CHAPTER 1

INTRODUCTION

1.1 INTRODUCTORY ORIENTATION

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

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

1.2 BACKGROUND TO THE STUDY

1.2.1 Disability and Spinal Cord Injury

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

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

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

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

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

1.2.2 The rehabilitation of people living with spinal cord injury

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

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

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

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

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

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

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

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

1.2.3 Stages/levels of rehabilitation

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

Table 1.1 Stages and levels of rehabilitation

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

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

1.2.3.1 Early stage rehabilitation

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

Level 0: Physiological instability

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

Level 1: Physiological stability

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

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

1.2.3.2 Mid stage rehabilitation

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

Level 2: Physiological maintenance

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

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

Level 3: Home or residential reintegration

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

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

1.2.3.3 Late stage rehabilitation

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

Level 4: Community reintegration

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

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

Level 5: Productive activity

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

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

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

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

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

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

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

1.2.4 Spinal cord injury rehabilitation in South Africa

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

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

1.2.2.1 Rehabilitation units available to people with SCI

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

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

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

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

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

1.3 PROBLEM STATEMENT

1.3.1 The challenges faced by PLWSCI observed by the researcher

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

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

13.2 Limited research on SCI rehabilitation in RSA

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

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

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

1.4 JUSTIFICATION OF THE STUDY

1.4.1 The importance of research on participation

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

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

1.4.2 The unique context of PLWSCI in South Africa

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

1.5 RESEARCH QUESTIONS

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

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

1.6 RESEARCH FRAMEWORK

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

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

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

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

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

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

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

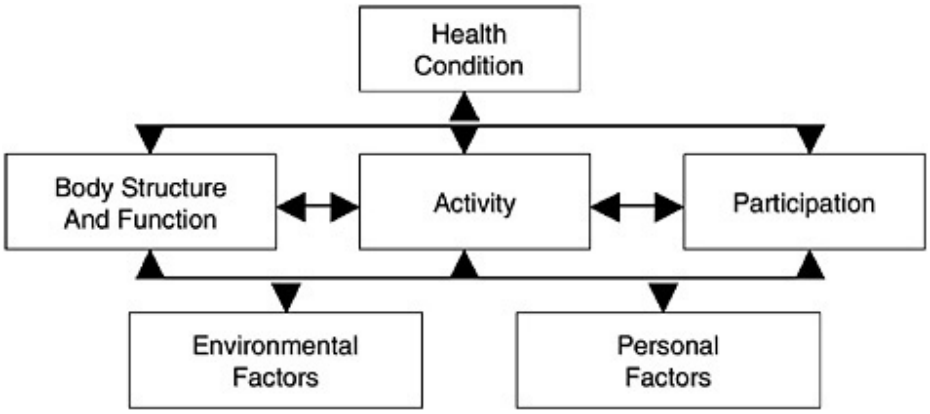

Figure 1.1 The WHO model - ICF (Source: WHO, 2002)

