CHAPTER 7

DISCUSSION OF THE INTEGRATED STUDY FINDINGS, CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

7.1 INTRODUCTION

This study arose out of concerns regarding the challenges facing PLWSCI in terms of community participation. The main aim of this study was therefore to explore the factors influencing the community participation by PLWSCI living in the Tshwane (Greater Pretoria) metropolitan area. The study was divided into two phases, namely a quantitative and a qualitative research phase, in order to address the distinct objectives underlying the main research aim. Firstly, the participants' level of satisfaction with their own participation in their own communities and the variables influencing this participation were quantified by implementing validated instruments. Secondly, the perceptions of the participants regarding their community participation were explored through individual interviews. The reason for using a mixed research methodology was that traditional quantitative research methods using measuring instruments such as questionnaires only are not suitable in an exploration of the complex nature of PLWSCI's perceptions and experiences of their community participation (Henderson & Ainsworth, 2003; Thomas & Nelson, 1996). In this chapter, the findings from the two phases of the study are discussed to provide a holistic view of the results and to draw conclusions regarding the factors influencing the community participation of PLWSCI in the Tshwane (Greater Pretoria) metropolitan area. These conclusions are discussed in the context of the limitations of the study, and recommendations for future studies are made.

In Chapter 1 of this thesis, Figure 1.3 was used as an initial point of departure framework in illustrating the factors influencing community participation. In this chapter, the conceptual framework, revised according to the results of phases 1 and 2, is presented and discussed in relation to the findings. This framework is used to discuss the implications of the study and to make recommendations to

relevant stakeholders regarding the optimisation of community participation by PLWSCI.

7.2 SUMMARY OF THE RESULTS OF PHASE 1 OF THE STUDY

The first phase of the study was a quantitative survey conducted on a sample of convenience comprising 160 PLWSCI. The sample size was determined using the principles of factor analysis.

7.2.1 Objectives of Phase 1 of the study

The objectives of the quantitative phase of the study were: (1) to determine the demographic and SCI profile of the participants; (2) to measure selected variables associated with community participation amongst the participants by using validated measurement instruments; (3) to statistically determine factors associated with community participation by PLWSCI; (4) to validate the measuring instruments psychometrically in order to ensure that the results obtained were reliable and valid.

7.2.2 Results of the quantitative phase of the study

The demographic profile indicated that the participants were predominantly young (58% had sustained SCI under 30 years of age), male (90%) and single (64%). Forty percent (40%) of the participants were dependent on a government disability grant for income support, and 60% lived townships. Regarding the SCI profile, 63% of the participants had sustained thoracic and lumbar level injuries (paraplegia), while 37% had sustained cervical level injuries (tetraplegia). Motor vehicle accidents were the major cause of injury, accounting for 71% of the injuries sustained by the participants, followed by violence as causes of SCI.

The instruments used in this study were the RNLI, SCIM II and the CHIEF-S. The psychometric properties of these instruments were investigated. The RNLI and the SCIM II were found to be reliable and valid with Cronbach's alpha values of 0.97 and 0.93 respectively. The validity of both instruments was also established, using

item convergent and discriminant techniques and factor analysis. The CHIEF-S, however, was not found to be valid or reliable for this study population of PLWSCI.

The participants' satisfaction with their community participation was generally low, with only 20% of them expressing satisfaction. Satisfaction with community participation was found to be significantly associated with the participants' race, level of education, whether they were employed or not, educational qualifications, years of living with SCI, level of SCI, health complications, perceived health status, functional ability and perceived environmental factors such as physical (structural and geographic) barriers and lack of transport. Further analyses using multiple regression revealed that employment and environmental barriers were significant predictors of participants' satisfaction with community participation, together accounting for 50% of the variance.

7.3 SUMMARY OF THE RESULTS OF PHASE 2 OF THE STUDY

The second phase of the study used a qualitative research technique, during which an interview was conducted with a purposive sample of PLWSCI, comprising 15 participants (purposively selected from the participants in phase 1 of the study) who could add rich information on the factors that influenced their community participation. T-tests indicated that there was no significant difference between the sample groups in Phase 1 and Phase 2 of the study, suggesting that the participants in Phase 2 were a truly representative sample of the group in Phase 1.

7.3.1 Objectives of Phase 2

The main objective of the qualitative phase of the study was to explore participants' perceptions and experiences of community participation.

7.3.2 Results of the qualitative phase of the study

The results of this phase of the study revealed that all the participants felt that the rehabilitation they had undergone had prepared them "somewhat" for community

participation. It appeared that those participants who had social support, both emotionally and financially, and those who were employed had a satisfactory experience of participation. The need for follow-up care from rehabilitation professionals was expressed, especially by those participants who lived in townships and those who did not have access to their own transport or to health care.

From the analysis of interview transcripts, two main themes emerged regarding factors influencing participation, that is, personal and environmental factors. Personal factors include features of an individual that are not part of his/her health condition. The categories of personal factors identified as influencing participation included participants' coping strategies, their rehabilitation experience, future aspirations, personal needs and their use of free time (leisure). Environmental factors are external to the person and include physical surroundings, social aspects and attitudes of others. The environmental factors identified as influencing participants' community participation in this study included attitudes of others, social support, and accessibility problems, mainly transport.

7.4 HOLISTIC DISCUSSION OF THE STUDY FINDINGS

The two phases of the study revealed that similar categories of factors influenced the participants' community participation. In Phase 1 of the study, three categories of factors namely, "personal factors", "disability factors" and "environmental factors" were identified as influencing participants' community participation. Similarly, in the second phase of the study "personal" and "environmental" factors were identified by PLWSCI as influential in their community participation. Collating the results of the two phases, it became clear that that the community participation of these PLWSCI was chiefly related to three major categories of factors, namely personal factors, disability-related factors and environmental factors.

