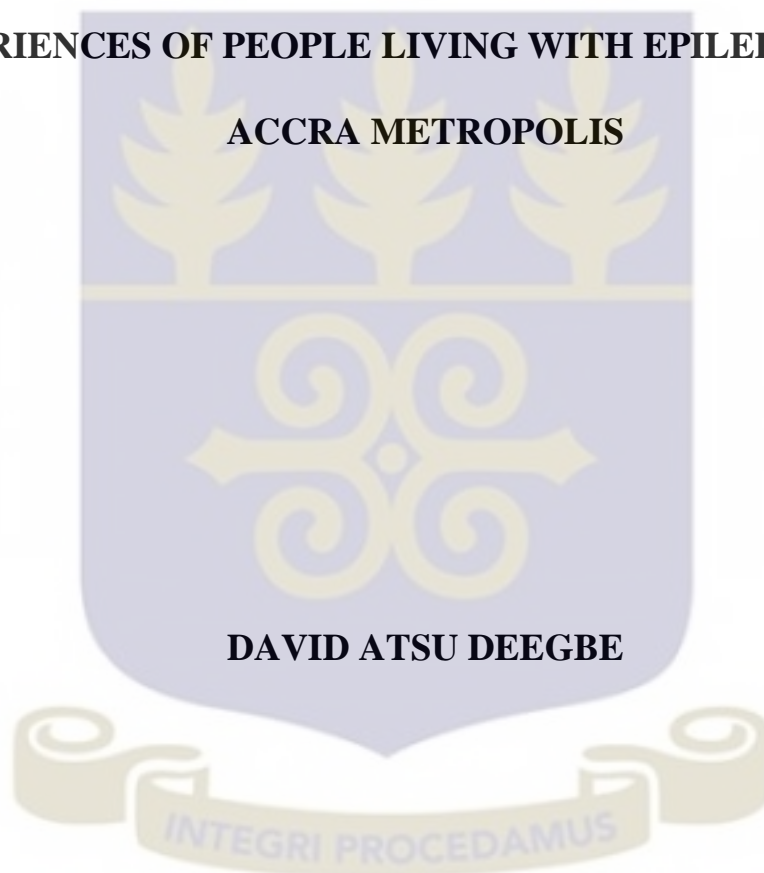


UNIVERSITY OF GHANA
COLLEGE OF HEALTH SCIENCES

**EXPERIENCES OF PEOPLE LIVING WITH EPILEPSY IN THE
ACCRA METROPOLIS**



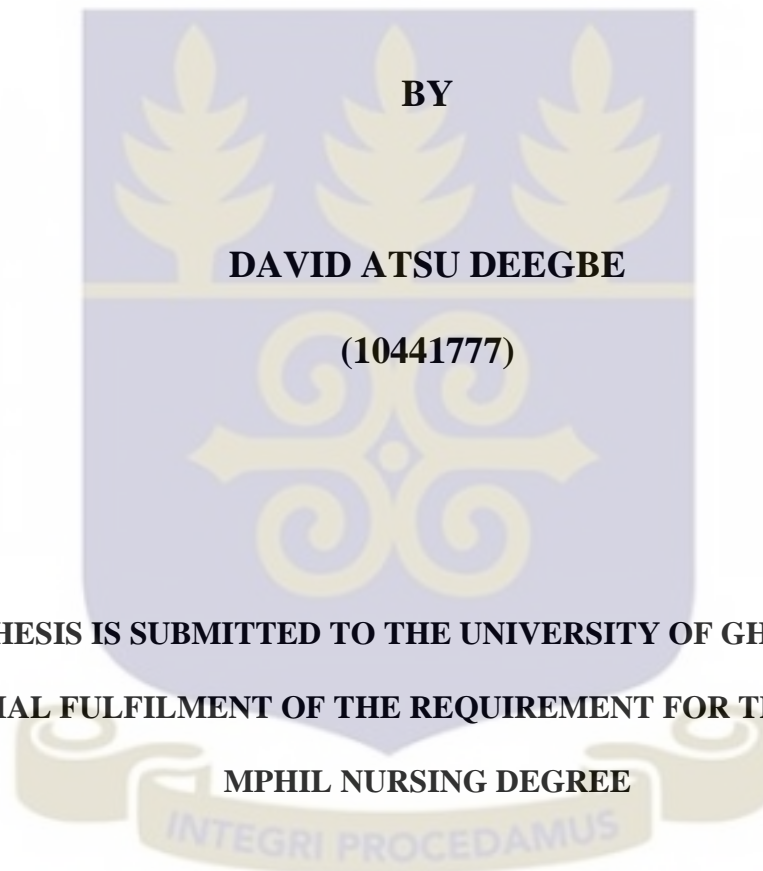
DAVID ATSU DEEGBE

SCHOOL OF NURSING

JULY, 2015

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ACCRA METROPOLIS**



SCHOOL OF NURSING

JULY, 2015

DECLARATION

I, David Atsu Deegbe, the author of this thesis, do hereby declare that with the exception of references to literature and works of other researchers which have been duly cited, this thesis is the product of my original work.

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ABSTRACT

The study explored the experiences of People Living with Epilepsy (PLWE) in the Accra Metropolis. The study aimed at describing the beliefs that PLWE have about the disease, their coping strategies and health outcomes. A descriptive-exploratory design was employed and the Leventhal's common sense model was used to guide the study. Participants were purposively sampled and saturation was achieved at the 13th participant. Face-to-face in-depth interviews were conducted and data were analysed using the thematic content analysis approach. The themes and sub themes were illness representations (identity, cause, timeline, consequences, cure and control, illness coherence, and emotional response), coping with epilepsy (problem focused coping; lifestyle changes; social support; faith in God; concealing diagnosis; thinking and worrying) and health outcomes (negative outcomes, positive outcomes and adjustment to work). Participants labelled epilepsy as a disgraceful illness. Most participants attributed the disease to spiritual causes which indicated a knowledge gap in the actual causes of epilepsy. Seizures caused injuries and affected their education, work and relationships. Fear, anxiety and sadness concerning seizures were commonly expressed. Treatment modalities for epilepsy were spiritual intervention, traditional or orthodox medicines or a combination of two or more. A reduction in the frequency and severity of seizures was a positive outcome and the worsening of seizures was a negative outcome. It was recommended that health care workers in collaboration with the media should intensify health education campaigns on epilepsy to demystify traditional concepts about epilepsy and help bring Ghanaians towards greater understanding and acceptance of PLWE.

DEDICATION

I dedicate this work to my wife, Eno Akyaah Deegbe, and my Son, Daniel Senyo Yao Deegbe.



ACKNOWLEDGEMENT

First of all I acknowledge the Almighty God for His ever faithfulness and sure mercies in my life.

Secondly, I acknowledge the immense encouragement and support given me by my two supervisors and the patience they had for me. I am so grateful to Reverend Alexander Attiogbe for his priceless advice and precious time spent teaching, guiding and diligently reviewing my work. I also acknowledge Dr. Lydia Aziato for her technical support and constructive critique of my work to a successful end.

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I acknowledge the authors of various literatures that were reviewed for this study.

To all who have in various ways contributed to the success of this work, I am very grateful.



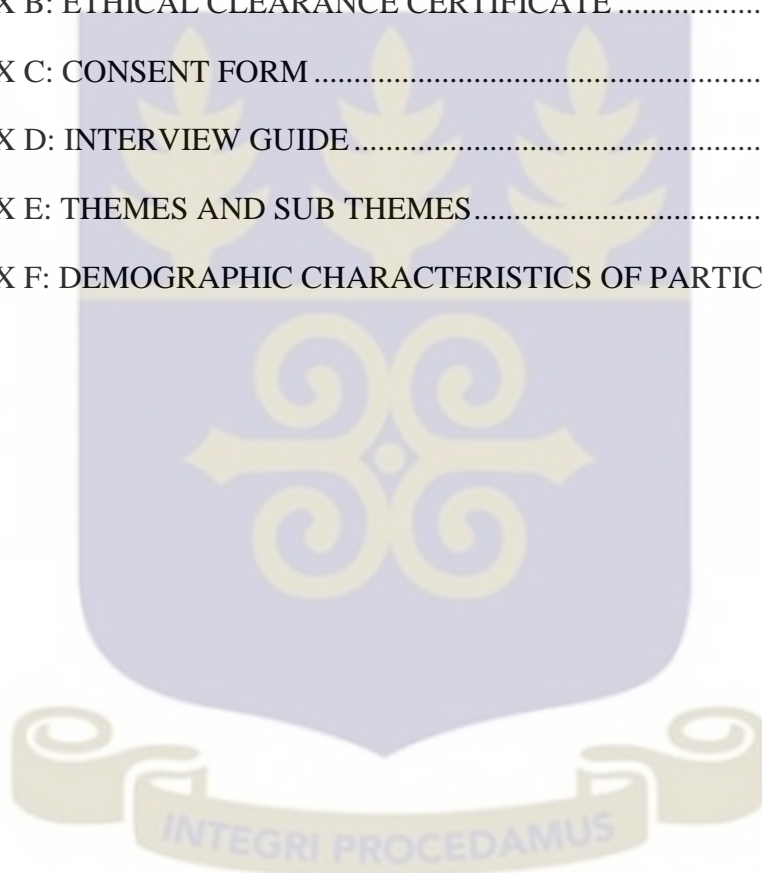
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LIST OF ABBREVIATIONS

AED:	Anti-Epileptic Drugs
CSM:	Common-Sense Model
DSM-IV:	Diagnostic and Statistical Manual Four
EF:	Epilepsy Foundation
ENT:	Ear Nose & Throat
IEC:	Information, Education and Communication
ISSER:	Institute for Statistical, Social and Economic Research
NGO:	Non-Governmental Organizations
OPD:	Out Patient Department
PLWE:	People Living with Epilepsy
QOL:	Quality Of Life
WHO:	World Health Organisation
WLWE:	Women Living With Epilepsy

CHAPTER ONE

INTRODUCTION

1.0 Background to the Study

Epilepsy is a group of central nervous system disorders that are manifested in seizures and is attributed to people who experience two or more unprovoked seizures (Banerjee, Filippi & Hausa, 2009). Epilepsy, also called seizure disorder, is a chronic brain disorder that briefly interrupts the normal electrical activity of the brain to cause seizures.

Seizures are abnormal, unregulated electrical discharges which occur within the brain's cortical gray matter and transiently interrupt the normal function of the brain (Heward, 2009). A seizure starts as atypical, excessive hyper-synchronous discharges from a collection of neurons in the brain and then affects surrounding neurons to comprise one or both hemispheres of the brain (Heward, 2009). The excitation or excessive nerve-cell discharges may be limited to a small area of the brain (a localized lesion or focus) giving rise to partial (focal) seizures. It may also start immediately in the whole brain or spread from the small area of the brain (focus) to the whole brain and spinal cord giving rise to generalized seizures. A seizure is usually referred to as a fit, convulsion or attack. The words "convulsion" or "fit" however, refer to seizures with tonic-clonic muscle movements. A seizure usually produces altered awareness, abnormal sensations, involuntary movements (such as jerking, shaking or twitching) or convulsions. Convulsions involving sudden and uncontrollable shaky movements of the body usually arise as a result of a seizure.

Epilepsy is one of the world's most common chronic neurological disorders. According to the World Health Organisation (WHO), roughly 50 million people worldwide suffer

from epilepsy (WHO, 2012). Epilepsy accounts for 0.5% of the global burden of disease, and 80% of the burden of epilepsy corresponds to developing countries. Epilepsy directly affects around 10 million people in Africa (WHO, 2012). Epilepsy has its highest prevalence in poor countries (Newton & Garcia, 2012) including rural areas and particularly within sub-Saharan Africa (Ngugi, Bottomley, Kleinschmidt, Sander, & Newton, 2010). The incidence of epilepsy in Ghana is believed to be high as compared to the sub-Saharan African region. However, most of the cases go unreported.

