DEVELOPMENT AND PILOTING OF MEASURING TOOLS

3.1 INTRODUCTION

The development of the measuring tools and scales used in the study, the reasons for choosing each scale and the steps taken to modify and adapt them for use in a South African context are described in this chapter. The chapter concludes with a description of the pilot study conducted to test the scales prior to commencement of the main study.

The broad domain of interest in this study are caregivers of children with CP living in poor areas, specifically their relationship with the child, their perceived personal quality of life, their mental health and the sources of support available to the family. Scales measuring aspects of these domains were therefore chosen. As demonstrated in Chapter 2, a host of assessment scales related to families of children with chronic illnesses already exists. Thus it was decided that it would be more advantageous to use existing scales than to try to develop new ones, as the development of a new tool was not the aim of the study and is a complex and time-consuming process. The aim of the study was to take existing tools and establish whether they would work in a poorly-resourced South African context. Once a tool has been modified or changed, the psychometric properties have to be re-established (Rosenbaum et al., 1990; Ketelaar et al., 1998; Streiner and Norman, 2003). This necessitates almost as much analysis as the development of a new tool. Thus the necessary procedures for establishing the psychometric properties were followed in this study.

From the Tables in Chapter 2, the following scales were chosen:

1. Judson Maternal Self-rating Scale (Appendix A1)
2. Family Support Scale (Appendix B2)
3. Caregivers’ Personal Quality of Life Scale (Appendix C)
4. Caregivers’ Mental Health Scale (Appendix D)

An additional domain of interest in this study was the caregivers’ perceptions of the degree of family-centredness of the therapy service. The Measure of Processes of Care (MPOC) was specifically designed for this purpose (Appendix E1). This scale has been used in a number of studies in North America and Europe (King et al., 1996; van Schie et al., 2004; Bjerre et al., 2004; McConachie and Logan, 2003) and thus was considered another suitable tool to use in this study.

In the following section, each of these scales is described and reasons given for considering each scale potentially suitable for the purposes of this study.

3.2 DESCRIPTION OF MEASURING TOOLS

3.2.1 Child and family background questionnaire (Appendix F1)
A child and family background questionnaire was drawn up to collect information about the child’s disability and cerebral palsy classification, the frequency and availability of therapy the child received, as well as demographic and socio-economic characteristics of the family. The questionnaire drew ideas and items from both demographic questionnaires employed in other surveys in poorly-resourced areas in South Africa (Saloojee H et al., unpublished observations) and the housing quality scale designed by Westaway (Westaway and Gumede, 2000).

As the usual socio-economic status (SES) indicators of occupation, employment status and education are not applicable to the majority of black South Africans (Kroeger, 1983), an indirect measure of SES, based on that developed by
Westaway and Gumede (2000), was employed. This index utilises measures of commodity ownership and housing quality.

The Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997, Appendix G) was used to classify the child according to his or her functional motor abilities. This is a standardised method for describing the gross motor functional ability of children with CP in one of five ordered levels. Children at Level I can perform most or all the activities of their normally developing age-matched peers (although the speed and quality of movement may be limited), whereas children at Level V have difficulty controlling their head and trunk posture in most positions or achieving any voluntary control of movement. The child’s age is also taken into account when determining the rating. The GMFCS, a reliable and valid tool, is widely used by health care professionals to guide physical management interventions (Morris and Bartlett, 2004).

Using the algorithm developed by the Surveillance of Cerebral Palsy in Europe (SCPE) (Cans, 2000) together with the classification system used by Rosenbaum et al. in the Ontario Motor Growth Study (Rosenbaum et al., 2002) and described by Gorter et al. (2004), the children were classified into one of five groups according to their predominant neuromotor abnormality, i.e., the type of motor impairment: spastic, dyskinetic, hypotonic, ataxic or mixed. The algorithm does not accommodate children who have “mixed” presentations or children who are predominantly hypotonic. In this study, children were classified as “mixed” only when it was impossible to decide what the dominant type of tone was. In these cases, the quality of tone and movement abnormalities were clearly listed and described.