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

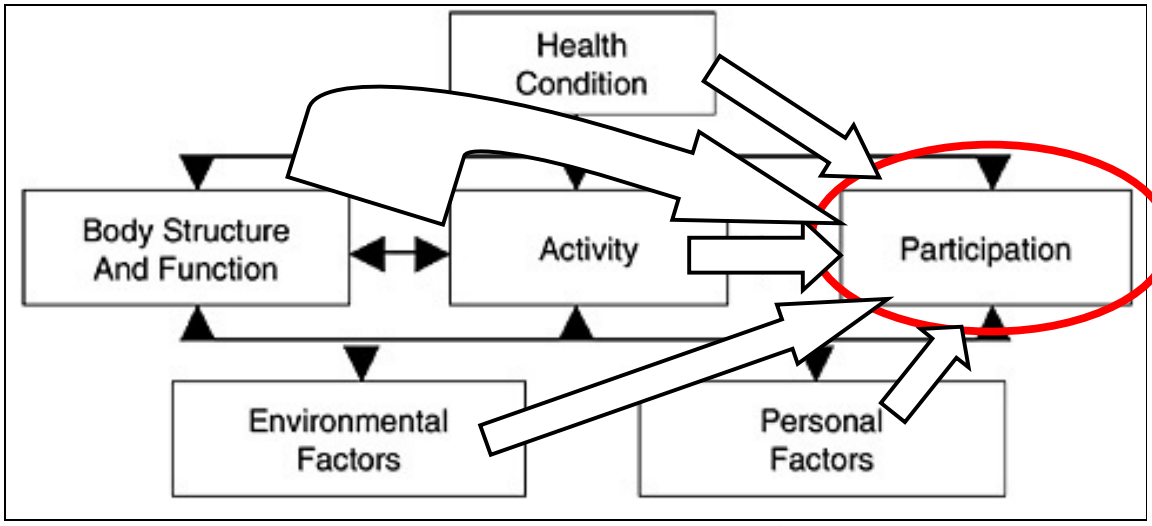

Figure 1.2 Factors influencing participation in the ICF framework

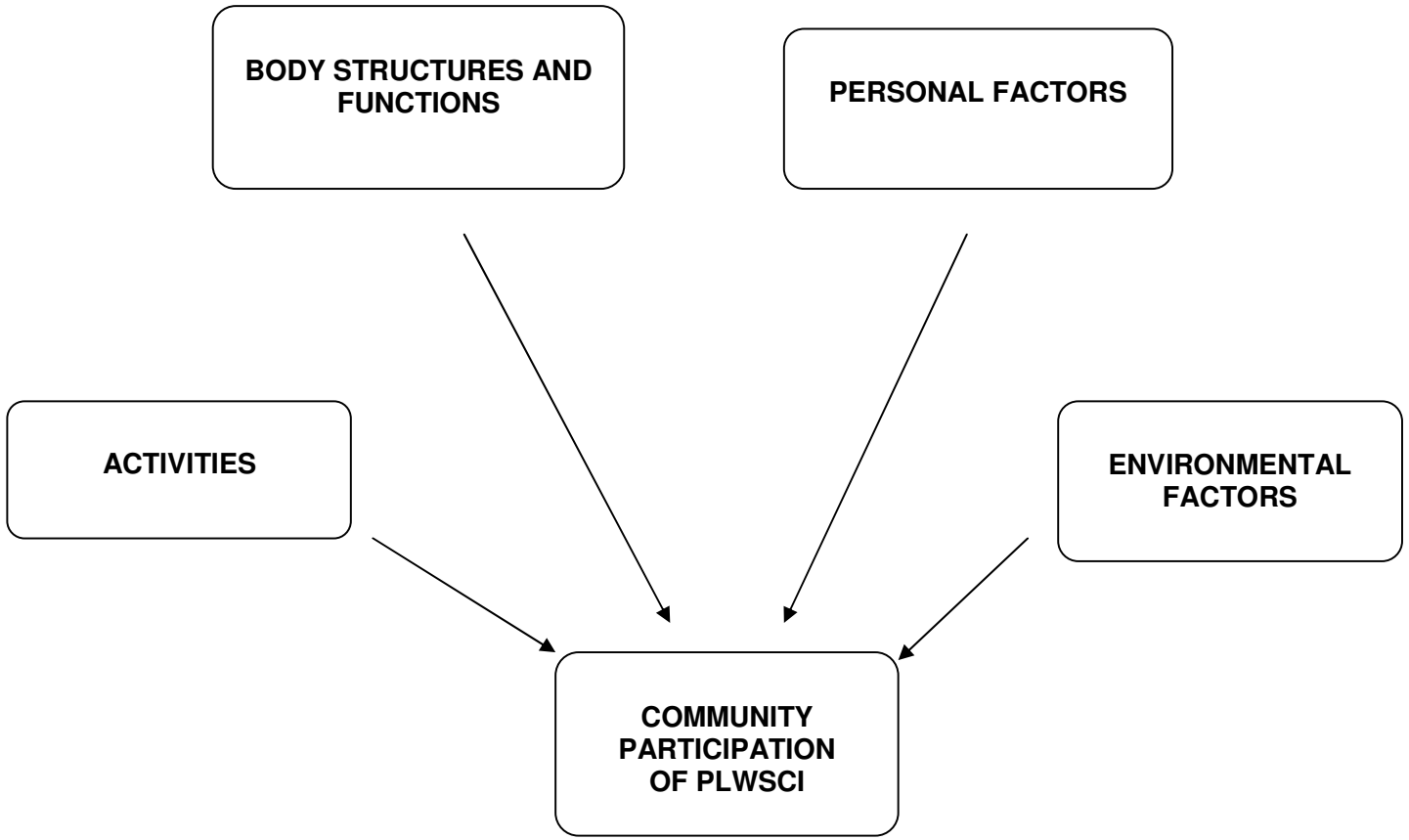

Figure 1.3: Conceptual framework for the study

1.7 AIMS AND OBJECTIVES

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

1.7.1 OBJECTIVES OF THE STUDY

The objectives of this study are:

1.7.1.1 To determine the demographic and injury profile of the participants.

1.7.1.2 To determine the participants' level of satisfaction with their community participation.

1.7.1.3 To determine the functional activity level of the participants.

1.7.1.4 To determine the impact of environmental factors on community participation.

1.7.1.5 To determine the influence of demographic and injury factors on the community participation of PLWSCI.

1.7.1.6 To determine the influence of environmental factors on the community participation of these PLWSCI.

1.7.1.7 To explore the perceptions of PLWSCI regarding factors that influence their community participation.

1.7.1.8 To develop a framework of community participation for PLWSCI and to make recommendations to relevant stakeholders (i.e. rehabilitation practitioners and policy makers) regarding measures to facilitate community participation by PLWSCI.

