

PARENT/CAREGIVER SATISFACTION WITH PHYSIOTHERAPY SERVICES FOR  
CHILDREN WITH CEREBRAL PALSY: AN EXPLORATIVE QUALITATIVE STUDY  
AT THE CEREBRAL PALSY CLINIC IN MULAGO HOSPITAL,  
KAMPALA, UGANDA.

BY

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## ABSTRACT

The extent to which customers are satisfied with the care they receive from the health professionals has been an important area of interest for researchers, managers and health care workers. The physiotherapy cerebral palsy clinic at Mulago Hospital in Kampala Uganda provides physiotherapy services for parents/caregivers of children with cerebral palsy. The parents/caregivers visit the clinic seeking physiotherapy services that will address their problems and those of the child. Many children are referred, but some parents/caregivers have been irregular in keeping their appointments and others never return after their first appointment. The purpose of this study was to use a qualitative research methodological approach to explore the satisfaction that the parents/caregivers of children with cerebral palsy get from utilising the physiotherapy services provided at the cerebral palsy clinic in Mulago hospital and, to identify the barriers/problems that parents/caregivers encounter that might affect their attendance. Two focus group interviews were conducted with nine of the parents/caregivers who had attended for a minimum of three sessions and more. Data was collected and a thematic analysis was undertaken. The results indicated that most of the parents/caregivers were satisfied with the physiotherapy services. These included the reception, information provided, treatment for their children, advice and support that they received from their physiotherapist. They were contented with the assurance, empathy, reliability of their physiotherapists and the outcomes of the service. The parents/caregivers were also satisfied with the home programmes recommended for each of them using the appropriate homemade assistive devices. They attributed most of the child's improvement to these home programmes. The majority of the parents/caregivers however, were dissatisfied with the information provided on the diagnosis and prognosis of

the child's condition. Parents/caregivers were also dissatisfied with the communication between them and the physiotherapist during the treatment process due to time limitations. As a result, the physiotherapist rarely found out the parent/caregivers' expectations, needs, difficulties, beliefs or concerns. Furthermore, the teaching of the home programmes was inadequate and lacked enough demonstrations, practice, feedback and joint decision-making. Lastly, the parents/caregivers were dissatisfied with the physiotherapist's poor time management and the irregularity of the appointments given to them. Transport and lack of funds were identified as key problems preventing regular attendance. In conclusion, the study recommends that the management of Mulago Hospital provides Continuing Professional Education for the physiotherapists through short courses or workshops as a way to promote up-to-date knowledge and skills and in turn the parent/caregiver satisfaction.

## **KEY WORDS**

Satisfaction

Expectations

Experiences

Parents/caregivers

Physiotherapy services

Cerebral palsy

Children

Physiotherapist

Barriers

Mulago/Uganda

## **ABBREVIATIONS**

CP

Cerebral Palsy

MOH

Ministry of Health

A.V.S.I

International Services Volunteer's Association

## **DECLARATION**

I declare that parent/caregiver satisfaction with physiotherapy services for children with cerebral palsy: an explorative qualitative study at the cerebral palsy clinic in Mulago Hospital, Kampala Uganda is my own work and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

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M H I O M A R E

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# **CHAPTER ONE**

## **INTRODUCTION**

### **1.1 Background**

Rehabilitation services are internationally recognised as one of the key components of health care (WHO, 1995). Presently, only 2% out of over one million people with disabilities in Uganda receive rehabilitation services (Ministry of Health (MOH), 2003a). This includes children with cerebral palsy (CP). Physiotherapy is one of the rehabilitation services that parents/caregivers of children with CP seek to alleviate the effects of disability on their children. In order to empower parents/caregivers in the care of children with CP and enable them to participate in the establishment of mutual goals of treatment for their children, Anderson and Vantor (1997) highlighted that physiotherapists need not only to treat the children but also to appropriately educate parents/caregivers about the diagnosis, expected outcome and services available. Furthermore, the issue of health care quality and customer satisfaction has drawn considerable attention from both academics and practitioners over the last past years. Thus the necessity to measure and monitor quality is critical in public health-care institutions (Anderson, 1995).

According to the researchers Fotter (1987), Donabedian (1988) and Fitzpatrick (1991) patient satisfaction constitutes a crucial aspect of quality of care. Accordingly, assessing patient satisfaction is assuming an increasingly prominent role in the current health care system (Pruitt, Varni, Seid & Setogichi, 1997). The researchers assert that it is important to understand and accurately measure healthcare quality from a patient-based marketing prospective because the patient's feedback provides the healthcare provider with insight into

alternative methods of organising, providing or improving the health care (Fitzpatrick, 1991). This observation has resulted in many researchers citing and using the assessment of patient satisfaction as a trustworthy approach for monitoring and evaluating health service quality (Westbrook, 1993; Unwin & Sheppard, 1995; Newacheck & Stein, 1996; Ireys & Perry, 1999; Roush & Sonstroem, 1999; Goldstein, Elliot, & Guccione, 2000). This kind of feedback cannot be obtained from administrative data or by observing care directly. Few studies have been written up in literature on parent satisfaction in physiotherapy. However, Unwin and Sheppard (1995) in their study recommended that parent satisfaction should be investigated as an outcome measure for paediatric physiotherapy services. Similarly, Newacheck and Stein (1996) recommended that the monitoring and evaluation strategies of services for children with chronic illnesses and disabilities should focus on outcomes.

In Uganda, (see map 1, next page) health indicators from the Ministry of Health (MOH, 2003b) indicating the proportion of surveyed population expressing satisfaction with health services, showed that the common procedures of obtaining the information on the quality of service is through administrative supervision reports. Indicators also showed that no information has been recorded on satisfaction of any medical services (MOH, 2003a). This suggests that apart from the administrative reports, there are no evaluations of patient satisfaction carried out in most of health institutions in the country.



Map 1 \_ Uganda. Source:  
<http://worldatlas.com/webimage/countrys/africa/lgcolor/ugcolor.htm>.  
 Accessed: 21/08/2004, time: 14:24.

Historically, rehabilitation services in many developing countries have been initiated and run by the non-government organisations (NGOs). The CP unit in Uganda for example, was started in 1991 at Mulago Hospital with the support of International Services Volunteer's Association (A.V.S.I), an Italian NGO. This unit provides physiotherapy services for the children with CP. However, over the last decade, the government of Uganda, together with the private sector, has also laid down strategies to establish rehabilitation services by



incorporating them in the existing primary health care services right from tertiary level down through regional, district to rural community levels (MOH, 2003b, c). But so far, the government has done very little in the area of CP and related disability (MOH, 2003b). The CP clinic at Mulago Hospital is one of the government's central localities of activity for cerebral palsy.

Mulago Hospital located in Kampala (see Map previous page) is both a national referral and training institute. The outpatient paediatric neurology clinic, which is one of Mulago Hospital's special clinics, is run once a week. The paediatric neurology clinic reviews most of the children that are referred to them requiring further assessment on neurological conditions. Tumwine, (1995) identified CP as one of the main conditions (37.5%) seen at the Mulago paediatric neurology clinic. This clinic refers most of the children diagnosed with CP to the physiotherapy CP clinic within the hospital. The services that the physiotherapy CP clinic is expected to provide include: assessment and management of the children with CP, providing supportive and mobility aids and support to the parents/caregivers.

## **1.2 Statement of problem**

The parents/caregivers of children with CP, who utilise physiotherapy services at the CP clinic at Mulago Hospital, come from all walks of life, travel long distances, have varied socio-economic status and educational levels. Parents/caregivers come to the clinic with various expectations including receiving services to their satisfaction. Records at the clinic show that many parents/caregivers are referred to the physiotherapy CP clinic, but only a few continue to attend regularly. It is therefore, important to find out whether these

parents/caregivers actually receive a service that meets their satisfaction. To date, there is no knowledge about the level of satisfaction that the parents/caregivers of children with CP attain as they seek physiotherapy services at the CP clinic in Mulago Hospital.

### **1.3 Research questions**

This study will specifically attempt to answer the following questions:

1. What satisfaction do parents/caregivers of children with CP attain by utilising the physiotherapy services at the Mulago Hospital CP clinic?
2. What are the barriers that the parents/caregivers encounter when using the physiotherapy services?

### **1.4 Aim**

The aim of this study was to explore parents/caregivers' satisfaction with the physiotherapy services delivered by the physiotherapist to their children in the CP clinic at Mulago Hospital.

### **1.5 Objectives**

The objectives of this study were:

1. To describe the physiotherapy services offered to parents/caregivers of children with CP at the CP clinic in Mulago Hospital.
2. To determine initial parents/caregivers' expectations when they visit the CP clinic at Mulago Hospital.

3. To determine parents/caregivers' experiences while utilising physiotherapy services at the CP clinic in Mulago Hospital.
4. To determine parents/caregivers' satisfaction while utilising physiotherapy services at the CP clinic in Mulago Hospital.
5. To identify the barriers that parent/caregivers encounter when utilising physiotherapy services.

### **1.6 Significance of study**

This study provides information on the satisfaction of parents/caregivers experience. The results of this study will be useful to the management and the physiotherapists of Mulago hospital to improve the quality of the physiotherapy services at the CP clinic. Improved quality of services could increase the use of the services. In addition, the management of Mulago Hospital, in conjunction with Uganda Association of Physiotherapy could use the information to organise short courses of Continuous Professional Education (CPE) for the qualified physiotherapists and students. The School of Physiotherapy could also use the findings to guide the undergraduate teaching and clinical supervision of physiotherapy students in the CP clinics. Lastly, the information would be valuable to the researchers interested in paediatrics and satisfaction with service provision.

## **1.7 Definitions**

### **Parent and caregiver**

In this study the term ‘parent’ refers to the child’s biological parent while ‘caregiver’ refers to other carers such as grandparents, and other relatives or supporters. The two terms are used because their biological parents may not necessarily be the prime caregiver of children with CP, or the person who comes to the clinic.

### **Physiotherapist**

Physiotherapists are health professionals who provide services to patients/clients who have impairments, functional limitations, disabilities or changes in physical function and health status resulting from injury, disease, or other causes.

### **Customer**

A customer in the healthcare sector refers to any person who uses the services. This was the key meaning for which it was used in this study.

A presentation of the relevant literature reviewed follows in the next chapter.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter covers the key themes derived from review of literature that highlight the context relevant for the study of parent/caregiver's satisfaction with physiotherapy services for children with CP. Firstly, the literature review presents a background of the concept of satisfaction, defines satisfaction and reviews the theoretical concepts that have been put forward by previous researchers to explain satisfaction. Secondly, the literature critically analyses the expectations and the domains that previous researchers have identified as related to parent/caregiver satisfaction. Thirdly, the definition, the prevalence, the causes and effects of CP are outlined to throw light on the problem for which the parents are seeking a service. This is followed by a description and discussion of the role of the physiotherapist in the management of children with CP. Emphasis is placed on satisfaction in relation to the way in which the services are offered by the physiotherapist. Finally, findings of previous studies on the barriers that parents encountered in the course of utilising physiotherapy and other medical services are presented.

Research studies that reviewed satisfaction in the marketing industry and in the health care sector referred to their recipient of service as either customer or patient (Steiber & Kowinski, 1990). Thus, this literature review uses the two terms synonymously to refer to the recipient of service.

## **2.2 Background of the concept of satisfaction in the healthcare sector**

According to Peters and Waterman (1982), the marketing industry recognised the importance of customer satisfaction in determining the success of their business ahead of the healthcare sector. Literature available from the marketing industry showed that customer satisfaction is recognised as the core of good business practice and, leads to corporate success. Companies that out-performed, outsold and out produced the rest of their competitors did so because they created and nurtured the culture of being innovative, more productive and responsive to their customers. Such companies made profits where others lost, and had significant success where others failed. In addition to offering better performance, excellent companies listened to their customers intently and regularly and got ideas from their customers. This helped the companies to sustain and improve their service quality.

Although the definition and measurement of quality, especially clinical quality and its outcomes is problematic, Conway and Willcocks (1997) asserted that, it is nevertheless an increasingly important area for researchers, practitioners and the consumer of healthcare services. Many definitions emphasised the meeting of customer needs and requirements. Hence, service quality has continued to receive attention both from the marketers and those in the healthcare sector in the recent years. This is partly because customers' perceptions of quality are closely related to their expectations (Lewis & Booms, 1983) and satisfaction level (Oswald, Turner, Snipes, & Butler 1998; Steiber & Kowinski, 1995). The rationale of recognizing customer satisfaction was that it determined whether customers appreciated the service and would recommend it to others, return for more purchases/services and remain

loyal to the industry or hospital (Mittal & Lassar, 1998; Woodside, Frey, & Daly, 1989). Consequently Goldstein et al. (2000) in their study observed that patients who were satisfied with the service that they had received were those who were more likely to remain loyal to the provider that is the therapist.

While customer satisfaction in the marketing industry is linked to more sales and profit generation (Woodside et al., 1989), in healthcare it ensures the provision of quality outcomes, which is the goal of every health facility (Steiber & Kowinski, 1995). Accordingly, every health provider and manager is challenged to deliver the specific expected outcomes to satisfy the patient/customer by providing superior service. Various studies have showed some of the outcomes from patient satisfaction. The outcomes included predicting adherence/compliance with medical advice, re-attendance for further care and improvement in health status as cited in May (2001). These outcomes represent the benefits of customer satisfaction in the healthcare sector. And, because satisfaction is linked to customers' perceptions of quality, dissatisfaction not only means losing the customer, it also means losing the institution's good name (Steiber & Kowinski, 1990).

### **2.3 Definition of satisfaction**

Though satisfaction is recognised as an extremely important concept, many authors and researchers find it an elusive construct that is difficult to define or describe (Goldstein et al., 2000; Steiber & Kowinski, 1990). The reason given is that satisfaction is always relative to the patient's expectations and changes with the changes of the expectations of what one would normally expect to happen even though the actual health care may stay constant.

Earlier researchers Linder-Pelz and Struening (1985) and Fitzpatrick (1991, 1997) who studied patient satisfaction, did not clearly define satisfaction, but described it as an outcome reflecting the quality of health care. As an outcome, satisfaction was described as a useful measure in the assessment of the patterns of communication and information-giving between the clinician and the patient, the involvement of patient in decision-making about care, and as a measure of the clinician's provision of reassurance to the patient (Fitzpatrick, 1991a). Goldstein et al. (2000) in the long run defined satisfaction specifically as: a health care recipient's reaction to aspects of the service delivered which over time resulted into perception of quality of service or care.

More researchers gradually recognised that customer expectations prior to service are a vital aspect to ultimate satisfaction (Conway & Willcocks, 1997; Goldstein et al., 2000; Linder-Pelz & Struening, 1985). However, the role of the 'expectancy theory' in the health care sector has been challenged by findings showing that patients may not always have clear expectations of a complex process of health care, or the expectations may rise with time (May, 2001). For example, Fitzpatrick and Hopkins (1993) in a qualitative study of patients' expectations and satisfaction with health care for headaches found that patient expectations were tentative and were modified by previous experience. Linder-Pelz (1982) moved further and tested the 'expectancy theory' using data on patients' values and expectations collected from 125 first-time patients at a primary care clinic. The overall conclusion was that very little satisfaction could be explained in terms of expectations and values despite there being some correlation. Sanchez-Menegay, Hudes and Cummings (1992) also found that although few patient expectations were met, this appeared to have no bearing on their satisfaction with care. Such findings have led commentators to suggest that there is little



evidence that expectations play a large role in evaluation of care. Conversely, other studies have found a relationship between expectations and satisfaction. For example, Hsieh and Doner Kagle (1991) found that expectations were the best predictor of patient satisfaction. Similarly Korsch, Gozzi and Francis (1968) found that the extent to which expectations were met influenced the outcome in terms of satisfaction. Thus, the evidence for a relationship between expectations and satisfaction remains mixed, some studies indicating that no relationship exists, while other studies suggest that expectations do have some effect on satisfaction. These findings suggest that the relationship between expectation and satisfaction is more complex, and more studies have continued to highlight the complexity of expectations and evaluation of care in determining satisfaction in healthcare (Haas, 1999; Staniszewska & Ahmed, 1999).

Furthermore, researchers observed that patients' lack of expertise to gauge clinical aspects made it extremely difficult for them to evaluate the healthcare quality effectively. For example, Haas (1999) in a qualitative study of patients' experiences of surgery for gynaecological cancer found that many women felt that their limited experience with/or knowledge about hospitals, medical procedures, and other technical details rendered them less than competent to form expectations about such factors. Yet, many of them finally expressed both general satisfaction and specific dissatisfaction in aspects of care with which they were dissatisfied. As a result, patient satisfaction has continued to be conceptualised as a multidimensional construct (Keith, 1998; Linder-Pelz & Struening, 1985; Nelson, 1990; Roush & Sonstroem, 1999). Multidimensional in that a person may be highly satisfied with

one or more aspects of a health care encounter and simultaneously dissatisfied with other aspects (Roush & Sonstroem, 1999).

