



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

**RESEARCH PROJECT**

**PTY540**

**A STUDY TO EVALUATE CAREGIVERS EXPERIENCES IN  
CARING FOR CHILDREN WITH HYDROCEPHALUS  
ATTENDING PHYSIOTHERAPY AT THE UNIVERSITY  
TEACHING HOSPITAL D-BLOCK AND CBI**

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**LIST OF ABBREVIATIONS**

<b>NINDS</b>	National Institute of Neurological Disorders and Stroke
<b>ASBAH</b>	Association for Spina Bifida and Hydrocephalus
<b>CSO</b>	Central Statistical Office
<b>UTH</b>	University Teaching Hospital
<b>USA</b>	United States of America
<b>WHO</b>	World Health Organisation
<b>CSF</b>	Cerebral Spinal Fluid
<b>CT</b>	Computerized Tomograohic
<b>ICU</b>	Intensive Care Unit
<b>MRI</b>	Magnetic Resonance Imaging
<b>MoH</b>	Ministry of Health
<b>CBI</b>	Community Based Intervention
<b>UK</b>	United Kingdom
<b>CNS</b>	Central Nervous System
<b>HFAO</b>	Hydrocephalus from Alzheimer’s Outreach
<b>HMIS</b>	Health Management Information System
<b>CH</b>	Hydrocephalus
<b>UTH</b>	University Teaching Hospital



**LIST OF KEY WORDS**

Caregivers

Hydrocephalus

Impact

Rehabilitation

Experiences

Caregiving

Emotional

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**DECLARATION**


I, Maifwani Jack, do hereby declare that the work presented in this study for the Bachelor of Science in Physiotherapy is the result of my effort and that it has not been presented either wholly or in part for any degree and it is not being submitted for any other degree.

Signed: MAIFWANI JACK ~~MA~~ Date: 11/05/09  
Student

Signed: Sr. Mweshi Margaret M. ~~MA~~ Date: 15/05/09.  
Supervising Lecturer

**STATEMENT**

I hereby certify that this study is entirely the result of my individual effort and my own independent investigations. The various sources to which I am indebted are clearly indicated in this paper and in the references.

Signed:                                          Date:                     11/05/09

**DEDICATION**

Dedicated to departed souls of Maifwani family: my father Mr. H. Maifwani and my sister Ms R. Maifwani. Last, but certainly not least, I dedicate this study to my beloved wife Ezra Mulenga Maifwani, my two wonderful sons Shungu and Kangwa who have added a very special dimension to my life, to my mother, brothers, sisters who have provided a life time of unconditional love and support to me.

## **ABSTRACT**

Hydrocephalus is a congenital or acquired condition marked by dilatation of the cerebral hemispheres, usually secondary to obstruction of the cerebrospinal fluid (CSF) pathways and this is followed by excessive accumulation of this fluid in the skull. Hydrocephalus is a serious problem and a major cause of disability in children. Children who are born with hydrocephalus or acquire it later are cared for in the home settings, by family caregiver and other professional caregivers. Caregivers cross all ethnic, economic, social and religious lines. Care giving is often stressful and can result in negative impact for the family caregiver. The purpose of this study was to evaluate the caregivers' experiences in caring for children with hydrocephalus attending physiotherapy at UTH D-block and CBI.

A quasi-experimental, cross sectional descriptive study was undertaken. Data was collected from 25 respondents, using a semi structured interview guide with open – ended questions and a semi structured questionnaire. Data was analysed using the statistical package for social sciences, descriptive and inferential statistics were used for the analysis of data. The results showed that most caregivers experienced profound sadness and rage; their care giving may be driven by empathy and love. Results show that 68% revealed to have experienced sadness on condition of their children and 12% shock. On psychological impact 52% were emotionally drained, 24% stressed, 12% depressed, 4% optimism. On activities that caregivers found enjoyable to do to their children 52% expressed exercising the child, 24% bathing the child, 16% found feeding the child more enjoyable and 8% changing nappies. The results also showed that, 44% were moderately affected, 40% severely and 16 % not at all by the child's condition. In conclusion, the psychosocial and emotional situations were perceived as causing a greater burden and greater difficulty in coping with everyday life. Health professionals need to understand and address the

experiences and psychosocial difficulties of the caregiver in order to provide support for the caregiver and promote positive growth and development of the child.

It is hoped that the results of this study could be used by rehabilitation professionals, especially physiotherapists, to implement or adjust rehabilitation programmes to include the experiences of caregivers caring for children with hydrocephalus.

## **CHAPTER ONE**

### **1.0 INTRODUCTION / BACKGROUND**

Hord (2006) defines Hydrocephalus as a disturbance of formation, flow, or absorption of cerebrospinal fluid (CSF) that leads to an increase in volume occupied by this fluid in the central nervous system (CNS). This condition also could be termed a hydrodynamic disorder of CSF. Novak (1995) also defines hydrocephalus as a congenital or acquired condition marked by dilatation of the cerebral hemispheres usually, secondary to obstruction of cerebrospinal fluid (CSF) pathways and accompanied by an accumulation within the skull. The term hydrocephalus is derived from two Greek words; “Hydro” meaning water and “Cephalus” meaning head (ASBHA, 2003) and NINDS (2005). They further state that it is a condition in which, the primary characteristic is accumulation of the fluid in the brain. Hydrocephalus was once known as water in the brain. Water is actually now known to be cerebrospinal fluid (CSF) surrounding the brain and the spinal cord, (Wikipedia, 2007).

Hydrocephalus has become a major cause of disability in the developing world and it affects both males and females equally (Silvia, 2005). Avellinos (2008), states that hydrocephalus happens to one child per 1000 live birth in china and is a major social, medical and economical problem. He further highlights that hydrocephalus is almost always a lifelong condition. Hydrocephalus causes stress and severe financial strains on families. Children with hydrocephalus have developmental disabilities and learning difficulties. Families need to be aware of the complexities of hydrocephalus to ensure



their children receive comprehensive ongoing care and appropriate intervention services and therapies as another effect on the family (HFAO (2007))

Wrong diagnosis (2005) states that the global prevalence of hydrocephalus is 0.06%. The 2007 report from HMIS unit of MoH could not provide the prevalence of hydrocephalus in Zambia. However, according to UTH D – block attendance register, a total of 5758 children attended paediatric surgical clinic during the period of April 2004 to April 2005. A total of 862 children had hydrocephalus representing about 15% of the total number of children who attended paediatric surgical clinic (Nkata, 2006). This disability calls for constant care of the caregiver who could be a parent, relative, employer or any other person executing this role of caregiving. Surgical correction is the only treatment for hydrocephalus. Usually, such surgery consists of insertion of a ventriculoperitoneal shunt, which transports excess fluid from the lateral ventricle into the peritoneal cavity, and caregivers are the ones that ensure that these procedures are done and cautions are taken care of.

A less common procedure is insertion of a ventriculoatrial shunt, which drains fluid from the brain's lateral ventricle into the right atrium of the heart, where the fluid makes its way into the venous circulation. Periodic lengthening of the shunt is necessary to accommodate growth in children. A clogged malfunctioning shunt will have to be replaced (Stoltz, 2008). Complications of surgery include shunt infection, septicemia (after ventriculoatrial shunt), adhesions and paralytic ileus, shunt migration, peritonitis, and intestinal perforation (with peritoneal shunt) (Stoltz, 2008)

The Zambian population is young with two thirds of the total population being below 25 years of age and only about 33% of its population being above 65 years of age Central Statistics Office, (CSO) 1999; Republic of Zambia, 2000), preliminary report of the population estimated the population to be at 10,285,631 of which 49.3% were males (5,070,891) while 50.7% were females (5,214,740). Health services in Zambia is largely provided by the Government which caters for about 60% of the total national bed capacity while 26% is provided by the Mission hospitals and 14% by the private and company hospitals and clinics (Ministry of Health, 2000a). Access to health services in Zambia is not equitable and it is worse for those people living in the remote areas in most rural parts of the country. In 1991, only 59% of the population of Zambia was living within the radius of 30kms of the hospital (Ndulo, 1999, Republic of Zambia, 2000). The quality of health care being provided varies widely in Zambia. In the urban set-up, the services are better than in the rural areas and there is also a great variation between Government and Mission hospitals (MoH, 2000b).

The referral system is categorized into three levels and these includes; the first level at the district hospital, second level is at the provincial hospital or general hospital, and the third level which is also called tertiary level is at the three major hospitals which are the University Teaching Hospital, Ndola and Kitwe Central Hospitals (MoH, 2000b). University Teaching Hospital being the referral hospital in Zambia, receives a lot of referral cases from various provinces. However some of cases that are referred to U.T.H include children with hydrocephalus and these children are admitted in the hospital

before shunting is done. These children are cared for by their parents and other caregivers who are made to travel long distances to seek for medical attention from specialized professionals like neurosurgeons who operates on these children. These specialized services involve a lot of constant care that demands a caregiver. Caregiving can be stressful especially on a caregiver from a distant place.

A caregiver is a primary person in charge of caring for an individual, usually with a family member or a designated health care professional ([www.alz.org/resources/glossary](http://www.alz.org/resources/glossary)) or it can be any person who provides companionship and non medical services related to the activities of daily living ([www.setnlegalservices.org/glossary.htm](http://www.setnlegalservices.org/glossary.htm)). Care giving is a process of providing care to any person who has been ill or disabled / and bed ridden for a longer period. There are two types of caregivers; formal caregivers who are referred to as health professionals , and informal caregivers who are referred to as relatives, brothers, and friends who provide in home care usually on unpaid basis. Informal care givers perform a variety of roles, whereby traditionally, family members have served as the primary caregivers. According to Kanhohak (1994) in his study, caregiving has been associated with a range of negative experiences including emotional crisis, physical discomfort, anxiety, feelings of guilt like not doing enough for the child with a disability, feeling of isolation, depression, hopelessness, and financial constraints.

Kerr and Smith, (2001) did a study on caregiving of stroke patients; both found that, the physical and emotional toll associated with care giving was enormous. Unfortunately the help and support provided by the health social services were often inadequate, inappropriate and poorly tailored to their individual needs and that there was little

evidence of a seamless flow of care between the secondary and the primary care setting. Avellinos (1995-2008) also states that many caregivers experience high levels of stress and negative effects on their health, employment, income and financial security.

## **1.1 DEMOGRAPHY OF THE UNIVERSITY TEACHING HOSPITAL**

The University Teaching Hospital (U.T.H) is located in Lusaka, which is the capital city of Zambia. The hospital has 56 wards, which are distributed in the following order of blocks; A – Paediatrics, B – Obstetric, C – Orthopedics’ and Gynecology, D – neonatal, E – medical and G – Surgical. In each of these wards are fee paying wings, called H-wards. There is also the filter clinic, the first place where patients referred from clinics go to before the doctors in the respective department can see them.

University Teaching Hospital is the largest of the tertiary hospitals in Zambia. U.T.H. provides several services among which are the following: general health care to the public, specialized diagnostic and surgical procedures, conduct research on commonly occurring diseases, acts as a referral center for other general hospitals in the country, provides training for medical, physiotherapy, pharmacy, biomedical sciences and nursing staff

Among the specialized services at U.T.H. are Physiotherapy, Radiology, Bio-medical services, Electroencephalogram (EEG), Electrocardiogram (ECG), and Computerized Tomographic Myelogram (C.T.M). All the mentioned departments for U.T.H. do receive

patients referred from outside the provinces and sometimes; referrals take place among departments within the hospitals.

## **1.2 STATEMENT OF THE PROBLEM**

Hydrocephalus has become a major cause of disability in the developing world and it affects both males and females equally (Silvia, 2005). Avellinos (2008), states that hydrocephalus happens to one child per 1000 live birth in china and is a major social, medical and economical problem. He further highlights that; hydrocephalus is almost always a lifelong condition. Caring for a child is stressful but caring for a child with severe disabilities is more stressful and can result in physical, social, psychological, spiritual and mental exhaustion outcomes for the family (Johnson, 2006)

Caregivers experience a lot of demands that can cause chronic fatigue, depression, economic hardships and insufficient rest, all which place caregivers at risk of emotional, psychological and physical problems (Rosenthal, 1987). Martinson and colleagues (1995) also found evidence of mothers being under great stress while caring for their children with chronic illness. Most of the mothers reported that their work units provided neither financial assistance nor flexibility to work schedule. In a study done by Martinson *et al* (1995), also states that, typically these mothers worked during the day and cared for their children at night. They reported lack of sleep, dizziness, and fatigue as well as intense feelings of fear, guilt, worry, and depression.

Bailey *et al* (1992), state that Caring for a person with disability especially with hydrocephalus is often very difficult, and many family and other unpaid caregivers experience high levels of emotional stress and depression as a result. Caregiving also has a negative impact on the health, employment, Income and financial security of many caregivers. Lin and Davis (1985), State that historically, the chronically ill, including children, have been cared for by the extended families.

The researcher's interest originate from the experience of handling children with hydrocephalus at UTH pediatric wing (CBI) who are being brought for treatment by caregivers who range from parents, brothers, sisters, and other family members.

Most of these caregivers bring their children with hydrocephalus for therapy two to three times per week and yet they have other responsibilities like caring for other siblings with no disabilities, therefore the question that arises is, how do they cope with life and what are they daily and life experiences in caring for children with hydrocephalus? Therefore, a study to evaluate caregivers experiences in caring for children with hydrocephalus attending physiotherapy at UTH; D – Block and CBI originated.

