CHAPTER 9

DISCUSSION: COMBINING PHASE ONE AND PHASE TWO

The motivation behind this study was the need to know whether current rehabilitation therapy service practices in public service hospitals in South Africa are effective in bringing about positive changes in the children or in the lives of their caregivers. Alongside this question was the recognition that rehabilitation professionals in public service hospital settings work in a multicultural and multilingual settings with little or no idea of how caregivers living in the poorest areas of the community live their lives and what they value and need from therapy.

To answer the first of these questions, outcome measures were needed to assess the impact of rehabilitation on the primary caregiver. The theoretical construct underlying this study is that in any intervention involving children with cerebral palsy, the child cannot be seen in isolation from the caregiver and the family. The perspectives and well-being of the caregiver were the outcomes of interest as these provide an indirect way of examining the effectiveness of the intervention on the child. In this study, caregiver outcomes included their personal quality of life, interaction with their child, their mental health and family support structures.

As many tools for measuring the outcomes of interest already exist, the starting point of this study was to ascertain whether scales and measures developed and used elsewhere could be applied in a South African setting. This would have provided a useful means of evaluating certain aspects of current services in public health settings and would also have avoided the need to develop measures from scratch. The frameworks adopted and the processes followed in finding answers were based on the available literature. This literature had
emerged from research in developed countries and was thus based mainly on a Western perspective regarding research methodology and research culture, as well as the underlying cultural assumptions from the Western world about disability and the impacts thereof on families.

Recognising that the context in which the therapy interaction took place, namely the caregiver and the family, was poorly understood, it was also important to explore the lives of the caregivers, including their perceptions about their children and the meaning and interpretation they had of the child’s disability, as these aspects were assumed to influence their expectations and experiences of therapy. To date, none of this information has been documented or described in disadvantaged settings. This study was consequently exploratory in nature as it sought to map the territory and identify the most suitable tools to use to start digging for the treasure.

The results have shown that many of the tools developed and used elsewhere, specifically in well-resourced settings, are not suitable for use in a poorly-resourced South African setting. Either they need to be modified, or in some cases completely new tools need to be developed. However, the actual process of asking the questions, together with caregivers’ descriptions of their experiences of looking after a child with cerebral palsy and their interaction with health care providers, have shed some light on why the tools did not work and what the new tools should look like.

This chapter synthesise the three main themes arising from the quantitative and qualitative phases of the study. These include a reflection on why most of the scales were not as useful as expected in this setting; insights into the lives of caregivers of children with cerebral palsy living in disadvantaged settings; and aspects of a rehabilitation service which caregivers most value. Recommendations for clinical practice and for future research arising from the discussion are given. The chapter
concludes with a discussion of the generalisability of the study findings, the challenges encountered when doing this kind of research as well as the significance of this study.

9.1 USE OF SCALES IN SETTINGS DIFFERENT TO THOSE IN WHICH THEY WERE DEVELOPED

The most significant, and unanticipated, finding of this study is the fact that despite a rigorous process of modifying, translating and administering the various measures that had been carefully selected for the purposes of this study, only one of the five scales proved to be a reliable and valid tool for use in a disadvantaged South African setting. Thus the study has highlighted the care that needs to be taken when using measures created for, and validated in, different settings, particularly in cross-cultural settings. This finding reinforces the advice of Rosenbaum et al. (1990) and Ketelaar et al. (1998) that a measure cannot automatically be used for a purpose other than the one for which it was designed or applied to a population dissimilar to that for which it was developed and validated.

It is not that the research questions were incorrect, that the questions being asked were wrong or that these questions should not be asked. Rather it is the process of finding answers that needs to be more closely examined. To do this, it is necessary to take a more careful look at the population and to recognize that presently the issues with which caregivers grapple, and how they live their lives, are not clearly understood. The qualitative phase of the study provides the start of the journey along this path of understanding.

The first key message of the study, therefore, is that even when adapted and modified, scales do not always perform as expected in settings which are different to those in which they were developed.

Of the five measures used in the study, only one, the Mental Health Subscale from the MOS Short-Form 20 Health Survey, proved to be both reliable and valid in the new
setting. The Family Support Scale was reliable but not valid whilst the Caregiver-Child Scale (based on the Judson Maternal Self-Rating Scale) and Personal Quality of Life Scale were neither reliable nor valid. The final measure, the MPOC, has possibilities for use in this new population if it is changed to an eight item scale using data derived from this exploratory work.

Why did the scales not perform as well as expected in this population? Two major categories of reasons for these findings can be identified, namely difficulties with the process of administration of the scale or asking the questions; and difficulties related to the content of the scale and the actual items in the scales.

Difficulties with the process of administering the scales included a number of factors.

