

KNOWLEDGE, ATTITUDES AND PRACTICES ABOUT EPILEPSY AMONG  
PARENTS OF CHILDREN LIVING WITH EPILEPSY

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By

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A Dissertation submitted to the University of Zambia in Partial Fulfillment of the  
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The University of Zambia


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2011

**DECLARATION**

I, Claire Chakale Sakubita declare that this dissertation is due to my own effort unless otherwise acknowledged and has never been submitted for a degree to this or any other university.

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# APPROVAL

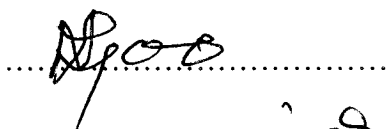
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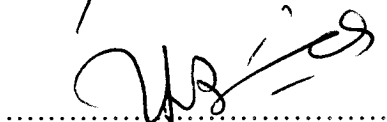
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## ABSTRACT

This study was designed to examine knowledge, attitudes and practices about epilepsy among parents of children living with epilepsy. This was in order to establish challenges faced by parents of children living with epilepsy in Lusaka urban district.

In order to provide relevant literature for the study, various sources of data were explored. Both qualitative and quantitative research methods were employed in this study. The study sample comprised 110 parents who were conveniently selected. Parents whose children were 8 years and below and at the time of the study were receiving treatment at the study sites were targeted.

Quantitative data was analyzed quantitatively using tables of percentages and frequency and other forms of computer generated graphics. Qualitative data was analyzed qualitatively using various themes.

Findings from the study have revealed that knowledge and understanding of epilepsy among parents was fairly good.

It was further revealed that the attitude of parents towards epilepsy treatment was positive. The majority of parents indicated that epilepsy was treatable. However, it was established that the majority of the parents doubted the effectiveness of AEDs for the treatment of epilepsy.

Unlike in other studies where contagion beliefs were high, this study registered low levels of contagion beliefs. The majority of the parents reported that epilepsy was not contagious because they had lived with their epileptic children, shared cups and plates but they had not contracted epilepsy.

This study has shown that parents of CWE were going through a number of challenges. Some of these included social discrimination, poor access to formal education for their children, marital disputes, loss of employment and chronic sorrow among other things.

The study has further revealed that women were most affected. The majority of women who participated in this study were not in any form of employment despite having relevant educational qualifications.

The conclusions drawn from this study are that epilepsy is not only a medical but a social challenge as well. It is capable of creating fear, stress and anxiety not only to the victim by the care-giver and the entire family. It is therefore, necessary that relevant authorities put in place deliberate policies that will enhance care for all those afflicted by epilepsy.

# DEDICATION

I dedicate this work to all the children living with epilepsy

## **ACKNOWLEDGEMENTS**

Sincere gratitude to my family members for the support rendered during my study period. I am indebted to my mother whose support has been tremendous. I wish to express my warmest appreciation to my four children Mwangala, Daniel, Sendoi and Liywalii for their patience and love at the time I was putting this work together.

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**ACRONYMS**

CWE .....	Children living With Epilepsy
PWE.....	People living With Epilepsy
AEDs .....	Anti Epileptic Drugs
AESZ.....	Epilepsy Associated Team in Zambia
EAZ.....	Epilepsy Association of Zambia
W.H.O.....	World Health Organization
UTH.....	University Teaching Hospital
TH.....	Traditional Healers
IBE.....	International Bureau of Epilepsy
ILAE.....	International League against Epilepsy



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# **1 CHAPTER ONE: BACKGROUND**

## **1.1 Introduction**

This study is divided into six chapters. Chapter one gives a background of the study. The statement of the problem, objectives of the study, significance of the study and other areas pertaining to this study have been highlighted. In Chapter two relevant literatures on epilepsy focusing on knowledge, attitude and practices about epilepsy have been discussed. Chapter three looks at the methodology used in this study. Chapter four looks at the findings of the study in line with the research objectives while Chapter five has provided the discussions of the study findings. The last chapter provides conclusions and recommendations.

## **1.2 Background of the study**

Epilepsy is one of the global health issues affecting humanity. According to (WHO et al, 2007) it is estimated that more than 50million people world over were living with epilepsy. Further estimates indicate that out of the total number of people living with epilepsy (PWE), 90 percent reside in developing countries and more than 50 percent of this figure accounts for children below the age of 16years (WHO et al 2007).

Research has shown that epilepsy is one of the chronic conditions that can have some significant impact on both the victim and the entire family. This is as a result of continued hospitalizations, long time treatment (which in some cases is life-long) and other complications which are associated with epilepsy. Naturally, every parent desires to have a healthy child, full of potential in life but in most cases the ideal child image is eroded the very moment the child is diagnosed with epilepsy. To some parents that would sound like the child has been condemned to death knowing very well that the condition

has no cure. This feeling is likely to occupy every parent's mind because traditionally epilepsy is not only known to have no cure but also that it is contagious.

In an effort to find cure for epilepsy, people engage in all sorts of activities such as offering sacrifices, prayers and consulting traditional healers while the ultimate goal is to find treatment for the problem (Dekker, 1998).

### **1.3 Epilepsy burden in Zambia**

Zambia still has a lot of challenges in terms of contributions towards epilepsy literature.

Getting information on the Zambian situation proved difficult as the only available literature is silent in terms of statistics about the number of people affected by epilepsy.

However, the fact is that many people in Zambia are living with epilepsy but most of these people do not seek medical care due to various factors such as inadequate information about epilepsy treatment, long distances to health care facilities and perceived negative attitudes of health care workers among other factors (WHO, 2007).

A door to door survey conducted by the African studies center (2007) in Chikankata-Southern Zambia revealed that in a catchment's area of about 55000 people, 799 were found to be living with epilepsy. The study further established that prevalence rates were higher in children below the age of 16 years.

The Epilepsy Association of Zambia (EAZ) newsletter of 2001 reports that, the association had managed to register more than 500 persons that were living with epilepsy with the majority of the members being children below the age of 16 years. This is in line with the assertions that more than 50% of PWE are children below the age of 16 years (WHO, 2005). Also in agreement with the above revelations are Chi-Wang et al (2008) who concluded from their study conducted in China that 50% of PWE in China were

children. However, there has been no information to show for the number in terms of gender disaggregated data on epilepsy.

#### **1.4 Statement of the problem**

Studies have shown that epilepsy is one of the health challenges affecting mankind worldwide. However, many studies have reported negative perception by people towards epilepsy and those that are living with the condition. In Zambia, just like elsewhere in the world epilepsy is reported to be rampant among children below the age of 16years. However, no study has been conducted to assess knowledge, attitudes and practices about epilepsy among parents of children living with epilepsy. It was against this background that this study was designed to examine knowledge, attitudes and practices among parents of children living with epilepsy in Lusaka urban district.

#### **1.5 Aim of the study**

The main aim of the study was to examine knowledge, attitude and practices about epilepsy among parents of children living with epilepsy (CWE) in order to establish challenges faced by parents in epilepsy care.

#### **1.6 Objectives of the study**

The following were the specific objectives;

- i) To determine parents' knowledge and understanding of epilepsy,
- ii) To examine the attitude of parents towards epilepsy;
- iii) To establish whether cultural beliefs play a role in epilepsy care;
- iv) To establish challenges faced by parents caring for children living with epilepsy.

### **1.7 The research questions**

1. What do parents know and understand of epilepsy?
2. What is the attitude of parents towards epilepsy?
- 3 Do cultural beliefs play a role in epilepsy care?
4. What are the challenges faced by parents caring for children living with epilepsy?

### **1.8 Significance of the study**

The information generated from this study will be beneficial to parents and health care workers providing epilepsy care better understand the support needed for parents of children living with epilepsy. Other than that, this study will provide the basis for policy formulation on gender, epilepsy and care. These should be policies that would ensure that parents of children living with epilepsy have their plight taken care of by relevant authorities. The information from this study will help add to the existing body of knowledge on epilepsy and care in Zambia.

### **1.9 Limitation of the study**

The study had some limitations. One major limitation was the inadequate literature about epilepsy in Zambia. There were no readily available statistics indicating the total number of people that were affected by epilepsy in Zambia. Secondly, some registers from the study sites did not have proper details in terms of gender, sex and age for the clients. This made it difficult to extract certain information from such registers.

### **1.10 Operational definitions**

In this study the following terms will be used in the following context:

**Knowledge:** the understanding of epilepsy with regard to how one defines it, how it is transmitted, whether it is contagious and if it can be treated.

**Attitude:** feelings towards epilepsy and those that are living with the condition.

**Practices:** ways in which knowledge and attitude are demonstrated through actions.

For instance, what do parents do to treat epilepsy? How do they handle seizures?

**Beliefs:** strong feelings and opinion about epilepsy with regard to its transmission, treatment and care for people living with epilepsy.

**Traditions:** beliefs, customs or ways of doing things that are believed to have existed for a long time among a particular group of people in relation to epilepsy care and treatment.

**Chronic sorrow:** continuous grief of a parent regarding his/her child's condition.

**Seizure:** a fit.

**Gender:** the differences between men and women that are socially constructed, changeable overtime and have wide variations within and between cultures.

**Gender mainstreaming:** Incorporating gender equality concerns and issues into all aspects of epilepsy care and treatment.

**Prevalence:** estimated people living with epilepsy in a given place

**Incidence:** annual diagnosis rate or the number of new cases diagnosed each year.



## **2 CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Introduction**

This chapter presents a review of literature on epilepsy; it looks at different studies that have been conducted on epilepsy. It starts with the general overview on epilepsy and narrows it down to the *Zambian* situation.

### **2.2 Historical overview about epilepsy**

Epilepsy is one of the oldest recognized conditions in the history of mankind. David (1982) refers it to way back in 2080 Before Christ (BC) where Hammurabi, the king of Babylon published laws regarding marriages of people living with epilepsy.

Epilepsy associated stigma is as old as epilepsy itself. In both China and India, epilepsy was commonly viewed as a reason for prohibiting or annulling marriages while in the United Kingdom (UK) laws that forbid PWE to marry were only repealed in 1970. Similarly, in the United States of America (USA) until the 1970s it was legal to deny people with epilepsy access to restaurants, theatres, recreational centers and other public places (<http://www.epilepsyfoundation.org>). All this was because epilepsy was believed to be contagious, a mental illness as well as a spell for having done something wrong. According to Culture, Medicare and Psychiatry, the belief that epilepsy was infectious was widely reported in relevant professional literature. However, what is clear is that the belief has not been subjected to scientific investigation and its magnitude has not been assessed despite the fact that it is one of the most obstacles to care and rehabilitation of PWE.

### **2.3 Epilepsy: A general overview**

Epilepsy is a condition characterized by repeated seizures or fits due to a disorder of the brain cells. According to Dekker, (1998), some people can have epilepsy for their whole lives while some just have it for some period and recover from it. However, the average duration of epilepsy is approximately 13years- meaning that longest period one can suffer from epilepsy is supposed to be 13 years. This disorder of the central nervous system is usually characterized by loss of consciousness with or without convulsions.

When it comes to epilepsy, everyone is vulnerable because anyone can develop the condition without any warning regardless of one's social status, ethnicity, physical appearance, race, religious inclination, gender or age. Seizures are unpredictable and quite some unpleasant experiences because they can occur anywhere at any time, sometimes accompanied by some bizarre behaviors such as screaming, passing urine or stool ( Birbeck, 2000). Seizures as noted by WHO, (2007) vary in frequency of once per year to several per day. In other words it means a person can have seizures up to several times in one day while others can experience seizures once a year. The variation in seizure patterns means that care for the victims of epilepsy will equally vary from one family to the other depending on the frequency and the severity of the seizures.