Epilepsy affects people of all ages, sex and races. It can be caused by head trauma, tumours, inherited conditions, strokes, brain cancer, drug and alcohol misuse, and infection of the central nervous system; most cases have no known cause (Renwick, 2013). There is a general trend towards an increase in prevalence in adolescents and young adults especially in developing countries (Banerjee et al., 2009).

A number of studies show that living with epilepsy is characterised by a number of challenges (Renwick, 2013; Choi et al., 2011; De Boer, 2010). The stigma attached to people with epilepsy impedes the human rights and social integration of People Living with Epilepsy [PLWE] (De Boer, 2010).

The symptoms of epileptic seizures are very frightening and horrific to onlookers (Forsgren, Ghanan & Ritcher, 2013). Although the seizures only last for a few minutes, the psychological and social repercussions to the patients and their family members are enormous. Marked ones such as generalised tonic-clonic seizures (grand mal) are openly noticeable to onlookers. Most patients with generalised tonic-clonic seizures feel embarrassed after a seizure in town, in school, at church, during an occasion or at work. Less marked ones like absence attacks (petit mal) appear to be

rather strange to onlookers. This may be interpreted by others as inattentiveness, rebellion or as mental, emotional or conduct problems. As a result of this some people mock them, gossip about them, avoid their company and portray them negatively. This results in emotional disturbances, lowered self-esteem and social withdrawal (Hills, 2007). Furthermore, drowsiness as a result of Anti-Epileptic Drugs (AEDs) and absenteeism from work and school as a result of the seizures leads to under achievement and low productivity among PLWE both at work and in school. This impedes their education and career development resulting in anxiety, depressive symptoms and sometimes, suicidal ideations (Jacobs et al., 2009).

The unpredictable nature of the disease creates some anxiety among PLWE (Jacobs et al., 2009), placing further restriction on PLWE (Gauffin, Flensner, & Landtblom, 2011). Moreover, the spoiled identity that the disease creates places additional stress and burden on the patient (Renwick, 2013). The chronicity of epilepsy, the unavailability of stable jobs, restricted social lives, lowered self-concept and family conflicts further affects their quality of life (WHO, 2012). This study employs Leventhal's Common Sense Model (CSM) of illness representation to explore the experiences of PLWE within the Accra Metropolis in Ghana.

1.1 Problem Statement

Fear, misunderstanding, discrimination and social stigma have surrounded epilepsy for centuries (Engel, Pedley, & Aicardi, 2008). The disease continues to be an often misunderstood and stigmatizing condition which affects the Quality of Life (QOL) of the PLWE (Choi et al., 2011). A clinical diagnosis of epilepsy often carries a silent social stigma (Hosseini, Sharif, Ahmadi, & Zare, 2013). Persons with epilepsy find it difficult to make life choices such as having children or choosing an education or

profession, and most of them are unable to fulfil their normal social roles and obligations (Gauffin et al., 2011; Choi et al., 2011). An estimated 80% of people with epilepsy living in developing countries are excluded from treatment either through lack of knowledge, stigma and discrimination, inaccessible health services or general levels of poverty (Ngugi et al., 2010).

People living with epilepsy face stigma and discrimination from the society (De Boer, 2010). Others attribute their condition to mental illness and some people avoid them for fear of contracting the illness (Renwick, 2013). This is mainly due to ignorance on the part of the society (Engel et al., 2008). People living with epilepsy tend to conceal their epilepsy as a result of the spoiled identity that the disease creates and fear of being stigmatised and discriminated. As a result of this some feel less worthy of themselves, tend to isolate themselves and reduce social contacts so as to avoid accidental disclosure of their condition. This felt stigma further exerts stress and restricts normal participation in society. Some PLWE experience actual discrimination (enacted stigma) in the form of actual termination or refusal of employment (Scambler, 2011), avoidance or rejection from the society (Hosseini et al., 2013) and rejection from actual or prospective life partners.

In many ancient and primitive societies, including Africa, epilepsy is usually attributed to sin and demonic possession (Engel et al., 2008). Seizures are often considered as bad omens. This traditional African belief system which attributes epilepsy to witchcraft and blames the victim all offer the ideal environment for stigma to flourish (De-Graft Aikins, 2012).

The researcher, through observation and personal interactions has noticed that people suffering from epilepsy have problems such as psychological and socio-economic

problems that are poorly understood. Psychological and social problems arising from the diagnosis of epilepsy (De Boer, 2010) and its effect on the QoL of PLWE can represent a greater challenge than its nursing and medical management. Although the problem exists, the researcher has not come across any study on the experiences of PLWE in Ghana. The only recent study that included Ghana was a cross-sectional study to determine the consequences of epilepsy in addition to clinical features and proximate causes in sub Saharan Africa (Kariuki et al., 2014). This has motivated the researcher to explore the experiences of PLWE, and how they cope with the disease.

1.2 Purpose of the Study

The purpose of the study was to explore the beliefs and illness representations of epilepsy including the personal experiences of living with epilepsy and how individuals cope with the disease.

1.3 Objectives of the Study

The objectives of the study were to;

1. Describe the beliefs that PLWE have about the disease
2. Determine how PLWE cope with the disease.
3. Assess the outcome of interventions carried out by PLWE to treat epilepsy

1.4 Research Questions

This study sought to answer the following research questions;

1. What are the beliefs that PLWE have about the disease?
2. How do PLWE cope with the disease?
3. What is the outcome of interventions carried out by PLWE to treat epilepsy?

1.5 Significance of the Study

The study findings will inform health professionals about the experiences that PLWE in Ghana go through. This will aid them to plan and provide the needed care and support for PLWE. Secondly, the study will provide information to the Ministry of Health, Non-Governmental Organisations (NGO's) and all stake holders on the current situation of PLWE for the development of specific policies and support systems to help improve upon the QoL of PLWE in Ghana. Findings from the study will provide information to the Ministry of Health, the Ministry of Information, the Media and NGO's for the development of appropriate Information, Education and Communication (IEC) materials to create awareness and educate the general public on epilepsy. The study will also extend the frontiers of nursing knowledge on the experiences of PLWE. The experience of carrying out such a study will equip the researcher with the necessary knowledge and skill to conduct similar studies in the future.

1.6 Operational Definition of Terms

1. Experience: The life situation that PLWE go through.
2. People living with epilepsy: Young adults from 18-40 years of age who have been diagnosed as suffering from epilepsy excluding those with mental retardation and psychiatric problems.
3. Stigma: A mark of disgrace or unworthiness and leads to discrimination against PLWE (Scambler, 2011).
4. Belief: The opinion that PLWE have about the identity, causes, timeline, consequences, cure and control, coherence and emotional response to epilepsy (Diefenbach & Leventhal, 1996).

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter presents a review of literature on the experiences of People Living with Epilepsy (PLWE). Literature was reviewed from articles retrieved online from Google Scholar, ScienceDirect, Pubmed and Willey Online Library. The literature review focused on epilepsy, the CSM, beliefs about epilepsy, experiences of PLWE and coping with epilepsy.

2.1 Epilepsy

According to Heward (2009), epilepsy is the condition in which seizures occur repeatedly in a person's life. According to the Epilepsy Foundation [EF] (2009), seizures are classified under four different categories: generalized, partial, non-epileptic, and status epilepticus. Generalized seizures differ from others in that both sides of the brain are affected throughout the life of the seizure (Svoboda, 2005). During this type of seizure consciousness is lost for a period of time. There are some seizures in which the focal cortical regions of the brain are involved. This causes selective deficiencies in one's level of consciousness without affecting one's overall level of consciousness or awareness. However, in generalized tonic-clonic seizures, all meaningful responses are usually lost due widespread severe deficits in corticothalamic function (Blumenfeld & Meador, 2014).

Generalized seizures are broken down into tonic-clonic, myoclonic, absence, and atonic by the Epilepsy Foundation (2009). Searson (2008) also added tonic and clonic seizures separately. Tonic-clonic seizures are those which are generally the most

recognizable and are the most common type of seizure, also called grand mal seizures (Epilepsy Foundation, 2009). These generally last for a period of 1 to 2 minutes. There are two phases to grand mal seizures which gives its name: tonic and clonic. During the tonic phase, the limbs stiffen and it is often accompanied by the person falling to the ground while very rigid. During the clonic phase the face and limbs jerk. As stated by Searson (2008), if the tonic phase or the clonic phase of the grand mal seizure is all that is experienced, this is just a tonic or clonic seizure, respectively. Myoclonic seizures are like a “mini” grand mal seizure. Searson (2008) found that it is often the arm or the leg that is affected by this type of seizure. They usually affect both sides of the body but not always. The body muscles jerk rapidly but usually looks like a twitch to others, rather than a seizure. According to the Epilepsy Foundation (2009), for those who are not epileptics, the closest experience may be when during sleep a body part jerks.

Absence seizures, or petit mal seizures, are usually not noticeable to outsiders. They start and stop suddenly, causing the affected person to “zone out” for several seconds. They are described as “a short cessation of physical movement and loss of attention” (Searson, 2008; p. 29). They usually last anywhere from 2 to 15 seconds and the person will resume whatever activity they were doing beforehand usually without realizing that the event just occurred (Epilepsy Foundation, 2009). The person may stare, flutter their eyes, or do certain motions such as smacking the lips or fumbling repeatedly. Atonic seizures are somewhat similar. Searson (2008) stated that they are often characterized by the affected person dropping to the floor, or dropping their head suddenly. The cause of this is a sudden lack of muscle tone in the body. These occur very suddenly and can cause head or face injuries because they happen so quickly and the person has no warning to protect themselves from the fall (Searson, 2008).

According to Searson (2008), partial seizures are those in which the activity in the brain affects only a portion of the brain, unlike generalized seizures, and may not spread to other areas. Svoboda (2005) indicated that this is important because the hemispheres control different aspects of learning. He noted that, “dominant-hemisphere discharges can impede language processing, while non-dominant hemispheric discharges may impede non-verbal functions” (Svoboda, 2005; p. 3), like movement. There are two subcategories of this type of seizure separated by whether consciousness is preserved or not. If the person is conscious throughout, it is a simple partial seizure. These usually last up to around a minute and a half. Complex partial seizures last around the same amount of time and can have the same outward signs as an absence seizure (Searson, 2008).

The last two categories of epilepsy are non-epileptic seizures and status epilepticus. Non-epileptic seizures can look like epileptic seizures outward but there are no electrical disruptions to the brain occurring in this instance (Epilepsy Foundation, 2009). Status epilepticus is when a seizure lasts more than thirty minutes in length (Klepping & Zaagman, 2009). When the seizure continues indefinitely, it can be very dangerous to the brain, as the entire body is deprived of oxygen during this time period. When the brain is deprived of oxygen, it may cause permanent damage (Klepping & Zaagman, 2009). In Kenya, Mung’ala-Odera et al. (2008) noticed moderate to severe neurological impairment in children with lifetime epilepsy. Cognitive impairment was 65%, motor impairment was 15%, vision impairment was 3% and hearing impairment was 18%.

Historically, seizures were thought to be caused by magic, curses, or insanity (Svoboda, 2005). Seizures are usually due to abnormal electrical discharges in the

brain. This often occurs in the cerebral cortex. A change in the chemistry (levels of potassium and sodium) around and inside of the nerve stem causes a charge to pass through the membrane. During a seizure, the electrical charges become less coordinated and systematic, causing essentially an overload of signals to the body. Excessive use of alcohol and head injuries also cause epilepsy (Heward, 2009). Those epilepsies that have a known cause are called symptomatic, while those without a known cause are called idiopathic (Wodrich, Kaplan, & Deering, 2006).

