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Caregivers' perceptions of services offered at the cerebral palsy clinic at Doctor George Mukhari hospital

Tshabalala, Muziwakhe Daniel

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CHAPTER 1

1.1 Introduction

According to the National Rehabilitation Policy (NRP) of South Africa (2000) all stakeholders are accountable for ensuring a high standard of service delivery. It stresses that services should be subject to regular quality control evaluations established in consultation with the users. The users of the service should be held accountable for keeping to their side of the deal, such as, keeping appointments and the proper use and care of materials and devices entrusted to them. This policy implies that the recipients of health service have a critical role in ensuring that health care delivered to them is of a high quality since they are active participants in its transaction.

Dr. George Mukhari hospital has two neurodevelopmental therapy (NDT) trained physiotherapists (PT), one speech and language pathology therapist (ST) and one occupational therapist (OT) assigned to work at the cerebral palsy (CP) clinic. The physiotherapists work on a rotation system so that only one therapist works per treatment session. The annual CP case-load at Dr. George Mukhari hospital is approximately 590 patients. Patients are treated once a month. Despite this high patient load, healthcare delivery should be acceptable, accessible and appropriate to the community being served.

Traditionally the focus of interventions for children with disabilities aimed to improve aspects of the child's functional status and there was seldom a distinct effort to address the needs of parents and families (King et al, 1996). Little work has been done to evaluate

the impact of processes by which services are provided to parents in developing countries. Further, there is little literature and research on service delivered to children with disabilities in South Africa.

Family-centered rehabilitation services are aimed at children with disabilities, their families and at a network of people around the children. Also, family-centered rehabilitation has to ensure that the interests of the child and family guide the process both in assessing needs and in planning and carrying out the program. Therefore, positive perceptions and experiences of families are pivotal in assuring success among service providers and users (Cass and Kugler 1999; Davidson 1999; McConachie et al, 1999; Granat 2002).

Kolobe (1983) identified that primary caregivers of children with disabilities exhibit variability in their responses to situations due to their attitudes and beliefs. This further reinforces the philosophy that each child, and each family of a child with a disability, is unique and should be treated as such. Other studies show that parents of a child with a disability suffer increased stress as a consequence of their child's disability and run an increased risk of social and mental illness (Cadman et al, 1991; Barakat and Linney, 1992; Brenhaut et al, 2004). The children and young people from families of a child with disabilities are also at enormous risk of psychological illness compared to other children (Helitzer et al, 2002). The findings suggest that professional support for families who have children with disabilities can have a definite effect both on the child's chances of

optimal rehabilitation, and on the well being of the parents. (Barakat and Linney, 1992; Rosenbaum et al, 1992; Granat et al, 2002).

Granat et al, (2002) stated that quality means doing the right thing at the right time for the benefit of those for whom the service is intended and that all health care services should be of a high quality. A quality system should include different methods to evaluate various aspects of the organization and its services. Moreover, the results obtained should function as a support to enable management to work towards its goals, the progression and successful development of the service for the benefit of families and should provide encouragement to staff in their efforts towards quality improvement. (Granat et al, 2002).

Zastowny et al, (1995) and Swaine et al, (1999) agree that consumer satisfaction has become an increasingly important measure of outcome and of good quality care in the evaluation of health-care services. Furthermore, it may influence the success of a health care organization, and has been identified as a factor influencing compliance with medical intervention. The South African government developed eight Batho Pele principles (1997) of putting people first that requires that all users of public services should be consulted about their needs, priorities and standard of services required (Crous, 2006). Crous (2006) further emphasized that the users of services should be consulted about the level and quality of services they receive and should, where possible, be given a choice about the services that are offered and their views should constantly be obtained to the quality of service delivery.

This philosophy of care has important implications for the Cerebral Palsy (CP) clinic at Dr. George Mukhari hospital where eight to fifteen children are seen within a three-hour session for their rehabilitation.

Children and their families have the right to an individualized treatment plan that fits into the family routine, meeting the needs of the family within the home context. This treatment plan should be "developed in collaboration with children and their families and should be monitored for appropriateness and for patient progress with their participation on a specific, regular basis" (International Society of Psychiatric Mental Health Nurses (ISPN), 2000). The purpose of this study is to investigate the perceptions of caregivers on service delivery using the measures of processes of care (MPOC) and to find out whether they are satisfied with the health care delivered to the child.

The MPOC is a relevant tool for use in this study. It is a well-validated and reliable self-report measure of parents' perceptions of the extent to which the health care services they and their child received are family centered. The original version comprising 56-item questionnaire was developed in 1995 (King et al, 1996); the shorter version of 20-items was developed in 1999 (King et al, 2004). The shorter version has also shown good reliability and validity. In this tool, caregivers reflect on the services they have received for their children. It describes specific actions taken by service providers when delivering health care to the families. The descriptions of these actions are represented in five domains which are as follows:

- Enabling and partnership: has to do with items that reflect actions where service providers actively involve caregivers in their children's care particularly in decision-making and in obtaining input, concerns and opinions regarding services.
- Providing specific information: this is information about the child, the diagnosis, investigations, progress and intervention that is relevant to the child's needs.
- Providing general information: this has items that meet the general information needs of caregivers
- Coordinated and Comprehensive care: the items encompass holistic needs of the child and family with regard to service provision that is continuous and consistent over time, settings and people.
- Respectful and supportive care: items reflect items where parents are viewed and treated as individuals and equals, and all family members are treated with respect.

The MPOC tool was developed in the United States of America which is a developed country. It has been translated into many languages and has been used extensively to monitor and evaluate services. The researcher hopes that this tool will be instrumental in determining perceptions about service provision in the South African context where there is strong emphasis on service delivery that is of high quality.

1.2 Main Aim

The aim of this study was to evaluate perceptions on quality of care delivered by service providers to families of children with disabilities, attending the CP clinic at Dr. George Mukhari hospital.

1.3 Objectives

The objectives of this study were:

- To determine the demographic and socio-economic profile of the caregivers of children with cerebral palsy attending the Dr. George Mukhari hospital Cerebral Palsy clinic.
- To establish how the caregivers of children with cerebral palsy perceive the provision of care as identified by the subscales of the MPOC.
- To determine the overall perception of caregivers with regard to their satisfaction from the service they received as enshrined in the Batho Pele principles.

1.4 Significance of the study

The study outcomes will add to the pool of knowledge for professionals involved in interventions for children with disabilities. This includes physiotherapists, occupational therapists, speech and language pathology therapists, and nurses among others.

The outcomes could help service providers improve any of the five areas identified as important in the MPOC. This will also be a way of improving the quality of care based on the principles of evidence based practice and ensure that the service rendered is satisfactory.

The community of caregivers could be made aware that they have a right to certain quality of care when consulting rehabilitation services for their children.

1.5 Hypothesis

1.5.1 Null Hypothesis:

Caregivers of children with cerebral palsy have a negative perception of the service rendered by service providers at Dr. George Mukhari hospital cerebral palsy clinic.

1.5.2 Alternate Hypothesis:

Caregivers of children with cerebral palsy have a positive perception of the service rendered by service providers at Dr. George Mukhari hospital cerebral palsy clinic.

1.6 Definition of Terminology

Caregiver: a parent or any person who is responsible for ensuring the well-being of a child at home, also spending most of the time looking after the child and ensuring that the child receives healthcare services.

Family-centered care: a philosophy of care in which the pivotal role of the family is recognized and respected in the lives of children with special needs ... [in which] families should be supported in their natural caregiving and decision-making roles ... [in which] parents and professionals are seen as equals in a partnership committed to the development of optimal quality in the delivery of all levels of health care. (Brewer et al, 1989).

Service Provider: a physiotherapist, occupational therapist and or a speech and language pathology therapist who may have received or did not receive neuro-developmental training (NDT) and/ but qualified to work with children with developmental delays.

Child: a person under the age of 18 (Child Care Act, 1983).

CHAPTER 2

LITERATURE REVIEW

The literature search for this study included the following electronic databases: Medline/Pubmed (1956 to November 2007), CINAHL (1982 to November 2007), the PAEDIATRICS online official journal of the American Academy of Paediatrics (1948 to November 2007), and the Science Direct Database for the journal of Social Science & Medicine. The search was limited to studies conducted in English. The keywords used to channel the search were 'cerebral palsy', 'child disability', 'caregiver', 'process of care', 'service delivery', 'family centered', and 'satisfaction'. The reference lists in studies and review articles where also considered. South African government websites i.e. www.polity.gov.za, www.info.gov.za and www.doh.gov.za, were also searched for various bills, policies and acts related to the topic.

The literature review for this study is presented in non exhaustive subtopics that the researcher feels encapsulate the study, and are derived from the objectives. The assessment tools used in the study will also be reviewed.

2.1 Cerebral Palsy

Cerebral palsy was first described by Little in 1861 (Shapiro, 2004). The Executive Committee for the Definition of Cerebral Palsy, came up with an updated definition and classification of cerebral palsy. According to a review by Bax et al, (2005) Cerebral Palsy (CP) describes a group of disorders of development of movement and posture, causing

activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder. This definition comes in an attempt to make the condition of CP understood when widely cited in literature that focuses on treatment services, advocacy and research.

According to Palmer (2004), the diagnosis of CP for inclusion in clinical trials or for tailored treatments may need to be very specific based on the requirements of the trial or the nature of the treatment. Furthermore, the diagnosis to determine eligibility for effective early interventions must be made early and should be sensitive to avoid errors of exclusion. Therefore it becomes important to clearly define CP so that health care services rendered to these children may meet their needs and demands.

Reddy (2005) when commenting on the consensual definition of CP approved that the new definition addressed the concepts of functional limitation and participation within the community context. These are most likely to be a sequel of CP. Moreover, Reddy highlighted the need for the definition to include coordination disorders and also to include older children as most of these children are receiving rehabilitation services in most developing countries (Reddy, 2005).

2.1.1 Prevalence of Cerebral Palsy

Literature suggests that CP affects one to three children in every one thousand live births in the developed world (Bax, 1994; Samson-Fang et al, 2002; Brehaunt et al, 2004), other authors estimate the prevalence of CP in developed countries to average two to two and half per 1000 live births (Grether et al, 1992; Murphy et al, 1993; Boyle et al, 1994; Robertson et al, 1998; Winter et al, 2002; Jackson, 2003; Aneja, 2004; Taub et al, 2004). Taub et al, (2004) further added that two per 1000 children have CP in the United States, and that more than one million children under the age of 21 who live in developing countries have CP. A study conducted by Serdaroğlu et al, (2006) showed contrary findings on the prevalence of CP in Turkish children which was determined at four point four per 1000 live birth. These higher figures according to Serdaroğlu et al (2006) could be attributed to an increased level of obstetric and neonatal problems and also due to other factors such as genetic disorders.

Brehaunt et al, (2004) further suggests that the prevalence in the developing world could be higher. Couper (2002) conducted a study in this province and estimated the prevalence to be ten per 1000 births. The KwaZulu-Natal department of health estimated the prevalence of cerebral palsy to be one and half to four per 1000 births (www.kznhealth.gov.za/cerebralpalsy.htm).

2.1.2 Causes and Classification of Cerebral Palsy

According to Simkiss (2002) and Aneja (2004) causes of CP are classically divided into three categories which are: prenatal, peri-natal and postnatal. Palmer (2004) highlighted that the majority of CP diagnosed in term infants in developed countries is caused by prenatal influences. Perinatal causes according to Aneja (2004) are appreciated in the neonatal period especially when the child is born in the hospital where intrapartum events are recorded as opposed to home deliveries. Simkiss (2002) further emphasized that in developing countries like South Africa, Uganda and India postnatal factors such as cerebral infections, particularly meningitis, cerebral trauma and cerebrovascular accidents are the major cause of CP. A study by Arens and Moltena (1989), conducted in Cape Town showed that postnatally acquired CP varied by racial group from 13.2 to 36.1 percent of the affected population.

Shevell and colleagues (2003) in one study classified CP into different types based on the predominant pattern of motor abnormalities and presenting clinical features. These authors have classified CP as follows: spastic quadriplegic (equivalent or greater spasticity in the upper extremities than lower extremeties), hemiplegic, diplegic (spasticity in lower extremities greater than in upper extremities), monoplegic, dyskinetic, ataxic-hypotonic and Worster-Drought syndrome or mixed (e.g. spastic and dyskinetic) (Shevell et al, 2003). Clearly shown above is a mixed picture of classification by distribution of tone and classification following the quality of tone. This classification does not take into account the degree of involvement, also known as the severity of tone.

The work of classifying CP has continued from the time of the Swedish subtypes by Hagberg et al, (1975) to recent literature by Carnahan et al, (2007), where the Gross Motor Function Classification System (GMFCS) by Palisano et al, (1997) is used together with another tool known as the Manual Ability Classification System (MACS) designed by Morris et al, (2006).These tools do not classify CP as such, but they measure the functional abilities of these children more objectively. Furthermore, the GMFCS and the MACS tools are used for stratifying these children for research purposes. The proper classification of CP is very important in clinical practice for assessment and management of the children diagnosed with this type of childhood disability (Carnahan et al, 2007).

