CHAPTER 1

INTRODUCTION

Caring for a child with cerebral palsy (CP) presents a multifaceted challenge to the caregiver and family. Managing and coping with the child’s functional limitations and possible longterm dependence has to happen whilst dealing with everyday living and the needs of the whole family. In disadvantaged and poorly-resourced areas, the pressure on caregivers is even greater. The majority of families are already living under difficult conditions with few resources and little access to support services such as rehabilitation and specialised education. Understanding how caregivers in these settings cope and the role and usefulness of rehabilitation therapy services is poorly understood and has not been explored.

This chapter provides background information on the health and rehabilitation services available to caregivers and children with CP who are the focus of this study. The structure and delivery of therapy interventions for children with CP living in disadvantaged areas in South Africa are described; the chapter concludes with the research questions addressed in this study and highlights the relevance and significance of this study.

1.1 ACCESS TO SERVICES FOR CHILDREN WITH CP

Children with a disability or a developmental delay who require assessment or therapy are usually taken to the local clinic or the nearest public hospital if the family has no medical aid cover. Generally speaking, most people attending public service hospitals would be from disadvantaged or poorer areas. Since 1994, health care in the public sector, which includes rehabilitation, has been free for children under six years of age and since 2004, free for children and
adults with a permanent disability (Pillay, 2001; Kapp, 2004; Saloojee and Pettifor, 2005).

If there is no therapist at the district hospital, the child is referred to the nearest hospital with a therapist. All secondary and tertiary hospitals have rehabilitation therapists (i.e., physiotherapists, occupational therapists, speech therapists and dieticians). Not all district hospitals have therapists, and only a handful of primary care clinics have a full time therapist. In rural areas, many of the larger hospitals have a monthly outreach service to local clinics or smaller district hospitals. This outreach service is often erratic as therapists depend on hospital transport to take them out to the clinics or smaller hospitals. Hospital transport is not always available, usually because there are not enough hospital vehicles in service and rehabilitation services appear to have low priority when requests for transport are made.

Since 2003, all newly qualified doctors, physiotherapists, occupational therapists and speech therapists have been required to do a year’s compulsory community service before they can register with the Health Professions Council of South Africa. This resulted in a substantial expansion of the provision of rehabilitation services, particularly at peri-urban community clinics and hospitals. However, as these therapists are inexperienced and only remain in these community service posts for a year, there is little continuity of service particularly in poorer and more remote areas. Consequently, the development and growth of services for children with cerebral palsy in these areas is hampered, with limited expansion of services.

Rehabilitation services in the public service are predominantly hospital-based. Since 1990, there has been a move towards community-based rehabilitation services and community rehabilitation workers (CRWs) are employed in some rural areas. However, the number of CRWs is small because only two out of the
nine provincial governments have created posts for them. Consequently, the need for community-based programmes far outstrips the resources available.

What this means is that access to rehabilitation for the majority of children with CP in South Africa is difficult. Caregivers need to take their children to the nearest hospital where there is a therapist. This is a problem for caregivers whose children are not mobile as they rely on the public transport system to reach the hospital.

Therapy is usually only available on a monthly basis at public service hospitals. There are two main reasons for this – the high client to therapist ratio, and difficulties with transport. There are simply not enough therapists working in public service hospitals and children often have to wait more than a month for an appointment. As mentioned earlier, caregivers are dependent on the public transport system (mainly minibus taxis) to get to the hospital, and this they have to pay for themselves. Many families do not keep their therapy appointments simply because there is no money for transport to get to the hospital (Saloojee et al., 2002). Two South African studies have shown that only about a third of children in need of long term rehabilitation, receive it (Couper, 2002; Saloojee G et al., in press).

The majority of children with CP attending public service hospitals are younger than five years. Reasons for this include:

- Children who are non-mobile have to be carried on their mothers' backs because taxi drivers charge extra for wheelchairs or buggies. As children become older and heavier, it becomes increasingly difficult for mothers to bring their children to the hospital. Some parents may hire private transport, but this is extremely expensive.