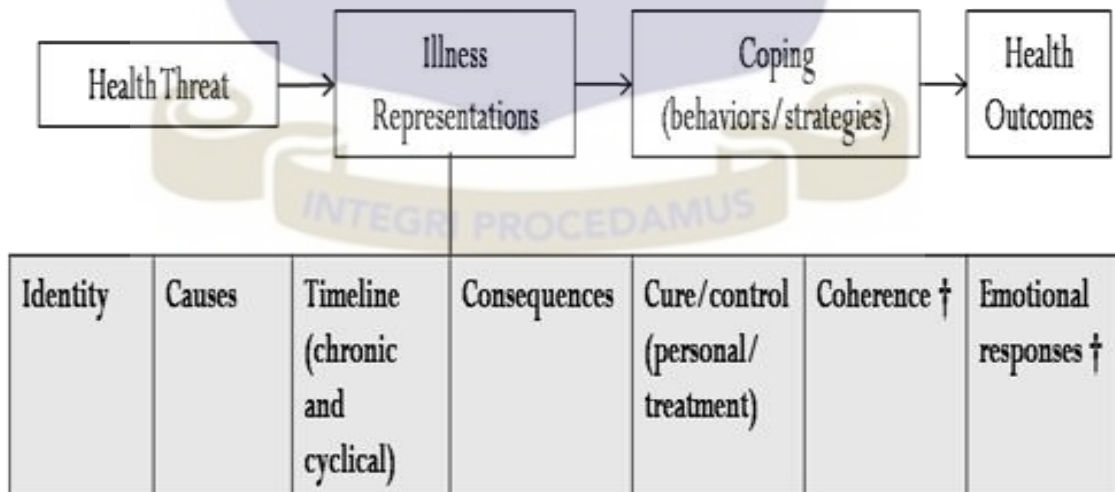
2.2 Theoretical Model

Numerous attempts have been made to construct models of lay beliefs or perceptions about health and illness. However, one distinct model that addresses beliefs about illness experience is the Self-Regulation Model, or Common-Sense Model (CSM). This model proposes that behaviour in relation to dealing with illness, as well as preventing it, can be seen in the context of the patient's own representation of the illness (Leventhal, Diefenbach, & Leventhal, 1992). The CSM assumes that people are active problem solvers and are motivated to avoid and treat illness in response to the perceived threat posed by the illness. The illness representation originally consisted of five elements: identity (symptoms and label), cause, consequences (effects on life or life-style), time-line (time to develop and duration) and controllability or cure. Two constructs namely; coherence and emotional response were later added to make it seven. In a three stage processing system, people are said to generate an emotional reaction to illness as well as the illness representation. Coping strategies are generated in the second stage and appraised in the third. The model has been used extensively in studies relating to a wide range of conditions (Green, Payne & Barnitt, 2004; Moran & O'Hara, 2006; Llewellyn, McGurk & Weinman, 2007; Graves, Scott, Lempp &

Weinman, 2009; Paddison, Alpass & Stephens, 2010). The CSM appears to be a useful framework for investigating experiences of PLWE.

2.2.1 Common-Sense Model (CSM) of Illness Representation

The Common-Sense Model (CSM) of illness representation was developed in the 1980s by Howard Leventhal and his colleagues (Diefenbach & Leventhal, 1996). This was based on Leventhal’s research on the effect of fear in relation to health related behaviours. The theory has various titles such as the, Self-Regulation Theory, Common Sense Model (CSM) of illness representation or Leventhal’s Theory. The primary goal and function of the theory is to explain how a person processes an illness threat. The CSM is centred on the individual and his or her idea of health and illness. It works under the premise that the individual is an active problem solver. The CSM also predicts that individuals’ representation of illness will be the primary cause of their actions and behaviour and the process of illness representation will lead the individuals to make common sense health behaviours (Diefenbach & Leventhal, 1996).



† added by Moss-Morris (2002)

The CSM (Source: Leventhal, Nerenz & Steele, 1984)

Self-regulation involves the processing of information by a patient regarding his/ her health and the actions that an individual takes to return to a normal state of health. A stimuli such as a symptom of an illness or a diagnosis starts a three-phase feedback cycle of self-regulation. First, the individual constructs a cognitive “representation” of the illness. Secondly, the individual acts and “copes” with the illness. In the third stage, the individual “appraises” the actions and makes necessary adjustments. The CSM is a “parallel-processing” model involving a cognitive pathway as well as an emotional pathway. In the cognitive pathway, the individual addresses the objective nature of the illness while on the emotional pathway the individual deals with the subjective reaction to the illness. Leventhal and his colleagues note that personal differences (i.e. personality types and personal experiences) as well as social, environmental and cultural differences can lead to different representations and coping strategies. Leventhal’s theory lays emphasis on the ability of the individual to actively reflect on his or her actions and emotions and the consequences that follow.

The individuals attempt to return to the ‘normal’ state of health is thus referred to as self-regulation. The theory also states that an individual’s interpretation of an illness is highly individualized and may not be in agreement with medical facts (Diefenbach & Leventhal, 1996).

The major themes of the CSM model include stimulus or health threat, Illness representation, coping and health outcomes. The first is stimulus or health threat or illness. This is the individual’s current experience of being sick. It is the symptoms the person is experiencing or being diagnosed with an illness (Fowler, Kirschner, Kuiken, & Baas, 2007). Illness representation or interpretation is the individual’s personal understanding and beliefs about their illness. There are five distinct attributes of illness representation (Diefenbach & Leventhal, 1996). Identity is what the client labels the

illness and what symptoms the client views as being part of the illness. Cause is the clients' views about what may have caused the problem, such as poor health habits, trauma, family history/ genetics, to mention but a few. Timeline is the clients' view about how long their problem will last and whether it is seen as short term or long-term illness. Consequences are the effects the clients are expecting from their illness and their views on the outcome. Cure or control refers to the clients' expectations as they recover from or manage and control the illness. However, two other dimensions of illness representations (namely illness coherence and emotional response) were added to the model by Moss-Morris et al. (2002). Illness coherence refers to belief about ones understanding of the health threat whilst emotional response refers to one's emotional reactions to the health threat.

Coping refers to the actions taken by the individual to cope with the illness. The goal of the coping strategies is to decrease the emotional distress as well as alleviating or ending the illness (Fowler et al., 2007). Health outcomes refer to appraisal or individual evaluation of the effectiveness of coping strategies adopted. The evaluation is a comparison of the perceived outcome versus the actual outcome (Fowler et al., 2007).

In this study, the concepts of the CSM were applied to explore the experience of PLWE. The stimulus represents the diagnosis of epilepsy among PLWE - thus the actual experience of living with epilepsy. Cognitive Representation or illness representation represents the beliefs that PLWE have about the disease. Coping or health behaviours represent conscious actions or behaviours put up by PLWE in order to deal with the burden of living with epilepsy.

2.3 Beliefs about Epilepsy

Various studies have shown that people have different beliefs and some misconceptions about the disease epilepsy (Engel et al., 2008; Choi et al., 2011; Renwick, 2013). These beliefs, thus either negative or positive, have influence on the attitude that people put up towards PLWE. Some of these misconceptions are mainly due to ignorance on the part of the society (Engel et al., 2008). However, PLWE also have their beliefs about the disease. The perception that PLWE have about the disease influences their health seeking behaviour and their social life (Kılınc & Campbell, 2009).

In a study conducted by Kılınc and Campbell (2009), which involved a phenomenological approach to epilepsy and stigma, the participants deliberated on different misconceptions about epilepsy with regard to themselves and the general public. These were beliefs before and after diagnosis of epilepsy. Majority of the participants believed that the general public had a lot of misconceptions about epilepsy. To some of them, epilepsy was perceived as a form of mental illness by the general public. Others explained how some people thought they were hooked on to drugs or were drunk with alcohol when they had an episode of seizure. Consequently, these perceptions that the PLWE had about the lack of awareness of epilepsy among the general public, affected their perceptions of their identity. As a result of this, most of them often felt distant from what they perceived as “normal” within society. However, negative perceptions of self were also evident in the accounts of PLWE. This made some of them to feel embarrassed about their condition. According to Rätty, Söderfeldt, & Wilde Larsson (2007) some PLWE even have doubts as to whether they are normal. Green et al. (2004) carried out a qualitative study using Leventhal’s CSM to describe illness representations among people who experienced non-epileptic seizures. The participants attributed epilepsy to psychological and physical causes such as stress, head

injury and heart problems. Rätty, Larsson, Starrin and Wilde-Larsson (2009) also found that PLWE attributed their condition to a mental disturbance due to lack of mental capacity and some also attributed it to psychosocial handicap. Epilepsy was described as a condition and as an illness that was related to disturbances in the physical body. Other PLWE described epilepsy as punishment and as an identity associated with being an epileptic. However, in the Ghanaian traditional and cultural belief system, chronic illnesses such as epilepsy are attributed to spiritual causes such as acts of witchcraft and sorcery and evil work of the devil (De Graft Aikins, Anum, Agyemang, Addo & Ogedegbe, 2012).

2.4 Experiences of People Living with Epilepsy

A clinical diagnosis of epilepsy is often characterised by untoward challenges. Green et al. (2004) explored illness representations among people who experienced non-epileptic seizures. Negative consequences of non-epileptic seizures reported by the participants included restrictions from certain activities and social isolation. Continuous seizures also result in psychological comorbidities and lifestyle restrictions which can affect one's QoL including work and school (O'Dell, Wheless & Cloyd, 2007).

In a study in five African countries, namely; South Africa, Ghana, Kenya, Tanzania and Uganda, Kariuki et al. (2014) found burn marks on 16% of people with active convulsive epilepsy which was also a negative consequence of epilepsy. Adults were found to have more burn marks (21.5%) than children (10.6%). Furthermore, about half (43.2%) of the participants lacked education and this was more common in children (49.3%) than in adults (37%).

In Zambia, Women Living with Epilepsy (WLWE) experienced urinary and/ or faecal incontinence during generalised seizures. This was described as inadvertent taboo breaking since it was socially prohibited to expose one's body fluids in public (Birbeck, Chomba, Atadzhanov, Mbewe & Haworth, 2008). The women also had concerns about losing their pregnancies as a consequence of seizures during pregnancy and fear that their children might be taken away from them. In a retrospective cohort in China, treatment of epilepsy was found to place very high economic burden on PLWE. A lot of money was spent in treating epilepsy and informal treatment accounted for about 41% of all costs (Liu, Liu & Meng, 2013). These negative experiences make some PLWE feel like an epileptic rather than a person (Rätty & Wilde-Larsson, 2011). However, Green et al. (2004) found that some other PLWE mentioned some positive consequences such as being able to spend more time with family. Although the participants hoped for their seizures to cease, most of them did not look to the future. Furthermore, in a randomized controlled trial to evaluate the effects of a daily patient reminder on seizure documentation accuracy in Germany PLWE, Hoppe, Poepel and Elger (2007) found that PLWE could not give valid account of all seizure episodes. The participants were unable to document 32% of all seizures when they were awake and 85.8% of all seizures that occurred during sleep. This was linked to a state of postictal seizure unawareness which occurs after a seizure episode.

The reality of living with such a chronic and unpredictable disease always brings about negative emotions in PLWE and makes life difficult for them (Gauffin et al., 2011). According to Hosseini et al. (2013), epilepsy often carries a silent social stigma and a sense of low self-respect experienced by PLWE.

2.4.1 Stigma and Discrimination against PLWE

In the work of Scambler (2011), epilepsy is described as a psychological, social as well as a biological phenomenon in the lives of PLWE. As a biological mechanism epilepsy can lead to cognitive impairment, depression or lowered self-esteem. Furthermore, this may lead to discrimination and consequent lowered job opportunities among PLWE (Scambler, 2011).

In describing the experiences of PLWE, Scambler (2011) posited that PLWE experience felt and enacted stigma. Enacted stigma refers to discrimination against PLWE due to their unacceptable ontological difference, while felt stigma is a personal and internalized feeling of shame and, crucially, a fear of experiencing enacted stigma (Scambler, 2011). In other words enacted stigma refers to sanctions that are individually or collectively applied to people on the basis of their belonging or perceived belonging to a particular group. However, felt (internalised) stigma refers to the feelings that an individual has about his or her condition and the fear of how others will react to this condition. This can be seen as the fear of, or anticipation of, enacted stigma.

The diagnosis of epilepsy makes PLWE develop a special view of the world that is pre-dispositional and characterized by felt stigma. This special view of the world makes PLWE develop the strategy of nondisclosure and concealment of the diagnosis. Finally, this leads to felt stigma which has a more disruptive effect in the lives of PLWE than enacted stigma.

