CHAPTER 4

METHODOLOGY

4.1 INTRODUCTION

This chapter outlines the steps taken to collect data, by first describing the study population, sample selection and the sample. This is followed by information on the process of recruiting and training the interviewers, procedures followed in collecting the data, steps taken to ensure the accuracy of the data and challenges encountered during the data collection.

The study comprised two phases and each is described separately in this chapter. A combination of quantitative and qualitative methods was used. Phase 1 involved mainly quantitative data collection whilst Phase 2 was a qualitative study, the main purpose of which was to enhance and augment the findings of Phase 1.

Combining both quantitative and qualitative research methodology enables the researcher to uncover a more complete and holistic picture of the relevant issues (Hartley and Muhit, 2003). This is particularly useful in studies dealing with the validity of measuring tools as the qualitative aspect of the study provides culturally relevant information about the issues and dimensions which are being measured (Hartley and Muhit, 2003). As this was the focus of this study, it was appropriate to use both quantitative and qualitative methods.
PHASE 1

4.2 STUDY DESIGN

In Phase 1, an exploratory, cross-sectional, analytical study design was adopted to address the research question “Can tools that have been developed and used in well-resourced settings and countries be used for to assess the impact of rehabilitation interventions on caregivers and families of children with CP in poorly resourced areas in South Africa?”

The specific objectives of Phase 1 were to ascertain:

1. Whether tools and scales developed in contexts different from the context of this study are appropriate for use in this community;
2. Factors which may predict a positive caregiver outcome in terms of their quality of life, mental health, interaction with their child and their involvement with family support networks;
3. Whether place of residence (that is, urban or rural) makes a difference to the outcomes of interest, namely caregivers’ quality of life, mental health, attitude towards their child and involvement with family support network; and
4. Whether the severity of a child’s disability has an impact on the caregiver outcomes described above.

4.3 STUDY POPULATION, SAMPLE SELECTION AND SAMPLE SIZE

4.3.1 Study population

The study population comprised caregivers of children aged between one and eighteen years with a diagnosis of cerebral palsy, living in poorly resourced peri-urban, urban and/or rural areas who received rehabilitation therapy services (physiotherapy, occupational therapy, speech therapy) at public hospitals in Gauteng and Limpopo Provinces.
Inclusion criteria:
To be eligible for inclusion in the study caregivers had to meet the following criteria:
Their children had to:

- Have a diagnosis of cerebral palsy (confirmed in their hospital records by a medical practitioner).
- Be between one and eighteen years old.

Exclusion criteria:
Caregivers were excluded from the study if their children had:

- Undergone surgery related to the CP condition (e.g., hamstring or Achilles tendon lengthening) in the past six months (as this may have changed the treatment approach and the intensity of therapy they had received).
- Attended rehabilitation therapy for less than three months (as the caregivers would have had insufficient exposure to therapy to have formed firm opinions regarding the service).
- Received therapy as part of a group session within the past six months. This was done to ensure that all study participants' children had received a similar kind of therapy intervention, viz., individual therapy sessions as opposed to group therapy sessions.

4.3.2 Study sites
Study sites included all public hospitals in Gauteng and Limpopo provinces which met the following criteria:

- Had established rehabilitation services for children with CP (i.e., had been providing a service for at least five years).
- Offered a service where children were seen on an individual basis.
- Had clinical records of children receiving therapy.
4.3.3 Sample selection and sample size

As this was an exploratory study, the main aim of which was to validate the measuring instruments and scales, a convenience sample of 260 caregivers who met the inclusion criteria were invited to participate in the study. This sample size met Nunnally’s (1978) suggested criterion for validating a scale (a minimum of 10 participants for each scale item). As the longest scale was the MPOC, a 24-item scale, a minimum of 240 participants was required.

4.4 PROCEDURE

Ethical approval was obtained from the Human Research Ethics Committee of the University of the Witwatersrand (Clearance Certificate R14/49 – in Appendix I). Institutional permission was obtained from the respective Departments of Health of Gauteng and Limpopo Provinces (Appendix J).