The significance of this study is that the information from the research will help to educate the caregivers and incorporate them in therapy sessions in order for them to appreciate the demands of caring for children with disabilities and the findings will provide information to rehabilitation professionals especially the physiotherapists.

### **1.3 OBJECTIVES**

#### **1.3.1 GENERAL OBJECTIVES**

To evaluate the experiences of caregivers in caring for children with hydrocephalus

#### **1.3.2 SPECIFIC OBJECTIVES**

1.3.2.1 To identify the nature of caregivers caring for children with hydrocephalus at UTH

1.3.2.2 To evaluate experiences of caregivers in caring for children with hydrocephalus

1.3.2.3 To determine the needs of caregivers caring for children with hydrocephalus

### **1.4 RESEARCH QUESTION**

What are the experiences of caregivers in providing care to children with hydrocephalus?

### **1.5 RESEARCH HYPOTHESES**

#### **1.5.1 NULL HYPOTHESIS**

Caring for children with hydrocephalus has positive impact on the caregivers.

#### **1.5.2 ALTERNATIVE HYPOTHESIS**

Caring for children with hydrocephalus has a negative impact on the caregivers.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 INTRODUCTION**

According to Hord (2006) he defines Hydrocephalus as a disturbance of formation, flow, or absorption of cerebrospinal fluid (CSF) that leads to an increase in volume occupied by this fluid in the central nervous system (CNS). This condition also could be termed a hydrodynamic disorder of CSF. Novak (1995) also defines hydrocephalus as a congenital or aquired condition marked by dilatation of the cerebral hemispheres usually, secondary to obstruction of cerebrospinal fluid (CSF) pathways and accompanied by an accumulation within the skull. The term hydrocephalus is derived from two Greek words; “Hydro” meaning water and “Cephalus” meaning head, ASBHA (2002-2003) and NINDS (2005). They further state that it is a condition in which, the primary characteristic is accumulation of the fluid in the brain. Hydrocephalus was once known as water in the brain. Water is actually now known to be cerebrospinal fluid (CSF) surrounding the brain and the spinal cord.

Normally, CSF flows continually from the interior cavities in the brain (ventricles) to the thin subarachnoid space that surrounds the brain and spinal cord.

The functions of CSF are as follows:

1. It balances the amount of blood in the head.
2. Baths and protects the brain and spinal cord from injury.



3. The CSF carries nutrients and proteins needed for nourishment and normal functioning of the brain.
4. Carries waste products from the surrounding tissues.

Acute hydrocephalus occurs over days, subacute over weeks, and chronic over months or years. Conditions such as cerebral atrophy and focal destructive lesions also lead to an abnormal increase of CSF in CNS. In these situations, loss of cerebral tissue leaves a vacant space that is filled passively with CSF. Such conditions are not the result of a hydrodynamic disorder and therefore are not classified as hydrocephalus. An older misnomer used to describe these conditions was hydrocephalus ex vacuum. Wikipedia (2007) also defines hydrocephalus abnormal accumulation of cerebrospinal fluid (CSF) in the ventricles, or cavities, of the brain. This may cause increased intracranial pressure inside the skull and progressive enlargement of the head, convulsion, and mental disability. Hydrocephalus is usually due to blockage of CSF outflow in the ventricles or in the subarachnoid space over the brain. In a normal healthy person, CSF continuously circulates through the brain and its ventricles and the spinal cord and is continuously drained away into the circulatory system.

## **2.2 INCIDENCE OF HYDROCEPHALUS**

Congenital hydrocephalus affects about 1 in every 1000 births. In the United States of America the overall prevalence is estimated at about 0.5% with most cases detected at birth or soon after birth, Health Communities (2005). Acquired hydrocephalus prevalence

is unknown as it occurs mainly due to injury, illness or environmental factors. In the U. K, the prevalence is subject to large geographical and temporal variations. The prevalence is 02 per 1000 live births, (WHO, 2005). In East and West Africa there is a higher prevalence of hydrocephalus due to both aquired and congenital aetiological factors. It is regrettable that aquired form of hydrocephalus are caused among others, sequelae of inadequate treatment or wrong diagnosis and thus meningitis is treated as malaria as in Tanzania, IFSBH (2005). It is noted that in developing countries like Zambia hydrocephalus and Spina Bifida are life threatening conditions that often result in cerebral palsy and severe physical, psychological and social disabilities (Taylor and Francis, 2005).

## **2.3 AETIOLOGY OF HYDROCEPHALUS**

About 80% of children with Spina Bifida have hydrocephalus and is due to congenital malformation of the brain structure at the back of the head which develop at an early stage of development and are called Type I and II Arnold Chiari malformation. Another study done by Baystone (2005) reveals that hydrocephalus occurs in children born prematurely, sometimes due to smoking by pregnant women and ill health also contributes significantly to this condition.

## **2.4 CAUSES OF HYDROCEPHALUS**

Walensky (1999) highlights the causes of Hydrocephalus and includes the following:

- I. Obstruction of CSF flow or dysfunction of absorptive mechanisms.
- II. Congenital hydrocephalus – may result from congenital malformations of the Nervous

System (e.g. isolated aqueductal stenosis, Dandy- Walker Malformation, Arnold- Chiari malformation).

III. Congenital tumors or arachnoic cysts.

IV. Intrauterine infection with inflammation of the ependymal lining of the ventricles or the meninges (e.g. rubella, Cytomegalovirus , Toxoplasmosis, Syphilis)

V. Acquired Hydrocephalus is caused by Central Nervous System (e.g. bacterial meningitis), brain tumors, and arachnoiditis secondary to subarachnoid bleeding (e.g. ruptured arteriovenous malformation, aneurysm, and trauma).

VI. Premature infants may develop Hydrocephalus secondary to intra ventricular hemorrhage.

NINDS (2005) also reveal the following as causes to hydrocephalus:

- I. Thrombosis of dura sinuses and infection
- II. Otitic hydrocephalus is also common in children with middle ear infection with thrombosis of lateral sinus adjacent to petrous bone.
- III. Vascular lesions such as vascular malformation of vein of Galen presents with childhood hydrocephalus due to blockage of cerebral aqueduct by enlarged vein of Galen
- IV. Escherichia Coli meningitis and Haemophilus influenza meningitis are usually causes of communicating hydrocephalus.

## 2.5 TYPES OF HYDROCEPHALUS

According to Wikipedia (2007) Hydrocephalus can be classified into communicating and non-communicating (obstructive) based on its underlying mechanisms. Both communicating and non-communicating forms can be either congenital, or acquired.

### **Communicating hydrocephalus**

Communicating hydrocephalus, also known as non-obstructive hydrocephalus, is caused by impaired cerebrospinal fluid re-absorption in the absence of any CSF-flow obstruction. It has been theorized that this is due to functional impairment of the arachnoid granulations, which are located along the superior sagittal sinus and is the site of cerebrospinal fluid re-absorption back into the venous system. Various neurologic conditions may result in communicating hydrocephalus, including subarachnoid / intraventricular hemorrhage, meningitis, Arnold Chiari malformation, and congenital absence of arachnoidal granulations (Pacchioni's granulations).

1. Normal pressure hydrocephalus (NPH) is a particular form of communicating hydrocephalus, characterized by enlarged cerebral ventricles, with only intermittently elevated cerebrospinal fluid pressure. The diagnosis of NPH can be established only with the help of continuous intraventricular pressure recordings (over 24 hours or even longer), since more often than not, instant measurements yield normal pressure values. Dynamic compliance studies may be also helpful. Altered compliance (elasticity) of the ventricular walls, as well as increased viscosity of the cerebrospinal

fluid, may play a role in the pathogenesis of normal pressure hydrocephalus (Wikipedia, 2007)

2. Hydrocephalus ex vacuo also refers to an enlargement of cerebral ventricles and subarachnoid spaces, and is usually due to brain atrophy (as it occurs in dementias), post-traumatic brain injuries and even in some psychiatric disorders, such as schizophrenia. As opposed to hydrocephalus, this is a compensatory enlargement of the CSF-spaces in response to brain parenchyma loss - it is not the result of increased CSF pressure.

### **Non-communicating hydrocephalus**

Non-communicating hydrocephalus, or obstructive hydrocephalus, is caused by a CSF-flow obstruction (either due to external compression or intraventricular mass lesions).

- I. Foramen of Monro obstruction may lead to dilation of one or, if large enough (e.g., in colloid cyst), both lateral ventricles.
- II. The aqueduct of Sylvius, normally narrow to begin with, may be obstructed by a number of genetically or acquired lesions (e.g., atresia, ependymitis, hemorrhage, tumor) and lead to dilatation of both lateral ventricles as well as the third ventricle.
- III. Fourth ventricle obstruction will lead to dilatation of the aqueduct as well as the lateral and third ventricles.
- IV. The foramina of Luschka and foramen of Magendie may be obstructed due to congenital failure of opening (e.g., Dandy-Walker malformation).

- V. The subarachnoid space surrounding the brainstem may also be obstructed due to inflammatory or hemorrhagic fibrosing meningitis, leading to widespread dilatation, including the fourth ventricle (Stotz, 2008).

### **Congenital hydrocephalus**

The cranial bones fuse by the end of the third year of life. For head enlargement to occur, hydrocephalus must occur before then. The causes are usually genetic but can also be acquired and usually occur within the first few months of life, which include 1) intraventricular matrix hemorrhages in premature infants, 2) infections, 3) type II Arnold-Chiari malformation, 4) aqueduct atresia and stenosis, and 5) Dandy-Walker malformation. In newborns and toddlers with hydrocephalus, the head circumference is enlarged rapidly and soon surpasses the 97th%. Since the skull bones have not yet firmly joined together, bulging, firm anterior and posterior fontanelles may be present even when the patient is in an upright position (Stotz, 2008).

3. The infant exhibits fretfulness, poor feeding, and frequent vomiting. As the hydrocephalus progresses, torpor sets in, and the infant shows lack of interest in his surroundings. Later on, the upper eyelids become retracted and the eyes are turned downwards (due to hydrocephalic pressure on the mesencephalic tegmentum and paralysis of upward gaze). Movements become weak and the arms may become tremulous. Papilledema is absent but there may be reduction of vision. The head becomes so enlarged that the child may eventually be bedridden (Wikipedia, 2007).

About 80-90% of fetuses or newborn infants with spinal bifida - often associated with meningocele or myelomeningocele - develop hydrocephalus (Engelhard, 2007).

### **Acquired hydrocephalus**

Acquired hydrocephalus is as a consequence of CNS-infections, meningitis, brain tumors, head trauma, intracranial hemorrhage (subarachnoid or intraparenchymal) and is usually extremely painful for the patient (Walensky, 1999).

## **2.6 PATHOPHYSIOLOGY**

The elevated intracranial pressure may cause compression of the brain, leading to brain damage and other complications (Engelhard, 2007). Conditions among affected individual vary widely. Children who have had hydrocephalus may have very small ventricles, and presented as the "normal case". This is the problem with this condition. If the foramina (pl.) of the fourth ventricle or the cerebral aqueduct are blocked, cerebrospinal fluid (CSF) can accumulate within the ventricles. This condition is called internal hydrocephalus and it results in increased CSF pressure. The production of CSF continues, even when the passages that normally allow it to exit the brain are blocked. Consequently, fluid builds inside the brain causing pressure that compresses the nervous tissue and dilates the ventricles. Compression of the nervous tissue usually results in irreversible brain damage. If the skull bones are not completely ossified when the hydrocephalus occurs, the pressure may also severely enlarge the head. The cerebral

aqueduct may be blocked at the time of birth or may become blocked later in life because of a tumor growing in the brainstem (Milhorat, 1996)

According to Engelhard (2007), internal hydrocephalus can be successfully treated by placing a drainage tube (shunt) between the brain ventricles and abdominal cavity to eliminate the high internal pressures. There is some risk of infection being introduced into the brain through these shunts, however, and the shunts must be replaced as the person grows. A subarachnoid hemorrhage may block the return of CSF to the circulation. If CSF accumulates in the subarachnoid space, the condition is called external hydrocephalus. In this condition, pressure is applied to the brain externally, compressing neural tissues and causing brain damage. Thus resulting to a much further damage of the brain tissue and leading to necrotization.

## **2.7 CLINICAL FEATURES OF HYDROCEPHALUS**

The nature and severity of the presentation depend on the rate at which Hydrocephalus develops the underlying primary process (e.g. tumor infection, hemorrhage) and the degree of Intracranial Pressure (ICP) elevation. Children may experience early morning headaches with vomiting, personality and behavioral changes (e.g. irritability, indifference) and cranial nerve deficits (iii, VI) with diplopia (Health Communities, 2005). Papilloedema may be evident.



In infants, the anterior fontanelle may become full or distended and excessive head growth with dilatation of scalp veins may be seen. Paralysis of upward gaze (HealthCentral.com, 2008) Spasticity may develop first in the legs and then in the arms. Dilatation of the 3<sup>rd</sup> ventricle with resultant pressure on the Hypothalamus can cause disturbances in sexual development and in fluid and electrolyte balance. Lethargy, drowsiness and changes in vital signs are relatively late findings (Milhorat, 1996)

## **2.8 DIAGNOSIS OF HYDROCEPHALUS**

According to Hord (2006), in most cases the following are done to ascertain the diagnosis and they help much in order to arrest the condition from progressing to severity:

- a) CT scan of the head delineates the degree of ventriculomegaly and, in many cases, the etiology. When performed with contrast, it can show infection and tumors causing obstruction. It also helps with operative planning. Ventricles usually are dilated proximal to the point of obstruction. In pseudotumor cerebri, the CT scan findings usually are normal.
- b) Performing MRI scan of head in most, if not all, congenital cases of hydrocephalus. This delineates the extent of associated brain anomalies such as corpus callosum agenesis, Chiari malformations, disorders of neuronal migration, and vascular malformations. Some tumors, for example the midbrain tectal gliomas, only can be detected with this study. T2-weighted images can show transependymal flow of cerebrospinal fluid.

