CHAPTER 8

DISCUSSION: PHASE TWO
IMPACT OF CAREGIVER PERCEPTIONS AND EXPERIENCES OF CARING FOR A CHILD WITH CEREBRAL PALSY ON EXPECTATIONS OF REHABILITATION THERAPY

8.1 INTRODUCTION

The main themes and sub-themes presented in the previous chapter are discussed here with reference to the existing literature.

Despite an abundance of literature relating to perceptions and coping strategies of caregivers living in Europe and America, there is only one published qualitative study directly relating to an African context (Hartley et al., 2005). This was conducted in one urban and two rural districts in Uganda and data were collected from 52 families with children with a range of disabilities. The objective was to develop an in-depth understanding of how Ugandan families cope with their children with disabilities in order to provide a basis for community-based rehabilitation services. Many of the findings from this study resonate with Hartley’s findings in Uganda.

8.2 ACCEPTANCE AND SUPPORT

Similar to the Ugandan study (Hartley et al., 2005), the theme of support was found to be common to all the caregivers interviewed and provided a key factor in their coping strategies. Social support from family, friends and neighbours is well-described in the literature and was echoed in this study. According to McConachie (1994), having relatives and colleagues to whom the family can turn for support is associated with positive adaptation. Bischoff et al. (cited in Thorburn, 1999) state that the role of neighbours can be very positive in some
cases, especially when the mother is outgoing and prepared to ask for help without expecting too much of her neighbours.

In describing the role of the family in rural Jamaica, Thorburn (1999) concludes that at least four main factors seem to be involved in the family response to disability: attitudes towards disability generally, family structure and cultural practices, responses of parents to their initial experience with services and enrolment in an early intervention or community based rehabilitation (CBR) programme. The presence of the father within the family seems to positively affect the acceptance of the child’s disability (Thorburn, 1999). This certainly seems true in this study where acceptance of responsibility by both the father and the father’s family was an important support mechanism for mothers: “...and the child’s father also showed us his support. His family then said we agree that our son gave your daughter a child like this. They then said we must not think that they will run away from this problem.” (HF2) This is in contrast to other caregivers, particularly in urban areas, who related stories of abandonment and rejection by the child’s father.

The struggle and initial difficulty caregivers expressed in coming to terms with their child’s diagnosis seems to be a universal phenomenon (Woolfson, 2004). In addition, when parents receive a diagnosis that their child is disabled, feelings of hopelessness, and of social isolation of the family within a community have been reported (Woolfson, 2004). This was certainly reflected in this study where negative attitudes, ignorance and lack of awareness within the wider community were common themes in all the focus groups. However, there were many examples of inclusion and acceptance amongst community members who knew the child: “They like her too much. Whenever I am sitting at home you will see children coming to take her with a wheelchair running with her on the street. They love her.” (HF1). This helped some caregivers to feel free to be open, assertive and to confront strangers: “If you see something, do not gossip. Come and
confront me, ask me as the mother of the child so I can explain to you what happened for this child to be like this.” (JH)

Woolfson (2004) argues that many parents of children with disabilities find their own ways of coping and adjusting to their child’s disability and that they subsequently hold views about disability that are different from dominant societal views and thus promote effective parenting, and this was illustrated to some extent in this study.

Utilisation of social support systems is well documented in the literature as being a significant factor in family coping and adjustment to the child’s disability (Woolfson, 2004). However, this is more likely to be true in more well-resourced areas where more social support systems exist. The provision of material and physical support in the form of wheelchairs and financial assistance from family members to attend hospital appointments was an important support mechanism for Ugandan caregivers (Hartley et al, 2005). This is true in this study as well, as caregivers frequently expressed the need for wheelchairs and appreciated financial assistance from family members.

In summary, caregivers generally appeared to have come to terms with dealing with their child’s disability and most of them enjoyed the support of close family, friends and neighbours. This acceptance and support stopped short within the wider community where ignorance and negative attitudes persisted. However, an emerging and encouraging theme was that some caregivers felt confident enough to confront the ignorance and secrecy surrounding disability.

