# LIVED EXPERIENCES OF YOUNG PEOPLE WITH ACTIVE CONVULSIVE EPILEPSY IN VIHIGA COUNTY, KENYA

**BY**

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# DEDICATION

This thesis is dedicated to young people living with epilepsy

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# ABSTRACT

Epilepsy is one of the chronic illnesses whose management is subjugated in policy documents although it affects over 1% of the population in Kenya. This has individualized its management causing those living with the illness to be discriminated, isolated and stigmatized. Using Interpretative phenomenological approach, this study investigated the lived experiences of young people with epilepsy and the implications on its management. Specifically, the study aimed to achieve the following objectives: to investigate the community's perceptions namely knowledge, attitudes and practices towards epilepsy and determined how these perceptions influenced the lived experiences and illness management of young people living with epilepsy. The study adopted mixed research method. Survey research design was adopted in collecting quantitative data on community perception towards epilepsy. These data were collected from 150 respondents who were selected through multistage sampling technique with the aid of a questionnaires which had open and close-ended questions. Case study design was adopted in collecting qualitative data on lived experiences and illness management. These qualitative data were collected using in-depth interviews from 15 young people living with epilepsy who were selected through snowball sampling technique. In- depth interviews were guided by an interview guide. The quantitative data which was collected with aid of questionnaires was code and descriptively analyzed with aid of SPSS computer program. The analyzed data was presented in form of frequency and percentage tables. Qualitative data from in-depth interviews was tape recorded, transcribed *ad verbatim* and thematically analyzed. The study found community perceptions namely knowledge, attitudes and practices about epilepsy drew both from biomedical and ethonomedical health systems which individualized the illness. This made those living with epilepsy to be discriminate, stigmatized and isolated. Thus, those living with the illness perceived it as biographical disruption due to the limitations it imposes on their life projects. Consequently, those living with epilepsy managed it through concealment as a way to socially fit into their significant social network. In conclusion, this study argues that community knowledge, attitudes and practices have influence on how people living with epilepsy live with the illness and manage it in their everyday lives. The study recommends that management of epilepsy at individual should incorporate the community's perception of the illness.

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# CHAPTER ONE

# INTRODUCTION

## 1.1 Background to the Study

Epilepsy is a chronic illness with many comorbidities that alter quality of life for many living with the condition. An estimated 70 million people suffer active epilepsy globally. Nearly 80% of them live in low- and middle-income countries (WHO 2017, ILAE 2017). In Kenya, the prevalence of the disease is 18.20/1000 which translates to about 728,000 people living with epilepsy. This constitutes to about 2% of Kenya’s estimated population of 42 million. This percentage is above the world prevalence rate of 1%. There is a likelihood that the prevalence in Kenya could be higher because some of the epilepsy cases do not attend mainstream health services due to stigma and therefore remain unreported.

Medically, epilepsy is a disorder of the brain characterized by recurrent seizures during which a person loses consciousness and control of bowel and bladder function (WHO Report, 2009). The seizures are a result of sudden, usually brief bursts of large electrical discharges in a group of brain cells (Khalid and Aslam, 2011) or product of abnormal paroxysmal discharges of cerebral neurons (McQueen and Swartz 1995).

Epidemiologically, epilepsy is a chronic non-communicable neurological disorder of the brain that affects people of all ages (WHO 2016). Socially however, epilepsy etiology is relative to various communities’ ethno medical health systems and cultural beliefs. These beliefs shape how people make meaning and respond to the illness. These meanings influences the social management at individual and collective level (Susan 1986). Among the Mijikenda of Kenya and people of Hurungwe district in Zimbabwe, for example, epilepsy is caused either by supernatural spirit or witchcraft (Kendal-Taylor *et al.*2009; Mutanara and Mutara 2015).

Epilepsy is not just a medical problem but a social problem with consequences on an individual psychosocial wellbeing. Epilepsy is problematized by its social and symbolic meanings in everyday life. As a social problem, the social pain of living with epilepsy is caused more by the failure of an individual to meet the socio-cultural life standard expectations due to imposed limitations of the illness. This is clearly captured by my childhood experiences with people living with epilepsy in my community. Persons with epilepsy were mostly isolated and discriminated. For example, there was a young man who was aged about 20 years and had active epilepsy. He could get frequent seizer attacks in public places. People in the village avoided him. Children were discouraged from having contact with him. Whenever people gave him something such as money or food, they avoided physical contact. His family too isolated him by building him a grass thatched house away from the family homestead. He never attended school despite their homestead bordering the school. He never married despite his appropriate age of marriage according to the community expectations. During seizer attacks, no one offered help, instead people ran away out of belief the illness was contagious. People also avoided using paths he frequently used. This was borne out of the belief that epilepsy was highly contagious and could spread through contact with saliva, urine from an epileptic or his her shadow. The experiences of the young man is reflected in many societies where people with epilepsy get similar reactions from their communities. For example, in Finland, before 1969 epilepsy was a legal obstacle to marriage because it was believed to be hereditary (D’Souza 2004). The notion of epilepsy being a pollutant, caused by spirits or being a punishment for breaking of taboo, together with belief that it is contagious greatly influences and problematizes the social management of the illness (Susan 1986).

The notion that epilepsy is caused by breaking a taboo was evident during my clinical health training. On one occasion while working at the Accident and Emergency center a young male patient was brought in having severe and violent seizers. A diagnosis of status epilepticus (relentless epileptic fits in quick succession) was made and treatment commenced. The patient was unresponsive to initial emergency intervention. As a result, he was scheduled for an emergency transfer to a more specialized facility. However, the relatives accompanying him declined the referral instead opted for a traditional healer. The relatives attributed his illness to breaking a taboo prohibiting him from consuming meat prepared for a ritual ceremony of remembering a deceased kinship member (*lovego*). In this case it was a taboo for him to partake the meat because he was born out of wedlock and thus had no "blood relationship" with the deceased. It was therefore construed that his continuous fits were a result of breaking this taboo. Unfortunately, he passed on shortly after the kin took him for traditional healing.

From the above narrative it is evident that epilepsy is not just a medical condition but a social problem characterized by cultural beliefs, rejection, discrimination, even ostracism. Since ancient times social structures have been a hindrance to quality of lives of people living with epilepsy, for example, in the 2nd and 3rd centuries, physicians and philosophers associated epilepsy with the lunar phases. This bred the misunderstanding that epilepsy was a form of lunacy (Chadwick 1997). Discriminatory laws are recorded as far back as 2000 BC, in the Babylonian code of Hammurabi (Fernandes *et al* 2011). Anti-marriage laws for people with epilepsy were in place in Europe and U.S.A. As recent as late 1960's-early 1980's. The Eugenics Movement legitimized sterilizations of PWE in the United States between 1907 and

1964. Perceptions on epilepsy are often negative. They comprise attitudes that impairs the patient's quality of life, reinforcing the stigma (Fernandes *et al.*2011; Austin *et al.*1997).

Consequently, this study sought to investigate the lived experiences of young people with epilepsy. Specifically, the study sought to understand the subjective experiences of these young people given the fact that societies and individuals have different understandings of illness regarding its cause and treatment. This understanding influences health seeking behaviors which in turn influences health outcome of individuals and societies. Kleinman (2007) and Eisenberg *et al* (1978) explain that illness experience is shaped by culture which is a crucial part of social system of meaning and norms that govern behavior. To understand these experiences, Fadiman (1997); Schachter *et al* (2008); Kleinman (1980) and, Swartz (1998) point to the need to explore personal narratives in order to understand how individuals make sense of their illness. Pierett (2003) also captures the importance of illness experience by stating that it helps in shedding light on social pain of living with stigmatized illness. In epilepsy the social pain compels individual to calibrate new ways of living as a way of avoiding further pain. This study therefore places importance of the lived experiences of epilepsy because they form part of a life story. The study sought to understand how young people with epilepsy make meaning of their condition and how they respond to illness in a contextual environment as individuals in relation to the collective cultural beliefs, knowledge, attitudes and practices.

## 1.2 Statement of the Problem

People with epilepsy struggle to understand and manage their condition because of different explanations and understandings about its cause and treatment (Kleinman 1980). Because of deeply embedded cultural beliefs about the illness, persons living with epilepsy may experience difficulties of coping within a society that has negative attitude about their illness. These have the potential to alter the quality of life of the individuals (Austin and de Boer 1997; Abigael *et al*, 2012; Baker *et al*, 1999; Collings 1990; Fisher et al, 2000; Jacoby et *al.*1996; Mittan 1986). This is exacerbated by the desire to meet collectively defined socio-cultural standards of life projects (Bury 2001). This imposes a heavy toll to the existing diseased subjects. This makes them to alienate themselves from the outside world as a way of cushioning themselves from stigma and oppressive structures (Aper *et al* 1991; Austin *et al* 1994; Matthews *et al* 1982). This destabilizes and undermines their sense of self-worth as existing beings. As a result, they are forced to come up with new ways of living cognizant of their limitations imposed by the illness. Thus, this study investigated the lived experiences of young people living with epilepsy. In doing so, this study was guided by the following questions:

### 1.3 Research Question

1. What is the level of knowledge, attitudes and practices of epilepsy in communities?
2. How does the community’s knowledge, attitude and practices of epilepsy influence individual lived experience of young persons affected by it?
3. How do these lived experiences influence illness management of young people living with epilepsy

### 1.4 Study Aim and Research Objectives

To gain an in-depth understanding of the lived experience of young people living with active convulsive epilepsy

a) To investigate the knowledge, attitudes and perceptions on epilepsy of the community members in Vihiga;

b) To examine how the community's knowledge, attitudes and perceptions of epilepsy influence individual lived experience

c) To determine how young people living with epilepsy manage their condition of epilepsy.

### 1.5 Justification of the Study

Epilepsy is an illness whose history is shrouded with myth and cultural beliefs that attracts varied etiological interpretation and treatment pathways. These interpretations form a basis for stigmatization of the illness. As a result, its management becomes problematic (ILAE 2003; Haworth *et al.*2015; Mula *et al* 2016). The intention for this study was firstly, to bring to light the plight of young people living with epilepsy through data and information sharing. The study targeted to document the impact of lived experiences and the social outcomes of those living with epilepsy with the hope of attracting and building networks and partnerships to improved quality of life for those living with epilepsy.

Secondly, the study sought to fill an intellectual gap. Epilepsy has attracted robust medical research. However, despite being a cultural phenomenon with a long standing history among human societies, studies on the social aspect of the illness have not been robust, especially in developing countries. Studies done have majorly focused on care givers of persons living with the condition. The few studies done on lived experiences of individuals with the illness have majorly focused on children. There is evidence to show that studies on epilepsy have been carried out in Kenya (Mung'ala-Odera *et al.* 2007; Kendal-Taylor *et al,* 2009). However, most of these studies have focused on prevalence and biomedicine management of the illness. Although there have been studies conducted on social aspects in Kenya, they have focused majorly on knowledge, attitude and practices towards the illness. There has been no study on lived experiences among young people in Vihiga County. In this study, the researcher sought to investigate the lived experiences of the affected persons.

Lastly but not least, the study sought to prompt a rethinking about management of epilepsy in Kenya through policy. Epilepsy is known to have many comorbidities that work to alter the quality of life of those suffering from the illness. Notably, persons living with epilepsy suffer many psychosocial problems that are a result of enacted stigma. Problems faced by those living with epilepsy are not universal but are experienced in context. The World Health Organization has recognized the need for contextual understanding of illnesses by appreciating social determinants of health besides the traditional biomedicine. Social determinants of health are the conditions, in which people are born, grow, work and age. Understanding and management of illnesses are shaped by these conditions among others such as culture, distribution of power and, resources (WHO 2017). Constructionist and phenomenology models postulate a multiple experiences of a phenomenon. By exploring subjective experiences and coping strategies of persons living with epilepsy this study offers an understanding of this problem area. Findings of the study may facilitate new understanding of managing epilepsy that can be incorporated in the medical management of the illness. This may play a major role in the management of the illness and impact on the social as well as the medical outcomes of young people living with epilepsy. Improved outcomes will enable individuals adjust appropriately to the illness and positively engage in their distinct stage of life by taking up expected social roles and expectations. This study therefore is appropriate and offers opportunities for policy formulation.

## 1.6 Definition of Variables

**Epilepsy:** The term epilepsy in this study means repeated episodes of falling, jerking of limbs, foaming at the mouth and incontinence, followed by sleep and confusion.

**Seizer:** The term seizer has been used interchangeably with the term "f**its"**. This term is used to mean violent and jerky movements of the limbs and the body during an epileptic attack.

**Young people:** WHO refers to people between age 10 to 19 as adolescents and the larger group 10-24 as young people. The US Centre for Disease Control (CDC) defines adolescents as persons between the ages of 13 and 16 years and 20-24 for young people. Pediatric Centre for adolescents and medicine defines young people as aged 13- 31. Harrison (2005) defines youths as a broad category of both men and women aged between 10-30 years. In this study, we define young people as persons aged 12-35. This is because among the Luhya living in Vihiga County, young people are those in the age group 12-35 Among the Maragoli and Tiriki of Vihiga county circumcision, which is carried on boys aged around 10-12 years signifies the transition from childhood to a young adulthood (man). Traditionally circumcision is done at an interval of ten years to allow a cohort of age mates. On the other hand, a girl who attains age 15 becomes of age and is referred to as *musoleli* (young lady).

**Lived experiences:** This is the subjective perception of one's experience of a phenomenon such as health or illness. Borrowing from Rosemarie Parse's Nursing Theory of Human becoming, universal lived experiences are people's perceptions of their personal health-related experiences. Through interviews, researchers engage respondents in a dialogical discussion that brings forth an open, honest display of feelings and emotions. Through hermeneutics, researchers can achieve an accurate understanding and interpretation of a respondent’s beliefs, values, and situations that supports explanations of meaning.

**Health seeking behaviors:** North American Nursing Diagnosis Association defines Health seeking behaviors as a state in which a person in stable health is actively seeking ways to alter his or her personal habits or environment in order to move toward a higher level of health. “Stable health” is defined as the achieving of age-appropriate illness prevention measures, with reporting of good or excellent health, and signs or symptoms of disease, when present, being controlled. From sociological standpoint, health seeking behavior is influenced by different factors, some that may enable people to seek health care from the place of their choice, others may act as barriers. Culture, time, income, status, insecurity and other socioeconomic factors may influence health care seeking behavior and how quickly people seek health care.

**Illness management:** Systems and modalities of handling an illness

**Symptom**: It is a subjective evidence of disease or physical disturbance. It is a reaction of the body to and external substance. Example of a symptom is drowsiness, headache or erectile dysfunction.

# CHAPTER TWO

# LITERATURE REVIEW AND THEORETICAL FRAMEWORKS

## 2.1 Introduction

Epilepsy has a large rapporteur of literature owing to myth and beliefs around it and its long standing history with mankind. Studies related to this phenomenon, especially the previously under studied social aspect of it have continued to yield new findings. However, there still exists knowledge gaps in the studies that need to be filled. Literature review in this study looked at number of peer reviewed research papers and theses on various perspective of epilepsy. The findings were juxtaposed to identify areas of knowledge gaps. Specifically, concepts of social construction of illness, etiological interpretations, stigma, and treatment practices were reviewed in line with the first research object of the study which sought to examine the knowledge, attitude and practices of epilepsy among members of the community. Objective two sought to examine how the community's knowledge, attitude and perception of epilepsy influence individual lived experience. In line with this objective the concept of perception and stigma are discussed. The third objective of the study sought to determine how young people living with epilepsy manage their condition of epilepsy. In line with the third objective the concepts of seizers, treatment pathways, quality of life and coping strategies were reviewed. The chapter begins by explaining epilepsy in general by drawing various definitions advanced by scholars. Two ontologies; biomedicine and social, emerge as two main perspectives of the illness. Biomedicine studies have majorly used positivists approach while studies on social aspect such as lived experiences have majorly used constructionists approach. Although the studies discussed in the literature review have extensively covered the two perspectives there still exists some knowledge gaps that remain conspicuous necessitating this study.

The literature review is presented under sub-headings of ; Medical and social definition of epilepsy, history of epilepsy, epidemiology of epilepsy, knowledge, attitudes and perceptions, health seeking behavior and, Phenomenology in lived experiences studies.

### 2.2 Medical and Socio-Cultural Meanings of Epilepsy

Epilepsy has largely been defined as a medical condition yet lay persons have advanced their definition of the illness from cultural and social perspective. Epilepsy has been discussed in literature from two main perspectives; Biomedical and Psychosocial. According to Pinikahana and Walker (2009) epilepsy is neither an illness nor a disease, but a brain disorder, frequently associated with neurological and psychosocial difficulties. Because epilepsy is not exclusively a neurological phenomenon it requires a juxtaposition of neurological and sociological components to elucidate grey areas of the disorder, such as the subjective experiences of the disorder. Hosseini *et al* (2012)describes epilepsy as a chronic disease with psychosocial and cultural ramifications unseen in any other condition.

Medically, WHO (2002) defines epilepsy as a disorder of brain cells characterized by recurrent epileptic fits. Epileptic fits are commonly referred to as seizers. Thompson, Osorio *et al.* (2005) define epilepsy as “a sudden, involuntary, time-limited alteration in behavior, motor activity, autonomic function, consciousness, or sensation, accompanied by an abnormal electro-graphic pattern (EEG)”. Baxendale (2006) states that epilepsy is an umbrella term that describes people who experience recurrent and unprovoked seizers. The seizers have to be two or more (Banerjee 2009) and have to be unprovoked (Guerinni 2006).

Hae Won Shin et al (2014) defines aseizure as “a clinical manifestation, resulting from a brief episode of abnormal excessive or synchronous neuronal activity in the brain.” A seizure, commonly referred to as fits in lay language, an abnormal behavior caused by abnormal electrical activity in the brain. Here the brain discharges large electrical activity than normal. The burst of large electrical waves in the brain causes the body to have sudden jerky and uncontrolled movement. According to Kumar Mukhopadhyay *et al* (2012) a seizure results from sudden imbalance between the excitatory and inhibitory forces within the network of cortical neurons. Although the cause of this imbalance is largely idiopathic, certain factors such as underlying injury or illness can explain the imbalance. When seizers occur oxygenation to the brain cell tissues diminishes and sometimes the brain becomes asphyxiated. This leads to unconsciousness, altered or disturbance of movement, altered sensations including disturbed vision, hearing and taste. Altered autonomic function, mood and mental function also occur.

Griffiths (1990) explains that hallucinations, sudden emotional outbursts, and other psychopathology are some of the behavioral symptoms expressed as a result of epileptic discharges. Hallucination maybe the auditory, visual, olfactory or tactile type.In hallucination individuals report unusual sensory phenomenon such as seeing ghosts, hearing odd sounds, strange smell or a sense that insects are crawling under the skin. Epileptic activity within the brain, according to Betts *et al.* (1976), influences the behavior, mood, and cognitive functions of a person suffering epilepsy. These behavioral symptoms have social meaning that act to stigmatize the illness. The exhibited behavior may be affected by the attitude of others towards the condition altering the social and psychological adaptations of persons with the condition.

Epilepsy thus becomes a social problem problematized by its social and symbolic meanings in everyday life.

Health and illness cannot be viewed separate from the social and cultural context in which we live. Social context is an important factor in determining health outcomes. Jacoby (1992) describes epilepsy as both a medical diagnosis and a social label. By social label he means that there are several psychosocial problems accompanying the disease, thus its impact on a person's everyday-life can be significant. The World Bank (2002) acknowledges the high psychosocial morbidity of epilepsy as cited by (Mung'ala-Odera *et al* 2008). These consideration and other stake holders informed the decision by ILAE (2014) to revise the definition of epilepsy to be "a disease characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. ILAE in defining epilepsy observes that a seizure is an event but epilepsy is a disease that involve recurrent unprovoked seizures.

Socially, there are varied explanations to what epilepsy is. In most of rural set ups worldwide epilepsy is attributed to supernatural causes. These varied explanations emerge from social systems, cultures and conditions which influence our beliefs on various illnesses. These beliefs become our realty in respect to the phenomenon in question. Epilepsy has deep embedded beliefs and cultural meaning attached to its presenting signs and symptoms. The social meaning becomes the reality to which we react and respond to. Social construction paradigm postulates that individuals and groups make their own conception of reality, and that from this conception we form our epistemologies. For example, Hanif *et a*l (2005) study on religious beliefs of persons living with epilepsy found that more than half were socialized to believe that their condition was induced by spiritual beings (jinis), further, they were socialized to believe they had been fated by God to suffer (Qadr Allah). Among the coastal people of Kilifi in Kenya, epileptic seizers are believed to be caused by a supernatural spirit referred to as *Nyagu*, (Kendall-Taylor *et al* 2006).

Marina (2013) study on epilepsy in Tanzania revealed that a significant number of people attributed epilepsy to either "*Uchawi/kurogwa* (witchcraft), "*Majini/Mashetani* (spirit possession) or *"kuvunja koo"* violation of taboo. Further, people believed etiology of epilepsy to be supernatural interference by an evil-doing "*mchawi"* (Swahili word meaning 'witch'). Taboos were mentioned to underlie epilepsy. The belief in breaking of taboo as cause of epilepsy is consistent with other cultural beliefs among ethnic groups across East Africa. Among the Maragoli and Tiriki sub-tribes of the Luhya in Kenya, violation of rituals regarding consumption of ritual meat during ceremonies to remember dead ("*lovego*") can cause one to experience fatal seizers. These beliefs are formed out of meaning attached to various aspects of epilepsy during socialization processes about illnesses across societies.

## 2.3 Medical and Social-Cultural Implications of Epilepsy

Reactions to epilepsy in contemporary societies is still colored by residual belief from the middle ages. In much of developing nations that have strong ancient traditions, more so in Africa, there exist beliefs and misconceptions of epilepsy that are influenced by traditional indigenous beliefs (Jilek 1979). These beliefs are surprisingly similar across the African continent despite varied cultural systems. The beliefs and misconceptions, along other comorbidities work to predispose those suffering epilepsy to psychosocial hardships and altered quality. Thus while managing epilepsy it is important to consider it as a cultural phenomenon that requires culturally oriented interventions and not just a clinical diagnosis (Hosseini *et al* 2012).

As explained in the introductory section of the literature review, medical explanation of epilepsy is that recurrent seizers are a result of sudden burst of abnormal electrical activity of the brain. These bursts are unpredictable. This unpredictability thus becomes a source of fear and insecurity among those living with epilepsy as well as their families. The unpredictability creates a constant feeling of being under threat. The violent and jerky movements during seizer attack accompanied by frothing in the mouth and urinary incontinence have negative cultural and symbolic meaning. These meanings influence the social interaction between the sufferer and the society and often becomes the basis of stigma projection.

Fear of social exposure of epileptic fits and feelings of disgrace after the epileptic fit often leads to social withdrawal. About 50 to 75 per cent of persons with epilepsy spend almost all their time at home (Mitan 1983). Goffman in his dramaturgy discourse explains how social identity is formed and how certain conditions can offer the sufferer the option of hiding their diagnosis as they attempt to renegotiate their social identity (Kılınc *et al* 2009). Jacoby (1992) describes epilepsy not just a medical diagnosis but a social label. By social label he means individuals with the illness are uniquely identified by certain attributes and psychosocial problems that impact their everyday-life. The illness is characterized by labelling, negative perceptions, attitudes and, stigma and therefore no longer remains solely a clinical phenomenon but a social one as well (Fernandes *et al* 2011; Austin *et al* 1997).

From the above presentation it can be concluded that social belief systems determine beliefs, attitudes and perceptions and, practices of epilepsy in defining the illness. This definition becomes the social construction of epilepsy and shapes the responses to and outcomes of those living with the condition. Understanding culturally specific beliefs about the causes of the illness can therefore help determine best modalities of managing the condition both individually and collectively, medically and socially.

## 2.4 History of Epilepsy

The disease's history is intertwined with human history and is laced with religious and cultural beliefs. The earliest description of epilepsy can be traced back to 2,000 B.C in the recordings of Akkadian text. The author of the description explains signs resembling those of epilepsy such as jerky body movements and frothing in the mouth (cited by Magiorkinis *et al*2011). In the text the exorciser diagnosed the condition as *'antasubbû'* (the hand of Sin) brought about by the god of the moon. Description of epileptic convulsions has been found in Ancient Egypt medical texts of 1700 BC. Other earlt text on epilepsy can also be found in ancient Babylonian text, Lonrigg (2000). The Sakikku, an old Babylonian text (1067-1046 BC) describe symptoms characteristic to epilepsy. Interestingly stigma towards epilepsy is described in the early texts. Hammurabi code (1790 BC) states that if one bought a slave and the slave was discovered to be epileptic, then the slave could be returned and money refunded. In fact, in subsequent years Plato (428/427 BC - 348/347 BC) suggested specific punishment for people selling slaves with epilepsy. The stigma continued in Roman times. The Romans referred to epilepsy as *morbus comitiali*. This was because epileptic seizer attack interrupted or postponed government activities such as the proceedings of the Senate whenever a senator was struck by epilepsy during a session. The epileptic attack tended to "spoil" the day of the *comitia*, the assembly of the people.

In Ancient Greece epilepsy was considered a "miasma" (a Greek word for pollution or a noxious form of 'bad air') cast upon a soul. Epilepsy was considered a divine punishment for sinners and aura of mysticism. Superstition surrounded epilepsy. It was regarded a disease connected with *Selene*, the goddess of the Moon, hence the term Lunacy. People who offended the Lunar were afflicted with epilepsy. Teeth gnashing or convulsions on the right side, screaming like a horse (an aura) are some of the recorded symptoms of epilepsy in the Hippocratic texts. ). In his work "The Historis" (Thaleia) Herodotus of Hallicarnassus (484 - 425 B.C.) cited by Magiorkinis *et al* (2011), describes symptoms resembling epilepsy afflicting the Persian King Cambyses II. The author describes the erratic behavior of the King which he attributes to either the retribution of an aggrieved god or to the so-called 'sacred disease', epilepsy. Herodotus also notes the hereditary characteristic of the disease (Herodotus, 2000).

The long standing philosophy and belief in supernatural being the cause of epilepsy would be challenged by Hippocrates who disputed the divine origin of epilepsy by saying: *"This disease is in my opinion no more divine than any other; it has the same nature as other diseases, and the cause that gives rise to individual diseases. It is also curable, no less than other illnesses, unless by long lapse of time it be so ingrained as to be more powerful than the remedies that are applied"* (Hippocrate, 1849a). Hippocrate attributed the cause of epilepsy to brain dysfunction (Hippocrate, 1849b). He also stressed the role of heredity in the disease. He identified changes in the wind and of temperature, crying and fear as predisposing factors to epileptic fit. Indeed this is consistent with contemporary knowledge on triggers of epilepsy which include, changes in the weather, emotional state, phobia of many king such as crowd or pools of water. Hippocrates linked head injuries to convulsions and introduced the idea of traumatic epilepsy (Hippocrate, 1849 i).

Aelius Galenus or Claudius Galenus (131-201 AD) improved on the works of Hippocrates on epilepsy by defining three forms of epilepsy in his classic treatise

*Medical Definitions* (Galen, 1821c) cited by Magiorkinis *et al* (2011). The three forms include; idiopathic epilepsy which he attributed to primary brain disorder (an analogue to grand mal epilepsies), Secondary epilepsy which he attributed to disturbance of cardiac function transmitted through the flow of liquids secondarily to the brain epilepsy (by sympathy), and a third type attributed to "disturbance of another part of human body which is secondarily transmitted to the brain." Association of epilepsy with supernatural cause continued despite Hippocrates medical model postulation that attempted to dissociate epilepsy and religion. Magical treatments of epilepsy continued to dominate the middle ages and the renaissance.

In the medieval times, a period characterized by a domination of mysticism and dogmatism in allfields of science, including Medicine, epilepsy along other illnesses such as hysteria and psychosis, were seen as being a result of demonic possession. Another theory advanced during this period was that epilepsy was contagious. The epileptics were excused from oblation and Eucharist because of fear that they would desecrate the holy objects and infect the common plate and cup. Epilepsy was enumerated as an infectious disease in the verse of the so-called *Schola Salernitana*, where it was named *pedicon*. Belief in Lunar as cause of epilepsy continued in the medieval period. Pagans attributed epilepsy to vengeance of the goddess of the moon. The explanation was that the waxing moon heated the atmosphere surrounding the earth, which in turn melted the human brain and provoked an epileptic attack.

Remarkable scientific progress on epilepsy was witnessed in the renaissance and enlightment in Europe (14th-17$^{th}$ Century) when science emancipated from the restrains of the Catholic Church. Various theories on pathophysiology of epilepsy were advanced. As cited by Magiorkinis *et al* (2011) from (Brain, 1959; R. Hunter & MacAlpine, 1957), this culminated in the establishment of neurology by William

Harvey, 1585-1657 AD as a clinical specialty to tackle neurological disorders including epilepsy. French, British, Dutch and German medical schools played a crucial role in expanding knowledge on investigation, causality and therapy of epilepsy. John Hughlings Jackson (1835-1911) laid foundation for modern epileptology by his pathological and anatomical studies on epilepsy. He discussed the pathophysiology or mechanisms of various forms of epilepsy and defined focal and generalized forms of epilepsy. In 1929, Hans Berger (1873-1941) made progress on recording human brain waves (Berger, 1929).

Frederic Andrews Gibbs (1903–1992) and Erna Gibbs (1904-1987) collaborated with William G. Lennox to establish a correlation between EEG findings and epileptic convulsions (Gibbs et al., 1935; Gibbs et al., 1937; Gibbs et al., 1936). During the same period, pharmaceutical intervention to control epilepsy was advanced by H. Houston Merritt (1902 – 1979) and Tracy Putnam (1894-1975) by the discovery of phenytoin, Merrit et al (1938a, 1938b, 1939, and 1940). Thus Phenytoin became the first-line medication for the prevention of forms of epilepsy. Various institution have since been established to expand knowledge on epilepsy. Such institution include; National Institute of Neurological Diseases and Blindness (NINDB), the International Bureau for Epilepsy (IBE) and International League against Epilepsy (ILAE). Psychosocial aspect of epilepsy continues to be a priority in development of new knowledge on epilepsy. Quality of Life tools have been developed to monitor quality of life of the epileptics. Advocacy to enlighten the plight of epileptics is ongoing with initiatives such as the Global Campaign against Epilepsy, which was launched in 1997 by the WHO in place. , ILAE and IBE have advocated for improved diagnosis, treatment, prevention and social acceptability of epilepsy.

The evolution of views presented above gives a perspective of an illness with land mark breakthroughs of understanding the etiology and treatment based on solid scientific basis but which cultural beliefs remain solid. The history shows that despite advances in biomedicine breakthroughs management of epilepsy remains problematic owing to misconception and beliefs pass through generations.

From the review of the history it can be concluded that two parallel worlds exist in regard to understanding epilepsy; the world of science and biomedicine where documented evidence show progression in diagnosis and treatment and, the world of superstitions and stigma characterized by cultural beliefs and practices that alter quality of lives of those living with epilepsy.

## 2.5 Epidemiology of Epilepsy

Sociologists are preoccupied with why certain phenomenon are persistent in the society despite constant social change. The interest has been to establish causal relation among the variables in the phenomenon. Medical sociology is a specialty within sociology that investigates disease phenomenon. This thesis lie in this sub specialty and endeavors to explore among other things, the distribution, determinants and frequency of epilepsy. This section discusses the epidemiology of epilepsy. We will first discuss incidence and prevalence of epilepsy at global level followed by Africa and, finally by Kenya.

To contribute to knowledge on occurrence of illness Medical sociology researchers need to be well grounded in the distribution, social determinants of disease and, impact of disease on individual and society. The occurrence is established through identification and analysis of experiences of individuals with illness through establishment of patterns. Thus epidemiology review becomes important in this thesis to help understand previous analysis and patterns so that successful procedures can be incorporated in this study.

To importance of disease occurrence cannot be over emphasized. Counting and documentation of persons who have a disease is one simple way of noting the occurrence. Such count and documentation is essential not only to health planners or health economists who wish to determine the allocation of health care resources but to sociologist who wish to understand the magnitude of the impact the disease or condition on society or individual. However, count data alone have very limited utility for sociologist. Advanced methods of capturing disease occurrence such as prevalence and incidence rates are considered (Hennekens s*et al* 1987).

## 2.6 Incidences of Epilepsy

Incidence quantifies the number of new events or cases of disease or conditions that develop in a population of individuals at risk during a specific time interval. For example, if we define children aged 1 to 5 years as being at risk of developing epilepsy and say follow up a sample of these children over a period of time-say one year and note that some developed epilepsy, we will be able to know the incidence .i.e. the number of children who developed epilepsy over the interval of one year. There are specific types of incidence measures, cumulative and incidence rate. Incidence rate is considered to be the measure of instantaneous rate of development of disease in a population. It is calculated by dividing the number of new cases of a disease during given time period by the total person-time of observation. The numerator of the incidence rate is the number of new cases in a population. The denominator, however, is now the sum of each individual's time at risk or the sum of the time that each person remained under observation and free from the disease. Basically, the incidence of epilepsy looks at the number of new cases of epilepsy in a given year or period of time. It is often given in ration such as “x” out of 100,000 develops epilepsy each year.