With reference to "personal factors", the study revealed that satisfaction with community participation was greater in participants who had been living with SCI for longer periods, who had more years of basic education, who were employed, who were not black Africans, who lived in suburbs, and who had their own source

of income. The results of the interviews indicated that community participation was enhanced if participants had a positive outlook on life and engaged in creative activities during their free time.

Under the theme “disability-related factors”, satisfaction with community participation was associated with the level of spinal cord injury, functional ability (SCIM) and perceived general health .

In the case of “environmental factors”, satisfaction with their community participation was greater in those participants who experienced fewer environmental barriers on the CHIEF-SF. The results of the interviews indicated that the “attitudes of members of society”, “accessibility of the environment” and “social support” were factors that influenced the participants’ satisfaction with community participation.

The factors that influence the community participation of PLWSCI are summarised in Table 7.1. This table makes it clear that employment (personal factor) and accessibility (environmental factor) were factors common to both phases of the study. This finding highlights the importance of these two issues in participation, and further confirms the results of the regression analysis in Phase 1, which identified both employment and accessibility as significant predictors of participation.

Table 7.1: Factors influencing community participation

THEME	SUB-THEME	SUB-THEME ASPECTS
PERSONAL FACTORS	Coping skills (Phase 2)	Acceptance
		Attitude to own condition
		Social comparison
	Rehabilitation experience (Phase 2)	Negative experiences
		Positive experiences
	Employment (Phase 1 and 2)	Employed vs. unemployed
	Residential area (Phase 1)	Township, suburb or other
	Race (Phase 1)	African vs. non African
	Aspirations (Phase 2)	Future hopes
		Personal needs
	Use of time (Phase 2)	Negative use of time
		Positive use of time
DISABILITY RELATED FACTORS	Years living with SCI (Phase 1)	Number of years
	Perceived health (Phase 1)	Fair, good or very good
	Functional ability (Phase 1)	Mobility and ADL
EVIRONMENTAL FACTORS	Attitudes of others (Phase 2)	Able bodied people
		Other PLWSCI
	Social support (Phase 2)	Emotional support
		Instrumental support
		Appraisal support
		Social companionship
	Accessibility issues (Phase 1 and 2)	Home accessibility
		Community accessibility
		Transportation

7.5 A CONCEPTUAL FRAMEWORK FOR ENHANCING THE COMMUNITY PARTICIPATION OF PEOPLE LIVING WITH SPINAL CORD INJURY

When individuals sustain a spinal cord injury, their life sphere balance becomes disrupted. The SCI affects not only the physical body, but every aspect of an individual's life, resulting in loss of physical function, disruption of social and family roles, and financial hardship. Following rehabilitation, PLWSCI are discharged into the community with the hope that they will adapt to their new identity (as a person with a disability), reintegrate into society and participate as near normally in

various social roles. The ultimate goal of rehabilitation for PLWSCI is to prepare them for community participation, which is the focus of this thesis.

In Chapter 1 (paragraph 1.10.4), community participation was defined as "being part of the mainstream of family and community life and being involved in everyday life situations". This definition makes it clear that the community participation of PLWSCI is influenced by characteristics of the person living with the spinal cord injury, and of those of the societal environment. Participation therefore represents a balance or "fit" of the individual within the environment.

In order to form a holistic picture of this person-environment "fit", which is at the core of participation, a comprehensive conceptual framework of the factors that influence community participation was developed, based on the results of Phase 1 and 2 of this study. This comprehensive conceptual framework was developed by revising the initial community participation framework that was presented in Chapter 1(Figure 1.4). A number of variables identified in both the quantitative and qualitative data analysis as being influential on community participation contributed to the revised framework illustrated in Figure 7.1. According to this framework, community participation of PLWSCI is influenced by factors related to the person with SCI, the resultant disability and the environment in which the person finds him/herself. The framework illustrates the complex and multidimensional nature of community participation. The complexity of the relationship between the various factors that influence community participation of PLWSCI is illustrated with single and bi-directional arrows.