Kılınç and Campbell (2009) explored the concept of felt stigma among PLWE. Three themes concerning felt stigma were evident from the participants' account of their experience of living with epilepsy namely; misconceptions versus ownership of epilepsy, avoiding versus sharing epilepsy and embarrassment versus normalising

epilepsy. Each theme illustrated a challenge in defining their identity within the society. Under the theme avoiding versus sharing epilepsy, it was evident that some participants were also responsible for the hidden nature of the condition. For some of them, having epilepsy meant staying home and avoiding certain situation that may expose their diagnosis to the public. Some of the participants experienced panic attacks when going out in public due to fear of having seizures.

Some of them also realized that it was impossible for them to avoid public places entirely. Therefore they had to venture into public places sometimes, although they only did this when they realised they had no choice but to do so. Some participants were concerned about the safety of having seizures in public places. Others also felt they will disturb people when they have seizures in front of them. Actively concealing the condition took a lot of effort and planning on the part of PLWE however, they were determined to conceal their diagnosis from others. Therefore their whole lives got engulfed in strategies to conceal their condition, hence increasing its negative impact on them. Some participants also realised that concealing their diagnosis of epilepsy may also limit public understanding of the condition (Kılınç & Campbell, 2009).

According to Kılınç and Campbell (2009), the process of disclosing the condition evolved over time, after PLWE realise that they don't have to allow the condition to restrict their lives. Some were of the view that they had to let everyone know, no matter what, while others were of the view that the diagnosis should be disclosed in certain situations where it becomes necessary. As a result of this the disclosure of epilepsy diagnosis was not a single event.

Kılınç and Campbell (2009) found that the diagnosis of epilepsy affected the participants' confidence; therefore they preferred to remain unnoticed. This was mainly

centred on the embarrassment of drawing public attention to themselves during a seizure episode and the negative impact this had on their self-image. Words such as “odd” and “reject” were used to describe how the participants felt different in society while struggling to reaffirm their identity in society. However, this appeared to be resolved when the frequency and severity of seizures reduced.

Leaffer et al. (2011) in their study, “Associates of stigma in an incident epilepsy population from northern Manhattan”, sampled 209 children and adults with incident seizures. Eighteen (22.5%) participants reported feelings of stigma, of which 11 (13.8%) felt uncomfortable, 14 (17.5%) felt inferior, and 13 (16.3%) felt avoided. This is an illustration of felt stigma (Scambler, 2011). According to Bielen et al. (2013), feelings of stigma are significantly associated with age 50 years and above, and younger age of epilepsy onset.

In Zambia, Birbeck et al. (2008) found that the social and economic wellbeing of women with epilepsy were greatly affected by the response of family members to their condition. Some families were found to be very supportive where as other families rejected the women with epilepsy. The women had difficulty in finding a marital partner whilst the married ones were neglected by their spouses or lived in fear of being neglected. Furthermore, forced disclosure associated with having seizures in public occurred in most of the WLWE. As a result of this, people who got to know about their condition avoided them and some of them reported the humiliating experience of children taunting them. In China, PLWE were found to have less cohesion with their family and received less emotional and instrumental support. They also experienced less marriage quality compared with the control group (Wang et al., 2015).

2.4.2 Emotional Experiences Associated with Epilepsy

Rätty et al. (2007) carried out a study to assess the impact of epilepsy in the daily life of young adults, described by their emotions. Positive emotions expressed were confidence and hope. Confidence was the most commonly expressed basic emotion associated with the daily life experiences of the participants. However, hope was also expressed, which was related to becoming free from the epilepsy condition. The expression of confidence was related to the use of AEDs; as long as the patients were on an AED(s), they felt safe. The patients also hoped to become and remain seizure-free. To them, this meant a good life and being less dependent on other people.

Anxiety, despair and fear were the common negative emotions related to the daily life experiences of living with epilepsy. Anxiety was associated with being exposed while having seizures in public. Females were concerned about pregnancy and parenthood. They were scared about taking AEDs during pregnancy. They had fears of harming their child with AEDs during pregnancy and/or by the epilepsy condition itself and they were also concerned about how epilepsy would impact on them as parents. Anxiety was also associated with possible side effects of long term AED therapy. Moreover, the perception of epilepsy as lifelong suffering often led to feelings of despair. They felt powerless and cried out for help and some feared being alone and having seizures. Those who had their seizures under control adhered strictly to their drug regimen for fear of seizures, and those still experiencing seizures feared to do things on their own (Rätty et al., 2007).

The positive complex emotions in the daily life of PLWE were forbearance, due to the lifelong nature of their condition, and harmony. Negative complex emotions were indignation, sadness, insecurity, anger, and resignation (Rätty et al., 2007). Those who felt satisfied, healthy and accepted their condition expressed feelings of harmony.

In order to adapt to epilepsy and stay healthy, some patients made changes in their lifestyles. Taking AEDs every day made the patients feel trapped. They were also tired, lacked energy and had difficulty concentrating. The patients expressed indignation to restrictions such as difficulty in choosing an occupation, rejection by employers and loss of one's driver's license, due to the epilepsy. Due to the shame of having epilepsy, some of the patients did not want others to know about their condition. Some even doubted if they were normal while others felt they were a burden to family and friends (Räty et al., 2007).

According to Räty et al. (2007) some patients felt inferior due to the continuous struggle they have to make with the restrictive nature of their condition. In an attempt to keep their epilepsy diagnosis a secret, they refused to take part in different social events. According to Gauffin et al. (2011), PLWE feel that they have to expend more effort compared to others to get the same results. They feel that they have to struggle for the same things that others do not have to struggle in life for.

Leaffer et al. (2011) in their study, found that comorbid lifetime history of depression was associated with stigmatization of PLWE. The Diagnostic and Statistical Manual Four (DSM-IV) criteria for lifetime history of depression were met by 18 (21.7%) participants. Half of the participants with lifetime history of depression reported experiencing stigma compared with the non-depressed ones.

In a qualitative study, Räty et al. (2009) employed a phenomenographic design to explore emotions that PLWE attach to conceptions about epilepsy. Happiness, shame, fear, sorrow, hope, confidence, annoyance, shame and guilt were the emotions associated with epilepsy. Confidence and happiness were related to the belief that epilepsy could be treated and hope was associated with expectations that the seizures

will stop. However, as the seizures came back anger was felt. The participants also felt ashamed because of the identity of having epilepsy and the feeling that they were not recognised as full members of the society. In a case-control study, Wang et al. (2015) found higher levels of depression and anxiety among Chinese PLWE compared to the general population.

Anxiety and depression are known to often coexist in the general population however, this is more common in the case of PLWE (Mensah, Beavis, Thapar, & Kerr, 2007). People living with epilepsy may be more prone to feel demoralised and may consequently have a more pessimistic view about life, which can have a negative impact on their affect and mood. According to Viteva (2012), depression and mental status impairment are consequences of stigmatization. People experiencing this may develop a very negative self-feeling (Guo et al., 2012). However, some neurobiological factors may also account for the link between psychopathology and epilepsy. A recent investigation on children with epilepsy by Jones et al. (2007) discovered that almost half (45%) of the participants had history of psychopathology (anxiety, depression and attention deficit disorder) which preceded the onset of their seizure disorder. According to Jones et al. (2007), there a number of ways by which increased feelings of anxiety in PLWE can be manifested. Anxiety may be present before and during a seizure activity. Furthermore, the fear associated with having a seizure may induce feelings of anxiety and the stigma associated with having epilepsy may make PWLE more anxious. Anxiety has also been associated with a number of epilepsy related factors including earlier age of onset, poor control of seizures, side effects of AEDs and increased frequency of seizure activity and severity (Mensah et al., 2007).

In a comparative study on the experience of stigma by persons with epilepsy in Sweden and Iran, Forsgren, Ghanean, Jacobsson and Richter (2013) found that the patients

from both countries evaluated that their epilepsy had made them “tough survivors”.

Majority of the Iranians expressed a need to hide their diagnosis in order to gain employment. There were a few reported problems with getting jobs among the Swedish and most of them never experienced discrimination because of their epilepsy.

2.4.3 Concerns of PLWE

Choi et al. (2011) studied factors contributing to concerns of persons living with epilepsy using the Concerns Index questionnaire. Less than 10% of PLWE were found to have the following concerns: medical costs of epilepsy, unfair by others, inability to do things on their own, sexual dysfunction, sleep problems and transportation difficulties. The common concerns of patients who have been seizure free for at least one year were; the desire for more information about epilepsy (27.5%), concerns about seizures re-occurring (25.5%), embarrassment about seizures (19.6%), concerns about the heritability of epilepsy (19.6%) and taking of AEDs (17.6%).

However, among patients who have had at least one seizure episode within the past one year, their main concerns were; concerns about having another seizure (23.8%), inability to do things for fun (22.8%), psychological problems such as depression (20.8%), desire for more information (19.8%) and taking of AEDs (19.8%). The only factor that significantly differed from those with controlled and uncontrolled seizures was the concern about the heritability of epilepsy.

Choi et al. (2011) found that fewer than 5% of the participants were concerned with being a burden to family, heritability, medication side effects, driving, inability to do things for fun, effects of epilepsy on family, fear of losing job, future, concealment, and sleep problems. According to Taylor, Baker and Jacoby (2011), reduced sense of

mastery, side effects of AEDs, poor cognitive function, feeling of being socially restricted and poor global Quality of Life (QoL) are also concerns associated with living with epilepsy.

Martin, Vogtle, Gilliam and Faught (2005) also found that the most frequently identified concerns of PLWE related to driving/ transportation restrictions (64%) and the side effects of AEDs (64%). Other concerns commonly cited by adults included safety issues, cost of medications, keeping a job, fear of embarrassment, and memory loss. According to Ghanean, Jacobsson and Nojomy (2013), unemployment and low education are significantly associated with a high level of internalized stigma.

Patients with epilepsy often consider themselves isolated and rejected from the community (Hosseini et al., 2013). This is a feeling which often starts early in life. It is usually noticed when peers avoid playing with a child with epilepsy at school. In many countries, epilepsy restricts people from living a normal life, staying on a job, obtaining financial security and educational opportunities. These restrictions deprive PLWE, pushing them toward dependency and becoming a burden on the family and the community (Hosseini et al., 2013).

Birbeck et al. (2008) studied women's experiences of living with epilepsy in Zambia. They found that the women felt vulnerable to assault during a seizure. They were also vulnerable to sexual assault anytime they were found alone. Most of them had been abandoned by their male protectors (husbands, uncles and fathers). The women felt that any man had the impunity to sexually assault them knowing very well that they have no male to stand up for them. Because they felt vulnerable to sexual exploitation, most of them felt very reluctant travel alone without any travel companion. The women needed a travel companion to accompany them for their monthly epilepsy clinic reviews. As a

result of this, those who did not have a travel companion were not consistent with epilepsy treatment.

One of the major challenges of using AEDs is ensuring strict adherence to drug regimen. This is usually affected by the actual or perceived side effects of medication. However, other PLWE have difficulty remembering to take medications as prescribed (Mushi et al., 2011).

2.5 Coping with Epilepsy

Coping here is referred to as the mechanisms that PLWE employ in order to be able to survive the challenges with living with a chronic disease such as epilepsy. Various studies show that PLWE adopt various means in order to cope with life (Kılınç & Campbell, 2009; Mushi et al., 2011; Gauffin et al., 2011).

Kılınç & Campbell (2009) in their study found that PLWE learnt more about epilepsy and in particular from their own epilepsy experience. Coping methods included accepting one's condition, knowing what to avoid and means to reduce the uncertainty of the occurrence of seizures. Acquiring knowledge about epilepsy helped participants to have a sense of control over their condition. The most beneficial form of knowledge was learning from their epilepsy experience, the triggers and ways that one could adopt to reduce seizure occurrence or its impact. However, due to negative public perceptions about epilepsy, some participants hid their condition.