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

1.8 STUDY METHODOLOGY

1.8.1 Research approach

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

I.8.2 Research setting

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

1.8.3 Participant selection

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

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

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

1.8.4 Data collection

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

1.8.5 Data analysis

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

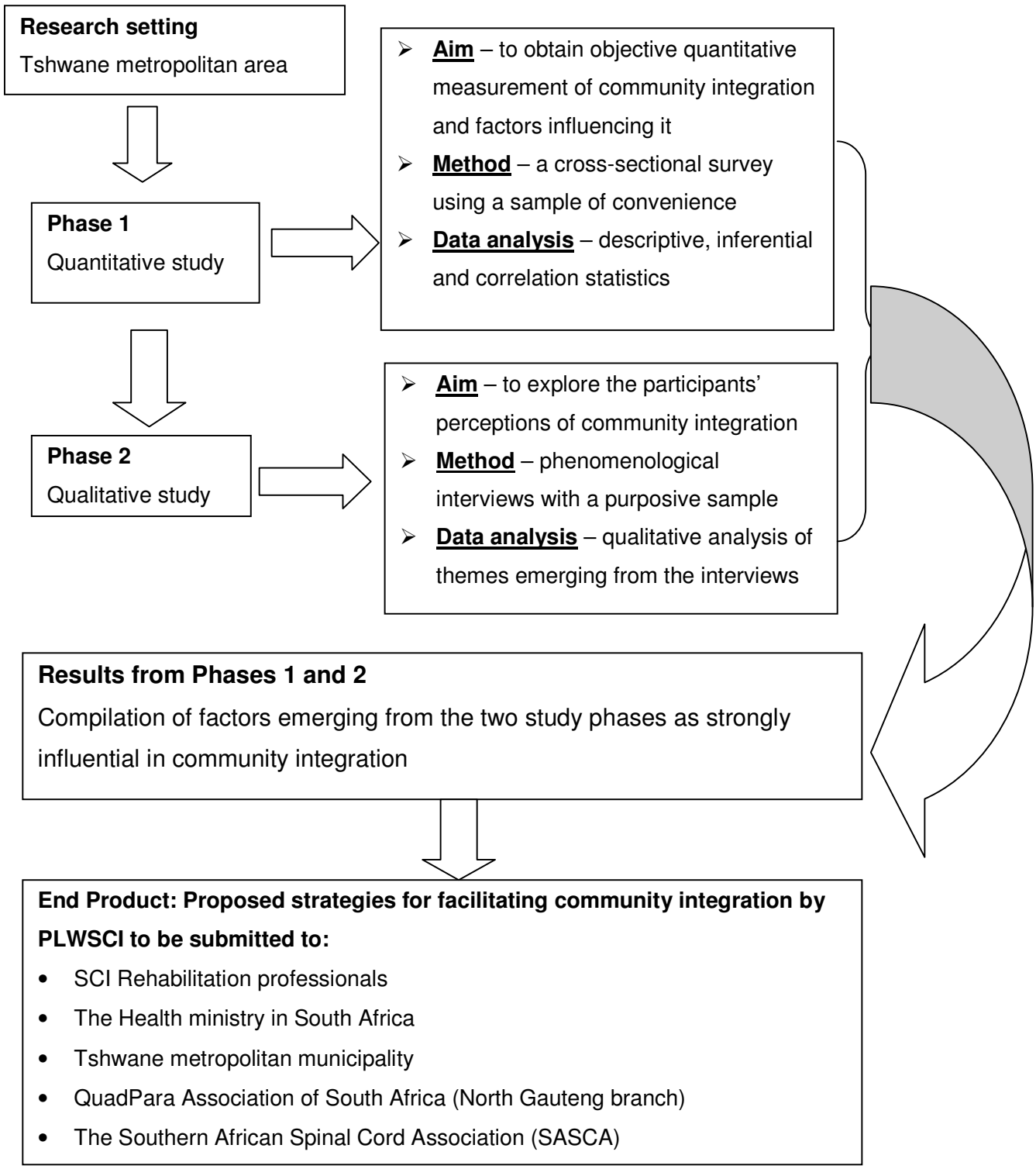

Figure 1.4: Overview of the methodology

1.9 SIGNIFICANCE OF THE STUDY

The following main stakeholders stand to benefit from this study:

1.9.1 The physiotherapy profession

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

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

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

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

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

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

1.9.2 The South African Department of Health

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

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

1.9.3 People living with Spinal Cord Injury

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

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

1.10 SCOPE OF THE STUDY

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

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

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

1.11 TERMINOLOGY

1.11.1 Disability

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

1.11.2 Spinal Cord injury

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

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

1.11.3 People Living with Spinal Cord Injury (PLWSCI)

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

1.11.4 Community participation

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

1.11.5 Rehabilitation

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

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

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

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

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

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

1.12 OUTLINE OF THESIS CHAPTERS

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

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

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

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

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