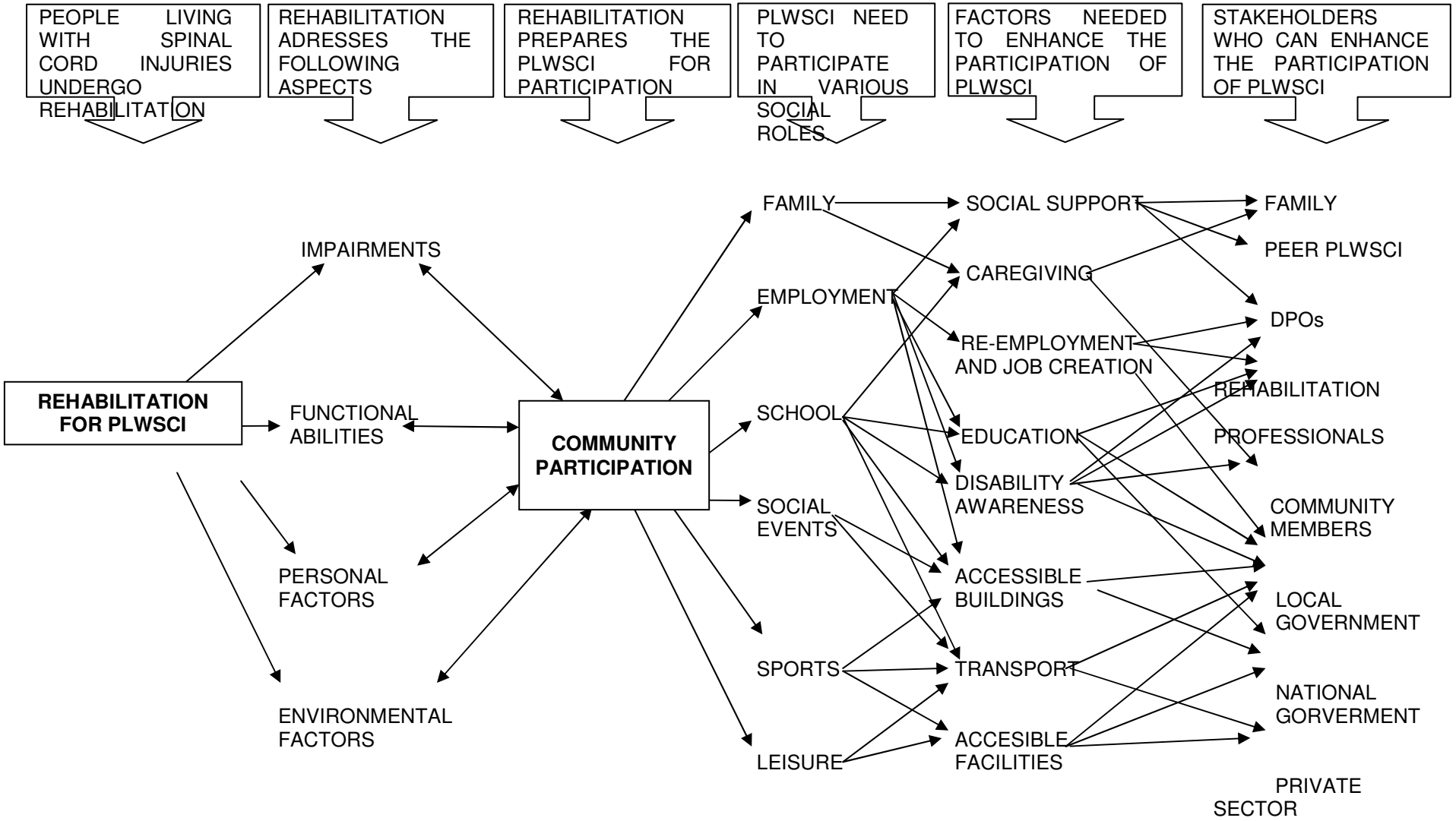

Figure 7.1: A framework of community participation for PLWSCI

7.6 RECOMMENDED STRATEGIES FOR FACILITATING THE COMMUNITY PARTICIPATION OF PLWSCI

In this section, strategies for facilitating the community participation of PLWSCI are presented, based on the framework in Figure 7.1. In drafting the strategies, Kipling's 5WH (**what, why, where, when, who and how)** approach was utilised (Kipling, 1987). The 5WH is a useful technique for addressing complex issues that require all the information to be identified before a way forward can be formulated (http://www.improvementnetwork.gov.uk): in this case, the development of a strategy/strategies or action plans to enhance the community participation of PLWSCI. The 5WH was used to describe:

- **What** are the key issues influencing the community participation of PLWSCI and **Why** are these issues a problem?
- **Where and when:** under what conditions do the issues pose problems?
- **Who** needs to be consulted to address which issues and **how** can these issues be addressed by the relevant stakeholders?

The identification (questions **what** and **why**) and exploration (questions **where** and **when**) of the factors influencing participation were discussed at length in Chapters 5 and 6. The recommended strategies presented in this section are derived from the framework presented in Figure 7.1, and are focussed on the question **how** to address the factors, by identifying **"what needs to be done by whom"**.The suggested strategies are directed at specific stakeholders, but require a multi-sector approach through which PLWSCI, family members, community members, rehabilitation professionals and policy makers at different levels of government can all be involved. Table 7.2 illustrates strategies proposed to facilitate the community participation of PLWSCI.

Table 7.2: Strategies for facilitating the community participation of PLWSCI.

THEME	SUB-THEME	PROPOSED STRATEGY (WHO SHOULD DO WHAT)
PERSONAL FACTORS	Coping skills	WHO: Rehabilitation professional and fellow PLWSCI WHAT: • PLWSCI should be educated about the various coping strategies that will enhance their community participation. • Fellow PLWSCI with experience living with SCI can be a useful resource in this regard (organized through support groups).
	Rehabilitation experience	WHO: Rehabilitation professionals WHAT: • More positive rehabilitation experiences in terms of what activities/ strategies? to be created for PLWSCI. • Rehabilitation professionals need to be educated on the importance of the professional-patient relationship for the rehabilitation outcomes of PLWSCI.
	Employment	WHO: National Department of Labour and the private sector WHAT: • Existing laws regarding the employment of PWD should be enforced, and maybe more incentives given to companies and/or organisations employing PLWSCI where relevant. • Opportunities for employment need to be created PLWSCI need to be empowered for employability or self employment
	Aspirations and Use of free time	WHO: Rehabilitation professionals, Disabled People's Organisations (DPOs) and PLWSCI WHAT: • Aspirations like participation in sport/ leisure activities as part of maintaining a healthy lifestyle (prevention of lifestyle diseases) should be encouraged from early on in rehabilitation. • Rehabilitation professionals should refer interested PLWSCI to sporting clubs of their interest via the relevant DPO (in this case QASA), to make sure that PLWSCI make constructive use of their free time through health beneficial activities.