9.1.1 Inexperience of the participants
As described in Chapter 4, section 4.4.5, virtually none of the caregivers had any experience in completing scales and questionnaires, and the process was unfamiliar to them. It is worthwhile noting that during the retest phase of the study, caregivers found the scales much easier to complete and the process took far less time. This might account for some component of the unreliability found in some of the scales. It also suggests that as caregivers are provided with more opportunities to complete scales and questionnaires, the process of administering scales will get easier. Thus it would be unwise to conclude that quantitative measures should never be used to evaluate aspects of therapy intervention in this population of caregivers. Furthermore, as the educational and functional literacy of the general population improves, it can be anticipated that in future, caregivers might be more familiar with the process of completing scales and questionnaires easier and thus find it easier to do.

9.1.2 Difficulty with Likert-type scales and the concept of grading a response.
Chapter 4, section 4.4.5, describes how caregivers struggled with the concept of rating an item on the scale. The focus group with the interviewers elaborated on some of these difficulties. As one caregiver remarked: “I couldn’t see where to point. I looked for the
word but I could not find it.” (IFG). Several caregivers had problems with items on the Personal Quality of Life Scale: “They say why should we give ourselves the number? And why do you want to know about myself?” (IFG).

The interviewers described how some of the caregivers struggled with the numbers on the rating scale: “She said to me, oh – I thought I must put one and one together. I said no, I didn’t tell you that. You should choose one number. Don’t take maybe 3 and 5 and you are saying 15. I didn’t say that. She says okay, I thought I have to add more numbers. I said no, I didn’t tell you that you must add numbers.” (IFG).

Caregivers found it easier to give categorical judgements, e.g., “yes” or “no" rather than continuous judgements, e.g., choosing among a series of alternatives. For example when asked to rate the statement “I am proud of my child", they would respond “Yes, I am proud of my child." The Mental Health Scale was the easiest to complete as it had mutually exclusive categories. This made it easier for the interviewers to explain the scale to caregivers, especially when a small diagram was used as an illustration to describe the amount of time in a month.

The results make it clear that much more practice in completing these kinds of scales is required before they can be used routinely in a clinical or research situation, particularly if a scale is to be self-administered. Clearly, it is not advisable to use the same scale continually on the same group of caregivers because the process of completing a scale may become a learned response.

Alternatively, other ways of asking the questions need to be devised. Harter (1982) has developed a variation of the Likert Scale which may have possibilities for use in this population. It is used primarily for children and utilises a categorical element, which caregivers in the current study found easier to use. The respondent first decides whether he or she is more like the person on the right or the left, and then whether the description is ‘true’ or ‘really true’ for him or her; there is no neutral position.
Applied to the Caregiver-Child Scale, an item might look like this:

<table>
<thead>
<tr>
<th>Some mothers find it difficult to look after their children</th>
<th>BUT</th>
<th>Other mothers find it easy look after their children</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Really true for me</td>
<td>□</td>
<td>□ Really true for me</td>
</tr>
<tr>
<td>□ Sort of true for me</td>
<td>□</td>
<td>□ Sort of true for me</td>
</tr>
</tbody>
</table>

Harter (1982) claims that this format reduces bias in responding, because contrasting two types of people reduces the possibility that one of the alternatives is seen as less desirable than the other. This format has been successfully used with children as young as eight years of age (Ronen et al., 2003).

Another alternative to Likert scales is to use a visual or pictorial scale. Streiner and Norman (2003) suggest that in geriatric populations, a vertical “thermometer” is easier to complete than a horizontal line.

9.1.3 Language
Having 11 official languages in South Africa will always present a challenge when doing the kind of research undertaken in this study. Apart from this, two specific aspects relating to language were identified as contributing to difficulties with the process of completing the questionnaire: firstly, the reading level of the material, and secondly, situations where the interviewer and caregiver did not share the same first language.

Some caregivers, particularly older caregivers who were grandmothers, found the language difficult. As one of the interviewers said: “… and the words I am supposed to use, this word is too difficult for her to use it.” (IFG). The literacy level of the study population was moderately good in that over 75% of the caregivers had had some secondary school education, so it was not unreasonable to expect the majority of caregivers to have been able to read and understand the questions.

However, from the comments from the interviewers, it was clear that although most caregivers had completed primary school, many had problems with functional literacy
and interpreting the meaning of the questions. Problems with functional literacy may in part be due to the inferior education caregivers in disadvantaged areas received - another legacy of the apartheid government. Furthermore, the concepts behind the words that people could read may have been complex for people to grasp.

In addition, some items on the scales were open to misinterpretation, for example in response to item 11 on the Caregiver-Child Scale “I am able to share my worries about my child” one caregiver responded “I am worried because my child does not have any equipment.” However, as can be seen from the comments caregivers made when completing the scales (Appendices O - S), there were relatively few examples of this kind of misinterpretation.

The usual rule of thumb is that the scale should not require reading skills beyond that of a twelve year old (Streiner and Norman, 2003). The reading levels of the scales in this study were not formally or systematically checked before translation, nor were the translated versions checked. This was clearly a limitation of the study. Establishing reading levels in the vernacular is logistically difficult because reading levels have not been established for all local languages. Local dialects, especially in deep rural areas, are another challenge which has to be overcome when ascertaining the reading level of a scale or the questionnaire.