8.3 CAREGIVER STRESS

Caregiver stress associated with looking after a child with a disability in a well-resourced setting has been frequently described in the literature (Knussen and Sloper, 1992; Sloper et al., 1993; Hassall et al., 2005). Mobarak et al. (2000)
observe that in developing countries, the pressure on caregivers is likely to be even greater. With fewer resources available in the form of experienced teachers and therapists, respite facilities (places where families can leave their children for a few days), assistive devices and support services, the physical and emotional burden of care carried by the primary caregiver is heavier. Results from this study suggest that the sources of stress may be different in a poor community.

Similarly to Ugandan caregivers, the burden of daily caregiving in this study falls primarily on the mother or grandmother (Hartley et al., 2005). As the majority of children were functioning on GMFCS Level IV or V, their activity limitations mean they remained fully dependent on their carers for all their daily needs. Thus the burden of care arising from daily management and caring is high. This burden is compounded by worry about the child’s health and concern about the future – what will happen when the caregiver is no longer able to care for the child. Concern over the child’s poor health is an aspect not readily identified in studies from Europe and North America but was a real concern for parents in this study.

Another source of caregiver stress is the daily hardship of life associated with poverty. Financial hardships reduce the funds available for transport to the hospital, particularly in rural areas. These conditions are similar to the challenges faced by caregivers living in Uganda (Hartley et al., 2005) and India (Pal and Chaudbury, 1998). In these populations, mothers felt drained of physical resources and as a result experienced physical ailments.

Feelings expressed by mothers such as joy, heartache, loneliness, difficulties with dealing with professionals as well as oscillating feelings of grief, acceptance and denial are the same as those identified in Australian and British mothers (Bower, 2000). This suggests that although the feelings associated with taking care of a child with a disability may be universal, coping strategies will differ as a function of the environment in which caregivers live.
8.4 COPING STRATEGIES

The resilience of caregivers living in difficult circumstances echoes the resilience found by Hartley et al. (2005) in Uganda where caregivers were found to be coping with their children’s disabilities without interaction with a rehabilitation programme. Coping strategies adopted by Ugandan caregivers were very similar to those in this study, namely searching for a cause and a cure; religion; and caregivers finding their own meaning for the disability.

Similarly to South African caregivers, Ugandan caregivers often found meaning through traditional beliefs and religion and the phrase “This child is a gift from God” resonates through both studies. Studies in Botswana and Mexico report that the birth of a disabled child is viewed as evidence of God’s trust in the specific parents’ ability to care well for a delicate child (Ingstad, 1988; Madiros, 1989). This is a similar view to that expressed by a caregiver from Gauteng in this study: “God saw something in me so that is why I love my child even more.” (JH) This further supports Miles’ (1999) contention that religious beliefs have been associated at many times and in many places with the idea that a person’s disability is “given” by an agent.

8.5 PERSONAL, TRADITIONAL AND CULTURAL BELIEFS AND PRACTICES

Traditional and cultural beliefs regarding the cause of the disability are not dissimilar to those described elsewhere. The belief that bewitchment was a cause of the disability is supported in the literature in that divine displeasure, witchcraft or evil spirits are all given in the ethnographic record as the reasons why disability occurs (Scheer and Groce, 1988; Groce 1999b). However Thorburn (1999) commented that in rural Jamaica, supernatural beliefs about the origins of childhood disability were more common among older age groups and among those with minimal education.
In contrast to other studies, this study highlighted the confusion that some caregivers expressed between traditional and western medicine. This finding is not well documented in the literature. Some caregivers in both rural and urban areas felt caught between different world views, both in terms of explanations for the child’s disability as well as in the search for a cure.

Several caregivers provided implausible explanations about causation, for example, that “lightning struck the house and smoke came out of the baby’s room”. However, as Groce noted, (1999a), cultural explanations about causality may be intriguing but must be used with some caution. Care needs to be taken to avoid generalisations and oversimplification.

Yet, as Groce and Zola (1993) point out, the culturally perceived cause of an illness or disability is relevant. The reason why an illness or disability is believed to have occurred in a particular individual plays a significant role in determining family and community attitudes towards the individual (Groce, 1999b). According to Ingstad (1999), beliefs about origin do play a part, but more so in the search for therapy than in determining the acceptance of individuals into society. The implication of this idea is that beliefs regarding causation may also colour the caregiver’s and family’s attitudes to rehabilitation and contribute to unrealistic expectations of therapy which were certainly identified in this study.

