CHAPTER SIX

DISCUSSION: PHASE ONE
THE RELIABILITY AND VALIDITY OF THE MODIFIED SCALES

This chapter discusses the main findings from the quantitative phase of the study. It covers the analysis of the five scales used as well as the relationships among some of the demographic variables. The results are compared to other studies which used the same scales. The implications for future research as well as the relevance for the clinical setting are discussed.

6.1 CAREGIVER-CHILD SCALE

As described earlier, the Caregiver-Child Scale was based on the Judson Maternal Self-Rating Scale (Judson and Burden, 1980). The scale was modified considerably for the present study and the scoring system changed from a semantic differential to a Likert scale. Thus it is not appropriate to compare the total scores from this study with the handful of studies which used it in its original format. In fact only McConachie et al. (2000) in Bangladesh provided total scores although details regarding the translation of the scale are not given. Sloper et al. (1991; 1993) used this scale when exploring families of children with Down syndrome and families of children with severe physical disability. In both studies the scores were used in multivariate analyses to investigate relationships amongst a number of parent and child variables and thus the raw scores were not given, making it difficult to compare results.

In this study, the low internal consistency, as measured by Cronbach's alpha, indicates that the items on the scale are not homogeneous, that is, they are not all measuring the same attribute. This lack of homogeneity is confirmed by the fact that only one of the corrected item-total correlation coefficients (r-values),
that is, the convergent validity (how each item correlates with the overall scale) was over the recommended value of 0.40 (Stewart et al., 1988). Although the scale has been used in a number of studies, notably in another poorly resourced area, Bangladesh, it has never been translated and none of the studies mentions whether it was found to be a reliable and valid instrument. Sloper and Turner (1993) found no clear factor structure in their study.

Multi-trait scaling in this study showed that a four-item version of the scale has acceptable item convergence, but with a Cronbach’s alpha value of 0.68 and an ICC of 0.34, the reliability is weak. However, visual inspection or face validity of these four items suggests that on the surface, these items do “hang together” in that they refer to the underlying dimension of the caregivers’ feelings towards the child. The mean scores for each of these items were very high – all above 4.4 on a scale which ranged from 1 to 6. These high mean scores are supported by the spontaneous comments made by several caregivers when completing the scale, for example “This child is a gift from God. I love my child.”

Although total scores for this scale are meaningless because they have been shown to be neither valid nor reliable in measuring the interaction between caregiver and child, the mean scores for each item can still provide valuable information in that each item can be evaluated on its own.

However, only four of the twelve items on the five point scale had a mean score below four. This means that the scale is distorted in that it is very strongly skewed towards the positive end and effectively produces a ceiling effect. This makes it almost impossible to detect any improvement over time, or to detect variations across the population. Various methods have been suggested by Streiner and Norman (2003) to counteract this bias, all based on the fact that the “average” need not be in the middle. Shifting the centre of the scale to the left or expanding the middle of the range at the expense of the ends are two methods suggested to overcome this distortion.
6.2 FAMILY SUPPORT SCALE (FSS)

Although the expanded version of the FSS was shown to be reliable, it was not shown to be valid when multitrait scaling was performed as part of the analysis. However, as the “units” in this measure are various sources of support rather than items which are linked together in the same as way one would expect on a measure such as the Caregiver-Child Scale or the Measure of Processes of Care, the face validity of the FSS is acceptable and it can certainly be used as a method of providing a simple count of the number of sources of support available to caregivers and whether those sources are primarily formal or informal. McConkey et al. (2000) point out that throughout the developing world families often receive little support in bringing up a child with a disability, thus a simple count of the number of sources of support available to caregivers as provided by the FSS is certainly useful.

To compare FSS scores from this study with other studies in similar settings, scores obtained from the original 18 item scale need to be used, rather than the expanded version. The mean scores for South African caregivers were much higher than those obtained for their Bangladeshi counterparts (37.07 compared to 16.65) (Mobarak et al., 2000). There were also differences in sources of support in the two studies. South African caregivers reported more sources of formal support (8.31 compared to 3.31), but fewer sources of informal support (10.31 compared to 14.81) (McConachie et al., 2000). These results are consistent with the fact that although South African caregivers are living in poorly resourced areas, they are much better off than the caregivers in Bangladesh, one of the poorest nations in the world. The South African families enjoy greater access to health care and rehabilitation professionals. These figures also suggest that where fewer formal sources of support are available, caregivers need to rely more heavily on informal sources of support, that is, family, friends and neighbours.
However, comparisons drawn and conclusions made need to be done with great caution because as this study demonstrated, the FSS is not a valid tool to use in South Africa. It was also not validated for use in Bangladesh. This illustrates the sense of frustration involved in this kind of work – recognising the importance of collecting this information because it tells us something about the lives of the caregivers, yet not being able to use the tools developed elsewhere to capture the information. A study comparing the perceived needs of and support for Puerto Rican mothers living in Puerto Rico with their counterparts living in Florida did not provide raw scores for the FSS, again making comparisons across studies difficult (Reyes-Blanes et al., 1999).

