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**THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE
PHYSIOTHERAPY DEPARTMENT**

RESEARCH REPORT

TITLE OF STUDY

**A STUDY TO DETERMINE CHALLENGES PARENTS AND
CAREGIVERS WITH CEREBRAL PALSY CHILDREN FACE AT
UNIVERSITY TEACHING HOSPITAL**

BY

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**SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF THE
BACHELOR OF SCIENCE DEGREE IN PHYSIOTHERAPY AT THE UNIVERSITY OF ZAMBIA**

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ABSTRACT

Introduction: Cerebral Palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. Parents/Caregivers of cerebral palsy children are faced with challenges that needs that needs to be addressed. Cerebral palsy is a major cause of disability and most survivors are left with residual disability and are dependent on others for essential care.

Objective: The main objective of the study was to determine challenges parents and caregivers of children with cerebral palsy face at University Teaching Hospital, Community Based Intervention Association center, Lusaka, Zambia.


Methodology: This study was a quantitative method using a cross-sectional descriptive survey. Data was collected using a structured questionnaire and data analysis was done using the Statistical Package for Social Sciences (SPSS). The study had 30 participants who were selected randomly.

Results and conclusion: The results of the study showed that the majority 66.7% of parents indicated that they stay far from the hospital this made them not to be consistent with the child's treatment. Among the reasons given for non-consistence was lack of transport money, lack of support from family members in terms of bringing the child for treatment, not satisfied with the treatment given at the hospital, non- improvement of the child's condition and travelling distance to come to the hospital.

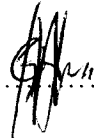
Recommendations: It is important that rehabilitation professionals are aware of the challenges faced by these caregivers so that their needs could also be addressed when managing the cerebral palsy patient and government should consider putting in place strategies/ measures to provide rehabilitation support to these children and their caregivers to reduce the disability burden.

DECLARATION

I, the undersigned, hereby declare that the work contained in this study is the result of my own investigations. The various sources and persons consulted and quoted having been clearly referenced and acknowledged.

Signed.....

Student

Signed.....

Supervisor

DEDICATION

This work is dedicated to my God who has given me strength and knowledge throughout the study, to my husband and friend Moses Chali Mutale, my Dad Mr Rainwick Nsama, my Mum Mrs Evelyn Nsama, my brothers and sisters Beatrice, Gwen, Chrispine, Given, Chiti, Mukupa and Chishaleshale, who have sacrificed so much to see me through University. May God bless you abundantly and add more years to your lives. I love you so much.

Also a dedication in memory of my late brother Musonda Nsama you were a wonderful brother to me, I will forever miss you but I know one day we will meet in heaven where there is no sorrow and death. You could have been around to see how your sister has progressed academically.

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ACRONYMS

CP	:	Cerebral Palsy
UTH	:	University Teaching Hospital
CBIA	:	Community Based Intervention Association
UNZA	:	University of Zambia
ADD	:	Action for Disability and Development
ICU	:	Intensive Care Unit
SPSS	:	Statistical Package for Social Scientists
WHO	:	World Health Organization
HIV	:	Human Immune-deficiency Virus
AIDS	:	Acquired Immune-Deficiency Syndrome
USA	:	United States of America

LIST OF KEY WORDS

Challenges

Parent/caregiver

Children

Cerebral palsy

Rehabilitation

DEFINITION OF TERMS

Challenges	Is a general term referring to things that are imbued with a sense of difficult
Cerebral Palsy	Is an umbrella term encompassing a wide range of different causative factors and describing an evolving disorder of motor function secondary to a non-progressive pathology of the immature brain.
Function	Ability to manage daily routines.
Rehabilitation	The restoration, following disease, illness, or injury, of the ability to function in a normal or near normal manner
Disability	Physical or mental impairment that has substantial and long-term adverse effects on a person's ability to carry out normal day to day activities.

CHAPTER ONE

INTRODUCTION

1.0 BACKGROUND

According to Maystone (2002), Cerebral Palsy (CP) describes a group of disorders of the development of movement and posture, on the other hand, Stokes (1997) defines CP as an umbrella term encompassing a wide range of different causative factors causing activity limitation, that are attributed to non-progressive disturbances that occur in the developing foetal or infant brain. Maystone further adds that the effect or lesion can occur in utero or during birth or shortly after birth and produces impairments and possible sensory deficits that are usually evident in early infancy.

It is estimated that worldwide up to 9.3% of youths under the age of 18 have a condition that can be classified as neuro developmental such as CP, epilepsy and developmental delay. The current estimated incidence of CP is 2 to 3 per 1000 live births in developed countries. However, it is difficult to establish the incidence of CP in most developing countries because CP is not captured in the population census or any other surveys in most developing countries, though the incidence is higher in males than in females (Surveillance of Cerebral Palsy in Europe SCPE, 2009). In India 4 million people are affected by CP annually (UNICEF, 2002). It is also important to understand that physical disabilities are common in nations with unequal (huge gap between the rich and the poor) levels of socio-economic development (WHO, 2001). Although impaired motor function is the hallmark of the CP syndromes, many children also experience sensory, communicative, intellectual impairments and may also have complex limitations in self-care functions such as feeding, dressing, bathing and mobility. These limitations can result in long-term care that far exceeds the usual needs of children as they develop. This leads to dependency for activities of daily living with significant economic impact on the family (Rimmer, 2009). In addition, physical and structural differences in children with CP are associated with social stigma, which has a psychological effect on the child.

Although caring for these children is a normal part of being the parent of a young child, this role takes on an entirely different significance when a child experiences functional limitations and possible long term dependence resulting from CP (Blundell, 2007).

Physiotherapists are essential members of the rehabilitation team in CP treatment both in developed and developing countries (Shack & Eastwood, 2006). Physiotherapists not only offer treatment to children with CP, but also educate parents/caregivers about the diagnosis, the treatment process and the expected outcome (Ireland, 2003). However, just as early diagnosis, proper assessment of the functional capacity and needs of the child and providing early intervention are important, active parental involvement in the treatment process through consistence to treatment requirements is also important for achieving good treatment outcomes (Shack & Eastwood, 2006). Patient's consistence with treatment is important for the therapeutic regimen to be effective. Without consistence, the therapeutic goals cannot be achieved, resulting in poor patient outcomes (Cameroon, 2001). Therefore, it is important to understand how parents/caregivers manage their children's treatment and the potential challenges these parents encounter during the utilization of CP treatment services.

1.1 STATEMENT OF THE PROBLEM

Cerebral palsy is one of the conditions frequently encountered by children in Zambia in order to achieve appreciable improvement levels, children with this condition need to be taken regularly for therapy. In the industrialized world, the incidence of cerebral palsy is about 2 per 1000 live births (free encyclopedia 2011). In the United States, approximately 10,000 infants and babies are diagnosed with CP each year (United Cerebral Palsy Research and Education Foundation, 2007). If calculated around the school entry age of about six years, the prevalence in the U.S. is estimated to be 2.4 out of 1000 children meaning that approximately 2.4 male and female parent are affected (Hirtz, 2007).

Clinical records of 2011-2012 at Community Based Intervention Association (CBIA) at UTH indicate that there are 104 CP children seen. It has been observed that parents/caregivers of children with CP often stop attending or miss one or two treatment sessions during the phase of CP Clinic. Some are given appointments to come twice in a week that is eight times in a month, others once in a week that is four times in a month. The researcher noticed that from the outpatient physiotherapy department CBIA, some children have been attending physiotherapy for more than one year but their parents have not been consistent with bringing them for treatment. The researcher also observed that

many parents were concerned with their child's progress in terms of physiotherapy treatment. Therefore, it is important to determine challenges parents/caregivers face that prevent them from taking the children for therapies on a regular basis.

1.2 JUSTIFICATION

Although there is no permanent treatment to CP, it is observed that children with CP can be assisted to live a normal or near normal life by consistently attending clinical sessions. Research in rehabilitation has shown that consistent attendance at treatment appointments plays a central role in both improving structure and function, is associated with good treatment outcomes, increased activity participation and improved quality of life of the patient. Therefore, determination of factors which affect non consistence of attendance cannot be over emphasized.

1.3 OBJECTIVES

1.3.1 General Objective

To determine challenges parents and caregivers of children with cerebral palsy children face at University Teaching Hospital.

1.3.2 Specific Objectives

- To determine challenges parents/caregivers experience in attending all treatment appointments.
- To determine why parents/caregivers with cerebral palsy children are not consistent with bringing the children for physiotherapy treatment.
- To determine if parents/caregivers are trained on how to take care of their cerebral palsied children.

1.4 RESEARCH QUESTION

What challenges do parents/caregivers with cerebral palsy children face at University Teaching Hospital?

CHAPTER TWO

LITERATURE REVIEW

2.0 INTRODUCTION

Cerebral palsy (CP) is a lifelong, non progressive but changing group of disorders affecting movement and postural development, often accompanied by disturbance of sensation, cognition, communication, behavior and musculo-skeletal problems resulting from a non progressive lesion of the fetal or infant's brain before, at or after birth. This results in limitations in the child's functional performance and development, because of abnormalities of postural tone, posture and movement control and lack of learning opportunities. Although the brain lesion is non progressive, the motor disorders evolve overtime and the clinical presentation may change (Maystone, 2002). Every person or (child), with CP is affected in a different way and has their own unique pattern of movement problems (Macnair, 2006). The author further adds that there are several different types of CP and while some people are severely affected, others have only minor disruption depending on which parts of the brain have been damaged.

Many CP children rely on regular physiotherapy in order to remain well enough to continue enjoying life in full. Although CP cannot be cured, in many instances it can be effectively treated and managed. Physiotherapy programs are designed to encourage the patient to build a strength base for improved gait and volitional movement, together with stretching programs to limit contractures. Many experts believe that life-long physiotherapy is crucial to maintain muscle tone, bone structure, and prevent dislocation of the joints. Stretches and exercises keep the child flexible and comfortable regular massage can be the most effective route to pain relief, to improve blood circulation, to help the child learn activities that children of his/her age can do.