## **2.4 Theoretical concepts of satisfaction**

As a construct, customer satisfaction has been described as a consumer attitude; it is a post-purchase phenomenon reflecting how much the customer likes or dislikes the service after experiencing it. Because of the multidimensional nature of satisfaction, researchers have over time, continued to develop models to explain the factors such as experience, expectation and quality of service that influence satisfaction (Conway & Willcocks, 1997; Fiebelkorn, 1985; Woodside, et al. 1989). Fiebelkorn considered the specific experience or encounters, and how the customer evaluates the encounter, to determine satisfaction attained in terms of attributes of the encounter. The researcher perceived the customer, as entering a service setting with needs, wants and expectations. The extent to which the provider fulfills them defines the degree to which the customer will be satisfied. Woodside et al. focused specifically on the field of healthcare and designed a framework linking service quality, customer satisfaction and behavioural intention. According to Woodside et al. the customer combined all the experiences gained at an encounter with the provider to determine the overall quality of service. The quality of service registered, in turn determined the customer satisfaction and the resultant behaviour.

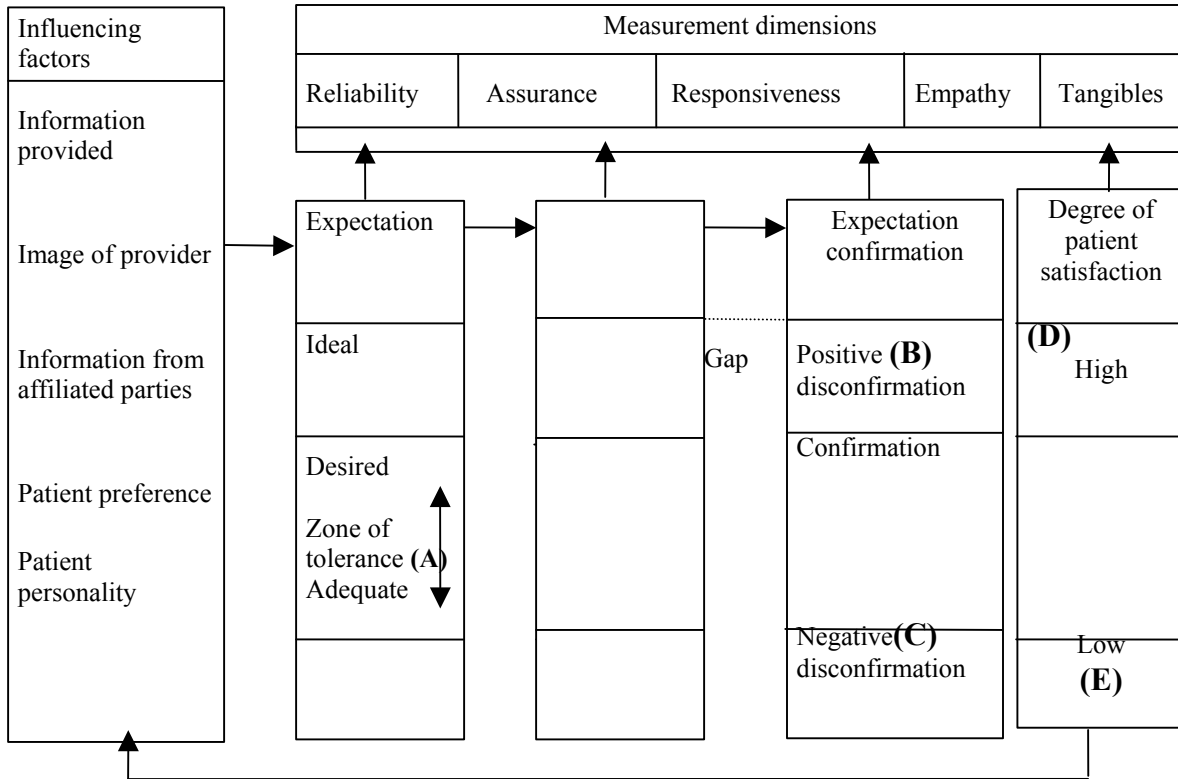
### **2.4.1 The conceptual model by Conway and Willcocks**

Conway and Willcocks (1997) considered measuring effectiveness centred on quality and utilising the 'expectation' approach. Quality was taken to mean the global judgment that

relates attitude to the superiority of the service. The researchers proposed a model that was intended to examine the possibility that customer expectations may be an important influence on the measurement of quality and effectiveness. Accordingly, Conway and Willcocks perceived some relationship between perceived service quality on one side and patient expectations, confirmation/disconfirmation of expectations and patient satisfaction on the other. They also incorporated in their model the relevant features of service quality as identified in literature applied to the health sector. Particularly included, are the normative expectations/measurement dimensions of quality cited by Parasuraman, Berry and Zeithaml (1988a), which spelled out what customers/patients usually consider when evaluating quality of healthcare. These expectations/measurement dimensions as illustrated in Figure 1 on the next page were described and outlined as follows:

- *Reliability*: the ability of provider to perform the promised service dependably.
- *Responsiveness*: the willingness to help customers and provide prompt service.
- *Assurance*: the knowledge and courtesy of employees and their ability to inspire trust and confidence.
- *Empathy*: the caring and individualised attention the firm provides to customers.
- *Tangible*: the physical facilities, equipment and appearances of personnel.

Parasuraman, et al. (1988a) applied these measurement dimensions to develop the SERVAUAL instrument used for measuring service quality. The instrument begins with the assumption that the service quality is critically determined by the difference between the customers' expectations of service and their experience of the service actually delivered. Researchers Anderson (1995) and Curry and Sinclair (2002) used the SERVAUAL instrument in their studies to measure and assess quality and verified that patients indeed utilise these dimensions when evaluating quality of service that they received.



**Figure 1:** A conceptual model on features of service quality to the healthcare context. [Source: Adapted from Conway & Willcocks (1997)].

The model is a logical/process flow model. The influencing factors such as, information provided and the image of the provider, the patient’s previous knowledge and experience of illness, patient’s preferences can on their own influence the degree of satisfaction right at the onset. In addition, the model consists of four key elements: expectations, experience, expectation confirmation and degree of patient satisfaction. Expectation is considered to have four levels of ideal, minimum tolerable, expected or desired, and deserved or adequate. The ideal represents the maximum attainable whereas the minimum is the least acceptable level. The expected/desired level would be based on an individual’s past experiences of

similar situations. The deserved/adequate is what the individual thinks he or she deserves. Thus, if the experience lies within the region of tolerance (**A**), which is between desired and adequate expectation, the patient registers good or satisfactory satisfaction. If there is a shortfall between expectation and experience, gaps are identified. When experiences exceed the desired expectations or conversely if they are lower than adequate service levels, expectations are disconfirmed either positively or negatively. Disconfirmation, that is, the extent to which expectations are not met, determines the individual's measurement of satisfaction. Very good and good experience is disconfirmed positively (**B**), the patient's expectation is confirmed and the degree of patient satisfaction is high (**D**). While poor experience receives negative disconfirmation of the expectation (**C**) and low satisfaction (**E**) (dissatisfaction) is registered. Patient degree of satisfaction /dissatisfaction that is registered in a single transaction feeds back into 'influencing factors'. Accordingly, the degree of satisfaction experienced during transactions also influence patient's expectation in the future. According to Conway and Willocks (1997), satisfaction registered continuously should lead to perception of service quality over time.

## **2.5 Customer/patient expectations**

### **2.5.1 Definition and classification of expectations**

Generally, definitions of customer expectations have varied among different researchers. Earlier studies defined expectations as beliefs about several product characteristics or attributes (Oliver, 1977; Swan & Trawick, 1980). Later, Williams, Weinman and Newman (1995) defined expectations as needs, requests or desires prior to seeking the doctor. While Buetow (1995) separated expectations from wants and defined expectations as comprising

of wants and predictions. Parasuraman, Zeithaml and Berry (1988a) however, observed that customer desires or wants sometimes turned out to be what the customers feel a service provider should do rather than what they do. Potter, Gordon and Hamer (2003) confirmed this observation in their study by showing that the expectations of the parents differed from those of their physiotherapists.

In order to streamline understanding and reliability of interpretations of satisfaction from expectations, Thompson and Sunol (1995) classified expectations into different types namely, predicted expectations, normative expectations and unformed or partly formed expectations. Predicted expectations expressed what the individual thought would happen during the encounter with the healthcare, and was probably influenced by their past experience and other sources of information. These types of expectations represent one of the most common ways in which expectations are included in studies (Staniszewska & Ahmed, 1999). The normative expectations include some notion of what is deserved in a certain situation and fit in with the Parasuraman et al. (1988b; 1991) description of desired expectations. The normative expectations seemed to be underpinned by a feeling of what should happen in a certain situation. Such a feeling has elements of equity, which have been proposed as important contributors of health evaluation (Swan, Sawyer, Van Matre & McGee, 1985). Thompson and Sunol (1995) however, pointed out that the definitions of expectations are not absolute.

According to Gabbott and Hogg (1994), the fundamental expectation in the healthcare sector is 'cure' or health, rather than healthcare service that is difficult to evaluate. The 'care'

expectations, which are equally as important as the 'cure' expectations, are the core expectations to the patients. That is why Conway and Willcocks (1997) argued that patient's expectations of the process of care, their role in the process and the overall outcome of the treatment, influenced how the patient evaluates the service throughout the healthcare process and to its completion. For example, to determine whether their desires or wants have been met, customers will make comparisons between the service performance and their prior expectations, and they will also apply their expectations to evaluate quality of service received (Anderson, 1995). Hence, Conway and Willcocks (1997) asserted that much of the overall measurement of satisfaction within the health care experience is influenced by the patient's prior expectations. In addition, studies have shown that unmet expectations have been associated with decreased patient satisfaction (Marple, Kroenke, Lucey, Wilder & Lucas, 1997; Sanchez-Menegay, Hudes & Cummings, 1992), no adherence (Linn, Linn & Stein, 1982), and possibly worse health-related outcomes (Kaplan, Greenfield & Ware, 1989).

### **2.5.2 Expectations expressed by parents**

Various studies have been conducted on parent utilisation of services and their expectations. Parkes, Donnelly, Dolk and Hill (2002) studied the use of physiotherapy and other alternatives in the treatment of children with CP in Northern Ireland. They reported that more than half of the parents wanted their children to achieve some form of independent walking. In another study on parental experiences of a CP clinic in a poor urban community in South Africa, Anderson and Venter (1997) reported that parents wanted their children, in addition to being able to walk, to become like other 'normal' children attending school,

attain a good quality of life, and to grow into economically independent and mature adults. Some of these expectations were ruled out as unrealistic, considering that their children were severely disabled. However, Miles and Frizzell (1990) found out that, through improved understanding for the need of exercises and appreciating the fact that progress begins with stages and movements well below their expectations, parents could gradually realistically target their expectations towards what was achievable for each child. Other expectations expressed by patients as cited by Anderson, (1995) included: timely provision of services and knowledgeable medical workers who make patients feel safe in their interaction with them, are sympathetic, reassuring, and willing to help patients.

### **2.5.3 Attributes/domains of satisfaction**

Attributes/domains of satisfaction are some of the 'care' expectations described by Gabbot and Hogg (1994), which were displayed by customers/patients. They represent what the customers/patients desire, want or need from the healthcare provider to be satisfied. Gronoos (1990) suggested that the attributes of perceived service quality could be divided into two sets of functional attributes and technical attributes. The functional attributes such as provider attentiveness, describe the quality of what is delivered. Unwin and Sheppard (1995); King and Cathers (2001) have referred to the functional as 'process' attributes and to the technical attributes as the outcome. Physical setting and resources were placed under 'structural' attributes.

Patients' evaluation of satisfaction includes both the structural aspect of care, the process and the outcome of the care. According to Hall and Dornan (1988), the structural aspect of care



has been studied less frequently than the process aspect. The argument medical professional researchers give for focusing their studies more on process, is that their customers evaluate quality according to the process; that is, the personal service they receive and not by the accommodation facilities of the hospital (Carman, 2000). Unwin and Sheppard (1995) indeed reported that parents rated the process of service delivery and the outcome as more important to them.

#### **2.5.4 Attributes/domains of satisfaction reported by parents**

Although parents perceived satisfaction differently, there were some key attributes/domains related to 'process' and outcome that were found to be common to most of them. Studies on parent satisfaction highlighted interpersonal-care giving as most important (Calnan, et al., 1994; Fitzpatrick 1991b; King, King, Rosenbaum, & Goffin, 1999). The attributes/domains of interpersonal interaction and process as identified by previous studies included: respectful and supportive care; the feeling of being listened to and attaining rapport with the provider; the amount and the clarity of general information supplied by the provider; the enabling partnership where the professional involves the patient as a team member in the ultimate decision-making as well as accommodating family needs and wishes and, the competence of the practitioner covering both knowledge and skills (Ireys & Perry, 1999; Newacheck & Stein, 1996; Roush & Sonstroem, 1999; Unwin & Sheppard, 1995; Unwin & Sullivan, 2000).

Meanwhile, Unwin and Sullivan (2000) explored parent satisfaction with newly developed physiotherapy services for preschools and identified some outcome satisfaction attributes

expressed by the parents. These included better understanding of the child's condition and prognosis; increased understanding of the child's movements following the physiotherapy visits; increased ability of the parents to handle the child; the child gaining symptomatic improvement; and the therapist providing home activities/programmes that were manageable by the parent. Earlier on, Chiarello and Palisano (1998) had identified that an enriched parent- child relationship resulted from an enriched home-based programme.

Later on, the researchers King and Cathers (2001) in a study to find out the elements related to parent satisfaction and dissatisfaction with paediatric services compiled and sorted the various attributes/domains of satisfaction cited in literature into structure, process and outcome. Their findings revealed that most of the highly satisfied parents made positive remarks about the following attributes/domains of satisfaction: respectful and supportive care, professionals' competence; the provider's attention to the child's needs; an enabling partnership; continuity and coordination of care; the general information provided; and information supplied by the provider. Most of these attributes emphasized the 'process'. The opposite was true for the dissatisfied parents who reported failure of the professional to provide the same attributes. King and Cathers also summarised the structural attributes/domains that were reported by various studies including accessibility of services; service cost; bureaucratic procedures; waiting times at the site; amount, frequency, length or quality of service; and the physical facilities in which the services were provided.

On the other hand, Curry and Sinclair (2002) and Anderson (1995) studied measurement of service quality of physiotherapy services in Dundee, Scotland and the services at a

university health clinic in Houston, Texas respectively. They found that the manner in which the service/care is delivered is most important when patients evaluate service quality. Their findings showed that the expectations of reliability, responsiveness and empathy were rated as equally important when patients evaluated service quality that met their satisfaction. Similarly, Adams, Whittington, Saunders and Bell (1994) in their study of affective/socio-emotional behaviours of physiotherapists while treating patients, found empathy/reassurance, encouragement/motivation, rapport, listening and other non-verbal behaviours as most important.

## **2.6 Cerebral Palsy (CP)**

There are various conditions affecting children that make the parents seek for physiotherapy services. Cerebral palsy is one of them. Stedman's dictionary (2000: 1301) defines CP as a "generic term for various types of non-progressive motor dysfunction present at birth, or beginning in early childhood". Kibel and Wagstaff (1995) however, clarified that although the lesion is non-progressive, these clinical manifestations often change with neurological maturation. These changes in turn change the functional abilities of the individual, their health and social needs (Backheit et al., 2001). This makes CP a lifelong condition with outstanding effects on the individual child and the carers, and as a result, also contributes to the increasing numbers of children with disabilities that the physiotherapists have to manage.