Most of the epilepsy incidence studies in African have focused on rural population. These studies have been carried in the sub Saharan region. Over 680 million people live in sub-Saharan Africa. More than half of this population is under age 15 years. Most of the population lives in rural areas. However, rural to urban migration is an emerging phenomenon. Pierre-Marie Preux *et al* (2005) reviewed five studies of epilepsy incidences done in sub Saharan Africa. The studies were done in rural areas. The demographic characteristics of the populations studied were similar but the methods were different. Two studies repeated cross-sectional surveys with an interval of 2·5 years in Uganda and 3·5 years in Ethiopia. The three others were retrospective and used the onset of seizures to estimate the average annual incidence over 5–10 years. In general, annual incidences were high (63–158 per 100 000 inhabitants) compared with those found in industrialized countries in non-tropical areas (40–70 per 100 000 inhabitants). Incidence in Uganda was twice that in Ethiopia. Pierre-Marie suggests that prospective studies including a register of epilepsy ascertained by a neurologist would give a more realistic estimate of the incidence of epilepsy in sub-Saharan Africa.

A study on prevalence, incidence and risk factors of epilepsy in older children in rural Kenya published by Mung’ala- Odera *et al* (2007) showed that incidence of epilepsy among children aged 6-9 years was 187 (95% CI) per 100,000 per year. A study of a small population in Tanzania over a 10 year period estimated the incidence of epilepsy in children aged 0-9 years to be 94/100 000 per year (Rwiza *et al*, 1992). A community based study in Ethiopia, also in children aged 0-9 years, estimated the incidence to be 68/100 000 per year (Tekle-Haimanot *et al*, 1997) over a period of 3.5

years. According to Abdul Wahab (2010) the high incidence in developing countries is attributed to poor obstetric services and the greater risk of intracranial infections and head injuries. Furthermore in these countries 80-90% of epileptic patients have difficulties in accessing treatment. This treatment gap has been mainly ascribed to inefficient and unevenly distributed health-care systems, cost of treatment, cultural beliefs, and unavailability of antiepileptic drugs. Wahab further observes that the diagnosis of epilepsy in developing countries is a difficult task.

## 2.7 Prevalence of Epilepsy

Prevalence quantifies the proportions of individuals in a population who have the disease or condition at a specific instant and provides an estimate of the probability (risk) that an individual will be ill at a point in time. In the case of this study, our interest is prevalence of epilepsy. The prevalence of epilepsy looks at the number of people with epilepsy at a point in time. This includes people with new onset of epilepsy as well as those who have had epilepsy for a number of years. This one is usually given in total number, such as “x” millions of people, but can also be given as ratio. To show the number of people affected right now, usually we use prevalence but to show how often epilepsy occurs, the incidence number is used.

Epilepsy affects all ages, ethnicities, social economic class as well as geographic location, (Ackerman, 2012). More than 70 million people suffer epilepsy worldwide (ILAE, 2016). The global prevalence of epilepsy is estimated as 1% of the total global population though prevalence in some specific less developed countries are much higher than the World prevalence. Epilepsy is more common in developing countries. Over 13 million people with epilepsy live in Africa (Wagner, 2014). Prevalence of epilepsy in developing countries doubles that of high-income countries. The prevalence is attributed to higher incidence of risk factor (Newton 2012). Epilepsy prevalence in Europe was 3.3-7.8/1000 (Aidan *et al* 2015). The reported prevalence rates of active epilepsy in developing countries range from 5 to 10 per 1000 people (Bulletin of World Health Organization 2001).

In Sub Saharan Africa active epilepsy is estimated to affect 4.4 million while lifetime epilepsy affects 5.4 million. It is observed that in developing countries epilepsy prevalence is higher in adolescents and young adults (Banerjee, 2008). The prevalence of active epilepsy peaks in the 20-29 age group at 11.5/1000 and also in ages 40-49 at 8.2/1000 (Abigail *et al,* 2012). Age group of above 60 years has the lowest prevalence at 3.1/1000. In South Africa, a study involving 2,341 adults revealed a prevalence of 13.8/1000 (Eastman, 2005). WHO, statistics 1988-2003 show a prevalence rate of epilepsy in Kenya to be 18.20/1000 (WHO 2004). This prevalence applied to Kenya population of 40 million will translate to about 728,000 people living with epilepsy. This means that about 2% of the Kenyan population has epilepsy. This percentage is above the world prevalence of epilepsy of 1%.

### 2.8 Epilepsy among Young people

Literature under this section discusses epilepsy among young people and how the illness impact their daily lives.

Erick Eriksson explains adolescence and young adulthood as a period associated with psychosocial development where developing relationships with peers becomes important. Self-identify and esteem are developed at this stage. Experiencing chronic illness such as epilepsy at this age may have negative influence on individual’s identity and self-image. This can alter their self-esteem and lead to behavioral and psychological problems that can affect successful adjustment of their stage of development (Smith, 1998). Kılınc *et al* (2009) study on epilepsy and stigma showed that being diagnosed with epilepsy alters self-esteem and confidence. This was particularly centered on participant's perceptions of themselves during a seizure and the embarrassment of drawing attention during a seizure episode.

Clark (2008) observes that young adulthood is a period dominated by "firsts", for example, the first time for being out of the direct control of parents, the first time for living away from home, the first time for forming intimate relationships, and the first time transitioning from school to work. All of these critical transitions can be made more difficult because of epilepsy and its management. For example, epilepsy require lifelong medication. Costs and side effects of AEDs, availability, and adherence to medication may also pose challenges to young people living with epilepsy. Socially, the lifelong treatment poses many challenges. For example, daily doses of antiepileptic drugs have unpleasant side effects such as flatulence, drowsiness, weight gain or loss, nausea, vomiting, fever, behavior changes, depression, headache, and dizziness (Baker *et al*, 1997; Bishop & Allen, 2003; Buelow, 2001; Jacoby *et al* 2014). We observe therefore that whereas AEDs are effective and intended to solve problems of seizers, the accompanying side effects have the potential of significantly altering quality of life of young people with epilepsy (Jacoby *et al.*, 2014). Further side effects such as headache, tiredness, blurred vision, drowsiness and dizziness may interfere with tasks such as learning and wok. For example, a young person who experience side effects of drowsiness, blurred vision or dizziness may have challenges performing certain tasks or seeing and maintaining attention during learning. This can greatly interfere with his or her reputation or learning outcomes.

Epilepsy is a stigmatized disease that affects the everyday life of families and individuals suffering the condition. As advanced by Erick Erikson, adolescence and early adulthood is time of life associated with considerable psychological and social development, with peer relationships and society approval becoming increasingly important issues. Self-identity and acceptance is established at this time. Epilepsy, because of the associated stigma may interfere with peer relationship that are important at this stage. Additionally, young people with epilepsy may encounter challenges in other areas of their lives. Studies on epilepsy reveal that children with epilepsy are at risk of overprotection from the parents, who, because of the stigma attached to epilepsy attempts are made to conceal the child's epilepsy from the world at any price, Ziegler (1981), Ferrari *et al* (1983). This may be extended to young adulthood. Lemyra study on Tewa Children with epilepsy showed that mothers of children with epilepsy paid more attention to the child with epilepsy more than those without. This resulted in other children being neglected. In other findings study showed that siblings close in age to epileptic sibling displayed many attention-seeking behaviors, especially when young, but such attempts were met with little response from overburdened parents. Mothers said they were more concerned about the sick child because the child was developing differently.

Baker *et al*, (2005), observed that young people who live with epilepsy have a significantly higher incidence of depression related to interpersonal problems, social anxiety, and more obsessive symptoms than do adolescents without epilepsy. Epilepsy has traditionally been associated with stereotyped behavior patterns and personality types, (the "epileptic personality theory), Pasternak (1981). Jacoby (2007) observed that, young people with epilepsy may also experience psychiatric problems, difficulties in cognition and sometimes, maladaptive social function. Yi chungwaun *et al* (2011), observes lack of knowledge, inadequate awareness and negative attitudes may impede PWE from seeking the correct diagnosis and appropriate treatment. Lemyra study on Tewa Children who had epilepsy indicate that emotional problems may be attributed to the way society responds to persons with epilepsy. In Lemyra study children who had frequent epileptic fits faced constant teasing from peers. In one incident a child whose epilepsy had progressed from petit mal through psychomotor to grand mal epilepsy was referred to as a “monster” Among the Zuni, Hopi, and Tewa people, emotional problems among persons with epilepsy begin just prior to or during adolescence (Levy, 1981), probably due to the parents' denial of the disorder. Lemyra study hypothesized that children whose epilepsy is not well controlled will have poor coping mechanism in their adulthood if their parents refused to face the implications of the disorder. Hoare *et al.*, (2000) stated in their studies in which they compared the life quality of epileptic children and that of diabetic children that, epileptic children were more negatively affected by psychosocial development and health problems than diabetic children. Results from their study indicated that attention, thought and social problems tended to be specific to children with epilepsy, whereas problems with withdrawal, somatic complaints, anxiety/depression, delinquency and aggression were similar to those found in either their healthy siblings or in children with other chronic physical conditions (Rodenburg *et al.*, 2005). Hoare et al., (2000) stated in their studies in which they compared the life quality of epileptic children and those of diabetic children that, epileptic children were more negatively affected by psychosocial development and health problems than diabetic children.

While treating epilepsy, it is important to pay attention to coping with the psychosocial aspects and not just the seizure control. The foremost factor in coping with the psychosocial aspects of epilepsy is getting accurate information because epilepsy does not affect each individual in a homogenous way. Every individual is affected in own unique way. Society tends to carry several misconceptions and stigmas that affect how they view epilepsy and those who live with this condition.

For adolescents with a chronic illness like epilepsy, the transition to adulthood can be complex and difficult to negotiate. Blum *et al* (1993) and Baker *et al.*, (2005) observe that altered physical impairment or mental abilities as effects of neurological conditions may affect many of the adolescent tasks such as gaining autonomy, personal identity and making educational and vocational choices, schoolwork, sports, employment, and driving. Wiebe's (1999) survey on burden of epilepsy that found that people suffering epilepsy had more days off work, a lower annual income and a lower quality of life than people with other chronic illnesses. The survey further revealed that children with epilepsy posted lower performance at school than other pupils, including those suffering from other chronic diseases that affected their attendance at school. These findings are similar to those of Martland, (2009) that many epilepsies directly impact on a child's brain and, therefore, on their cognitive development, language and social skills.

Adolescents may also experience medical setbacks because of the perceived prognosis of the condition. These have the potential of reducing quality of life (McEwan *et al.*, 2004). Schalock *et al*. (2002) conceptualize quality of life as "subjective general feelings of wellbeing, positive social involvement, and opportunities to achieve personal potential". Further, Ronen *et al*.(2011), observes that quality of life issues are highly individual and perceptions of health outcomes cannot be determined by biomedical variables alone, thus highlighting the importance of considering multi-dimensional factors (Ronen *et al*., 2011).

### 2.9 Health seeking behavior

This section discusses literature on health seeking behavior. Discussion is guided by Wade *et al* (2004) definition of health seeking behavior as an action undertaken by individuals who perceive themselves as having a health problem or to be ill for the purpose of finding an appropriate remedy. The section uses Kleinman works on approaches to treatment.

### 2.9.1 Approaches in treatment of epilepsy

Kleinman (1980: 49-70) distinguishes three sectors of healthcare where the sick seek remedy for their illnesses; the popular sector, the folk sector and the professional sector. In the popular sector, we self-medicate or receive treatment or advice from non-professionals such as parents, relatives, workmates, etc. For example, one is having a diarrhea and a relative recommends a certain medicine over the counter. Folk sector is also commonly referred to as "traditional Medicine" and is usually not included into the official medical system. Traditional medicine are enduring practices, usually discreet that are associated with social groups who share certain beliefs, language and share common residence. These beliefs are distinguishable from other discreet and enduring practices associated with other such groups' (Luedke and West, 2006: 4-5). Traditional medicine may involve use of herbs, traditional paraphernalia, etc.

### 2.9.2 Traditional treatment of epilepsy

WHO (2003) defines traditional medicine as the health practices, approaches, knowledge and beliefs incorporating plant, animal and mineral based medicines, spiritual therapies, manual techniques and exercises, applied singularly or in combination to treat, diagnose and prevent illnesses or maintain well-being. Traditional medicine belief is that the cause of the condition or illness is external of the patient's body, i.e. supernatural and is not confined to the patient and his body, for example, witchcraft, curse, incest, kin, breaking a taboo, and spirit possession, etc.) (cf. Ademuwagun *et al.* 1978; Giles 1987; Devisch, 1993; du Toit & Abdallah, 1985; Feierman & Janzen 1992; Janzen 1982; Turner 1967). Traditional medicine places the individual in a set of relationships with the social and supernatural. For example it connects an individual to Lunar (moon) and links the effects of lunar to illness in the individual. Traditional medicine goes beyond treating the patients' bodies instead "intervenes" with the supernatural. The aim of the traditional medicine is to eliminate these malevolent forces that cause the illness or condition. This can be done through rituals such as slaughtering of animals to appease the causative spirits of illness, use of herbs or use of traditional paraphernalia, etc. Traditional medicine is usually static using the same procedures or practices. Traditional medicine practices are usually passed from one generation to the other of the practicing family or clan. Traditional medicine is common in developing countries, more so Africa where traditions are strongly held.

### 2.9.3 Biomedicine approach

On the other hand the professional sector involves biomedicine. This sector has its origin in Europe and is associated with modernity. Cooper (2005: 113-114) relates modernity to a very particular location in a very particular period of time, which is characterized as dynamic, progressive, civilized, and prone to change. The location he is referring to is 'Europe' and the time that is modern or 'modernity'. Contrary to modernity he say is tradition, which is everything that modernity is not, i.e., non-European, uncivilized, backward, static, primitive, and atavistic.

Biomedicine as a practice is concerned with treating patients as physical bodies by using material substances (Langwick, 2011: 23). Biomedicine largely rides on the medical model assumption that disease is a breakdown of the human body caused by a specific biological agent. Using this model medical science investigates the pathophysiology of the disease to elucidate on the exact cause of the disease. Traditionally medical model has had three dimensions, namely; that a specific etiology could be found underlying a specific disease: that disease cause lesions in the body which alter its anatomy and physiology and: that these two processes, in turn, give rise to symptoms (Gabe *et al*, 2004). In the case of epilepsy the cause is attributed to lesions in the body (in this case neurons in the brain) which alters the anatomy and physiology of the neurons. This alteration leads to excessive or hyper synchronous neuronal activity in the brain (American Academy of Neurology, 2012). This abnormal brain activity then causes seizers. The objective of biomedicine is to control or eliminate these seizures using material substances namely AEDs or surgery.

### 2.9.4 Pharmaceutical interventions in management of epilepsy

In biomedicine pharmacological treatment using AEDs is the preferred mode of treating or controlling epilepsy. The aim of pharmacological treatment is to control seizures and improve the quality of life with minimum side effects. Pharmacological treatment is based on seizure type but considerations should also include factors such as availability, affordability and side effect profile or toxicity. Patients usually receive individualized prescriptions of these medication based on a careful risk- benefit ratio (Perucca and Tomson 2011) with consideration to type of seizer, age, weight, sex, childbearing potential and side effects of the medication among other considerations.

AEDs work by decreasing neuronal excitability. However not all AEDs have the same relationship between electrophysiological slowing and decreased neuropsychological ability (Salinsky *et al*. 2007).The International League against Epilepsy (ILAE) has listed drugs that should be taken as first line treatment for epilepsy (Glauser *et al*.,2006). They include; phenobarbital, Carbamazepine, levetiracetam, and phenytoin. Other AEDs include Sodium Valproate and Benzodiazepines. By far phenobarbital is the most commonly used AED and is classified as an essential drug for the management of epilepsy. However, the efficacy and suitability profile of adverse events of Phenobarbitone have been questioned (Shorvon *et al*, 1988). Phenobarbitone is noted to be of little use in absence of seizures and has several disadvantages in some childhood epilepsies (ILAE, 1996). The preference of this drug is based on economic factors rather than on efficacy and suitability. A study survey (Cameron 2011) on drug availability in 40 developing countries including 12 countries of Sub-Saharan Africa showed that phenobarbital and/or phenytoin was available in only 40.3% and 29.4% of facilities in the private and public sectors, respectively. There existed other challenges in accessing AEDs especially in low and middle income economies. This challenges create treatment gaps that are witnessed in epilepsy treatment and management.

### 2.9.5 Treatment gaps of epilepsy in biomedicine approach

WHO (2017) defines treatment gap in epilepsy as the proportion of people with epilepsy who require treatment but do not receive it. Understanding treatment gap is important because it informs about the quality of care of people living with epilepsy. WHO (2017) states that up to 90% of people living with epilepsy in Sub-Sahara Africa and parts of Asian continent do not receive adequate medical treatment or do not receive the treatment at all.

In Sub-Saharan Africa for example, the epilepsy treatment gap was found to be above 67% in Congo and 67.8% in Rwanda (Koba Bora, *et al*, 2015). For Ruanda of 67.8 % treatment gap, 43% received no treatment and the remainder of the gap was attributed to traditional healer treatment or a mixture of traditional and medical treatment. In Kenya epilepsy treatment gap based on AEDs detected in blood samples was 62.4% (Mbuba *et al*, 2012). In Al-Quseir region of Egypt, treatment gap of epilepsy was found to be 83.8% (El Tallawy, 2016). Medical treatment for epilepsy is intended to control and eliminate seizers. In the absence of seizers controlling medicines people with epilepsy are exposed to dangers such as burns, drowning and suffocation among other injuries

There are many constraints and hindrances to adequate treatment of epilepsy in many developing countries. These constraints exist within economic, political and social frameworks of societies. For example, the varying cultural beliefs that influence our health seeking behavior happened within the social framework. If, for example, the cultural beliefs about epilepsy attract stigma, people may not seek treatment and the AEDs or lack of knowledge, and illiteracy can also lead directly to problems of compliance with medication regimens. Here the hindrance is happening within the social framework. Within the economic framework constraint to access of AEDs could be attributed to trade and profit issues within the pharmaceutical industry. For example, the prices of certain AEDs may be very expensive for consumers.

Jerome H.. They included: Inadequate supplies and costs of anti-epileptic medications, Chin (2012) identified five determinants of epilepsy treatment gap in Sub-Saharan Africa lack of primary health workers trained to diagnose and treat epilepsy, limited access to health facilities particularly in rural areas, social stigma, misinformation, and traditional beliefs, and limited opportunities for specialty training in Neurology. WHO (2013) and Katchanov (2012) estimate the World to have over 70 million people suffering epilepsy, majority of who live in low and middle income countries that have limited access to effective treatment. The limited resources contribute to the wide epilepsy treatment gaps existing in among the poor population.

### 2.9.6 Side effects of antiepileptic drugs

Research on quality of life among persons living with epilepsy has informed the need to reshape priorities in epilepsy care with a focus on being keen on the social functioning, mood and cognition of the individual and not just the control of seizer. Whereas the principal goal of epilepsy treatment is the achievement of seizer free status care should be taken not to introduce a new burden of side effects of the treatment. Much emphasis has been on control and elimination often neglecting the implication of side effects of the treatment on the quality of life of the patient. The importance of addressing of AEDs side effects is because people with epilepsy are on prolonged treatment often years or lifelong. Thus side effects become an issue of concern to persons with epilepsy.

Side effects are symptoms caused by medical treatment. A symptom is a subjective evidence of disease or physical disturbance. It is a reaction of the body to and external substance. Example of a symptom is drowsiness, headache or erectile dysfunction. There are two classifications of AEDs; Type A and Type B. Side effects of type A are predictable and usually occur at the beginning of medication. Type B is also referred to as adverse effects. While they are always unintended, they are not entirely unexpected in epilepsy treatment. They are the commonest type and have been reported in 40-50% of epilepsy patients receiving AED treatment, Baker *et al* (1997); Mattson *et al* (1985). The commonest side effects of type A side effects if AEDs include drowsiness, fatigue, dizziness, blurry vision, and in coordination. Type B side effects are unpredictable and not possible to foresee (Zaccara *et al*. 2007). One of the serious side effect of type B is the anaphylactic shock which is a medical emergency and can result in sudden death if quick and expertise intervention is unavailable.

Although most patients get concerned and report the side effects, some do not because, having grown used to the side effects while receiving AED treatment perceive the adverse effects as a natural consequence of their treatment. Mayo Clinic

(2009) notices that patients' fears of ongoing seizures tend to overshadow complaints about medication toxicity, that, seizure-free patients are often too comfortable with and grateful for their outcomes to broach the risk of lowering or withdrawing AEDs producing adverse effects, despite limitations in QOL. Physician also ignore the impact of side effects of AEDs because their primary concern is to suppress seizers. Another factor that makes side effect issue fade back is the busy schedule of epilepsy clinics where patients do not have adequate time to communicate their experiences of medication side effects.

Side effects have significant impact on quality of life. Patients often fail to adhere to drug regime because of the accompanying side effects of their medication. In a study on AEDs side effects, Kwan (2000); Perucca (2009), nearly 25% of the patients discontinued due to side-effects of the medication they were taking. There are social and economic cost implications for side effects. The economic implication is tied to the reduced productivity of the individual while the social costs is tied to altered social interaction. Some of the serious side effects of AEDs include teratogens in women of child bearing potential, bone density loss, neuropathy, and severe gingival hyperplasia.

### 2.9.7 Challenges people with epilepsy face in health care systems

WHO (2015) acknowledges the importance of health as a prerequisite in human capital development and places emphasis on access to quality healthcare. Governments are thus obliged to ensure universal health coverage of their citizens. Whereas developed nations have elaborate health systems that ensures this coverage, developing nations face a myriad of many challenges in healthcare provision resulting in lack of access to affordable and accessible healthcare. This lack of access is a key constraint to the management of people living with epilepsy. Factors such as lack of trained health care works, inaccessible health facilities, inadequate supply of epilepsy medication, stigma and myth about epilepsy and cultural belief systems may explain why many people living with epilepsy in developing nations remain untreated (Keikelame et al, 2006).

In their study on about their perceptions about management of epilepsy in primary care settings, Keikelame *et al*, (2006) found that epilepsy was perceived to be poorly managed in primary care settings and that that management of epilepsy should take into account factors such as stigma, illiteracy, poverty, and the effect of HIV/AIDS.

Literature cited in Wilmshurst *et al* (2016) study on challenges of managing children with epilepsy in Africa shows that access to modern health care facilities may be nonexistent among the rural population. This population often traverse great distances to seek medical assistance. Many African countries have poorly developed public transportation system that translate to costs. This incurs an added expense that may not be affordable for all. This expense is further heightened when the patients have to meet the entire cost of the required medications and investigations. Where governments offer free AEDs, that main hindrance to epilepsy treatment has been the frequent stock out of the medicines. Mung'ala-Odera *et al* (2008) study in rural Kenya found that 89% of children with epilepsy had neither been diagnosed nor received AED therapy. The study further found that health care facilities are often long distances for patients to reach, supply of AEDs tends to be unreliable, and compliance is often poor based on a combination of limited access to AEDs, cost, and lack of understanding of the nature of the disease.

Access to diagnostic equipment to assist in the management of epilepsy such as electroencephalography and neuroimaging machines is extremely limited in many parts of Africa. Even where equipment is available, it is not uniformly affordable or accessible and often breakdown because of lack of biomedical technicians. As such many individuals with epilepsy disorders remain undiagnosed because of the limited diagnostic facilities at health centers, more so in the rural settings.

Another challenge identified is the lack of qualified medical practitioners to manage epilepsy. Although there are variation among some countries having no neurologists, the ration of persons to Neurologist in Africa typically ranges from 1,612,039 to 5,099,908 persons per neurologist. In addition, these few skilled health professionals tend to work in the private sector. As such persons with epilepsy or their caregivers opt for the more accessible traditional health providers or other allied health providers who have limited options for epilepsy care to offer. There is also a major challenge of trained staff emigrating from Africa for higher salaries and better working conditions and job opportunities. Political instability also plays a part in necessitating the human resource flight (Burch *et al*, 2011; Hagopian, 2005). Challenges to access to health care services present in less developed nations and especially in Africa are further exacerbated by social, geographic, and economic barriers.

## 2.10Gaps Identified in the Literature

Majority of studies on epilepsy were focused on biomedicine. Those that looked at the social aspect centered on psychosocial issues in general manner and were done on assumption that communities had misconception on epilepsy. Studies carried out in Kenya were either on prevalence or focused only on beliefs regarding epilepsy or knowledge and attitude. A few studies talked about lived experiences but focused on care givers. This study therefore aimed to explore a comprehensive understanding of how epilepsy as a phenomenon is experienced in a context, by focusing on young people living with epilepsy among a community whose perception on epilepsy is established by a study. The objectives of this thesis are in tandem with literature in a number of ways, most conspicuous is the lived experience aspect and inclusion of the qualitative phenomenological approach, and semi-structured interviews. This enabled subjective experiences of young people living with epilepsy to be explored and interpreted

## 2.11 Theoretical Framework

### 2.11.1 The Phenomenological perspective

This study sought to gain an in-depth understanding of lived experience from young people living with epilepsy. Qualitative approach, using phenomenology, specifically interpretative phenomenological analysis is used as the framework for the study. In studies exploring lived experiences qualitative exploratory approach is considered the most appropriate (Bowling, 2014; Holloway and Wheeler, 2010; Mertens, 2015). Qualitative research is derived from the philosophy of constructivists and interpretivist. It involves social inquiry that attempts to make sense of people's experiences and the world in which they live (Holloway and Wheeler, 2010; Polit & Beck, 2013). Interpretivist views reality as something that is constructed by humans, who use language to put forward concepts, models and schemes to make sense of experience, and modify these constructions or meanings in the light of new experience (Schwandt, 2000). Accordingly, the researcher settled on a theory that could guide investigation of people experience thus selection of Interpretive Phenomenological Analysis. Phenomenology is selected based on its characteristic to describe the lived experience of several people (Creswell, 2007). Phenomenology however is quite challenging because of difficulties in understanding its complexity. The complexity arise from it being considered a philosophy as well as a theory, research methodology and, a research method (Caelli, 2000, 2001; Giorgi 1997, 2006;

Dahlberg and Nyström, 2008). There are also two forms of phenomenology that make choice challenging; Hermeneutic phenomenology (interpretative phenomenology) and, Husserl (descriptive phenomenology). Annelise Norlyk and Ingegerd Harder (2010) point and emphases the need to clarify how phenomenology philosophy is implemented in studies and proposes that it should articulate how it is a adopted, show if it is implemented as an approach, methodology or method clearly showing how it is incorporated to deal with phenomenon of interest. This section therefore details with how Interpretative Phenomenology Analysis emerges as the framework of the study. The section discusses phenomenology in general then narrows to two main types of phenomenology showing their merits and demerits used in selecting one that formed the theoretical framework of this study.

Van Manen, (1990) defines phenomenology as the study of phenomena or "towards the things themselves". Langdridge (2007), on the other hand defines phenomenology as a discipline that focuses "on people's views of the world in which they live and what it means to them; a focus on people's lived experience". She further highlighted that phenomenology, was a method of qualitative research, with a focus on the human experience as a theme or topic in its own right. It is concerned with meaning and the way in which meaning arises in experience. Phenomenology describes the lived experience of several people (Creswell, 2007). "It assumes that we make sense of lived experience according to its personal significance for us, and implies that experiential, practical and instinctive understanding is more meaningful than abstract, theoretical knowledge" (Standing, 2009. p. 20). The focus of phenomenology is not what appear but rather how it appears. Phenomenology investigation majorly aims at obtaining vivid explanation and interpretation of a human experience through careful exploration using the lens of the participant. Phenomenology yield rich data of narrative accounts regarding knowledge and experience of participants. There are two type of phenomenology namely Husserl's descriptive phenomenology (descriptive phenomenology) and Heidegger's Hermeneutic phenomenology (Interpretive Phenomenology).

**Husserl's descriptive phenomenology:** This was advanced by Husserl. It's also referred to as Transcendental Phenomenology. It focuses on describing human experience as "understood and described from the perspective of those who have had the lived experiences and are able to describe it" (Polit & Beck, 2008, p. 228; Ironside, 2005, p. 204). One of the assumptions of Husserl's postulation is that human experience possesses value and qualifies to be an object of scientific study (Lopez and Willis, 2004). Husserl pointed out that while using phenomenology as a research method one has to put aside their own experience, preconceptions, and theoretical leanings. He termed this practice as *bracketing*. His belief was that true understanding of a phenomenon could only be obtained when bracketing was performed. He therefore advocated for researchers examination of a phenomenon "in the right way" through bracketing. (Lewis and Staehler, 2010, p. 5) as cited by Hellman, 2016. The idea of Husserl is that as researchers we need to shed off our emotions and preconceptions while using this method. This idea is similar to positivist detached approach in discovering natural laws. The basic interest of Husserlian school is to discover and describe "lived world" (Narayan Prasad Kafle 2011). The intention for this study was to explore lived experiences and meaning made out of the experiences and not merely description of the lived experience. Further, the problem with Husserlian phenomenology is that it advocates for a single reality, more or less like positivist tradition pointing out that if there exist more than one reality then it leaves doubt and lack of clarity. In lived experiences one expects several realities owing to diverse circumstances of living (Narayan Prasad Kafle 2011). Therefore Husserlian approach was dropped.

**Interpretive Phenomenological Analysis:** This is also known as hermeneutic phenomenology and is focused on subjective experience of individuals and groups. It is an attempt to unveil the world as experienced by the subject through their life world stories. The idea of this postulation is that interpretations are all we have and description itself is an interpretive process. To generate the best ever interpretation of a phenomenon it proposes to use the hermeneutic cycle. Fundamental to hermeneutics is the need to properly interpret and understand the meaning of daily occurrences or experiences in life. Human experiences are interpreted historically and contextually (Koch, 1995). This means that interpreting human experience is based on our understanding of the culture and background in which the situation occurs. Heidegger (1929) assertion is that humans cannot be divorced from their culture and society practices. For example, in order to understand the phenomenon of lived experiences of epilepsy one needs to consider the social and cultural context in which epilepsy occurs for the study participants, and how it influences perceptions. The main principle of hermeneutics is interpretation and understand the meaning of daily occurrences or experiences in life. Human experiences are interpreted historically and contextually (Koch, 1995). This means that interpreting human experience is based on our understanding of the culture and background in which the situation occurs. Much of the literature on phenomenology as a framework has scanty information on sample size and sampling procedure (Giorgi, 1997) cited by Annelise Norlyk and Ingegerd Harder (2010). However, it is elaborate on procedure for data collection and analysis and explained in the following section on the application of IPA section in the study.

In applying Interpretive Phenomenological Analysis (IPA), this study uses guidelines of Manen (1997), which consider analysis of everyday lived experiences of individuals. Meanings of the captured experiences are then extracted through “hermeneutic cycle” (Langdridge, 2007). Essentially, researcher engages study participants in an-in-depth conversational interview to obtain detailed information on daily experiences. The researcher is keen to record the language used to express the experiences as this language reveals “being” (or existence) within some historical and social context and gives meaning to data. The language forms part of the analysis (Manen, (1997). In conducting the interviews the researcher acknowledges previous experience, knowledge and beliefs noting how these may influence research process. In analyzing phenomenological data using ‘hermeneutic circle’ the researcher scans through the text to identify specific texts and connecting them to the whole data set in an attempt to establish truth and make sense of phenomena (Langdridge, 2007). IPA is adopted because it is easily applicable and aids in maintaining focus on the phenomenon and the meaning of the experiences. Some studies that have successfully applied IPA are captured in table 2.1 below;

**Table 2.1: Examples of studies that have employed IPA**

| Title | Theoretical Framework | Author | Year |
|---|---|---|---|
| A Hermeneutic Phenomenological Study of the Lived Experience of Adult Female Sexual Assault Survivors | Hermeneutic Phenomenology (interpretative) | Ann N. Hellman | 2016 |
| Exploring the Lived Experiences of First-time Breastfeeding Women: A Phenomenological Study in Ghana | Hermeneutic phenomenology | Georgina Afoakwah | 2016 |
| A Phenomenological Study of East African Refugee Mothers' Experiences of Trauma and How It Affects Parenting | Interpretative Phenomenological Analysis | Binh Hoa Pham | 2016 |

## 2.12Conceptual Framework

Conceptual frameworks are important in research as they provide story lines or "World view" of the topic (Lacey 2010). Whereas Smyth (2004) defines conceptual framework as a set of broad idea and principle derived from relevant field and is used to structure a presentation of an inquiry, Hanson (2011) views a conceptual frameworks as skeletons on which to build an inquiry. Conceptual framework is different from theoretical framework in that whereas the conceptual framework is the researcher's "image" or structure of what he or she believes is the best explanation of the progression of the phenomenon being studied (Camp, 2001), theoretical framework is a specific theory or theories regarding subject matter and act as blueprint or roadmap or guide to the study (Grant & Osanloo, 2014). Conceptual framework emerges out of study process. This study adopted Jabareen (2009) definition of conceptual framework which views conceptual framework as a network of relating concepts that form to provide a comprehensive understanding of a phenomenon or phenomena. Conceptual framework is therefore not merely a collection of concepts but a relationship between them. The intention of the conceptual framework in this study is to provide an understanding of the relationships between concepts in the conceptual framework through interpretation rather than analysis of causal relationships (Levering, 2002). Conceptual study of this thesis was constructed from the initial comprehensive literature review. However, as data collection and analysis progressed new concepts were discovered which enhanced the framework (Glaser & Strauss. 1967; Strauss & Corbin. 1990). Robson (2002) cited by Helen Elise Green (2014) observes that it is useful to come up with a diagrammatic form of a conceptual framework and have it refined as data collection and analysis takes place. The concepts were then synthesized to make sense as illustrated in Figure

2.2. Specifically, the conceptual framework shows knowledge, attitude and, practices as being basis of perceptions and behavior towards epilepsy. The KAP influences the lived experiences with seizers as the main reference point. Seizers in return determines outcomes, such as, enacted stigma, low level of education and special living arrangement. The concepts of KAP are pegged to the cultural beliefs and ethonomedical systems of the community. The premise of this study was that illness experience, to a large extent, and is shaped by social systems and social construction of illnesses. These influences how individuals respond to those living with the illness. The proposition of this study is that if seizers are effectively controlled positive outcomes for those living with epilepsy can be achieved.

