be of any race and gender
- have a medical diagnosis of SCI, irrespective of the cause (traumatic or otherwise)
- have been living in the community with SCI for at least two years. The minimum of two years takes into account the fact that most SCI are expected to stabilise after 2 years (Fawcett et al., 2007).

Potential participants who do not meet these criteria would be excluded from participating in the study. Before they can participate in the study, details of the study will be explained to eligible participants, who will then be asked to sign a consent form (Appendix A).

3.2.6.4 Selection of data collection instruments

This section describes the selection of the measurement instruments to be used in this phase of the study and the reasons for choosing each instrument. The term “instruments” refers to tools, scales or measures used for data collection purposes.

The selection of data collection instruments took cognisance of the following factors as recommended by McKenzie (2000):

- Appropriateness of the instrument to the research question/s.
- Evidence of validity and reliability of the instrument to measure or to collect the relevant data from the specific population that is under study.
- Practical applicability of the instrument.

Using the above criteria, the following instruments described below were selected from the tables presented in Chapter 2:

- The Socio-Demographic and Injury Profile (SDIP) was selected for collecting personal factor information in terms of demographics and SCI data.
- The Reintegration to Normal Living Index (RNLI) was selected to measure the participants' level of satisfaction with their community participation.
- The Craig Hospital Inventory of Environmental Factors – short form (CHIEF-SF) was selected to measure participants' perceived barriers to community participation.
- The Spinal Cord Independence Measure II (SCIM II) was selected to measure participants' functional abilities in terms of activities of daily living, respiration and bladder management and mobility.

Permission to use the RNLI and the SCIM was freely obtained from the developers on their websites, while permission to use the CHIEF- SF was sought in writing from the developers (Appendix E).

These four instruments were compiled into a battery of instruments to be used for data collection. The battery of instruments was compiled in English only, and was not translated into any of the other South African languages for the following reasons:

- The languages in the black townships in the Tshwane metropolitan area are not pure Sepedi, Sesotho or Setswana, but a mixture of Afrikaans, English, Sepedi and IsiZulu. Thus a questionnaire in a pure ethnic language would have been irrelevant.
- In addition, the high rates of functional illiteracy among black and coloured South Africans, and a lack of questionnaire completion sophistication among Blacks, Indians, Coloureds and some Afrikaans-speaking Whites (Westaway, Olorunju & Rai, 2007), meant that translated self-report questionnaires would have little meaning to the majority of prospective respondents. Due to the researcher's fluency in the languages spoken in the research setting, she was

able to explain questionnaire items to participants who did not understand English.

3.2.6.5 Data Collection Procedures

The battery of data collection instruments described in 3.2.6.4 will be administered by the researcher, and not given to participants to complete. The main reason for not administering the instruments as self-reports is that a high degree of literacy is necessary for self-administration, and the functional literacy level of the study population is not known. It is anticipated that the majority of potential participants will be from disadvantaged settings; therefore many of them may experience functional literacy difficulties and may have little or no experience in completing self-administered questionnaires (Westaway, Olorunju & Rai, 2007). It is acknowledged that some of the participants would have been able to complete the instruments as self-reports. However, for purposes of consistency and to standardise the data collection, the instruments will be researcher administered.

3.2.6.6 Data analysis

The data collected using the SDIP, RNLI, CHIEF-SF and SCIM will be captured and analysed using version 17 of the Statistical Package for Social Scientists (SPSS 17). Descriptive statistics will be the first step in analysis of data from all the instruments. Further data analysis for this phase of the study will include the following procedures:

3.2.6.7 Calculation and analysis of individual instrument results

a) Analysis of the SDIP

Descriptive statistics using frequencies, means and averages will be used to describe the socio-demographic and participant characteristics.

b) Analysis of the RNLI

The adjusted RNLI score will be converted to a percentage, in keeping with the original scoring guidelines of Wood-Dauphinee et al. (1988). Higher scores indicate a higher level of satisfaction with community participation.

- A score of 100 indicates that the participants are fully satisfied with their community participation;
- Scores of between 60 and 99 indicate mild to moderate restrictions in self-perceived community participation; and
- Scores lower than 60 indicate severe restrictions in self-perceived community participation (Caters et al., 2000; Pang, Eng & Miller, 2007).

b) Analysis of the CHIEF-SF scores

Each item on the CHIEF-SF is scored in three stages. Firstly, participants are asked to indicate the frequency of occurrence of each type of barrier that they experience.

This is then scored on a five point Likert scale where

- 0 = never
- 1 = less than monthly
- 2 = monthly
- 3 = weekly
- 4 = daily

Secondly, participants will be asked to indicate the extent of the perceived barrier and this is scored using the scale:

- 1 = little problem
- 2 = big problem

Using the above two scores, a product score indicating the overall impact of the perceived barriers is derived by multiplying the frequency score by the magnitude score to yield a product score on a scale of 0-8 per item. The maximum and minimum values on this scale have conceptual meaning. For example, a value of zero means there are no environmental barriers in the domain in question, while a score of 8

means participants perceive environmental barriers of great magnitude in the domain in question.

c) Analysis of the SCIM II scores

The SCIM II evaluates three domains of functioning, namely self-care, respiration and sphincter management and mobility. These subsections of the SCIM are scored in the following manner:

- Self-care (with a score range of 0 – 20)
- Respiration and sphincter management (with a score range of 0 – 40)
- Mobility (with a score range of 0 – 40).
- The total SCIM II score ranges between 0 and 100, with higher scores representing a higher level of function.

3.2.6.8 Psychometric testing of the measuring instruments

Good research practice requires that the psychometric properties of an instrument be re-evaluated each time the instrument is used in a new setting (e.g. in a different country) or with a different group of people than that for which it was originally designed (Dijkers, 1999; Streiner & Norman, 1989). Therefore psychometric testing of the data collection instruments will be conducted during the pilot study and in the main study in order to enhance the validity and reliability of the study. Psychometric testing for validity and reliability will be conducted on the RNLI, CHIEF-SF and the SCIM because no publication in which these instruments were tested on a South African population could be identified.

a) Validity testing

Validity is the degree to which a test measures what it is supposed to be measuring (Polit & Hungler, 1999). The validity of an instrument provides a measure of the degree of confidence which can be placed in the inferences drawn from the scores on the instrument (Streiner & Norman, 2003).

There are different aspects of the validity of an instrument which can be assessed, namely content validity, face validity, criterion-related validity and construct validity.

- Content validity

Content validity is concerned with the sampling adequacy of the content area of the variable being measured. Areas covered in the instrument should represent a wide area of the variable being studied (Polit & Beck, 2006). In this study, the Kaiser-Meyer-Olkin measure of item sampling adequacy will be used to ascertain content validity of the items (Child, 1970; Nunnally, 1978).

Principal component analysis using alpha factoring will also be conducted on the measurement instruments to ascertain a common factor model and content validity (Kim & Mueller, 1978). Principal component analysis groups the items into clusters of variables (or factors) that are related to each other but measure a distinct aspect of the phenomenon (McDowell & Newell, 1996).

The factor analysis will be followed by a two-factor orthogonal (VARIMAX) rotational solution, to ascertain the underlying dimensions of each measurement instrument. Only items with communality estimates (common factor variance) ≥ 0.30 will be taken into consideration, in keeping with Child (1970) who states that items with unique variance (specific variance + error variance) > 0.70 tend to be unreliable. In order to ascertain significant factor loadings at the 1% level, loadings $> \pm 0.50$ will be examined (Child, 1970; Nunnally, 1978).

- Face validity

Face validity is a weak form of validity, used mainly to determine the readability and clarity of the content of the instrument. It is based on the judgments of the experts in the field (Brink, 2006). In this study, face validity of the data gathering instruments was ensured with input from the project supervisors who critically evaluated the instrument and commented on its content.

- Construct validity

According to Burns and Grove (2003), construct validity aims to find out how well the instrument reflects the concept being studied. In this study, construct validity will be established through principal components analysis, whereby items loading > 0.70 on one factor will provide support for construct validity (Andaleeb, 2001). Construct validity will also be established by correlating individual item scores with total instrument scores. Pearson Correlation Coefficients will be used to assess these associations.

T-tests, Chi-squared tests, one-way analyses of variance (ANOVA), with Bonferroni adjustments for multiple comparisons, and Pearson product-moment correlation coefficients will be used to determine the relationships between demographic factors and the other measures.

- Criterion validity

Criterion validity refers to the correlation of an instrument with another instrument that measures the same variable of interest. The other instrument is ideally a “gold standard” which has been widely used and that is accepted in the field. Criterion validity assesses how a person who scores at a certain level on a new instrument will do on some criterion measure.

There are two types of criterion validity, namely *concurrent* validity and *predictive* validity. In order to establish concurrent validity, a new instrument is correlated with the criterion measure by administering both instruments simultaneously. This type of criterion validity is not applicable here, however, because it is not the aim of this study to develop a new instrument.

Predictive validity includes convergent and discriminant validity and refers to an instrument's success in predicting some important future state or behaviour. In this study, multi-trait scaling will be used to test convergent validity of the RNLI, CHIEF-SF and SCIM. Through this method it can be determined whether individual items in

an instrument are substantially related ($r > 0.40$) to a summation of the items in the other instrument (Stewart et al., 1988). Fisher's z test will be used to compare the inter-correlation coefficients among items in the instrument which have a coefficient alpha (item discriminant validity criterion), with the criterion of $z > 1.96$ (Gaski & Nevin, 1985).

b) Reliability testing

The reliability of an instrument is the degree of consistency with which it measures the attributes it is supposed to measure. An instrument is considered reliable if it yields similar results on separate occasions (Burns & Grove, 2002). There are three main methods of establishing reliability:

- test-retest reliability or repeated assessments over a short period of time using the same rater,
- Inter-rater reliability of observations of the same phenomena made by different people and,
- Internal consistency as measured by co-efficient alpha (Boyce et al., 1991; Streiner & Norman, 2003).

The first two methods are not applicable to this study because it is a cross-sectional survey and only one person will administer the measuring instruments. In this study, the reliability of the RNLI, CHIEF-SF and SCIM will be tested by means of "internal consistency" testing.

The internal consistency of the measurement instruments will be assessed by using the Cronbach alpha, a statistic calculated from the pair wise correlations between items. (Cronbach, 1970). A measurement instrument is considered reliable if scores on similar items are related (internally consistent), and each score contributes some unique information to the measurement. Internal consistency ranges between zero and one.

In accordance with Nunnally (1978), Arias and de Vos (1996) and George and Mallery (2003), the coefficient alpha is graded as follows:

- a coefficient alpha of 0.70 is regarded as acceptable,
- between 0.71 and 0.80 as respectable,
- between 0.81 and 0.90 as very good,
- and above 0.90 as excellent.

3.2.6.9 Inferential statistics

The inter-relationships among the different variables were examined using T- tests, Pearson product-moment correlation coefficients and one way analyses of variance (ANOVA), with Bonferroni adjustments for multiple comparisons. In order to clarify the results, all variables were entered into a regression analysis model. Multiple stepwise regression analysis was used to determine the most significant predictors of community participation. Stepwise regression is an “exploratory technique useful for such purposes as eliminating variables that are clearly superfluous in order to tighten up future research” (Tabachnick & Fidell, 2001, 144). The regression uses the F test to investigate whether independent variable(s), if any, uniquely influence the dependent variable. The R^2 , or the multiple correlation coefficients, are used to indicate how much variance can be accounted for in the dependent variable from the independent variable(s).

3.2.6.10 Analysis of comments made by participants on sections of the instruments

The researcher will record comments and reasons given by participants for awarding very high or very low scores to an item on the RNLI instrument. The aim of recording these comments is to establish whether the scores allocated to a particular item are logical considering the reasons provided, and also to confirm that the participants have understood the items.

3.2.7 Phase 2 of the methodology as planned

3.2.7.1 Aim of the phase

The aim of this phase of the study was to explore the perceptions and experiences of PLWSCI regarding community participation.

3.2.7.2 Objectives of the phase

- To ascertain how participants experience community participation in terms of barriers and facilitators;
- To determine the views of the participants on how rehabilitation prepared them for community living;
- To obtain suggestions from the participants on how community participation by PLWSCI could be enhanced.

3.2.7.3 Research design

In this phase of the study, a qualitative approach to the research design was deemed most appropriate to answering the question “What are the perceptions and experiences of PLWSCI regarding community participation?” The questionnaire planned for use in the first phase, although useful from a quantitative aspect, may not necessarily identify all issues that PLWSCI consider important to their community participation. Therefore the researcher may obtain a perception of reality that is in fact not the reality of the situation as perceived by PLWSC. Therefore, adding a qualitative phase to the study is necessary, to allow PLWSCI themselves to explain in their own words the issues as they affect their community participation.

There are numerous strategies available in qualitative research such as biography, ethnography, phenomenology, grounded theory and the case study (De Vos, 2002). A phenomenological research design was selected for this phase of the study. Phenomenological research examines the human experience through descriptions that are provided by the people involved (Brink, 2000). The purpose of phenomenology is to describe a certain aspect of life as it is lived by the participants. In this study, phenomenology will be used to investigate the perceptions of PLWSCI

regarding community participation and to describe the PLWSCI's perceived barriers to and facilitators of community participation. The phenomenological approach is appropriate to this study because very little research has been conducted on the phenomenon of community participation, particularly in the South African context.

3.2.7.4 Participant selection

Random sampling methods are rarely used in qualitative studies. Instead, specific participants who would be able to supply the relevant information needed to answer the research question are identified through a process known as purposive/judgement sampling (Denzin & Lincoln, 1994). Purposive sampling is frequently used in qualitative research, and is necessary when the researcher wishes to identify and select a sample of "information-rich" participants or "experts". In purposive sampling, selected key informants are used to ensure that the sample is composed of participants who feature the most characteristic, representative or typical attributes of the population (De Vos, 2002a).

A large sample is not necessary in qualitative research, as the focus of the researchers is to seek "an information rich sample", and not numbers (Burns & Grove, 2003). Unlike quantitative research, qualitative research aims to find the reasons behind behaviour; therefore the need is for smaller but more focussed samples to provide the data (op. cit.). This researcher made use of maximum variation sampling as the purposive sampling strategy. In order to obtain a wide range of variation in the samples and maximum information about the phenomenon under study, key participants in this study were selected by taking into consideration the level of the lesion, gender and socioeconomic status (SES). These variables were identified in the literature as affecting community participation (Krause 1996, 1997; Krause, Sternberg, Lottes & Maides, 1997). SES was determined using place of residence and employment. Participants who satisfied the criteria of lesion, gender, place of residence and employment status were targeted for participation (Table 3.1). For example, a key participant would be a PLWSCI who is male, with paraplegia, living in

the suburbs and unemployed; or female, with quadriplegia, living in the township and employed.

Table 3.1 Guide to key participant selection

GENDER and LEVEL	RESIDENCE	RACE	EMPLOYMENT	MARITAL STATUS
Male- Para	Township	Black	Employed	Single
Male – Quad	Suburb	White	Unemployed	Married
Female- Para	Other	Indian		
Female - Quad		Coloured		

According to this guide, at least 44 participants could qualify for participation in Phase 2 of the study. Potential participants who meet these criteria will be identified during Phase 1 and asked whether they would be willing to take part in in-depth interviews. Those who indicate such willingness will be contacted and appointments for interviews will be arranged. A fixed sample size will not be pre-determined: key informants will be added to the study until data saturation is reached (i.e. until no new information can be obtained from the participants through the interviews). This is in line with the principles of qualitative data collection (De Vos, 2002a).

3.2.7.5 Data collection technique

A number of data collection techniques are available to the qualitative researcher to explore a given phenomenon. These include questionnaires, face-to-face interviews, telephonic interviews and focus group discussions. Telephonic interviews would not allow the researcher to observe the participants' expressions and environment, thus this was not a viable option. As potential participants are scattered over a vast geographic area, group interviews were also not a viable option. Individual, face-to-face interviews, using a semi-structured Interview schedule were thus selected as the data collection technique of choice in this phase of the study, after weighing up the advantages and disadvantages of the technique as outlined in Table 3.2.

During a semi-structured interview, questions can be asked in different ways, depending on the response of the participant, without veering from the study themes outlined in the interview schedule. In this way, a semi-structured interview allows questions to be adapted to what the individual respondent says and so remain flexible (Lindlof & Taylor, 2002). Therefore, semi-structured interviews produce more in-depth information on subjects, beliefs and attitudes than any other data-gathering procedure (Brink, 2002) therefore they are appropriate to the study.

Table 3.2: The advantages and disadvantages of an interview (Brink, 2002)

Advantages	Disadvantages
1. Participants do not have to be able to read or write.	1. Interviews can be time consuming and expensive.
2. Responses can be obtained from a wide range of participants.	2. Arrangements for interviews may be difficult, especially if potential participants cannot be contacted telephonically.
3. Non-verbal behaviour can be observed.	3. Subjects may feel obliged to provide socially acceptable responses.
4. Questions can be clarified if they are misunderstood.	4. Subjects may be anxious because answers are being recorded.
5. In-depth responses can be obtained.	5. Subjects may be influenced by interviewer characteristics, especially if the interviewer is known to them.
6. More natural form of interacting with people than any other method of data collection.	

A semi-structured interview guide was developed by the author to explore the views on community participation of people living with SCI (refer to Table 3.3). The guide facilitated the probing of interviewees' views and experiences regarding their community participation.



Table 3.3 Interview guide

OPEN-ENDED QUESTIONS	PROBING QUESTIONS
Tell me what it is like to live with a spinal cord injury in the community.	How do you cope with living with the spinal cord injury? Who helps you? Who gives you support?
How do your family and the community treat you now that you have a disability?	How do you feel about the attitudes of family, friends and the community in general?
How do you feel about the rehabilitation you received for your SCI?	Were you satisfied with it? Why? Was it enough to prepare you for living with SCI in the community?
Are there some things that you think therapists should do, which they are not doing at the moment, to make life easier for PLWSCI?	What can therapists do to enhance the community participation of PLWSCI?
Is there anything else you would like to discuss?	

3.2.7.6 Data collection procedures

Participants who have been identified by the researcher as potential candidates (according to section 3.2.6.3) for this phase of the study will be asked to participate in the interviews.

Data will be collected from the purposely selected participants, as described in 3.6, until data saturation has been reached. At the beginning of the interview, the following broad, question will be asked: *“What has your experience of living with SCI been like since you were discharged from hospital?”*

The participants will be invited to add further information or to clarify their initial response. Probing follow-up questions will be asked in order to encourage the participants to elaborate on the topic that is being discussed. This probing will provide

the interviewer with an opportunity to clarify and expand responses and meaning, and to ensure that the participant's experiences have been truly understood (Brink, 2002). "The interviewer will also encourage participants to continue talking by using non-verbal techniques such as nodding the head or making sounds that indicate interest" (Burns & Grove, 2001).

Participants will be encouraged to talk openly about their experiences of living with SCI in the community, and they will be allowed to raise any other themes for discussion. During the interviews, participants will be assured that they will not be judged and that there are no right or wrong answers to the questions.

The interview will be recorded using an Olympus DS 2 digital voice recorder. All the recorded data will then be transferred to a computer and saved. The researcher will also take notes and make observations during the interview. At the end of the interview, the participants will be thanked for their participation.

When conducting a phenomenological study, a few basic steps should be considered (Brink, 2002). These steps are: bracketing, intuiting, analysing and describing. Bracketing means that the researcher must identify his or her own preconceived ideas about the phenomenon and consciously ignore them. By bracketing oneself, one will be entirely open to the subject's individual and unique experiences. Intuiting is a process by which the researcher immerses him or herself in the lived experiences of the subject. This means that the researcher must attempt to see the experience as the participant sees it.

3.2.7.7 Data analysis

The analysis of the qualitative data will be conducted until a full understanding of common themes emerges. Relationships that exist between the themes will also be highlighted. These specific relationships and themes must be described so that they become clear and comprehensible to the readers (Brink, 2002).

The analysis of the data will begin with verbatim transcription of the recorded interviews into a typed format in preparation for analysis in accordance with the procedure described by Henning et al. (2004). Transcriptions will be compared to audio-taped recordings to verify their accuracy. Non-English transcripts will be translated into English before coding. The translated transcripts will be back translated from English to their original language by an independent translator to ensure accuracy. Once this has been established, all transcripts will be read and re-read very carefully so that the researcher thoroughly understands the data.

Data was coded into broad categories in line with the research questions. The researcher identified and coded themes that emerged and ran through the data from each interview (Patton, 2002). Emerging themes were written in the margins of each interview transcript. All the themes were listed and then grouped into categories. These categories were further grouped into themes related to the topic.

3.2.7.8 Reliability

In an effort to ensure the reliability of the identified themes, the researcher and an independent coder conducted the coding of these themes independently and then met to reach consensus on the codes. The independent coder was a physiotherapist who was familiar with qualitative data analysis but was not involved with the data collection. The agreement level between the coders was set at 80% to ensure that the themes agreed upon were understandable, exhaustive and mutually exclusive. In cases where agreement could not be reached, a third, external, coder was consulted.

3.2.7.9 Use of computer-assisted qualitative data analysis

The researcher decided not to use any of the available software packages for qualitative data analysis, as these programs do not perform the data analysis, but merely provide tools for assisting the process. The researcher is also an instrument of data analysis in qualitative research: in this type of research, data collection and analysis are interactive processes that occur in overlapping cycles, referred to as a “spiral” analysis (Creswell, 1998; McMillan & Schumacher, 2005). The process starts

from the “bottom up”, with data organised systematically from the concrete transcriptions of data recordings to abstract patterns or themes (Creswell, 2007: 38; McMillan & Schumacher, 2005: 322-323).

3.2.7.10 Measures to enhance the trustworthiness of phase two of the study

In qualitative research, researchers talk about the data being credible and trustworthy instead of using words like validity and reliability. Trustworthiness is a concept that denotes rigour in qualitative research, defined as the “degrees of confidence qualitative researchers have in their data, assessed using the criteria of credibility, transferability, dependability and confirmability” (Polit & Hungler, 1987). Therefore, to ensure the trustworthiness of the study, the researcher paid attention to the points illustrated in Table 3.4, making the research more robust (Brink, 2006; Kreftin, 1991).



Table 3.4: Strategies used to ensure trustworthiness of findings (table adapted from Van der Walt, Redivo, Bredenhann, Essa, Eloff & Mostert-Wentzel, 2009)

STRATEGY	CRITERIUM	APPLICATION
Credibility	Prolonged engagement	The researcher has more than 20 years of experience in spinal cord injury rehabilitation, initially as a clinician and currently as an educator responsible for teaching rehabilitation of patients who have sustained a spinal cord injury to under- and postgraduate level physiotherapy students.
	Peer review	Meetings were held to reach consensus on codes, categories and themes.
Dependability	Dense description of methodology	<ul style="list-style-type: none"> The data collection methods and procedures are comprehensively described. After the finalisation of the list of codes, the text was re-coded to achieve consensus.
Confirmability	Audit trail	<ul style="list-style-type: none"> Interviews were recorded and saved on computer in audio and transcript format. Reflective notes were kept that captured decisions taken. All versions of the coding process, illustrating the development of the findings, were kept.
Consistency	Repeatability of procedures	<ul style="list-style-type: none"> All interviews were conducted in a similar style, using the same leading questions.
Transferability	Description of the sample	<ul style="list-style-type: none"> The study population is clearly described. Various characteristics of the participants were described, making it possible for the reader to compare their context with that of this study.

3.2.8 Phase 3 of the methodology as planned

The aim of this phase is to allow the researcher to make objective observations of the participants' home environments and social interactions. These observations were to

be made informally during the other two phases and recorded in a book for content analysis at a later stage.

3.2.9 Summary of the planned study methodology

In this section, the planned methodology of the study was presented with details of the sampling, data gathering and data analysis procedures. The next section describes the pilot study that was conducted to validate the methodology.

3.3 SECTION B: PILOT STUDY

A pilot study is “a small scale version, or trial run, conducted in preparation for a major study” (Polit, Beck & Hungler, 2001), using similar participants (De Vos et al., 2002). The aim of a pilot study is to orientate the researcher to the project in mind and also to test the validity and reliability of the measurement instruments. This section describes the pilot study that was conducted to validate and assess the feasibility of the proposed methodology described in the section above. The changes that were made to the main study as a result of the findings of this pilot study are presented at the end of this section.

3.3.1 PHASE ONE OF THE PILOT STUDY

3.3.1.1 Aims and objectives – Phase 1 pilot study

The objectives of phase one of the pilot study were the same as those described in the planned methodology (section 3.2.6.1).

3.3.1.2 Research design – Phase 1 pilot study

The research design used in phase one of the pilot study was the same as described in the section concerning methodology above (section 3.2.6.2).

3.3.1.3 Participant selection - Phase 1 pilot study

The pilot study was conducted with 12 participants who had been discharged from rehabilitation for more than 24 months. The participants were identified through word of mouth, and met the inclusion criteria specified in section 3.2.6.3.

3.3.1.4 Data collection technique - phase 1 pilot study

Data for the pilot study was collected using the instruments described in section 3.2.6.4, and following the procedure outlined in section 3.2.6.5 of the proposed methodology.

3.3.1.5 Data analysis – phase 1 pilot study

Data for the pilot study was analysed as described in the section dealing with the proposed methodology (section 3.2.5.5).

3.3.1.6 Results – phase 1 pilot study

Twelve PLWSCI participated in this phase of the study (eight males and four females). The demographic profile of the pilot study participants is illustrated in Table 3.5.

Table 3.5: Demographic profile of participants in pilot study

Variable	Categories	Frequencies
Gender	Male	8 (66.7)
	Female	4 (33.3)
Current age (in years):	18 – 29	4 (33.3%)
	30 – 39	6 (50%)
	40 – 49	2 (16.7%)
Race	Black	12 (100%)
Employment before SCI	Employed	5 (41.7%)
	Unemployed	7 (58.3%)
Employment after SCI	Employed	2 (16.7%)
	Unemployed	10 (83.3%)
Source of income	1 = From family	2 (16.7%)
	2 = Disability grant	8 (66.7)
	3 = Employment	2 (16.7%)

The participants in the pilot study were asked to comment on the clarity of the items in the instruments in terms of their wording (De Vos et al., 2002). Based on the participants' responses to the data gathering instruments, a number of changes were made to Phase 1 of the study.

a) Changes to the socio-demographic and injury profile

Most of the pilot study participants could understand the questions as explained by the researcher, but some found a few questions problematic. One such item was the demographic question on the number of years of schooling completed by participants. This question was confusing, particularly to those participants with a low level of education. It was therefore decided to change the phrasing of the question to “how far had they gone with schooling”, and then use the participants' responses to work out the number of years of schooling. For example, a participant who stated that he or she only went up to standard 2 (grade 4) was reported as having four years of schooling, unless they specifically mentioned having repeated some grades. In such cases the repeated grades were added as extra years of schooling.

Issues regarding the presence and severity of pain and spasticity were raised by participants, even though they were initially not part of the questionnaire. Questions on these aspects were therefore added to the final questionnaire.

b) Changes to the Reintegration to Normal Living Index

During the pilot study, it became clear that the wording of the following two RNLI statements required clarification:

- “I am able to take trips out of town” was rephrased to read “I am able to travel out of my home area” (town/township).
- “I spend days doing work that is important” was rephrased to accommodate participants who said they did not work by replacing the word “work” with “doing things”.

The visual analogue scale proved to be a difficult concept for most of the participants to comprehend, even after thorough explanation. It was therefore decided that in this study, participants should be asked to rate their satisfaction with the 11 RNLI statements using a 4-point ordinal scale (Pang, Eng & Miller, 2007), as outlined below:

- 1 = the statement does not describe my situation,
- 2 = the statement describes my situation a little,
- 3 = the statement describes my situation a lot,
- 4 = the statement fully describes my situation.

The 4-point method of rating the RNLI is a deviation from the original 10-point Visual analogue scale used in the original RNLI by Wood-Dauphinee et al. (1988), but it was understood better by the participants in the pilot study. This is not a new practice, as different rating scales have been used with the RNLI in the past to accommodate the comprehension levels of various patient population groups. Examples of such scales include the 3-point scale by Bourdeau, Desrosiers and Gosselin (2008) and the agree/disagree response format of Daneski, Coshall, Tillingand and Wolfe (2003).

c) Changes to the CHIEF-SF

Some items were not applicable to all participants, because not all of them were working or at school. These items were excluded in the case of those participants to whom they were not applicable, in accordance with the recommendations of the developers of the instrument (Whiteneck et al., 2001).

d) Data analysis

During the analysis of the RNLI data in the pilot study, it was found that too many participants fell into the category mild to moderate (60 – 99). For purposes of differentiation, it was decided that the mild to moderate category was too wide and should be broken down further into two categories in which

- A score between 80 and 99 indicated mild restrictions in participation and
- A score between 60 and 79 indicated moderate restrictions in participation.

Further analysis of the pilot study data indicated that this provided a clearer differentiation, without deviating from the original recommended categories (i.e. the two new sub-categories still made up the original mild to moderate category).

3.3.2 Phase 2 – pilot study

The methodology for Phase 2 was carried out as initially planned in the original study plan (section 3.2), with the same 12 participants who took part in Phase 1. There were no problems with the data collection instruments and procedures in this phase; hence there was no need for any changes. However, because the pilot sample was small, it was not possible for the researcher to purposely select participants for this phase as outlined in the proposed methodology (section 3.2.7.4). It was therefore necessary to modify the study. It was decided that ,a washout' period of three months would be allowed to lapse between phase 1 and 2 in the main study, for the following two reasons:

- The researcher needed to know the participants in order to select a purposive

sample of information rich key participants for Phase 2. Therefore Phase 1 (with its 160 participants) had to be completed before Phase 2 could commence. This would allow the researcher time to study the characteristics of the Phase 1 participants and identify the potential Phase 2 sample. It was therefore decided that Phase 2 would take place at least two months after the completion of Phase 1.

- The two month wash out period was necessary to avoid bias by preventing participants' responses to the Phase 1 instrument from influencing the views they expressed in Phase 2.

The final methodology was therefore going to be sequential, with Phase 1 being completed before Phase two.

3.3.3 Phase 3 of the Pilot study

The researcher was able to make the necessary observations as planned in section 3. However, during the pilot study it emerged that the objective observations did not need to be a separate study phase, but could be included in both Phase 1 and 2. The main study therefore comprised two phases.

3.3.4 Summary of methodological changes following the pilot study

The pilot study informed the following main changes to the planned methodology:

- Changes to the content of the data collection instruments.
- Changes to the analysis of the data from these instruments.

These changes were subjected to further psychometric testing during the main study and validated.

3.4 METHODOLOGY AS IMPLEMENTED IN THE MAIN STUDY

The broad research aims, research design, research setting and study population are as described in sections 3.1, 3.2, 3.3, 3.4 and 3.5 respectively. In the sections that

follow, the implementation of the main study as dictated by the pilot study findings is presented in two phases.

3.4.1 Phase 1 – main study

3.4.1.1 Objectives

As previously indicated in section 3.2.6.1, the objectives of Phase 1 of the study were:

- To obtain a personal (socio-demographic and health) profile of the participants;
- To obtain quantifiable measurements of the variables identified in the literature as having an influence on community participation;
- To test the psychometric properties of the measuring instruments;
- To determine relationships between community participation and other variables.

3.4.1.2 Participant selection

A minimum sample of 160 participants was targeted for participation in this phase of the study. The number was arrived at using psychometric testing principles as stated by Nunnally (1978), and which are explained later in this section. Because the study made use of instruments developed in other countries to measure community participation and associated factors, it was necessary to establish the validity and reliability of these measures in a South African population. One of the tests for validity is factor analysis. Nunnally (1978) recommends a minimum sample size of 10 respondents per item for factor analysis. Because a number of instruments were used in this study, the instrument with the largest number of items was considered: this was the Spinal Cord Independence Measure (SCIM) with 16 items (described in 3.4.3.5 below). Thus the targeted minimum sample size was 160 (16 X 10).

In selecting the 160 participants, the researcher used the databases that had been made available by the two participating rehabilitation units, namely, Just at Meulmed Rehabilitation Centre (Appendix F) and Tshwane Rehabilitation Centre (Appendix G).

The selection process started with identifying qualifying potential participants from the databases:

- Firstly, people who appeared on the database but did not have a diagnosis of SCI were eliminated.
- Secondly, PLWSCI not residing in the Tshwane metropolitan area were eliminated.
- Of the remaining PLWSCI on the databases, those who were discharged from the rehabilitation units after March 2007 were eliminated from the list as they would not have lived with SCI for the required minimum of two years at the time of data collection.

Following these eliminations, a database of potentially qualifying PLWSCI from which participants could be selected was created. Additional potential participants were referred by word of mouth.

A number of PLWSCI were not available for participation owing to death, relocation, lack of interest or incorrect contact details. However, the target sample of 160 was eventually obtained after a long and tedious process. As soon as the minimum sample size had been reached, participant recruitment was stopped.

3.4.1.3 Data collection instruments

The following data collection instruments, described in section 2.5, were used:

- The socio-demographic and injury profile
- The SCIM II
- The CHIEF-SF
- The RNLI.

3.4.1.4 Data analysis

The analysis of data in this phase of the study included the following techniques, described above in the section on the pilot study:

- Calculation and analysis of individual instrument results
- Statistical testing

- Psychometric testing
- Analysis of comments made by participants on sections of the instruments.

3.4.2 Phase 2 Main Study

This phase of the study took place two months after the first phase had been completed. As stated above (section 3.3), it was deemed necessary to allow a time lapse between the two phases.

3.4.2.1 Aims and objectives of Phase 2

The aim of this phase of the study was to explore community participation from the perspective of PLWSC, as outlined in section 3.2.7.1 of the proposed methodology.

- The objectives of this phase were as outlined in section 3.2.7.2 above.

3.4.2.2 Research design

A qualitative research design using the phenomenological approach was implemented in this phase of the study as explained in section 3.2.7.3 above.

3.4.2.3 Participant selection

Participants for this phase were purposely selected as discussed in the proposed methodology (section 3.2.7.4).

3.4.2.4 Data collection technique

A semi-structured interview was used for data collection purposes. Details of the interview and the rationale behind the technique are discussed in section 3.2.7.5 above.

3.4.2.5 Data collection procedure

Data was collected as planned in section 3.2.7.6, using semi-structured interviews. Prior to conducting the in-depth interview, the researcher explained the details of the study to the participants, who were asked to agree to an estimated one hour, audio-

taped interview. Signed informed consent was again obtained from the participants prior to the interviews.

3.4.2.6 Data analysis

Qualitative data analysis techniques, as described in section 3.2.7.7 above, were used. Themes were generated from this data. The thematic generation process is illustrated in Appendix M.

3.5 ETHICAL CONSIDERATIONS

Ethical approval (Ethical approval number. 38/2006) was granted by the Ethics Committee, Faculty of Health Sciences, University of Pretoria, to conduct this study in 2006 (Appendix A). The formulation of the title and research methodology was changed slightly in October 2007 after approval by the Postgraduate Committee of the School of Health Care Sciences, Faculty of Health Sciences, University of Pretoria. An amendment was therefore submitted to the Ethics Committee and this was approved in November 2008 (Appendix B: approval of amendment).

Other ethical considerations included receiving permission from the managers of the various rehabilitation centres to access the databases of patients discharged from their institutions. These included the Tshwane Rehabilitation Centre (Appendix G) and the Meulmed Rehabilitation Centre (Appendix F).

Participants received detailed information leaflets explaining the research purpose and procedures. This information leaflet, which covers protection from harm, confidentiality and anonymity, was individually explained to the clients, allowing them to make informed decisions about whether to participate in the study or not (Refer to Appendix C and D: Participant Information leaflet and consent form). Written or verbal consent, depending on the literacy level of the participant, was obtained from all participants or proxies, where applicable (Appendix D).

Participants did gain some benefit from the study in that the researcher assisted them in every practical way possible, in line with the ethical principle of beneficence as outlined by Bluestein (2007). Practical assistance included positioning, answering questions, giving advice and referring them where appropriate to follow up healthcare facilities.

The following are some of the benefits that participants enjoyed during the study:

- One of the participants was referred to the nearest community health centre with a suspected urinary tract infection. He was subsequently put on medication.
- One participant had been living with SCI for six years but could not make the “wheelie” manoeuvre to negotiate inclines. The researcher taught this manoeuvre to the participant.
- One of the participants phoned the researcher to ask for advice on managing a swollen hand. The participant was given the necessary exercises and was advised to visit the local clinic.

3.6 SUMMARY

In this chapter the methodology used in the study, which included a combination of quantitative and qualitative approaches to data collection, was outlined. Changes were made to the original methodology based on the findings of a pilot study. The main methodology was revised and data was collected accordingly. The following two chapters present the results of the study according to the study aims and objectives. Firstly, chapter 4 presents the results of Phase 1, and these are discussed in chapter 5. The results of Phase 2 are presented and discussed in chapter 6. The results of both phases are then integrated in chapter 7, Chapter 8 summarises the whole study and presents the conclusion and recommendations.