Epilepsy was described by most of the participants as a hidden illness, due to the fact that no one would know about it unless one had a seizure. Majority of the participants felt that concealing the condition meant they could be perceived by others as a person and not as someone with epilepsy. Many of the participants felt epilepsy should not be

worn as a label, therefore they preferred to hide their diagnosis from others (Kılınc & Campbell, 2009).

Mushi et al. (2011) explored the social–cultural aspects of epilepsy in Kilimanjaro Region, Tanzania. They found that majority (93%) of the participants sought more than one type of care, including traditional healers, faith healers (prayer groups), and modern health facilities. This usually occurred when they don't see any improvement in their condition. In addition to receiving modern health care from local health facilities and hospitals, majority of participants attended prayers.

Majority of the PLWE sought professional care very late, from 4-15 years after the seizures began and most of them were getting treatment from traditional and spiritual healers. The patients were told by their traditional healers that they developed epilepsy because they failed to observe certain traditional rules or they have been bewitched by jealous friends or a close family member. Traditional forms of treatment included slaughtering of goats or chickens for rituals to please ancestral or evil spirits and offering patients charms and herbs. This cost them a lot of money. In order to meet these costs, some had to sell their cattle, goats and maize while others borrowed from family members to pay for their traditional cost of epilepsy treatment. However, almost all of the patients who started using AEDs confessed that it had been effective in reducing the frequency of their seizures (Mushi et al., 2011).

In their study on religious beliefs about causes and treatment of epilepsy among South Asian communities in the UK, Ismail, Wright, Rhodes and Small (2005) noticed that most PLWE used some form of religious healing irrespective of their ethnicity. This was mainly in the form of individual prayers or privately reciting religious texts. Others

also took the pain to go on religious trips to places of worship to pray for forgiveness of their sins so as to be healed from epilepsy and some turned to religious healers for help.

However, Birbeck (2000) found that the primary treatment of epilepsy among PLWE in Zambia was from traditional healers. Although 31% of the PLWE ever received AEDs, they were frequently under dosed. Becker and Maiman (as cited in Eatock & Baker, 2007) noticed that patient adherence to AEDs was influenced by factors such as patient-doctor relationship, social support, patients' age and familiarity with drug regime. They however, realized that patients who had belief in the effectiveness of their treatment regimen and were more knowledgeable about their seizures and its treatment were likely to adhere more to treatment regimen. Green et al. (2004) found that PLWE mostly attributed improvement in their condition to their own effort.

Räty and Wilde-Larsson (2011) found that PLWE had both positive and negative feeling towards the condition. Maintaining control of epilepsy and living a normal life signified a positive feeling. This was associated with feeling of acceptance and taking responsibility. In their study, participants with positive feeling towards their condition adapted to their situation by accepting epilepsy as part of their life. They tried to live life to the fullest and do things they wanted to do but, with some caution. They also avoided any situation that could trigger seizures. When they realised they are about to have a seizure, they stop anything they are doing and lie down so as to reduce risk of injury to themselves and others. Those with negative feeling about their condition focused on the problem and they ended up giving up hope of recovery (Räty & Wilde-Larsson, 2011).

In an attempt to protect themselves from injury during seizures Birbeck et al. (2008) noticed that most women with epilepsy in Zambia were torn between relinquishing

domestic tasks such as fetching of water and cooking to others or to take the risk of continuing with their normal domestic tasks. However, giving up of domestic roles meant loss of identity to most of the women, and this caused them great distress. People living with epilepsy also try to avoid situations where they will be disclosed as an epileptic (Räty & Wilde-Larsson, 2011).

Overall, Kılınç and Campbell (2009) in their study posited that the hidden nature of epilepsy made it possible to conceal the condition. Strategies used to conceal the condition included non-disclosure and reduction of social contacts. They found that PLWE expended much effort to conceal the condition and this often also meant that others will be left surprised and unprepared if a seizure occurred in their presence. As such, one some of the PLWE realised that been known to have epilepsy was not a threat to their identity, they begun to disclose their diagnosis to others. However, this was not a single event. Disclosure was also seen as preparing others in case a seizure occurs in their presence. Others also tried to return to their normal social lives.

In the findings of Räty et al. (2007), PLWE with a positive attitude felt normal and healthy. Most of them took the initiative to solve their own problems and declared that the diagnosis of epilepsy was nothing catastrophic. As such, they focused on ways of getting rid of epilepsy; they prayed, others hoped for cure. According to Gauffin et al. (2011), PLWE had different strategies for overcoming memory difficulties. Some outlined tasks to be performed at work as notes while others used their cell phones as reminders of tasks to do at work and to take medications. Others also tried to maintain a strict daily routine.

Conclusively, the above literature reveals that an epilepsy diagnosis can challenge a person's identity and sense of self, reducing their confidence and engagement in social

interactions. This brings an inevitable challenge to the life of PLWE – a reality that almost all of them have to deal with for the rest of their lives. It can also be inferred from the literature that none of the studies employed a theory in exploring the experiences of PLWE. This study therefore employed Leventhal’s CSM to explore the experiences of PLWE.



CHAPTER THREE

METHODOLOGY

3.0 Introduction

This chapter presents a description of the research design, setting and target population. It also includes a description of the sample and sampling technique, data collection tool, data collection procedure, methodological rigour and ethical issues observed in this study.

3.1 Research Design

The study employed a qualitative approach and a descriptive-exploratory design. Qualitative designs are approaches that are used to discover knowledge and to understand the rich descriptions of meanings from social experiences from the participants' perspective (Fain, 2013). It is a method of enquiry in which phenomena are explored in their natural environment (Mayan, 2009).

The qualitative approach was chosen for this research because of the objectives of the study. This aided the researcher to explore the depth of the phenomenon under study and to understand such human experiences. This was to explore and describe the experiences of PLWE and how they coped with the disease.

The exploratory design aids one to see the world as the participant sees it (Brink & Wood, 2001). The use of the exploratory design requires personal involvement of the researcher with a small number of people (usually less than 25 people) (Wood & Ross-Kerr, 2006). It is usually used when little is known about the phenomenon under study or in situations where the topic being studied is relatively new so as to allow the researcher to discover new phenomena or gain insight into an unknown phenomenon

(Brink & Wood, 2001). The descriptive design involves objective and accurate presentation of the characteristics of the persons or subjects under study and how often certain phenomena occur (Polit & Hungler, 2001). This was employed by the researcher to explore and describe the experiences of PLWE.

3.2 Research Setting

The study was conducted at the community psychiatry units of three health facilities within the Accra Metropolis namely; Ussher Polyclinic; Maamobi General Hospital and La General Hospital.

Ussher Polyclinic is one of the main government health facilities within the Ashiedu Keteke Sub-Metro District. The facility offers 24 hour health care service to the people in the community. The Ussher Polyclinic Community Psychiatric Unit is located in the Ussher Polyclinic. The mental health nurses in the unit liaise with the hospital and the community by attending to clients with epilepsy and mental illness in their homes. With staff strength of four, the Community Psychiatric Unit has 328 clients within the community. One hundred and eighty four of them have epilepsy, accounting for 56% of the total client population.

Maamobi General Hospital is located in the Ayawaso District. The facility also provides 24 hour health care service to the people in Maamobi, Pigfarm, Nima and surrounding towns. The community psychiatric unit at the Maamobi General Hospital has staff strength of four with a total of 761 clients in the community out of which 214 were living with epilepsy, accounting for 28% of their total client population.

La General Hospital is situated in La in the La Sub-Metropolitan District and occupies a unique status within the framework of Health Care Delivery in the country. The hospital serves the population of La, Osu, Teshie, Nungua and its surrounding environs. The hospital runs a 24-hour Out Patient Department (OPD), In-Patient and Emergency Services. Main services provided by the hospital are General Medicine, Paediatrics, General Surgery, Obstetric, Gynaecological Care and Maternal Health/Family Planning. Other specialized services rendered are Eye, Dental, Community Psychiatry, Public Health, Ear Nose & Throat (ENT) and Diabetic Clinics. The community psychiatric unit at the La General Hospital has staff strength of three with a total of 80 clients in the community, out of which twenty were living with epilepsy, accounting for 25% of their total client population. These community psychiatry units in the Accra Metropolis were selected due to the evidence of high number of clients in the sub district as compared to the other sub districts within the Accra Metropolis.

3.3 Target Population

The target population consists of people or subjects with certain properties that are of interest to the researcher (Nieswiadomy, 2008). This comprises the total aggregate of people or subjects that the researcher would generalise the findings of the study to. The target population for the study was PLWE living in the Accra Metropolis.

3.4 Inclusion Criteria

This consisted of young adults from 18-40 years of age who were diagnosed as suffering from epilepsy and were able to understand and speak English or “Twi”.

3.5 Exclusion Criteria

All persons suffering from epilepsy with co-morbid mental retardation and psychiatric problems were excluded from the study.

3.6 Sampling Technique

Sampling is the process of selecting persons or subject from a group in order to collect information that describes the group (Khan, 2012). The purposive sampling method was used to identify and select participants for the study. This is a form of non-probability sampling technique whereby the researcher deliberately selects a sample from a population that has certain characteristics that are required for the study (Khan, 2012). People living with epilepsy from 18-40 years old were purposively selected with the help of the Community Psychiatric Nurses at the La General Hospital, Ussher Polyclinic and the Maamobi General Hospital within the Accra Metropolis. The Community Psychiatric Nurses served as contact persons to help the researcher identify and recruit PLWE within their respective communities. People living with epilepsy who met the criteria for selection and were willing to participate in the study were recruited for the study.

3.7 Sample Size

The sample size is a subset that is drawn from a population to represent the population (Nieswiadomy, 2008). A total of 20 PLWE were contacted for the study however, saturation was achieved at the thirteenth participant. This was when the contents and themes of the interviews became redundant.

3.8 Tool for Data Collection

The study employed a semi-structured interview guide (Appendix D, pg. 107) to conduct face-to-face in-depth interview technique to collect data for the study. This

method of data collection creates a conducive atmosphere for the interviewees to freely express themselves and gives the interviewer the opportunity to seek clarification by probing into the issues arising from the interview (Kusi, 2012). The interview guide had two sections namely sections A and B. Section A was on demographic data. Section B comprised of guiding open-ended questions on beliefs about epilepsy, coping strategies and health outcomes of coping strategies. Field notes were also used to collect information on observations that were made during each interview session.

3.9 Data Collection Procedure

After obtaining ethical clearance, an introductory letter was sent to the office of the Greater Accra Regional Coordinator for community mental health nursing to inform them about the study. After approval from the regional coordinator to carry out the study, letters were sent to the nurse managers in-charge of the community psychiatry units at La General Hospital, Maamobi General Hospital and the Ussher Polyclinic to inform them about the study and to seek permission to collect data for the study. The staff in these various units served as contact persons and they helped the researcher identify PLWE in the community who met the inclusion criteria. After obtaining consent from the participants, interview sessions were arranged in the participants' own environment or a preferred setting of the participants. Nine of the interviews were carried out in the community psychiatric units of the selected health facilities whilst the remaining four were conducted in clients own home environment. The interviews involved open ended questions and subsequent probing questions where the participants were allowed to talk freely without any interruption. Each interview session lasted 45 to 90 minutes. The interviews were conducted in English and "Twi". This covered issues about their experiences with living with epilepsy, including beliefs about epilepsy, coping strategies adopted and their health outcomes. The interviews were all audio

recorded and field notes were also taken from observations made during each interview section.

3.10 Data Management

Data management involves the process of organizing and keeping data properly to enable easy access and analysis (Padgett, 1998). Information about each interview, the date, time and place were all recorded in the field diary. Each transcript was numbered and pseudonyms were used to identify each participant. All the transcripts, field diary and the soft copies of audio recordings of the interviews have been kept safely under lock. However, demographic data of the respondents were separated from the transcripts and audio recordings to avoid linking them together. All stored data are only accessible to the researcher and his supervisors. This will be kept under lock and key for a period of five years.