Table 7.2 (cont): Strategies for facilitating the community participation of PLWSCI

THEME	SUB-THEME	PROPOSED STRATEGY (WHO SHOULD DO WHAT)
	Health problems	WHO: Rehabilitation professionals WHAT: • Intensified education regarding self management during rehabilitation • Monitoring of the PLWSCI's health and assistance by family and/or community members • Follow up visits by rehabilitation professionals to check up on the health and wellbeing of the PLWSCI and to determine whether the rehabilitation goals have been achieved. • Ensure that PLWSCI are engaged in health promoting activities by continuously emphasising the importance of diet, physical activity and pressure relief. The activities can take the form of individual follow up, or public health campaigns.
	Functional ability	WHO: Rehabilitation professionals WHAT: • Ensure that PLWSCI have reached their expected maximum level of functional ability before discharge from rehabilitation' • Follow up visits to make sure the PLWSCI progress towards the expected level of functioning.
EVIRONMENTAL FACTORS	Attitudes of others	WHO: Rehabilitation professionals and PLWSCI WHAT: • Disability awareness programmes for the general public to be organised in the relevant local communities where PLWSCI live
	Social support	Support from Family WHO: family and caregivers WHAT: • Emotional and physical support with some ADL's Support from Peers WHO: Peer PLWSCI WHAT: • Participation in local peer support groups

Table 7.2 (cont): Strategies for facilitating the community participation of PLWSCI

THEME	SUB-THEME	PROPOSED STRATEGY (WHO SHOULD DO WHAT)
EVIRONMENTAL FACTORS	Accessibility issues	Home accessibility WHO: Rehabilitation professionals and peer PLWSCI WHAT: • Advice regarding adaptation of the home environment • Advice regarding coping with different challenging home accessibility issues Community accessibility WHO: Local government WHAT: • Enforce accessibility rules for buildings Transportation WHO: National Department of Transport WHAT: • Make public transport accessible (fast track the DoT strategy)

7.7 ROLES OF VARIOUS STAKEHOLDERS IN FACILITATING COMMUNITY PARTICIPATION OF PLWSCI

This study identified a number of factors that influence community participation of PLWSCI. However, not all the factors identified can be directly addressed by rehabilitation professionals. Personal factors such as gender, race or age related factors (years of basic education and years living with SCI) are not amenable to change through any rehabilitation intervention. Disability related factors like 'functional ability' can be directly influenced by rehabilitation. On the other hand, environmental factors like accessible buildings and road conditions need to be addressed by other stakeholders in collaboration with rehabilitation professionals.

Table 7.1 identifies numerous stakeholders who have a role to play in the community participation of PLWSCI. These stakeholders include physiotherapists and other rehabilitation

professionals; the government and the private sector; the family of the PLWSCI, peer PLWSCI's, DPO's and community members.

In the ensuing paragraphs, strategies for facilitating the community participation of PLWSCI (as indicated in Figure 7.1) are discussed by highlighting the roles of various stakeholders (people, groups and institutions). Further research is, however, indicated to develop evidence based guidelines for addressing each strategy. Because disability issues affect all sectors of society, a multi-sectoral approach to those affecting the community participation of PLWSCI is indicated, as shown by the links between various factors and stakeholders which are indicated by the arrows in the framework in Figure 7.1.

The roles of the following groups of stakeholders are discussed together:

- Physiotherapists and other rehabilitation professionals
- Government and the private sector
- Family, peer PLWSCIs, DPOs and community members.

7.7.1 Role of physiotherapists and other rehabilitation professionals in facilitating the community participation of PLWSCI

The framework illustrated in Figure 7.1 indicates that physiotherapists and other rehabilitation professionals need to address a number of factors in order to facilitate the community participation of PLWSCI. Disability related factors can be directly influenced by physiotherapists and other rehabilitation professionals. Direct measures include physically rehabilitating the PLWSCI to a point at which they are functionally capable of fulfilling various roles in the community, educating them and empowering them to take responsibility for their own health and well-being after discharge from rehabilitation. Through optimum physical and functional rehabilitation, the participation of PLWSCI in society, including participation in gainful employment, may be facilitated. Other personal factors such as lack of basic education and unemployment could be partly addressed through vocational rehabilitation by the relevant rehabilitation professional (mainly occupational therapists).

Vocational rehabilitation should therefore be incorporated in the treatment of spinal cord injuries to prepare PLWSCI for reintegration into the workplace and the community. Vocational

rehabilitation is aimed at assisting PLWSCI to secure gainful employment that commensurate with their abilities and capabilities. The ability to return to, or secure an employment that offers remuneration is a vital outcome of integrating PLWSCI back into the community. Employment provides people with better social reputation, good sense of self worth, purpose in life and financial stability. Ways to upgrade occupational outcome are based on education, peer groups, vocational counseling, and changing employer's perception, improving transportation, and reducing financial disincentives to employment.

On the other hand, environmental issues such as transport, social support and discriminatory practices require a different intervention at local and/or national policy or societal level. Physiotherapists and other rehabilitation professionals can play an advocacy role on policy issues affecting PLWSCI. Advocacy is part of the social responsibility of physiotherapists and other rehabilitation professionals.

7.7.1.1 Social responsibility implications for rehabilitation practitioners

Social responsibility means that an individual is bound as a human being to strive towards enhancing the quality of life of his/her fellow human beings (Bezner, 2004). The WHO's Jakarta Declaration on Health Promotion of 1997 highlights social responsibility as an important aspect for addressing pertinent social health issues and emerging health threats (Mittelmark, 2001). Physiotherapists and other rehabilitation professionals have a social responsibility to optimise the community participation of PLWSCI and to minimise the burden of disability due to SCI on society.

