CHAPTER 7

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

Results from the qualitative aspect of the study are presented in this chapter. It addresses the second research question posed in Chapter 1: “What are the perceptions and experiences of caregivers of children with CP living in poorly resourced areas regarding their child’s diagnosis and how does this impact on their expectations of rehabilitation therapy?”

As described in Chapter 4, the data were analysed using a grounded theory approach. This chapter summarises the main findings relating to each theme whilst the next chapter discusses these themes in relation to findings from other studies.

7.1 INTRODUCTION

Five focus groups were conducted with a total of 24 caregivers. Twenty of these caregivers were mothers, two were grandmothers and two were siblings of the children with CP. An additional focus group was conducted with the interviewers. The data consisted of transcriptions from over nine hours of taped discussions.

Abbreviations used to identify each focus group are as follows:
MH Malamulele Hospital focus group
HF1 Helene Franz Hospital focus group 1
HF2 Helen Franz Hospital focus group 2
SH Sebokeng Hospital focus group
The five main themes identified from the data are displayed in Table 7.1.

Table 7.1: Main themes identified from focus groups

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance and support</td>
<td>Personal acceptance</td>
</tr>
<tr>
<td></td>
<td>Family acceptance</td>
</tr>
<tr>
<td></td>
<td>Community acceptance</td>
</tr>
<tr>
<td></td>
<td>Sources and types of support</td>
</tr>
<tr>
<td>Caregiver stress</td>
<td>Feelings</td>
</tr>
<tr>
<td></td>
<td>Hardships</td>
</tr>
<tr>
<td></td>
<td>Caring for child</td>
</tr>
<tr>
<td></td>
<td>Child’s birth</td>
</tr>
<tr>
<td>Coping strategies</td>
<td>Caregivers’ personal attributes</td>
</tr>
<tr>
<td></td>
<td>Denial</td>
</tr>
<tr>
<td></td>
<td>Searching</td>
</tr>
<tr>
<td></td>
<td>Finding meaning</td>
</tr>
<tr>
<td></td>
<td>Religion</td>
</tr>
<tr>
<td>Personal, traditional and cultural</td>
<td>Regarding cause</td>
</tr>
<tr>
<td>beliefs and practices</td>
<td>Regarding caring and curing</td>
</tr>
<tr>
<td></td>
<td>Conflict and confusion</td>
</tr>
<tr>
<td>Health care service provision</td>
<td>Positive experiences</td>
</tr>
<tr>
<td></td>
<td>Needs</td>
</tr>
<tr>
<td></td>
<td>Dissatisfaction</td>
</tr>
<tr>
<td></td>
<td>Misconceptions</td>
</tr>
</tbody>
</table>

Each theme was developed from sub-themes which in turn were developed from categories in the manner described by Strauss and Corbin (1990). The categories and sub-themes together with examples of the supporting data can be found in Appendix V. The remainder of this chapter describes each theme under a separate heading.

7.2 THEME 1: ACCEPTANCE AND SUPPORT

Acceptance was one of the central themes running through the data. Four sub-themes were identified: personal acceptance, family acceptance, community acceptance and support (Table 1 in Appendix V).
For many of the children, it took time for the clinical manifestations of the disability to become clear, for example when the child was late in sitting. This was both helpful and puzzling to caregivers – helpful because it gave them time to adjust to the fact that their child was not going to be like other children yet puzzling because in the beginning the child “was born healthy” (MH). Even when the diagnosis was made at birth, recognizing the long-term implications was difficult: “Yes, I was unable to see that C is someone who is disabled … I just saw her being like other babies.” (HF2). Caregivers expressed their difficulty with initial acceptance of the disability: “I as a parent found it very difficult when I looked at the condition he was in.” (MH)

Caregivers demonstrated their acceptance by the way that they felt free and open to talk about their children: “Even when they ask questions, I feel open. This means I wouldn’t feel scared to walk around with her using public transport.” (SH)

Regarding acceptance, or lack of it, by the immediate family, four categories were identified from the data:

- abandonment and rejection
- difficulty with acceptance
- support and acceptance
- inclusion and participation.