The classification of CP is based on clinically defined symptom complex applied to individuals with a static, nonprogressive motor impairment of early onset (Kuban and Leviton, 1994; Shevell et al, 2003). Rosenbaum and Stewart (2004) emphasized the importance of using the International Classification of Function, Health, and Disability (ICF) not only as a classification tool, but also as a framework for social policy, research, education and clinical practice. The ICF model enshrines the "biopsychosocial" approach to health, functioning, and disability that provide "a coherent view of different perspectives of health from a biological, individual and social perspective" (WHO 2001:28).

Badawi et al, (1998) identified and excluded disorders that did not fall within the traditional cerebral palsy definition, such as neural tube defects and neuromuscular disorders among others. The modified Swedish classification shown below, is widely

used and it is based on the tone, number and distribution of the affected limb(s) (Mutch et al, 1992; Aneja, 2004).

Table 2.1: Modified Swedish Classification of Cerebral Palsy (Motor Impairment)

Tone and Topography	
Spastic:	Quadruplegia, Diplegia, Hemiplegia
Dyskinetic:	Pure athetosis, Choreoathetosis, dystonic
Ataxia:	Diplegia
Mixed:	Congenital (simple)

[Source: Adapted from Aneja S (2004:628)].

Classification of CP using impairment focuses on defects at the organ or system level. Impairment according to Palmer (2004) includes abnormalities in muscle tone, strength, and control; involuntary movements; and other findings on the neuromotor examination such as motor asymmetries, abnormal primitive reflexes, and late development of postural responses.

Palmer (2004) presented other types of classification of CP which are the following: physiological (motor); topographical; etiological; supplemental; neuroanatomical; functional (severity such as the GMFCS); and therapeutic. Further stated by the author is that the classification of CP requires revision, and that the functional and therapeutic classifications need modification to reflect the current expectations for persons with disabilities.

2.1.3 Impact of Cerebral Palsy on the Child

Children with CP have various challenges and associated difficulties affecting many systems of the body and further impacting their lives negatively. Bhatia and Joseph

(2000) and Singhi (2001) reviewed the associated difficulties in children with CP. Their findings are supported and reflected by Simkiss (2002:320) in table 2.2 below. Bhatia and Joseph (2000) observed that eighty-two percent of children with cerebral palsy had one or more disabilities apart from locomotor disabilities, and that visual defects was the second most common with 54 percent. Further observed by Bhatia and Joseph (2000) was that in 43 percent of children at least one associated disability had not been recognized at the time of referral. The main conclusion of the above reviews emphasize the need for comprehensive evaluation of all children with cerebral palsy and a multidisciplinary approach to management with parents taking an active role to help the child achieve his potential.

Table 2.2: Associated difficulties in Cerebral Palsy

Learning difficulties: mild, moderate or severe
Visual problems: refractive errors, strabismus, optic atrophy, cortical blindness
Speech and language difficulties
Hearing difficulties: conductive and sensorineural of all degrees
Epilepsy
Behavioural difficulties
Feeding difficulties and significant malnutrition of macro- and micronutrients
Gastrointestinal problems including gastro-oesophageal reflux and constipation
Orthopaedic problems: scoliosis, subluxation, and dislocation of the hip, contracture, fractures
Dental decay

[Source: Adapted from Simkiss (2002:320)].

A number of studies show sufficient evidence that children with CP have gross motor functional limitations and difficulties with activities such as sitting, walking, dressing, playing or interacting with the environment. Self-care will also be limited by the severity of cerebral palsy and gross motor abilities of the child (Bower and McLellan, 1994;

Adams et al, 1999; Butler and Durrah, 2001). Therefore most of these children are dependent on a caregiver for basic activities of daily living (Mobarak et al, 2000).

Children with CP commonly present with mental involvement in 60 to 72 percent of cases and this is the main cause of learning disorders (Singhi et al, 2002; Sankar and Mundkur, 2005). Sankar and Mundkur (2005) also reported that children with spastic quadriplegia have greater degree of cognitive impairment than children with hemiplegia. Further reported is that CP also causes visual impairment and disorders in 28 percent cases with increased presence of strabismus, amblyopia, nystigmus, optic atrophy, and refractory errors. Hearing impairments and disorders occur in 12 percent of children.(Sankar and Mundkur, 2005).

Speech and language disorders were observed in 38 percent of children with CP, and these children also present with oromotor problems that cause feeding difficulties, swallowing dysfunction and drooling (Reilly et al, 1996). This will inevitably result in nutritional problems affecting physical growth (Srivastava et al, 1992; Ojturk et al, 2002).

Sankar and Mundkur (2005) reported that epilepsy is common in children with CP, and it develops in 35 to 62 percent of children. Some children with CP who present with epilepsy will require anti-epileptic drugs for the rest of their lives (Jekovek-Vrhovsek, 2000). Carbamazipine and phenobarbitone are the most commonly prescribed anti-epileptic drugs for children with CP. These drugs increase the catabolism of vitamin D (Sheth et al, 1995; Pettifor et al, 1996; Henderson, 1997; Jekovek-Vrhovsek, 2000;

Bischof et al, 2002). Other children develop pathological long-bone fractures due to a number of factors such as Vitamin D deficiency (Bischof et al, 2002), poor nutrition status and non-ambulation, anticonvalsent therapy (ACT), lower limb rigidity, joint contracture, hip dislocation and disuse osteopenia.

The health condition of the child with CP may be affected by two contextual factors that are key components of the ICF model (WHO, 2001). The first contextual factor is the "environmental factors" which can be physical, social, cultural or institutional in nature. The second contextual factor is the "personal factors" such as gender, age, education, and lifestyle. Figure 2.1 below portrays the ICF model, and clearly summaries how the health condition of the child, in this case CP, can influence and in turn be affected in an integrated manner.

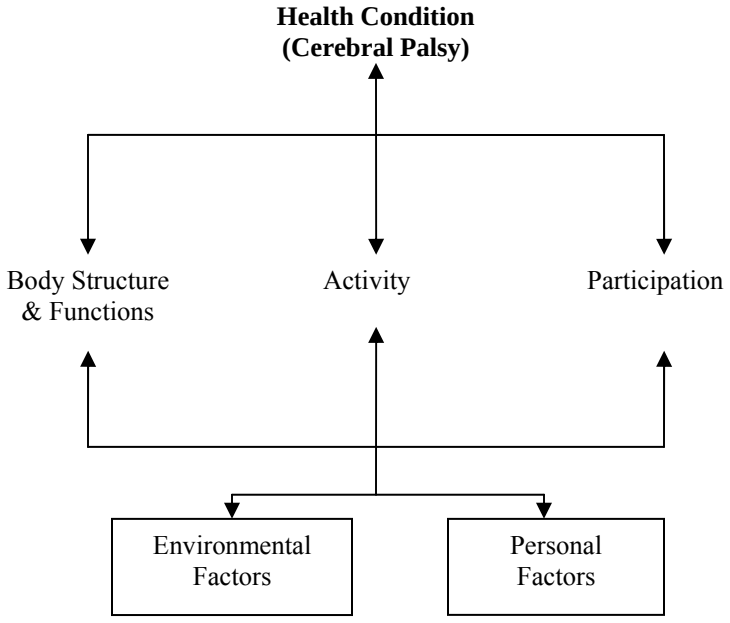


Figure 2.1. The ICF Model (WHO, 2001)

Rosenbaum and Stewart (2004) highlighted that these contextual factors influence and modify the other components of disease or disorder, and they need to be identified and considered in the mix of forces that together contribute to the dimensions of "body function/structure," "activity," and "participation,".

Currently, the focus of research is on health-related quality of life (HRQL) which measures the child's ability to fulfill their childhood roles (Feldman et al, 2000; Saigal et al, 2000; Sheridan et al, 2000; Schneider et al, 2001). Feldman et al, (2000) observed that children referred for rheumatologic care had a lower HRQL compared to the overall quality of life. This finding agree with Saigal et al, (2000) who reported that the HRQOL of children with disabilities was fairly higher when compared with that of their controls. Dijkers (1999) highlighted the difficulty of measuring quality of life due to diverse worldviews on the conceptualization of a 'good life' and what constitute health. These studies have confirmed the known concept that although two children may have the same functional limitations it cannot be assumed that they will experience the same quality of life (Schneider et al, 2001).

2.1.4 Impact of Cerebral Palsy on the Family

Mothers of children with cerebral palsy are usually the primary caregivers of their children, and the care of these children occurs mostly at home (Adams et al, 1999). In some instances the whole family becomes active participants in caring for the child. This role places great demand on time and energy of the family and primary caregivers and also requires more resources. Ordinary handling during activities of daily living (ADL) usually results in an increase in spasticity and discomfort, which necessitates the teaching

of therapeutic handling techniques to caregivers (Humphry, 1995; Butler and Durrah, 2001; Brenhaut et al, 2004).

According to Eisner (1993), caring for any child takes an inordinate amount of time, and the demand increases even more when the child is disabled. This is supported by Helitzer et al, (2002) in that over and above the time demand for looking after a child with a disability, mothers may feel overwhelmed with their daily care routine, find themselves isolated, lose their identity, and expect less from their careers. Smith et al, (1993) further stated that the reason why women are often more vulnerable is that they are often the primary caregivers of the child. Moreover, mothers of children with disabilities may give up other important roles such as hobbies, friends and studies (Crowe et al, 1997). The above evidence shows that primary caregivers are able to sacrifice every important aspect of their lives including education in order to look after their child with disabilities.

Adams et al, (1999) who conducted a study on maternal stress in caring for children with feeding disabilities reported that children with CP have feeding problems. Moreover, caregivers of these children reported that they spend more than one hour feeding their child at each meal. The study also emphasized that families of children with disabilities who have adequate social resources have less stress and greater family harmony. Children with feeding disabilities are often excluded from family interactions, thus, Adams et al, (1999) recommended that dieticians should encourage families to determine ways to facilitate inclusion of their child into family interactions.

Other studies show that caring for children with disabilities has negative implications on the health of caregivers, and they may present with emotional problems, depression, distress, low self-esteem and chronic sorrow (Ross and Mirowsky, 1989; Hanojosa, 1990; Brenhaut et al, 2004) or recurrent grief which is renewed at subsequent developmental stages and transitions of the child's life (Bruce et al, 1996; Helitzer et al, 2002).

Nelson (1999) and Shevell et al, (2003) state that caring for a child with CP results in considerable personal, familial and societal burden because this condition is a lifelong disability. This implies that the family with a child diagnosed with cerebral palsy will face many challenges over and above having to look after the child. Read (2000) in Leiter (2004) added that mothers provide care within the home and coordinate care with other providers outside.

Lin (2000) observed that families of children with disabilities face unique stressors and demands over time, because the child grows and their needs may change. Riana et al, (2004) brought forth evidence that suggests that there is a considerable variation in how caregivers adapt to these stressors and demands. Some families of children with CP may perceive their family situation as not very stressful, while others experience life as difficult and more negative (McCubbin and McCubbin, 1992). Rentinck et al (2006), report that if professionals are able to identify families at risk of adaptation problems, they might be able to provide services that are adjusted to the needs of the family.

Gallimore et al, (1989, 1993) and Weisner and Gallimore (1994), de-emphasized psychology when caring for a child with disabilities, and placed more emphasis on the ecocultural theory. This theory hypothesizes that the key adaptational problem of the family is the organization of the daily routine so that it is sustainable, meaningful, and congruent with the individual needs of family member. Gallimore et al, (1993) state that to cope with disability successfully, families must find ways to accommodate and adjust to the demands of daily life in the following domains: 1) family subsistence, 2) services, 3) home/ neighbourhood safety and convenience, 4) domestic workload, 5) child care tasks, 6) child peer groups, 7) marital roles, 8) instrumental or emotional support, 9) father/ spouse/ partner role, 10) parent information. This approach looks at all other aspects of the family and finds ways of enabling families to cope with having to look after a child with disabilities.

2.1.5 Impact of poverty on the family of the child with cerebral palsy

Studies have shown that poverty, and particularly chronic poverty, does influence caregiving. Poverty can be defined as inadequate financial resources to meet daily living needs (Huston, et al, 1994; Humphry, 1995). Other studies show that low income is associated with poor housing, overcrowding, nutritional problems, neighborhoods that fail to offer a safe environment for play and poor social support to compensate for family problems (Halpern, 1990; Kaplan-Sanoff et al, 1991; McLoyd and Wilson, 1991; Duncan, et al, 1994; Humphry, 1995).

Frye and Magasela (2005) of the National Labour and Economic Development Institute (NALEDI), emphasized that 'poverty is one of the most urgent social and economic factors that has to be addressed in South Africa'. The Copenhagen Declaration was cited, and this states that: Poverty has various manifestations, including lack of income and productive resources sufficient to ensure sustainable livelihood; hunger and malnutrition; limited or lack of access to education and other basic services; increased morbidity and mortality from illness; homelessness and inadequate housing; unsafe environments; and social discrimination and exclusion'. Further, that 'women bear a disproportionate burden of poverty, and children growing up in poverty are often permanently disadvantaged'. This is particularly true in the case of caregivers of children with disabilities, who live far from the hospital who care for children who are dependent on them for activities of daily living (Porterfield and McBride, 2007).