4.4.1 Interviewers

Three interviewers were recruited. The following criteria were used to make the final selection:

- They were mothers of children with disabilities – two were mothers of children with CP and one was the mother of a child with a metabolic disorder resulting in obesity and developmental delay.
- They were able to speak and understand a number of local languages – between them they were able to read, speak and understand all six languages required for the study.
- They were comfortable talking about their own children and talking to other mothers.
- They were literate and could speak and understand English well.
- They were unemployed and thus available to assist with the study.
4.4.2 Training

Over a period of three days the interviewers received extensive training from the researcher in administering questionnaires, interviewing techniques and the process of obtaining informed consent. This took place at the CP Clinic at Chris Hani Baragwanath Hospital. Emphasis was placed on interviewing skills as some of the questions were of a sensitive nature. The training included discussions, role-plays and practical sessions where the interviewers practised on each other and completed the questionnaire. An “Interviewer’s Manual” was compiled, detailing the interviewing process and a copy given to each of the interviewers (see Appendix K).

The training continued at Alexandra Health Centre where three caregivers of children with CP were interviewed by each of the interviewers. The purpose of this training session was to practise administering the questionnaire, to further refine the questionnaire and to establish inter-rater reliability.

At the end of this training session, it was clear that the questionnaire was still too long, and that the inter-rater reliability was unsatisfactory. The training then overlapped with the pilot study (i.e., pilot testing the questionnaire) as described in Chapter 3 (section 3.6). By the end of the pilot study, inter-rater reliability was satisfactory and the time taken to complete the interview was reduced to less than one hour. Data collected during this pilot study were not included in the final data analysis.

4.4.3 Procedure

Written and telephonic contact was made with the most senior rehabilitation professionals, the deputy-directors of rehabilitation, in the Gauteng and Limpopo provincial health departments. A letter explaining the nature of the study and outlining the information and participation required from the provincial therapists was sent to them (see Appendix L). A follow-up telephone call was made to further explain the study, to secure their agreement and to request information
regarding services for children with CP in all the hospitals. All the personnel contacted at a head office level expressed their full support for the study and were happy to provide the necessary information which included a list of all hospitals with names and contact details of the therapists in each of the two provinces.

Through the offices of the deputy-directors an information letter was sent to all rehabilitation departments in Gauteng and Limpopo Provinces (see Appendix M). This letter explained the nature and purpose of the study and requested information about therapy services in each hospital for children with CP. Therapists were asked to complete a form supplying details of therapy services for children with CP and return it to the researcher. Very few rehabilitation departments returned the forms, mainly as a result of communication problems within the departments so that the therapist actually responsible for treating children with CP never received the letter or the form. For this reason direct telephonic contact was made with each hospital to ascertain the nature of the therapy service offered to children with cerebral palsy. A total of 18 hospitals in Gauteng and 40 hospitals in Limpopo were contacted and details regarding services for children with CP in each hospital recorded.

Thirteen (of 18) hospitals in Gauteng and 18 (of 40) hospitals in Limpopo met the inclusion criteria for the study sites (see 4.3.2). A timetable was drawn up based on which days each hospital held its Cerebral Palsy Clinic and the number of children who were expected to attend. Therapists were informed ahead of time of the day/s the researcher and interviewers would be attending the Cerebral Palsy Clinic at their respective hospitals. Where possible, the therapists informed caregivers ahead of time that the researcher and interviewers would be coming to interview them. This meant that the hospital and the caregivers were prepared for the study. Consequently the interviews/data collection could proceed with minimal disruption and inconvenience to the therapy service and the caregivers.
Data collection took place over a three-month period, from July to September 2004, in Gauteng and over a two-month period, from October to November 2004, in Limpopo Province.

All eligible caregivers attending rehabilitation therapy at each of the hospitals were invited to participate in the study when they arrived for their therapy appointment at the facility or clinic. Caregivers were reassured that their therapy would not be compromised due to the time taken to complete the interview. Written informed consent was obtained prior to the commencement of the interview. Verbal consent was obtained only from caregivers who were unable to read or write. The English version of the caregiver information leaflet and informed consent forms can be found in Appendix N. The caregiver information leaflet and informed consent forms were available in all six languages used during the study.