2.1 INCIDENCE AND CAUSES OF CEREBRAL PALSY

In the industrialized world, the incidence of cerebral palsy is about 2 per 1000 live births (free encyclopedia 2011). In the United States, approximately 10,000 infants and babies are diagnosed with CP each year (United Cerebral Palsy Research and Education Foundation, 2007). If calculated around the school entry age of about six years, the prevalence in the U.S. is estimated to be 2.4 out of 1000 children meaning that approximately 2.4 male and female parent are affected (Hirtz, 2007). In India 4 million people are affected by CP annually (UNICEF, 2002).

CP is as the result of brain malformation or damage affecting those areas involved in motor functions (Johnson, 2006). Congenital malformations of the brain include congenital cysts, fusion defects, failure of normal migration of grey matter and aplasia. According to (Russman, 2004), the causes CP may be divided into three main groups according to the time of occurrence: those that happen before birth (prenatal), around the time of birth (perinatal), and also after birth (postnatal). Among the Prenatal causes are Intrauterine infections, Congenital malformation, Toxic or teratogenic agents, Multiple births, Abdominal trauma and Maternal illness. The Perinatal causes may include; Prematurity, Asphyxia, Disproportion, Forceps delivery, Breach delivery, Intracranial haemorrhage, Prolonged labour etc, on the other hand, post natal causes may include; Haemorrhage in pre-term neonates, head injury, Suffocation, Shaking injury, intracranial infections, Hyperbilirubinaemia, Hypoglycemia. These varieties of prenatal, perinatal and postnatal factors may contribute to the aetiology of CP singly or multifactorially.

In Zambia, poor antenatal and postnatal care, delayed recognition and improper treatment of meningitis, severe neonatal jaundice, malaria and prolonged convulsions are the identified preventable common causes of cerebral palsy. The major causes of CP in Zambia include meningitis at 37% and cerebral malaria at 20%. (Stanfield, 1997). He also reports that if parents were aware of the signs and symptoms of malaria and meningitis and took the treatment early, the complications of these conditions could have been reduced which include CP. Apart from the above notable causes, jaundice and poor health or infections of the mothers who transmitted the disease to the child.

2.2 TYPES OF CEREBRAL PALSY

The types of movement disorder that occur in CP were classified by the American Academy for CP in 1956. Each disorder is classified according to two factors.

According to the limb involvement

- Monoplegia-one limb
- Hemiplegia-upper and lower limb on the same side
- Paraplegia-lower limbs only
- Diplegia-major involvement is the lower limbs and minor is the upper limbs
- Triplegia-three limbs, usually one upper limb and both lower limbs
- Quadriplegia-major involvement of all four limbs (also called tetraplegia)
- Double hemiplegia-rarely used, upper limbs more involved than lower limbs.

According to the movement (physical classification)

- Spasticity
- Rigidity
- Ataxia
- Tremor
- Mixed
- Athetosis

Spasticity

Pharaoh (2007) explains that, Spastic CP is by far the most common type, occurring in 70% to 80% of all cases. Moreover, spastic CP accompanies one of the other types in 30% of all cases. People with this type are hypertonic and have a neuromuscular condition stemming from damage to the corticospinal tract or the motor cortex that affects the nervous system's ability to receive gamma amino butyric acid in the area(s) affected by the disability. Spastic CP is further classified by topography dependent on the region of the body affected. In this type of CP the limb muscles are tight and contract strongly (increased stretch reflex) with sudden attempted movement or stretching, which may then lessen abruptly. In spastic paralysis, the movement is exaggerated even to the

point that the muscles will continue contracting repetitively. Children who have spasticity also have deep tendon reflexes of the involved limb and also extensor plantar responses. Deformities of the joints develop, which may become fixed contractures with time as the child grows, because the muscles become shorter.

Rigidity

Christopher (2010) explains that, rigidity appears to be the severe form of spasticity, such that even the increased stretch reflexes are deepened. If an attempt to move the rigid limb is made, it gives way as if it were a lead pipe or cogwheel. These children are usually quadriplegic.

Ataxia

Ataxia type of CP can be caused by damage to the cerebellum. The forms of ataxia are less common types of cerebral palsy, occurring in at most 10% of all cases. Some of these individuals have hypotonia and tremors. Motor skills such as writing, typing, or using scissors might be affected, as well as balance, especially while walking. It is common for individuals to have difficulty with visual and/or auditory processing.

Tremor

Tremor is shakiness of the limb involved. Tremor might only be noticed when the child attempts to use the limb (intensional tremor). Continuous tremor at rest is not common in children as it is in adults with Parkinson's disease of the brain.

Mixed

This is a mixture of different types of cerebral palsy. A common combination is spastic and athetoid. Usually children with mixed CP are quadriplegic. Tremors can be observed mixed in with other types of CP.

Athetoid

According to Ben (2000), athetoid or dyskinetic is mixed muscle tone — People with athetoid CP have trouble holding themselves in an upright, steady position for sitting or

walking, and often show involuntary motions. For some people with athetoid CP, it takes a lot of work and concentration to get their hand to a certain spot (like scratching their nose or reaching for a cup). Because of their mixed tone and trouble keeping a position, they may not be able to hold onto objects (such as a toothbrush or pencil). About one quarter of all people with CP have athetoid CP. The damage occurs to the extrapyramidal motor system and/or pyramidal tract and to the basal ganglia. It occurs in 10% to 20% percent of all cases. In newborn infants, high bilirubin levels in the blood, if left untreated, can lead to brain damage in certain areas (kernicterus). This may also lead to athetoid cerebral palsy.

2.3 SIGNS AND SYMPTOMS

According to Judith (2008), all types of CP are characterized by abnormal muscle tone (i.e. slouching over while sitting), reflexes, or motor development and coordination. There can be joint and bone deformities and contractures (permanently fixed, tight muscles and joints). The classical symptoms are spasticity, spasms, other involuntary movements (e.g. facial gestures), unsteady gait, problems with balance, and/or soft tissue findings consisting largely of decreased muscle mass. Scissor walking (where the knees come in and cross) and toe walking are common among people with CP who are able to walk, but taken on the whole, CP symptomatology is very diverse. The effects of CP fall on a continuum of motor dysfunction which may range from slight clumsiness at the mild end of the spectrum to impairments so severe that they render coordinated movement virtually impossible at the other end of the spectrum.

Babies born with severe CP often have an irregular posture; their bodies may be either very floppy or very stiff. Birth defects, such as spinal curvature, a small jawbone, or a small head sometimes occur along with CP. Symptoms may appear or change as a child gets older. Some babies born with CP do not show obvious signs right away. Classically, CP becomes evident when the baby reaches the developmental stage at six and a half to 9 months and is starting to mobilize, where preferential use of limbs, asymmetry or gross motor developmental delay is seen.

Secondary conditions can include seizures, epilepsy, aphasia, dysarthria or other communication disorders, eating problems, sensory impairments, mental retardation, learning disabilities, and/or behavioral disorders.

Judith (2008) further states that, Speech and language disorders are common in people with CP. The incidence of dysarthria is estimated to range from 31% to 88%. Speech problems are associated with poor respiratory control, laryngeal and velopharyngeal dysfunction as well as oral articulation disorders that are due to restricted movement in the oral-facial muscles. There are three major types of dysarthria in cerebral palsy: spastic, dyskinetic (athetosis) and ataxic. Speech impairments in spastic dysarthria involve four major abnormalities of voluntary movement: spasticity, weakness, limited range of motion and slowness of movement. Speech mechanism impairment in athetosis involves a disorder in the regulation of breathing patterns, laryngeal dysfunction (monopitch, low, weak and breathy voice quality). It is also associated with articulatory dysfunction (large range of jaw movements), inappropriate positioning of the tongue, and instability of velar elevation. Athetoid dysarthria is caused by disruption of the internal sensorimotor feedback system for appropriate motor commands, which leads to the generation of faulty movements that are perceived by others as involuntary. Ataxic dysarthria is uncommon in CP. The speech characteristics are: imprecise consonants, irregular articulatory breakdown, distorted vowels, excess and equal stress, prolonged phonemes, slow rate, monopitch, monoloudness and harsh voice. Overall language delay is associated with problems of mental retardation, hearing impairment and learned helplessness. Children with CP are at risk of learned helplessness and becoming passive communicators, initiating little communication. Early intervention with this clientele often targets situations in which children communicate with others, so that they learn that they can control people and objects in their environment through this communication, including making choices, decisions and mistakes.

2.4 COMMON ASSOCIATED IMPAIRMENT WITH CEREBRAL PALSY

Because damage to the brain is likely to be generalized, other neurological problems may also be present and should be looked out for (Johnson, 2006).

2.4.1 Visual Problems

This involves the optic nerve damage leading to visual handicap. Damage to visual pathways will lead to cortical blindness. Many of these children are far sighted (hyperopia). Near sightedness (myopia) is seen mostly in premature. Failure to upward gaze is characteristic of athetosis due to Rh incompatibility.

2.4.2 Hearing Problems

This is nerve deafness. High frequency loss in kernicterus is due to bilateral cortical damage. It is most common in athetosis that is caused by Rh factor incompatibility or rubella syndrome. Only 2 per cent of spastic children have hearing problems.

2.4.3 Speech Problems

Some speech or language defects are present in about 48 per cent of children with CP. The speech disorder might be due to paralysis or the incoordination of the speech musculature (dysarthria). Disorders of articulation as in bulbar palsy associated with quadriplegia or movement disorders affecting as in athetosis or ataxia. Cerebral damage to language centers is rare.