2.2 Family Centered Care

There is no cure for cerebral palsy and it is a chronic condition, thus the child will persistently have special needs which the family will need to meet (Rosenbaum, 2004). Cadman et al, (1991) observed that families face more challenges in raising a child with disabilities than they do any child without special needs. Rosenbaum (2004) noted that service providers may impose pressure on families that can create stress, anxiety and frustration. Further observed is that caregivers have to answer the same questions repeatedly over the years, or retell their child's story, or reveal personal details about family issues. This results in caregivers wondering whether "professionals actually communicate with each other, given what they experience as redundancy in providers'

activities in history-taking, assessments of child and family, and information gathering" (Rosenbaum 2004:23).

Stein and Jessop (1982) and Taylor (1982) state that service providers need to develop an approach that will help them understand the dynamics of parenting when a family is raising a child with special needs. Furthermore, that service providers need to shape service delivery in ways that will consider different families' perspectives, experiences and needs that are likely to be more similar than their children's diagnosis spectrum. Therefore providers can efficiently and effectively assist families and provide services of high quality.

Current literature has shown a growing trend within the health care system towards family-centered service (FCS). According to King, et al (2004), FCS is both a philosophy and an approach to service delivery that is considered to be the best practice in early intervention and paediatric rehabilitation. Carl Roger was the pioneer for family centered practice (King el al, 2004) and did extensive work with families of children with special needs then known as the "problem" child (Roger, 1939). In the mid 1960's the Association for the Care of Children Hospitals was founded with a quest to promote a more holistic approach to care for children who were hospitalized, and was more concerned with the psychosocial issues and family involvement in the treatment of children with special needs. Further literature on FCS has come from the fields of family support and early intervention, and more recently it is applied in the fields of paediatric rehabilitation (King et al, 1997; Hosler, 1997; King et al, 2004).

A definition for Family-centered Care (FCC) has been developed by health care professionals, and has helped service providers and families to better understand its ideology and concept (King et al, 2004).The definition that communicate the ethos of this study was developed by the CanChild Centre for Childhood Disability Research and is as follows:

> "Family-centered service is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. It recognizes that each family is unique; that the family is the constant in the child's life; and that they are the experts on the child's abilities and needs. The family works together with service providers to make informed decisions about the services and supports the child and family receive. In FCS, the strengths and needs of all family members are considered" (King et al, 2004:79).

The above definition delineates a fundamental framework that is principle for both research and service delivery. King et al, (2004) emphasized that FCS provide important guidelines for how health care professionals should approach the delivery of services and their interaction with families. The guidelines in the above definition outline three principles which are: 1) that parents know their children and want the best for them, 2) that families are unique and different, and 3) that optimal child functioning occurs within a supportive family and community context. This framework has evolved and developed to encompass specific behaviors of health care providers that impact service delivery

making it more accessible and acceptable to consumers and thus providing a good level of satisfaction.

The FCS principles conceptualize the practical framework that guide service delivery since they relate family needs to service provider behaviours. The first principle that "parents know their children best and want the best for them, stems from the idea that families should have the opportunity to decide on the level of their involvement in decision-making about their child's needs. This necessitates that they should have the ultimate responsibility for the care of their child, while for service providers the key behaviour is to facilitate collaboration and encourage the caregivers' decision-making at every decision point. Further, the principle includes the provision of information by service providers as a basis for caregivers to make informed decisions, assisting them to identify both their children's and their own needs, as well as their personal and family strengths (King et al, 2004; Rosenbaum, 2004).

The second principle states that "families are unique and different". The practical implications of this principle to service providers demand that each child and family be recognized and thus be addressed individually. This concept also implies that families will have different backgrounds; goals, views, and needs which the service providers will need to take into account when rendering services (Rosenbaum, 2004).

The third principles that says: "optimal child functioning occurs within a supportive and family and community context" implies that child development is influenced by the

immediate family's stresses and coping mechanism (Rosenbaum, 2004). This means that when the family is struggling with unmet needs, the child will be affected as a consequence.

This concept of unmet needs has not been extensively studied, and need further exploration especially in developing countries. Moreover, a family centered approach to service delivery is acclaimed to be best practice in early intervention services (Bailey et al, 1992; Baird and Peterson, 1997).

Literature shows that the family centered approach produced sufficient evidence that when practiced in the context of paediatric rehabilitation, results in greater parental satisfaction with services, better parental psychosocial well-being, and better psychological adjustment of children (King et al, 1996; King et al, 1998; Rosenbaum et al,1998; King et al, 1999; King et al, 2004).

2.3 The Process of Health Care Delivery

The term 'process of care' refers to the actions of health care providers and focuses on how they interact with clients rather than what specific techniques they perform. In brief it entails what is done and how it is done (King et al, 1996). Donabedien (1988) in King et al, (2004) emphasized the three important features to be considered when assessing the quality of services or care to be: structure, process, and outcome. Measurement of the caregiving process from the perspective of recipients contributes to a better understanding of how services are actually delivered and received.

The previous notion of service delivery was based on professionals assessing and prescribing treatment, whereas families were supposed to be compliant with treatment recommendations that were based on the provider's model of disease, disability and therapy (Stewart et al, 2000). Rosenbaum (2004) documented that the nature of the relationship between caregivers and service providers was hierarchical and unbalanced, implying that the caregiver and family perspective did not play a central role in defining the problem or its management.

Various authors reported stress, psychosocial outcomes, socioeconomic status and satisfaction with services as important parameters that should be determined, and these may influence how the process of care should be delivered (Brinker et al, 1994; Swaine et al, 1999; King et al, 2004). Jessop and Stein (1991) observed that psychosocial outcomes and mother's satisfaction with care were better after six months of attending a comprehensive paediatric home-care program than mothers receiving standard clinic-based care. Further, this study demonstrated that these effects were attenuated after a year for mothers in the standard based care program. This implies that if there is more contact between service providers and recipients a relationship of trust develops, thus leading to good collaboration.

Another study by Miller et al, (1992) reported an inverse relationship between caregivers' distress and provision of information about medical and educational matters and about available resources. Brinker et al, (1994) found that caregivers were more stressed if the

family was involved with many agencies, while frequency of attendance at a single comprehensive program addressed the needs of both the child and family and was inversely related to stress. King et al, (1996) emphasized that it is imperative to understand what parents experienced in the caregiving process and how these experiences affected their psychosocial outcomes. In another study by Rossi and Freeman (1985) a strong argument is posed urging that recipients of a service may be the only source of information about what was actually received, and that their perspectives give reference about the provision of care and the outcome of that care.

Within the context of FCS the process of health care delivery should constitute parental involvement in decision making, collaboration and partnership during treatment, mutual respect, and acceptance of the family's choices, support, individualized and flexible service delivery, information sharing, and empowerment (King et al, 2004). These components provide a framework that need to be adopted by service providers to enhance their relationship with caregivers in order to optimize service delivery.

2.4 Perceptions of Caregivers on Processes of Care

There is a paucity of literature to determine the perceptions on the processes of care/ service delivery for children with disabilities in South Africa. The South African government enacted a National Health Bill (NHB) in 2003 that has now become law. Promulgated in this bill is a framework noteworthy for users of the services (caregivers and their children) and service providers to assure quality in the process of healthcare delivery.

The NHB emphasizes that health care providers must ensure that caregivers understand the benefits and risks of the treatment being offered to them. Further, the service providers must provide the caregiver information in the language they understand and in a manner which takes into account their literacy level. The NHB also encourages the need to plan, co-ordinate and evaluate the rendering of services; which also include quality control and consulting with the communities and encouraging their participation in the planning, provision and evaluation of health services (NHB, 2003).

In 1999, Swaine and co-workers conducted a study comparing parental perceptions of care with those of the service providers of children hospitalized for head injury. The study revealed that parent's needs were met by service providers to varying degrees. The rating for the domain 'respectful and supportive' was 'to a great extent'. The ratings for 'provision of specific information' and 'provision of general information' were both observed 'to a fair extent'. Documented in this study is that service providers seemed to be successfully meeting caregivers' needs that are associated with 'enabling and partnership' and 'coordinated care' aspects of their services. Further, this study showed that the results of caregivers were closely matched by those of service providers (Swaine et al, 1999).

King et al, (1998) acknowledged that little is known about the extent to which children's rehabilitation services are delivered in a family centered manner. The study found a correlation in responses of both parents and service providers with regard to interpersonal

aspects of service delivery, but that the provision of information was relatively weak. This study supports the observations of Swaine et al, (1999). Provision of information is very important, and may affect the perception of users about the service that was delivered to them. These findings reinforce the need to constantly evaluate services and provide quality services as stipulated by the SA government.

Anderson and Hinojosa (1984) and Bailey (1987) emphasized the need for service providers and caregivers to establish a collaborative relationship which takes into account the importance of identifying and adjusting services to different values and beliefs of individual caregivers. Humphry (1995) supports these findings by emphasizing that professionals have an obligation to examine how to enhance communication with caregivers. This author further suggests that demographic characteristics may contribute to problems in establishing a working, collaborative relationship with some poor families.

There are good initiatives from the South African health sector to improve access to rehabilitation and social services to caregivers and children with disabilities. The South African Human Rights Commission (SAHRC) emphasized that there is an "enormous task" that remains post-apartheid " in transforming the institutions, attitudes, practices, buildings, facilities and environments that continue to deny people with disabilities their rights to dignity, equality and freedom" (SAHRC, 2002). Philpott (2006) highlighted the need to monitor health care services and ensure caregiver involvement in service delivery. Moreover, she emphasized the need to improve access and ensure that services are appropriate for children with disabilities and their families.

Saloojee et al, (2006) reported that there is a formidable gap between needs of children with disabilities and services that are available to them in South Africa, they found that only a quarter of children in need of rehabilitation therapy receive it. Couper (2002) in another study in a rural part of South Africa observed that only a third of children requiring rehabilitation were known to the rehabilitation services. These studies show that there are definitely unmet needs in health care provision in South Africa. There may be lack of access to services or there may be other factors that influence under-utilization of services. The measure of process of care domains explores various components of service provision that may impact on access and utilization of these services.

2.5 Satisfaction with provision of Health Care Services

There is a paucity of literature on satisfaction of caregivers on health care service delivery, let alone on studies of children with disabilities. Rahi et al, (2005), observed that caregivers were satisfied with the services they had received. In this study there were important variation in their views based on the characteristics of the child, ethnicity and social class. This observation is supported by Swaine et al, (1999); Saxena et al, (2002); and Cooper et al, (1998), who showed that, despite sociocultural factors and ethnicity, parents tends to show overall satisfaction with services, and that the greatest common need is that of information transmission.

A study by Myburgh et al, (2005) focused on patient satisfaction with health care provision in South Africa by investigating the influences of race and socioeconomic

status. The results revealed that both are significant predictors of levels of satisfaction with the services of the health care provider. Research focusing on satisfaction with provision of health care service in South Africa, and particularly on the perceptions with regard to service delivery and quality of care is limited. The implications of socioeconomic status on satisfaction or perceptions about health care provision are also not well researched.

2.6 Assessment tools

2.6.1 The Gross Motor Function Classification System (GMFCS)

Palisano et al, (1997) developed a gross motor function classification system (GMFCS), which is an age-related, five level system for assessing gross motor function in children with disabilities (see Appendix IV). Morris et al, (2006) stated that it was developed in response to the need to have a standardized system for describing and classifying the severity of movement disability among children with cerebral palsy. Further, this tool describes the functional ability of children in one to five ordinal levels as summarized in table 2.3 below. The abilities of children are described across four age groups: less than two years, two to four years, four to six years, and six to 12 years, with an adolescent age group currently under development.

Table 2.3: Overview of Gross Motor Functional Classification System (Palisano et al. 1997)

Level	***Ability***
Level I	Walks without assistance
Level II	Walks without assistive devices, limitations outdoors and in the community
Level III	Walks with assistive devices, limitations outdoors and in the community, requiring wheelchair use in these settings
Level IV	Self-mobility in wheelchair with limitations, transported or uses power mobility in a community
Level V	Very limited self-mobility, even with assistive technology

Papavasiliou et al, (2007:79) and Carnahan et al, (2007) supported the findings of Liptak and Accardo (2004) that the GMFCS offers functional disease assessment that is very important in both prognosis as well as in identifications for therapy. Gorter et al, (2004) emphasized that the traditional description of CP type by limb distribution does not indicate severity level and very often does not offer prognostic utility. According to Beckung and Hagberg (2000) the application of this tool is not time-consuming and moreover, it can be evaluated retrospectively. The GMFCS has been tested for validity and reliability (Palisano et al, 1997; Wood and Rosenbaum, 2000; Chitra and Nandini, 2005; Morris et al, 2006).

Liptak et al, (2001) in a study to determine the health status of children with moderate to severe CP, observed that children at level V of GMFCS were the most severely affected, had nutritional deficiency, missed more days of usual activities, had increased use of resources, had low quality of life and were more likely to have respiratory problems. This

implies that the more affected the child, the more demands will be placed on the caregiver when looking after this child.

According to Schneider et al, (2001), the clinical assessment of children needs to be closely related to function rather than focus on impairment and the ability to attain motor milestones. In the early nineties other studies focused on measuring function and helping the child to attain sequential milestones of development (Nelson, 1995; Haley et al, 1991). Clinicians realized that around this time that they should focus on the ability of the child to complete activities of daily living at home and in the community (Haley et al, 1991; Haley 1994; McAuliffe et al, 1998). The advantage of this shift is that children with milder impairments could equally benefit from rehabilitation services (Saigal et al, 2000; Schneider et al, 2001).