Many caregivers described how they had been abandoned and rejected by the child’s father: “It is stressful because his father disposed of me, he does not want me. He does not want anything to do with the child.” (JH) Some families still experienced difficulty accepting the child. However, there were many stories of strong family support as well as examples of how the child participates in daily activities of the family and community: “Then they take E – herding cattle. You will find them running with him going with a wheelchair. When he sees those cattle, aai!! He becomes interested so much.” (HF1)
Ignorance, lack of awareness and negative attitudes of the community in general were commonplace and stressful for caregivers. Caregivers were subjected to taunting and mockery with comments like: “God has served you well by giving you a crippled child.” (SH) There were very few examples of acceptance by the community.

Caregivers’ sources of support included siblings, peers, the church, and in a few cases, the child’s father. Practical support at home from siblings and close family in sharing the burden of caring, thus giving the mother short periods of respite, was important: “My older brothers are also at home. When I leave him with someone there, I know that he will not go hungry, I know that he will be washed and so on.” (MH)

7.3 THEME 2: CAREGIVER STRESS

Sources of stress included caring for the child; unresolved feelings arising from difficulties during the child’s birth; and financial hardships (Table 2 in Appendix V). Feelings of isolation, hurt, anger, depression and a sense of hopelessness were clearly indicative of caregivers’ emotional stress: “But sometimes to keep alive is hard.” (JH)

Caregivers described a life of hardship with financial burdens; problems in finding money to pay for transport to the hospital and dealing with family tensions as well as personal hardship: “For me it was difficult because T was born on 8 February and his father died on 18 February.” (JH)

Difficulties surrounding birth and poor perinatal care contributed to caregivers’ stress. Many caregivers related detailed stories of problems encountered during labour such as: “If only they took me [from the clinic] to the hospital, and give birth through a Caesarean section, I could have been fine. I think it is a long time,
from Monday morning to Thursday [to be in labour]. That is where the mistake is. I see that they wasted my time.” (SH)

Caring for the child involved concern over the child’s health; daily management with many of the children requiring constant attention; as well as dealing with the child’s severe activity limitations and communication difficulties: “And you must think on their behalf. When she is sick, you have to think for her as to what could be the problem. You must feed her and also give her water to drink. Because she cannot speak for herself that she wants water, or she wants to go to the toilet or she wants to eat.” (HF2)

The burden of care is high and although, as already mentioned, some caregivers receive practical help and support from family members, the burden of everyday care-giving falls primarily on the mother: “My worry is that if it happens I should leave, they are not able to feed her.” (SH) One caregiver commented on how daily caring has affected her life: “It’s like you do not have a life. You cannot go out. Where will you go? How will you carry the child? Carrying the child on your back, picking the child up – you’re getting tired. You stay home always. If you are going to a person’s party – who will you give the child to? No-one will want to carry the child. Wherever you go where will you put the child? Your arms will tire.” (JH)

Constant hospital appointments also took their toll: “You just arrive there being tired.” (HF1) It is not surprising therefore that one caregiver remarked: “They are making us tired. You then take him to a mattress to get some rest.” (HF1)

7.4 THEME 3: COPING STRATEGIES

Coping strategies included caregivers’ personal attributes of resilience, their ability to find solutions and their patience; denial; a history of searching for
causes, cures, help and information; and finding their own meaning for the child’s disability (Table 3 in Appendix V)

Religion and personal faith played an important part in helping caregivers to accept and cope with the child’s disability, with many caregivers saying: “This is something that God gave me. I will not give it to anyone. It is a gift that I must be proud of.” (JH) Some caregivers saw themselves especially blessed: “The thing that keeps me going is that I love my child and God has purpose in giving me this child. God saw something in me so that is why I love my child even more.” (JH)

Denial was usually expressed as hope for a normal outcome or future for the child: “…one day she’ll be like other children.” (SH) Caregivers spend a great deal of time and money searching for help and some remained hopeful of finding a cure: “I was thinking about that thing that if it can be said that I should go to doctor so and so and pay R15000 she will be right” (SH) and “Yes, now his uncle said there is someone in Jo’burg who heals people, he makes people well. Now they said I must come on Sunday.” (HF2)