### **2.6.1 Prevalence of CP**

Finnie (1997) and Winter, Auntry, Boyle, and Yeargin-Allsopp (2002) estimate the prevalence of cerebral palsy in developed countries as 2 per 1000 children. The developed countries during the period of 1975–1991, reflected a modest increase in the overall prevalence of CP from 1.7 to 2.0 per 1000 as a result of use of advanced medicine and technology. These lead to increased chances of survival of babies with congenital heart diseases, pre- term and low-birth weight deliveries (Majnemer, Sheivell, Rosenbaum, & Abramamowicz, 2001; Winter et al, 2002). In Australia for example, the CP prevalence is 2.0 - 2.5 per 1000 live births (Flett, 2003). On the contrary, whereas it is estimated that 85.0% of the world's disabled children of less than 15 years of age live in developing countries, not much is known about the prevalence of CP in these countries (Shawky, Abakhail & Soliman, 2002). But according to Kibel and Wagstaff (1995), by 1995 it was largely determined by the high incidence of potentially brain damaging illnesses among the poorer communities. Uganda, as in the rest of the developing countries, has no reliable data on the CP prevalence. But the country recognised an estimate of prevalence of disabilities at 4.8% for developing countries as was cited by Helander (1999). Tumwine (1995) however, identified CP as one of the most common conditions (37.5%) seen at Mulago paediatric neurology clinic.

### **2.6.2 Causes of CP**

Kibel and Wagstaff, (1995) classified the various causes of CP in three parts of firstly, prenatal, secondly, perinatal, and thirdly post natally acquired. The prenatal causes include some of those factors that may interfere with the foetal development while in the uterus such

as malformations, intra-uterine infections, pregnancy complications such as eclampsia, and multiple pregnancies. The peri-natal causes include some of the complications that could occur before and during the process of delivery. These include prematurity and associated complications, perinatal asphyxia, birth trauma, bilerubin encephalopathy, hypoglycaemia and others. The post-natally acquired causes include some cerebral infections such as meningitis, cerebral malaria, accidental and non-accidental, trauma and cerebro-vascular accidents. Tumwine (1995) identified the post- natally acquired as currently the most common cause of CP in Uganda. Furthermore, according to the UNAIDS report (2000), approximately one million children in Sub- Saharan Africa are infected with HIV, and 25 – 40 % of them who are HIV positive, have developmental delay (Potterton & Eales, 2001).

### **2.6.3 Common problems of the child with CP**

The end result of a disorder of movement and posture means that all children with CP have motor dysfunction and may, depending on the extent of the lesion, have associated handicaps of sight, hearing, speech and feeding as well (Flett, 2003; Kibel & Wagstaff, 1995). The dysfunction manifests itself in three basic areas of neuromuscular problems, abnormal patterns of movement and musculo-skeletal problems (Flett, 2003). The neuromuscular problems include problems of spasticity, dystonia, incoordination, the loss of selective motor control and weakness. Depending on the parts affected the symptoms manifest in hemiplegia, diplegia and quadriplegia. Abnormal patterns of movement manifest themselves in the child's inability to carry out functional movements such as head control, turning, sitting, standing, walking, and running. In addition, there is a tendency to develop asymmetrical posture (Finnie, 1997; Kibel& Wagstaff, 1995). Musculo-skeletal

problems include muscle contractures, bony deformities, muscle weakness, failure and difficulty to use hands both to reach out and fine manipulative movements (Flett, 2003). Problems of communication and eating are common in cases of severe spasticity and athetosis (Edwards, 1998).

## **2.7 Role of the physiotherapist**

According to Levitt and Goldschmied (1990), physiotherapists are expected not only to treat people, but also to teach and advise others in the course of their work. Physiotherapists working with parents must instruct parents, relatives and other carers in how to reinforce therapy. This makes physiotherapy services important in supporting the parents/caregivers in their management of children with CP, both at the early stages and as they become older. Ekenberg (2001) reported that parents of younger persons with CP ranked physiotherapy as most important for their children. The main reason was that, the parents felt the physiotherapist may be the only person in the medical team whom the patient/parent spends sufficient time, over a reasonable period (Rooijen, 1993). In light of the relatively stable prevalence of CP, the proportion of children with disabling CP, and the level of parent interest in the service, Parkers et al. (2002) asserted that the demand for physiotherapy services is likely to continue.

Backheit et al. (2001), though arguing that effectiveness of physiotherapy is not supported by any clear and firm evidence-based intervention data, described the roles of the physiotherapists in the management of children with CP. The roles included: giving therapy to improve posture and mobility; the use of strategies to try and prevent deformities; the provision of mobility aids; sensory stimulation and support of the carers. Furthermore, the

researchers emphasised that the physiotherapist should work as part of the multidisciplinary team involved in the management of the children with CP. Flett (2003) elaborated on the important tasks performed by physiotherapist as a member of the team involved in managing children with CP. They included: defining the child's disability, performing a baseline functional and biomechanical assessment, providing mobility aids/ therapy/castings or orthoses and providing targeted motor training or exercises for the parents or carers to implement.

Furthermore, Bhatia and Joseph (2001) identified the importance of physiotherapists performing a comprehensive assessment of all children with CP prior to the physiotherapy management. In their review of 100 children in rural India, the researchers found that 82 percent had one or more associated disabilities. And in 43 per cent of the children at least one associated disability had not been recognised at referral. The physiotherapist's assessment therefore, helps in locating even those associated disabilities, hence enabling effective rehabilitation. Backheit et al. (2001) however, pointed out that the way the parents are initially informed about their child having CP, may influence parents' future relationship with the team caring for their child and their attitudes to their child. The researchers recommended that a parent should be given an explanation of the diagnosis to rule out any uncertainty about it and, a written record covering the main issues discussed with the parent. In addition, Anderson and Venter (1997), and Miles and Frizzell (1990) found that the explanations on diagnosis help the parents to set their expectations within what is achievable for each child. While Backheit et al. suggested that another way to help parents come in terms with the diagnosis could be for the physiotherapist to facilitate parents to meet with

others who have a child with CP. The meeting could be through self-help groups, other parents at the clinic and voluntary organisations.

Backheit et al. (2001); Finnie (1997); Kibel and Wagstaff (1995) assert that the care and management of children with CP, needs to be based on a goal oriented, problem- solving approach involving a core team. According to Backheit et al. (2001), the core team in UK usually comprises of a physiotherapist, psychologist, paediatrician, occupational therapist, speech and language therapist, a nurse and an orthopaedic surgeon. Liaison is a responsibility of each of the team members to make each other aware what they need to know and do for the child. The physiotherapist in addition to receiving those referred to them should also make referrals to the relevant members of the team whenever necessary. Personnel of such skills are however lacking in most developing countries, Uganda included (Miles & Frizzell, 1990). The researchers also suggested that the goals of the treatment be discussed and negotiated with the parents and the child. Indeed, Gerteis, Edgman-Levitan, Daley, and Delbanco (1994) found that involving the parent in decision-making concerning their child's care can lead to greater parent satisfaction, less anxiety, better adherence with the health care recommendations, improved physical outcomes, decreased rates of re-hospitalisation, fewer complications and reduced malpractice suits.

Miles and Frizzell (1990) illustrated the use of goal oriented problem-based approach in Pakistan and recommended it as an efficient way of managing many patients in a situation where there are few trained physiotherapists. According to Miles and Frizzell, the assessment of each child is continuous throughout the handling process. Furthermore, the physiotherapist plans each activity with a purpose in mind. The chosen activity is explained



and discussed with the parent before the parent is taken through the learning and handling techniques. The physiotherapist then demonstrates the purposeful positioning and handling techniques for daily activities, such as those described by Finnie (1997), to the parents/caregivers. Miles and Frizzell further suggested that the exercises be incorporated with the positioning in the normal developmental patterns, accompanied with explanations to the parent about their benefit to the child's development. Thereafter, the parent is made to practice the activity repeatedly with the guidance and feedback from the physiotherapist until the parent is comfortable and confident enough to continue independently at home. The researchers reported that the parents found the handling techniques they were taught together with the use of low cost appropriate aids, very beneficial and supportive in their day to day handling of the child at home. The researchers also recommended the use of corner seats and standing frames, but where possible they emphasized improvisation to avoid delay and to counteract the idea that 'special apparatus' are the key to success.

Meanwhile, Chiarello and Palisano (1998) recommended physiotherapists to encourage home-based child-parent interaction because it contributes to the child's development. The physiotherapist promotes child-parent interaction by designing interaction programmes to guide parents in understanding and responding to their child's behaviour, interests and needs. Such interaction involves the maternal use of verbal and non-verbal controls to lead her child's behaviour during interactions such as play, feeding and responding to behaviours exhibited by the child. According to Chiarello and Palisano, the home environment fosters spontaneous use of skills by providing the natural cues and reinforcement for the parent/caregiver and the child.

However, accomplishing all these roles effectively is not an easy task. Miles and Frizzell (1990) emphasised that the effective implementation of the physiotherapist's role requires the therapist to be knowledgeable, competent in teaching and communication skills, and if possible, have additional training in paediatrics. Effective communication skills include: questioning, explaining/informing, giving instructions, counseling, emphasising important points, use of language, identification/correction of errors, feedback and demonstration (Adams, Whittington, Saunders, & Bell, 1994). It also demands the physiotherapist to have a particular interest in children and patience, since CP is a complex and trying condition with slow progress in improvement.

## **2.8 Parent compliance**

Many studies that the researcher reviewed were done on compliance in relation to patients and only a few were done on parents. Walker (1995) defined patient-compliance as the extent to which patients do or do not follow their physiotherapist's advice and the factors that affect it. According to Walker, patient's beliefs about efficacy of a particular treatment or service may relate to the patient/parent's understanding of their (or the child's) condition. The researcher recommended that it is important for the physiotherapist to agree upon the diagnosis and treatment with the patient or parent. What's more, the researcher asserted that patient-therapist relationship is among the most important factors that influence patient compliance. Although many parents will have little knowledge of the principles of diagnosis and treatment, the quality of the relationship becomes the main source of information available to the parent about the physiotherapist's skills. According to Basset & Petrie (1999), collaboratively set goals appeared to lead to higher levels of compliance,

though not completely. Hence parents were more likely to turn elsewhere to another provider when they felt disappointed with personal aspects of their care than with the technical aspect (Goldstein et al., 2000; Walker, 1995). On the contrary, Mittal and Lassar (1998) in their study of why customers 'switch', also concluded that while dissatisfaction nearly guarantees 'switching' of provider, satisfaction does not ensure loyalty. Researchers confirmed compliance to be closely related to patient satisfaction as was cited by Walker (1995).

## **2. 9 Barriers to utilisation of physiotherapy services**

Parents may experience a number of barriers when using physiotherapy services. Research on health service utilisation in general services (Green, 1999), specific required services (Marx, Hirozawa, Soskolne, Liu & Katz, 2001) and on specific groups of patients with particular conditions such as low back pain (Gwenda, 2000), identified some of barriers that affect the utilisation of services. Green broadly categorised the barriers into environmental, social, cultural and economic and personal characteristics of the patient or carer. While, Gwenda identified that patients encounter both physical and psychological barriers: the access to the services; the patient's own attitude to pain; the patient's perceived attitudes to the health professionals; the lack of information of the patient's condition; the lack of information on the services available to provide assistance; and cost of therapeutic agents and health services.

In addition to the lack of knowledge about the availability of services, how to access them, and the cost of care, Marx et al. (2001) reported the agency-related barriers previously identified by other researchers. These included: the wait listing; that is, the waiting time

before receiving the attention/therapy or appointment; the office waiting time and the attitude of the employer on absenteeism from work; the lost income during time spent at the clinic; the inconvenient hours/location; the travel time to and from facility; and the difficulty in scheduling an urgent and emergency care. The researchers also reported psychological or emotional barriers such as the unwillingness to use the services, and denial or fear of loss of confidentiality. According to Rastall and Fashanu (2001), patients with chronic conditions who are seeking rehabilitation, usually stay longer on the waiting lists and gradually stop utilising the services.

Furthermore, Feldman, Champagne, Korner-Bitensky and Meshefedjian (2002) observed that parents, who are referred to a facility and reside far away from the facility, might lack the required knowledge about the services. Empowered parents appeared to manoeuvre within the system to reduce waiting time and get their children seen by the health professional. Most people would prefer strategies that are convenient, inexpensive, of easy access, and those that do not demand major changes in either behaviour or routine (Gwenda, 2000).

## **2.10 Summary**

This literature reviewed in this chapter has shown that customer/patient satisfaction is important in determining the success and effectiveness of a business both in a marketing industry and in the healthcare sector. Various researchers identified the factors that influenced customer/patient satisfaction. These factors have continued to vary and have made it difficult for the researchers to define satisfaction, leaving it as a multidimensional construct. Some of the factors discussed included, patient experience, expectations and

service quality. A conceptual model based on the 'expectancy theory' explores the possibility that customer/patient expectation may have an important influence on the measurement of service quality and, the outcome of satisfaction or dissatisfaction whenever parents/caregivers encounter healthcare providers.

Various researchers found the definitions and the measurement of expectations to vary according to the recipients. Expectations also varied depending on the emphasis of the study that was performed. For purposes of understanding and reliability of interpretations of satisfaction from expectations, patient expectations were classified into predicted, normative and unformed or partly formed expectations. Most important in the healthcare were the 'cure' expectations. These were further classified into functional ('process') attributes/domains and technical (outcome) attributes/domains. Researchers reported both 'process' and outcome attributes/domains as important in influencing parent satisfaction. In addition, normative expectations of reliability, responsibility and empathy were rated as equally important when parents evaluated service quality that met their satisfaction.

In order to incorporate parent/caregiver satisfaction of the services that they receive from the physiotherapists, the diagnosis of the child was reviewed. The literature review of CP covered its definition, prevalence, causes and the common problems exhibited by a child with CP. A physiotherapist was found to play an important role in the management of most of the problems of the child with CP. The roles included assessment, providing information and/or disclosure of diagnosis, treatment, counselling, and support. However, in order to implement these roles effectively, and also meet the parent's expectations and attain their

satisfaction and compliance, the researchers recommended that the physiotherapists were required to be knowledgeable, and skilled in communication and teaching skills. Finally, barriers/problems that parents encountered when utilising physiotherapy services were presented. Apart from the physical and environmental ones, some of the barriers encountered during physiotherapist-parent interaction included lack of information of the child's diagnosis, waiting time, and cost of therapeutic or health services.

The methodology used in the study is presented in the next chapter.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1 Introduction**

This chapter discusses the methodology used in this study. The discussion covers the research design; the research setting; the sampling procedure; the sample; the research instruments; the procedure; the pilot study; the data analysis; trustworthiness and ethical issues.

#### **3.2 Research Design**

This study used the qualitative research design. Creswell (1998) posits that the nature of the research question and the topic that needs to be explored determine what approach could be chosen. A research question starting with ‘what’ or ‘how’, or a topic such as the parent’s satisfaction as in this study, that needs to be explored in depth in order to explain the parents’ feelings, is most suitable for the qualitative exploratory research approach.

In this study, the qualitative approach was used because of its advantages. It places emphasis on understanding the individual’s life experiences through examining closely peoples’ words and actions and it brings out the situation as experienced by the participants (Maykut & Morehouse, 1994). In addition, the qualitative research design also permits the description of problematic moments in the individual’s life (Denzin & Lincoln, 1994). The qualitative approach was thus used to describe the expectations, experiences, satisfaction attained, and the problems encountered by the parents/caregivers of children with CP while

utilising the physiotherapy services at Mulago hospital CP clinic. Presenting the situation by using statistics would stop the ‘meaning’ as experienced by the parents/caregivers (Maykut & Morehouse, 1994). Also, in practical terms, it was felt that finding the large number of parents/caregivers required for the quantitative approach would be difficult since the clinic is a small one.

### **3.3 Research Setting**

Maykut and Morehouse (1994) assert that it is important to meet people in the context of their own natural setting to be able to understand their experiences. This study was conducted at the physiotherapy CP clinic in Mulago hospital in Uganda, the natural setting where the parents/caregivers of children with CP received their physiotherapy services.

The physiotherapy CP clinic is an outpatient clinic located within the orthopaedic workshop enclosure in Lower Mulago in Kampala. As earlier mentioned in the introduction, the physiotherapy CP clinic was opened in 1991 with the support of an Italian NGO, International Services Volunteers’ Association (A.V.S.I.). This clinic has been running for the last twelve years. It was started specifically to provide physiotherapy services for children with CP, away from the main physiotherapy department of the hospital, which provides general physiotherapy services. Compared to clinics in the districts or community health centres, the clinic is fairly well equipped. The services provided are free of charge as this is a public referral hospital. However, parents/caregivers have to pay for the appliances, which they may need for their children.