3.11 Data Analysis Procedure

All aspects of the data collected including the field notes and the interviews were analyzed using thematic content analysis approach. This involved data reduction, data display, conclusion drawing and verification (Miles & Huberman, 1994). The interviews were listened over and over again after which they were transcribed verbatim. However, the researcher discussed the audio recordings of the interviews in “Twi” with someone competent in the “Twi”, whilst ensuring confidentiality in the process. This helped the researcher to transcribe the “Twi” recordings in the same way they mean in English. Transcription and analysis were done after each interview so that probing questions would be identified and asked in subsequent interview sections. This helped the researcher to identify the stage where no new information emerged and data was redundant.

Transcribed data were read through several times to get the real meaning of each transcript. Coding was then carried out by identifying similar words, phrases, sentences and ideas which were highlighted with similar colors. They were then grouped together to form categories subthemes and main themes. Data from field notes were also analysed and added to the results to enhance the meaning of the information gathered. These were then arranged under the constructs of the model. The themes and sub-themes were also supported with verbatim quotes of participants from transcribed data.

3.12 Methodological Rigour

The trustworthiness criteria recommended by Lincoln and Guba (1985) was employed in this study in order to ensure methodological rigour. According to Lincoln and Guba (1985) trustworthiness is ensured by establishing credibility, transferability, dependability and confirmability in qualitative research.

Credibility refers to the confidence one has in the truthful nature of the research findings. To ensure credibility in this research, prolonged engagement was carried out by spending sufficient time with the respondents during each interaction process. This helped the researcher to establish proper rapport with the participants and to understand them better. It also allowed some measure of trust to be built between the researcher and the participants. Member checking was also carried out by making follow up interviews with some of the participants whereby participants were asked to validate the accuracy of the transcribed data and the themes that emerged. Furthermore, credibility was ensured by allowing a colleague experienced in qualitative analysis to code two of the transcripts after which comparisons were made to ensure objectivity in the coding process and to eliminate any bias. This is consistent with verification by peer debriefing.

Transferability refers to the ability of the study findings to be applied in similar contexts (Lincoln & Guba, 1985). This is achieved through thick descriptions. This involves a description of the research process in sufficient detail for one to be able to evaluate how conclusions drawn from the research are applicable to similar settings, situations, and people as recommended by Polit and Hungler (1999). This was achieved through a description of the research setting, methodology and background of participants and the interview process. All important notifications and observations were documented as field notes so that the researcher's decisions, choices and insights could be monitored by the supervisors. All transcribed data in addition to the field notes have been kept for the purposes of audit trail.

Dependability refers to the consistency of the findings and whether or not it can be repeated by other researchers (Polit & Hungler, 1999). This was ensured by pre-testing the interview guide on two PLWE at the Pantang Hospital in Ghana, but these were not included in the main study sample. The questions were then discussed with the supervisors and more probing questions were added to help generate data to meet the desired objectives of the study. Pre-testing the interview guide enhanced the credibility and dependability of the study. Secondly, the research supervisors examined of the process and findings of the research to evaluate the accuracy of the study findings to determine whether or not the study findings and conclusions drawn are supported by the data.

Lincoln and Guba (1985) described confirmability as the degree of neutrality or the extent to which study findings are determined by the respondents without any bias, motivation or interest on the part of the researcher. Confirmability was ensured by exploring in-depth experiences of the respondents, clarifying all information provided and presenting findings in the voice of the respondents. All transcriptions were also

done immediately after each interview to ensure that the exact meaning of each interview is portrayed in the transcript. An audit trail was also kept to ensure confirmability.

3.13 Ethical Consideration

Ethical clearance for the study was obtained from the Ethics Review Committee of the Institute for Statistical, Social and Economic Research (ISSER), University of Ghana, Legon (Appendix B, pg. 105). An introductory letter (Appendix A, pg. 104) was sent to the Community Psychiatric Units at the Ussher Polyclinic, La General Hospital and the Maamobi General Hospital to inform them about the study. Participants were made to demonstrate consent to participate by signing a consent form (Appendix C, pg. 106) for the study. The participants were informed that they can opt out of the study anytime they wished despite signing the consent form. No form of coercion was used to attract or retain them. Participation was entirely voluntary. The participants were also informed that each interview session would be recorded with a digital audio recorder and that they were free to answer or not to answer the questions put to them. Privacy was ensured by interviewing each participant alone without anyone listening in. All data including digital audio recordings and field notes of all interviews and other relevant materials were kept safely under lock by the researcher, to ensure confidentiality. In place of their real names, pseudonyms were used in reporting findings in order to ensure anonymity.

CHAPTER FOUR

RESULTS

4.0 Introduction

This chapter presents the findings of the study. It comprises the experiences of People Living with Epilepsy (PLWE). Study findings were based on in-depth face-to-face interviews carried out with PLWE within the Accra Metropolis. These interviews were carried out from October 2014 to January 2015. The interviews were recorded with a digital audio recorder and transcribed verbatim. Data was analysed using thematic content analysis based on the constructs and themes of the Common Sense Model (CSM). Other sub themes that emerged from the data were derived using content analysis. Additional information in the form of field notes was taken during the interviews. This was analysed and added to the data to provide additional explanation and clarity to the findings of the study. Verbatim accounts of respondents have been used to support the themes and sub themes emerging from the data.

In all, thirteen participants suffering from epilepsy were interviewed for the study. The interviews ended with the thirteenth respondent after data saturation was achieved. Pseudonyms were used, instead of the respondents' real names, to conceal their identity; these were Peter, James, John, Michael, Ken, Max, Adam, Rose, Rita, Ana, Miriam, Mabel and Mimi.

4.1 Demographic Characteristics of Respondents

The demographic data of the respondents that was taken included age, sex, level of education, marital status, employment status, religion and duration of illness. The age range of the respondents was from 18 to 40 years. One was below 20 years, two were between 20 and 30 years and ten were from 30 to 40 years. Seven of them were males

and six were females. All of them had some form of formal education. Seven of them attained basic education and six had attained secondary education. Ten of them were not married however, two were married and one was divorced.

With regards to employment status, five of them were self-employed and three were private employees. However, four were unemployed and one was a student. Only one was a Muslim. The remaining 12 were Christians. The duration with which the respondents have lived with epilepsy was from 11 to 36 years. Seven of the participants have lived with epilepsy for 20 years and below, four have lived with epilepsy for 21 to 30 years and two have lived with epilepsy for 31 to 36 years. The demographic characteristics of the respondents have been presented in Appendix F (pg. 109).

4.2 Themes and Categories

From the thematic and content analysis that were carried out on the data, three themes and sixteen sub themes emerged. The three main themes and seven sub themes were from the main constructs of the CSM that was employed to guide the study. The remaining nine sub themes emerged from content analysis of the data.

The main themes and sub themes on the experiences of PLWE were illness representations (identity, cause, timeline, consequences, cure and control, illness coherence, and emotional response), coping with epilepsy (problem focused coping; lifestyle changes; social support; faith in God; concealing diagnosis; thinking and worrying) and health outcomes (negative outcomes, positive outcomes and adjustment to work). The sub themes under the themes “coping with epilepsy” and “health outcomes” emerged from content analysis of the data (Appendix E, pg. 108).

4.2.1 Illness Representations

Illness representations were described in terms of beliefs about epilepsy. In expressing their beliefs about epilepsy, PLWE described their opinion to represent their illness experiences of living with epilepsy. People living with epilepsy described their beliefs about epilepsy under seven cognitive and emotional dimensions, representing seven subthemes namely; beliefs about the identity, cause, timeline, consequences, cure and control, illness coherence and emotional response to epilepsy. This theme and the sub themes are in conformity with the CSM.

4.2.1.1 Identity

The sub-theme, identity describes the label given to epilepsy and the beliefs associated with the signs and symptoms of epilepsy that the participants experienced. This was described as label, signs and symptoms of epilepsy, lack of awareness of signs and symptoms, passing of urine, warning signs and triggers of epileptic seizures.

Epilepsy was labelled as a disgraceful illness by the participants.

I think it (epilepsy) is a bad illness that wants to disgrace me just like that ... It is a disgraceful illness – (Miriam).

The participants explained that due to the sudden and unannounced nature of seizure attacks, they had seizures in public places such as the church and in the market which disgraced them. Hence participants labelled the disease as a disgraceful illness.

The other day my mother sent me to the market and it disgraced me at the market – (Miriam).

... Sometimes at church it happens, I get the attack and it disgraces me – (Ken).

It's a disgraceful illness because at times, it happens at church. When I go to church I like to sit in front. I was sitting in the first chair and it happened. By the time I realised I was sent to the Hospital. So I think it's a disgraceful sickness – (Mabel).

One participant who was a JHS student said seizure episodes disgraced her in school.

I have seizures when I go to school it (epilepsy) disgraces me - (Miriam).

With regard to beliefs about the signs and symptoms of epilepsy, participants stated falling down after becoming unconscious, being semi-conscious and unable to respond to external stimuli and banging of head against surfaces. Becoming unconscious and falling down during a seizure episode were associated with severe form of seizures. These were said to be typical of seizure episodes that occurred at the onset of the seizures.

At first when the seizure attack occurs, it causes me to fall down – (Ken).

Upon sensing an impending seizure episode, some participants tried to take cover by finding a safe place but they fell down in that attempt.

At first when it is about to happen and I want to enter the room, I will fall down on my way to the room – (Mavis).

Symptoms of epileptic seizures were also described as becoming semiconscious where the person was partially aware of his or her environment but, was unable to respond to stimuli.

It's only that I do lose consciousness. At times it will happen within, may I say in two minutes but, at times when you are speaking to me, I will never hear anything you are telling me and then after two minutes I will be hearing some noise from you when you are talking to me. I will be hearing your voice but I may not hear the actual thing you are telling me. But, after half a minute I can get you but I cannot answer you at that moment but within a minute or two I will be back from everything and we can proceed with whatever we are talking about – (Michael).

Banging of head against surfaces was also described by one participant as typical of her seizure episodes after falling down.

They said I used to hit my head against surfaces continually... if I sleep here and have seizures I can hit my head on the floor until the seizure is about ending before I will stop hitting my head on the floor – (Ana).

Most of the PLWE were not aware of signs and symptoms of their seizures. Participants reported that during a seizure episode, they became unconscious and fell down without knowing anything that went on after that. Most PLWE were not aware of the signs and symptoms associated with their seizure episodes. As a result of this most of them were not able to give detail account of their seizure episodes. Due to this, some were not even aware that they were suffering from epilepsy.

I do not know exactly what happens to me during a seizure but, anyone sitting next to me sees what goes on. Even if I have seizures I am not aware. It is the person next to me that notices it. I didn't even believe that I had such an illness. If it were not to be my father and mother who told me about it and the burns I had after falling into fire during a seizure which drew my attention to this, I would not even know that I had such an illness – (Ana).

Some got to know about the signs of their seizures from onlookers.

As for me when it happens I am not really aware. Whatever happens I don't know. By the time I wake up, I am okay. So when someone is close then the person will tell me that this is what happened. But for the seizures, when I say I really know about how it happens then it is not true – (Ken).

Others were completely unaware of seizure episodes. They only suspected they had a seizure after they noticed bruises, body pains and dirt on their skin or dress.

When I fall, I don't even know that I have fallen to the ground ... I will sleep for a long time and only realize that I got injured when I wake up. So I do wonder whether the illness occurred or not. So I get to know when I have a conversation with my mother and she tells me that it occurred. I would never have known whether it occurred or not. They don't normally tell me; I only suspect the occurrence when I notice an injury or realise I am dirty – (Max).

Passing of urine during a seizure episode was experienced by some participants. In describing their seizure experience, some participants said they soiled themselves with urine during the process. However, this was not a regular occurrence.

Sometimes the urine comes ... Sometimes I urinate in my pants and my pants get wet – (Peter).

Usually when it happens, before I realise, I would urinate on myself. Sometimes the urine drips on me without my control – (Rita).

Warning signs of epilepsy were also described under identity. Some participants attributed certain signs and symptoms they experienced to an impending seizure. Having palpitations and feeling dizzy were the warning signs associated with epilepsy in this study. Most of them experienced these signs and symptoms prior to a seizure episode.