2.4.4 Mental Retardation

Loss of associated fibers linking parts of the brain cause learning and memory problems. Studies have shown that approximately 75 percent of children with CP have some mental retardation. Athetoid children are less likely than spastics to have mental retardation. Ataxic and spastic hemiplegics have better intellectual prospects than any other in the whole group.

2.4.5 Sensory Defects

Loss of shape and texture sensation (astereognosis) of the hand is well documented especially in spastic hemiplegic. Generally the shorter and smaller the affected upper limbs (atrophy) relative to that of the normal side, the more we suspect sensory loss.

2.4.6 Convulsion Disorders

Convulsion disorders occur in 86 percent of spastic patients and in 12 percent of athetoids. In post natal CP, seizures occur in 55 percent of the hemiplegics. Seizures are rare in athetosis. Epilepsy is a common complication of CP and can complicate management of the child especially at home (Potters, 1997).

2.5 CHALLENGES FACED BY PARENTS/CAREGIVERS WITH CEREBRAL PALSY CHILDREN

CP is a lifelong condition that holds many challenges for the child, the caregivers and the family as a whole. When a child is diagnosed with CP, the family is faced with a dilemma. Society generally has positive perceptions of parenthood, but more negative views of the birth of a disabled child. This ambivalence contributes to the family's internal stress (Vijesh & Sukumaran, 2007). When parents learn that their child is disabled, they experience mixed emotions that evoke fairly clear reaction patterns. They experience a crisis in which their expectations are disrupted (Sen & Yurtsever, 2007). The typical reactions of parents are grouped under three primary categories (Abidoğlu & Gümüşçü, 2000; Kearney & Griffin, 2001). The primary reactions include shock, denial, suffering and depression (Vijesh & Sukumaran, 2007); the secondary reactions include experiencing feelings of guilt, indecision, anger and shame; while the tertiary reactions include bargaining and acceptance and adaptation.

2.6 CHALLENGES TO ACCESS TREATMENT

Research in rehabilitation has shown that consistent attendance at treatment appointments plays a central role in both improving structure and function, is associated with good treatment outcomes, increased activity participation and improved quality of life of the patient.

According to Lerman et al (2004), patient/caregivers behaviour during treatment is influenced by interactions within the family system, between the patient/caregiver and the health provider, and within the health care system and the external environment. Kerkorian et al (2006) on the other hand suggests that the quality of experience obtained by the patient or caregiver during treatment influences treatment-seeking decisions and keeping treatment appointments. Positive assessments of the previous contact with a health care provider are associated with higher intentions to seek treatment in future whereas negative experiences and expectations they produce have the reverse effect.

2.6.1 Travelling Distance

Studies have found that location of the health facility and geographical accessibility to these facilities remains a central determinant of participation and continuation of the treatment regimen by the patient or caregiver. The distance needed to travel to and from treatment imposes costs on patients/caregivers in the form of both greater time commitment and increased economic expenses that affects continuation with the required prescribed treatment (Beardsley et al, 2003). The longer the distance a patient can travel to a health facility, the lower the consistence to the treatment. In another study on access and discontinued mental health care among adolescents in Minnesota USA, Samargia et al (2006) found inability to pay for the health services and lack of transport as perceived barriers that hindered adolescents from utilizing and continuation with the treatment requirements of mental health. Results from these studies indicate that the location of a health facility from the homes of patients/caregivers can determine the utilisation of medical services from the health facility. On the other hand, transit time may also affect consistence to treatment.

2.6.2 Social/Family Support

Unpublished study done by Chiluba (2012) in which literature stated that the main issues of concern with regard to the social and economic aspects are alteration of social relations with friends, social isolation and lack of finances, particularly in countries such as Zambia where social security funds for the disabled and parents/caregivers are non-existent. CP care giving demands an increase in finances that are related to rehabilitation especially in communities where no rehabilitation programs exist. Funds are needed for

transportation, hospital fees, medication and sometimes, a special diet. The ones affected most are those in the middle and lower economic classes and that includes Zambia which recently attained the low-middle income country status. Bowling (2009) argues that those in the higher socio-economic groups are more likely to pursue healthy life styles than those in the lower socio-economic groups. Life style is determined partly by a person's access to financial resources to support the chosen lifestyle (Roelotsen et al, 2003). Financial problems are most relevant among families especially where the main wage earner takes up the care-giving role (Anderson et al, 2005).

According to Hanneman & Blacher (2000), one of the ways in which families with children that have physical and mental impairments buffer stress is through the use of support systems for instance friends, immediate family members, other relatives or professionals such as social workers, counselors, community and government policy and programs. They suggest that the purpose of support systems is to alleviate strain related to care giving, strengthen or improve family functioning and to improve the quality of life of the parents/caregivers and that of the patient. Furthermore, Letvak (2002) indicates that people with high levels of social support experience less stress when in stressful situations and are able to cope more successfully during difficult times than those without social support. The development of strong social support networks within the family is a strong predictor of well-being and health within the family and facilitates follow up for the required treatment.

2.6.3 Waiting Time

According to Lonnroth et al (2001), treatments regimens with repeated visits and long waiting times at each visit are inconvenient for the patient and caregiver and are less likely to be attended to as required. According to Terricone (2006), the value of lost production as a result of time spent attending treatment at the health facility affects the family in terms of loss of time from paid work and unpaid work and the value (to the caregiver) of leisure activities forgone in terms of quality of life. In addition, according to Waseem et al (2003), evaluating waiting time for pediatric treatments may be important because parents or caregivers may become unduly stressed and intolerant of what may seem as an excessive wait. Lengthy waiting times tend to cause dissatisfaction with the

care, which may lead to inconsistency with the treatment recommendations. The time spent by patients and caregivers in health facilities waiting for treatment is a social cost in terms of lost productivity to the family and may influence the consistency of patients/caregivers to the required treatment.

2.6.4 Socio-Economic Factors

Socio-economic factors may hinder access to health care services in most resource-poor settings. Alaje (2005), assert that despite the availability of effective treatment interventions and the high cure rate, the outcome of treatment in many parts of Africa remains sub-optimal due to poor socio-economic conditions and poor health seeking behaviours. Shawky et al (2002) in a study on attitudes and practices of families towards children with CP in Kenya, found that poor socio-economic situations in families affected the parents' use of medical services for their sick children at health facilities. This led them to resort to the least costly services such as religious or traditional treatments. He further document that accessing health care services for children is affected by monetary issues on a number of different levels. Likewise, travel expenses may increase the costs of providing and obtaining health care.

2.6.5 Communication

Communication is a vital tool in ensuring that rehabilitation is of continuous and systematic form. Good communication between health personnel and the parent/caregivers is very important to both parties. Health professionals have information that the parents/caregivers does not have direct access to, even though such information concerns the rehabilitation process that has to be followed when the child is at home. Unfortunately, in general practice, communication with the parent/caregiver is valued only when conducting assessments and during re-assessments. In the process, various needs of the parent/caregiver are overlooked and not addressed. The parents/caregivers need information in helping the CP patient in various activities. The amount of contact patients have with their health provider may also be an influential factor in the continuation with the prescribed treatment. For example in one study conducted on patients with epilepsy in USA, Buck et al (1997) found that patients who had a regular

arrangement to see their physician about epilepsy had a better compliance with the treatment regimen than those who saw the physician irregularly. Good communication skills, listening to patient's needs and tailoring treatments to the needs of the patient helps to establish a two-way flow of information that enables the negotiation of a contract of management between the health provider and the patient or caregiver. Similarly, Bultman & Svarstad (2002) assert that proper clinician communication does not only influence patient or caregiver's knowledge about treatment but also changes his or her initial beliefs about the effect of treatment.

2.6.6 Accessibility to Physiotherapy Clinic

Non accessibility to treatment can bring about complications which can vary from mild to severe. Nicholas (2004) explains that there is evidence that consistent treatment can be beneficial for young people with cerebral palsy. To successfully implement this programme the physiotherapist should consider factors that can affect accessibility to the clinic. The department should have wider doors in order not to restrict children who uses wheelchairs as their mobility aid. They should be able to accommodate every child. Availability of wheelchairs to assist children who have difficulties with movement. Some children with cerebral palsy will have multiple handicaps and may require long term care and adherence to treatment.

CHAPTER THREE

3.0 METHODOLOGY

This chapter contains the following: study design, research setting, study population and sampling. It also includes data collection tool, data analysis and ethical consideration.

3.1 STUDY DESIGN

The study design for this study was a quantitative method using a cross-sectional descriptive survey. According to Hicks (2004), quantitative responses are easily aggregated for analysis because they are systematic and easily presented in a short space of time. In addition, this design provided baseline data upon which other studies can be built. Therefore, this research design suitably addresses the objectives of this study.

3.2 STUDY SETTING

This study was conducted at the University Teaching Hospital, Department of Pediatrics, Community Based Intervention Association (CBIA) formerly known as Action for Disability and Development (ADD). The employees of the Department included Physiotherapists and Speech Therapists. The center was instituted to rehabilitate children with disabilities the most common being CP. The most commonly seen conditions are-hemiplegia, spastic paraplegia, spastic quadriplegia and athetoid. The University Teaching Hospital is located in the capital city of Zambia, Lusaka. The hospital occupies approximately eight hectares of land spread over one and a half kilometers. The hospital has a total of fifty-six wards scattered in the following categories: A-block-Pediatric ward, B-block-Maternity ward, C-block-Orthopedic wards, D-block-Neonatal wards, E-block-Medical wards and G-block-Surgical wards. The hospital has two intensive care units namely, the main ICU and the NICU. The UTH is the biggest referral hospital in Zambia offering health services at tertiary level. Lusaka has an estimated population of over 2 million people. The hospital offers the following services:

- Provision of general health care to the Zambian population.
- Conducting research and establishing better management of the commonly occurring diseases in Zambia and the southern region.