CHAPTER 4

RESULTS – PHASE 1

4.1 INTRODUCTION

In this chapter, the results the quantitative phase of the study (Phase 1), are presented. The objectives of this phase of the study were to:

- Ascertain a socio-demographic and spinal cord injury profile of each participant;
- Investigate the reliability and validity of the measurement instruments;
- Determine relationships among and between the measurement instruments; and
- Determine if there were significant differences between the full sample and the interviewed sub-sample in terms of the relationships between demographics, injury profile, interviewee status and measuring instruments.

The results are presented in sections based on these objectives. A short summary of the findings is presented at the end of each section.

4.2 SECTION1: SOCIO-DEMOGRAPHIC AND INJURY PROFILE OF PARTICIPANTS

4.2.1 Socio-demographic characteristics of the sample

The study sample consisted of 160 participants, 124 males and 36 females. The participants' socio-demographic profiles are presented according to the following characteristics: age, gender, marital status, education, geographical location, living arrangements and source of income.

4.2.1.1 Age of the participants

a) Age at the time of injury

The ages of the participants at the time of injury ranged from 15 to 52 years (*mean age = 29.19 years, sd = 8.05*). The majority of the participants (58.1%) were between 15 and 30 years at the time of injury, which corresponds to international trends (Ones, Yilmaz, Beydogan, Gultekin & Caglar, 2007). Table 4.1 depicts the participants' ages at the time of injury.

Table 4.1: Participant age at time of injury

Age	Frequency	Percent	Valid Percent	Cumulative Percent
15	4	2.5	2.5	2.50
16	4	2.5	2.5	5.00
18	4	2.5	2.5	7.50
21	7	4.4	4.4	11.9
22	15	9.4	9.4	21.3
23	21	13.1	13.1	34.4
24	6	3.8	3.8	38.1
25	4	2.5	2.5	40.6
26	7	4.4	4.4	45.0
28	4	2.5	2.5	47.5
30	17	10.6	10.6	58.1
31	8	5.0	5.0	63.1
32	11	6.9	6.9	70.0
33	3	1.9	1.9	71.9
34	14	8.8	8.8	80.6
36	4	2.5	2.5	83.1
38	4	2.5	2.5	85.6
39	3	1.9	1.9	87.5
41	12	7.5	7.5	95.0
42	1	0.6	0.6	95.6
44	1	0.6	0.6	96.3
49	4	2.5	2.5	98.8
52	2	1.3	1.3	100.0
Total	160	100.0	100.0	

b) Participants' age

The age of the participants at the time of the study ranged between 18 and 58 years as reflected in Figure 4.1:

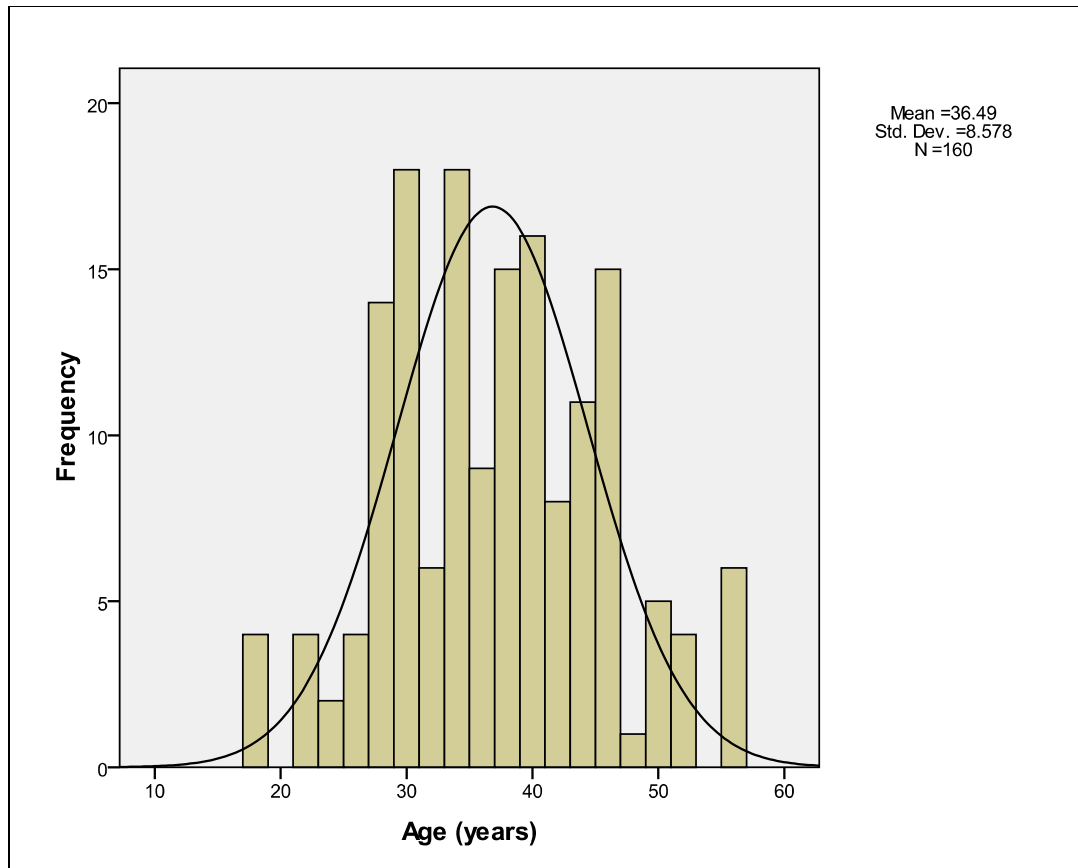


Figure 4.1: Age of participants at the time of the study

4.2.1.2 Gender

The gender distribution of the participants was 124 males (77.5%) and 36 females (22.5%) (Ratio 3.4:1, as indicated previously). Figure 4.2 below depicts the gender distribution in the different age categories.

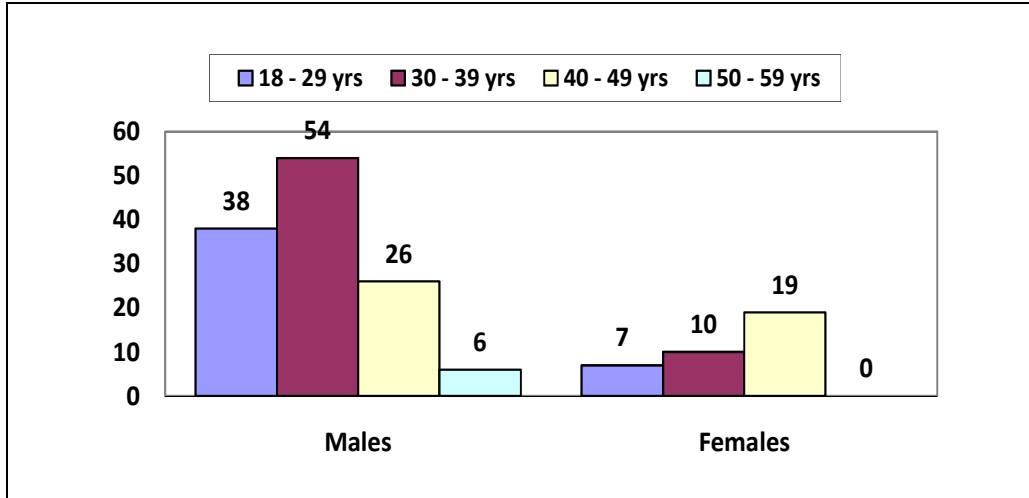


Figure 4.2: Percentage Gender distribution in the different age categories.

4.2.1.3 Marital status

Sixty-four percent of the sample were single (never married) at the time of their injury, and 36% were married. After the SCI, single participants remained single, while the marital status of five of the married participants changed. Two males were widowed, two others were divorced and one female was separated. The marital status of the participants at the time of the study is reflected in Figure 4.3.

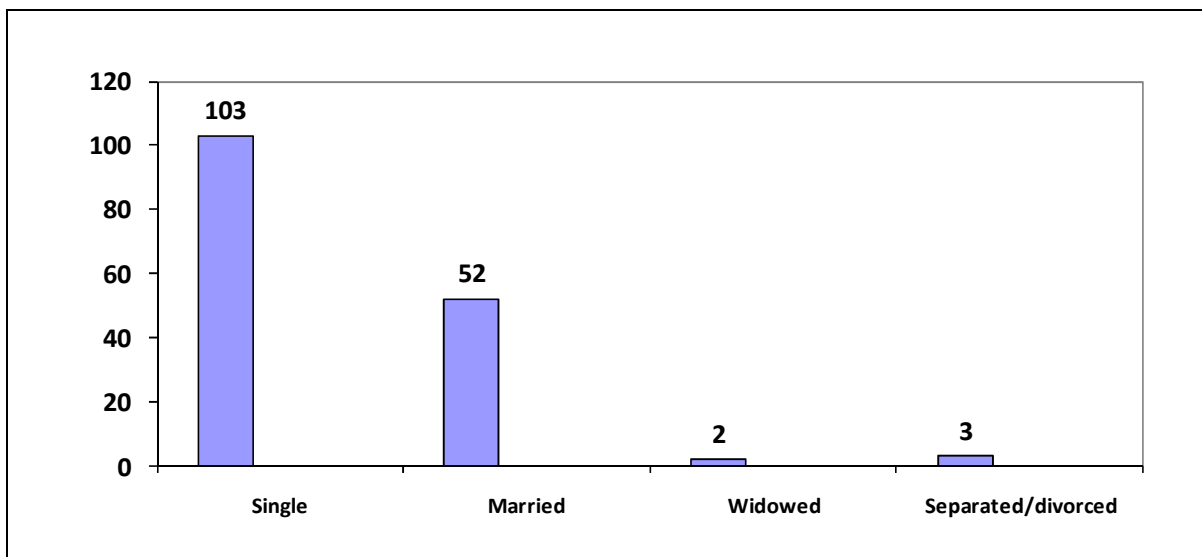


Figure 4.3: Marital status of participants at the time of the study

4.2.1.4 Educational background

All the participants in this study had some form of basic education; the level of education of the participants ranged from two to 12 years of formal basic education (*mean years = 9.87, sd = 2.57*). Figure 4.4 reflects the basic education level of the participants.

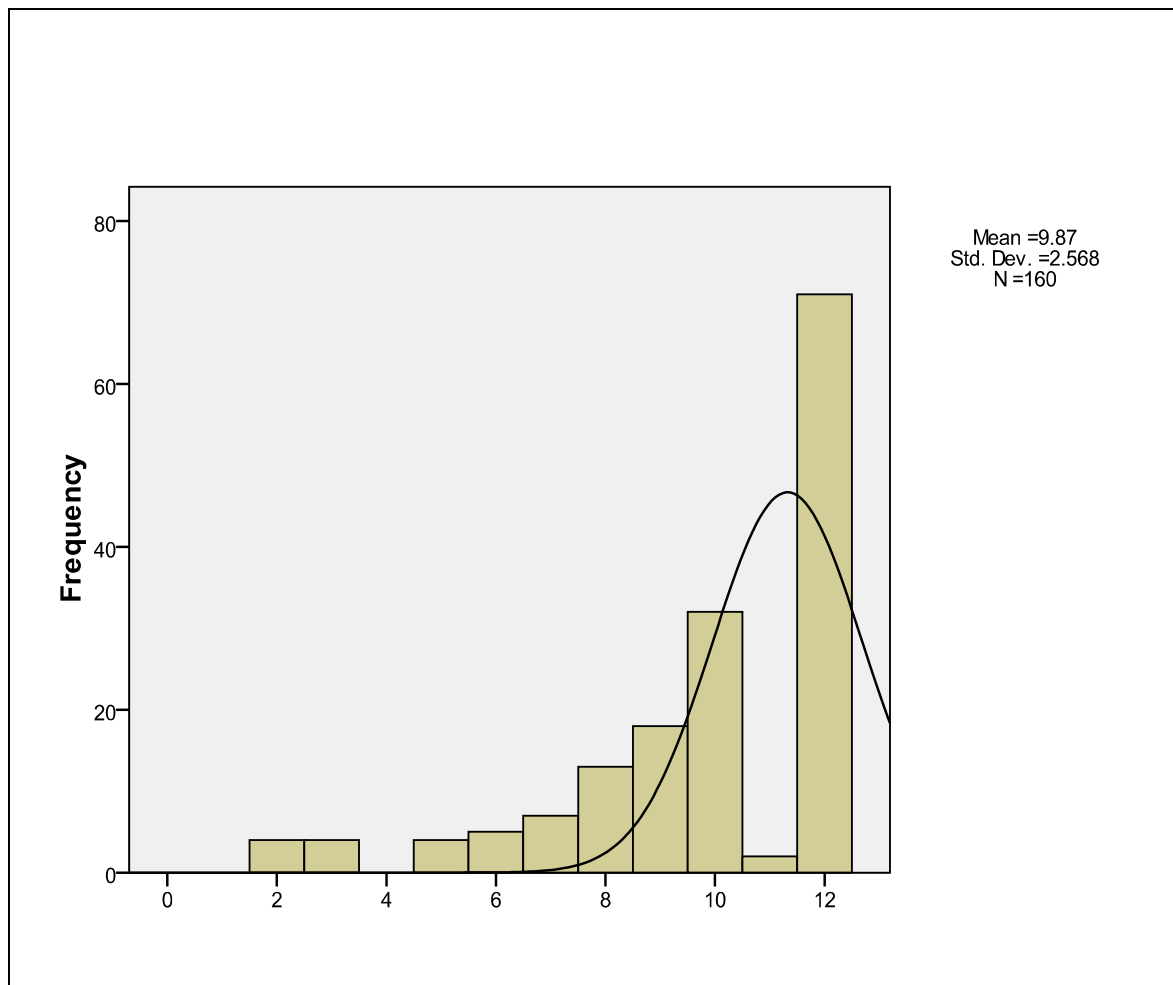


Figure 4.4: Participants' level of basic education

Of the 113 participants who had matriculated (completed high school), 67 (59.3%) had post school qualifications (39 = post basic certificate, 10 = tertiary diploma and 18 = tertiary degree), as indicated in Figure 4.5.

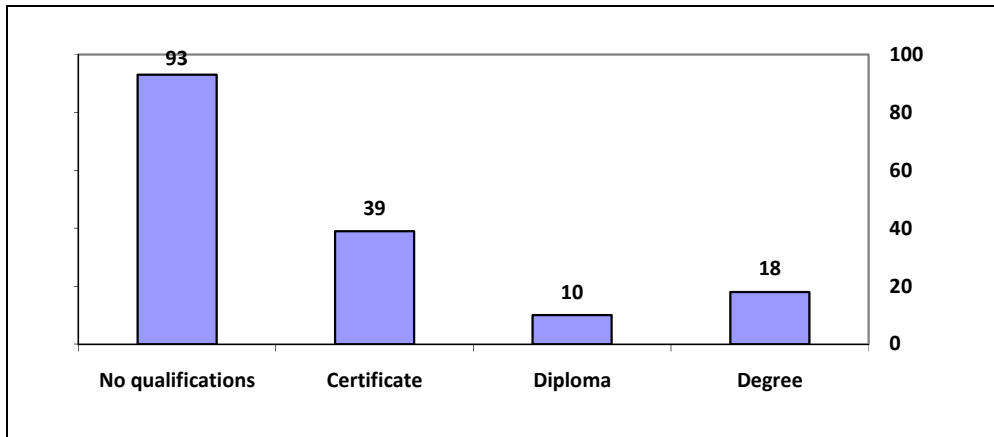


Figure 4.5: Post basic qualifications of participants

4.2.1.5 Residential areas of participants

The majority of the participants were living in townships (60%), while 25% resided in the suburbs of the Tshwane metropolitan area. The remaining 24 participants who indicated “other” (15%) were living in informal settlements or farms and plots outside the township or suburban areas at the time of the study.

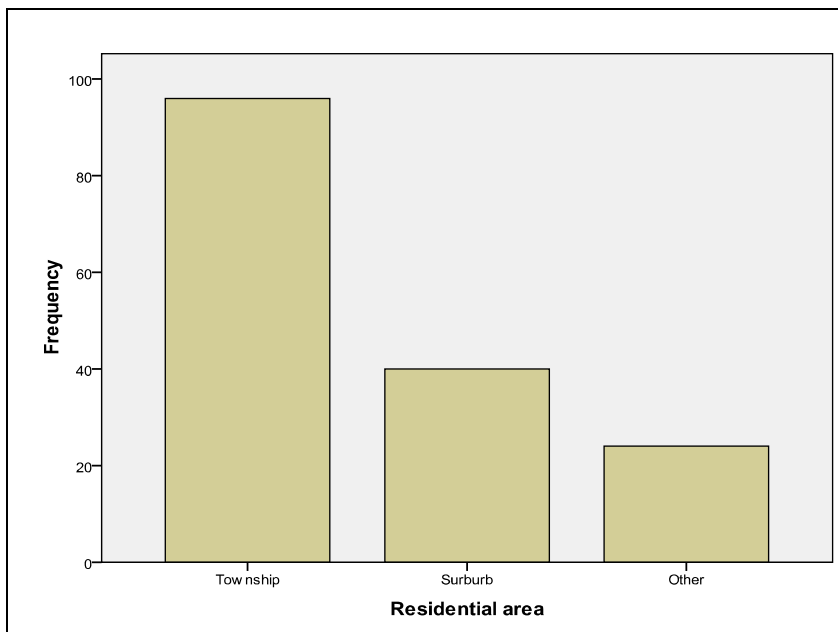


Figure 4.6: Residential area of participants

4.2.1.6 Living arrangements of participants

The vast majority of participants (144 or 90%) were living with their families (own family or parents), eight (5%) were living with friends while another eight participants (5%) resided in shelters or special homes. Figure 4.7 depicts the living arrangements of the participants.

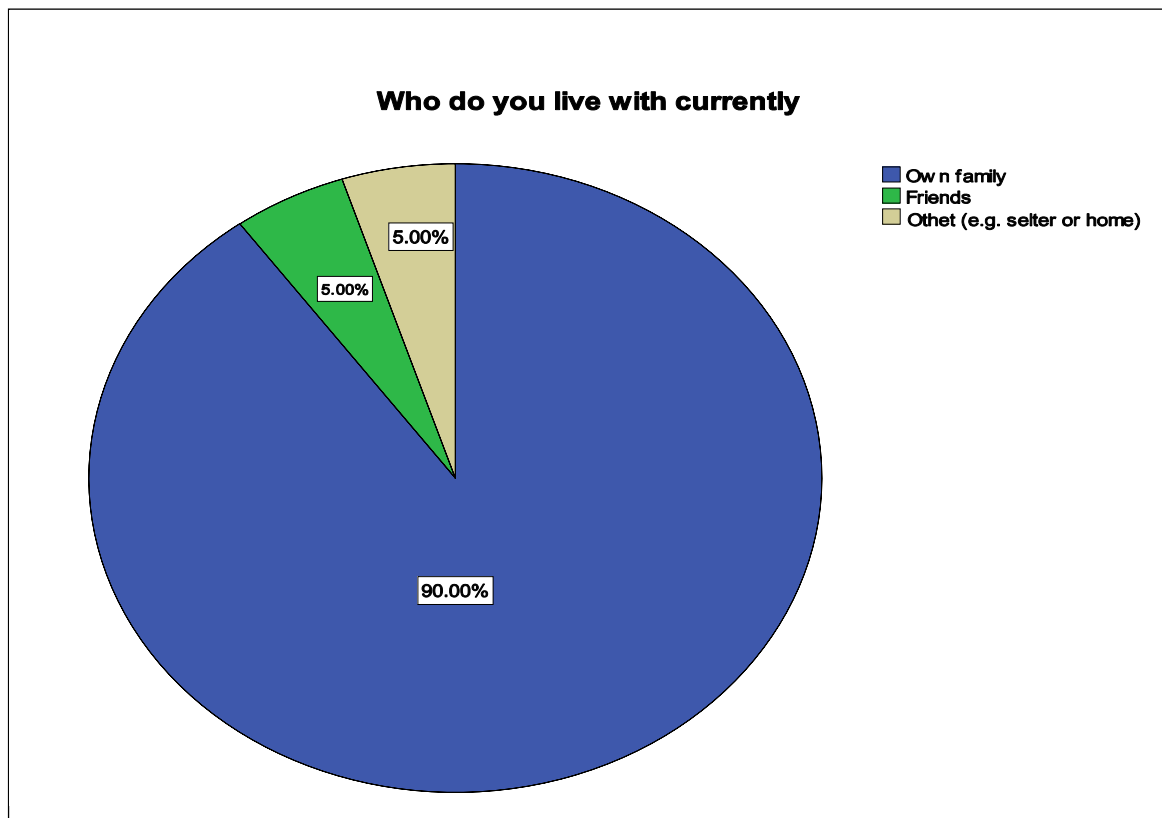


Figure 4.7: Living arrangements of participants'

4.2.1.7 Employment

The employment rate of participants was low, especially in the age groups expected to be in the economically active period of their lifespan (18 - 39 years). Figure 4.8 reflects participants' employment status at the time of the study.

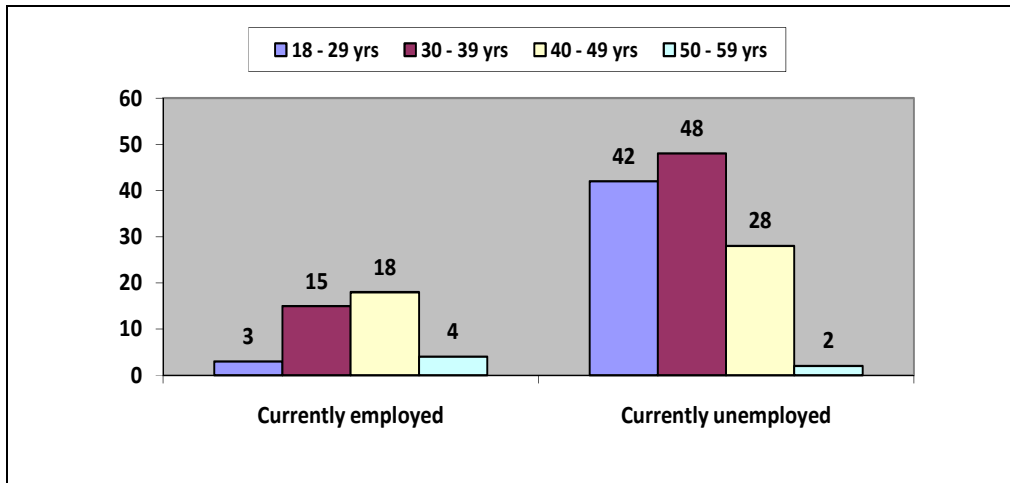


Figure 4.8: Employment status vs. age of participants

Before the SCI, 91 participants (56.9%) had been employed, while only 41 (25.6 %) were employed at the time of the study. Of the 41 employed participants, twelve had been previously unemployed and had gained new employment after sustaining the SCI, meaning that effectively only 29 participants had returned to work. Of these 29, 15 returned to their previous jobs, while 14 changed jobs. Forty-four participants lost their employment post injury, of which 20 were manual labourers (three domestic workers, four gardeners, five farm labourers and eight construction workers). Eighteen participants stopped working because they had received financial compensation from various sources (Road Accident Fund, compensation for occupational Injuries and personal disability insurance). As indicated earlier in this paragraph, only 12 of the 59 previously unemployed participants found new employment after the SCI, leaving 47 still unemployed post injury.

4.2.1.8 Source of income

More than a third of the participants (40%) stated that their main source of income was a disability grant. Forty-one participants (25.6%) were employed, 34 (21.3%) had other sources of income including a disability pension and compensation for occupational injuries, while 24 participants (15%) had no income at all and were

financially supported by other family members. The sources of income among participants are illustrated in Figure 4.9.

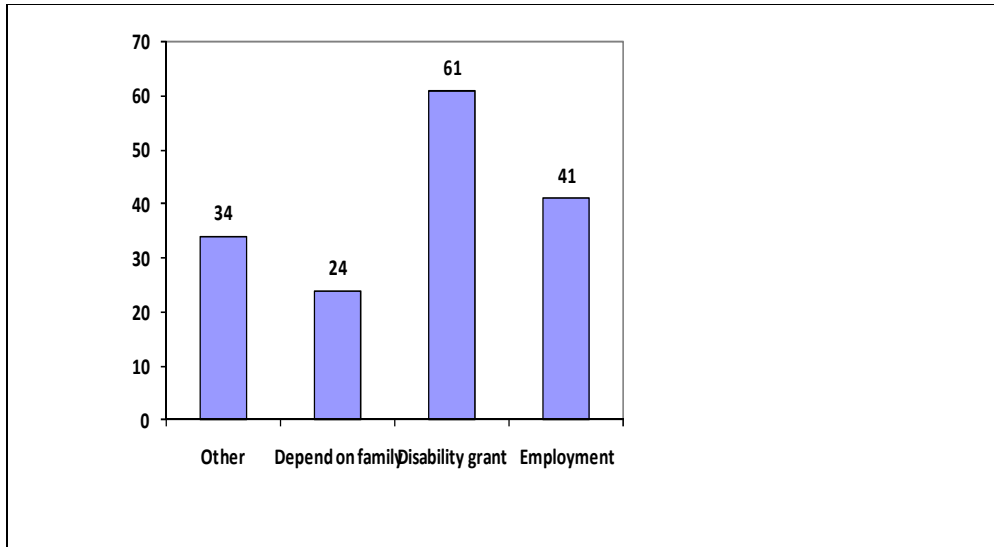


Figure 4.9: Participants' source of income (n = 160)

4.2.1.9 Number of years of living with SCI

The period in which participants had been living with SCI ranged between two and 25 years (*mean = 7.25 years, sd = 5.38*), as reflected in Figure 4.10. There were 13 outlier PLWSCI who had lived with the injury for more than 20 years and these caused the high variance in the responses.

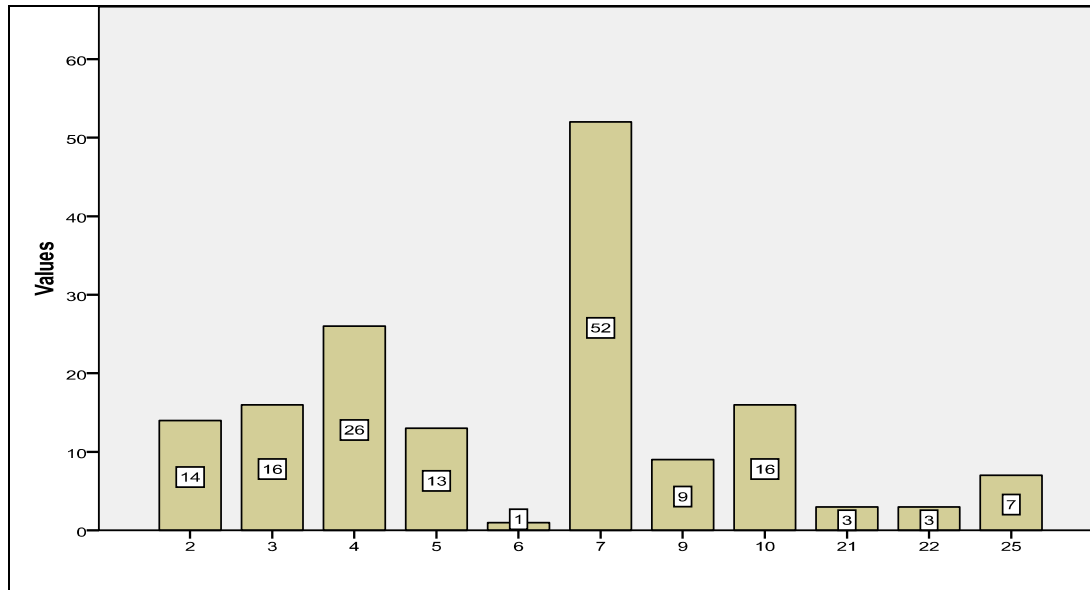


Figure 4.10: Number of years of living with SCI

4.2.2 Spinal cord injury and general health profile

4.2.2.1 Causes of Spinal Cord Injury (SCI) among participants

Figure 4.11 illustrates the causes of SCI among the participants.

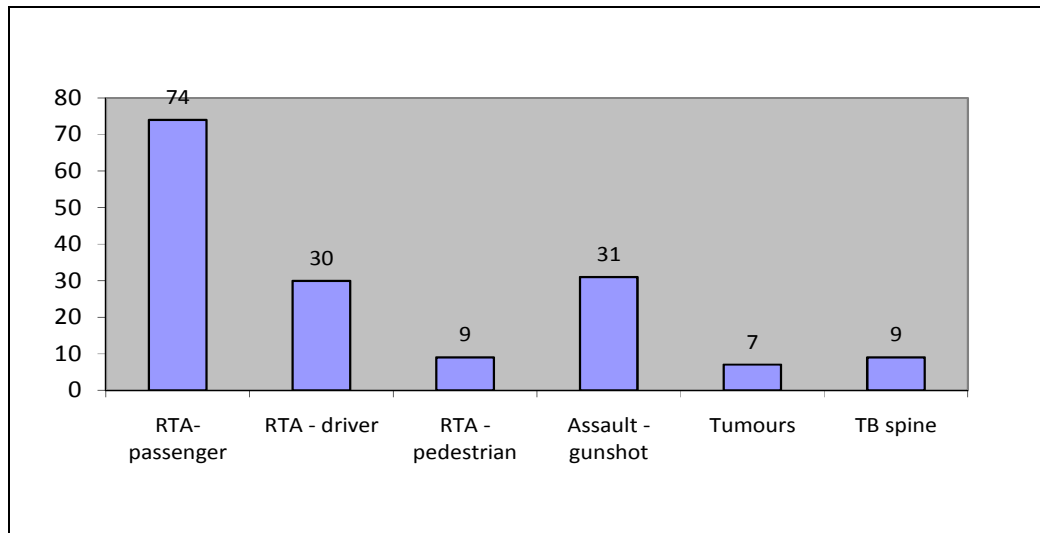


Figure 4.11: Cause of SCI in participants

The majority of participants (n = 144: 90%) had sustained traumatic spinal cord injuries in road traffic accidents or from violent gunshot injuries. Road traffic accidents (RTAs), whether the participant had been the driver of the vehicle, a passenger or a pedestrian accounted for 70.6% of all causes of SCI. Passengers constituted the majority of these RTA related causes (46.3%), while gunshot assaults (from hijackings, house robberies or personal attacks) were the cause of 19.4% of SCIs.

4.2.2.2 Level and completeness of lesion

One hundred participants had sustained lesions below T1 (paraplegia), while 60 (37.5%) had sustained cervical lesions (tetraplegia). Over half (101 or 63.1%) of the participants suffered complete lesions while 59 (36.9%) had incomplete lesions. The level of injury versus completeness of lesion distribution is illustrated in Figure 4.12.

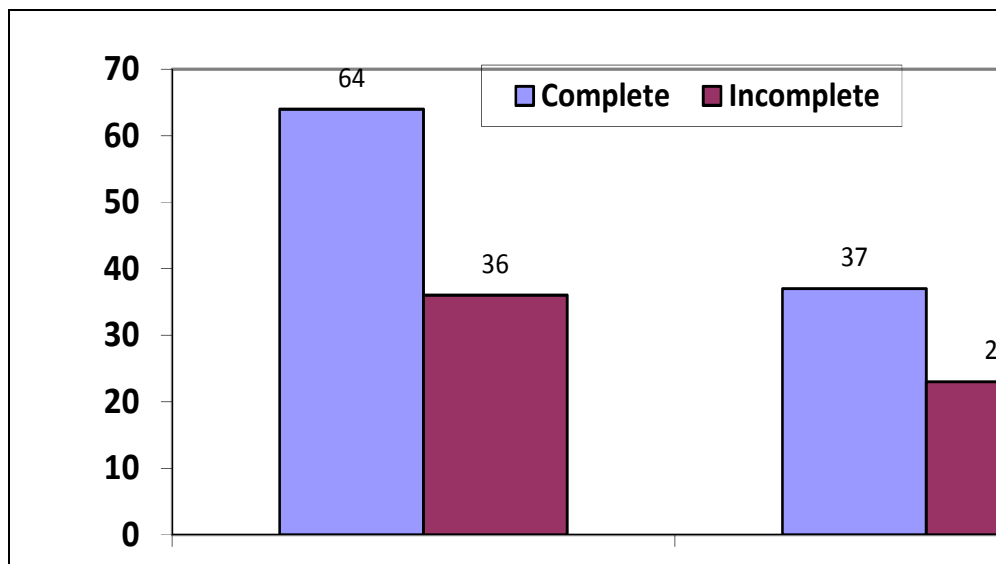


Figure 4.12: Level and completeness of SCI

4.2.2.3 Hospitalisation post rehabilitation

Almost half the participants (48.1%) had been re-admitted to hospital for some reason after having been discharged. Pressure ulcers were the main reason for re-admission (60 participants or 78% of re-admissions). Other reasons for re-admission

included urinary tract infections and respiratory problems. Figure 4.13 illustrates the reasons for re-hospitalisation of participants.

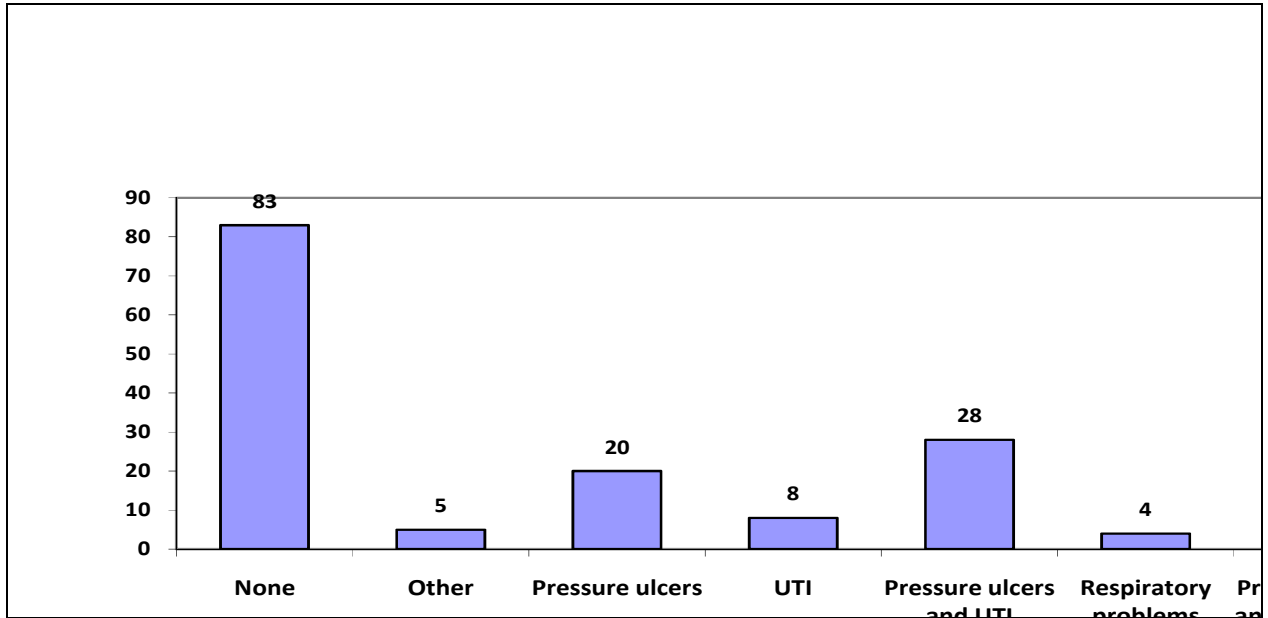


Figure 4.13: Reasons for re-hospitalisation following discharge from rehabilitation

4.2.2.4 Perceived general health status

Overall, the participants rated their general health as fair, good or very good (Figure 4.14). None of the participants rated their health as poor.

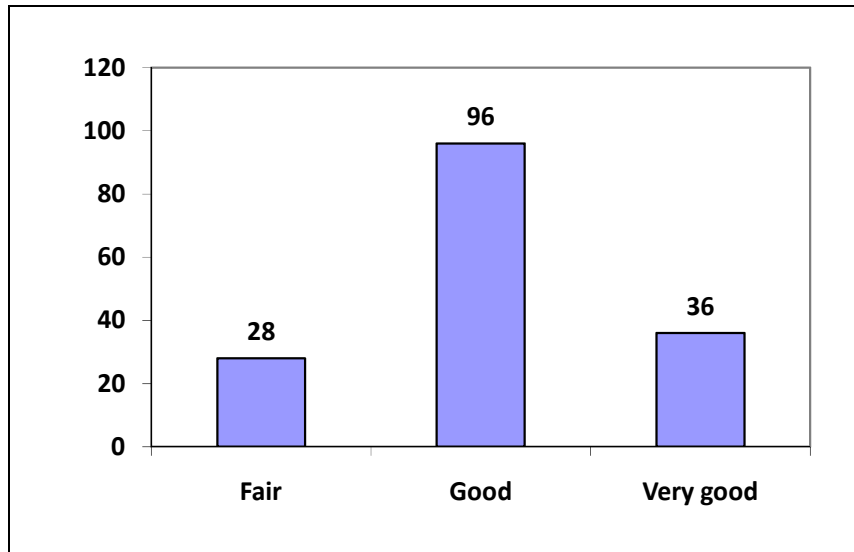


Figure 4.14: Participants' perceived rating of their health

4.2.2.4 Current health problems

Most of the participants (61.2%; $n = 98$) did not report any other health problems over or above the SCI. Of those who reported health problems, only two mentioned non-SCI related problems, namely HIV. One of two participants who mentioned HIV also suffered from tuberculosis. The remaining participants reported circulatory problems (pressure ulcers and oedema of the legs) and musculoskeletal problems (pain and spasms), as shown in Figure 4.14.