3.2.2 Judson Maternal Self-rating Scale (Judson and Burden, 1980) (Appendix A1)
This scale measures parental attitudes and adaptation to their disabled children. The main reason for choosing this scale was that it was originally designed to
measure one aspect of an intervention programme (parental attitudes to children) (Judson and Burden, 1980). It was also used as an outcome measure in a randomised control trial of three types of therapy interventions for children with cerebral palsy in an under-resourced area (McConachie et al., 2000). Furthermore, it specifically looked at parents of “handicapped” children, as opposed to other measures [such as the Parenting Stress Index (Abidin, 1989)] which focus on families of children with “developmental delay”.

This scale has been used mainly in the United Kingdom where it was renamed the Parental Adaptation to Child Scale (Sloper et al., 1991; Sloper and Turner, 1993). It has been used in studies with children with severe disabilities (Sloper and Turner, 1993), Down syndrome (Sloper et al., 1991) and more recently children with autism (McConachie et al., 2005). Results from the study involving caregivers of children with Down syndrome showed that caregivers’ adaptation to the child was significantly related to their perceived satisfaction with life. Unfortunately there are no published studies regarding the reliability and validity of this scale. McConachie et al. (2005) reported an internal consistency of 0.88. Sloper and Turner’s study (1993) failed to reveal a clear factor structure during factor analysis. Despite this limitation, it was decided to use the scale in this study because as already mentioned, it is the only scale designed to measure the interaction between mothers and severely disabled children which had been used in a poorly-resourced area.

The original scale contains 22 semantic differential items measured on a 7-point scale (Appendix A1). A semantic differential scale contains a bipolar scale for each item. Respondents have to place themselves at a point along the scale between two opposite statements, for example, “Nobody is interested in my child” and “Lots of people are interested in my child.” For this study, the scale was initially modified by the researcher to a 12-item Likert-type scale (Appendix A2) to suit local conditions, as previous research in poorly-resourced areas in South Africa indicated that participants struggled with a semantic differential scale
(Westaway, 1986). All items dealing with the interaction or relationship between the caregiver and the child were retained. Two items were reversed. Each item is scored on a 1 (none of the time) to 5 (all of the time) basis and summed. The higher the score, the more positive is the caregiver's attitude to, and interaction with, the child.

3.2.3 Family Support Scale (FSS) (Dunst et al., 1994)  (Appendix B1)
This scale, designed by Dunst and colleagues (Dunst, 1994), consists of 18 items, each describing a source of support (Appendix B1). Respondents indicate how helpful each source of support is on a 5-point scale from 1 (not at all helpful) to 5 (extremely helpful). Scores are then summed to give an overall measure of social support networks in families with children with disabilities. The 18 items on the scale are organised into five subscales: informal kinship, formal kinship, spouse/partner support, social organizations and professional services. Family support is reported in terms of overall level of support, which is the average of the composite score, as well as types of supports, which are the averages of the items that compose the subscales of the FSS (Dunst et al., 1984). Reliability of the FSS as measured by co-efficient alpha was 0.79 and by test-retest was 0.91 for the total score and 0.75 for the separate items. Discriminant and construct validity for the FSS has been demonstrated in several studies (Frey et al., 1989).

Dunst's scale is based on a conceptual model developed by Bronfenbrenner (1979). The scale distinguishes four ecological levels of support: nuclear (and extended) family, formal and informal kinship members, formal and informal social groups and organisations (church, neighbourhood, etc), and service professionals and agencies. According to Bronfenbrenner (1979), ecological units do not operate in isolation but impact upon one another both directly and indirectly so that provisions of support in one unit may reverberate and influence the behaviour of persons in other social units. These factors influence the well-being of the recipients of the support, which in turn is likely to affect how caregivers interact and treat their children, which in turn is likely to influence the
child’s behaviour and development (Bronfenbrenner, 1979; Cochran and Brassard, 1979 cited in Dunst et al., 1994).