**Independent Variables Intervening Variables Dependent Variables**

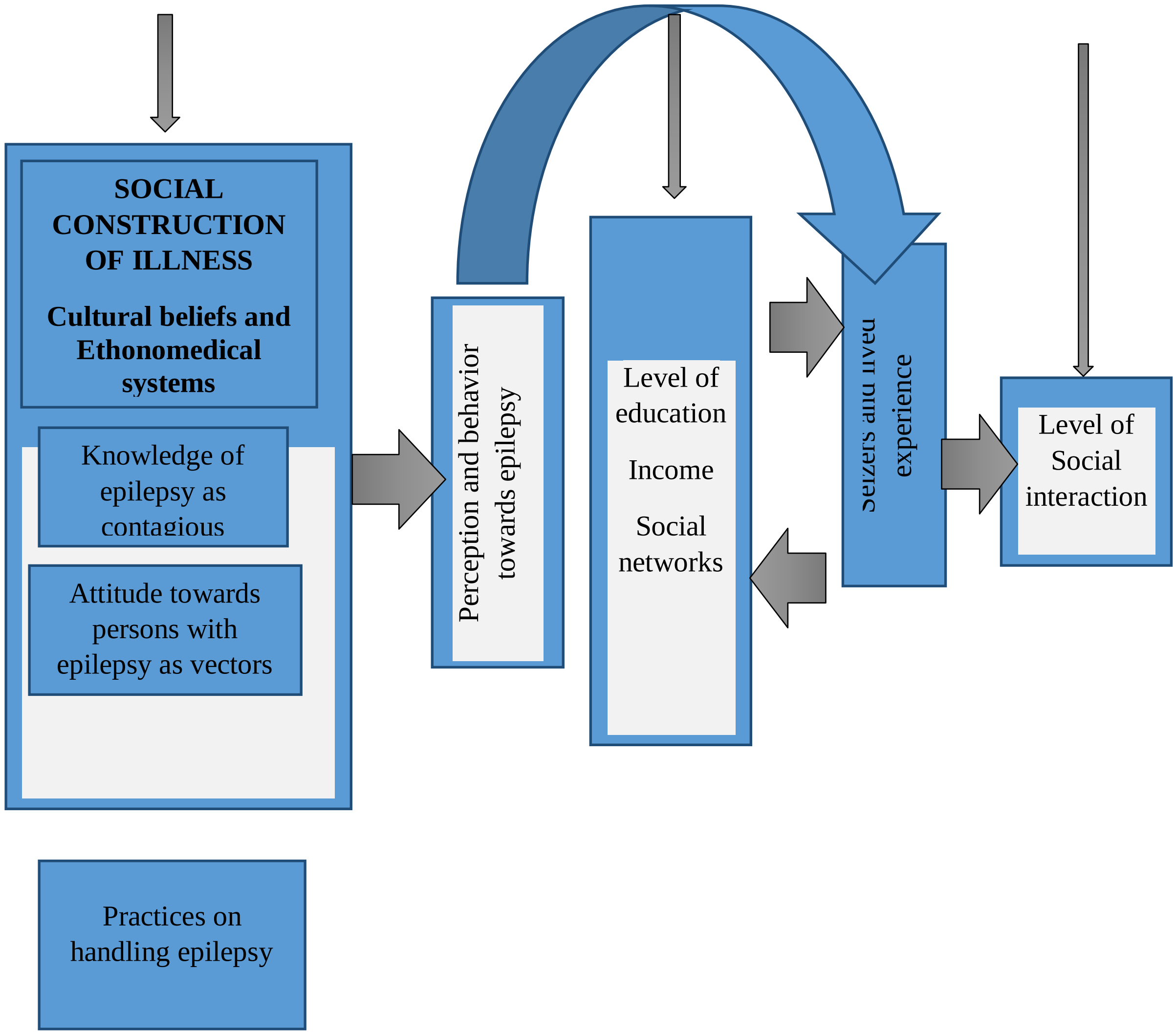

Figure 2.2: Conceptual Framework

## Operational Definitions

**Knowledge:** Knowledge as used in this study means the community ideas, mentalities and beliefs regarding epilepsy. The knowledge encompasses the understanding about illness causality, presenting signs and symptoms and, meaning attached to the symptoms as well as transmission of epilepsy. The knowledge is the product of social interaction and socialization on epilepsy among members of communities in Vihiga County.

**Attitude:** Attitudes in this study is used to mean community's responses or behavior towards epilepsy or those having epilepsy. The responses may be cognitively or physically expressed. The responses are consistent. They are been formed out of beliefs or observations on epilepsy

**Practices:** Acts directed towards persons with epilepsy by member of the community such as forms of isolation, fear

**Perceptions:** Interpretations regarding epilepsy such as interpretation of cause, spread and Treatment

**Seizers:** Episodes where persons living with epilepsy experience loose of consciousness, falls down and have jerky movements of all limbs and body. In the process they may produce a loud cry. The episode maybe accompanied by tongue biting, frothing of the mouth and, urine or fecal incontinence.

# CHAPTER THREE

# METHODOLOGY

## 3.1 Introduction

This chapter describes the study site, design, methods used to collect and analyze data and findings. The chapter demonstrates appropriateness of the theoretical framework, and methods used to get an in-depth understanding of the phenomenon of epilepsy. This study had two phases; a survey on community's Knowledge, Attitudes and Practices survey and, qualitative study on lived experience study of young people living with epilepsy. Methodologies and methods for each study are juxtaposically discussed based on underlying philosophies of either positivism or constructivists. The chapter begins with description of study followed by details of research designs, its methods for data collection and sampling techniques and procedures of data analysis for each of the phases.

## 3.2 Description of Study Area

The study site was Vihiga County in the Western part of the Republic of Kenya. Vihiga is mainly made up of the Luhya sub-tribes of Maragoli, Banyore and, Tiriki; which are Bantu. However, there are none Bantu communities living in the area attributed to exogamy and urbanization. Vihiga borders Nilotic communities of Luo and Nandi. Administratively, Vihiga is administratively structured as presented in table 3.1 below:

**Table 3.1 Administrative units of Vihiga County**

| Sub County | No of Divisions | Wards | Sub-wards | Area(Sq KM) |
|---|---|---|---|---|
| Sabatia | 2 | 8 | 31 | 110.9 |
| Vihiga | 1 | 5 | 18 | 90.2 |
| Hamisi | 4 | 8 | 28 | 156.4 |
| Emuhaya | 2 | 7 | 25 | 89.5 |
| Luanda | 2 | 10 | 29 | 84 |
| **Total** | **11** | **38** | **131** | **531.0** |

Vihiga lies on an altitude range of between 1300m and 1800m above sea level. There are two agro-ecological zones, the upper and lower midlands, which support mainly subsistence and tea farming. Long rains are experienced from March to June while short rains from September to October. The county has a population of 590,013 persons on a land of 563.8 sq. Km. The population is composed of 283,678 males, 306,323 females and 12 intersect, KNBS (2019). Vihiga is the third most densely populated county at 1,047 persons per sq. Km after Nairobi and Mombasa Counties. The total number of households in the County is 143, 365.

Regarding health, the number of people at risk of developing epilepsy in the County is over 650/100,000 Vihiga County Statistics office (2017). Life expectancy among the population of the County is 56.2 years compared to national average of 63.4 years. The infant mortality in the county is estimated at 64/1000 against a national average of 39/1000. The Maternal Mortality Rate (MMR) is at 344/100,000, compared to national's 362/100,000. The County adult literacy level stands at 93.8 % as compared to national figure of 78 %. The primary school Gross Enrolment Rate (GER) was 116 % whereas the Secondary school GER is 48.5 % compared to the national figures of 103.6 % and 62.9 % respectively. The County poverty level is at 39 % compared to national's 45%.

Vihiga has one referral and teaching hospital, three sub-county hospitals, 18 health centers, 32 dispensaries and 34 private and mission based healthcare facilities. The referral and teaching hospital an epilepsy clinic. These health facilities offer primary health care, curative services as well as maternal and child health services. The average distance from homestead to the nearest health facility is 5 Km (Vihiga County statistics office 2017). Malaria and other diseases such as HIV/AIDS related illness, upper and lower tract infections, diabetes, hypertension, cancer, diarrhoea and skin diseases are the most prevalent and cause of morbidity and mortality. For example the County has a HIV prevalence of 3.8 percent with 9900 adults and 1929 children living with HIV by the year 2014 (NACC, 2014). Malaria prevalence rate is 27 %, diarrhoea 5.4 %, respiratory diseases (upper and lower), and skin diseases 19.3 %. As stated in chapter 1, Epilepsy is a significant illness in Vihiga. The area was selected as a study site because of a high population at risk of epilepsy and the researcher's experience with persons living with epilepsy in the area.

### 3.3 Research Designs

The aim of this study was to explore the lived experiences of young people living with epilepsy in Vihiga County. To get an in-depth understanding of the context of the lived experiences a community survey on perception of epilepsy was done. The survey was important because it gave insight to the collective understanding of epilepsy by the community. This helped to understand rationale for specific every day behavior by persons living with epilepsy. Because of different philosophies behind the two studies different research designs based on their philosophical grounding were used. The first phase of the study intended to generalize findings therefore used Quantitative approach and survey in line with the positivism paradigm. The second phase which was lived experiences study used qualitative approach and case study design.

### 3.3.1. Research design for community KAP survey

The researcher used quantitative approach to obtain community perception using survey method. In this study the researcher was interested in understanding the knowledge, attitudes and practices on epilepsy among households in Vihiga County. The findings provided a point of reference on the lived experiences of young people living were explored. Survey was used as the method for collecting data. Surveys are designed to provide a ‘snapshot of how things are at a specific time’ (Denscombe, 1998). Surveys are suitable in studies that are interested in variations. For examples, this study probed on variations in beliefs about cause of epilepsy. Surveys as methods are effective in producing information on among others, socio-economic characteristics, knowledge, attitudes, perception and opinions. Survey design is also used to determine data collection instruments to be used in a study. Descriptive survey design was used to select respondents from the large population of people in the study area.

In this study the researcher used survey to collect information from the sampled individual. As stated before the purpose of the survey was to shed light on the community’s understanding, beliefs and practices on epilepsy. The intention of understanding the beliefs and practices regarding epilepsy was that it would provide the researcher with an understanding of the social environment in which persons with epilepsy live in. Descriptive survey studies involve gathering of information about prevailing conditions or situations for the purpose of description and interpretation (Salaria 2012).

### 3.3.2 Research Design to study Lived experiences of young people living with epilepsy

This section discusses the case study designed used in the second phase of the study to achieve the second and third objectives of the study, which were the primary objectives of the thesis. The section demonstrate the appropriateness of the design in getting an in-depth understanding of epilepsy as an experienced phenomenon.

### 3.3.3 Case study design

The lived experience study was carried on the premise of constructivist philosophy. Constructivists seek to gain in-depth understanding of a phenomenon through exploration and construction of reality. Since this study sought to explore and understand realities of daily living of persons with epilepsy a qualitative exploratory approach was seen as most appropriate for the study (Mertens, 2015; Bowling, 2014; Holloway & Wheeler, 2010). Qualitative research is based on the philosophy of Interpretivism. Schwandt (2000) and Sontag (1989) note that Interpretivism is an attempt to understand reality of a phenomenon as perceived and interpreted by each individual, whether participant or researcher. The reality is thus constructed from individual’s experiences of the phenomenon. This constructivist epistemology assumes that no objective truth is waiting to be discovered. Instead, truth or meaning comes into existence in and from our engagement with the realities of our world, (Brynja, 2006). In this study individual young persons living with epilepsy were confronted with realities of community’s perception of epilepsy. The realities are unique to individual since they are derived from specific interactions and specific context of their community. Their realities are not universal laws awaiting discovery as philosophized by the positivists but rather as individually experienced and perceived hence the researcher inclination to the interpretivist philosophy.

Case study was an appropriate design because it’s in line with principles of constructivist philosophy as it seek “an in-depth and detailed investigation of the development of a single event, situation, or an individual over a period of time”. Yin (1984) defines case study as “an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used” This design suited this study because of its aspect of investigating a phenomenon within “ real-life context”. The study sought to understand epilepsy in context of lived experiences of young person living with the illness.

## 3.4 Target Population

There were two target populations in the study; household heads and young persons with living with epilepsy. Households’heads were the target population for the KAP survey study while young persons living with epilepsy were the target population for lived experience study. The survey focused on households in Vihiga because household are units where socialization regarding knowledge, attitudes and practices on health take place. Young people living with epilepsy were the target population because they were the focus of the study.

## 3.5 Units of analysis

A unit of analysis is an entity that is being analyzed in a study. There were also two units of analysis in the study to correspond to the two target population. In the community KAP survey the unit of analysis was household head or any adult in the household. Members of the household were selected as unit of analysis because they were assumed to be socially oriented on how they make meaning of epilepsy. It was assumed that household head or adult in the household was knowledgeable about community's beliefs and practices on epilepsy because of socialization from older generations regarding epilepsy illness. . The other reason was that the household heads were assumed to have social networks within the community that provided a rapporteur of information relating to illness of epilepsy that form perception towards epilepsy. In the second phase of the study the focus was on lived experiences and it therefore became the unit of analysis. The definition of lived experience as defined by Depraz *et al*. (2003), and cited by Dieumegard *et al* (2019) is, the first-hand acquaintance which an individual is subjected to at any given time and place, to which s/he has access "in the first person". By "first person" we mean the subject's perspective of the unfolding social interaction within a given context.

## 3.6Sampling Procedures and Techniques

### 3.6.1 Determining sample size for community KAP survey

Sample size is majorly determined by resources and statistical parameters of confidence interval and confidence levels. However, the rule of thumb in social sciences research and among statisticians is that for basic survey studies that need a rough estimates of the results, a minimum sample size of 100 is adequate and can yield meaningful result.  It is suggested that you choose a number closer to the minimum if there are limited resources and time and, if you only need a rough estimate of the results. The intention for the KAP survey in this study was to get a general idea of the perception of households on epilepsy. Two administrative locations with a total household population of 7275 (Vihiga County Commissioner's Office, 2017) were sampled as explained in the subsequent section. Using sample size calculator from *surveysystem.com*, at confidence level of 95% and confidence interval of 7.92 a sample of 150 households was determined.

#### 3.6.1.1 Sampling procedure for community KAP survey

To sample households to participate in the study two wards were sampled using multistage sampling techniques. Vihiga County has 5 sub Counties, from which two sub counties (Sabatia and Emuhaya) were systematically randomly selected as shown in table 3.1.

Sabatia Sub County has 8 wards from which one ward (Wodanga) was sampled while North East Bunyore was sampled from Emuhaya Sub County of 7 wards. Proportionate sampling was used to get household sample size for the sampled wards of Wodanga and North East Bunyore as illustrated in tables 3.1. To sample households proportionate to each location the following procedure was used;

Wodanga and North east Bunyore wards had 3275 and 4000 households, respectively. The formula used to get the number of households that participated in the study was;

$$\text{No. of households per Ward (n1)} = \frac{\text{Household Population of the Ward (x) 150 (n)}}{\text{Total no. of households in the two Wards}}$$

**Table 3.2 Sampled wards and household sample size**

| Location | Population (M & F) | No. of households per location | Sample size from Each location |
|---|---|---|---|
| Wodanga | 30,095 | 3,275 | 68 |
| North East Bunyore | 35,908 | 4000 | 82 |
| **Total** | | | **150** |

#### 3.6.1.2 Sampling of households and young people with epilepsy

To sample each specific household to participate in the study, the researcher obtained a household list for each location from KNBS. Kth number formula ***(K= population/sample size)*** was applied to select every household on Kth household position to participate in the KAP survey. Location of the Kth household was identified by the help of Assistant Chiefs and N*yumba Kumi* heads. Household head or eldest person in the household was selected to respond to the questionnaire. Young people with epilepsy were sampled from the two wards using purposive sampling and snowballing techniques as is explained in the following section.

#### 3.6.1.3 Response rate for KAP survey

The study targeted a sample size of 150 respondents. A total of 121 questionnaires were completed representing 82% response rate. 29 questionnaires were incomplete and were therefore excluded from analysis. The sample size of 121 is adequate because it meets the required threshold of a quantitative study that requires a minimum sample size of 100.

### 3.6.2 Sampling procedure for Lived experience study

Fifteen participants were purposively selected to the study using snowball sampling techniques and principal of saturation from the two sampled wards. Eight participants were sampled from Wodanga while 7 were sampled from North East Bunyore ward. Purposive sampling is a non-probability sample method, characterized by the researcher's effort to gain representative samples (Holloway & Miles, 2002). Purposive sampling selects information-rich units or participants for in-depth study (Patton (1990). The researcher used this method because it selects specific individuals who are known to have knowledge and an understanding of the phenomenon under study (Creswell, 2007, p. 125). This method does not seek a representative sample for generalization to population, instead focus is on context. In this case the context was lived experiences within a specific community with specific social construction of the phenomenon (epilepsy). In this study, the researcher considered a purposeful sampling method as most appropriate because research participants specifically had had the experience of the phenomenon being investigated. This approach helped in the selection of young people living with active epilepsy. Therefore, sampling was intended to ensure the inclusion of young people living with epilepsy who could provide context-rich information regarding lived experiences of epilepsy (Streubert & Carpenter, 2010; van Manen, 1990). Snow balling was used to recruit participants to the study. Snowballing is used in studies where participants are not easily available or willing exposure owing to various reasons such as sensitivity of the phenomenon such as; security or illicit drug trafficking and, stigmatized conditions such as HIV or epilepsy. The researcher identifies a respondent who is willing to recommend another respondent. This goes on until saturation of data is achieved. In this study participants were identified by help of community health workers, the subsequent participants were introduced to the study through interviewed participants who had knowledge of pothers or through community gatekeepers who were familiar with the community.

#### 3.6.2.1 Sample size determination for young people with epilepsy

Sample size for lived experiences study was determined by saturation. Saturation is used in qualitative research as a criterion for discontinuing data collection. Saturation means that no additional data are being found whereby the researcher can develop properties of the category. As he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated. In this study 15 respondents were interviewed. The researcher realized saturation at the 10thhrespondent. Morse *et al* (1995) and Smith, *et al*, (2009), considers a sample size of 6-10 adequate for a phenomenological study. Data saturation is not about the numbers per se, but about the depth of the data (Burmeister and Aitken, 2012). A large sample size does not guarantee one will reach data saturation, nor does a small sample size, rather, it is what constitutes the sample size (Burmeister and Aitken, 2012).

### 3.7 Methods of data collection

This section discusses methods for data collection in the first and second phase of the study.

#### 3.7.1 Data collection in the KAP survey

The KAP survey used a structured questionnaire that had closed and open ended questions (see Appendix 1). The questionnaires were administered through one on one interview conducted in a conducive environment within each of the respondents' compound. Oral consent was sought from respondents before commencement of the interviews.

#### 3.7.2 Data collection from the young people with epilepsy

A semi-structured interview guide was used to conduct in-depth conversational interviews that were tape recorded. Structured interview was appropriate for this study because unlike the structured interview that has a rigorous set of questions that do not allow for reflection and probating, a semi-structured interview is open and non-directional allowing flexibility to go forth and back as new ideas emerge during the interview. Merrill (1999), explains that, a conversational interview is a two way process where the interviewer interacts with the interviewee in a conversation. Conversational interviews aim at understanding participant world of experiences. The researcher follows participant‘s path by actively listening (Kvale, 2007) and jointly constructing the narrative and meaning (Mishler, 1986, cited by Riessman, 2008, p.23). This method of data collection was appropriate for this study because it enables the researcher to follow up the conversation by reflecting and probing because conversational interviews are open, allowing new ideas to be brought up during the interview as a result of what the interviewee says.

Data collection begun by researcher taking time to create rapport with a participant and significant others. Consent for interview and audio recording of the conversation was sought before commencement. The interview sessions were interactional with participants asking questions as much as they responded in the interview. However, the researcher took caution not to turn the interview sessions into epilepsy health talk as Mason (2002) cautions. In most of the interviews care givers interjected in bid to help participants whenever they had difficulties keeping concentration. It came spontaneous that the researcher shared his life experiences as much the respondent shared theirs. The researcher talked about his family life, schooling and career as sociologist. He shared his field research experiences in different societies. The research experiences fascinated most respondents and improved the rapport and bonding between the researcher and participant. The researcher was morally obliged to share his e experience because respondents too were talking about theirs.

Interviews lasted an average of 2 hours. Subsequent visit interviews lasted 30-40 minutes. Data collection for lived experience study was done over a period of 4weeks. Semi-structured interview guide (Appendix B) used was partially derived from existing literature on psychosocial aspects of lived experiences of chronic illness on the concept of making meaning of illness and quality of life but was improved on in the course of data collection as new perspectives emerged from participants. All interviews were conducted by the researcher with an assistant who took side notes and managed the audio tape. The researcher is a trilingual and conducted the interviews in English, Kiswahili and Luhya to accommodate the language preference of respondents. Four interviews that were underway were discontinued and rescheduled. Three were discontinued to maintain privacy because visitors arrived in the homesteads unexpectedly while in one the participant had seizer attacks. The flow of interviews are captured in table 3.3 below.

**Table 3.3 Flow of interview matrix**

| | | |
|---|---|---|
| 1 | Could you please describe your illness of epilepsy to me? Probe for triggers of epileptic fits or seizures, the nature of the fits and duration, medication side effects, hospital visits and what does the illness mean to you. | General experiences of epilepsy<br>↓<br>Moving to more specific experiences and understandings<br>↓<br>General questions on daily life<br>↓<br>Specific questions coping with epilepsy<br>↓<br>Specific questions life trajectories |
| 2 | Could you please describe your illness of epilepsy to me? Probe for triggers of epileptic fits or seizures, the nature of the fits and duration, medication side effects, hospital visits and what does the illness mean to you. | |
| 3 | How do people relate to you as a person living with epilepsy | |
| 4 | Describe to me how you feel after having an attack of epileptic fit. Probe for forgetfulness, behavioral disturbances, worries about what others will say and self-esteem | |
| 5 | Describe to me your daily activities. Probe for impediments to daily activities brought by the epilepsy. Probe for home activities, school and social activities- (sports, drama, dating, outings etc.) with peers | |
| 6 | Describe to me how you socialize with your peers in school and other places. Probe for the reaction of peers, teachers and significant others to respondent illness of epilepsy. | |
| 7 | Describe to me your expectations in future and what you are going to do to achieve your expectations. Probe for worries about illness, studies, employment, independence and marriage and family. | |

## 3.8 Validity and Reliability Instruments

In any research the measurement instruments must be reliable and valid. Reliability is the degree to which a test consistently measures whatever it measures (Gay, 1987). For example, the questions on the instruments should yield consistent responses when asked multiple times (reliability). According to Brynja (2006) measurements are reliable to the extent that they are repeatable and that any random influence, which tends to make measurements different from occasion to occasion or circumstance to circumstance, is a source of measurement error. On the other hand validity is the extent to which a test measures what it claims to measure (Brynja 2006)). In this study a dry run on 10 respondents in the community KAP survey and one participants in the lived experience study were done to determine the reliability and validity of the questionnaire. The pilot study was done away from the selected study site. The instruments were verified for response errors. Final questionnaire and interview scheduled were then refined.

### 3.9 Credibility and Dependability in Lived Experience Study

Credibility is the extent to which findings of a study can be trusted, or the extent of ‘confidence in the truth’ of the reported results (Morse, 2007). Credibility in phenomenological studies can be enhanced by ‘prolonged engagement’, ‘negative case analyses’, ‘member checking’, ‘peer-debriefing’ and ‘referential adequacy’ (Lincoln and Guba, 1985). Credibility in this study is enhanced by quality time spent with participants in conversational interviews. The interviews yielded rich data that informed experiences of participants. After the initial interview the researcher paid other several visits to spent time with participants in the event any hidden or other information about lived experience could come forth. A peer debriefing exercise by supervisors was done as another form of enhancing credibility of the study. Supervisors closely regarding data management including formation and refinement of themes. All important data were maintain in the analysis. Dependability which shows the consistency and the ability for the research to be repeated (Lincoln and Guba, 1985) was achieved by application of a solid and well thought theoretical framework and an illustrated conceptual framework to the study.

### 3.10 Method for Data Analysis

This section details analysis of data in the two phases of the study

#### 3.10.1 Method for analysis of KAP survey data

KAP survey yielded both quantitative and qualitative data. Therefore both qualitative and quantitative analysis were applied. Firstly, all questionnaires were cleaned for completeness by perusing through each questionnaire on details such as demographics and follow-up questions. The questionnaires were then serialized 1-150. Out of 150 questionnaires 121 were found to be complete and appropriate for analysis. Manual coding was done for each question. The main feeder for qualitative data were open ended questions. The qualitative data was first managed by manually creating and assigning categories. The researcher went through each open ended question comparing with other responses. Similar responses were grouped together. Categories were further reviewed and collapsed into smaller ones before assigning a code. Quantitative data were coded. The coded data was put on a spread sheet in a sequence corresponding to numbering on the questionnaire. Data entry unto the SPPSS was done. Data was analyzed using the SPSS version 17. Results were presented using cumulative percentage frequency tables.

### 3.10.2 Data analysis for lived experiences study

Data for lived experience study was analyzed in keeping with interpretative phenomenology analysis theoretical framework that provided the method. In analyzing phenomenological data the goal was to “transform lived experience into textual expression of its essence – in such a way that the effect of the text is at once a reflexive, re-living and a reflective appropriation of something meaningful” (van Manen, 1997, p.36) cited by Georgina Afoakwah (2016). As discussed under application of hermeneutic phenomenology in the literature review, phenomenological data is analyzed using ‘hermeneutic circle.’ The researcher scans through the text to identify specific texts and connects them to the whole data set in an attempt to establish truth and make sense of phenomena (Langdridge, 2007). This process involves ‘a thick description that accurately captures and communicates the meaning of lived experience for the informants being studied (Cohen *et* al.2000, p.72).

### 3.10.3 Procedure of analyzing qualitative data from lived experience phase of the study

At first, the researcher transcribed the audio taped interviews. Files were created for each respondent. The transcripts were perused through one at a time numerous times to match each to audio tape recordings. IPA analysis begun at the level of the individual case. The researcher combed through the scripts, doing line-by-line analysis of the experiential claims, concerns and understandings of each participant (Larkin *et al*., 2006). Field notes and photos taken during interviews were attached to specific files of transcripts. This helped the researcher recall specific respondent and the interview interaction. In the field notes the researcher had recorded various observations such as nature of house and living arrangements. The researcher also captured how respondents expressed themselves by way of body language and metaphors used to explain lived experiences. Studies point to significant role metaphor play in illness narratives (Kleinman, 1988), especially illness of chronic illnesses such as epileptic seizure (Plug *et al*., 2009).Metaphor were useful in understanding meaning of some of the experiences. Narratives that were similar were identified and recorded on a sketch with arrows to show relationships

In the second step of analysis using IPA, the researcher went through each transcript, this time using a highlighter pen, underlined important point that pointed to the objectives of the study. The researcher captured areas that were emphasized by participants. IPA involved identifying emerging patterns of participant’s narratives. Patterns were drawn from the commonality in responses, (Eatough and Smith, 2008). To identify emerging patterns the researcher returned to the transcript to transform the initial notes into emerging themes or concepts, ensuring that the themes did not lose the connection between the participant's words and the researcher's interpretation.

In the third step, the researcher constructed a matrix table that showed areas of similarities and emphasis in respondents' narratives. The contents in the matrix table were then critically analyzed and grouped to form emerging themes. Larkin *et al*., (2006) and Smith (2004) explain that the third step in IPA data analysis involve researchers view and interpretation of the emergent themes. They point out that there is a 'dialogue' between the researchers, their coded data and their psychological knowledge, about what it might mean for participants to have these concerns in this context. This leads to further interpretation of the themes. The researcher examines the emerging themes and clusters them together organizing them to conceptual similarities and likeness. The clusters are given descriptive labels, which convey the conceptual nature of the themes in each cluster

The fourth and fifth step involved the researcher reexamining the emerging patterns in the narratives. Four themes emerged. The emerging themes were further examined to see if the narratives in the themes were beginning to form answers to the study objectives. In the sixth and final step of IPA analysis the researcher sought the views of his thesis supervisors on the emergent themes. The researcher also revisited reviewed literature on similar studies and how they were analyzed. Refinement of the themes was completed and logically arranged in chapters five and six of this thesis.

### 3.11 Ethical Consideration

This study dealt with experiences of a health problem of young persons. Health issues are private and confidential individual matters requiring protection of respondent's privacy and wishes. Age is also an important aspect regarding ethical issues. It is required that consent of parents or guardian must be sought if interviews are involving minors and persons below 18 years. Authorization to carry out the study was sought from the Moi University and National Commission for Science Technology and Innovations (NACOSTI). In this study all the participants were above 18 years of age. Informed consent was sought and confidentiality assured.

Among the important ethical considerations is the safety of the respondent. Safety may take varied forms such physical or emotional safety, the right to discontinue an interview, anonymity, privacy and confidentiality. Guba and Lincoln (1994) observe that ethical concern about privacy, confidentiality and anonymity can easily arise in phenomenological inquiry because in such inquiries people reveal their personal experiences. Researchers are thus prevailed upon to protect human rights of the respondent. Contemporary guidelines emphasizes informed consent as a prerequisite for conducting such studies with humans, and require researchers to make arrangements in regard to possible harm entailed by participation in the study. In regard to physical and emotional safety the researcher was diligent in ensuring that there was no physical and emotional harm to respondents.

### 3.12 Conclusion

This chapter has examined the research designs, methods and the processes. The philosophical orientations applied to guided choice of methods were examined. The chapter has highlighted KAP survey as the most appropriate choice for KAP survey and case study as the research design of choice for the phenomenological study. IPA has been presented as the appropriate method of data analysis. The chapter is crystalized by discussing the trustworthiness and accuracy of the study.

# CHAPTER FOUR

# COMMUNITY MEMBERS' KNOWLEDGE, ATTITUDES AND PRACTICES ON EPILEPSY

## 4.0 Introduction

This chapter presents community perceptions towards epilepsy and in particular it discusses the cultural beliefs, knowledge, attitudes and practices. The chapter argues that illness perceptions play an important role in its management. This perceptions arise from community's socialization and influence how individuals respond to a particular illness.

## 4.1 Characteristics of the Household Members

In this study, characteristics of the respondents were held to influence their knowledge, attitudes and practices on epilepsy. The characteristics were: Gender, age, formal education, marital status and occupation.

### Gender:

Data for this study was collected from 121 respondents. As shown in table 4.1 below, 41.3% were male and 58.7 % female. There were more females than males in this study because the ratio of female is higher than that of male in the study site. This is confirmed by KNBS (2013) which show the number of females in Vihiga to be 291,904 against that of males of 262,718. Further the high ration of females against males is attributed to the community's cultural division of labour where women are allocated the roles of nurturing. Nurturing involves the role of taking care of the family health hence women are expected to know more about how to handle illness and thus presumed to be more knowledgeable about illness than men. During data collection the household members preferred giving the females an opportunity to answer the questionnaire owing to the nurturing role assigned to them as explained above.

**Table 4.1 Gender distribution of the household members**

| Gender | Number | Percent |
|---|---|---|
| Male | 50 | 41.3 |
| Female | 71 | 58.7 |
| **Total** | **121** | **100** |

**Age:**

As shown in Table 4.2 below, 25.6% of the respondents were aged 15 – 25 years, 16.5% aged 26-35 years, and 18% were aged 36-45 while 31% were above the age of 56 years. These findings are consistent with the general Kenya's population which shows that young people form majority of the population. Kenya's population is composed of 35% of youth and 43 % children, KNBS, (2015). UN report (2017) estimates 61 per cent of Kenya's population to be either children age 0 to 14 or youth age 15 to 24.