Social responsibility was identified as a core value of professionalism by the American Physical Therapy Association (APTA) at their consensus conference in July 2002. The APTA consensus statement encourages physiotherapists to embrace all aspects of social responsibility, including advocacy, promotion of cultural competency and community service. It is important that physiotherapists adopt social responsibility as one of the core values for the development of the profession (op cit).

The APTA consensus statement defines social responsibility as "the promotion of the mutual trust between the professional and the larger public that necessitates responding to societal

needs for health and wellness" (Bezner, 2004). Indicators of social responsibility according to APTA include:

- *Advocating for health and wellness needs of society including access to health care and physical therapy services.*
- *Promoting cultural competence within the profession and the larger public.*
- *Promoting social policy that effect function, health, and wellness needs of patients/clients.*
- *Ensuring that existing social policy is in the best interest of the patients/clients.*
- *Advocating for changes in laws, regulations, standards, and guidelines that affect physical therapist service provision.*
- *Promoting community volunteerism.*
- *Participating in political activism.*
- *Participating in achievement of social health goals.*
- *Understanding of current community-wide, nation-wide and worldwide issues and how they impact society's health and well-being and the delivery of physical therapy.*
- *Participating leadership in the community.*
- *Participating in collaborative relationships with other health practitioners and the public at large.*
- *Ensuring the blending of social justice and economic efficiency of services.*

Being "socially responsible" implies that rehabilitation professionals have an ethical obligation to strive for a better quality of life for their clients (in this case PLWSCI) (Clark, 1993). Advocacy is thus a crucial element of the physiotherapy profession. However, some physiotherapists do not think that social advocacy is part of their professional role. Physiotherapists participating in a study to evaluate a service provider's perspective on the physiotherapy services required at primary health care level indicated that advocacy and mediation **were not important roles** and that these belonged to other professionals, like lawyers (Maleka, 2009). Physiotherapists who make such or similar comments, or who identify with such comments, do not seem to understand that advocacy is an important aspect of their role as professionals and part of their social responsibility. Such an attitude or viewpoint is a matter of serious concern in this era of the bio-psychosocial approach to healthcare, where rehabilitation and other healthcare practitioners are expected to practise from a holistic perspective of patient care.

This "role denial" is probably historical, based on the slogan of the physiotherapy association in South Africa which states that "the difference is in our hands". This slogan may lead some physiotherapists to believe that their role is only to "handle" patients, and not to get involved with socio-political issues. In response to this, the Private Practitioners group of the SASP has created a new slogan which states "***together, we are the difference"*** (SASP, 2009). This slogan moves the emphasis from treating only with the touch of the hands, to the collaborative involvement of professionals in making a difference in patient communities. Advocacy should therefore be emphasised in the profession, during both undergraduate and postgraduate training, and in continuing professional development activities.

Awareness of advocacy and other dimensions of social responsibility such as providing leadership in society, engaging in political activism to influence healthcare policy, and promoting cultural competence and ethical practice within the profession must be raised among physiotherapists. In the Annual Report of 2008-9, the South African Society of Physiotherapy (SASP) purported to have embraced the concept of social responsibility and it has already conducted a survey of the membership regarding this concept (SASP, 2009). The SASP, as the official mouthpiece of the profession in South Africa, is the ideal vehicle for organising continuing professional development activities which could include educating physiotherapists about social responsibility.

The following quotation from one of the participants in Phase 2 of the study highlights the advocacy role that physiotherapists and other rehabilitation practitioners should play:

> *I wish they (therapist) could help me get some job. Yeah, the job is the big problem my sister. Even before I was a 'para, I did not have a real job, just piece jobs. We all want the job. It is more difficult for us who are 'paras' to get job. I don't know… maybe if the government can help somehow. The disability grant is too little - very little. Maybe some spare jobs must be reserved for the wheelchair people (Tumelo).*

7.7.2 Role of the Government and the private sector in facilitating the community participation of PLWSCI

Policies and legislation regarding the health and well-being of the citizens of this country are determined and promulgated by government at various levels. Since the democratic dispensation began in South Africa in 1994, health sector reforms have been instituted, resulting in the development of policies on the provision, financing and regulation of health care. The guiding principle behind these policies is the establishment of equity and efficiency within the overall health system, as dictated by the Bill of Rights enshrined in the Constitution. With specific reference to health issues affecting PLWSCI and other PWD, the following pieces of legislation have been promulgated:

- The White Paper on an Integrated National Disability strategy
- The Promotion of Equality and Prevention of Unfair Discrimination Act
- The Department of Public Service Administration's *Bathopele* (people first) principles
- The Disability Rights Charter
- The National Department of Health's Patients' Rights Charter
- National Rehabilitation Policy and
- Free Health Care for People with Disabilities at hospital level.

While the country has these excellent policy documents in place, the results of this study have indicated that PLWSCI still experience huge challenges in terms of living with SCI in the community. These challenges suggest that there is a gap between policy formulation and implementation. This gap between policy and practice demonstrates a lack of "implementation capacity" which must be highlighted through advocacy action by all stakeholders including rehabilitation practitioners.

The government (both local and national) and the private sector should work together as partners in addressing the policy issues related to the factors influencing community participation which were identified in this study, namely access to rehabilitation, employment and transport.