So far statistics about PWE worldwide raises some concern. There are approximately 50million people living with the condition which according to Mbewe et al (2004), is viewed as one of the highly stigmatized condition. The given statistics represent the number of people who have sought treatment while some people have chosen to remain silent for fear of being stigmatized.

## **2.4 Types/ causes of epilepsy in people**

Dekker, (1998) states that there are two categories of epilepsy and these are: idiopathic and symptomatic epilepsy.

The idiopathic type of epilepsy has no known cause and is the most common type. It is not preventable and likely to be found in six out of ten people living with epilepsy. Symptomatic epilepsy according to [http:// www.epilepticoslibres](http://www.epilepticoslibres) is otherwise known as secondary epilepsy because its cause is usually connected to some known event like trauma resulting from accidents, brain tumor or an infection such as meningitis. This type of epilepsy is preventable. (Dekker, 1998)

## **2.5 Epilepsy in developed countries**

*“When it comes to epilepsy most countries are developing countries”*. This was a statement given in conclusion by the authors of the Atlas of epilepsy care published by WHO, ILAE and IBE referring to many difficulties most countries encounter in implementing epilepsy programs (the lancet, 1997).

Epilepsy prevalence in developed countries may not be as high as in developing or third world countries. This could be attributed to the good living styles that do not expose people to developing epilepsy. Medical facilities are well equipped to attend to those that are afflicted by the pandemic. Knowledge about epilepsy is vast therefore; people are able to seek medical care early enough unlike in the third world countries where PWE spend most of their time consulting traditional healers at the expense of consulting medical doctors.

A study conducted by Pond, (1960) showed that prevalence rates were between 3 and 8 per 1000 people and a similar study conducted in England in 1960 revealed some prevalence rates of 6.2 per 1000 people (Dekker, 1998). According to ([http:// www cure](http://www.cure)

*research.Com*) it was reported that in the United States of America more than 2.3 million people were living with epilepsy.

## **2.6 Epilepsy prevalence in developing countries**

Developing countries account for about 90% of epilepsy cases worldwide (Wang, 2003).

While developed countries' annual new cases ranged from 40 to 70 per 100,000 people per general population, in developing countries the figures are twice as high and the people have no access to treatment (Radhakrishnan, 2000). Failure by many PWE to have access to treatment is not deliberate but a contribution by various factors such as stigma and cost of Anti Epileptic Drugs (AEDs), long distances to medical centers and cultural beliefs about the cause and treatment of epilepsy (<http://www.epilepsyfoundation.org>).

According to WHO,(2005) PWE and their families suffer from stigma and discrimination not only from the neighboring communities but from close relatives as well. This trend is not only an issue of developing countries but many parts of the world as well.

In Asia, a study conducted in China by WHO, et al (2005) as part of the global campaign against epilepsy revealed that about 9 million people were battling with epilepsy but only a few were receiving treatment.

In South America, there were more than 5 million PWE and out of this number only 2 million were receiving treatment for it (<http://www.epilepticoslibres.com>). In a study conducted to assess the medical treatment gap, it was revealed that treatment gap in resource poor countries was at 56%. Latin America had 55%, Asia had 64% and Africa stood at 49%. The treatment gaps were caused by a number of factors such as cost of

treatment, non availability of AEDs, beliefs in traditional treatment and superstitions and some cultural beliefs ([www.epilepsy foundation .org](http://www.epilepsyfoundation.org)).

Africa accounts for more than 10 million PWE and the majority of them are found in the sub Saharan region and access to treatment was challenge (WHO, 2006 report). The treatment gap is 80 to 85% resulting from lack of specialized personnel, lack of drugs or high cost of Anti-Epileptic Drugs, cultural interpretation as well as supernatural affiliation.

A study that was conducted by Kamugisha and Feksi (1998) in a semi urban area of Nakuru- Kenya found a prevalence of 18.2% per 1000 population. In another survey in Kibwezi district in which 1,674 children under the age of 15 years were screened, the epilepsy prevalence rate was found to be 10.2% per 1000 children.

## **2.7 Knowledge and attitude about epilepsy**

Knowledge is indeed a powerful tool in shaping one's destiny. A knowledgeable person is able to make some informed decisions that may work to the advantage of that individual. When it comes to epilepsy, it is not an exception. It is important that those that are living with epilepsy and the care givers have a clear understanding about epilepsy if they are to address it adequately. In most instances people's attitude and practices are shaped by what they know and believe in. In the same vain epilepsy treatment is to a larger extent is determined by their knowledge and understanding about the cause and how epilepsy can be treatment.

Due to insufficient sensitization about epilepsy, the majority of PWE suffer discrimination and are highly stigmatized in various spheres of life such as education, employment and even marriage. This comes as a result of some beliefs that epilepsy is a

highly contagious and shameful condition (Rwiza et al, 1993) which no one would like to be associated with.

Studies conducted in Nigeria and Liberia both revealed high levels of discrimination against PWE (Nyame, 1997). A study about knowledge, attitude among students in Tanzania revealed that 46% of the respondents had fair knowledge about epilepsy. Rwiza et al (1993) further revealed that the contagion beliefs were quite high among the students in which 60% of the respondents indicated that the condition was contagious.

Similarly, a study conducted by Mbewe et al, (2006) to assess knowledge, attitude and practices among police officers revealed that only 40% of the respondents indicated that they had heard about epilepsy with 13.9% attributing the cause to witchcraft. Some respondents indicated that the condition was contagious.

A study conducted in Egypt on knowledge and practice with respect to epilepsy among school teachers revealed that although all the teachers had heard about epilepsy, only 23.8% of the respondents would apply first aid to a student with a seizure. It further revealed that positive attitudes were common among females and single teachers (Ghaydaa, 2010). The findings suggest that more educational programs on epilepsy need to be directed towards the causes and treatment of epilepsy in order to change the mind set of many people in our societies.

Birbeck et al (2006) in a study entitled "*Zambian teachers: What do they know about epilepsy and how can we work with them to decrease stigma*" revealed that about 70% of the teachers recognized epilepsy as a brain disorder and the majority of them had witnessed a seizure. Despite the level of knowledge being generally good, supernatural beliefs such as witchcraft and spirit possession were evident even in this educated

population. Only less than half stated that they wouldn't mind their sons or daughters marrying someone with epilepsy ([www.sciencedirect.com](http://www.sciencedirect.com)).

Universally suspicion, socio-cultural and legal stigma surrounding epilepsy is evident as shown in many studies that have been conducted. What came out clearly was that the epilepsy has been associated with some evil spirits or seen as punishment. In some countries in Africa PWE were not allowed to eat food from the same plate with others for fear of transmitting the disease. Developed countries have had its share of epilepsy-associated stigma. Until 1956, there were various laws that allowed discrimination against PWE. For instance, in the USA nearly 20 states prohibited PWE from marrying and provided for their sterilization (the lancet, 1997).

In Hong-Kong, people wrongly believed epilepsy was a mental illness and not a neurological disorder. In some quarters of society, epilepsy was referred to as a “crazy disease” implying that those that lived with epilepsy were not “normal” people. The negative perception about epilepsy has contributed to PWE be shunned and ostracized not only by their teachers but also members of the public. For them, isolation has become more painful than epilepsy itself.

However, despite the general perception about epilepsy being contagious there hasn't been any scientific research to determine whether epilepsy was contagious. From the social point of view epilepsy is believed to be highly contagious hence the discrimination of those that live with the condition (Nyame, 1997).

## **2.8 Epilepsy management**

Epilepsy management through Anti-Epileptic Drugs (AEDs) calls for patience and commitment on the part of the patient and the care-giver. This is because the drugs have

to be taken for many years possibly a life-time (Dekker, 1998). Adherence plays a pivotal role in the way epilepsy is managed because failure to do this can result into serious consequences which will be too difficult to contemplate.

However, due to ignorance on the availability of AEDs and strong supernatural cultural beliefs regarding epilepsy many patients fail to seek medical help from health care for fear of being stigmatized and discriminated against. This attitude has continued to impact negatively on the lives of PWE and their families. Fear and misunderstanding have forced many people to shun seeking medical health care from health centers but instead consult traditional healers for treatment.

A study on traditional healers indicated that the majority of PWE prefer consulting traditional healers for treatment to medical doctors. Birbeck, et al (2005) in their study on the same subject discovered that 70% of the PWE had sought treatment from traditional healers. This confirmed assertions by WHO report of 2000 that estimated that more than 70% of PWE in third world countries seek epilepsy treatment from traditional healers (TH). The reasons for seeking care from traditional healers vary from socio-economic to cultural. Apart from the services offered by TH not only perceived fair in terms of charges, they are also conducted in some conducive environment where privacy is guaranteed. Other than, that traditional medicine is perceived to work well for the treatment of epilepsy as compared to the conventional methods of treatment.

Though the situation in China may appear promising, there is a growing trend among patients to integrate Chinese traditional medicine with the modern one. A study in Henan province of China, revealed that 55% of the respondents indicated that they would visit a medical doctor the moment they are diagnosed with the disease (Kale, 2002). However, it



was observed that the same people would eventually end up incorporating the Chinese traditional medicine into the modern one.

In Nigeria for instance, patients are resuscitated by forcing them to drink a mixture of cow urine (which can lead to further complications). Dekker, (1998) advises against this trend of combining herbal treatment with the modern medicine saying it is dangerous as the interaction between the herbs and the drugs cannot be predicted.

Seizures are a common trend among PWE and sometimes victims have no clue about the onset. This creates anxiety not only to the patient but the close relatives as well. For those that have witnessed seizures would admit that indeed they are a worrisome experience. Parents of CWE develop fear for their children. They fear for their children to sustain injuries resulting from falling and burns. A study by Chomba et al (2005) highlighted one strong belief by many Zambians that once a PWE sustains burns, they become untreatable. Because of this myth, a life of PWE is subjected to restrictions such as movements in order to prevent accidents.

Gunzburg (1973) likens a PWE to a tourist and coined a phrase “a stranger in his own country” describing some difficulties experienced by PWE in a modern society. He further explains that the only difference between the two is that the tourist’s stay is temporal while epilepsy is in some cases a lifelong condition. However, David (1982) states that it is imperative that stringent measures were put in place so that lives of PWE was not at stake. Some activities such as bathing, swimming and climbing should be supervised.

Views on how seizures are managed have in some cases taken different dimensions. The most common practice among parents is where a spoon is placed between the teeth to

prevent the patient from biting the tongue at the time they experience a seizure. David, (1982) however, discourages people against this practice citing dangers of one swallowing their tooth in an event where there is a breakage. The best thing to do was to ensure that the environment was free from hazardous situations.

## **2.9 Formal education for children living with epilepsy**

Despite education being a right for everyone, the majorities of CWE have significantly failed to access formal education as compared to their counterparts with other chronic conditions. Previous research in rural Zambia has shown that adults with epilepsy have less education as compared to their age counterparts with other conditions (Birbeck, 2006). Sometimes parents are worried about taking their children to regular government schools for fear of disrupting lessons in case they developed a seizure in class. This is due to some aggressive behavior sometimes exhibited by CWE. Teachers, on the other hand teachers have failed to tolerate CWE despite their significant levels of knowledge about the condition. The situation is worsened if a child experienced a seizure in class. School authorities have in some cases ejected these children from school for fear of disturbing lessons. The impact is not only on the child but the entire family as such children will have to perpetually depend on other people for their survival for the rest of their lives as Toose, (1991) observed;

*“a dependant child will be a dependant adult and as such will*

*be unable to achieve his/her true potential and such, as an adult is likely either to have, ‘a chip on his shoulder’ or ‘to retreat into his/her shell’.*

On the other hand society has not recognized CWE as a vital human resource useful to national development. Care-givers find it a challenge to take their children living with epilepsy to school because for such children education is not viewed as an investment that pays off. For that reason, Chibowa, (2000) states that only a fraction of PWE has access to formal school and basic education. In other words, such children will grow into perpetual dependants on their immediate family members.

