

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 Natalspuit 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
	Use of time	Personal needs
		Negative use of time
		Positive use of time
	ENVIRONMENTAL FACTORS	Attitudes of others
Other PLWSCI		
Social support		Emotional support
		Instrumental support
		Appraisal support
		Social companionship
Accessibility issues		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.