The researcher used the neurodevelopmental therapy (NDT) approach to determine the functional ability of each child and to classify them using the GMFCS. The NDT approach was developed as early as the 1940's by Bertha Bobath who was a physiotherapist (physical therapist) and Karel Bobath who was a neuropsychiatrist (Barry, 2001). This approach according to Buttler and Darrah (2001) focuses on the sensorimotor components of muscle tone, reflexes and abnormal movement patterns, postural control, sensation, perception, and memory components thought to be most affected following brain injury. The NDT approach uses handling techniques that control various sensory stimuli to inhibit spasticity, abnormal reflexes, and abnormal movement patterns, and is also used to facilitate normal muscle tone, equilibrium responses, and

movement patterns (Barry, 2001; Buttler and Darrah, 2001). This approach uses the normal developmental sequence of movement as a framework for treatment.

The NDT approach according to Buttler and Darrah (2001) has for half a century 'heavily' influenced the clinical practice of physiotherapists, occupational therapists and speech therapists treating children with cerebral palsy. The researcher is NDT trained and has used this approach for more than 5 year in the treatment of children with CP and for training university students studying physiotherapy. The NDT approach is particularly useful for determining the child's functional ability and how both the environmental and personal factors influence their movement patterns and participation in various daily activities.

2.6.2 The Measure of Processes of Care (MPOC)

The original instrument was developed by King et al. (1996), it describes aspects that parents and health professionals consider to be important in service delivery was used. MPOC is a well validated and reliable self-report measure that has shown strong relationship between people's scores on the measure of processes of care, their overall satisfaction with services and their degree of stress in dealing with their child's service provider.

The original MPOC questionnaire contains 56 items which have five domains that are analytically determined. The MPOC tool captures both the qualitative and quantitative

nature of the caregivers' experiences with service delivery rather than a mere frequency count of their experience with the process of care. The domains are:

- Enabling and Partnership: reflecting on caregivers' involvement in the health-care process; particularly on aspects of decision making.
- Providing General Information: focuses on activities that meet the caregivers' general information needs.
- Providing Specific Information about the Child: reflecting on the child's condition, accessibility, the environment surrounding the child, the physical and personal aspects of the child.
- Coordinated and Comprehensive Care for the Child and Family: tapping on care that is holistic, continuous, and consistent over a period of time; and
- Respectful and Supportive Care: measures aspects of care in which parents are treated with respect as individuals, equals and experts when they interact with service providers.

The reliability of the MPOC Swedish version also showed good reliability as described by Bjerre et al, (2004). The findings of this study are shown on table 2.4 below.

Table 2.4 Reliability of the Measure of Processes of Care in the Swedish context

Scale	**Number of questions**	**Chronbach's Alpha**
Enabling and Partnership	16	0.9573
Providing General Information	9	0.9000
Providing Specific Information	5	0.8009
Co-ordinated and Comprehensive Care	17	0.9328
Respectful and Supportive Care	9	0.9181

[Source: Bjerre et al, 2004:126]

The Swedish MPOC version has good reliability in that non of the factors scored less than 0.80 using Chronbach's alpha. The MPOC in its original form is thoroughly evaluated not only in the United States of America but in other countries such as Sweden and Nederland.

Other versions such as the shorter version with 20 items (MPOC-20) developed by King et al, (2004) and the version for service providers (MPOC-SP) have been developed and discriminatively tested for validity and reliability. These instruments have demonstrated good internal consistency, test-retest reliability and validity when they were tested in other studies. The MPOC-20 by King et al, (2004) was directly translated to develop the MPOC-20 Dutch version (Siebes et al, 2007).

The internal consistency analyses had Chronbach's alphas ranging from 0.75 t0 0.87, and the test-retest analyses which measured the intraclass correlation coefficients (ICCs) ranged from 0.78 to 0.91. This confirmed that the MPOC-20 Dutch tool is reliable. The construct validity of this tool was confirmed by significant intercorrelations ranging from r=0.41 to r=0.84 as shown by Seibes et al, (2007).

6.2.3 The Measure of Processes of Care-South Africa (MPOC-SA) version

This tool was developed by Gillian Saloojee in 2005. She used four focus groups comprising of 25 therapists and two focus groups containing nine parents. The groups were arranged such that there would be an average of five people per focus group. The groups discussed the suitability of the MPOC-SA version measurement tool and

suggested how it should be adapted for use in South Africa. The following changes were made:

1) The language was simplified but made more specific with regard to context. They added many examples to make ensure that the questions were clear and unambiguous.

2) Questions requiring written information were removed since caregivers do not receive written reports, assessments or treatment plans.

3) Two new items were added: "… explain what they want you to do between visits" and "… give you suggestions and ideas of things to do which make it easier to handle and look after your child at home". These items were found to be relevant to the South African context because children receive therapy treatments monthly, and throughout this time the caregivers are expected to make use of the home program.

4) Two other items were added to the MPOC-SA from the original MPOC-56 (item 16 and 20) which were '… make sure you have a chance during visits to the center to say what is important to you" and "… follow up at the next appointment on any concerns you discussed at the previous visit". The therapists felt that these aspects of service were not captured on the MPOC.

The study by Saloojee (2007) had very low chronbach's alphas which are shown in table 2.5 below. The ICCs for test-retest were also very low. The conclusion that was drawn from this study was that there were eight items with the possibility for use in the South African context.

Table 2.5 Chronbach's alphas of the MPOC-SA version.

MPOC domain	**Chronbach's alpha**
Enabling and partnership	0.30
Providing general information	0.66
Providing specific information	0.24
Co-ordinated and comprehensive care	0.42
Respective and supportive care	0.60

The above table suggests that there may be a number of factors that contribute to the poor values since the MPOC is a rigorously designed tool that have been used extensively in developed and developing countries. This may suggest the need to review the contents of the tool and contextualize to our population in South Africa. The researcher had already prepared a research protocol to use the MPOC short-version, when he met Gillian Saloojee who had just developed the MPOC-SA version. Thus the need to explore this tool in a single setting and determine the perception of caregivers on the services they received.

The CP clinic at Dr George Mukhari hospital operates on Monday and Thursday of every week and the treatment sessions start at 9 o'clock until 12 o'clock. Most often there are three therapists i.e. a physiotherapist, occupational therapist and a speech therapist who work together in a small room. Sometimes there is one physiotherapist working alone. Caregivers of children with CP receive appointments for subsequent sessions and some are referred by doctors working in the hospital and community clinics to the healthcare facilities. The physiotherapy department uses a rotation system for therapists to work with caregivers and children with CP and there is one therapist who is NDT trained who oversees the CP clinic but is not designated or dedicated to working with these families in

the CP clinic. The length of each treatment session ranges from 20 minutes to about an hour depending on whether the patient is seen for the first time. There is a high volume of patients and sometimes the researcher has observed treatments that are as sometimes much shorter than 20 minutes.

2.7 Conclusion

There are no studies that focus on family-centered care in context of developing countries where there are challenges ranging from cultural issues and human resources, to socio-economic status. There are no studies that evaluated the processes of care in hospitals or any other specialized units like the cerebral palsy clinic. There is a need to evaluate service delivery and the processes by which the services are delivered to various users. The services at the CP clinic of Dr George Mukhari have not been evaluated and there is a need to determine the perception of users of the services in order to strengthen stronger aspects of care beneficial to them and to determine aspects were services need to improve. This study hopes to determine aspects of service delivery that caregivers perceive as well delivered and aspects that need more attention to ensure good quality of care.

CHAPTER 3

RESEARCH METHODOLOGY

This chapter discusses the methodology used in this study. The discussion covers the study design, the sample and sampling procedure, the research instruments, data collection procedure, pilot study, data analysis and the ethical considerations.

3.1 Study Design

A correlation study design using a questionnaire (MPOC-SA version) for caregivers of children with cerebral palsy. According to Bless and Higson-Smith (1995: 46), correlation research is conducted to determine the relationship between variables, and allows for an estimation of the type and strength of the non-causal relationship. This study design is not focused on the cause-effect relationship between variables but on the importance of the relationship. It is quantitative in nature.

3.2. Sample Size

The study population consisted of a convenient sample of sixty-seven (67) caregivers of children with Cerebral Palsy attending physiotherapy, occupational therapy and/ speech therapy at Dr. George Mukhari Hospital. Through the help of the statistician the nQuery Advisor Release 5.0 software was used to determine the sample size. The sample power was set at 80%.

3.2.1 Inclusion criteria:

- Caregivers who have been attending rehabilitation with their children for 3 months or more.
- All participants must have attended the rehabilitation services at least three times and must be responsible for looking after the child regularly.

3.2.2 Exclusion criteria:

- Caregivers who have not been to the rehabilitation facility for a minimum of three months will be excluded from the study.

3.3 The Research Instrument

The instruments used for this study was a questionnaire with the following sections:

1) Adapted demographic questionnaire (Saloojee, 2007) containing the interview details, child characteristics, caregiver's characteristics, and socio-economic indicators (see appendix II). The translations were done by professional translators.
2) The Gross Motor Function Classification System (see appendix IV); and
3) The "Measure of Processes of Care – South African version" (MPOC-SA) questionnaire, adapted by Saloojee (2007) was used. The MPOC-SA version was developed from the MPOC original version, and was tested for reliability and validity.

3.4 DATA COLLECTION PROCEDURES

3.4.1 Pilot study

Whilst developing the MPOC-SA version, Gillian Saloojee (2007) had questionnaires translated by professional translators into the following languages: IsiZulu, seSotho, Sepedi, Setswana, and IsiXhosa. She then piloted the translated questionnaires for internal validity and reliability.

Eight caregivers participated in the pilot study. A quiet room used for genetic counseling was booked for conducting interviews; this room is situated next to the CP clinic within the same building. The pilot study was done to determine the time it takes to complete the questionnaire, the appropriateness of languages that were translated by professional translators, and whether the questionnaire was understood and easy to complete. The other reason for doing the study was to familiarize the researcher with the questionnaire and prepare for the actual research project. The structured interviews were conducted with caregivers who gave consent to participate in the study. The structured interviews were timed and conducted in two days for the eight participants.

3.4.2 The results of the pilot study

The languages used for the structured interviews were seSotho and Setswana, and the translated questionnaires were easy to use. The average time it took to complete the questionnaires was about 35 minutes. The statistician was consulted to check for internal consistency of the MPOC and based this he advised that there was no need to make changes on the questionnaire since the sample was very small. The test-retest could not

be done because only three participants were able to come back to the CP clinic within two weeks.

3.5 DATA CAPTURING AND ANALYSIS

The data collected from the questionnaires was both nominal and ordinal in nature. Data was numerically captured using Microsoft excel program. It was then imported to the Stata Statistical software for further analysis with the help of the statistician. Data analysis was done in two stages: During the first, the descriptive statistics approach was used to determine the frequencies, means, modes and standard deviations. The second stage used inferential statistics from the Stata statistical software to determine the Chronbach's alpha for the inter-item reliability of the MPOC-SA domains. The Pearson product moment correlation coefficient was used to determine the correlation between the MPOC-SA domains to Satisfaction with the services rendered to caregivers. A one-way ANOVA test was done to statistically determine associations between the income category and the responses of the caregivers on the MPOC-SA domains.

Data is presented using tables, histographs, and bar charts.

3.6 ETHICAL CONSIDERATIONS

A letter of information as well as a consent form was given to participants and clearly explained the objectives of the study. See appendix.

Ethical clearance was obtained from the Committee for Research on Human Subjects (Medical) at the University of the Witwatersrand. (Protocol number is M 40401).

Participants were not required to give their names or the name of the child, only file numbers were recorded on the questionnaires for administrative use.

Participants were allowed to withdraw from the study at anytime, without giving reasons for doing so. They could begin filling in a questionnaire and if they could not complete it in time, they were allowed to withdraw.

The participants were informed that their participation was voluntary, and that their decision to participate or not to participate in the study would not affect the treatment they expect to receive for their child.

3.7 Procedure of Data Collection

A non-probability sample of convenience was used by the researcher to recruit participants to volunteer for this study.

Informed consent was obtained from each participant before they could participate in the study, during this process; ethical considerations were observed. A research assistant was trained to assist with the collection of data. The assistant read the information leaflet to the participants together with the introductory part of the MPOC-SA version. Participants

who gave consent to volunteer were given the leaflet for their perusal and further inquiries.

The researcher took the appointment card of the participant into the CP clinic so that they would maintain their position on the queue for the treatment of the child by the therapists. The assistant ushered the participants to the genetic counseling room that was arranged for the structured interview. The volunteers were asked for language preference and the appropriate questionnaires were used for the structured interview (see appendices II and III).

During the time the participants were conducting the structured interview, the researcher would assess the child and complete the GMFCS score for each child whose caregiver participated in the study. The researcher is very familiar with the GMFCS tool and uses it in teaching physiotherapy students. The researcher personally assessed the milestones and neurological development of each child and confirmed the clinical diagnosis. The movements and functional abilities of the child were documented as succinctly as possible following the GMFCS guideline (appendix IV). Then the scores for all the 67 children who participated in the study were written by the researcher on the completed interview questionnaire.

Participants who had completed the structured interview were ushered by the research assistant to the CP clinic for the treatment of the child. Some participants would take part

in the structured interview immediately after their child was treated by the therapists in the CP clinic.

Data collection was completed in 16 weeks, and the coded questionnaires were captured on Microsoft excel.