One thing for sure is that at school, youths' relationships with teachers and peers are influential in shaping their sense of belonging, wellbeing and success (Cameron, 2006). In particular, research points to the significant impact of teacher behavior, and teacher-student relationships on youths' academic success and psychosocial adjustment. A child who has warm relationship with her/his teacher is less likely to suffer from peer rejection. Unfortunately, people diagnosed with epilepsy are likely to experience weaker social support relative to their peer (Geller et al 2005, Lambert, 1988, Meadow et al, 2006)

Probably, all hope is not lost as the Ministry of Education has shown commitment to the education of children with special needs (the category of which some CWE fall). The policy states that children with special needs shall be mainstreamed to the largest extent possible. In this regard, those with severe difficulties shall be provided for in the special schools and units. The policy further states that in order to achieve this, learners with special needs should be detected at an early age with the help of national assessment instrument designed for this purpose. However, with the perceived negative attitude of teachers and stigma associated with epilepsy some parents don't see the need to enroll their children in schools for fear of being harassed in an event of them experiencing a seizure. *Something tangible should be done to alleviate the suffering of not only of CWE*

but also their parents. When this is done, many parents to CWE will be comfortable to enroll their children in schools.

### **2.10 Gender and child care**

Not until some women movements started fighting for the rights of women in the 1800s so that they could be allowed participation in politics and employment, the role of women was merely that of a domestic worker. That was the traditional view which was held against women that they were homemakers and belonged to the domestic service industry of child rearing and supporting their husbands. This was what society viewed a woman to be while on the other hand her male counterpart went for work in the industries and brought food on the table.

However, due to changing times, society's views about gender roles were slowly changing. Today both men and women were able to take up responsibilities that were long before dominated by one gender. One such a role was child care. Men no longer find it strange to actively take up domestic roles that include child care as the case was some centuries ago. Nevertheless, a study conducted in the on the subject in the United States revealed that some factors will motivate fathers to take an active role in care giving activities and they include;

- If a father worked few hours than other fathers,
- If they were psychologically well adjusted,
- Mothers worked more hours than other mothers,
- When mothers reported greater marital intimacy, and
- When mothers reported greater marital intimacy ([www.nature.com](http://www.nature.com)).

In another study by the National Institute of Child Health and Human Development (NICHD) it was found that fathers who had less traditional child-rearing beliefs were more engaged in child-rearing activities. The study further indicated that fathers started engaged in care-giving activities when the child was between 15 and 24 months old and mostly with sons (<http://www.nature.com>)

The involvement of men in child care helps relieve some of the pressures that some women go through. Apart from child bearing and caring Boserup (1970) points out that, women play major roles in the food production industry. She goes further to state that about 70% of the food is produced by women. It is necessary therefore for the men folk to take a lead in ensuring that they take an active role in child care so that the load is made lighter for the women. According to Hoffman, (1983) the involvement of fathers in child care helps to diffuse the pressure of work women go through. This was against the background that mothers find themselves with other responsibilities. Apart from relieving women from pressure of work, paternal participation allows fathers to become closer to their children, observe and participate in their development more closely. However, research has shown that there factors that may affect fathers' participation in child care and one such factor is experience. The early un involvement by fathers allow mothers to develop their skills while fathers remain unskilled and when men realize this they tend to sit back and leave everything to the woman (Russell,1982).

Charlie and Margaret (1987) alludes to the point that failure by the fathers to involve themselves in the caring of their children may result in family conflicts and that such fathers were perceived to be more punitive by their children.

## **2.11 Maternal depression**

Maternal depression can have consequences not only on the mother but the child as well. According to Feldman, (2007) and Feng et al, (2008) depressed mothers lack adequate skills to provide emotional regulation and training for their infants; and this includes infant development of active regulatory abilities. Failure by mothers to train their children on how to regulate their emotion can result into children turning to self-directed regulatory behaviors (Tronick and Gianino, 1986). Mangelsdorf et al (1995) further asserts that children whose mothers are depressed are likely to exhibit some negative behaviors such as fussing, crying, and arching back. Depending on the severity of epilepsy and the frequency of seizures the child's health can deteriorate if the mother goes into depression because all aspects of care is likely to be compromised. Nevertheless, it must be appreciated that not every care-giver is likely to suffer from depression as the experience for epilepsy care may vary from one person to another.

The impact of epilepsy on the victims varies from one person to another. The spectrum of disability it creates is broad ranging from a very limited effect on the individual to a devastating impact on all aspects of life. According to Epilepsy Foundation of America (EFA) of 2009, for the majority of CWE, seizures can be substantially minimized or completely stopped enabling the patient to live a normal life or close to normal life. For some people epilepsy can be disabling if seizures are frequent, and can bring about other impairments such as memory and other cognitive effects leading to a highly compromised standard of life (<http://www.epilepsy>).

Children whose seizures are not controlled may suffer from social, emotional and academic problems that may in turn compromise various stages of development. These problems in most cases extend into adult life where the same issues become chronic

barriers to employment and independence (David, 1952). To this effect EFA, (2009) gives three areas of severity and these are uncomplicated, compromised and devastated.

### **2.12 Different categories of epilepsy**

**The uncomplicated---**According to ([www.epilepsy foundation.org](http://www.epilepsyfoundation.org)) CWE who fall under this category are likely, to have gained control of seizures. They rarely experience or have infrequent seizures, experience limited if any side effects from medication, are cognitively intact and have no additional physical or mental impairments. CWE categorized as uncomplicated may not suffer from societal stigma, may be academically active and have no problem accessing employment.

**The compromised---**The compromised category are for those children whose seizures are controlled and do not have serious mental or motor problems. However, they are likely to experience side effects from medication due to higher dosage they take to maintain control. This category experiences greater levels of social, emotional and educational/employment problems.

**The devastated---**This is a category for epilepsy resulting from brain disease or injury. It impairs learning, memory attention and motor and emotional function. Seizures probably started early in life and may never be controlled despite the use of multiple medications. This category is likely to be heavily medicated, may experience some retardation or slowing down, have difficulty in maintaining family support and social relationships, require help in everyday life and are susceptible to bouts of continuous seizures.

The above stages have the potential to affect the parents either positively or negatively depending on the severity of the child's problem. According to *epilepsy foundation.org*, depression is likely to occur to a parent whose child's condition is so severe that coping

becomes a problem. The impact of epilepsy on one's child can have some effects on the parent especially one closest to the child. It could lead to stress, depression, mood changes or frustration.

Some children may not only suffer from epilepsy but other ailments as well. In this case the burden of having to look after such a child is doubled. The parents don't only need to worry about epilepsy but other disabilities the child may suffer from. The reaction to these complications will differ from family to family. For others, chronic sorrow becomes the order of the day while others resort to excessive drinking as a way of reliving their sorrow.

### **2.13 Challenges faced by parents in epilepsy care**

Despite advances in the understanding about epilepsy and treatment in the past years, PWE have continued to be stigmatized. Negative attitudes towards PWE have had significant impact on both the victim and the parent(s) psychological well-being and their quality of life. According to Epilepsy and behavior, (2002) parents may be under considerable strain especially if the child's seizures are frequent and accompanied by injuries. When the situation is not well handled parents or relatives to PWE are likely to be depressed as a result of constant sobbing.

Some studies have revealed that in some homes, social conflicts have taken center stage due to accusations and counter accusations of witchcraft pertaining to the cause of epilepsy in the child. In a study by Chomba et al, (2005) it was revealed that some parents especially women have foregone their jobs in order to nurse their sick children. This has resulted in levels of poverty going up in such homes, especially if the care-giver happens to be the only breadwinner in the family.



### **3 CHAPTER THREE: METHODOLOGY**

#### **3.1 Introduction**

This chapter presents the research design and it discusses the sources of data and instruments used in the data collection.

#### **3.2 Research Design**

This study used both qualitative and quantitative methods of data collection and analysis. The idea of combining these methods dates back to 1959 when they were used to study validity of psychological traits. This way ensures that the researcher minimizes on the biases and limitations that would have been experienced through the use of one method (Creswell, 2003). Since the study was designed to assess knowledge, attitude and practices about epilepsy among parents of children living with epilepsy (CWE), the mixed methods approach was appropriate to capture both qualitative and quantitative data. Quantitative brings out information in terms of numbers for both men and women involved in the study while qualitative data brings out views, feelings, opinions and experiences about the subject (Orodho and Kombo, 2002).

#### **3.3 Study Site**

The study was conducted at four different sites namely, the University Teaching Hospital (pediatrics' clinic 2), Chainama Hills Hospital, and Kanyama and Kamwala clinics. These sites are located in the district of Lusaka urban-Lusaka province which is a highly urbanized place. It comprises of people from all the seven major ethnic groups (lozi, Tonga, Bemba, Nyanja, Kaonde, Luvale and Lunda) found in Zambia. English is the official language. Apart from the indigenous Zambian tribes, Lusaka is home to other nationals as well. Kanyama health centre is situated in Kanyama compound which is

about five kilometers from the city centre. It is one of the densely populated compound in Lusaka. Kamwala clinic is found in Kamwala trading area just about a kilometer from the city center. It caters for patients around Kamwala and the surrounding compounds such as Misisi, Kuku and John Laing compounds and other areas. These two facilities were picked due to their involvement in epilepsy care provisions. Chainama Hills Hospital situated east of Lusaka city receives patients from all over Zambia. It has no specific catchment area. The University Teaching Hospital is Zambia's biggest hospital. In most cases it handles cases referred from various hospitals and clinics.

The study population comprised parents of children living with epilepsy in Lusaka urban district. The study sample was 110 parents. The study registered a low number of men probably due to the nature of the condition coupled with age of children involved. Another contributing factor could be cultural beliefs that alienate men from getting involved in child care because it is perceived to be a woman's role (Charlie and Margaret, 1987).

### **3.4 Sampling Techniques**

The study units were sampled using convenient sampling techniques due to their involvement in epilepsy care. These were parents of CWE, aged 8 years and below who at the time of the study had their children receiving treatment were included in the study sample. The technique proved perfect for the study because the researcher had direct contact with the parents as they brought their children for treatment. The justification for targeting only children aged 8 years and below was to try and assess the involvement of men as the age group required parents care in all spheres of life.

### **3.5 Research instruments**

According to Kombo and Tromp, (2006) these are instruments used to collect information. In this study questionnaires and an interview guides were **used** to collect data from the respondents.

Questionnaires were administered to women and interviews guide was administered to the men. This was in order to get in-depth and rich information about epilepsy care. In depth interviews were appropriate for men as they provided an opportunity for increased interaction with the respondents and probe for more information. They also reduced on the low turn over of unanswered questions because the respondents came face to face with the researcher. At the end of the day the relevant information needed for the study was obtained. These were the reasons an interview guide was opted for men.

**Questionnaires:** A questionnaire is a quantitative data collection method. The questionnaire used in this study comprised open and close-ended statements which respondents reacted to. The open and close-ended questions were used to gather data from the parents. The justification for using questionnaires is that it was easier for the respondents to answer questions because respondents had only to choose an appropriate response from a set of options. It also reduced on the possibility of respondents wandering about since they were guided by the possible responses. The set of options offered an opportunity for the respondents to provide their responses in more detailed manner. The combination of both open and close-ended questions enabled the respondents to provide rich data that was required for the study.

### **3.6 Pre-test**

A pilot study was conducted prior to the actual data collection. It was conducted in the period of two weeks, on the actual target group using the actual tools. This was in order to check for the accuracy and validity of the questions and the relevance to the study. After the assessment relevant adjustments were done.