Finding their own explanations for the disability, either the cause or why it should happen to them, also was a way of coping and coming to terms with the problem as illustrated by the following statements: “Then when he started his crying, that is where it all began. I think it was that crying – he could not bend his body parts, the way that he did not bend his body parts, then we found he was no longer well” (MH); and “On the father’s side, I am not blood that falls too much on their side. I say that it is that. Maybe also when they mention crippled, it is in the family.” (SH)
7.5 THEME 4: PERSONAL, TRADITIONAL AND CULTURAL BELIEFS AND PRACTICES

Traditional and cultural beliefs and practices influenced how caregivers perceived the cause of the child’s disability as well as how they sought solutions to the problem (Table 4 in Appendix V). This theme cut across many of the themes and sub-themes already mentioned.

It was clear that caregivers needed a definitive explanation for the cause of the disability and often turned to traditional beliefs for answers. Thus many implausible ideas emerged, ranging from emotional stress during pregnancy for example: “He (the child’s father) denied this child saying it is not his. I think maybe these are the things that made the child to be like this. They say it is stress.” (SH), to natural events such as lightning striking the house: “Then lightning struck our house, then smoke came out of the room where the baby was lying.” (HF2)

Bewitchment and a sense of being cursed were also hinted at by some caregivers: “My husband’s sisters thought that my friends had bewitched me.” (HF2)

Alongside traditional beliefs regarding the cause of the disability were misconceptions stemming from medical procedures at around the time of birth such as the caregiver who believed that the phototherapy her baby received was the cause of the child’s problem. Some caregivers said they did not know what the cause was and simply replied when asked by friends: “I say aaaaah... she just arrived being like this. I do not know what happened.” (HF1)

A consequence of traditional beliefs is that traditional solutions are sought, as in the example given above where the family went to traditional healers: “…who gave them herbs so that we can exhale that smoke. We also gave the baby
...even if the baby can just say ha-ha!! the smoke could have come out. Or if the baby can sneeze those things would have come out.” (HF2)

The data suggested that many caregivers, particularly those who were grandmothers, felt that failure to observe cultural rituals around the time of a child’s birth contributed to the misfortune as demonstrated by the statement: “They said the mother had not done the cultural rituals.” (SH) Hence they encouraged their daughter or daughter-in-law to seek a traditional healer: “We bought Vaseline where she put in this and that, she took it and went into the bedroom where they performed their cultural rituals.” (SH)

Not all caregivers adhered to traditional beliefs and practices. As one caregiver remarked: “I do not believe that a person can have power over me. So I think where did the problem happen. I blame those nurses.” (SH)

Caregivers were open about their confusion about traditional medicine and Western medicine: “So I cannot understand if I must believe the traditional healers or what they told me in hospital.” (HF2) and: “At some stage is it not that we take these children to these people. We mix with the cultural rituals. It is that confusion.” (SH)

7.6 THEME 5: HEALTH CARE SERVICE PROVISION

Several questions asked during the focus groups concerned caregivers’ experiences of formal therapy and health care services. Four sub-themes emerged from the data: positive experiences; needs; dissatisfaction; and misconceptions (Table 5 in Appendix V).

Caring, kind and helpful attitudes from therapists, good communication with doctors, practical help and training/exercises combined with seeing progress in their children contributed to caregivers’ positive experiences of rehabilitation: “... I
feel that they show us love, which is good as it shows us how we should treat our children and how we should listen to them.” (MH) Observing progress was an important motivating factor: “But since I have been bringing him to the hospital, he has been doing a lot of things and I can now see that there will be a change.” (MH)

A need for assistive devices, especially wheelchairs, was a persistent plea, especially from caregivers in rural areas: “My child is 8 years but he doesn’t have a wheelchair. When I come here I always registered him so that his name can be on a waiting list. I asked for a wheelchair because he is old now and heavy for me.” Caregivers also wanted more practical help such as nappies, and access to specialist services such as dieticians and orthopaedic surgeons.