**Table 4.2 Age distribution**

| Age group | Number | Percentage |
|---|---|---|
| 20-25 | 31 | 25.6 |
| 26-35 | 20 | 16.5 |
| 36-45 | 22 | 18.2 |
| 46-55 | 10 | 8.3 |
| 56< | 38 | 31.4 |
| **Total** | **121** | **100** |

**Level of education:**

The results show that 20.7% of the respondents had university education, 24% had tertiary education, 33.9% had secondary school education and 4.1 % had primary education while 15.7 had no formal education. From the findings we note that there is high literacy level among households. This finding is consistent with KNBS (2013) figures of Vihiga County on adult literacy level which stands at 93.8% higher than the national figure of 78% and a total of 18% of the residents having no formal education. The primary school gross enrollment of the County was 116% compared to national enrollment of 103.6%. This high literacy rate could be attributed to the high number of missionaries in the County. These missionaries came to the area in the early 19th century to spread Christianity. In the process they educated the locals through the various learning institutions they established. As Christianity spread the churches established more learning institutions and encouraged schooling. For example, Friends (Quakers) missionaries established schools, hospitals, and training institutions such as Kaimosi Girls high school, Kaimosi Friends Mission Hospital and Kaimosi Teachers Training College. Pentecostal assemblies of God missionaries as well as other missionaries such as Anglican Church, Church of God and Catholic churches also established schools and trainings institutions that continue to educate the catchment population. As per KNEC (2005) statistics there were 396 primary schools and 117 secondary schools in the study area.

**Table 4.3 Level of formal education of the household members**

| Level of education | Number | Percent |
|---|---|---|
| University | 25 | 20.7 |
| Tertiary | 29 | 24.0 |
| Secondary | 41 | 33.9 |
| Primary | 5 | 4.1 |
| No formal education | 19 | 15.7 |
| No response | 2 | 1.7 |
| Total | 121 | 100.0 |

**Occupation:**

The results from table 4.4 on occupation show that 35.5 % of the respondents were employed, 31.4% were peasants, 10.7 percent were involved in various businesses such as hawking maize, banana or sugarcane, and running small business such as a retail shop and Mpesa finance agency for a livelihood income. Nearly 17.4 % were students while 5 % were retired citizens. Despite the high number of households with formal education there is high unemployment rate among the households with only 35.5% in formal employment.

**Table 4.4 Occupation**

| Occupation | Number | Percent |
|---|---|---|
| Student | 21 | 17.4 |
| Retired civil servant | 6 | 5.0 |
| Formally employed | 43 | 35.5 |
| Business person | 13 | 10.7 |
| Peasant | 38 | 31.4 |
| **Total** | **121** | **100** |

### Marital Status:

Regarding marital status 52.1 % were married, 26.4 % were single and 14% were widows while 7.4 % were widower. In this community married people enjoy high social status. Being unmarried especially when one has attained socially acceptable and legal age for marriage attracts stigma. The stigma is worse if the unmarried happens to suffers from epilepsy. This may explain the high number of marriages among the households. Apart from avoiding stigma or motivation for improved social status, marriage has other benefits such as psychosocial support, economic support and security that may motivate one to marry.

**Table 4.5 Marital status**

| Marital status | Number | Percent |
|---|---|---|
| Married | 63 | 52.1 |
| Widow | 17 | 14.0 |
| Single | 32 | 26.4 |
| Widower | 9 | 7.4 |
| **Total** | **121** | **100.0** |

## 4.2 Household Members' Knowledge about Epilepsy

The first objective of the study was to investigate the knowledge, attitudes and perception on epilepsy of the community members of Vihiga. The indicators for these objectives are knowledge, attitudes and perceptions.

### 4.2.1 Respondents' knowledge of epilepsy

Respondents' knowledge of epilepsy was measured by examining their sources of information on the illness, their knowledge of its causes, knowledge of its symptoms and signs and epileptic seizures and, treatment.

#### 4.2.1.1 Sources of information on epilepsy

Respondents gave varied sources of information regarding their knowledge on epilepsy. As shown in Table 4.6 a majority of the respondents at 47.9% got information on epilepsy from their routine social interactions with neighborhoods, friends and relatives, 26.4% got the information from media, 10.7% got their knowledge on epilepsy from institutions such as schools and churches while 9.1% got from informal social groups and gatherings such as women groups, while 5.8% got information from health institutions. The significance of sources of data is that it informs on institutions that socialize about illness and that can be targeted for intervention.

**Table 4.6: Sources of information**

| Source of your information on epilepsy | **Number** | **Percent** |
|---|---|---|
| Health institutions | 7 | 5.8 |
| Media | 32 | 26.5 |
| Institutions such as schools and church | 13 | 10.7 |
| Informal social groups and gatherings such as *"Chamas"* (women groups) | 11 | 9.1 |
| From random social interactions with neighborhoods, friends and relative | 58 | 47.9 |
| **Total** | **121** | **100.0** |

#### 4.2.1.2 Respondents' knowledge on causes of epilepsy

Regarding the knowledge about cause of epilepsy, 7.4% believed one could contract epilepsy by coming into physical contact with person living with epilepsy, 91% however disagreed. 12.4% said epilepsy can be contracted by sharing food with person suffering epilepsy, 86% disagreed. 12.4% said epilepsy can be caused by a curse but 86% disagreed. 62.8% agreed that complications of illnesses such as malaria and meningitis could lead to develop epilepsy, however, 23% disagreed while 13.2% said they don't know. 65.3% also agreed that one can develop epilepsy as a result of injuries to the head while 21% disagreed. 12% said they did not know. Although 91% and 86% had disagreed that epilepsy can be contracted by being in physical contact or sharing food with person with epilepsy respectfully, 50% of the respondents as shown on table 4.7 below said epilepsy is a contagious illness, 49% agreed and 1% said did not know. 85.1% agreed that epilepsy is inherited from parents while 13.2 disagreed. 1.7 % said they did not know.

The finding on epilepsy as an inheritable illness is consistent with other studies that found people to believe epilepsy develops through heredity (Shibre T*et al* 2008; Krishnaiah B*et al* 2016; Kabir, 2005). However, WHO attributes a very low percentage of epilepsy to genetic factors. Sander (1990) mentions possible causes of epilepsy as; cerebrovascular disease 11−21%, trauma 2−6%, tumors 4−7%, infection 0−3%, and idiopathic 54−65%. Although the percentage of those who agreed to epilepsy as caused by benevolent cause was smaller, previous studies found a significant number to believe in benevolent causes. In Tanzania for example, Winkler *et al* (2010) study on belief systems of epilepsy and attitudes toward people living with epilepsy in a rural community of northern Tanzania found that, the 62 family members, and 46 villagers, 46.7% believed in the supernatural causes of epilepsy including curses and breaking of taboo. In Mali, Youssoufa *et al* (2014) study on current beliefs and attitudes regarding epilepsy in Mali found that 52% and 29% of the families with and without epilepsy respectively, attributed supernatural causes and witchcraft including curses and retribution for past behaviors to epilepsy. Other studies that show belief in supernatural or witchcraft causes of epilepsy include, Youssoufa et al (2014), Kendall-Taylor NH et al (2009) and Baskind R, et al (2005). In the findings of Andermann (2000, p.170), cited by Broch, (2011), Andermann (2000) groups traditional beliefs about epilepsy into four categories namely; epilepsy as a punishment or sin, epilepsy as bewitchment or possession, epilepsy as contagious disease and epilepsy as a disease of the brain. Misconceptions and deficits in knowledge underlie perceptions and response towards an illness.

**Table 4.7 Household members' Knowledge of causes of epilepsy**

| **Cause of epilepsy** | **Agree** | **Disagree** | **Don't know** | **No Response** | **Total** |
|---|---|---|---|---|---|
| | % | % | % | % | % |
| One can get epilepsy by contact with a person with epilepsy such as shaking hand | 7.4 | 91 | .8 | .8 | 100 |
| One can get epilepsy by sharing food with epilepsy | 12.4 | 86.0 | | 1.6 | 100 |
| Epilepsy is caused by a curse | 10 | 85.1 | 4.1 | .8 | 100 |
| Epilepsy is caused by violating a taboo | 12.4 | 86.0 | .8 | .8 | 100 |
| Epilepsy is inherited epilepsy from parents | 85.1 | 13.2 | | 1.7 | 100 |
| One can get epilepsy through head injuries such as in accidents | 65.3 | 33.9 | 0 | .8 | 100 |
| One can get epilepsy from severe complications of disease such as meningitis and malaria | 62.8 | 23 | 13.2 | .8 | 100 |
| One can get epilepsy from delivery complication during birth | 65.3 | 21.5 | 10.7 | 2.5 | 100 |
| Epilepsy is contagious | 50 | 49 | 1 | 0 | 100 |

Respondents had varied ways of knowing epilepsy. In this study as shown in table 4.8 below, 66.3% knew epilepsy through symptoms and signs such as seizers and marked injury scars. For example, respondents said epilepsy is a disease where one experiences seizers causing one to jerk violently, froth in the mouth and, go unconscious, experiencing urine incontinence or a disease where a person suffering from it has several visible scars, smirked lips and deformed limbs as a result of injuries sustained during epileptic seizer. Some respondents said epilepsy is an illness where the "*gaze of the person appears abnormal*". 19.8 % knew epilepsy through its causes. For example, respondents said "it *is a disease caused by witchcraft"*; "*it is a disease you get when you handle saliva of an epileptic*"; "*kifafa ni ugonjwa ambao unaletwa na ushirkina na uchawi*" [epilepsy is an illness caused by witchcraft]. 13.3 % knew epilepsy through the consequences of the illness. For example, respondents said "*epilepsy is a risky disease that can kill someone because it comes suddenly and can cause one to fall into fire and burn or drown in water if help is unavailable*"; "*an illness that leads to mental disorder* (psychosis)"; "*epilepsy is a disease that makes people isolate you if you suffer from it*".

**Table 4.8 Ways in which epilepsy was defined**

| Definition of epilepsy | Number | Percent |
|---|---|---|
| By describing symptoms | 80 | 66.1 |
| By describing causation | 24 | 19.8 |
| By describing consequences of epilepsy | 16 | 13.3 |
| No response | 1 | .8 |
| **Total** | **121** | **100.0** |

### 4.2.1.3 Respondents knowledge on symptoms and signs of epilepsy

Respondents identified signs and symptoms by way of description. Responses were categorized according to their similarities. Three categories were created as shown in table 4.9 below. 18.2% described the physical appearance that could indicate one is suffering epilepsy, 27.3% described behavior exhibited by a persons living with epilepsy while the majority at 54.5% described body movements such as seizers that would indicate one was suffering

**Table 4.9 Way in which signs can were described**

| **Description** | **Number** | **Percent** |
|---|---|---|
| Physical appearance | 22 | 18.2 |
| Behavior | 33 | 27.3 |
| Body movements | 66 | 54.5 |
| Total | 121 | 100.0 |

As shown in table 4.10, 37.2% of the respondents said signs and symptoms of epilepsy vary while 62.8% said there were no similarities. The 37.2% who said the signs and symptoms were not similar attributed dissimilarity to cause and stage. For example; regarding dissimilarity attributed to cause respondent “43” said

> “ *the sign for epilepsy that is as a result of bitwtchnment is aggressive behavior but that one caused by violation of breaking taboo the person gives aloud cry when he is having a fi*t”

Regarding dissimilarity due to stage of illness respondent “83” said

> “*If one does not urinate in the cloth then the disease is still developing but if the person forth in the mouth and urinate then you know the illness is mature* [fully developed]”

**Table 4.10 Similarities of signs and symptoms of epilepsy**

| **Are there similarities in symptoms of epilepsy** | **Number** | **Percent** |
|---|---|---|
| Yes | 45 | 37.2 |
| No | 76 | 62.8 |
| **Total** | **121** | **100.0** |

The 62.8% who said there were similarities in the signs and symptoms of epilepsy among persons suffering epilepsy. For example a respondent pseudonym “24”, “54”, “91” and, “109” respectively said;

> “*Any person with epilepsy must have a fit, urinate in cloth, bites the lips hence signs are similar”*
>
> “*All epileptics become unconscious for a while”*
>
> *“Persons suffering must froth in the mouth otherwise you know it’s not epilepsy”*
>
> *“They all shout and emit gaggling sounds just before a seizer”.*

Respondents who said there were no similarities in presenting signs and symptoms of epilepsy said that cause of illness determined the presenting signs and symptoms. Respondents attributed epilepsy to causes such as curse, witchcraft and heredity. Respondents said that each cause had specific signs or symptoms. The following are sampled responses regarding the differences in presenting signs and symptoms.

> "*Those whose epilepsy was inherited from parents do not cry loud before they go into a fit but those whose epilepsy was due to sins and breaking of taboo usually produce a loud cry before they fall* (seizer) *that show the invading spirits*" [Respondent "24" of KAP survey]
>
> "*Those whose epilepsy was inherited usually urinate and froth in the mouth and become unconscious with little body shakes* (Jerking) *but other epilepsies usually have violent body shakes*. [Respondent "66" of KAP survey]
>
> *People who developepilepsy because of curses in the family or bewitchment usually see ghost (visual hallucination) before a seizer but other epilepsies do not bring about the ghosts*" [Respondent "7"of KAP survey]

This finding shows how people have different understanding of epilepsy and meaning attached to its signs and symptoms. The varied meanings may influence how individuals respond to persons living with the illness.

#### 4.2.1.4 Respondents' knowledge of epileptic seizers

Recurrent seizers is the main indicator of epilepsy. Biomedicine categorizes seizer as either partial or generalized. A partial seizure is presumed to start in a part of the brain and may or may not spread hence a variation in the way the signs are exhibited away from the generalized seizer. In generalized, clinical manifestation of a seizer consists of sudden and transitory abnormal phenomena which may include alterations of consciousness, motor, sensory, autonomic or psychic events. Having explained epileptic seizers, respondents were asked the possible triggers of the seizers. Nearly thirty five percent (34.7%) as shown on table 4.11 attributed the seizers to physical state of an individual such as hunger, surprise or sudden happenings and menstrual flow. 23% of the respondents said events could trigger an epileptic fit, for example, ‘*epileptics usually get seizers during events where there are huge crowds such as in markets, wedding ceremonies or burial gatherings where there is a lot of noise’*. 17% said that emotional status of an epileptic could trigger a seizer for example anger and anxiety. For example, Respondent “88” explained that moments that creates high excitement such as dowry or wedding occasion could trigger an epileptic fit.

Identifying and managing triggers of epileptic seizers is a neglected area or often underestimated. Understanding and avoiding precipitants of seizers can improve outcomes of persons living with epilepsy and improve quality of life. For example, knowing specific triggers of epilepsy can facilitates management of the illness through timely and appropriate interventions such as having adequate rest, use of relaxation techniques or anticipation and avoidance of the precipitants.

**Table 4.11. Knowledge on triggers of seizers**

| Triggers of epilepsy | **Number** | **Percent** |
|---|---|---|
| Events | 28 | 23.1 |
| Weather | 28 | 23.1 |
| Emotional state | 21 | 17.4 |
| Physical state | 42 | 34.7 |
| No response | 2 | 1.7 |
| **Total** | **121** | **100.0** |

Respondents identified various signs that indicated an impending seizer attack. Identification of an impending seizer can help prevention of injuries and complications that can arise from a seizer. As shown in table 4.12, 14.9% said they could tell an impending seizer attack from facial expressions of the persons with epilepsy such as a “blank gaze”, or a strain on the face. 34.7% could tell of an impending seizer by body signs such as lethargy, “lazy or tired posture” and trembling of the body. 29.8% said individual with an impeding seizer attack exhibited unusual behavior such as pacing up and down, poor concentration and uneasiness.

**Table 4.12 Respondents' perceptions of warning signs of an impending seizer**

| Warning signs | Number | Percent |
|---|---|---|
| Facial appearance | 18 | 14.9 |
| Body signs | 42 | 34.7 |
| Unusual behavior | 36 | 29.8 |
| Don't know | 25 | 20.7 |
| Total | 121 | 100.0 |

### 4.2.1.5 Respondents' knowledge on vulnerability to epilepsy

After understanding respondents knowledge of epilepsy the researcher sought respondents' knowledge regarding those that were more prone to developing epilepsy. 46.3% said children or other members of the family of persons with epilepsy, 2.5% said youth, 43% said anybody was at risk of developing epilepsy and less than one 1% said those who break a taboo while 7.4% said they did not know.

**Table 4.13 Respondents' perceptions of vulnerability to epilepsy**

| Who are vulnerable to developing epilepsy | Number | Percent |
|---|---|---|
| Children or members of family of persons living with epileptic | 56 | 46.3 |
| Youth | 3 | 2.5 |
| Those who break taboos | 1 | .8 |
| Anybody | 52 | 43.0 |
| Don't know | 9 | 7.4 |
| **Total** | **121** | **100.0** |

Respondents were then asked to explain why the group of people they mentioned were more vulnerable to developing epilepsy. As shown on the table 4.14 below, 38.8% said family members of persons living with epilepsy can get the illness through heredity, 13.2% said those who come into contact with saliva or urine of person with epilepsy were prone because could contact the illness from the contact. 40.5% said brain injury during complicated birth or in the event of an accident predisposes to one developing epilepsy. 7.4% did not respond because they had stated earlier they did not know those who were more vulnerable to epilepsy as had been captured in table 4.15

**Table 4.14 Reasons provided by the respondents for vulnerability to developing epilepsy**

| Reasons for their vulnerability | **Number** | **Percent** |
|---|---|---|
| Can inherit from parents | 47 | 38.8 |
| Can contract from saliva and urine from epileptic | 16 | 13.2 |
| Brain complications from injuries during birth or accidents | 49 | 40.6 |
| No response | 9 | 7.4 |
| **Total** | **121** | **100.0** |

It is clear from the above data that respondents signs and symptoms of epilepsy but had varied beliefs on causes of the illness. It came out strongly that respondents had a strong belief that epilepsy is contagious and it can be inherited.

### 4.2.2 Attitude towards persons with epilepsy

Attitude was measured by specific behavior of respondents towards epilepsy and persons living with epilepsy. Respondents were asked about how people behaved towards persons living with epilepsy. As shown in table 4.15, 58.6% said people fear and avoid persons with epilepsy, 28.1% said people neglect persons living with epilepsy, 9.9% said persons living with epilepsy are treated like any other persons who do not suffer epilepsy and, 1.7% persons living with epilepsy are treated more kindly. 1.7% did not respond.

**Table 4.15 Community's attitude towards persons living with epilepsy**

| How do people react to persons living with epilepsy | **Number** | **Percent** |
|---|---|---|
| They neglect person with epilepsy | 34 | 28.1 |
| They fear and avoid | 71 | 58.6 |
| They treat persons with epilepsy more kindly | 2 | 1.7 |
| They treat person with epilepsy like other normally as other people | 12 | 9.9 |
| No response | 2 | 1.7 |
| **Total** | **121** | **100.0** |

Respondents were then asked to explain why people responded to persons living with epilepsy as stated. As shown on table 4.16 table below, 71.9% said people feared persons living with epilepsy because they be believed epilepsy to be contagious. 11.6% said people fear persons suffering epilepsy because seizers are scary when they occur. However 9.1% said people interact well with persons living with epilepsy because they are normal like others while 4.1% said person with epilepsy are treated with kindness because they are perceived to be neglected.

**Table 4.16: Reasons for attitude towards person living with epilepsy**

| Reason for behavior towards persons with epilepsy | **Number** | **Percent** |
|---|---|---|
| the condition is scary | 14 | 11.6 |
| fear of being infected | 87 | 71.9 |
| They are neglected | 5 | 4.1 |
| They are normal people | 11 | 9.1 |
| No response | 4 | 3.3 |
| **Total** | **121** | **100.0** |

### 4.2.2.1 Illness comorbidities

Regarding comorbidities of epilepsy, 76.9% harbored belief that epilepsy leads to serious injuries and death, 7.4 % believed the illness attracts stigma and 7.4% believed epilepsy leads to memory loose of the affected person while 8.3 % saw the illness as a burden to the family.

**Table 4.17: Possible comorbidities of epilepsy**

| Comorbidities of epilepsy | **Number** | **Percent** |
|---|---|---|
| Can led to serious injury like severe burns, drowning or death | 93 | 76.9 |
| can lead to loose of memory | 9 | 7.4 |
| It is a burden | 10 | 8.3 |
| Can lead to family being isolated and stigmatized | 9 | 7.4 |
| **Total** | **121** | **100.0** |

#### 4.2.2.2 Treatment prognosis

In relation to treatment prognosis 56.2% agreed to statement that epilepsy is not treatable while 41.3% disagreed, 2.5% said they did not know. The belief among the communities in Vihiga is that since epilepsy is an illness that runs in the family it cannot be eliminated. This finding is significant because it informs the need for education on prognosis of epilepsy and the need for treatment for improved outcome.

**Table 4.18: treatment prognosis**

| Epilepsy is not treatable | **Number** | **Percent** |
|---|---|---|
| Agree | 68 | 56.2 |
| Disagree | 50 | 41.3 |
| Don’t know | 3 | 2.5 |
| **Total** | **121** | **100.0** |

#### 4.2.2.3 Intervention on witnessing an epileptic seizers

Almost all respondents at 90.9% had witnessed a person living with epilepsy have a seizer attack. Those who witnessed the seizer were asked to explain what action they took. As shown in table 4.19, 12.4% said they ran away, 34.8% said they got shocked and fearful, and did not take any action to assist, 37.2% said they assisted the person after the seizer had stopped while 15.7% said they assisted the person during the attack. Those who ran away or got fearful explained that the violent jerking of the body frighten them. Those who did not take action said they feared contracting the illness through contact with the fluids from the person who was experiencing seizer

**Table 4.19 Reaction on witnessing an epileptic seizer**

| Action taken on witnessing a seizer | **Number** | **Percent** |
|---|---|---|
| Ran away | 15 | 12.4 |
| Got shocked, fearful and did not do anything | 42 | 34.8 |
| Assisted the person after the seizer | 64 | 37.2 |
| Assisted the person during the seizer | 19 | 15.7 |
| **Total** | **121** | **100.0** |

### 4.2.2.4 Burden of epilepsy

Burden of epilepsy in this study was the extent to which epilepsy affected the quality of life of the person living with epilepsy as well his or her immediate family or caregiver. 50.4 % agreed epilepsy was a burden while 49.6% disagreed.

**Table 4.20 Burden of epilepsy**

| Epilepsy is a burden to individual and the family | **Number** | **Percent** |
|---|---|---|
| Agree | 61 | 50.4 |
| Disagree | 60 | 49.6 |
| **Total** | **121** | **100** |

As shown in table 4.21, of the 50.4% who agreed epilepsy was a burden, 16.4%attributed the unpredictable nature of epileptic seizers to the burden, 13% attributed costs due to frequent hospitalization, majority at 63.9% attributed stigma towards persons with epilepsy and their families to the burden, and 6.6% attributed diminished income opportunities to the burden.

**Table 4.21 Factors attributed to burden of epilepsy**

| What makes epilepsy a burden | **Number** | **Percent** |
|---|---|---|
| The unpredictable nature of epileptic seizers | 10 | 16.4 |
| Costs of frequent hospitalization | 8 | 13 |
| Stigma associated with epilepsy | 39 | 63.9 |
| Diminished income opportunities | 4 | 6.6 |
| **Total** | **61** | **100.0** |

### 4.2.2.5 Perception towards an epileptic person.

Regarding perception 53.7% agreed to the statement that persons with epilepsy were mentally ill and 36.4% disagreed while 8.3% said they did not know while 1.7% did not respond to this question. The reason why persons living with epilepsy were perceived as psychotic was that the person acted in an abnormal way such as being easily irritable, behaving confused and appearing unkempt.

**Table 4.22 Perception of people living with epilepsy as having mental illness**

| People with epilepsy are psychiatric (have mental illness) | **Number** | **Percent** |
|---|---|---|
| Agreed | 65 | 53.7 |
| Disagree | 44 | 36.4 |
| Don't know | 10 | 8.3 |
| No response | 2 | 1.7 |
| **Total** | **121** | **100.0** |

Respondents were asked if persons living with epilepsy were violent. As shown in table 4.23, 33.1% agreed but majority at about 60% disagree while 5% said they did not know. 2.5% did not give a response.

**Table 4.23 People with epilepsy are violent**

| | **Number** | **Percent** |
|---|---|---|
| Agree | 40 | 33.1 |
| Disagree | 72 | 59.5 |
| Don't Know | 6 | 5.0 |
| No response | 3 | 2.5 |
| **Total** | **121** | **100.0** |

Majority of respondents at about 82% disagreed that persons living with epilepsy performed poorly in school. This finding is significant because it can form the basis for interventions hat can encourage persons living with epilepsy to pursue their education.

**Table 4.24 People with epilepsy perform poorly in schools**

| | **Number** | **Percent** |
|---|---|---|
| Agree | 17 | 14.0 |
| Disagree | 99 | 81.8 |
| Don't know | 2 | 1.7 |
| No response | 3 | 2.5 |
| **Total** | **121** | **100.0** |

It is clear from these data that respondents acted with fear and avoided contact while dealing with persons living with epilepsy as demonstrated by actions towards an epileptic seizer. There is deep rooted belief that epilepsy is contagious hence people fear direct contact with persons with epilepsy. This perpetuates stigma towards persons with epilepsy. It further acts to alter social outcomes of those affected due to reduced social interaction beyond the family. This leads to poor social outcomes and poor quality of life

### 4.2.3 Community practices on epilepsy

As explained in the conceptual framework community practices are socialized health and social measures by the community regarding illness of epilepsy. This include reduced social interaction with person living with the illness, living arrangements for persons with the illness and, treatment modalities.

#### 4.2.3.1 Social interaction with persons living with epilepsy

Social interaction in this study was the extent and to which individuals in the community would interact with persons living with epilepsy and the nature of the interaction, either as being spontaneous such as with others without epilepsy or degree of precaution.

**Table 4.25: Forms of interaction with persons living with epilepsy**

| People interaction with persons living with epilepsy in their daily lives | **Number** | **Percent** |
|---|---|---|
| Take precautions while interacting with persons living with epilepsy | 105 | 86.7 |
| Interact freely | 12 | 9.9 |
| Avoid interacting with persons living with epilepsy | 2 | 1.7 |
| **Total** | **121** | **100.0** |

#### 4.2.3.2 Living arrangements of persons with epilepsy

Majority of the respondents at 55.4 % said persons living with epilepsy are accommodated with the rest of the family members, 13.2% observed that that they have an isolated hut or room while 31.4% said they live with other relatives from the main homestead. Because of misconceptions of epilepsy as a contagious illness and also an illness needing close attention, findings show that there are special arrangements are purposely to reduce contact or help adjust to demands and care of persons living with epilepsy

**Table 4.26 Living arrangements for persons living with epilepsy**

| living arrangements for persons living with epilepsy | **Number** | **Percent** |
|---|---|---|
| live in an isolated room or hut | 16 | 13.2 |
| live normally with other members of the family | 67 | 55.4 |
| taken to live with relatives far from the homesteads to avoid stigma to the family | 38 | 31.4 |
| **Total** | **121** | **100.0** |

### 4.2.3.3 Curative practices for epilepsy

Curative practices are ways in which the community treats various illnesses. In this study curative practices are specific activities taken to remedy the condition of epilepsy. As shown in table 4.27, 40% said epilepsy is treated medically, 25% said it is treated by traditional medicine, another 25% said it is treated using both medical and traditional ways, while 10% said its treated by forms of diet. The various modalities may be attributed to varied beliefs of cause of the illness hence specific causes respond to a specific treatment. For example, if the belief of cause is thought to be natural such as malaria then medical then the illness will respond to medical treatment unlike if it were caused by says violation of taboo.

**Table 4.27 curative practices**

| Ways of treating epilepsy | **Number** | **Percent** |
|---|---|---|
| Medical treatment | 25 | 40 |
| Traditional medicine | 16 | 25 |
| Both traditional and medical | 16 | 25 |
| Diet such as dog meat/donkey milk | 7 | 10 |
| **Total** | **64** | **100.0** |

### 4.2.3.4 Marriage practices with persons living with epilepsy

Although marital status has been associated with improved social outcomes among the study community, households among the community were not in favor of marrying a person living with epilepsy or who has history of the illness. This is reflected in the findings of this study that show disapproval of marriage among persons living with epilepsy. As shown in Table 4.28 81% of respondents said families disapprove one marrying from family of known history of epilepsy. This finding shows persistent stigma towards person's living with epilepsy.

**Table 4.28 Marriage practices**

| Marriage practices to person living with epilepsy | **Number** | **Percent** |
|---|---|---|
| Families disapproves one marrying from families with any history of epilepsy | 98 | 81 |
| Separation or divorce if husband or wife is discovered to suffer epilepsy | 9 | 7.4 |
| Marriage breaks up if off springs has epilepsy | 14 | 11.6 |
| **Total** | **121** | **100** |

### 4.2.3.5 Preventive practices of epilepsy

Preventive practices in this study are those measures taken by households to prevent its members from developing epilepsy because the illness is highly stigmatized and is believed to be contagious. As shown on table 4.29 below, 56 % said they would discourage members of family from marrying from a family with any history of epilepsy, 34% said they avoid contact with bodily fluid of persons with epilepsy because of contracting the illness and 10% said they would avoid consuming foods offered during cultural rituals because such foods can cause one to suffer epilepsy if they breached a taboo knowingly or unknowingly.

**Table 4.29 Ways in which households prevent epilepsy**

| How can one prevent epilepsy | **Number** | **Percent** |
|---|---|---|
| Avoid marrying persons with family history of epilepsy | 68 | 56 |
| Avoid contact with fluid or urine from epileptic | 41 | 34 |
| Avoid consuming meat offered during ritual practices if you have breached any taboo | 12 | 10 |
| **Total** | **121** | **100.0** |

## 4.3 Summary

From the findings presented above, it can be summarized that epilepsy is understood through biomedical and ethonomedical systems. The illness is individualized and highly stigmatized as evidenced by findings on practices such as marriage

# CHAPTER FIVE

# LIVED EXPERIENCES OF EPILEPSY

## 5.0 Introduction

This chapter addresses the second objective of the study which sought to examine how the community's knowledge, attitudes and perceptions of epilepsy influenced participants lived experiences. The findings are presented in five sections. The first section discusses demographics of participants. Sections 2-5 presents findings on how the community influenced the daily living of the participants. The findings are presented under four thematic areas of; onset of illness, everyday life, experiencing seizers and, forming relationship, as presented in table 5.1. The chapter argues that presentation of epilepsy is characterized by social and symbolic meanings in specific context. This social and symbolic meanings influence lived experiences of those living with the illness by imposing limitations on their life trajectories. These limitations compel them to calibrate a new life story, coping mechanisms and new life plans which in turn influence how they engage in their everyday life.

**Table 5.1 Emerging themes and sub themes**

| SECTIONS | THEME | Subthemes |
|---|---|---|
| LIVED EXPERIENCES | • Explaining illness | • Onset of illness<br>• Concealing illness |
| | • Influence on everyday life | • Experiencing stigma<br>• Altered social identity<br>• Diminished social interaction |
| | • Influence on how seizer is experienced | • Precipitants to seizers<br>• Post seizer experience<br>• Seizers and injuries<br>• Seizer and livelihood |
| | • Influence on forming Relations | |

## 5.1 Socio-Demographics

### Age

Fifteen research participants took part in the study. All the respondents were aged 18-24 years. There were 10 Females and 5 males in the study.

### Marital status

Majority of the participants were single. Their single status was attributed to community's stigmatization of their illness which discourages relationship with persons living with epilepsy because of perception of epilepsy as contagious. However, 4 of the 15 participants had previous intimate relationships that later broke as explained by 24 year old "Janepher" and 22-year old "Georgina.

"Janepher"

> "*We had lived together for about two years. We had this child* [respondent shows a male child about 5 years]. *Myparents suggested we formalize our relation to which my husband's clan agreed and came to formalize. . On the day of the ceremony I became anxious…………..like any other woman would do. As I served them food I felt that thing* [Epileptic seizer] *come. What followed I can't tell but Jane* [close friend] *told me I had very nasty fits that caused commotion in the sitting room and the visitors just left. My mother even got depressed because it became the talk of the village. After that incident my husband changed so much and eventually left me with this boy. I asked him and he said his parents said they did not want me in their family because they feared their family would be stigmatized*

These findings are consistent with other studies that show that people living with epilepsy had a lower marriage rate than the general population and women with epilepsy had a higher divorce rate (Agarwal *et al*, 2006). 'Georgina' narrates similar experiences as "Janepher"

> "*It* [epilepsy)] *got worse when Iwas in form three. I was taken to Nakuru to have treatment and live with my brother who was taking care of me. I got well but since the schools were closing I did not go back……..it was long Christmas holiday. I fell in love with a boy in the estate and later got married to him I decided to leave school. . There is a time I cooking and had seizer. I feel on hot stove and sustained severe burn as you can see* [respondent shows extensive wounds on the left arm]. *He* [husband then] *took me to hospital*

> *where I stayed for a long time. He suddenly stopped visiting me after the doctor explained to him that I should not be left alone while cooking because I had this disease* [Epilepsy].