### **3.7 Data Analysis**

This is a process of examining data that has been collected in the field and making deductions and inferences. It uncovers underlying structures, extracting important variables, detecting any anomalies and testing any underlying assumptions. It calls for scrutiny of acquired data and making conclusions about the subject (Kombo and Tromp, 2006).

Data was entered using the epi-info statistical software and Microsoft excel. Qualitative data was analyzed using emerging themes while quantitative data was analyzed using tables of frequencies and percentages as well as graphs. In some cases cross tabulations were run to determine the relationships between some key variables.

### **3.8 Problems encountered during data collection**

The major problem encountered was the refusal by some parents to participate in the study. Those that declined were skeptical about the motive behind the study.

### **3.9 Ethical consideration**

Permission to conduct research from the study sites was obtained from the centers through their individual sites administration after obtaining an introductory letter from the University of Zambia (UNZA). The research ethics committee of School of Humanities granted permission for the study to be conducted.

While in the field, ethical issues of confidentiality, anonymity and privacy were upheld. Both informed and written consent was obtained from the participants. None of the participants was coerced to take part in the study. Those who could not continue with the interview were allowed to withdraw without any penalty.

4 CHAPTER FOUR: FINDINGS OF THE STUDY

4.1 Introduction

In this chapter, findings from the study have been presented in line with the research objectives. Data has been analyzed using tables of frequencies and percentages, and other graphics using computer aided presentations and summaries.

The findings are in accordance with what the researcher obtained from the respondents through the use of a semi-structured questionnaire and an interview guide. The instruments were aimed at obtaining detailed and relevant information needed for the study. The findings have been arranged according to themes.

4.2 Presentation of background information

This section presents some information about the respondents.

Table 4.1: distribution of respondents according to gender

Gender	Frequency (n=110)	Percentage
Male	10	9.1%
Female	100	90.9%
Total	110	100.0%

The information from the table above shows that 9.1% of the respondents were male parents and 90.9% were female. There were more women who participated in this study than men.

**Table 4.2** Age of the respondents

Age-range	Frequency (f)	Midpoint (x)	Frequency by midpoint (fx)	Estimated Mean Age (years)
20-25	17	22.5	382.5	
26-30	22	28.0	616	
31-35	32	33.0	1056	
36-40	24	38.0	912	
41-45	10	43.0	430	
46-50	5	48.0	240	
Total	110		3636.5	33.06

The above table shows the various age groups of the respondents with the average age around 33years.

**4.2.1 Marital status of the respondents**

Findings from the data revealed that 80.9% of the respondents were married at the time of the study. In this category all (10) the men were married and for the women, 79 out of 100 were married. Of the 100 women in the study 10 were never married, 8 widowed, 2 were on separation with their spouses with 1 divorcee.

When probed on the causes of separation, the two women cited marital conflicts resulting from the child’s condition as the major reason for the separation.

**4.2.2 Educational attainment among parents**

The findings show that all the respondents had attained some level of formal education categorized as follows; 47.3% had reached senior secondary, 27.3% had junior secondary education, 23.6% had reached upper primary while 1.8% had lower education as their highest level of education.

#### **4.2.3 Occupation of the respondents at the time of the study according to sex**

The study revealed that the majority of the female respondents were unemployed. All the male respondents were either in formal or informal employment. Of the 100 women 65 were not in any form of employment compared to 21 who were in formal employment and 14 were in informal employment.

### **4.3 Sources of energy**

When asked to state their sources of cooking, the following were the responses

The majority (78%) of the respondents were using electricity as their source of cooking while 20% and 2% were using charcoal and firewood respectively.

### **4.4 Sources of water**

When asked to state their sources of water, the majority (94%) of the respondents reported that they were using communal taps, 4% used pumps and 2% were using open wells as their source of water.

### **4.5 Type of toilet used by the respondents**

On what type of toilets the respondents used, 52% reported that they were using pit latrines while 48% were using flush toilets.

### **4.6 Characteristics of the children**

This section presents the findings about various characteristics of the children.

#### **4.6.1 Gender of the children**

The gender of the children whose parents were involved in this study was 40.9% female and 59.1% male. The findings have revealed that there were more boys than girls under the age of 8 years who were found to be living with epilepsy.



#### **4.6.2 Speech of the child**

The findings of the study have shown that 72.7% of the respondents were able to speak clearly and 27.3% of the children could not speak clearly. Apart from living with epilepsy, some children had speech deficit which made it difficult for them to communicate clearly.

#### **4.6.3 Ability to walk**

The study has revealed that 95.5% of the children had no mobility problems while 4.5% had stiff legs an indication that they were not able to walk.

#### **4.6.4 Whether the child was equal to age counterparts (normal)**

According to the responses 69.1% of the respondents reported that their children were equal to their age counterparts while 30.9% said they were not. This shows that a good number of children living with epilepsy were mentally challenged.

### **4.7 Knowledge about epilepsy among parents**

When the respondents were asked to state what they knew and understood about epilepsy 57.3% reported that epilepsy was a condition that was as a result of some brain complications. 25.4% reported that they were not sure about what epilepsy was. The other respondents reported that epilepsy was some form of madness, demon or spiritual possession and/or some mental retardation. When probed further to state their sources of information about epilepsy the majority of respondents pointed out health workers and relatives as their main sources of information.

#### **4.8 Parents' perceived cause/s of epilepsy in the child**

From the study findings, 10.9% of the respondents reported that their children developed epilepsy due to some brain injury. Some of the parents reported that because they gave birth to their children in homes where there were no qualified birth attendants and according to them this could have contributed to the condition of their children. 29.9% reported that they did not know why their children developed epilepsy. 11.8% of the respondents reported that their children's condition was caused by witchcraft. A further 35.5% of the respondents attributed the cause of epilepsy in their children to various factors. They could not single out one specific cause of epilepsy in their children.

#### **4.9 Attitude towards epilepsy treatment**

In responding to the question of whether epilepsy was treatable, 78.2% of the respondents indicated that epilepsy could be treated. About 10% of the respondents indicated that the condition was not treatable. A further 11.8% were not sure whether or not epilepsy could be treated. When probed further to state why they were bothered to bring their children for treatment if they felt that epilepsy could not be treated, the following reasons were given;

- *Failure to find help elsewhere.*
- *Encouragement from friends and medical people.*
- *Hoping for some positive response.*
- *The information from some television programs.*

#### **4.10 Effectiveness of Anti-Epileptic Drugs (AEDs) in the treatment of epilepsy**

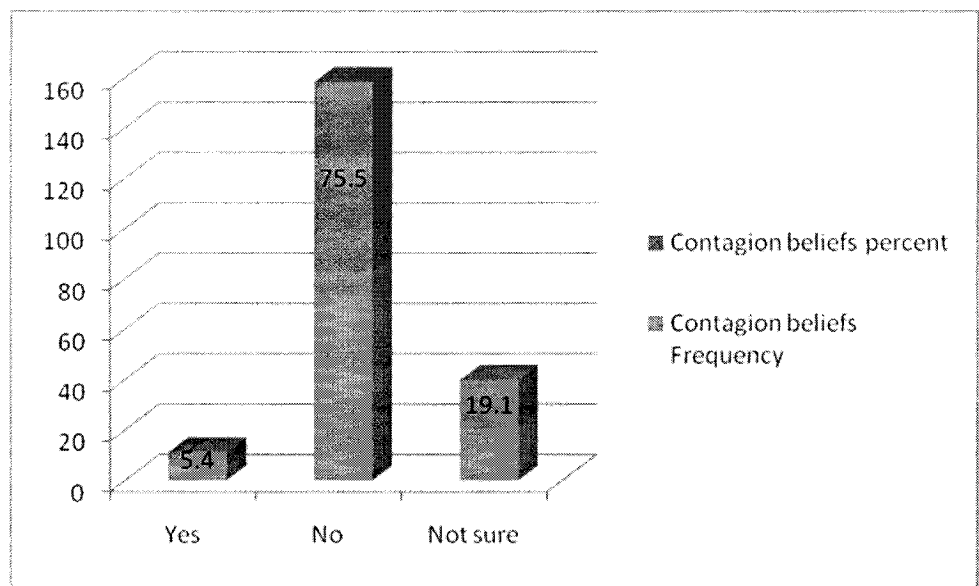
The findings from this study revealed that 62.7% of the respondents reported that the AEDs were slightly effective. 35.5% reported that the AEDs were extremely effective and 1.8% reported that the drugs were not at all effective.

In order to establish why the majority parents felt the AEDs were not helping out, they stated that failure by their children to improve or be cured made them to believe that the drugs were not effective. For some it was all about the slow pace at which their children were responding to treatment that made them indicate that the drugs were slightly effective.

#### **4.11 Contagion beliefs among parents**

Despite lack of scientific evidence about whether epilepsy was contagious, some people strongly believe that the condition was contagious as indicated by some studies ([http://www.Culture\\_medicure.com](http://www.Culture_medicure.com)). From the social point of view, a question was raised to find out parents responses on the subject. The figure below has the details.

**Figure 4-1 The graph below show responses on epilepsy contagion belief**



The above graph shows the responses from the respondents where the majority (75.5%) reported that epilepsy was **not** contagious and 19.1% were not sure while 5.4% indicated that epilepsy was contagious. This shows that the majority of parents did not believe that epilepsy was contagious.

**4.12 Use of traditional medicine for the treatment of epilepsy**

The study revealed that 74.5% of the respondents reported having used traditional medicine to treat epilepsy. 25.5% stated that they had used traditional medicine in the treatment of epilepsy. This shows a widespread use of traditional medicine in the treatment of epilepsy. In order to establish why so many parents admitted having used traditional medicine to treat epilepsy below were some of the reasons that they gave;

*“When one is convinced that the child has been bewitched, one has no option but to consult traditional healers for help and after consulting a number of THs and the herbs fail on the patients that’s when one would end up here(hospital)”, said Mrs. X*

*“Sometimes one is compelled to use traditional medicine when the patient fails to improve despite having taken medicine for a long time. One is left to wonder and begin to look elsewhere for help. Due to such situations people are left with no options but to use traditional medicines”, said Mr. B.*

*“I did not want to give my child the AEDs because I was told that they worsen the situation once a patient is commenced on them, therefore I had to seek help from the THs but unfortunately my child couldn’t be treated and that’s how I ended up here”, said one of the respondents.*

**4.13 Availability of drugs**

The study findings revealed that 91.8% of the respondents reported that drugs prescribed for their children were available at the health centers while 8.2% reported lack of prescribed drugs at the health centers.

**4.14 Epilepsy and stigma**

Since epilepsy is said to be one of the most stigmatized condition, it was important that parents were asked to indicate how they were treated by family members. The table below has the details.