One of the caregivers’ biggest problems was schooling with several mothers expressing a wish for rehabilitation staff to assist with finding a school: “They must build a school for them. I have been looking for a special school but I can’t find one. A special school for them. If we can get a plot where we can keep our children every day and have people who can look after them.” (HF2)

The search for answers and the need to understand the child’s problem was further expressed by one caregiver: “Like E’s mother, she is old (a granny) do you see her, she would not understand if they tell her that your baby has this and that. So it means they can take her to x-rays and say to her, do you see mommy this bone is working and is being disturbed by a bone at the back. If a bone that is at the back can be able to work the child can be able to hold one, two, three. Even with nerves they will be able to know.” (HF1)

Insufficient equipment and resources were a cause for concern: “I understand we are running short of doctors here. Our doctors are few” (HF1). Unhelpful and uncaring attitudes, especially from hospital clerks were also causes of dissatisfaction with the health care services: “The problem is with the clerks. We
struggle a lot. Some of us end up sleeping in other people’s homes because we miss our taxis.” (HF2).

Poor communication and explanations from hospital staff together with inconsistent medical care were also sources of dissatisfaction. As one caregiver put it: “We have to start the story from the beginning. You don’t feel right. We all have that problem. I think many hospitals have that problem. When you go to the doctor sometimes you do not find the doctor that knows the child. You find another one. He is new in the hospital and does not know what is going on with the child. You must start from the beginning and explain. Think about it, you explain a thing of 14 years back.” (JH).

Inconsistent medical care was more of a problem in urban hospitals and often caused confusion to caregivers: “The doctors at this hospital they did not have enough time to explain what is happening to your child. We are seen by different doctors each time. The first doctor did not say that the child needs this or that. The other doctor told me that the child needs a brain scan. The next doctor told me that the child is smiling and does not need a brain scan.” (JH)

The data suggested that many caregivers had little idea of what to expect when they were referred for therapy: “We thought we would ask for doctors to check them and tell us where the problem is. So when we arrived here they just exercised them!!” (HF1); and: “But when I got there they told me it’s only the training. Training little by little. And they tell us that we must not be impatient.” (HF2)

There were also misconceptions regarding therapy with some caregivers expecting that they might find a machine. As one caregiver described: “I sometimes ask myself that maybe they will ... they will give her a machine... I was just imagining. I just gave myself imaginations. I thought they would give her a machine and put her down in the machine. Then her legs… maybe they can tie
her with ropes so that her legs can stand because her legs don’t want to become straight. There are things they will use to keep her legs apart and then they will give her something to support her neck.” (HF2). This idea that there would be a machine was confirmed during the focus group with the interviewers: “She wanted this machine. She said they told her that there is a machine that she can put her child in and her child will be walking.” (IFG)

One caregiver also expressed disappointment that therapy only consisted of exercises when she commented: “Here they are only exercising, when a baby picks up, there is nothing she will be able to do because she does not know the others, they only know about exercising a baby.” (HF1)

7.7 SUMMARY

Using the qualitative results the original conceptual framework was revised as follows:

![Diagram of revised conceptual framework]

Figure 7.1. Revised conceptual framework of factors underlying caregivers’ perceptions and experiences of therapy
Information gained from the focus groups complements the data obtained during Phase 1 and sheds light on caregivers' feelings and experiences of caring for a child with CP. This information is helpful in understanding caregivers' needs, perceptions and experiences of encounters with health care services including rehabilitation therapy.

Taking care of a child with cerebral palsy in a disadvantaged area poses many challenges to the family of the child. Caregivers display amazing resilience and optimism in the face of many hardships. Together with practical and emotional support from close family members, understanding the cause of the disability and finding meaning assists caregivers in accepting their child's disability. Misconceptions regarding the cause and management of the condition abound. The majority of caregivers had very positive experiences of rehabilitation therapy and valued therapists' caring attitudes.

These findings are discussed in the following chapter together with results from similar studies.