In this study, the high mean score and low standard deviation obtained for therapists on the FSS is not altogether surprising considering that the study population regularly attended therapy and that the study setting was the therapy department in each hospital. This high mean score may also be a reflection of a desire to please on the part of the participants (a social desirability bias). The second highest score obtained was for doctors, again suggesting a possible source of bias as the study was conducted in a hospital setting. However, these scores would seem to indicate that health care providers are perceived as important sources of support to caregivers.

In the process of completing the FSS, the confusion over the interpretation of the category of “not available” is similar to the observations of Darling and Gallagher (2004) in their study comparing needs and support for African American and European American caregivers. Participants in their study also interpreted “not available” as meaning either that the source of support is physically unavailable, for example because the person lives far away, or that the named support is deceased.

The difficulties encountered in using the Caregiver-Child Scale and the Family Support Scale in a cross-cultural setting have been highlighted by Mobarak et al.
(2000) in their study in Bangladesh. They emphasised the need for culturally appropriate measures of family adaptation and informal support as these are an important mediating role in coping behaviour. This need has been reinforced in this study as the limitations of existing scales have been clearly shown.

6.3 PERSONAL QUALITY OF LIFE SCALE

That the PQOL scale was not suitable in this population is a surprising result considering that it has been successfully used in similar South African settings (Westaway et al., 1999a). Observations made when presenting these results in the previous chapter hint at possible reasons why this scale did not perform well in this population – firstly, the wide standard deviations for some of the items (e.g., partner; friends; my time to do things; social life) suggest that these may not be part of the dimensions or underlying constructs of personal quality of life for caregivers because there was such wide variation in caregivers' responses. Secondly, as can be seen from Table 5.13 in Chapter 5, although five of the items had an average score of around five, the mean score for "life in general" was over eight. Intuitively this does not make sense – if a person is dissatisfied or unhappy with five out of ten items on a scale, it does not follow that he or she would say they are very satisfied with life in general. A possible conclusion to be drawn from this is that the dimensions for personal quality of life in caregivers of children with CP are different from those for adults with chronic illnesses. More research is required to discover what these dimensions could be.

Although the items cannot be summed into an overall score measuring a caregiver's personal quality of life, each item can be assessed separately, thus providing useful information about the personal qualities and attributes of the caregivers. Generally, caregivers are most satisfied with their lives in general, their health and family life, and least satisfied with their income, their time to do things and their friends. The qualitative data from Phase 2 supplement and
expand on these data and the themes are synthesised and presented in Chapter 7.

6.4 MENTAL HEALTH SUBSCALE

The results in Chapter 5 demonstrated that the Mental Health Subscale can be successfully used to assess general mental health status in South African caregivers of children with CP. It has the added advantage is that it is freely available and does not require the purchase of a licence for its use.

However, the experience of administering it during this study has shown that, ideally, it needs to be interview administered rather than self administered. In this study, the interviewers were instrumental in explaining the concept of the scale to caregivers. Each question in the scale is preceded by the statement “During the past month, how much of the time….” and the responses on the Likert scale vary from “None of the time” to “All of the time.” The interviewers drew a diagram representing a month and then indicated on this diagram what proportion of the month each response was equivalent to and how some of the items were mutually exclusive. For example, if caregivers stated that for most of the time during the past month they had been “a very nervous person”, it did not make sense to give the same response to the question “how much of the time have you felt calm and peaceful?” In this way, caregivers found it easier to complete the scale and to give appropriate and logical responses.

The mean score obtained suggests that caregivers of children with cerebral palsy enjoy better mental health than adults with diabetes living in similar socio-economic conditions. Together with the results of the PQOL and the demographic data regarding socio-economic status, this suggests that despite a life of great hardship, the majority of caregivers have excellent mental health. This theme is explored in more depth in the analysis of the qualitative data.
In the study by Mobarak et al. (2000) in Bangladesh, 41.8% of mothers of children with CP suffered from stress, as determined by the Self-Report Questionnaire (SRQ) and mothers in rural areas were more stressed than urban mothers. As different scales were used these results cannot be directly compared with this study. However the finding that caregivers living in rural areas are more stressed than caregivers in urban areas is not confirmed in this study.