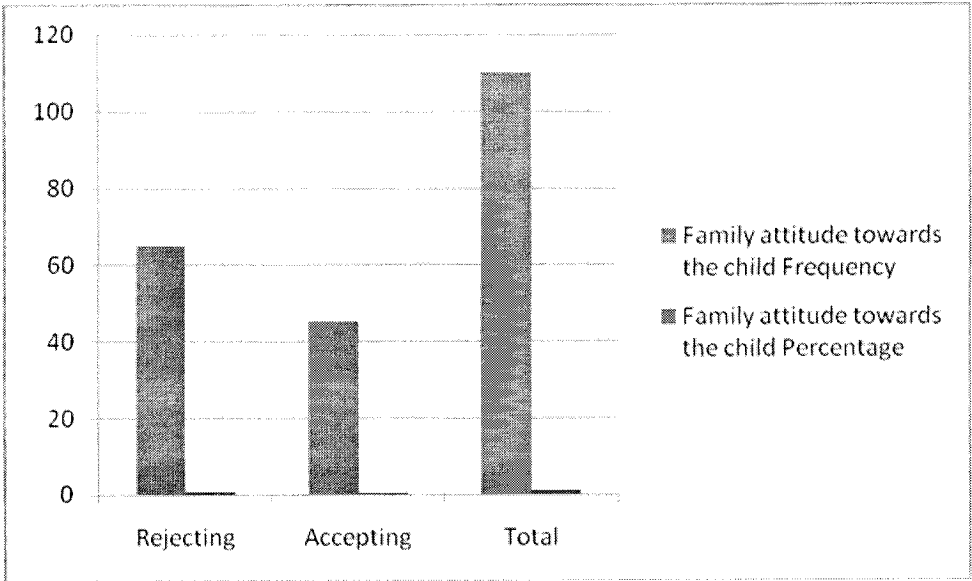
**Table 4.3 This table shows the response on epilepsy and stigma**

Response	frequency	percentage
Rejecting	10	9.1%
Accepting	100	90.9%
Total	110	100%

Findings from the study revealed that the majority of parents felt that they were not stigmatized for having children living with epilepsy. Data from the table above indicate

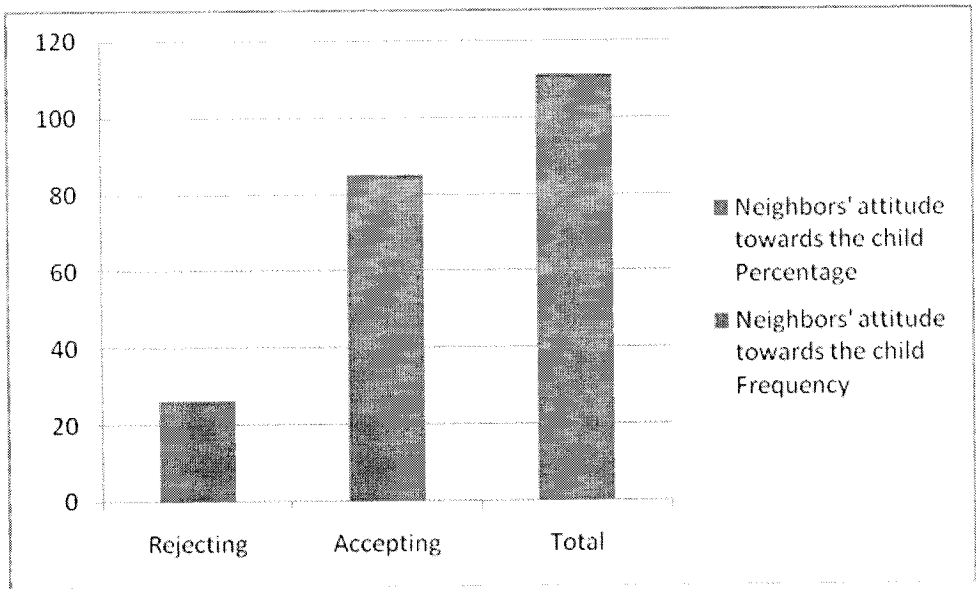
that 90.9% of the respondents stated that they were not stigmatized while 9.1% felt they were stigmatized for having a child living with epilepsy.

**Figure 4-2 The graph below shows perceived stigma towards the child from within the family**



The findings revealed that 59.1% of the respondents indicated that their children were rejected by the family members while 41.9% stated that their children were accepted by family members. This shows that children living with epilepsy were more likely to be rejected by family members.

**Figure 4-3** The graph shows perceived stigma by neighbors towards the child

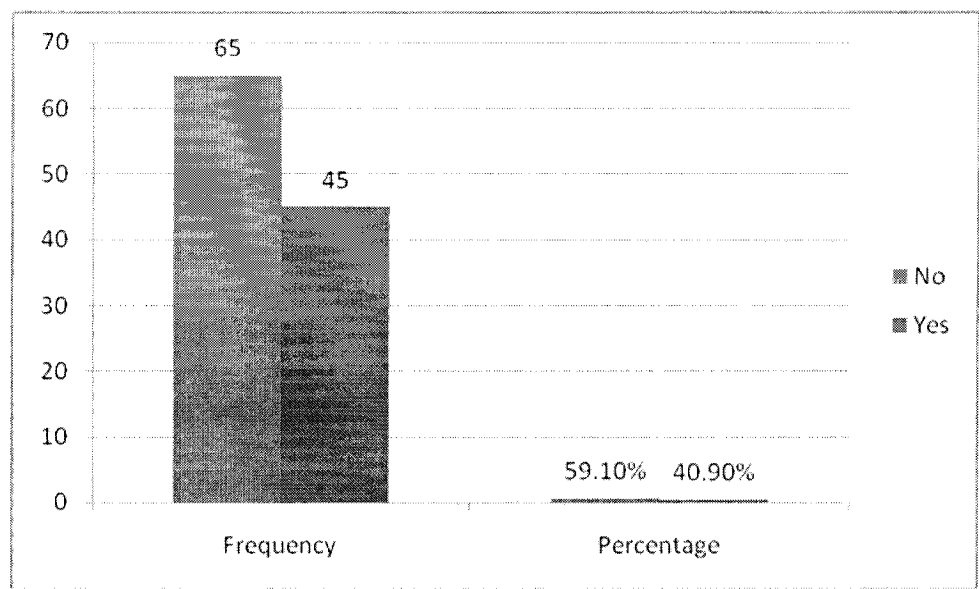


The information from the above graph shows that 23.6% of the respondents stated that there were some rejection from the neighbors towards the children while 76.4% of the respondents indicated that their children were accepted by the neighbors:

**4.15 Formal education for children living with epilepsy**

Following a number of assertions that most people living with epilepsy had low access to education as compared to their colleagues with different chronic illnesses, it was important that such assertions were ascertained. See fig 4 for details.

**Figure 4-4** The figure below shows responses towards education for children living with epilepsy



The above graph indicates that 59.1% of the children were not in school while 40.9% of the children were in school. This means that the majority of children living with epilepsy were not in school.

**4.16 Reasons for not enrolling their children in school**

- Severity of the condition could not allow some parents to enroll their children in school. The majority of these parents had children who were crippled, hyperactive, and poor sighted, deaf and dumb and those who appeared to be mentally challenged.
- Some parents indicated willingness to have their children enrolled into schools but due to lack of resources they could not afford to take their children to school going by the demands that were made by schools.



- Some parents cited distance to special schools as reasons for not taking their children to school. They equally bemoaned lack of schools for children with special needs in their areas.
- For others, they felt that teachers would not treat their children fairly therefore, prefer to keep them at home where their movements could easily be monitored.

#### **4.17 Seizure management**

The findings of the study revealed that the respondents had various ways of managing seizures or fits. 46.4% of the respondents reported that they managed seizures by laying the victim on the side. 9.1% were inserting objects in between the teeth. 29.1% had no specific way of managing seizures. 8% reported having used the dual method of inserting an object and laying the patient by the side. 7% held their children in their arms until they stabilized.

#### **4.18 Roles played by parents and other relatives in epilepsy care**

The findings from the study revealed that mothers played a major role as compared to fathers and other relatives. In this study 81.8% of the respondents indicated that mothers more involved in physically caring for the children. 18.2% of the respondents stated that other relatives such as aunties, grandmothers, cousins and maids assisted in caring for the children. It was further reported by 72.7% of the respondents that fathers were major providers of financial support for the child while 27.3% of the respondents cited mothers and other relatives as major providers of financial support for the children.

#### **4.19 Decision making about the child**

The study findings show that 40.9% of the respondents reported that men were major decision makers about the affairs of not only the child but the entire family. About the

child men were reported being responsible about where the family should seek treatment for the child. On the other hand 33.6% of the respondents indicated that they consulted each other every time a decision had to be made about the child. A further 25.5% reported that women were the major decision makers about the welfare of the child. In most cases these were women who were not living with the father to the child.

#### **4.20 Income generating activities**

Findings from this study revealed that 76.4% of the respondents reported that they had withdrawn or were laid off from their formal employment or income generating activities. None of the male respondents were represented in this subject. In terms of gender, the majority of women reported to be negatively affected both socially and economically due care giving.

#### **4.21 Sleeping pattern among parents**

This question sought to find out whether parents were able to sleep normal hours or they were sleeping shorter hours than usual.

The findings revealed that 77.3% of the respondents reported to have been sleeping shorter hours. A further 22.7% reported to have normal sleeping pattern. In this category 2 out of 10 men reported to have experienced shorter sleeping time while 8 out of 10 did not.

When probed further on why the majority of parents experienced poor sleeping patterns, the following reasons were given;

- Monitoring the child during sleep to ensure their safety.
- Worries about the future of the child.
- Negative comments from family members.

- Worries about failure the child to respond to treatment.

#### **4.22 Chronic sorrow**

Chronic sorrow refers to the continuous grief parents go through as a result of caring for CWE. As such a question was asked to state whether parents were continuously worried about their children.

The findings revealed that 84.5% of the respondents were constantly worried about the condition of their children. 15.5% of the respondents reported not to be worried about their children's condition. When the men were asked to state how they felt about their children's condition 4 out of 10 said it was worrisome while 6 out of 10 stated that they were not worried.

At the end of the questionnaire and interviews parents were asked to make a comment about epilepsy and their children. The views in the box below are what they had to say on the subject.

**Table 4.4** Views from the respondents about epilepsy and their children

Women	Men
<ul style="list-style-type: none"> <li>• <i>Sensitization programs should be put in place, so that more people were aware of epilepsy.</i></li> <li>• <i>Mothers should not be discouraged by negative comments directed to them and their children but instead develop a positive attitude towards epilepsy. Lack of special schools in some areas is hindering most of the children from assessing education.</i></li> <li>• <i>Society should realize that children with epilepsy need to be loved not ridiculed because it wasn't their desire to develop epilepsy.</i></li> <li>• <i>All types of Anti-Epileptic Drugs (AEDs) should be made available in all health centers.</i></li> <li>• <i>There is need for parents to CWE who are currently on treatment to be educated on how to care for their children.</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>Men need to realize that caring for children especially those that are affected by epilepsy should not be left to women alone.</i></li> <li>• <i>Men who shun their children on the basis of epilepsy should realize that epilepsy can affect anyone. CWE need love not rejection.</i></li> <li>• <i>More medical personnel should be trained in epilepsy related field so that healthcare can be accessed anywhere around the country.</i></li> </ul>

In order to determine whether the loss of income was influenced by the severity of seizures, a cross tabulation was done between the two variables. See table below for details.

**Table 4.5** The table below shows Seizure description\*loss of income

	Have you lost your earning due to care giving?			Total
		Yes	No	
How would you describe your child's epilepsy?	Severe	7	1	8
	Moderate	66	5	63
	Mild	18	13	29
<b>Total</b>		<b>91</b>	<b>19</b>	<b>110</b>

The findings revealed that the majority of parents (7 out of 8) whose children’s seizures were described as severe had lost their earning as compared to 1 out of 8 who reported that they did not lose their income despite their children’s seizures having been described as severe. This shows that parents whose children’s seizures were severe were likely to lose their income.

**Table 4.6 The table below shows the responses on whether level of education had some influence on the perception towards the effectiveness of AEDs in the treatment of epilepsy.**

What is your highest educational level?				Anti-Epileptic Drugs for the treatment of epilepsy			
				Extremely effective	Slightly effective	Not at all effective	Total
Lower primary				7	15	3	26
Upper primary				5	30	2	39
Junior secondary				8	8	1	14
Senior secondary				19	11	1	31
Total				39	64	7	110

The table above shows that 39 out of 110 parents who stated that the drugs were extremely effective, the majority had reached senior secondary school while 3 out of 7 parents who stated that the drugs were not at all effective had lower primary as their highest level of education.