- c) Fetal and neonatal cranial ultrasound is a good study for monitoring ventricular size and intraventricular hemorrhage in the neonatal ICU setting. Certainly, prior to treatment, perform other imaging studies.
- d) Lumbar puncture can be used to measure intracranial pressure, but it should only be performed after imaging studies rule out an obstruction. A diagnostic high-volume lumbar puncture in normal pressure hydrocephalus can assist in making decisions regarding shunting. Spinal fluid can show the type and severity of infection (Sahrakar, 2002).

## **2.9 MANAGEMENT**

Hord (2006) in his literature illustrates the management of Hydrocephalus as follows:

### **MEDICAL CARE:**

1. Medical treatment is used to delay surgical intervention. It may be tried in premature infants with post hemorrhagic hydrocephalus (in the absence of acute hydrocephalus). Normal CSF absorption may resume spontaneously during this interim period.
2. Medical treatment is not effective in long-term treatment of chronic hydrocephalus. It may induce metabolic consequences and thus should be used only as a temporal measure.
3. Medications affect CSF dynamics by the following mechanisms:
  - a) Decreasing CSF secretion by the choroid plexus - Acetazolamide and furosemide
  - b) Increasing CSF reabsorption - Isosorbide (effectiveness is questionable)

## 2 SURGICAL CARE:

Surgical treatment is the preferred therapeutic option and the following options are attempted.

1. Repeat LPs can be performed for cases of hydrocephalus after intraventricular hemorrhage, since this condition can resolve spontaneously. If reabsorption does not resume when the protein content of CSF is less than 100 mg/dL, spontaneous resorption is unlikely to occur. LPs can be performed only in cases of communicating hydrocephalus.
2. Alternatives to shunting include the following:
  - Choroid plexectomy or choroid plexus coagulation may be effective.
  - Opening of a stenosed aqueduct has a higher morbidity rate and a lower success rate than shunting, except in the case of tumors. However, lately cerebral aqueductoplasty has gained popularity as an effective treatment for membranous and short-segment stenoses of the sylvian aqueduct. It can be performed through a coronal approach or endoscopically through suboccipital foramen magnum trans-fourth ventricle approach.
  - In these cases, tumor removal cures the hydrocephalus in 80%.
  - Endoscopic fenestration of the floor of the third ventricle establishes an alternative route for CSF toward the subarachnoid space. It is contraindicated in communicating hydrocephalus, ([www.emedicine.com](http://www.emedicine.com))
3. Shunts eventually are performed in the majority of patients. Only about 25% of patients with hydrocephalus are treated successfully without shunt placement.

The principle of shunting is to establish a communication between the CSF (ventricular or lumbar) and a drainage cavity (peritoneum, right atrium, pleura). Remember that shunts are not perfect and that all alternatives to shunting should be considered first.

- A ventriculoperitoneal (VP) shunt is used most commonly. The lateral ventricle is the usual proximal location. The advantage of this shunt is that the need to lengthen the catheter with growth may be obviated by using a long peritoneal catheter.
- A ventriculoatrial (VA) shunt also is called a "vascular shunt." It shunts the cerebral ventricles through the jugular vein and superior vena cava into the right cardiac atrium. It is used when the patient has abdominal abnormalities (e.g., peritonitis, morbid obesity, or after extensive abdominal surgery). This shunt requires repeated lengthening in a growing child.
- A lumboperitoneal shunt is used only for communicating hydrocephalus, CSF fistula, or pseudotumor cerebri.
- A Torkildsen shunt is used rarely. It shunts the ventricle to cisternal space and is effective only in acquired obstructive hydrocephalus.
- A ventriculopleural shunt is considered second line. It is used if other shunt types are contraindicated.

4. Rapid-onset hydrocephalus with increased ICP is an emergency. The following can be done, depending on each specific case:

- i. Ventricular tap in infants
- ii. Open ventricular drainage in children and adults
- iii. LP in post hemorrhagic and postmeningitic hydrocephalus
- iv. VP or VA shunt

## **PHYSIOTHERAPY**

Most children will be assessed by a physiotherapist to ascertain whether they have any motor deficits or motor developmental delay. If the child has a neurosurgical procedure they will also be reviewed post-operatively and provided with acute rehabilitation as appropriate. Often the main problem will be lack of balance, or developmental delay ([www.ich.ucl.uk](http://www.ich.ucl.uk)). Treatment may involve positioning, facilitatory techniques, advise to help with management of tone/ movement disorders, rehabilitation to assist with regaining and improving functional abilities (Bakheit, *et al* 2001).

## **2.10 CAREGIVERS**

A caregiver is a primary person in charge of caring for an individual, usually with a family member or a designated health care professional ([www.alz.org/resources/glossary](http://www.alz.org/resources/glossary)) or it can be any person who provides companionship and non medical services related to the activities of daily living ([www.setnlegalservices.org/glossary.htm](http://www.setnlegalservices.org/glossary.htm)) and care giving is a process of providing care to any person who has been ill or disabled / and bed ridden for a longer period. There are two types of caregivers; formal caregivers who are referred to as health professionals , and informal caregivers who are referred to

as relatives, brothers, and friends who provide in home care usually on unpaid basis. Informal care givers perform a variety of roles, traditionally; family members have served as the primary caregivers.

### **2.10.1 CAREGIVING TASKS**

The kind of help provided by family and other unpaid caregivers depend on the needs of the child with hydrocephalus and changes as the condition worsens. Care giving tasks include:

1. Helping the person take medications correctly and follow treatment recommendations for his or her medical condition.
2. Supervising the child to avoid unsafe activities such as wandering and getting lost.
3. Bathing, dressing, feeding, helping the use the toilet or providing incontinence care;
4. Managing behavioral symptoms
5. Making arrangements for medical care and paid in-home, assisted living or nursing home care (Jackson, 1997).

### **2.10.2 IMPACT OF CAREGIVING ON THE CAREGIVER**

According to Kanhohak (1994) in his study, caregiving has been associated with a range of negative experiences including emotional crisis, physical discomfort, anxiety, feelings of guilty like not doing enough for the child with a disability, feeling of isolation, depression, hopelessness, and financial constraints. Kerr and Smith, (2001) did a similar

study on stroke patients; both found that, the physical and emotional toll associated with care giving was enormous. Unfortunately the help and support provided by the health social services were often inadequate, inappropriate and poorly tailored to their individual needs and that there was little evidence of a seamless flow of care between the secondary and the primary care setting

According to hydrocephalus association (2008), caring for a child with hydrocephalus or another disability poses special challenges. Although lack of independent living is the best known symptom, this condition also causes loss of judgment, orientation, mobility and ability to communicate effectively and frequent changes in personality and behavior. Individuals require increasing levels of supervision and personal care, and many caregivers experience high levels of stress and negative effects on their health, employment, income and financial security. Caregiving has also an impact on the caregiver's emotional well being. Most family and other unpaid caregivers are proud of the help they provide, and some manage caregiving tasks with little difficulty. Yet many caregivers experience high levels of stress and depression and new hypertension associated with care giving (Scott, 1990).

### **2.10.3 IMPACT ON THE CAREGIVERS EMPLOYMENT**

According to National Alliance for Caregiving (2006), many caregivers of people with Alzheimer's and other dementias have to quit work, reduce their work hours or take time off because of caregiving responsibilities. One study of family and other unpaid caregivers of people with Alzheimer's and other dementias in USA found that 57 percent were employed full time or part time. Of those who were employed, two-thirds said they

had to go in late, leave early or take time off because of caregiving; 18 percent had to take a leave of absence; 13 percent had reduced their hours; and 8 percent had turned down promotions. Eight percent of caregivers in the study had to quit work entirely because of caregiving. Hence caregiving is more demanding on both formal and informal caregivers ([www.alz.org](http://www.alz.org).)

#### **2.10.4 SOCIAL-ECONOMIC IMPACT**

The families experience financial difficulties caused by numerous medical visits and surgical procedures which deplete a family's financial reserve and private insurance may not be attainable unless it is offered by a large group employment policy (Nkata, 2006)



## **CHAPTER THREE: METHODOLOGY**

### **3.1 INTRODUCTION**

This chapter gives a description of the study design, research setting, study population, data collection tool, data collection procedure, data analysis, variables, ethical consideration, time plan and budget.

### **3.2 Study Design**

The study was a quasi-experimental study. It is known as half experiment because it does not meet exacting criteria for experimental designs but it manages to approximate experimental conditions and can achieve similar level of scientific rigour (Bless and Smith, 1995). It was both quantitative and qualitative, cross sectional descriptive study aimed at investigating the caregiver experiences in caring for children with hydrocephalus attending physiotherapy at pediatric wing (D-block) UTH.

### **3.3 Research setting**

This study was conducted at the UTH D-Block and (CBI). The UTH was chosen because it is the largest and final referral centre in Zambia that caters for various referred cases including hydrocephalus. The UTH was also chosen for the study because the researcher resided within its vicinity and thus it was convenient and cost effective.

### **3.4 Sample size**

Sim and Wright (2002) defined sample as the selection of accessible population on which a study is to be conducted. A convenient sampling method was used to capture at least 25 (n=25) participants caring for children with hydrocephalus attending physiotherapy at UTH.

### **3.5 CRITERIA**

#### **3.5.1 Inclusion criteria**

Caregivers who have been caring for children with hydrocephalus for at least more than 3 months

#### **3.5.2 Exclusion criteria**

Caregivers who have been caring for children with hydrocephalus for less than 3 months

### **3.6 Data Collection Instrument**

Data collection was done using a semi structured interview guide with open – ended questions and a semi structured questionnaire. This instrument was chosen because it was appropriate for the study as it contains dependable measurements of the variables. According to Polit and Hughes (1991) an independent variable is the presumed cause of an effect while a dependent variable is the presumed effect.

### **3.7 Data collection procedure**

According to Polit and Hughes (1991), data collection procedure is a process of gathering information needed to address a research problem. Eligible participants filled in a questionnaire which was assisted by the researcher and guided interview was done by asking open and closed ended questions to respondents who were caregivers, 16 were biological parents and 9 were other caregivers. The information collected was documented on an interview-administered questionnaire in the respondents own words for questions that needed clarity. The researcher was meeting these caregivers during the ward rounds at U.T.H, D-block and other when they brought their children for physiotherapy at CBI. The researcher was sometimes asking questions and ticking answers. The questionnaire was in English language but where the respondent was conversant with Bemba or Nyanja, these languages were used accordingly. The researcher alone conducted the study.

### **3.8 Pilot study**

A Pilot study is the process of carrying out a preliminary study or testing the whole methodology of the study, which is going through the whole methodology with a small sample (Varkevisser, 1990). A pilot study was done on 5 caregivers caring for any child with any sought of disability to test the effectiveness of the questionnaire, in order to make questions more specific and easier for the caregivers to understand. The researcher observed that the questionnaire did not answer the aim of the study. The questionnaire was therefore, adjusted to make the questions more specific and easier for participants to understand. For instance a questions like “can you please tell me about your typical day on

caring for your child with hydrocephalus?” was changed to a question like “what time do you wake up to prepare for your child with hydrocephalus?” and this question was more specific and clear to the participants.

### **3.9 Variables**

Variables were captured and coded as follows;

Age: This is the period of time that a person has lived or expected to live (Collins English Dictionary 1989).

1. Gender: is the state of being male or female (Collins English Dictionary 1989).
2. Economical Status
3. Social status
4. Psychological

### **3.10 Data analysis**

Quantitative data was analyzed using the descriptive and inferential statistics and statistical package for social sciences. Qualitative data was transcribed, coded and presented as verbatim.

### **3.11 Ethical consideration**

The protocols for the study and a copy of informed consent were submitted to the Research Ethics Committee of the University of Zambia for protection of human subjects involved in the research. Permission was sought to carry out a study at UTH and access relevant data. Participants were asked to read the information sheet and thereafter to sign informed

consents before a formal interview. Confidentiality was maintained by not identifying the subjects and informants (participants) by names. As soon as they agreed to participate in this study, all participants (caregivers) were informed that they were at liberty to withdraw from the study at any time and that their refusal to participate or withdraw would not deprive their child of the right to physiotherapy services. They were also informed that there were no physical risks involved in participating in the study and that no direct benefit was to be derived from participating in the study. However, the caregivers as participants were informed that the results of the study might help physiotherapists and other rehabilitation officers to improve quality of health of children with hydrocephalus and also provide psychosocial counseling.

## **CHAPTER FOUR: RESULTS**

### **4.1 INTRODUCTION**

In order to meet its objectives, the research had to take into account a number of background variables. These variables included sex and gender of children, the sex and age of caregivers, their marital status and their relationship to the child. The aim of this study was to evaluate experiences of caregivers caring for children with hydrocephalus attending physiotherapy at UTH (D-block) and CBI, as well as to identify the relationship between the child and caregivers and their basic needs in caring for these children. This chapter endeavours to give meaning to the data by presenting it clearly using both quantitative and qualitative method. The analysis and interpretation of the qualitative responses obtained through face to face are described under themes and categories. A semi-structured interview guide was used to collect data. This was based on informants, personal experiences in caring for children with hydrocephalus.