CHAPTER 4

RESULTS

4.1. Introduction

This chapter presents the descriptive analysis of data which is divided into two parts, first the demographic data of participants, and second, the Measure of Process of Care (MPOC-SA).

4.2. The Sample

Sixty-nine participants volunteered for the study. Two of these where excluded due to not having sufficient information about the child and the rehabilitation service offered to the family and the child. Thus the final study sample was a non-probability sample of convenience, consisting of sixty-seven participants.

Table 4.1 Characteristics of Participants of children with Cerebral palsy and their Households (N=67)

Characteristic	n	%
Participants in the Study		
Mother of the child	57	85.07
Caregiver	10	14.93
Age		
18 – 20	7	10.45
21 – 30	24	35.82
31 – 40	21	31.34
41 – 50	8	11.94
51 – 60	5	7.46
61 – 70	1	1.49
No response	1	1.49
Marital status of the Primary Caregiver		
Single	36	53.73
Married	28	41.79
Divorced	1	1.49
Widow	2	2.99
Educational Status of Caregiver (highest standard passed)		
Never	1	1.49
Grade 3 – 7	12	17.91
Grade 8 – 10	18	26.87
Grade 11	13	19.40
Matric	14	20.90
Tertiary	9	13.43
Person assisting mother in caring for the child		
Grandmother	65	97.01
Sister	59	88.06
Father	0	0.00
Grandfather	1	1.49
Employment status of participants		
Full time	4	5.98
Part time	5	7.46
Piece jobs	9	13.43
Unemployed	49	73.10

Table 4.1. shows that the participants in the study comprised of 57 (85%) Mothers and 10 (15%) Caregivers who usually bring children in for their therapy appointments. Further shown above is that more than 45% of caregivers are 30 years of age and younger, about 9% are between age 51 and 70 years. Slightly more than half of the participants (53.73%) are single. The marital status of participants reflects that out of the 41.79% of caregivers married, only 34.33% are married to the father of the child.

The findings of the study showed that 99% (66) of the participants have been exposed to formal education, and only 1 (1%) participant has not been to school at all.

Illustrated in table 4.1 is that 9 (13.43%) of the participants have had tertiary education, 14 (20.90%) of participants have matriculated, and 13 (19.40%) have passed grade 11. Furthermore 11.94% of participants' partners had tertiary education, 44.78% had matric, and the remaining 14.93% had between grade 3 and 11 education. There was only one (1.49%) who never went to school.

The employment status of participants shows that 49 (73.1%) are unemployed, and only 4 (6%) are employed full time. Five (7.5%) are employed part time and another 9 (13.4%) do piece jobs. Reflected by participants' responses is that most participants are not able to be employed full time whilst looking after a child with CP, and this necessitating a need for financial subsistence.

4.3. Source of Income for the Family

The participants receive a supplement income from the government, and in some families there are no bread winners except the child receiving a grant.

Table 4.2 Total Income of household per average month

Income Category	Responses n (%)	Income range
Category 1	23 (34.3%)	Less than R500
Category 2	24 (35.8%)	R501 – R3000
Category 3	20 (29.9%)	More than R3000

The table above shows the total income of household of the participants per average month which include wages, grants, pensions and any other supplementary income. The responses from participants show that 23 (34.3%) receive less than R 500, and 24 (35.8%) receive between R 501 to R 3000, whilst the other 20 (29.9%) receive more than R 3000.

4.4 Housing Infrastructure

This is another indicator of the socio-economic status of the participants (Frye and Magasela, 2005). Most participants are unemployed and have to look after a child with disability.

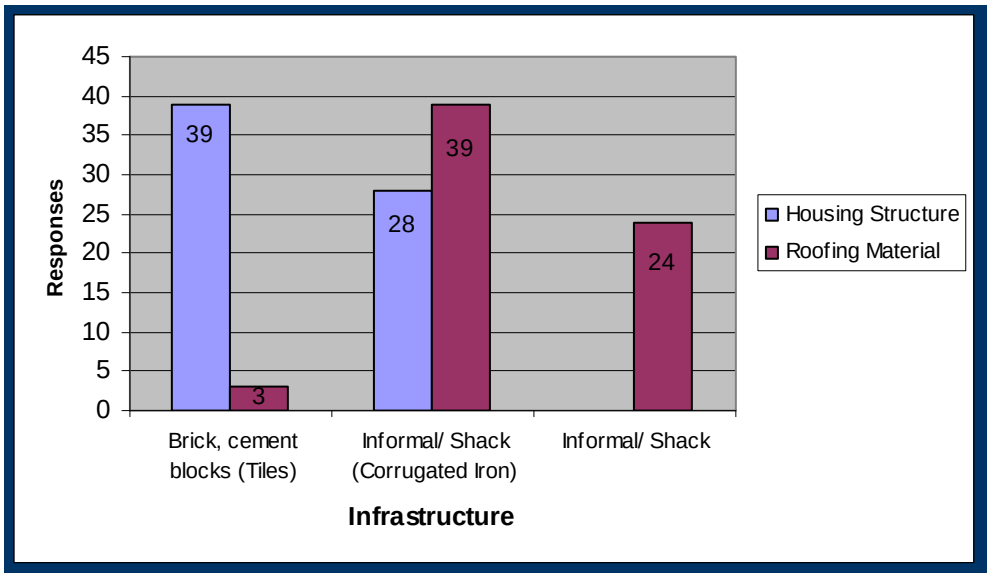


Figure 4.1 Housing Infrastructure

In the above figure 4.1, more than half of the participants 39 (58.2%) live in brick houses, whilst the remaining 28 (41.8%) live in shacks or informal settlements. The roofing material also shows that only 3 (4.5%) are tiled, and the rest are roofed with corrugated iron.

4.5 Transportation

The table below shows the mode and cost of transportation reported by the participants in this study.

Table 4.3 Transportation to Hospital per visit

Characteristic	n	%
Transport cost for single trip per visit*		
Less than R 10	18	26.87
R10 – R25	35	52.24
R 26 – R 50	11	16.42
R 51 – 100	2	2.99
More than R100	1	1.49
Time traveling to Hospital*		
30 minutes or less	25	37.31
31 to 60 minutes	24	35.82
Between 1 hour – 2 hours	13	19.40
More than 2 hours	5	7.46
Mode of Transport*		
Taxi	65	97.01
Bus or foot or private car	0	0.00
Train	2	2.99
Number of Taxis per visit (one-way)**		
1 Taxi	17	26.15
2 Taxis	45	69.23
3 Taxis	1	1.54
4 Taxis	2	3.08

*n = 67 and **n=65, where n represents the number of responses

The above table 4.3 shows that almost 79.11% of participants spend not more than twenty-five rand for a single trip to the hospital. Most of the participants (73.13%) travel for an hour or less, 19.40% travel for less than two hours and 7.46% spend more than two hours travelling to the hospital. This implies that most participants travel for up to two hours a day when taking the child to the CP clinic for their rehabilitation. More than 70% of participants use 2 taxis or more to get to the hospital.

There was no statistically significant relationship for the cost and the time it takes to access the rehabilitation services, when using the Fisher's exact test the p-value was 0.981. When analyzing the duration of attendance of therapy, the mode for attendance of

rehabilitation services was 2 to 4 years, and on average the children in this study had attended therapy for 18 months. Only 8.95% of participants (n = 6) had attended therapy for more than 5 years. There was also no statistically significant relationship for the duration the child has attended the rehabilitation service and the cost of transport to the health facilities, the p-value from the Fisher's exact test was 0.943. This could be due to the fact that the majority of caregivers (69.23%) used two taxis to access the health care facilities, and that they reported that it did not influence their attendance of the rehabilitation services. The other important factor that could have contributed to this is that they attend rehabilitation services once a month.

4.6 Child Characteristics

The results in table 4.4 show the child characteristics and impairment profile of the children brought to Dr. George Mukhari hospital cerebral palsy clinic. Shown in this table are: the mean age, the Gross Motor Function Classification System score, the diagnosis and the associated neurological findings, which are epilepsy and communication abilities of these children.

Table 4.4 Child Characteristics and Impairment

		Responses n (%)
*Mean Age **(SD):**		***3 years, 4 months (± 3.11)**
Gender: **Male:**		**45 (67.16%)**
Female:		**22 (32.84%)**
Gross Motor Function Classification System: (GMFCS)		
Level I:		**5 (7.46%)**
Level II:		**12 (17.91%)**
Level III:		**12 (17.91%)**
Level IV:		**13 (19.40%)**
Level V:		**25 (37.31%)**
Classification of Cerebral Palsy by quality of tone:		
Spastic Quadruplegia:		**25 (37.31%)**
Spastic Hemiplegia:		**16 (23.88%)**
Spastic Diplegia:		**4 (5.97%)**
Mixed CP:		**3 (4.48%)**
Athetosis (Pure & Choreo):		**14 (20.90%)**
Hypotonic CP:		**2 (2.98%)**
Associated Findings		
Hydrocephalus:		**2 (2.98%)**
Microcephalus:		**1 (1.49%)**
Epilepsy:	**Children with epilepsy**	**29 (43.28%)**
	Currently on medication:	**28 (41.79%)**
	Previously on medication:	**1 (1.49%)**
	Non epileptic:	**38 (56.72%)**
Communication:	**Speech**	**25 (37.31%)**
	Gestures:	**23 (34.33%)**
	Crying/ Sounds:	**19 (28.36%)**

* The mean age is the only variable not represented in terms of percentages.

The table above shows that the mean age of children attending rehabilitation services was 3 years and 4 months. The majority of these children were males (67.16%). Children who were severely affected and classified on the GMFCS at level IV and V were 38 (56.71%). Most of the children were diagnosed with spastic quadriplegia 25 (37.31%) followed by hemiplegia and athetosis, 16 (23.88%) and 14 (20.90%) respectively. More than 40% of children in this study had epilepsy and received medication. Communication of these children was poor with only 25 (37.31%) speaking, and the rest of the children were

using gestures or crying/making sounds. Caregivers reported that people did not understand their children when communicating.

4.7 Rehabilitation Services Received by the Child

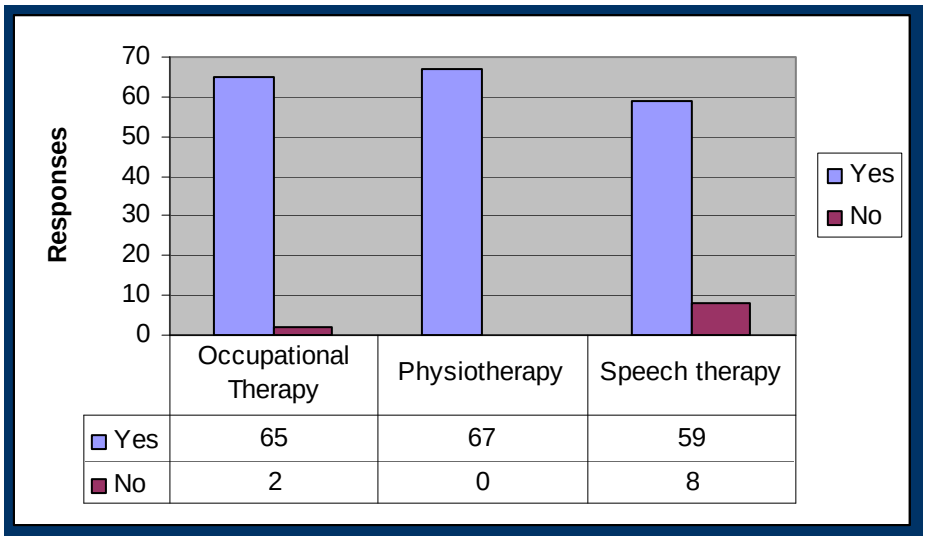


Figure 4.2 Rehabilitation Services received by the child

The figure 4.2 shows that 100% of participants receive physiotherapy, 97.01% receive occupational therapy and 88.06% receive speech therapy treatment at the Dr. George Mukhari hospital, CP clinic. Children receiving physiotherapy are usually treated by other members of the multidisciplinary team providing rehabilitation services. The physiotherapists, occupational therapists and the speech and language pathology therapists share the same room when treating these children.

4. 8 The MPOC-SA Scores for Caregivers of Children with Cerebral Palsy

The MPOC instrument (measure of processes of care) was used for caregivers to determine their perception of service delivery at the CP clinic. Table 4.6 shows the responses for each individual question where the mean and standard deviation (SD)

represents the responses of the caregivers (n = 67). Furthermore, the table shows the range of responses for the caregivers.