People object their family members from marrying persons with epilepsy even if they had well controlled seizers because of belief that epilepsy is a hereditary illness that will be introduced to the family by the epileptic person (Batzel *et al* (1984); Elliott *et al* 2008). As a result of rejection young people living with epilepsy may experience altered self-esteem and consequently have poor quality of live.

### Level of formal education

Regarding the level of education, the study found out that all the 15 participants had not finished their formal education/schooling or taken long to reach the expected level of formal education as per their age. As found out, 4 participants had dropped out of school at primary school level, 3 were continuing their education at primary level but had delayed schooling and 4 had completed primary education but did not proceed to secondary school while 4 participants had secondary education. Of the 4 who had secondary education 2 were still schooling and, one had dropped out at form 3 while one had completed secondary school but did not proceeded for further education. The low level of education among the some participants was attributed to stigma, absenteeism as a result of frequent itinerary in search of treatment for the illness. For example, 23 year old "Josephine" explained her reason for dropping out of school at a lower level;

> "*Teachers forced me repeat classes due to absenteeism when I was sick. I found myself with much younger classmates. When we went out for games, they were out for games then they* [classmates] *could tease me and make me feel bad. They said things like I was old and could not compete fairly with them. They even refused to include me in their teams saying I made them finish last in competition events. They used to laugh at my breasts saying they were for big girls………..it used to embarrass me a lot. I told the teacher but couldn't listen to me instead just told me to work hard and be promoted to a higher class. A friend I had started school with sat her Standard eight exams*

> *and left me behind. I really felt lonely………..she was the only friend I had…………..we are still good friends. She is now a teacher at Museywa* [a local Primary school] *and she will come to visit tomorrow. After she left I did not go back to that school. Now at my age there is no way I can go back to those children* [refereeing to primary school]*"*

"Tokessy" a female aged 24 years narrated circumstances surrounding her dropping out of school an early age;

> *"I dropped out of school when I was in class three. My dad told me that I often fell sick and fainted* [experience seizers] *while at school. Other parents started talking ill about my illness and he didn't like the way I was being treated at school. So he pulled me out of that school".*

"Tokessy" narrative is confirmed by her father during an informal interview within the homestead. The father gives details of pulling "Tokessy" out of school at a young age. He narrates;

> *"She had been sick for a while by then she was in class 3 and they had put her on a dose and started medicine. They gave us some medicine which she used to take .She used to insist that she goes to school. Even when she fainted (had seizers) she used to force herself to go to school. Mmmh……"* The father pauses and seem to drift in thoughts and then continues and says *"There was a day, when she fainted while at school. That was the second time she had fainted at school. That that thing (epileptic seizer) surprised people. Later other children started pushing her away from them while playing. They were told by their parents not to play with my child because she had a bad disease. It was then she disliked school. Parents who were on school committee talked bad about her seizers saying she would infect others. I heard that them saying that parents were planning to withdraw their children from that school because my daughter was falling (having epilepsy) and could infect them. So it reached a point I got fed-up with the bad talk from other parents. I stopped her from going to school because I felt pain people talking bad about my child"*

Similar experiences where discrimination has been practiced against pupils in schools have been found in other studies. For example, studies by Baskind et al (2005), Winkler et al (2010) and Youssoufa, (2014) found that some schools in parts of sub Saharan Africa expelled children suffering from epilepsy from school.

"Josephat" male aged 22 years narrates a similar story of stigma and prejudice as "Tokessy"

> "*I used to fall [have seizer] frequently so on many occasions I missed school. When I could go back to class I had difficulties in remembering things and teacher could tell me I am daft. They [teachers] kept saying I write like chicken. That made me hate school so I did not proceed but I wish I was not having this illness. My age mates are in Universitie*s".

Cognitive challenges resulting from effects of seizers have been reported (Poul Jennum et al 2011; Eliott2005). These challenges are responsible for delayed schooling or fewer years of schooling among school going persons with epilepsy. This is because they perform poorly in examinations necessary to move them to the next level and are forced to repeat same level. As a result they find themselves older than their classmates. Because of challenges of adjusting to the younger group in their class persons with epilepsy eventually drop out of school. These findings are consistent with other finding that show that persons with epilepsy have less years of schooling than those who do not have, Aldenkamp and Bodde (2005); Kwan and Brodie 2001; Meador (2002) and, Motamedi and Meador (2003). In Kenya, pupils are expected to complete their primary education while at 12-14. In this study it is observed that there is delayed schooling of about 4 years among pupils living with epilepsy.

For "Ronald" aged 26 had delayed schooling

> "*sa wasee shule ilikuwa hatuelewani kabsaa coz walikuwa wanachocha eti mimi ni kaa mzae, unacheki. Azn hii beard ya mine ndo walikuwa wanacheki, unaona….. Sa kuitwa mzae mbele ya madem kwa class maze haikuwanga inanifurahisha, unaona. Sa……… kuna day budaa!!! tumepigana na chali juu ya hio stori. Si nilichapa msee mbaya…waaa! Acha ma odijo wanilete kwa ofisi bana! Walai sinimechapwa kichapo cha doggy.Hawakutaka kuelewa huyo boy ndo alinitusi. Toka io day n'kasuea kutoklezea io chuo zii, Na ndoo stori ya chuo iliishianga apo*"
>
> [I didn't get well with my classmates because they used to refer me as old enough to be a dad. They used to look at my beard and tease me over it. They did that to humiliate me in front of girls. A fight broke out over the teasing and I beat a boy senseless. The teachers called me and beat me badly without getting to know the side of the story. It was humiliating and I swore never to go back to that school. That was the end of my schooling]

"Aznet" aged 24 has a similar story as Ronald

> "*I was schooling at Gidimo primary in standard seven but I discontinued school. The teachers used to accuse me of beating other pupils. I hit a pupil on the head she unconscious, from then I feared going back to school*".

The Researcher probed further on the alleged violent behavior. "Aznet" continued with her narration;

> "*I was not violent. Pupils used to push and pinch me without any provocation so I used to retaliate by throwing stones at them……I am a left handed and good aimer, and never miss my target. They used to report me and lie that I started the fight. The teachers could believe them. The teacher asked my motherto take me to another school because I was indiscipline but am very disciplined myself*'.

"Ronald" and "Aznet" experience is similar to one captured in the literature review of this thesis on experience of epilepsy among Tewa community. In an incident, a child whose epilepsy had complicated to grand mal epilepsy was referred to as a "monster" in reference to the frightening nature of the violent seizer in grand mal epilepsy cases and subsequent emotional disturbances Lemyra (1990). In Ronald's case he becomes aggressive upon provocation while Anne's case the teachers perceive her to be the "aggressor" short of being referred as "monster"

Tom, male aged 20 years narrated stigma faced from friends when he developed Epilepsy.

> "*I used to enjoy playing with my friends on our way back home. We often bought sugarcane and ripe bananas on our way home and enjoy together. I remember we really used to have fun during second term of school when green maize was ready. We could roast them and carry them in our pockets to school and share as we walk backed to school. We used to lace hot pepper on some for our naughty friends …….hahahaha* [participant bursts into a hearty laughter gazing up seemingly reflecting with nostalgia with tears in his eyes]………. *but all that changed when I got sick and started falling (having epileptic seizers). Word spread that I was suffering that disease (having epilepsy) but my parents told me it was meningitis which had been treated but a few of it had remained in the brain. Most of my friends except Kennedy* (childhood closest friend) *begun to decline my snack or sugarcane offers. I asked one why he didn't want* the sugarcane I had offeredand he told me that

> *it had my saliva on it. I was surprised. I asked him what was wrong with my saliva because we had been sharing and he said his parents had said that I could infect him with my disease if we shared bites. I told my mother about that. She got angry and went and fought the parents of my friend who said that. People heard about the fight and started talking ill about our family having that disease. My mother was hurt to see me being +9avoided by other children so she decided to take me to a different school. I went to stay with my uncle. My aunt (wife to the uncle) did not like me plying with my cousin so I was taken back home and did not continue school*"

As narrated by participants the low level of education and high dropout rate in this study is attributed to the participant's illness of epilepsy and stigma. Participants who dropped out of school gave reasons such as long interruption of schooling for long period in search of treatment for their illness and the injuries they sustained as a result of seizers. Respondents who dropped out of school because of stigma narrated how they were constantly teased and discriminated at school by classmates because they were thought to either be infectious or mentally ill.

Contrary to experience of the majority of the participants who faced stigma at school, "Mary" female aged 26 years and "Kezia" female aged 18 did not faced stigma while at school. For Mary she completed her secondary education though she did not proceed to tertiary or higher education. . She narrates how she managed to complete his secondary education.

> "*I did not have any problem in school. I was in boarding school and my parents made sure I had medicine throughout the term. Our school nurse was good because she used to keep an eye on me. I interacted well with other students…..I was a prefect you know and students respected me much. I played hokey and we went up to Nationals* (Kenya Secondary school National Competition*). I only had a seizer in form 2. I had suffered severe malaria and got admitted at Mukumu Mission Hospital. I got a C plain at form four and was to go to go abroad where my Uncle is but things have not worked out yet*".

From the narration of "Mary" we see that she was in a boarding school. In boarding school there is a mixture of pupils or students from different communities and who typically do not know the background of each other unlike in day schools where pupils or students come from the same locale and can know background of each other and subject stigma. It is also observed that she had well controlled seizers only experiencing one seizer as her illness was closely monitored by the school nurse. In absence of seizers there is no reference for stigma as stigma is mostly pegged to occurrence of seizer

In Kezia's case who was due for her final primary school (KCPE) exams at the time of interview she did not face any stigma at school as she narrates;

> "*I only have the problem of not recalling things when I get seizers. They* (seizers) *kind of disorganizes my library in the head. My teachers tell me am very bright. You can even see how I score good grades* (Participant shows report cards that show fluctuating performance)…..*are as you observe showing poor grades is because I had bad seizers and that affected my performance that term. I was in and out of hospital for almost two years that is why I am still in primary. At school I have good friends, they don't discriminate me in any form. In fact they are always around me".*

From her narration we observe that she gets encouragement from the teachers. This was significant because it worked to boost self-esteem of Kezia who went ahead to enjoy support of her friends despite the frequent seizers.

It is clear from the above findings that with adequate attention of treatment and social support young people living with epilepsy can have a normal schooling life.

### Living arrangement

Majority of the participants lived with their grandparents because of stigma projected to their families. 10 participants were under the care of their grandparent and 3 participants lived with their parents while 2 lived were under the care of their aunts. Participants had varied narrations about their living arrangements. .

"Emmanuel", male aged 22 narrates circumstance that lead to him living with his grandmother.

> "*We used* to *live near Luanda (local market In Vihiga). There is this man who used to do business with my mother later and later my mother got married to him. We moved from Luanda to Ugunja. There I continued with school in class four. While there I got severe malaria and was hospitalized. After that I started fainting* [experiencing epileptic seizers] *frequently. It was then they* [family of the step father] *started treating me indifferently saying I was an epileptic. They said I could not do well in school so I was withdrawn from school to look after cattle. My mother complained about this but those people despised her. It was then my grandmother took me after seeing what was happening to me"*

From the above description, it is observed that because of stigma young people living with epilepsy are made to have separate living arrangements from other members of the family. "Emmanuel" is rejected are isolated based on stigma towards his condition. Withdrawing "Emmanuel" from school is a case of preventing stigma where the family acts to protect itself from being stigmatized because of "Emmanuel". It could as well be that the family belief that persons with epilepsy do not perform well in school. Whereas cognitive impairment has been reported in epilepsy not all epilepsy cases suffer the cognitive impairment. As such it benefits the family to educate members with epilepsy and seek appropriate management in cases of impaired cognitive abilities.

"Janet" aged 19 narrates a different story about living arrangement. Her living arrangements are occasioned by economic and income needs. She explains her circumstances.

> "My uncles called her (the mother) for a job in Nairobi. They had got a job for her to work as a house help for a Mzungu (White man). They made arrangements to have me stay with my grandmother while my mother went for the work. She works there (Nairobi) now. At least she sends us money whenever we need the money, we used to struggle much when she was here though she takes long to come. The mzungu normally goes for holidays abroad in December that's the time she (the mother) gets time to come for Christmas. . I have asked if I can live with her in Nairobi and she says the mzungu does not allow people to live in his compound".

From the description above, we observe that persons living epilepsy illness seem to require close attention of the individual and may pose significant challenges especially for young families who need an income for family upkeep. This impacts of other activities of the family, notably income activities. This prompts the family to adjust the living arrangements so that other member of the family are liberated from care of those with epilepsy to enable them accomplished assigned roles.

"Jane" aged 18 on her part narrates inability of her mother to cope with multiple roles and need to free her.

> "Mama*yakubaaa zikwiri lwuadagwiza.Yahenda mwoyo ndamila amadya. Guku yaza navola mama aleke yinzi nzie kumenya naye na mama atigale nahenza indanya. Mama yali mwivu nakinyunya, na yali anyala kumbila musivitali nidwaye mbaa*"
>
> [My mother used to get frighten and scream whenever I got seizers. She could worry I would die from seizers. My grandmother came and took me to live with her while my mother took care of the infant she had just had and was still breastfeeding. She (mother) could not cope with taking care of me at the same time the new baby]

The above findings reveals that caring for persons living with epilepsy can be emotionally draining owing to the frightening and unpredictable nature of seizers as narrated by "Jane". Findings regarding challenges faced by care givers of young people living with epilepsy is consistent with other studies. For example, O'Dell (2007) found out that that epilepsy not only impacts the quality of life (QOL) of persons living with epilepsy but those of care givers as well. The family feels overwhelmed with care of member having epilepsy necessitating special living arrangements to other members of family with lesser productive activities such as grandparents.

## 5.2 Explanation of Illness of Epilepsy

As explained in the methodology, participants were initially identified with the help of community health workers or local administrative staffs who had knowledge about known persons with epilepsy in their area of jurisdiction. Subsequent participants were recruited through snowballing as explained under the sampling section of lived experiences study in chapter three of this thesis. A total of 15 participants participated in the study. At first contact, 13 out of the 15 participants did not disclose their condition of epilepsy. This was attributed to meeting a new acquaintance and needed to gain trust but most importantly because the illness stigmatized among their community as captured in the findings of the community KAP survey and participants were in fear of stigma should they disclose. In early stages of explaining their illness, participants used non-stigmatizing symptoms and illnesses away from epilepsy. However, as a deeper researcher-participant relationship established, participants begun to open about their condition as being epilepsy and how it has affected their lives and, how they coping with it. This part of the chapter explains the initial reactions of participants when they were asked to talk about their condition.

### 5.2.1 Onset of illness

All the 15 participants started explaining their illness by describing the onset of their illness and attributing it to an immediate cause. In early stages of explaining their illness, participants attributed their illness to non-stigmatizing illnesses and symptoms away from epilepsy. This was because they wanted to protect themselves from possible stigma associated with epilepsy because epilepsy is an illness that is highly stigmatized in their community as discussed in chapter four of this thesis. However, as a deeper researcher-participant relationship established, participants begun to open about their condition as being epilepsy, how the condition has affected their lives and, how they coping with it. Ten participants had the onset of epilepsy at age 3-10 years and 5 participants developed epilepsy at 11-14.

Some participants, most of whom the onset of their illness was age 11-14, vividly recalled the onset of their illness. For example, “Phil”, a female aged 18 years described circumstances of onset of her illness.

> “My illness started when I has in standard 7. I had visited my aunt in Seme for holiday. On my way back home I started filling dizzy then fell while in the vehicle (fell here means that she experienced a seizer). When I reached home my mother was surprised to see how I looking like. She told me that I was not speaking normally and that I looked tired. At home I fell again. I was taken to hospital where I was admitted. I got well but that thing continued to come especially when it was hot”.

Participants who said they developed epilepsy in their early childhood were probed on how they recalled the dates of onset. “Aznet”, a female aged 21 years narrates how she got to know about her illness

> *“I don’t know very well about how my illness started but I once heard my grandmother tell the herbalist how my illness started. She told him that I had severe pneumonia that almost killed me when I was still young. I was taken to hospital and given an injection at my lower back to release pressure inside me. She told him that I was once admitted at night after fainting several times and sleeping into a comma. When it was nearly morning I came back to my senses but started talking as if I was obsessed by demons. She said the doctor told her that I was having that illness* (epilepsy) *but she did not see such disease in me. She said that my body only stiffen but not fall the way epileptics fall, groin and urinate in cloth. She told him that after the stiffening stopped I could stand up and wonder into the bush aimlessly collecting firewood, even if I was called I could not respond until I came back to my normal senses. That is how unto today I usually get confused after the convulsions are over. My grandmother keeps wondering what my disease is because I don’t fall and struggle* (struggle is a metaphor used to mean there are no violent jerky movements typical of epileptic fit*) the way people with epilepsy do but just stiffen the body then it goes away”* ”.

As explained by the above participant she heard information of onset from conversations of her grandmother with a healer during treatment visits. This is significant because it shows keenness of persons living with epilepsy about their illness and treatment and eagerness to understand their illness. It also shows the importance to involve sufferers in their treatment and not to treat them as objects but rather consider their subjective.

"Jennifer" aged 24 narrates onset of her illness

> *"ilianza nikiwa stardard four. Nilikuwa naishi na my brother kule kericho. Kuna day ndazia kufana muluu ma vwongoi vuza mutsimoni ningwa haasi.Ndashai hakekeke kigila muluu gwali gukili kwaduka munene.Vambila mu sivitali nenyola madameku navutwa vwongoi vwazilira. Kutula hene yaho is when vulwalwe vuwazizagila. My brother yanzilanyia yengo yego ivologoli ku nyole tsinyasi tsia kienyeji. Ndamenya yengo madiku manyingi ma nendeka kutsia musukulu So, kwamanya kutsie kogelitsa kuvasali konyola vokonyi. Vasala nivavola mbeye na madimoni dave. Vambaku lunyasi mukivuyi vavola ndi ndumikiliku kwivaka havweni nu mumakono.Lakini mabadiliko galiho mbaa.Kwamanya kutzie kolola mundu wetsinyasi. So, nikaendelea na hio dawa lakini niliendelea kuona kizunguzungu.. Sikuendelea na shule sababu nilipata mimba. Wakati wa mimba kizunuzungu ilizidi so daktari akaniambia niende clinic nipate phenorbarb ndo ugonjwa usifikie mototo. Sa nilipate motoi vizuri tuko naye hapa. Kwa sasa naskia nafuu isipokuwa bado mimi huona kizunguzungu alafu najikuta nimeanguka chini. Hawajawahi ona ile kitu inafanya nikuwe na kizunguzungu"*
>
> ["It (illness) started when I was in standard Four. I used to stay with my brother in Kericho. There is a time I went to prepare porridge for a meal, so when I bent to fun the fire I got dizzy and fell in the fire. I got burnt but luckily the burns were superficial and nit extensive because the fire was still small. I was taken to hospital where o got treated. However that the dizziness kept coming and I could often fall (experience a seizer). After a while I was taken back home in Maragoli to be prayed for. The healers prayed for me but my convulsion kept coming. They said that my problems was not caused by demons. I was given some medicine in a small jerrican container and told to use twice daily by smearing it on my forehead and back of my palm. After that we visited a herbalist who gave me more medicine but my convulsions were getting worse. By then I had stayed home for a long time and dropped out of school. I got pregnant while at home. When I visited the Ante Natal clinic the Midwife told me that my pregnancy will be in danger if I don't adhere to treatment and that epilepsy will affect my child if I failed to take phenorbarb (AED). I feel a bit of relief but I experience dizziness and fall often. They have never discovered what brought my dizziness]

It is clear from the above findings that participants experienced a sudden onset of illness. This experience is consistent with medical explanation of epilepsy onset as paroxysmal. The implication for sudden onset of illness is that it makes adjustment to the illness problematic especially in regard to seizers. Again, it suddenly and abruptly alters the everyday lives of those affected. Paroxysmal onset of illness can be an "*upsetting*" and confusing experience especially when characterized by "loss of control" as in epilepsy (Gregg Rawlings et al 2017).

Participants were probed on details of their illness. The next section presents finding on participants' presentation and experiences of their illness.

### 5.2.2 Concealing epilepsy

Participants presented their illness by selectively using non stigmatizing symptoms or illnesses. This was in bid to conceal their illness of epilepsy because of stigma attached to it by the community. For example, "Josephine" aged 22 uses "faint", "fever" and, "malaria" to describe her condition.

> "*I suffered cerebral malaria when I was 14 years, I was told that I had fever and malaria had accumulated in my body and traveled to the brain. It affected my brain and caused me to faint repeatedly. The illness I now suffer comes when I get strong malaria. It comes more mostly frequently during the season of maturing green maize when there is a lot of malaria*"

As noted in the narration on onset of illness, participants, just like "Josephine", presented their illness using non-stigmatized illnesses such as malaria, pneumonia and, meningitis as cause of their illness or symptoms such as fainting, fever or convulsions. They used the terms such as "*okhu shinda or ukukinda* and, *"oludejera".Okhu shinda and oludejera* are the words that mean convulsion and fever respectively among communities in Vihiga County. Convulsions are common in Malaria because of the accompanying fever. Convulsion are similar to epileptic fits/seizers. Although convulsions have similar characteristics as epileptic seizer they do not attract stigma as epileptic seizers known as *indulumi* among Vihiga communities, thus participants were comfortable saying they experienced convulsion and not *indulumi* or epileptic fit. The term *indulumi* (epilepsy) is derogatory in the community. “Asneth”, for example, relates her illness to malaria because malaria is accompanied by fever and possible convulsions. She identifies with Malaria because it is a common non-stigmatized tropical illness that affects households in Vihiga County. The current prevalence of malaria in Vihiga County is 41,402 per 100,000 people though the prevalence is much higher than the national prevalence which is 20,252 per 100,000 (MOH, Kenya, update May 2015). Malaria commonly occurs during rainy season and when maize plants are maturing. The explanation to “Jennifer” connecting her illness to maturing maize is that the climatic conditions and the environment of the maturing maize stems are conduce for mosquito breeding and spread of malaria. The malaria is accompanied by fever that triggers “Jennifer’s’” seizers.

“Aznet” aged 21 years, attributes her illness to meningitis and uses absence of classical signs of epilepsy to deny she suffers epilepsy.

> “*People do not understand my illness. It is not epilepsy, if it were epilepsy I could be urinating in my cloth [urine incontinence] when I get a seizer. I was told that my illness was caused by a disease called meningitis. The disease attacked my brains when I was young and made it very sensitive to fever. That’s why I fall* [experience seizers] *whenever am exposed to heat*”

From her narration “Aznet” explain epilepsy as one in which there is urine incontinence. “Aznet” belief is consistent with finds in the community KAP survey as captured in chapter four where some respondents said a condition is said to be epilepsy only when signs and symptoms such as frothing in the mouth, having fits that results in urine incontinence and, experiencing loose of consciousness are present. By defining epilepsy according to community’s beliefs “Alice” hopes to avoid stigma associated to her seizers. She brings in urine incontinence as a distinct feature of epilepsy. Because she doesn’t experience the incontinence she hopes to convince she does not suffer epilepsy but another illness which meningitis is the underlying cause. As captured in literature review in the chapter two of this thesis there are many forms of epilepsy some of which do not involve urine incontinence. Nether-the-less they remain epilepsy and are characterize by seizers. By explaining the incontinence part “Aznet” attempts to convince that her seizers are not related to epilepsy but to meningitis. Though a serious infection, meningitis is not stigmatized as epilepsy is and people suffering from it are embraced without prejudice thus used by “Aznet”.

Participants also used non-stigmatizing benevolent causes to explain their illness. They used metaphor such as *evil eye*. They also used terms such as *kuanguka* [none stigmatizing term to mean fall] and Feud as cause of onset of their illness to explain their illness. For example, “Phil” a18 year old uses “fall” and “evil eye” to explain epilepsy

> “*My illness started when I has in standard 7. I had visited my aunt during school holiday. On my way back home I started filling dizzy then fell while in the vehicle* [fell here means that she experienced an epileptic attack]. *I was told a neigbour had cast an evil eye on me because of revenge on land dispute our family had with her”*

“Ronald” aged 26 year had a similar experience as “Phil”. He describes a non-stigmatizing cause to his illness

> “*There is a day my mother quarreled with a neighbor. After a bitter exchange the neighbor told her that she will teach her a lesson she will never forget. After about a week I started experiencing seizers*”.

For “Tom” age 20, though he acknowledges his illness as a brain disorder he nevertheless attributes it to “blocked blood vessels” and “high blood pressure” in the brain” and not epilepsy

> “*Imichi gya masahi gialwala, sijisila masahi ku vwongo vulahi mbaa, ku manyola ndakugwa. Masahi ganyagula vwangu manyola vwongoi vunyingingi*”

> [“Blood vessels to my brain are disease and the brains doesn’t get enough blood, when the blood pressure in the brain is high I get dizzy and fall”]

From the above narratives we observe that participants avoided using the term “epilepsy” because of community’s’ stigmatization and derogatory reference to it. Thus the community influences how young people manage information regarding their illness. In describing their illness Participants did not directly say they suffered epilepsy instead explained their illness in terms of specific symptoms of non-stigmatizing illness such as malaria, fever and dizziness and causation such as *evil eye* that could absolve them from the illness. Evident from the interviews the most common expression used to mean epilepsy was “*kuanguka*” meaning to fall, a non-stigmatizing way of saying they experienced a seizer. The findings show that young people living with epilepsy avoid being discriminated or isolated by devising ways to conceal their illness. They form ways to present illness as a “normal” or socially “acceptable”. They purpose to appear “normal people” i.e. absence of the illness so as to escape stigma so that they may be treated as others without the epilepsy in society.

These findings are consisted with other findings regarding concealment and disclosure of epilepsy as a way of handling stigma. For example, Schneider et al (2019) discusses strategies of concealment using the “closet” concept where they point out that people living with epilepsy are conscious of information management regarding their illness. This is informed by the fact that there is “potential stigma” that needs to be avoided and that strategies’ to avoid the “potential stigma” include titrated disclosure or concealment. That, there are some people you can share your illness with while others you cannot, (Goffman, 1963). Schneider‘s study demonstrates the rationale for concealment as is in this study. Schneider s’ study found that concealing epilepsy was necessary to prevent situation where individual where predisposed to attacks on their image as demonstrated by a woman in their study who if she disclosed she was epileptic her neighbors would use the information against her in the event she got into a quarrel or feud. It can thus be concluded the community perception of illness influenced how young people with epilepsy made meaning of the illness.

### 5.3 Everyday Life with Epilepsy

This part of the chapter presents findings on daily lives as experienced by young people living with epilepsy. As hereafter discussed, epilepsy disrupts the diseased subjects lives through imposed limitations by community practices. This causes them to suffer isolation and other social injustices

#### 5.3.1 Experiencing sigma

Thirteen out of the 15 participants reported having experienced stigma from the community. Two participants described their daily lives as free of stigma. Those who experienced stigma described circumstances they experienced stigma. For examples, “Tom” male aged 20, describes actions of a neigbour towards him.

> “*When I go there* [neighbor’s place] *they normally tell me to seat a distance from them. They serve me tea but in a cup they refer to as mine. They usually think my illness is contagious*”.

The experience of “Tom” is consistent with experience of other persons living with epilepsy in various studies. For example in a study by Youssoufa *et al* (2014) found that community members limited their interaction with persons living with epilepsy. In their study the limited interaction was as a result of belief that epilepsy is spread by bodily fluids hence need to limit contact with affected persons. As discussed under history of epilepsy in literature review chapter two, history of epilepsy is riddled misconceptions that work to prejudice people living with epilepsy (Baskind *et* al

2005; Baskind *et* al 2005; Kendall-Taylor *et* al 2009). “Tokessy” aged 24 years also experienced stigma because of perceived contagious seizers she suffered.

> “*I once fell into a village water spring and nearly drowned. All the people at the river run away on seeing me convulse* [epileptic seizer] *in the water. I almost drowned but I was told that it was a small child who is a friend to my sister who went running to our home to alert my father. He rushed down the river and found me in the spring of water. If he had delayed I could have drowned. After that incident it became the talk of the village. They talked very many bad things about me. I contemplated suicide. They refused to draw water from it saying I had polluted it with my disease and they didn’t want to be infected*”

Evident from above narratives, participants experiences actual acts of discrimination as described by “Tom” and “Tokessy” who were perceived as vectors of epilepsy. Marina Denisenko (2013) citing Reis et al (2002) distinguishes forms of stigma; perceived stigma and enacted stigma. Perceived stigma “refers to the type of behavior a stigmatized person *expects* to encounter”, while enacted stigma ‘denotes the *actual* behavior that is encountered’. In this study therefore participants experienced enacted stigma. The findings on stigma were not surprising because much of literature on lived experiences of epilepsy as a highly stigmatized illness especially in developing nation with more of enacted stigma being experienced. It is observed from the above findings that epilepsy-related stigma was a product of social structures (community-households, religious and, traditional healing systems beliefs) which produced multiplicity of interpretations of epilepsy.

In the KAP survey findings of this study some of the mentioned characteristic of epilepsy that formed basis of stereotyping of individual suffering epilepsy were; being contagious, perceived as unproductiveness, unable to effectively perform expected social roles, being a burden and potential of reproducing offspring with the illness (heredity) and, possibility of mental illnesses. As such epilepsy was presented as a contagious, of the supernatural spirits or magic induced. These attributes discredited those suffering epilepsy by what Goffman says “reducing them from a whole and usual person to a tainted, discounted one” (Goffman, 1963: 3). This thus establishes stigma.

The stigma works to deny individual of various social privileges such as association, work and forms of intimate relationships (Nguyen & Peschard, 2003: 467). Crocker *et al* (1998) argue that in being stigmatized one is seen to possess some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context. In other illness that are stigmatized for example, HIV and AIDs, attributes such as; individuals had engaged in deviant behavior , illness was a result of immorality, illness as contagious and threatening to community and associated with an undesirable and unaesthetic form of death work to blemish and stigmatize the individual, (Alonzo et al (1995). Epilepsy was also stigmatized on ground that it is associated with taboo and witchcraft occasioned by individuals’ faults (Youssoufa Maiga et al 2014). Young people living with epilepsy in this study therefore experience lives characterized by isolation and discrimination. This acted negatively on their self-esteem largely due to diminished social interaction especially in their stage of life where forming relationships is important.

### 5.3.2 Altered social identity

Another way in which participants experienced stigma was by being labeled. The labeling influenced their lived experiences by altering self-esteem. Participants described being labelled “*wi minyika*” [meaning a wrestler but used derogatively] *“wiindulumi*” [the epileptic] or “*mulalu*” [mad person]. As discussed earlier in the literature review chapter, the term “*indulumi*” is derogative in the community. Being labeled "*wiindulumi*" is demeaning and alters ones image. Thus participants' self-esteem was altered as described by 20 year old "Tom"

> "*People do not see me as a normal person like the others. They refer to me as an epileptic….it makes me feel bad. All they see in me is my illness. There are times when I do labour for neighbors on their tea plantation they serve me meals they serve me separate from other laborers. They refuse to share meals with me. I think they feel I might infect them with my illness……... It's very demeaning but I just have to live on. When I try to interact with others of my age they verbally abuse me out of trivial misunderstandings. They say "tula yaha gundu gwe indulumi* [go away you epileptic person]*"*

"Kenneth" male, aged 21 describes how his step-father labels him as an "epileptic"

> "*My father often quarrels my mother about my disease telling her she brought an epileptic to the family. He doesn't like associating with me*"

"Josephine 23 year old describes how she in labeled as a psychotic case

> "*When am walking to the shop and I happen to meet children they run away calling me a mad person. Even adults refer to me as a mad girl but am not. Even our neighbor sometimes calls me a mad girl especially when I fall. They normally think am untidy like those mad people at the market. I just keep to myself at home without talking to people*".

"Phily" however does not feel stigmatized

> "*We live with other people well. Whenever my neighbors have an event they always call us to help. We don't have any issues with people. Our family doesn't have the notion that we are stigmatized because of my illness*".

Because of labeling individuals living with epilepsy feel degraded. This affects their social standing and the ability to socially interact and form social networks that can improves the quality of life.

### 5.3.3 Reduced social interaction

As a result of prejudice from the community, participants experienced diminished social interaction. Participants described how community members acted towards them forcing them to reduce their social interaction within the community. For example, “Aznet” 21 year female narrates her daily experiences with community members and need to reduce social interaction.

> *“Whenever I walk to the shop and I usually meet children on the way. Most of the time they run away because they have been told am a mad person. Even adults refer to me as a mad girl but am not. Even our neighbor sometimes calls me a mad girl especially when I fall. This makes me feel bad and never want to meet them but circumstances just forces one to interact with them. They normally think am untidy and timid like those mad people at the market. So I just prefer staying at home without being bothered”.*

“Emmanuel” aged 22 narrates about abandoning school games

> “*I dreaded experiencing seizer while we had gone for competitions in other schools. I was worried I could get a seizer and lose my reputation”. I opted to be staying behind when others visited places for competitions*”.

Evident from the above interviews is that participant’s social interaction and networks were diminished because of negative perceptions towards their illness. Participants have described how some community member avoided making contact or associating with them because of perceived a danger of contracting epilepsy. Participants feel that they are not just treated as vectors of some deadly disease but also perceived as polluted or contaminated with taboo related evil spirits.