For the first six years, A.V.S.I provided a full-time physiotherapist who had specialized in neuro-developmental therapy (NDT) to run the clinic from Monday to Friday. At the same time the Mulago hospital physiotherapy department assigned one physiotherapist twice a week, Tuesdays and Thursdays to help her to run the clinic. However, not all the physiotherapists from the main department got a chance to work with her in order to acquire some of the techniques. In essence, none of the physiotherapists from that time or those who are currently employed in the hospital have had specialised training in NDT or any other training in CP. At the end of the contract with A.V.S.I in 1996, the main physiotherapy department took over responsibility to run the CP clinic. Because of the shortage of physiotherapists, the department opted to open the clinic twice a week, on Tuesday and Thursday mornings only. To date, the clinic has one physiotherapist. The same physiotherapist is also assigned work in other wards in the hospital on the other days of the week. The reduction from a full-time therapist to a part-time therapist twice a week has meant a big reduction in the amount of physiotherapy time being provided at the clinic.

Most of the children with CP who receive physiotherapy at the CP clinic are referred from Mulago paediatric neurology clinic. Other children with CP are referred from other district hospitals, and a few from the private sector. A few parents refer themselves on learning about the availability of the services at Mulago hospital either through their colleagues or the awareness programmes in the community or through the media.

### **3.4 Sampling Procedure**

According to records in the appointment and attendance registers at the clinic, the clinic currently registers an average attendance of visits of 48 children per month, including new ones. Out of this population, the researcher used purposive sampling to select the twelve parents/caregivers for the study. Purposive sampling was chosen because it allowed the researcher to make a judgment and to ensure that the sample was composed of participants with characteristics representative or with typical attributes of the parent/caregiver population (De Vos, 2002). These characteristics and typical attributes guided the formulation of criteria for selecting the sample. Thus the following were the selection criteria:

- The child had been attending the clinic as shown by the name in the attendance/appointment register.
- The parent/caregiver had adequate experience of having brought their child for a minimum of three treatments or more.
- The parent/caregiver willingly agreed to take part in the study.
- The parent/caregiver confirmed their availability to participate in the focus group discussion.

Furthermore, expectations and experiences could only be best described by parents/caregivers who have experienced the service and not by observers (Oswald et al., 1998). Based on the above criteria, only the parents/caregivers of children with CP who were receiving physiotherapy services at Mulago CP clinic were considered.

The researcher visited the clinic every Tuesday and Thursday morning from 9<sup>th</sup> December 2003 onwards, (with a short break of two weeks of Christmas and New Year season holidays), to select the required sample of twelve parents/caregivers. The researcher short-listed the names of all those parents/caregivers who satisfied the selection criteria. However, a search through the names in the attendance register showed that the numbers of those parents/caregivers who had attended the clinic the previous years and during the early months of 2003 were few. Most of them had with time stopped attending the clinic. The majority of those attending joined the clinic in August / September 2003 and others had recently been referred. Furthermore, because of the Christmas and New Year holidays, most parents/caregivers tend to stay away and gradually resume attending the clinic only in the second week of January. These factors reduced the available population from which the sample satisfying the selection criteria could be drawn.

As the parents/caregivers queued for treatment, the researcher checked who were on the list and requested to have a word with each of them individually. The parents/caregivers were briefed about the purpose of the study and were verbally requested to participate in the focus group discussion. Appointments were made on that particular morning of the first meeting with each of the parent/caregiver who agreed to participate and had confirmed their availability on the agreed date of the discussion. This was done ahead of the date of the planned focus group interview to which each of them had been assigned. This allowed parents/caregivers time to arrange for travel and to reschedule their commitments.

### **3.5 The Sample**

#### **Parents/caregivers**

Twelve parents/caregivers were selected to participate in the study. This sample size was the suitable number needed for holding two focus group discussions, each consisting of six parents/caregivers. But only nine of them turned up, eight females and one male. Six of them were those selected for the first focus group discussion and other three were part of those selected for the second focus group discussion. They were all parents/caregivers who had been attending for some time. Four of them had attended the clinic since 1999; two for one year; and the other three had attended since September 2003. The parents/caregivers came from different parts of the country and were from different educational and social backgrounds.

### **3.6 Method of data collection**

#### **Focus group interviews**

This study used focus group interviews/discussion as a principal source of data collection because it is an appropriate method for exploring a topic that is new to a researcher or for which little information is available (Maykut & Morehouse, 1994). The inquiry was based on parents/caregivers' words and actions. Expectations, experiences, satisfaction attained and problems encountered, were all unknown issues that the researcher wanted to find out from the parents/caregivers of children with CP who received physiotherapy services from the CP clinic in Mulago hospital. It therefore required an appropriate data collection method such as participant observation, in-depth interviews or focus group interviews to capture the language, actions and the behaviour of the parents/caregivers. Participant observation and

in-depth interviews were however not chosen because they were beyond the scope of this study.

Krueger (1994: 6) defined focus group interviews as:

“A carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive and non threatening environment”.

Thus, focus group interviews provided the environment that enabled the researcher to bring together the small group of six parents/caregivers and the other group of three parents/caregivers in order to explore their views/responses on what they feel and think about the physiotherapy services. Fundamentally, focus groups create a line of communication and promote self-disclosure among the participants, making it a recognised powerful way of exposing reality (De Vos, 2002). And because the process of group discussion is familiar in most African cultures, participants find focus group discussions less threatening (Bless & Higson-Smith, 2000). Collecting the data using two groups was used to provide diverse information. This outlined what was common to most of the parents/caregivers and enabled the researcher to make a comparison between the responses of the parents/caregivers from the two groups. The weakness however with focus group, was that on some occasions parents/caregivers tended to agree with dominant views expressed by group members which they may not have done if they had been interviewed separately.

### **3.7 Research Instrument**

#### **Semi-structured interview guide**

A semi-structured interview guide was used to moderate the study. The *cerebral palsy: Mulago parents/caregivers satisfaction interview guide* was made of seven broad themes and questions as shown in the appendix 1. The guide was based on the parent's/caregiver's expectations, needs and attributes/domains of satisfaction as identified from the literature. The questions in the guide sought to draw out on parents'/caregivers' experiences of the physiotherapy services provided to their children with CP, their needs, experiences and expectations of these services and the satisfaction that they attained. A specific question was also included to determine the barriers/problems that the parents/caregivers encounter in utilising physiotherapy services at the CP clinic in Mulago hospital.

The questions in the interview guide covered the following themes:

- A. Parent /caregivers expectations.
- B. Interaction and communication between parents/caregivers and the physiotherapist while at the clinic.
- C. Understanding the child's problem.
- D. Management of the child by the parents/caregivers.
- E. Enabling partnership between the parents/caregivers and the physiotherapist in planning and implementing the home programme.
- F. Overall parents/caregivers satisfaction.
- G. Barriers/problem encountered by parents/caregivers.

Before using the interview guide, it was translated from English into Luganda which was the language understood by the majority of the parents/caregivers. Two Luganda language specialists translated the guide separately to produce drafts. Then they worked together on their drafts to produce a final copy, which was used for the pilot study. The moderator is affluent Luganda speaker. So, together with the researcher, they reviewed the interview guide to ensure that the meaning remained the same before using it for the pilot study.

### **3.8 The Pilot study**

A pilot study, which is, “ a small study conducted prior to a large piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate”(Bless & Higson-Smith, 2000: 155), was conducted at Katalemwa Cheshire CP unit that is similar to Mulago CP clinic. The main purpose was to test the accuracy and appropriateness of the interview guide, provide the moderator and the researcher an opportunity to gain an experience of their roles and restructure the procedure to follow during the main study.

#### **3.8.1 Moderator training**

An appointment to train the moderator how to conduct a focus group discussion was sought with the physiotherapist from Mengo Hospital who had been identified to moderate the focus group interview discussions for the study. The training consisted of a briefing of the moderator on the purpose of the research, the moderator's role in the study, the understanding of the study and her participation in the post-meeting analysis of the sessions. A tentative date for the pilot study was agreed upon subject to obtaining permission from the

administration and physiotherapists from Katalemwa Cheshire home to access the clinic for the pilot study. The written permission (see appendix 2) was granted and the pilot study was conducted on 18<sup>th</sup> December 2003 at Katalemwa Cheshire CP unit.

### **3.8.2 Sample and procedure**

The pilot study involved a group of 4 parents/caregivers. The moderator, using the final draft of the translated interview guide, moderated the discussions while the researcher as the observer, took care of the tape-recording and field-note taking. The discussion took approximately one hour and twenty minutes. After the session, the researcher and the moderator immediately reviewed the proceedings, clarity of the questions, the participation and responses of the parents/caregivers in relation to what the questions were expected to draw out of them. The researcher and moderator also reviewed whether any other new important issues came up that needed to be included in the guide.

### **3.8.3 Evaluation of pilot study**

The outcome of evaluation of the pilot study was that the clarity of the interview guide questions was achieved. The translation of the questions; *what explanation did the therapist give you about the problem of the child;* and *what would you say about the way your therapist talks you,* were not clear to the parents/caregivers. These two questions were reviewed and modified for use in the main focus group discussions. In addition, the procedure to follow during the main study interviews was developed, and the moderator and the researcher had practice that enabled them to gain the necessary standard of skills for the



main study investigation. An observation was also made that there was need to ensure that parents/caregivers are reminded to speak loudly enough for good recording.

### **3.9 Procedure of main study**

Two focus groups were arranged. The focus group discussions with the parents/caregivers commenced in January 2004. Prior to contacting the parents/caregivers, a comfortable non-threatening room for hosting the meeting, was secured at the School of Public Health Dental Assistants (PHDA) nearby to the clinic.

The discussion with the first group took place on 8<sup>th</sup> January 2004, and the second one was held on 20<sup>th</sup> January 2004. Before each session, the parents/caregivers were briefed about the purpose of the study, the importance of their participation in the study and the procedure that the discussion would follow. The parents/caregivers were also assured of confidentiality to eliminate their fear that their child's physiotherapist could get to know about individual responses. Permission to tape-record the discussions was sought from each group. The moderator, using the questions in the interview guide, conducted the discussion while the researcher as the observer got the opportunity to listen, write field notes and take care of the recording. The two group discussions were tape-recorded. Each session lasted approximately one and half-hours. Since the moderator was more fluent in Luganda than the researcher, each of them separately transcribed the recorded data and then met later on agreed dates to compare and discuss the transcripts. This helped to ensure that what is transcribed was truly what the participants said.

### **3.10 Trustworthiness**

In order to increase the trustworthiness of the study findings, the researcher and the moderator met immediately after every focus group discussion to discuss how the proceedings went and to assess whether the interview guide was fully covered and include any new issues that were brought up. They also critiqued the detailed field notes to ensure that what the researcher recorded was a true version of what the parents said. In addition, the researchers met again a week later with the moderator as a peer reviewer, to compare their transcribed data and to critique the meanings and interpretations of the transcribed data (Creswell, 1998).

### **3.11 Data analysis**

The data analysis commenced immediately after each of the meetings that the researcher held with the moderator after every focus group interview discussion and continued throughout their transcribing of the recordings. In order to ensure effective translation during the transcription of the findings, the transcribed data was scrutinised alongside the field notes. Then, the two transcripts from each focus group were compared and put together to make one transcript for each focus group.

The analysis of the qualitative data incorporates the processes of data reduction, data display and conclusion/verification, which occur before, during and after data collection (Huberman & Miles, 1994). It involves examining the meaning of peoples' words, actions and inductively deriving the research findings from the data (Maykut & Morehouse, 1994). The researcher continued the process of data transcription and categorisation. Through thorough

repeated reading of the transcripts and listening to the recordings over and over again, the emerging ideas were coded and grouped together into categories. The codes, which are abbreviations applied to a segment of words, sentence or paragraph, were derived from the research questions, theoretical concepts and important themes discussed in the literature review. Categories that were unique were left to stand on their own while the related categories were further coded into themes. A summary of the combined responses from the two focus groups was categorised into the pre-determined themes ready for interpretation.

### **3.12 Ethical issues.**

Permission to carry out the research was granted by the Faculty of Community Health Science higher degrees committee. Before commencing the study in Uganda, the necessary written permission to gain access and to use the CP clinic for the study was sought and granted by the Deputy Director of Mulago Hospital Complex and for Ethics and research committee (See Appendix 2). In this study, parents/caregivers were verbally asked for their consent to participate after they were thoroughly and clearly informed about the research and its purpose. They were assured their freedom to choose to withdraw at anytime and to ask questions before and during the focus group discussion. Consent to tape-record the discussion was obtained from the participants. Confidentiality and anonymity were guaranteed by not involving any of the staff working in Mulago as a moderator or observer in the study and avoiding use of participants' names. The information obtained will only be used for research purposes.

### **3.11 Summary**

This chapter discussed the research methodology used in the study. A qualitative exploratory research design employing focus group interviews was selected for the study. The site for the study was the CP clinic at Mulago Hospital in Uganda, which provides physiotherapy services for children with CP. Nine parents/caregivers who had met the specified selection criteria participated in the focus group discussions. The semi-structured interview guide was piloted and the necessary improvements were made on it before its use at the main study. Appropriate ethical issues were considered to gain access to the study site and to maintain confidentiality of the parents. The data was thematically analysed.

The next chapter presents the results of the study.

## CHAPTER FOUR

### RESULTS

#### 4.1 Introduction

This chapter presents the findings of the study that explored the expectations, experiences, satisfaction attained and the barriers/problems encountered by parents/caregivers of children with CP in Uganda. Transcribed verbatim excerpts from the parents/caregivers are quoted in such a way that the language of the informants is preserved. As a continuation of data analysis, the researcher continued with the coding of the transcribed data and categorizing the data into four main themes namely expectations, experiences, barriers/problems and suggestions. Sub-categories that emerged from the theme of experiences included: relationship with physiotherapist, physiotherapist's competence, knowledge gained by parent/caregiver, treatment process and parent/caregiver development of skills, home programme, child's improvement/outcome and meeting other parents. A brief description of the physiotherapy services at the CP clinic in Mulago hospital, as presented by the parents/caregivers, will be described first. This will be followed by a description of the parents/caregivers' expectations prior to coming to the physiotherapy CP clinic. The parents/caregivers' experiences of the treatment process and outcomes, the barriers/problems that prevent the parents/caregivers from regular attendance will follow and conclude with parents/caregivers' suggestions.

## **4.2 Services that parents/caregivers received from the physiotherapists at the CP clinic in Mulago hospital**

As the parents/caregivers had similar problems and interests, it did not take them long to acclimatize to the discussion. They listened to each other's contributions, which often stimulated new insights and helped them to develop their ideas more clearly.

Parents/caregivers talked about the information that the physiotherapist gave them about the problems of their children and how the therapists managed these children at Mulago hospital CP clinic. The physiotherapy services at the CP clinics as parents/caregivers described them can be broken into three broad categories namely the treatment, the support, and developing the necessary knowledge, skills and the positive attitude towards the child and themselves that is required in the management of a child with CP.

Parents/caregivers observed that after they are received at the clinic, the physiotherapist makes an assessment of each child's condition before starting treatment. Thereafter, parents/caregivers reported that the therapist spoke to each parent/caregiver. They say the physiotherapist explained to them the causes of cerebral palsy and how these causes bring about the problems that they see in their children. Some of the possible causes that they learnt from the physiotherapist included: prematurity at birth, prolonged labour leading to failure of the child to cry, fever and jaundice.

The Physiotherapist also briefly explained to the parents/caregivers the treatment that they would provide, the expected improvement and the prognosis of the condition of the child.

Parents/caregivers reported that the physiotherapist explained to them that the exercises given were meant to enable the children to perform those things that they are unable to do, or are doing poorly. The physiotherapist informed them that there is no cure for CP but parents/caregivers could expect some gradual improvements in the child's posture, body movement, performance of activities and independence in activities of daily living such as feeding and dressing. The improvement would vary from child to child depending on the degree of brain injury that the child incurred. Accordingly, parents/caregivers say the physiotherapist advised them to be patient and committed to the treatment regimes.

The parents/caregivers reported that before starting treatment, the physiotherapist usually encouraged the parents/caregivers to closely observe and follow what they were doing. The physiotherapist then proceeded to position the child and apply the various techniques to mobilise, stimulate, balance and correct the child's posture sometimes using equipment, apparatus and toys in the clinic. Most of these activities were carried out in the form of play while speaking with the child. After the exercises, parents/caregivers said they were usually asked to continue with what they observed at the clinic as part of their home programme.

In addition to the exercises, parents/caregivers reported that the physiotherapist sometimes advised them to buy apparatus such as corner seats, wheelchairs and brightly coloured toys or toys that make sounds. Such apparatus would help to stimulate the child and contribute to the improvement of the development of the child. However, most parents/caregivers reported they found the apparatus and the toys expensive. They were also not easily available. In order to ensure continuity of the treatment and home programme,

parents/caregivers said the physiotherapist advised them to improvise by making the apparatus using materials available locally such as, banana stems, household materials and furniture. However, although the physiotherapist described how to make the improvised apparatus and toys, parents/caregivers said they never demonstrated to them how to make to them while at the clinic.