6.5 MEASURE OF PROCESS OF CARE

The 20 item version of the MPOC, the MPOC-20, was developed in Canada where its reliability and validity were established (King et al., 2004). It has also been translated into Dutch and found to be a reliable and valid measure (Siebes et al., in press). Here the internal consistencies for the five subscales ranged from 0.75 to 0.87, the ICCs for the test-retest analyses were between 0.78 and 0.91 and concurrent, predictive and construct validity were confirmed.

The 56 item version of the MPOC has been evaluated for use in a number of countries (Sweden [Bjerre et al, 2004]; the Netherlands [van Schie et al., 2004]; and the UK [McConachie and Logan, 2003]). In two of these instances, Sweden and the Netherlands, it was translated. Values for the internal consistencies in all these studies were >0.80 for each of the subscales. Confirmatory analysis in the Dutch study confirmed the construct and concurrent validity (van Schie et al., 2004). Only the Dutch study reported on ICC values for the test-retest reliabilities which were all above 0.79. A different factor structure was found in the United Kingdom study suggesting that the MPOC factor structure may be inherently unstable (McConachie and Logan, 2003). In McConachie and Logan’s study, the first factor, “Respectful and Supportive Care”, accounted for 48.8% of the variance.

These results suggest that in well resourced Western settings, the MPOC-56 is generally stable and can easily be used. However, results from this study
suggest that, in a poorly resourced African setting, the 20 item version needs considerable modification and should be changed to an eight item version, the MPOC-8(SA). Reasons for this are in part due to the process of asking questions and caregivers’ unfamiliarity with the format of the scale, as was the case with the other scales. Other reasons are because of differences in service provision in Canada and other well resourced countries. In a South African public service hospital, therapy is usually available once a month and there are few instances where there are sufficient therapists to constitute a multidisciplinary team. This is in contrast to Canada, the Netherlands and the United Kingdom where there are well resourced Child Development Centres staffed by multidisciplinary teams and children receive therapy more frequently than monthly. Consequently, the dimensions of “co-ordinated and comprehensive care” and “enabling and partnership” are less relevant in a poorly resourced setting. Also, South African caregivers have had much less exposure to the resources asked about in the MPOC.

The eight items in the MPOC-8(SA) are very similar and thus the reliability can be expected to be high. Cronbach’s alpha for the MPOC-8(SA) was 0.73 which is regarded as “respectable” (Arias and de Vos, 1996). Whilst a value of above 0.7 is desirable, it should not be above 0.9 as then it suggests that there are redundancies and questions can be eliminated. The detailed psychometric analysis of the MPOC-8 clearly demonstrated that these eight items “hang together” well. A clear two factor structure was identified, which means that these eight items assess two dimensions of a service, namely respectful and supportive care; and the provision of information and advice.

The two factors identified in the MPOC-8(SA), that is, respectful and supportive care and providing information, are confirmed by caregivers’ comments regarding aspects they liked most about the service. Therapists’ caring attitudes combined with being taught specific skills in how to handle their children thus making daily management easier were two aspects highly valued by caregivers and this is
reflected in the factor structure. These inter-personal and informational elements or aspects of care appear to be universally important as they were highlighted in all studies where the MPOC was developed or used (King et al., 1995; 1996; McConachie and Logan, 2003).

Practical assistance such as the provision of assistive devices, food supplements and nappies together with assistance in finding schools and accessing welfare grants were important to caregivers in this study and these factors are not covered in the MPOC. This suggests that although there are similarities between caregivers living in differently resourced areas, there are additional factors which need to be taken into account when working in disadvantaged settings.

The MPOC was specifically designed to assess the “processes” of care, that is, the “how” of the caregiving process or the extent to which caregivers perceive services to be family-centred. It was not designed to assess the technical elements or the “content” of the service, that is, the “what” of the service provision. The data in the present study suggest that for caregivers living in poorly resourced areas, this technical or practical element is equally important. The implication of this finding is that additional questions specifically related to the technical components of therapy need to be asked in addition to the MPOC-8(SA). Further research is required to confirm the validity of the MPOC-8(SA) and the additional questions for use in resource-poor South African settings.