Findings from other studies (Baskind et al 2005 and Baskind et al 2005)show that beliefs such as  epilepsy being contagious and spread by bodily fluids and flatus make people avoid interacting with people living with epilepsy hence persons living with epilepsy having  limited interaction. This is a strongly embedded belief that needs elaborate community sensitization and education on epilepsy. Sociologically, the implication of this diminished social interaction is that participants will suffer poor quality of life and may be unable to take social roles appropriate to their ages.

## 5.4Community's Influence on how Seizers were Experienced

Experiencing seizers emerged as the main thematic area of the study. All other lived experiences described by participants revolved around recurrent seizers. Participants described how reaction of the community to seizers influenced the way they experienced the seizers. This them describes triggers of the seizers, onset of a seizer, experiences after a seizer attack and, injuries sustained during a seizer, as well as, disruption of livelihood activities as narrated by participants. Disruption of daily activities was described as the most distressing consequence of seizers. Twelve out of the 15 participants reported a frequency of 0-2 seizers in a month and, 2 participants experienced more than three seizers a month. One participant had been seizer free for six months preceding the study. Whereas participants recalled circumstances leading to a seizer, they could not recollect what happened during the seizer. However, they recollected happenings immediate after the seizer. Findings are discussed under sub themes; precipitants of seizers, experiences after seizers, injuries resulting from seizers and disruption of livelihood by seizers

### 5.4.1 Precipitants of seizers

Feeling of anxiety, noise, hunger, heat and menstrual periods were described as precipitants of seizers. Participants had little control over this factor, however they worked to avoid them. 4 female participants believed their monthly menstrual triggered seizer they experience. Heat and noise were particularly singled out as other main triggers of the seizers. "Janepher", aged 24 describes triggers of seizers she experiences;

> "*The problem used to be fever and malaria but over the years I have noticed my fainting* [seizers] *to come just around or during my periods. I met others at the hospital who have similar problem* [epilepsy] *and it during periods*"

"Emmanuel" aged 22 explains triggers of seizers he experience as;

> "*When the sun is hot, especially when am in crowded areas like the market I get worried……………I hardly attend events or anything that will keep me in such because that thing will to come*".

"Tom" aged 21 experienced change in triggers to his seizers

> "*I dread the appearance of the crescent. When I see it am definite I am going to faint* [experience seizer attacks]. *It has just remained so up to now. I even tried traditional medicine and healers but the crescent is more powerful*"

"Aznet" aged 21 describes her seizers are medicine related

> "*If I miss Tegratol for some time I end up with the convulsions*"

Recurrent seizers are the main indicator of epilepsy illness. While medically they remain as indicators to show prognosis, socially, they are form labels that define persons with epilepsy and work to stigmatize and impose social limitations to individuals. Effective control of seizers can therefore work to improve social outcomes of those living with epilepsy. Findings on precipitants of seizer in this study are in line with what the community describes as triggers of seizers. In the community KAP survey findings households identified physical state of an individual such as hunger, apprehension or unpleasant experiences and, menstrual flow as factors that have been known to precipitated a seizer among persons suffering epilepsy. They also identified events or huge crowds and, emotional state as other known factors that trigger an epileptic fit.

### 5.4.2 Onset of seizer experiences

All the 15 participants described their experience moments before a seizer. Some of the symptoms described by participants were; feeling of loss of control, feeling of exhaustions and, experiencing forms of hallucinations such as visual and auditory hallucination. For example, Kenneth aged 21 years describes loss of control of his body during seizer

> "*I feel something taking over my body and I have no strength to stop it. It overpowers me. It suddenly grips me then I get that feeling of my braining being quizzed and I find my chest heavy and unable to breathe properly. When I wake up I feel very exhausted and unable to do anything*"

Previous studies show that persons living with epilepsy describe a feeling of being "overwhelmed" or "powerlessness" before onset of a seizer. This feelings extends to period after recovering from the seizer whereby they rely on others to re-establish control (Laryssa Bilinsky, 2015). Participants also described experiencing hallucinations moments before seizer attack. For example, "Phil";

> "*I know when it is approaching. I feel heavy in the head then I see a big bearded man coming out of a bush. I feel him seating on my chest then I loose breath. I only find myself awake after that.*

"Aznet" aged 21 similarly experiences hallucination

> *"When it* [seizers] *started I used to feel something crawling inside my head then I see big pumpkins that turn to ghosts that attack me. These days I don't see many things but sometimes I see coffins and dead people. People tell me a scream before I fall"*

Loss of control can be a source of anxiety that can cause apprehension and anxiety in daily lives of individuals. The findings on onset experiences of seizers are consistent with literature on seizers as captured in chapter two of his study. For example, experiences of "Phil" and "Aznet" of visual hallucination are typical in persons experiencing seizers (Griffiths (1990). The literature under seizers in chapter two discussed seizers as being accompanied by altered sensations such as disturbed vision, hearing and taste Griffiths (1990). In the literature it was reviewed that hallucination maybe manifest in the form of auditory, visual, olfactory or tactile type. It was further discussed that in hallucination individuals report unusual sensory phenomenon such as seeing ghosts, hearing odd sounds, strange smell or a sense that insects are crawling under your skin and so forth, such as experienced by "Phil" and "Aznet". In the literature review we observed that epileptic activity within the brain influences the behavior, mood, and cognitive functions of person (Betts et al, 1976) and this then becomes a social problem problematized by its social and symbolic meanings in everyday life. Participants did not recall what happens when they are in seizer attack but recalled events after regaining consciousness from seizers.

### 5.4.3 Post seizers experiences

All the 15 participants described their experiences of the period immediately after a seizure attack. Among the experiences included; feeling of confusion or disorientation, feeling of shame and feeling of pain from injuries related to the seizer. For example, “Phil” 18 year female feels disoriented after a seizer though her life rebounds to normal.

> “*It (seizer) can attack me anywhere, even when am washing cloth or at school or when I’ve go to the river. When I get it, afterward I forget where I am for a while but when I cool off my mind becomes alert and can continue with what I was doing”*

“Jane 18 year old experiences in public places are different from having seizers at home

> “*I normally wake up with blood and pain in the mouth because I bite my tongue when that thing comes. It depends where I am when I fall. At home I just wake up myself but in other places I find people surrounding me……..it’s a little bit embarrassing sometimes…….because you don’t know if people have seen your nakedness……..it hurts..* [Participant becomes emotional when explaining the experience].

“Josephine” aged 23 years describe discomfort after a seizer

> “*It’s an embarrassing moment……..when I wake up from the fall* [seizer] *I find I’ve wet my cloth. I feel ashamed………..a grown up lady like me walking with soiled cloths. I don’t know what men think of me……the facial expression from people usually tells me am looking horrible*”

Seizers work to stigmatize individual by entrenching the already existing social labelling of the illness. Uncontrolled seizers can alter individuals’ sense of esteem and subsequently alter quality of life (Matthews *et al*. 1982; Westbrook *et al*. 1992). The finding on disorientation, pain and, temporary loss of memory is consistent with medical explanation of the post seizer (*Post ictal*) stage where consciousness gradually returns over minutes to hours but the individual becomes confused or disoriented, complain of headache, fatigue, or muscle aches, temporarily loss memory and, in extreme cases, individual becomes combative (C. Apala Livio, 2016). In this study however, some participants, despite experiencing seizers, did not see it as an embarrassment or major problem. For example, "Mary" aged 26 describes her post seizer experience as normal.

> "*I could experience seizers during the lesson is on or sometimes when we were out for break. My friends told me it used to slightly disrupt the lesson but that's it. The teacher of the lesson could help but in most cases they called Madam Maggie* [a trained Special needs teacher at the school] *to come and help me. Ok, a few colleagues could shy away not knowing what to say but the following day we just talk (interact) normally".*

"Mary's" narration is similar to finding in studies that do not support the notion that epilepsy correlates with low self-esteem (Lee et al. 2008; Reeve and Lincoln 2002). Persons with adequate knowledge and social support about their illness cope better than those without. This is supported by the concept of sense of coherence (SOC) by Antonovsky. Sense of coherence as defined by Antonovsky (1987) is the ability to perceive a stressor as comprehensible, manageable and meaningful. In this study, seizers can be seen as the stressor. If well managed, persons with epilepsy will be well adjusted and have improved social outcomes. Studies such as (Adams et al. 2000; Skirka 2000) have shown that people with strong sense of coherence handle stress better and are healthier than people with weak sense of coherence .

### 5.4.4 Life of uncertainty

Fourteen of the 15 participants described seizers as unpredictable. The unpredictable seizers made them live in uncertainty not knowing when and where the next seizer will come. The seizers came unexpectedly and disrupted whatever engagements participants had at the time. For example."Jenifer's' seizers disrupted her income activity and also caused her to worry about her child.

> *"Not knowing when they* [Seizers] *will come just makes you anxious not knowing what to expect. Sometime when I am on my way to the market way to the market I get dizzy and fall* [experience epileptic fit]. *I just find myself on the ground and my baby crying with onlookers surrounding me. When I fall the ripe bananas crush and get spoilt and groundnuts just scatter…… I am left with nothing to sale. I normally get up with help of people then go back to home. When am ok* [absence of seizer] *I normally make good sales". What worries me though is the safety of my daughter. I always fear someone can come a take her away while am fallen"*

On his part "Ronald" aged 24 years narrated how he incurs business loses occasioned by unpredictable seizer.

> *"mimi hujishugulisha na bizna ndgo ndogo apo stage za kuuza ma sweets, fegi ivi, ma design perfume na tuvitu tu hapo. Siste angu alinichangianga kadoo nikaanzisha hako ka bizna.Sa challenge huwa wakati naangukanga watu hu take advantage afu wanuchukua tule bidha expensive kama perfume. Sa inabidi nikiamuka napata ntaenda hasara. Lakini nikiwa poa bila kuanguka watu hubuy vipoa. Issue tu niko naye ni joto…..waaah..kama kuna joto mimi hujua tu msee ndo huyo ataanguka. Na nikifall maze mimi huskia mbaya inabidi tu io siku niisheie home mapema coz huwa uchungu afu pia guo husoil kiasi"*
>
> [I sale merchandise at the market. Seizers come unexpectedly. When am experiencing a seizer people steal some of my merchandise leaving me with loses. Whenever I get a seizer my day is ruined]

"Tokessy" aged 24 describes disruption of routine family activities.

> "*It* [seizer] *make me sick……..whenever it comes it disorganizes everything. I am caught off guard. It makes people stop what they are doing to have me taken to hospital. My father has to close his workshop for day"*

It is clear from the presentation above that participants faced uncertainty in their daily lives occasioned by unpredictable occurrence of seizers. Evident from participant's responses seizers are unpredictable and cause apprehension with ill parson not knowing when the seizers will occur. However participants formed behaviors that were intended at reducing the threat of disruption. For example, “Ronald” aged 24 years formed friendship with other traders through partnership

> “*Other traders at the market liked my marketing skills. I partnered with them and agreed to give me goods to sale on their behalf, for a profit. With that arrangements I became sure of myself in the event I get a seizer people will not steal my goods because my partners will stop them.*”

For “Jenifer’ she formed a mindset that her illness was not a hindrance to her from her role as a mother and provider to her baby.

> “I don’t see my i*llness as a disability. I have hands and healthy body. The only problem is the seizers that come on and off. My partner left me but I resolved to take care of my girl and give her the best education so that she doesn’t end up like me…….young people understand my illness unlike older people who spoiled my marriage by talking ill of my condition*”

As discussed in literature review in Chapter two of this thesis, unpredictability is one of the most troubling aspects of living with epilepsy (Hosseini et al., 2013). The findings in this study are concurrent with findings in similar studies that found out that uncontrolled seizers creates a life of uncertainty. For example, Rhodes *et* al (2008) found that the unpredictability of seizures was more disabling than the seizures themselves, that, person with epilepsy restricted their interactions because of the risk for social embarrassment, accident or injury as a result of a seizure. Rhodes finding is similar to finding in this study where participants narrate how epilepsy has determine their daily lives activities. Participants have narrated how they adjust to challenges of unpredictable seizers, typical of what Whittemore *et al* (2008) describes when referring to adjustment to chronic illness as, “the fluctuating tension between living a life and living an illness” such that daily life becomes unpredictable. However, the study argues that impact of seizers on livelihood can be diminished through better control of seizer. Not only will there be lessen impact on livelihood but a reduction of stigma and handicap associated with it (Baker 1997).

### 5.4.5 A life of imminent injuries

All participants had sustained injuries during some of the seizer attacks though at varying degree from mild to severe. Female participants had severe injuries than male participants. The injuries sustained included burns, cut wounds, lacerations, and smirked lips. Three had burn injuries on more than one occasion. Two female participants reported near drowning. All participants had some form of scars from injuries related to seizer. Five participants had conspicuous wounds that had healed by scarring, keloids and deformities. Almost all participants were unable to recollect what happened during the eventful seizer but recollected vividly events surrounding the injury. "Aznet" aged 21 year narrated the near drowning incident;

> "*I had gone to the river to fetch water. I experienced seizer and fell into the water. The girls who had accompanied ran away but an old lady who was tilling a farm nearby came to my rescue when she heard the commotion."*

24-year old "Tokessy" describes her burns injuries

> "I was preparing porridge for lunch then I just found myself in pain in a hospital bed. My mother told me I nearly died in that fire because I fainted and fell into the fire and pan of hot porridge, my dress caught fire and my hair also caught fire. My mother had gone to work for a neigbour. Likely she arrived when I had just fallen in the fire. Otherwise I could not be alive. So she poured water in the fire and rescued me but I was unconscious. She called neighbors who helped her put me on the wheelbarrow because cars and motorcycles cannot reach our house as you can see the stipe slope [the homestead is on a stipe slope]. That's how I sustained these burns (participant shows extensive burns on forearms, neck and head with deformed fingers.) At the hospital I was told I suffered 40% burns. I stayed at the hospital for six month. The wounds healed but my fingers got deformed*"*

Kenneth, 21 year male currently in secondary school in Four Three describes how he sustained multiple wounds over his face, arms and body. The wounds have healed forming huge keloids.

> “I often fall and sustain injuries. That thing (seizer) does not give me time …………I can tell when it’s about to come but I can’t find time to evade it, it just invades me quickly before I make a move. It comes so suddenly. I have several lacerations wounds on my arms as you see and on forehead [visible multiple scars]. All these came as a result of that thing I experience then I collapse [gets a seizer then goes unconscious]. I just find myself on the ground.

“Ronald” 24 describes circumstances of injuries sustained

> “*It was routine preparation of Madazi (Doughnuts) for the market. I was rolling the flour while my sister did the frying. I felt dizzy* [had seizer] *and tripped over. My sister prevented me from falling direct to the boiling oil but the oil splashed burning me here* [participant shows keloid formed scar on the left arm]. *It also caught my sister whose burns were worse than mine*”

It was not surprising that female participants in this study had fire related injuries from burns than male participants. This is because of role allocation in the community where females are allocated food preparation roles which include cooking. As they perform their cooking role they become predisposed to dangers of fire. Among triggers of epilepsy is heat and balls of fire or flames as discussed under triggers of seizers in literature review. The findings on seizer related injuries are consisted with other studies done on seizer related injuries among persons with epilepsy. The studies show that among injuries sustained during seizer attack were mainly burns, head injury, fractures and, soft tissue injuries which accounted for the highest percentage of the injuries (Asadi-Pooya *et al* 2012; Tiamkao and Shorvon, 2006). Injuries in epilepsy have been attributed to poorly controlled epilepsy. A study by Mativo (2014) at Kenya’s main teaching and referral hospital, Kenyatta National hospital, found a prevalence of 40% of poorly controlled epilepsy. The results are similar to findings of this study which show high percentage of patients with poorly controlled epilepsy. 13 participants in this study experienced seizers at least twice a month, which according to Helena (2012) is poorly controlled epilepsy. Epilepsy is said to be well controlled if there is absence of seizers for more than six months (Helena, 2012)

### Seizers and Psychological problems

Four participants had severe injuries that had deformed parts of their bodies such as limps, face, hair and, abdomen. The injuries, especially those affecting skin and face were found to have psychosocial toll on the respondents. The deformities attracted onlookers whenever the affected person was in the public. The scars also served to entrench the identity of "epileptic" as narrated by 24-year old "Tokessy".

> "I get disturbed when people see my wounds and deformities on my hands. They normally start talking while pointing at me. I have to cover my head because almost all the hair got burnt and the wounds look ugly………. It reminds me of the pain at the hospital. I used to have very beautiful hair till that day I fell into fire. I sometimes wish I could get a wig……………… When I go for clinic at Mbale people stare at me and start talking. It stresses me a lot but sometimes I just ignore"

The finding as described by "Tokessy" is similar to findings of Loyola *et a*l 2015, which showed that female participants expressed distress about their change in appearance. Face is a central focus for one's identity and facilitates important social interactions. Face facilitates an array of important nonverbal communications. Some of these nonverbal communication are necessary for developmental stage of young people such as establishing relationships (Loyola *et a*l 2015; Pines 1980; Sainsbury 2009). Sustaining injury to face therefore can be traumatizing.

Kenneth aged 21 describes how injuries causes him stress

> *"One day I fell and knocked my front teeth on the table. I also sustained a deep cut on my scalp from the edge of the table. You see now I find it uncomfortable to talk to people directly because I don't have the front teeth. My friends take any slightest opportunity to laugh at me because of gap (missing teeth) in the teeth. This is embarrassing you……..I really get stressed about that".*

*"Emmanuel" aged 22 years has been compelled to cover his scars.*

> *"I cover the ones on the hands [scars]. People ask many questions why I have several of them. It's difficult to answer those questions you know……"*

It is clear from participants' narration that injuries cause psychological problems. The injuries can lower self-esteem and cause one to have poor quality of life by way of reduced social interaction or withdrawal as they avoid people to look at the scars.

### 5.4.6 Challenges of forming or maintaining relationships

Due to misconception on epilepsy young people living with epilepsy face challenges in developing or maintaining a relationship with the opposite sex. Five of the 15 participants had a relationship. Three of the 5 said community members influenced relations by purposely causing relations to break through gossip and misinform to partners, for example by saying one will be infected with epilepsy or their offspring will inherit. Two participants said schoolmates contributed a breaking of their relations. Participants narrated how epilepsy impeded development and maintenance of intimate relations with the opposite sex.

"Janepher", female aged 24 years narrates her broken relationship

> "I had been seeing a man who later made me pregnant. Our relations was very good. I was still staying with my parents but I could go stay with the man for several months. He used to frequent our home. We were planning to wed. On occasions during his visits he could not find me so he used to ask my neighbors my whereabouts. It was during this interaction with neighbors that they started gossiping about my illness. He all along knew my health problem of falling (epilepsy) but the neighbors made him change his mind. So he came to me one day and told me that he had consulted the elders of his clan and they told him that if he marries me my offspring would have the same problem as me and that we will always be having the problem and spending money on treatment. I was hurt broken I almost committed suicide. I didn't understand because my baby does not have the illness I have. I have a problem with my neighbors and friends. They intrude so much into the relationships. Whenever I get a man and he is ready to marry me, he just get fake advices on my condition and he disappears never to be seen again".

"Josephat" aged 22 years narrates his interaction with the opposite sex as he seeks to establish a relationship

> *"I can never tell them*[girls] *that I fall* [have epilepsy]*, they will not just reject me but will tell others that I wanted them and that is a shame. I once had a girlfriend secretly. Our relationship blossomed but when others discovered the*

> *relation got strained and ended. They could tease my girlfriend that she is in love with an epileptic. It got worse that she left the school for another where no one knew her".*

"Ronald" aged 24 years explains how his relationship with the opposite sex broke

> *"I get very beautiful girlfriends. They always tell me that I talk nice and treat them like a gentleman. You know I sell merchandise like sweet scented perfume, nail polish and jewelry, …………..and you know you have to have a persuasive language and a nice smile, so when I talk to women they listen and we end up in relation, but always, when they see me fall [experience epileptic seizer], they takeoff never to come back. I once asked one to come back and she said she would never ever because the way I fell [had a seizer attack] scared her so much she thought I would die and people accuse her of poisoning me".*

"Kenneth" aged 21year old student at form three narrates his relationship theory

> *"I date but it is very difficult for me because of my condition since all ladies here are aware of my condition. I have tried to get one from here but it is impossible. Whenever I approach them they say they do not want to be jailed because of killing. They tell me that I might fall (have epileptic seizer) during the process (during sexual intercourse) and die on top of them, then be accused of killing me. So in short the ladies around here do not cooperate. But I am a man, so when I feel like having a lady I normally go to town, I know somewhere where they are very cheap, with only Ksh. 200 I can do what I want then come back home...so in short that s how my dating experience is all about.'*

"Emmanuel" 22-years old explains how he feel s when people talk about his epileptic condition to his partner.

> *"Discrimination is all that I can remember since some of my classmates used to talk ill about me especially when I was not around. At times, some boys could use my condition to discredit me and cause my girlfriend could rebel against my wish. I have sweet words for girls I usually win them but people ruin my relations by telling them I will infect them or I will sire an abnormal child and they end up getting the girl from my relation.* The participant was asked what he feels when a girl he is dating comes to learn his condition and break up the relation. His response was "*ouch! It hurts and it's very painful. Sometimes I feel like murdering someone, but when it happens I just have to accept since there is nothing much I can do. There are so many girls out there so I have to start the process afresh.*

From the finding we observe that female participants did not have a problem establishing a relationship but their challenge was the partner walking out of the relationship. For male participants they had difficulties in establishing relations with females. The major challenge was rivalry from peers who did not have epilepsy. The peers often used participants' condition to dissuade girls from dating the individual with epilepsy thereby making it difficult for them to get or maintain a relationship. From the findings we observe that males had had developed multiple relationships because once a partner discovered they had epilepsy they broke up the relation forcing them to start a new relation. Two male respondent indicated that they preferred relationship with commercial sex workers because the commercial sex workers did not bother about their epilepsy condition. The implication for this is that participants were predisposed to possible sexual risks.

## 5.5Summary

The study findings clearly show that epilepsy is a major impediment in forming relationship because of the stigma which imposes limitations. Stigma remains a single significant barrier to improved quality of life of persons living with epilepsy. To realize improved social outcomes in building and maintaining relations control of seizers and follow needs to be enhanced.  Absence of seizers can significantly improve acceptance among the community.

# CHAPTER SIX

# MANAGEMENT OF EPILEPSY

## 6.0 Introduction

This chapter addresses the third and final objective of the study. The objective sought to determine how young people living with epilepsy manage their condition. The chapter is presented under four thematic areas; illness causality, biomedical treatment, social treatment and, preventative practices as presented in table 6.1. The chapter describes how participants determined their treatment pathways. The chapter urges that treatment pathways are largely determined by significant others of individual with illness. Treatment pathways are drawn from knowledge and belief of cause and keep changing depending on available information on perceived cause at the moment. Two pathways participants took were biomedical and traditional treatments. Whereas biomedical system yielded better seizer control, participants faced numerous challenges within the system that compelled them to seek alternative treatment in the traditional system.

**Table 6.1. Themes and subthemes on participant's management of Epilepsy**

| MANAGMENT OF EPILEPSY | Theme | Sub themes |
|---|---|---|
| | Illness causality | • Natural causes<br>• Social causes<br>• Mixed etiology |
| | Treatment pathways | • Biomedical treatment<br>• Social treatment<br>• Divine intervention |
| | Social treatment | • Traditional treatment<br>• Divine intervention<br>• Dietary practices |
| | Preventative practices | |

## 6.1 Illness Causality

This theme describes how the understanding of perceived immediate cause of illness influenced the course of action for treatment. Although the interview guide did not include a direct question on perceived cause of illness, participants spontaneously made reference to onset of the illness and the perceived immediate cause when asked to narrate on how they manage their condition. All participants started by describing onset of symptoms or cause of their illness and how they were initially treated. In seeking remedy participants were drawn to various etiological interpretations of their illness. These interpretations formed basis for their choice of treatment pathways. The theme presents these interpretations under three sub themes; natural cause belief, social cause belief and double etiology beliefs.

### 6.1.1 Natural causes

12 out of the 15 participants initially attributed natural cause to onset of their illness by describing the presenting symptoms or illness such as fever, dizziness, malaria and environmental factors such as change in the weather. Natural causes of illness are explained as specific and identifiable agents which can be explained in terms of the language of chemistry and physics, such as, plasmodium in the case of malaria or pneumococcus that cause bacterial meningitis. These agents cause disease and can be destroyed by cures (Soma Hewa 2016). Natural causes have been treated using medical science of biomedicine. In the biomedicine system the doctor is perceived as the healer. He or she possess knowledge and expertise on natural occurring illnesses and in a position to alter its course of illness through use of medicine or surgery. The most frequently mentioned causes by participants in this study were Malaria, Fever, Pneumonia and, environment. For example, significant others of ‘Tokessy’ aged 24

years attributed onset of her condition to severe attack of malaria and sought remedy tin the medical system;

> "*I was told my condition started when I was young. I suffered ludegera* [shivering-high fever] and experienced convulsion. *I was admitted to hospital and told I had severe malaria that had affected my brain."*

In 'Tokessy" case, for example, her significant others perceived her fever and convulsions to be a natural occurrence that is treated by doctors who have expertise treating various diseases. Within the community malaria is known to occur naturally and is treated effectively in the biomedicine system. She is thus taken to health facility where appropriate treatment for her fever and convulsion is offered. Apart from identifiable microbial agents, environment is identified as another agent that can cause illness. For example "Emmanuel's aged 22 years described onset of his condition and attributed it to unfavorable environment and variations in the weather

> "My illness started when I got admitted to Form1 at St. Bhurkhita [a local high school]. The teachers were talking to us at the parade grounds when I suddenly felt hot and dizzy. I was told that I fainted and had convulsion. They said it was due to the weather because I was new at that place. I was taken to Maseno mission hospital and got admitted for five days because the convulsions were persistent. They said it was due to the weather because I was new at that place and that I will adapt to it. I got well and continued with first term, but in second term I experienced severe convulsions. They started when we were out for games. My father was called to pick me. He took me to Mbale hospital where I was given medicine. The medicine worked but after some time the convulsions come back"

'Emmanuel's' significant others determined that his convulsion could be related to the environment and therefore based on that sought medical treatment that could provide appropriate intervention.

Evident from participant's responses action to seek treatment at medical facilities was based on belief that their illness was of natural cause. From the sampled responses above we observe that decision to seek remedy was done by significant others of individual participants and was based on perceived cause of illness at the time.

Regarding decision making it may be argued that participants were under age of consent at the time of onset of illness but, as will be discussed in subsequent sections significant others continued to influence health seeking behavior even when participants had turned adults and of age of consent owing to their state at the moment. Regarding belief about cause of illness it may be argued that participants may have opted for biomedicine because they had not interacted with others at different social levels who could influence decision on treatment paths. Much as the participants got relief from frequently reoccurring seizers while attending medical health facilities, most continued to experience seizers. This not only raised the question of efficacy of medical treatment but also whether illness was of natural cause. In all the 15 study cases illness persisted necessitating search for newer remedy outside medical system

### 6.1.2 Social and Malevolent causes

Other than belief in natural causes, participants harbored belief in social causes of their illness. When belief in natural cause was no longer sustainable owing to failure of biomedicine to explain cause and treat seizers and, with emerging new information on epilepsy management, participants beliefs shifted by attributing their ailment to social elements such as witchcraft. In this belief participants attributed human deliberate human involvement in their illness. Witchcraft is an invisible force that operates through an agent or spirit known locally as *muloji* or *emoni indamanu* (evil eye). The witchcraft is activated through use of paraphernalia orcasting spellslocally known as *viganda* (paraphernalia) and *kwuhela (*casting spells through an evil eye). The target is then held hostage by invincible beings and spirits and tormented through seizers or auditory or visual hallucinations. As such medical doctors do not have powers to handle spirits and invincible beings but witchdoctors possess that power.

For example, the significant others of “Phil” made her believe that her sickness was as a result of witchcraft and determined that the sickness was only treatable by witchdoctors.

> *“*I had visited my aunty but got sick while I was there. My mother called her to ask her about my illness. She told her that that people of Seme (place she had visited recently) are witches and might have bewitched me through an evil eye while there. She said I needed to visit Ajuoga (witchdoctor) who could undo the witchcraft. We went to see Ajuoga who told my mother that my illness was brought about by a neighbor of my aunt who wanted to punish her over ancestral land dispute they had”.

For “Georgina” aged 22 her significant others suggested her illness was due to supernatural causes that were beyond medical intervention.

> “*My aunty talked to my dad and told him that my problem was because of demons that’s why hospitals medicine could not respond to”*

Epilepsy has a long standing history of deeply embedded beliefs of it being caused by witchcraft and spirits. Findings from participants view are reflected in findings of chapter four of this thesis on KAP survey. As stated in KAP findings in Chapter of this thesis a significant number of households in vihiga attributed epilepsy to spirits and demons. Further, they stated that epilepsy respond to interventions by the supernatural of religion that has powers to influence spirits and demons. This belief seem deeply embedded in the community given the number of religious organization in the area. Majority of the population are Christians who have strong beliefs in supernatural power of Almighty God. There are many denominations among the Christians. Notably, Quakers, Pentecost and Anglican. Others are African Divine church, African Israeli church, Catholic and Orthodox Church. In their prayers for the sick, congregants in these churches have a ritual of casting out demons that are believed to be responsible for illnesses and other social problems such as marital feuds, lack of employment and, poor performance in schools. It is common to hear congregants shout in chorus intended to drive away demon. For example, the religious leader will shout saying "*mademoni gosi agu vulwale, zibodoka zya vandu nende kokendeka, kusalanga ipatwe kushindwa,* and the congregants in unison say ..... *ritswaaaaah*!. [We pray to cast out all demons causing sickness and jealous and command them to leave….]. Quakers have invested in health care for example by establishing missionary hospitals such as Kaimosi Friends Hospital and Sabatia Eye Hospital. Despite their belief in biomedicine, they, however believe God to be the ultimate healer. This is illustrated in their hospital establishments such as Sabatia Eye Hospital whose Motto is "*We treat, God Heals*". This could be seen as an indicator of strong belief in religion and healing. There are other mission Hospital in the County such as Maseno Mission hospital, Itando Catholic Mission Hospital and Kima Mission hospital. Walsh, (1998) observes that religious beliefs act a source of inspiration in sickness and influence individual health behavior positively. However, religious beliefs may also influence negatively when they are linked with guilt and punishment, Ahmad (2000). For example, there are sects that discourage their members from seeking medical treatment even when faced with serious health problems. Helman, (2000) points out that beliefs about health and illness affect people's decisions regarding their choice of treatments. Finding in this study are consistent with Helman ideas regarding religious influence on choice of treatment. Ismail*et al* (2005) study on religious beliefs about causes and treatment of epilepsy showed that people turned to religiospiritual treatments in desperation for a cure after a perceived failure of the "western medicine". They often did this with influence of their families. Like many cultures that believe social elements to cause epilepsy this study found that majority of the participants, having perceived failure or ineffectiveness of biomedicine shifted their belief to social cause.

Further, the findings are similar other studies that show belief epilepsy being caused by possession by spiritual beings (*jinns/jinis/majini*). As discussed in literature review in chapter two of this thesis, (Kendall-Taylor *et al* 2006) study among the costal people of Kilifi in Kenya found that the community believed that epileptic seizers are caused by a supernatural spirit referred to as *Nyagu*. There are a variety of spirits and other social causes that attract specific interventions, for example, illness caused by spirits are treated by a religious healer who removes the spirits by deflection and by invoking readings of divine writings. Even in the Ancient Greek, and in many contemporary societies, diseases has been seen as acts or intrusion by the gods, demons, or evil spirits, and as such treated by the invocation of supposedly supernatural powers. As shown in literature review ancient societies such as that of Babylonians believed that their environment was haunted by evil spirits. The spirits were responsible for illness by invading individuals. To heal, individuals had to atone their sins to be liberated from the spirit. This involved rituals of sacrifice and incarnations (Longrigg 2000). These beliefs seem to have successfully be transmitted through generations to contemporary societies. More recent studies in sub Saharan Africa show a high prevalence of beliefs that epilepsy is caused by the supernatural and witchcraft including breaking of taboo, Mushi *et al* (2011), Baskind *et al* ( 2005) and Winkler *et al* (2010).

### 6.1.3 Double etiology beliefs

There were participants who simultaneously believed both in natural and social causality of health. Koen et al, 2012 uses the concept of double causality to explain a situation where an individual believes in both natural and social causes of illness. Double causality “refers to an illness having both natural and mystical derivations”. This concept has used in this study to define a situation where participant’s beliefs hooped from natural to mystical aetiologies and vice versa or simultaneously harbored both beliefs. In this study, change in beliefs about perceived aetiology was occasioned not only by failure of an intervention but also by anticipated improvement in seizer control even when participant had stabilized health. This was based on availability of new knowledge on the illness and hope. For example,

"Ronald", male aged 24 narrates the changing beliefs on cause of his illness

> "They [Healthcare workers] seem not to be sure of the exact disease troubling me though the medicines they give are very helpful. But something tells me my illness is from somewhere…………….my sister had a fight with our neighbors' daughter. They exchanged bitterly. She told my sister our family has a curse. It troubled me because she was referring to me. I asked some old people about her allegation and they told me that my grandfather had some cultural issues but the family had been was cleansed. They didn't want to talk more but I think they are hiding something concerning my illness and a taboo".