## **5 CHAPTER FIVE: DISCUSSIONS OF FINDINGS**

### **5.1 Introduction**

This chapter presents discussions of findings that have been presented in chapter 4. The discussions are according to what the study revealed as guided by the research questions and objectives.

### **5.2 Gender of the respondents**

In this study very few men were captured not by the desire of the researcher but probably due to negative attitude of men towards child care. From time in memorial child care has always been seen as a woman's responsibility. The findings from this study justify what one of the early feminist talked about gender and child- care where a woman was expected to be a home keeper while her male counterpart goes to work in the industries (Mills, 1869). This goes to show that men have continued to lag behind when it comes to child care.

A probe on the low participation of male parents in epilepsy care revealed a number of factors. Some of these factors included sex of the child, age of the child and the severity of the condition. It was established that men were more comfortable with their older sons and whose epilepsy was not severe. This meant that men were only limited to a particular group of CWE unlike women who had no choice but to take on every child regardless of age, sex of the child and the severity of the condition. This was in agreement with Charlie and Margret (1987) who observed that men were more likely to take their male children when it comes to seeking health care. There was need for men to realize the importance of their involvement in child care especially if the family has a child living with epilepsy. Care giving should not be left to women alone as the demands that go with epilepsy care are huge. Therefore, men need to come aboard and support their families

not only financially but also provide physical care in terms of house chores and taking the children for medical attention regardless of age, sex and condition of the child in order to lighten the burden of care women go through.

### **5.3 Age of the respondents**

The average age of the respondents was 33 years while the majority of the respondents were aged between 31 and 35 years suggesting a youthful age group. This could imply that the young parents were free to seek medical care for their children despite the stigma associated with epilepsy. Apart from that, the other factor for this could be attributed to the level of education. The information revealed in this study was that most of these parents had grade 12 school certificates meaning that they were an enlightened age group therefore, view epilepsy issues from an informed point of view. The assumptions could be supported by the majority of parents who indicated that epilepsy was far from being contagious as perceived by some sections of society. According to [www.nature.com](http://www.nature.com) epilepsy was viewed as a contagious condition not only in developing countries but developed countries as well. Due to this belief, those that lived with the condition were highly stigmatized.

### **5.4 Educational level of the respondents**

The majority of the parents who participated in this study were educated with most of them having acquired secondary education with the least qualification recorded being lower primary. However, despite the majority parents possessing grade 12 certificates only a few were in formal employment. A few that were in formal employment were civil servants (mainly teachers and police officers). The majority were not in any form of



employment, not because they did not qualify but mainly due to caring for their sick children as seen from some of the reasons advanced below.

#### **5.4.1 Reasons for high level of unemployment**

The majority of the unemployed respondents attributed their situation to the care giving roles. Some of the respondents stated that before their children developed epilepsy they were engaged in full time formal employment and some were involved in small scale businesses and they were able to look after their families from the little that they raised from the businesses. With the onset of epilepsy and frequent seizures, the majority of the parents had to forego their jobs and take up the care giving roles. As seen from the previous chapter, women are the most affected in this area as compared to their male counterparts. This was attributed to inadequate support from fathers as well as other relatives. Apart from lack of support, it was observed that some of the children were hyperactive to such an extent where some parents were compelled to stay home in order to monitor and supervise them. The types of toilets that most of these families used were not user-friendly to children living with epilepsy. This situation forced the majority of women to forego their income generating activities and look after their children. For instance, one of the respondents narrated how she resorted to locking her child in the house to avoid getting into trouble with the neighbors. She further went on to narrate how her child cheated death after falling into the pit latrine. Such were some of the predicaments the parents to CWE were facing. Not only do they have to deal with the disease itself but other challenges attached to the condition. The findings about high unemployment levels among women due to care-giving roles were in agreement with what (Chomba et al 2006) reported in their study on the socio-economic impact of

epilepsy on households in which it was revealed that due to stigma attributed to epilepsy, mothers were overwhelmed with various aspects of care giving and in the process resign from their jobs and other income generating activities to look after their ailing children. Referring to the safety of the children, Dekker, (1998) stated that seizures that are not fully controlled can have a negative impact on both the patient and the care giver especially mothers who were regarded as custodians of homes (Lewis and O'Brien, 1954). Therefore, to avoid unnecessary accidents children with epilepsy have to be monitored and supervised when it comes to bathing or swimming. When visiting the toilet, such children need to be accompanied by an elderly person. Cooking that is done using braziers has to be done in safe places away from such children as they were prone to burns.

### **5.5 Characteristics of the children**

A good number of the children with epilepsy whose parents were involved in this study appeared not only to live with epilepsy but have other ailments that impact negatively on their wellbeing. Some of the children were either mentally or physically challenged meaning that they were dependent upon other people for survival. The situation created a challenge to most parents especially mothers and this probably explains why the majority of parents especially women were not in any form of employment. Caring for such children appeared challenging because for them the challenge is not only epilepsy but other ailments as well. Therefore, assistance for such parents should not only be financial but physical too due to overwhelming demand for the physical care for such children.

## **5.6 Knowledge about epilepsy among parents**

The respondents according to the findings in this study exhibited some positive level of knowledge and understanding about epilepsy. Unlike a study conducted by Birbeck et al (2005) on teachers about epilepsy where levels of knowledge were high (70%) this study did reveal that a good number of respondents understood epilepsy to be a brain related disorder. Though the parents who actually recognized epilepsy as a brain disorder were not in the overwhelming majority, it was gratifying to note that the majority were able to associate epilepsy with brain disorder. However, just like the findings of Mbewe et al (2004) study where some supernatural beliefs about epilepsy were recorded, this study had some few cases where epilepsy was associated with some superstitious beliefs.

## **5.7 Cause/s of epilepsy in the child**

From the findings of this study, it was evident that the majority of parents did not know why their children developed epilepsy. From the medical point of view, epilepsy is said to be a neurological disorder (Dekker, 1998). What came out clearly from this study was that, a good number of the respondents pointed out that epilepsy could develop in someone as a result of brain disorder. Despite a good number of parents relating epilepsy to a brain disorder, very few were able to attribute their children's condition to some brain disorder. For some parents their children's conditions were as a result of witchcraft. Nyame et al (1997) in their study conducted in Ghana recorded the same findings in which a lot of traditional misconceptions about the causes of epilepsy were widespread. This then creates a challenge to health care workers because a parent who succumbs to traditional beliefs and practice about epilepsy to a larger extent is likely to compromise the adherence to treatment. When that happens it becomes difficult for such parents to appreciate the efforts made by healthcare workers in as far as treatment is concerned. In

this study, it was revealed that the majority of parents doubted the effectiveness of Anti-Epileptic Drugs stating that they only reduced the frequency of the seizures hence the statement “slightly effective”. The response was attributed to the fact that their children were still experiencing seizures even after being on treatment for a long period. The understanding here could mean failure to adhering to treatment which Dekker, (1998) stresses as cardinal in the treatment of epilepsy. The conflicts in the cause of epilepsy could probably be linked to why there has been a widespread usage of traditional medicine to treat epilepsy. In this study, the majority parents confirmed having used traditional medicine. These findings are consistent with World Health Organization, (2001) estimations that more than 70% of PWE consulted traditional healers for treatment before consulting medical doctors. Birbeck et al, (2004) in their study on epilepsy and traditional healers in Zambia revealed a similar trend where it was discovered that more than 80% of the PWE seek help from traditional healers for various reasons which include supernatural beliefs about the cause and treatment of epilepsy. The widespread use of traditional medicine had nothing to do with lack of Anti-Epileptic Drugs (AEDs) in the health centers because it was clear from the responses given from the study regarding the availability of drugs in the centers where the majority of the respondents indicated that drugs were available at the health centers. The negative attitude exhibited towards the effectiveness of AEDs could be prompted by rapid response parents expect to see immediately the child is commenced on treatment. What parents do not seem to understand is that AEDs are a long term treatment and there is need to adhere to treatment if the drugs were to be effective. For some parents to have their children treated

they combine both AEDs and traditional medicine a situation which Dekker, (1998) condemns because the reaction of the two could have a devastating effects on the patient.

### **5.8 Attitude of parents towards epilepsy treatment**

From the responses as to whether epilepsy could be treated, the number of those who stated that it could be treated outnumbered those who responded in the negative. There were more respondents who strongly felt that the condition could be treated. Those that stated that they were “not sure” had their own reasons which ranged from failure by their children to respond to treatment, not having seen someone who was treated from epilepsy and the information from healthcare workers who have been assuring them that the condition was treatable. The conflicting information has put them in a situation where they were not sure of what to believe hence the “not sure” response. However, these were in the minority as compared to those that believed that epilepsy could be treated. All in all the attitude of parents as to whether epilepsy could be treated was positive and this needs to be cemented by ensuring that epilepsy care-givers are provided with correct information regarding epilepsy treatment stressing that it is long term and in some cases lifelong therefore, needs adherence and perseverance. This would assist to cement the understanding of parents towards epilepsy treatment.

### **5.9 Perceived stigma among parents**

Results from this study showed that though there were cases of parents being discriminated against for having children living with epilepsy, the problem was not huge. However, stigma against children living with epilepsy was more pronounced as compared to that of their parents. Most parents talked to bemoaned society’s negative attitude towards persons with epilepsy. One characteristic that appeared more pronounced was



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that those that lived in one community for a long time and neighbors informed about the child's condition were likely to be less stigmatized as compared to those who were new in a location and did not disclose the child's condition. One other comment that was prominent was that female neighbors were more likely to speak ill about an epileptic child and were the ones at the fore front discouraging their 'normal' children from playing with those that were perceived 'abnormal' (those that live with epilepsy).

From the findings of the study, it has shown that women were more likely to feel stigmatized as compared to their male counterparts. The majority of the mothers reported that in most instances their children were stigmatized by their paternal relatives. Some of them were accused of bringing a shame to the family for having a child that had epilepsy. One woman stated that her husband had deserted the family after the child was diagnosed it is indeed regrettable to note that in some parents could shun their children simply because they have developed epilepsy. As reported from this study in most cases the men are the culprits in this issue but what should be borne in mind is that epilepsy has no boundary, it affects all. The rejection by some male parents for the children creates a double burden to the women who on one hand has to look after the child and on the other fend for the family. It is therefore, most likely that if a child is rejected by a biological parent, it is expected that society will equally reject such children.

According to such men they regard CWE as an embarrassment and in most cases mothers are blamed for that. Such women, will not only suffer from being stigma for having a CWE but suffer the loss of marriage.



### **5.10 Formal education for children living with epilepsy**

As observed by (WHO, 2007) on the educational opportunities for CWE, it was clearly observed from this study that many CWE with epilepsy were not in formal schools. Various reasons were given as to why these children were not in school. These reasons ranged from social, medical to economic. Some parents felt that school authorities would not be accommodative enough knowing very well that some of the children with epilepsy were hyperactive. A few that were in school, the majority were in private schools as compared to a handful that were in government schools. This was due to the understanding that private schools were more accommodative than government schools. Severity of the condition could not allow some parents to enroll their children in schools. The majority of these parents had children who were crippled, hyperactive, and poor sighted, deaf and dumb and those who appeared to be mentally challenged. According to parents of such children there was no point in enrolling such children in schools because their conditions were too severe for them to learn. The findings were in agreement with what Toose, (1981) alluded to when he pointed out that most parents and society in general doesn't appreciate the education for children with disabilities; children living with epilepsy are not an exception as parents have shown that parents were not keen to put CWE in schools. The question one might ask is that "What will happen to these children when they grow into men and women?" Will such parents be bold enough to tell their children that they did not take them to school because they suffered from epilepsy? This in itself is stigma against CWE perpetuated by the biological parents for failing to take their children to school.