Each caregiver was interviewed by one of the trained interviewers. The questionnaires were administered verbally and the caregivers’ responses were recorded in writing on the questionnaire by the interviewers. All questionnaires were available in English, Isizulu, Sesotho, Xitsonga, Sepedi, Tshivenda and Setswana and caregivers were interviewed in their own language. They were also free to read the questions together with the interviewer.

However, at some of the hospitals in Limpopo Province where the CP Clinic was held only once a month, there were too many caregivers to enable each to be interviewed individually. In these cases, the interviews were done in groups of three or four caregivers, provided the caregiver was literate and comfortable about completing the questionnaire on her own. The interviewer went through each question with the group and the caregiver then filled in her response. Working in groups was necessary because all the caregivers were keen to participate in the study.
The researcher was present during all the interviews. She checked the child’s file to confirm the CP diagnosis and classification, to ascertain when the child first started therapy and the length of time the child had been attending therapy. The classification was confirmed through clinical observation and assessment as described in Chapter 3 and the child’s Gross Motor Function Classification status was established.

Each caregiver was thanked for his/her participation and given refreshments whilst the child was given a snack and juice. Caregivers were not paid for participating in the study. If, at the conclusion of the interview the caregiver indicated that she needed to discuss any issues raised during the interview, the researcher offered advice and support and raised any concerns expressed by the caregivers with the treating therapists.

As the interviews took place during the children’s routine therapy appointments, treatment sessions and interactions between the treating therapists and caregivers could be observed by the researcher. Observational notes were recorded with particular reference to the process of care and the nature or type therapy administered. Children’s records were also examined to establish therapeutic regimens and therapy attendance.

4.4.4 Steps taken to ensure reliability and quality of data during the data collection:

To help participants feel comfortable and to establish a climate of trust and openness so that the caregivers would give honest responses, the following steps were taken:

- Each of the interviewers had a small album of photographs of their own children. After introducing themselves to the participants, they showed them the photographs and told them about their children. This immediately broke the ice and helped the participants to feel more relaxed and free to talk openly.
• Consideration was given to the environment in which the interviews took place. A space in each of the therapy departments was created which offered participants privacy without taking them away from the therapists. It was found that participants became anxious if they could not see what was happening in the therapy department as they thought they might be missing out on their therapy time.

• The interviewers made certain that participants clearly understood the time required to complete the interview. Caregivers who had other commitments such as further appointments at the hospital (e.g., for X-rays or medication) or who had to catch public transport often indicated that they did not have the time to stay and complete the interview. They were thus excluded from the study. If parents did not understand the time required for the interview, they tended to become impatient and this affected the quality of their responses as they were rushing to complete the interview.

• Supplying biscuits to the participants and snacks to the children helped because it was a long morning and the children became hungry.

• If, during the interview, the child became fractious or irritable, the researcher volunteered to pacify and look after the child. This allowed the caregiver to concentrate on the interview without being concerned about her child.

• Where possible, caregivers had been told in advance by the therapists that some researchers would be coming to talk to them. This was especially useful in the rural areas because then caregivers came prepared and understood why there were strangers visiting the hospital. This made them less suspicious and more open during the interviews.

• At the end of each interview, the researcher checked each questionnaire to ensure that all questions had been answered and that the responses were consistent (i.e., that they made sense).
• A mini “debriefing” session with the interviewers took place at the end of each morning where the interviews were discussed and any problems or questions clarified.

• Some of the interviews were randomly taped. During the playback of the tape, the responses and comments recorded on the questionnaire were compared with what actually transpired in the interview as heard on the tape. This was done by the interviewer/s not involved in the interview, as well as by an independent therapist who was fluent in the language used during the interview.