6.6 PREDICTIVE FACTORS FOR GOOD MENTAL HEALTH AND FAMILY SUPPORT NETWORKS

Predictors of maternal well-being and mental health include child behaviour problems such as lack of independence, not going to sleep, night and day wetting, soiling and hyperactivity, caregiving demands, and family function (Mobarak et al., 2000; Raina et al., 2005). These findings were not confirmed in this study as they were not specifically measured or assessed. Apart from
specific items on the Caregiver-Child Scale, and one question “Compared with other children you know, is this a difficult child?” in the demographic questionnaire, child behaviour was not specifically addressed in this study as it was not part of the study objectives. Besides, the tools required to measure these predictors do not exist.

Significant variations between urban and rural areas exist in terms of child, caregiver and household characteristics. It is likely that these findings are robust, that is, that actual differences do exist. However, there are insufficient data to explain the variation observed because place of residence (that is, whether caregivers live in urban or rural areas) may well be a marker for something else, i.e., there are other factors which determine whether caregivers and children live in urban or rural areas, and it could be these factors or confounders which contribute to and explain the observed variations between rural and urban caregivers and children. The variations need to be explored further in future research in order to discover an explanation for them. However, the clinical implication is that some aspects of service delivery may need to be different in urban and rural areas.

At this stage, it is only possible to speculate on likely reasons for the differences between urban and rural caregivers, for example, the fact that children in rural areas are older and more severely disabled may be because the child’s mother may be working in an urban area where there are no day care facilities for children with severe disabilities and so the child is looked after by members of the extended family in the rural areas; or because the child’s mother can’t find work in urban areas because her child is severely disabled and there are no day care facilities, forcing her to stay with her extended family in the rural areas.

It can also be surmised that caregivers living in Limpopo are more likely to be living a more traditional lifestyle and in close proximity to the extended family and with a stronger sense of community than caregivers in Gauteng which is perhaps
one reason why they enjoyed more sources of support than their urban counterparts.

6.7 ROLE OF FATHERS

Although the majority of fathers (65%) provided some emotional support as described by the caregivers, only 40% of fathers lived in the same household as the child and the child's mother and over a quarter of the caregivers (28%) felt that fathers provided no support at all. This relative lack of involvement by fathers is consistent with research findings in disadvantaged areas in India, Guyana and Jamaica (Goldbart et al., 1999b; O'Toole, 1989; Thorburn, 1999). However, what is not known from this and other studies is how the role of the father in the study households compares with neighbouring households where there is no child with a disability. This points to yet another area requiring further research.

6.8 SUMMARY

The quantitative findings relating to the measurement tools and the demographic variables were discussed in this chapter. This answers the first objective of the study, which was to ascertain whether tools and scales developed in contexts different from the context of this study are appropriate for use in this community. These results are summarised in Table 6.1.
Table 6.1  Summary of analysis of scales

<table>
<thead>
<tr>
<th>Scale</th>
<th>Reliability</th>
<th>Validity</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Test-retest</td>
<td>Cronbach’s α</td>
<td>Equivalent variance</td>
</tr>
<tr>
<td>Caregiver-child</td>
<td>0.42</td>
<td>0.61</td>
<td>X</td>
</tr>
<tr>
<td>Family Support</td>
<td>0.53</td>
<td>0.78</td>
<td>X</td>
</tr>
<tr>
<td>PQOL</td>
<td>0.85</td>
<td>0.61</td>
<td>X</td>
</tr>
<tr>
<td>Mental Health</td>
<td>0.63</td>
<td>0.85</td>
<td>√</td>
</tr>
<tr>
<td>MPOC – SA 20 (5 subscales)</td>
<td>0.51 – 0.61</td>
<td>0.30 – 0.66</td>
<td>X</td>
</tr>
<tr>
<td>MPOC – SA8</td>
<td>0.61</td>
<td>0.73</td>
<td>√</td>
</tr>
</tbody>
</table>

The main finding was that only one of the five scales used in this study was shown to be both reliable and valid in a new setting. The argument has been made that as every effort was made to avoid errors in the administration of the instruments, the problem lies with the instruments themselves. The qualitative data presented in the next chapter provide many clues as to why the instruments did not work as well as expected in South African public services settings in poor areas.

The limitations of the quantitative measuring instruments meant that there were insufficient data to establish the predictive factors for maternal well-being and good mental health, which formed part of the objective of the study. Caregivers living in rural areas appear to be happier and to be coping better despite being poorer and having fewer resources. Caregivers in this study also seem to be better off than their counterparts in Bangladesh, most probably because they enjoy easier access to health and rehabilitation services.

Results of the second phase of the study, namely the qualitative data, are presented and discussed in the next two chapters.