### **4.2 DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS.**

Data was collected from 25 caregivers caring for children with hydrocephalus attending physiotherapy at U.T.H and C.B.I., construction of frequency tables and analysis was done using statistical package for social sciences (SPSS).

4.2.1 DEMOGRAPHIC DATA OF CHILDREN WITH HYDROCEPHALUS

4.2.1.1 GENDER

The results of the study shows that the majority (72%, n=18) of the children were males and the minority (28%, n=7) of the children were females (Figure 1.1). The results from this study identified important issues. It can be seen from the results that most children that were being cared for were a male gender.

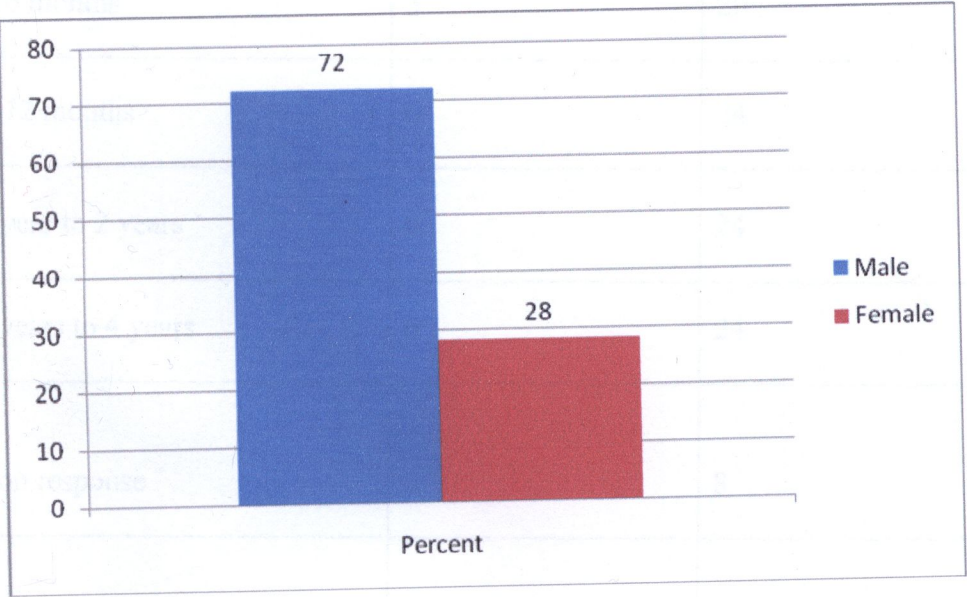


Figure 1.1: The percent distribution of the gender of the children

4.2.1.2 AGE

The results of the study reveals that the majority (24%,n=6) of children were in the age group 7-12 months, 1year to 2 years and 3 years to 4 years. The minority (20%, n=5) of the children were in the age group 0-6 months, (8%, n=2) did not indicate the response on the questionnaire, this could mean they forgot or deliberately left (Table 1.1).

Age	Frequency	Percent
0-6 months	5	20
7-12 months	6	24
1 year to 2 years	6	24
3 years to 4 years	6	24
Non response	2	8
Total	25	100

Table 1.1: The percent distribution of the age of children



4.2.1.3 DURATION OF ILLNESS

The results of the study on duration of illness of the child shows that the majority (52% ,n=13) of the children have been ill for 0-6 months and the minority (12%,n=3) have been ill for 7-12 months and (12% ,n=3) have been ill for 3 years to 4 years, while (24% ,n=6) have been ill for 1 year to 2 years. (Fig 1.2).

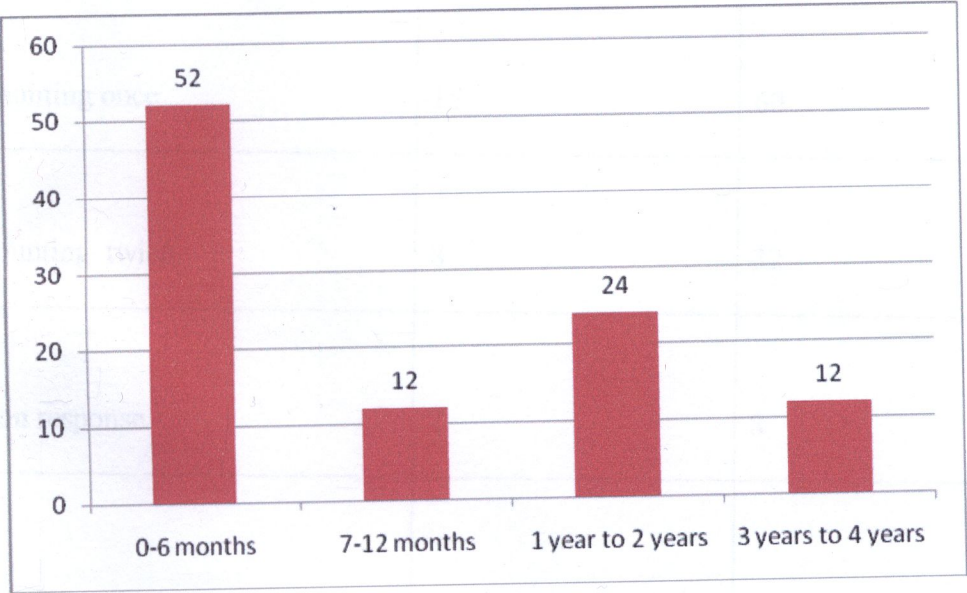


Figure 1.2: The percent distribution of duration of illness of children

4.2.1.4 OPERATION

The results of the study explored that the majority (60%,n=15) of the children have had an operation performed with shunting, (32%, n=8) were operated on twice and the minority (8% ,n=2) of the children did not respond to the question. (Table 1.2).

What has been done so far toward the illness?		
Type of operation	Frequency	Percent
Shunting once	15	60
Shunting twice	8	32
Non response	2	8
Total	25	100

Table 1.2: The percent distribution of the intervention made to ill children

4.2.2 DEMOGRAPHIC DATA OF CAREGIVER

4.2.2.1 GENDER

The results of the study on gender of caregiver explored that the majority (84%, n=21) of caregivers were females. The minority (16%, n=4) of caregivers were males (Fig 1.3). This study revealed that female gender were majority as caregivers.

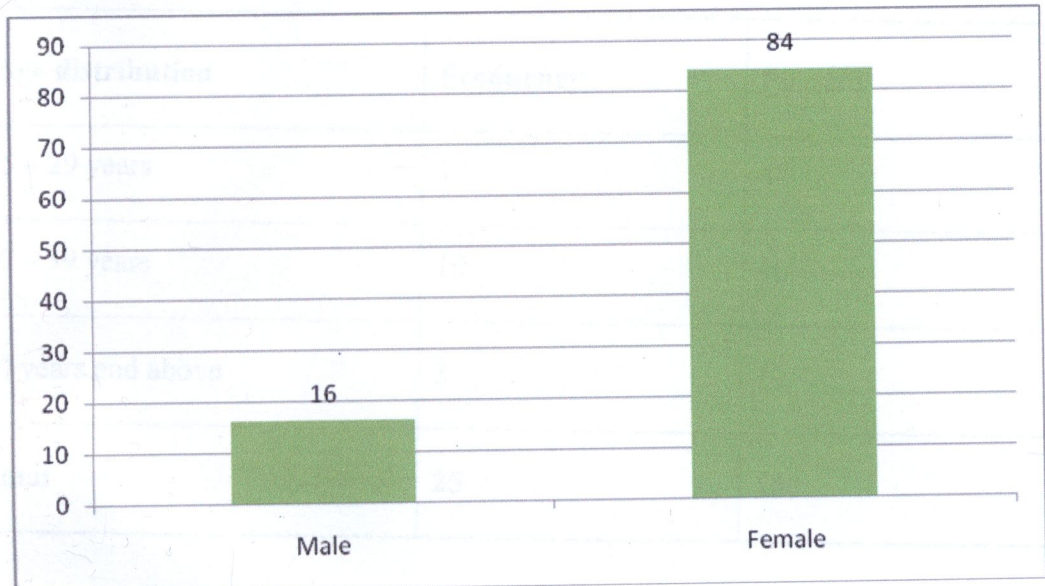


Figure 1.3: The percent distribution of the gender of caregiver

4.2.2.2 AGE

The results of the study shows that the majority (48%, n=12) of caregivers that cared for children with hydrocephalus were aged between 15-29 years, while the minority (12%, n=3) were in the age group 40 years and above (Table1.3).

The percent distribution of the age distribution of the caregivers		
Age distribution	Frequency	Percent
15 – 29 years	12	48
30 – 39 years	10	40
40 years and above	3	12
Total	25	100

Table 1.3: The percent distribution of the age distribution of the caregivers

4.2.2.3 MARITAL STATUS OF CAREGIVER

The results of the study on the marital status of caregivers explored that the majority (72% ,n=18) of the caregivers were married while the minority (8% ‘n=2) of the caregivers were widowed and the rest (20%, n=5) were single(Fig 1.4).

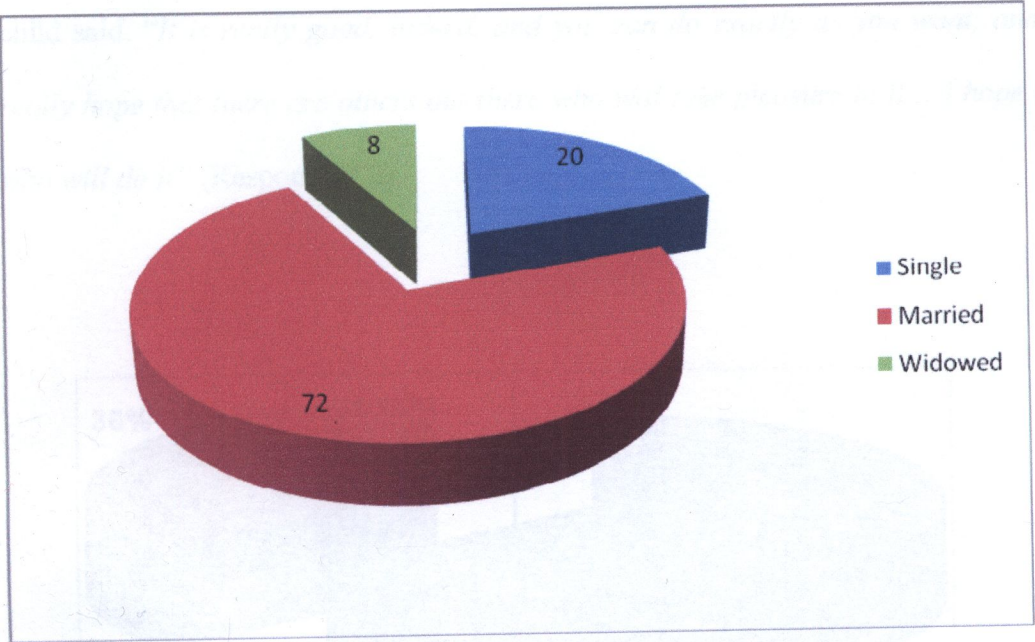


Figure 1.4: Percent distribution of the marital status of Caregivers



4.2.2.4 RELATIONSHIP BETWEEN CHILD AND CAREGIVER

The results of the study shows on the percent distribution of the relationship between the child and the caregiver that the majority (64%, n=16) of the caregivers were biological parents of the child being the father or the mother while the rest (36%, n=9) were non biological caregivers (Table 1.4). One of the respondents who were asked how he felt looking after her biological child said. *“It is really good, indeed, and you can do exactly as you want, and I hope... yes I really hope that there are others out there who will take pleasure in it... I hope there are others who will do it”* (Respondent 6).