- Provision of training for all medical staff.

The choice of this site was based on its level as it happens to be the biggest referral hospital in Zambia located in the capital city of Lusaka, Zambia. The site was chosen because it is familiar, easily accessible to the researcher and it is the place she does her clinical practice when at school.

3.3 SAMPLE SIZE

In this study, a non-probability convenience sampling procedure was used to select participants. Being a quantitative, the study had 30 participants who were selected randomly.

3.4 INCLUSION AND EXCLUSION CRITERIA

3.4.1 Inclusion Criteria

The inclusion criteria were parents/caregivers of children with CP at the selected setting on the time of data collection and were willing to participate.

3.4.2 Exclusion Criteria

- Parents/caregivers who had no children with CP
- Parents/caregivers who were available at the time the study was being conducted.
- Parents/caregivers who were not consented to take part in the research.

3.5 PILOT STUDY

A pre-test was conducted using 8 participants to test the instruments (questions). It was conducted at UTH Pediatric Physiotherapy Department. After this five questions were added to the questionnaire in section B to get the required information. Any parent who had a cerebral palsied child who was undergoing physiotherapy treatment was used to test the credibility, validity and reliability of the questionnaire in answering to the research objectives. The test helped to expose the weakness or strength of the research tools.

3.6 DATA COLLECTION METHODS

In this research, a structured questionnaire in appendix V, on page 50 which had 20 questions was used to collect data. It was chosen because it is less expensive, does not require research assistant and permits anonymity which results in more honest response. The independent variables in this research were age, gender, age of the child, marital status, kind of transport used and parent/caregiver's employment status while the dependent variables were challenges.

3.7 DATA ANALYSIS

The dependent variables which were challenges and independent variables age, gender, age of the child, marital status, kind of transport used were summarized, edited, coded and scored. Data was then be analyzed using the Statistical Package for Social Sciences (SPSS) version 16.0 for windows to determine the numerical significance of the results. The results were presented as pie charts and graphs.

3.8 ETHICAL CONSIDERATION

Permission was sought from University of Zambia Bio-medical and Research Ethics Committee (UNZABREC). Permission was requested from the Senior Medical Superintendent of U.T.H and the Head of Physiotherapy Department. All study participants signed an informed consent form before any information was collected from them. Confidentiality and anonymity of the participants was highly maintained by not identifying them by name. The researcher explained to the participants that the research was purely for academic purposes.

CHAPTER FOUR

PRESENTATION OF RESULTS

4.0 INTRODUCTION

This chapter displays the results of the study which the researcher undertook on thirty parents (n=30) who have cerebral palsy children. Data was collected through questionnaire which was answered by parents. The data gathered is summarized and presented using various graphic methods and compilations, and analysis of quantitative data made use of the Statistical Package for Social Sciences (SPSS) version 16.0. The results of the study include the socio-demographic characteristics of the parents/caregivers; physiotherapy treatment of the child, communication between physiotherapists and parents/caregivers; challenges encountered by parents/caregivers to regular attendance of treatment.

4.1 SOCIO DEMOGRAPHIC DISTRIBUTION

4.1.1 Parent/Caregivers Residential Address

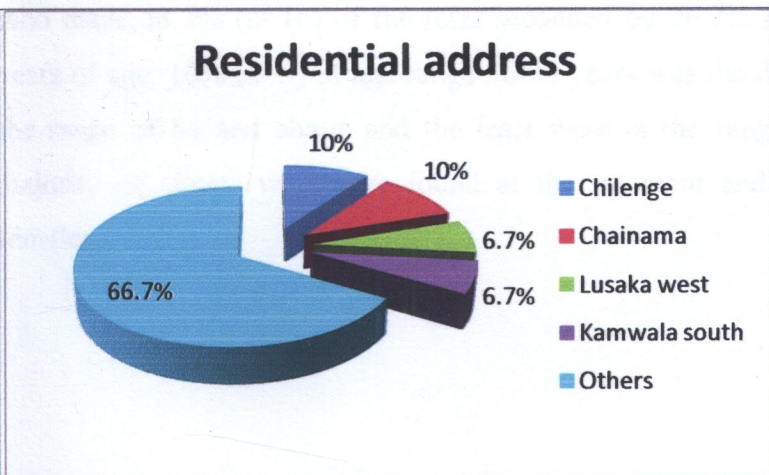


Figure 4.1.1 shows residential areas

From the information collected, the majority 66.7% (n=20) of the parents/caregivers were coming from Jack compound, Roma, Chilulu garden, Arakan barracks, Unza, Matero, 10.0%

=3) from Chainama and Chilenje (n=3), 6.7% (n=2) Lusaka west and another 6.7% (n=2) were coming from Kamwala south.

1.2 Parents/Caregivers Specific Age of Distribution

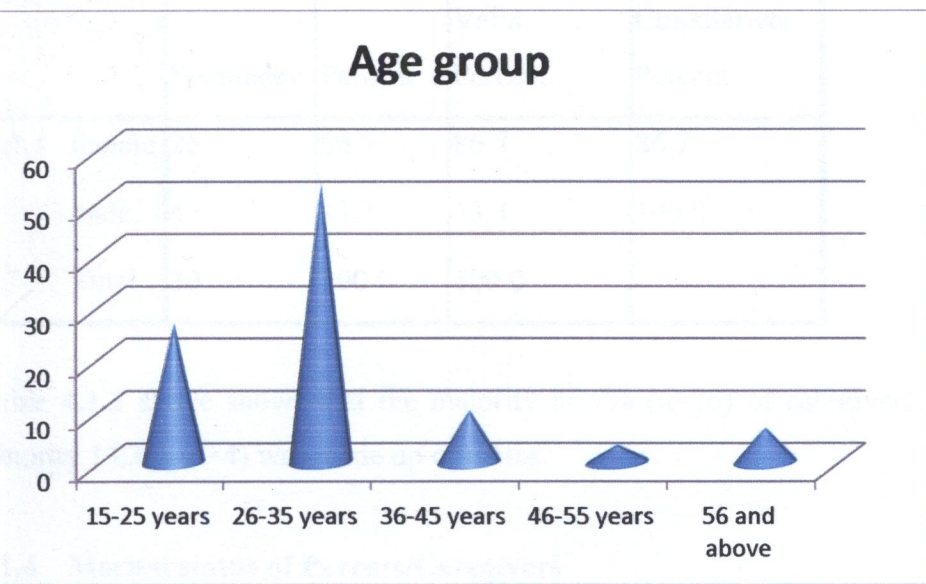


Figure 4.1.2 Age Group of Parent/caregivers

The majority of parents who took their children for physiotherapy were in the range 26-35 years who made 53.3% (n=16) of the total seconded by 26.7% (n=8) who were in the range 15-25 years of age. 10% (n=3) of age range 36-45 years was the third then followed by 6.7% (n=2) in the range of 56 and above and the least were in the range 46-55 which is 3.3% (n=1). The majority of clients who were found at that moment and answered the questionnaires were males.

4.1.3 Gender Distribution of Parents/Caregivers

Parents/Caregivers Gender

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid female	26	86.7	86.7	86.7
male	4	13.3	13.3	100.0
Total	30	100.0	100.0	

Table 4.1.3 above shows that the majority 86.7% (n=26) of caregivers were females and the minority 13.3% (n=4) was made up of males.

4.1.4 Marital status of Parents/Caregivers

Marital Status in Percentage

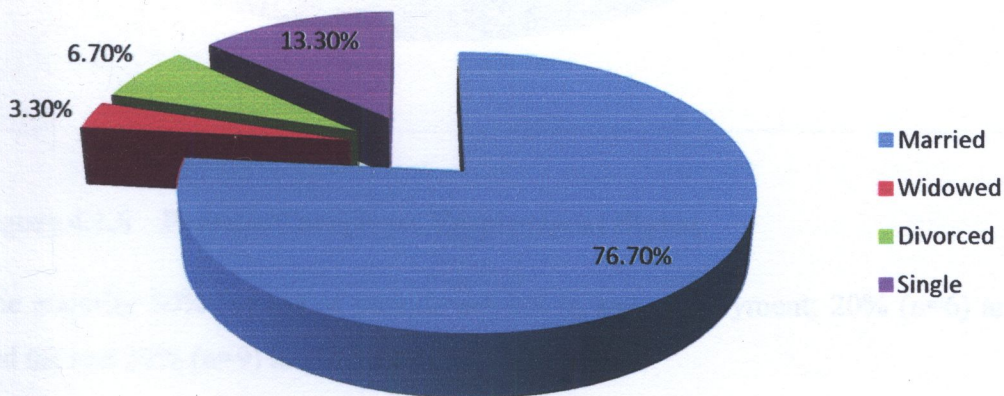


Figure 4.1.4 Parents/Caregivers Marital Status

As shown in figure 4.1.3 above, the majority of the parents/caregivers were married. Out of the 30 who participated in this study, those who were married gave a representation of 76.7% (n= 23) of the entire group. Those who were single were the second largest group and these gave a representation of 13.3% (n= 4). Those who were divorced giving a representation of 6.7% (n= 2) and 3.3% (n=1) of parents were widowed.