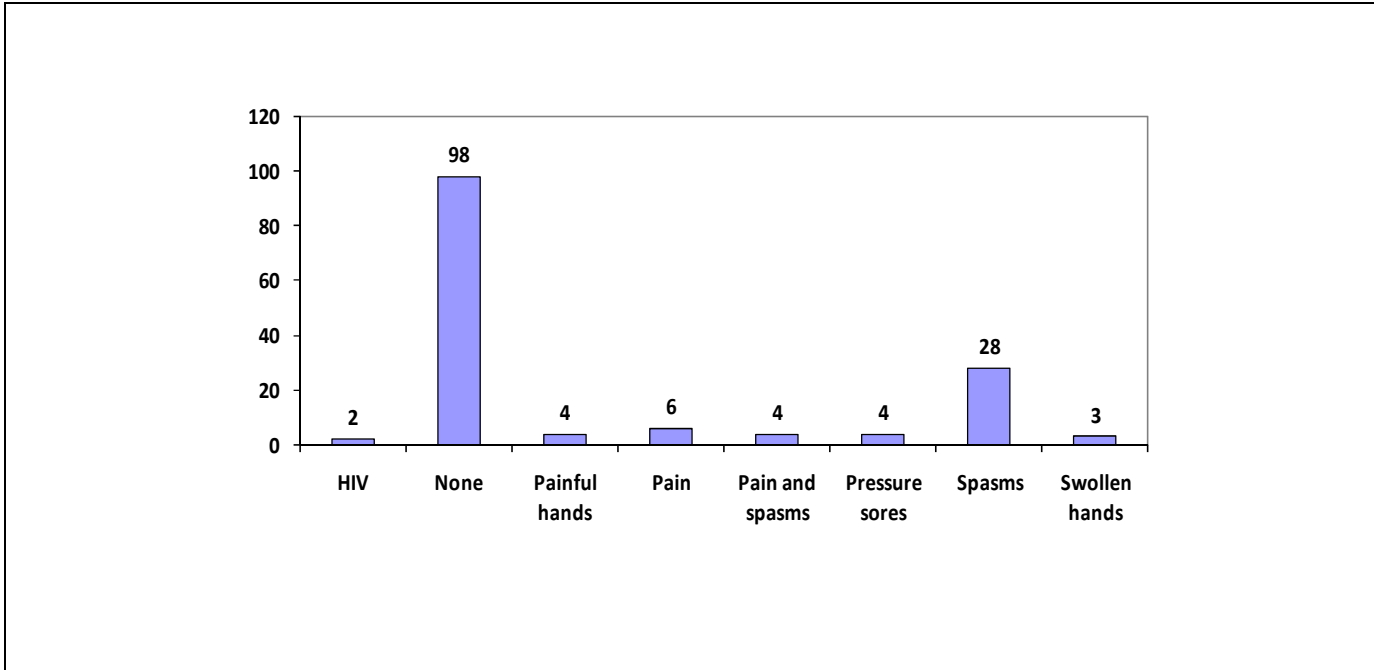


Figure 4.15 Health problems reported by participants

4.2.3 Summary of the socio-demographic and Spinal Cord Injury data

The descriptive statistics from the demographic information enabled the researcher to form a profile of the participants who comprised the study population. This demographic profile indicated that participants were predominantly young (58% had sustained SCI under 30 years of age), male (90%) and single (64%) The basic education of the respondents was satisfactory, with a mean of nine years of schooling. Employment dropped from 91 participants employed pre-injury to only 29 employed at the time of the study: the injuries they sustained thus imposed a substantial financial burden on the PLWSCI. Forty percent of the participants were dependent on government disability grants for financial support.

The level of SCI in the majority (63%) of the participants was paraplegia, while 37% of them presented with tetraplegic lesions. Road traffic accidents were the major cause of injury, accounting for 71% of the SCI. Almost half of the participants had been re-admitted to hospital for one or more complications after discharge from rehabilitation:

pressure ulcers (either alone or combined with UTI and/or respiratory problems) were the main reasons for re-admission to hospital in 78% of participants.

In the next section, the analysis of the data from the other three instruments used in this study, namely the RNLI, SCIM and CHIEF-SF, is presented.

4.3 SECTION 2: STATISTICAL ANALYSES OF THE INSTRUMENTS

In this section, the results of the statistical analysis of the Return to Normal Living Index (RNLI), the Spinal Cord Independence Measure - II (SCIM II) and the Craig Hospital Inventory of Environmental Factors short form (CHIEF –SF) are presented separately. In the case of each instrument, the descriptive statistics were the first step in the analysis, followed by psychometric tests for reliability and validity.

Reliability testing was performed by calculating internal consistency of the measurement instruments using Cronbach's alpha (Cronbach, 1970). Cronbach's alpha is a statistical comparison of the observed correlations or co-variances of the items with each other, and is used to express the internal consistency or reliability of a test (McDowell & Newell, 1996, 499). A coefficient alpha of 0.70 is regarded as acceptable for research purposes, between 0.71 and 0.80 as respectable, > 0.80 as good and > 0.90 as excellent (Arias & de Vos, 1996; Cronbach, 1970; George & Mallery, 2003; Nunnally, 1978). The intra-class correlation (ICC), with a two-way mixed effects model, established average measure reliability and 95% Confidence Interval (CI).

Multi-trait scaling was used as the first step in establishing validity. Equivalent item means and item variances were determined. In item convergent validity, corrected item-total correlation coefficients are the relationship between the specific item and a summation of the other items in the scale. The criterion for corrected item-total correlation coefficients was set at $r > 0.40$ (Stewart, Hays & Ware, 1988). Two methods were followed for item discriminant validity: inter-correlations among items in

a scale were compared with the scale's alpha coefficient; and relationships between factors were compared with the square root of the product of their reliability coefficients (Gaski & Nevin, 1985). Both methods used Fisher's z- test, with the criterion for discriminant validity set at $z > 1.96$ (Rosner, 1986).

The Kaiser-Meyer-Olkin (KMO) measure of item sampling adequacy was used to test the partial correlations between instrument items (Kaiser, 1974), as a preliminary measure of content validity. The KMO is a measure that indicates the amount of shared variance in the item pool, and may range from zero to one. The guide for interpreting the KMO (Kaiser, 1974) states that values in the 0.90s are marvellous, meritorious in the 0.80s, middling in the 0.70s, mediocre in the 0.60s, miserable in the 0.50s and unacceptable below 0.50.

Factor analysis, in particular principal components analysis and alpha factoring, was conducted on the measurement instruments for the following reasons:

- To reveal item sampling adequacy (content validity) and to confirm that the population matrix was not an identity.
- To provide an estimate of item reliability using the communalities.
- To provide a graphic representation of the Eigen values using the scree plot (Kim & Mueller, 1978).
- To examine the factor loadings in order to provide information on the underlying dimensions of each instrument; in order to ascertain significant factor loadings at the 1% level, loadings ≥ 0.50 were examined (Child, 1970; Nunnally, 1978).
- To provide support with this overall information for previous research and an estimate of the content and construct validity of the instruments in the case of this specific study population (Kaiser, 1974; Nunnally, 1978).

4.3.1 Return to Normal Living Index (RNLI)

The participants' satisfaction with their community participation was measured using the RNLI. Each RNLI item is scored on a 4-point scale with higher scores reflecting greater satisfaction with community participation.

4.3.1.1 Descriptive statistical analyses of the RNLI

Means for the RNLI items ranged between 2.49 and 3.14, as reflected in Table 4.4.

Table 4.4 Descriptive statistics of the RNLI

RNLI items	mean	Sd
I move around my living quarters as I feel necessary.	3.33	0.94
I move around my community as I feel necessary.	3.03	0.98
I am able to make trips out of town as I feel necessary.	2.49	1.03
I am comfortable with how my self-care needs are met.	3.28	0.95
I spend most of my day occupied in work activity important to me.	2.81	1.13
I am able to participate in recreational activities as I want to.	2.96	1.13
I participate in social activities with my family, friends and/or business acquaintances as is necessary or desirable to me.	2.96	1.05
I assume a role in my family which meets my needs and those of the other family members.	2.94	1.05
In general I am comfortable with my personal relationships.	3.10	1.00
In general I am comfortable with myself when I am in the company of others.	3.14	0.96
I feel that I can deal with life events as they happen.	2.91	1.16

The lowest mean (2.49) was for the item "I am able to make trips out of town as I feel necessary", although this item also had a high standard deviation of 1.03, indicating greater variation in participants' responses to this question. The highest mean (3.30) was for the item "I move around my living quarters as I feel necessary".

Total RNLI scores were converted to an adjusted score by calculating the percentage. The percentages were used to determine the participants' RNLI categories according

to Caters et al. (2000) and Pang, Eng and Miller (2007), as described in section 3.6.1.2, where:

- A score of 100 indicates that the participants are fully satisfied with their community participation;
- A score between 80 and 99 indicates perceptions of mild restrictions in participation;
- A score between 60 and 79 indicates perceptions of moderate restrictions in participation; and
- A score of less than 60 indicates severe restrictions in self-perceived community participation.

Figure 4.15 illustrates the distribution of the RNLI categories among the participants.

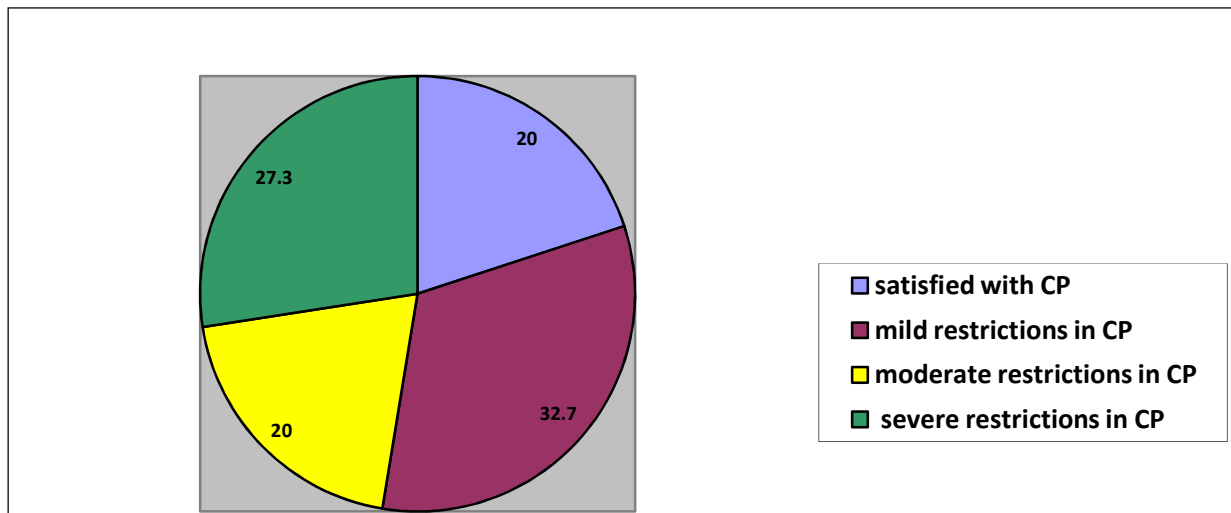


Figure 4.15: Participants' distribution in the RNLI categories

4.3.1.2 Psychometric analysis of the RNLI

Cronbach's alpha for the RNLI instrument was 0.97 (ICC 95% CI: 0.97 – 0.98), which is regarded as an excellent reliability coefficient (Arias & de Vos, 1996; George & Mallery, 2003).

Item convergent and discriminant procedures were used as the first step in establishing validity of the RNLI. As far as an item's convergent validity is concerned, corrected item-total correlation coefficients are the relationship between the specific item and a summation of the other items in the scale. The first two criteria for item convergent validity, namely equivalent item means and variance of all items in the instrument and corrected item-total correlation coefficients, were determined for this instrument. Inspection of the means and standard deviations for the 11 items revealed roughly equivalent means and variance, with the exception of one item, thereby satisfying the first criterion. Corrected RNLI item-total correlation coefficients ranged between 0.73 and 0.91, satisfying the criterion of $r > 0.40$ for item convergent validity (Stewart, Hays & Ware, 1988).

In order to determine item discriminant validity of the RNLI, Fisher's z test for comparing two correlations was used, with the criterion for discriminant validity set at $z > 1.96$ (Rosner, 1986). Firstly, inter-correlations between the RNLI items were compared with the RNLI's alpha coefficient. The highest inter-correlation coefficient was 0.92, and the coefficient alpha was 0.97. A z-score table was used to transform the highest correlation and coefficient alpha into z-scores.

The formula for Fisher's test is: $z_1 - z_2 / \sqrt{2/n - 3}$, where z_1 is the z-equivalent of the coefficient alpha (2.092), z_2 is the z-equivalent of the largest inter-item correlation (1.589) and n is the sample size (160). Using the above formula,

$$\begin{aligned} z &= \frac{2.092 - z_2 \ 1.589}{\sqrt{2/160-3}}, \\ &= \frac{0.503}{\sqrt{0.013}} \\ &= 4.45 \end{aligned}$$

The z- value of 4.45 is greater than 1.96, the criterion for z. Therefore item discriminant validity of the RNLI was established.

Alpha factoring was conducted on the 11 RNLI items to ascertain a common factor model (Kim & Mueller, 1978). In alpha factoring, variables included in the factor analysis are considered as a sample from the universe of variables, while assuming

that these variables are observed over a given population with a key emphasis on psychometric inference rather than statistical inference. The condition of the data matrix was examined by calculating the Kaiser-Meyer-Olkin (KMO) measure of item sampling adequacy. The KMO index for the 11 x 11 matrix was 0.90, which is in the “marvellous” category according to Kaiser (1974). Bartlett’s test of sphericity indicated that the population matrix was not an identity (Chi-square = 2174.83, $df = 45$, $p < 0.001$). Both tests confirmed that factor analysis was the correct procedure for the RNLI data.

A minimum of 10 participants per item has been recommended as the smallest acceptable sample size for factor analysis (Coakes & Steed, 1996; Nunnally, 1978). The sample size of 160 therefore fulfilled this minimum criterion. All communality estimates exceeded the criterion of 0.30 for reliable items (Child, 1970), and ranged between 0.71 and 0.90. Alpha factoring identified only one component in the RNLI (see scree plot and Table 4.5 below), suggesting that all items were useful in measuring RNLI. Item loadings ranged between 0.86 and 0.93 (> 0.71) on all the items, providing support for construct validity of the RNLI as a pure measure of community participation (Tabachnick & Fidell, 2006).

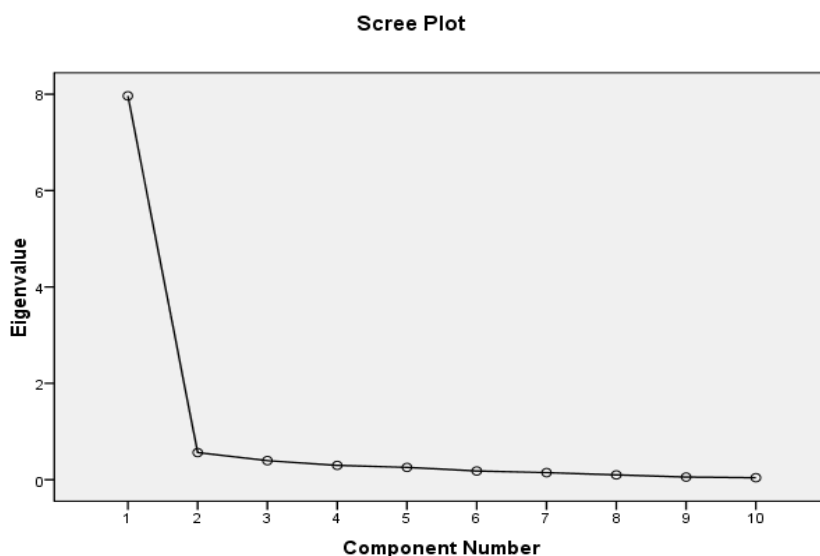


Figure 4.5 Scree plot of the Eigen values from the factor analysis of the RNLI

Table 4.5: Alpha factoring for the RNLI

RNLI items	Factor 1
I move around my community as I feel necessary.	.915
I am able to make trips out of town as I feel necessary.	.776
I am comfortable with how my self-care needs are met.	.859
I spend most of my day occupied in work activity important to me.	.889
I am able to participate in recreational activities as I want to.	.856
I participate in social activities with my family, friends and/or business acquaintances as is necessary or desirable to me.	.927
I assume a role in my family which meets my needs and those of the other family members.	.923
In general I am comfortable with my personal relationships.	.912
In general I am comfortable with myself when I am in the company of others.	.941
I feel that I can deal with life events as they happen.	.916

4.3.1.3 Summary – RNLI psychometrics

These results demonstrate that the RNLI is psychometrically sound for this sample and has excellent reliability as measured by the internal consistency coefficient and ICC. The instrument was shown to have item convergent and item discriminant validity as well as content and construct validity. Analysis of participants' comments indicated that the scores allocated were consistent with the reasons provided. The RNLI is therefore a reliable and valid instrument for use on this population of PLWSCIs in the Tshwane metropolitan area, Gauteng, South Africa.

4.3.2 Spinal Cord Independence Measure (SCIM II)

The Spinal Cord Independence Measure, version II [SCIM II] (Appendix J) was used to measure the participants' functional abilities, in terms of activities of daily living, respiration and sphincter control and mobility.

4.3.2.1 Descriptive statistical analysis of the SCIM

Table 4.8 provides the descriptive statistics of individual items of the SCIM II. The lowest mean (0.83) was on the item “stair management”. This item also had a high standard deviation of 1.38, indicating a greater variation in participants’ responses to this question. The highest mean (10.00) was for the item “respiration”. It must be mentioned here that three tetraplegic participants performed “self-assisted” coughing. They were therefore given a full score as assistance was not provided by an external person, thus they were independent in this activity. There was no variation in this item, as all 160 participants were able to breathe and cough independently and therefore scored 10: hence the standard deviation of 0.00. In more complex analyses, this item was therefore removed.

Table 4.8: Descriptive statistics of the SCIM II

Item	SCIM II item description	Mean	sd	N
1	Feeding, cutting food, opening containers, bringing food to mouth	4.60	0.82	160
2	Bathing - soaping, manipulating water tap, washing	4.23	1.41	160
3	Dressing - preparing clothes, dressing upper and lower body, undressing	4.28	1.38	160
4	Grooming - washing hands and face, brushing teeth, combing hair, shaving, applying make-up	4.30	1.40	160
5	Respiration	10.0	0.00	160
6	Sphincter management – bladder	9.63	5.06	160
7	Sphincter management – bowel	7.75	2.74	160
8	Use of toilet	3.68	2.21	160
9	Mobility in bed and action to prevent pressure sores	4.95	1.70	160
10	Transfers from bed to wheelchair - breaks, footrests, armrests, transferring, lifting feet	1.78	0.91	160
11	Transfers from wheelchair to and from toilet	1.63	0.66	160
12	Mobility indoors - short distance	2.75	1.92	160
13	Mobility for moderate distances (10 - 100 metres)	2.65	1.80	160
14	Mobility outdoors (more than 100 metres)	2.45	1.79	160
15	Stair management	0.83	1.38	160
16	Transfer from wheelchair to car - approaching car, brakes, arm- and footrests, transferring to and from car, bringing wheelchair into car	1.83	0.92	160

4.3.2.2 Psychometric analysis of the SCIM II

It is generally assumed that the SCIM II comprises three components: activities of daily living (ADL), respiration and mobility. However, this assumption requires testing. The condition of the data matrix was examined by calculating the Kaiser-Meyer-Olkin (KMO) measure of item sampling adequacy. The KMO index for the 15 x 15 matrix was 0.90, in the “marvellous” category according to Kaiser (1974). Bartlett’s test of sphericity indicated that the population matrix was not an identity (Chi-square = 4024.19, $df = 105$, $p < 0.000$). Both tests confirmed that factor analysis was the correct procedure for the SCIM II data. The sample size of 160 participants fulfilled the minimum recommended criterion of 10 participants per item for factor analysis (Coakes & Steed, 1996; Nunnally, 1978). Principal component analysis with a two factor (VARIMAX) rotational solution was conducted on the 15 SCIM II items. This

principal component analysis revealed two factors, as illustrated in the scree plot of Eigen values in Figure 4.5.

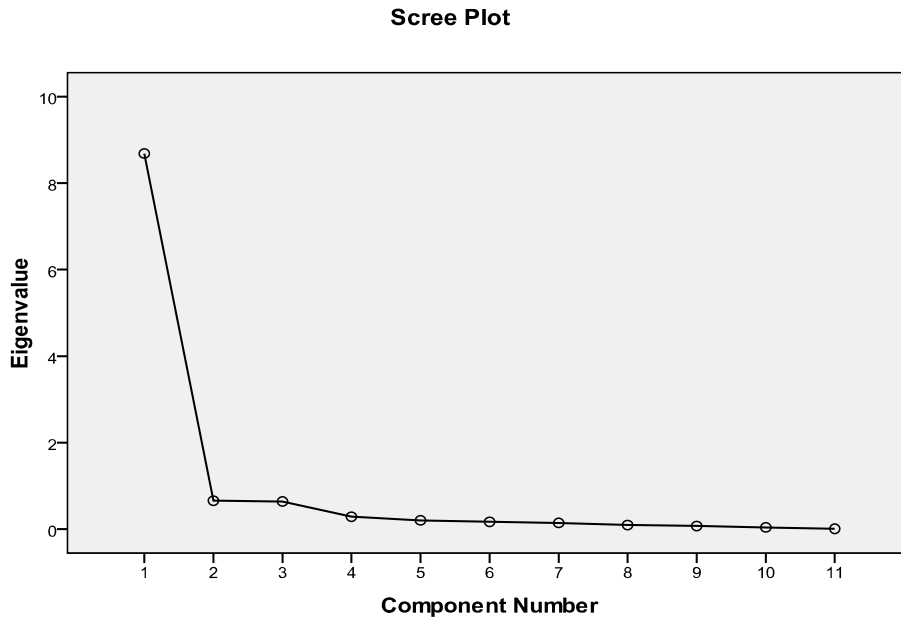


Figure 4.5: Scree plot of the Eigen values from the factor analysis of the SCIM II

Based on the Eigen values, the percentage of total variance accounted for by the factors and the scree plot, a two factor orthogonal (VARIMAX) rotational solution was conducted. All communality estimates exceeded the criterion of 0.30 (for reliable items) and ranged between 0.50 and 0.88. The two factors explained 83.9% of the variance. Factor I contained 11 significant loadings and accounted for 54.6% of the variance. Factor II contained four significant loadings and accounted for 29.3% of the variance. One item (sphincter management – bladder) loaded on both factors, but at a lower level on the second factor.

Table 4.9: Factor analysis of the SCIM II

No	SCIM items	Factor	
		I	II
1	Feeding, cutting food, opening containers, bringing food to mouth	.90	.20
2	Bathing - soaping, manipulating water tap, washing	.92	.24
3	Dressing - preparing clothes, dressing upper and lower body, undressing	.95	.22
4	Grooming - washing hands and face, brushing teeth, combing hair, shaving, applying make-up	.91	.20
5	Sphincter management – bladder	.72	.54
6	Sphincter management – bowel	.68	.37
7	Use of toilet	.83	.28
8	Mobility in bed and action to prevent pressure sores	.88	.27
9	Transfers from bed to wheelchair - breaks, footrests, armrests, transferring, lifting feet	.78	.06
10	Transfers from wheelchair to and from toilet	.92	.25
11	Mobility indoors - short distances	.26	.95
12	Mobility for moderate distances (10 - 100 metres)	.26	.95
13	Mobility outdoors (more than 100 metres)	.27	.91
14	Stair management	.11	.94
15	Transfer from wheelchair to car - approaching car, brakes, arm- and footrests, transferring to and from car, bringing wheelchair into car	.87	.19

Significant loadings in bold

Factor I consisted of items one to 10, and item 15. The major items on Factor I were: Feeding, cutting food, opening containers, bringing food to mouth (0.90); Bathing - soaping, manipulating water tap, washing (0.92); Dressing - preparing clothes, dressing upper and lower body, undressing (0.95); Grooming - washing hands and face, brushing teeth, combing hair, shaving, applying make-up (0.91); Mobility in bed and action to prevent pressure sores (0.88); Transfers from wheelchair to and from toilet (0.92); Transfer from wheelchair to car - approaching car, brakes, arm- and footrests, transferring to and from car, bringing wheelchair into car (0.87). As the items appear to represent a combination of ADL and use of a wheelchair, this factor was labelled the “SCIM: ADL-wheelchair” factor.

Factor II comprised items 11 to 14. The major items on Factor II were: Mobility indoors - short distances (0.95); Mobility for moderate distances (10 - 100 metres) (0.95); Mobility outdoors (more than 100 metres) (0.91); Stair management (0.94). This factor contained items related to mobility and stair management and was labelled the “SCIM: mobility” factor, owing to its emphasis on mobility, both on flat surfaces or when negotiating stairs.

These two SCIM II factors were further factor analysed (Andeleeb, 2001) and all loadings were greater than > 0.71 , satisfying the criterion for factor loadings (Nunnally, 1978) and providing support for the construct validity of the SCIM II factors. This finding indicated that the two factors (subscales) represented pure SCIM: ADL-wheelchair use and SCIM: mobility factors (Tabachnick & Fidell, 2006). The two factors were significantly related to each other ($r = 0.57$, $p < 0.001$). It would appear that previous assumptions about the three components of the SCIM II did not fit the data for the present sample.

Corrected item-total correlation coefficients ranged between 0.61 and 0.89, satisfying the criterion for item convergent validity (Stewart, Hays & Ware, 1988). In order to determine the item discriminant validity of the SCIM, the relationships between factors were compared with the square root of the product of their reliability coefficients (Gaski & Nevin, 1985). The square root of 0.91×0.97 (coefficient alphas for the two factors) was 0.94. The correlation between the two factors was 0.57. The formula for discriminant validity is $0.94 (z = 1.738) - 0.57 (z = 0.648) / \sqrt{2/157}$. $1.738 - 0.648/0.113 = 9.65$. The value of 9.65 is higher than 1.96, the criterion for z . Therefore item discriminant validity of the SCIM II was established.

Coefficient alpha was 0.91 (95% CI: 0.89-0.93) for the SCIM: ADL-wheelchair use, 0.98 (95% CI: 0.97-0.98) for the SCIM: mobility and 0.93 (95% CI: 0.91-0.94) for the full SCIM II instrument; all excellent reliability coefficients (Arias & de Vos 1996; George & Mallery, 2003).

4.3.2.4 Summary – SCIM II psychometrics

These results demonstrated that the SCIM II was psychometrically sound and had excellent reliability as measured by the internal consistency coefficients. The instrument was shown to have item convergent and item discriminant validity, and content and construct validity. The SCIM II can therefore be regarded as a reliable and valid instrument for use on this population of PLWSCI in the Tshwane metropolitan area, Gauteng, South Africa.

4.3.3 Craig Hospital Inventory of Environmental Factors – short form (CHIEF – SF)

The Craig Hospital Inventory of Environmental Factors short form (Appendix K: CHIEF-SF) was used to evaluate the impact of perceived environmental barriers on community participation, as reported by individuals with a SCI.

4.3.3.1 Descriptive statistical analyses of the CHIEF-SF

The CHIEF-SF asks participants to rate how frequently they experience environmental barriers and the magnitude of these perceived barriers. The total score is a product of the frequency and magnitude: the overall impact. The following results are based on the CHIEF-SF impact score. Table 4.6 depicts the mean scores of the perceived impact of environmental factors on CHIEF-SF.

Table 4.6: Descriptive Statistics CHIEF-SF

CHIEF-SF items	Min	Max	mean	sd
Impact of transport barrier	0	6	2.06	2.05
Impact of natural environment	0	6	0.73	1.23
Impact of surroundings	0	2	0.13	0.46
Impact of information needs	0	4	0.28	0.81
Impact of service availability	0	2	0.33	0.72
Impact of help at home	0	4	0.45	1.00
Impact of help at school or work	0	1	0.05	0.22
Impact of people's attitude at home	0	4	0.25	0.77
Impact of people's attitude at school or work	0	4	0.30	0.93
Impact of discrimination	0	6	1.32	1.80
Impact of organisational or business policy	0	4	0.60	1.29
Impact of government policy	0	4	0.40	1.12

As can be seen from Table 4.6 above, the CHIEF-SF item that was perceived to be the environmental factor with greatest impact on PLWSCI was “transport barrier”, with a mean score of 2.06. This item also had the highest standard deviation of 2.05, suggesting greater variability in the participants’ responses. The CHIEF-SF item that was perceived to be the environmental factor with the lowest impact was “surroundings”, with a mean score of 0.13. This item also had the lowest standard deviation, suggesting little variability in the participants’ responses.

4.3.3.2 Psychometric analysis of the CHIEF-SF

The condition of the CHIEF-SF data matrix was examined by calculating the KMO measure of item sampling adequacy. The KMO index for the 15 x 15 matrix was 0.44, in the “unacceptable” category according to Kaiser (1974). Although Bartlett’s test of sphericity indicated that the population matrix was not an identity (Chi-square = 999.74, $df = 66$, $p < 0.000$), the “unacceptable” KMO values indicated that the CHIEF-SF data was not appropriate for factor analysis.

Therefore, further psychometric testing of the CHIEF-SF was not performed, as there is no point in testing the reliability of an instrument that is not valid. Only the descriptive statistics will therefore be used in further discussions of the CHIEF-SF. All CHIEF-SF item scores were summed to obtain an overall CHIEF-SF score for further analysis.

4.3.4 Summary – CHIEF-SF psychometrics

In section 4.3, the psychometric properties of the three instruments used in this study (RNLI, SCIM II and CHIEF-SF) were presented. The RNLI and SCIM II were found to be psychometrically sound, but with a different factor structure, while the CHIEF-SF was not psychometrically acceptable.

The next section presents the relationship between the various variables measured by the various instruments in this study.

4.4 RELATIONSHIPS BETWEEN SOCIO-DEMOGRAPHIC DATA, SCI DATA AND THE MEASURING INSTRUMENTS

Because the factor analysis of the SCIM II yielded two distinct subscales (factors), the ensuing results will present these two separately, and not as a single SCIM II. Throughout the discussion of the results, references to the “four instruments” will refer to the RNLI, CHIEF-SF and the two SCIM II subscales (SCIM: ADL wheelchair use and SCIM: mobility).

4.4.1 Age, years of living with SCI, years of basic education and the four instruments

The inter-relationships among age at time of injury, years of basic education, years of living with SCI and the different measurement instruments are indicated in Table 4.10.

Table 4.10: Inter-relationships among age at time of injury, years of basic education, years living with SCI and different measurement instruments

	Years of schooling	Years living with SCI	RNLI	CHIEF-SF	SCIM:ADL wheelchair	SCIM: mobility
Age at time of injury	.029	-.159*	-.024	.185*	.241**	.235**
Years of schooling		.125	.380**	-.332**	.087	.117
Years living with SCI			.157*	-.069	-.037	-.204**

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Participants' age at the time of injury was modestly but negatively related to years of living with SCI ($r = -0.159$, $p < 0.05$). This implies that those participants who were younger at time of injury had more years of living with SCI at the time of the study. Another modest but positive correlation was found between participants' age at time of injury and CHIEF-SF score ($r = 0.185$, $p < 0.05$). This finding suggests that the younger the person at the time of injury, the fewer environmental barriers they experienced; or, the older the person at the time of injury, the more environmental barriers they experienced. Strong and positive correlations were found between age at time of injury and ADL-wheelchair ($r = 0.241$, $p < 0.001$) and mobility ($r = 0.235$, $p < 0.001$). This finding indicates that the older the PLWSCI were at the time of injury, the better their functional ability (SCIM: ADL-wheelchair and SCIM: mobility) scores at time of the study.

Years of basic education was strongly positively related to RNLI ($r = 0.380$, $p < 0.001$), suggesting that PLWSCI with more years of basic education had a better chance of being satisfied with their community participation than those with only a few years of basic education. Years of basic education were also strongly but negatively related to CHIEF-SF, suggesting that PLWSCI with less education were likely to be exposed to greater environmental barriers than those with a higher level of education.

Years of living with SCI were modestly and positively related to RNLI ($r = 0.157, p < 0.05$), suggesting that PLWSCI who had been living with SCI for a longer period had a greater chance of being satisfied with their community participation than those who had not lived with SCI as long. Years of living with SCI was, however, negatively related to mobility ($r = -0.204, p < 0.001$), suggesting that PLWSCI who had been living with SCI for longer were likely to have more mobility limitations than those PLWSCI who had lived with SCI for a shorter period.

4.4.2 Chi square tests of independence

The relationship between various categorical variables was tested using the chi square test of independence. Significant relationships are presented in the tables below.

4.4.2.1 Employment versus residential area

Table 4.11: Cross tabulation of employment by residential area

Currently employed	Current residential area type			Total
	Townshi p	Subur b	Othe r	
No	78	24	17	119
Yes	18	16	7	41
Total	96	40	24	160
% Employed	18.8	40	29.2	25.6

From the above cross tabulation, it appears that employment is associated with residential area, indicating that more participants living in suburbs were employed than those from townships or “other” areas. This observation is confirmed by the chi-square test [$\chi^2 (2) = 20.5, p < 0.001$].

4.4.2.2 Current employment versus previous employment

Table 4.12: Cross tabulation of current employment by previous employment

Current employment	Employment before the SCI		Total
	NO	YES	
No	57	62	119
Yes	12	29	41
Total	69	91	160
% Employed	17.39	31.9	25.6

From the above cross tabulation, it appears that current (post SCI) employment is associated with previous (pre SCI) employment. It was expected that previous employment would be an advantage for post-injury employment. The chi-square test of independence confirmed that PLWSCI who were employed pre-injury were more likely to be employed post-injury than those who had not been employed before their injury [$\chi^2 (2) = 4.3, p < 0.05$].

4.4.2.3 Current employment versus perceived health rating

Table 4.13: Cross tabulation of employment by perceived health rating

Currently employment	Health rating			Total
	FAI R	GOO D	VERY GOOD	
No	25	79	15	119
Yes	3	17	21	41
Total	28	96	36	160
% Employed	10.7	17.7	58.3	25.6

It appears from the table above that employment is associated with participants' perception of their health, with more employed participants having good and very good perceived health ratings [$\chi^2 (2) = 26.6, p < 0.001$].

4.2.2.4 Perceived health rating by gender

Table 4.14: Cross tabulation of perceived health rating by gender

Perceived health rating	Gender		Total
	MALE	FEMAL E	
Fair	28	0	28
Good	71	25	96
Very good	25	11	36
Total	124	36	160
% Good and very good	77.4	100	82.5

It would seem from the above cross tabulation that participants' gender is associated with their health perception, with only male participants having a fair health rating, and a higher percentage of females having combined good and very good perceived health ratings. A chi-square test of independence confirmed that association, [$\chi^2 (2) = 10.2, p < 0.05$].

4.4.3 Interrelationships among the measuring instruments

Table 4.15 reflects the interrelationships among the measuring instruments used in the study.

Table 4.15: Interrelationships among the measuring instruments

	CHIEF-SF	SCIM:ADL wheelchair	SCIM: Mobilit y
RNLI	-.700**	.177*	.216**
CHIEF-SF		-.073	-.231**
ADL			.580**

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

The four measures were significantly related to each other with exception of the CHIEF-SF and the SCIM: ADL wheelchair subscale which had a negative and insignificant relationship ($r = -0.073$). RNLI was positively related to SCIM: ADL-wheelchair ($r = 0.177$, $p < 0.05$) and to SCIM: mobility ($r = 0.216$, $p < 0.001$), suggesting that an increase in the one meant an increase in the other and vice versa. RNLI was negatively related to CHIEF-SF ($r = -0.700$, $p < 0.001$), suggesting that an increase in the one corresponded to a decrease in the other and vice versa. The CHIEF-SF was strongly and negatively related to mobility ($r = -0.231$, $p < 0.001$), indicating that an increase in the one corresponded to a decrease in the other and vice versa. ADL-wheelchair and mobility were both significantly related to each other ($r = 0.580$, $p < 0.001$), indicating that an increase in the one corresponded to a decrease in the other and vice versa.