The physiotherapist also encouraged parents/caregivers to interact with the children through speaking and play. Parents/caregivers reported that the physiotherapist advised them to make toys and create some activities/ games that they, together with other children and members of the family, make time to play with the child.

Apart from treatment and developing the necessary knowledge and skills, parents/caregivers said that the physiotherapist supported them by giving them information on other matters. Parents/caregivers specifically mentioned support on relevant nutrition, keeping the child clean and healthy and, referring them to schools for children with special needs for education when necessary.

#### **4.3 Parents/caregivers' prior expectations of the child's improvement and service from the physiotherapist**

Parents/caregivers spoke about their expectations for their children's improvement through physiotherapy treatment before coming to the physiotherapy CP clinic at Mulago hospital. The parents/caregivers reported that they expected their children to grow and develop like other children without disabilities, (*“normal”*) children. All of them said they expected the



child to progress through all the stages and finally be able to walk. Some of the parents for example said:

*“I expected my child to be able to carry out the normal things that other children can do”.*

*“I expected that my child would learn to stand and eventually be able to walk...”.*

*“I wanted the therapist to work on my child so that she could be able to crawl, sit, stand and walk...”.*

Parents/caregivers also expected their children to be able to use their hands to hold objects and feed themselves as exemplified by the following statements made by two parents:

*“When I brought the child for exercises, I expected her first to be able to sit and then feed herself”.*

*“I also expected my child to be able to reach out and hold objects which right now she cannot do...”.*

Apart from the child attaining independence in those activities, parents/caregivers also expected to learn the causes of their children’s condition from the physiotherapist, how long the condition would take to improve and to be shown how to overcome it. Thus some of them said:

*“I expected the physiotherapist to explain to me what is wrong with my child, how long it would take for the child to get all right...”.*

*“I wanted to know what happened to my child, how long I am expected to do exercises before the child becomes “normal” like other children”.*

*“I expected to be shown exercises that would strengthen my child’s body ... so that he could be able to carry out some activities. I also expected to receive proper treatment from the clinic”.*

#### **4.4 Parent/caregiver’s experiences of the provision of physiotherapy services at**

##### **Mulago hospital CP clinic**

##### **4. 4. 1. Parent/caregiver’s relationship with the physiotherapist**

Parents/caregivers spoke about their relationship with the physiotherapist. All the parents/caregivers reported that they were well received by the physiotherapist at the clinic. They described the physiotherapist as social, courteous and kind. The physiotherapist also showed a lot of compassion and concern for the parents/caregivers and the children. No parent/caregiver reported harassment, discrimination or neglect at the clinic. The physiotherapist attended equally well to all the parents/caregivers irrespective of their social status:

*“They received us well, talked to us with great concern without segregating on whether the child was clean or poorly cared for and minding about the parent’s status”.*

*“They handled us well, and also took good care of the children... There was no shouting at the parent or child”.*

Furthermore, parents/caregivers described how the physiotherapist worked on their children with great care and empathy. They extended love, compassion and concern to both the children and the parents/caregivers. In addition, the physiotherapist was responsive to parents/caregivers' needs and those of the children as were reflected in the parents/caregivers' statements below:

*“The physiotherapists handled us with care and also took good care of the children”.*

*“The physiotherapist that I found here never harassed me and handled my child with kindness...she advised me too to be kind to the child”*

#### **4.4.1.2 Physiotherapist's competence**

The majority of the parents/caregivers expressed that they were impressed with the way the physiotherapist handled the child. They felt that the physiotherapists were competent and that their work on the children met with their satisfaction:

*“They have the skill, but may not have the time...”*

*“I am impressed with the services that I received. The child was well handled...”.*

*“They worked on the child and by the end of the session, you could also admit that the child had really been treated”.*

Three of the parents/caregivers however, felt that because of the short time that physiotherapist spent with each child, the treatment given was inadequate. Other parents/caregivers also felt that not all physiotherapists were equally skilled. They said that

some physiotherapists did not address some obvious key functional problems of the children and which, were the reason why they had actually come to the clinic:

*“My child for example, has a floppy neck and cannot sit. They just moved the neck and the legs and that was all”.*

*“Sometimes the therapist would want to train my child standing by strapping her on the frame... But because of her stiffness and the many jerky movements, it was a real struggle to strap her. The moment she cried the therapist removed her in less than ten minutes. Then I would lament on how much had been achieved...”*

Meanwhile, to describe the responsiveness that they saw, parents/caregivers explained that their physiotherapist always reported to work and attended to all parents/caregivers who came. Sometimes the physiotherapist needed to work through lunchtime in order to see everybody:

*“The physiotherapist at least never failed to turn up...”.*

*“The physiotherapist made sure that all the parents that had come were attended to and no one went away without treatment”.*

*“That is true; they never left any child untreated”.*

*“They would come late, but they worked on us all. They sometimes would not go to eat their lunch”.*

However, two parents/caregivers pointed out that there were occasions when the physiotherapist was not responsive to their needs or their child’s needs:

*“I one time came and I was kept waiting unattended for so long and yet the physiotherapist was inside doing her own things... I felt bad because both the child and I became tired and hungry”.*

*“When you come to hospital, you would expect some help.... But when you arrive and the person does not care and it appears like you have gone there to treat yourself.... You either help yourself or start to find your way out.... Do you see what I mean...? The physiotherapist was however still better than some clinics where you may not even be attended to”.*

Parents/caregivers were also not happy with the frequency of the appointments and the opening hours at the clinic. They complained that the appointments were spread over long periods. Appointments were given a month or more apart irrespective of whether the child was a new or an old attendant at the clinic. In addition, the clinic did not open before eleven o'clock in the morning and yet some appointments were given for as early as 8 a.m. Parents/caregivers felt that this was not fair for parents/caregivers who arrived at their appointment time or who came from far away and expected treatment at the time they were given hoping to return home early to attend to other things. Parents/caregivers described the long waiting time as exhausting, irritating and time wasting. The following are some of their statements:

*“The appointments were too far apart. Probably they could be made more regular”.*

*“The bad thing was that you were given an early appointment of eight o’clock and indeed you arrived that early and sat up to ten o’clock without seeing any physiotherapist.... When finally the physiotherapist arrives, and since he/she is alone, by the time they finalise organising themselves, the clinic starts operating by eleven o’clock.*

*“I arrived hoping the therapist would immediately attend to me...but I sat in the line until I could fall asleep, my God! Then I began to lament; ‘there goes another time wasted’ ...”*

In addition, parents/caregivers complained about the rotation of the physiotherapists and how it affected them. Sometimes the new physiotherapist was not seen to be as good or as competent as the one they had before. All these changes in physiotherapists had negative impact on both the parents/caregivers and the children. Some parents/caregivers said:

*“Sometimes by bad chance, the physiotherapist brought may not be good, caring and hardworking like the one who was there before...it discourages us. The parent loses enthusiasm that had been gained in caring and helping the child”.*

*“Usually when one is in a new place, it is only right to inquire from the parent what they have been doing with the previous therapist. But the incoming physiotherapist never did so. They straight away start on their own programme...”*

#### 4.4.2 Experiences of knowledge gained by parents/caregivers

Parents/caregivers spoke of the explanations that they had been given by different physiotherapists. Some physiotherapists gave them clear explanations. Others did not explain the problem of the child, the purpose of the treatment or how it would help the child. Others would try to explain but failed to explain clearly. But they were all in agreement that the physiotherapists usually explained whatever they did as they worked on the child and parents/caregivers were free to ask the physiotherapist to repeat whatever they had not understood.

Most of the parents/caregivers reported that the explanations about the causes of CP were clear and they understood them well. However, the majority of the parents/caregivers in the first focus group reported that they never received any explanation on how these causes brought about the problems that they see their children experiencing. On this point the parents were divided into groups of those who knew a lot and those who did not know much about the child's condition. As a result some of the parents did not understand the condition of their children or what progress to expect:

*“The physiotherapist did not explain to me why the child is like that, yet I would very much have liked to know”.*

*“The physiotherapist did not explain to me why the child is floppy but only told me to buy a corner seat...”*

*“The physiotherapist never told me why the child could not sit, crawl or even walk; she only told me to continue with exercises...”*

*“But those jerky movements... that is why I wanted the physiotherapist to tell me, when would those strange movements stop? What should I do to make sure that she does not jerk?”*

One of the parents/caregivers felt that sometimes the physiotherapists were not always direct or frank with them, but only kept giving them reassurance:

*“Most physiotherapists did not explain how long it would take for the child to improve. They kept on saying that the child would be all right...I would have liked to be told that perhaps in 5 years times the child will sit...”.*

The other parents/caregivers, who said they had received sufficient explanation about the effect of brain damage on the child, recognised that their interaction with the physiotherapists had enabled them to learn a lot about the child’s problems. These parents/caregivers said they were now aware that the child would develop slowly, would be delayed in learning the normal activities of movement and may never be able to study in an ordinary primary school. They assertively said:

*“I was given explanations and I came to fully understand my child’s problem”.*

*“My visit to the physiotherapist has helped me a lot. I received enough explanation about my child’s problems... I came to understand why he is like that”.*



*“The physiotherapist explained to me my child’s problems... He told me that it does not take one day or week for the child with CP to improve, but it takes long...I learnt that it would take him long to improve...”*

*“The physiotherapist told me that the child had a brain damage would not be able to study in any ordinary primary school where other “normal” children (children without disabilities) go...”*

#### **4.4.3 Experiences of the treatment process and the parent/caregiver’s development of skills**

Parents/caregivers spoke about how the physiotherapist taught them, talked to them and decided on what home programme to give them. The majority of the parents/caregivers reported that whenever they attended the clinic, the physiotherapist treated the child while they observed. Thereafter the physiotherapist would ask them to do the same exercises at home. Most of them said:

*“The physiotherapist would first work on the child while I watched on, then she would tell me to go and carry out the same exercises at home...”*

Earlier in the discussion, parents/caregivers in the first group were asked how the physiotherapist taught them how to handle and exercise the child. Some of them said the physiotherapist told them what to do, did some demonstrations and then supervised them trying it out. Those parents/caregivers said they understood most of what was shown to them. But with further probing, the majority of the parents/caregivers complained about the amount of teaching, the demonstrations and the feedback/correction of their skills that the

physiotherapist provided. They felt the teaching was as inadequate. Parents/caregivers said that the physiotherapist did not set time aside for teaching, demonstrating techniques to parents/caregivers individually or time for parents/caregivers to practice techniques under the physiotherapists' guidance and supervision. They concentrated more on doing the activities themselves. Thus, the parent/caregivers' teaching and learning was limited to what they observed when watching the physiotherapist treating the child. The following statements from the parents/caregivers support this:

*“Did you want to know whether the therapist had time to teach us how to do this or the other? Ahha, that never happened...”*

*“Teaching, they never taught us”.* (All together)

*“The physiotherapist did not have enough time to teach us skills. We had to follow along what she was doing and made sure that we grasp what to do by watching her working... But she did not have the time to get back to teach you or demonstrate to you...”*

In addition, the physiotherapist rarely gave the parents/caregivers a chance to ask questions to clarify their understanding. Neither did they take the initiative to find out from the parents/caregivers whether there were any issues they may have liked to discuss with them. This is illustrated by some of the following statements from the parents/caregivers:

*“The physiotherapist never asked me any question. As long as they finished working on my child, they reminded me to do the same at home”.*

*“But fortunately, since I usually watched her closely, I grasped what she was doing. But I have never been asked whether there was anything that I had not understood”.*

Parents/caregivers whose children have feeding problems felt that the physiotherapist did not help them to understand the child’s problem nor guide them on how to manage it. They therefore continued feeding the children by forcing food and drinks into their mouths. This left them feeling frustrated and discouraged:

*“I have never been advised on how to feed the child or what to give him...”.*

*“He sits well.... But he has kept on biting his fingers and pouring a lot of saliva. I asked the physiotherapist what I could do and she told me to continue taking care of him. But I do not see any more care that I should provide. I have given up on the finger biting and saliva”*

*“My child has a problem with feeding.... I told the therapist about it and she advised me to give him milk in porridge, but the problem still continues.... I have continued to give him the porridge by force by just pouring it into his mouth...”.*

*“My child drinks well, but eating is his big problem. He does not like the food. We sometimes have to give him by force”.*

The parents/caregivers in their explanations attributed the failure of their physiotherapist to attend to their individual problems adequately to the large number of children that the physiotherapist had to handle, thus forcing them to limit the time spent on each parent:

*“The problem here is the little time available to the physiotherapists”*

*“Yes, the time was not enough”*

*“That is why we feel that there should be another physiotherapist to help her, because the children are many and they all have to be worked on”.*

The few parents/caregivers, who had a chance to have more time with the physiotherapist asked more questions and also reported that the physiotherapists helped them solve some problems, taught as well as demonstrated to them what to do. As a result, they had learnt some skills from them. These parents/caregivers stated with satisfaction:

*“They were good to me... they solved my problems and answered any questions that I asked them”.*

*“The physiotherapist taught me how to carry out exercises for the whole body...position the head in the middle and align the trunk correctly so that the child could sit...”.*

*“I am impressed...I never expected that my child could ever sit... I was taught what to do... I was shown how to use sticks for standing and I tried that as well. I have already constructed parallel bars at home”.*

Parents/caregivers also encountered problems with acquiring appliances recommended by the physiotherapist such as corner seats, wheelchairs or splints. Most of them said that they

were poor and therefore could not afford the apparatus and appliances. Those parents/caregivers who could afford to purchase them were frustrated by the fact that they were not available at the clinic. Although the workshop at Mulago hospital made some of the appliances, the bureaucratic procedures of getting them discouraged parents/caregivers following up to purchase them especially those who came from districts far way. The parents/caregivers expressed their feelings as follows:

*“The truth is that sometimes the physiotherapist would tell us to buy for the child apparatus like a chair, but the truth was that we did not actually have the money”.*

*“Sometimes they recommended for the child certain items such as shoes, chairs.... I would suggest that the prices of these appliances be reduced so that even we who are poor can help our children to gain some function and ability to participate in daily activities.... As it is now, it is only the children of the rich parents who can afford who benefit... my child continues to grow, becomes more stiffer and adds us more problems”.*

#### **4.4.4 Experience of development of parent/caregiver’s attitudinal changes**

Parents/caregivers were not specifically asked about their attitudes towards having a child with CP, but some of them made following observations:

*“When I observed the way the physiotherapist showed friendliness to my child and others, I came to appreciate that my child needs to be shown understanding and kindness. I actually started showing love of my child and being keen to learn what the therapist taught me”*

*“I began to appreciate the value of exercises in helping my child. Originally I thought that my child needed drugs to gain strength”.*

*“...It has made people to appreciate that exercises are good for these children... those who visit us and who were doubtful became convinced that exercises are helpful”.*

#### **4.4.5 Parent/caregiver’s experiences of home programmes**

Most of the parents/caregivers appreciated the benefits of the exercises and home programmes that had been recommended to them. They reported that the home programmes had contributed immensely to the improvement in the movements and activities that their children were able to do:

*“The home programme has helped my child a lot... For a long time she could not sit and lay down most of the time...then gradually I realised the neck improving, she sat, crawled and she can now stand”.*

*“I confidently say that I have noticed a great change in my child as a result of what we did at home...the child I never hoped to rise can now sit, and crawl...”*

*“The way I see it, the exercises or home programme have helped my child a lot... I am much better off than if I had not attended or received advice on home exercises”*

*“The home programme has drawn the family closer to the child and he is also aware of it...”*

In addition, the improvised appliances they used at home had also contributed to enhancing the condition of the children. The use of a corner seat or a chair for sitting for example had made the feeding of the child easier, improved the child's vision and made the children more active as was described by two of the parents/caregivers:

*“Feeding the child while seated on a chair has made the feeding much easier. The chair limits her from continuously moving the head from one side to the other. The hands are held in one place on the table and she eats well in that position”.*

*“When I sit him on the chair...he can see very well, is more active and it is also easier to take him outside to play.... And it is different from when I carried him on my lap where he would just relax away... I can also leave him there while I do my work...”*

When asked whether the physiotherapist involved them in deciding the home programmes, the parents/caregiver reported that the physiotherapist usually first inquired what materials were available in ones home. It was on the basis of this information that the physiotherapist recommended suitable materials and how to make the improvised appliances or toys:

*“The physiotherapist showed me the roll and said “look at this thing, I am not asking you to buy it because it is expensive. But when you return home, get a blanket and roll it into this shape...”.*

*“She asked me whether I could find a banana stem or a 20-litre jerrycan at home. Then she told me to cut a piece of the banana stem, cover it with cloth.... Then she*

*told me to continue at home with the same exercises that I saw at the clinic using these apparatus”.*

However, apart from the sharing ideas and how to improvise when making the appliances for home use, the parents/caregivers reported that they were not consulted in deciding the home programme and, how often the parent/caregiver was supposed to implement it. They complained that the physiotherapist always worked in a hurry, leaving them limited chances for discussion or for asking questions. As a result, the physiotherapist sometimes never inquired whether or not the home programme had been implemented. Parents/caregivers were quick to add that, since they were interested in the child’s improvement, they always tried to implement the home programme as directed by the physiotherapist. Parents/caregivers had this to say:

*“The physiotherapist decides which programme to give you depending on the level of activity that your child has reached...she is guided by what the child could have done as a “normal” person...you are told what to do according to your child’s performance”.*

*“But the physiotherapist was always in a hurry. Once you were in the room and they had worked on your child, you were told to leave the room so that another person enters. Could you really stay on hanging on because you want to ask questions when another person has already been called in?”*

*“The physiotherapist at times would not bother to find out whether you had done the home exercises or not... there was no discussion to follow up whether the home*



*programme was implemented or how much was achieved... ”*

Two parents/caregivers however, who usually stayed at home with their children, reported that they had enough time and people at home to help exercise the child. They found no problems with implementing the home programmes. This would be even easier if the appropriate appliances were available. The majority of parents/caregivers found it difficult to implement the home programme because of lack of time, pressure from other work, fatigue and the absence of other persons and children in the family to assist.