It is observed that though "Ronald" is receiving medical treatment that seem effective in treating his condition, he nevertheless seem to labour, at the same time, thoughts that social causes might be responsible for his ailment. "Mary" aged 26 years on the other hand is receiving biomedicine and traditional medicine simultaneously, indicating that she believes inasmuch natural cause is responsible for her illness she cannot rule out social cause.

> "I attend clinic [Epilepsy clinic] every last Tuesday on the month. I am given Tegratol and Phenorbarbe that last for a month. I also take this……..lunyasi lwo vuhindi [participant goes to the bedrooms and comes with a grey powder traditional medicine]….this one [showing the powder] repels any witchcraft spells that may be cast my way. It also protects me from demon attacks at night. Demons used to attack me strangle me to the ground [have epileptic seizer]"

As evidenced in the above responses there were simultaneous beliefs in natural and social causality among participants. This finding is similar to other studies that showed persons living with epilepsy accessed both Western and Traditional medicines simultaneously (Bartolini *et al*, 2011).

In the course of illness persistence and progression there was increased interaction of participants with their environment at different levels. These interaction changed participants' perspective of their illness as evidenced by changing beliefs on illness causality. With increased interaction came new suggestions for treatment. People's behavior, including health seeking behavior, gets modeled and shaped by the environment. Bronfenbrenner (1994, 2005) identifies five levels through which persons living with epilepsy can or are influenced by the environment; (i) the micro-system, which is characterized by direct interaction with significant others. Here exposure of the significant others regarding beliefs and practices of illness can influence course of action and outcomes for the ill individual, (ii) the meso-system. Here, the individuals with epilepsy interact with the micro system such as peers, school and the community either can have influence over the other, (iii) the exo-system, which refers to the level at which there are interconnections between other systems where a person with epilepsy does not have direct interaction – but can have an indirect influence on the individual and the family such as secondary social agents like health systems, media, the church or support group, iv) the macro-system, such as the community collective understanding and attitudes towards an illness which can have a negative or positive impact on the individual and the family; and, (v) the chrono-system, which is lived experiences of the illness. In this study the interactions paved influenced new beliefs and search for remedy.

## 6.2 Treatment Pathways

This section discusses treatment pathways taken by participants. Treatment pathways taken were majorly negotiated by significant others of participants. Significant others were both the parents, and immediate relative such as aunt, uncle and grandparents. The negotiation occurred within the socio-cultural context of the community. As discussed in the introduction section of this chapter treatment pathways were based either natural or social causality however participants hooped from one treatment to the other based on available information and changing beliefs. The section is presented under the sub themes of; biomedicine treatment, accessibility, availability, acceptability, affordability, side effects of medication, social treatment, traditional healers, divine intervention and, dietary practices

### 6.2.1 Biomedicine Treatment

All participants sought treatment from medical health facilities at onset of their illness. Participants whose onset of illness was in adulthood could not recollect events during initial admission and treatment at health facilities because they were unconscious following seizer attack. They only remembered events that followed after they regained consciousness. Participants whose onset of illness was in childhood narrated events of initial treatment as told by their significant others. This section presents findings of participants' interaction within the medical healthcare systems. There were varied therapeutic experiences among participants all of which shifted to traditional system.

#### 6.2.1.1 Decision making access to health facilities

In all 15 cases of the study decision to seek medical help was made by significant others. Significant others included father, mother, aunt and elder sibling. Participants were not in a position to make decision owing to either their condition at the time, age or role play. Distance, time, and financial position at time of onset of illness were factors that determine the health facility to be visited. For example, "Tokessy", 24 year female describes onset of her illness and accessibility to two health facilities

> "*Another time I was helping my mother prepare when that thing* [seizer attack] *got hold of me again. Luckily this time my father was around. He rushed me rushed to Buyangu Health center although the sister* [Nurse] *there referred us to Mbale* [a referral hospital]. *She said I needed to be admitted because my illness had become serious. I was taken to Mbale and got admitted. I can't remember much about the movements but I just woke up in the morning to see many beds with patients. I was on water* [infusion drip]*".*

"Josephat" aged 22 faced accessibility challenges while seeking specialized care

> *"My mother was told that my sickness had advanced and needed specialize treatment at Kenyatta* [Main National Referral and Teaching Hospital in Nairobi]. *When we arrived there were asked to pay Ksh 6000. We didn't have that money so we went back to stay at my mother's relatives in Huruma* [a residential estate in Nairobi]. *She got the money and paid but they put us on waiting list for one week".*

As evidenced in participant's responses, local health facilities were accessible but participants did not get adequate services instead were referred other facilities where they encountered other challenges such as long waiting time for services. As discussed under treatment gap in the literature review Chin,(2012) identified five determinants of epilepsy treatment gap in sub Saharan Africa among them lack of primary health workers trained to diagnose and treat epilepsy. Whereas this study cannot conclude that primary health care workers who attended to participants in this study lacked training on diagnosis and treatment of epilepsy, it can be inferred from the findings that primary health care facilities face challenges of handling and managing persons living with epilepsy. Other challenges encountered during referral processes were; costly itineraries and challenges of staying in new environments as well as long specialized procedures resulting to increased burden to the participants and their families increased. Owing to these some participants discontinued their medical treatment. This finding is similar to findings of Kendall-Taylor *et al*, (2009 and WHO (2012) on disease burden. As earlier discussed under treatment gaps in literature review in chapter two, population in developing nations face a number of challenges in accessing appropriate healthcare. Keikelame *et al* (2006) cites inaccessible health facilities as one of the reasons why many people living with epilepsy in developing nations receive inadequate care.

### 6.2.1.2 Availability

Participants described their experiences with medical services at health facilities visited. Although availability encompasses a number of services such as consultation, laboratory and, pharmaceutical, participants majorly described how they were seen by the clinician and how they received medication. All the participants were attended to at the primary facility. All were referred for some form of specialized services outside the primary facility. 10 out of 15 participants said they received treatment before being referred for further treatment while 5 were referred without receiving any form of treatment.

"Georgina" female age 22 narrates challenges as she sought treatment.

> *"I could visit the hospital and take hours waiting for my medical records to be retrieved. I wasn't getting any attention. No one was telling me the progress of my illness. I could hardly have 5 minutes with the doctor. I saw no need of going back to that place"*

"Georgina" narration reveals lack of adequate medical staffs. It also points to possible lack of skills by health workers to create rapport and engage their clients. WHO 2020 defines availability as "sufficient supply and appropriate stock of health workers, with the competencies and skill-mix to match the health needs of the population". One of "Georgina's" health needs can be identified as need to understand her diagnosis. In this case her need is not met which leads her to withdrawing from the system

For "Emmanuel" aged 22 years he narrates availability of services.

> *"I hadtried kienyeji* (traditional medicine) *but we didn't see any difference. My grandfather tried herbs here and there but the condition persisted. My mother then took me for prayer at a shrine but we didn't see any difference .It was*

> *then someone told us that there is a health person* [community health worker] *at the market who gives people medicine to stop seizer. We went and meet her and she gave us these medicines* [Participant shows packets of Phenorbarbe tablets]. *She also organized for us to visit Mbale (a referral hospital) where I now attend treatment. It has been eight month since I got a seizer*"

"Kezia" aged 18 year describes availability of AEDs.

> *"The medicines I have been taking have helped me a lot although that thing [epilepsy] has not gone away completely. But I thank God I don't faint as frequent as I used to. Every month I go to the clinic for people with my illness [Epilepsy clinic] to collect medicine. Many people don't know I suffer this terrible disease (epilepsy).*

Josephine, female aged 23 years described accessibility to AEDs

> "*Medi*cations are always given. They don't charge for our medicine because the County provides them free. We only pay for registration 20 bob. But if you have any other problem other than convulsion (convulsion here means Epilepsy) you have to pay. When I got burnt and was admitted for several months my parents paid a lot of money………it's very expensive. Sometime you are asked to get medicine from the other pharmacy of ordinary patients. There you find many patients and one has to endure long queues"

Evidence from above responses shows there were varied experiences regarding access to care and treatment. Some participants received free AEDs while others were impeded from medicine due to other factors such as costs or stock outs of medicines. This finding concurs with other findings that show that access to AEDs is determined by many contextual factors such as logistics and stock outs. In some instances lack of steady supply of AEDs has led to non-compliance and poor treatment outcomes (Mung'ala-Odera et al 2008).As narrated by "Emmanuel" a steady supply and availability of AEDs can improve adherence and improve seizers control and subsequently improve social outcomes and quality of life of persons living with epilepsy. This finding is significant because it shows importance of community health workers a link to improving healthcare accessibility.

### 6.2.1.3 Acceptability

Acceptability in healthcare is the extent to which recipient of the services assesses the appropriateness of care received. In this study participants described their experience within the healthcare system. Although majority of the participants said they had experienced reduced seizer attacks, seizer would reemerge as a result of many hindrances to adequate attention within the healthcare system. These challenges impeded continual medication and compelled participants to seek alternatives. One of the major challenge faced by participants was lack of engagement by healthcare workers on explaining the diagnosis and treatment. For example, “Ronald”, male aged 24 had difficulties engaging the clinician.

> “*They (clinicians) don’t bother to ask you questions apart from how you are faring on. They don’t explain your illness in the first place. And they don’t want you to ask questions, when you ask them to explain why they are giving you certain medication they take it as if you are questioning their knowledge. They just take your book (medical record) and write you some medicine….that’s all. No one is there to explain to you your illness. They seem not to know the exact type of disease troubling you.*

“Josephine” aged 23 describes lack of engagement by the doctors.

> “*I was referred to Moi* (One of the main referral hospitals in Kenya). *The waiting queue is very long. When I got into the doctors room I found many doctors. They discussed about my illness for a very long time. I was there and I didn’t get what they were discussing. In the end they told me I needed to be on treatment for ever. I couldn’t understand because they did not explain my illness well. They said I was epileptic………… but I don’t urinate when I fait (have seizers), but they insisted saying that my type of the epilepsy was different.* [Participant becomes emotional and starts to cry]. *How do you just tell someone she has such a disease? My parents decided we seek help from traditional people.*

“Josephat”, a male aged 22 described the complex language used by the attending doctor as an impediment to understanding diagnosis.

> “*The doctor explained something to do with how electricity flows in my brain saying it was faulty but I could hardly understand what he meant. They* (health care workers) *are always in a hurry and they talk difficult language that a*

> *small person* (lay person) *like me cannot understand. When we opted to visit the traditional healer he told us my health problem and what was causing it".*

"Tokessy", a 24 year female participant describes poor outcome of a specialized diagnostic intervention

> *"They referred us to Moi referral Hospital where they put some machines on my head to look inside the brains* (EEG and CT Scanning procedures*). After the tests we were referred back to Mbale Hospital with the films from the procedure. When we reached Mbale the Doctor there told us that there was no report accompanying the films and we needed to travel back to Moi. We had no money left so we did not go at that time"*

Evident from the interviews there inadequate communication was a major faced by participants. Participants described failure by healthcare workers to engage them in discussion about diagnosis. This finding is similar to that of Kendall-Taylor *et al*, (2009) which found that patients considered time spent with the doctor as insufficient compared with personalized and leisurely consultations with traditional healers. Regarding referrals, participants said they were subjected to many referrals that proved expensive and that the procedures prescribed were lengthy. Although some of the specialized diagnostics or treatment services were free participants waited for prolonged period to get a booking. Some of the procedures participants identified were skull x-ray and ultrasound scanning, MRI and encephalography. All these were not available at the nearest facility and they had to travel long distances and hours to get the services. Similar results have been found in previous studies such as Kendall-Taylor *et al*, (2009). WHO (2012) estimates in over 80% of the countries of sub-Saharan Africa, where the majority of people with epilepsy live are not receiving appropriate care due to shortages of trained health workers, limited diagnostic equipment, inadequate anti-epileptic drug supplies, cultural beliefs, and social stigma. Analysis of epilepsy treatment gap in developing countries by Mbuba et al, (2008) reveals that the major hindrance to adequate care of person living with epilepsy in developing countries is inadequate skilled manpower. The analysis show that there is a paltry of 0.3 neurologist per 1 million population. Only 11 countries have more than 10 neurologists per country

Studies have found that majority of persons living with epilepsy in low and middle income countries do not receive appropriate treatment (Keikelame 2013, Mbuba *et al* 2008 and, Eseigbe *et al* 2014). During data collection period of this study, it was established that although Vihiga County Referral and Teaching Hospital had a functional Epilepsy clinic there is no resident Neurologist nor specialized epilepsy Nurse to attend to routine management of patients with epilepsy.

#### 6.2.1.4 Affordability

Affordability was discussed by participants as a major impediment to specialized treatment. In health, affordability describes the ability of an individual or organization to pay for health services. Participants described challenges in meeting the costs of health care services. 14 out of 15 participants paid out of pocket for various services received such as diagnostic procedures of CT scan and, Electroencephalogram EEG. Only one participant was insured as a dependent under the National Hospital insurance Fund (NHIF) but the cover did not include most of the services required such as diagnostic procedures. Participant therefore paid out of pocket which further increased the disease burden. Majority of the participants encountered bills they had not anticipated. This happened often when faced with referral. As a result participants did not pursue further treatment. Although participants received free AEDs they met the costs of travelling to collect the medicines, for example “Tom” aged 20 years who has challenges of income.

> "*All these years I have received treatment from the doctors they haven't got rid of the seizers. They have changed medicines several times and taken me to machines [diagnostic equipment's] but nothing has worked. I get brief reliefs then am back to my seizers………its expensive…….getting money when you are sick is not easy because people don't give you work"*

"Asneth" 21 year describes challenges of affordability.

> "The *medicine given at the hospital were the same ones we I got before I was referred for special x-ray. I had expected new medicines. My family spent a lot of money and they feel drained………like on CT scan alone they paid 12,000 shillings. In the end there was no improvement of my condition. !*

24 year old "Janepher" narrates the changing costs of medication

> "*I used to get free Phenorbarbe and Tegratol. The Community Health Worker used to get me a monthly dose. Even the clinic at Mbale was free but now they insist I have to have an NHIF card. Its expensive m for me. They need me to pay 300 shillings per month*"

"Tokessy" 24-year narrates cost incurred during hospitalization

> "*I was admitted for 8 months. I had severe burns. The bill shot up my parents could not afford. The hospital could ask us to buy material for cleaning my wounds. It turned out to be very expensive for us. My mother used to stay with me at the hospital but when the Ward became full she was asked to leave. I could take days before seeing her because it was very expensive for her to travel*"

Evident from participant's description, access to specialized treatment was curtailed by costs beyond participants reach as most of them did not have a stable source of income. In their description on living arrangements participants talked about their families struggling to have make an income. In order for the families to find time for income, they made special living arrangements so that the sick member was taken to live with relatives such as grandparent while the family worked for income.

Participants also faced challenge of getting a job for an income because of discrimination on the basis the illness is contagious. Further, participants had very low level education that could not help them attract jobs. As described in chapter 5, participants who had business reported making loses as a result of disrupted hours occasioned by seizer attacks. It can therefore be inferred that diminished income of participants underlie poorly controlled seizers because there is inadequate resources to sustain treatment.

#### 6.2.1.5 Side effects of Medication

Almost all participants were on AEDs at one time. Although most said they had good control of seizers they reported having discontinued the medication due to some unpleasant side effects of the medication. Three participants narrated suffering bloated stomach and uncontrolled flatulence. They said this made people isolate them. All participants experienced the side effect of drowsiness. For example "Kenneth" aged 21 years described challenges of AEDs on schooling

> *"mwigizi yangungu mukilasi navola mbwana ndakogona mu gada, nesievanga mu valivayo navutwa tsiali tsinyasi ziakola nitengeza. Kundamanya ndeke kumila vifungu yivyo nivambenzela masambu"*
>
> [The teacher send me out of class because I was drowsy thinking that I had spent time dancing at night at a funeral but that was not true. The medicines were making me feel sleepy all the time so I decided to stop and seek traditional herbs].

"Kenneth" talks about his class teacher sending him out of class accusing him of being sleeping while in class after spending the previous night dancing to a ritual ceremony for a diseased person. In Vihiga community people gather at a diseased home keeping vigil for three days. During this period they dance at night to various dirges. The night ceremony is popularly known as Gada where people beat drums and dance around the compound of the dead. The ceremony goes on throughout the night till morning.  So, "Kenneth" who is enduring drowsiness side effects of AEDs is perceived as having attended Gada and is sent out of class.

"Georgina" female age 22

> "*I was given some medicines that were very effective on my condition but they used to make me pass a lot of wind* [meaning flatus]. *I was always uncomfortable I decided to discontinue the medicine"*

Whereas AEDs help to control seizers, their side effects bring social problems that work to counteract AEDs positive effects on quality of life for those living with epilepsy. Individuals have discontinued medication because of harsh side effects of AEDs (Kwan, 2000; Perucca, 2009). Findings on medication side effects in this study are consistent with other studies on impact of AEDs side effects on quality of life of persons living with epilepsy, (Jacoby et al., 2014).

Participants in this study, as evidenced by narrations of participants on poor patient-doctor relationship felt their concern regarding side effects of AEDs were ignored by healthcare workers who solely focused on seizer control. However, a few participants said they coped well with the side effects of the medication because they got used to them. Mayo Clinic (2009) observes that patients' fears of ongoing seizures tend to overshadow complaints about medication toxicity, that, seizure-free patients are often too comfortable with and grateful for their outcomes to broach the risk of lowering or withdrawing AEDs producing adverse effects, despite limitations in QOL. Studies on quality of life among persons living with epilepsy have informed the need to reshape priorities in epilepsy care with a focus being on the social functioning, mood and cognition of the individual and not just the control of seizer.

### 6.3 Self-Medication

Participants having had a prolonged encounter with the illness had formed individual knowledge on how to handle their condition. Although they reported reduced seizer as a result of taking AEDs, participants cited side effects and diminishing effectiveness of the medicine as a constant challenge that made them be on the "look out" for seizers. Thus they resorted to "listening" to the body. Participants used the phrase "listening to the body" to describe how they gauged their body to determine if they needed to take medicine. Apart from taking prescribed medicine participants self-medicated with drugs they thought could get them relief.

"Josephat" described how he listens to his body to detect for any impending seizer;

> "*I'm now used to this illness* [epilepsy]. *These days I understand how my body works. I listen to each part of it and I can sense if am going to have trouble (experience a seizer), so I tune it by running to my Tegratol (AED). Whenever I am doing nothing I focus on my body listening to how it is responding. I am very alert of everything. If I sense something like flu or headache and no other feeling I just take Panadol or Sona Moja (analgesics). If I feel something funny coming up like the world is spinning then I know am going to have convulsion, I swallow my Tegratol. I used to suffer at the beginning when I had not understood my body*".

"Josephine" aged 23 described why she self-medicates by saying;

> *"It's long since I went to clinic. I stopped going to clinic around 2010. My people (relatives) once organized I see a certain Doctor who was performing circumcision in this area during the circumcision period. He is son of XXX and works in Busia. They tried to explain my illness to him. He gave me two long tablets. This made me feel better for some time (did not experience seizers for a period) but the doctor went back and it was not easy reaching him because his place (Busia) is very far. Since then the only time I take medicine is when I have headache. I take Mara moja or Action (Painkillers). When that thing (seizers) comes back I get anxious and can be awake all night so I take Piriton to get some sleep. When it comes it can come for two to three days. When it attacks I can take a whole day and even a whole week having convulsions. The best way I handle it (epilepsy) is to take the Piriton to calm me and give me sleep"*

24-year "Ronald" described how he "listens" to his body and respond

> "*I have medicines from the Hospital but I don't take them regularly until I feel some sensation in my body indicating I am about to faint* [have epileptic seizer]. *Sometimes those convulsions come with a lot of force and overpower the medicine. Even if I increase the dose the medicines don't work*"

## 6.4 Summary of Biomedicine Treatment

Naturalistic standpoint on which biomedicine is based considers illness as an act of natural cause that is related to organism or altered physiological process which can be treated by medicine. Using biomedicine model or germ theory medical science investigates pathophysiology of the disease in order to elucidate on the exact cause of the disease. In regard to epilepsy, biomedicine model uses AEDs to regulate the altered physiology of electrical current system of the brain (seizers). About 70% of patients with epilepsy can be seizer free with use biomedicine (Meyer et al 2010; Baskind et al 2010 and, Coleman et al 2000). In literature review chapter two under biomedicine review, it was observed that phenobarbital, Carbamazepine, levetiracetam, and phenytoin were first line treatment for epilepsy recommended by The International League against Epilepsy (ILAE). Even though participants receiving biomedical treatment had numerous challenges within the medical system that jeopardized the treatment, AEDs were effective in controlling or limiting frequency of seizers experienced.

## 6.5 Social Treatment

Social treatment is used in this thesis to mean treatment that is based on perceived social causes of epilepsy. As earlier discussed under treatment approaches in literature review in chapter two of this work, social treatment is based on belief that the cause of illness is external of the patient’s body, i.e. it is supernatural and is not confined to the patient and his body, for example, witchcraft and possession by spirits (Feierman & Janzen, 1992). Social treatment is discussed under sub themes of traditional medicine, divine intervention and dietary treatment

### 6.5.1 Traditional healers

Traditional healers were sought by participants because they were perceived to possess powers that can discern spirits and drive them out of the body either through supernatural power or by herbal medicine or kinds of paraphernalia. For example “Josephat” described procedure used to expel demons from his body.

> “The neighbors who had accommodated us in Nairobi suggested to my mother to take me to witchdoctor who had powers to remove the demons that were disturbing me. I was then taken to the witchdoctor. We carried a black hen because our neigbour had told us to carry one when visiting the healer. When we arrived at the witchdoctor’ house ….it was in Kariobangi, he asked my mother for the hen before commencing the healing. He asked me to hold the hen then took me to a dark room……I could hardly see. He then asked me to lie on the floor. He asked me to remove my shirt and hold the hen with its head facing me. He then told me to utter some words after him. I repeated the words severally. He was instructing demons of the dead to move out of my body. As I uttered the words he made cut marks on my abdomen using a razor. He rubbed certain medicine in the cuts………..these are the marks [participant shows the area around umbilicus and lower abdomen with several strip wound marks that have healed by scaring]. He then told my mother that the demons had oozed out of me. He then took the hen and put it in a pot. He gave us a certain medicine in liquid form to take for a month. I got healed for about a two weeks but it (seizers) came back again. I have been visiting different witchdoctors and sometimes hospital”.

“Janepher” describes her itinerary to traditional healers in search of remedy

> “I was introduced to a traditional healer in Bungoma who protects boys undergoing traditional circumcision from evil eyes. He performed cleansing rituals on me. His medicine worked well and I didn’t experience seizers for some time. Someone told me that there is a healer in Kitui who treats such illness as mine once and for all. She said the person had helped many with similar problems. We got his contact from an advertisement post. His name is “Dr Quick”. We made calls and he directed me to his place in Ukambani called Mbitini. I saved money from relative and traveled to meet him. He performed rituals on me then gave me various powders to lick with instructions. I improved a lot, I only fall occasionally”.

As discussed in literature review traditional medicine goes beyond treating the patients’ bodies instead “intervenes” with the supernatural. The aim of the traditional medicine is to eliminate malevolent forces that cause the illness or condition. Performing rituals is one way in which traditional healers connect with the perceived supernatural. In majority of participants who sought remedy from traditional healers, rituals and use of paraphernalia was part of treatment procedure and was performed in secrecy. Evident from participants we continue to observe that participants were influenced in their decision to seek treatment.

### 6.5.2 Divine intervention

Divine intervention in this study is used to describe religious beliefs about the power of a supernatural force that govern over man, God Almighty. Use of divine intervention as treatment for participants' illness was premised on social causality of epilepsy, specifically the spiritual causation and faith that Almighty God heals illnesses. Divine intervention in this study involved prayers and, religious rituals. For example, "Georgina" aged 22 who earlier explained about her challenges with AEDs and their side effects describes prayer and rituals that helped her get relief, at least temporarily.

> "She invited healers to our home to perform prayers. I remember they came and cleansed the compound through rituals of springing holly water around the compound. They unearthed hair and teeth that were wrapped in a cloth and buried on the hedge near our house. They said someone evil had buried the hair and primary teeth I had. They told my dad that spiritual powers had directed them to hedge and that spirits that were contained in the cloths were the ones causing my problems. They prayed and released the spirits from me. From that time I got well for about two month but then that thing returned"

Tom, male aged 20 describes prayers and his liberation from possession.

> "She (Mother) told me she prayed to God to help me heal. She used to rebuke and cast out demons from me. She used to say "if it was God's plan then let it be so but if it is people evil work then I rebuke". I could recover and stay without convulsions for about a month. She used to organize church people to come and pray for me. At one time a religious leader came and said my illness was due to demons of dead peoples who came in shadows (reincarnated souls). He cast way the demons and I got relief"

Literature on health outcomes on other conditions that show mixed outcomes (Cha, Wirth, and Lobo 2001, Aviles *et al*. 2001 and, Abrams, and Moore 2006). Significantly, exclusive divine intervention with no attempt to complement with either biomedicine or traditional treatment has resulted in poor health outcomes Benson *et al*. (2006). Like many cultures that believe epilepsy is caused by demon or spirits possession this study found that majority of the participants related their illness to demon or spirit possession. The above findings are similar to others that show that epilepsy is believed to be caused by possession by spiritual beings [jinns/jinis/Majini] (Kendall-Taylor et al (2006). The method for treating epilepsy among this group based on the type of spirit and kind of symptoms, and the treatment practice also depend on religion affiliation. For example if the healer is a Muslim, the methods of treating spirits will involve removal and deflection, and reading the Koran. In Ancient Greek, and in many contemporary societies, diseases have been seen as acts or intrusion by the gods, demons, or evil spirits, and as such treated by the invocation of supposedly supernatural powers. Literature by Longrigg, (2000) shows that Babylonians believed that their environment was haunted by evil spirits. The spirits were responsible for illness by invading individuals. To heal, individuals had to atone their sins to be liberated from the spirit. This involved rituals of sacrifice and incarnations. These beliefs seem to have successfully been transmitted through generations to contemporary societies. More recent studies in sub Saharan Africa show a high prevalence of beliefs that epilepsy is caused by the supernatural and witchcraft including breaking of taboo, Mushi *et al* (2011), Baskind *et al* ( 2005) and Winkler *et al* (2010).

### 6.5.3 Dietary practices as treatment

There were suggestion for participants to have specific diets that would heal participant's illness. As captured in community KAP survey on epilepsy in chapter four there was a small percentage of respondents who said epilepsy could be treated by diets such as dog meat. Surprisingly a respondent, 25 year old "Asneth" was given dog meat as treatment for seizers.

> "*Someone told my grandmother to secretly cook dog for me because the meat had powers to absorb evil spirits that were troubling me…………haaah … She actually served me a cooked dog meat but it did not work. She asked that*

> *person why she had lied to her and the person explained that I was supposed to have vomited after eating for the treatment to be successful. The meat was to suck and drain the disease from my intestines*".

"Tokessy" aged 24 years narrates dietary practices advised as therapy to seizer

> "*I was advised to be taking donkey milk. I searched for that milk but it was not available' they also told me to be taking certain vegetable in plenty but it all did not work*"

Significance of diet in management of seizers and epilepsy is not well documented in biomedicine system. However, there is literature regarding cultural practices and beliefs on foods that are believed to precipitate or treat seizers. A number of studies have shown control of seizers through foods with a low-glycemic index (Kossoff et al 2009). Dietary practices have been used on trial and error to treat various maladies. However diet as an intervention might prove impractical in developing countries where high level of lack of adequate nutrition among other related food factors exist. For example preparing for special meals for individuals with epilepsy may prove a challenge because of costs of cooking fuel or the availability of the food. Socialization on dietary practices may also act as a barrier to dietary intervention as method of treatment because the community is socialized to share meals. Having special meals may act to further myth about the illness.

### 6.6 Preventative Practices

Aware of unpredictable seizers and predisposition to danger and, stigma, participants engaged in harm-reduction practices. Participants were particularly cognizant of seizure triggers. Participants' desire was to attain a seizer free status and enjoy a "regular" lifestyle. For example, "Janet" aged 19 years describes her daily routine applying precautionary measures;

> "*I normally do what I have set for the day whether the attack [seizer] comes or not. I know the pattern of my illness and I avoid things that bring the attack. I avoid markets like plague because of noise and heat, unless am with a friend*

> *who understands me. People don't know why I don't attend church regularly but when that noise of drums* [music instruments at the church] *get to my ears I start having ringing sounds in my ears then experience a seizer attack. Even sharp noise of children screaming make me have seizers*"

"Phil", a female aged 18 narrates dilemma of using a vehicle because it's one of the triggers of her seizers

> "*I know things that make me faint [experience seizers]. I can for example seat near window of a moving car. I have vertigo and the next thing I see is people surrounding when am waking up from a seizer. I used to visit my aunt in Seme and that thing [seizer] used to attack me once the car starts moving. I don't know what I can do if aim to travel to Nairobi or Mombasa. I think I'd rather travel at night because its dark and you can't see the moving bushes. You know I can't even ride on a motorcycle. I normally walk to avoid that thing [seizer] attacking me".*

As captured in chapter 5 findings of this study described how seizers particularly disrupted their daily lives. In practicing preventive measures participants attempted to normalize their lives and adjust appropriately in order to socially fit to and be accepted into social networks.

### 6.7 Summary

This chapter has made an attempt to provide a better understanding of how young people living with epilepsy manage their condition. The chapter demonstrates that social structures and significant others of individuals with epilepsy determine course of treatment. Choice of treatment pathway are shaped by beliefs on cause of illness. These beliefs keep shifting depending on available information at the time. Beliefs in natural or social causes are not exclusive to one another rather may occur simultaneously.

# CHAPTER SEVEN

# DISCUSSION

## 7.1 Introduction

The aim of this study as articulated in chapter 1 has been to explore the lived experiences of young people living with epilepsy. The three objectives set at the beginning have been achieved through a KAP survey and in-depth interviews with research participants. The concepts that emerged in relation to the research questions and objectives include; dominant influence of society's interpretation and management of epilepsy; uncertainty of everyday life experienced by young people living with epilepsy due to unpredictable seizers and; coping strategies to live with the illness. These concepts provide stakeholders with new knowledge of how epilepsy is interpreted and lived. The knowledge provide opportunity for reexamination of current policy on the illness and formulation of new policy on management of epilepsy.

## 7.2 Theoretical Framework

As discussed under theoretical framework in literature Interpretive Phenomenology Analysis (hermeneutic phenomenology) was most appropriate theory to guide the study. The philosophy behind IPA is the understanding of "being". It focuses on our experiences of the world. It goes beyond the mere knowing of occurrences we have, "our world" and seeks to understand what that world means to us. In this study the focus was on what epilepsy meant to those with the illness. IPA is oriented to seek meaning that is embedded in the "being" or "experience" or in the everyday occurrences. The central tenet of this philosophy is interpretation (Creswell J.W. 1994). This study sought to describe the lived reality of persons living with epilepsy and what that "world" meant to them. In understanding the realities the study drew meaning of the occurrences in the everyday life of young people living with epilepsy. For example, while describing the occurrence of a seizer the study sought to interpret what the seizer meant to the individual. For example, does the individual see the seizer as a shame, risk to self, risk to significant others or, an interrupted day? IPA goes beyond the mere description of the occurrence (Lopez 2004). IPA is particular in exploring how people make sense of their experience (Smith *et al*., 2009). As such it is conceptualized at a level of the *person-in-context* and therefore an idiographic approach in understanding meaning. IPA therefore commits to an individual level of analysis – which implies a focus on the particular, rather than the general (Gina M. Reiners 2012).

IPA proposes rich qualitative data collected through interviews. Because of the richness of data the approach proposes a fewer sample size. Further, because of the known phenomenon the approach proposes purposive sampling of participants relevant to the phenomenon under study. The interviews are fluid and non-directional (Smith, 1996), in-depth and conversational focusing on participants' experience, understandings, perceptions and views (Reid, Flowers, & Larkin, 2005), from which a rich rapporteur of personal accounts are built. The researcher explores the participants' "subjective reports rather than the formulation of objective accounts" (Flowers, Hart, & Marriott, 1999) as applied to this study. Our understanding of the lived experiences is derived from interpretation of these accounts.

As captured in chapter 1, I was motivated to pursue this study based on my childhood experience of people living with epilepsy and how they were treated by the community, as well as my previous clinical experience with persons living with epilepsy. Heidegger IPA asserts that personal awareness and previous experience are intrinsic to interpretative phenomenological research. He further observes that the experiences become an integral part of data analysis. This is so because it is not possible to shade off past experiences related to the phenomenon under study because researchers become enmeshed with them. Therefore, studies that ask for meaning of the phenomenon but do not require bracketing of prior experience with the question under study call for IPA approach ((Gina M. Reiners 2012). In the process of analyzing the qualitative data, the researcher perused through individual transcripts back and forth highlighting conspicuous descriptions, comparing them with others and relating them to the overall objectives of the study. This process of data analysis is referred to as the hermeneutic circle where understanding and interpretation of the phenomenon takes place (Drew 1998). This section has demonstrated the application of IPA in this study. The major assumptions of the approach has been detailed. It can be concluded that IPA is the most appropriate approach for this study.