4.4.4 Mean comparisons across the measured variables

4.4.4.1 T-tests

Independent-samples t-tests were conducted to determine the influence of gender, race, employment, marital status, completeness of the lesion and interviewee status on the four measures (instruments). Gender and the level of the lesion had no significant influence.

a) Employment

Employed participants performed better than unemployed participants across all the measures except the ADL-wheelchair subscale. Table 4.16 reflects the t-test results of the employment differences in the measured variables.

Table 4.16: Means, standard deviations and group statistics according to employment

Measure	Employment				<i>t</i>	<i>df</i>	<i>p</i>
	Employed (n= 41)		Unemployed (n = 119)				
	<i>M</i>	<i>sd</i>	<i>m</i>	<i>sd</i>			
RNLI	41.9	3.4	30.0	9.9	-11.27	158.0	.000
SCIM:ADL- Wheelchair	51.0	14.6	46.5	17.0	-1.488	158.0	.139
SCIM: mobility	11.3	8.5	7.8	5.7	-2.449	53.1	.018
CHIEF-SF	1.9	3.8	8.6	6.9	7.734	126.4	.000

There was a significant difference between the RNLI scores of employed and unemployed participants: $t(158) = -11.266$, $p < 0.001$. The higher mean RNLI scores of employed participants ($m = 41.9$; $sd = 3.4$) suggests that they were more satisfied with their community participation than unemployed participants ($m = 30.9$; $sd = 9.9$).

Another strongly significant difference was noted in the CHIEF scores: $t(126.4) = 7.73$, $p < 0.001$. The low mean CHIEF-SF scores of employed participants ($m = 1.9$; $sd = 3.8$) suggests that they experienced fewer environmental barriers than the unemployed participants ($m = 8.6$; $sd = 6.9$).

A modestly significant difference in the SCIM: mobility scores [$t(53.12) = 2.25$, $p < 0.05$] indicates that employed participants ($m = 11.3$; $sd = 8.5$) had a slight mobility advantage over unemployed participants ($m = 7.3$; $sd = 5.7$). There was no significant difference in the SCIM: ADL- wheelchair-use scores of employed and unemployed participants.

b) Race

The original data for race was captured in four categories, namely Black, White, Indian and Coloured. The results revealed few white, Indian or coloured participants and many black participants. The race variable was therefore re-coded to capture all the “minority” participants under a single category of “non-African”. The black

category was re-coded “African”. These two categories were computed for t-test purposes. Table 4.17 shows the t-test results of the variations in employment according to the variables measured. Non-African participants performed better than black African participants across all variables except the SCIM: ADL-wheelchair subscale.

Table 4.17: Means, standard deviations and group statistics according to race

Measure	African (n = 124)		Non-African (n =36)		t	df	p
	M	sd	M	sd			
RNLI	31.4	10.4	38.8	6.7	-5.040	87.9	0.000
SCIM: ADL-Wheelchair	46.8	17.3	50.7	12.9	-1.490	75.6	0.140
SCIM: mobility	8.8	6.9	8.2	5.8	0.404	158	0.659
CHIEF-SF	8.2	7.114	2.4	3.5	6.645	119.6	0.000

There was a significant difference between the RNLI scores of black African participants and non-African participants: $t(87.89) = -5.0, p < 0.001$. The higher mean RNLI scores of non-African participants ($m = 38.8; sd = 6.7$) suggests that they were more satisfied with their community participation than were black African participants ($m = 31.4; sd = 10.4$).

Another strongly significant difference between Africans and non-Africans was noted in the CHIEF scores: $t(119.6) = 6.65, p < 0.001$. The low mean CHIEF-SF scores of non-African participants ($m = 2.4; sd = 3.5$) suggest that they experienced fewer environmental barriers than African participants ($m = 8.2; sd = 7.1$).

There was no significant difference in the SCIM: ADL-wheelchair-use or SCIM: mobility scores between African and non-African participants.

c) Marital status

The original data for marital status was captured in four categories, namely single, married, separated/divorced and widowed. The results revealed very few participants

in the separated/divorced and widowed categories. The main characteristics of these categories were that individuals were living without partners. The variable was therefore re-coded to capture all participants without a partner in a single category for t-test purposes. Table 4.18 reflects the t-test results of marital status differences according to the variables measured.

Table 4.18: Means, standard deviations and group statistics according to marital status

Measure	Single (n = 108)		Married (n =52)		t	df	p
	m	sd	M	sd			
RNLI	32.3	10.5	34.6	9.7	-1.339	158	.183
SCIM: ADL-Wheelchair	43.7	17.8	55.8	8.9	-5.721	158	.000
SCIM: Mobility	8.1	6.6	10.0	6.8	-1.677	158	.097
CHIEF-SF	74.8	7.0	5.9	6.6	1.319	158	.189

There were no significant differences between single and married participants across all the variables except the ADL-wheelchair subscale. Marital status was strongly related to ADL-wheelchair [$t(158) = 6.65, p < 0.001$], with married participants ($m = 11.3; sd = 8.5$) having higher ADL-wheelchair scores than single participants ($m = 11.3; sd = 8.5$). This finding suggests that married PLWSCI have a better chance of coping with their functional activities (ADL-wheelchair) than single PLWSCI. This is possibly due to the availability of support from a partner.

d) Type of injury

Table 4.19: Means, standard deviations and group statistics according to level of injury

Measure	Paraplegia (n = 100)		Tetraplegia (n =60)		t	df	p
	m	sd	m	Sd			
RNLI	34.1	10.6	31.4	9.3	1.6	158	0.58
SCIM: ADL- Wheelchair	54.5	1.0	36.3	18.7	7.0	79.261	0.000
SCIM: mobility	8.9	5.3	8.9	8.4	-0.252	88.166	0.000
CHIEF-SF	7.2	7.3	6.3	6.1	0.78	158	0.093

The level of injury was significantly related to the participant's functional ability, as seen on the ADL- wheelchair factor [$t(79.3) = 7.0, p < 0.001$] and Mobility [$t(-88.2) = -0.2, p < 0.001$]. These findings suggest that participants with paraplegia were likely to have better functional abilities than those with tetraplegia.

e) Full sample versus interviewed sample

There was no significant difference on RNLI, ADL-wheelchair use, Mobility or the CHIEF-SF between those who were interviewed and those who were not ($p > 0.05$), suggesting that these four measures were equally applicable to both groups. In addition, this lack of difference appears to indicate that the sub-sample of interviewees was representative of the whole main sample.

4.4.4.2 Analysis of variance (ANOVA)

A series of one-way analyses of variance (ANOVAs) was conducted to determine the influence of residential area, source of income, level of injury and perceived health on the four measures (RNLI, SCIM: ADL-wheelchair, SCIM: mobility and the CHIEF-SF). Bonferroni t-tests were calculated for multiple comparisons of the four measures.

a) Relationship between participants' residential area and the four measures

Table 4.20 indicates the means, standard deviations and group statistics for current residential area in relation to the four measures.

Table 4.20: Means, standard deviations and group statistics according Residential area in relation to the four measures

Measure	Current residential area						F	df	p
	Township (n =96)		Suburb (n =40)		Other (n =24)				
	M	Sd	m	sd	M	Sd			
RNLI	31.42	10.9	37.3	8.1	32.8	8.3	5.0	2,157	0.008
SCIM:ADL- Wheelchair	48.9	16.4	51.7	12.3	35.8	18.1	8.4	2,157	0.000
SCIM: Mobility	9.1	6.7	9.6	7.6	5.3	3.3	3.7	2,157	0.026
CHIEF-SF	8.8	7.5	2.8	4.5	5.8	4.0	13.0	2,157	0.000

There was an overall significant difference on all the measures by current residential area, with RNLI [$F(2,157) = 5.0, p < 0.001$], SCIM: ADL-wheelchair use [$F(2,157) = 8.4, p < 0.001$], SCIM: mobility [$F(2,157) = 3.7, p < 0.05$] and the CHIEF-SF [$F(2,157) = 13.0, p < 0.001$].

Post hoc comparisons using the Bonferroni t-test indicated the following:

- a significant difference existed only between the RNLI scores of participants from the townships and the suburbs ($p < 0.05$). This suggested that satisfaction with participation is influenced by the socioeconomic status of the residential area.
- a significant difference existed only between the CHIEF-SF scores of participants from the townships and the suburbs ($p < 0.05$), suggesting that participants from townships were more likely to perceive environmental barriers than their suburban and “other” counterparts.

- a modestly significant difference existed only between the mobility scores of participants from “other” areas and both townships and suburbs ($p < 0.05$). These results suggested the mobility of participants was more affected in “other” areas (e.g. informal settlements) than in townships and suburbs.

b) Relationship between participants’ source of income and the four measures

Table 4.21: Means, standard deviations and group statistics according to source of income in relation to the four measures

Measure	Source of income								F	df	p
	From family		Disability grant		Employment		Other				
	m	sd	m	sd	M	sd	m	sd			
RNLI	26.3	12.0	27.8	8.4	41.9	3.4	36.8	7.6	34.0	3, 16	0.00
SCIM:	40.8	21.9	45.7	17.1	51.0	14.6	52.1	10.	3.2	3, 16	0.03
ADL-											
Wheelch											
air											
SCIM:	5.5	2.6	8.8	6.2	11.3	8.5	7.5	6.0	4.2	3, 16	0.01
Mobility											
CHIEF-	15.8	5.1	7.7	5.4	1.9	3.8	5.2	6.9	35.7	3, 16	0.06
SF											

The mean scores and standard deviations for all four measures in relation to the participants’ source of income are reflected in Table 4.21. There was an overall significant difference on all the measures by current residential area, with RNLI [$F(3,156) = 34.0, p < 0.001$], SCIM: ADL-wheelchair use scores [$F(3,156) = 3.2, p < 0.05$] SCIM: mobility [$F(3,156) = 4.2, p < 0.05$] and CHIEF-SF score [$F(3,156) = 35.7, p < 0.001$].

Post hoc comparisons using the Bonferroni t-test indicated that:

- significant differences existed between the RNLI scores of participants whose source of income was family, employment and other ($p < 0.001$). These results suggested that participants who were employed had more satisfaction with their community participation.
- significant differences existed only between SCIM: mobility scores of participants whose source of income was from the family or employment ($p < 0.05$). This finding suggests that participants whose source of income was employment were more likely to have better mobility than those whose source of income was their family.

c) Relationship between level of injury and the four measures

Table 4.22 Means, standard deviations and group statistics according to level of injury in relation to the four measures

Measure	Level of injury						df	F	p.
	Cervical (n = 68)		Thoracic (n = 76)		Lumbar (n = 16)				
	m	sd	m	sd	m	Sd			
RNLI	31.1	9.9	33.4	10.7	40.1	4.5	2,16	5.40	.005
ADL- wheelchair	36.3	19.7	55.6	4.6	58.3	5.5	2,16	43.14	.000
Mobility	9.0	8.0	7.1	2.7	15	8.6	2,16	10.63	.000
CHIEF-SF	6.8	6.0	7.2	7.5	6.0	7.8	2,16	0.21	.815

There was no overall significant difference on the CHIEF-SF by level of injury ($p > 0.05$). However, level of injury was significantly related to RNLI [$F(2,157) = 5.4, p < 0.05$], SCIM: ADL-wheelchair use [$F(2,157) = 42.139, p < 0.001$] and SCIM: mobility [$F(2,157) = 10.626, p < 0.001$].

Post hoc comparisons using the Bonferroni t-test indicated that:

- a significant difference in the ADL-wheelchair scores existed between participants with cervical and thoracic level injuries ($p < 0.001$), and between those with cervical and lumbar level injuries ($p < 0.001$). These results indicate that participants with thoracic and lumbar level injuries were more likely to be able to perform their ADL-wheelchair related functions than those with cervical level injuries.
 - a significant difference in the mobility scores existed between the participants with thoracic and lumbar level injuries ($p < 0.001$) and between those with cervical and lumbar level injuries ($p < 0.05$). These results suggest that thoracic level injuries present different mobility challenges than cervical and lumbar level injuries.
- d) Relationship between participants' perceived health and the four measures

Table 4.23: Means, standard deviations and group statistics for perceived health in relation to the four measures

Measure	Perceived health rating						F	df	P
	FAIR		GOOD		VERY GOOD				
	m	Sd	m	sd	m	sd			
RNLI	28.4	9.6	32.5	9.5	38.4	10.	8.9	2,15	0.000
SCIM: ADL- Wheelchair	28.0	19.3	51.7	13.1	52.3	10.	34.	2,15	0.000
SCIM: mobility	6.8	6.5	10.3	5.7	11.1	8.6	3.7	2,15	0.027
CHIEF-SF	10.4	4.7	6.7	6.7	4.9	8.1	4.6	2,15	0.012

Perceived health rating was significantly related to all four measurements, as reflected above in Table 4.23. There was an overall significant difference on all the measures by perceived health, with RNLI [$F(2,157) = 8.9, p < 0.001$], ADL-wheelchair use scores [$F(2,157) = 34.5, p < 0.001$], mobility [$F(2,157) = 3.7, p < 0.05$] and CHIEF-SF scores [$F(2,157) = 4.6, p < 0.05$].

Post hoc comparisons using the Bonferroni t-test indicated that:

- significant differences existed between RNLI scores of participants who perceived their health as very good and those who rated it as fair or good ($p < 0.001$), and not between with those who perceived their health as good and those who rated it as fair. These results suggest that participants who perceived their health as very good had a greater chance of being satisfied with their community participation.
- significant differences existed between ADL-wheelchair scores of participants who perceived their health as fair and good ($p < 0.001$) and fair and very good ($p < 0.001$). These results suggested that participants who perceived their health as very good were likely to have better functional abilities (ADL-wheelchair).
- significant differences existed only between the mobility scores of participants who rated their health as fair and those who rated it as very good ($p < 0.05$). These results suggest that participants who perceive their health as very good are likely to have better mobility.
- significant differences existed only between the CHIEF-SF scores of participants who rated their health fair and those who rated it as very good ($p < 0.05$). These results suggest that participants with better perceived health are less likely to experience environmental barriers than their counterparts.

4.4.4.3 Multiple regression analyses

Multiple regression analyses were conducted to determine the most significant predictors of community participation (RNLI). The command for the first step was ENTER, and it was used to enter all categorical variables into the regression model. The beta coefficients were inspected to identify significant predictors. The criteria for entry were set at 0.05. In the second step of the analysis, the command STEPWISE was used to enter all continuous variables into the regression model. Again, beta coefficients were inspected to identify significant predictors. The results of the regression analyses are shown in Table 4.24.

Table 4.24 Results of the stepwise multiple regression analyses with the RNLI as a dependent variable.

Dependent variable	Predictor variables	Adjusted R ²	β	<i>t</i>
RNLI	(constant)			38.10
	Employment status	0.26	0.26	4.39
	CHIEF-SF	0.50	-0.59	-9.89

$F(2, 157) = 94.11, p < 0.001$

Significant predictors [$F(2, 157) = 94.11, p < 0.001$] of community participation (RNLI) were employment status and environmental barriers (CHIEF-SF), accounting for 26% and 24% of the variance respectively. The positive β coefficient for employment indicated that if participants were employed, they were more likely to be satisfied with their community participation than those who were not employed. As far as environmental barriers were concerned, the negative β coefficient indicated that participants who reported fewer perceived environmental barriers (i.e. who had lower CHIEF-SF scores) were more likely to be satisfied with their community participation than those who reported more perceived environmental barriers (higher CHIEF-SF scores).

4.5 SUMMARY OF PHASE 1 RESULTS

In this chapter, the results of Phase 1, the quantitative part of the study, were presented. The demographic and SCI profiles of the participants were described and the results of the validity and reliability of the RNLI, SCIM II and the CHIEF-SF instruments were provided. The RNLI and the SCIM II were found to be valid and reliable for use in this study sample, albeit with different factor structures. The CHIEF-SF did not meet the criteria for factor analysis, thus further psychometric tests could not be performed, rendering the instrument invalid and unreliable for this study population of PLWSCI living in the Tshwane metropolitan area, Gauteng, South Africa.

The relationship between demographic variables, SCI variables and the measuring instruments was statistically examined to determine factors related to community participation of PLWSCI. These statistical tests indicated that the number of years of living with SCI, years of basic education, employment, race, residential area, source of income, level of injury, environmental barriers, SCIM: mobility, SCIM: ADL-wheelchair use and perceived health were all significant factors associated with participants' satisfaction with community participation. However, multiple regression analyses identified only employment and environmental barriers as significant predictors of participants' satisfaction with community participation.

These findings are discussed in the next chapter (Chapter 5) in relation to the literature.

CHAPTER 5

DISCUSSION OF PHASE 1 RESULTS

5.1 INTRODUCTION

In this chapter, the results of the quantitative phase of the study, in which the participants' level of satisfaction with participation and related variables were quantified through validated instruments, are discussed.

The discussion of the results covers:

- Epidemiology of SCI in relation to the literature in terms of
 - Socio-demographic profile and
 - Spinal cord injury profile of the participants.
- Reliability and validity of the measurement instruments and possible reasons for findings in relation to the literature, and
- Factors associated with and/or predictive of community participation in relation to the literature.

5.2 THE EPIDEMIOLOGY OF SCI

Although a large body of research has been conducted internationally regarding the global epidemiology of SCI, very little has been done locally in the South African context. As previously indicated in Chapter 2, there are no official statistics on the epidemiology of SCI in South Africa. This is a problem in most developing countries as they have no established SCI registries or population-based data on SCI. According to Thanni and Kehinde (2006), this lack of information is complicated by poorly managed medical record keeping in many hospitals. The limited data that is available from developing countries cannot be generalised to all countries, as this data is mostly derived from single centre, hospital based surveys, most of which are retrospective (Rathore, 2010). Large scale multi centre trials and/or population based

surveys are therefore necessary if we are to assess the true magnitude of the problems associated with SCI in the developing world.

5.2.1 Socio-demographic profile

The socio-demographic and SCI profile of the participants in this study is generally consistent with the international trends reported in the spinal cord injury literature.

5.2.1.1 Age

An SCI can affect people in any age group, but it is more prevalent among young people in the prime of their economically active lives (Rathore, 2010). This was certainly the case in the present study: the mean age at the onset of injury of participants was 29.19 years, ($sd = 8.05$), typical of the SCI population as reported in the literature (Ones, Yilmaz, Beydogan, Gultekin & Caglar, 2007; Rathore, 2010). However, in Australia, the mean age at onset of SCI is reported to be 42 years (Norton, 2010), while in the USA it is reported as 41 years (NSCISC, 2009).

In the present study, 58.1% of the participants were between 15 and 30 years of age at the time of injury. A similar trend was reported 15 years ago in the National SCI Database in the United States, where 57% of the spinal cord injuries were reported to have occurred to individuals under the age of 30 years (Go et al., 1995). This trend has, however, changed in the USA over the last decade or so, as indicated above. The incidence of SCI in economically active young individuals in South Africa can be explained by the fact that these individuals are more susceptible to motor vehicle accidents (either as pedestrians or passengers in taxis, buses or their own vehicles) on a daily basis. However, the fact that SCI affects mostly young people is cause for concern because this is the stage in life where young people should be choosing and developing their careers, establishing relationships and starting families.

5.2.1.2 Gender

The present study sample consisted of 124 males and 36 females (ratio of 3.4:1). The gender distribution of the participants was similar to studies in international literature on spinal cord injury in terms of a male predominance (Norton, 2010; NSCISC, 2009; Rathore, 2010). The male-female ratio is; however, lower than what has been reported in the literature, where the ratio is 4:1 or higher (Hill 1994, 1995; Levi et al., 1996; Nesathurai, 2000; Norton, 2010; Rathore, 2010 & NSCISC, 2009). Some previous South African studies have also reported a male to female ratio of 4:1 (Hart et al., 1994; Mothabeng, 1997), however, suggesting that the male population is slightly under-represented in this sample.

5.2.1.3 Marital status

The percentage of single participants in this study is slightly higher than reported in the National Spinal Cord Injury Database in the United States (NSCISC, 2009). According to this database, 53.5% of people with spinal cord injuries treated in the Model Systems in the United States were single at the time of injury, 30% were married, 9% divorced and 4.4% separated (NSCISC, 2009). In this study, 64.4% of the participants were single, 32.5% married, 1.9% separated or divorced and 1.3% were widowed. The higher percentage of single participants in this study can be explained by the fact that the majority of the sample was black and therefore more likely not to be married, as they tend to marry much later in life (Stats SA, 2004).

According to the NSCISC (2009), the population of PLWSCI is predominantly single because of one of three main reasons. Firstly, SCI affects mainly young people who may not yet be married. Secondly, the likelihood of getting married after sustaining a SCI is greatly reduced and thirdly, PLWSCI who were married before or even after sustaining a SCI, find it difficult to keep their marriages intact (Kreuter, 2000).

The high percentage of single people in the sample was consistent with the young mean age of the participants. The fact that the number of single participants did not change after the SCI suggests that the consequences of the injury and subsequent

disability had an impact on their personal life and social (Rathore, 2010). This finding confirms earlier concerns about the potential of PLWSCI to engage in and maintain meaningful relationships, and eventually to marry.

5.2.1.4 Level of education

The ensuing discussion on the participants' education considers two aspects, namely basic formal education and further (academic/post basic) qualifications. The participants in this study had between two and 12 years of formal education (*mean years = 9.9, sd = 2.6*). There was no participant who had had no basic education at all. The basic education level of the participants in this sample compares well with that of the Tshwane metropolitan area, which is reported to "have on average the highest educational level in the country" (<http://www.tshwane.gov.za/cityprofile.>). This educational profile is also in keeping with a report of the National Household Transport Survey (2007:33) which states that "metropolitan areas have the fewest people with no education, as well as the most with matriculation and post-matriculation qualifications".

The high basic education level in the sample is quite different from the general South African population, which is reported to have 6.1 mean years of basic education (www.nationmaster.com), with the black population having the lowest education level. According to Statistics South Africa (2004), only 14% of Blacks (Africans) have received education up to high school or higher, whereas 40% of Indians and 65% of Whites have completed high school or higher (op. cit.).

5.2.1.5 Race

In this study, 77.5% of the participants were Black (African). This percentage compares well with the population of the Tshwane metropolitan area which is reported to be 73% Black/African (www.tshwane.gov.za). The race profile is also a reflection of the South African population in general, where Blacks (Africans) make up 79.3% of the population, Coloureds (9%), Indian/Asians (2.6%) and Whites (9.1%) (Statistics South Africa, 2004).

5.2.1.6 Employment

In this study, 91 participants (56.9%) were employed before they sustained the SCI. However, only 41 participants (25.6 %) were employed after the SCI, suggesting that some participants who had been employed pre-SCI had lost their jobs. A similar employment percentage was reported by Krause, Saunders and Staten (2010), who found that only 26.8% of the participants in their sample were employed. Out of the 41 employed participants in this study, 12 had gained new employment after sustaining the SCI. This means that employment actually dropped from 91 to 29 (a drop of 40%). This finding confirms reports that people often lose their employment after an SCI and those who were unemployed before struggle to find employment after the injury (Anderson et al., 2007). A number of variables associated with (re)employment after SCI are discussed later in this chapter.

The return to work is one of the most meaningful measures of successful rehabilitation (Krause, Steinberg, Maides, & Lottes, 1998; Krause et al., 1999). However, because of the very limited number of studies on the employment of PLWSCI in less-industrialised and more developing countries, employment statistics for PLWSCI are virtually non-existent (Gosselin & Coppotelli, 2005). In Zimbabwe, a report by Levy et al. (1998) indicated that only 13% of the participants in their study were employed two to eight years after injury. The 13% of employed PLWSCI in this study by Levi et al. (1998) is much lower than the present study in which 26% of the participants were employed three to twenty years post injury. However, the results confirm the problem of unemployment following SCI, especially in developing countries. A review of the literature on the return to work (RTW) of PLWSCI by Lidal, Huynh and Biering-Sørensen (2007) confirmed that employment rates after SCI are low, and highlighted the need for future research to explore interventions aimed at helping people with SCI to obtain and sustain productive work.

Several studies have been conducted around the globe to determine factors related to the return to work and employment of PLWSCI (Anderson et al., 2007; Chan & Man, 2005; Lidal et al., 2007). These studies identified a number of variables

associated with return to work and/or employment, albeit with great variability across studies. This variability exists because returning to work is a complex process resulting from the interaction of personal and environmental factors (Chan & Man, 2005). Despite the great variability in the studies regarding the factors associated with the return to work, some generalisations do consistently emerge. Anderson et al.(2007) recently reviewed the literature on factors associated with the employability of PLWSCI and identified 11 key factors: education, type of employment, severity of disability, age, time since injury, gender, marital status and social support, vocational counselling, medical problems related to SCI, employer attitude, environmental factors and professional interests.

In the present study, 90% of participants who had diplomas and degrees were employed, and qualifications were a significant predictor of employment [$F(2, 157) = 94.11, p < 0.001$]. These results confirm previous reports by Jang et al. (2005), that education and functional independence were the strongest factors in predicting a return to work. The results also support Krause et al. (1996), Jang et al. (2005) and Lin et al. (2009), who all concur that if individuals have higher levels of education, they have a better chance of being employed.

Dawodu (2008) also suggested that the likelihood of employment after a SCI is greater in patients who are younger, male, white, have more formal education, higher reported intelligence quotient (IQ), greater functional capacity and less severe injury. The importance of education is supported by Krause et al. (2010) who reported that PLWSCI who had a college education had a better chance of returning to work than those with only high school qualifications or less. In the current study, most of the participants who were not employed post SCI did not have high levels of education and had worked before their injury as unskilled labourers, such as gardeners, domestic workers or building contract workers. These are physically demanding jobs with which someone with SCI will generally not be able to cope. Researchers have also suggested that higher levels of education prepare PLWSCI for occupations that

are less physically demanding (Krause et al., 1998; Noreau et al., 1999; Tomassen et al., 2000).

Some researchers have also suggested that engaging in educational activities post-injury is a significant predictor of employment (El Ghatit & Hanson, 1979; Tomassen et al., 2000). Whether participants had improved their education during or after rehabilitation was not investigated in this study, and this is recommended for future research.

The race of the participants was significantly associated with employment [$\chi^2(1) = 4.3, p < 0.05$], with only 21.7% of the Africans being employed as opposed to 79.9% of the non- Africans. Similar trends have been reported in the United States, where it was found that Caucasians had greater opportunities to find employment following spinal cord injury (Arango-Lasprilla et al., 2009; Hess et al., 2000; Krause & Anson, 1996; Krause et al., 1999; Meade et al., 2004). In all the studies, Caucasians were found to have a higher employment status than their counterparts. In addition, Krause (1998) found that PLWSCI who were Caucasian had a higher employment status than African Americans at the time of the study, although there was no difference between the two groups in the average number of years worked before onset of SCI.

Other socio-economic (“race related”) correlates of employment found in this study were residential area and perceived health rating. Residential area was associated with employment [$\chi^2(2) = 6.9, p < 0.05$], with only 18.8% of the township participants being employed, as opposed to 40% of the suburb participants. The majority of unemployed participants were from the townships, which are predominantly African. There was a strong association between perceived health rating and employment [$\chi^2(2) = 26.6, p, 0.001$], with 95% of the non-African participants rating their health as good or very good as opposed to 76% of the African participants.

Krause (1998) reported that differences in the employment status between Caucasians and African Americans existed only after the SCI. However, this study’s

results indicate that Whites had an employment advantage both before and after sustaining the SCI. In this study, white PLWSCI also had a higher chance of returning to their pre-injury jobs in comparison to their Black, Indian or Coloured counterparts, similar to the findings of Krause (1998). According to Krause (1998), this is because the African American PLWSCI had jobs which required more physical skills, lacked transportation, and experienced physical inaccessibility and employer injustice. The reasons advanced by Krause (1998) are most probably also applicable to the Blacks in the present study: as indicated above, most had done unskilled work before their injuries. However, further research into this aspect is required to confirm this.

As expected, being employed prior to sustaining the SCI was significantly associated with employment after injury in this study [$\chi^2(2) = 4.3, p < 0.05$], supporting previous reports by Krause et al. (1999) and Jang et al. (2005).

Some authors have suggested that PLWSCI who were married (Hess et al., 2000; Jang et al., 2005) and younger at the time of injury (Jang et al., 2005) had a better chance of being employed after their injury. However, these variables did not significantly influence the post-injury employment status of participants in this study.

Other factors that have been identified as affecting employment post SCI include having access to transport and, in particular, being able to drive oneself (Noreau et al., 1999) and vocational training after injury (Jang et al., 2005; Lin et al., 2009). These factors were not quantitatively measured in this study; however, the issue of transport was raised by all the interviewees in the second phase. Transport is discussed with other accessibility issues in section 6.4.3.3.

5.2.1.7 Source of income

The employment of participants in this study dropped by 39.6% from 91 PLWSCI employed pre-injury to only 36 employed post-injury. Unemployment can pose a significant financial disadvantage to PLWSCI. According to the Employment Equity Report 2007/2008, only 0.5% of people with disabilities (including PLWSC) are

represented in the South African workforce. As a result, most unemployed people with disabilities rely on government disability grants. Fifty-one percent of the unemployed participants in this study were dependent for their income on a disability grant. This grant plays an important role in poverty alleviation and income redistribution. However, because of widespread unemployment in many families, this income (R1050/US\$117 per month in 2009) is used to provide for general family and household needs, and not only for the needs of the PLWSCI. As a result of this income sharing, which is the norm rather than the exception, the basic needs of the PLWSCI are not met (Westaway, Olorunju & Rai, 2007).

Of the participants receiving disability grants, 41% said they were not seeking employment. Their reasons for this were not investigated in this study. However, in France, Chan and Man (2005) reported that PLWSCI who have low levels of education and who may find it difficult to find similarly paying jobs to what they had pre-injury tend to prefer government financial assistance. Financial compensation programmes, policy and services can have a direct impact on RTW. Chapin and Kewman (2001) reported that many persons who sustained a SCI were not inclined to RTW for fear of losing their financial benefits. Similarly, Jongbloed, Backman, Forwell and Carpenter (2007) reported that in British Columbia, Canada, benefits received while on social assistance, such as dental care and prescription medication, are lost once PWD earn more than \$400/month. It would appear therefore, that social assistance tends to deter recipients from returning to work or seeking employment. Whether this reason applies to this study population remains to be investigated further.

5.2.1.7 Geographic location and living arrangements

The majority of the participants in this study (61.3%) lived in townships and were black (African). This is typical of the population of the Tshwane metropolitan area, which is made up of 80% black residents (<http://www.tshwane.gov.za/cityprofile>), the majority of whom reside in townships and informal settlements. Statistics South Africa (2001) confirms that 75% of the almost two million inhabitants of the Tshwane

metropolitan area live in townships. A possible explanation for the high proportion of Blacks in the Tshwane metropolitan area is urban migration that is typical of the informal settlements and squatter camps that form around cities in the RSA.

The vast majority of the participants (90%) were living with their families at the time of this study. Because of strong family structures in South Africa, based on social customs (e.g. the extended family), the majority of the participants were able to return to their families (spouses or parents) after their injury (Rathore, 2010; Westaway, 2007). The advantage of living with family is the availability of care giving, as the spouse and/or other family members become dedicated care givers of the PLWSCI, with no extra cost of care giving in many cases. Similar results were reported in the USA, where 87.8% of all persons with SCI were discharged to private, non-institutional residences, which were in most cases their homes before injury (NSCIRS, 2009). The USA has a socio-culturally different context, therefore this similarity is probably not due to cultural values, but the fact that it is much cheaper to live with family than in a care centre.

5.2.2 Spinal Cord Injury and general health profile

5.2.2.1 Causes of SCI

The results of this study revealed that the causes of SCI among the participants were both traumatic (road traffic accidents = 71%; violence = 19.4%) and non-traumatic (tumours = 5.6%; TB spine = 4.4%).

a) Traumatic causes of SCI

Road traffic accidents (RTAs) were the highest cause of SCI in this sample (71%). The predominance of RTAs as a cause of SCI was also reported in two previous South African studies (King, 2007; Mothabeng, 1997). This trend is comparable to the international literature, which confirms that the common global traumatic causes of spinal cord injury are motor vehicle accidents (Divanoglou & Levi 2009; Hulsebosch, 2002; NSCISC, 2009; QASA, 2009; Rathore, 2010). In this study, vehicle occupants

(drivers and/or passengers) constituted the highest number of people who sustained SCI from RTAs. Similar results were reported in Australia and the USA, where the majority of people who sustain an SCI in a motor vehicle accident are occupants of light passenger vehicles: 75% in Australia (O'Connor, 2002) and 82% in the USA (Thurman et al., 1995). In these RTAs, the cervical segments of the spine are most frequently affected, resulting in tetraplegia (O'Conner & Brown, 2006). The SCI outcome in this study was different, however, with more PLWSCI having sustained paraplegia than tetraplegia. Possible reasons for this are discussed in section 6.2.2.2.

RTAs have also been found to be a major cause of death in South Africa as a whole, and specifically in the Tshwane metropolitan area. A report on the profile of fatal injuries in South Africa indicated that the Tshwane (Greater Pretoria) metropolitan area does not only have the highest transport mortality rate (45.4/100 000 population), but also the highest recorded rate for driver deaths (Donson, 2007).

The WHO and UNICEF (WHO, 2008) have predicted that the number of deaths and injuries from vehicle accidents will increase by 67% before the year 2020. This is owing to the increase in the number of vehicles around the world (Roberts, Mohan & Abbasi, 2002), which will in turn increase the number of pedestrian vehicle-related injuries. Pedestrian vehicle-related injuries are high on the African continent, where it is common for people to walk to their destinations (WHO, 2008). In the RSA, fatal pedestrian vehicle-related injuries have been reported to account for 52% of road traffic accidents (Brysiewicz & Bruce, 2008; Matzopoulos, Groenewald & Bradshaw, 2007).

It has been reported that approximately 34 000 pedestrian vehicle accidents occur annually on South African roads (Dhoda & Allopi 2005), resulting in serious and devastating injuries such as SCI. Brysiewicz (2001: 194) reported that "*pedestrian collisions typically involve black males aged 20 to 29 years of age, who are dressed in dark clothes at the time of the incident and almost all of the pedestrians injured on a Saturday night are under the influence of alcohol*". A similar trend was observed in

this study, where **all nine participants** who had sustained SCI following pedestrian vehicle accidents were male, black and under the age of 30.

As indicated previously in Chapter 2, the occurrence of RTAs in the RSA tends to be “seasonal”, with more accidents happening around the Easter (March/April) and Christmas (December) festive periods. For example, during December of 2008, NetCare 911 (a private ambulance service provider) attended to 436 pedestrian vehicle-related injuries out of a total of 3103 road accidents (Arrive Alive, 2009). According to Arrive Alive (2009), 41% of these incidents occurred in the Gauteng province, the economic hub of the RSA, where the majority of cars in the country are found. There is therefore an urgent need to address prevention strategies regarding pedestrian vehicle-related injuries.

The road traffic fatality rate in South Africa (39.7 per 100 000) is higher than for any WHO region and almost double the global average (Norman et al., 2007). Road traffic accidents contribute to the high burden of injuries in South Africa. According to Norman et al. (2007), this high burden of injuries is caused by unsafe road environments, poor enforcement of existing traffic laws, road rage, aggressive driving and alcohol misuse. The National Injury Mortality Surveillance System reveals that 53% of the samples of road traffic accident victims had detectable blood alcohol levels, with pedestrians more intoxicated than drivers (Matzopoulos, 2005). While alcohol consumption appears to be declining in most of the developed countries, the opposite is true for the developing world (WHO, 2001).

Other major causes of traumatic SCI, depending on the country and/or context, include falls, sports-related injuries and violence-related injuries including gunshot wounds and stab wounds. For example, a previous South African study by Hart et al. (1994) reported results contrary to the current study findings: violence was found to be the main cause of SCI. Hart et al. (1994) reviewed the records of 616 patients in the Natalspruit Hospital Spinal Rehabilitation programme over a six-year period (1988–1993) to determine the epidemiology of SCI. Their results revealed that

violence was the most predominant traumatic cause of injury (56%), followed by RTAs (25%). It is worth noting that this particular study was conducted during the immediate pre-democratic era of South Africa, when there was an increase in violence due to the changing economic and political systems (Hart et al., 1994). Politically motivated violence was also rife in the townships, including the East Rand, where the Natalspruit Hospital Spinal Unit is situated.