7.7.2.1 Improving accessibility to follow-up healthcare and rehabilitation

In November 2000, the South African National Department of Health launched the National Rehabilitation Policy (DoH, 2000). This policy (NRP) was developed in response to the issues raised in the Integrated National Disability strategy (1997). The main aim of the NRP was to improve access to healthcare (including rehabilitation follow up) for previously disadvantaged communities, especially those residing in socio-economically disadvantaged areas.

In order to address the challenges of access to healthcare and rehabilitation, "compulsory community service" (CCS) was instituted for all health professionals by the South African National Department of Health (DoH, 2003). However, the findings of this study suggest that there is still a great deal to be done if CCS is to achieve its intended goals. This study has established that a lack of resources (finances and/or transport) makes it difficult for some PLWSCI to visit hospitals for general health check ups. Therefore a major rehabilitation policy implication, based on the findings of this study, is the need for follow-up care for PLWSCI. The government should be encouraged to make financial resources available to allow for the implementation of a variety of follow-up programmes for PLWSCI.

The following methods of follow up could be implemented (Bloemen-Vrencken et al., 2005):

a) Tele-rehabilitation

Tele-rehabilitation is the use of Information and Communication Technologies (ICT), mainly telephone and the internet, to provide rehabilitation services remotely to people in their homes or other environments. By using ICT, clients' access to care will increase and the reach of clinicians will extend beyond the physical walls of a traditional healthcare facility, thus providing for continuity of care to persons with disabling conditions. Through tele-rehabilitation, healthcare professionals can provide follow-up support and education to people living far away from rehabilitation centres. As there is an enormous number of cell phones in South Africa, telephone follow up would be the most viable method, particularly as internet usage is very low among South Africa's black population.

b) Home visits by rehabilitation professionals

Home visits will provide the rehabilitation practitioners with a real life picture of how PLWSCI are living in their communities, allowing them to identify needs and areas of

intervention or referral. As indicated in Chapter 1, home visits are very effective but unfortunately, for various reasons, they are not routinely made.

c) Outpatient consulting services

This service is invaluable for those PLWSCI who are able to access the local clinics and hospitals for physical check-ups. During these check-ups, rehabilitation professionals can identify difficulties PLWSCI may have with daily functioning and provide the necessary support.

7.7.2.2 Creating opportunities for employment

Given the general unemployment of the participants in this study, it is no surprise that 40% of them were dependent on disability grants as their main source of income. The proportion of PWD (including PLWSCI) who are unemployed remains high in South Africa, despite legal mandates such as the Employment Equity Act of 1973 and the Integrated National Disability Strategy (1997) which were promulgated to improve employment opportunities for people with disabilities. According to the Integrated National Disability Strategy White Paper (OSDP, 1997), 99% of people with disabilities (including PLWSCI) in the RSA are unemployed. It is therefore important that the issue of employment for PLWSCI be addressed as a matter of urgency by various stakeholders.

The South African government is a signatory to the United Nations' (UN) convention on the rights of people with disabilities (UN, 2006). The convention requires that governments and other relevant stakeholders recognise the right of persons with disabilities to work, and to compete for employment on an equal basis with others. This includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and a work environment that is open, inclusive and accessible to persons with disabilities.

The convention expects governments to safeguard and promote the realisation of the right to work, including of those who have acquired a disability during the course of employment, by taking appropriate steps, which include legislation. The South African government has established policies that accommodate physically challenged people in the workplace and prevent (limit) discrimination. One such legislation is the Employment Equity Act (EEA), No. 55 of 1998 (DoL, 1998), an employment equity law designed to prohibit discrimination and to promote

affirmative action in the workplace. This law is intended to protect people with disabilities against unfair discrimination and to entitle them to affirmative action measures.

Closely linked to the EEA is the "The Code of Good Practice on Key Aspects of Disability in the Workplace", which was issued in terms of Section 54 (1) (a) of the Employment Equity Act (DoL, 2000). This code is a guide for employers and employees on key aspects of promoting equal opportunities and fair treatment for people with disabilities as required by the Employment Equity Act (the Act). The Act stipulates that the staff complement of any company with more than fifty employees must include people with disabilities (at least two percent). If properly implemented, the act will offer people with disabilities the opportunity to enter the open labour market and mainstream employment (South African Employment Equity, 1999).

In order to accommodate PLWSCI in the workplace, employers are encouraged to make environmental adjustments such as building ramps for wheelchairs and adaptive devices for sanitation usage, inserting railings and increasing work space for wheelchair manoeuvres. Worksite visits and evaluation by rehabilitation professionals could assist employers in this regard. These professionals could advise employers of PLWSCI on how to accommodate them in the workplace. This might include worksite adjustments or placement of PLWSCI in an alternative type of employment.

The field of Information and Communications Technology (ICT) is a very promising intervention for enhancing the employment of PLWSCI because any level of SCI can be trained to use a computer. Computer literacy could therefore facilitate the return to work (RTW) and contribute to the employability of PLWSCI. Pell, Gillies and Carss (1997) examined the impact of computers and assistive device use on the employability of people with physical disabilities in Australia, and found that the provision of computer technology and training to people with physical disabilities improved employment prospects. A new employment development using ICT is termed tele-work (Lidal et al., 2007):

> *Tele-work permits home-based work, as a strategy for RTW for individuals with SCI. The advantages of home-based tele-work include less dependency on community accessibility, or transportation, less focus on physical limitations, medical complications, increased self-efficiency, decreased employer biases, and stress.* (Lidal et al., 2007, 1371)

Being employed influences other life domains and has the potential to enhance the overall quality of life of PLWSCI by increasing financial resources, self-esteem, and participation in community roles. Strategies that are aimed at creating, supporting and/or expanding employment options are therefore vitally important for PLWSCI. In addition, employment is crucial in preventing poverty.