4.4.5 Challenges encountered during the data collection

Skills and experience of interviewers:
The interviewers were mothers who had a basic education but who had never had formal employment or research experience. This presented a challenge to the data collection phase because the accuracy and reliability of the data largely depended on their interviewing skills and ability to extract information from caregivers. As mothers of children with disabilities themselves, it was felt that they were the most appropriate people to be trained as interviewers because:

• Their status levelled the playing field for the caregivers. It was felt that “mother to mother” interviews were more likely to elicit caregivers’ true feelings than “health worker to mother” or “researcher to mother” interviews.

• They shared a similar cultural and ethnic background with the caregivers, compared to the researcher who was from a different cultural and ethnic group.

However disadvantages of using mothers as interviewers were that:

• They had no research experience at all.

• They themselves had never completed questionnaires using Likert-type scales before.
Although the training sessions were conducted thoroughly and it appeared that the interviewers understood the questionnaire, it soon became apparent that despite understanding the questions, the interviewers had not “internalised” the scales and questions for themselves. It was only as they became more familiar with the instruments after interviewing a number of caregivers that they began to internalise these and the questions became more meaningful and clearer to them. This meant that the training process and pilot study took longer than anticipated. The first 20 interviews were therefore regarded as part of the pilot study and training process and were excluded from the data analysis.

Language:
Although between them, the three interviewers spoke all six languages used in the study, they were not equally proficient in all six languages. This created problems in the more rural areas of Limpopo Province where Xitsonga and Tshivenda are the predominant languages. The interviewers were then interviewing in their second or third language and some of the mothers had difficulty following the questions – despite the fact that all the questions had been translated into their own language. In these cases a local interpreter assisted when there was one available. The interpreter was briefed on the purpose of the interview.

Caregivers’ prior experience of completing questionnaires:
As virtually none of the caregivers had ever participated in a study before and they had never previously completed a Likert-type scale, this was a new and unfamiliar experience for them. Even though the questionnaire contained a mini-training exercise for completing a Likert-type scale, the concept of rating an item or giving themselves a number was very foreign and many caregivers struggled with this, particularly those living in more rural areas. As a result, a few interviews took over an hour and a half to complete. Interviewee and interviewer fatigue then posed an additional potential problem.
**Likert-type scales:**
Caregivers struggled with the concept of rating or giving numbers to items on the various scales – they would provide a “yes/no” response and the interviewers had to probe and ask “how strong is the yes or the no?” in order to obtain a number on the scale. The categories of “very great; great; fairly great” or “most of the time; a good bit of the time; some of the time” are difficult to translate into African languages as there is often only one word which encompasses all three categories or differentiations.

**Abstract versus concrete scale items and concepts:**
The more concrete the item on the scale was, the easier it was for caregivers to understand. The interviewers therefore provided examples of the more abstract items – but without leading the caregivers.

Fairly early on into the data collection, the researcher recognised the limitations of the quantitative measurement tools in that they failed to capture the essence of the caregivers’ experiences. Thus any comments or stories which caregivers provided, either spontaneously or with prompting, to explain their responses were captured in writing on the interview form.

### 4.5 DATA ANALYSIS

An Access database was used for data entry. The data were analysed using SPSS® (Version 13.0) for Windows statistical package (SPSS Inc, Chicago, USA). Descriptive statistics and frequency tables were the first step for data analysis. One-way analysis of variance (ANOVA), t-tests, Chi-squared tests, Pearson product-moment correlation coefficients and multiple regression were used to ascertain socio-demographic effects, relationships among measures, the effects of severity of disability on caregiver outcomes and the potential predictors of caregiver mental health. The procedure followed when doing regression
analysis was to enter categorical variables as a block and then to use stepwise regression for the continuous variables.

Multi-trait scaling, factor analysis (including principal components analysis), Cronbach’s alpha, intra-class correlation coefficients and t-tests were used to establish the psychometric properties of each scale. Factor analysis examines the pattern of relationships among variables and tries to explain that pattern in terms of a smaller number of underlying hypothetical factors (Streiner and Norman, 2000).

As a convenience sample was used, an exploratory rather than a confirmatory analysis of the scales was done. Multi-trait scaling and factor analysis are the recommended statistical procedures for scale development and exploratory analysis (Child, 1970; Nunnally, 1978; Stewart et al., 1988).