4.1.5. Occupational Background

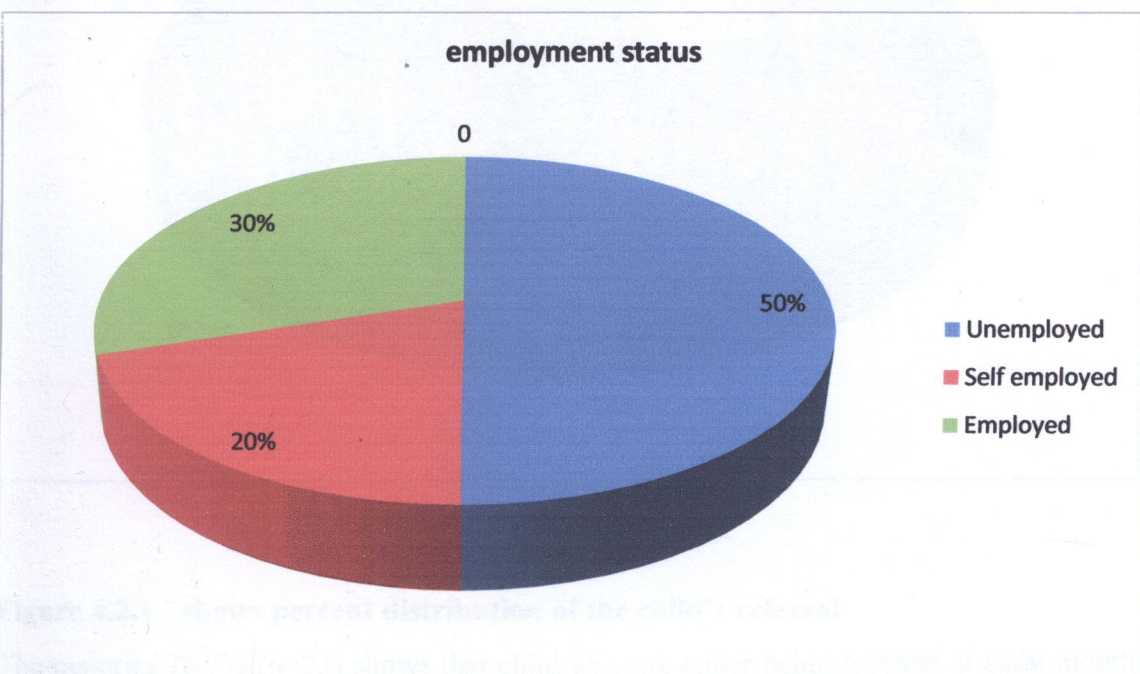


Figure 4.1.5 Parents/Caregivers Employment Status

The majority 50% (n=15) of parents are not in any employment; 20% (n=6) are self employed and the rest 30% (n=9) are in formal employment.

2 Physiotherapy Treatment

2.1 Referral of the Child to Physiotherapy

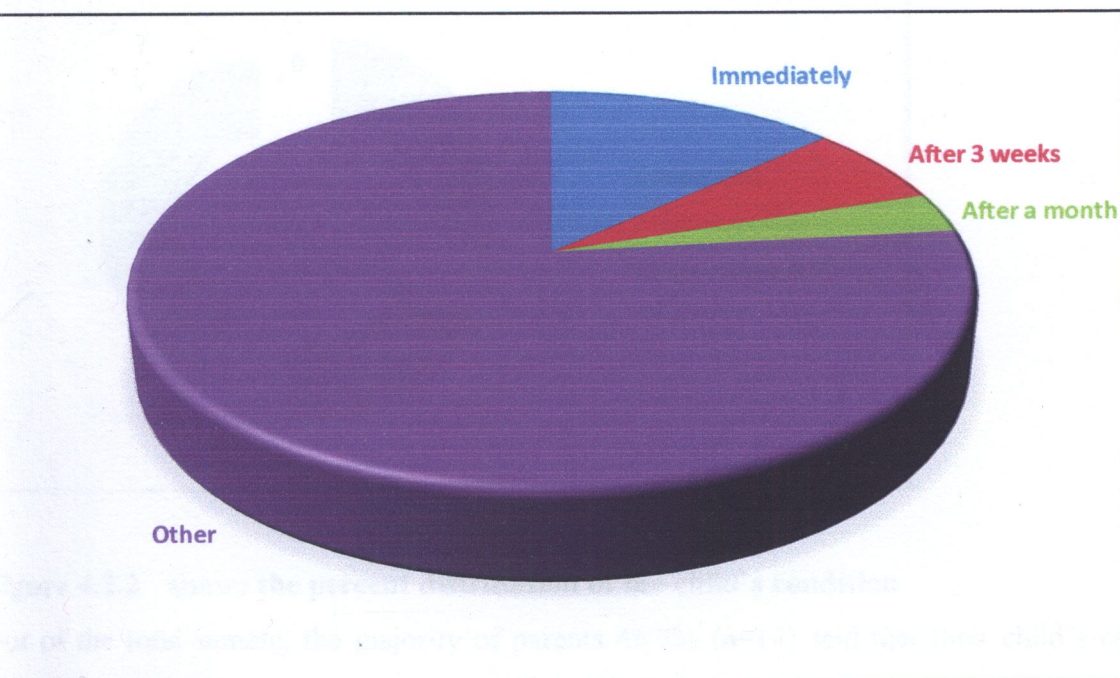


Figure 4.2.1 shows percent distribution of the child's referral

The majority 76.7% (n=23) shows that children were either being referred at eight months (8), at one year (1), at one year three months (1 year 3 months) or late after two years (2 years), followed by 13.3% (n=4) where referred immediately, then 6.7% (n=2) where referred after three weeks, and finally 3.3% (n=1) was referred after a month.

4.2.2 Condition of the child

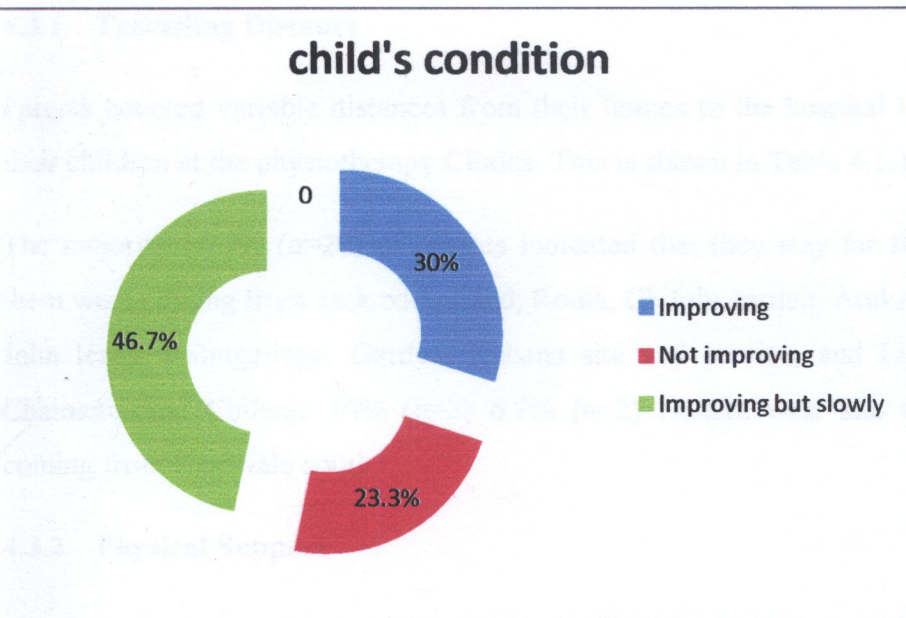


Figure 4.2.2 shows the percent distribution of the child's condition

Out of the total sample, the majority of parents 46.7% (n=14) said that their child's condition was improving but slowly, 30% (n=9) Improving, and the least 23.3% (n=7) their child's condition was not improving.

4.3 Challenges to Physiotherapy Regular Treatment Attendance

4.3.1 Travelling Distance

Parents covered variable distances from their homes to the hospital in pursuit of treatment for their children at the physiotherapy Clinics. This is shown in Table 4.1.1

The majority 66.7% (n=20) of parents indicated that they stay far from the hospital. Most of them were coming from Jack compound, Roma, Chilulu garden, Arakan barracks, Unza, Matero, John lengi, Kalingalinga, Garden, Kabana site and service, and Lilayi, 10.0% (n=3) from Chainama and Chilenje 10% (n=3) 6.7% (n=2) Lusaka west and another 6.7% (n=2) were coming from Kamwala south.

4.3.2 Physical Support

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid No	22	73.3	73.3	73.3
Yes	8	26.7	26.7	100.0
Total	30	100.0	100.0	

Table 4.3.2 Percent distribution of physical support

Out of the total sample, the majority of parents 73.3% (n=22) indicated that they didn't have someone at home to take care of their other children and this was reported as one of the factors that enabled them not to bring the child for treatment every week. While the minority (26.7%) (n=8) said they do.

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4.3.3 Kind of Transport used to and from UTH.

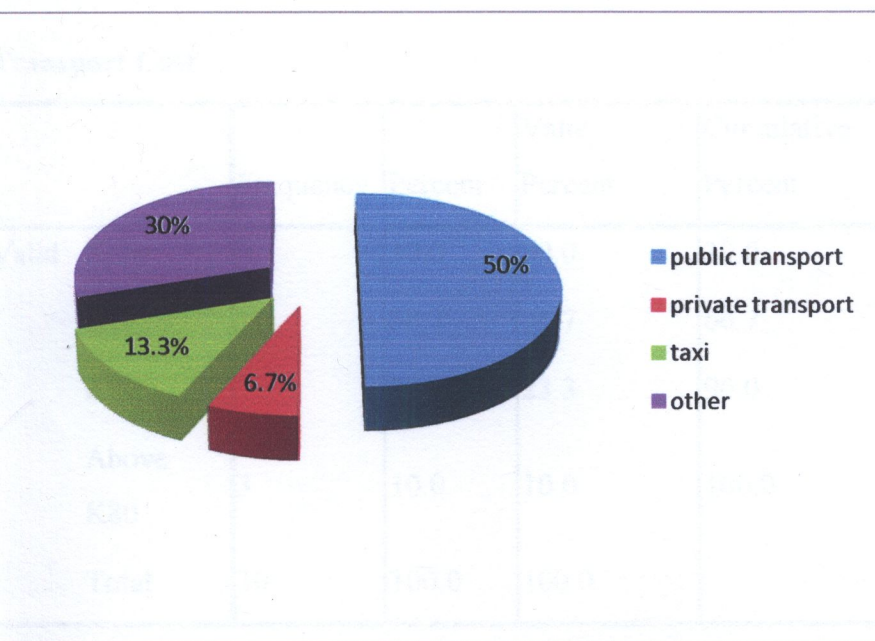


Figure 4.3.3 The percent distribution of the kind of transport used to and from UTH.