Table 4.5 Mean MPOC-SA scores and response range for caregivers

Question*	Mean n = 67	Standard Deviation	Range of responses
1	5.25	±0.79	1.00 – 6.00
2	5.39	±0.78	2.00 – 6.00
3	5.45	±0.84	2.00 – 6.00
4	4.72	±1.03	2.00 – 6.00
5	3.00	±1.65	1.00 – 6.00
6	2.37	±1.53	0.00 – 6.00
7	2.15	±1.65	1.00 – 6.00
8	5.25	±0.93	2.00 – 7.00
9	5.31	±0.70	3.00 – 6.00
10	4.94	±1.25	1.00 – 6.00
11	4.87	±0.90	1.00 – 6.00
12	5.34	±0.91	1.00 – 6.00
13	1.16	±0.59	1.00 – 5.00
14	4.12	±1.93	1.00 – 6.00
15	3.21	±1.35	1.00 – 6.00
16	2.88	±1.58	0.00 – 6.00
17	1.33	±0.94	1.00 – 6.00
18	2.84	±1.23	1.00 – 7.00
19	2.33	±1.16	1.00 – 6.00
20	4.69	±1.35	1.00 – 6.00
21	4.31	±1.18	1.00 – 6.00
22	5.75	±0.68	2.00 – 6.00
23	5.15	±1.08	1.00 – 6.00
24	5.51	±0.91	1.00 – 6.00

For questions please refer to appendix, Mean & (SD) refer to responses of Caregivers.
Meaning of Scores: 1= Not at all, 2 = to a very small extent, 3 = to a small extent, 4 = to a moderate extent, 5 = to a fairly great extent, 6 = to a great extent, and 7 = to a very great extent

The findings on table 4.5 above shows that the lowest scores for caregivers were on question 13 (service providers explain what they want you to do between visits) and 17 (service providers provide opportunities for the whole family to obtain information) presented as 1.16 (±0.59) and 1.33 (±0.94) respectively. These scores imply that the caregivers had a poor experience of being explained to what they should do between visits. This is done by service providers giving specific advice and treatment ideas that

should be done with the child at home. The other aspect that was poor was that the families were not given opportunities to obtain information by coming with the caregiver to therapy session or attending open days.

Nine items from the MPOC-SA were rated with high scores of more than five (fairly great extent) were as follows:

Respectful and Supportive Care: 1, 3 and 8;

Providing Specific Information: 2 and 12;

Enabling and Partnership: 9 and 22

Satisfaction with services received: 23 and 24.

The process of care for these items was observed to a fairly great extent and taking the standard deviation into account, in some cases the process of service provision occurred to a great, and closer to a very great extent for item 23 (5.07 to 6.43).

Six items were rated with scores of more than 4 (behavior occurred to a moderate extent): 10, 11, 4, 20, 21, and 14. Item number 10 with a score of 4.94 (±1.25), ranges from 3.69 (to a small extent) to 6.19 (to a great extent). The standard deviation shows how the caregivers differed in their perception of the observed behavior.

The lowest scores were observed on two items which were item 13 with a score of 1.16 (±0.59) and item 17 with a score of 1.33 (±0.94). The ranges of scores are 0.62 to 1.70

and 0.32 to 2.27 respectively. This implies that some caregivers perceived that the process of health care delivery had not occurred at all.

4.9 Five (5) domains of the MPOC-SA tool:

The five analytically determined domains that were observed are:

1) Enabling and Partnership
2) Providing General Information
3) Providing Specific Information about the Child
4) Coordinated and Comprehensive Care for the Child and Family, and
5) Respectful and Supportive Care.

Table 4.6 below shows the summary of the five MPOC-SA domains as determined during analysis of the findings. These MPOC-SA domains were unadjusted and represented the perception of caregivers on each.

Table 4.6 MPOC-SA Domains Results showing Mean and Standard Deviation (n = 67):

Domain	Mean	Standard Dev.	Range (min –max)
Enabling and Partnership	3.26	± 1.10	1.33 – 6.00
Providing General Information	2.34	± 0.95	1.25 – 5.75
Providing Specific Information	5.09	± 0.82	1.67 – 6.00
Coordinated and Comprehensive Care	4.25	± 0.90	1.50 – 6.00
Respectful and Supportive Care	5.34	± 0.61	2.67 – 6.33

Meaning of Scores: 1= Not at all, 2 = to a very small extent, 3 = to a small extent, 4 = to a moderate extent, 5 = to a fairly great extent, 6 = to a great extent, and 7 = to a very great extent

The table above shows the extent to which caregivers experienced the service delivery. The responses show the strength or weakness of each domain according to the way caregivers received the service. The above results however, are not rated in order of importance, but are reflection of how well each domain is experienced during service delivery. Caregivers perceived the Respectful and Supportive Care aspect of service delivery to be executed at the clinic to a fairly great extent, with the mean score of 5.34 (±0.61) followed by Providing Specific Information with a mean score of 5.09 (±0.82). "Respectful and Supportive Care" together with "Providing Specific Information" are the two areas of strength in service delivery at the CP clinic. "Coordinated and Comprehensive Care" was rated 4.25 (±0.90) which means this aspect of care was occurring to moderate extent. The weakest areas observed by caregivers were "Providing General Information" and "Enabling and Partnership" which had mean scores of 2.34

(±0.95) and 3.26 (±1.10) respectively. This implies that these aspects of service delivery were elicited to a very small extent and to a small extent. These are the two domains that need to be improved.

4.10 The process of care as perceived by caregivers

This section provides the analysis of caregivers perceived the process of care delivered by service providers. The tables below, shows how often the process of care was perceived as occurring "sometimes" or less, with the score of 1 to 4 (table 4.7), these are aspects that management may change to meet the needs of users of the service. Table 4.8 reports observations of more than two thirds of caregivers who report the process of care as occurring "more than sometimes", with a score of 5 to 7. The results also explore the areas that are weak and those that are strong in the service delivered by the service providers.

Table 4.7 MPOC Items on which at least one-third of caregivers indicated the process of care occurred "Sometimes or Less" (n = 67)

To what extent do the people who work with your child …	Scale Name	% Responding "Sometimes" or Less*	% Responding More than "Sometimes"**
Look at the needs of your "whole" child (e.g. mental, emotional and social needs) instead of just the physical needs? Do they help with equipment, making toys, etc ?	Coordinated & Comprehensive Care	40.30	59.70
make sure that at least one member of the team is someone who works with you and your family over a long period of time?	Coordinated & Comprehensive Care	81.82	18.18
fully explain treatment choices to you (e.g., operations or plasters (cement) to make the muscles longer; gastrostomy?) i.e do they fully explain WHY they want to do certain things like operations or special tests to the child	Providing Specific Information	85.08	13.43
Give you the opportunity to make decisions about treatment (rather than just tell you "this is what we will be doing to your child)?	Enabling & Partnership	85.07	14.93
explain and tell you about the results from assessments (e.g., hearing tests, brain scans, X-rays, videofluoroscopy?)	Providing Specific Information	40.30	59.70
Give you information about the types of services offered at the hospital or clinic or in your community (e.g., referral to the dietician; day care centres in your area,)?	Providing General Information	77.61	22.39
have information available about your child's disability (e.g., the causes, how it progresses, the future)? e.g. like a pamphlet, or posters on the walls	Providing Specific Information	80.60	17.91
provide opportunities for the whole family to obtain information (e.g., open days, doing home visits, inviting the rest of the family to come with you to therapy)?	Providing General Information	98.51	1.49
have information (e.g. about day care centres, care dependency grants, how to find a school; or Things to do with your child at home) available to you in various forms, such as pictures, booklets, video, pamphlets, etc	Providing General Information	92.54	7.46

provide advice on how to get information (e.g. about finding a school or getting a grant) or how to contact other parents (e.g., parent groups such as DICAG, or other disabled peoples organizations)	Providing General Information	92.54	7.46
follow-up on the things you discussed or wanted to know?	Coordinated & Comprehensive Care	55.22	44.78

* Values of 1 – 4 on the 7-point scale
** Values of 5 – 7 on the 7-point scale
Note: Percentages may not add to 100% due to items being answered as "not applicable"

The above table 4.7, shows eleven items of the MPOC-SA. Four items of the domain providing **general information** were perceived to be weak by the responses of caregivers, and the range was from 77.61% to 92.54%. The provision of **specific information** was also perceived to be weak and the responses ranged from 40.30% to 85.08% of participants perceiving the behavior to occurring sometimes or less. Three items under the domain of **coordinated and comprehensive care** had responses ranging from 40.30% to 81.82%. This implies that the caregivers observed that the services they received were not well coordinated and were generally weak in providing the needed information. The identified weak areas point out aspects that need to be improved.

Table 4.8 MPOC Items on which at least more than two-thirds of caregivers indicated the process of care occurred "More than Sometimes" (n = 67)

To what extent do the people who work with your child …	Scale Name	% Responding "Sometimes" or Less*	% Responding More than "Sometimes"**
make you feel that as a parent, you are doing a good job in looking after your child ?	Respectful & Supportive Care	7.46	92.54
Talk to you and tell you what they are doing when they are treating your child	Providing Specific Information	7.46	92.54
provide a caring atmosphere rather than just give you information - do they show love for your child?	Respectful and Supportive care	7.46	92.54
provide enough time to talk so that you don't feel rushed?	Respectful & Supportive Care	10.45	89.55
treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "Mom" or "Dad")?	Enabling & Partnership	10.45	89.55
Give you information about your child that is the same from one person to the next?	Coordinated & Comprehensive Care	28.36	71.64
treat you as an individual rather than as a "typical" parent of a child with a disability? (e.g. do they know your name; do they remember specific details about you and your child; are they interested in you as a person ?	Respectful & Supportive Care	17.91	82.09
explain what they are doing during your child's therapy?	Providing Specific Information	10.45	89.55
explain what they want you to do between visits?	Enabling & Partnership	2.99	97.01
ensure that you have had the chance to explain the concerns and the things which worry you most about your child	Respectful & Supportive Care	17.91	82.09
Give you suggestions and ideas of things to do which make it easier to handle and look after your child?	Enabling & Partnership	5.97	94.03

* Values of 1 – 4 on the 7-point scale
** Values of 5 – 7 on the 7-point scale

The above table 4.8 shows the responses of caregivers on eleven aspects of the MPOC-SA where the domain of **respectful and supportive care** had five responses ranging from 82.09% to 92.54%. The domain of **enabling and partnership** had three responses

with the highest range of between 89.55% to 97.01%. The other domains that were also observed by more than two-thirds of participants are: **coordinated and comprehensive care** (71.64%) and **providing specific information** (89.55% to 92.54%). The strength of the process of care delivered by the service providers is observed by the participants to be on two domains which are: enabling and partnership, and respectful and supportive care. Clearly reflected by the participants' responses is that there is generally poor provision of general information since it is not reflected in the above table.

The table below, Table 4.9, shows a summary of the chronbach's alpha and the inter-item correlation of the five domains of the MPOC which have been adjusted. The reason that the findings were adjusted was to determine the questions within the domains that produced the highest score close to 1, which implies that the domain would produce more reliable and valid responses. The chronbach's alpha was used to identify items that may be eliminated on the MPOC-SA version by Saloojee (2007) and choose items that would be more appropriate for the population that is being investigated.

Table 4.9 MPOC Factor analysis using the Inter-item correlation and Chronbach's alpha

Domain*	Inter-item Correlation	Chronbach's alpha	Number of Items
Enabling and Partnership	0.63	0.77	2
Providing General Information	0.47	0.78	4
Providing Specific Information	0.31	0.65	4
Coordinated and Comprehensive Care	0.34	0.60	3
Respectful and Supportive Care	0.32	0.49	2

* N = 67

Shown above is that Providing General Information and Enabling and Partnership had the highest chronbach's alpha results at 0.78 and 0.77, and the inter-item correlation was 0.47 and 0.63 respectively. The lowest chronbach's alpha score is for Respectful and Supportive care at 0.49, this shows that only two items inter-related at 0.32. This implies that the items in the scale are weakly related to each other. Munro (2005), states that the chronbach's alpha coefficient measures the internal consistency reliability, which is an alternative way of looking at the extent to which items go together.

The above table implies that MPOC-SA version can further be reduced to 15 items. The principle followed to arrive at 15 items is similar that used in the development of the original MPOC-56 tool by King et al, (1995). They developed a factor loading criteria that was guide by the principles of parsimony, independence factors and conceptual meaningfulness (Kleinbaum and Kupper, 1978). The criteria were: 1) retain items with factor loading of ≥ 0.50, or as low as 0.30 to ensure six items per factor; 2) if an item

loaded on two factors, retain it on the factor with the highest loading, provided the difference between loadings was ≥ 0.50; and 3) if an item loaded on three or more factors, eliminate the item (King et al, 1995). The final solution for solution resulted in 15 items being retained. The content of each factor was reviewed by the researcher to finalize the tool. The reason for having smaller scores can be attributed to a small sample size.

4.11 Satisfaction with Service Delivery

There were two questions from the MPOC-SA asked that explored satisfaction with the service offered at the Dr. George Mukhari hospital. The responses are shown below.

Table 4.10 Summary of satisfaction with service delivery

Question	Caregiver	Std Deviation	Range
To what extent do you feel that you gain something from every session?	5.15	±1.08	1.00 – 6.00
Finally, to what extent are you satisfied with the therapy services you receive here?	5.51	±0.91	1.00 – 6.00

*CG – responses of caregivers n = 67
Meaning of Scores: 1= Not at all, 2 = to a very small extent, 3 = to a small extent, 4 = to a moderate extent, 5 = to a fairly great extent, 6 = to a great extent, and 7 = to a very great extent

The above table 4.10 shows that the caregivers were generally satisfied to a fairly great extent with the service delivered and provided ratings at 5.51 (±0.91). They also feel that they had gained something from each session of therapy, scoring 5.15 (±1.08). These responses imply that the caregivers were satisfied with the service they received.

Table 4.11 below correlates the mean scores of the five domains of the MPOC-SA with the mean score of satisfaction. The Pearson product moment correlation coefficient was

used to test two sets of parametric data for their degree of association. This means that every domain of the MPOC-SA was correlated to satisfaction, and could also be correlated to every other domain to determine whether their association was statistically significant.