In the current study, violence in the form of gunshots was the second major cause of injury, accounting for 19.4% of the SCI in the sample. The majority of gunshot injuries were sustained in criminal acts, where participants were robbed (house robberies, car hijackings, etc.) or from domestic violence. It is worth noting that all the gunshot SCI victims were from the suburbs. Although not the leading cause of injuries, violence is a serious problem that needs to be addressed by the relevant sectors.

b) Non- traumatic causes of SCI

Non-traumatic causes of SCI in this study population included TB spine and tumours. Spinal tuberculosis (TB spine) is still an important cause of non- traumatic SCI in the underdeveloped and developing countries of the world (Turgut, 2001). South Africa has one of the highest incidences of TB in the world, ranked fifth on the list of 22 high-burden tuberculosis (TB) countries (Gandhi, Moll, Sturm, Pawinski, Govender, Lalloo, Zeller, Andrews & Friedland, 2006; WHO, 2009). Tuberculosis (TB), combined with HIV, multi-drug resistance (MDR) and extremely drug-resistance is a major public health problem in South Africa.

Untreated HIV infection leads to progressive immunodeficiency and increased susceptibility to infections, including TB. HIV is driving the TB epidemic in many countries, especially in sub-Saharan Africa and, increasingly, in Asia and South America (WHO, 2004: 25).

TB spine is the most common and most dangerous form of musculoskeletal tuberculosis, and the most frequent cause of non-traumatic SCI in most parts of Africa (Akinyoola, Adegbehingbe & Ashaleye, 2007). Delays in establishing diagnosis and

management result in spinal deformities which cause spinal cord compression and SCI.

One of the participants in this study who had sustained SCI from TB of the spine disclosed that he also had HIV. Although only one participant disclosed their HIV status in relation to TB spine, the literature suggests that there could be more (Godlwana, Gounden, Ngubo, Nsibande, Nyawo, Puckree, 2008). Mothabeng (2006) reported that while traumatic causes remain the major cause of SCI in South Africa, numerous patients sustain SCI as a result of HIV-related diseases (mainly TB spine), and a significant number of patients with traumatic SCI only discover that they have HIV following the injury. HIV-SCI is therefore a challenging vicious circle: from cause to co-morbidity, a new face in the gallery of causes is emerging. This observation by Mothabeng (2006) was later confirmed by a statistical report on SCI in Gauteng. In her report presented to the Gauteng Physiotherapy Forum on SCI Statistics, Serobatse (2010) indicated that while traumatic causes appear to be decreasing, non-traumatic causes are on the increase.

A retrospective review of the records of all patients with spinal tuberculosis seen and treated in the Obafemi Awolowo University Teaching Hospitals Complex, Ile-Ife, Nigeria, revealed that 7.4% of the patients with spine tuberculosis tested positive for HIV (Akinyoola et al., 2007). A South African study, also reporting on a retrospective review of patient records at a major provincial public hospital serving patients with spinal injuries/pathology in Kwazulu-Natal revealed that all the patients with TB spine had a history of pulmonary TB, and 28% had tested positive for the human immunodeficiency virus (HIV) (Godlwana et al., 2008). The TB-HIV/AIDS co-infection rate is high in South Africa, with an estimated 73% of new TB patients co-infected with HIV (WHO, 2004). HIV and TB are preventable conditions, which are usually seen as co-morbidities, and should be managed before causing disabilities like SCI.

5.2.2.2 Level and completeness of the SCI

The injuries sustained by the majority of the participants in this study were complete and mostly resulted in paraplegia. Similar results have been reported from other developing countries (Chacko et al., 1986; Maharaj, 1996; Rathore et al., 2008; Singh et al., 2003). These findings are in contrast with what has been reported in studies from the developed world, where most patients have incomplete cervical spine injury at presentation (NSCISC, 2009; Rathore, 2010).

A possible explanation for the disparity, according to Rathore (2010), is that in developing countries, patients with cervical spine injuries are unlikely to survive the injuries due to poor pre-hospital (emergency) care and careless handling of the spine at the trauma site. This poor emergency care results in a high number of patients with paraplegia surviving the SCI (Nguyen et al., 2008; Solagberu et al. 2009). There is therefore an urgent need for improved pre-hospital care of patients with SCI, especially higher lesions in the cervical area.

A potential contributor to the high number of paraplegic type injuries is the violent causes of SCI, mainly gunshot injuries. In this study, all the gunshot cases resulted in thoracic injuries. Gunshot injuries commonly affect the thoracic (gunshot chest) and lumbar (gunshot abdomen) areas, resulting in paraplegia.

5.2.2.3 Causes of re-admission to hospital

The literature states that the highest incidence of hospital re-admissions occurs in the first three to five years following spinal cord injury, and decreases with increasing time since injury (Basson et al., 2006; Chen et al., 1999). Recurrent and/or prolonged hospital admissions are disruptive to a person's ability to maintain meaningful family or social relationships. As a result of prolonged hospitalisation, the PLWSCI may require long periods of sick leave if employed, thus further impacting on their participation in society. There is unfortunately a dearth of research data on the hospital readmission rates for individuals with spinal cord injury in South Africa. The

findings from this study therefore contribute to filling this gap, and to informing strategic intervention policies and plans for addressing the problem.

Almost half (48.1%) of the participants in this study had been re-admitted for one or more complications after discharge from rehabilitation. Pressure ulcers (either alone or combined with UTI, and/or respiratory problems) were responsible for hospital re-admissions in 78% of the readmitted participants. This corresponds with the literature, which states that the most common reasons for re-admissions are pressure ulcers, urinary tract infections and respiratory infections (Bloemen-Vrencken, Post, Hendriks, De Reus & De Witte, 2005).

One of the main causes of the development of pressure ulcers is considered to be the inactivity of the patient as well as prolonged pressure, mainly in the sitting position (Dini et al., 2006; Eksteen et al., 2006;). Frequent pressure relief should be performed to prevent tissue damage and reduce static pressure (Burns & Betz, 1999). The prevention of pressure ulcers should be an integral part of each SCI patient's rehabilitation programme and education. Pressure ulcers are an avoidable complication, provided one understands the mechanics of his/her own skin care and is vigilant in its management and the holistic array of factors contributing to the development of pressure ulcers (Davidoff et al., 1990; Dunn, Carlson, Jackson & Clark, 2009; MacLeod, 1988).

However, because of prior socio-economic disadvantages (which characterise the majority of black African participants in this study), some PLWSCI do not have adequate life skills, self-esteem or a framework from which to develop coping skills or appropriate problem solving skills to manage their own health and live fairly healthy lives with a spinal cord injury (Trospen, 1998). As a result, these PLWSCI present with self-neglect behaviours. Self-neglect is considered an indicator of adjustment difficulties amongst the spinal cord injured population (Davidoff et al., 1990; MacLeod, 1988). Self-neglect or non-adherence to medical regimes can result in life threatening medical complications such as pressure sores and urinary tract infections that have

serious implications on the quality of life, health and even survival of the injured person.

5.2.2.4 Perceived health rating

The majority of the participants in this study perceived their health as 'good', (60%), while only 17.5% perceived it as fair, and 22.5% as excellent. The participants' perceived health was related to gender ($p < 0.05$) and employment ($p < 0.001$). Krause, Broderick, Saladin and Broyles (2006) suggest that gender differences in functional and health outcomes exist following SCI, and that the relationship among race/ethnicity, gender, and socio-economic status shapes the perception of health of the PLWSCI. There is thus a need for further research to explore the race and gender influences on the perceived health status of PLWSCI.

5.3 RELIABILITY AND VALIDITY OF THE MEASURING INSTRUMENTS

This section discusses the psychometric analysis of the instruments used in the study, namely the Return to Normal Living Index (RNLI), the Spinal Cord Independence Measure II (SCIM II) and the Craig Hospital Inventory of Environmental Factors short form (CHIEF-SF). The results are compared to other studies in which the same instruments were implemented.

5.3.1 The Return to Normal Living Index (RNLI)

As described earlier, the RNLI was used to determine participants' satisfaction with community participation in this study. The RNLI was found to be both valid and reliable, with a Cronbach's alpha of 0.97, which is regarded as an excellent reliability coefficient. Similar results were reported by Stark, Edwards, Hollingsworth and Gray (2005), who found the RNLI to have a Cronbach alpha value of 0.91. The high internal consistency, as measured by Cronbach's alpha in this study, indicates that the items on the RNLI are homogenous, implying that all items measure the same attribute. This homogeneity is further confirmed by the fact that all of the corrected

item-total correlation coefficients (r-values) were higher than the recommended value of 0.40 for convergent validity (Stewart et al., 1988).

Factor analysis of the RNLI using principal component analysis followed by alpha factoring identified a single factor structure for the RNLI. This finding differs significantly from what was reported in other studies, where a clear factor structure was not revealed. For example, the developers of the instrument (Wood-Dauphinee et al., 1988) identified two subscales to the RNLI namely: Daily Functioning (indoor, community, and distance mobility, self-care; daily activity (work and school), recreational and social activities, and general coping skills) and Perception of Self (family role(s), personal relationships, and presentation of self to others.). Stark et al. (2005) also found a different factor structure with two different subscales, a social subscale (five items) and a physical subscale (six items). In all the proposed factor structures, the 11 RNLI items remained unchanged.

A possible explanation for the factor structure differences could be the fact that the current study used a homogeneous disability sample made up of PLWSCI only, while other studies used heterogeneous samples (including PLWSCI amongst people living with other disabilities). The mixed diagnostic groups in the other studies (SCI, Multiple Sclerosis, stroke, Cerebral Palsy, Poliomyelitis) were likely to experience different medical problems and psycho-social challenges than the pure SCI diagnostic group in this study. Further studies are therefore recommended, in which PLWSCI are compared with other disabling diagnostic groups in a South African context.

5.3.2 The Spinal Cord Independence Measure II (SCIM II)

As mentioned earlier in this section, this study used the SCIM II to measure functional ability. While this study was being conducted, a new version, SCIM III, was published by the instrument developers. The results of this study will be compared with studies using the SCIM II, but the researcher is cognisant of the existence of the SCIM III.

The SCIM II was found to be a valid and reliable instrument in this study. However, only 15 of the original 16-item SCIM instrument were used for the validity and reliability analysis. The reason for using 15 items is that one item (respiration) had to be excluded from the analysis as there was no variability in the item scores. All 160 participants were able to breathe independently and therefore all scored 10: hence the standard deviation of 0.00.

Principal components analysis of the 15-item instrument revealed a two factor structure to the SCIM II (ADL-wheelchair use and Mobility), which is a deviation from the accepted three factors (ADL; Respiration and sphincter control; Mobility) reported by the developers (Catz et al., 1997). A possible explanation for this different factor structure relates to the exclusion of one item in the instrument (respiration) as explained in Chapter 4 (section 4.3.2.1). It should also be noted that the developers of the SCIM II used a different statistical procedure (Rasch analysis).

Statistical analysis of the two SCIM II factors revealed that they had item convergent validity, with corrected item-total correlation coefficients ranging between 0.61 and 0.89 (Stewart, Hays & Ware, 1988). Item discriminant validity ($z = 9.65$) and content and construct validity (factor loadings > 0.71 ; Nunnally, 1978; Tabachnik & Fidell, 1996) were established. The “modified” SCIM II was found to be internally consistent, with coefficient alpha values of 0.91 (95% CI: 0.89-0.93) for ADL-wheelchair use, 0.98 (95% CI: 0.97-0.98) for mobility and 0.93 (95% CI: 0.91-0.94) for the full instrument, all excellent reliability coefficients (Arias & de Vos 1996; George & Mallery, 2003). Similar results were reported by Catz et al. (2001) on the 16-item scale: they found that the SCIM II is a valid and reliable instrument, albeit with a different factor structure.

The SCIM II is therefore a reliable and valid instrument for use on this sample of a PLWSCI in the Tshwane metropolitan area, Gauteng, South Africa, albeit with a different factor structure. Further research is still needed, however, to establish cross-cultural validity on the new version of this instrument (SCIM III). This research should

also include PLWSCI with different levels of respiratory function (including those needing assistance with breathing, e.g. those on ventilators) in order to test all the SCIM II items.

5.3.3 The Craig Hospital Inventory of Environmental Factors – short form (CHIEF-SF)

The CHIEF-short form (CHIEF-SF) could not be tested for validity and reliability as the instrument did not meet the requirements of factor analysis. The KMO was 0.44, which is in the “unacceptable” category according to Kaiser (1974). Therefore the validity of the CHIEF-SF could not be established for this population of PLWSCI. This is contrary to previous reports by the instrument developers, who stated that the CHIEF-SF “had the highest correlations with subscale and total scores, and best differentiated between people with and without disability” (Whiteneck et al., 2004, 1328).

The different findings in the current study can possibly be attributed to the problem of “long term recall”. As in the original CHIEF instrument, the CHIEF-SF requires participants to recall which environmental barriers they experienced a year ago and how those barriers impacted on their lives (12 months later!). This is quite a daunting task, as few people are able to recall something like this for longer than four weeks (Krause et al., 2006). Furthermore, there is always the prospect of some degree of bias in such a lengthy period of retrospective recall.

Another possible explanation for the different findings in the current study is related to the terminology used in the instrument. As explained in Chapter 3, some participants struggled to comprehend certain concepts in the instrument (e.g. government and business policies, and discrimination). Even though the researcher explained these concepts, it was evident that some participants still could not quite grasp them; therefore, their answers could have been based on their lack of understanding of the concepts.

The CHIEF-SF is a relatively new instrument, used mainly in the USA. No studies have investigated its psychometric properties in the South African context. The different findings of this study confirm the importance of testing the psychometric properties and applicability of an instrument before it is implemented in a context different from the one for which it was developed.

5.4 FACTORS ASSOCIATED WITH COMMUNITY PARTICIPATION

A number of factors that are associated with the community participation of PLWSCI were identified in Chapter 4 (section 4.4) and correlated using statistical analyses [chi-square tests, Pearson product-moment correlation coefficients, t- tests, one way analysis of variance (ANOVA), with Bonferroni adjustments for multiple comparisons and multiple regressions]. For the purpose of this discussion, the factors were categorised as personal, environmental or disability related, and are discussed as follows in relation to the literature.

5.4.1 Personal factors

The personal demographic factors that were found to be significantly associated with community participation in this study were race [$t(87.89) = -5.0, p < 0.001$], level of education ($r = 0.380, p < 0.001$), residential area [$F(2,157) = 5.0, p < 0.05$] and employment [$t(158) = -11.266, p < 0.001$]. All these factors are related to the socioeconomic status of the participants, and are thus discussed together.

Race was a significantly associated with participation, with African participants scoring lower than non-Africans on the RNLI. Caucasians were more likely to be satisfied with community participation than their African counterparts (Anderson, 2007; Belgrave et al., 1991; Krause et al., 2010). Belgrave et al. (1991) suggested that social support, self-esteem, health locus of control, perception of disability

severity, acceptance of disability, transportation source and education were the factors that influenced community participation in black PLWSCI.

Employment was also found to be strongly associated with satisfaction with participation, with employed participants having higher RNLI scores ($m = 41.9$; $sd = 3.4$) than unemployed participants ($m = 30.9$; $sd = 9.9$), suggesting that they were more satisfied with their community participation. Employed PLWSCI tend to view their disability with greater acceptance and report greater satisfaction with their quality of life (Krause, 1996a; Krause, Steinberg et al., 1998). A possible explanation for this finding is that being employed provides the financial resources to manipulate one's environment (e.g. to modify one's home or purchase equipment to aid independence). Participants with greater financial resources therefore have a wider range of choices available to them and thus perceive themselves to have greater control over their lives.

Higher educational levels were found to be associated with employment in this study, similarly to previous findings (Hess et al., 2000; Krause, 1996a; Krause, Steinberg et al., 1998). Employment is important because it provides financial security and enhances self-esteem, independence, social relationships, self-worth, and personal identity, all of which are important for PLWSCI (Yasuda et al., 2002). The problem of unemployment is further discussed in chapter 6, and policy recommendations are made in chapter 7.

5.4.2 Disability Related Factors

For purposes of this discussion, disability related factors refer to impairments of body structure and function and functional activity limitations experienced by PLWSCI as a result of the condition SCI. In this study, the significant disability related factors associated with community participation were years living with an SCI, perceived health, and functional ability.

5.4.2.1 Years living with a spinal cord injury

The number of years living with spinal cord injury was significantly associated with participation ($r = 0.157$, $p < 0.05$), confirming previous reports that the longer people live with SCI, the better their community participation (Charlifue & Gehart, 2004; Pentland et al., 1995).

5.4.2.2 Health status

In this study, participants with lower levels of education were re-hospitalised more frequently for medical complications than those with higher levels of education, supporting the findings of previous studies by Davidoff et al. (1990) and Meyers et al. (1989). In a study on the health-related quality of life among Canadians living with SCI, Leduc and Lepage (2002) found that participants who had not been hospitalised for any medical complications related to SCI had a better quality of life than those who had been hospitalised.

Perceived health status was significantly associated with satisfaction with community participation [$F(2,157) = 8.9$, $p < 0.001$], with participants who perceived their health as not good also having lower scores of satisfaction with community participation. This finding highlights the importance of health promotion for PLWSCI. One way of achieving this is through increased physical activity (PA). The literature suggests that the PA levels of PLWSCI may not be adequate to promote health (Buchholz, McGillivray & Pencharz, 2003), owing to the sedentary nature of most PLWSCI.

Physical activity is important for PLWSCI because increased levels of PA will lead to healthier lifestyles which will enable PLWSCI to participate more in various societal roles (Anderson 2004; Kehn et al., 2009). The literature also suggests that non-communicable diseases (NCDs) associated with limited physical activity are a leading cause of mortality among PLWSCI (Buchholz et al., 2003; Washburn, Weimo, McCauley, Frogley & Figoni, 2002). Physical activity is therefore important for maintaining the health of PLWSCI and preventing further disease and disability (Fernhall, Heffernan, Young, & Hedrick, 2008).

5.4.2.3 Functional ability

The literature suggests that the ability of patients to perform functional activities is closely associated with the type (complete vs. incomplete) and level (paraplegia vs. tetraplegia) of the lesion (Vogel, Klaas, Lubicky & Anderson, 1998). Functional ability and independence is more affected in people with tetraplegia than in those with paraplegia (Manns & Chad, 2001). In this study, type of injury was significantly related to the participants' functional ability, as seen on the ADL- wheelchair factor [$t(79.3) = 7.0, p < 0.001$] and Mobility [$t(-88.2) = -0.2, p < 0.001$].

Regardless of type and level of injury, higher functional ability scores were associated with greater satisfaction with community participation in this study. Participation was positively related to the SCIM: ADL-wheelchair ($r = 0.177, p < 0.05$) and SCIM: mobility ($r = 0.216, p < 0.001$) subscales of the Spinal Cord Independence Measure II (SCIM II). Similar results were reported in a longitudinal study of 149 individuals with long-standing spinal cord injury by Daverat, Petit, Kemoun, Dartigues and Barat (1995), who found that participation was significantly correlated with functional ability as measured by the Functional Independence Measure (FIM) (Hamilton, Granger, & Sherwin, 1987). In this study, however, functional ability was measured using the SCIM II, which is a more relevant measure of function for PLWSCI (Catz et al., 2001). It is therefore important for rehabilitation professionals to ensure that PLWSCI reach their highest functional level in order to enhance their community participation.

5.4.3 Environmental factors

The results of this study revealed that perceived environmental factors, with specific reference to accessibility issues, were significant predictors ($p < 0.001$), accounting for 24% of the variance in satisfaction with community participation. This finding supports the findings of Whiteneck et al. (2004), who reported that the experience of barriers may reduce the PLWSCI's life satisfaction, and hence affect participation. The three main environmental accessibility issues that emerged from Phase 1 of this

study as influencing participation were access around the home, access around the community and transportation.

Inspection of the accessibility issues within the RNLI instrument indicated the following:

- *I move around my living quarters as I feel necessary* ($m = 3.33 \pm 0.94$)
- *I move around my community as I feel necessary* ($m = 3.03 \pm 0.98$)
- *I am able to make trips out of town as I feel necessary* ($m = 2.491 \pm 0.03$)

The participants had mean RNLI item scores of 3.33 (± 0.94) and 3.03 (± 0.98) respectively regarding access around the home and in the community, suggesting that participants were moderately satisfied with these accessibility aspects that influenced their community participation. However, being able to make trips out of town (transportation) had the lowest mean score of the three accessibility items, suggesting that transportation was the one accessibility issue that influenced participants' satisfaction with community participation negatively.

Transport barriers also emerged as the perceived environmental factor with the greatest impact on PLWSCI, with the highest mean impact score of all: CHIEF-SF items ($m = 2.06, sd = 2.05$) (see section 4.3.2.2). This finding supports what has been stated in the literature: architectural barriers and transportation issues are common accessibility problems that individuals with spinal cord injuries encounter in the physical environment once back in the community (Anderson & Vogel, 2002; Levins, Redenbach & Dyck, 2004). The main effect of these factors on PLWSCI is isolation, which limits their participation in the community. These findings suggest that there is an urgent need to address the transport problem. This is discussed in chapter 7, where the results of Phases 1 and 2 are integrated.

5.5 Summary

In this chapter the findings of the quantitative part of the study were presented. The demographic and SCI profiles of the participants were discussed in relation to the literature, and found to be generally similar to global trends. The validity and reliability of the measuring instruments used in the study were also discussed in relation to the literature, and a need for further research was indicated.

The factors that influence the community participation of PLWSCI were summarised in three categories, namely disability (SCI) related factors, environmental factors and personal factors. Disability related factors included functional ability, number of years of living with SCI, level of SCI, re-admission to hospital for health complications and perceived health status. Environmental factors were all aspects of the CHIEF-SF, while personal factors included race, level of education, residential area and employment.

In the next chapter (chapter 6), the results of Phase 2 of the study are presented and discussed. The findings of both Phase 1 and 2 are integrated in chapter 7, and a framework for optimising community participation for PLWSCI is presented.

CHAPTER 6

RESULTS AND DISCUSSION – PHASE 2

6.1 INTRODUCTION

This chapter reports on the results that emerged from the qualitative phase of the study, using a narrative report writing style. The aim of this phase was to establish, from the participants' point of view, how they experienced community participation as PLWSCI. The chapter begins with an outline of the demographic profile of the participants who were interviewed. Participants' views on community participation are presented through the use of descriptive statements illustrated by selected verbatim quotations from the transcripts of the interviews to emphasise the highlighted themes. These themes are discussed in relation to the literature. In order to protect the anonymity and confidentiality of the participants, pseudonyms are used throughout the chapter. The conclusion of this chapter is incorporated into the final framework for community participation by PLWSCI, developed from the initial framework presented in Chapter 1.

6.2 DEMOGRAPHIC PROFILE OF THE SAMPLE

The participants were purposely selected to ensure maximum representation of PLWSCI in terms of age, gender, years spent living with SCI, place of residence, level of lesion and completeness of lesion. As this was a qualitative study, interviews were conducted with participants up to a point at which no new information could be obtained (i.e. until data saturation was reached). Data saturation was reached by the twelfth interview. In order to ensure that no more new data was forthcoming, three more participants were interviewed, bringing the total sample to 15. These fifteen participants comprised 11 males and four females, as illustrated in Table 5.1. The male-female ratio of the interviewed participants was 2:1, which is not in keeping with SCI trends, owing to the purposive sampling in this phase of the study.



Table 6.1 Demographic profile of the 15 interviewees

Pseudonym (Interviewee id)	Age	Gender	Race	Cause of SCI	Type of SCI	Complete- ness of SCI	Years living with SCI	Residential area	Employment status	Marital status
George (1)	50	Male	Black	RTA-dr	Paraplegia	Complete	9	Suburb	Unemployed	Married
Thabo(137)	52	Male	Coloured	RTA-dr	Tetraplegia	Incomplete	21	Township	Unemployed	Married
Sipho (136)	25	Male	Black	RTA-pas	Tetraplegia	Incomplete	5	Suburb	Employed	Single
Tumelo (4)	28	Male	Black	Gunshot	Paraplegia	Incomplete	8	Other	Unemployed	Single
Frans (43)	29	Male	White	RTA-pas	Paraplegia	Complete	7	Township	Unemployed	Married
Sifiso (66)	29	Male	Black	RTA-ped	Tetraplegia	Complete	7	Township	Unemployed	Single
Selina (142)	27	Female	Black	RTA-pas	Paraplegia	Complete	5	Township	Unemployed	Single
Thabang (2)	30	Male	Black	RTA-pas	Paraplegia	Complete	7	Suburb	Unemployed	Single
Christina (10)	44	Female	White	TB spine (HIV)	Paraplegia	Complete	3	Suburb	Unemployed	Single
Sarah (3)	34	Female	Black	TB spine	Tetraplegia	Incomplete	2	Suburb	Unemployed	Single
Pauline (115)	43	Female	White	RTA-dr	Paraplegia	Complete	13	Suburb	Employed	Single
Nthabiseng (24)	45	Female	Black	RTA-pas	Tetraplegia	Incomplete	4	Township	Employed	Married
Ruan (26)	33	Male	White	RTA-dr	Paraplegia	Complete	4	Suburb	Employed	Single
Peter (23)	33	Male	White	Gunshot	Paraplegia	Complete	10	Suburb	Unemployed	Single
Samuel (56)	49	Male	White	RTA-dr	Tetraplegia	Complete	25	Suburb	Unemployed	Single
Summary	Range 27 – 52 yrs <i>mean</i> = 36.7	10 male 5 female	9 Blacks 5 Whites 1 Coloured	5 RTA- pas 5 RTA-dr 1 RTA- ped 2 TB spine 2 Gunshot	6 tetraplegia 9 paraplegia	10 complete 5 incomplete	Range 2 – 25 yrs <i>mean</i> = 8.6	5 Township 9 Suburb 1 Other	4 Employed 11 Unemployed	3 Married 12 Single

*RTA-pas = Road traffic accident – passenger; RTA-ped = Road traffic accident – pedestrian; RTA-dr = Road traffic accident - driver

6.3 DATA ANALYSIS

Interviews were used to collect data. The researcher read through the transcribed interview transcripts to form an understanding of the general themes and then proceeded to code the transcribed interviews independently. The codes were then clustered into categories, labelled and listed. From the categories, two main themes were identified, namely personal and environmental influences on community participation. These themes encompassed a number of sub-themes (illustrated in Table 6.2) that are discussed in the following sections in relation to participants' responses to interview questions.

Table 6.1: Themes and sub-themes

THEME	SUB-THEME	Sub-theme aspects
PERSONAL FACTORS	Coping strategies	Acceptance
		Attitude towards own condition
		Social comparison
	Rehabilitation experience	Negative experiences
		Positive experiences
Aspirations	Future hopes	
ENVIRONMENTAL FACTORS	Attitudes of others	Able-bodied people
		Other PLWSCI
	Social support	Emotional support
		Instrumental support
		Appraisal support
Accessibility issues	Social companionship	
	Home accessibility	
	Community accessibility	
	Transportation	

6.3.1 Personal factors

The theme of personal factors encompasses participants' perceptions of personal aspects that influence their community participation, but which are not part of their health condition (Bornman, 2004). These aspects include age, motivation, educational level, employment and experience of living with the health condition, including their personal struggle with adjustment to a "new identity" after the injury. The personal factors which were identified in this phase of the study and are discussed in this section include coping strategies, rehabilitation experience, aspirations (future hopes and personal needs) and the use of time.

6.3.1.1 Coping strategies

This sub-theme describes the various strategies employed by the participants to re-integrate into and participate in community roles. A number of cognitive and behavioural strategies used as coping strategies by the participants emerged from the data. These included accepting their condition, having a positive outlook on life and social comparison.

a) Acceptance of the condition

When participants were asked to describe what it was like to live with a spinal cord injury, all the interviewees, regardless of their age, circumstances of the injury or resulting disability, reported that it was a challenge, but they added that they had accepted their condition. For instance, Thabo stated that:

Eish (heavens) my sister – it is life. What can I say? It is not okay but it is okay you know – thank God I am alive. One day things will get better. But I have accepted my disability.

Some interviewees had drawn on their spirituality to come to terms with their situation. They expressed a belief in a God who knew why they were experiencing the disability and who had saved them for a reason, as reflected in the following quotations:

I mean I am glad I am alive. Since I became paralysed, there are many things that I have noticed and I am grateful for in my life, because, eh, God saved my life for a reason, you know. (Tumelo)

Sometimes I ask why God did not take my life during the accident; I would not be facing [silence]. But you know, God knows everything, and I must not give up, yeah, but it is hard. (Sipho)

The acceptance of their disability by a PLWSCSI is desirable, as it facilitates adjustment to living with this disability and eventual community participation. Acceptance is one of the coping skills that a patient needs to develop in order to cope with the injury (Elfstrom et al., 2002). PLWSCSI who positively accept their situation generally lead healthy, active and happy lives after injury while those who do not accept it have difficulty coping with life in the community, leading to poor integration, low satisfaction with participation and, possibly, depression.

b) Attitude towards own condition

The majority of the participants had a positive outlook on life, evident in their determination to “get on with life”, as reflected in the following quotations:

There is a life to live even when you are in a wheelchair. I always say to myself, when I can do something, I better do it myself, when I know I need help, I better get help from anybody who is offering, I don't mind. (Thabang)

Who knows, a miracle might happen and I walk one day – ha-ha (laughs). (Tumelo)

Now I am ready to face life with a future job. A partner is not one of my immediate plans right now. I want to work for people with disabilities and make sure things happen like jobs, transport etc. (Selina)

c) Social comparison

Social comparison is a strategy used by people when facing challenging contexts. It involves relating one's own particular situation to that of other individuals (Taylor & Lobel, 1989). Some authors have suggested that social comparison is a coping strategy for people facing challenging contexts such as living with a disability (Taylor & Lobel, 1989; Tennen, McKee, & Affleck, 2000). There are two main types of social comparison: downward comparison and upward comparison (Taylor & Lobel, 1989; Wills, 1997). Downward comparison involves comparing oneself to someone regarded as less fortunate. This comparison results in a positive response relative to one's own situation, when one realises that others are worse off (op. cit.). The opposite of downward comparison is upward comparison, which means feeling unhappy in response to others' better fortune (Buunk et al., 2006).

The use of downward comparison by participants in this study is reflected in the following quotation from George's interview:

I think you people must keep on checking people like us, especially poor people in shacks and rural areas – those people struggle. You know when you meet them at “check up” you can tell by the smell that someone has not had a bath in a long time – they are really suffering. It is hard to be disabled and poor – I am lucky, I have my sick pension, my wife is working – we are doing fine. But some people are struggling out there – they need your help...

While George suggests that some PLWSCI are struggling, upward comparison was not used by any of the participants in this phase of the study. This is possibly a result of participants' generally positive outlook on life, and the fact that some of them felt they were “lucky to be alive” and thus not “worse off”.

Buunk, Zurriaga, and González (2006) also found that downward comparison was a common social coping strategy used by PLWSCI in Spain. However, the relationship between downward comparison and coping has been questioned. According to Tennen and Affleck (1997), downward comparison only constitutes coping when it represents an active, effortful process. These authors argue that

downward comparison simply means that “one feels better-off than others”, and is not necessarily a coping strategy.

6.3.1.2 Experiences during rehabilitation

This sub-theme describes the participants’ views on their rehabilitation experience with specific reference to whether rehabilitation prepared them adequately for community participation. Participants were generally satisfied with their rehabilitation, as can be seen in the following quotations:

I would not have survived without rehab. I was so up and down - I don't know how they put up with me - but then I was a child – the youngest person in the unit. I guess they felt sorry for me. They must keep up the good work. Thanks to the rehab, I got placed in a special school for my entire high school. (Selina)

Rehabilitation helped me a lot – I am thankful. Even though I am like this, at least I can do things for myself . (George)

I think the training was good and must stay like that. It helped me get strong and I can use the wheelchair now. Physio helped me a lot - I will always be grateful to them. They must keep on helping the paralysed people – what they do is great. (Tumelo)

I am very happy with the training of the physio and occupational therapy. It helped me a bit, now I can do something like walk a bit. Maybe they must check on people in the home after discharge - some people they just sit and don't train and they get sick. The physio - they must come and check. (Sipho)

This overwhelming appreciation of rehabilitation must, however, be interpreted with caution. Previously, Mothabeng et al. (2007) indicated that patients are usually grateful for the help they receive, regardless of the quality thereof and will therefore report satisfaction with their rehabilitation. Patient satisfaction is an important outcome measure of rehabilitation (Kramer, 1997). Although satisfaction was not objectively measured with a validated tool in this study, it is interesting to

note that the majority of the participants in this study reported satisfaction with their rehabilitation experience. It would be interesting to determine the satisfaction rating should an objective, validated measure be used.

Although all participants expressed satisfaction with their rehabilitation experience, a number of participants expressed dissatisfaction with the way some rehabilitation professionals treated them. For example, Thabang, who came to South Africa as a refugee with a SCI 10 years ago, not speaking any of the local languages, described his rehabilitation as a “tough experience”. He said:

.... I did not speak any English so I did not understand a lot of things. They tell me things, they write me things on paper but I did not experience a great deal of what's going on. It was very hard and painful. I just focussed myself on getting better and do what I can do and what I can't (do), I can't (do). That was my experience but in the long run I think they (therapists) do quite well. With the pain I was in I just wanted to get out of the hospital and – oh well, yeah – to adapt to my condition and all that. At that time I was also very angry.

Most of the expressions of dissatisfaction were directed at the nursing staff, as reflected in the following responses from participants:

I would like to ask the nurses to treat us (PLWSCI) well, please. You know, when a patient calls a nurse and says, “Nurse, I am not okay (like soiled himself) and the nurse replies, “You are not my husband”, that is not nice. I am not saying all nurses were like that, most of them are good. I just ask that they should feel for us – we did not choose to be like this. (George)

The problem was some nurses in the ward – many of them are nice but some really talk bad to us, my sister. You find a man crying and that is not nice. Some nurses must try and be kind to us – when you are like that, you need people to treat you nice. (Tumelo)

One of the participants complained about the physiotherapists, saying:

The physios - they push us very hard. We know that they are help us but they must not be so pushy. Especially early in rehab, when one is still trying to understand what is happening with his body... .(George)

These findings support what was reported by previous authors, who suggest that the experience of PLWSCI during institutionalised rehabilitation has a bearing on their outcome following discharge (Cott, 2004; Cott et al., 2007; Hammell, 2007). The rehabilitation experience is said to be shaped to a large extent by the attitude of rehabilitation staff (Cott et al., 2007; Mothabeng et al., 2007; Nolan, 2008), who “hold the power to facilitate or to thwart the process of reconstructing the meaning of life” through their intimate involvement in the early stages when a PLWSCI forms a new identity as a PWD (Hammell, 2007). Rehabilitation professionals should thus take great care in their interactions with PLWSCI during rehabilitation.

6.3.1.3 Aspirations

a) Future hopes

This sub-theme encompasses the important role played by hope in helping participants to cope with living with a disability, even though some of them expressed dissatisfaction with their participation in community roles and activities. Some of the participants expressed the hope to walk again, while others hoped for a future with a life partner.

Even those respondents who had complete injuries and who were aware that there was really no hope of recovery expressed hope of improvement. For example,

Sifiso, who was living with a complete SCI, said:

I hope to walk but they say I am complete - so they did their best.

When asked about a life partner, Thabang said he did not have a girlfriend at the moment, but added:

No, but I am planning to (marry). That subject needs somebody who will understand who I am... I used to have a girlfriend but not at the moment.

Thabo also expressed the hope to “*maybe get married one day...*”

b) Personal needs

This sub-theme includes participants’ statements about the things they need in order to participate more ably in their communities. These included the need to acquire further education, the need to exercise, the need to be independent and the need for employment.

(i) Education

The desire to study was expressed by Thabang, who was a medical student before sustaining the SCI. He said:

Yes, every day I think about studying. Now becomes the problem of funds and things like that. I lack that and I really want to study.... I'd really love to study again.... But now I have decided at least if I can do pharmacy. It is something close to medicine that I will really enjoy much. I'd really love to study again.

Although the educational background of people who sustain SCI has received little attention in the literature, education is considered a predictor of re-employment status following severe injury such as a spinal cord injury (Krause & Anson, 1996b; Murphy et al., 1997). It is generally understood that when people do not have adequate education, their chances of obtaining employment may be limited, ultimately affecting their ability to ensure an income. Addressing the need Thabang expresses above is therefore important as this would enhance his community participation.

(ii) Sports participation

Only one participant indicated the desire to participate in exercise or sporting activities.

I'd really like to be part of sport, I did play basketball at the time of my rehabilitation and even now, I still want to hold the ball. I try to join the sports team in Pretoria academic (hospital) but due to lack of transport I can't go so I am not part of any sport now. (Thabang)

The literature suggests that PLWSCI do not participate in enough physical activity to promote health (Buchholz, McGillivray & Bencharz, 2003). A number of factors, including the transport problems mentioned by Thabang, limit their participation in physical activities like sports (Cox, Amsters & Pershouse, 2001; Johnson, Gerhart, McCray, Menconi & Whiteneck 1998; Kennedy & Rogers 2000; Whiteneck et al., 2004). A recent study by Mothabeng (2009) identified personal factors (e.g. knowledge and motivation) and environmental factors (e.g. social support and environmental barriers) as important in limiting the participation of PLWSCI in physical activities.