#### **4.4.6 Parent/caregiver’s experience of their child’s improvement/outcome**

All the parents/caregivers cheerfully reported some improvement in their children. Those who had received treatment at the clinic for a longer period reported more improvement. The improvement included a change in behaviour such as reduced crying, drooling and banging the head against objects as well as active involvement in many activities. The improvement in activities included the child’s ability to control the head, to hold objects to feed him or herself, to sit, to creep, to crawl and to stand or walk with support. Parents/caregivers for example said:

*“I have really noticed a lot of improvement.... He used to sit stooping forwards but he now sits upright... was pouring a lot of saliva but that has stopped. He cried for a whole year... but even that stopped. He could not stand on his own...but can now do so with some support. I really have strong hope that he will continue to improve”.*

*“When I brought my child, the neck was very soft and floppy. There is improvement in the neck/head control now...”*

*“At first my child could not hold a cup, but through exercises, she can now grip, hold her cup and drink”.*

*“She has managed to attain all the major activities.... The only activities that are remaining for her to learn are standing, walking and speaking... So I have noticed a lot of improvement”.*

*“Mine cannot stand, but can try to feed herself with someone helping to stabilize the cup...she understands everything that anybody tells her...craws to fetch any object...points at something if she needs it since she cannot talk”.*

Furthermore, parents/caregivers described how improvement gained had enabled the child to participate in activities of daily living such as dressing, bathing, feeding, toileting and communicating with members of the family:

*“The arms have become less stiff...dressing and bathing him have become much easier. He puts his arms out of the sleeve much faster...He can sit and I give him something to eat or drink... and he plays while I carry out some washing of clothes”.*

*“His hearing has greatly improved. He smiles when he hears people chatting or laughing...”*

*“He turns around to look at the person calling him...then he smiles.*

*Originally he could not turn around at all...he now appreciates what is done to him”.*

*“He wriggles about and cries when he wants a ‘potty’. He only soils himself if someone delays to attend to him”.*

#### **4.4. 7 Parent/caregiver’s experiences on meeting other parents**

All the parents/caregivers reported that they were pleased to meet other parents with children who have similar problems like those of their own child. Some parents/caregivers said they were able to see children of different ages, some of them with even more disabilities than their own child. Parents/caregivers, who had stayed longer in the clinic, said they had noticed that the number of children with CP brought to the clinic was increasing. They asserted that they learnt a lot from meeting other parents/caregivers at the CP clinic as they had shared their problems and achievements in their discussions. The discussions gave them encouragement and motivation to continue with the treatment. Seeing other children and parents/caregivers with the same difficulties strengthened their resolution to struggle on. It relieved them of frustration and gave them reassurance that all was not lost, and that they were not alone:

*“I do not have bad comments... I met other parents and I got encouraged. Whereas when I was in the village, I thought I was the only one with such a child. But I realised from here that there are many such children.... I feel more encouraged to look after my child well”.*

*“When I came to the clinic, I sometimes noticed that my child was much better than the others...then I convinced myself to persevere and continue to struggle...after all other parents of children with problems worse than mine had not given up”.*

*“...I met other parents with children of different ages; some were young and others were older...I was able to notice the different stages of the possible improvement from observing the children and through talking with their parents”.*

*“Whenever I came to the clinic, I found that the number of children was increasing...each child that was brought presented differently from the one I last saw and each had own specific problems...”.*

One parent however, pointed out that it is sometimes frustrating to hear other parents narrate some of their child’s achievements. This is particularly so for those achievements associated with benefits of using appliances or things that cost much money which one could not afford yet, if one could get them, would help ones’ child as well.

#### **4.5 Barriers/ problems to parent/caregiver’s utilisation of physiotherapy services at Mulago hospital CP clinic.**

Parents/caregivers were asked what encounters prevented them from frequently attending the clinic. Most parents/caregivers reported that they stayed a distance away from Mulago hospital. Some of them said they came from far away and incurred high costs on transport. Most of the parents/caregivers identified the lack of funds for transport as their main problem:

*“My problem is that when I am given the appointment date, I have to look for money to bring me from Busoga to Kampala and to take me back...”*

*“Transport indeed is our major problem... sometimes the appointment finds me when I have not yet raised the funds for transport...”*

*“My home is 3 miles from the main road so I have to walk to where I can take a taxi. But the hospital itself is also far away”*

In addition, parents/caregivers claimed there were other parents/caregivers in the community who have children with CP, but could not bring them to the clinic because they were very poor. Some parents/caregivers, they said, might not be aware of the availability of these services at Mulago hospital. While some of the parents/caregivers, who have never visited the hospital, may not know how to find their way within the hospital to the clinic.

Carrying bigger or older children in public transport to the clinic was also a big problem. Parents/caregivers said some taxi operators harassed the mothers and their taxis did not have racks for transporting wheelchairs. This was compounded by the unhelpful attitude of some spouses who denied the child and mother assistance, making it difficult for the mother to meet expenses like transport and drugs and the moral support she needed to persevere. Some parents/caregivers had this to say:

*“Transporting these children to hospital is expensive...I have to carry him on my back for two miles from my house to a point where I can take a taxi...even if I decided*

*to wheel him on the wheel chair that I was lucky to get, the taxi owners do not have room for it. So they resort to uttering words at me, asking where we get such children”.*

*“I am the one who looks after the child and the father insists he does not produce “disabled” children. I have to make sure that I get some kind of job to earn money to meet the expenses”.*

Other barriers included societal attitude of associating the child’s condition with unfulfilled ritual of even witchcraft. Parents/caregivers also expressed that other commitments like workload in the home, office or business, often competed with the appointments, making it difficult for them to fulfill the appointments or home programme as instructed.

#### **4.6 Parents/caregivers’ suggestions for improvement**

Parents/caregivers presented some suggestions in relation to the delivery of services at the CP clinic. They felt that they could benefit more from the services if the appointments were made more frequent and the clinic opened early say, by 8.30 am or 9.00 am. They also suggested maintaining the same physiotherapist to work in the clinic for a minimum of two years or, have one to stay there permanently. They felt that the physiotherapists needed time to establish a relationship with the parents that would enable them to communicate adequately and freely with the parents. In addition, the number of physiotherapists at the clinic should be increased to be able to cope effectively with the rising number of children

that are brought each day to the clinic. Parents/caregivers also suggested that corner seats, and other appliances be made available at the clinic at subsidised and affordable prices.

Furthermore, parents/caregivers were concerned about the other parents/caregivers of children with CP who are within the community and are too poor to travel to Mulago hospital clinic. They proposed extending services to these parents through physiotherapy out-reach clinics operated at the community levels and in the districts as well.

The critical analysis of these parents/caregivers' expectations and their actual experiences at the clinic will form the focus of the discussion in next chapter to determine the satisfaction that these parents/caregivers attained by utilising the services provided in the CP clinic at Mulago hospital.

## CHAPTER FIVE

### DISCUSSION

#### **5.1 Introduction**

This chapter discusses the findings from parents/caregivers who received physiotherapy services from the CP clinic at Mulago hospital. This discussion aims to answer the research question: what satisfaction do parents/caregivers of children with CP attain by utilising the physiotherapy services provided at Mulago CP clinic? Various researchers have related service quality and customer satisfaction to ‘matching’ the expectation of the service with what is actually experienced by the customer. This discussion will therefore focus on the experiences parents/caregivers reported on service quality and ‘match’ them with their prior expectations before coming to the clinic. In addition, the discussion will also outline the barriers/problems reported by the parents/caregivers.

#### **5.2 Parent/caregiver experience on child “normalisation” and improvement/outcome**

One of the expectations that most of the parents/caregivers in this study reported was that they expected their children to grow and develop like other children without disabilities (“*Normal*”) children. This expectation is consistent with the findings by Anderson and Venter (1997) in South Africa and, Parkes et al. (2002) in Northern Ireland where parents expected their children to attain various levels of independence in different activities including walking. Parental hopes for a normal child are not uncommon in any society. But because physiotherapy focuses on facilitating the child’s ability to do things by him or her self, it may contribute to some high expectations and unrealistic hopes among the parents.



This is very true especially among those parents who are not given explanations about the child's condition.

After receiving physiotherapy services from the CP clinic at Mulago hospital, all the parents/caregivers gladly reported some improvement in their children. Those who had received treatment at the clinic for a longer period reported more improvement than those who had just started attending the clinic. Each parent/caregiver was eager to express the satisfaction they had attained each time they noticed improvement in the child's behaviour, activities and any independence that the child showed. Potter, Gordon and Hamer's (2003) finding that symptomatic relief is one of the most important patient expectations, could explain the reason for the parents/caregivers' satisfaction. Their expectations had been fulfilled by the symptomatic improvement that each of them had seen in their children and so they had reason to be satisfied with the service.

However, it is not certain as to whether the parents/caregivers continued to maintain the expectation of a "normal" child. Although a few of them, especially those who were satisfied with the explanations that they received about the child's condition, seemed to have accepted the child as "all right" with the disability. Nonetheless, Jackson and Kroenke (2001) in their study of unmet expectations among adults presenting with physical symptoms, concluded that parents who seek for physical changes and do not leave the encounter with an unmet expectation are more likely to be satisfied with their care and have less worry about the serious illness. So it is possible that more parents/caregivers may begin to accept the

child's disability, as they keep realising gradual increase in improvement in the child's physical function and activities.

Meanwhile, Rey, O'Brien and Walter (2002) studied the relationship between outcome and parent satisfaction in a child and adolescent mental health service. The researchers reported that satisfied parents were eight times more likely to have a child rated as having had a satisfactory outcome by the clinician. Also, children of satisfied parents were six times more likely to have been rated as improved. Consequently, Rey et al. (2002) suggested that parental satisfaction is associated with outcome of treatment contrary to previous reports. Although it is argued that many variables such as rapport with the physiotherapist (Rey, Plapp & Simpson, 1999), explanation of diagnosis and prognosis (Potter et al., 2003) influence parental satisfaction with treatment. Nevertheless, Rey et al. (2002) asserted that it makes intuitive sense that clinical improvement and achievement of the goals of the intervention are important factors. That is why all the parents/caregivers in this study, despite some dissatisfaction that they might have experienced, reported satisfaction with the services since each had noted some improvement of the child.

### **5.3 Parent/caregiver's experience of provision of knowledge and information**

Parents/caregivers also expected the physiotherapists to provide them with clear explanations about their child's condition. According to Hargie, Saunders and Dickson, (1994), the purpose of explanations is to provide others with information that they may otherwise not have access to, simplify for others more complex phenomena and to clarify any uncertainties during any interaction. Most medical conditions and issues are complex

phenomena to most parents/patients. Therefore, explaining the child's condition required the physiotherapist to give parents/caregivers information about the diagnosis and the prognosis of the child's health and care which they found unfamiliar. The parents/caregivers' desire for information could be compared with those from other studies elsewhere. For example, Potter et al. (2003) in a study to identify physiotherapist and patient expectations in private practice in Australia found that out of the sample of twenty six patients, 50% of the patient groups expected that their physiotherapist would provide appropriate explanation about the problem, liaise with other professionals treating them and, would provide them with diagnostic and prognostic information about their condition. Similarly, Russell, Luthra, Wright & Golby (2003) while investigating parent's concerns, experiences and expectations in managing otitis media in children in Manchester also reported that parents expected the physician to primarily make a diagnosis followed by an explanation and discussion.

Parents/caregivers in this study however, reported inconsistency in the ability of the physiotherapists to explain the problem of the child, the purpose of the treatment or how it would help the child. Likewise, Hiidenhovi, Hannele, Nojonen Kaija, Laippala and Pekka (2002) at Tampere University hospital in Finland, found that the poorest ratings from outpatients' views on quality of service in the hospital were related to access to information. According to Hargie et al. (1994), explaining involves giving facts, information, directions, reasons and views or opinions. And, the capability to explain is directly related to the background knowledge and mental ability. More so, most medical situations that involve interpretive explanations expect the therapist to define or clarify issues, procedures and

statements and also be prepared prior to the actual explaining episode. Based on these facts, one could deduce that the inconsistency to give clear explanations indicates that the physiotherapists working at the CP clinic at Mulago hospital lacked adequate knowledge in CP and/or were at times not fully prepared for the explanations.

Secondly, Hargie et al. (1994) emphasise that any explanation must contain language, which is appropriate to the intellectual capacity of the listener. Whereas professionals inevitably use technical terms to their fellow workers, it is important to translate the 'specialised' terms into everyday terms so that the clients are not confused in their understanding of facts and events. Sluijs, Van der Zee, and Kok (1993) from their findings reported that physiotherapists do encounter some problems when educating patients/parents. The researchers for example, reported that many physiotherapists find it difficult to put medical terminology into a language that is readily understandable by patients. They also find it difficult to tailor advice to the patient's situation and also to motivate patients to change their beliefs. Considering that the parents/caregivers were from different social and educational status, it was the onus of the physiotherapists to ascertain at what level to pitch the explanation in order to achieve a balance between being too complicated on one hand and too belittling on the other. Besides, many patients/parents have a tendency to forget half of the information when given a lot of it at one time. In addition, the researchers observed that physiotherapists differed in the amount of stress-related counselling and the attention that they give to patients' demands and perceptions. So one cannot therefore rule out the possibility that in addition to the problems that physiotherapists might have encountered, a few physiotherapists at the CP clinic in Mulago hospital did not consider it important to

provide the parents/caregivers with information on the diagnosis or prognosis of their child, while some others did so, or they just did not have the skill to do it.

This indicates, in this study, that parents/caregivers who were well informed about the child's condition were satisfied with the physiotherapist's explanations. They kept their expectations within the child's level of impairment and ability, felt comfortable with the child and were willing to participate in whatever would promote the child's improvement. Whereas the other parents/caregivers who received incomplete or no explanation lamented, were dissatisfied and remained frustrated about not understanding the child's problems. These findings are consistent with other studies, demonstrating that the patients value information highly (Hall, Roter & Katz, 1998; Krupart, Fancey & Cleary, 2000), particularly health education and discussion of treatment (Robbins et al., 1993).

Furthermore, Starke and Moller (2002) in their study to understand parents' need for knowledge showed that the parents have a motive to learn more about the condition of their child. Satisfied mothers particularly argued that they needed information to enable them to explain the condition to others. In addition, Jackson and Kroenke (2001) found that all patients (98%) usually have at least a pre-visit expectation, the core one being that they will learn what the diagnosis is. They also found out that immediately after the visit, that the most common unmet expectations were related to information on prognosis or on diagnosis. Patients with no unmet expectations had greater satisfaction. Accordingly, the researchers concluded that diagnostic and prognostic information are particularly valued by patients and may be associated with greater improvement in symptoms and functional status after the

visit. This could therefore explain why those parents/caregivers who failed to get the information on the diagnosis or prognosis of their child were dissatisfied with the explanations that they received from their physiotherapist.