When I am about to get an attack, I feel dizzy, my heart beats fast and I get anxious - (Miriam).

Others also had tremors heralding their seizure episodes

Sometimes I experience my legs or hands shaking for some time. When that happens I get to know that there is going to be an attack – (John).

One participant explained that he sometimes felt thirsty prior to his seizure episodes but, was unable to do anything about it.

At times I do feel thirsty. Before I quickly ran to fetch the water, I will have an attack but, at times there will be no sign before the attack – (Adam).

However, others had no warning signs prior to the seizures. As a result of this they were mostly caught unawares and were unable to do anything about their sudden and unannounced seizure episodes.

Before a seizure episode, I don't feel any sign. It just happens – (Peter).

As for this sickness the way it is, when it occurs I don't even know how it happens. I don't even know that I am about to experience it ... When it does I don't realise I am about to have an attack. I don't get any warning sign that the seizure is about to occur for me to go and take my medicines – (James).

Triggers of seizure episodes were described under the sub theme identity. Triggers of seizures described by the participants were being in a bad mood or remaining quiet for a long time or thinking a lot.

They say if I sit down for a long time without conversing or if I get angry or think a lot then I will have a seizure during sleep ... They say sometimes when I am not happy and I sleep in that sad mood then I have a seizure ... they said too much anger makes me have the seizures – (Ana).

Eating of sugary foods and having the urge to defecate or urinate were also mentioned by one participant as one of the factors that triggered seizure episodes.

I do exercise at home but that does not cause the attack but sugary foods. Though they said it was anger that causes it; I got angry at times but noticed it was not anger but sugary foods like coca cola that initiate the dizziness and causes me to fall to the ground – (John).

John also explained that, having the urge to visit the toilet or to pass urine triggered his seizure episodes;

When I feel like visiting the toilet sometimes or even feel like passing urine then I experience a seizure soon after that – (John).

Lack of sleep was also mentioned as one of the triggers of seizure episodes.

I noticed that at times if I don't have enough sleep I do have seizures. So when I don't have enough sleep I have severe seizures, so I go and sleep for an hour – (Michael).

4.2.1.2 Beliefs about Causes of Epilepsy

The second sub theme under beliefs about epilepsy is the belief about the causes of the illness. Belief about causes of epilepsy was described as physical causes, spiritual causes and unknown causes of epilepsy.

Physical cause of epilepsy was attributed to hunger and starvation. One participant believed that starving himself during childhood by sometimes eating only once in a day was the cause of his epilepsy.

From what I read they told me that from childhood maybe if someone is not able to eat a lot the person will develop epilepsy. I could remember that in the evenings, during my childhood I don't eat. At times I could even eat once in a day and I think that has caused this epilepsy – (Max).

The participants believed that their illness was spiritual. Most of the participants attributed their condition to spiritual forces.

As for me I think that it is a bad spirit that caused this sickness – (Peter).

I think it (epilepsy) is a spiritual illness – (Miriam).

Some of the participants had these beliefs about spiritual causes of epilepsy after consulting spiritualists and pastors. These persons proclaimed that epilepsy is caused by evil spirits, making the sufferers believe that epilepsy is caused by evil spirits.

They took me to some medicine man (spiritualist). Then they said that it is some bad spirit. Now some people said it may be some evil spirit that it causing that – (Rita).

Others believed that it was someone with evil intentions against them who was indirectly afflicting them with epilepsy spiritually. Among the participants who believed that it was someone who was afflicting them with epilepsy spiritually, the people they suspected were a father, aunt and a co-tenant.

But some time ago I went for prayers and they told me that it was my father who is the cause of my epilepsy – (Rose).

In my opinion, it is someone who gave me this illness. Because I used to live with a certain girl who was my co-tenant and she gave me some food to eat. She put some medicine inside the food and after I ate the food I began to have seizures. She started to mock me when I started having seizures – (Adam).

Hmmm, as for this sickness, the way they explained it to me, they said it is one of my aunties who is responsible for my sickness.... They said she was the one who put that medicine into my food – (Ana).

The participants had the belief that these persons who were using spiritual means to afflict them with epilepsy knew about their destiny and the successes they will achieve in life hence their motivation was to destroy them with epilepsy due to envy for their bright future.

I think it is a spiritual illness. Maybe someone could have sold it to me spiritually. When I go to my pastors they say because the witches in my family knew that I will be a great person in the future, work hard and take good care of my parents, they want to destroy my life – (Miriam).

Some participants in this study also expressed having no idea about the cause of their condition.

I don't know the reason why. I just don't know the cause of this illness – (Peter).

...I really can't point out that the actual cause of this illness – (Ana).

I don't know the cause and I cannot say it is this or that because the thing just happened. I was in my bed one night and by the time I realised I was at the Hospital. As for the cause I don't know – (Mabel).

4.2.1.3 Timeline

The third sub theme under beliefs about epilepsy was timeline. In this context, participants expressed their view about the duration of their epilepsy, whether they believed it was a short term or long-term illness. Most of the participants believed that epilepsy was a short term illness and that their seizures would not last.

It (epilepsy) is an illness that does not keep long on people – (Miriam).

Others believed that with the medication they were on, their condition would not last.

I know now that it (epilepsy) will not last for a long time especially with this medication I am taking – (John).

Some also used to believe that their seizure would be short lived however, after a long period of treatment with no significant improvement they were unable to tell how long their seizures would last.

At the beginning I thought the seizures will not last. When I asked the doctor whether my seizures will stop soon so that I can return to my normal work, he said yes. However, since the year 2009 up till now I am still not totally cured from my epilepsy – (Michael).

As for this I don't know how long it (epilepsy) will last because this thing started since 1994 up till now. It has been so many years now – (Mabel).

4.2.1.4 Belief about Consequences of Epilepsy

Participants described various consequences of living with epilepsy that they believed to be a result of epileptic seizures. These included injuries in the form of sores, bruises and burns during seizure episodes. Epileptic seizures also affected their work, school and social relationships. Beliefs about the consequences of epilepsy were described in the form of injuries, effect on work, financial challenges, effect on education, stigma, disgrace, restrictions from general activities, effect on relationship with friends and family and effect on love relationships.

With regard to injuries, the participants stated that they fell due to seizures. Some fell to the ground and into gutters causing bruises and sores on their bodies.

If I have a seizure I fall and I sometimes get injured – (Peter).

Some time back, I even fell into a gutter ... I got injured and had a lot of bruises ... As for that gutter it was very deep so I got severely injured – (James).

When it happens, I fall to the ground and sometimes I have bruises all over my body – (Miriam).

One girl narrated one incident where she nearly fell into a pit latrine if not for the timely intervention of her mother and her siblings.

I returned from church and went to the toilet to ease myself but I kept too long in there. Then my mother said she heard me screaming. When they rushed there, my trousers and my sandals have fallen into the pit latrine and I was about to fall into it. Then my mother, my sister and my brother pulled me out – (Miriam).

Others fell into fire and got burnt. Two female participants fell into fire when they were in the process of cooking and got themselves severely burnt. One said she would have died if she had not been pulled out of the fire in time.

I was cooking and then I fell into the fire during a seizure episode. That was one of my first seizures – (Mavis).

I had a seizure in the process of cooking something and I got burnt ... if no one were around to pick me up from the fire, I would have died – (Rose).

One male participant also sustained burns on his hands after hot tea poured on him one morning during a seizure episode after he began to feel dizzy before falling down.

I prepared tea and I felt dizzy just before a seizure episode. This caused the tea to pour on my hand and I got burnt – (John).

As a result of this the participants developed scars on their bodies from the bruises, sores and burn injuries sustained during severe seizure episodes.

This is the scar from the burns I had [Shows burns scars on right arm and right thigh]. It is on my arms and my legs. They said I sat on fire ... At that time the dress got stuck onto my skin. It became sore – (Ana).

These scars were caused by fire during a seizure episode [shows her arms and side of her face scarred as a result of burns during seizures] – (Rose).

Injuries from seizures caused a lot of scars on my face which worries me a lot [he pointed his hands at the sores and bruises on his face, lips, jaw temples, eye brows and fore head] – (Peter).

Due to the severity of falls and injuries sustained, some of the participants complained of having bodily pains and headaches as a result of hitting body parts against hard surfaces.

They said when it (seizure episode) happens I hit my head against surfaces. So if there is any injury, it usually occurs around my head because I use it to hit against surfaces continuously – (Ana).

... I was about to fall into the pit latrine during a seizure episode. My neck hit the logs on the pit latrine and my throat got stuck in between the logs ... So for about three days I could not eat or drink well. I had pains in my throat; I could not even drink water – (Miriam).

One woman aborted her pregnancies repeatedly as a result of injury from seizures.

Because of this illness ... anytime I get pregnant I lose it because of the seizures – (Rita).

The work of the participants was disrupted by epileptic seizures. Some were rendered jobless and had to remain at home to receive treatment for their seizures. Others had to stop work on their own due to disruptions from frequent seizures at work.

One woman lost two previous jobs because she had seizures at the workplace.

At first I was working at the airport and I had an attack there so they sacked me. I went to another company and the same thing happened – (Mabel).

Some were also asked by relatives to stay at home and not work so as to protect them from fatal injuries at work due to epileptic seizures.

I started to work but I had to stop because of the seizures. I had seizures at the work shop where I was learning how to make glass windows ... Because of this sickness my brothers stopped me from working – (Peter).

Some had to stop their cooking and selling of food business to avoid getting close to sources of fire.

Because of my sickness, I have stopped my cooking and selling business because they said I should not get close to sources of fire – (Rose).

One participant in an attempt to protect his life declined to learn driving, metal works and masonry as a result of his epileptic seizures.

A friend of mine was ready to teach me driving free of charge. He had a car and was putting pressure on me to learn driving. However, looking at the nature of this sickness (epilepsy), when I get an attack whilst driving a car, it is not only my life that is in danger but other people's lives as well, so I refused to learn driving. Another one wanted to teach me welding but I refused... A friend of mine, who was a mason, asked me to come so that he could train me. He later on told me that I may have to climb a ladder whilst doing the mason work. If I have an attack up there, I can even fall and break parts of my body and that will worsen my health condition. This has prevented me from doing all these things – (Michael).

Financial challenges also emerged as one of the consequences of epileptic seizures.

Some participants had to rely totally on relatives and others for financial support.

As for monetary issues, it is really a problem. It is only my mother that takes care of me. She is the only one that takes care of me – (James).

Some lost their work as a result of their seizures and some complained of lack of capital to start a business.

When I came to the hospital, they said I should not do any work. I used to sell meat pie and cocoa from which I used to save from the profit I made to take care of my son – (Ana).

I need money to buy some things and sell – (Rita).

Others found it difficult to get money to buy their medicines and even buy food to eat.

The interest in this business is small so I cannot afford to buy my medicines – (John).

I don't have money to buy anything to eat. Yesterday for instance, I didn't get any food to eat in the morning – (Rose).

With regard to effect on education, participants could not climb high the educational ladder due to disruption of school activities by their epileptic seizures. Some had to stop schooling midway because of repeated seizures in school which disrupted their learning activities.

Because of this sickness I have stopped schooling. Now I don't go to school again. Sometimes it happens in school. It happens on the way to school. So that is why my mother stopped me from going to school – (Peter).

Some of them could not continue with their education after completing their basic education.

After completing junior high school, I gained admission to a secondary school. That was where it started and the head master asked me to come home and treat it. So I was not able to continue – (John).

The seizures also affected the ability of some participants to learn. They found it difficult to understand and even memorize what was taught in school.

Sometimes I will learn and write exams thinking I am writing the right thing but at the end I will fail. I can take books, stay awake throughout the night and learn but, after an hour of learning, I will lose concentration. I will still be awake but I will be thinking about my seizures and lose concentration on what I am learning – (Mabel).

At first I was intelligent in school ... but now I have noticed that when they teach I am not able to understand it well – (Miriam).

When I was in school I used to have seizures. As a result of that, I was not intelligent in school – (James).