The importance of physical activities for PLWSCI is well documented in the literature and cannot be over-emphasised (Buchholz et al., 2003; Krum et al., 1999; Levins, Redenbach & Dyck, 2004; Washburn et al., 2002). Besides the social companionship and peer support of meeting with other people in similar circumstances, physical activities have numerous health benefits for PLWSCI (Buchholz et al., 2003; Washburn, Weimo, McCauley, Frogley & Figoni, 2002) and should therefore be encouraged. The fact that only one participant expressed the desire to participate in sports as a form of physical activity is a cause for concern, however, and should be investigated further.

(iii) Independence

The desire to be independent and to look after themselves was expressed by most of the participants, as reflected in the following statement:

If you can't do things for yourself it is really tough especially for a man my sister- you understand. I mean, no girl wants a man who can't ... you know... . Well, my girlfriend she likes me but I have no job. If I marry her on the disability grant, what is the life going to be like... . (Sipho)

(iv) Employment

The importance of employment was emphasised by all participants, and is reflected in the following remarks:

I think if I get a job and look better after myself I will be happier. I just wish I can find a job and stop being a burden to my parents. The disability grant helps, but it is not enough! What happens to me when they (his parents) die? (Thabo)

I just need to find something to do and continue living. I wish they (therapists) could help me get some job. Yeah, the job is the big problem my sister. Even before I was paralysed I did not have a real job, just piece jobs (casual labour). We all want the job. It is more difficult for us who are paralysed to get a job. I don't know, maybe if the government can help somehow. The disability grant is too little - very little. Maybe some spare jobs must be reserved for the wheelchair people. (Tumelo)

Job is the big problem, my sister. We all want the job. It is more difficult for us with the spinal cord to get job. Eish (I don't know), maybe if the government can help somehow,. (Sipho)

However, the prospect of employment was bleak for some of these participants, as Sifiso indicates:

Of course, I wish I was working so I can look after myself better. I've never really worked even before... you know. I only have Standard 4 (six years of formal education). Who will give me job? What job can they give me – I don't know any job. Only selling fruits on the street – now I don't have money to buy. (Sifiso)

Other participants had ideas for employment, but lacked financial resources to get started. This is reflected in Tumelo's words:

... so we can start some business like making things (crafts) and sell them to make money. But we need money to start, we need help. Maybe you can talk to somebody to help us, my sister – he-he... your rich friends? (Laughs)
(Tumelo)

The lack of basic education was not found to be a major contributor to unemployment in this sample, as opposed to the general problem of unemployment in South Africa, with employment rates shrinking on an annual basis (Statistics South Africa, 2009). It is well known that PLWSCI (and other PWD) struggle to find employment in South Africa. This may explain the high rate of unemployment (74.4%) among the participants in this phase of the study. The chances of finding employment are even slimmer if PLWSCI are not suitably qualified. Sifiso confirms the importance of education in finding employment:

... I only have standard 4. Who will give me job? What job can they give me – I don't know any job. Only selling fruits on the street – now I don't have money to buy. (Sifiso)

These findings intimate that the majority of the participants will experience poverty as a result of their lack of financial resources. Braithwaite and Mont (2008) have suggested that poverty and disability are closely related, and that disability increases people's vulnerability to greater poverty, creating a vicious cycle. Poverty can contribute to the exacerbation of disabilities among PLWSCI as it affects nutrition, access to medical care and the ability to live in safe environments (Hays et al., 2000).

Chronic poverty is a grave concern, affecting one in four South Africans, with the greatest chronic poverty affecting the African population (Westaway, Olorunju & Rai, 2007). Poverty reduction is the main focus of the eight United Nations' Millennium development goals (UN, 2000). The Millennium development goals (MDGs) are time-bound and quantified targets for addressing extreme poverty in

its many dimensions, including income poverty, hunger, disease, lack of adequate shelter, and exclusion, while promoting gender equality, education, and environmental sustainability. The eight MDGs that respond to the world's main development challenges and which the UN hopes to achieve by 2015 are to:

- eradicate extreme poverty and hunger
- achieve universal primary education
- promote gender equality and empower women
- reduce child mortality
- improve maternal health
- combat HIV/AIDS, malaria, and other diseases
- ensure environmental sustainability
- create a global partnership for development.

The first two MDGs, namely (1) to *eradicate extreme poverty and hunger* and (2) *to achieve universal primary education* are related to the findings of this study. People require employment to obtain the financial resources needed to eradicate poverty and hunger. The reviewed literature in Chapter 5 (e.g., Jang et al., 2005; Krause, 2010; Krause et al., 1998; Noreau et al., 1999; Tomassen et al., 2000) and the results of this study confirm that education places people at an advantage where employment is concerned. Employment in turn will improve their socio-economic circumstances and thus reduce poverty. It is thus imperative that mechanisms are put in place to ensure the education and employment of PLWSCI.

(v) Follow up after rehabilitation

The majority of the participants (8/15) appreciated being visited by the researcher, and viewed the visit as a form of follow up by the rehabilitation professional. The following remarks reflect this:

Thanks for checking on people like us – it is nice to see that people care, you know. God bless you sister. (Thabo)

When you check us, you can see for yourself our circumstances and how some of us are doing... some (are) abused by their own people. The government must send more people to check on us. (Tumelo)

George stated previously:

... I think you people must keep on checking people like us, especially poor people in shacks and rural areas – those people struggle ... (George)

Since there is a variety of short- and long-term complications that may develop in PLWSCI after discharge from rehabilitation, it is vital that follow-up care be conducted (Bloemen-Vrencken, de Witte & Post, 2005). The medical complications and readmissions to hospital remarked on in phase 1 of the study, together with the pleas of participants in this study to be “checked up on”, stress this need for focussed attention on the follow-up of PLWSCI post-discharge from inpatient rehabilitation. Follow-up care is a multidisciplinary approach and should involve all team members to ensure that individuals do not develop secondary complications (Bloemen-Vrencken et al., 2005). Follow-up programmes implemented through structured and systematically planned measures to promote community reintegration and ensure maximal participation are required. Details of various follow-up strategies are discussed under policy implications in Chapter 7.

6.3.1.4 Use of free time

This sub-theme refers to the activities that participants engaged in “to keep busy” and make use of their free time through the day. Some participants had positive ways of using their free time, while others engaged in activities which were less constructive.

a) Positive use of free time

Positive uses of time included being employed, attending school or engaging in constructive activities even when unemployed. For instance, George, an unemployed family man supported by a disability pension and living in the suburbs, remarked:

I read books and newspapers, I watch TV when I am tired of reading. I chat with my visitors – I have many friends – you can see this one here (he points at a visitor waiting outside).

Tumelo, who is unemployed and living with paraplegia in the township, said:

*... I always go to the shops and hang out with the other guys – there are so many guys who are not working here, my sister. We talk, **share some smoke and drink** and just hang out. (Tumelo)*

These two comments are examples of the more positive ways in which PLWSCI make use of their free time, instead of just sitting alone at home, bored and feeling sorry for themselves. Similar results were reported by Lee, Mittelstaedt and Askins (1999) in their study to identify factors explaining free time boredom (FTB) among people with spinal cord injury (SCI). These authors found that PLWSCI who had “nothing to do” but occupied themselves by watching TV or spending time with friends had a better quality of life. Those who had no constructive activities to occupy themselves had negative outcomes such as depression and other medical complications (op. cit.).

b) Negative use of time

Less constructive ways of filling their time included idleness, boredom and loneliness, and emotions such as hopelessness stemming from a lack of productive occupation. For example, Thabo described his time thus:

My friends sometimes visit, but most of the time I am just in the house – it’s easier that way When I am alone at home – I don’t bother anyone you know – asking for help with this or that. (Thabo)

Sifiso said:

... but when everyone is at work or school, it is just me and my wheelchair - I wish I could do something during the day.

Although it was remarked earlier in this section that Tumelo spent his time positively “hanging out” with his friends, a potentially negative aspect of his use of time was what they did when he get together with his friends – (“*sharing a smoke or drink*”). This *could suggest* substance abuse, not simply socially acceptable smoking and drinking.

Substance abuse by PLWSCI as a way of “passing time” was mentioned by Ruan:

I don't remember much about the accident – ek was poep dronk, jy weet (I was very drunk, you know) ... alone in the car, and the last thing I remember was approaching the bend. I don't touch alcohol anymore now. But I know some para people drink to pass the time and drown their problems, some even do drugs. It is hard to be in a wheelchair you know, especially if you have no job. (Ruan)

Researchers have suggested that psychosocial issues such as loneliness, stress and social isolation among PLWSCI are linked to the use of substances such as alcohol, tobacco and drugs (Heinemann, 1991; Hogan et al., 2000). Young et al. (1995) assessed the prevalence of self-reported alcohol and marijuana use, along with alcohol abuse, in a community-based sample of 123 PLWSCI and found that one in five people engaged in alcohol abuse. In South Africa, a study exploring the health promotion needs of youth living with SCI revealed that participants were involved in risky health behaviours including sedentary lifestyles, use of alcohol, tobacco and drugs (Njoki et al., 2007a). These findings mandate that screening and intervention in the potentially destructive use of spare time that may result in alcohol or drug abuse should be part of rehabilitation and follow-up programmes.

It has been found that PLWSCI who abuse alcohol, drugs and tobacco become more susceptible to medical problems such as cardiovascular, respiratory and liver

problems (Radnitz & Tirch, 1995). Substance abuse among individuals with spinal cord injuries has been associated with adverse rehabilitation outcomes in terms of higher rates of depression, higher stress levels and poorer physical health (Heinemann et al., 1990; Tate, 1993). In addition, Tate (1993) notes that people with a spinal cord injury and a drinking problem spend less time in productive behaviour such as physical activities. PLWSCI who abuse alcohol and drug substances may neglect themselves (for example, by sitting in a wheelchair for too long without relieving pressure) and ultimately develop pressure sores.

The extent of substance abuse was not quantitatively investigated in this sample of PLWSCI. Further research in this area is therefore essential, given the serious implications of substance abuse on the psycho-social outcomes of PLWSCI.

6.3.2 Environmental factors

Environmental factors refer to those aspects of the physical environment (including buildings and roads), social environment (including family and friends) and attitudinal environment, including the attitudes of people in the community (Bornman, 2004), that influence community participation by PLWSCI. These environmental factors may act either as barriers to or facilitators of PLWSCI's community participation, depending on how they are perceived and/or experienced. The environmental factors identified in this phase of the study are the attitudes of others, social support and accessibility issues.

6.3.2.1 Attitudes of others

This sub-theme refers to negative experiences participants may have had regarding the attitudes of community members and others to PLWSCI. Societal attitudes are a significant factor in defining the life experiences, opportunities and help-seeking behaviours of people with disabilities. Attitudes are "a combination of beliefs and feelings that predispose a person to behave a certain way" (Noe, 2002, 108).

According to Kilbury (1996), negative attitudes and perceptions about people with disabilities (like PLWSCI) are tenaciously held, and manifest in behaviours such as avoidance or extreme forms of pity, as mentioned in the following two quotations:

I don't like it when people go "ag (oh) shame". It irritates me that kind of attitude, but I understand I would probably do the same if I was able-bodied too - I don't know, maybe. It is okay at school and around home – everyone knows me and they are fine. I guess when you meet new people, they react differently, and you can feel that – I suppose it is human but... I don't know. (Selina)

I try to live normal, but people they see you as abnormal and it's not nice. Some look at you and say shame and you feel sad sometimes you ignore them. (Thabo)

It is human nature to feel sorry for someone who is in a disadvantaged position, therefore saying "oh shame" may be acceptable. However, it has been established that such remarks represent attitudes that originate from ignorance, misunderstanding, stereotyping, backlash and fear (Peck & Kirkbride, 2001; Smart, 2001), and can lead to isolation and discrimination (Scope, 2003). Negative societal attitudes toward people with disabilities are therefore "invisible barriers" to successful rehabilitation outcomes (Chubon, 1992).

An interesting comment regarding attitudes of other PLWSCI was made by Thabang, who remarked angrily:

Most of the time I see the patients they need to be pushed they need to be fed even when their hands are working. They are just lazy (sounds angry) and they just make everybody to feel pity and that makes me angry... that's what makes everybody think that when you are in a wheelchair you can't do anything for yourself. They can't even hire you for job because you will be relying on them for things. (Thabang)

6.3.2.2 Social support

This subtheme refers to the emotional and other tangible forms of support that participants received from family, friends and members of the community. Social support has been defined as “the availability of people whom the individual PLWSCI trusts, on whom he can rely, and who make him feel cared for and valued as a person” (McDowell & Newell 1996, 125). This implies that social support comes from family, friends, peers and healthcare professionals who are people “trusted” by the PLWSCI, and who value him/her as a person.

Social support has two main components, namely structure and function. Structure refers to the available social relationships (e.g. family, friends, marital status and group membership). The functional component is the available support, including emotional, instrumental, appraisal and informational support and social companionship (Cohen & Wills 1985; Weiss 1974).

The participants in this study generally reported positive experiences of social support for themselves, although some indicated that “other PLWSCI” did not enjoy such positive support. These experiences are elaborated upon in the ensuing sections, in which the various types of social support are discussed.

a) Emotional support

This sub-theme describes participants’ remarks on the caring, love and empathy, which they received through encouragement and motivation from family, professionals and peers.

Peer support refers to the support offered by other PLWSCI, who may not necessarily be age and/or life stage peers. According to Hampton (2001) and Pearcey, Yoshida and Renwick (2007), peers can provide emotional support that is more easily received than family members or rehabilitation professionals because they (as fellow PLWSCI) are perceived to “really understand what it is like” to live with SCI. By virtue of “being in the same boat”, peers can challenge or confront fellow PLWSCI in a way that is more readily accepted. Peers can also help to maintain hope, provide information and practical tips about how to achieve certain tasks and/or overcome barriers.

An example of peer support is mentioned in the following quotation:

The guy from the other block, his mother is too old to help him, shame. I visit him sometimes but I cannot help too much as I am also paralysed. (Sipho)

Sipho took it upon himself to visit a peer PLWSCI in his neighbourhood, even though he could not offer any physical support; but he was emotionally present for his peer. Such behaviour is commendable, and should be encouraged from early on in the rehabilitation process and reinforced in the community through peer support groups. Professionals should also pay extra attention to functionally dependent PLWSCI who do not have adequate social support, such as the person referred to in the quotation above. Such people are at risk of developing health complications from a lack of care giving (e.g. assistance with pressure relief). Lehman (1995) suggests that there is a link between health complications and social support. Positive social support is associated with positive health outcomes (Hogan, Linden & Najarian, 2002; House, Landis & Umberson, 1988) because supportive family and friends will encourage the PLWSCI to cooperate with the recommendations and prescriptions of a health professional (DiMatteo, 2004).

Some of the interviewees indicated that their family members were “very supportive” and “always being there for you”, thus helping them cope with the challenges of community participation. For instance, George said:

Life is okay, auntie Joyce ... My wife... supports me well.

Sifiso mentioned that:

My neighbour comes and then prays for me. My family is very much helping.

b) Instrumental support

Instrumental support refers to the availability of practical help or assistance in the form of care giving, financial support and other tangible (material) support (Van Leeuwen et al., 2010). The literature consistently indicates that availability, or lack of, instrumental support has a great influence on the community participation of

PLWSCI (Hampton, 2001; Larson Lund et al., 2005; Post, Ross & Schrijvers, 1999; van Leeuwen et al., 2010).

Positive experiences of instrumental support were echoed by Selina, who was grateful for her parents who were able to afford private rehabilitation for her. She stated:

Having parents who were both working and could afford something (like my computer studies) really helps. I can't imagine being poor and disabled - it must be really tough. I really thank God for my parents. Not everyone is as lucky as me – I have everything I need.

Negative instrumental support through lack of care giving is reflected in the following words of Siphso, (mentioned previously):

The guy from the other block, his mother is too old to help him, shame. I visit him sometimes but I cannot help too much as I am also paralysed.

Negative support may also take the form of abuse. Although none of the participants complained of being personally abused, some reported on other PLWSCIs who were being abused by family members. Tumelo suggests that some family members are abusing PLWSCI:

The problem is that some people in the families they take the money for themselves. They use the money to buy alcohol and stuff, and the paralysed person does not get his money. They 'eat' his money and don't even buy him healthy food (voice loud – looks angry). That is a huge problem.

Situations like this require urgent attention because they could have negative outcomes. In the case of patients with chronic conditions like SCI, inadequate social support has been shown to be related to poorer functioning, poorer general health and well-being, higher hospital re-admission rates, increased complications and increased mortality (Westaway, Seager, Rheeder & van Zyl, 2005)

c) Appraisal support

Appraisal support involves information relevant to self-evaluation. Informational support is related to advice or feedback that can provide a solution to problems. In this study, one participant, a second year medical student in his own country before sustaining the SCI, expressed the need to pursue further education:

Yes, every day I think about studying. Now becomes the problem of funds and things like that. I lack that and I really want to study... . I'd really love to study again. (Thabang)

The main challenge for this participant was financial constraints as he was not a South African citizen and therefore did not qualify for any study funding. A previous study on the perceived information needs of community-dwelling PLWSCI by Gontkovsky, Russum and Stokic (2007) revealed a broad range of needs including information on aging (73%), on research (72%), on financial aid (66%) and on education (63%). These authors found that if the needs of PLWSCI regarding information are not fully met after discharge from acute inpatient rehabilitation, this will impact on their participation in community life.

d) Social companionship

Social companionship involves spending time with others (Cohen & Wills, 1985). Some participants enjoyed social companionship while others experienced difficulties in engaging in social relationships. These differences are revealed in the following two comments:

... I always go to the shops and hang out with the other guys... . (Tumelo)

... but when everyone is at work or school, it is just me and my wheelchair - I wish I could do something during the day. (Sifiso)

However, challenges in the environment made it difficult for some PLWSCI to go out and meet people, as can be seen from the following remark:

Where I live it is difficult for the wheelchair. There are big holes (potholes) on the road, see my wheelchair is broken. So, I don't go out a lot, I live only with my family. (Sifiso)

6.3.2.4 Accessibility issues

A number of accessibility issues were raised by the participants. These included access around the home, access in the community and transport to facilities (e.g. health facilities).

a) Access in the home

Access in the home was mainly a problem in relation to wheelchairs in small houses. In this regard, Tumelo noted:

That is another problem, my sister –the wheelchair cannot get in the house easy because it is big for the door. You see my shack is small. I do not have a good place to live. Some people who are quadras (tetraplegic) never get out because of the steps at the door. (Tumelo)

Selina added:

Well, people need jobs, better houses – you know some people live in zozos (shacks) with wheelchairs and it is difficult to move around. (Selina)

b) Access in the community

Participants who experienced problems with mobility around their communities cited problems arising from the geographic landscape and roads. Thabang had the following to say about the steep inclines he had to negotiate in his suburban environment:

You see the way coming here, the high hill ... it is heavy (steep). You can go down but coming up it is heavy (too steep). You can ask people to push you but as I told you I like doing things for myself but its heavy (steep).

Selina, who lives in the suburbs, remarked:

Hm... and the township – the roads can be bad for wheelchairs – they must all be tarred. (Selina)

Similarly, Tumelo from the township said:

... when it rains the streets are not okay with the mud for the wheelchair (not good for wheelchairs due to the mud).

Community accessibility was made particularly challenging by environmental barriers which limited PLWSCI's social interaction. This is indicated in Sipho's words:

... There are big holes (potholes) on the road... . So, I don't go out a lot, I live only with my family. (Sifiso)

c) Transport

All the participants in this phase of the study highlighted the importance of transport in community participation. Transport plays a vital role in the lives of PLWSCI because of their limited mobility. Transportation barriers present a challenge to PLWSCI in all aspects of community re-integration, including access to employment (Chan & Man, 2005; Kiyono, Hashizume, Matsui, Ohtsuka & Takaoka, 2001; Liesel, MacLeod &, Drews, 2002; Murphy & Young, 2005; Wang, Yang, Yen & Lieu, 2002). Lack of transport posed serious obstacles to respondents' participation in community life, as indicated in the following quotations:

When I want to go somewhere, first you struggle to get to the taxi, then you pay more; or else you must hire a car and it is too much... . The money gets finished on transport if you go to "Academic" (Steve Biko Academic Hospital) for check up. The taxis charge you a special (expensive) rate. (Sifiso)

Transport is also a problem for many people. Someone in the government must do something for those who are suffering. (Selina)

I think that “Maspala” (the municipality) must help us – yes the government must do something... like special transport because it is expensive to hire transport to go to clinic. (Tumelo)

Most of the participants who had difficulty accessing facilities such as gyms or health care institutions mentioned transport as the main cause of the problem. This is illustrated in the following quotation from Thabang’s interview, previously cited:

I have to pay R150 just to go and come back from hospital. That is the most challenging part of my life. The little bit I have is for transport and food. I don’t go to physio because of transport now I am forced to exercise by myself. (Thabang)

Tumelo said:

I need transport to go to check up.

Samuel, who is a 49-year-old unemployed white male living with tetraplegia, made the following remark regarding accessibility:

I am lucky I live close to the hospital, and having an electric wheelchair helps a lot. I don’t have to organise transport to go for check up, I just “drive” around the block. It helps a lot this wheelchair of mine.

According to Kiyono et al. (2001), having one’s own transport, preferably with “driving ability”, is an important factor that allows individuals with SCI to participate in their communities, including by working. Unfortunately, only three participants in this phase of the study had their own transport. The majority of South Africans do not have their own transport (DoT, 2003) and public transportation in South Africa cannot yet fully accommodate the transport needs of people with physical disabilities, especially those using wheelchairs like PLWSCI. The good news is that progress is being made in this regard, as discussed in the following chapter (Chapter 7, section 7.4.2.3)

6.4 SUMMARY

This chapter discussed the findings of Phase 2 of the study, which was qualitative and based on interviews with information-rich participants. Two main themes emerged from these interviews, namely personal factors and environmental factors. Participants' views were presented through the use of thick descriptive statements illustrated by selected verbatim quotations from the transcripts from the interviews. It transpired from these two themes that accessibility (especially transportation) and employment are the two main barriers to community participation by PLWSCI. Other issues such as access to facilities and financial needs are directly linked to these two themes.

Living with SCI in the community poses many challenges to PLWSCI, especially those from disadvantaged environments. However, the participants in this study displayed amazing resilience and optimism in the face of many hardships. This resilience appears to be strengthened by practical and emotional support from family members and friends, as well as by the participants' own coping strategies which are embedded in their spirituality. The majority of the participants were very positive about their experience of rehabilitation therapy and valued rehabilitation professionals' caring attitudes.

Information gathered in this phase of the study complements the data obtained during Phase 1 and sheds light on the participants' views on and experiences of community participation. This information will be helpful in understanding the needs, perceptions and experiences of PLWSCI. The findings from both the quantitative and qualitative phases of the study are integrated in the next chapter (Chapter 7) in developing a final framework for community participation, and in highlighting the implications of this study for various stakeholders.

CHAPTER 7

DISCUSSION OF THE INTEGRATED STUDY FINDINGS, CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

7.1 INTRODUCTION

This study arose out of concerns regarding the challenges facing PLWSCI in terms of community participation. The main aim of this study was therefore to explore the factors influencing the community participation by PLWSCI living in the Tshwane (Greater Pretoria) metropolitan area. The study was divided into two phases, namely a quantitative and a qualitative research phase, in order to address the distinct objectives underlying the main research aim. Firstly, the participants' level of satisfaction with their own participation in their own communities and the variables influencing this participation were quantified by implementing validated instruments. Secondly, the perceptions of the participants regarding their community participation were explored through individual interviews. The reason for using a mixed research methodology was that traditional quantitative research methods using measuring instruments such as questionnaires only are not suitable in an exploration of the complex nature of PLWSCI's perceptions and experiences of their community participation (Henderson & Ainsworth, 2003; Thomas & Nelson, 1996). In this chapter, the findings from the two phases of the study are discussed to provide a holistic view of the results and to draw conclusions regarding the factors influencing the community participation of PLWSCI in the Tshwane (Greater Pretoria) metropolitan area. These conclusions are discussed in the context of the limitations of the study, and recommendations for future studies are made.

In Chapter 1 of this thesis, Figure 1.3 was used as an initial point of departure framework in illustrating the factors influencing community participation. In this chapter, the conceptual framework, revised according to the results of phases 1 and 2, is presented and discussed in relation to the findings. This framework is used to discuss the implications of the study and to make recommendations to

relevant stakeholders regarding the optimisation of community participation by PLWSCI.

7.2 SUMMARY OF THE RESULTS OF PHASE 1 OF THE STUDY

The first phase of the study was a quantitative survey conducted on a sample of convenience comprising 160 PLWSCI. The sample size was determined using the principles of factor analysis.

7.2.1 Objectives of Phase 1 of the study

The objectives of the quantitative phase of the study were: (1) to determine the demographic and SCI profile of the participants; (2) to measure selected variables associated with community participation amongst the participants by using validated measurement instruments; (3) to statistically determine factors associated with community participation by PLWSCI; (4) to validate the measuring instruments psychometrically in order to ensure that the results obtained were reliable and valid.

7.2.2 Results of the quantitative phase of the study

The demographic profile indicated that the participants were predominantly young (58% had sustained SCI under 30 years of age), male (90%) and single (64%). Forty percent (40%) of the participants were dependent on a government disability grant for income support, and 60% lived townships. Regarding the SCI profile, 63% of the participants had sustained thoracic and lumbar level injuries (paraplegia), while 37% had sustained cervical level injuries (tetraplegia). Motor vehicle accidents were the major cause of injury, accounting for 71% of the injuries sustained by the participants, followed by violence as causes of SCI.

The instruments used in this study were the RNLI, SCIM II and the CHIEF-S. The psychometric properties of these instruments were investigated. The RNLI and the SCIM II were found to be reliable and valid with Cronbach's alpha values of 0.97 and 0.93 respectively. The validity of both instruments was also established, using

item convergent and discriminant techniques and factor analysis. The CHIEF-S, however, was not found to be valid or reliable for this study population of PLWSCI.

The participants' satisfaction with their community participation was generally low, with only 20% of them expressing satisfaction. Satisfaction with community participation was found to be significantly associated with the participants' race, level of education, whether they were employed or not, educational qualifications, years of living with SCI, level of SCI, health complications, perceived health status, functional ability and perceived environmental factors such as physical (structural and geographic) barriers and lack of transport. Further analyses using multiple regression revealed that employment and environmental barriers were significant predictors of participants' satisfaction with community participation, together accounting for 50% of the variance.

7.3 SUMMARY OF THE RESULTS OF PHASE 2 OF THE STUDY

The second phase of the study used a qualitative research technique, during which an interview was conducted with a purposive sample of PLWSCI, comprising 15 participants (purposively selected from the participants in phase 1 of the study) who could add rich information on the factors that influenced their community participation. T-tests indicated that there was no significant difference between the sample groups in Phase 1 and Phase 2 of the study, suggesting that the participants in Phase 2 were a truly representative sample of the group in Phase 1.

7.3.1 Objectives of Phase 2

The main objective of the qualitative phase of the study was to explore participants' perceptions and experiences of community participation.

7.3.2 Results of the qualitative phase of the study

The results of this phase of the study revealed that all the participants felt that the rehabilitation they had undergone had prepared them "somewhat" for community

participation. It appeared that those participants who had social support, both emotionally and financially, and those who were employed had a satisfactory experience of participation. The need for follow-up care from rehabilitation professionals was expressed, especially by those participants who lived in townships and those who did not have access to their own transport or to health care.

From the analysis of interview transcripts, two main themes emerged regarding factors influencing participation, that is, personal and environmental factors. Personal factors include features of an individual that are not part of his/her health condition. The categories of personal factors identified as influencing participation included participants' coping strategies, their rehabilitation experience, future aspirations, personal needs and their use of free time (leisure). Environmental factors are external to the person and include physical surroundings, social aspects and attitudes of others. The environmental factors identified as influencing participants' community participation in this study included attitudes of others, social support, and accessibility problems, mainly transport.

7.4 HOLISTIC DISCUSSION OF THE STUDY FINDINGS

The two phases of the study revealed that similar categories of factors influenced the participants' community participation. In Phase 1 of the study, three categories of factors namely, "personal factors", "disability factors" and "environmental factors" were identified as influencing participants' community participation. Similarly, in the second phase of the study "personal" and "environmental" factors were identified by PLWSCI as influential in their community participation. Collating the results of the two phases, it became clear that that the community participation of these PLWSCI was chiefly related to three major categories of factors, namely personal factors, disability-related factors and environmental factors.

With reference to "personal factors", the study revealed that satisfaction with community participation was greater in participants who had been living with SCI for longer periods, who had more years of basic education, who were employed, who were not black Africans, who lived in suburbs, and who had their own source

of income. The results of the interviews indicated that community participation was enhanced if participants had a positive outlook on life and engaged in creative activities during their free time.

Under the theme “disability-related factors”, satisfaction with community participation was associated with the level of spinal cord injury, functional ability (SCIM) and perceived general health .

In the case of “environmental factors”, satisfaction with their community participation was greater in those participants who experienced fewer environmental barriers on the CHIEF-SF. The results of the interviews indicated that the “attitudes of members of society”, “accessibility of the environment” and “social support” were factors that influenced the participants’ satisfaction with community participation.

The factors that influence the community participation of PLWSCI are summarised in Table 7.1. This table makes it clear that employment (personal factor) and accessibility (environmental factor) were factors common to both phases of the study. This finding highlights the importance of these two issues in participation, and further confirms the results of the regression analysis in Phase 1, which identified both employment and accessibility as significant predictors of participation.

Table 7.1: Factors influencing community participation

THEME	SUB-THEME	SUB-THEME ASPECTS
PERSONAL FACTORS	Coping skills (Phase 2)	Acceptance Attitude to own condition Social comparison
	Rehabilitation experience (Phase 2)	Negative experiences Positive experiences
	Employment (Phase 1 and 2)	Employed vs. unemployed
	Residential area (Phase 1)	Township, suburb or other
	Race (Phase 1)	African vs. non African
	Aspirations (Phase 2)	Future hopes Personal needs
	Use of time (Phase 2)	Negative use of time Positive use of time
DISABILITY RELATED FACTORS	Years living with SCI (Phase 1)	Number of years
	Perceived health (Phase 1)	Fair, good or very good
	Functional ability (Phase 1)	Mobility and ADL
ENVIRONMENTAL FACTORS	Attitudes of others (Phase 2)	Able bodied people Other PLWSCI
	Social support (Phase 2)	Emotional support Instrumental support Appraisal support Social companionship
	Accessibility issues (Phase 1 and 2)	Home accessibility Community accessibility Transportation

7.5 A CONCEPTUAL FRAMEWORK FOR ENHANCING THE COMMUNITY PARTICIPATION OF PEOPLE LIVING WITH SPINAL CORD INJURY

When individuals sustain a spinal cord injury, their life sphere balance becomes disrupted. The SCI affects not only the physical body, but every aspect of an individual's life, resulting in loss of physical function, disruption of social and family roles, and financial hardship. Following rehabilitation, PLWSCI are discharged into the community with the hope that they will adapt to their new identity (as a person with a disability), reintegrate into society and participate as near normally in

various social roles. The ultimate goal of rehabilitation for PLWSCI is to prepare them for community participation, which is the focus of this thesis.

In Chapter 1 (paragraph 1.10.4), community participation was defined as “being part of the mainstream of family and community life and being involved in everyday life situations”. This definition makes it clear that the community participation of PLWSCI is influenced by characteristics of the person living with the spinal cord injury, and of those of the societal environment. Participation therefore represents a balance or “fit” of the individual within the environment.

In order to form a holistic picture of this person-environment “fit”, which is at the core of participation, a comprehensive conceptual framework of the factors that influence community participation was developed, based on the results of Phase 1 and 2 of this study. This comprehensive conceptual framework was developed by revising the initial community participation framework that was presented in Chapter 1 (Figure 1.4). A number of variables identified in both the quantitative and qualitative data analysis as being influential on community participation contributed to the revised framework illustrated in Figure 7.1. According to this framework, community participation of PLWSCI is influenced by factors related to the person with SCI, the resultant disability and the environment in which the person finds him/herself. The framework illustrates the complex and multidimensional nature of community participation. The complexity of the relationship between the various factors that influence community participation of PLWSCI is illustrated with single and bi-directional arrows.

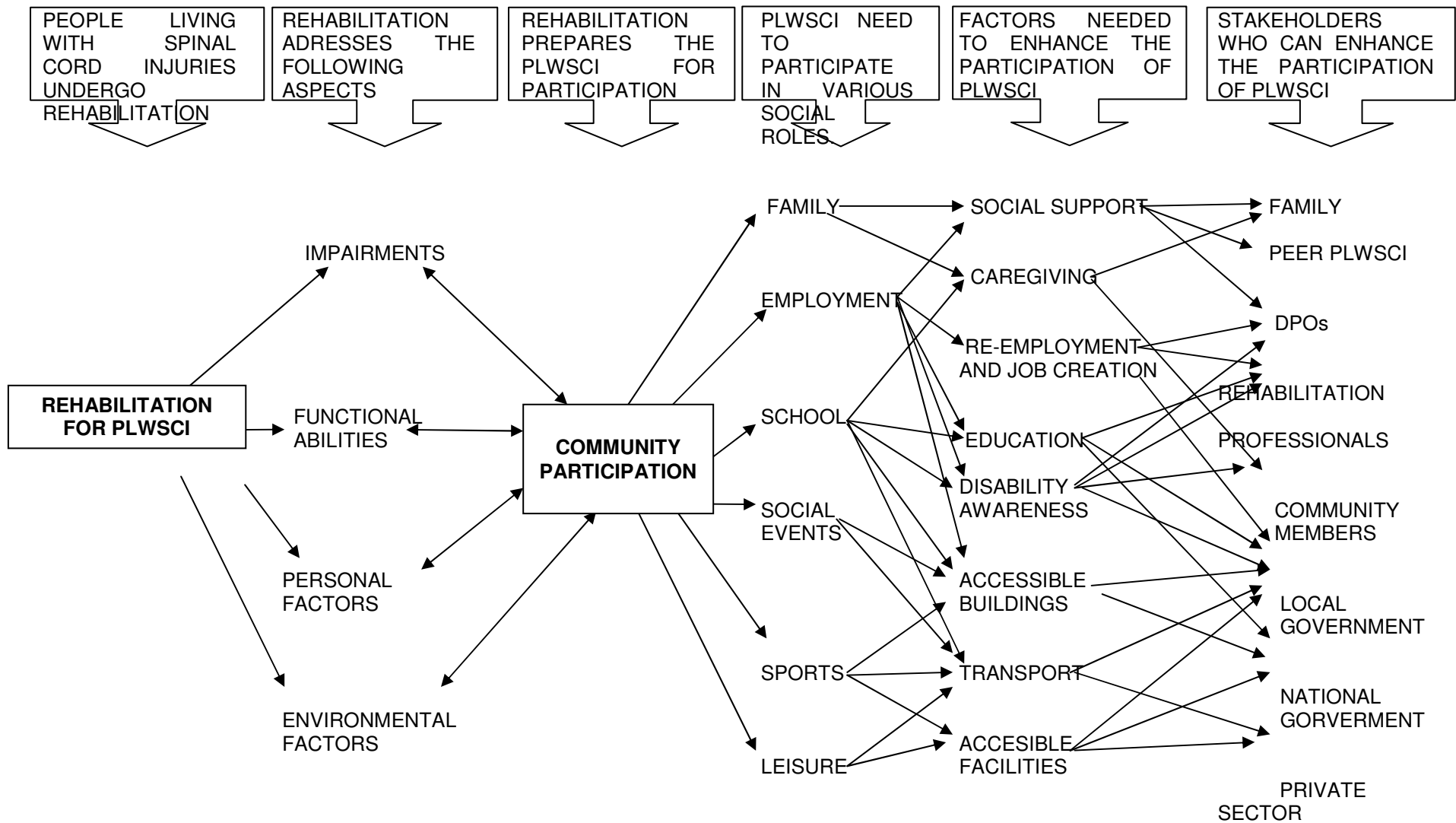


Figure 7.1: A framework of community participation for PLWSCI

7.6 RECOMMENDED STRATEGIES FOR FACILITATING THE COMMUNITY PARTICIPATION OF PLWSCI

In this section, strategies for facilitating the community participation of PLWSCI are presented, based on the framework in Figure 7.1. In drafting the strategies, Kipling's 5WH (**what, why, where, when, who and how**) approach was utilised (Kipling, 1987). The 5WH is a useful technique for addressing complex issues that require all the information to be identified before a way forward can be formulated (<http://www.improvementnetwork.gov.uk>): in this case, the development of a strategy/strategies or action plans to enhance the community participation of PLWSCI. The 5WH was used to describe:

- **What** are the key issues influencing the community participation of PLWSCI and **Why** are these issues a problem?
- **Where and when:** under what conditions do the issues pose problems?
- **Who** needs to be consulted to address which issues and **how** can these issues be addressed by the relevant stakeholders?