### 7.3 Knowledge, Attitude and Practices on epilepsy

The first objective of this study was to investigate the KAP of households on epilepsy in Vihiga County. Epilepsy was majorly defined by its characteristics of seizer, and the accompanying occurrence such as becoming unconscious, urine incontinence and frothing of the mouth. 35 % defined epilepsy by describing what happens during an epileptic fit. For example, Respondent J: "*epilepsy is a condition whereby, if you are affected, you fall down and urinate in your cloth*". This particular aspect on urine incontinence and frothing of the mouth is reflected in the lived experiences study. One of the participants narrated "*It is not epilepsy, if it were epilepsy I could be urinating in my cloth*. 30% defined epilepsy by giving signs and symptoms of the condition, such as, smirked lips and body wounds such as burns wounds. Person with epilepsy are prone to injuries occasioned by epileptic seizer. Seizers are uncertain and people who live with epilepsy are unaware on when a seizer will occur. On some occasion the seizer may occur when the person is in a potentially dangerous situation such near fire place, place with sharp object and pools of water.

Epilepsy is usually evident by recurrent, typically unprovoked epileptic seizures (Guberman and Bruni, 1999). Seizures are transient episodes 'of neurological dysfunction brought about by abnormal, synchronous and excessive discharges of cerebral neurons' (Oxbury, Polkey, and Duchowny, 2000, p.11). Epilepsy is characterized by seizers and unconsciousness accompanied by urine incontinence and frothing in the mouth although not all types of epilepsies will have these distinct features. WHO (2015) defines epilepsy a chronic disorder characterized by recurrent seizures. The seizers are a result of brief disruption in normal brain activity that interferes with brain function, Ontario, (2015). From these findings it can be concluded that majority of respondents in the KAP survey were fairly knowledgeable about the definition of epilepsy. However, when asked about the causes of epilepsy there were varied explanations. These misconceptions revealed misconception about the illness. The misconceptions formed the basis for stigmatization of the illness. Explanations given as the cause of epilepsy included possession by demons, curse, violating of taboos and heredity. Other explanations as the cause of epilepsy were birth complications, complications of meningitis and malaria. 49.6 per cent of the respondents in the KAP survey said epilepsy is infectious. 85.1 % of the same respondents said one can inherit epilepsy from parents. 12 % of the respondents said one can get epilepsy by sharing food with epilepsy. These explanations are fundamental because they are points of reference of health seeking behaviors i.e. Health seeking behaviors are influenced by perceived cause of illness. If the cause is natural the treatment likely to be taken is biomedicine because of the underlying belief that naturally occurring illnesses are treatable by biomedicine. Similarly if the belief is about social causes then treatment is likely to be the form of traditional interventions. Knowledge deficit regarding biomedicine etiology of epilepsy can lead to poor utilization of health care services and lead to altered quality of life for those suffering the illness.

## 7.4 Lived Experiences of Young People Living with Epilepsy

The second objective of this study was to examine how the community's knowledge, attitude and practices on epilepsy influenced individual lived experience. Participants gave narratives about what living with epilepsy meant to them. Three major findings emerged under lived experiences; epilepsy as a disruptive illness, epilepsy as a labeling illness and, concealing epilepsy.

Seizers disrupted the daily lives of the respondents in two significant ways. Most seizer came suddenly in an unpredictable manner. As such epileptics are caught unaware. This meant a disruption of the activity they engaged at the moment of seizer attack. Participants report warning signs of an impending attack but seizers overwhelmed them before any action. For example, one said "*it is too late to prepare for it* [seizer]". Specifically seizer disrupted the daily lives of the participants by disrupting planned schedule. This forced participants to discontinue their plans. Among reasons for disengaging the day were; felt disorientated after seizer episode, had suffered injury and were in pain and, had soiled cloth and felt embarrassed. Participants reported often falling either on rough or hard surfaces during the seizer. Almost all the participants had visible injury marks. Participants felt that the injury marks altered their image, particularly in case where the individual sustained severe burns that deformed face, hand and skin. One participant had suffered fingers making it difficult to obtain a national identification card because her finger prints could not be captured because burns destroyed his finger prints.

Most participants in the study had low levels of education. This finding has been reported in majority of studies among persons living with epilepsy. Delayed schooling, stigma at school and absenteeism due to frequent hospitalization emerged as the main reason for low levels of education. Other factors such as medicine side effects and, loss of cognitive ability contributed to fewer years of schooling. Almost all participants did not have employment. This was attributed to stigma and discrimination and, low level of education.

Participants had difficulties maintaining intimate relation with opposite sex. Previous studies have shown that men with epilepsy are less likely to marry, and women are less likely to be the first wife. Additionally, women with epilepsy may have problematic pregnancies, adding to their stigmatization. Previous studies show that persons living with epilepsy face major challenges in forming and maintaining intimate relations owing to stigma associated with their illness of epilepsy as evidenced in this study. Additionally females living with epilepsy face challenges of frequent brea up if in a relation. Young males living with epilepsy face challenges of rejection from in their search for intimate relationship with female. Both have developed coping mechanism to overcome emotional strain related to unstable intimate relationships depending on their sex. Majority of male respondents who indicated that they are in intimate relation preferred commercial sex workers because the sex workers are not bothered with the epileptic condition unlike girls in the community. The unstable intimate relation experienced by epileptics could be attributed to society’s perception of the illness as contagious, thus once a partners discovers one has epilepsy they breaks up the relation. Young people with epilepsy in search of a stable relation end up having multiple partners. Multiple partners predisposes the young persons with epilepsy to STI and poor coping mechanisms.

Even though the findings of the KAP revealed majority of households in Vihiga agree that people with epilepsy should have intimate relation or marry, young people living with epilepsy and who have experienced intimate relations think otherwise. Previous studies have indicated that persons with epilepsy are less like to marry and women with epilepsy less likely to be married. This is attributed to negative perception and stigma on epilepsy. Majority of the young people living with epilepsy narrated how some members in the community contributed to their intimate or married relationships breaking. For example, a female respondent who had married and had a child had her marriage broken when some of her neighbor talked about her illness to her husband. In another narrative a male respondent explained how female partners could break intimate relationship with them when their peers revealed the epileptic condition.

Another conspicuous finding of this study was that majority of the respondents in the qualitative interview study did not live with their parents instead stayed with their grandparents. Respondents were asked to explain why they did not stay with their parents. Five out of the 15 respondent said that they thought their parents were protecting their siblings from “bad talk” of people. “Bad talk” in this context means discrimination. From an informal conversation with four of the respondents care givers (all were grandmothers), they said that the epilepsy condition was causing conflict between the mother and father of the child, and that one parent often the female, opted to take the epileptic child to live with grandparents. This may indicate fear of stigmatization of the family or maybe misconception about the cause of illness. It may also indicate denial by the parent that the child is having epilepsy. It may as well indicate that members of the families may fear the illness is contagious and may infect other children or members of the family while still young. It might yet suggest the burden of epilepsy overwhelms the family and therefore need for help. All these possibilities could be investigated further.

All respondents in the qualitative study said they had experienced forms of prejudice and discrimination. Verbal teasing was commonest form of prejudice encountered such as use of derogatory terms as “the epileptic” or “the mad person”. Name calling was cited by respondents as very distressing. Name calling was common in primary school while “back-biting” was common in secondary schools. These findings are similar to those by Meriel Wilde and Haslam Cheryl (1996). The respondents also experienced forms of physical assault and insults from peers especially in primary schools. The physical assault included throwing stones, pushing and beating with sticks. Insults included teasing and use of derogatory language. The discrimination experienced included being isolated from teams or groups such as play or discussion groups. The young persons with epilepsy reacted to this forms of prejudice, assault and discrimination with anger and frustration. Four of the respondents reacted to the physical assault by throwing stones or fighting the offending peers. It could be argued that insults are more hurtful and traumatic during adolescent and young adulthood because of the vulnerability of individual self-esteem. However, it can also be argued that because of over protection from care givers persons with epilepsy may have poorly developed social and interaction skills and may interpret what is actually normal comments of peers in a negative way.

### 7.5 Managing Epilepsy

The third objective of this study was to investigate how young people manage their illness. The study found that participants were preoccupied with search for remedy for seizer described as causing uncertainty daily living. Participants oscillated between medical and traditional systems in search of treatment. Participants made several itineraries in search of relief from seizers. Itineraries were made to; health facilities, religious healers, traditional healers, herbalists and witchdoctors.

Changing beliefs and ineffectiveness of treatment were reasons for changing treatment pathways. For example, change in beliefs that the illness was not treatable by medical system was occasioned by failure of medicine prescribed to eliminate seizer. The belief was compounded by failure to get explanation from health workers about cause of the illness. As such, participants felt that the clinicians did not understand their illness and that explanation of their illness lay elsewhere such as traditional or religious system. Apart from feeling that medication from hospital failed to control seizers, participants described side effects, expenses of travelling, long queues of treatment and procedures and, pressure from significant others to change treatment path as reasons that compelled them to try treatment elsewhere. Another reason participants described as reason for changing treatment path was that they felt they were given false hope about treatment of medicine to stop seizers only for the seizers to recur. This made them lose trust in the clinicians. We therefore observe that lack of adequate biomedicine information on cause and management or failure of clinicians to communicate clearly about the illness led to cultural beliefs and perceptions about epilepsy flourish, thereby reinforcing long standing beliefs and behaviors that foster stigma.

Participants faced a number of challenges while seeking treatment within healthcare system. For example, they were subjected to referrals for specialized care. This translated into burden because of costs involved. Although some referral services were free participants had to wait for prolonged period to get a booking. Some of the procedures described for referral were skull x-ray, ultrasound scanning, MRI and, encephalography which required special preparation and extra cost participants were not told by referring clinician. In addition to ineffectiveness of AEDs to control seizers most participants the supply of the medication from health facilities was not consistent which contributed to participants missing daily dosage and subsequent seizers. Participants reported difficulties in adhering to prescribed medicines related to either unavailability or side effect of the medication. Whereas AEDs, in some cases, were described as available at health facility, only a monthly dose was given requiring the persons to go back to the facility in a month. In the event one failed to go for the monthly refill he or she missed out on the treatment for a whole month. Majority of participants did not honor medical appointments scheduled because of various reasons such as lack of bus fare, fear of being spotted at Epilepsy clinic or forgetting the scheduled appointments.

As captured in the literature on biomedicine management, epilepsy can be treated effectively using AEDs but about 30% of individuals diagnosed with medically refractive epilepsy do not respond to two or more antiepileptic drugs (CCSO, 2014). Among side effects of the medication are; tiredness, dizziness and forgetfulness. These particularly affected schooling or income activities. For example, drowsiness made some participants appear drunk and uninterested in conversation with others hence being labeled antisocial or uninterested.

In regard to traditional treatment participants were compelled by factors explained above to seek alternative health path. In particular, those who sought traditional medicine were introduced to traditional healers either by relatives or community members. It was observed that participants only sought traditional medicine after biomedical treatment failed to control their seizer. It was also observed that participants opted for traditional medicine when they could not get a clear explanation of their illness from health professional as explained earlier. At traditional healer participants described receiving adequate explanation about their illness. For example, Traditional healers explained how epilepsy “entered” the body and how herbal concoctions had the power to conquer the epilepsy in the body. Participants said the explanations from traditional healers made them understand their illness better and felt well cared for. Traditional medicine was obtained in homesteads of known healers who were also treating other diseases. Participants described having had a rich therapeutic interaction with traditional healers than they had with medical professionals at medical facilities. Participants stated having been explained to the cause of their treatment and what the herbs would do to treat the illness unlike in health facilities where there was a scanty information on diagnosis and treatment. Traditional medicine has been used virtually in all societies to treatment ailments. The medicines are usually referred to by the name of either the society or continent. For example, folk medicine used in African is referred to African medicine, those in Chine are referred to as “the Chinese medicine, in Indian we have Indian herbal medicine while in Japan its referred to as Japanese medicine (Li, 2000), (Saito, 2000), (Morgan, 2002). Apart from seeking remedy from traditional healers, participants were attended to by divine healers. Belief in spirits as cause of seizers influenced participants to seek divine intervention. Other studies have revealed similar findings where there are strong beliefs in spirits causing seizers, Kendall-Taylor et al.’s study (2009), Millogo et al. (2004), and Baskind and Birbeck (2005).

### 7.6 Strengths and limitations of the study

This study is the first to document the knowledge, attitudes, and practices of households and lived experiences of young persons living with epilepsy in Vihiga County in Kenya. Findings of this study should help inform stakeholders on deficiencies and challenges of managing epilepsy. More importantly the findings point to the need for a holistic approach that encompasses the social aspect of epilepsy. A major limitation of this study was the difficulty in communicating with young persons living with epilepsy. It was difficult for them to express themselves often requiring the intervention of the immediate care giver. Care givers also posed challenges by wanting to express their own lived experiences rather than those of the ill person.

# CHAPTER EIGHT

# CONCLUSION AND RECOMMENDATIONS

## 8.1 Introduction

This study aimed to provide in-depth understanding of the lived experience from young people living epilepsy in Vihiga County, Kenya. This final chapter provides a conclusion of the study by highlighting areas of priority for practice, policy and research relevant to improve quality of live for young people living with epilepsy.

## 8.2 Conclusion of the Study

The study identified thematic areas that offered insight into the phenomenon of epilepsy experienced by young people in Vihiga County, Kenya. The insight created an understanding beyond a known stigmatized illness by revealing a complexity of experiences influenced by social structures and long standing belief systems and, myths. Evidence reveal that despite community's fairly good biomedicine knowledge on epilepsy there is deep rooted beliefs of the illness having social causes and being contagious. These work to problematize the daily lives and life projects of persons living with epilepsy because of stigma emerging out of the beliefs. Further, these and other challenges within the medical health systems work to problematize update of biomedicine which is known to effectively control seizers. Control of seizers is significant because seizers are the single characteristic around which the lives of those living with epilepsy revolve. Evidence of this study show that problematic domains of young people living with epilepsy were pegged to occurrence and frequency of seizers. These problem domains included experiencing stigma, uncertainty in daily life, unpredictable seizers and injuries, delayed schooling and low level of education, difficulties in forming and maintaining intimate relationships and, poor social outcome. As a result young people experience an altered quality of life because of limitations imposed by their illness. Evidence from the study may attract interest to new ways of looking at persons living with epilepsy. Based on these findings, the following recommendations are suggested for practice, policy and future research.

### 8.3 Recommendations for Practice

Based on findings and discussion of this study, the study recommends the following in bid to improve the altered quality of life and self-esteem of young people living with epilepsy;

1. Contextualization of healthcare management of individuals by incorporating lived experience in management of the illness
2. Based on the findings of this study about misconception of epilepsy as being caused by supernatural forces and being contagious, there be health education campaigns to educate households on the causes and biomedicine treatment of epilepsy. This help demystify epilepsy and reduce stigma associated with it.
3. Based on participant's description of challenges of illness progression and side effects of medication as affecting their learning and based on benefits of counseling services received by some participants, there be cognitive and psychosocial interventions for all young adults with epilepsy attending school.
4. There be a community sensitization campaign regarding the availability and efficacy of anti-epileptic drugs.
5. Social workers and community health workers to act as link with mainstream health systems.
6. Based on participants challenges during referrals for specialized diagnosis there be prior arrangements with facilities offering specialized services before travel is made. This will avoid incidences where clients have long waiting time. Burden of costs will be reduced significantly

### 8.4 Recommendations for Policy

Findings of this study points to the need to modify policy pertaining to management of epilepsy in Kenya. This study therefore recommends the following;

1. There should be consideration for collaborating traditional healers in the management of epilepsy. All cultures have systems of health beliefs that explain what causes illness, how it can be cured or treated, and who should be involved in the process. In this study majority of respondents said they would consult with a traditional healer to heal epilepsy. Traditional healers have the potential of entrenching misconceptions about epilepsy among households in society because they offer alternative explanation to medical science explanation of illness and that those seeking healing from the traditional healers trust and believe what the healers say and prescribe. Thus a need to educate traditional healers on the pathology and contemporary treatment of epilepsy. This would be significant not only in demystifying epilepsy but also improving the quality of life of those living with epilepsy by clearing misconceptions about the illness. The significance of traditional healer in the management of epilepsy is therefore valid as educating traditional healers can change their beliefs and notion about epilepsy having a supernatural cause and being contagious. The model adopted by Ministry of Health in Kenya of training and utilizing traditional birth attendants in management of pregnant mothers can be used as a template to replicate a similar model to help manage epilepsy. The approach could be to train with identified traditional healers with basic pathophysiology and treatment knowledge on epilepsy and utilize them healers in the management of epilepsy. The approach will have the benefit of changing the beliefs of epilepsy as having a supernatural cause and

being contagious, and giving appropriate treatment or referral for adequate medical intervention. The traditional birth attendants model was adopted was largely successful because most mothers in rural parts of Kenya had preference for traditional birth attendance than hospital care and that hospitals were keen to incorporate tradition birth attendants to enhance safe pregnancy and delivery.

2. Regular update training for all workers involved in the management of epilepsy on new and evidence-based practices. This recommendation is based on concerns raised by a majority of respondents on challenges of understanding their illness from clinicians. This study therefore recommends training of healthcare providers on communication of diagnosis to clients. Further, healthcare workers in primary health facilities have improved capacity on identification and diagnosis of epilepsy, to facilitate early detection and management of the condition. There is need to communicate epilepsy as a chronic illness with therapy intended to control seizer and not cure epilepsy so as to avoid families spending resources looking for an elusive cure that will never come. In the study investigating the experiences of young people with epilepsy attending outpatient clinics, Wilde and Haslam (1996) the respondents complained about the doctor’s failure to discuss the epilepsy condition adequately especially when the subject is younger. The respondents stated that the doctors seemed overly concerned with the medical management of the respondent’s condition at the expense of giving practical advice about living everyday with epilepsy. Some subjects indicated that they had known little about epilepsy when they were diagnosed, and their present knowledge

of the condition was gained by their own effort rather than from the information imparted on them by their doctors.

## 8.5 Recommendations for Future Research

Arising from the study, the researcher wishes to observe that there is potential for further research as an outcome of this study. In this regard, the researcher recommended that;

1 Comparative studies should be carried out to ascertain any variations in lived experiences of persons with epilepsy in the context of urban and rural setup

2 Further research should be done on the social aspect of the condition of epilepsy with a view or reviewing the treatment protocol of epilepsy to incorporate the contribution of social sciences

3 There is need for research on gender experiences of epilepsy with view of capturing specific challenges faced by gender

4 There is need for research to be conducted on the significance of community stakeholders on the elimination of stigma related to epilepsy

## 8.6In closing

Using phenomenological approach this study has been able to establish that that poorly controlled seizers and neglect of psychosocial needs significantly affects education of young people living with epilepsy as evidenced by the few years of schooling. The study has also established that young people living with epilepsy experience altered quality of life courtesy of enacted stigma from the community. The young people with epilepsy have developed coping mechanisms to adjust to community’s perception of their illness. Stigma and other forms of social injustices are a result of long standing cultural beliefs and misconception of epilepsy as a contagious illness.

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# APPENDICES

## Appendixes I: Consent Form

Dear Participant,

My name is Wycliffe Kigan, a doctoral student from Moi University. I will be conducting a research study on Epilepsy among young people as part of my doctoral studies

This letter provides information about the research study. Read carefully about the information or I or my research assistant may read the information for you. You will sign below as an indication that you have agreed to participate in this study.

**Purpose of study:** The purpose of the study is to explore the lived experiences of young people living with epilepsy. I will explore various factors that relate to quality of life in young people with epilepsy so that I may understand ways to improve their physical and psychosocial well-being. I want to learn more about what things impact the hung people living with epilepsy" It is hoped that information from this study will form the basis for policy formulation on good quality of life for young persons with epilepsy.

**What participation requires:** If you/ your child agree to take part in this study, you will be requested for interviews on several occasions. You will be followed for above nine months. Several visits by the researcher will be made to your home and to the school of your child. Some of the visits will be impromptu. You and your child may be asked to attend a group discussion with other parents who have children living with epilepsy. The researcher may ask to accompany you while you seek treatment of your child, may it be from a traditional healer or health worker.

**Risks and benefits:** There are no direct risks or benefits to you/ your child for participating in this study; however, by participating you will provide valuable information about the factors that impact the quality of life of children with epilepsy.

**Confidentiality**: Research ethics require that all participants remain anonymous as the research carries out and records his or her study. Any information you give will be confidential. I may publish what I learn from this study; however, nothing will be published that would let people know who you are.

**Voluntary Participation:** You and your child's participation in this study is completely voluntary. If at any time you have questions or concerns regarding this study, please contact the principal investigator (Wycliffe Kigan at 0722 866 879) or kiganwycliffe@yahoo.com

**Consent to/ for Child to Take Part in this Research Study**

I give consent for myself / my child to participate in this study.

__________________ _____________________ __________

Signature of Participant/Parent: Name of Participant: Date

**Investigator/ Research Assistant Statement:**

I certify that participants have been provided with an informed consent form and that the consent explains the nature, demands, risks, and benefits involved in participating in this study. I further certify that a phone number has been provided in the event of additional questions.

___________________ __________________________ ________

Signature of Investigator/ Research assistant: Name of Investigator/RA: Date

## Appendixes II: KAP Survey Questionnaire

### Full Profile of the respondent

Social demographic features

Age: _________ Gender; Male: Female

What is your occupation? ________________________________________________

Marital status: ☐ Married Single ☐ Divorced ☐

☐ Widow Widower ☐

Level of formal education: ☐ University Tertiary College ☐

☐ Secondary School Primary not attended ☐

1. What is epilepsy?

   …………………………………………………………………………………

   …………………………………………………………………………………

   …………………………………………………………………………………

   …………………………………………………………………………………

2. What might trigger a seizure (an epileptic fit)?

   ………………………………………………………………………………..

   …………………………………………………………………………………

   …………………………………………………………………………………

   ………………………………………

3. Are there any warnings and/or behavior changes before the seizure occurs?

   YES NO

   If YES, please explain:

   …………………………………………………………………………………….

   …………………………………………………………………………………

   …………………………………………………………………………………

4. What are the signs and symptoms of epilepsy?

   …………………………………………………………………………………

   …………………………………………………………………………………

   …………………………………………………………………………………

   …………………………………………………………………………………

5. In the above, are these signs and symptoms similar to everyone with epilepsy?

   Yes NO

   Explain your answer…………………………………………………………

6. Do you know anybody with Epilepsy? Yes No
7. If yes, how did you know the person has epilepsy? ……...................................

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8. Have you ever witnessed someone having epileptic fits? Yes No

   If yes, what did you do?

   .......................................................................................................................

   .......................................................................................................................

   .......................................................................................................................

   .......................................................................................................................

9. How do people treat those people with epilepsy?

   .......................................................................................................................

   .......................................................................................................................

   ......................................................................................................................

   In the above answer, Why are they treated so?

   .......................................................................................................................

   .......................................................................................................................

   .......................................................................................................................

   ......................................................................................................................

10. Have you ever gotten information on epilepsy Yes No

    If yes, what were the sources of your information? ……………………………

11. Who are prone to get epilepsy? ………………………………………………...

    In the above question, why are they prone to epilepsy?

    ………………………………………………………………………………

    ………………………………………………………………………………

    ………………………………………………………………………………

12. Can this illness affect anyone? Yes No

    If Yes how……………………………………………………………………..

    ………………………………………………………………………………

    ………………………………………………………………………………

    …………………………………………………..……………………………

If No why…………………………………………………………………………

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…………………………………………………………………………………

13. As an individual, do you think you can get epilepsy? Yes NO

If yes, why do you think so?

…………………………………………………………………………………

……………………………………………………………………………….....

If No, why…………………………………………………………………..

………………………..……………………………………………………………

…………………………………………………………………………………….

14. Is epilepsy a serious illness Yes No

If yes why? ……………………………………………………………………

…………………………………………………………………………………

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If no, why do you think so?..........................................................................

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15. Can epilepsy be treated? Yes No

If yes, how can it be treated?

..........................................................................................................................

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If No, why can it be treated?

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……..……………………………………………………………………………

……………………………………………………………………….…………

16. Can one heal completely from epilepsy? Yes No

Explain your answer…………………………………………………………

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…………………………………………………………………………………

17. Which is the best age to seek treatment? ……………………………………..

    Explain your answer…………………………………………………………

    ……………………..………………………………………………………………

    ………………………………………………………………………………..

18. Which is the most suitable place to seek treatment for Epilepsy?

    ..........................................................................................................................

    Explain your answer…………………………………………………………….

    ……………………………..…………………………………………………

    ………………………………………………………………………..……

19. Can Epilepsy be prevented Yes No

    If yes, how can it be prevented? ........................................................................

    ………………………………………………………………………………

    ……………………………………………………………………………….

    If No, Why can it be prevented…………………………………………………

    ………………………………………………………………………………

20. Are there ways in which one could prevent his/her kins from getting Epilepsy?

    Yes NO

    If Yes, Explain how?

    ……………………………………………………………………………..

    ………………………………………………………………………………

    ………………………………………………………………………………

Tick in the box for the answer you give

| | **KNOWLEDGE** | AGREE | DISAGREE | DON'T KNOW |
|---|---|---|---|---|
| 21 | Epilepsy is infectious | | | |
| 22 | One can get epilepsy by contact with a person with epilepsy such as shaking hand | | | |
| 23 | One can get epilepsy by sharing food with epilepsy | | | |
| 24 | One can get epilepsy because of a curse | | | |
| 25 | One can get epilepsy because of violating a taboo | | | |
| 26 | One can inherit epilepsy from parents | | | |
| 27 | One can get epilepsy through head injuries such as in accidents | | | |
| 28 | One can get epilepsy from severe complications of disease such as meningitis and malaria | | | |
| 29 | One can get epilepsy from delivery complication during birth | | | |
| 30 | People with epilepsy should be isolated | | | |
| 31 | Persons with epilepsy should not mix with other people during events such as school, weddings and funerals | | | |
| 32 | There is no need to educate a child with epilepsy | | | |
| 33 | People with epilepsy should be avoided during the time they get a fit | | | |
| 34 | People should not employ epileptic people | | | |
| 35 | People should not marry person who have epilepsy | | | |
| 36 | People should help people with epilepsy when they get a fit | | | |
| 37 | In public places epileptics should be served separately | | | |
| 38 | In the family, epileptics should use marked utensils | | | |
| 40 | Epilepsy is a serious contagious disease | | | |
| 42 | People with epilepsy are mentally sick or will become mentally sick | | | |
| 43 | People with epilepsy are violent | | | |
| 44 | People with epilepsy cannot do well in school | | | |

| | | | | |
|---|---|---|---|---|
| 45 | People with epilepsy cannot have normal children | | | |
| 46 | People with epilepsy should pursue their schooling | | | |
| 47 | People with epilepsy should not marry or be married | | | |
| 48 | People with epilepsy should not get children | | | |
| 49 | People with epilepsy should be avoided by others | | | |
| 50 | People with epilepsy should not be employed | | | |
| 51 | People with epilepsy do not perform well in school | | | |
| 52 | People with epilepsy are not a burden to their families | | | |

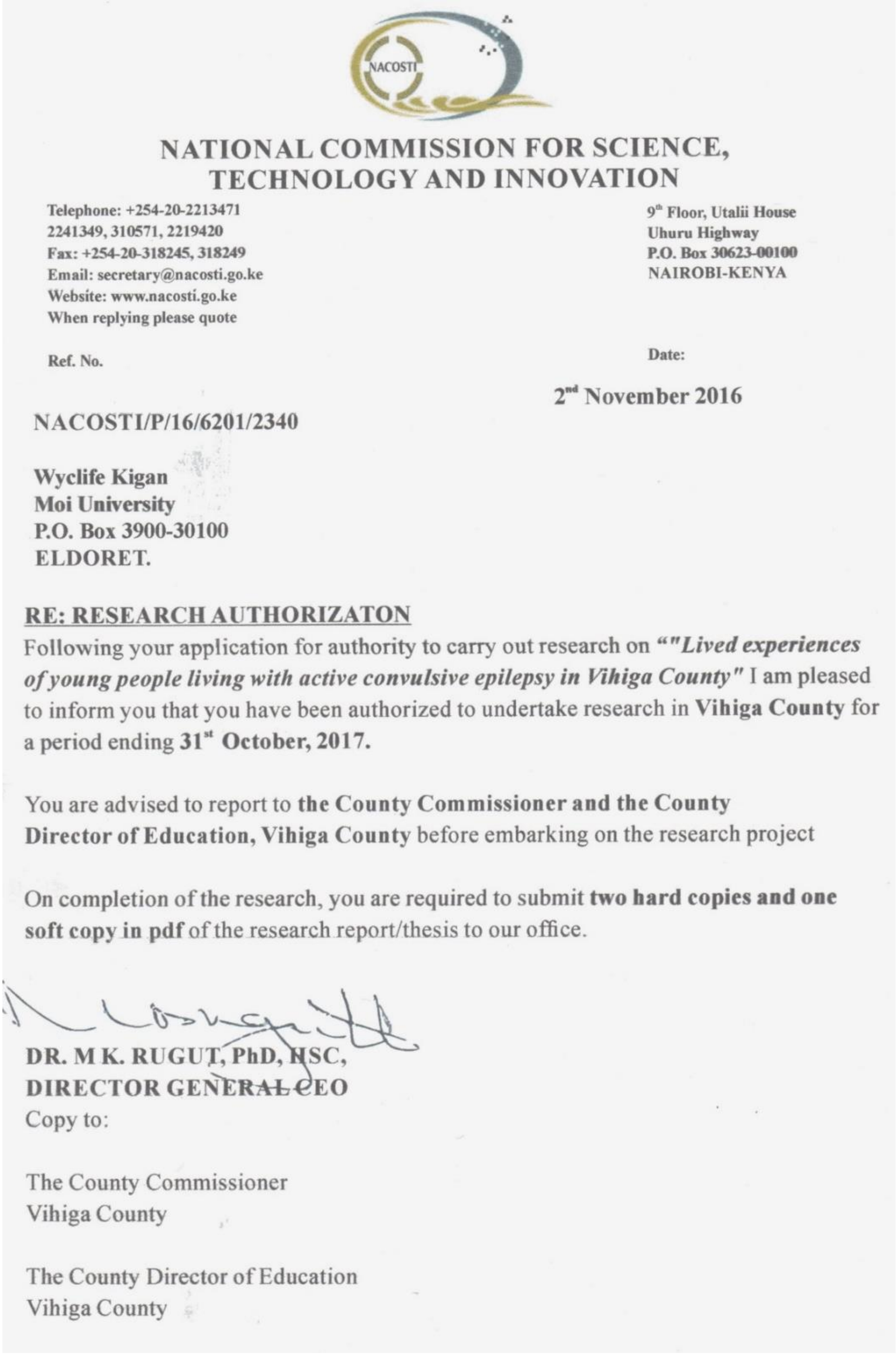
## Appendixes III: Interview Guide for Lived Experiences Study

Age: _________ Gender; Male: Female

School______________, Class or Form or year of study

1. Could you please describe your illness of epilepsy to me? Probe for triggers of epileptic fits or seizures, the nature of the fits and duration, medication side effects, hospital visits and **what does the illness mean to you.**
2. What is your experience regarding living with epilepsy
3. How do people relate to you as a person living with epilepsy
4. Describe to me how you feel after having an attack of epileptic fit. Probe for forgetfulness, behavioral disturbances, worries about what others will say and self-esteem.
5. Describe to me your daily activities. Probe for impediments to daily activities brought by the epilepsy. Probe for home activities, school and social activities-(sports, drama, dating, outings etc) with peers.
6. Describe to me how you socialize with your peers in school and other places. Probe for the reaction of peers, teachers and significant others to respondent illness of epilepsy.
7. Describe to me your expectations in future and what you are going to do to achieve your expectations. Probe for worries about illness, studies, employment, independence and marriage and family.

## Appendixes IV: Research Authorization- NACOST



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2nd November 2016

NACOSTI/P/16/6201/2340

**Wyclife Kigan**
**Moi University**
**P.O. Box 3900-30100**
**ELDORET.**

**RE: RESEARCH AUTHORIZATON**

Following your application for authority to carry out research on ***""Lived experiences of young people living with active convulsive epilepsy in Vihiga County"*** I am pleased to inform you that you have been authorized to undertake research in **Vihiga County** for a period ending **31st October, 2017.**

You are advised to report to **the County Commissioner and the County Director of Education, Vihiga County** before embarking on the research project

On completion of the research, you are required to submit **two hard copies and one soft copy in pdf** of the research report/thesis to our office.

**DR. M K. RUGUT, PhD, HSC,**
**DIRECTOR GENERAL/CEO**

Copy to:

The County Commissioner
Vihiga County

The County Director of Education
Vihiga County