### 4.5.1 Reliability

Two methods of assessing reliability were used – internal consistency and test-retest reliability. Cronbach’s alpha, a measure of internal consistency reliability, was estimated for each scale (Cronbach 1970). Reliability coefficients of \( \geq 0.70 \) were regarded as satisfactory, based on Nunnally’s recommendation (Nunnally, 1978). There is no consensus on the minimum acceptable coefficient alpha (Arias and de Vos, 1996). Based on the work of De Vellis (1991) and Carmines and Zeller (1979), Arias and de Vos (1996) suggest that a value below 0.60 is “unacceptable”; between 0.60 and 0.65 is “undesirable”; between 0.65 and 0.70 is “minimally acceptable”; between 0.70 and 0.80 is “respectable” and between 0.80 and 0.90 is “very good.” However a very high value, that is, one above 0.90 suggests that there is redundancy (Streiner and Norman, 2003).

To assess test-retest reliability, thirteen caregivers whose children attended a day care centre in an informal settlement in a peri-urban area of Gauteng were interviewed on two occasions, with an interval of between two and four weeks
between the first and second interviews. The reason for doing the test-retest reliability on this group of caregivers was to facilitate follow-up, that is, it was easy to find them for the second interview. In Limpopo Province, fourteen caregivers were re-interviewed between two and four weeks after completing the first interview. In this case, arrangements were made to revisit the particular hospitals two to four weeks after the initial interview to find the caregivers.

This sample size of 27 was considered adequate for the assessment of reliability based on general guidelines of a minimum sample size of 20 subjects (King et al., 1995). The interval of between two and four weeks between the two test administrations was considered appropriate and was logistically feasible. It was unlikely that caregivers would recall their responses over this period and as most caregivers received monthly therapy, it was not expected that caregivers' responses would be influenced greatly by new experiences during this time. Intraclass Correlation Coefficients (ICC) were used to assess test-retest reliability (Shrout and Fleiss, 1975). The intraclass correlation coefficient is the most appropriate reliability coefficient for this type of data (Streiner and Norman, 2003).

### 4.5.2 Validity

A multi-trait scaling method was used to test two aspects of content validity, namely item convergent and discriminant validity of each of the scales. This method consists of three steps designed to determine whether items have equivalent variance, whether each item in a hypothesized group is substantially related ($r \geq 0.40$) to the total score computed from other items in that group (item convergent validity criterion) and whether each item correlates significantly higher with its hypothesized scale ($z \geq 1.96$) than with another scale (item discriminant validity criterion). If these conditions are met, it is appropriate to combine items as hypothesized into simple summated ratings (Stewart et al., 1988).
Principal components analysis was used to examine the underlying dimensions of each measure. Only items with communality estimates (common factor variance) ≥ 0.30 were taken into consideration, as items with unique variance (specific variance + error variance) > 0.70 tend to be unreliable (Child, 1970). In order to ascertain significant loadings at the 1% level as recommended by Nunnally (1978), loadings > ± 0.50 were examined (Child, 1970; Nunnally, 1978). The results of the factor analyses were used for subscale definition.

The Kaiser-Meyer-Olkin measure of item sampling adequacy and Bartlett’s test of sphericity were used to ascertain whether factor analysis was the correct procedure for the data. Kaiser-Meyer-Olkin is also useful to ascertain item sampling adequacy and content validity.

Construct validity was established by correlating the scale scores with other variables to which the scale was hypothesized to be related; for example, for the MPOC, each subscale was correlated to the scores obtained for two additional questions “To what extent do you feel that you gain something from every session?” and “To what extent are you satisfied with the therapy service you receive here?”. It was hypothesized that there would be a positive correlation between the MPOC scale scores and satisfaction as measured by these two questions. It was reasoned that respondents who experienced “more” of the behaviours comprising the MPOC measure (i.e., had higher MPOC scale scores), would have higher satisfaction with the service. Pearson correlation coefficients were used to assess these associations.