The second problem regarding language occurred when the caregiver and interviewer did not share the same first language. Although between them the interviewers were fluent in all six languages used during the study, it became apparent that local variations or dialects exist within each language. This was especially true when caregivers came from deep rural areas, for example: “Maybe someone she can speak Sotho, she understands the Sotho, but not this Sotho that I understand, maybe a stronger Sotho than this” (IFG), and: “You know, I am a Zulu, I’m a Gauteng Zulu and then we’ll take the one from Umlazi ne, my Zulu and the one from Umlazi, they are totally different. Like Sotho also – the one we are using on this side and the one they are using in Qwa Qwa and the one they are using in Lesotho, they are very much difficult, different, but you
can hear what the person wants to say. You can compare, but they are similar. So it was tough” (IFG).

9.1.4 Cross-cultural applicability of the scales

With hindsight, perhaps another reason for the minimal success in using the scales in a different setting is that insufficient attention was paid to the cross-cultural applicability of the scales. Although the recommended protocol for translation was followed, in retrospect perhaps this process did not go far enough in establishing cross-cultural applicability. As outlined in the Literature Review, Ustun et al. (2001) recommend that key informant interviews, “concept mapping” and “pile sorting” together with a linguistic protocol which includes technical equivalence in addition to semantic and conceptual equivalence are the processes to follow when establishing the cross-cultural applicability of a scale.

It could be argued that the above steps are a laborious process involving almost as much work, if not more, than the initial development of the original scale. This process was clearly not possible in the context of the present study where five scales were translated into six languages. However, experience from this study has shown that language and translation were more of a problem for respondents than initially anticipated. This may have been because questions were not phrased in the words which would be familiar to the respondent, that is, it was not necessarily the questions or the scale items themselves that were the problem, it was rather finding the language and words that caregivers themselves would use to express these concepts. Therefore when planning future studies in this field, more attention needs to be given to linguistic analysis in order to achieve equivalence between the original version and the translated version of the scale.

9.1.5 The process of administering scales

The process of administering scales is clearly more complex than initially envisaged. It is only when the expected results were not achieved that a more detailed analysis of the process was made.
Based on the theories of Tourangeau (1984) and Schwarz and Oyserman (2001), Streiner and Norman (2003) describe five cognitive requirements or steps that respondents need to go through when answering a question. Each step presents an opportunity for bias:

1. Understanding the question.
2. Recalling the relevant behaviour, attitude or belief.
3. Inference and estimation.
4. Mapping the answer onto the response alternatives.
5. Editing the answer.

In this study, the process of administering the scales was further complicated by the fact that the study was conducted in a different cultural setting from those in which the scales were developed and they needed to be translated. Thus the very first step in the above list, understanding the question, is compromised. If the question is not clearly understood then recalling the relevant behaviour, attitude or belief is difficult for respondents. Respondents’ lack of experience and unfamiliarity with the concept of mapping their answers onto the response alternatives further compromises the process.

9.1.6 Summary
With regard to the use of scales in settings which are different from those in which they were developed, an important finding from this study is that it cannot be assumed that scales developed for caregivers of children with cerebral palsy in well-resourced areas or in different cultures will be applicable to caregivers in a different setting even if they have been modified and translated. This is true even for a scale (such as the PQOL) developed in a similar setting but for a different population group.

This finding has important implications when comparing results across cultures and countries. If insufficient attention has been given to translation and cross-cultural applicability, it will not be clear whether differences observed are actual differences or whether they are a reflection of cultural or other factors, or perhaps subtle variations in
the instruments. However, making comparisons across population groups needs to be done. Thus similarities and differences observed should be interpreted with extreme caution.

The finding that the scales developed in contexts different from the context of this study are not appropriate for use in this community, although unexpected, is nonetheless an important lesson. It has highlighted the many factors which need to be taken into account when working in a multicultural and multilingual population living in a poor socio-economic environment, which will ultimately result in the development of more appropriate tools and better quality research.

9.1.7 Recommendations for clinical practice and for future research

One of the values of this study is that it has laid the groundwork for future studies involving the use of scales in cross-cultural settings as well as the use of questionnaires in clinical settings. As a result, a number of recommendations can be made.

- Caregivers need practice and experience in completing questionnaires before they can be routinely used within a clinical setting. It is recommended that until caregivers are more comfortable and familiar with the process of answering a questionnaire, interviewer-administered questionnaires should be used. Interviewers need to “train” respondents through the use and repetition of a variety of practice items.

- The language used needs to be kept as simple and as clear as possible to avoid misunderstanding and misinterpretation. It is strongly recommended that ways be found to check the reading level of scales once they have been translated.

- The issue of variations within each language is a more difficult problem to overcome in South Africa where there are eleven official languages. Except in very rural areas, it is unlikely that the interviewer and respondent will always share the same first language. This will always be a challenge which needs to be borne in mind when working with more than one language group, as will be the case in most urban settings in South Africa.
• An alternative or a modification to the Likert Scale, such as a pictorial scale, or the Harter scale mentioned above, should be explored. This would be especially useful when redesigning the Caregiver-Child Scale.