Some of the parents indicated willingness to have their children enrolled into schools but due to lack of resources they could not afford to take their children to school going by the demands that are usually made by some schools.

Some parents gave distances to special schools as reasons for not taking their children to school. They equally bemoaned lack of special schools in areas where they reside therefore, making it very difficult for their children to be enrolled in formal schools.

For others, they felt that probably teachers wouldn't treat their children fairly therefore, prefer to keep their children at home where their movements could be monitored, especially in highly hyperactive cases. One woman, whose child was expelled from school for lacking 'good' character' described as 'bad' the attitude of some teachers towards children living with epilepsy (CWE).

This study suggest that attitude of parents towards the education of children living with epilepsy was negative. It confirms some assertions that PWE have lower educational opportunities as compared to their age counterparts. Despite reasons given by parents justifying why their children were not enrolled in school, it was incumbent upon these parents to realize that education was a right for all children regardless of their physical or mental status; therefore, denying them this right was tantamount to violation of such a right.

### **5.11 Seizure management**

Tendencies of inserting objects between the teeth when a person is experiencing a seizure have been described as medically incorrect. David, (1952) for instance, advises against the practice because it exposes patients to greater danger. In an event that a tooth breaks, it means the patient is likely to swallow the tooth particle. Instead, patients should be in a

hazardous free environment, away from fire and any dangerous object that may be life threatening to the patient. Other than that, patients should be turned on the side to prevent the patient from choking themselves with saliva.

Results from this study revealed that parents applied various methods in managing seizures an indication that there wasn't a specific method that the parents could single out as the appropriate way of managing seizures. Though the majority of parents were able to manage seizures appropriately, there were some parents who were not sure of the correct way of managing seizures. Information gaps about seizure management that seem to exist among parents need serious attention from relevant authorities so that parents are empowered with the appropriate knowledge of managing seizures. One best way one can interpret these findings is that health workers were not doing enough to help parents in seizure management.

### **5.12 Fathers' role and their significance in epilepsy care**

Gender roles are interchangeable, and vary across cultures, classes and situations because they are socially constructed. Unlike sex roles which are biologically determined, gender roles are influenced by either one's background or environment in which they are brought up. This shows that when it comes to gender roles there are no restrictions as the case is with sex roles. In this study questions pertaining to the different roles played by both men and women were asked. This was in order to ascertain whether men were actively involved in epilepsy care.

The research findings suggest that very few men were involved in activities such as washing for the child, administering drugs, bathing and feeding the child. In the same vein, the majority of men offered financial support not only to the child but the entire

family. It was interesting that women came out clearly to state their financial dependency on the men. Though some women stated that they had single handedly supported their children financially, those that were dependent on men were more. To this effect, men should realize the need for them to participate in issues of child care especially if it is an illness that takes long to treat. Conditions such as epilepsy that take long to heal may be devastating if the care giving responsibilities are left to one person. Men should join hands with their wives so that the load is well balanced failure to which the other gender may be overloaded with responsibilities.

It was also reported that of all the male respondents that were captured in this study, 70% had taken their male children for medical attention. The findings suggest that when it comes to taking children for medical care, men prefer their male children to female children. The findings were in agreement with one study that was conducted in the United States of America which pointed out that when it comes to child care men would mostly get involved with their sons than daughters ([www.epilepticoslibres.com](http://www.epilepticoslibres.com)).

### **5.13 Challenges faced by parents due to epilepsy care**

The effects of epilepsy care vary from one family to the other. These problems will range from social to economic. Some families have disintegrated due to epilepsy. For some parents having a child living with epilepsy was a disgrace as one woman narrated how her husband deserted his matrimonial home after their child was diagnosed with epilepsy. The man blamed it on the wife and eventually packed his bags and left his home to stay with his mother. Marital conflicts were rife in some homes following accusations and counter accusations about who was responsible for the child's condition. In most homes

where the breadwinner happens to be the care giver, poverty levels were on the increase as the care givers had to forego some of their income generating activities to care for their children. This study has recorded a high level of unemployment especially among women due to care giving roles.

The amount of sleeping for the parents in epilepsy care has been described as poor. This study has shown that the majority of parents experienced loss of sleep due to constant worry about their children's condition and the responsibilities that go with caring for a child with epilepsy. Some parents had to wake up every so often in the middle of the night to check on their children. This was against the background that some children experience seizures during sleep, creating anxiety and fear among parents who had to ensure that their children were safe throughout the night thereby compromising on their sleeping time.

## 6 CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

### 6.1 Introduction

This study was designed to assess knowledge, attitude and practices about epilepsy among parents of children living with epilepsy in order to establish challenges faced by parents caring for children living with epilepsy. This chapter presents the conclusions drawn from this study and recommendations have been outlined thereafter.

### 6.2 Conclusion

Knowledge and understanding of epilepsy among parents was fairly good. This was attributed to the information availed to them by healthcare workers. The attitude of parents towards epilepsy treatment was positive as the majority of parents stated that epilepsy could be treated. However, the majority of parents doubted the effectiveness of AEDs in the treatment. Furthermore, cultural beliefs and myths about epilepsy and its transmission had no significant impact in the way parents cared for their children. This was justified by the rejection of the notion that epilepsy was contagious.

Epilepsy cause was a challenge to most parents as they could not state why their children developed epilepsy except in some few incidences where supernatural causes were singled out.

Women appeared to be more affected by epilepsy care as compared to their male counterparts. This was justified by the overwhelming numbers of unemployed women in this study despite acquiring grade 12 certificates and other relevant qualifications.

Conclusions that can be drawn from this study were that epilepsy was not only a medical problem but a social one as well. Its effects do not only affect the victim but the caregiver and the entire family. It creates fear, anxiety, stress, rejection and to some extent

disputes within families. It is therefore, incumbent upon relevant authorities to provide policy guidelines that will help alleviate sufferings of both victims of epilepsy and the care givers.

### **6.3 Recommendations**

- More information on epilepsy be provided to parents (not only in English but also in local languages) to enhance knowledge levels and understanding of epilepsy
- Healthcare providers should consider carrying out sensitization workshops on Anti-Epileptic Drugs if the attitude of care givers towards AEDs was to improve.
- There is need for government to establish day care centers to provide relief for parents whose children are devastated by epilepsy.
- Government to consider constructing more special education schools.
- There is need to include epilepsy in the education curricular so that learners can have access to epilepsy information at a tender age. This way will help to empower the young generation with the rightful knowledge about epilepsy.
- Introduce counseling sessions for parents whose children seem to be devastated by epilepsy.
- More health personnel should be trained to help alleviate shortage of staff to manage epilepsy.
- Gender sensitive policies in terms of child care should be put in place so that both parents are compelled to take care of their children especially those that suffer from long term illnesses such as epilepsy.

## **6.4 Suggestions for further research**

Due to the wide nature of the subject, future research should consider the following topics;

1. Epilepsy care and marital conflicts.
2. Challenges in accessing epilepsy treatment in Zambia: The way forward.
3. Epilepsy: Who is more affected? -The gender perspective.



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<http://www.nature.com>

## APPENDICES

### APPENDIX 1

#### INFORMATION SHEET TO THE PARTICIPANTS

You are being requested to participate in this study on knowledge, attitude practices about epilepsy among parents of children living with epilepsy. This study is purely academic and your responses will be treated with the highest privacy and confidentiality it deserves. For that reason, nothing of any sort that might link to your identity will be included in this survey. There are no risks involved as a result of you participating in this survey. There may be no direct benefits to you from this study but what is learned may help healthcare workers providing epilepsy care better understand the support needed for the parents of children with epilepsy.

Your participation in this study is absolutely voluntary. You are free **not** to answer any question which you are not comfortable with and you may stop participating at anytime without penalty. There are a number of questions and estimations are that you will spend about 30 minutes to complete the interview. You are therefore requested to exercise some patience as this may take much of your time. I would like to thank you in advance.

If you have any questions regarding this study you may contact my academic supervisor on the following:

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**APPENDIX 3**

**Questionnaire for the mothers (administered by the researcher)**

**Guidelines to the interviewer**

- A. Mother’s responses will be provided by ticking in the brackets [ ] provided.
- B. Responses that require explaining will be given in underlined spaces provided.
- C. Names or any personal identification are not to be written anywhere on this paper.
- D. Mothers will be free to seek clarification where they may not be sure.

**1. Demographic data for the mother**

- 1.1. Age..... (Years)
- 1.2. Tribe.....
- 1.3. Which church do you go to?  
.....
- 1.4. Highest grade obtained..... Other training.....
- 1.5. Marital status (*check one*)
  - [ ] married.
  - [ ] divorced.
  - [ ] widowed.
  - [ ] Other.....
- 1.6. Number of children .....
- 1.7. Employment.....
- 1.8. Residence [ ] High density [ ] Low density

**2. Demographic data for the child**

- 2.1. Age ..... (Years + months)
- 2.2. Gender..... [M] [F]
- 2.3. Birth order.....
- 2.4. Number of siblings  
..... Living

.....deceased

2.5. Presently in school? ☐ Yes ☐ No

If No, why not? .....

If yes, describe school? .....

2.6. Are the child's immediate sister/ brother in school?

☐ yes

☐ No

☐ Others.....

2.7 Father's employment.....

### **3. Nutritional status of the child**

3.1. Weight of the child..... (cm)

3.2. Height..... (cm)

3.3. Arm circumference..... (cm)

### **4. Housing & Material Goods**

4.1 What is the main construction material for the outside walls of your dwelling?

☐ Mud/ mud bricks

☐ Wood

☐ Corrugated iron

☐ Stones/ burnt bricks

☐ Cement/ concrete blocks

☐ Others.....

4.2 What is the main construction material for the roof of your dwelling?

☐ thatch

☐ corrugated iron

☐ asbestos

☐ others.....

4.3 What is the main source of cooking for your dwelling?

☐ electric stove

☐ wood

☐ charcoal

☐ kerosene/ gas stove

4.4 What is the main source of light for your dwelling?

☐ electricity

☐ generator

☐ kerosene/ gas/ paraffin

☐ candles

☐ fire

4.5 Do you have running water in your dwelling?

☐ Yes

☐ No

4.5.1 If No, what is your source of water?

☐ Pump

☐ Tap

☐ Well

☐ Stream / river

☐ others .....

4.6 If No in 4.5 above, how far is your source of water?.....(Meters)

4.7 What type of toilet do you use?

☐ flush

☐ Pit latrine

☐ Open air

☐ others .....



4.8 Material Goods

Material Goods

Resource	Check if owned by household	How many?
Cattle		
Goats		
Pigs		
Poultry		
Bike		
Radio		
Motorbike		
Television		
Video player		
Refrigerator		
Stove		
Vehicle		

5. Child medical status:

5.1. Compared with other children, does your child have any serious delay in sitting, standing, or walking?

[ ] Yes

[ ] No

5.2. Compared with other children, does your child have difficulty seeing either in the daytime or night?

[ ] Yes      [ ] No

5.3. Does your child appear to have difficulty hearing?

[ ] Yes

[ ] No

5.4. When you tell your child to do something, does he / she seem to understand what you are saying?

☐ Yes

☐ No

5.5. Does your child have difficulty in walking or moving his / her arms or has he / she got weakness and / or stiffness in the arms or legs?

☐ Yes

☐ No

5.6. Before this illness did your child have fits, become rigid, or lose consciousness?

☐ Yes

☐ No

5.7. Does your child learn to do things like children his / her age?

☐ Yes

☐ No

5.8. Does your child speak at all (can he / she make himself / herself understood in words? Can he / she say recognizable words)?