- As children grow older, the need for the caregiver to find employment takes precedence over child care, both for economic reasons and as it becomes clearer that the child is not going to get “better”. The disabled
child may then be left with a grandmother or another family member, and this person is often caring for other children as well. This means that there is no one to bring the child in to the hospital (Saloojee et al., 2002).

- Some hospitals have a policy of not treating children over a certain age, simply because they have insufficient staff.
- A few children are admitted to special needs schools where they may obtain therapy on-site. However, not all special needs schools, particularly those in poorer areas, have therapists. Thus, not all children with CP who are at school are guaranteed therapy (Saloojee et al., 2003).

South Africa has an Inclusive Education Policy (Department of Education, 2001) that promotes full integration and participation of all learners who experience barriers to learning. However, this is a 20-year vision which is still being phased in. Presently, less than half of all school-going aged children with CP attend a school or training centre (Department of Education, 2001; Saloojee et al., 2003; Saloojee G et al., in press). There are no state-run educational facilities for children with multiple and complex needs. In many areas, parents and non-governmental organisations (NGOs) have started day care centres that offer basic care and some kind of simple stimulation. These centres qualify for a small government subsidy but are dependent on ongoing self-generated fundraising and income-generation projects. All children with disabilities between one and 18 years of age requiring full-time support and care are eligible for a Care Dependency Grant of R820 per month (in 2006) from the Department of Social Development.

Thus, the population of caregivers who are the focus of this study live in an environment that is not supportive in terms of the needs of children with CP, with limited access to both rehabilitation and educational services.
Environmental factors place additional burdens on families of children with CP and create barriers to the child’s participation in daily life activities. These include:

- Stigmatisation and negative attitudes towards disability within the community.
- Limited access to education and rehabilitation.
- Minimal provision of equipment and assistive devices.
- Poverty (Saloojee et al., 2003, Schneider and Saloojee, 2006).

With access to therapy being so difficult, infrequent and irregular, the obvious questions that arise are “Given these circumstances, how effective can therapy be?” and “What is the most appropriate therapy intervention service in this setting?” These were the questions which initiated this exploratory study.

1.2 REHABILITATION THERAPY IN PUBLIC SERVICE HOSPITALS FOR CHILDREN WITH CEREBRAL PALSY

What do current therapy services in the public sector for children with CP comprise and what is presently being offered? There is no written documentation describing current services. The following description is based upon the researcher’s fifteen years of experience of working at CP Clinics at public service hospitals in Gauteng and Limpopo in addition to the observations made while visiting hospitals throughout these same provinces.

In the public sector, approaches to service delivery for children with CP at local level have evolved as a result of available staff resources, the district health service structures and policies, distances patients have to travel to the hospital, and transport issues (e.g., whether rehabilitation staff have transport into the community, or whether families have the financial resources for transport to the hospital or local clinic). Services are, therefore, variable and are a function of staff availability and resources. Current approaches to service delivery include
individual one-to-one therapy, clinic or hospital-based group therapy, home visits, support groups run by parents, as well as support groups facilitated by community rehabilitation workers.

Most hospital rehabilitation departments have a “CP Clinic” where children with CP are seen on particular days each week or month. A team approach is adopted where physiotherapists, occupational therapists, speech therapists and sometimes dieticians are all present, and in a few hospitals, a paediatrician or paediatric neurologist is also available. The experience level of the therapists and therapy assistants varies widely. While all have received undergraduate training in working with children with cerebral palsy, few have specialised in neuro-developmental therapy (completion of an eight-week course in the neuro-developmental therapy approach to the assessment and management of children with cerebral palsy), or attained a post-graduate degree in early childhood intervention or paediatric neurology (Elma Burger, personal communication).