• Wherever possible, categorical yes/no type of responses based on actions or behaviours should be used when designing scales and items for these population groups.

• The advantages and disadvantages of translating the questionnaire and the scales need to be carefully weighed up, taking into consideration the purpose of collecting the information and what it will be used for. The literature contains many examples of a scale being translated specifically for the purposes of that study, but the reliability and validity of the translated scale are often not established in the new population. This clearly places a potential limitation on the interpretability of the study findings.

• If scales are to be translated, a forward and backward translation is insufficient. Ideally, the translation process probably needs to include a linguistic analysis (which would include semantic, conceptual and technical equivalence), concept mapping and pile sorting as described above.

9.2 MOVING TOWARDS A DEEPER UNDERSTANDING OF THE LIVES OF CAREGIVERS LIVING IN DISADVANTAGED AREAS

The second key message arising from this study is that caregivers of children with CP living in disadvantaged South African settings face many challenges and have developed numerous coping strategies.

The first part of the study revealed that to answer the quantitative questions posed at the beginning of the study, it is necessary to find the words and the ways that caregivers use to describe and talk about these concepts. The qualitative results have shown that caregivers living in disadvantaged South African settings live their lives very differently from their counterparts in more well-resourced areas. To date these differences (and similarities) have not been documented. This is the second key contribution of this study.
– that there is now some baseline information about how families living in disadvantaged areas in South Africa cope with a child who is disabled.

Data from the focus groups, from comments made by caregivers as they completed the questionnaires, and from observations made throughout the course of the interviews, taken together, have yielded valuable and useful information about the way in which caregivers live their lives; their experiences, beliefs and hopes; their coping strategies; and what they value in a rehabilitation service. This knowledge will assist in redesigning the format and process of asking questions in future research as well as restructuring the delivery and content of therapy services.

From the data, many important and relevant aspects regarding caregivers’ lives which will impact on how we ask questions and design therapy programmes have been identified. These aspects are outlined below and from these observations, recommendations regarding clinical practice and therapy intervention services are made.

9.2.1 The resilience displayed by caregivers despite a life of hardship.
Caregivers in this study described a life of hardship. Living out their lives against a background of material poverty, beset by financial concerns, often abandoned and rejected by their partners and enduring gossip as well as insensitive and ignorant attitudes from neighbours and the community, it is remarkable that they are happy, healthy and generally well satisfied with their lives. The majority appear to enjoy excellent mental health and feel positive about themselves. This is seen both from their comments as well as from the scores of individual items on the PQOL scale. On a scale of zero to ten, the mean scores were 8.74 for happiness; 8.89 for health; 9.37 for how they felt about themselves and 8.68 for satisfaction with life in general. Considering that nearly half of the caregivers were single parents with a mean income of just over R1000 per month, and that the majority of children were severely disabled, this is astonishing to the outsider. Caregivers demonstrate amazing problem solving skills in keeping their families together with minimal resources.
This strength and resilience of caregivers living in disadvantaged settings is rarely recognised and acknowledged by therapy professionals. The starting point for most intervention programmes is “needs based” rather than “strengths based”. As Knussen and Sloper (1992) have pointed out, professionals tend to overestimate the negative effects of the child on the family and to underestimate the parents’ strength and coping abilities. This has contributed to a somewhat “pathological” approach to intervention services where it is assumed that having a child with a disability inevitably leads to stress and poor family functioning. In addition, therapists tend to overestimate their role in helping caregivers cope, so it is somewhat humbling for therapists to have to recognize that in most poorly-resourced areas, parents and carers are coping without interaction with rehabilitation programmes (Hartley et al., 2005).

**Recommendations and implications for clinical practice**

Greater recognition and acknowledgement needs to be given to the strengths caregivers possess. Therapists all too easily slip into the role of the professional with all the power and knowledge, particularly when working in a cross-cultural setting, and in so doing, caregivers may be further disempowered.

The adoption of family-centred services which not only emphasise a partnership between parents and service providers but also uses a strength or asset-based approach is strongly recommended in public service settings. The starting point for intervention should be the recognition of the coping strategies and resilience of the caregivers.

**9.2.2 Caregivers’ coping strategies and support structures**

“Acceptance and support” was one of the main themes from the qualitative data. Linked to this were the numerous coping strategies adopted by caregivers. Support from informal support structures such as relatives and close family members, together with formal support structures, was an important dimension in helping caregivers cope.
This finding highlights the fact that there are other elements of care, apart from the technical aspects such as hands-on therapy, which need to be identified and included in an intervention programme. These aspects are part of what therapists need to be concerned about and need to address. The ICF framework recognizes that sources of support are part of the environmental factors, or the context within which the caregiver and child live their daily lives. Knowing the importance of the role of support networks to caregivers and families means that service providers (in this case the therapists) need to pay attention to it and that it is “legitimate” to do so. This does not necessarily mean that therapists have to attend to this personally (bearing in mind the limited amount of time therapists have available to spend with the caregivers); the important message here is that it needs to be part of the fabric of the rehabilitation therapy service and should not be ignored.