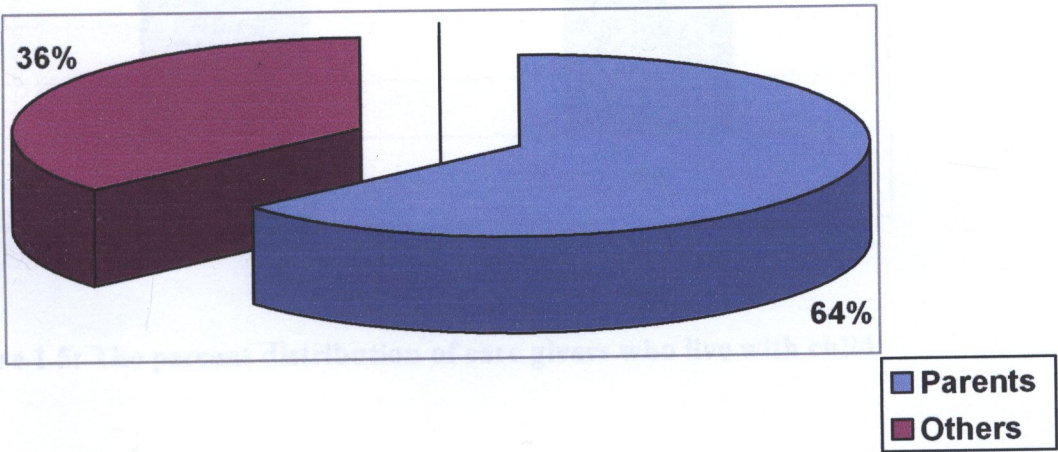
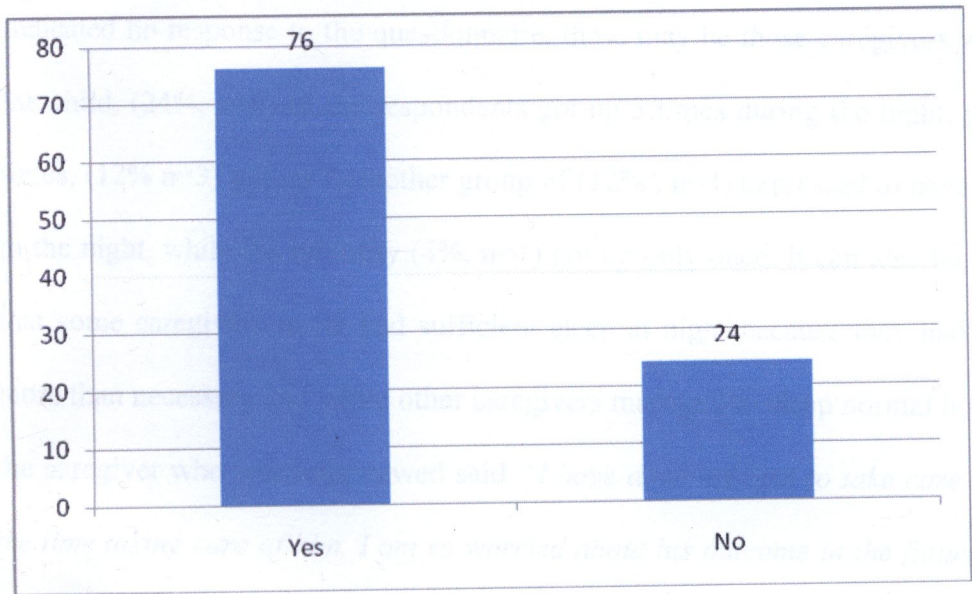


Table 1.4: The percent distribution of the relation of the caregiver to the child

4.2.2.5 CAREGIVER LIVING WITH THE CHILD

The results of this study shows that the majority 76% (n=19) of caregivers lived with the child while the minority 24% (n=6) of the caregivers did not live with the child (Fig 1.5).



**Figure 1.5: The percent distribution of care givers who live with child**

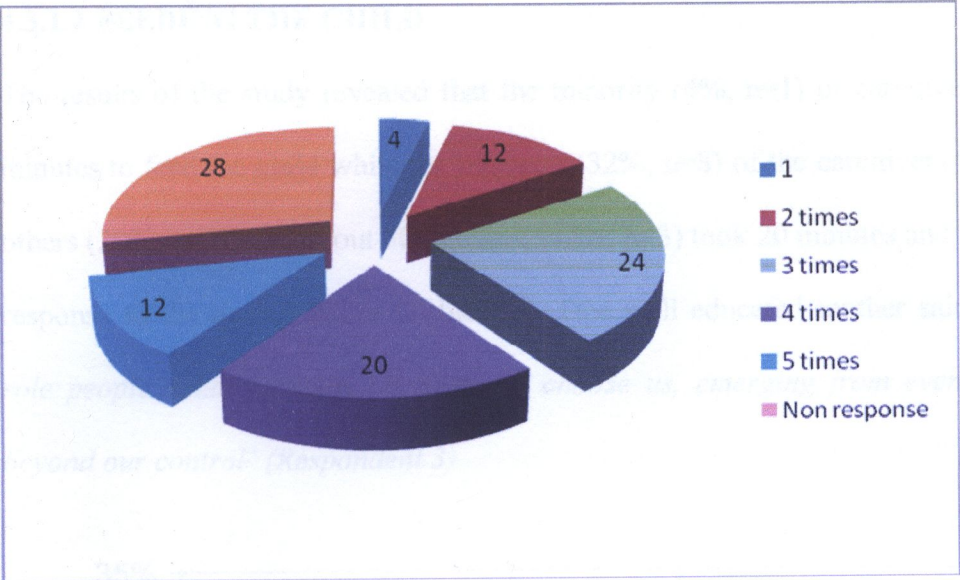
### 4.3 EXPERIENCES OF CAREGIVERS IN CARING FOR CHILDREN WITH HC

#### 4.3.1 SUPPORT GIVEN TO THE CHILD

##### 4.3.1.1 WAKING UP AT NIGHT

The results of the study on support given to the child in the night shows that majority (28% ,n=7) indicated no response to the questionnaire, these may be those caregivers who did not stay with the child, (24%, n=6) of the respondents got up 3 times during the night, (20% , n=5) got up 4 times, (12% n=3) got up 5, another group of (12% , n=3) expressed to have woke up twice only in the night, while the minority (4%, n=1) got up only once. It can also be seen from the results that some caregivers never had sufficient sleep at night because they had to wake up at night more than necessary and while other caregivers managed to sleep normal hours (Fig 1.6). One of the caregiver who was interviewed said *'I have done my best to take care of him ... I spend all the time taking care of him. I am so worried about his outcome in the future. He is a boy; being independent is very important for him. I am greatly influenced by his illness. Sometimes I cannot fall to sleep until midnight.. Sometimes I am so depressed ... I give my whole life to help him. I am old, and I have high blood pressure and sugar disease. Sometimes I am so tired and so stressed. I feel pretty good now because the illness of my grandchild is stable'* (Respondent 9)





**Figure 1.6: Percent distribution of the number of times care givers got up at night to attend to their children.**

4.3.1.2 FEEDING THE CHILD

The results of the study revealed that the minority (4%, n=1) of caregivers took more than 30 minutes to feed the child while the majority (32%, n=8) of the caregivers took 15 minutes only, others (20%, n=5) took about 30 minutes, (12%, n=3) took 20 minutes and 32% (n=8) showed no response to the questionnaire (Table 1.5). One well educated mother said *'caregiving is not a role people usually choose, it seems to choose us, emerging from events and circumstances beyond our control'* (Respondent 3)

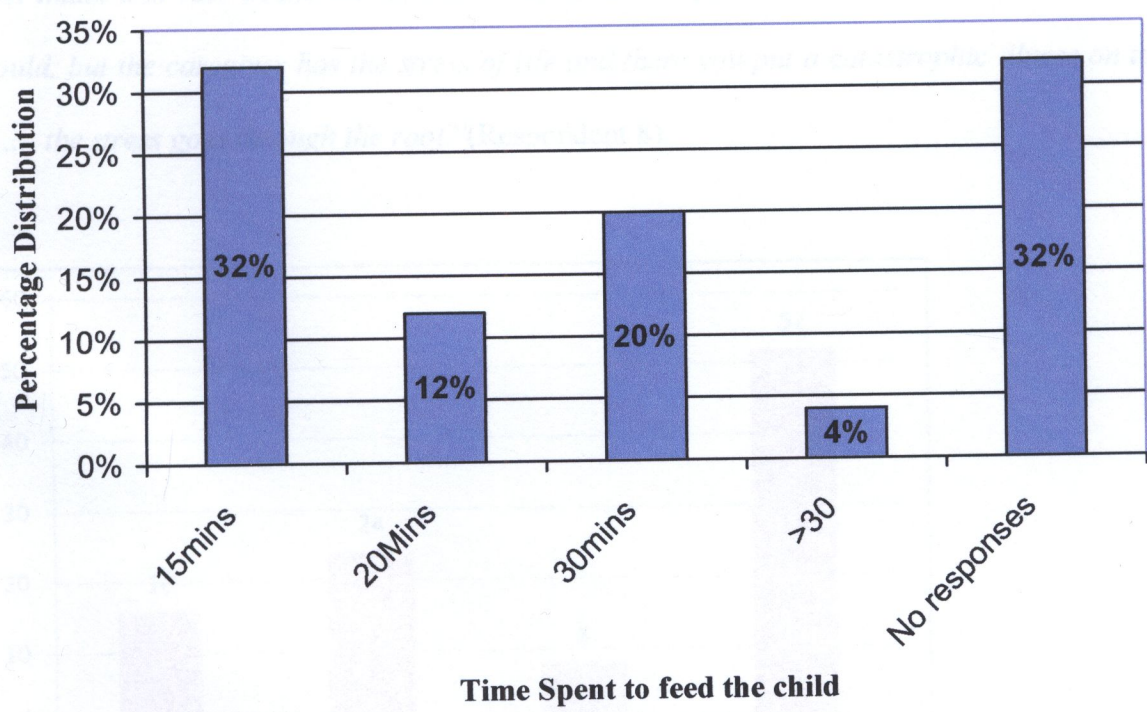


Table 1.5: The percent distribution of the amount of time spent to feed child

4.3.1.3 ACTIVITIES OF DAILY LIVING

When caregivers were asked which activity of daily living they most enjoyed doing to their children; the majority (52%, n=13) of the caregivers enjoyed exercising the children while the minority (8%, n=2) found changing child’s nappies most enjoyable. The rest, (24%, n=6) found bathing to be most enjoyable and (16%, n=4) expressed that, they found feeding their children most interesting (Fig 1.7). One caregiver had this to say concerning long term caregiving, “*I do this because I know I am doing this to my own child*’ she further said, ‘*being a caregiver is the most thank less role in the world, everybody gives the patient some slack “not busy” as they should, but the caregiver has the stress of life and there you put a catastrophic illness on top of it....., the stress goes through the roof.*”(Respondent 8).

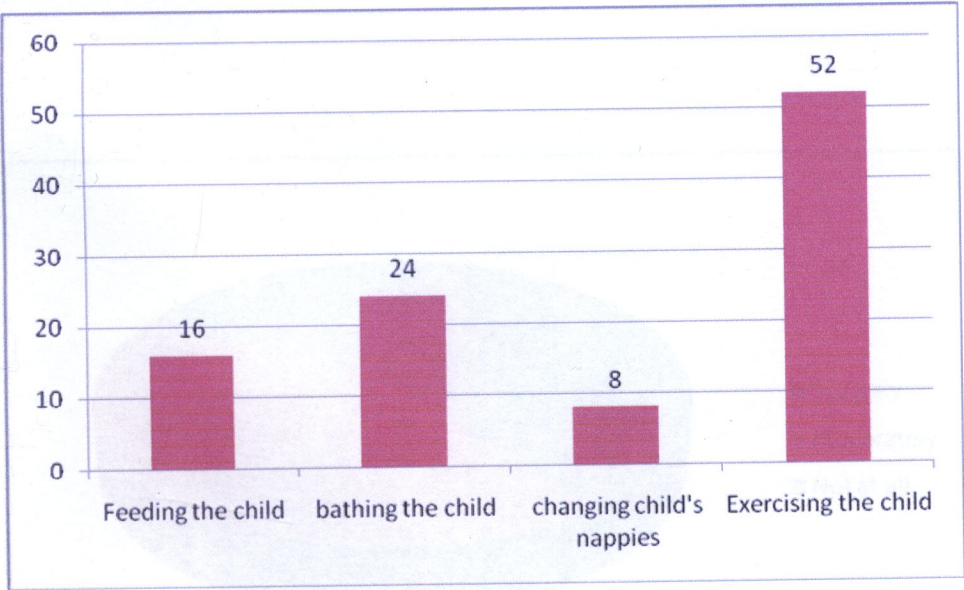


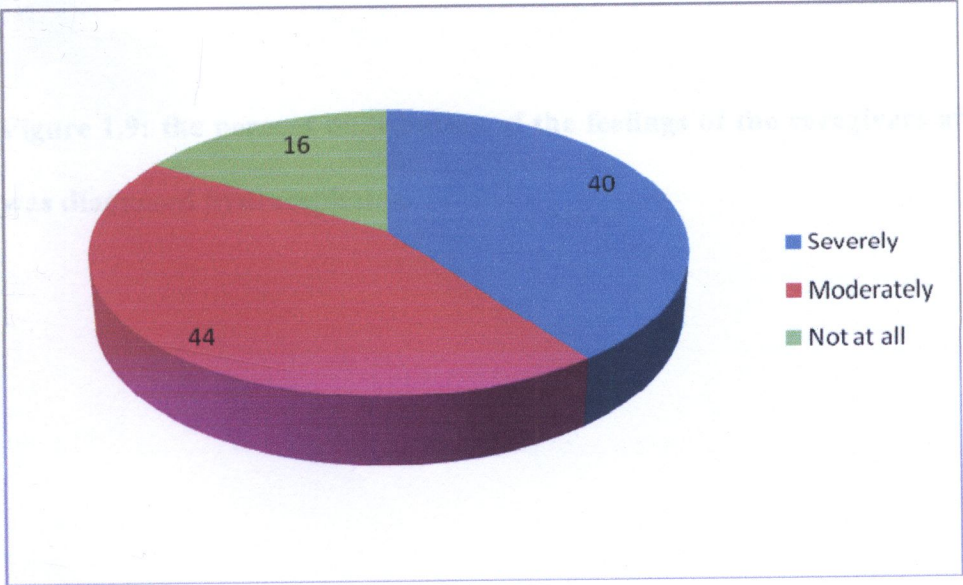
Figure 1.7: The percent distribution of what care givers found enjoyable to do

Figure 1.8: Percent distribution of how they have been affected by child's condition