The majority (50%) (n=15) of the participants use public transport and (30%) (n=9) use other modes of transport (walking). About 13.3% (n=4) use taxi and only 6.7% (n=2) use private transport.

4.3.4 Amount used on Transport to and from UTH

Transport Cost

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid None	9	30.0	30.0	30.0
K30	11	36.7	36.7	66.7
K50	7	23.3	23.3	90.0
Above K80	3	10.0	10.0	100.0
Total	30	100.0	100.0	

Table 4.3.4 shows Transport Cost. Parents indicated the transport expenses incurred in bringing the child for treatment. 36.7% of parents use the amount K30 said that they found it expensive to bring children for treatment every week, while the minority 10% use above K80 on transport to and from UTH.

4.3.5 Waiting Time

The majority 56.7% (n=17) of parents/caregivers waited for approximately 20 minutes, followed by 40% (n=12) less than 15 minutes and the minority 3.3% (n=1) waited approximately 40 minutes.

4.3.6 Community Reaction

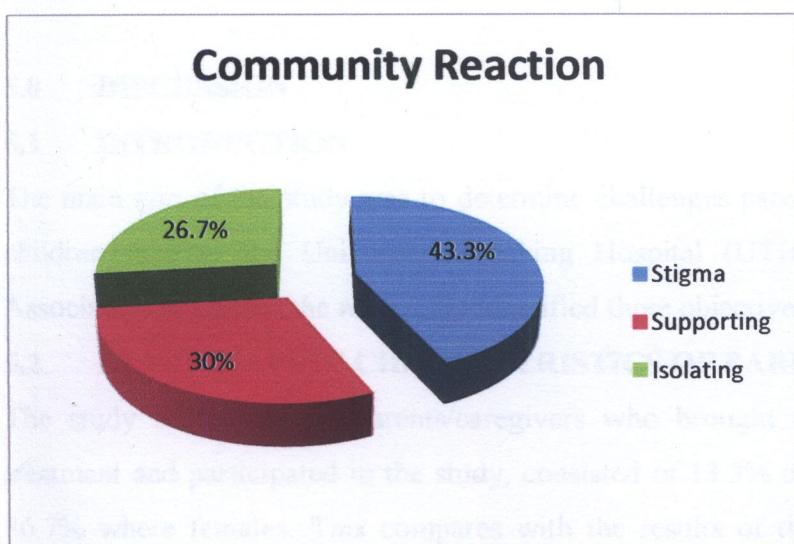


Figure 4.3.6 shows that the majority 43.3% (n=13) were stigmatized and 26.7% (n=8) where being isolated and 30.0% (n=9) where being supported.

4.3.7 Parent/caregivers Session Attendance

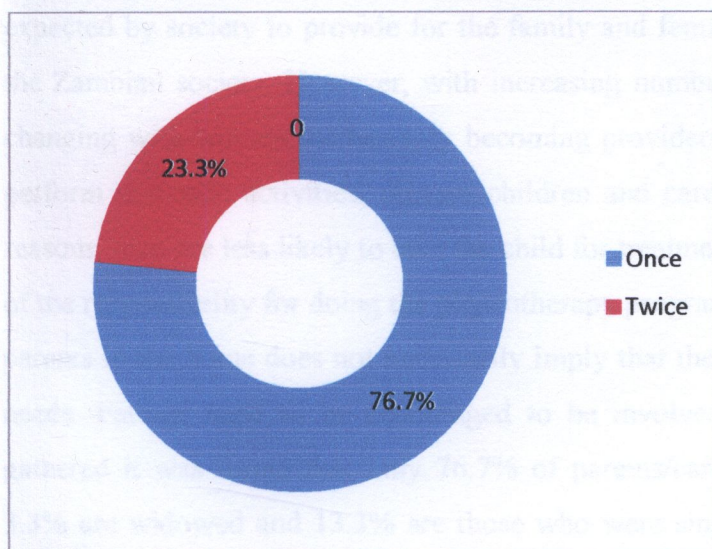


Figure 4.3.7 shows the session attendance and percentage of parents/caregivers who used to take their children for physiotherapy

Out of the total sample, 76.7% (n=23) of parents/caregivers that participated in the study at the hospital indicated that they brought their children for treatment once a week, that is, four times in a month, 23.3% (n=7), twice in a week, that is, eight times in a month.

CHAPTER FIVE

5.0 DISCUSSION

5.1 INTRODUCTION

The main aim of the study was to determine challenges parents/caregivers of children with CP face at the University Teaching Hospital (UTH) community based intervention Association in Lusaka the researcher identified three objectives.

5.2 DEMOGRAPHIC CHARACTERISTICS OF PARENTS/CAREGIVERS

The study sample of 30 parents/caregivers who brought their children to the hospital for treatment and participated in the study, consisted of 13.3% of the respondents being males and 86.7% were females. This compares with the results of the study done by (Chiluba, 2012) where he found that 92% of the caregivers interviewed were females and 8% were males. (He further stated that a high number of female caregivers indicate discrimination against women, because care-giving prevents them from having equal opportunities in life, especially in a country like Zambia whose society view care-giving as a responsibility for females). Males are under-represented and this should be understood in relation to the higher number of males being expected by society to provide for the family and females' dominant role in domestic duties in the Zambian society. However, with increasing numbers of educated women, gender roles are changing with women increasingly becoming providers as well as carers. They are expected to perform domestic activities, nurture children and care for the sick. As a result for economic reasons, men are less likely to take the child for treatment. It seems that mothers bear a large part of the responsibility for doing the physiotherapy programs. It is therefore evident that having two parents in the home does not necessarily imply that there is more support in meeting the child's needs. Fathers need to be encouraged to be involved as much as possible. From the data gathered it was found that only 76.7% of parents/caregivers are married, 6.7% are divorced, 13.3% are widowed and 3.3% are those who were single. The family is faced with a dilemma with the birth of a cerebral palsy child. Society generally views parenthood positively, but more negative views with the birth of a disabled child, this causes problems in marriage. This corresponds with what is explained by Vijesh (2007) that awareness of society's ambivalence, adds to the stress the family feels within themselves and the marital relationship may suffer unduly from the added stresses of blame, guilt and anxiety. It affects the relationships within the

family, the families' economic situation, daily lifestyle, plans and expectations for the future.

3 OBJECTIVE ONE: CHALLENGES PARENTS/CAREGIVERS EXPERIENCE

3.1 Child's Referral

From the study it was observed that the majority 76.7% shows that children were being referred after eight months (8), at One year (1), at One year three months (1 year 3months) or late after Two years (2years years), followed by 13.3% who were referred immediately, then 6.7% were referred after three weeks, and finally 3.3% was referred after a month.

The medical staffs from where most of these children came were being referred late for physiotherapy. The earlier the commencement of treatment the greater the chances of improving, this however, would have motivated parents to start treatment early, and also follow up the treatment appointments, resulting in them becoming consistent with the treatment regimen. This is in line with Bultman & Svarstad (2002) who assert that proper clinician communication does not only influence patient or caregiver's knowledge about treatment but also changes his or her initial beliefs about the effect of treatment. Good communication between health personnel and the parent/caregivers is very important to both parties. Health professionals have information that the parents/caregivers does not have direct access to, even though such information concerns the rehabilitation process that has to be followed when the child is at home but, in general practice, communication with the parent/caregiver is valued only when conducting assessments and during re-assessments. In the process, various needs of the parent/caregiver are overlooked and not addressed. The parents/caregivers need information in helping the CP patient in various activities. If the treatment process is explained to parents/caregivers, they are more knowledgeable, have more positive beliefs about their treatment and feel more satisfied with care.

3.2 Traveling Distance and Transport Cost

From the data collected, it was found that 66.7% of parents/caregivers were coming from other places like Jack compound, Roma, Chilulu garden, Arakan barracks, Unza, Matero, 10.0% from Chalinama and Chilenje, 6.7% Lusaka west and another 6.7% were coming from Kamwala south. The distance from home to the nearest health care facility, determines how much the patient will pay before accessing the health services. Most of the parents/caregivers said they stay in far places and cannot afford coming for treatment all the days in a month, they complained lack of

transport money to and from UTH. This is a very big challenge for the parents/caregivers considering the fact that 50.0% of the parents/caregivers that participated in the study were unemployed housewives and it was difficult for them to estimate how much their husbands spent on transport and other medical costs. However, this study did not investigate the income status of the fathers or mothers of these children.

Beardsley et al (2003), states that the distance needed to travel to and from treatment imposes costs on patients/caregivers in the form of both greater time commitment and increased economic expenses that affects proper treatment outcome. The study also asked parents, how much money they were paying for transport to and from the hospital. According to the survey data in table 4.3.4, the minimum amount of money parents paid for transport was k30 kwacha, the majority said they found it expensive to bring their children for treatment every week. Since most of these parents who attended the clinics were unemployed, it is likely that they were financially dependent on their spouses or relatives and, had no direct control over the financial resources that were required to meet transportation costs and other necessary expenses. Most parents/caregivers gave reasons as for instance, if the husband or relative who provides finances to the parent failed to raise money for transport of the mother to take the child to the hospital, the mother had either to borrow the money to meet transport costs or cancel the treatment visit to the hospital. Most parents used more than one mode of transport to reach the hospital and return home, apart from the very few who use private transport. Letvak (2002) indicates that people with high levels of social support experience less stress when in stressful situations and are able to cope more successfully during difficult times than those without social support. The development of strong social support networks within the family is a strong predictor of well-being and health within the family and facilitates follow up for the required treatment. In another study on access and discontinued mental health care among adolescents in Minnesota USA, Samargia et al (2006), found inability to pay for the health services and lack of transport as perceived barriers that hindered adolescents from utilizing and complying with the treatment requirements of mental health. Results from these studies indicate that the location of a health facility from the homes of patients/caregivers can determine the utilization of medical services from the health facility.