Table 4.11 Correlations among the MPOC-SA domain and satisfaction with service delivered to the participants

Domain vs. Satisfaction	**Satisfaction**	**Enabling and Partnership**	**Providing General Information**	**Providing Specific Information**	**Coordinated and Comprehensive Care**	**Respectful and Supportive Care**
Satisfaction p-value	1.00 -					
Enabling and Partnership p-value	0.18 0.15	1.00 -				
Providing General Information p-value	0.25 0.03*	0.55 0.000*	1.00 -			
Providing Specific Information p-value	0.37 0.002*	0.52 0.000*	0.45 0.0001*	1.00 -		
Coordinated and Comprehensive Care p-value	0.10 0.43	0.38 0.002*	0.32 0.008*	0.29 0.01*	1.00 -	
Respectful and Supportive Care p-value	0.16 0.19	0.0197 0.87	0.38 0.002*	0.20 0.10	0.45 0.0001*	1.00 -

The p-value was set at $p \leq 0.05$

The table above (table 4.11) shows that there is a positive correlation in all the quantified variables. Cohen (1987) defines a small effect as a correlation coefficient, r = 0.10; a moderate effect as r = 0.30; and a large effect as r = 0.50. The correlation coefficient also tells us the type of relationship that exists, that is, whether the relationship is positive or negative, as indicated by a positive or negative sign before the r - value. The findings

show that the correlation of Providing General Information and Providing Specific Information to Satisfaction was moderate at 0.25 and 0.37 respectively.

The strongest correlation is shown between Enabling and Partnership and two domains viz. Providing General Information (0.55) and Providing Specific Information (0.52). These findings imply that provision of information is very important in empowering the caregivers. Further, Providing General Information is shown in the above table to be significant in all MPOC domains. It has shown moderately higher correlation coefficients ratings at 0.32 for Coordinated and Comprehensive Care; 0.38 for Respectful and Supportive Care and 0.45 for Providing Specific Information.

In table 4.11 we see that the correlations between satisfaction and the domains of MPOC-SA are all positive. This relationship when used to test the hypothesis for the study rejects the null hypothesis. It adopts the alternate hypothesis that states that caregivers of children with cerebral palsy have a positive perception of services rendered at Dr. George Mukhari hospital cerebral palsy clinic.

The perception of caregivers differed statistically at a p-value of 0.03 for the domain "Providing General Information" for parents of children who had attended services longer than 24 months. The length of attendance was not statistically significant on other domains irrespective of the length of time the child had attended rehabilitation services. This implies that caregivers who had attended services longer need more general information from service providers about other services that can benefit the child and the family.

The caregivers of children who are more dependent with the GMFCS level IV and V showed marginal statistical significance on the Provision of General Information domain with a p-value of 0.09 and on the Coordinated and Comprehensive Care domain with a p-value of 0.07. These imply that the perceptions tend to be influenced on these domains by the severity of the child's disability. Caregivers of these children tend to need more general information and feel their needs are not met in a coordinated and comprehensive way during service delivery at the health care facility.

4.12 Summary of Results

The findings of this study revealed that 99 percent of caregivers are females. Their average age is 32 (± 9.15) years and more than 75 percent of them are aged between 18 and 40 years. More than half of the caregivers (52.24%) are single and about a third (34.33%) have matriculation or tertiary educational level, this means that about two thirds have grade eleven education or less. Seventy three percent of caregivers are unemployed. The economic status shows that about a third (34.33%) leave in chronic poverty, receiving less than R500 per average month. Porterfield and McBride (2007) in their study emphasized that poverty is a risk factor for poor health among children and that low parental education adds to this risk. Moreover Porterfield and McBride reported that lack of education is highly associated with low family income.

The children in this study had an average age of three years and four months. Boys made up two third of the population consulting the CP clinic at the time of the study. Their GMFCS score showed that more than half were classified at level IV and V, scoring

19.40 and 37.31 percentages respectively. Two thirds of these children had the spastic type of CP, 43.28 percent had epilepsy and 41.79 percent are on anti-epileptic medication. The children have communication problems with about two thirds not using speech but only gestures and sounds/crying for communication.

The MPOC-SA results of the factor analysis in this study show that a shorter tool consisting of 15 items may be used for participants in this study. The chronbach's alpha ranges from 0.49 to 0.78, these are generally lower values compared with the original and the Dutch version of the MPOC. These low values imply that this tool may need to be reconstructed by asking more questions pertaining to the way in which caregivers experience service delivery. Therefore, this may be used for measuring the family centeredness of services received by children with disabilities and their caregivers in the South African context.

The participants in this study have responded positively on aspects of satisfaction. This implies that they are generally satisfied with the services they receive at Dr. George Mukhari hospital CP clinic despite low scores on the domains of the MPOC-SA version.

The MPOC areas that need improvement are: Enabling and Partnership, Coordinated and Comprehensive Care, and Respectful and Supportive care. Participants have identified these as week areas which once improved will influence their perception about services delivered to them, and will ensure more satisfaction with the services they received.

CHAPTER 5

DISCUSSION

This chapter discusses the main findings of the study. It includes further interpretation of the results presented in Chapter 4 and how they might relate to other studies. There is discussion on the demographic and socio-economic information, limitations of this report as well as recommendations for future research in service delivery and evaluation.

5.1 Demographic and Socio-economic information

5.1.1 Study population

Most of the 67 participants (85%) were biological mothers of the child and the remaining 15% were extended family members and therefore directly related to the child. This finding is supported by a number of studies where mothers are actively involved in providing the bulk of health care work (Hill, 1995; Abel, 2000; Read, 2000; Leiter, 2004).

Furthermore, a number of studies also observed that extended members of the family, as seen in the study who were assisting the mother care for the child with CP were the grandmothers (97%) and the sisters to the mother of the child (88%), they are involved in the provision of health care (Hill, 1995; Hill and Zimmerman, 1995; Leiter, 2004). It would be noteworthy in future to explore the family systems theory which suggests that anything happening to a family member has an effect on other family members because

they are interconnected and operate as a group (Olson and DeFrain, 1997; Adams et al, 1999).

The participants were caregivers of children aged 9 months to 12 years (mean, 3.7 years; standard deviation (SD), 3.11). Swaine et al, (1999) conducted a study comprised of 73 participants with parents of children aged 9 months to 17 years (mean, 7.0 years; SD, ± 5.3). These studies are also comparative to the study by King et al (1996), where subjects in the study ranged from 7 months to 20 years, with a median age of 6 years and 8 months. This suggests that the participants in both studies look after children who have various social and rehabilitation needs as the studies show the age range from infancy and continue right to the time when they are in the adolescent stage and sometimes through to adulthood.

Approximately two-thirds (67.16%) of children were males and 43.28% had epilepsy. The majority of children in this study (88.06%) receive all three therapies i.e. physiotherapy, occupational therapy and speech therapy. This is consistent with a study by King et al, (1996) where more than half the participants received two or three of the major developmental therapies.

5.1.2 Financial background

Caregivers in this study come from a poor socio-economic background with only 6% employed full-time and 7.5% employed part-time. This is consistent with the observation that providing care to children with disability impacts on maternal employment (Baldwin

and Carlisle, 2004; Leiter et al, 2004). Leatt (2006) reported that Statistics South Africa (2006) conducted the General Household Survey (GHS) in 2005 which depicted that Africans had a 31% unemployment rate. Furthermore, the official unemployment rate for women was 30%. This report is important since the study revealed that 41.79% of participants in the study are married. Leatt (2006) further emphasized that far more children live with women than with men. It is clear that the low level of employment pose financial challenges to women who have to take care of children with cerebral palsy since they will need to use health care services more than other 'healthy' children.

Approximately 54% and 48% of participants' households have three (3) to six (6) adults and children respectively. Only 22.39% of these families have regular income, and less than a third (31%) receive financial support from the husband. These participants live in poverty which is defined as inadequate financial resources to meet daily living needs (Huston et al, 1994). The poverty datum line in South Africa was R640 per month (Frye and Magasela, 2005), and now, according to the GHS it is said to be R800 per month (Leatt, 2006). This study showed that 34.3% of participants were earning less than R500 per average month, and another 35.8% were earning between R501 and R3000. This shows that there is over a third of families that live in poverty.

Poswell (2002:14) states that in South Africa 'high levels of poverty result from low real wages and high unemployment', this finding is true in this study. This study observed that almost 70% of participants are in households that earn less than R3000 per average month; this implies that the majority of participants still live in poverty. Furthermore,

Poswell noted that 38.2% of Africans were living below the poverty line which is currently an amount of R800 per month (Leatt, 2006), and that female-headed households were most vulnerable. In agreement with the above, Booysens (2002) states that ill-health increases poverty, diminishes household savings and increases debt, and therefore, lowers learning ability and decreases the quality of life. This is particularly the case when there is an ongoing medical follow up.

More than 40% of the participants live in informal settlements. This is attributed to low household income which has been reported in other studies to be associated with factors such as poor housing, overcrowding, nutritional problems and poor social support to the caregivers, moreover, low SES has been reported to compromise the child's development. (Halpern, 1990; McLoyd and Wilson, 1991; Duncan et al, 1994; Humphry 1995; Booysen, 2002).

Davidson (1999) emphasized that families of children with special needs may be more economically deprived compared to other families, and that the disabling condition of the child can itself impact on the economic status of the family. Further emphasized is that these economic issues can affect both the needs and the ability to access care (Skinner and Slifkin, 2007). Saloojee et al, (2006) noted that caregivers of children with disabilities are unfavourably affected by high unemployment rates and very low household incomes to a point where they are unable to prioritize the child's needed care. Guthrie (2002) in a paper on family social security benefits in South Africa, highlighted that families of children with disabilities may be discouraged from seeking employment

or other sources of income with the fear of losing the social grant. This further supports the finding of this study where only 7.5% of caregivers get some income through part-time jobs.

Du Plessis and Conley (2007) emphasized that 66% of children in South Africa live in severe poverty and face shortages of food, clothing, shelter and access to basic services. In an attempt to address this, Guthrie (2002) highlighted a move towards a comprehensive social security package for families and children with disabilities. This will be in a form of a basic income grant together with care dependency grant as a 'top up' amount, and will include additional support services that are based on the child's special needs. Furthermore, children with special needs will be eligible to enjoy free primary, secondary and tertiary health care; free assistive and rehabilitative medicine, equipment, therapy, support; free or subsidized special schooling where necessary; free transport vouchers; nutritional supplements; emergency food and cash aid if malnourished (Guthrie, 2002).

There were no significant differences found on the measure of process of care and satisfaction of the caregivers with regard to income category when the one-way ANOVA was applied, the p-value was greater than 0.05.

5.1.3 Educational background

The study has shown that only 20.90% of caregivers had matriculated and 13.43% had acquired tertiary education. In a study conducted by Masasa et al, (2005) in Cape Town,

the results depicted that 3% of caregivers had received schooling up to primary level, and 18% up to tertiary level. These findings were not comparative to a first world study by King et al, (1998) which reported that the majority of the mothers (61.1%) had education beyond high school. Another important finding is that almost a fifth (18%) or more of caregivers need an interpreter when attending rehabilitation services at Dr. George Mukhari hospital, CP clinic, since they do not understand English. Booysen (2002), emphasized that intellectual and physical development of people, and enhanced school attendance and learning result when there is better health and no poverty.

5.1.4 Transportation to the Hospital

Transportation is considered as one of the barriers to accessing health care services for the child and the caregiver (Yantzi et al, 2001). A barrier is defined by health behavior theorists as consumers' perceptions or beliefs concerning the taking of a particular health action (Cummings et al, 1980; Yantzi et al, 2001). Other barriers that have been identified among others are: time, distance, transportation, availability of services and demographic factors. The findings of this study suggests that cost, distance and time to access the rehabilitation services does not affect attendance as revealed by the Fisher's exact test that yielded no significant relationship between these variables. However, literature strongly suggests that there is a relationship between cost, distance, time and attendance of rehabilitation services (Sauerborn et al, 1995; Frew et al, 1999; Terra de Souza et al, 2000; Ensor and Cooper, 2004). Therefore the this research report may not have sufficiently explored this aspect of accessing health facilities or participants may

have not perceived transport issues as notable barriers for them and their children attending the rehabilitation services.

All (100%) participants rely on public transport for accessing the rehabilitation facilities. This study found that 97% of the participants use taxis regularly to access health care services. Approximately seventy percent (69.23%) of these use two taxis, and 4. 62% use two to three taxis from their home to the hospital. The time it takes for them to reach the hospital ranges from 30 minutes to more than two hours of traveling. On average the participants spend three to five hours traveling each time a child goes for consultation. The other major challenge is that these children grow and are heavy to carry, and the taxis are not adapted transport the child's buggy or wheelchair. According to Manuel et al, (2003) and Aneja (2004), parents of children with CP face a lot of challenges when consulting rehabilitation facilities, the cost of traveling long distances, and other socio-cultural considerations makes it important for service providers to plan service delivery.

5.1.5. Child Characteristics:

The mean age of the children in this study 3 years and 4 months (±3.11), which was similar to a study by Law et al, (2003) where the majority of children were between 3 and 8 years. There were about two-thirds (67.16%) male children, which was similar to findings by Swaine et al, (1999) where approximately 70% were boys who used the rehabilitation facilities during the study. These observations are supported by King et al, (1996); King et al, (1998) Biard et al, (2000); Morris et al, (2006) where the majority of children with CP are boys.