Social networks and the social support they provide lessen stress, promote well-being and enhance use of coping strategies (Dunst et al., 1994). Social support may reduce the negative effects of a stressor (in this case looking after a child with a disability), although the family or community may also create conditions that add to the stress of the parent (Hartley et al., 2005).

The FSS was chosen for this study because it can be used to gauge the success of interventions which aim to empower families of children with special needs and which facilitate social support networks. These are aspects which may be influenced by an intervention therapy programme. The FSS is also a sensitive instrument for discriminating between individuals who manifest differing levels of stress and coping because it has been shown that social support may have a mediating effect on physical and emotional well-being (Dunst et al., 1994). As this scale had been used as an outcome measure for caregivers of children with cerebral palsy in a poorly-resourced setting in Bangladesh (McConachie et al., 2000), it was considered appropriate for this study.

The Family Support Scale has been widely used in a variety of different settings. It has been administered to caregivers of children with disabilities in several countries in urban, rural, well-resourced and under-resourced settings (Reyes-Blanes et al., 1999, Crowley et al., 1995, Darling and Gallagher, 2004). It has been used for caregivers of children with traumatic head injuries (Hanley et al., 1998), sickle cell syndromes (Ievers et al., 1998), intellectual disability (Hassall et al., 2005) as well as parents of infants in Neonatal Intensive Care Units (Feldman-Reichman et al., 2000)

3.2.4 Personal Quality of Life (PQOL) Scale (Westaway et al., 1999a)
(Appendix C)
Quality of life measures are one way of capturing the personal and social context of patients' lives (Bowling, 1995). As the impact of intervention on the caregiver and the family is central to this study, the PQOL scale was included to measure satisfaction with the personal domain (e.g., self, partner, family, friends) of quality of life. It is a 10-item scale, adapted by Westaway et al. (1999a) from Adams’ scale (Adams, 1992) for a South African survey in a poorly-resourced area. Coefficient alpha was 0.76 in Adams’ study and 0.75 in Westaway’s study, indicating respectable reliability (internal consistency). Each item is scored on a 0 (completely dissatisfied) to 10 (completely satisfied) basis and summed. The higher the score on this scale, the better the perceived personal quality of life.

The PQOL scale has been used in a number of studies in informal settlement areas in South Africa and for people with diabetes (Westaway et al., 1999b, 2001, 2003). It has not been used for caregivers of children with disabilities.

3.2.5 Mental Health Subscale of the Medical Outcomes Study (MOS) Short-form 20 Health Survey (Stewart et al., 1988, 1989)

(Appendix D)

The Short-Form-20 Health Survey is a 20-item abbreviation of the Rand Medical Outcomes Study (MOS) instrument designed as a general outcome measure in clinical studies and as a health status measure in population studies (Stewart et al., 1988). The Mental Health Subscale of this survey provides a measure of general mental health. This scale defines mental health as a “general mood or affect, including depression, anxiety, and psychological well-being during the past month” (Stewart et al., 1988, p. 726). It contains six items which are scored on a 1 (all of the time) to 6 (none of the time) scale. The scale is scored by summing item responses after reversing the score of two items. The score is then transformed linearly to a 0 - 100 scale, with 0 and 100 assigned to the lowest and highest possible scores, respectively. The formula used for the transformation is 

\[ \frac{(score-5)}{25} \times 100 \]

A high score is indicative of better health. A score of 67 or lower is defined as “poor mental health” (Stewart et al, 1988; 1989; Westaway et al, 1999b, 2001, 2003).
al., 1999c). An alpha co-efficient of 0.88 was observed for the Mental Health subscale in the USA, indicating very good reliability.