4.5.3 Additional analysis of Family Support Scale
In addition to calculating an overall score for the Family Support Scale as described in Chapter 3, a simple count of the number of individuals or groups of people providing support was computed for each study participant. Any item in the Family Support Scale scoring a 0 “not applicable” or a 1 “not at all helpful” was given a new score of 0. Values between 2 “sometimes helpful” and 5
“extremely helpful” were given a new score of 1. These new scores were then added together for each participant, giving an overall count of the number of sources of support available to each participant.

To ascertain which groups of people offered the least and the most amount of support, scores of 0 and 1 and scores of 4 and 5 for each group, respectively, were summed. This resulted in two lists with a ranking for each group.

4.5.4 Socio-economic status (SES)
Using the methodology described by Westaway and Gumede (2000), principal components analysis was used to generate an SES equation, based on housing quality and commodity ownership. An overall score for each participant could thus be computed and then quartiles were used to determine the cut-off points for low, moderate and high SES. The following equation was generated:

\[ \text{SES} = 0.57(\text{walls}) + 0.61(\text{roof}) + 0.59 (\text{water supply}) + 0.64(\text{stove}) + 0.67 (\text{fridge}) \\
+ 0.50(\text{microwave}) + 0.69(\text{television}) + 0.45(\text{car}) + 0.53(\text{cell phone}). \]

Using quartiles, a score of 3.52 or lower was defined as “low SES”, between 3.52 and 7.20 as “moderate SES” and above 7.20 as “high SES”.

4.5.5 Analysis of comments
As described at the end of section 4.4.5 in this chapter, interviewers recorded participants’ comments and reasons for giving scale items a particular score. One of the main reasons for recording these comments was to establish whether the score caregivers gave for an item was logical in view of the reasons, or justification, they provided. This was done in order to confirm caregivers’ understanding of each item. These comments were collated and summarised and appear in Appendices O to S.
PHASE 2

4.6 STUDY DESIGN

In Phase 2 a qualitative study design was deemed most appropriate to answer the question “What are the perceptions of caregivers of children with CP living in poorly resourced areas in South Africa and how does this impact on their expectations of rehabilitation therapy?”

It was felt that the questionnaire and scales used during the first phase, although useful from a quantitative point of view, may not have identified issues that caregivers considered important. As Hartley and Muhit (2003) point out, the perception of reality as reflected on the scales may in fact not have been the reality of the situation as perceived by caregivers. Only the caregivers themselves could really explain the issues that troubled them. In order to conceptualise and describe this dimension, a qualitative methodology was required where caregivers could freely articulate and describe their experiences in their own words. Qualitative research seeks to find the answer to questions about the meaning and individual interpretation of life and is appropriate and effective when little is known about the situation and when working with vulnerable groups such as people with disabilities (Hartley and Munit, 2003).

A qualitative study design using the grounded theory approach (Strauss and Corbin, 1990) was used. This is “a qualitative research method that uses a systematic set of procedures to develop an inductively derived theory about a phenomenon” (Strauss and Corbin, 1990, p.24). It builds a theory which is faithful to the evidence, as well as being precise, rigorous and capable of replication. The process involves identifying a theme and attempting to verify, confirm or qualify it by searching through the data (Pope and Mays, 2000).
4.7 CONCEPTUAL FRAMEWORK

A conceptual framework is the first step in qualitative research (Neumann, 2000). An initial framework based on pre-existing ideas and theories was drawn up by the researcher to assist with generating questions for data collection (Figure 4.1).

![Conceptual Framework Diagram]

Figure 4.1. Initial conceptual framework of factors underlying caregivers' perceptions and experiences of therapy

4.8 SAMPLE SELECTION

A purposive sample of 24 caregivers was asked to participate in one of five focus groups. The following criteria were used when selecting these caregivers:

- Caregivers had to know each other and have attended therapy together. This was done in order to make it easier for mothers to talk to each other.
- Caregivers had to have attended therapy on a regular basis for more than a year.
• Caregivers had to feel comfortable to talk freely about their feelings, their experiences and their children.