5.3.3 Waiting Time

From the data collected, it was noted that the majority 56.7% of parents/caregivers waited for approximately 20 minutes which they considered it to be minimal and that did not pose any discouragement of going back for treatment even though they had to wait for such a time, this is a very long a period to wait for treatment for children who easily tire and get hungry after an excessive wait and, for the parents/caregivers who have other responsibilities at home. Parents/caregivers of which the majority 83.3% were parents to these children they must have been inconvenienced in one way or another looking at the time spent at the clinic for the child to be treated. Parents do not give up on their children but persist and the negative impact that comes out is that parents do not have enough time left to attend to the needs of the other children, chores, work and little time to deal with other important family issues. Lonnroth et al (2001), argues that treatments regimens with repeated visits and long waiting times at each visit are inconvenient for the patient and caregiver and are less likely to be attended to as required. According to literature by Terricone (2006) the value of lost production as a result of time spent attending treatment at the health facility affects the family in terms of loss of time from paid work and unpaid work and the value (to the caregiver) of leisure activities forgone in terms of quality of life. Lengthy waiting times tend to cause dissatisfaction with the care, which may lead to poor consistence with the treatment recommendations.

5.3.4 Walking Aid

From the results obtained, it was noted that 90% of parents/caregivers carry their children on their backs to the department these children had no walking aids like wheelchairs; this however imposed a very big challenge when taking children for therapies considering the fact that most of the children 43.3% were above the age of 3 and 5years. This may impose a great risk on the health of the parent/caregiver. The main effects of care giving, described in (Finn 2004; Bressick & Harvey 2007) are stress and deleterious effects on health (mainly worry, exhaustion and mental strain). Others are: anxiety over whether they are providing the best care, frustration that they could not restore function and anger at disruption of their lives' daily routine. Caring for a physically disabled child can be physically and emotionally stressful, placing the parent/caregiver at heightened risk of illness and the onset of chronic disease (Anderson et al,

05). It is a challenge to both the mental and physical resources of the individual parent/caregiver.

3.5 Community Reaction

This shows how public perceptions of disability can exert a negative influence on the lives of parents of a child with cerebral palsy, adding appreciably to the already considerable challenges they face in caring for their child, and in negotiating public encounters. This negative influence is experienced in the form of stigma, whereby the stigma which attaches to the child because of their disability, is extended to the parents, simply as a function of their relationship with their child. From the survey, it was found that the majority 43.3% were stigmatized and 26.7% where being isolated and 30.0% where being supported. Stigma may stop parents/caregivers from seeking professional help. It causes confusion and keeps people from seeking help in the end. Children end up with permanent contractures leading to disability. Literature by Robert (2002) agrees that having a disability or chronic health condition saddles the person with more than just the physical complaint. One has to struggle with the social meaning of that disorder as well. Often society is not very accepting of illness and disability and the person affected becomes stigmatized as a result. Stigma is a common problem among the disabled community. It not only affects the person with the disability, but may extend to include his or her whole family as well. The person is shunned. Social opportunities are denied.

4 OBJECTIVE TWO : REASONS FOR NON CONSISTENCE WITH PHYSIOTHERAPY TREATMENT.

4.1 Commencement of Treatment

The other factor that contributed to the parents/caregivers not to be consistent with bringing their children is improvement in the condition of the child. Potter et al (2003) argue that improvement in the condition is the most important outcome patients and caregivers expect to achieve during treatment. They argue that improvement in the condition is a vital factor motivating patients and caregivers to adhere to the recommended treatment requirements. The fact that these children were being referred late for treatment and by the time physiotherapy is being commenced it was too late for the parent to have seen any improvement in the child. Data shows that 46.7% of

parents, their child's condition were improving but slowly, 30% Improving, and the least 23.3% their child's condition was not improving.

It could be argued that the small improvement that parents/caregivers observe during each treatment session motivates them to attend every treatment session in anticipation of complete recovery. This shows that it is important to explore the reasons for non consistence of CP treatment in parents/caregivers, so that parents who are not consistent can be helped and motivated to adhere to the treatment regimen. This will improve the effectiveness of the treatment and, will reduce CP disability in the community.

5.4.2 Family Support

From the data collected majority of parents 73.3% indicated that they didn't have someone at home to take care of their other children and this was reported as one of the factors that made them not to bring their children for treatment every week. While the minority 26.7% said they do. This indicates that parents/caregivers who had someone at home to take care of other children were more likely to attend regularly for treatment than those who didn't have. Physical support received from family members relieves parents/caregivers of strain and the burden of domestic responsibilities and care.

5.4.3 Frequency of Contact with Physiotherapy Treatment

The study found that 76.7% of parents that participated in the study at the hospital indicated that they brought their children for treatment once a week, that is, four times in a month; 23.3% twice in a week, that is, eight times in a month. The amount of contact patients have with their health provider may also be an influential factor in enhancing consistence with the prescribed treatment. For example in one study conducted on patients with epilepsy in USA, Buck et al (1997), found that patients who had a regular arrangement to see their physician about epilepsy had a better treatment outcome than those who saw the physician irregularly. One parent said "we started coming here in August 2009 and my child still can't walk so I see no point of coming every time" my child is not improving. When planning for rehabilitation services especially for children with physical impairments in many developing countries, it is usually taken for granted that all affected children and their parents/caregivers will attend these rehabilitation services. However, in reality, not all children requiring evaluation and treatment do attend (Whitworth et

al, 2000). Even those parents who do attend experience a number of challenges, which are poorly understood by the rehabilitation care providers, and, if not addressed, could affect the effective utilization of rehabilitation services.

5.5 OBJECTIVE THREE : TO DETERMINE IF PARENTS/CAREGIVERS ARE TRAINED ON HOW TO TAKE CARE OF THEIR CEREBRAL PALSIED CHILDREN.

5.5.1 Parents’ Experience of Communication with the Physiotherapist

The results show that the majority 66.7% did not have enough information about the treatment on how to take care of their children while the minority 33.3% had information as regard to treatment. Providing explanations to parents about the treatment process was part of the treatment practice at the physiotherapy Clinic, some parents were not satisfied with the treatment depending on who is treating the child most parents/caregivers do not like it or has little confidence if it’s a student or caregivers treating their child. They feel like the treatment is not effective, In addition, they feel like they would not have a chance to talk about their other problems, this however discourages the parents from bringing their children for treatment they would rather treat them from their homes. It is most likely that parents wanted physiotherapist to understand some of the problems they encountered in treating their children so that they could provide some solutions or advice on how to overcome these problems. This agrees with (Van et al, 2002) who states that relationships between the health care provider and patient/caregiver determine the patient/caregivers behavior during treatment. Consultations without mutual understanding often result in dissatisfaction with the treatment and more often end in defaulting on treatment appointments.

CHAPTER SIX

6.0 CONCLUSION, RECOMMENDATIONS AND STUDY LIMITATIONS

6.1 CONCLUSION

The research was aimed at determining the challenges parents and caregivers of children with cerebral palsy face at the University teaching hospital (CBIA) pediatric wing. Cerebral palsy affects parents/caregivers in various ways yet it can be included in rehabilitation in order to yield positive outcomes. The results raise important concerns in regard to inadequate research done in the area of challenges faced by caregivers of cerebral palsy children. The study highlights the difficulties and amount of input needed to address cerebral palsy parents/caregivers' experiences and needs. Team members need to communicate closely in order to better understand the needs of the child and the whole family.

However, the majority of parents were concerned with some aspects of treatment, in particular communication with the physiotherapist regarding explanation of the treatment process. In addition, the study identified some difficulties parents experienced in attending to the required treatment program. These may have been challenges to attendance for other parents/caregivers. These include financial constraints to meet transportation costs, travelling distance, inadequate parent-physiotherapy communication, waiting time, community reaction.

6.2 RECOMMENDATIONS

1. There is need for physiotherapist to be trained in counseling skills so that when they are faced with such situations as those expressed by the parents/caregivers of these children, they will be able to know how to handle the situations.
2. The researcher also recommends that more research that involves both qualitative and quantitative approaches be done on the same topic at other hospitals or clinics to assess the rate of consistence of parents/caregivers and the difficulties they go through in these areas. This would capture data and views of parents in different settings, which could be used to develop programs that could improve the treatment of CP in Zambia.

The following recommendations are for the Ministry of Health

1. They should put more community based rehabilitation centers and provide treatment equipment's in all the centers. This will help the parents/caregivers not to spend too much on transport.
2. There is need to explain to the parents/caregivers the nature of cerebral palsy which affected their children and understand that it takes long to see the results of the rehabilitation intervention.
3. Community awareness programs through the Ministry of Health and the University Teaching Hospital should be put into place to sensitize the parents/caregivers of cerebral palsy children about the consequences of non- consistence to physiotherapy treatment. This will help them to be aware of how the child can be when they stop attending the treatment.
4. The parents/caregivers need to have psychological and social support in the care of their disabled children. This should be provided to the parents/caregivers when they attend or bring their children for treatment or rehabilitation.

5.3 STUDY LIMITATIONS

The research did not consider parents/caregivers at other health centers in Lusaka but concentrated on the University Teaching Hospital.

The data collected was only from the parents/caregivers who brought their children for treatment.

Unable to carry out the research on a big sample because the attendance was low.