The identification (questions **what** and **why**) and exploration (questions **where** and **when**) of the factors influencing participation were discussed at length in Chapters 5 and 6. The recommended strategies presented in this section are derived from the framework presented in Figure 7.1, and are focussed on the question **how** to address the factors, by identifying “**what needs to be done by whom**”. The suggested strategies are directed at specific stakeholders, but require a multi-sector approach through which PLWSCI, family members, community members, rehabilitation professionals and policy makers at different levels of government can all be involved. Table 7.2 illustrates strategies proposed to facilitate the community participation of PLWSCI.

Table 7.2: Strategies for facilitating the community participation of PLWSCI.

THEME	SUB-THEME	PROPOSED STRATEGY (<u>WHO SHOULD DO</u> <u>WHAT</u>)
PERSONAL FACTORS	Coping skills	<u>WHO:</u> Rehabilitation professional and fellow PLWSCI <u>WHAT:</u> <ul style="list-style-type: none"> • PLWSCI should be educated about the various coping strategies that will enhance their community participation. • Fellow PLWSCI with experience living with SCI can be a useful resource in this regard (organized through support groups).
	Rehabilitation experience	<u>WHO:</u> Rehabilitation professionals <u>WHAT:</u> <ul style="list-style-type: none"> • More positive rehabilitation experiences in terms of what activities/ strategies? to be created for PLWSCI. • Rehabilitation professionals need to be educated on the importance of the professional-patient relationship for the rehabilitation outcomes of PLWSCI.
	Employment	<u>WHO:</u> National Department of Labour and the private sector <u>WHAT:</u> <ul style="list-style-type: none"> • Existing laws regarding the employment of PWD should be enforced, and maybe more incentives given to companies and/or organisations employing PLWSCI where relevant. • Opportunities for employment need to be created PLWSCI need to be empowered for employability or self employment
	Aspirations and Use of free time	<u>WHO:</u> Rehabilitation professionals, Disabled People's Organisations (DPOs) and PLWSCI <u>WHAT:</u> <ul style="list-style-type: none"> • Aspirations like participation in sport/ leisure activities as part of maintaining a healthy lifestyle (prevention of lifestyle diseases) should be encouraged from early on in rehabilitation. • Rehabilitation professionals should refer interested PLWSCI to sporting clubs of their interest via the relevant DPO (in this case QASA), to make sure that PLWSCI make constructive use of their free time through health beneficial activities.

Table 7.2 (cont): Strategies for facilitating the community participation of PLWSCI

THEME	SUB-THEME	PROPOSED STRATEGY (<u>WHO SHOULD DO WHAT</u>)
	Health problems	<p><u>WHO</u>: Rehabilitation professionals</p> <p><u>WHAT</u>:</p> <ul style="list-style-type: none"> • Intensified education regarding self management during rehabilitation • Monitoring of the PLWSCI's health and assistance by family and/or community members • Follow up visits by rehabilitation professionals to check up on the health and wellbeing of the PLWSCI and to determine whether the rehabilitation goals have been achieved. • Ensure that PLWSCI are engaged in health promoting activities by continuously emphasising the importance of diet, physical activity and pressure relief. The activities can take the form of individual follow up, or public health campaigns.
	Functional ability	<p><u>WHO</u>: Rehabilitation professionals</p> <p><u>WHAT</u>:</p> <ul style="list-style-type: none"> • Ensure that PLWSCI have reached their expected maximum level of functional ability before discharge from rehabilitation' • Follow up visits to make sure the PLWSCI progress towards the expected level of functioning.
ENVIRONMENTAL FACTORS	Attitudes of others	<p><u>WHO</u>: Rehabilitation professionals and PLWSCI</p> <p><u>WHAT</u>:</p> <ul style="list-style-type: none"> • Disability awareness programmes for the general public to be organised in the relevant local communities where PLWSCI live
	Social support	<p>Support from Family</p> <p><u>WHO</u>: family and caregivers</p> <p><u>WHAT</u>:</p> <ul style="list-style-type: none"> • Emotional and physical support with some ADL's <p>Support from Peers</p> <p><u>WHO</u>: Peer PLWSCI</p> <p><u>WHAT</u>:</p> <ul style="list-style-type: none"> • Participation in local peer support groups

Table 7.2 (cont): Strategies for facilitating the community participation of PLWSCI

THEME	SUB-THEME	PROPOSED STRATEGY (<u>WHO SHOULD DO</u> <u>WHAT</u>)
ENVIRONMENTAL FACTORS	Accessibility issues	Home accessibility WHO: Rehabilitation professionals and peer PLWSCI WHAT: <ul style="list-style-type: none"> • Advice regarding adaptation of the home environment • Advice regarding coping with different challenging home accessibility issues
		Community accessibility WHO: Local government WHAT: <ul style="list-style-type: none"> • Enforce accessibility rules for buildings
		Transportation WHO: National Department of Transport WHAT: <ul style="list-style-type: none"> • Make public transport accessible (fast track the DoT strategy)

7.7 ROLES OF VARIOUS STAKEHOLDERS IN FACILITATING COMMUNITY PARTICIPATION OF PLWSCI

This study identified a number of factors that influence community participation of PLWSCI. However, not all the factors identified can be directly addressed by rehabilitation professionals. Personal factors such as gender, race or age related factors (years of basic education and years living with SCI) are not amenable to change through any rehabilitation intervention. Disability related factors like ‘functional ability’ can be directly influenced by rehabilitation. On the other hand, environmental factors like accessible buildings and road conditions need to be addressed by other stakeholders in collaboration with rehabilitation professionals.

Table 7.1 identifies numerous stakeholders who have a role to play in the community participation of PLWSCI. These stakeholders include physiotherapists and other rehabilitation

professionals; the government and the private sector; the family of the PLWSCI, peer PLWSCI's, DPO's and community members.

In the ensuing paragraphs, strategies for facilitating the community participation of PLWSCI (as indicated in Figure 7.1) are discussed by highlighting the roles of various stakeholders (people, groups and institutions). Further research is, however, indicated to develop evidence based guidelines for addressing each strategy. Because disability issues affect all sectors of society, a multi-sectoral approach to those affecting the community participation of PLWSCI is indicated, as shown by the links between various factors and stakeholders which are indicated by the arrows in the framework in Figure 7.1.

The roles of the following groups of stakeholders are discussed together:

- Physiotherapists and other rehabilitation professionals
- Government and the private sector
- Family, peer PLWSCIs, DPOs and community members.

7.7.1 Role of physiotherapists and other rehabilitation professionals in facilitating the community participation of PLWSCI

The framework illustrated in Figure 7.1 indicates that physiotherapists and other rehabilitation professionals need to address a number of factors in order to facilitate the community participation of PLWSCI. Disability related factors can be directly influenced by physiotherapists and other rehabilitation professionals. Direct measures include physically rehabilitating the PLWSCI to a point at which they are functionally capable of fulfilling various roles in the community, educating them and empowering them to take responsibility for their own health and well-being after discharge from rehabilitation. Through optimum physical and functional rehabilitation, the participation of PLWSCI in society, including participation in gainful employment, may be facilitated. Other personal factors such as lack of basic education and unemployment could be partly addressed through vocational rehabilitation by the relevant rehabilitation professional (mainly occupational therapists).

Vocational rehabilitation should therefore be incorporated in the treatment of spinal cord injuries to prepare PLWSCI for reintegration into the workplace and the community. Vocational

rehabilitation is aimed at assisting PLWSCI to secure gainful employment that commensurate with their abilities and capabilities. The ability to return to, or secure an employment that offers remuneration is a vital outcome of integrating PLWSCI back into the community. Employment provides people with better social reputation, good sense of self worth, purpose in life and financial stability. Ways to upgrade occupational outcome are based on education, peer groups, vocational counseling, and changing employer's perception, improving transportation, and reducing financial disincentives to employment.

On the other hand, environmental issues such as transport, social support and discriminatory practices require a different intervention at local and/or national policy or societal level. Physiotherapists and other rehabilitation professionals can play an advocacy role on policy issues affecting PLWSCI. Advocacy is part of the social responsibility of physiotherapists and other rehabilitation professionals.

7.7.1.1 Social responsibility implications for rehabilitation practitioners

Social responsibility means that an individual is bound as a human being to strive towards enhancing the quality of life of his/her fellow human beings (Bezner, 2004). The WHO's Jakarta Declaration on Health Promotion of 1997 highlights social responsibility as an important aspect for addressing pertinent social health issues and emerging health threats (Mittelmark, 2001). Physiotherapists and other rehabilitation professionals have a social responsibility to optimise the community participation of PLWSCI and to minimise the burden of disability due to SCI on society.

Social responsibility was identified as a core value of professionalism by the American Physical Therapy Association (APTA) at their consensus conference in July 2002. The APTA consensus statement encourages physiotherapists to embrace all aspects of social responsibility, including advocacy, promotion of cultural competency and community service. It is important that physiotherapists adopt social responsibility as one of the core values for the development of the profession (op cit).

The APTA consensus statement defines social responsibility as "the promotion of the mutual trust between the professional and the larger public that necessitates responding to societal

needs for health and wellness” (Bezner, 2004). Indicators of social responsibility according to APTA include:

- *Advocating for health and wellness needs of society including access to health care and physical therapy services.*
- *Promoting cultural competence within the profession and the larger public.*
- *Promoting social policy that effect function, health, and wellness needs of patients/clients.*
- *Ensuring that existing social policy is in the best interest of the patients/clients.*
- *Advocating for changes in laws, regulations, standards, and guidelines that affect physical therapist service provision.*
- *Promoting community volunteerism.*
- *Participating in political activism.*
- *Participating in achievement of social health goals.*
- *Understanding of current community-wide, nation-wide and worldwide issues and how they impact society’s health and well-being and the delivery of physical therapy.*
- *Participating leadership in the community.*
- *Participating in collaborative relationships with other health practitioners and the public at large.*
- *Ensuring the blending of social justice and economic efficiency of services.*

Being “socially responsible” implies that rehabilitation professionals have an ethical obligation to strive for a better quality of life for their clients (in this case PLWSCI) (Clark, 1993). Advocacy is thus a crucial element of the physiotherapy profession. However, some physiotherapists do not think that social advocacy is part of their professional role. Physiotherapists participating in a study to evaluate a service provider’s perspective on the physiotherapy services required at primary health care level indicated that advocacy and mediation **were not important roles** and that these belonged to other professionals, like lawyers (Maleka, 2009). Physiotherapists who make such or similar comments, or who identify with such comments, do not seem to understand that advocacy is an important aspect of their role as professionals and part of their social responsibility. Such an attitude or viewpoint is a matter of serious concern in this era of the bio-psychosocial approach to healthcare, where rehabilitation and other healthcare practitioners are expected to practise from a holistic perspective of patient care.

This “role denial” is probably historical, based on the slogan of the physiotherapy association in South Africa which states that “the difference is in our hands”. This slogan may lead some physiotherapists to believe that their role is only to “handle” patients, and not to get involved with socio-political issues. In response to this, the Private Practitioners group of the SASP has created a new slogan which states “**together, we are the difference**” (SASP, 2009). This slogan moves the emphasis from treating only with the touch of the hands, to the collaborative involvement of professionals in making a difference in patient communities. Advocacy should therefore be emphasised in the profession, during both undergraduate and postgraduate training, and in continuing professional development activities.

Awareness of advocacy and other dimensions of social responsibility such as providing leadership in society, engaging in political activism to influence healthcare policy, and promoting cultural competence and ethical practice within the profession must be raised among physiotherapists. In the Annual Report of 2008-9, the South African Society of Physiotherapy (SASP) purported to have embraced the concept of social responsibility and it has already conducted a survey of the membership regarding this concept (SASP, 2009). The SASP, as the official mouthpiece of the profession in South Africa, is the ideal vehicle for organising continuing professional development activities which could include educating physiotherapists about social responsibility.

The following quotation from one of the participants in Phase 2 of the study highlights the advocacy role that physiotherapists and other rehabilitation practitioners should play:

I wish they (therapist) could help me get some job. Yeah, the job is the big problem my sister. Even before I was a ‘para, I did not have a real job, just piece jobs. We all want the job. It is more difficult for us who are ‘paras’ to get job. I don’t know... maybe if the government can help somehow. The disability grant is too little - very little. Maybe some spare jobs must be reserved for the wheelchair people (Tumelo).

7.7.2 Role of the Government and the private sector in facilitating the community participation of PLWSCI

Policies and legislation regarding the health and well-being of the citizens of this country are determined and promulgated by government at various levels. Since the democratic dispensation began in South Africa in 1994, health sector reforms have been instituted, resulting in the development of policies on the provision, financing and regulation of health care. The guiding principle behind these policies is the establishment of equity and efficiency within the overall health system, as dictated by the Bill of Rights enshrined in the Constitution. With specific reference to health issues affecting PLWSCI and other PWD, the following pieces of legislation have been promulgated:

- The White Paper on an Integrated National Disability strategy
- The Promotion of Equality and Prevention of Unfair Discrimination Act
- The Department of Public Service Administration's *Bathopele* (people first) principles
- The Disability Rights Charter
- The National Department of Health's Patients' Rights Charter
- National Rehabilitation Policy and
- Free Health Care for People with Disabilities at hospital level.

While the country has these excellent policy documents in place, the results of this study have indicated that PLWSCI still experience huge challenges in terms of living with SCI in the community. These challenges suggest that there is a gap between policy formulation and implementation. This gap between policy and practice demonstrates a lack of "implementation capacity" which must be highlighted through advocacy action by all stakeholders including rehabilitation practitioners.

The government (both local and national) and the private sector should work together as partners in addressing the policy issues related to the factors influencing community participation which were identified in this study, namely access to rehabilitation, employment and transport.

7.7.2.1 Improving accessibility to follow-up healthcare and rehabilitation

In November 2000, the South African National Department of Health launched the National Rehabilitation Policy (DoH, 2000). This policy (NRP) was developed in response to the issues raised in the Integrated National Disability strategy (1997). The main aim of the NRP was to improve access to healthcare (including rehabilitation follow up) for previously disadvantaged communities, especially those residing in socio-economically disadvantaged areas.

In order to address the challenges of access to healthcare and rehabilitation, “compulsory community service” (CCS) was instituted for all health professionals by the South African National Department of Health (DoH, 2003). However, the findings of this study suggest that there is still a great deal to be done if CCS is to achieve its intended goals. This study has established that a lack of resources (finances and/or transport) makes it difficult for some PLWSCI to visit hospitals for general health check ups. Therefore a major rehabilitation policy implication, based on the findings of this study, is the need for follow-up care for PLWSCI. The government should be encouraged to make financial resources available to allow for the implementation of a variety of follow-up programmes for PLWSCI.

The following methods of follow up could be implemented (Bloemen-Vrencken et al., 2005):

a) Tele-rehabilitation

Tele-rehabilitation is the use of Information and Communication Technologies (ICT), mainly telephone and the internet, to provide rehabilitation services remotely to people in their homes or other environments. By using ICT, clients’ access to care will increase and the reach of clinicians will extend beyond the physical walls of a traditional healthcare facility, thus providing for continuity of care to persons with disabling conditions. Through tele-rehabilitation, healthcare professionals can provide follow-up support and education to people living far away from rehabilitation centres. As there is an enormous number of cell phones in South Africa, telephone follow up would be the most viable method, particularly as internet usage is very low among South Africa’s black population.

b) Home visits by rehabilitation professionals

Home visits will provide the rehabilitation practitioners with a real life picture of how PLWSCI are living in their communities, allowing them to identify needs and areas of

intervention or referral. As indicated in Chapter 1, home visits are very effective but unfortunately, for various reasons, they are not routinely made.

c) Outpatient consulting services

This service is invaluable for those PLWSCI who are able to access the local clinics and hospitals for physical check-ups. During these check-ups, rehabilitation professionals can identify difficulties PLWSCI may have with daily functioning and provide the necessary support.

7.7.2.2 Creating opportunities for employment

Given the general unemployment of the participants in this study, it is no surprise that 40% of them were dependent on disability grants as their main source of income. The proportion of PWD (including PLWSCI) who are unemployed remains high in South Africa, despite legal mandates such as the Employment Equity Act of 1973 and the Integrated National Disability Strategy (1997) which were promulgated to improve employment opportunities for people with disabilities. According to the Integrated National Disability Strategy White Paper (OSDP, 1997), 99% of people with disabilities (including PLWSCI) in the RSA are unemployed. It is therefore important that the issue of employment for PLWSCI be addressed as a matter of urgency by various stakeholders.

The South African government is a signatory to the United Nations' (UN) convention on the rights of people with disabilities (UN, 2006). The convention requires that governments and other relevant stakeholders recognise the right of persons with disabilities to work, and to compete for employment on an equal basis with others. This includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and a work environment that is open, inclusive and accessible to persons with disabilities.

The convention expects governments to safeguard and promote the realisation of the right to work, including of those who have acquired a disability during the course of employment, by taking appropriate steps, which include legislation. The South African government has established policies that accommodate physically challenged people in the workplace and prevent (limit) discrimination. One such legislation is the Employment Equity Act (EEA), No. 55 of 1998 (DoL, 1998), an employment equity law designed to prohibit discrimination and to promote

affirmative action in the workplace. This law is intended to protect people with disabilities against unfair discrimination and to entitle them to affirmative action measures.

Closely linked to the EEA is the “The Code of Good Practice on Key Aspects of Disability in the Workplace”, which was issued in terms of Section 54 (1) (a) of the Employment Equity Act (DoL, 2000). This code is a guide for employers and employees on key aspects of promoting equal opportunities and fair treatment for people with disabilities as required by the Employment Equity Act (the Act). The Act stipulates that the staff complement of any company with more than fifty employees must include people with disabilities (at least two percent). If properly implemented, the act will offer people with disabilities the opportunity to enter the open labour market and mainstream employment (South African Employment Equity, 1999).

In order to accommodate PLWSCI in the workplace, employers are encouraged to make environmental adjustments such as building ramps for wheelchairs and adaptive devices for sanitation usage, inserting railings and increasing work space for wheelchair manoeuvres. Worksite visits and evaluation by rehabilitation professionals could assist employers in this regard. These professionals could advise employers of PLWSCI on how to accommodate them in the workplace. This might include worksite adjustments or placement of PLWSCI in an alternative type of employment.

The field of Information and Communications Technology (ICT) is a very promising intervention for enhancing the employment of PLWSCI because any level of SCI can be trained to use a computer. Computer literacy could therefore facilitate the return to work (RTW) and contribute to the employability of PLWSCI. Pell, Gillies and Carss (1997) examined the impact of computers and assistive device use on the employability of people with physical disabilities in Australia, and found that the provision of computer technology and training to people with physical disabilities improved employment prospects. A new employment development using ICT is termed tele-work (Lidal et al., 2007):

Tele-work permits home-based work, as a strategy for RTW for individuals with SCI. The advantages of home-based tele-work include less dependency on community accessibility, or transportation, less focus on physical limitations, medical complications, increased self-efficiency, decreased employer biases, and stress. (Lidal et al., 2007, 1371)

Being employed influences other life domains and has the potential to enhance the overall quality of life of PLWSCI by increasing financial resources, self-esteem, and participation in community roles. Strategies that are aimed at creating, supporting and/or expanding employment options are therefore vitally important for PLWSCI. In addition, employment is crucial in preventing poverty.

Disability and poverty are intricately linked as both a cause and consequence of each other. Poverty causes disabilities and can furthermore lead to secondary disabilities for those individuals who are already disabled, as a result of poor living conditions, health endangering employment, malnutrition, poor access to healthcare and education opportunities etc. Together, poverty and disability create a vicious circle.

One of the eight Millennium Development Goals of the UN (2007) is the eradication of extreme poverty and hunger amongst all people. This goal that cannot be achieved without taking PWD into consideration, as they are a group of people that is so disproportionately represented among the world's poorest people. Creating employment opportunities will therefore contribute to achieving the MDG of poverty alleviation for PWD, including PLWSCI.

7.7.2.3 Improving access to and availability of public transport

The most important influence on accessibility which emerged from this study was transportation. Transport is vital in the lives of PLWSCI because of their limited mobility. The UN Convention on the Rights of Persons with Disabilities (PWD) addresses issues of accessibility in article nine (UN, 2006). According to this article, governments are required to take appropriate measures to ensure that PWD have access (on an equal basis with others) to the physical environment, to transportation, to information and communication, and to other facilities and services open or provided to the public, both in urban and in rural areas. Measures must be put in place to identify and eliminate obstacles and barriers to accessibility to enable PLWSCI and other PWD to live independently and participate fully in all aspects of life.

Transport is a problem for the general public in South Africa, not only PLWSCI. The National Household Transport Survey of the DoT (2005, page 36) revealed that:

- (i) almost **half** of the households in the survey said that public transport was either not available or too far away;
- (ii) **one third** of households reported that safety from accidents and bad driver behaviour was the most **serious transport problem**;
- (iii) **for 20%** of the households the cost of transport was a serious obstacle.

The South African government has therefore put measures in place to address the transport problem through the Public Transport Strategy devised by the Department of Transport (DoT), which will include the following services (DoT, 2007):

a) Accelerated modal upgrading of public transport

This is the short term transformation of road (bus, taxi) and rail services. An existing example is the Bus Rapid Transit system (BRT), which will provide a solution in the form of high quality mass transit services on a cost effective basis to urban areas through a functional network of public transport corridors.

b) Integrated rapid public transport networks

This is an affordable but rapid service to minimise travel time and to ensure safe, convenient and comfortable travel.

These services are expected to be 100% accessible by PWD including PLWSCI, and will include non-motorised transport facilities. The DoT anticipates that by 2014, BRT Corridors will be fully functional in at least 12 metropolitan cities and six rural districts. By 2020, it is envisaged that more than 85% of any metropolitan city's population will be within 1km of an accessible Integrated Rapid Public Transport Network. PLWSCI are involved in the DoT strategy through the South African Disability Alliance (SADA). SADA has mandated the QuadPara Association of South Africa (QASA) and the National Council of People with Physical Disabilities in South Africa (NCPDPSA) to lead all access issues in the DoT strategy (QASA, 2009).

A significant milestone in this regard was that in May 2010, a private company, the Public Utility Transport Corporation (PUTCO) started a disability friendly bus service between the townships of Garankua, Mabopane, Soshanguve and the Pretoria central business district (Appendix P). This is a good example of private sector involvement in facilitating the community participation of PLWSCI. PUTCO's efforts represent not only a significant step towards achieving the goals of the DoT strategy, but they will also have a positive impact on the lives of PLWSCI in terms of

alleviating transportation challenges. As such, they will facilitate community participation. However, despite this positive move, more effort is required to address accessibility issues, as PLWSCI reside not only in the four townships covered by the PUTCO project.

Physiotherapists and other rehabilitation professionals can contribute to the solution of the transport challenge in two ways. Firstly, PLWSCI should be properly trained in transfer techniques in order to be able to move from a wheelchair to a particular mode of transport. Secondly, where applicable, PLWSCI must be provided with suitable equipment to assist this access to transport systems (e.g. crutches or other orthotic devices).

7.7.3 Role of the family, peer PLWSCI and the community at large in facilitating the community participation of PLWSCI

As indicated in Chapter 6, family members and peers living with SCI are a valuable source of social support for PLWSCI. If these PLWSCI are to be integrated and to participate meaningfully in society, the community needs to be educated in accommodating them. An accepting and accommodating environment will be conducive to participation by PLWSCI as productive members of society, within the limits of their disability.

Having outlined the strategies required to facilitate community participation by PLWSCI in this section, the next section presents the limitations of the study. These form the basis for recommendations made regarding further research into the community participation of PLWSCI.

7.8 LIMITATIONS OF THE STUDY

The limitations of this study are mainly methodological and include the possibility of selection bias due to non-coverage and/or no response bias. Non-coverage bias could have occurred as a result of the method of contact used with potential participants, which was telephonic. The possibility exists that those participants who did not have a telephone (i.e. landline or cellular telephone) and were therefore not included in this study may have had a different experience of community participation than those who had telephones. Similarly, the possibility of selection bias exists because those who refused to participate and those who were difficult to contact may also have had a different experience of community participation. To minimise this bias, the

researcher made use of both telephonic and face to face contact to invite participants to be involved in the study.

Another limitation of this study is the fact that it was cross-sectional in nature, and therefore the change in community participation over time could not be explored. This limitation was, however, mitigated by including participants with a wide range of years of living with SCI (range 2 – 25 years) in the sample. Using post hoc comparisons of data obtained from participants with a wide number of “years of living with SCI” helped to shed some light on the change in community participation that took place over time. However, a longitudinal design would have had the advantage of exploring the change in participation over time per individual participant, not across the group of participants.

7.9 RECOMMENDATIONS

The following recommendations are made, based on the findings of the study, in order to address the limitations identified. These recommendations are directed at rehabilitation professionals specifically, and broader multisectoral recommendations are also included.

7.9.1 Recommendations for further research

This study has revealed that two of the instruments used for data collection, namely the RNLI and the SCIM II, were reliable and valid for use in this population of PLWSCI living in the Tshwane (Greater Pretoria) metropolitan area. One instrument, however, the CHIEF-SF, was found to be neither reliable nor valid. There is therefore scope for more work in the area of refinement of the instruments.

7.9.1.1 Further development and refinement of the CHIEF-SF

Further research is required to refine and validate the CHIEF-SF. The language used in the instrument should be adapted (terms like “policy” were a challenge for most participants, despite explanations and examples provided by the researcher). Furthermore, to expect participants to recall the impact of the environment on their experiences over an entire year is a daunting task, especially for participants who are functionally illiterate. An ideal method of determining the

impact of environmental factors on participants' community participation would be to conduct a longitudinal follow-up study at regular intervals (three or at most six months apart).

7.9.1.2 Further development and refinement of the SCIM II

As indicated in Chapter 6, the SCIM II instrument that was used in this study is outdated, and a newer version has just been released following multi-centre validation studies. Although the SCIM II was found to be reliable and valid, further validation using the new SCIM III on the same or similar study population is required.

7.9.2 Recommendations preventing causes and complications of SCI

The causes of spinal cord injury in this sample and the health complications experienced by the participants are preventable issues of concern. Measures need to be put in place to prevent and/or manage these concerns.

7.9.2.1 Preventing causes of SCI

The majority of causes are preventable. Traumatic causes, especially RTAs, require road users to be more careful. More stringent traffic law enforcement is an absolute necessity. A multi-sector approach to this problem is therefore recommended in addressing road conditions and in keeping road users (drivers and pedestrians) in check. In this regard, rehabilitation professionals could partner with agencies such as Arrive Alive in educating the public on road safety issues and, by using SCI, in highlighting the serious implications of not complying with traffic regulations.

The non-traumatic causes identified in this study were TB of the spine, HIV/AIDS, and tumours. TB of the spine can be treated successfully if identified early. Therefore, patients with non-traumatic backache need to be screened thoroughly, and not just symptomatically treated, in order to exclude the diagnosis of TB. Known pulmonary TB patients must be encouraged to adhere strictly to their TB treatment and to finish the course of treatment in order to prevent the infection from spreading to other areas such as the spinal column.

7.9.2.2 Preventing complications of SCI

In this study, pressure ulcers were identified as the most prevalent complications for which PLWSCI were readmitted to hospital. Pressure ulcer management is costly to the patient, the government and taxpayers, and measures should be put in place to prevent these pressure ulcers. The following strategies are recommended for prevention:

- Intensified education and skills training during rehabilitation, to ensure that PLWSCI have the necessary skills to effectively manage their health after discharge.
- Monitoring by family and/or community members, who must be educated about pressure ulcers and what PLWSCI can do to prevent these and the assistance they require to maintain their health after discharge from rehabilitation. Follow up by rehabilitation professionals, as discussed in section 7.7.2.1, is essential.

7.10 CONCLUSION AND SIGNIFICANCE OF THE STUDY

The main aim of this study was to determine the factors influencing the community participation of PLWSCI in the Tshwane (Greater Pretoria) metropolitan area. The study revealed three categories of factors influencing community participation: disability-related factors, personal factors and environmental factors. Employment and environmental barriers were found to be significant predictors of participation, and strategies for addressing these were proposed.

This study breaks new ground in that it is the first in South Africa to investigate the community participation of PLWSCI from a mixed method approach and simultaneously to validate outcome measures related to participation in this population.

The study will make a major contribution to SCI rehabilitation research, policy and practice for the following reasons:

- For rehabilitation professionals, the study has highlighted the importance of being careful when using instruments developed in other settings to measure rehabilitation outcomes. The fact that the CHIEF-SF was not found to be reliable or valid confirms that it cannot be assumed that instruments developed in settings different from the setting of interest will work.
- The study has provided a framework for enhancing the community participation of PLWSCI, which highlights the complexity of factors affecting community participation, and the roles of

various stakeholders from different sectors (rehabilitation researchers, practitioners and policy makers) in promoting community participation among PLWSCI.

- Whereas a large body of research exists internationally on the epidemiology and impact of SCI, there has been a dearth of such studies on the subject in Africa, and more specifically in southern Africa. This study has determined the epidemiology of SCI in the research setting. The findings of this study, together with valuable projects like the QASA database project of listing members and persons with spinal cord injury (QASA, 2008) will contribute to the formation of a national database. A national database will provide the epidemiological information necessary for informing preventative measures and policy directives regarding SCI.
- The study has also identified several rich areas for further research that physiotherapists and other rehabilitation practitioners should pursue further.

7.11 SUMMARY

In this last chapter of the thesis, the integrated findings of the two study phases were discussed and a framework of community participation for PLWSCI was presented. The rehabilitation and policy implications of the framework model were highlighted. A number of strategies for facilitating the community participation of PLWSCI were also presented. The limitations of the study were highlighted and recommendations for further research were proposed.

This thesis has addressed a number of questions in an area of SCI research where there has hitherto been a very limited number of studies, especially in the South African context. This has opened the door to further SCI research, as indicated in the recommendations section of this Chapter

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APPENDIX A ETHICAL CLEARANCE CERTIFICATE

Faculty of Health Sciences Research Ethics Committee
University of Pretoria
Room 2 – 19 MRC-Building, Soutpansberg Road
Private Bag x 385
Pretoria 0001
Date: 27 / 07 / 2006



Number : 38/2006
Title : Factors influencing the rehabilitation outcome of clients disabled by spinal cord injury
Investigators: Mrs D J Mothabeng; Department of Physiotherapy; Pretoria Academic Hospital and Kalafong Hospital University of Pretoria ; Pretoria
joyce.mothabeng@up.ac.za T:012-354 1200 F: 012-354 1226 C: 0829565528
Sponsor : **None.**
VAT No : **None.**

Study Degree: **PhD Physiotherapy (Rehabilitation)**

This Protocol and Informed Consent have been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 26/07/2006 and found to be acceptable.

Mr P Behari B.Proc. KZN; LLM – Unisa; (Lay Member)
*Advocate AG Nienaber (female) BA(Hons) (Wits); LLB; LLM (UP); Dipl.Datometrics (UNISA)
*Prof V.O.L. Karusseit MBChB; MFGP (SA); M.Med (Chir); FCS (SA): Surgeon
Dr M E Kenoshi MB,CHB; DTM & H (Wits); C.E.O. of the Pretoria Academic Hospital
Prof M Kruger (female) MB.ChB.(Pret); Mmed.Paed.(Pret); PhD. (Leuven)
Dr N K Likibi MB.BCh.; Med.Adviser (Gauteng Dept.of Health)
*Dr F M Mulaudzi (female) Department of Nursing,
*Mrs E.L. Nombe (female) B.A. CUR Honours; MSC Nursing – UNISA (Lay Member)
+Snr Sr J. Phatoli (female) BCur (Et.AI) Senior Nursing-Sister
***Dr L Schoeman (female) Bpharm, BA Hons (Psy), PhD**
*Prof J.R. Snyman MBChB, M.Pharm.Med: MD: Pharmacologist
*Dr R Sommers (female) MBChB; M.Med (Int); MPhar.Med;
*Prof TJP Swart BChD, MSc (Odont), MChD (Oral Path) Senior Specialist; Oral Pathology
*Prof C W van Staden MBChB; Mmed (Psych); MD; FTCL; UPLM; Dept of Psychiatry

DR R SOMMERS; MBChB; M.Med (Int); MPhar.Med.
SECRETARIAT of the Faculty of Health Sciences Research Ethics Committee - University of Pretoria



Date: 20/11/2008

APPENDIXB: Approval of ammendment

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- * **FWA** 00002567, Approved dd 22 May 2002 and Expires 24 Jan 2009.
- * **IRB** 0000 2235 IORG0001762 Approved dd Jan 2006 and Expires 13 Aug 2011.



AMENDMENT PROTOCOL NO.	Topic Change 38/2006
PROTOCOL TITLE	An assessment of factors influencing community integration for people living with Spinal cord injury
INVESTIGATOR DEPARTMENT	Mrs D J Mothabeng; joyce.mothabeng@up.ac.za T:012-354 1200 F: 012-354 1226 C: 0829565528 Department of Physiotherapy; Steve Biko Academic Hospital and Kalafong Hospital University of Pretoria ; Pretoria
STUDY DEGREE MEETING DATE	PhD Physiotherapy (Rehabilitation) 19/11/2008

This **Amendment** has been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 19/11/2008 and found to be acceptable.

* *Members attended & Feedback at the meeting .*

- | | |
|------------------------|---|
| Dr A Nienaber | (female) BA (Hons) (Wits); LLB; LLM (UP); Dipl.Datametrics (UNISA) |
| *Prof V.O.L. Karusseit | MBChB; MFGP (SA); MMed (Chir); FCS (SA) |
| Prof M Kruger | (female) MB.ChB. (Pta); MMed. Pead. (Pret); PhD. |
| (Leuven) | |
| Dr N K Likibi | MB.BCh; Med.Adviser (Gauteng Dept.of Health) |
| *Dr T S Marcus | (female) BSc (LSE), PhD (University of Lodz, Poland) |
| *Mrs M C Nzeku | (female) BSc (NUL); MSc Biochem (UCL, UK) |
| *Snr Sr J. Phatoli | (female) BCur (Eet.A) BTec (Oncology Nursing Science) Snr Nursing-Sister |
| *Dr L Schoeman | (female) BP harm, BA Hons (PSy), PhD |
| *Dr R Sommers | (female) MBChB; MMed (Int); MPharMed; |
| *Mr Y Sikweyiya | MPH; Master Level Fellowship in Research Ethics; BSC (Health Promotion)
Postgraduate Dip in Health Promotion |
| Prof TJP Swart | BChD, MSc (Odont), MChD (Oral Path), PGCHE |
| *Dr A P van Der Walt | BChD, DGA (Pret) Director: Clinical Services of the <small>Pretoria Academic Hospital</small> |
| *Prof C W van Staden | MBChB; MMed (Psych); MD; FCPsych; FTCL; UPLM; <small>Dept of Psychiatry</small> |

Dr R Sommers; MBChB; MMed (Int); MPhar.Med.

SECRETARIAT of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, Pretoria Academic Hospital

◆ H W Snyman Building (South) Level 2-34 ◆ P.O.BOX 667 Pretoria, South Africa, 0001 ◆ Tel:(012)3541330 ◆
◆ Fax: (012)3541367 / 0866515924 ◆ E-Mail: manda@med.up.ac.za ◆ Web: [//www.healthethics-up.co.za](http://www.healthethics-up.co.za) ◆



DEPARTMENT OF PHYSIOTHERAPHY

PARTICIPANT INFORMATION LEAFLET

(To be read to the participant in his or her own language)

TITLE OF THE STUDY

An Assessment of Factors Influencing the Community Integration of People Living With Spinal Cord Injury in the Tshwane Metropolitan Area

INTRODUCTION

My name is _____ and I am a Physiotherapy Assistant. I am working together with Joyce Mothabeng, the researcher for this study. Joyce is a PhD student at the University of Pretoria. You have been identified from the database of a Spinal Rehabilitation unit as someone who has been rehabilitated for a spinal cord injury. You are hereby invited to take part, as a volunteer, in this research study.

This information leaflet is to help you to decide if you would like to participate. By participate, we mean that we are asking you to agree to be interviewed. We will ask you some questions about your condition, how you find living with it and what you think needs to be done to improve life for people living with spinal cord injury.

Before you agree to be interviewed, you should fully understand what is involved. If you have any questions which are not fully explained, do not hesitate to ask me or Joyce. You should not agree to be interviewed unless you are completely happy to do so.

1) THE NATURE AND PURPOSE OF THIS STUDY

The aim of the study is to determine the things that affect people who are disabled by spinal cord injury to cope with functioning as members of society. The information that will be gained will assist the physiotherapists and other members of the rehabilitation team to plan the rehabilitation programs in a way that will better prepare future patients to cope in society. The information will also be used to lobby other

relevant people in positions of power to address issues that we as physiotherapists may not be able to address (e.g. transport, buildings etc).

2) EXPLANATION OF PROCEDURES TO BE FOLLOWED.

The researcher will visit you at your home (or other place of your choice) at a time convenient for you to conduct the study. The study will involve measurement of your ability to perform activities of daily living, and asking you questions (interview) regarding the following aspects of living with SCI:

- How you cope with it and what you think need to be done to help you cope better.
- How it influences your daily life (at home, work or school)

The people who take care of you may also be asked some questions concerning your condition, but only with your permission and if you feel that they might be able give us more information on some of the questions we might ask you.