Each focus group had between four and six participants. Two of the focus groups took place in Gauteng (therapy departments at Sebokeng and Johannesburg Hospitals) and three focus groups took place in Limpopo (one at Malamulele Hospital and two at Helene Franz Hospital). Participants in four of the five focus groups had participated in Phase 1 and were thus familiar with the background and purpose of the research. The focus group members from Johannesburg Hospital were not eligible to take part in Phase 1 as they received their therapy as part of a group, rather than individual one-on-one therapy. They were included in Phase 2 as they had heard about the research and were keen to participate in it – in fact they asked to be included.

4.9 PROCEDURE

Caregivers were informed ahead of time (one month) that the research team would be returning to ask them more questions. This meant they arrived willing and prepared to participate. From the initial conceptual framework (Figure 4.1), an outline of open-ended questions was drawn up as a guide to facilitate discussion (Table 4.1). After each focus group, the questions were modified and refined to ensure greater clarity and “probe’ questions were used to get more information if needed.
Table 4.1: Questions used for the focus groups

<table>
<thead>
<tr>
<th>OPEN-ENDED QUESTIONS</th>
<th>EXAMPLES OF PROBE QUESTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tell us your story – what happened to your child</td>
<td>How did you find out your child was disabled? How did it make you feel?</td>
</tr>
<tr>
<td>How is the day to day life now?</td>
<td>Who helps you? Who gives you support? What about the child’s other brothers and sisters – how do you manage?</td>
</tr>
<tr>
<td>What do you think was the cause of the problem (the disability)?</td>
<td></td>
</tr>
<tr>
<td>How did your family and the community react when they found out about the child’s disability?</td>
<td>What about the father of the child – how helpful is he?</td>
</tr>
<tr>
<td>Tell us about your experience of coming to the hospital for therapy – what help did you get?</td>
<td>When you first came for therapy, what did you expect to find? What did you think that therapy could do?</td>
</tr>
<tr>
<td>Are there some things that you think therapists should be doing, which they are not doing at the moment?</td>
<td>What things would help you as mothers, or help your children?</td>
</tr>
<tr>
<td>What do see in the future for your children?</td>
<td>What would you like to see happen to your children in the future?</td>
</tr>
</tbody>
</table>

After sharing refreshments, the field workers explained the purpose and structure of the focus groups and invited the caregivers to participate. Written informed consent (or verbal in the case of caregivers unable to read or write) and permission to tape record the discussion were obtained prior to the commencement of the focus group (Appendix T). The caregiver information leaflets and written informed consent forms were available in all six languages used in this study.

All the focus groups were conducted in the participants' own language, that is, the caregiver was free to express herself in her own language. This meant that more than one language was used for some of the focus groups – however, before the discussion commenced, the facilitators ensured that the participants could understand one other.

The first focus group was conducted by the field workers who had been the interviewers for Phase 1. They were coached in how to run a focus group by the
researcher and provided with a discussion guide (Appendix U). However, their lack of experience in conducting focus groups was evident from the transcript. For the subsequent focus groups, a paediatric occupational therapist experienced in facilitating discussions with caregivers, from a similar cultural background to the caregivers and who spoke the local languages, assisted in facilitating the discussions.

Each focus group lasted between one and one and a half hour. A sufficient number of focus groups (i.e., five) were conducted to ensure saturation of the data (Strauss and Corbin, 1990), which is the stage at which no new data are being obtained. During the first two focus groups, the interactions and body language of the caregivers and facilitators were observed by the researcher and observational notes recorded.

4.9.1 Challenges encountered
The biggest challenges were language and the field workers’ lack of experience in conducting focus groups. As the researcher did not speak any of the local languages, she could not facilitate the focus group and the quality of the discussion could only be ascertained once the interviews had been transcribed and translated.

Mothers who had participated in Phase 1 were more comfortable, spoke more freely and the discussion was more focused when compared to the focus group at Johannesburg Hospital. Although the participants of this group knew each other very well, the purpose of the research and the interviewers and researcher were unfamiliar to them. Consequently, there was less interaction amongst the participants themselves and more reliance on the facilitator to lead the discussion.
4.9.2 Steps taken to assure quality of focus group discussions

Lengthy debriefing sessions were held with the facilitators after each focus group and consequently there was better preparation and focus for subsequent groups. The order of the questions and themes was changed when it became clear that caregivers found it easier to start talking about themselves and their stories than about their experiences and perceptions of therapy. It was also observed that at the hospitals where a close relationship between the treating therapist and the caregivers existed together with support for the research from the treating therapist, caregivers found it easier to trust the facilitators and were more open in expressing their views.