Several authors have suggested caregivers’ mental or psychological health may be influenced, either negatively or positively, by a therapy intervention programme (McConkey, 1995; Mobarak et al., 2000; McConachie, 2001; Jansen et al., 2003; Raina et al., 2005). Thus this dimension was included in the study. The Mental Health Subscale of the MOS Short-Form-20 was chosen not only because it has been shown to have very good reliability, but more importantly because it is freely and easily available. This is a key consideration when working in resource-poor settings. This scale has been used in a disadvantaged South African setting (Westaway and Wolmarans, 1995)

3.2.6 Measure of Processes of Care - 20 (MPOC-20) (King et al., 2004) (Appendix E1)

The MPOC assesses parents’ reported experiences of family-centred behaviours of rehabilitation service providers. It describes caregivers’ perceptions of the care they and their children receive from the therapy service. The measure is designed for families of children with neurodevelopmental disorders (King et al., 2004a), which is one of the reasons it was considered to be a suitable tool for this study. The MPOC does not examine the efforts of individual professionals. Instead, it examines the parents’ care experience in its entirety.

MPOC is a 20-item self-report scale covering five target areas: enabling and partnership; providing general information; providing specific information; co-ordinated and comprehensive care; and respectful and supportive care. For each item, the caregiver responds to a common question “To what extent do the people who work with your child …” followed by an item that begins with a verb describing a service provider behaviour. Items are scored on a 1 (never) to 7 (to a great extent) basis. Data for each respondent yield five scores, one for each of the factors. A scale score is obtained by computing the average of the items'
ratings. Internal consistencies of the five subscales are very good with co-efficient alphas ranging from 0.83 to 0.90 (King et al., 2004a). Test-retest reliability (on the MPOC-56), using intraclass correlation co-efficients, ranges from 0.78 to 0.88, demonstrating good stability (King et al., 1996).

Therapy which is family-centred in addition to being child focused is associated with higher levels of caregiver satisfaction, better mental health and lower stress in dealing with service programmes (Rosenbaum et al., 1998). It has been suggested that this ultimately results in a more positive impact on the child (Rosenbaum et al., 1998; Rosenbaum, 2004). As these are the domains of interest in the present study, this scale was included. The MPOC score sheet and training manual can be downloaded free of charge from the CanChild website (www.canchild.ca). The training manual provides clear guidelines for administering the scale and it is easy to score.

The MPOC has been used in a number of countries to measure the experiences of parents with children with a variety of neurodevelopmental disabilities (King et al., 1996; Larsson, 2000; McConachie and Logan, 2003; Bjerre et al., 2004), such as acquired head injury (Swaine et al., 1999) and cleft lip and palate (King et al., 1997). It has, however, never been used in resource-constrained settings.

### 3.3 MODIFICATION AND ADAPTATION OF MEASURING TOOLS

Written permission to use the scales was obtained from the authors of the Judson Maternal Self-rating Scale, the Personal Quality of Life Scale and the Measure of Processes of Care. Permission to use the Family Support Scale and the MOS Short-form Scale is not required.

All the scales were designed to be self-administered i.e., caregivers complete the questionnaires on their own. For this study, it was decided to train interviewers to administer the questionnaires because:
• A high degree of literacy is necessary for self-administration of all the scales. The functional literacy level of the study population was not known, but as the caregivers lived in disadvantaged settings, it was assumed that some of them may have experienced functional literacy difficulties.

• By virtue of the fact that the caregivers were living in unsophisticated and poorly-resourced environments, the assumption was made that most of them would have had little or no experience in completing self-administered questionnaires.

The tools were modified and adapted for use in a South African setting using a two-step procedure:

1. A series of focus groups with therapists and parents was held to discuss the suitability, appropriateness and “understandability” of each test item.
2. A pilot study was conducted to test the modified questionnaire as well as its administration by trained interviewers.