Children at hospital-based outpatient CP Clinics are usually seen on an individual basis, either by one member of the team or by the whole team. A typical therapy session lasts 20 - 25 minutes. At a few of the larger hospitals, a different approach to therapy has been adopted. Children are treated in groups, and there is greater emphasis on caregiver empowerment, support and training. In some rural hospitals, hospital-based therapy is supplemented by home visits conducted by community-based rehabilitation workers.

1.3 HISTORICAL AND CULTURAL CONTEXT OF HEALTH SERVICE DELIVERY IN SOUTH AFRICA

When discussing rehabilitation services in public service hospitals, the historical and cultural context of health service delivery in South Africa cannot be ignored. Although the country recently celebrated ten years of democracy, the oppression,
inequalities and inequities of the past continue to cast a shadow over the provision of rehabilitation services today.

Under the old apartheid regime, therapists were mainly white, middle-class, English or Afrikaans speaking, whereas the majority of the population they served were poorly educated black people living in poverty who sometimes spoke little or no English or Afrikaans. This created a major imbalance and chasm between therapists and their clients. The learning of an African language was not part of the school curriculum of white children; socialising with members of different race groups was actively discouraged; and undergraduate therapy training programmes tended to follow a Western medical model (University of the Witwatersrand, 1980). This meant that new graduates were ill equipped to understand the needs of black caregivers of children with disabilities and to plan appropriate intervention strategies. This discordance between therapists and caregivers resulted in a situation where caregivers and children with CP were often disempowered passive recipients of therapy programmes while frustrated therapists could not understand why therapy attendance was erratic and compliance with home programmes low (Anderson and Venter, 1997).

Although the number of black therapists has increased since 1994, a gulf still persists between therapists and clients, largely based on disparate socio-economic status, educational levels, language and culture. This has to have had a negative impact on the provision of rehabilitation therapy services in South Africa, where historical and demographic issues are additional barriers to establishing collaboration between therapist and client (Moja, 2004).

Public service health care facilities in South Africa are an interface between different cultures and world views. Rehabilitation departments serve as a meeting place between English and local languages and between the Western medical models of health and traditional cultural beliefs (Jelsma, 2000). In traditional African societies traditional medicine remains the major way of coping with
Ilness, particularly in rural communities (Ataudo, 1985; Pinkoane, 2005). Traditional African societies regard health as a state of balance or equilibrium, both internal and external, and traditional medicine helps to achieve this balance (Ataudo, 1985; Pinkoane, 2005).

This meeting place of traditional and Western cultures and beliefs regarding health needs to be explored in order to reach a common understanding of disability and rehabilitation therapy. Only with such understanding will it be possible to use the existing resources most effectively and to argue for additional support and services. Even in developed countries such as the United States of America (USA), it has long been recognised that little information exists as to how to incorporate ethnic and cultural definitions of, and meanings attached to, disease and disability into appropriate mechanisms for health care provision (Brookins, 1993). Finding answers to the questions raised earlier regarding the effectiveness of current therapy intervention activities is only possible if the context or milieu in which the interaction between therapists and caregivers takes place is explored and understood.

1.4 HOW EFFECTIVE ARE CURRENT THERAPY SERVICES?

This question can best be answered by deciding on what the desired outcomes of therapy intervention are, and then finding suitable tools or scales to measure these outcomes. This has been done in several well-resourced areas where children with cerebral palsy have access to a wide range of specialised services and support systems (Siebes et al., 2002). However, the literature pertaining to the determination and measurement of outcomes in poorly-resourced areas where little support is available to families is very scanty, and no South African studies have been conducted.

Thus, when evaluating the outcome of rehabilitation interventions for children with CP and their families, the question is whether the plethora of tools and
scales developed and used in industrialised countries is appropriate and suitable for use in a South African public service setting. In disadvantaged settings socio-cultural and economic factors need to be taken into consideration and are likely to play an important role in determining outcomes. Can South African therapists learn and implement research findings from studies conducted in well-resourced settings? Or should therapists in this country start at the beginning and develop a new set of tools to evaluate the outcome of current therapy interventions?