Disability and poverty are intricately linked as both a cause and consequence of each other. Poverty causes disabilities and can furthermore lead to secondary disabilities for those individuals who are already disabled, as a result of poor living conditions, health endangering employment, malnutrition, poor access to healthcare and education opportunities etc. Together, poverty and disability create a vicious circle.

One of the eight Millennium Development Goals of the UN (2007) is the eradication of extreme poverty and hunger amongst all people. This goal that cannot be achieved without taking PWD into consideration, as they are a group of people that is so disproportionately represented among the world's poorest people. Creating employment opportunities will therefore contribute to achieving the MDG of poverty alleviation for PWD, including PLWSCI.

7.7.2.3 Improving access to and availability of public transport

The most important influence on accessibility which emerged from this study was transportation. Transport is vital in the lives of PLWSCI because of their limited mobility. The UN Convention on the Rights of Persons with Disabilities (PWD) addresses issues of accessibility in article nine (UN, 2006). According to this article, governments are required to take appropriate measures to ensure that PWD have access (on an equal basis with others) to the physical environment, to transportation, to information and communication, and to other facilities and services open or provided to the public, both in urban and in rural areas. Measures must be put in place to identify and eliminate obstacles and barriers to accessibility to enable PLWSCI and other PWD to live independently and participate fully in all aspects of life.

Transport is a problem for the general public in South Africa, not only PLWSCI. The National Household Transport Survey of the DoT (2005, page 36) revealed that:

(i) almost **half** of the households in the survey said that public transport was either not available or too far away;

(ii) **one third** of households reported that safety from accidents and bad driver behaviour was the most **serious transport problem**;

(iii) **for 20%** of the households the cost of transport was a serious obstacle.

The South African government has therefore put measures in place to address the transport problem through the Public Transport Strategy devised by the Department of Transport (DoT), which will include the following services (DoT, 2007):

a) Accelerated modal upgrading of public transport

This is the short term transformation of road (bus, taxi) and rail services. An existing example is the Bus Rapid Transit system (BRT), which will provide a solution in the form of high quality mass transit services on a cost effective basis to urban areas through a functional network of public transport corridors.

b) Integrated rapid public transport networks

This is an affordable but rapid service to minimise travel time and to ensure safe, convenient and comfortable travel.

These services are expected to be 100% accessible by PWD including PLWSCI, and will include non-motorised transport facilities. The DoT anticipates that by 2014, BRT Corridors will be fully functional in at least 12 metropolitan cities and six rural districts. By 2020, it is envisaged that more than 85% of any metropolitan city's population will be within 1km of an accessible Integrated Rapid Public Transport Network. PLWSCI are involved in the DoT strategy through the South African Disability Alliance (SADA). SADA has mandated the QuadPara Association of South Africa (QASA) and the National Council of People with Physical Disabilities in South Africa (NCPPDSA) to lead all access issues in the DoT strategy (QASA, 2009).

A significant milestone in this regard was that in May 2010, a private company, the Public Utility Transport Corporation (PUTCO) started a disability friendly bus service between the townships of Garankua, Mabopane, Soshanguve and the Pretoria central business district (Appendix P). This is a good example of private sector involvement in facilitating the community participation of PLWSCI. PUTCO's efforts represent not only a significant step towards achieving the goals of the DoT strategy, but they will also have a positive impact on the lives of PLWSCI in terms of

alleviating transportation challenges. As such, they will facilitate community participation. However, despite this positive move, more effort is required to address accessibility issues, as PLWSCI reside not only in the four townships covered by the PUTCO project.

Physiotherapists and other rehabilitation professionals can contribute to the solution of the transport challenge in two ways. Firstly, PLWSCI should be properly trained in transfer techniques in order to be able to move from a wheelchair to a particular mode of transport. Secondly, where applicable, PLWSCI must be provided with suitable equipment to assist this access to transport systems (e.g. crutches or other orthotic devices).

7.7.3 Role of the family, peer PLWSCI and the community at large in facilitating the community participation of PLWSCI

As indicated in Chapter 6, family members and peers living with SCI are a valuable source of social support for PLWSCI. If these PLWSCI are to be integrated and to participate meaningfully in society, the community needs to be educated in accommodating them. An accepting and accommodating environment will be conducive to participation by PLWSCI as productive members of society, within the limits of their disability.

Having outlined the strategies required to facilitate community participation by PLWSCI in this section, the next section presents the limitations of the study. These form the basis for recommendations made regarding further research into the community participation of PLWSCI.

7.8 LIMITATIONS OF THE STUDY

The limitations of this study are mainly methodological and include the possibility of selection bias due to non-coverage and/or no response bias. Non-coverage bias could have occurred as a result of the method of contact used with potential participants, which was telephonic. The possibility exists that those participants who did not have a telephone (i.e. landline or cellular telephone) and were therefore not included in this study may have had a different experience of community participation than those who had telephones. Similarly, the possibility of selection bias exists because those who refused to participate and those who were difficult to contact may also have had a different experience of community participation. To minimise this bias, the

researcher made use of both telephonic and face to face contact to invite participants to be involved in the study.

Another limitation of this study is the fact that it was cross-sectional in nature, and therefore the change in community participation over time could not be explored. This limitation was, however, mitigated by including participants with a wide range of years of living with SCI (range 2 – 25 years) in the sample. Using post hoc comparisons of data obtained from participants with a wide number of "years of living with SCI" helped to shed some light on the change in community participation that took place over time. However, a longitudinal design would have had the advantage of exploring the change in participation over time per individual participant, not across the group of participants.

