CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

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

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

- Section A describes the methodology in three phases as it was originally planned during the conceptualisation of the study. The section is therefore presented in the future tense. In each phase, the objectives, data gathering techniques, participant selection procedures, data collection procedures and methods of data analysis are described.

- Section B describes the pilot study that was conducted to validate the research methodology and data gathering instruments prior to the main study. The findings of each phase of the pilot study are presented. Based on the results, suggestions are made on how to adapt the methodology.

- Finally, Section C describes how the main study methodology was implemented based on the pilot study results.

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

3.2 SECTION A: METHODOLOGY AS ORIGINALLY PLANNED

3.2.1 Introduction

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

3.2.2 Research aim

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

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

3.2.3 Research Approach

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

3.2.4 Research Setting

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

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

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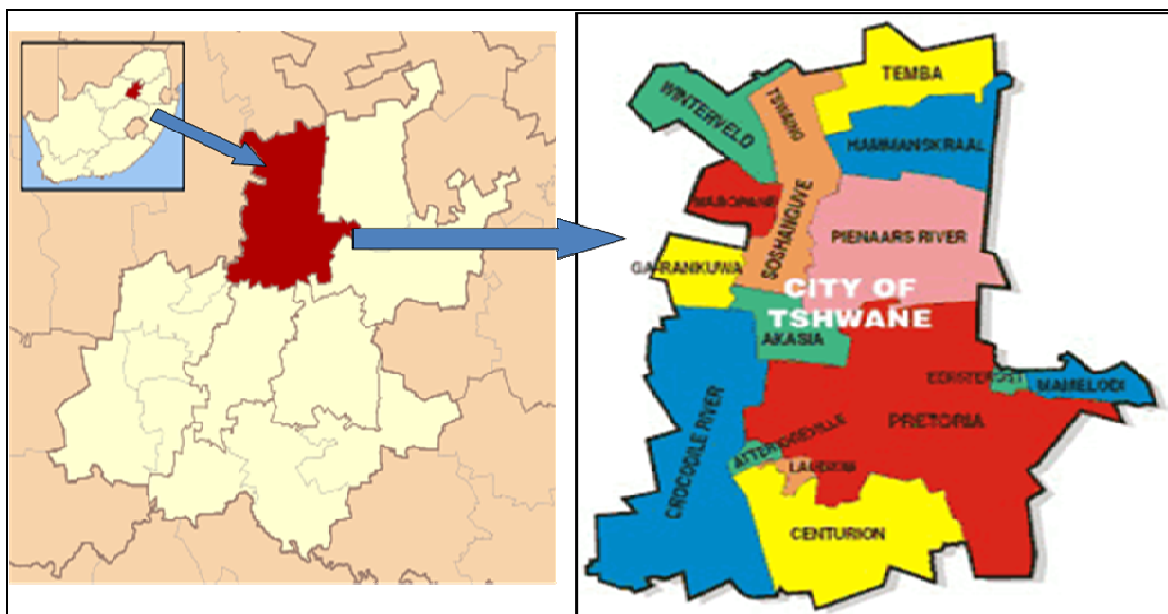

Figure 3.1 Map of the Tshwane Metropolitan area in South Africa

3.2.5 Study Population

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

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

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

3.2.6 Phase 1 of the methodology as planned

3.2.6.1   Objectives of the planned Phase 1

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

3.2.6.2   Research design

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

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

3.2.6.3   Participant selection

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

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

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

3.2.6.4   Selection of data collection instruments

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

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

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

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

- The Socio-Demographic and Injury Profile (SDIP) was selected for collecting personal factor information in terms of demographics and SCI data.

- The Reintegration to Normal Living Index (RNLI) was selected to measure the participants' level of satisfaction with their community participation.

- The Craig Hospital Inventory of Environmental Factors – short form (CHIEF-SF) was selected to measure participants' perceived barriers to community participation.

- The Spinal Cord Independence Measure II (SCIM II) was selected to measure participants' functional abilities in terms of activities of daily living, respiration and bladder management and mobility.

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

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

- ➢ The languages in the black townships in the Tshwane metropolitan area are not pure Sepedi, Sesotho or Setswana, but a mixture of Afrikaans, English, Sepedi and IsiZulu. Thus a questionnaire in a pure ethnic language would have been irrelevant.

- ➢ In addition, the high rates of functional illiteracy among black and coloured South Africans, and a lack of questionnaire completion sophistication among Blacks, Indians, Coloureds and some Afrikaans-speaking Whites (Westaway, Olorunju & Rai, 2007), meant that translated self-report questionnaires would have little meaning to the majority of prospective respondents. Due to the researcher's fluency in the languages spoken in the research setting, she was

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

3.2.6.5 Data Collection Procedures

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

3.2.6.6 Data analysis

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

3.2.6.7 Calculation and analysis of individual instrument results

a) Analysis of the SDIP

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

b)   Analysis of the RNLI

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

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

b) Analysis of the CHIEF-SF scores

Each item on the CHIEF-SF is scored in three stages. Firstly, participants are asked to indicate the frequency of occurrence of each type of barrier that they experience. This is then scored on a five point Likert scale where

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

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

- 1 = little problem
- 2 = big problem

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

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

c) Analysis of the SCIM II scores

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

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

3.2.6.8   Psychometric testing of the measuring instruments

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

a)   Validity testing

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

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

- Content validity

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

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

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

- Face validity

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

- Construct validity

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

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

- Criterion validity

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

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

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

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

b) Reliability testing

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

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

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

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

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

- a coefficient alpha of 0.70 is regarded as acceptable,

- between 0.71 and 0.80 as respectable,

- between 0.81and 0.90 as very good,

- and above 0.90 as excellent.