Given that sources of support are so important, the Family Support Scale (FSS) is thus a very useful tool to use in both further research and the clinical setting in identifying who the caregiver’s important sources of support are and in measuring or counting these sources of support, both formal and informal. By including the FSS in the initial assessment in public service hospitals, the role of support structures in helping caregivers cope can be acknowledged.

Caregivers in this study have described how close family members and the child’s siblings provide practical and financial support and how this kind of support helps with daily caregiving demands. Several caregivers described their sense of isolation, especially when their children were young. By knowing the extent of support systems available or not available to the caregiver, therapists can decide whether there is anything that can be done as part of the therapy intervention programme; for example, if the caregiver has very few sources of support, being part of a parent support group may be a priority. The FSS also assists in identifying what needs to change within the environment. For example, if all caregivers in one geographical community report no assistance from a particular source, the advocacy role of the therapists becomes more focused.
Data from the FSS in this study indicate that street committees (in urban areas) and tribal leaders (in rural areas) were a useful source of support in assisting families to access sources such as land, or providing material help. Bearing in mind the general ignorance combined with negative and unhelpful attitudes towards families of children with a disability within the wider community, this suggests that therapists need to adopt an advocacy role when working in public service settings in poor communities. This may include speaking to street committees or tribal leaders directly, giving talks to community organizations, or holding open days in the rehabilitation department and targeting community leaders to attend.

Recommendations and implications for clinical practice
Initial assessment at public service hospitals should include the FSS. This will assist therapists in identifying support systems available to caregivers as well as identifying gaps which could be addressed as part of an intervention programme. Therapists also need to recognise that they have a role as advocates for children with disabilities and this is an essential part of a rehabilitation therapy service.

9.2.3 Caregivers’ search for a cause, for a cure and for specialist help, and their unrealistic expectations of therapy
The belief that if only the cause of the problem can be identified then the problem can be cured or a remedy found is fairly universal and is well described in the literature in different population groups and cultures (Hartley et al., 2005). However, the health seeking behaviour surrounding the quest to find a cause together with the interpretation and attaching meaning to the disability is often an individual response which will be influenced by culture and context. This is an area where it is tempting to generalise but where it is important for the health worker to understand the local prevailing traditional and cultural beliefs and how these might influence health seeking behaviour and adherence to therapy programmes.
In this study, caregivers volunteered a variety of explanations for the perceived cause of the disability, ranging from traditional and cultural notions to medical ideas, and to frank confusion between the two. This was accompanied by the belief that if only the hospitals had machines which could diagnose the problem or specialists that could “fix” the bones, the child would improve or be cured. Similarly, in Uganda considerable time and money appeared to be spent by families in seeking a cure (Hartley et al., 2005). This often took a disproportionate amount of resources when considered against the level of success of these ‘treatments’ and help for the family.

What is not known in this study is how, when and by whom the diagnosis and explanations were first given to caregivers and what, if any, counselling caregivers received. This would certainly be useful to establish in future qualitative studies with caregivers. A deeper understanding of caregivers’ insights and perceptions will make it easier to find the words to transmit information clearly and unambiguously as well as the best way of counselling caregivers when a diagnosis is first made. This may assist in decreasing the confusion expressed by caregivers and enable them to come to terms with coping and caring rather than searching for a definitive cause and a cure.

Information is one of the external resources that facilitates the development of coping behaviour (Hartley et al., 2005), thus it is essential for caregivers to be given accurate and relevant information and for health care providers to find the most appropriate way of transferring this knowledge to caregivers and families.

However, Groce and Zola (1993) point out that traditional beliefs and practices do have positive and functional aspects, and these should not be ignored. They suggest that rather than convincing people of the scientific validity of current ideas and approaches, it may be wiser and more efficient to build on the strengths already demonstrated by these traditions. This again reinforces the point that in cross-cultural settings, health care providers need to understand and document local traditions and practices if they are to use these as a starting point for intervention.
Recommendations and implications for clinical practice

Being aware that many caregivers will have misconceptions surrounding the cause of their child’s disability, may be confused between traditional and medical explanations, and have unrealistic expectations of therapy strengthens the argument for anticipatory guidance and comprehensive counselling when caregivers are first given a diagnosis or referred for rehabilitation therapy. It is not that this counselling is presently not being done; rather it is the way in which it happens, and the words and language used, which need to be understood. Based on what caregivers in this study have said, suggestions for more appropriate counselling would include the following:

- Creating a non-judgmental environment where a mother feels comfortable about talking about her own beliefs surrounding the cause and being honest about her expectations of therapy.

- Where the therapist and mother do not share a similar language or background, a “cultural broker” may facilitate the process of information transfer. Ideally the “cultural broker” could be a parent of an older child with CP who has travelled the same road and who has a good understanding of both medical and traditional concepts. In busy public service therapy departments, where therapists may not have sufficient time to spend counselling mothers and where language is a problem, the “cultural broker” may be a volunteer or member of an advocacy group (such as the Disabled Children’s Action Group) who works with the rehabilitation team.

- There may be merit in rehabilitation therapists working together with local traditional healers as they are often the first point of contact for caregivers.