### **5.3.1 Disclosure of diagnosis and/or prognosis**

A complaint was raised by one of the parents/caregivers that most physiotherapists did not directly inform them how long it would take for the child to improve. The parent wanted to be given an idea about the duration of full recovery. Similarly, one third of the 53 families of parents of children suffering from Duchenne muscular dystrophy were not satisfied with the way the diagnosis had been communicated. Parents preferred to know as soon as possible if there was something wrong with their child Firth (1983). Both Duchenne muscular dystrophy and CP are chronic physically disabling conditions that keep parents anxious and frustrated. In such circumstances, Hough (1987) argues that no news is bad news because imaginary fears are usually worse than reality. Recent studies have showed that parents were more likely to be satisfied with the disclosure if the professional making the disclosure has a sympathetic understanding and appropriate manner; was direct and communicated well; and if they had been given sufficient information and opportunities to ask questions (Hasnant & Graves, 2000; Solper & Turner, 1993). Furthermore, it was also observed that parents who found the amount of information they received overwhelming were more satisfied than parents who found the amount adequate. This was an indication that the parents wish to receive as much information as possible at the time of disclosure. According to Firth (1983), honest information facilitates the adjustment process of the parent or person

incapacitated by the disability. Hence, the researcher asserts that evidence from parents of children with disabilities shows that providing information as soon as possible is desirable.

Other studies however have shown that people differ in their style of coping. Some may wish to be more and better informed than others. Kai (1996) suggests that information and education for parents is best made available to those who want it rather than disseminating it to everyone. Alternatively, if the parent complains of receiving inadequate information, they can be advised to prepare questions ahead of the meeting with the physiotherapist (Hough, 1987). Nonetheless, it is also reported that anxiety and fear alter the way a person listens, remembers and chooses what to hear. And sometimes medical staff may tend to conceal the information in order to reduce the perceived distress. This could explain why some of the physiotherapists at Mulago Hospital CP clinic delayed telling the parents the truth about the prognosis of their child.

#### **5.4 Parent/caregiver's experience of the provision of knowledge and skills**

Another important expectation that parents/caregivers reported was that they expected to get the necessary knowledge and skills from their physiotherapist that would enable them to understand and manage the child. They said that they came to the clinic expecting the physiotherapist to show them how to do exercise that would enable their children to recover or at least to improve. These findings are similar to those reported by Potter et al. (2003), which in addition to symptomatic relief, identified self-management strategies and "hands-on" treatment as most important patient expectations.

A review of what parents/caregivers reported shows that most of the parents/caregivers in this study were satisfied with the way the physiotherapist explained their actions as they worked on the child. Some of them were satisfied with the competence of the physiotherapist while the majorities were satisfied with the practical solutions and/or alternatives that their physiotherapist recommended to them especially on the home programmes and the appropriate appliances. In addition, the few parents/caregivers who had encountered a physiotherapist who taught them solved their problems and demonstrated to them what to do, have learnt some skills. This group of parents/caregivers too, was satisfied with the service that they had received. However, the majority of the parents/caregivers were dissatisfied the teaching, which they felt, was inadequate.

Patient education forms part of nearly all physiotherapist-patient encounters. But, it is also known that there are large variations in the kind and amount of education that patients/parents receive from physiotherapists (Sluijs, 1991). Sluijs, et al. (1993) cited the works of many other researchers who confirmed that the quality, the kinds and the amount of education provided to patients as well as the manner in which it is given are important. These 'quality' aspects can contribute to patients' satisfaction and boost memory and compliance. In their study, Sluijs et al. found that those physiotherapists who believed in the view that their education of patients contributes to 'patients becoming more interested in the treatment', 'patients becoming more satisfied', and 'patients recovering from illness quickly', gave their patients both more and better education than those who did not believe in the same view. Furthermore, the physiotherapists who were more optimistic about their patients' compliance gave them more instructions in home exercises and appeared to have better relationship with their patients. To the researchers, these findings meant that the



physiotherapists, who inform, instruct and advice their patients most are those who follow a systematic plan of treatment, provide counseling in case of psychosocial complaints and have a good relationship with their patients. The achievement of such a service requires that the physiotherapists spend more time with their patients. Parents/caregivers in this study complained that the time that the physiotherapist spent with each of them and the child was inadequate. This means that the parents/caregivers missed a lot from their physiotherapist due to limitation of time. This could have influenced their dissatisfaction. Indeed, Siu-chee Chan and Twinn (2003) reported that parents in Hong Kong also felt very dissatisfied with the time allocated for the consultation.

According to Sluijs et al. (1993), overworked practitioners are less likely to pay attention to their patients' demands, perceptions or follow a systematic approach to treatment. They are also likely to be judged to have poorer relationships with their patients. In addition, Bagwell (1987) observed that 'feeling rushed' influenced parents' perception of quality of services provided. These observations could explain why the parents/caregivers in this study were dissatisfied with the physiotherapist working in a hurry. They perceived the teaching as poor and above all, they did not achieve much of the knowledge, skills and attention that they expected from it. While it is true that the physiotherapist had limited time or was overworked, the problem could also be due to their failure to follow a systematic approach to treatment. This was illustrated by the observations by some of the parents/caregivers who were dissatisfied with the treatment they received. They said that some physiotherapists did not listen to parents/caregivers' needs nor did they address some obvious key functional problems of the children, which had actually brought the children to the clinic.

The parents/caregivers most affected were those who had children with feeding problems. This made them feel that some of the physiotherapists were incompetent and provided them with inadequate treatment. It is true that some of the physiotherapists may be unskilled, since the majority of them have not had any other further training on the management of CP.

#### **5.4.1 Communication during the treatment process**

Klaber Moffett and Richardson (1997) pointed out that generally the quality of communication and patient education form an essential basis for success in outcome. In addition, patients also appreciate information given in form of discussion (Russell et al., 2003). In this study, parents/caregivers were dissatisfied with the amount of communication between them and their physiotherapist particularly during the treatment process. This signified how important interpersonal interaction is to parents during the treatment process as was earlier observed among the attributes of satisfaction in the literature review. The physiotherapist did not ask the parents/caregivers their needs, nor did they listen to them, answer their questions or discuss much with them. Parents/caregivers said that the physiotherapist were always in a hurry:

*“But the physiotherapist was always in a hurry. They called in one person after the other. As soon as your child had been worked on, you were immediately asked to get out so that the next person enters. The next you would hear was; come back on twenty seventh... You did not enter into any conversation such that you tell them this or the other, aaaha”.*

Failures in communication within healthcare system have been extensively documented, and are claimed as a primary focus of patient dissatisfaction (Volicer & Bohannon, 1975). Yet,

according to Hough (1987), communication is the backbone of psychological care. Previous studies on psychological issues related to paediatric practice, demonstrated that parents have a great desire for knowledge about psychological issues (McCune, Richardson & Powell, 1984). Other than for provision of knowledge and skills, communication during medical visits has been linked to important outcomes such as satisfaction, functional status and patient adherence as cited by Lewis, Pantell & Lee Sharp (1991).

As early as 1982, Wagstaff had suggested that finding out the parent/patient expectations is an important component of physiotherapist-parent or patient interaction. Levit and Goldschmied (1990) too emphasised this suggestion. Levit and Goldschmied explained that by inviting them to talk about which of their everyday routines of feeding, dressing, washing, toileting, playing mobility they would like to do better or to help the child achieve, the parents/caregivers are helped to clarify their expectations or wants. Thus, Potter et al. (2003) recommended that, questioning parents about their expectations should be an integral part of assessment and treatment. The simplest method would be to ask the parent directly about their expectations during the initial consultation and to pursue ongoing expectations in subsequent sessions.

The parents/caregivers in this study were not asked whether their physiotherapist usually asked them their expectations from the treatment. Perhaps that could form another area for further study. But previous studies showed that rarely, in less than 19% of the sessions, do physiotherapists ask patients to talk about their perceptions, feelings and expectations. The larger part of consultation time is spent exploring the nature of the illness or injury, or the

treatment plan or providing home exercises (Sluijs et al., 1993). These findings seem to explain the experiences that parents/caregivers in this study reported. It would therefore be appropriate for physiotherapists at Mulago CP clinic, to take time and identify the parents/caregivers' expectations prior to embarking on treatment, if they are to satisfactorily guide and meet the parents/caregivers' expectations.

Physiotherapists have the advantage staying face-to-face with the parent/patient for longer treatment duration, the practical benefit of the treatment and the physical contact, that facilitate them to establish effective communication with the parent/patient (Pratt, 1978; Klaber Moffett & Richardson 1997). The parents/caregivers in this study however, felt that their physiotherapist needed to stay longer in the clinic before the roster reshuffle in order to allow them time to establish a relationship that would enable them communicate adequately and freely with the parents/caregivers. They also suggested increasing the number of physiotherapists working in the clinic so that each can spend ample time with the parent/caregiver. According to Klaber Moffett and Richardson (1997), to be effective, communication with parents/patient requires the physiotherapist to recognise the difficulties and needs of the parents/ patients. The information given should be consistent and address the concerns, beliefs and the perceived or expressed needs of the parents/patients (Kai, 1996). In addition, it should also incorporate parents/patients' skills and experience (Kai, 1996). Principally, the information should be specific (Wagstaff, 1982) and given in small digestible doses to aid recall and understanding (Hargie, et al. 1994), as well as to avoid overload (Hough, 1987). Also, Hargie et al. (1994) and Russell et al. (2003) suggested using drawings or diagrams, charts, and booklets to help in explaining some complex techniques,

skill or problems. Apart from aiding explanations, these audio-visual materials provide a concrete basis for conceptual thinking, create interest, develop continuity of thought and make learning more permanent. This all requires ample time. However, it seems that the physiotherapists at Mulago CP clinic disregarded or were not aware of these aspects of communication and what the parents expected to learn from them. Yet, these factors are important since according to Potter et al. (2003), most patients ranked communication as their most important expectation.

Furthermore, according to Klaber Moffett & Richardson (1997) seeing the same person over and over in the course of a few weeks facilitated the development of an effective therapeutic relationship. Contrary to this, parents/caregivers at the CP clinic at Mulago hospital were seen once a month irrespective of whether the child was a new or old attendant in the clinic. The parents/caregivers felt that they could benefit more from the services if the appointments were made more frequent and the clinic opened early say, by 8.30 am or 9.00 am. They also suggested maintaining the same physiotherapist working in the clinic for a minimum of two years or have one stay there permanently. These suggestions are indicators of how parent/caregivers value the amount of time they would like to spend with their physiotherapist. Besides, Klaber Moffett and Richardson (1997) insist that patient empowerment is now recognised as an important aspect of health care, and can only be achieved through good communication and provision of appropriate information provided regularly over time. It is also the physiotherapist's responsibility to provide the parent with information that will promote active parent involvement, understanding and self-efficacy.

In addition, researchers rated communication as one of the factors commonly used by customers to evaluate service. Hill, Garner and Hanna (1989) identified the top issues important for good communication as: acting interested in the problem; asking appropriate questions; explaining the actions; offering practical solutions or alternatives and spending enough time with the customer. Providing better information to the parent could be one of the main factors in improving parents' satisfaction with the consultation or any treatment (Russell et al., 2003). Parents who received moderately long answers to their questions were most likely to report that they were listened to (Goore, Mangione-Smith, Elliot, McDonald & Kravitz 2001). Moreover, Hasnat and Graves (2000) established that the amount of information received and overall satisfaction have a statistically significant association, with parents receiving more information being more likely to be satisfied.

### **5.5 Parent/caregiver's experience of interpersonal relationship with the physiotherapists**

Parents/caregivers in this study were satisfied with the reception that they received from their physiotherapist. Courtesy is an area that is important because it is an occasion when a customer and an employee come into contact with each other. It is a moment that provides the employee with the opportunity to establish rapport and to form a long lasting favourable impression (Cina, 1989). Courtesy contributes to the assurance that patients/parents seek in their evaluation of service quality (Parasuraman et al, 1988a). On some occasions the physiotherapist made a good impression on the parents/caregivers as shown in this quotation:

*“The physiotherapists really have good manners... It made me to contemplate whether they were all taught to be courteous”.*

Parents/caregivers also reported satisfaction with the responsiveness of their physiotherapist. Responsiveness requires the awareness of the patient or parents’ needs, desires and difficulties. As Patterson and Marks (1992:19) put it: “It includes for example being in time for appointments, and willing to do a little more of something “extra” for the customer”. The physiotherapist at CP clinic in Mulago hospital for example, went out of their way to work through lunchtime in order to ensure that all parents/caregivers are seen and the children are treated. But, they made the parents/caregivers feel dissatisfied by not keeping to the time specified on their appointments and opening the clinic late. The same experience was reported by Hiindenhovi et al. (2002) who found that adherence to appointment times in their study received the poorest rating from their outpatients. According to El Shabrawy and Mahmoud (1993), long waiting times influenced the level of patient satisfaction negatively. Apart from influencing parents’ level of satisfaction, inconvenient clinic practices such as not keeping appointments and opening the clinic late also frequently influenced the parents’ choice of centre for obtaining health care services (Boyle & Gillam, 1993). That was why Siu-chee et al. (2003) reported that in Hong Kong the most frequently cited reason for parents leaving the Family Health Service (FHS) was lengthy waiting time. This, in addition to other factors, could explain some of the reasons why some parents/caregivers stopped attending the CP clinic at Mulago hospital.

Parents/caregivers also appreciated the empathy and respect that their physiotherapists extended to them:

*“They did not look down on us.... They did not shout at us or send anybody away because the child smelt of urine.... They held the children and carried them in their arms...something that I have not seen in other clinics”.*

*“At least all the physiotherapists that have worked on my child have been good to me. They solve my problems. They show me respect and courtesy”.*

These findings are consistent with those of a study on clinician-parent interaction by Wasserman et al. (1984) in Washington University hospital, which showed that mothers exposed to high levels of empathy had higher satisfaction and greater reduction in concerns. Because of the high levels of encouragement, they also had positive opinions of their clinicians and higher satisfaction. In addition, Knafl, Breitmayer, Gallo & Zoeller (1992) in their study of 102 parents of children with chronic illness, suggested that if expertise was communicated with compassion and respect, an increase in levels of satisfaction with the service would occur. Indeed, despite some the weaknesses that the parents/caregivers had noted with the services, they had attained a feeling to anticipate that this dependable services which they experienced, would continue whenever they would come. So they confessed that they will confidently advice other parents/caregivers of children with CP to take them to the CP clinic at Mulago Hospital. Patterson and Marks (1992) however, observed that reliability is still a big challenge to rehabilitation professionals, because they have to



promote reliability on an individualised basis by living up to what they promise will do to each person and at the right time as promised.

### **5.6 Parent/caregiver's experiences of home programmes**

Most of the parents/caregivers reported that the home programmes had contributed immensely to improvements in their children. This finding is consistent with the report of parents in Pakistan who also found the use of handling techniques and low cost appropriate aids as very beneficial and supportive in their daily handling of the child at home (Miles & Frizzell, 1990). However, most of the parents/caregivers in this study found it difficult to implement the programmes while at home:

*“We do not actually implement the home programme as many times as the physiotherapist will have recommended. We have other children as well to attend to.”*

*‘That is true; we do not fulfil the instructions. We have a lot of work at home’.*

Various researchers have studied the importance of involving patients/parents in decision-making. McKinsty (2000) carried out a study to determine patient's preferences for shared or directed style of consultation in the decision-making part of general practice consultation. The findings showed that patients varied in their preferences for involvement in making decisions in the consultation depending on the presenting problem. Siu-chee et al. (2003) observed that sometimes parents' expectations might influence their perception of the extent to which they are involved in decision-making. Therefore, the choice is left to the professional to use their skills and knowledge of their patients to determine at which level

their patients/parents wish to be involved in decision-making (McKinsty, 2000). Russell et al. (2003) urges the practitioners to be flexible in involving patient/parents in the decision-making process.

The parents/caregivers in this study reported that apart from sharing ideas on how to improvise appliances at home, they were not consulted in deciding the home programme, and how often they were to perform the exercises while at home. The implementation of a home programme is one decision in which the physiotherapist needs to involve the parents/caregivers. This is because each of the parents/caregivers knows their own commitments at home or at work and would know best how to modify them to accommodate the home programme. Together, they would come up with what is achievable and implementable within the parent/caregiver's schedule of duties, hence avoiding the experience of failure to carry out the home programme as was reported by most of the parents/caregivers. Above all, Klaber Moffett (2002) asserts that the practitioner together with the parent/patient should develop the programme based on realistic goals, activity and grade of difficulty as well as positive systems that provide encouragement and feedback of performance.