Against this background, the questions and the objectives that this study sets out to address are now presented.

1.5 PROBLEM STATEMENT

The majority of children with CP in South Africa are dependent on the public service for rehabilitation therapy, where therapy is usually only available on an infrequent (monthly) basis. Therapy intervention and service delivery for young children with CP living in South Africa is largely based on a Western medical model of health and rehabilitation. This intervention needs to be contextualised and needs to acknowledge traditional and cultural beliefs. Caregivers' beliefs surrounding a diagnosis of CP, its causes and how this influences their perceptions of therapy have not been studied. Further, whether therapy interventions change anything in the life of the child or the caregiver is not known and has never been formally evaluated.

1.6 SIGNIFICANCE OF THE RESEARCH

The appropriateness, the outcomes and the effectiveness of therapy interventions in a South African setting have not been studied. It is not known whether outcome measures developed and used in well-resourced settings are suitable for use in disadvantaged cross-cultural settings. No studies have been conducted to determine whether the current approaches to service delivery are
suitable and relevant to disadvantaged and resource-poor settings. The influence of traditional and cultural perceptions of disability on therapy in a South African setting has not been described.

This then is uncharted territory. By listening to caregivers' stories of their own lives and those of their children, their experience of bringing up a child with CP in a poor community, and their perceptions and expectations of therapy enables this study to begin to “map the territory.” Information gained from caregivers’ narratives, and their perceptions and experiences of current rehabilitation services available in poorly-resourced areas, may assist in developing an evidence base for the structure, processes and content of rehabilitation therapy in poor areas. Establishing whether the therapy programme makes a difference to the life of the family and the caregiver will assist in determining whether, in terms of the family as well as the health care system, the scarce resources available in a poor area are being optimally used. To date, none of these issues has been studied or described. The data obtained from this study will assist in developing appropriate and effective therapy intervention programmes and services for children with CP in South Africa.

This exploratory study needs to be viewed in the context of a long term programme of research in which information gained from each study component will be used to plan further studies and to explore the broader question: “What approaches to service delivery work best for families of children with CP in poorly-resourced South African communities?”

1.7 RESEARCH QUESTIONS

Two research questions were addressed in this study:

1. Can tools that have been developed and used in well-resourced settings and countries be used to assess the impact of rehabilitation interventions
on caregivers and families of children with CP in poorly-resourced areas in South Africa?

2. What are the experiences and perceptions of rehabilitation therapy of caregivers of children with CP living in poorly-resourced areas in South Africa and how do these impact on their expectations of rehabilitation therapy?

1.8 AIMS AND OBJECTIVES

The aims of this study were twofold: firstly to ascertain whether tools and scales developed in contexts different from the context of this study are appropriate in a poorly-resourced South African setting; and secondly, to describe parental perceptions and experiences of current rehabilitation therapy for children with cerebral palsy in poorly-resourced rural and urban areas of South Africa.

The specific objectives were to ascertain:

1. Whether tools and scales developed in contexts different from the context of this study are appropriate for use in this community;
2. Factors which may predict a positive caregiver outcome in terms of their quality of life, mental health, interaction with their child and their involvement with family support networks;
3. Whether place of residence (that is, urban or rural) makes a difference to the outcomes of interest, namely caregivers’ quality of life, mental health, attitude towards their child and involvement with a family support network; and
4. Whether the severity of a child’s disability has an impact on the caregiver outcomes described above.
To answer these questions, the study reported here was conducted in two phases. Phase 1 was predominantly quantitative and sought to answer the first research question as well as Objectives 1 - 4. To answer the second research question, a deeper perspective was needed and this called for a different approach. Phase 2 was thus qualitative in nature and addressed the second question.