A tape recorder will be used as we talk to you and ask you some questions. However, the information that will be recorded will only be used for the purpose of this study and not for anything else. The researcher will also be taking some notes by hand.

3) RISK AND DISCOMFORT INVOLVED.

The only problems and discomfort that you may experience during this study is that you will be visited at home by the researcher. You may feel uncomfortable with some of the questions asked. If at all you feel unhappy about some of the questions you will be asked, you are not obliged to answer those questions, and you are free to discontinue with the participation. Even if you decide to stop participating in the study, your current and future health care will not be affected in any way.

Taking part in the survey by agreeing to be interviewed will not cost you anything, just a few minutes of your time.

4) POSSIBLE BENEFITS OF THIS STUDY.

This study will highlight the issues that affect the functioning of people disabled by spinal cord injury. The information will be used by the physiotherapists and other health professionals to make sure that rehabilitation efforts are in line with the needs of the people in society, thus better preparing them for life out there.

The information will also be used to alert policy-makers and other relevant authorities to the needs of people with spinal cord injury, so they can put measures in place to address them.



5) CONFIDENTIALITY.

All the information that you will give us during this study shall not be given to any other person. It will only be used for the purpose of this study. If at all the results of the study gets published by the researcher, your name and identity will not be revealed. And no one will know where the information came from.

6) INFORMATION

If you have any questions about the interview, please contact the researcher, **Ms. Joyce Mothabeng**. Her telephone number is 012 354-1343 or 0829565528. You can also contact the study supervisor, Dr. Carina Eksteen at the Physiotherapy Department at the University of Pretoria. Her telephone number is 012 354-3718.

Thank- you very much for your help.



APPENDIX D: Consent form



CONSENT TO PARTICIPATE IN A STUDY

(Written consent by participant)

TITLE OF THE STUDY

An Assessment of Factors Influencing the Community Integration of People Living With Spinal Cord Injury in the Tshwane Metropolitan Area

Ihave read, and it has been read to me in a language that I understand, the above information before I signed this consent form. The meaning of this information has been explained to me. I have been given an opportunity to ask questions and I am happy that my questions have been answered very well. I therefore, volunteer to take part in this study.

I understand that even if I refuse to participate in this study, I will not be penalized in any way. I will still be able to receive any necessary health care including Physiotherapy whether I participate in the study or not. I also understand that I can withdraw from the study at any time.

I hereby freely consent to be interviewed by.....

I have been given a copy of the information leaflet and a signed copy of the consent form that indicates that I have given consent to participate in this study.

.....
Participant' signature Date

.....
Person obtaining informed consent Date

.....
Witness Date





DEPARTMENT OF PHYSIOTHERAPY

CONSENT TO PARTICIPATE IN THIS STUDY

(Verbal consent by participant who cannot read or write)

TITLE OF THE STUDY

An Assessment of Factors Influencing the Community Integration of People Living With Spinal Cord Injury in the Tshwane Metropolitan Area

I, the undersigned,, declare that the investigator named has fully read and explained to me and my relatives the content in the patient information leaflet, which indicates the nature and purpose of the study in which I have been asked to participate. The explanations I have been given has mentioned both the possible risks and benefits of the study. I understand that I am free to withdraw from the study at any time for any reason and without jeopardizing my usual treatment and management.

I hereby freely consent to be interviewed by.....

I have been given a copy of the information leaflet and a signed copy of the consent form that indicates that I have given consent to participate in this study.

.....
Proxy signature Date

.....
Person obtaining informed consent Date

.....
Witness Date



APPENDIX E: PERMISSION TO USE THE CHIEF AND CHART

Subject: RE: Request for permission to use research instruments
Date : Tue, 16 Aug 2005 07:24:44 -0600
From : "Charlifue, Susie" <Susie@CraigHospital.org>
To : "Joyce Mothabeng" <mothadj@med.up.ac.za>

Dear Joyce,

Please feel free to use CHART and CHIEF for your studies. The training should be fairly clear from the manuals that can also be downloaded. We only ask that the appropriate citations be given when you are publishing your results. I look forward to meeting you at the SASCA conference.

Best wishes,

Susan Charlifue, PhD
Research Supervisor
Craig Hospital
3425 S. Clarkson St.
Englewood, CO 80113
Phone: 303/789-8306
Fax: 303/789-8441
e-mail: susie@craighospital.org

-----Original Message-----

From: Joyce Mothabeng [mailto:mothadj@med.up.ac.za]
Sent: Tuesday, 16 August, 2005 07:49
To: Charlifue, Susie
Subject: Request for permission to use research instruments

Dear Suzie Charlifue

My name is Joyce Mothabeng, a physiotherapy lecturer at the university of Pretoria in South Africa. I am also a member of SASCA. I am registered for Ph.D. studies, looking at SCI rehabilitation outcomes.

I am interested in using instruments from your institution to evaluate outcome of patients post discharge (i.e. in the community). I am particularly interested in using the CHIEF and the CHART. I therefore request permission to download and use these instruments in my study. Kindly let me know if there are any licensing issued involved or training required.

I noticed you will also be one of the speakers at our SASCA congress later this month. I will also be delivering a paper and I hope it will be possible to meet and discuss my request and proposed study. Attached find a summary of the proposed study.

Thanking you in advance

Yours truly

Joyce Mothabeng
Tel: +2712 354-1200
Fax: +2712 354



**APPENDIX F: PERMISSION TO USE THE SCI DATABASE AT THETSHWANE
REHABILITATION CENTRE**

From: "Management" <management@muelmedrehab.co.za>
To: mothadj@med.up.ac.za
Date: 2009/03/12 01:18 PM
Subject: Dr Theron says ok

Hi joyce

Dr Theron says you can come use our Data base you will just have to arrange with Nadia for suitable times her number is 012 3411909 or email info@muelmedrehab.co.za

Melanie



APPENDIX G: PERMISSION TO USE THE SCI DATABASE AT TSHWANE REHABILITATION CENTRE



TSHWANE REHABILITATION CENTRE



Enquiries : Françoise Law
☎ : 012 354 6131
☎ : 012 354 6131
E-mail: Francoise.Law@gauteng.gov.za

Ms DJ Mothabeng
PhD Physiotherapy candidate

Dear Ms Mothabeng

RE: PERMISSION TO ACCESS PATIENT DETAILS IN THE SPINAL UNIT OF TSHWANE REHAB CENTRE

Thank you for your letter dated 6 March 2009. Having considered your application to conduct research on the patients who have been discharged at our institution, we have noted that you already have ethical clearance from the Faculty of Health Sciences Research Ethics Committee of the University of Pretoria and that you request permission to access the spinal ward's patient register.

Management hereby grants you permission to conduct your research as requested, by spending two hours per morning for one week in the spinal unit, obtaining the patient's contact details. Could you kindly inform this office or the Clinical Executive of your proposed dates so that the ward can be notified.

The Centre wishes you all of the best for your research and management would be very interested in your findings and kindly requests that you do a presentation and or provide a executive summary of your results so that the institution can utilize/ apply the findings that you may discover.

Please do not hesitate to contact myself or the Clinical Executive, Ms F Mokgokong should you have any queries.

Yours sincerely

Ms FK Mokgokong
Clinical Executive
Date: 26/03/2009

Ms Françoise Law
CEO: Tshwane Rehabilitation Centre
Date: 26/3/09



Tshwane Rehab Centre Private Bag X169 Pretoria 0001



APPENDIX H: SOCIO-DEMOGRAPHIC AND INJURY PROFILE

STUDYNUMBER

Participant:.....

Date:.....

1. Age when injured:
1 = less than 18, 2= 18 – 29, 3 = 30 – 39, 4 = 40 – 49, 5 = 50 – 59, 6 = 60 and above
2. Gender 1 = Male 2 = Female
3. Years of schooling _____
4. Levell of schooling
1 = 0 school, 2= junior primary, 3 = senior primary, 4 = junior high, 5 = senior high, 6 = matriculated
5. Academic qualifications (degree, diploma)
1 = none 2 = Certificate 3 = Diploma 4 = Degree.
6. Home (preferred) language
1 = Zulu 2 = Sotho 3 = Xhosa 4 = Tsonga
5 = Pedi 6 = Tswana 7 = Afrikaans 8 = English
9 = Venda 10 = Ndebele 11 = Swazi
7. Marital status
1 = Single 2 = Married 3 = Widowed 4 = Separated/divorced 5 = living together
8. Residential area
1 = township 2 = suburb 3 = informal settlement
4 = Other – specify
9. How long have you lived here (years)? _____
10. Where did you live before the SCI?
1 = township 2 = suburb 3 = informal settlement
4 = Other – specify.....
11. How long did you live there (years)?

12. With whom do you live now?
1 = Own family ; 2 = Friends ; 3 = other (e.g. shelter/home) _____
13. Are you working? 1 = no; 2 = yes
14. If yes, what kind of work?

15. If no, how do you get money to live? _____



- 16 If no, are you looking for work?
1 = NO 2. YES
17. If yes, do you think you will find work?
1. NO ; 2. YES; 3 = don't know
18. Did you work before you got injured?
1. NO 2. YES
19. If yes, what kind of work?

- 20 Years living with SCI.....
14. Cause of SCI
1. MVA – passenger; 2. MVA – driver, 3 MVA – pedestrian, 4. ASSAULT – gunshot
5. Assault – stab, 6. Assault – other, 7. Sporting accident, 8. Tumour, 9. TB Spine
10. Other
- 21 Type of SCI
1. Paraplegia 2 = Quadriplegia
- 22 Level of SCI
1= Cervical (neck) 2 = thoracic (chest) 3 = lumbar (waist and below)
- 23 Completeness of lesion
1 = complete, 2 = incomplete 3 = don't know
24. Did you receive rehabilitation at a specialized Rehab centre?
0 = no centre; 1 = specialized rehab centre public; 2= specialized rehab centre private
- 25 CENTRE NAME:.....
- 26 Have you been hospitalised for any health problems after discharge?
1 Yes
2 No
27. 1 If yes, which health problem
1 = Pressure ulcers; 2 = UTI; 3 = Respiratory complications
4 = Pressure ulcers and UTI, 5 = Pressure ulcers and respiratory complications
6 = UTI and respiratory complications 7 = Pressure ulcers, UTI and respiratory complications
8 = OTHER _____ 9 = NONE
- 28 Tell me about any other health problems you have experienced.
- 29 In general, how would you rate your current state of health?
a. = Poor 2 = Fair = Good 4 = Excellent

APPENDIX I: THE REINTEGRATION TO NORMAL LIVING INDEX (RNLI)

Please rate your satisfaction with your community participation, using the following, on a 1 -4 point scale where

- 1 = the statement does not describe my situation
- 2 = the statement describes my situation a little
- 3 = the statement describes my situation a lot
- 4 = the statement fully describes my situation

QUESTION	STATEMENT	SCORE
RNLI 1	I move around my living quarters as I feel necessary.	
RNLI 2	I move around my community as I feel necessary.	
RNLI 3	I am able to take trips out of town as I feel are necessary.	
RNLI 4	I am comfortable with how my self-care needs (dressing feeding toileting bathing) are met.	
RNLI 5	I spend most of my days occupied in work activity that is necessary or important to me.	
RNLI 6	I am able to participate in recreational activities (hobbies crafts sports reading television games computers etc.) as I want to.	
RNLI 7	I participate in social activities with family friends' and/or business acquaintances as is necessary or desirable to me.	
RNLI 8	I assume a role in my family which meets my needs and those of other family members.	
RNLI 9	In general I am comfortable with my personal relationships.	
RNLI 10	In general I am comfortable with myself when I am in the company of others.	
RNLI 11	I feel that I can deal with life events as they happen.	
RNLI TOT	TOTAL SCORE	/44
RNLI	ADJUSTED SCORE (AS A PERCENTAGE)	

total score = SUM (points for all 11 items)

adjusted score = (total score) /44 * 100

Comments on very high or very low scores



APPENDIX J: SPINAL CORD INDEPENDENCE MEASURE

PATIENT NAME: _____

ID: _____

Self-Care

1. Feeding (cutting, opening containers, bringing food to mouth holding cup with fluid)

- 0. Needs parenteral, gastrostomy or fully assisted oral feeding
- 1. Eats cut food using several adaptive devices for hand and dishes
- 2. Eats cut food using only one adaptive device for hand; unable to hold cup
- 3. Eats cut food with one adaptive device; holds cup
- 4. Eats cut food without adaptive devices; needs a little assistance (e.g., to open containers)
- 5. Independent in all tasks without any adaptive device

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2. Bathing (soaping, manipulating water tap, washing)

- 0. Requires total assistance
- 1. Soaps only small part of body with or without adaptive devices
- 2. Soaps with adaptive devices; cannot reach distant parts of the body or cannot operate a tap
- 3. Soaps without adaptive devices; needs a little assistance to reach distant parts of body
- 4. washes independently with adaptive devices or in specific environmental setting
- 5. Washes independently without adaptive devices

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3. Dressing (preparing clothes, dressing upper and lower body, undressing)

- 0. Requires total assistance
- 1. Dresses upper body partially (e.g. without buttoning) in special setting (e.g. back support)
- 2. Independent in dressing and undressing upper body. Needs much assistance for lower body
- 3. Requires little assistance in dressing upper or lower body
- 4. Dresses and undresses independently, but requires adaptive devices and/or special setting
- 5. Dresses and undresses independently, without adaptive devices

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4. Grooming (washing hands and face, brushing teeth, combing hair, shaving, applying makeup)

- 0. Requires total assistance
- 1. Performs some tasks using adaptive devices, needs help to put on/take off devices
- 3. Performs some tasks using adaptive devices; puts on/takes off devices independently
- 4. Performs all tasks with adaptive devices or most tasks without devices
- 5. Independent in all tasks without adaptive devices

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TOTAL SELFCARE=

Respiration and Sphincter Management

5. Respiration

- 0. Requires assisted ventilation
- 2. Requires tracheal tube and partially assisted ventilation
- 4. Breathes independently but requires much assistance in tracheal tube management
- 6. Breathes independently and requires little assistance in tracheal tube management
- 8. Breathes without tracheal tube, but sometimes requires mechanical assistance for breathing
- 10. Breathes independently without any device

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6. Sphincter management – Bladder

- 0. Indwelling catheter
- 5. Assisted intermittent catheterization or no catheterization, residual urine volume >100cc
- 10. Intermittent self-catheterization
- 15. No catheterization required, residual urine volume < 100cc

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7. Sphincter management – Bowel

- 0. Irregularity, improper timing or very low frequency (less than once in 3 days) of bowel movements
- 5. regular bowel movements, with proper timing, but with assistance (e.g. for applying suppository)
- 10. Regular bowel movements, with proper timing, without assistance

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8. Use of toilet (perineal hygiene, clothes adjustment before/after, use of napkins or diapers)

- 0. Requires total assistance
- 1. Undresses lower body. needs assistance in all the remaining tasks
- 2. Undresses lower body and partially cleans self (after); needs assistance in adjusting clothes and/or diapers
- 3. Undresses and cleans self (after); needs assistance in adjusting clothes and/or diapers
- 4. Independent in all tasks but needs adaptive devices or special setting (e.g. grab-bars)
- 5. Independent without adaptive devices or special setting

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TOTAL RESP AND BLADDR =

Mobility (room and toilet)

9. Mobility in bed and action to prevent pressure sores

- 0. Requires total assistance
- 1. Partial mobility (turns in bed to one side only)
- 2. Turns to both sides in bed but does not fully release pressure
- 3. Release pressure when lying only
- 4. Turns in bed and sits up without assistance
- 5. Independent in bed mobility; performs push-ups in sitting position without full body elevation
- 6. Performs push-ups in sitting position

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10. Transfers: bed-wheelchair (locking wheelchair, lifting footrests, removing and adjusting arm rests, transferring, lifting feet)

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision
- 2. Independent

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11. Transfers: wheelchair-toilet-tub (if uses toilet wheelchair – transfers to and from; if uses regular wheelchair – locking wheelchair, lifting footrests, removing and adjusting arm rests, transferring, lifting feet)

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision, or adaptive device (e.g. grab-bars)
- 2. Independent

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Mobility (indoors and outdoors)

12. Mobility indoors (short distances)

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Walks with a walking frame
- 4. Walks with crutches
- 5. Walks with two canes
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without aids

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13. Mobility for moderate distances (10 – 100 meters)

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Walks with a walking frame
- 4. Walks with crutches
- 5. Walks with two canes
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without aids

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14. Mobility outdoors (more than 100 meters)

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Walks with a walking frame
- 4. Walks with crutches
- 5. Walks with two canes
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without aids

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15. Stair management

- 0. Unable to climb or descend stairs
- 1. Climbs 1 or 2 steps only, in a training setup
- 2. Climbs and descends at least 3 steps with support or supervision of another person
- 3. Climbs and descends at least 3 steps with support of handrail and/or crutch and/or cane
- 4. Climbs and descends at least 3 steps without any support or supervision

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16. Transfers: wheelchair-car (approaching car, locking wheelchair, removing arm and foot rests, transferring to and from car, bringing wheelchair into and out of car)

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision, and/or adaptive devices
- 2. Independent without adaptive devices

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MOBILITY subtotal /40

TOTAL SCIM SCORE/ 100



APPENDIX K: THE CRAIG HOSPITAL INVENTORY OF ENVIRONMENTAL FACTORS – Short form

Item	RESPONSE								IMPACT
	Frequency						Magnitude		Frequency X Magnitude
	4 = Daily	3 = Weekly	2 = less than monthly	1 = Monthly	0 = Never	N/A	2 = Big problem	1 = Little problem	
1. How often has the availability of transport been a problem to you?									
2. How often has the natural environment – temperature, terrain, and climate – made it difficult to do what you want or need to do?									
3. How often have other aspects of your surroundings – light, noise, crowding etc. – made it difficult to do what you want or need to do?									
4. How often has information that you wanted or needed not been available in the format you use or understand?									
5. How often has the availability of health care services and medical care been a problem to you?									
6. How often did you need someone else's help in your home and could not get it easily?									
7. How often did you need someone else's help at work or school and could not get it easily?									
8. How often has other people's attitudes towards you been a problem at home?									
9. How often has other people's attitudes towards you been a problem at school or work?									
10. How often did you experience prejudice or discrimination?									
11. How often did policies and rules of businesses and organizations make problems for you?									
12. How often did policies and rules of government make problems for you?									

Thank you for participating in this phase of the study. Would you be willing to be interviewed in the next phase of the study

APPENDIX M: THEMES AND SUB-THEMES GENERATED

THEME 1: PERSONAL INFLUENCES

SUBTHEME	CATEGORIES	SUPPORTING STATEMENTS
Coping skills	Acceptance of condition	But I have accepted my disability. (Thabo)
	Positive outlook on life	<p>There is a life to live even when you are in a wheelchair. (Thabang)</p> <p>Who knows, a miracle might happen and I walk one day – ha-ha (laughs). (Tumelo)</p> <p>I always say to myself, when I can do something, I better do it myself, when I know I need help, I better get help from anybody who is offering I don't mind. (Thabang)</p> <p>Now I am ready to face life with a future job. A partner is not one of my immediate plans right now. I want to work for people with disabilities and make sure things happen like jobs, transport etc. (Selina)</p>
	Spirituality	<p>I mean I am glad I am alive. Since I became para, ---there are many things that I have noticed and I am grateful for in my life, because, eh, god saved my life for a reason you know. (Tumelo)</p> <p>Sometimes I ask why God did not take my life during the accident; I would not be facing [silence]. But you know, God knows everything, and I must not give up, yeah but it is hard.</p> <p>Eish my sister – it is life. What can I say? It is not okay but it is okay you know – thank God I am alive. One day things will get better. (Thabo)</p>

SUBTHEME	CATEGORIES	SUPPORTING STATEMENTS
Rehabilitation experience	Positive experience	<p>I would not have survived without rehab. I was so up and down- I don't know how they put up with me- but then I was a child – the youngest person in the unit. I guess they felt sorry for me. They must keep up the good work. Thanks to the rehab, I got placed in a special school for my entire high school. It was easier, and the school was in my town, so I had had my family- that helped. Now I am fine, I am studying computers and next year I'll be working (if I pass). (Selina)</p> <p>I am very happy with the training of the physio and occupational therapy. It helped me a bit, now I can do something like walk a bit. Maybe they must check on people in the home after discharge- some people they just sit and don't train and they get sick. The physio -they must come and check. (Sipho)</p> <p>Rehabilitation helped me a lot – I am thankful. Even though I am like this, at least I can do things for myself.....(George)</p> <p>Because my parents had medical aid, I had the best rehab – I think, because it was in the private hospital. (Selina)</p> <p>I think the training was good and must stay like that. It helped me get strong and I can use the wheelchair now. (Tumelo)</p> <p>Physio helped me a lot- I will always be grateful to them. They must keep on helping the</p>

		paralysed people – what they do is great. (Tumelo)
	Negative	<p>I would like to ask the nurses to treat us (PLWSCI) well please. You know, when a patient calls a nurse and says “nurse I am not okay (like soiled himself) and the nurse replies “you are not my husband”, that is not nice. I am not saying all nurses were like that, most of them are good. I just ask that they should feel for us – we did not choose to be like this. (George)</p> <p>The problem was some nurses in the ward – many of them are nice but some yo-yo, they really talk bad to us my sister. You find a man crying and that is not nice. Some nurses must try and be kind to us – when you are like that, you need people to treat you nice. (Tumelo)</p> <p>Some nurses must try and be kind to us – when you are like that, you need people to treat you nice.(Tumelo)</p> <p>The physios – eish, they push us very hard. We know that they are help us but they must not be so pushy. Especially early in rehab, when one is still trying to understand what is happening with his body...(George)</p> <p>.... I did not speak any English so I did not understand a lot of things. They tell me things, they write me things on paper but I did not experience a great deal of what’s going on. It was very hard and painful. I just focused myself on getting better and do what I can do and what I can’t, I can’t. That was my experience but in the long run I think they (therapists) do quiet well. With the pain I was in I just wanted to get out of the hospital and-oh well yeah-to adapt to my condition and all that. At that time I was also very angry. (Thabang)</p>



Future hopes	Find life partner	<p>No, but I am planning to (marry). That subject needs somebody who will understand who I am... I used to have a girlfriend but not at the moment...(Thabang)</p> <p>....may be get married one day....but who knows. (Thabo)</p> <p>A partner is not one of my immediate plans right now..... (Selina)</p>
	Walk again	<p>I hope to walk but they say I am complete- so they did their best. At least I can move in the wheelchair. (Sifiso)</p>
Personal needs	Study	<p>Yes, everyday I think about studying. Now becomes the problem of funds and things like that. I lack that and I really want to study.... I'd really love to study again. (Thabang)</p>
	Exercise	<p>I'd really like to be part of sport, I did play basketball at the time of my rehabilitation and even now, I still wanna hold the ball. I try to join the sports team in Pretoria academic but due to lack of transport I can't go so I am not part of any sport now. (Thabang)</p> <p>I always want to involve myself with sport. I love sport but I don't find club and don't even have one due to lack of transport. (Thabang)</p>
	Independence	<p>If you can't do things for yourself it is really tough especially for a man my sister- you understand. I mean no girl wants a man who cant ... (indicating sexual performance) you know. ...Well, my girlfriend she likes me but I have no job. If I marry her on the disability grant, what is the life going to be like.... (Sipho)</p> <p>I just wish I can find a job and stop being a burden to my parents. The disability grant helps, but it is not enough! What happens to me when they (parents) die? (Thabo)</p>



		<p>I just need to find something to do and continue living (Tumelo)</p>
	Employment	<p>Of course I wish I was working so I can look after myself better. I've never really worked even before...you know. I only have std 4. Who will give me job? What job can they give me - I don't know any job. Only selling fruits on the street – now I don't have money to buy. (Sifiso)</p> <p>Job is the big problem my sister. We all want the job. It is more difficult for us with the spinal cord to get job. Eish, I don't know, maybe if the government can help somehow. (Sipho)</p> <p>I think if I get a job and look better after myself I will be happier (Thabo)</p> <p>.....so we can start some business like making things and sell them to make money. But we need money to start, we need help. Maybe you can talk to somebody to help us my sister –he-he... you rich friends? (laughs). (Tumelo)</p> <p>I wish they (therapist) could help me get some job. Yeah, the job is the big problem my sister. Even before I was para I did not have a real job, just piece jobs We all want the job. It is more difficult for us who are para to get job. Eish, I don't know, maybe if the government can help somehow. The disability grant is too little- very little. Maybe some spare jobs must be reserved or the wheelchair people. (Tumelo)</p>



	Follow up after discharge	<p>Maybe they must check on people in the home after discharge- some people they just sit and don't train and they get sick. The physio -they must come and check. (Sipho)</p> <p>Thanks for checking on people like us – it is nice to see that people care you know. God bless you sister. (Thabo)</p> <p>I think you people must keep on checking people like us, especially poor people in shacks and rural areas – those people struggle. You know when you meet them at check up you can tell by the smell that someone has not had a bath in a long time – they are really suffering. It is hard to be disabled and poor – I am lucky, I have my 'sick pension, my wife is working – we are doing fine. But some people are struggling out there – they need your help...(George)</p> <p>When you check us, you can see for yourself our circumstances and how some of us are doing, some abused by their own people. The government must send more people to check on us(Tumelo)</p> <p>....if they (therapists) can go to there areas and help the person in the community and just encourage them to do things and help where they can help(Thabang)</p>
Psycho-emotional issues	Anger	I hate that taxi man who was driving us but I hear he died in the accident. (Selina)
	Sadness	<p>Other people see you first time and they cry – that makes you cry.</p> <p>I try to live normal, but people they see you as abnormal and it's not nice. Some look at you and say shame and you feel sad sometimes you ignore them. (Thabo)</p>
Use of free time	Positive	I read books and newspapers, I watch TV when I am tired of reading. I chat with my visitors –

		I have many friends – you can see this one here (he points at a visitor waiting outside) (George)
	Negativebut when everyone is at work or school, it is just me and my wheelchair- I wish I could do something during the day. (Siffso) Otherwise I always go to the shops and hang out with the other guys – there so many guys who are not working here my sister. We talk, share some smoke and drink and just hang out.(Tumelo) My friends sometimes visit, but most of the time I am just in the house- it's easier that way..... When I am alone at home – I don't bother anyone you know – asking for this or for help with that. (Thabo)

THEME 2: ENVIRONMENTAL INFLUENCES

SUBTHEME	CATEGORIES	SUPPORTING STATEMENTS
ATTITUDE OF OTHERS	OTHER PLWSCI	Most of the time I see the patients they need to be pushed they need to be feed even when their hands are working. They are just lazy (sounds angry) and they just make everybody to feel pity and that makes me angry.... that's what makes everybody think that when you are in a wheelchair you can't do anything for yourself. They can't even hire you for job because you will be relying on them for things (Thabang)
	MEMBERS OF THE	Other people see you first time and they cry – that makes you cry. (Thabo)



	COMMUNITY	<p>I try to live normal, but people they see you as abnormal and it's not nice. Some look at you and say shame and you feel sad sometimes you ignore them. (Thabo)</p> <p>I don't like it when people go "ag shame". It irritates me that kind of attitude, but I understand I would probably do the same if I was able bodied too- I don't know, maybe. It is okay at school and around home – everyone knows me and they are fine. I guess when you meet new people, they react differently, and you can feel that – I suppose it is human but... I don't know. (Selina)</p>
SOCIAL SUPPORT	POSITIVE	<p>Life is okay auntie Joyce. I just feel sorry for my wife because I don't satisfy her sexual needs. But she supports me well.(George)</p> <p>My neighbour comes and then prays for me. My family is very much helping (Sififso)</p> <p>Having parents who were both working and could afford some thing (like my computer studies) really helps. I can't imagine being poor and disabled- it must be really tough. I really thank God for my parents. Not everyone is as lucky as me – I have everything I need. (Selina)</p>
	NEGATIVE	<p>The problem is that some people in the families they take the money for themselves. They use the money to buy alcohol and stuff, and the paralysed person does not get his money. They eat his money and don't even buy him healthy food (voice loud –</p>

		<p>looks angry). That is a huge problem. (Tumelo)</p> <p>The guy from the other block, his mother is too old to help him, shame. I visit him sometimes but I cannot help too much as I am also paralysed (paraplegic).</p> <p>I also don't have many people who visit me. (Sifiso)</p> <p>.... I always go to the shops and hang out with the other guys – there so many guys who are not working here my sister. We talk, share some smoke and drink and just hang out. (Tumelo)</p>
TRANSPORTATION	AVAILABILITY AND COST	<p>When I want to go somewhere, first you struggle to get to the taxi, then you pay more; or else you must hire a car and it is too much.... The money gets finished on transport if you go to Academic for check up. The taxis charge you a special. (Sifiso)</p> <p>Transport is also a problem for many people. Someone in the government must do something for those who are suffering. (Selina)</p> <p>I think that "Maspala" (the municipality) must help us- yes the government must do something. Like special transport because it is expensive to hire transport to go to clinic. (Tumelo)</p>



ACCESS	AT HOME	<p>That is another problem my sister---the wheelchair can not get in the house easy because it is big for the door. You see my shack is small. I do not have a good place to live. Some people who are quadras (quadruplegic) never get out because of the steps at the door. (Tumelo)</p> <p>Well people need jobs, better houses – you know some people live in zozo’s with wheelchairs.</p>
	AROUND THE COMMUNITY	<p>You see the way coming here, the high hill...it is heavy. You can go down but coming up it is heavy (too steep). You can ask people to push you but as I told you I like doing things for myself but its heavy. (Thabang)</p> <p>Where I live it is difficult for the wheelchair. There are big holes on the road, see my wheelchair is broken. I don’t go out a lot, I live only with my family. (Sififso)</p> <p>Hm... and the township – the roads can be bad for wheelchairs – they must all be tarred. (Selina)</p> <p>.... when it rains the streets are not okay with the mud for the wheelchair. (Tumelo)</p>
	TO FACILITIES	<p>I have to pay R150 just to go and come back from hospital. That is the most</p>



		<p>challenging part of my life. The little bit I have is for transport and food. (Thabang)</p> <p>I don't go to physio because of transport now I am forced to exercise here by myself. I have all the exercise things; I know exercise is healthy for me so I do all the movements. Let me show you my 'home gym' (shows me the equipment he has for exercising – weights and an abdominal exerciser) (Thabang)</p> <p>I need transport to go to check up.(Tumelo)</p>
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APPENDIX N: TRANSCRIBED AND TRANSLATED INTERVIEW

I: Ke lebogela nako ye le mphileng yona go tlo boledishana le lena ka bophelo bja lena e sale le gobala ka 'spinal cord injury' Ke ratA go 'cheka' gore bjale ka ga le 'kreile' rehabilitation, le phela bjang mo gae. E kaba go na le mathata ao le kopanang le ona, and le a bereka bjang. Gape ke rata go tseba gore e kaba go na le eng se re ka se dirang during rehabilitation go thusa gore batho ba phele betere magaeng ge ba na le SCI.
Thank you for giving me this time to come and talk to you about how your life has been since you sustained a spinal cord injury. I would like to find out now that you have been through rehabilitation, how do find life out here at home? Are there any problems that you encounter and how do you cope with them? I also wish to find out if there is anything you can be done during rehabilitation to better prepare people with SCI for life in the community

P: Okay...

I: Ge eba go na le potso e o sa e thlaologanyeng, kgotsa o sa rateng go e araba, o lokologile gore o re bjalo.
If there is any question that you do not understand or don't feel like answering, you are free to say so.

P: Gape le g eke sa tsebe karabo ke re bjalo:
Also if I don't know the answer I must tell you?

I: Nods

P: Okay - gone ga go na bothata
Okay then, no problem.

I: Mpolelle gore o fumana bophelo bo le bjang ga o na le SCI?
Tell me, how are you coping with living with SCI:

P: Ah.. mmane Joyce, nna ke a iphelela waitisi, ga ken a bothata ga kalo.
Ah.. auntie Joyce, I am living okay. I have no problems really.

I: So mo gae, o kgona go itirela dilo tsohle?
So you are able to do everything for yourself here at home?



P: Ee, ke a kgona.

Yes, I can

I: Ke ra gore o kgona go itérela dijo, go ithlapisa, go ya toilet, le dilo tse bjalo?

I mean can you make your own food, bath yourself, go to the toilet etc?

P: Ee ke a kgona...ts tsohle. Go ya toilet ke ne ke dirisa 'gloving' Jaanong ke tsaya dipilisi, ka be ke ya toilet ka nako e rileng.

Yes, I can do them all. For the toilet I was using the glove, now I use the timing method with tablets

I: Ga o na bothata go 'tsamaya' around mo ntlung le ka fo ntle?

Don't you have any problems moving in and around the house?

P: Nyaya – bothata fela ke steps se ka mo pele

No problem except for the step at the entrance

I: Go tsamaya mo motseng gone – ga a na bothata?

Any problem moving around the neighbourhood

P: Ga go bothatha – ke ya le ko 'complexeng' ntle le bothata – ene wa e bona tsela e ya namella.

No problem – I even go to the shopping complex without any problem – and you can see the road is a bit steep

I: O dira eng letsatsi lohle:

How do you spend your days?

P: Ke bala dibuka le di-newspaper, ke sheba TV ga ke lapile go bala. Ke tlotla le baeti bame – ke na le dichomi tse dintsi – o a mmona le yena o (o supa moeti o letileng ko ntle)

I read books and newspapers, I watch TV when I am tired of reading. I chat with my visitors – I have many friends – you can see this one here (he points at a visitor waiting outside)

- I: O bona bothselo bo le jwang ka mo gae
How do you find life with the family
- P: Botshelo bo tamaya pila mmane Joyce, Ke utlwela mofumagadi bothloko
gonne ga ke mo kgotsofatse dikobong. Empa yema o nsapota pila.
*Life is okay auntie Joyce. I just feel sorry for my wife because I don't satisfy
her sexual needs. But she supports me well.*
- I: Mpolelle ka rehabilitation ya gago – e ne e le bjang
Tell me about your rehabilitation experience
- P: Rehabilitation e nthusitse thata – ke a le leboga. Le fa ke le jana, at least ke
kgona go itirela tsohle.
*Rehabilitation helped me a lot – I am thankful. Even though I am like this, at
least I can do things for myself*
- I: (NODS)
- P: Ke rata fela go ikopela gore ma-nurse a re treate pila. Waitsi ga molwetsi a
bitsa nurse a mmolella gore 'nurse ga ke alright (gongwe o itshinyeditse)',
ya ba nurse e mo araba ka gore "ga o monna wame"... - ga go pila waitsi.
Ga kere bohle ba bjalo, bontsi bo lokile. Re kopa gore ba re naganele, ga
rea itira gore re nne bjana.
*I would like to ask the nurses to treat us (PLWSCI) well please. You know,
when a patient calls a nurse and says "nurse I am not okay (like soiled
himself) and the nurse replies "you are not my husband", that is not nice. I
am not saying all nurses were like that, most of them are good. I just ask
that they should feel for us – we did not choose to be like this.*
- I: Training yona ene e le bjang ko rehabilitation?
What about the training at rehab – how was it?
- P: Maphysio – eish, ba trainana thata – ba a go pusha! Re a itse gore ba a re
thusa empa ba tshwanetse go leka go se be so pushy. Segolothata kwa

tshimologong, ga motho a sa leka go thlaologanya gore go irega eng ka mmele wa gagwe...

The physios – eish, they push us very hard. We know that they are help us but they must not be so pushy. Especially early in rehab, when one is still trying to understand what is happening with his body...

I: A go na le sengwe se o ratang re ka bua ka sona:
Anything else you would like to say

P: Ke nagana gore go ka nna pila ga le ka etela batho ba ja ka rona, thata ba nnamg mo mekhukhung le ko magaeng – batho bao ba a sotlega. Waitsi ga o kopana le bona ko ‘check-up’ o utlwa fela ka monkgo gore ke kgale mothe a sa thlape – ba sotlega e le tota. Go boima go golofala o le modidi. Nna ke lehlogonolo gone ken a le ‘sick pension’, mofumagadi o na le tiro – re phela sentle. Fela batho ba bang ba a sotlega – ba hloka thuso ya lona.
I think you people must keep on checking peple like us, especially poor people in shacks and rural areas – those people struggle. You know when you meet them at check up you can tell by the smell that someone has not had a bath in a long time – they are really suffering. It is hard to be disabled and poor – I am lucky, I have my ‘sick pension, my wife is working – we are doing fine. But some people are struggling out there – they need your help...



APPENDIX O: DECLARATION BY LANGUAGE EDITOR

Ruth Scheepers

Language Specialist

30 November 2010

To whom it may concern

This is to confirm that I, Ruth Angela Scheepers, edited Joyce Mothabeng's doctoral dissertation for language and style. The onus is, however, on the student to implement the changes that I suggested.

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