Moreover, most of the parents/caregivers were dissatisfied with the physiotherapist's failure to provide them with demonstrations, practice, guidance and feedback. Apart from the verbal explanation, demonstration is another method of aiding an explanation, particularly when the type of information being conveyed is of a practical nature. According to Klaber Moffett (2002), home programme is an essential part of most patient education where the

teaching should include a demonstration of each exercise, followed by the parent trying it out with guidance from the physiotherapist. In addition, the parent or patient needs a clear explanation of purpose of each exercise, which needs to be written down and illustrated to them to improve the level of adherence. Depending of the complexity of the skill, the complete action can be broken down into logical segments, which the parent can practice in parts. Finally, the parent/patient needs to be given the feedback of how well they have performed and what needs to be improved. This description is in consistence with that earlier outlined by Miles and Frizzell (1990). Most parents/caregivers in this study experienced limited amount of this opportunity and also missed practicing making the recommended improvised appliances together with the physiotherapist at the clinic.

#### **5.6 Barriers/problems encountered by parents/caregivers**

The barriers/problems encountered by parents/caregivers can be divided into those that they experienced while utilising the physiotherapy services at the CP clinic in Mulago hospital and those that prevented them from attending the clinic regularly. The parents/caregivers encountered problems with the acquisition of appliances such as corner seats, wheelchairs or splints that were recommended by the physiotherapist. Most of them said that they were poor and therefore could not afford the apparatus and appliances. Those parents/caregivers who could afford to purchase them were frustrated by the fact that not all the appliances were readily available at the clinic. Sometimes it required making several journeys to Mulago Hospital to follow them. This is expensive for parents/caregivers who come from districts far way.

In addition, the majority of parents/caregivers found it difficult to implement the home programme because of other commitments. They cited the lack of time, pressure from other work, fatigue and the absence of other persons and children in the family to assist as their main problems as. Parents/caregivers identified transport, as a major barrier that prevented them from regularly attending the clinic. Transport costs were prohibitive, particularly for those who came from districts far away from the clinic. As a result most of the parents/caregivers identified the lack of funds for transport as their main problem. Another problem was the carrying of bigger or older children in public transport to the clinic. Getting them to the road where they could access public transport was cumbersome. Parents/caregivers also reported harassment by some operators of public transport and the lack of suitable facilities in some public vehicles for transporting the wheelchairs.

Meanwhile at home, some of them reported lack of both financial and moral support from the fathers of the child. Apart from these barriers, some parents/caregivers lacked the awareness of either the availability of these services at Mulago hospital or how to find their way within the hospital to the clinic.

## **5.7 Summary**

In this chapter, the findings of this study were discussed in respect to parent/caregiver satisfaction with the physiotherapy services rendered to them in the CP clinic at Mulago hospital. The parents/caregivers' expectations prior to visiting the clinic and what they actually received were highlighted. Their experiences with provision of information,

knowledge and skills, how the physiotherapist related with the parents/caregivers and guided them on the homecare programme were discussed, particularly in respect to the satisfaction the parents/caregivers attained. Barriers/problems that parents/caregivers experience were also presented.

The findings show that overall the parents/caregivers were satisfied with the services that they received from the physiotherapist in the CP clinic at Mulago hospital. The findings in various areas of outcome of treatment, interpersonal relationship, provision of information, knowledge and skills, were consistent with findings of other researchers elsewhere on the same subject. The expectation of recovery or at least improvement of the child was a common want as was the need for information, education and transfer of skills.

However, the physiotherapists were found not to be so apt in providing adequate information, parent/caregiver training and involving the parents/caregivers in planning homecare programmes. These shortcomings affected service quality and influenced parent/caregiver satisfaction. Economic and social factors were found to be major barriers to access to service.

The limitation of the study, conclusions and recommendations follow in the next chapter.

## **CHAPTER SIX**

### **CONCLUSION AND RECOMMENDATIONS**

#### **6.1 Introduction**

This chapter provides the limitations of the study. It also presents the conclusion and recommendations for future interventions as well as for future research.

#### **6.2 Limitations of the study**

This study has the following limitations, which need to be taken into consideration when interpreting the findings:

- The size of the sample was small as it involved a sample of only those parents/caregivers attending physiotherapy services at the CP clinic in Mulago hospital. This restricts the generalisation of these findings to other physiotherapy CP clinics elsewhere in other hospitals or districts in Uganda.
  
- It was also difficult to get the feedback on the verbatim to the participants after wards to share their comments and approval. This was because most of them were expected back at the clinic a month later after the researchers had returned to South Africa.
  
- Apart from what was reported by the respondents, it is not possible to know the views of other parents/caregivers of children with CP who also received services from the same clinic, particularly those who stopped attending the clinic.

- The time and resources available limited the nature of this study. The study was thus restricted to only focus group discussions for data collection. Focus group discussions have some weaknesses. Triangulation with in-depth interviews would have helped to deepen and clarify the findings.
- The study interviewed the parents/caregivers only. Again because of limitations of the size of study (mini-thesis) the physiotherapists were not interviewed. It would have been appropriate to interview the physiotherapists too, to get a balanced picture and compare and understand the source of the experiences and findings.

#### **6.4 Conclusion**

Parents/caregivers of children with CP who received physiotherapy services from the CP clinic at Mulago Hospital were satisfied with the outcome of the services and interpersonal relationship with the physiotherapist. However, some parents/caregivers were concerned with some aspects of care, in particular information on diagnosis and prognosis, time spent with the parent/caregiver, the teaching, communication and involvement of parent/caregiver in decision making. Most of these issues involved the interaction ‘process’ of the treatment. The study also supports earlier research findings that prior expectations to a certain extent influence parent satisfaction.

#### **6.5 Recommendations**

The weaknesses in the service quality can be addressed both administratively and through training. The following recommendations are made on basis of the present findings.

### **Administrative action**

- Management at the Physiotherapy Department in Mulago hospital should put in place measures to ensure good time management and increase punctuality among the physiotherapists working at the CP clinic.
  
- Parents/caregivers value the time they spend at the clinic. To reduce workload of the physiotherapist and reduce working hurriedly, Mulago Hospital management should post a full-time physiotherapist to the CP clinic. This opinion was echoed by the parent/caregivers as one of their suggestions for improvement of services. An additional physiotherapist could be availed twice a week to support the full-time one. This would enable them to spread out their appointments such that new referrals are seen regularly. The frequency of visits could gradually be reduced to say, once a month as parents/caregivers become familiar with what to do.

### **Training**

- The lack of standards and protocols in physiotherapy gives physiotherapists considerable flexibility when treating their patients. Protocols in neuro-developmental techniques are necessary for quality control, uniformity and continuity in the management of a child with CP. It is therefore recommended that interested physiotherapists be identified and sent for further training in the Neuro-Developmental Training (NDT) courses. Graduates of such training would be the full-time physiotherapists appointed to run the CP clinic at Mulago hospital.



- Although physiotherapists are aware of teaching, motivation, adherence/compliance to exercise and the importance of good communication, they may not have the skills to address these problems. The Mulago Hospital management in conjunction with the Department of Physiotherapy and the School of Physiotherapy should ensure that these skills are imparted to both to undergraduate trainees and qualified physiotherapists through Continuous Professional Education (CPE). This could be achieved by organizing tailor-made short courses or workshops addressing specific needs of the physiotherapists.
  
- Training related to communication is needed. The recommended topics on communication would include: the use of open questions, recognition of verbal and non-verbal cues, listening and the use of silence, clarification and reinforcing, offering practical solutions/alternatives, giving information appropriately, acting interested and spending enough time with the customer. Another recommended area for training is the effective methods for teaching practical or home exercises.
  
- The School of Physiotherapy should advocate to the Ministry of Education and Sports for the review of the physiotherapy undergraduate curriculum. The review should consider including communication covering listening and hearing customer/patient expectations, explaining medical issues or procedures to customers/patients, and assessing their satisfaction as well as time management and its importance to customers.

- The researcher also recommends that more research be done on the same topic on a wider scale using a survey. That way the views of many parents/caregivers of children with CP who utilise the physiotherapy services at the CP clinic, together with those of the physiotherapists, would be captured. The findings would be used for proposing strategies for improvement of services for children with CP in Uganda.

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## APPENDICES

### CEREBRAL PALSY CLINIC: PARENT/CAREGIVER SATISFACTION INTERVIEW GUIDE

#### A. Background:

**Set the group at ease: explain purpose of interview.**

- *Researcher introduces self and the moderator to the parents, explains the purpose and importance of parents' participation in the study and assures them of anonymity, confidentiality and the ground rules for a smoother group discussion.*
- *Proceeds to give participants their nametags for easier communication.*

#### B. Parents' expectations

1. When you first came to Mulago CP clinic, what did you expect from the physiotherapist?  
***Probe for expectations for parent and child.***

#### C. Interaction and communication between parents and physiotherapist

2.
  - i. What explanation did the physiotherapist give you about the problem of the child?
  - ii. How did the physiotherapist teach you about the handling and exercising of the child?
    - *Probe about the problem with the child, the treatment and its teaching process, the opportunity to try out demonstration under supervision, the opportunity to ask question and as to whether the questions are usually answered, and the expected child improvement (prognosis)*
  - iii. What would you say about the way your physiotherapist talks to you?
    - *Probe for courteousness, empathy, the clarity of the explanations, whether parent understands anything from the information, and the adequacy of time spent talking with the physiotherapist.*

#### D. Understanding the problem of the child

3. How have the visits to the physiotherapist helped you to appreciate your child's problem?
  - *(Probe for adequacy of information and reassurance attained.)*
  - ii. How have your meetings with other parents in the clinic helped you to appreciate and manage your child's problem?

### **Self-management of child by the parent**

- *(Probe for the parents' understanding and application of suggestions advised by physiotherapist, effect of meeting other parents and the feeling of satisfaction with independent control of the child's daily handling).*
- ii. What improvement have you noticed since you started attending the clinic?

### **E. Enabling partnership between the parent and the physiotherapist**

- 4. Do you have a home care programme for your child?
  - i. How was the home programme decided upon for each child?
  - ii. What difficulties do you encounter in implementing the home care programme?
  - iii. How does the physiotherapist help you to sustain active participation and confidence in carrying out the home programme independently?
  - iv. How helpful has the home programme been in your daily handling of the child at home?
- *(Probe to find out the parent involvement in goal setting, whether parent's opinion is sought, whether parent encounters any problems implementing the programme at home, how the physiotherapist encourages parent to become active and confident in managing the child independently and whether the practical suggestions given are helpful, easy or difficult to implement).*

### **F. Efficacy/ overall satisfaction of parent**

5 i

What would you say is particularly good or bad about the physiotherapy services you have received from Mulago CP clinic?

*(Probe to confirm what was helpful and what was not)*

- ii. Generally, in what ways are you satisfied or not satisfied with the services you received from the physiotherapists at Mulago CP clinic?

### **G. Parents Barriers/problems encounter**

- 6. What problems do you encounter at the clinic or elsewhere that prevents you from regular attendance of the CP clinic?
- 7. What other information related to delivery of services in this clinic would you like us to talk about?

## ENSONGA ENONYEREZEBWAKO

### OKUMITIZIBWA KWA'ABAZADDE MU NZIJANJABWA Y'A BAANA ABALINA OBUNAFU KU BWONGO: OKUNONYEREZEBWA KU MULIMU GUNO MU KILINIKA Y'OBW'ONGO OBUNAFU E MULAGO

#### EBIBUZO

##### A. Omusawo asoka onyonyola abazadde

##### B. Abazadde byebasubira okufuna okuva mu kilinika

1. Byewali otandika okujja mu kilinika eno, eyabaana abalina obunafu ku bwo'ngo e Mulago, kiki kyewasubira okufuna okuva eri omusawo we ekisasayisi?

##### C. Enkolagana ne'mpulizaganya wakati w'omuzadde n'omusawo w'ekisasayisi

- i. Omusawo yaku nyonyola atya ku bikwata ku obulwadde bw'omwana wo?
- ii. omusawo yakuyigiriza atya okundabirira y'omwana awamu n'okumuyamba okukozesa omubiri gwe ?

**Probe:** Bwebuba nga musoma oba nga amase okusomesa, omusawo akuwa akaseera n'omubuusa kyototedde, nebakudamu?

- liii Kiki ky'oyinza okwogera kungeri omusawo wo gy'ayogera naawe?  
(omusawo y'eyisa atya ng'ayogera naawe?)

**Probe:**

- Empissa
- Byayogera obifuna no bitegeera bulungi oba nnda?
- Mufuna akaseera aka mala no omusawo nga akunyonyola kubwo mwana?

##### D. Okutegeera ekizibu ky'omwana

- 2.i Okukyalira omusawo w'ekisasayisi mu clinic eno, kakuyambwe kutya okwongera okutegeera ekizibu, ky'omwanawo n'okusobola okumulabirira obulungi?

**Probe:** for adequacy of information and reassurance attained

- i. . Okusisinkana abazadde abalala abalina ekizibu ng'ekikyo mu kilinika eno kakuyambwe kutya mukwongera okutegeera ekizibu, ky'omwanawo n'okusobola okumulabirira obulungi?

ii. Enjawulo ki kyolabye kati ku mwanawo ?

**E.. Okusoboseza okuteekawo enkolagana wakati w'omuzzade n'omusawo**

4. Olina pulogulamu yokuyambibwako abakugu mukulabirira omwana awaka?

i.Mwabituuka ko mutya n'omusawo okusalawo ebiri mu pulogulamu eno?

**Probe:**Pulogulamu ogitukirizza bulungi oba wazibu okituukiriza?

ii. Bizibu ki by'osanga mu kutukiriza pulogulamu eno?

iii. Omusawo akuyambye atya okusobola okujjumbira era n'okufuna obumalirivu okutwala pulogulamu mumaso wekka nandibadde nga taliwo?

iv. Pulogulamu eno ekuyambye etya mu ndabirira y'omwanawo eyabulijjo ewaka?

**Probe:** on self-management of child by parent

**F. Okumattira kw'omuzadde okutwalira awamu**

5. Birungi ki oba ebibi ki by'oyinza okwogera kumpereza ya kilinika eno eya baana eya Mulago?

ii.Okukwatira awamu, wa w'owulira nti osimwe oba tosiimwe mungeri gy'werezeddwamu okuva wa'omusawo wano e Mulago?

**G. Ebizibu abazadde byebasanga**

6. Bizibuki by'osanga wano mu kinika oba awalala ebikuziyiza okubeera ng'ojja mu kilinika bulilw'oba otekeddwa okujja?

**7. Biki ebirala ebikwata kumpereza y'emirimu mu kilinika eno byemwandyagadde twogeroko?**

**Webale Nnyo olw'okuddamu ebibuuzo bino.**

## LETTERS

### 1. MULAGO HOSPITAL COMPLEX



University of the Western Cape

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Private Bag X17 Bellville 7535 South Africa  
Telephone: (021) 959 2542 Fax: (021) 959 1217

#### DEPARTMENT OF PHYSIOTHERAPY

21 October 2003

Dr Lawrence Kaggwa  
The Director  
Mulago Hospital Complex  
P.O. Box 7051  
Kampala  
Uganda

Dear Dr Kaggwa

Research: Margaret Helen Omare

Margaret Helen Omare is a Masters student in the Physiotherapy Department at the University of the Western Cape. As a part of her degree for the M Sc Physiotherapy she needs to complete a research project.

She has prepared a proposal that has been accepted by the University Higher Degrees Committee. The research is entitled: Parent satisfaction with physiotherapy services for children with cerebral palsy: An explorative study at the cerebral palsy clinic, Mulago, Uganda.

Please can you assist her by giving her permission to conduct her study at the cerebral palsy clinic for this study that should provide valuable qualitative data and help with the improvement of services for children with cerebral palsy.

Yours sincerely

Patricia Struthers  
(Supervisor, Senior lecturer)

## 2. KATALEMWA CHESHIRE HOME

Paramedical Training Schools,  
Mulago Hospital Complex  
P.O Box 34025  
KAMPALA.

18<sup>TH</sup> December 2003

The Officer in Charge  
Katalemwa Cheshire Home

Dear Sir/Madam.

**RE: USE OF THE PHYSIOTHERAPY CLINIC FOR CHILDREN WITH CEREBRAL PALSY.**

I am a student pursuing post-graduate studies in physiotherapy at the University of the Western Cape in South Africa. As part of fulfillment the course, I am researching on parent satisfaction of physiotherapy services at Mulago cerebral palsy clinic. Before embarking on the actual study, I would like to pilot the instrument.

The purpose of this letter is to request you for permission to use your cerebral palsy clinic to conduct the pilot study.

I would like to thank you in advance for your assistance and cooperation.

Yours sincerely,

Helen M. Omare (Mrs.)