3.3.1 Focus groups

Four focus groups were arranged involving a total of 25 therapists and two focus groups involving a total of nine parents. There was an average of five people in each focus group. The purpose of these focus groups was to discuss the suitability of the measurement tools outlined above and to suggest how they should be adapted for use in South Africa. Physiotherapists, occupational therapists and speech therapists with several years of experience working with children with cerebral palsy from 12 public sector hospitals were invited to attend the focus groups. Three of the therapist focus groups were held in urban areas (Johannesburg, Pretoria and Durban), and one in a rural area (Northern KwaZulu Natal). These therapists were considered to be representative of a wide spectrum of the therapists in public service.

The two focus groups with parents took place at Chris Hani Baragwanath Hospital in Soweto, Gauteng. The reason for limiting the focus groups to this
hospital was that this was a hospital known to the researcher where there were parents proficient in English, with years of experience of attending therapy and who could actively and usefully participate in a focus group.

Participants for all the focus groups, both therapists and caregivers, were purposively selected as they were considered to be “information-rich” with valuable experience and knowledge to contribute to the discussion. Each focus group lasted 1½ – 2 hours and was tape-recorded. This enabled the researcher to carefully note the changes and modifications to the test items suggested by the focus group participants.

The modifications and adaptations of each questionnaire are discussed below.

3.3.2 Child and family background questionnaire (Appendix F)
The child and family background was considered to be much too long, with several irrelevant questions. It was therefore shortened considerably. Ambiguous questions were clarified. The revised questionnaire can be found in Appendix F2.

3.3.3 Judson Maternal Self-rating Scale (Parental Adaptation to Child Scale- Appendix A)
During the focus group discussions and the pilot study, this scale was revised to such an extent that it barely resembled the original 22-item scale (Appendix A2). Therapists attending the focus groups commented that many items taken from the original scale were too abstract and they suggested that more concrete items be added. Thus two more items “I understand my child (e.g., I know when he is hungry, or when he feels pain” and “I feel I can cope when strangers ask questions or say negative things about my child” were added to the twelve item scale.

Concerns raised by both parents and therapists during the focus group discussions were borne out in the piloting of this scale, when it became clear that
caregivers found it easier to answer questions relating to actual behaviour (e.g., “I am finding it difficult to look after my child”) than abstract statements (e.g., “I am happy about my child”). Translating the items into six local languages also revealed a number of difficulties in that the phrases “I am enjoying my child”, “I am comfortable with my child” and “I am happy about my child” all sounded the same when translated, as the same word is used for happy, comfortable and enjoy in almost all the local languages. Table 3.1 summarises the changes made to the twelve items taken from the original scale.

Table 3.1: Changes made to items from the Judson Maternal Self-rating Scale

<table>
<thead>
<tr>
<th>Original item</th>
<th>Modification</th>
<th>Final version</th>
</tr>
</thead>
<tbody>
<tr>
<td>My child and I have lots of fun together</td>
<td>No change</td>
<td>My child and I have lots of fun together</td>
</tr>
<tr>
<td>Lots of people are interested in my child</td>
<td>No change</td>
<td>Lots of people are interested in my child</td>
</tr>
<tr>
<td>I am enjoying my child</td>
<td>No change</td>
<td>I am enjoying my child</td>
</tr>
<tr>
<td>I find it easy to show affection to my child</td>
<td>No change</td>
<td>I find it easy to show affection to my child</td>
</tr>
<tr>
<td>I am proud of my child</td>
<td>Retained, but example added</td>
<td>I am proud of my child (e.g., I am happy to take my child anywhere)</td>
</tr>
<tr>
<td>I am comfortable with my child</td>
<td>Left out</td>
<td></td>
</tr>
<tr>
<td>My child seems a happy child</td>
<td>Left out</td>
<td></td>
</tr>
<tr>
<td>I am noticing great progress with my child</td>
<td>Left out</td>
<td></td>
</tr>
<tr>
<td>I know how much to expect of my child</td>
<td>Modified</td>
<td>I know that my child may not be able to do things like other children of the same age</td>
</tr>
<tr>
<td>I am happy about my child</td>
<td>Left out</td>
<td></td>
</tr>
<tr>
<td>I am able to share my worries about my child</td>
<td>No change</td>
<td>I am able to share my worries about my child</td>
</tr>
<tr>
<td>I am optimistic about my child’s future</td>
<td>Left out</td>
<td></td>
</tr>
</tbody>
</table>

New items added:

- I find it difficult to play with my child (e.g., because I don’t know how to play with him/her).
- I feel that I have a relationship (a bond) with my child.
• I am finding it difficult to look after my child.
• I understand my child (e.g., I know when he is hungry, or when he feels pain).
• I feel I can cope when strangers ask questions or say negative things about my child.