In some cultures the reason for the misfortune is explained in terms of disturbed social relationships (Ingstad, 1999). This was certainly true in this study where emotional stress caused by unhappy relationships during pregnancy or family jealousies were considered as causes of the disability.

Thorburn (1999) observed that in Jamaica, about 50% of parents studied felt their children’s disability was due to negligence, maltreatment of a previous illness or to an obstetric event. Although this study does not provide quantitative
data, a high proportion of caregivers related stories of perceived medical negligence. These included having to wait many hours for an emergency caesarean, poor care received at a particular clinic; or that the baby “did not get enough oxygen at birth”.

The data regarding causation in this study suggest that similar to Ugandan caregivers (Hartley et al., 2005), finding a cause or explanation for the occurrence of the disability is important. However, this study has revealed how confusing and complicated beliefs regarding causation are and how short-sighted it is to generalise and oversimplify these beliefs to a particular population of caregivers. As McCubbin (1993) has pointed out there is the danger that this may reinforce stereotyping and oversimplification.

8.6 HEALTH CARE SERVICE PROVISION

Given the variety of beliefs surrounding causation and how these beliefs may influence attitudes towards therapy, it is not surprising that many caregivers had unrealistic expectations of therapy and misconceptions about therapy and the outcome thereof. However, as the study population comprised caregivers who attended therapy consistently, it is likely that their expectations and hopes for a cure were more realistic than those caregivers who no longer attended, perhaps because they did not find the cure they were seeking. This is illustrated by comments such as: “You need patience and love. That is the most important.” (SH) and “You don’t become impatient, you just go (to therapy). They don’t say they will be able to help but they say they will try.” (HF2).

An earlier study in a similar South African setting concluded that parental hopes for their children’s future were often unrealistic: in that 87% of caregivers study expressed the hope that their child would become normal, 11% did not think that their child would be normal and 2% said they had no hope at all (Anderson and Venter, 1997). Hope for a cure and a normal outcome is echoed in this study:
“...one day she’ll be like other children.” (SH) and “I came to the hospital to seek help. I came to have my child fixed.” (MH)

Expectations regarding therapy and its outcome in poorly resourced settings have not been described in the literature, thus comparisons with other studies are not possible. From this study it appears that many caregivers expected therapy to provide a cure. This was expressed as a desire for specialists, for example, “doctors who specialise with bones” (HF1) and machines which could pinpoint the problem because “it is this machinery that would give them direction in how to help these children.” (MH) The need to find a cure as opposed to seeking help with caring is described in the literature (Hartley et al., 2005). However as many caregivers expressed the need for practical assistance such as the provision of nappies as well as dietary advice, it is misleading to think that all caregivers were looking for a cure. Rather this reflects the spectrum of hopes, ideas and expectations regarding therapy that caregivers have. Therapists perhaps do not fully recognise or address the great need caregivers have for information regarding their child and their child’s disability.

Caregivers’ comments regarding processes of providing care, that is, valuing respectful and supportive care and good communication from health care professionals, resonate with other studies (King et al., 1996; Rosenbaum et al., 1998) suggesting that these are universal phenomena. However, it appears that the content of the service will differ across cultures, mainly as a function of the context and the environment. This means, for example, that in poorly resourced areas therapy services need to provide caregivers with much more than simply “hands on” therapy within a family-centred service philosophy. This may include the provision of assistive devices and equipment in the face of inadequate budgets and limited choice; assistance with schooling where no educational facilities exist; and facilitating peer support groups and interaction.
8.7 SUMMARY

Qualitative data obtained from this study were an invaluable asset in understanding and interpreting the quantitative results and raising issues regarding taking care of a child with a disability in poorly resourced South African settings. To date, little of this information has been explored or documented.

When compared to other studies, results from the qualitative data are useful in revealing those aspects or dimensions of caregiving together with expectations and experiences of rehabilitation which are universal and common to all caregivers. Simultaneously, the differences are highlighted. These differences are mostly a result of living in an environment characterised by poverty and having fewer resources together with a wide range of cross-cultural issues.

The following chapter combines and consolidates information from the two phases of the study. This information can be used to suggest how findings from other studies involving caregivers of children with cerebral palsy conducted in different settings need to be modified for use in poorly resourced South African settings. There are many bridges linking caregivers together, but often different pathways are required to reach the bridges.