#### 4.4 EMOTIONAL IMPACT

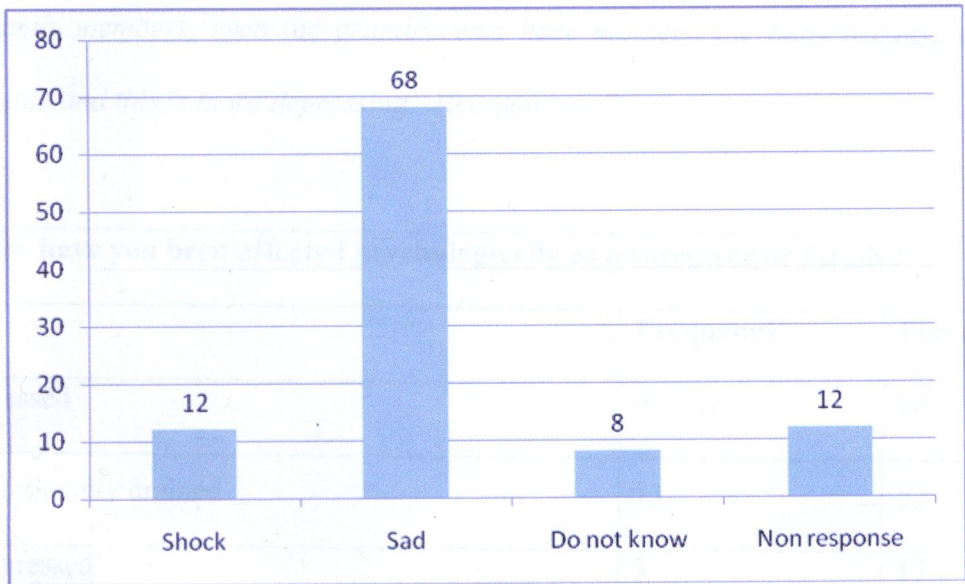
The figure below shows that the majority (44%, n=11) of caregivers were moderately affected by the child's condition while the minority (16%, n=4) was not affected at all by the child's condition and the rest (40%, n=10) were severely affected. One respondent expressed the importance of having been able to fulfill the wishes of his loved one, despite being affected emotionally and said. *"well, I will put it like this: if I had not wanted to it, and she had had to go somewhere else to die, then I think I would have bee ashamed of myself for the rest of my life that I could not...be the one who could be closest...well, that I think I could not bear to live with"* (Respondent 4)



**Figure 1.8: Percent distribution of how they have been affected by child's condition**

4.4.1 FEELINGS ABOUT THE CHILD’S ILLNESS

The results of the study revealed that the majority ( 68%, n=17) of caregivers felt sad about the child’s illness, (12% ,n=3) were shocked and the minority (8%, n=2) did not know how they felt. The rest (12%, n=3) were non response on the questionnaire (Fig1.9).



**Figure 1.9: the percent distribution of the feelings of the caregivers after child’s condition was diagnosed hydrocephalus.**

4.4.2 PSYCHOLOGICAL IMPACT

The results of the study shows that the majority (52%, n=13) of caregivers had been emotionally drained while the minority (4%, n=1, 1) of caregivers have neither been optimistic nor don't know, (24%, n=6) were stressed and (12%, n=3) were found to have been depressed, the rest (4%, n=1) indicated no response to the questionnaire (Table 1.6). One mother said. *'Many family members, even the grandparents have not seen the baby because they are afraid of a curse and this is more depressing.'* (Respondent 7)

How have you been affected psychologically as a caregiver or family?		
	Frequency	Percent
Stressed	6	24
Emotionally drained	13	52
Depressed	3	12
Optimistic	1	4
Do not know	1	4
Non response	1	4
Total	25	100

Table 1.6: The percent distribution of how caregivers are affected psychologically

4.5 ECONOMICAL IMPACT

The table below shows that the majority (40%, n=10) of caregivers spent between K100, 000 to K200, 000 of expenditure on the child and the minority (4%, n=1) of caregivers have an expenditure of between K200, 000 and K400, 000 while others (16%, n=4) spent between K400, 000 and K600, 000 and the rest (40%, (n=10) indicated no response to the questionnaire. These are monthly expenditures of caregivers on their children living with hydrocephalus. When one respondent was asked whether he affords every appointment for review or surgery this is what he had to say. *‘Most of the times I miss appointments because of the strain on our financial and my monthly salary which is K250000 I am not educated I only work as a house helper so I don’t afford to pay even for surgery, however the church helps sometimes (Respondent 5).*

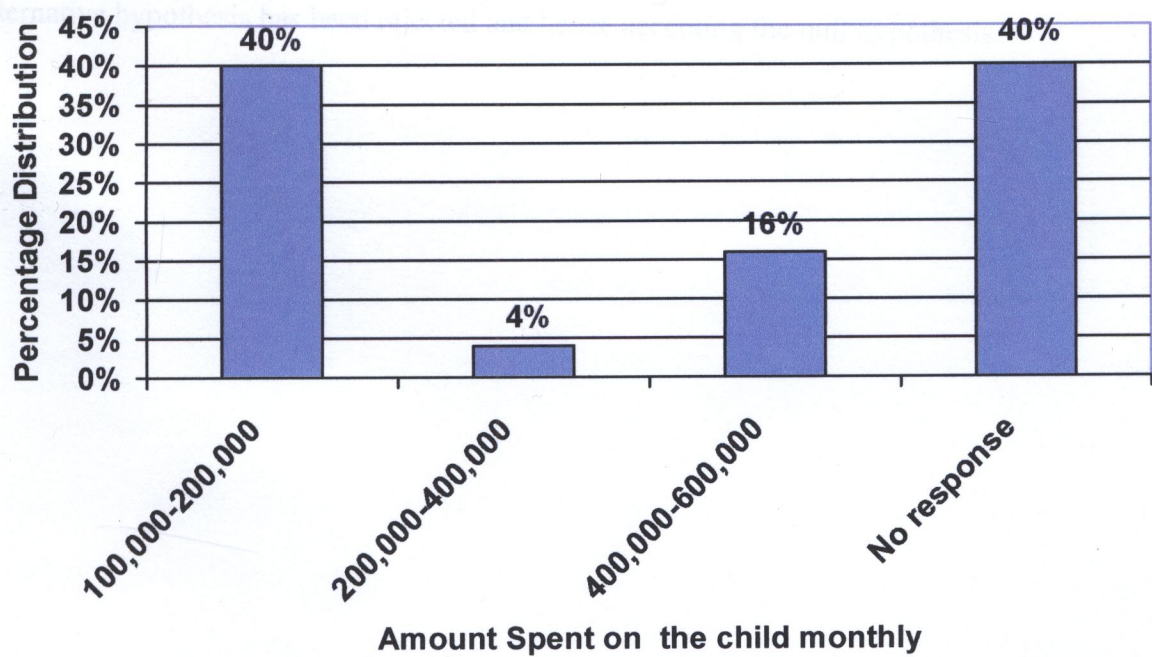


Table 1.7: The percent distribution of the amount of money spent on the child



Chi-Square Tests

	Value
Pearson Chi-Square	(a)
N of Valid Cases	25

No statistics are computed because Have you been affected psychologically as a caregiver or family when caring for a child with hydrocephalus? is a constant.

The alternative hypothesis has been rejected and hence accepting the null hypothesis.



## **CHAPTER FIVE: DISCUSSION**

### **5.1 INTRODUCTION**

In this chapter, the results are discussed with reference to the aim and objectives of the study, as well as to the relevant literature. The study sought to evaluate the caregivers' experiences in caring for children with hydrocephalus attending physiotherapy at U.T.H, D – block and C.B.I. The sample size consisted of 25 participants that were chosen conveniently by the researcher, who were caring for children with hydrocephalus. Majority 64% (n=16) of the total caregivers were found to be biological caregivers to the children, being mother or father, while the rest 36% (n=9) were non-biological caregivers for children with hydrocephalus.

### **5.2 SOCIAL DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS**

Section A of the questionnaire (Appendix II) explored information on socio-demographic characteristics of the child with hydrocephalus, and section B of the questionnaire (Appendix II) explored information on socio-demographic characteristics of the respondents. The study revealed that from the 25 respondents, who took part in the study, 84% (n=21) were female caregivers and represented the majority, while 16% (n=4) were male caregivers being the minority. Majority of the caregivers in the study represented females, as they often cared for, and nursed children, this would be because it was a traditionally accepted norm. World Health Organisation (WHO) reported that, the primary providers of care of the child were inextricably linked with situation of the household and women, explaining why majority of the caregivers were women. Women

are more sympathetic than male genders who were the minority participants as caregivers caring for children with hydrocephalus.

The age of children ranged from 0 to above 40 months, and this is in agreement with mayo clinic (2005) which states that, this was age vulnerable to hydrocephalus. The study revealed that 72% (n=18) of the children were males (boys), where as 28% (n=7) were females (girls). The majority of the respondents, 32% and 28% (Table 1.3) aged between 25-29 and 30-35 years old respectively; the significance being that it was the child bearing age and the age with heady of responsibilities. According to Zambia Demographic Health Survey (ZDHS, 1996) revealed that, that was the age found to be very productive and sexually active, the likely explanation why so many of those caregivers had children at that age. ZDHS (1996) further stated that reproductive histories of women ranged from 15 – 45 years old with the peak age, specific fertility rates of 25 – 29 years, hence the probable reason why fewer caregivers below the age of 20 and above 40 years.(Table1.3) in chapter four. The study also shows that male children were more cared for than female children, this could mean that male gender were more affected or culturally male gender is more valued than female gender in terms of maintaining family name.

**5.3 IDENTIFYING THE NATURE OF CAREGIVERS CARING FOR CHILDREN WITH HYDROCEPHLUS**

The ages of the respondents that were caring for children with hydrocephalus who were captured in this study ranged from 15-29 years old representing 48% (n=12), which was

the majority, and the minority were 12% (n=3) whose age ranged from 40 years old and above. In this study it was noted that most caregivers were females representing 84% (n=21), while male caregivers were the minority representing 16% (n=4). This shows that more females were caring for children with hydrocephalus than males, and the reason is that traditionally it is accepted as a norm (WHO, 1996). WHO (1996), further reported that the primary provider of care for young children in all cultures were women and therefore care for children was directly linked with situation of household and women, this explains why the majority of the caregivers were females in this study. Therefore, the findings in this study are not dissimilar to the study done by the WHO (1996).

This study also revealed that 76% (n=19) lived with the children in their homes and this made their work lighter than caregivers commuting everyday to where the child lived in order to provide care. This has an adverse effect on the caregiver's expenditure, and this is agreement with a study by Arno (2004) who explored that distance caregiving has a negative effect on the family caregivers resources and very stressful. Arno (2004), further reported that long-distance caregivers had higher caregiving-related out of pocket expenditures than did other caregivers.

Women caregivers were between 15-29 years, 30-39 years of age and older 72% (n=18) of caregivers were married, 8% (n=2) widowed and 20% (n=5) reported to be single caregivers, and informal caregivers, who provided more intensive and complex care for children with hydrocephalus; most caregivers expressed to have had difficulty with care provision and balancing caregiving with other family responsibilities. This study also

explored on the relationship of the caregiver to the children they provided care for and findings were that, 64% (n=16) were biological parents representing the majority and 36% (n=9) were non biological parents, constituting grandparents, aunties, and other formal caregivers representing nurses, close to the children and physiotherapists attending to children at various clinical appointments.

## **5.4 EVALUATION OF EXPERIENCES OF CAREGIVERS CARING FOR CHILDREN WITH HYDROCEPHALUS.**

### **5.4.1 Physical experiences when caring for children with hydrocephalus**

In the study, 52% (n=13) respondents expressed that they enjoyed doing exercises with the children they were caring for, on other hand they also expressed that caring for children with hydrocephalus especially doing exercises made them so tired. Those who enjoyed bathing these children with hydrocephalus reported becoming tired especially when lifting the child who is not independent, these activities caused some strain and made the caregivers weak and lowered their level of their physical well-being. These findings are supported by Han and Halley (1999), who said females, younger caregivers, caregivers of patients with severe disabilities and caregivers in ill health or in poor physical health were at risk of burnout. Physical aspect of caregivers was being affected because of a lot of work to do for their recipients of care, this was due to caregivers doing their own work as well as providing care for their children who were not independent. Other aspect of the study looked at how many times caregivers got up in the night to attend to their children with hydrocephalus and majority 24% (n=6) expressed that, they

got up 3 times to attend to the needs of their children, this indicates that they did not have sufficient sleep and never rested enough to be well physically. Some respondents reported to have gotten up more than 3 times in the night and these represented 20% (n=5) four times, 12% (n=3) five times, this finding is in line with a study done by Martinson (2007) who reported on caregivers to have no energy any more due to insufficient sleep at night to attend to their children with chronic illnesses at home in China.

#### **5.4.2 Emotional effects when caring for children with hydrocephalus.**

The results of this study on emotional impact and effects revealed that majority 44% (n=11) were moderately affected by the child's condition emotionally, 40% (n=10) were severely affected and the minority 16% (n=4) expressed that they were not affected at all this shows that the minority did not demonstrate a reduced quality of life compared to the majority that suffered moderate and severe emotional strain (Fig 1.8).