The sampling method (random sampling) which was used was not very representative of the study population as it only considered parents/caregivers who took their children to the University Teaching Hospital on the day of interview. Parents who did not attend may have experienced more challenges than parents who were attending the clinics. Future research should attempt to track down parents who do not attend to the treatment appointments at the clinics as required and identify the challenges they encounter.

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APPEDICES

APPENDIX 1

LETTER TO THE RESEARCH ETHICS COMMITTEE

The University of Zambia,

School of Medicine,
P.O Box 50110,
Lusaka.

The Chairperson,
Research Ethics Committee,
University of Zambia,
P.O Box 50110,
Lusaka.

Dear Sir/Madam,

**RE: A STUDY TO DETERMINE CHALLENGES PARENTS AND CAREGIVERS WITH
CEREBRAL PALSY CHILDREN FACE AT UNIVERSITY TEACHING HOSPITAL**

With reference to the above, I wish to apply for the research topic above to be approved by your committee. I am a fifth year Bachelor of Science in physiotherapy (BSc.PT) student in the School of Medicine at the University of Zambia. In partial fulfillment of the degree program, I am expected to carry out a research project whose title is underlined above and the objectives are as follows:

- To determine challenges parents/caregivers experience in attending all treatment appointments.
- To determine why parents/caregivers with cerebral palsy children are not consistent with bringing the children for physiotherapy treatment.
- To determine if parents/caregivers are trained on how to take care of their cerebral palsied children.

Your consideration will be greatly and highly appreciated. Thank you.

Yours faithfully,



Nsama Chola

Student Number: 10070117

APPENDIX 11

LETTER TO THE UNIVERSITY TEACHING HOSPITAL

The Managing Director,
University Teaching Hospital,
Pediatrics Department,
Lusaka.

Dear Sir/ Madam,

RE: PERMISSION TO COLLECT DATA FROM UTH CBIA.

I am a fifth year physiotherapy student at the University of Zambia, School of Medicine. In partial fulfillment of the program, I am required to undertake a research study. My research topic is **“A study to determine challenges parents and caregivers with cerebral palsy children face at UTH”**.

I am hereby requesting for permission to collect data for my research. Data collection will be through administering of the scheduled questionnaire to the parents/caregivers who bring their children for physiotherapy treatment at UTH pediatric wing CBIA.

Your consideration will be highly appreciated.

Yours faithfully,



Nsama Chola

APPENDIX III

INFORMATION SHEET

Dear participant,

I, Nsama Chola, a 5th year physiotherapy student at the University of Zambia, School Of Medicine, is expected to undertake a research in partial fulfillment of Bachelors of Science degree in Physiotherapy. This will contribute to the body of knowledge and improve health delivery in our country.

This study aims to determine challenges parents and caregivers with cerebral palsy children face at UTH, CBIA pediatric wing.

Your participation in this study is purely voluntary and the information that you will provide will be confidential. You are not required to write your name or initials on the questionnaire to avoid identity. Your refusal to participate in this study does not jeopardize your child's access to treatment.

Be informed that there is no monetary or any material gain in participating in this study as it is purely an academic exercise.

I am requesting for your permission to be allowed to ask you questions that would meet the requirements of my study.

For any questions contact me or the secretary of the Research Ethics Committee

Your support and corporation will be greatly appreciated.

Miss. Nsama Chola

The Chairperson,
Biomedical Research Ethics Committee,
P.O. Box 50110,
Lusaka.

The University of Zambia,
School of Medicine,
Department of Physiotherapy,
P.O Box 50110,
Ridgeway,
Lusaka.

Tel: 256027

Mobile 0977- 104998 or 0967- 104998

Email: **cholansama@yahoo.com**

APPENDIX IV

INFORMED CONSENT

I.....having understood the aims and benefits of this study, do hereby acknowledge that am aware of my rights in not participating in this study and it will not affect my child’s right to treatment. Am also aware that I can withdraw from participating in this study at any time without a prior notice.

Therefore I have agreed / not agreed to participate in this study with my own free will.

Participant’s signature or left thumb print.	Date
.....

Witness signature or left thumb print.	Date
.....

Researcher’s signature.	Date
.....

APPENDIX V

QUESTIONNAIR

Research Title

A STUDY TO DETERMINE CHALLENGES PARENTS AND CAREGIVERS WITH CEREBRAL PALSY CHILDREN FACE AT UNIVERSITY TEACHING HOSPITAL.

INSTRUCTIONS

Answer clearly by ticking in the box or writing in the spaces provided.

SECTION A

DEMOGRAPHIC DATA: PARENT/CAREGIVER

(Mark items with an X in the space provided)

1) Gender:

i. Female []

ii. Male []

2) Residential address

i Chilenje []

ii Chainama []

iii Lusaka west []

iv Kamwala south []

v Others (specify) []

3) Age

- i. 15-25 years []
- ii. 26-35 years []
- iii. 36-45 years []
- iv. 46-55 years []
- v. 56 and above []

4) Marital status

- i. Single []
- ii. Married []
- iii. Widowed []
- iv. Divorced []

5) Employment

- i. Employed []
- ii. Unemployed []
- iii. Self-employed []

6) Education

- i. Primary []
- ii. Secondary []
- iii. Tertiary []

7) How old is the child?

- i 0 – 2 Years []
- ii 3 – 5 Years []
- iii 5 and Above []

8) Relationship to the child

- i. Parent []
- ii. Grandparent []
- iii. Sister/brother []
- iv. Uncle/aunt []
- v. Others (specify)..... []

SECTION B

9) When was child referred for physiotherapy?

- i. Immediately []
- ii. After one week []
- iii. After 3 weeks []
- iv. After a month []
- v. Others (specify)..... []

10) How many sessions do you have for physiotherapy treatment in a week?

- i. Once []
- ii. Twice []
- iii. 3 times []
- iv. Others (specify)..... []

11) Other than physiotherapy, which of these options do you use for your child's condition?

- i. Traditional healers
- ii. Religious guidance
- iii. Others (specify)

12) How long do you wait for treatment?

- i. Less than 15 minutes []
- ii. Approximately 20 minutes []
- iii. Approximately 40 minutes []

13) What kind of transport do you use when coming?

- i) Private transport []
- ii) Taxi []
- iii) Public transport []
- iv) Other (specify)..... []

14) How much do you spend on transport to UTH?

- i. K30 []
- ii. K50 []
- iii. K80 []
- iv. Above K80 []
- v. None []

15) Have you been trained on how to take care of the child?

- i. Yes []
- ii. No []

16) Do you feel the physiotherapist gives you enough information about the treatment?

- i. Yes []
- ii. No []

17) If Yes to Q16, how do you consider your child's condition?

- i. Improving []
- ii. Not improving []

iii. Improving but slowly []

18) Do you have anyone who can bring the child to the hospital if you are not there?

i. Yes []

ii. No []

19) How do you bring your child into the department?

i. By wheel chair []

ii. On the back []

iii. Child walks []

iv. Other (specify)..... []

20) What reaction do you get from the community concerning your child?

i. Supporting []

ii. Isolating []

iii. Stigma []

THANK YOU FOR YOUR TIME AND GOD BLESS.



THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE

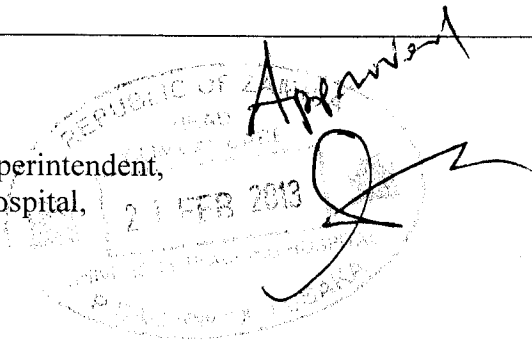
DEPARTMENT OF PHYSIOTHERAPY

Telephone: 257938
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Telex: UNZALU ZA 44370
Fax: + 260-211-257938

Dean's Office
P.O. Box 50110
Lusaka, Zambia

21st February, 2013.

The Senior Medical Superintendent,
University Teaching Hospital,
P/Bag RW 1X,
Lusaka.



Dear Sir,

**RE: REQUEST FOR PERMISSION TO ALLOW NSAMA CHOLA
COLLECT DATA FOR HER STUDY**

Reference is made to the subject above.

We write to introduce to you our above named student pursuing a Bachelor of Science in Physiotherapy. Nsama is required to carryout a Research in partial fulfillment of the requirements for the award of the Bachelor of Science Degree in Physiotherapy.

Her proposed study is: **“Determining the challenges parents/caregivers of children with cerebral palsy face.”**

We are therefore seeking permission from your office to enable her collect data from the Paediatric Department of Physiotherapy-CBIA. We would like to request that she be allowed to access data related to her research. The data collected will be for academic purposes only and will be treated as confidential.

Thanking you for your support.

Yours faithfully,

Dr Esther Munalula-Nkandu
BSc PT (Hons), MSc, PgD R/Ethics, MA Bioethics, PhD
HEAD – DEPARTMENT OF PHYSIOTHERAPY



THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

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IRB00001131 of IOR G0000774

22nd February 2013

Chola Nsama
Physiotherapy Department
UNZA
LUSAKA

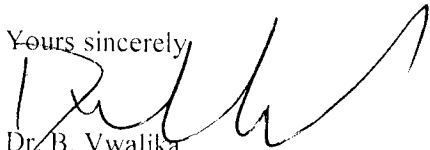
Dear Chola Nsama

RE: **"A STUDY TO DETERMINE CHALLENGES PARENTS AND CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY FACE AT UNIVERSITY TEACHING HOSPITAL"**

Your Supervisor has written to confirm that you have made the changes to your proposal as recommended by UNZASOMUBREC. I have reviewed your corrections and I am satisfied with your effort.

The proposal is now approved.

Yours sincerely


Dr. B. Vwalika

CHAIRPERSON - UNZASOMUBREC

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