Each of these ideas could be the focus of further research that could include randomised controlled trials of these strategies.

9.2.4. Daily management of the child and the burden of care:

From the demographic questionnaire, the Caregiver-Child Scale and the qualitative data it was clear that the burden of caring for the children in this study was high. The majority of children were functioning in either GMFCS Level IV or V with minimal communicative
abilities and little or no independence and therefore were dependent on their caregivers for most of their daily needs.

Communication difficulties made it problematic for caregivers to understand their children’s needs and some caregivers expressed their frustration at not knowing what their child wanted when they cried. This was often interpreted as the child being “difficult to look after.” Communication difficulties also made it hard for caregivers to play with their children. Child behaviour and caregiving demands have been shown to be one of the greatest predictors of caregiver stress (Mobarak et al., 2000; Raina et al., 2005). Caregiving demands are indirectly linked to the level of severity of impairment, activity limitations and communication problems.

However, against this background of a high burden of care is the deep affection and love caregivers have for their children. This was seen in both the quantitative and qualitative data. The high mean scores on the Caregiver-Child Scale are supported by the spontaneous comments made by several caregivers when completing the scale “This child is a gift from God. I love my child” as well as from the focus groups: ”The way I love him means I don’t want anything befalling him” (JH). This deep affection and concern about the child’s well-being is a strength which needs to be utilised more in therapy intervention programmes.

**Recommendations and implications for clinical practice**

The influence of communication difficulties and caregiving demands on caregivers’ stress levels and coping mechanisms needs to be recognised and addressed in therapy programmes. Clearly there is a need for a greater emphasis on communication intervention within the therapy programme. This will help caregivers to play with their children and to understand and interpret their children’s communication needs more easily. Anticipatory guidance also needs to include counselling regarding play and behaviour, and caregivers could be shown strategies for enhancing their children’s lives in ways that they may not recognise.
9.2.5 Summary
What has been learnt from this information is how caregivers’ concerns are not that much different from those of caregivers elsewhere. However, the solutions are not always the same and as Groce and Zola (1993) point out, the strengths shown by caregivers may present alternative ways of addressing needs that merit our careful attention. Thus the starting point for finding solutions to the challenges faced by caregivers within the context of a rehabilitation programme is the caregivers themselves. A greater understanding of the beliefs and attitudes which determine their behaviour, guide decisions and influence their interaction with health care providers provides an important conceptual tool for therapists in designing therapy intervention programmes.

9.3 THE “IDEAL” THERAPY SERVICE IN A PUBLIC SERVICE HOSPITAL

The third key message is that data from this study can be used to outline what an “ideal” therapy service in a public service hospital would look like.

As described in the previous section, a greater understanding of caregivers’ lives, their perceptions and experiences of current rehabilitation services and the data on aspects of service most valued by parents make it possible to outline what an “ideal” rehabilitation therapy service might look like in a public service setting in disadvantaged communities in South Africa. Information from this study can therefore be used to help service providers do their work more effectively.

9.3.1 Aspects of the present services most valued by caregivers
Scores from the FSS and the MPOC as well as comments from caregivers all indicate that caregivers value the therapists highly. However, the possibility of bias cannot be excluded here as the interviews took place in the rehabilitation departments of the various hospitals and the participants were caregivers who attended therapy regularly. Thus their responses are not altogether surprising.
The two traits that caregivers most valued in the therapists were their kind and caring attitudes ("They show love to my child" [comment from MPOC scale]) and the fact that therapists “did” something with the children (“They give my child good treatment.” [comment from MPOC scale]). This aspect of training and practical help and advice with daily management was a consistent theme throughout the data.

The two factors identified in the MPOC-8(SA) – respectful and supportive care and providing information – are supported by the qualitative data. This strongly suggests that services need to be family-centred, an approach widely advocated and increasingly adopted globally.

In addition to the above two factors, caregivers valued practical assistance in the form of the provision of assistive devices, food supplements and nappies together with advice regarding finding schools and accessing welfare grants.

In summary, the four key aspects of current services most valued by caregivers are:

- Kind and caring attitudes
- Training and practical help with day to day management
- Practical help with obtaining assistive devices, nappies, schools, welfare grants, etc.
- Information regarding their child’s disability and available services and support structures

9.3.2 Aspects of the present service least liked by caregivers

Caregivers also described aspects of the current service with which they were least satisfied and most frustrated. The main dissatisfaction was around the long queues at the dispensary waiting for medicine or at OPD waiting for their files. Financial hardships made it difficult for many caregivers to find money for transport, particularly for families in rural areas where distances to the hospital are greater. These aspects are less amenable to change as they require shifts in policies at a level beyond which therapists currently have much influence. However, there are some initiatives therapists could
take, such as starting a transport fund to assist caregivers with transport costs or doing occasional home visits. At Chris Hani Baragwanath Hospital in Gauteng for example, a voluntary association called “Friends of Chris Hani Baragwanath Hospital” donates funds to the CP Clinic each month specifically to be used to assist needy caregivers with transport costs.

