CHAPTER 10

CONCLUSION AND RECOMMENDATIONS FOR FUTURE RESEARCH

Having outlined recommendations and implications for clinical practice, this chapter considers recommendations for future research. It is presented in three sections. The first section summarises the study’s main findings. This includes a review of the performance of each of the five scales used in this study. Recommendations for the further development and refinement of the scales, where appropriate, are presented in the second section together with suggestions for future research arising from the other main findings of the study. Concluding remarks are made in the final section.

10.1 SUMMARY OF THE MAIN FINDINGS OF THIS STUDY

The three main findings of this study were the extent of the reliability and validity of scales in settings different from those in which they were developed; a greater understanding of the lives of caregivers; and the components of an “ideal” rehabilitation therapy service in a poorly-resourced South African setting.

10.1.1 Reliability and validity of outcome measures and tools

When working in cross-cultural settings and in poorly-resourced areas, it cannot be assumed that scales developed in other settings will work, even if they have been modified and adapted. This is particularly true for questionnaires and scales which examine personal aspects of caregivers’ lives, their feelings and interactions with their children and with the health services. Problems were encountered with both the content of the scales as well as the process of administering them. There is more work to be done in understanding and capturing these important concepts in the language and style used by caregivers in these settings. Suggestions and recommendations regarding the process of
administering scales in cross-cultural settings where translation is required have been dealt with in the previous chapter.

From the performance of each of the scales in this study, a number of lessons have been learned.

The Caregiver-Child Scale, even though modified and adapted for use in South Africa through a series of focus groups, is not a reliable or valid measure for South African caregivers living in poor areas. It does, however, contain four items which from a psychometric point of view can be grouped together. They are:

- I am enjoying my child
- I find it easy to show affection to my child
- I am proud of my child
- I feel that I have a relationship (a bond) with my child

These items could be used as the basis for developing a new scale or tool which specifically assesses the interaction between the caregiver and the child as well as the caregiver’s feelings towards the child.

The Family Support Scale is a useful means of providing a simple count of the number of supports available to caregivers. The role and importance of support in assisting caregivers with coping were highlighted in the qualitative data. Thus the FSS may serve as a marker for tracking the sources of formal and informal support available to caregivers. It is also useful as a guide to identify target groups for advocacy and awareness campaigns within a particular community.

The Personal Quality of Life Scale offers an additional dimension in ascertaining caregivers’ well-being and quality of life. Despite the fact that this scale is appropriate for adults with chronic illnesses who live in poorly-resourced South African settings, the present scale is not suitable for caregivers of children with cerebral palsy living in similar settings. Thus it needs to be developed from
scratch and the underlying dimensions of personal quality of life established for the new population.

The **Mental Health Subscale** of the MOS Short-form 20 Health Survey is appropriate in this setting and provides an easy way of establishing caregivers’ general mental health.

The **MPOC-20**, although adapted and modified for use in a South African public service setting, is not suitable for this population. However, an eight item version of the scale, MPOC–8(SA), has good psychometric properties and with further development, has possibilities for use in South Africa.

### 10.1.2 A greater understanding of the lives of caregivers

Caregivers of children with CP living in disadvantaged areas demonstrate amazing strength, resilience and optimism against a background of poverty and hardship. Caring for their children is a full-time occupation for most caregivers as many of the children have severe motor and communication impairments and are dependent on their carers for all their daily needs. Thus the burden of caring is high. The majority of caregivers appear to have excellent mental health although feelings of isolation are not infrequent. Many caregivers see their child as “a gift from God” and practical and emotional support from close family members has helped them to accept and care for their children. Searching for and finding the cause of the disability is an important part of the journey and is characterised by mystery as traditional beliefs often co-exist alongside medical explanations.

### 10.1.3 Components of an “ideal” therapy service

Although caregivers often had misconceptions and unrealistic expectations of therapy and some were still seeking or hoping for a cure, they valued the practical assistance with daily management and the kind and caring attitudes they received from rehabilitation professionals. In addition to facilitating access to assistive devices and providing information in a language and format that
caregivers understand, the ideal therapy service in a poorly-resourced setting needs to go beyond traditional services focused on technical expertise. Adopting a family-centred approach; facilitating parent support groups and networks; finding innovative ways of enhancing caregivers’ understanding of cerebral palsy and therapy; involving fathers and close family members in the rehabilitation process; linking up with traditional healers; and taking on an advocacy role have been identified as important components of an ideal service. Creating a post for a “key worker” was also recommended. Ideally, this would be a mother of an older child with CP who acts as a cultural broker as well as source of information regarding access to resources and services.