The study also found that, most of respondents 52% (n=13) were affected emotionally. They had feelings of anxiety, frustrations, feelings of uncertainty and losing patience with their children's condition of hydrocephalus. The study also revealed that, 24% (n=6) were stressed, 12% (n=3) were reported to have been depressed, and other were not able to tell how they felt emotionally. Stewart (1998) said that, hydrocephalus can be a major cause of long term disability, often with devastating consequences for individuals and their families. Vermeas (2005), also in their study noted that, most family and unpaid caregivers were proud of the help they provided, and some managed caregiving tasks with difficulty, yet many caregivers experienced high levels of stress and depression

associated with caregiving. This is not the first study demonstrating that depressive moods occur more frequently in caregivers of children with hydrocephalus than in caregivers of healthy children. In a recent American study half of the caregivers of children with SCD were at risk of clinical depression, as measured by the Center for Epidemiologic Studies-Depression scale (CES-D) (Moskowitz & Butensky, 2007).

The findings on emotional drain and stress agrees with Vermeals *et al* ( 2005) who in their study concluded that families and especially female caregivers suffered emotional drain and stress due to caring for children with hydrocephalus and spina bifida. Jackson (2005) also agrees with Vermeals *et al* and added that hydrocephalus caused severe physical and emotional burden on the family. An important point to note here also is that stress tends to increase over times if the caregivers needs are no met. Some of these needs, mentioned by caregivers include the need for information especially better understanding of the emotional and behavioral changes of these children. This is also supported by Dorothy (2006) who said, emotional reactions that caregivers may feel can be one or more of the following; anxiety, guilt, depression, fears, frustrations, resentment and impatience over the condition of their recipient of care. This is suggesting that, hydrocephalus has a lot of negative impact on the caregiver, which further leads caregivers becoming emotional. Most parents of children with hydrocephalus constantly worry about continued shunt function, with every malfunction of shunt there is a need for surgery and perceived threat of brain damage. This constant worry and daily responsibilities and stress of caring for a child who may have multiple medical problems

is very difficult for caregivers. Other sources of worry are the concern about the child's ability to be self-supporting and independent in future.

Parents emphasized the need to be physically and emotionally healthy in order to properly look after their child. Lifting, sleep problems, and the chronic care and supervision needs of the child were some of the factors that threatened parents' physical and emotional well-being. Accepting and adjusting to the child's diagnosis was an ongoing emotional task, with changes in the child's condition and times of transition bringing such issues back to the surface. Watching the child suffer from ill-health or pain was emotionally distressing. Having to use a service that was inadequate or inappropriate was a source of anxiety and even despair. To maintain physical well-being, appropriate equipment, suitable housing, short-term care, and skills in dealing with their child's sleep problems were seen as important.

#### **5.4.3 Economical effects on caregivers caring for children with hydrocephalus**

This study found that 40% (n=10) of the respondents spent between K100,000 and K200,000 on the child monthly, and minority 4% (n=1) spent between K200,000 and K400,000, other respondents 16% (n=4) expressed that, they had to part away with the amount of between K400,000 and K600,000. These funds were mainly spent on their children to transport them to the health facility for surgery and subsequent reviews and taking their children for physiotherapy. It was also revealed that other respondents who were in good employment and had support from their family members had no complaints about resources. This is also in agreement with information from hydrocephalus

association in America (hydroassoc.com, 2008) which said that, family caregivers went through financial strain which was caused by numerous medical visits, and surgical procedures depleted family's financial resources.

The findings of this study are in agreements with a study done by Moskowitz and Butensky (2007) on caregivers caring for children with sickle cell disease, who said that caring for a patient can be a difficult task especially if family resources and finances are limited. Forster *et al* (2005) also reported that in their study, many caregivers who encountered some financial constraints had problems in providing care to their children especially in terms of meeting day to day needs. The significance of this study on economical income was that the less the money the family had the more difficulty it was for the to access proper treatment for their children and on time. International Labour Organisation (ILO,2001) report state that 80% of the population in Zambia lived in poverty, and can explain why most caregivers expressed that they were economically affected by caring for their children with this chronic and disabling condition.

#### **5.4.4 Social impact on caregivers caring for children with hydrocephalus**

In the study most of respondents talked to expressed that, they were affected very much such that they stopped going out, visiting friends and families and they also said that it was not ideal for them to go out and leave the child with no one to for him/her. In a study done Hirst (1999), found that, social impact of the caregivers experiences was immense, caregivers did manifest diminished social function. A study done by Sloper and Turner (1992) showed that many caregivers lost their networks and separated from their friends,



even their dreams were often sacrificed due to high levels demanding of caregiving roles. Sloper and Turner (1992) further said that, many caregivers abandon their hobbies, stop going out to have fun, forgo vacation and dangerous of all give up the very relationship in their life time. This study is also in support with the findings of this study on caregivers' social experiences in caring for children with hydrocephalus. Some of respondents described feeding as stressful and unenjoyable, prolonged feeding period were reported by 20% (n=5), these results highlights that, feeding problems in children with hydrocephalus were common and severe and caused parental concern. Many of these children would benefit from nutritional assessment and management as part of their overall care. This is supported by Anderson (2002), who reported on children to have choked when being fed.

## **5.5 CONCLUSION**

This study focused on the caregivers' experiences in caring for children with hydrocephalus. The results of the study showed that more females cared for these children than male caregivers and the average age was 25-34 years, uneducated and unemployed. According to this study, caregiving was associated with range of negative experiences that included emotional crisis, profound sadness, social isolation, anxiety, stress, depression, fear, physical discomfort, low energy levels and financial problems. The results of the study reveals that majority (72%, n=18) of the children were male and minority (28%, n=7) were the female gender, this shows that most of children that were being cared for were male gender. The age ranges were from 3 months to 3 years and above. The results demonstrated that the majority (52, n=13) of the children had been ill

for a period of 0-6 months, this age group is in line with a study by Mayo clinic (2005) which stated that this age group was the most vulnerable to illnesses. On other hand (12% n=3) had been ill for 7-12 months, (12%, n=3) also had been ill for a period of 3-4 years. This also reveals that hydrocephalus is a chronic disabling condition. This study also explored on the type of operation that was done to the children and it demonstrated that (60%, n=15) had been shunted once and (32%, n=8) had been shunted twice, those that were shunted twice had complications such as infection and blockages of the shunt. Majority of the caregivers (84%, n=21) were female while the minority (16%, n=4) were the males. Women being more sympathetic than male gender were the majority participants as caregivers caring for children with hydrocephalus. The age range of the caregivers ranged from 15 to 40 years and above. This study also explored the marital status and the findings were that majority (72%, n=18) were married, minority (8%, n=2) were widowed and the rest (20%, n=5) were single caregivers. on relationship of caregiver to the child, it revealed that majority (64%, n=16) of the caregivers were the biological parents being mother or father, while minority (36%, n=9) were non biological parents but caring for children with hydrocephalus. Majority (76%, n=19) of caregiver lived with the child, minority (24%, n=6) of the caregiver did not live with the child. This study revealed that children a lot of support from their carers and majority (24%, n=6) woke up at night to attend to children's needs 3 times, minority (4%, n=1) got up only once. On average the majority (32%, n=8) took about 15 minutes to feed their children, and (52%, n=13) enjoyed exercising their children on activities of daily living. Emotionally, (44%, n=11) of the caregivers were moderately affected, (40%, n=10) were severely affected. Economically, majority of the caregivers were impacted negatively,

(40%, n=10) reported to have spent between K100,000 and K200,000 on the child's welfare and one caregiver reported to have been missing important appointments like reviews and surgery because of the financial challenges as she was not even in formal employment.

Lastly I would like to quote from the book by Reinhard (2004), and I quote "there are only four kinds of people in the world; those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers, that's how universal this issue is".

## **5.6 RECOMMENDATIONS**

Bearing in mind that caregiving is very complex, more research is needed to.

- To better understand the effects of care of family caregivers and on patients outcomes
- Rigorously explore and define caregivers roles, responsibilities, knowledge and skills. For instance, what do caregivers do well? What do caregivers not do well? What areas cause caregivers more distress? Once these questions are, we can target interventions at those who are at risk and intervene early in the care situation, rather than late.
- Interventions must recognize professional or formal caregivers and family caregivers as partners in health care provision – partners who offer unique and vital skills and resources

- Programme planners, policy makers, and formal care providers must act together to provide, accessible, affordable and innovative support services and programmes that reduce family caregiving strain.

## REFERENCES

Alzheimers association (2008) **Abstract of US data on Alzheimer's Statistical disease facts and figures**; available on [www.alz.org](http://www.alz.org)

Anderson J.G (2002) **The challenge of caring for the severely disabled children**, 2<sup>nd</sup> edition, New York

Arno P.S (2004) **Wellbeing of caregivers: The economic issues of caregiving: National survey of Families and Households**.

Avellinos M.A (1995-2008) **Hydrocephalus research**, Children's hospital and medical centre, Washington

Association for spinal bifida and hydrocephalus (2008) **spine bifida**; available on [www.asbah.org](http://www.asbah.org)

Bailey DB, Blasco PM, Simeonsson RJ. (1992) **Needs expressed by mothers and fathers of young children with disabilities**; American Journal of Mental Retardation 97: 1–10.

Bayston R, (2005) **Hydrocephalus**; available on [www.dmoz.org](http://www.dmoz.org)

Bakheit, A.M.O., Bower, E., Cosgrove, A., Fox, M., Morton, R., Phillips, S., (2001) **Opinion statement on the minimum acceptable standards of healthcare in cerebral palsy. Disability and Rehabilitation,**

Bless C and Smith H (1995) **Fundamentals of Social Research Methods.** An Africa perspective. 2<sup>nd</sup> edition Juta and Co. Ltd. Cape Town S.A

Buggy, C., Alexander, H., Hage, S. (1999) **Stroke Patients' Informal Caregivers: Patient, Caregiver, Service Factors that Affect Caregivers Strain.**

Central board of health-central statistical office (1999-2000) **Republic of Zambia demographic and Health survey-Lusaka, Zambia**

Central board of health-ministry of health (2000a) **Republic of Zambia**

Central Statistical Office Zambia, (2000), **The 2000 Population and Housing Census of Zambia, Lusaka**

Collins English dictionary (1989) new edition, Williams Collins & Sons, London

Dorothy Edwards (2006) **Associate Professor of Occupational Therapy and Neurology at Washington University School of University**

Engelhard, H.H (2007) **Hydrocephalus**; available on [www.emedicine.com](http://www.emedicine.com)

Forster, A., Smith, J., Young, J., Knapp, P., House, A., Wright, J. (2005) **Information Provision for Stroke Patients and their caregivers**. Cochran Library

Fried A. Mel. H. Epstein M (2005) **Childhood hydrocephalus; clinical features, treatment and slit ventricle syndrome**. [www.alwebs.com](http://www.alwebs.com)

Han.B and Halley W.E (1999) **Family Caregiving for Patients with Stroke patient: a review of the literature**, journal of Advanced Nursing 26(3), 580 – 588.

Health communities (2005) **hydrocephalus** [www.neurologychannel.com/hc](http://www.neurologychannel.com/hc)

Health Encyclopedia – **Diseases and Conditions** (2008); available on HealthCentral.com

Hirst M. (1999) Patterns of impairment and disability related to social handicap in young-people with cerebral palsy and spinabifida..*Journal of Biosocial Science* 21: 1–12.

Hord A.M (2006) Hydrocephalus. emedicine; available on [www.emedicine.com](http://www.emedicine.com)

**Hydrocephalus from Alzheimer’s outreach (2008) hydrocephalus fact sheets**

Hydrocephalus association (2008)

International Federation of Spina Bifida and Hydrocephalus (IFSBH) (2005) **the prevalence of hydrocephalus in East and Central Africa.** [www.ifglobal.org](http://www.ifglobal.org)

International Labour Organization (2001) **Priority Survey Report**

Jackson, P.L (1997) **information sheet for the primary needs of children with hydrocephalus;** available on [www.hydrocephalus.ass.com](http://www.hydrocephalus.ass.com)

Johnson, R.W (2006) **A Profile of Frail Older Americans and their caregivers.** Washington D.C

Kahn C (2004) **hydrocephalus medical college of Wisconsin;** available on [www.hydrocephalus.EN.htm](http://www.hydrocephalus.EN.htm)

Kanhohak T (1994) **experiences of caregivers caring for stroke patients;**3(1) 67-68,88-89  
discussion

Kerr, S.M and Smith, L.N (2001) **hydrocephalus: an exploration of the experiences of care giving**

Krulik, T, Hirschfeld, M.J and Sharon R (1984) **family care for the severely handicapped children and aged in Israel.** Sackler School of medicine. Report of the study

Lin, J.Y and Davis, A.J (1985). Janforum - **health care and nursing in the People's Republic of China Journal of Advanced Nursing,** 10, 279-284.



Martinson, Tuna H, Unalan H, Tuna F, and Kokino S (1995) **Quality of life of primary caregivers of children with cerebral palsy: a controlled study with Short Form-36 questionnaire.**[\[CrossRef\]](#)[\[ISI\]](#)[\[Medline\]](#)

Martinson.I (1997) **the experiences of the family of children with chronic illness at home in china;** available on [www.emednine.com](http://www.emednine.com)

Masters, J, and O’grandy (1992) **normal pressure hydrocephalus-A potentially reversible form of dementia** *Journal of psychosocial nursing*

Mayo Clinic (2005) **Causes and Risk Factors Related to Childhood Hydrocephalus**  
[www.Mayoclinic.org](http://www.Mayoclinic.org)

Milhorat,T (1996) **Hydrocephalus; Pathophysiology and Clinical Features, Neurosurgery**

Ministry of Health (2000a), **Health Annual Report for Zambia-Lusaka**

Ministry of Health (2000b), **Health Bulletin in Zambia, 1<sup>st</sup> and 2<sup>nd</sup> Quarter, Lusaka**

Ministry of Health (2001), **Health Institution in Zambia** – a list of health facilities according to levels and location, Lusaka

Moskowitz JT and Butensky E (2007), **Caregiving time in sickle cell disease: psychological effects in maternal caregivers.**

National Alliance for caregiving and United Hospital Fund (2006), accessible at [www.caregiving.org](http://www.caregiving.org) date retrieved 19<sup>th</sup> November 2008.