Children's GMFCS scores were 7.46% for level I, 17.91% was the same for level II and III respectively, 19.40% for level IV and 37.31% level V. The GMFCS showed that 56.71% of the participants' children where classified as level IV and V. The importance of the GMFC according to Morris and Bartlett (2004) is that it may assist with intervention planning; in this case children at level IV can expect reliance on wheelchair for mobility at home, school and community settings. Children classified as level V can expect limited self mobility, even with assistive technology. These children will be dependent on the caregiver for most activities of daily life (Rosenbaum et al, 2002; Morris and Bartlett, 2004; Bangley et al, 2007 and Oeffinger et al, 2007). According to Morris et al, (2006), the GMFCS has become the standard way to describe the movement ability of children with CP; and classification is typically undertaken by therapists. The GMFCS classifies children with CP into five levels were level I children are the most functional and level V are the least functional and are completely dependent on the caregiver for activities of daily living (Bangley et al, 2007; Oeffinger et al, 2007).

5.2 The Measure of Processes of Care

5.2.1 The perception of more than two-third of participants about service delivery

The responses on both table 4.7 and table 4.8 highlight the perception of more than a third of participants' observation of the process by which service providers delivered the service. A third of participants according to King et al, (1998) constitute a substantial proportion.

The responses on the provision of specific information and provision of general information were observed by caregivers to have occurred "sometimes" or less, and the ranges were 40.30% to 85.08% and 77.61% and 92.54% respectively. According to these responses, there is poor communication between the service providers and the caregivers. Provision of general information about finding a school, how to contact other parent groups or other disabled peoples organizations was noted by 92.54% of caregivers to be lacking. Provision of information about day care centers, care dependency grants, how to find a school for the child was also identified by 94.54% of caregivers to be poor. These findings are supported by the studies which observed that the majority of the problem items deal with the information provision (King et al, 1998; Davidson, 1999; Granat et al, 2002; and Dyke et al, 2006). This means that the service providers need to improve on communication.

Provision of specific information about the child's specific disability such as causes, how it progresses, how the child's future would be like (prognosis) has been noted by 80.60% of caregivers to be poor. At least 40.30% of caregivers reported that service providers did not tell then nor explain results from assessments that include hearing among others tests, brain scans, X-rays and videofluoroscopy done on the child. Palisano (2006) emphasized that sharing of information is a reciprocal process where the family and the service provider share information about the child. Communication is reported to empower the caregivers and ensure continuation of treatment within the home context (Dunst and Bruder, 2001; Valvano, 2004).

The findings on table 4.7 showed that 98.51% of participants' needs were not met with regard to service providers providing opportunities for the whole family to obtain information (e.g. open days, doing home visits, inviting the rest of the family to come with you to therapy). Another 92.54% reported poor provision of information e.g. about day care centers, care dependency grants, how to find a school; or things to do with the child at home, and that it was not available to them in various forms, such as pictures, booklets, video, pamphlets, etc. These findings identify a need for service providers to improve more on involving the whole family in the rehabilitation process and providing information in various forms to families of children with disabilities.

The above finding is supported by research work of Gitlin et al, (1995) and Clark et al, (1995) that further emphasizes the need for service providers to view their role as that of an enabler as opposed to a prescriber. The findings of this study are also in agreement with the suggestion by Gatlin et al, (1995) that caregivers are more receptive to the knowledge and skill of formal providers when this knowledge and skill is transmitted in a manner that is consistent with the beliefs and values of the family unit.

The score on enabling and partnership in this study is 3.26 (± 1.10) which implies that caregivers perceived this aspect of service delivery to have been carried out to a small extent. This domain showed poor results when compared with those by Woodside et al, (2001); King et al, (2004) and Raghavendra et al, (2007). The later were perceived to deliver enabling and partnership services to a fairly great extent, with scores of more than 5.00. The caregivers (85.07%) reported that they were not given an opportunity to make

decisions about the child's treatment. This implies that service providers tend to follow the medical model of care were caregivers are passive recipients of healthcare. Despite the low scores caregivers were perceived that they were explained to what to do between visits, and were treated as equals rather than just as a parent of a child. Caregivers also reported perceived that they were given ideas of things to do which makes it easier to handle and look after the child.

Coordinated and comprehensive care was perceived to be poor and in need of improvement. Service providers were perceived by 55.22% of caregivers to fail in following-up things discussed or that needed further clarity with regard to the management of the child. Another concern was that 40.30% of caregivers perceived that service providers did not look at the needs of the "whole" child including the mental, emotional and social needs, instead their focus was more on physical needs. There is a need of extending services beyond physical rehabilitation to include other aspects such as the psycho-social aspects in keeping with the ICF ethos. The ICF model makes available a good clinical framework that encompasses the 'biopsychosocial' needs of the users of health care services (WHO, 2001).

King and Meyer (2006) emphasized that service coordination has to do with client specific activities that aim to assist individual families to obtain appropriate and needed services from other agencies in a community or geographical area. Furthermore, that this brings different services into an efficient relationship for a given family, thus enabling them to navigate the system and obtain services they need (King and Meyer, 2006). The

coordinated and comprehensive aspect of service delivery in this study was found to be provided to a moderate extent by caregivers, this implies the there are gaps in providing families with complete health packages as promoted by the Primary Health Care model. The service providers at the Dr George Mukhari hospital CP clinic do not have a comprehensive approach when delivering healthcare, but rather tend to operate in a fragmented manner. The other observation from this study is that service providers do not give caregivers information that is the same from one professional to the other. This has to do with fragmentation may be with regard to record keeping or lack of documentation on availability of resources and support structures that can benefit the families, and particularly caregivers and their children diagnosed with cerebral palsy.

Service providers need to encourage partnership with caregivers to empower them in looking after themselves and their children with cerebral palsy. The empowerment can be in various forms such as service providers making it easier for caregivers to be decision-makers with regard to how they can be more involved in looking after the child. There has to be some training for new staff members on basic skills such as communication skills and community diagnosis and facilitation skills that will help caregivers to interact with others experiencing similar challenges.

5.3 Satisfaction

The results of Table 4.10 show that the participants were satisfied to a fairly great extent with the process of health delivered by service providers at Dr. George Mukhari hospital, CP clinic. They also felt that they gained something from every session they attended.

King et al (1996:764) reasoned that participants who experience 'more' of the process of service delivery comprising the MPOC-56 measure and thus scoring high, would have higher satisfaction with the center from which they received the services, since higher scores on all MPOC items reflect 'better' care as judged by the caregivers.

The challenge with the MPOC-SA version is that it is a first world tool that does not seem to capture other interpersonal aspects of care that are more relevant to the South African context particularly with regard to culture. In our culture and the day to day language of black people we do not have a seven likert or rating scale with seven degrees of comparison as used in the MPOC original version. The MPOC – SA version has its use in measuring service delivery but my intuition is that it has laid a good foundation for exploring more rigorously service delivery in the South African context taking into account the cultural aspects of the majority of the users of healthcare services. Most health care users are reluctant to suggest how healthcare services should be improved, they tend to look at service providers as experts who have all the answers to their needs and therefore who need not be criticized or questioned.

Xu (2007) highlighted that when service providers are collaborating with families from culturally and linguistically different backgrounds, they tend to either act as the authority to step in and make decisions for the child and the family or they withdraw from the family in fear of making mistakes due to lack of communication and understanding. Chronbach's alpha score appears low for all the domains compared with the original MPOC-56. The reason for this may be due to a small sample size used in this study. This

study focused only on one clinical setting and on children presenting with cerebral palsy, thus other conditions that are generally treated by service providers in the CP clinic were excluded. The findings of this study singled out some threads that may need to be evaluated not only in the CP population but in children presenting with all disabilities, who use the CP clinic at Dr. George Mukhari hospital. This implies that a shorter version may be used to assess perceptions of caregivers about services they and their children have received at Dr. George Mukhari hospital CP clinic.

The findings of this study concur with Butler and Durrah (2001) who highlighted that when caregivers are an integral part of the therapeutic endeavor instead of an outsider in the child's treatment their sense of satisfaction about the intervention might increase. Caregivers need to be encouraged to communicate more with service providers about aspects that affect their satisfaction with services they received, and the environment for this communication must be created by the hospital management and service providers.

5.4 Contributions to Service Delivery from outcomes of this study

The following points highlight aspects that will enhance the quality of service delivery for caregivers of children with CP who use Dr. George Mukhari hospital. I hope there will also be more satisfaction with service provision by service providers and reciprocally satisfaction from recipients of service delivery. Contributions to service delivery from this study are the following:

- The CP clinic may benefit from using simple tools like the MPOC and the GMFCS tools in a move towards evidence-based physiotherapy practice. These are just two of

many tools available to use in the CP population. This research report has determined that another tool similar to the MPOC-SA version but more adapted to Dr George Mukhari hospital may be developed without great expenses. Caregivers are willing to collaborate and participate in making service delivery to be of high quality. This efforts need to be enhanced and encouraged.

- There is a need of a dedicated person to work and monitor the CP clinic, though there could be rotations within the CP block, this study has determined that caregivers need coordinated and comprehensive care. This will ensure that at least one person will be able to follow up all the aspects of care discussed with the caregivers and make sure that they are able to curb as much as possible fragmentation in service delivery.
- Communication is fundamental to service delivery and this study has determined weakness that can be strengthened. There is a need for service providers to have a resource booklet where they may keep important contacts of organizations and other services that may benefit caregivers and their children with cerebral palsy. There is also a need to ensure that there is printed material about cerebral palsy and encourage caregivers to ask for any help and freely discuss with the a dedicated or key person about services they need.
- Caregivers are more interested in starting a support group, the service providers may be instrumental in assisting to facilitate this process without taking over the operation of this endeavor. This may be an opportunity to empower caregivers and their families in a family centered approach that may have positive outcomes.

The researcher hopes that this study will not only benefit the caregivers and service providers only, but the results will stimulate the hospital management to have systems in

place that will encourage participation in service monitoring and evaluation that involves users of the services.

5.5 Limitations of the Study

- The findings of this study cannot be generalized to all the users of the Dr. George Mukhari hospital Cerebral Palsy clinic due to the small sample size and the exclusion criteria of other conditions treated at the CP clinic.
- The structured interviews using the MPOC-SA assistants were time consuming, and may have limited the total number of participants who volunteered for the study. More than eight participants could not complete the questionnaire, and had to be excused from the study since they felt they needed to rush for some other business.
- The study was restricted in that it was quantitative in nature and could not explore any other qualitative aspects perceived by caregivers of children with CP. Qualitative methods could be used to gain more depth of the perceptions of caregivers of children with CP about the processes of health care delivery they experienced.

5.5 Suggestions for further research

- The study revealed that there was poorly coordinated health care provision; a more in-depth study could be conducted to determine the aspects of service delivery that will facilitate this.
- A correlation of caregivers' and service providers' perception of the measure of processes of care could give us more insight on commonly observed aspects that need to change from both the provider and the user of the services. This may give two

sides that may inform policy and management strategies for the health care delivery system in each hospital.

- There is a need to develop a study that measures the processes of care in the South African context that will influence service delivery according to the government' ethos. The MPOC tool can be used as a good base for designing this new tool following the procedures used in its design.

CHAPTER 6

CONCLUSION

The aim of this study was to evaluate perceptions on quality of care delivered by service providers to families of children with disabilities, attending the cerebral palsy (CP) clinic at Dr George Mukhari hospital. In order to achieve this aim, the study determined the demographic and socio-economic profile of the caregivers; how the caregivers perceive the provision of care as identified by the domains of the Measure of Processes of Care-South African (MPOC-SA version); and determine the overall perception of caregivers with regard to their satisfaction from the service they received.

The results showed that 85 percent of caregivers were mothers of the child. Their socio-economic status revealed that about half the population was single, three quarters were below 40 years of age, more than three quarters had education below matriculation, and only about five percent of mothers of children with CP had full time employment. More than two thirds of participants had a total income of less than R3000 per average month, and 34% had less than R500 per average month income. The mean number of adults was 3.03 (± 1.26) and of children was 2.63 (± 1.25) who depended on this income.

The MPOC-SA version score for providing specific information and the respectful and supportive care domain were rated highest at 5.09 (±0.82) and 5.34 (±0.61) respectively. This implies that the perception of caregivers about service provision with regard to providing specific information and respectful and supportive care was rated to be

delivered to a fairly great extent. The scores on providing general information and enabling and partnership were lowest at 2.34 (±0.95) and 3.26 (±1.10) respectively. These two need urgent improvement since the caregivers only consult and use the CP clinic services once a month or less. The study also revealed that caregivers were generally satisfied to a fairly great extent with the service delivered and provided ratings at 5.51 (±0.91). They also feel that they had gained something from each session of therapy, scoring 5.15 (±1.08). These responses imply that the caregivers were satisfied with the service they received.

There was a positive correlation between Satisfaction and all the domains of the MPOC-SA, though the relationship was somewhat weak. This led to adopting the alternate hypothesis which states that caregivers of children with cerebral palsy have a positive perception of the service rendered by service providers at Dr. George Mukhari hospital cerebral palsy clinic.

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