7.9 RECOMMENDATIONS

The following recommendations are made, based on the findings of the study, in order to address the limitations identified. These recommendations are directed at rehabilitation professionals specifically, and broader multisectoral recommendations are also included.

7.9.1 Recommendations for further research

This study has revealed that two of the instruments used for data collection, namely the RNLI and the SCIM II, were reliable and valid for use in this population of PLWSCI living in the Tshwane (Greater Pretoria) metropolitan area. One instrument, however, the CHIEF-SF, was found to be neither reliable nor valid. There is therefore scope for more work in the area of refinement of the instruments.

7.9.1.1 Further development and refinement of the CHIEF-SF

Further research is required to refine and validate the CHIEF-SF. The language used in the instrument should be adapted (terms like "policy" were a challenge for most participants, despite explanations and examples provided by the researcher). Furthermore, to expect participants to recall the impact of the environment on their experiences over an entire year is a daunting task, especially for participants who are functionally illiterate. An ideal method of determining the

impact of environmental factors on participants' community participation would be to conduct a longitudinal follow-up study at regular intervals (three or at most six months apart).

7.9.1.2 Further development and refinement of the SCIM II

As indicated in Chapter 6, the SCIM II instrument that was used in this study is outdated, and a newer version has just been released following multi-centre validation studies. Although the SCIM II was found to be reliable and valid, further validation using the new SCIM III on the same or similar study population is required.

7.9.2 Recommendations preventing causes and complications of SCI

The causes of spinal cord injury in this sample and the health complications experienced by the participants are preventable issues of concern. Measures need to be put in place to prevent and/or manage these concerns.

7.9.2.1 Preventing causes of SCI

The majority of causes are preventable. Traumatic causes, especially RTAs, require road users to be more careful. More stringent traffic law enforcement is an absolute necessity. A multi-sector approach to this problem is therefore recommended in addressing road conditions and in keeping road users (drivers and pedestrians) in check. In this regard, rehabilitation professionals could partner with agencies such as Arrive Alive in educating the public on road safety issues and, by using SCI, in highlighting the serious implications of not complying with traffic regulations.

The non- traumatic causes identified in this study were TB of the spine, HIV/AIDS, and tumours. TB of the spine can be treated successfully if identified early. Therefore, patients with non-traumatic backache need to be screened thoroughly, and not just symptomatically treated, in order to exclude the diagnosis of TB. Known pulmonary TB patients must be encouraged to adhere strictly to their TB treatment and to finish the course of treatment in order to prevent the infection from spreading to other areas such as the spinal column.

7.9.2.2 Preventing complications of SCI

In this study, pressure ulcers were identified as the most prevalent complications for which PLWSCI were readmitted to hospital. Pressure ulcer management is costly to the patient, the government and taxpayers, and measures should be put in place to prevent these pressure ulcers. The following strategies are recommended for prevention:

- Intensified education and skills training during rehabilitation, to ensure that PLWSCI have the necessary skills to effectively manage their health after discharge.
- Monitoring by family and/or community members, who must be educated about pressure ulcers and what PLWSCI can do to prevent these and the assistance they require to maintain their health after discharge from rehabilitation. Follow up by rehabilitation professionals, as discussed in section 7.7.2.1, is essential.

7.10 CONCLUSION AND SIGNIFICANCE OF THE STUDY

The main aim of this study was to determine the factors influencing the community participation of PLWSCI in the Tshwane (Greater Pretoria) metropolitan area. The study revealed three categories of factors influencing community participation: disability-related factors, personal factors and environmental factors. Employment and environmental barriers were found to be significant predictors of participation, and strategies for addressing these were proposed.

This study breaks new ground in that it is the first in South Africa to investigate the community participation of PLWSCI from a mixed method approach and simultaneously to validate outcome measures related to participation in this population.

The study will make a major contribution to SCI rehabilitation research, policy and practice for the following reasons:

- For rehabilitation professionals, the study has highlighted the importance of being careful when using instruments developed in other settings to measure rehabilitation outcomes. The fact that the CHIEF-SF was not found to be reliable or valid confirms that it cannot be assumed that instruments developed in settings different from the setting of interest will work.
- The study has provided a framework for enhancing the community participation of PLWSCI, which highlights the complexity of factors affecting community participation, and the roles of

various stakeholders from different sectors (rehabilitation researchers, practitioners and policy makers) in promoting community participation among PLWSCI.

- Whereas a large body of research exists internationally on the epidemiology and impact of SCI, there has been a dearth of such studies on the subject in Africa, and more specifically in southern Africa. This study has determined the epidemiology of SCI in the research setting. The findings of this study, together with valuable projects like the QASA database project of listing members and persons with spinal cord injury (QASA, 2008) will contribute to the formation of a national database. A national database will provide the epidemiological information necessary for informing preventative measures and policy directives regarding SCI.

- The study has also identified several rich areas for further research that physiotherapists and other rehabilitation practitioners should pursue further.

7.11 SUMMARY

In this last chapter of the thesis, the integrated findings of the two study phases were discussed and a framework of community participation for PLWSCI was presented. The rehabilitation and policy implications of the framework model were highlighted. A number of strategies for facilitating the community participation of PLWSCI were also presented. The limitations of the study were highlighted and recommendations for further research were proposed.

This thesis has addressed a number of questions in an area of SCI research where there has hitherto been a very limited number of studies, especially in the South African context. This has opened the door to further SCI research, as indicated in the recommendations section of this Chapter