Although the researcher was present during the first two focus groups, in order to observe body language, interaction and the level of participation, it was recognized that her presence could influence or intimidate the caregivers because she was from a different cultural group and was a professional therapist. The historical context of “white therapists” being perceived as being superior and having “Western” ideas could not be ignored. Consequently, she was not present during the last three focus groups. The focus group facilitators confirmed that this enabled caregivers to speak more openly and candidly.

4.10 DATA ANALYSIS

The taped discussions were transcribed by a professional language agency then translated into English by lay and professional translators. Five languages were used during the discussions and often more than one language was used during any one of the focus groups. This meant that the transcription and translation of the tapes into English was time consuming and not straightforward.

One of the lay translators, a physiotherapist, assisted the researcher with a “cultural translation” as there were several idiomatic expressions and an implicit
understanding of some concepts which made no sense when directly translated into English.

The data were analysed using a grounded theory approach (Merriman, 1998; Strauss and Corbin, 1990; Pope and Mays, 2000; Neuman, 2000). This involved the following steps:

**Open coding**
The transcripts were read through several times in order to have an overview of the body of material. A line-by-line analysis was completed to establish common concepts.

**Axial coding**
The concepts were then grouped into discreet categories, similar categories were grouped into broader categories and then these categories were appropriately coded into sub-themes. This enabled comparisons to be made across interviews (Merriman, 1998; Strauss and Corbin, 1990; Pope and Mays, 2000).

**Identification of themes**
Connections between the categories in the open coding were then made so that the most important themes could be identified. From this, the relationships between categories could be established by considering causal conditions, context, interactive effects and consequences (Strauss and Corbin, 1990).

**Reliability check**
The categories identified in the transcribed data were then checked for reliability. A physiotherapist familiar with qualitative data analysis and not involved in the data collection reviewed subsets of the data and independently coded the data. The percentage agreement between these two sets of open coding was 86%. This process ensured that the codes and themes generated were understandable, exhaustive, mutually exclusive and independent.
Trustworthiness of the data

Trustworthiness of the data was established through:

1. Triangulation of data, that is looking at the data from several angles in order to corroborate data items and hence maximise confidence in the validity of the findings (Pope and Mays, 2000). Three types of triangulation as described by Neuman (2000) were used: triangulation of measures (using data from focus group discussions, field notes, debriefing memos, observational notes, hospital therapy records); triangulation of observers (researcher and field workers); and triangulation of methods (combining both quantitative research methods, as used in Phase 1, and qualitative methods, as used in Phase 2). Credibility of the data is ensured when the same factors, for example, caring attitude from health care providers, are identified from a number of different sources (Strauss and Corbin, 1990).

2. Use of “thick descriptions” built on low inference data (Strauss and Corbin 1990). This ensured that the exact language used by the caregivers was analysed.

3. Data saturation, that is collecting and analysing data using multiple methods until no new concepts or categories emerged.

Member checking is another step in establishing the trustworthiness of data. Participants are given the opportunity to listen to the tape recordings or to read through the transcripts and make any changes (Strauss and Corbin, 1990). However, in this study, logistical considerations such as the large distances involved which made it difficult to locate caregivers a second time precluded this step.

4.11 SUMMARY

As highlighted in the previous chapter, steps taken to ensure the quality of data collected again illustrate the difficulties involved in applying quantitative research
methodology involving questionnaires and scales in a population unaccustomed to thinking quantitatively or expressing themselves openly. Working in a cross-cultural setting using six languages added to the complexity of data collection. The methodology had to be rigorous yet flexible enough to be appropriate to local conditions and to overcome unexpected challenges encountered.

Results and the ensuing discussion from each phase are presented separately in the following four chapters.