3.2.6.9   Inferential statistics

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

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

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

3.2.7 Phase 2 of the methodology as planned

3.2.7.1   Aim of the phase

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

3.2.7.2   Objectives of the phase

- To ascertain how participants experience community participation in terms of barriers and facilitators;

- To determine the views of the participants on how rehabilitation prepared them for community living;

- To obtain suggestions from the participants on how community participation by PLWSCI could be enhanced.

3.2.7.3   Research design

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

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

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

3.2.7.4 Participant selection

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

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

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

Table 3.1 Guide to key participant selection

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

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

3.2.7.5   Data collection technique

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

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

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

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

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

Table 3.3 Interview guide

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

3.2.7.6   Data collection procedures

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

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

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

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

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

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

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

3.2.7.7   Data analysis

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

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

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

3.2.7.8 Reliability

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

3.2.7.9 Use of computer-assisted qualitative data analysis

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

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

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

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

STRATEGY	CRITERIUM	APPLICATION
Credibility	Prolonged engagement	The researcher has more than 20 years of experience in spinal cord injury rehabilitation, initially as a clinician and currently as an educator responsible for teaching rehabilitation of patients who have sustained a spinal cord injury to under- and postgraduate level physiotherapy students.
	Peer review	Meetings were held to reach consensus on codes, categories and themes.
Dependability	Dense description of methodology	• The data collection methods and procedures are comprehensively described. • After the finalisation of the list of codes, the text was re-coded to achieve consensus.
Confirmability	Audit trial	• Interviews were recorded and saved on computer in audio and transcript format. Reflective notes were kept that captured decisions taken. • All versions of the coding process, illustrating the development of the findings, were kept.
Consistency	Repeatability of procedures	• All interviews were conducted in a similar style, using the same leading questions.
Transferability	Description of the sample	• The study population is clearly described. • Various characteristics of the participants were described, making it possible for the reader to compare their context with that of this study.

3.2.8 Phase 3 of the methodology as planned

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

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

3.2.9 Summary of the planned study methodology

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

3.3   SECTION B: PILOT STUDY

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

3.3.1 PHASE ONE OF THE PILOT STUDY

3.3.1.1   Aims and objectives – Phase 1 pilot study
The objectives of phase one of the pilot study were the same as those described in the planned methodology (section 3.2.6.1).

3.3.1.2   Research design – Phase 1 pilot study
The research design used in phase one of the pilot study was the same as described in the section concerning methodology above (section 3.2.6.2).

3.3.1.3 Participant selection - Phase 1 pilot study

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

3.3.1.4 Data collection technique - phase 1 pilot study

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

3.3.1.5 Data analysis – phase 1 pilot study

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

3.3.1.6 Results – phase 1 pilot study

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

Table 3.5: Demographic profile of participants in pilot study

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

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

a) Changes to the socio-demographic and injury profile

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

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

b) Changes to the Reintegration to Normal Living Index

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

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

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

        1 = the statement does not describe my situation,

        2 = the statement describes my situation a little,

        3 = the statement describes my situation a lot,

        4 = the statement fully describes my situation.

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

c) Changes to the CHIEF-SF

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

d) Data analysis

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

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

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

3.3.2 Phase 2 – pilot study

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

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

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

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

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

3.3.3 Phase 3 of the Pilot study

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

3.3.4 Summary of methodological changes following the pilot study

The pilot study informed the following main changes to the planned methodology:
➢ Changes to the content of the data collection instruments.
➢ Changes to the analysis of the data from these instruments.
These changes were subjected to further psychometric testing during the main study and validated.

3.4 METHODOLOGY AS IMPLEMENTED IN THE MAIN STUDY

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

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

3.4.1 Phase 1 – main study

3.4.1.1   Objectives

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

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

3.4.1.2   Participant selection

A minimum sample of 160 participants was targeted for participation in this phase of the study. The number was arrived at using psychometric testing principles as stated by Nunnally (1978), and which are explained later in this section. Because the study made use of instruments developed in other countries to measure community participation and associated factors, it was necessary to establish the validity and reliability of these measures in a South African population. One of the tests for validity is factor analysis.   Nunnally (1978) recommends a minimum sample size of 10 respondents per item for factor analysis. Because a number of instruments were used in this study, the instrument with the largest number of items was considered: this was the Spinal Cord Independence Measure (SCIM) with16 items (described in 3.4.3.5 below). Thus the targeted minimum sample size was 160 (16 X 10).

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

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

- Firstly, people who appeared on the database but did not have a diagnosis of SCI were eliminated.

- Secondly, PLWSCI not residing in the Tshwane metropolitan area were eliminated.

- Of the remaining PLWSCI on the databases, those who were discharged from the rehabilitation units after March 2007 were eliminated from the list as they would not have lived with SCI for the required minimum of two years at the time of data collection.

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

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

3.4.1.3   Data collection instruments

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

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

3.4.1.4   Data analysis

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

- Calculation and analysis of individual instrument results
- Statistical testing

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

3.4.2 Phase 2 Main Study

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

3.4.2.1   Aims and objectives of Phase 2

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

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

3.4.2.2   Research design

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

3.4.2.3   Participant selection

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

3.4.2.4   Data collection technique

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

3.4.2.5   Data collection procedure

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

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

3.4.2.6   Data analysis

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

3.5   ETHICAL CONSIDERATIONS

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

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

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

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

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

- One of the participants was referred to the nearest community health centre with a suspected urinary tract infection. He was subsequently put on medication.

- One participant had been living with SCI for six years but could not make the "wheelie" manoeuvre to negotiate inclines. The researcher taught this manoeuvre to the participant.

- One of the participants phoned the researcher to ask for advice on managing a swollen hand. The participant was given the necessary exercises and was advised to visit the local clinic.

3.6   SUMMARY

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