In summary, only six items from the original scale were retained; one item was modified; and five new items were added. These new items represented aspects of caregiving, and caregivers’ feelings and relationship with their children, that both therapists and parents felt were important. As this version of the scale was so far from the original scale, it was inaccurate to continue to refer to it as Judson Maternal Self-rating Scale. It was therefore renamed the “Caregiver and Child Scale” (Appendix A3). This is not the first time the scale has been renamed. In the UK, it is referred to as the Parental Adaptation to Child Scale (Sloper et al., 1991: Sloper and Turner, 1993) or the Parental Feelings Questionnaire (McConachie et al., 2005), presumably to reflect that it is a modified version of the original scale devised by Judson and Burden (1980).

3.3.4 Family Support Scale (Appendix B1)
The original 18-item scale was expanded to 31 items (Appendix B2). The inclusion of so many additional items is a reflection of the complexity of social and community relationships in the South African population. Additional items included several groups of people considered significant to caregivers, namely traditional healers, prophets or spiritual healers, community rehabilitation workers, street committees, tribal leaders. The item ‘My relatives/kin” was divided into close family (sisters and brothers) and extended family (cousins, aunts, uncles). The extended family plays an important role in child rearing in traditional African culture, thus it was felt necessary to distinguish between close and extended family (Groce and Zola, 1993). The items “Professional helpers” and “Professional agencies” were subdivided into individual categories, e.g., therapists, doctors, nurses, social workers, Department of Education, Department
of Home Affairs, etc., as it was felt inappropriate to combine too many groups of people or agencies into one category. The item “Early Childhood Intervention Programme” was excluded as local therapy services are not known by this term.

3.3.5 Caregiver’s Personal Quality of Life (PQOL) (Appendix C)
As this scale had been developed for use in a South African environment setting similar to the study setting and with a group of people similar in terms of literacy and socio-economic status, this scale was not changed.

3.3.6 Mental Health Subscale of the Medical Outcomes Study (MOS) Short-form 20 Health Survey (Appendix D)
Although the focus group participants felt that caregivers might experience difficulty with this subscale questionnaire because it dealt with feelings and emotions, it was decided not to change any of the items, as the scale had successfully been used in a similar South African setting (Westaway and Wolmarans, 1995).

3.3.7 Measure of Processes of Care -20(MPOC – 20) (Appendix E1)
All therapists participating in the focus groups agreed that all the items included in the MPOC represented the “ideal service” and there were very few items that they would remove.

However, most of the therapists felt disillusioned and disheartened about the use of the MPOC in a public service setting because it highlighted the discrepancy between the kind of service they felt they should be delivering and what in reality they were able to deliver. The main reason for this was the time available for therapy. Despite this, they felt that it was a tool they would like to use in their clinical settings.

The focus groups suggested the following changes to the MPOC:
• The language needed to be made as simple as possible. The meaning of each statement needed to be very clear so that it could not be open to interpretation. This would assist with translation, so that the original meaning was not lost.

• Some of the concepts and language were too abstract – each item needed to be as concrete as possible, e.g., the concepts of “perceptions, competent, consistent, parent as a partner” were not easily translatable.

• The meaning of some of the items was not clear to the researcher and the focus group participants. This was probably due to differences in the nature and structure of the services between Canada, where the MPOC was developed, and South Africa. One of the authors of the MPOC (P. Rosenbaum) was contacted to clarify the meaning of some of the questions.