9.4 SUGGESTIONS FOR A MORE EFFECTIVE THERAPY SERVICE

In addition to what caregivers value and want from a service and what they least like about the present services, information from this study provides several clues as to the kind of service that providers should be offering to render a more effective service. An “ideal” rehabilitation therapy service would include the following components.

9.4.1 Parent support groups
Feelings of isolation, depression and hopelessness were a subtheme from the qualitative data with caregivers commenting “…I was thinking maybe my child is the only one."(HF1). In addition, the items on the FSS and PQOL scales regarding support from, and satisfaction with, friends received low scores. Facilitating informal support groups and putting caregivers in touch with each other would go a long way in helping caregivers cope and providing them with a support network. Parents of children with disabilities are uniquely qualified to help each other, and Kerr and McIntosh (2000) have urged therapists to become more aware of the potential benefits of parent-to-parent support groups.

9.4.2 Finding ways of involving fathers and close family
Many caregivers in this study received considerable practical and emotional support from close family members, including the child’s siblings. This was seen in both the qualitative data and the scores from items in the FSS and PQOL. This is a similar situation to caregivers in India where Goldbart and Mukherjee (1999b) suggest that to maintain this level of support, it would be helpful for therapy services to acknowledge the role played by relatives. This might involve open days or social events, awareness
and information workshops and support groups for grandparents, and other relatives. This is also strongly part of an FCS strategy.

Fathers have often been ignored in studies concerning caregivers and children with disabilities. Thorburn in Jamaica (1999) maintains that greater involvement of fathers helps with acceptance. Data from the present study as well as from Goldbart and Mukherjee in India (1999b) and Hartley et al. (2005) in Uganda argue for therapy strategies aimed at informing fathers and encouraging their support for interventions with the child with CP, either through direct participation or by facilitating the mother’s involvement.

9.4.3 Finding ways of ensuring clearer communication and enhancing understanding between caregivers and therapists

Many of the misconceptions and much of the misinformation caregivers had regarding the cause of the child’s problem and expectations and outcomes of therapy could be attributed to problems with communication. In this setting, these were compounded by language and cultural differences. Earlier in this chapter, the idea of a “cultural broker” was suggested as one way to overcome some of these barriers. However, there are other avenues to explore which may help promote clearer communication between therapists and caregivers.

For example, in non-literate societies, the art of story telling and listening is often well developed and could be a very useful medium to exploit (Stout and O’Toole, 1999). These authors further suggest that adding a visual accompaniment such as drawings, puppetry, mime, role play or participatory theatre could enhance effectiveness.

9.4.4 Incorporating traditional medicine and traditional healers in rehabilitation

In African societies, traditional medicine remains the major way of coping with illness and misfortune (Puckree et al., 2002; Pinkoane, 2005). Traditional healers share the same culture, common beliefs, values and symbols of caregivers and are often the first person caregivers seek out for advice (Dheyongera, 1994; Pinkoane 2005). They deal
with the misfortunes of their patients with a shared and understood pattern of action (Tanner, 1999). Although very few caregivers in this study found traditional healers very helpful (as demonstrated in the FSS), many caregivers had traditional beliefs about the cause of the disability and some had tried traditional remedies. As some participants in the focus groups commented on how confusing it was mixing traditional and cultural beliefs with Western medicine, it makes sense to identify the strengths of traditional medicine and to find ways of integrating these into the therapy service. This is not a new concept – it happens in countries like Nigeria and Ghana (Morris, 2001) and although it has been advocated in South Africa, this practice is still in its infancy (Puckree et al., 2002). This remains largely uncharted territory in the field of cerebral palsy and rehabilitation, and thus ways of integrating the two systems of care in this field warrant further investigation.

9.4.5 Providing information and advice to caregivers

In the United Kingdom, Sloper (1999; 2006) has suggested the concept of a “key worker” or “link person” whom caregivers approach for advice regarding any problem related to their child. The role of the key worker includes providing information and advice to families; identifying and addressing needs; accessing and co-ordinating services for the family and acting as an advocate for the family. This concept may be very useful in a South African setting. A “key worker” at a hospital-based CP Clinic would be a resource person responsible for providing caregivers with information and practical guidance on how to access services and support (such as welfare grants, nappies, food supplements, day care centers). As it is unlikely that public service hospitals will create such posts, a short-term solution might be to identify a willing volunteer to take on this role at the CP clinic or alternatively to seek small grants to pilot in order to validate the utility of this role, as a basis for an evidence-based argument about its usefulness. Ideally, this person would be the mother of a child with CP, or a member of the Disabled Children’s Action Group (DICAG), an advocacy group for children with disabilities.
9.4.6 Summary

In planning a more effective therapy service in a public service setting, the suggestions emanating from this research confirm what Groce (1999a) has already noted – that in poor settings, rehabilitation professionals need to do more than simply deliver services in a clinical setting. In these areas the need for rehabilitation rarely exists in isolation from social needs. Thus the message to therapists concerns the necessity of having a broad outlook when planning and delivering a service for children with cerebral palsy. It is not sufficient to focus only on technical expertise within a family-centred framework. Environmental factors such as physical resources, culture and tradition influence caregivers’ perceptions and utilisation of therapy services and need to be taken into account.