10.2 RECOMMENDATIONS AND SUGGESTIONS FOR FURTHER RESEARCH

The findings of this study give rise to several recommendations and suggestions for future research.

10.2.1 Further development and refinement of the scales

This study has shown that many of the issues around family adaptation to a child with a disability and coping mechanisms are universal. However there is more work to be done in developing the tools which can be used to capture these important concepts in communities which use different words and phrases to express these concepts.

The PQOL Scale

The underlying dimensions or domains of a PQOL scale need to be identified through in-depth discussions and focus groups with caregivers. Ascertaining what caregivers considered their own personal quality of life to be comprised of and which dimensions are important to them would be valuable. Already it can be anticipated that the item “your partner” would not be included whilst an item such as “your child’s health” may be included.
The Caregiver-Child Scale
This scale needs to be redesigned using the four items identified in this study as a starting point. An observational study combined with focus groups and in-depth discussions with caregivers would yield a list of behaviours which demonstrate healthy caregiver-child interaction. This would help to select items for the tool. The Harter approach to scaling is recommended as a possible method of recording responses.

The MPOC–8(SA)
The eight item version of the scale needs further testing to confirm aspects of its reliability and validity. It would be useful to establish whether it is sensitive enough to detect differences between services where actual differences exist, and if it is sensitive enough to detect changes in people’s experiences over time if services are changed.

To reflect the finding that caregivers valued the technical aspects of the service (the provision of “exercises” and “training”) in addition to the interpersonal qualities of the service providers, further items need to be added to the scale. Suggested additional items for the MPOC–8(SA) could include the following:

To what extent do the therapists working with your child:

- train your child to do more things by himself or herself (like sitting, holding his/her head up, or dressing or eating)
- give you training which makes it easier for you to look after your child (like how to hold your child; or dress your child; or feed your child; or play with your child)
- give you suggestions and ideas of things that you and your child can practice and do at home?

10.2.2 Variations between urban and rural families and caregivers of children with cerebral palsy
Variations between urban and rural caregivers were seen in this study. Further work is required to characterise and explain these variations.

10.2.3 The role of fathers in caring for a child with CP
As with many other studies involving caregivers, the focus here was primarily on mothers as they are usually the primary caregivers. Finding and interviewing fathers and exploring their perspectives on caring for a child with CP would add another dimension to our understanding of how families cope and the role and feelings of fathers.

10.2.4 Service delivery
Few children had any functional communication and this contributed to the burden of care for caregivers. An intervention study focused on the provision of alternative and augmentative communication within a family-centred setting is recommended.

This study only included caregivers currently attending rehabilitation therapy. It would be helpful to repeat the study with caregivers who had stopped attending therapy as their perceptions on service delivery are likely to be different. In addition, knowing the reasons why caregivers stopped attending therapy may assist in identifying unmet needs.

Components of the “ideal” service have been identified. The next step in the journey would be to conduct randomised control trials comparing current therapy practice and service delivery with a variety of services modelled on the observations and suggestions made in this study.

10.3 CONCLUDING REMARKS

This was an exploratory study which has successfully identified the elements that are linked to caregivers’ well-being, mental health and quality of life (the
outcomes of interest explored). The qualitative phase of the study helped to identify those aspects which need to be measured. Further studies are now required to explain how these elements relate to each other and how they impact on caregivers’ quality of life, as well as their physical and mental health.

However, until the right tools are available to measure these elements, these questions cannot easily be answered. Presently, our capacity to measure these aspects of interest is limited because appropriate tools do not exist. This study has provided information on what the tools should look like. They need to be culturally specific and take into account the difficulties encountered in the process of asking these complex and sensitive questions.

An “ideal” rehabilitation therapy service for children with cerebral palsy attending public service hospitals has been described. This service would recognise and acknowledge the context, and the environment in which caregivers, families and children live. It is based on what caregivers have said they value and want from a therapy service. Interestingly, and not surprisingly, most of the elements identified by the parents in this study are very similar to those identified by studies in other countries.

This study has helped to map the territory and has provided signposts for future work and studies. It provides the starting point for delivering more effective and appropriate rehabilitation therapy for children with cerebral palsy and their families living in disadvantaged areas – and for evaluating these changes in service provision as they are implemented.

*The journey has only just begun – the real work lies in implementing and studying the recommendations and suggestions.*