Based on the above suggestions, the following modifications were made:

• Language was simplified, and made as concrete as possible. Many examples were added for additional clarity.

• References to written information were removed – because of problems of language and literacy, caregivers are not usually given written reports, assessments and treatment plans.

• Changes were made to reflect current practice – i.e., children seen only monthly; they often travel long distances; services are hospital based, not centre based; there is more emphasis on home programmes and giving caregivers activities to do at home.

• Item 2 “…let you choose when to receive information and the type of information you want?” and item 10 “…plan together so they are all working in the same direction” were removed as they were too abstract, and therapists felt caregivers would be unable to give a response to these items.

• Two items from the MPOC-56 (items 16 and 20) were added (“…make sure you have a chance during visits to the centre to say what is important
to you” and “follow up at the next appointment on any concerns you discussed at the previous visit”) as therapists felt these items were particularly relevant to the type of service offered in this country.

- Two new items added (“…explain what they want you to do between visits” and “…give you suggestions and ideas of things to do which make it easier to handle and look after your child at home.” As children in South Africa generally receive therapy monthly, home programmes are an essential part of therapy in this country. The therapists felt that these aspects of service in South Africa were not captured on the MPOC.

- Two “check” items were added as a way of establishing concurrent validity (“…to what extent do you feel that you gain something from every session” and “…finally to what extent are you satisfied with the therapy service you receive here?” Concurrent validity refers to the similarity between the target measure and another measure for which validity is known (Payton, 1988). However, since no comparable measure was available, these two questions were used as they were similar to what the overall scale was measuring.

These changes and modifications were discussed with one of the authors of the MPOC-20 (P. Rosenbaum) who suggested that the South African version of the MPOC be called the MPOC-22(SA) (Appendix E2). A comparison between the MPOC-20 and the MPOC-22(SA) version can be found in Appendix E3.

3.4 LIKERT SCALES

Several ways of presenting and labelling the Likert scales were tried, i.e., having only the numbers (e.g., 1, 2, 3), or only the descriptive labels (e.g., some of the time, all of the time, most of time) or both. It was finally decided that having the numbers together with the descriptive labels both in English as well as the African language translation altogether in each block gave participants a choice of three ways of understanding the meaning of each value. Dickinson and
Zellinger (1980) report that respondents are more satisfied when many or all of the points on the scale are labelled and this view is also supported by Guilford (1954, in Streiner and Norman, 2003, p. 36) who stated “Nothing should be left undone to give the rater a clear, unequivocal conception of the continuum along which he is to evaluate objects.”

3.5 TRANSLATION

A translation protocol based on recommendations from Streiner and Norman (2003) and Jelsma et al. (2000) was drawn up. The background information questions and the scales were first translated by professional and lay translators into six languages: Isizulu, Setswana, Sesotho, Sepedi, Xitsonga and Tshivenda. Secondly, each scale was back translated into English by six lay translators who were not involved in the forward translation. Each lay translator had one of the six languages as his or her first language or mother tongue and all were proficient in English. The back translations were then compared with the original English version and any discrepancies were discussed with the lay translators and the final translation agreed upon.

Following the forward and back translations, two of the translations (the Sesotho and Isizulu versions) were discussed with the translators and the interviewers together to ensure semantic equivalence and further changes were made. Isizulu and Sesotho were the first languages of the interviewers and are also the dominant languages used in Gauteng. A “conceptual strategy” was used where the significance of the questions was preserved, rather than a direct text translation.

As the translation protocol for two of the six languages had been very carefully followed and because all the interviews were to be conducted by the same three interviewers, the process of ensuring semantic and conceptual equivalence for the remaining four language translations was not considered necessary.
Logistical considerations were also a factor bearing in mind there were a total of five scales and six languages. Between them, the interviewers were competent in speaking all six languages and as they had been involved in establishing semantic and conceptual equivalence for two of the translations, this was considered adequate for the purposes of this study.