9.5 Generalisability of the Findings

As this study focused on caregivers who regularly brought their children for rehabilitation therapy, they are a self-selected group. Despite financial difficulties, they had the means and the motivation to attend therapy regularly and so it can be expected that they would be more positive about therapy and about themselves. In addition, their children were young, the majority being under four years of age. Thus the study findings cannot be generalised to caregivers who have stopped attending therapy or to caregivers of older children.

A convenience sample was used for this study as the initial objective was to validate a series of scales. Thus generalising results from the quantitative phase should be done cautiously. However, closer inspection of the convenience sample reveals minimal sources of bias. All hospitals in Gauteng qualifying for inclusion were visited during the month of October, 2004. If a hospital had a CP clinic only once a month, the hospital was visited on that particular day. If a hospital had a clinic once or twice a week, the hospital was visited more than once during the month. There is no reason to suppose that caregivers attending therapy on the days that interviews were not conducted are systematically different in any way from caregivers who were included in the study. All
caregivers who met the inclusion criteria and consented to be interviewed were included.

With the exception of the two largest hospitals, all the Limpopo hospitals had CP clinics just once a month. The two larger hospitals had clinics once a week and each was visited twice during the same month. The remaining hospitals were all visited on their monthly clinic day during October or November 2004. The sample included fourteen of the eighteen hospitals in Limpopo. The reason for not visiting four hospitals was that a sufficient number of caregivers had already been interviewed. There is no reason to suppose that these four hospitals are in any way different from the hospitals visited.

Thus the results from the quantitative phase may be generalised with caution to caregivers of young children who attend therapy regularly in the two provinces included in the study, Gauteng and Limpopo.

9.6 CHALLENGES ENCOUNTERED IN THIS KIND OF RESEARCH

Research of the nature explored in this thesis, which focuses on the rehabilitation of children with neurodisabilities, is complex because the issues surrounding disability are always multidimensional and multifaceted. These issues include the reality that most ‘outcomes’ are multi-determined, and that the developing child represents a constantly moving and changing ‘target’. It is also often not clear what ‘outcomes’ are most relevant, and from whose perspective. Consequently outcomes of rehabilitation are hard to define and measure. This becomes even more difficult when working in cross-cultural settings and in poor communities. The execution of this study reflected the challenges encountered in this kind of research.

It may be argued that this study was too ambitious in that it involved five scales and six languages. Working in six languages made it difficult to do a thorough linguistic analysis of the back-translations in each language. However, it was important not to exclude any caregiver on the basis of language and it was essential that the caregiver was
interviewed in her first language. The six languages chosen are the main languages spoken in Gauteng and Limpopo. As only two interviewers conducted all the interviews, they were very familiar with the questions and as they spoke all six languages fluently between them, all the questions were asked in more or less the same way. This almost certainly helped to overcome the limitations of not doing a thorough linguistic analysis of each translation.

Including five outcome measures meant that caregiver fatigue was a risk when completing the questionnaire. This risk was recognized and steps were taken to minimise it. The demographic questionnaire was shortened during the pilot phase and, as outlined in Section 4.4.4, caregivers were advised that the interview would take up to an hour to complete, and they were also provided with refreshments.

9.7 SIGNIFICANCE OF THE THESIS

This thesis was important for several reasons:

- It has highlighted the extreme care and caution which needs to be taken when using scales developed in high-income settings to measure outcomes of therapy interventions in disadvantaged South African settings. It cannot be assumed that scales developed in settings different from the setting of interest will work.

- It has shown that the MPOC-20, a scale increasingly widely used internationally in rehabilitation services, does not work in a disadvantaged South African setting. However, an eight item version of the MPOC, the MPOC–8(SA), has been shown to have possibilities in this population. The dimensions of this scale are similar to the underlying dimensions of the original scale, lending support to the relevance of these constructs across countries and cultures.
This is the first study to document the lives of caregivers with children with CP in disadvantaged areas in South Africa as well as their experiences and expectations of rehabilitation therapy.

This study has provided guidelines and recommendations of what an ideal service for children with CP should look like in a public health setting serving caregivers living in disadvantaged areas.

Several rich areas for further research have been identified.

9.8 SUMMARY

The need for the qualitative data emerged from the limitations of the quantitative data and these data have informed and enriched the results enormously. Two kinds of information have emerged - first, information regarding the lives of caregivers and their children, and second, information regarding methodological issues and how to proceed in continuing to explore these issues. Using this information, the components of an “ideal” rehabilitation service have been identified and described. The convergence of the quantitative and qualitative aspects of the data is an important aspect of validation, making it possible to place more confidence in the study findings.

The main findings of the study relate to the use of scales in contexts different from those in which they are developed; a greater understanding of the lives of caregivers and the components of an ideal therapy service. From this, suggestions and implications for clinical practice have been made. In the final chapter, recommendations for further research arising from this study are outlined.