☐ Yes

☐ No

5.9. *For 3 – 6 year olds:* Is the child's speech any different from normal (not clear enough to be understood by people other than his/her immediate family)? *For < 3 year olds:* Is he/she unable to name at least one object?

☐ Yes ☐ No

5.10. Compared with other children of your child's age, does your child appear in any way mentally backward, dull, or slow?

☐ Yes

☐ No

## **6. Mom's KAP (knowledge, attitudes, practices)**

6.1. Do you think your child's epilepsy can be treated?

☐ Yes

☐ No

6.2. Do you think your child's epilepsy is contagious?

☐ Yes

☐ No

☐ Not sure

6.3. How effective is the modern treatment your child has been receiving?

☐ Extremely effective

☐ Slightly effective

☐ Not at all effective

6.4. Epilepsy is a form of..... (*Check all that apply*)

☐ Madness

☐ Spirit or demon possession

☐ Mental retardation

☐ Brain disease

6.4. Have you tried traditional medicine on your child?

☐ Yes   ☐ No

6.5. What do you think is the cause of your child's epilepsy? (*Check all that apply*)

☐ Brain injury

☐ Runs in families

☐ Birth injury

☐ Blood disorder

☐ Witchcraft

☐ Curse from God

☐ Sprit possession

☐ Excessive worry

6.6. Which of the following activities does your child participate in? (*Check that apply*)

☐ Attend school

☐ Participate in sports

☐ Climb trees

☐ Swim

☐ Play with other children

☐ Helping in the house/home

6.7. What do you do for your child when he/she has a seizure? *(Check that apply)*

- ☐ Turn the patient on the side
- ☐ Place a hard object in the mouth
- ☐ Hold them down
- ☐ Keep a distance

6.8. Has epilepsy affected your child’s ability to understand and think compared to other children his/her age?

- ☐ Yes
- ☐ No
- ☐ Others, explain.....

**8. Perceived stigma**

**Mother:**

8.1. What is the attitude of your neighbors/community towards?

- | <b>(Your child)</b>                | <b>(You)</b>                       |
|------------------------------------|------------------------------------|
| <input type="checkbox"/> Accepting | <input type="checkbox"/> accepting |
| <input type="checkbox"/> Rejecting | <input type="checkbox"/> rejecting |
| <input type="checkbox"/> Fearful   | <input type="checkbox"/> fearful   |

8.2. Generally, what is the attitude of family members towards?

- | <b>(Your child)</b>                | <b>(You)</b>                       |
|------------------------------------|------------------------------------|
| <input type="checkbox"/> Accepting | <input type="checkbox"/> Accepting |
| <input type="checkbox"/> Fearful   | <input type="checkbox"/> rejecting |
| <input type="checkbox"/> Rejecting | <input type="checkbox"/> fearful   |

8.3. Because of my child’s epilepsy:

8.3.1. I feel that some people are uncomfortable with:

- | <b>(My child)</b>  | <b>(Me)</b>  |
|--|--|
| <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |

8.3.2. I feel some people would prefer to avoid

- | <b>(My child)</b>            | <b>(Me)</b>                  |
|------------------------------|------------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Yes |
| <input type="checkbox"/> No  | <input type="checkbox"/> No  |

8.3.3. I feel some people treat me/ my child like an inferior person

**(My child)**

**(Me)**

☐ Yes

☐ Yes

☐ No

☐ No

8.4. Is the family supportive of your child? (Check all that apply)

☐ Willingly

☐ If I request

☐ No, they don't have the means

☐ No, they have the means but do not assist in the supportive of my child.

8.5 What is the general attitude of other children to your child?

☐ positive

☐ negative

8.6. *(For school age children)*

Is your child in school? Yes ☐ No ☐ *If no, why not?* \_\_\_\_\_

*If yes,*

a. Do you think your child's teacher(s) treats him/her the same as the other pupils?

☐ Yes

☐ No (Describe \_\_\_\_\_)

b. What is the general attitude of your child's classmates towards him/her?

☐ positive

☐ negative

**9. During the course of the past week...**

9.1. Did you have times in which you were thinking deeply or thinking about many things?

☐ Yes

☐ No

9.2. Did you find yourself sometimes failing to concentrate?

☐ Yes

☐ No

9.3. Did you lose your temper or get annoyed over trivial matters?

☐ Yes

☐ No

9.4. Did you have nightmares or bad dreams?

☐ Yes

☐ No

9.5. Did you see something or hear things which others could not see or hear?

☐ Yes

☐ No

9.6. Was your stomach aching?

☐ Yes

☐ No

9.7. Were you frightened by trivial things?

☐ Yes    ☐ No

9.8. Did you sometimes fail to sleep or loose sleep?

☐ Yes

☐ No

9.9. Were there moments when you felt life was so tough that you cried or wanted to cry?

☐ Yes

☐ No

9.10. Did you feel run down (tired)?

☐ Yes

☐ No

9.11. Did you at times feel like committing suicide?

☐ Yes

☐ No

9.12. Were you unhappy with things you were doing each day?

☐ Yes

☐ No

9.13. Was your work lagging behind?

☐ Yes

☐ No

9.14. Did you feel you had problems in deciding what to do?

☐ Yes

☐ No

**10. Questions on care giving and other aspects**

10.1. How often does the child fit?

☐ Everyday

☐ Once a week

☐ Once a month

☐ Others, (indicate) \_\_\_\_\_

10.2. How would you describe your child’s fits?

☐ Severe

☐ Moderate

☐ Mild

10.3. Are you able to access the care at the clinic when you need it for your child?

☐ Yes

☐ No

10.4. Is the drug your child is taking readily available at the clinic?

☐ Yes

☐ No

10.5. Has the need to care for this child affected your ability to earn?

☐ To a larger extent

☐ A little bit

☐ Never

10.6. Who is responsible for the following activities for the child?

Activity	Father	Mother	other relative
Washing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Bathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Administering drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10.7. Who do you leave the child with whenever you are away from home?  
.....

- 10.8. How difficult do you find caring for your child?
- ☐ Extremely difficult
  - ☐ Fairly difficult
  - ☐ Difficult
  - ☐ Not difficult

10.9. What role does the father play in relation to care giving for your child? (Please explain)

.....

.....

.....

10.10 Who makes decisions concerning your child?

.....

- 10.11 How satisfied are you with the care you have given to your child?
- ☐ Definitely yes
  - ☐ Yes
  - ☐ I have tried



[ ] Not sure

If you have any comment or anything you want to say about epilepsy and your child feel free to express your views.

**Comment**

.....

.....

.....

.....

.....

THANK YOU FOR TAKING PART IN THIS STUDY!

**APPENDIX 4**

In depth interview for the male respondents

**Instructions**

- a. The interviewer will greet the interviewee and do some self introduction.
- b. Assure confidentiality and privacy
- c. No names, pictures or anything that will lead to the identity of the person will be included in the interview.
- d. The researcher will thank the respondent after the interview

Study site.....No.....

**A. Demographic data**

- 1. What is your age?.....
- 2. How far did you go in education?.....
- 3. Marital status?.....
- 4. Where do you stay? .....
- 5. Sex of the child?.....
- 6. Age of the child?.....
- 7. Your employment status?.....
- 8. Spouse’s employment status?.....

**B. Knowledge about epilepsy**

- 1. What do you know about epilepsy?.....
- 2. What caused your child to develop epilepsy?.....

**C. Attitude/Beliefs about epilepsy**

- 1. Do you think epilepsy can be treated using AEDs?.....
- 2. What are your views about the modern AEDs and epilepsy treatment?.....
- 3. Do you think epilepsy is contagious?.....
- 4. Is your child in school?..... If NOT, why?
- 5. How do neighbors treat

- (a) You? .....
- (b) Your child?.....

6. How do you manage seizures?.....

**D. Roles**

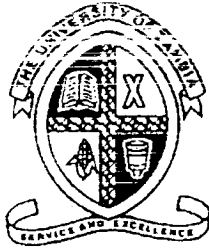
- 1. What role do you mainly play in caring for your child? .....
- 2. Do you think you have contributed enough in caring for your child?
  - (i) If no, why?
  - (ii) If yes, how have you contributed (explain).....
- 2. If you have to make a decision about the child, who makes the final decision?.....

**E. Effects of epilepsy care**

- 1. How has epilepsy impacted on your well being?
- 2. Do you sometimes have problems with sleeping?
- 3. Are there moments when you think deep about your child’s condition?
- 4. Have you ever thought of committing suicide as a result of your child’s condition?
- 5. How would you describe your child’s epilepsy?

\*Any other comment about what we have just discussed?

We have come to the end of the questionnaire and thank you for your time.



# THE UNIVERSITY OF ZAMBIA

## DIRECTORATE OF RESEARCH AND GRADUATE STUDIES

### HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

Phone: 290258/291777  
0-1-290258/253952  
Director@drgs.unza.zm

P.O Box 32379  
Lusaka,  
Zambia.  
Your ref:  
Our ref:

Dr. Sakubita-Simasiku,  
Department of Gender Studies,

April, 2010.

Dr. Sakubita-Simasiku,

#### Re: Final Ethical Clearance

Reference to your research proposal entitled:

**Parents' Knowledge, Attitudes and Practices in the Care-Giving for Children living with Epilepsy."**

In response to my letter of the 9<sup>th</sup> April 2010 identifying concerns raised by the HSS Research Ethics Committee, I am in receipt of a letter from Dr. T. Kusanthan, Head of the Department of Gender Studies, dated 1<sup>st</sup> April, 2010. I am satisfied that this letter gives the required clarification to the issues raised.

Consequently, on behalf of the HSS Research Ethics Committee, you now have ethical clearance to proceed with your research.

Thank you!

*Dr. Dillian-Malone*

Dr. Dillian-Malone,  
Head,  
Research Ethics Committee.

Dr. Dillian-Malone,  
Assistant Director, DRGS.  
Head, Gender Studies. ✓



# THE UNIVERSITY OF ZAMBIA

## DIRECTORATE OF RESEARCH AND GRADUATE STUDIES

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P O Box 32379  
Lusaka  
ZAMBIA

13<sup>th</sup> July, 2011

Ms. Claire Chakale Sakubita  
C/o School of Education  
**LUSAKA**

Dear Ms. Sakubita,

### RE: RECEIPT OF JOURNAL ARTICLE

I am glad to acknowledge receipt of your journal article entitled "*Knowledge Attitudes and Practices about Epilepsy among Parents of Children Living with Epilepsy*" submitted for possible publication in the Journal of Law and Social Sciences. The article has been submitted to three reviewers who will advise us on its eligibility for publication and, once we receive their feedback, we shall notify you immediately.

Let me take this opportunity to remind you of the current postgraduate regulations pertaining to publishing in a journal. Before one can graduate:-

- (a) a doctoral candidate is required to show evidence of a paper published in a journal and
- (b) a candidate doing Masters by Research should show evidence of a paper accepted in a journal and
- (c) a student undertaking Masters by Taught courses followed by a dissertation must show evidence of a paper submitted to a journal.

Since this is the first time the University of Zambia is implementing such a regulation, and in order to enforce it, we shall request you to show us the evidence applicable to you from the three scenarios described above at the time you will be collecting your transcript of results.

Once more, many thanks for your journal article as you wait to hear from us.

Yours sincerely,

C. M. Namafe (Dr.)

**CHIEF EDITOR – JOURNAL OF LAW AND SOCIAL SCIENCES**

cc     Director – Directorate of Research and Graduate Studies  
        Assistant Director – Directorate of Research and Graduate Studies  
        Assistant Registrar (Research) – Directorate of Research and Graduate Studies  
        Editors – Journal of Law and Social Sciences