A major problem encountered with the translations was that African languages do not always contain the range of vocabulary needed to describe some of the nuances of items, which meant that several items, especially in the Caregiver-Child Scale, sounded very similar. There were also difficulties in translating all the response terms for the Likert type scale; for example, it was difficult to distinguish between terms such as “to a very great extent” and “to a great extent.”

3.6 PILOT STUDY

The piloting of the questionnaires and the scales overlapped with the training of the field workers who conducted the interviews. The first pilot study took place at the Alexandra Health Centre in Johannesburg. This health centre serves Alexandra, a dense and overcrowded urban township where conditions and services for children with CP were similar to those in the study sites. Four mothers were interviewed by each of the field workers to establish inter-rater reliability. At the end of this session, it was clear that the questionnaire was much too long, some questions were ambiguous, and the field workers did not clearly understand all the questions themselves.

Thus the demographic part of the questionnaire was shortened. Confusing questions were clarified and further concrete examples added to explain some of the items. The piloting and training continued at Leratong, Kalafong and George Mukhari Hospitals where altogether twenty caregivers were interviewed. Two of the lay translators (one a Setswana speaking paediatric occupational therapist and one a Sesotho and Isizulu speaking paediatric speech therapist) observed
the interviewing session at George Mukhari Hospital. This was very useful as they were familiar with the background to the study and could moderate and comment on the interview process, whether the interviewers were asking the questions correctly (clarifying where necessary), and whether they correctly recorded the caregivers’ responses. The discussion at the end of the session between the two translators and the interviewers was valuable in assisting the interviewers to further “internalise” the questions and scales for themselves.

Throughout this training and piloting phase, items on the scales were refined, new items were added to the Caregiver-Child Scale (as described in 3.3.3) and confusing and ambiguous items were deleted. The fact that the piloting took place in four different settings provided the researcher and the interviewers with an idea of the variations in how the CP service was structured in each hospital and this assisted with compiling a wider range of examples which could clarify the items in the MPOC.

The final version of the questionnaire, which includes all the scales, can be found in Appendix H.

3.7 SUMMARY

Scales chosen for this study and the steps taken to adapt them to a South African context are summarised in Figure 3.1.
Review of available scales relating to caregivers and children with CP

Five scales identified as being suitable for the purposes of this study

Where necessary, written permission obtained from authors of scales

Series of focus groups with therapists and with caregivers to modify and adapt scales for a poorly-resourced South African setting

Process of translation and back translation into six languages. Back translations compared with original English version

Translators, researcher and interviewers meet to discuss and establish semantic equivalence

Interviewers trained in use of scales and pilot study conducted

Further modification to scales

Final version of scales

Figure 3.1: Summary of steps followed in modifying and translating scales
The process illustrates the complexity of studying and measuring the “human dimensions” of health services as opposed to measuring a clinical aspect like haemoglobin levels in the blood. It also highlights the challenges involved when using scales in a population and environment which is markedly different from that in which the scales were originally developed.

The scales used in this study were chosen after a careful and thorough search of the literature. Using existing scales, some of which had been employed in similar settings, as opposed to starting from the beginning to develop a new tool, was logical and sensible. Whilst “on paper” the scales seemed appropriate and well-suited to the purposes of the study, it was only once they were examined a little more closely during the focus groups, the translation process and the field testing during the pilot study that their shortcomings became more obvious. The work described in this chapter on modifying the scales was a revelation in that only when the process of adaptation began did the magnitude of the task (working with five scales and six language groups) become apparent. These experiences highlighted the fact that because there are no scales suitable for the questions and the setting to be explored in this study, sweeping modifications to most of the existing scales were needed to the extent that some of them ended up being virtually new measures.

At this stage of the study it started to become apparent that what initially appeared to be a relatively straightforward study objective, namely ascertaining whether scales developed in other settings could be used in a poorly-resourced South African setting, was going to be more complicated than anticipated.