Nation Institute of Neurological Disorders and Stroke (2005) **hydrocephalus fact sheet**

Ndulo (1999) Republic of Zambia

Nkata E (2006) **causes and Common impact of hydrocephalus on families in children attending paediatric surgical clinic at UTH** (unpublished *dissertation*)

Nova k P (1995) **Dorland's pocket medical dictionary**, 20<sup>th</sup> edition. Philadelphia WB Saunders

Polit D. and Hughes B (1991) **Nursing Research Principles and Methods**, lippincott company. Philadelphia.

Reinhard S.C (2004). **The work of caregiving**: What do ADLs and IADLs tell us? In: Levine C. ed. **Family caregivers on the job: Moving beyond ADLs and IADLs**. New York: United Hospital Fund.

Rosenthal, M.M (1987).**The experiences of the family of Children with chronic illness at home in China.**

Sahrakar. K. (2002) **Hydrocephalus**; available on [www.emedicine.com](http://www.emedicine.com) date retrieved 16<sup>th</sup> November 2008

Scott, R (1990) **hydrocephalus**. Vol3: concept in neurology, Williams and Wilkins publishers  
Baltimore

Silvia B (2005) **congenital hydrocephalus**; [www.curriculum.calstatela.edu/webnag](http://www.curriculum.calstatela.edu/webnag)

Sims, J and Wright, C (2002) **Research in Health Care** 2<sup>nd</sup> edition, Nelson Thornes publishers

Sloper P, Turner S. (1992) **Service needs of families of children with severe physical disability**. *Child: Care, Health And Development*18: 259–82.

Stewart, M.J Dobie, S., Hart, G., Langille L Mac Pherson, K., (1998) **Peer visitor support family caregivers of children with chronic disability**. *Can J. Nursing research*.

Stoltz C (2008) Health encyclopedia – **diseases and conditions**

Taylor and Francis (2005) **The Prevalence of Hydrocephalus in East and Central Africa**

Varkevisser M.C (1990), **Designing and Conducting Health Systems Research Projects,(2), IDRC**

Vermeas I Janssen J, Bosman A, Geras J (2005) **Parents Psychological Adjustment in Families of Children with Spina Bifida**

[www.virtualtrials.com](http://www.virtualtrials.com)

**BUDGET FOR RESEARCH**

ITEMS	QUANTITY	UNIT COST (KWACHA)	COST (KWACHA)
STATIONERY			
A4 BOND PAPER	6REAM	25,000	150,000
PENCIL	10	500	5,000
PENS	10	1,000	10,000
RUBBERS	5	1,500	7,500
FOLDERS	5	6,000	30,000
DISKETTES	2BOXES	3,500	70,000
METAL CLIPS	10	1,000	10,000
STAPLES	1BOX	25,000	25,000
<b>SUB TOTAL</b>			<b>327,000</b>
PHOCOPYING			100,000
TYPING			500,000
BINDING	5*5		200,000
DATA ENTRY AND ANALYSIS			
REPORT PRINTING			250,000
TRANSPORT			
<b>SUBTOTAL</b>			<b>200,000</b>
TOTAL			200,000
CONTINGENCY			1.450,000
FUND 10% OF TOTAL			1.777,000
			177,700
<b>GRAND TOTAL</b>			<b>1.954,700</b>

**BUDGET JUSTIFICATION**

The above listed and costed items were important for the researcher to carry out this study as partial fulfillment for his BSc in physiotherapy.

## TIME PLAN

### TIME FRAME IN MONTHS

[illegible]

## INFORMATION SHEET

Dear participant,

I am a final year student at the University of Zambia School of Medicine. I am expected to undertake a research in any area of health care that will contribute meaningfully to the provision of quality care and improve on the body of knowledge.

The aim of this study is to determine caregiver's experiences in caring for children with hydrocephalus attending physiotherapy at UTH – CBI.

The information that will be obtained will help the physiotherapists on setting the strategies to assist the caregivers on managing this role, and will help physiotherapists and other rehabilitation professionals in the provision of quality health care.

Your participation in this study is purely voluntary and the information that will be given shall be handled with strict confidence. You are required not to write your name or initials on the questionnaire to avoid identity. Be also informed that not participating in this study shall not affect your right to bring your child for physiotherapy services at any given time.

Be notified that this study is purely academic and there are no monetary benefits.

You are being requested to answer a questionnaire and if you have any questions feel free to contact the researcher or the secretary of the Research Ethics Committee

Your support will be highly appreciated.

Research Ethics Committee  
University of Zambia  
Box 50110  
Lusaka  
Tel 02 256067

Maifwani Jack  
University of Zambia  
Physiotherapy Department  
Box 50110  
Lusaka  
Mobile – 0978-504676

**INFORMED CONSENT**

I.....having had the aims and benefits of this study explained to me. I am aware of my rights in not taking part in the study and that it will not affect my child from receiving any physiotherapy services at any given time. I am also aware that I can withdraw from the study at any point without giving any notice.

I have therefore agreed / disagreed to take part in the study with my own free will

Participant’s signature/Thumb print                      Date.....

-----

Witness    Date.....

-----

Researcher’s signature                                      Date.....

-----

**QUESTIONNAIRE**  
**THE UNIVERSITY OF ZAMBIA**  
**PHYSIOTHERAPY DEPARTMENT**

AIM OF THE STUDY IS TO EVALUATE THE CAREGIVER'S EXPERIENCES IN PROVIDING CARE FOR CHILDREN WITH HYDROCEPHALUS ATTENDING PHYSIOTHERAPY AT THE UNIVERSITY TEACHING HOSPITAL D - BLOCK AND COMMUNITY BASED INTERVENTION.

**SECTION A: DEMOGRAPHIC DATA OF CHILD WITH HYDROCEPHALUS**

(Mark an item with X where appropriate)

1. Gender (a) Male  
(b) Female

2. Age; -----

1. Duration of illness or condition-----

2. What has been done so far towards the illness? -----  
-----

5. School status: Enrolled in school  
Not enrolled in school

6 Has the child been operated on? -----



7 If yes to question 6, what type of operation is it? -----

**SECTION B: CAREGIVER’S DEMOGRAPHIC DATA**

(Mark item with an X where appropriate)

1. Residential Area -----

2. Gender : (a) Male  
(b) Female

3. Age : -----

4. Marital status: (a) Single  
(b) Married  
(c) Divorced  
(d) Widowed

5. Employment status (a) Employed  
(b) Unemployed

6. Home language (a) English  
(b) Nyanja  
(c) Bemba  
(d) Other languages please specify -----

7. Relationship with the child (a) parents; mother or father  
(b) Brother or Sister  
(c) Others; please specify -----

8. Caregiver lives with the child; Yes or No

9. Time lived with the child? -----

10. Religion of the caregiver? -----

**SECTION C: SUPPORT GIVEN TO THE CHILD**

**QUESTIONS**

**SUPPORT IN THE NIGHT**

1. What time do you wake up to prepare for your child with hydrocephalus? -----  
-----
2. How many times do you wake up to attend to the child at night?  
I= 1, II= 2, III=3, IV=4, V= 5

**FEEDING THE CHILD**

1. How long does it take you to feed your child if the child is fed? -----  
----- Other tasks  
please specify-----  
-----
2. Of the following tasks, which task do you enjoy doing?  
I= feeding the child, II= bathing the child, III= changing child’s nappies  
IV= Exercising the child.  
Others, please specify-----
3. Who else attends to the child on the above listed tasks? -----  
-----

**EMOTIONAL IMPACT**

1. How has caring for a child with hydrocephalus affected you emotionally? -----  
-----
- (I). Severely (II). Moderately (III). Not at all
2. If your answer to question 1 is (I) or (II), please state how? -----  
-----

3. What was your reaction when you saw your child's head growing abnormally and the Doctors confirmed the diagnosis?

I= Anger, II= Shock, III= Sad, IV= Calm, V= do not know

4. How have you been affected psychologically as a caregiver or family?

I= Stressed, II= emotionally drained, III= depressed, IV= optimistic, V= do not know

---

**SOCIAL IMPACT**

1. How have you been affected socially as a caregiver? I= Stopped visiting friends, II= stopped going out to have fun, III= still go out normally, IV= do not know

2. Has the child been discriminated against because of his/ her condition? yes or no

3. If the answer is yes to question 2, how? -----

4. How do other family members feel about his/her presence?

I= Sympathetic, II= empathetic, III= resented, IV= abomination, VI= curse VII= blessing  
VIII= do not know

**IMPACT OF DISABILITY ON MARRIAGE**

1. Has the presence of the child affected your marriage if you are the parent? Yes or no -----  
-----

2. If yes to question 1, please state how? -----

**FEELING OF GUILT OVER DISABILITY OF THE CHILD**

1. Do you feel responsible for the child's condition? Yes or No

2. If your answer to question 1 is yes, please state how?-----  
-----  
-----

**MEDICAL SUPPORT**

1. Who else takes the child for physiotherapy and other medical procedures e.g. surgery?

Other activities specify? -----  
-----

2. What is your average monthly expenditure on your child with hydrocephalus? -----

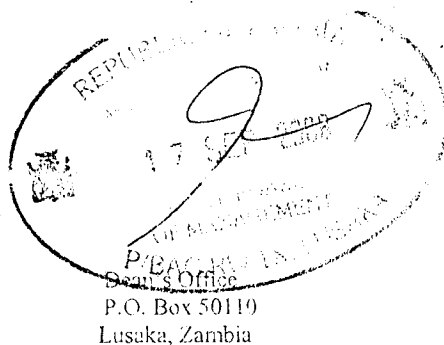
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**THANK YOU**



THE UNIVERSITY OF ZAMBIA  
SCHOOL OF MEDICINE  
DEPARTMENT OF PHYSIOTHERAPY

Telephone: 252641  
Telegrams: UNZA, LUSAKA  
Telex: UNZALU ZA 44370  
Fax: + 260-1-250753



12<sup>th</sup> May, 2008.

The Managing Director,  
University Teaching Hospital,  
P/Bag RW 1X,  
LUSAKA.

Dear Sir,

**RE: REQUEST FOR PERMISSION TO ALLOW MAIFWANI JACK CARRY  
OUT A STUDY AT YOUR INSTITUTION**

Reference is made to the above subject.

The Department of Physiotherapy under the School of Medicine would like to introduce to you its above-named 5<sup>th</sup> year student pursuing a Bachelor of Science in Physiotherapy. The Curriculum requires him to carry out a Research Project as partial fulfillment to the award of the Bachelor of Science Degree.

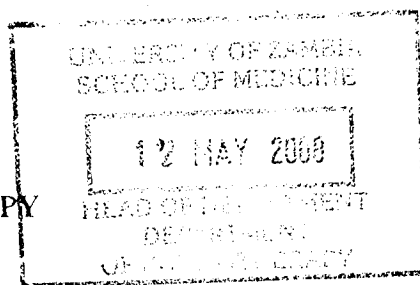
The proposed study title is: **“To Determine Caregiver’s Experience Caring For  
Hydrocephalus Patients At The University Teaching  
Hospital.”**

We therefore seek permission from your office to enable the student carry out the study as proposed at your institution and the D-Block in particular. May he also be allowed to use any stock data that relates to the targeted patients.

Thanking you.

Yours faithfully,

Mrs M.B Chalwe,  
**ACTING HEAD – DEPARTMENT OF PHYSIOTHERAPY**





# THE UNIVERSITY OF ZAMBIA

## BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067  
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Telex: UNZALU ZA 44370  
Fax: + 260-1-250753  
E-mail: unzarec@zamtel.zm

Ridgeway Campus  
P.O. Box 50110  
Lusaka, Zambia

Assurance No. FWA00000338  
IRB00001131 of IORG0000774

30 September, 2008  
Ref.: 016-09-08

Mr Jack Maifwani  
Department of Physiotherapy  
School of Medicine  
University of Zambia  
LUSAKA

Dear Mr Maifwani,

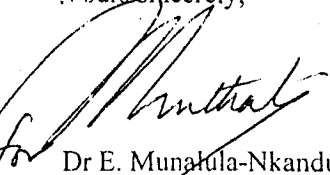
RE: RESEARCH PROPOSAL ENTITLED: "A STUDY TO EVALUATE CAREGIVERS EXPERIENCES IN CARING FOR CHILDREN WITH HYDROCEPHALUS ATTENDING PHYSIOTHERAPY AT UNIVERSITY TEACHING HOSPITAL – CBI AND D-BLOCK"

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee Secretariat and was found to have minimal ethical issues. The proposal has now been approved.

### CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.

Yours sincerely,

  
Dr E. Munakula-Nkandu, BSc (Hons), MSc, PgD R/Ethics, PhD  
CHAIRPERSON

Date of approval: 30 September, 2008

Date of expiry: 29 September, 2009.

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