One female JHS student had seizures disrupting her learning process and that affected her performance in examinations to the extent that she had to be repeated twice in one class.

In class when I pick a pen or when the teacher comes to the class and I raise my hand to answer a question then I have a seizure and I fall in the classroom ... During examination periods I am not able to write the exams. Last term when I had seizures, I could not go to school. During the examination period, I could not write the exams ... When it happens I stay at home and I am not able to move on to the next class. If it were not so I would have been in JHS three by now. So when I started again, they sent me back to JHS one – (Miriam).

One of the participants could not continue with her schooling because of financial constraints due to the seizures. Money that could have been used to pay her school fees was rather channelled to buying AEDs and seeking treatment for her epilepsy.

I could not continue schooling any longer. Because my parents were using the money to buy medicines for me so I could not continue my education due to inability to pay school fees – (Mabel).

Stigmatising attitudes towards PLWE emerged as one of the consequences of living with epilepsy. Stigmatising attitudes were in the form of disrespect, mockery, avoidance

and isolation due to fear of contagion. The perpetrators were family members, friends and neighbours.

One woman was disrespected, mocked and hated so much by her in-laws to the extent that it turned into a fight when she tried to defend herself.

His relatives don't respect me and they talk to me anyhow ... One of my husband's sisters mocked at me saying, "Look at this epileptic woman that my brother has gone in for as a wife with a crooked leg". So when she passed by me I slapped her and it turned into a fight – (Rita).

Due to fear of contracting the illness, some participants were avoided by friends and their neighbours, and some prevented their children from getting close to them.

Sometimes, the children of my neighbours want to come to me but, their parents prevent them. When the children come to me, they signal them not to come to me again – (John).

The participants reported stigmatising attitudes against them by their own colleagues in school. Their class mates avoided playing with them.

As a result of this, none of my friends in school even wants to play with me. They said if they play with me or come into contact with me they will contract the disease from me. So they don't play with me in the school – (Miriam).

In one incident, some parents of school mates came to the school and asked teachers not to allow their children to play with their colleague who was suffering from epilepsy due to fear of contracting the illness.

Some mothers of some of my colleagues in school even came to tell the teachers in my school to watch their children well and to see to it that they don't come into close contact with me – (Miriam).

Stigmatising behaviour was also reported among family members of the participants.

Family members isolated themselves from a participant to the extent that she had to use her own cup and bucket at home.

In the past when the seizures used to be severe, even when I pick something for someone around, my mother will take it from me. They don't even allow me to touch anything belonging to someone. It even got to a time that I was asked to buy my own cup and bucket to use – (Ana).

Getting disgraced due to having seizures in public and in front of people from whom the diagnoses of epilepsy had been concealed and other unsuspecting individuals was one of the reported consequences of living with epilepsy. Participants gave account of incidences where they had seizures at the mosque and in church during church service at the full glare of the entire congregation.

I went to pray at the mosque and I had an attack. So when I regained consciousness, I saw a lot of people around me so I was ashamed that all those people had seen me – (Rita).

I had a seizure at church. I was playing instruments (drums) during church service and I fell behind the drums – (Peter).

The PLWE felt disgraced and felt shy when they met people who saw them having seizures in such public places.

After I wake up from my seizures I begin to feel shy when I see people. Thus I feel shy that people will point fingers at me that I have epilepsy. Then it becomes shameful to me – (Ken).

When it happens like that I feel shy – (Miriam).

From that time onwards I could not sit in front at church anymore. I felt ashamed among my church members and among my friends because I didn't tell them that something was wrong with me – (Mabel).

Some ended up resigning themselves to staying at home.

I feel shy going into the midst of people. My mother asked me not to go outside when I tried to; therefore I get stuck at home – (John).

After I had seizures at church I wasn't able to go to church for about a month because I felt ashamed – (Mabel).

As a consequence of epileptic seizures, participants were restricted from some general activities they normally carried out. Most of these restrictions were interventions by relatives or advice from friends which was intended to avoid any fatal incident that may occur in the event of any seizure episode. These were in the form of restrictions from cooking or getting close to sources of fire.

They said I should avoid getting close to fire. So when I put something on fire, I stay away from the fire and just come over to check whether the food is ready or not. As of now, my mother does not allow me to cook "banku". Because they said I should not stay too close to fire for a very long time, she does not allow me to cook – (Ana).

When they are cooking and I want to help they stop me. They don't want me to get close to the fire because they say it (epileptic seizure) can happen at any time – (Mabel).

Others were in the form of restrictions from social gatherings such as parties for fear of having seizures in public.

My brothers do not allow me to go for any party because of this sickness. They don't allow me to go out for social gatherings. They say they are afraid that I will have a seizure episode outside – (Peter).

Some were not even allowed to handle electrical gadgets for fear of getting injured as a result of having seizures in the process of using these gadgets.

My father does not even allow me to handle electrical gadgets. Even if I had to heat water to bath, another person does it for me – (Ana).

Although these restrictions were as a result of good intentions, some of these restrictions made the participants feel uncomfortable.

When I want to do something they don't allow me to do it, but I feel like doing it. So I don't feel happy about that restriction – (Mabel).

The experience of living with epilepsy did not have negative effect on the relationship between some participants and their friends and family members. Some friends and family members who were concerned about the condition of the participants felt pity and drew closer to help and, this strengthened their relationship.

All my relatives are free with me and they all get close to me. No one rejected me – (Ken).

My friends were aware about my seizures but they did not avoid me. They know that I have epileptic seizures but we get along very well – (John).

However, one participant whose friends were uncomfortable with the seizures and had fears of contagion distanced themselves from her.

They said the way my seizure episodes occur suddenly, and the saliva that comes out of my mouth prevent them from getting close to me and playing with me. Because they feared that if they played with me I would transfer the illness (epilepsy) to them – (Miriam).

The effect of living with epilepsy negatively affected the love relationship of majority of the participants. Two women got themselves impregnated by their lovers but the men refused to marry them. The men who impregnated them, abandoned the women and their children to their own fate.

He didn't marry me! However, he was aware I had epilepsy – (Rose).

One of the men who impregnated one female participant run away after he was caught cheating on his partner with another woman.

I have a son, and his father run away from us. His father went for another woman. I went with my son to collect money from him and we found a girl in his room ... As for my son, I am managing with the little I have with him – (Ana).

One woman also had a bad experience with her in-laws which finally led to the dissolution of her marriage. She was maltreated by her in-laws and finally thrown out of her matrimonial home. As a result of that she refused to return to her husband.

His sisters asked me to park out of the house and said their brother was no longer interested in me. I am now living with my junior brother and the marriage between my husband and I is over ... He later asked me to return to him but I refused to go back because of the way his relatives maltreated me insulted me – (Rita).

The men had a similar problem in their love relationships with the women they intended to marry. These ladies ended up quitting the love relationship after finding out that the man they intended to marry had epilepsy.

After I decided to get married, the ladies I proposed marriage to later got to know about my epilepsy and they refused to accept my marriage proposal. At least two ladies have come and left - (John).

I have been in a love relationship with a few women but they all finally left me because of my epilepsy – (Max).

One man even went ahead to buy materials for the marriage ceremony but the lady eventually quitted the relationship.

I bought all the things needed for our engagement but I never succeeded; she left me – (John).

Some suspected they had seizure episodes occurring in the presence of their lovers.

However, one of the participants suspected some other persons might have given the women hints about his condition.

I believe it happened in their presence. Apart from that I cannot tell whether someone gave them the hint before they decided to leave me – (John).

As a result of repeated failures in their love relationships some of them have lost hope and would not want to get into any love relationship that might later fail.

I don't want to have any love relationship with any lady who may later disappoint me again – (John).

One of the men who was in a love relationship at the time of interview was not even confident that the lady would agree to marry him.

I am now in a love relationship with a lady who is aware that I have epilepsy. We live well and even have sex but, who knows as to whether she will agree to marry me – (Max).

Only two of the participants (one man and one woman) had a positive love relationship and enjoyed a peaceful marriage life despite their epileptic seizures.

It (epilepsy) hasn't affected my marriage. I am married with two children. My husband hasn't divorced me because I told him before he came and sought for my hand in marriage from my parents (Mabel).

As for me if I say it has affected the relationship between me and my wife then it is a lie. We get along well and I don't have any problem with my wife – (Ken).

4.2.1.5 Beliefs about Cure or Control of Epilepsy

Participants' belief about cure and control of their seizures was one of the sub themes under the beliefs about epilepsy. This addressed the expectations that the participants had concerning their recovery from seizures as they managed or took steps to control their seizures. Despite the long duration the participants had lived with epilepsy, most of them had positive expectations with regard to cure and control of their seizures.

Most of the participants expressed hope for cure.

I hope that this illness (epilepsy) will by all means go away – (Peter).

It can be cured ... I believe that I can be cured - (Ana).

They expressed these beliefs about cure and control through their belief in God for cure and control of their seizures.

As a result of the prayers and the medicines I take, I believe that God can heal me completely – (Miriam).

Some were confident that the medications they were taking would help them control and put an end to their seizures.

I know now that it (epilepsy) will not last long because of the medicines I am taking – (John).

Others also explained that they have gained control over the frequency and severity of their seizures.

I will say I have been able to deal with this illness (epilepsy) and put it under control. I will not call it a problem anymore ... I mean it has reduced the severity and frequency of the seizures. I believe I have gained control over this illness (epilepsy) – (Ken).

Only one participant had the opinion that not all sicknesses were curable and as such was not all that concerned about any expectations for total cure.

Not all sicknesses are curable. Maybe they are only helping me to cope with it (epilepsy) or just to prevent it to some extent - (Michael).

4.2.1.6 Illness Coherence

Illness coherence was also a theme under beliefs about epilepsy. Illness coherence is about the understanding that the participants had about epilepsy. The participants expressed a general lack of understanding about their condition.

When I think about it, I just don't understand. If I say I understand this illness then I am lying - (Ken).

To some of them, it came to them as a surprise and they did not understand how they got the disease.

There is no such illness in my family. So it came to me as a surprise – (Ken).

This sickness is a surprise to me. I don't know about it ... it just happened all of a sudden – (Rita).

However, one of the participants believed he got some understanding about his condition after reading a lot about it.

After I developed epilepsy, I read a lot about it that even comforted me and made me less anxious about the illness – (Michael).

4.2.1.7 Emotional Response

Emotional response was one of the sub-themes under beliefs about epilepsy. This addresses the emotional reaction of the respondents to epilepsy. Fear, anxiety and sadness emerged as the emotional responses of participants to their condition.

Fear and anxiety were often around concerns of the frequency of their seizures, concerns about getting hurt during seizure episodes and concerns about having seizures in public. As a result of this, they feared to go out.

When it happens, I fear; I become afraid and anxious – (Miriam).

I am even afraid because of my seizures. I am not able to stay at public places for long and I become anxious when I am among people ... Even when I go to the market I fear; anywhere I go I fear - (Rita).

Some became anxious when people looked at them suspiciously in public.

Even if I am walking and someone looks at me twice then I become anxious. I feel because the person knows I have epilepsy that's why he/she is looking at me to see if I will have a seizure - (Rita).

Participants also felt sad due to the disabling nature of the seizures. They felt sorry for themselves and some were often unhappy.

I am just not happy, so I just sing to myself whilst walking – (Ana).

As a result of this, some of them lost interest in daily activities and remained at home.

I become very sad and feel it in my heart. When it happens I become very sad and I am not able to go out – (John).

Others sometimes became full of sorrow to the extent that they lost appetite and were unable to do anything for themselves.

I am sad and always sorrowful. It makes me sit quietly and helpless and I am not able to do anything for myself. When it happens I lose appetite for three days – (Miriam).

One woman felt lonely, even in the company of her family members.

I don't feel happy. Even when I am with my family members I feel lonely – (Mabel).

One man felt so discouraged and disturbed about his seizures.

The seizures make me feel discouraged and disturbed – (Ken).

4.2.2 Coping with Epilepsy

The second theme in the findings was coping with epilepsy which is consistent with the CSM. This represents activities carried out by PLWE to manage or deal with their health threat – epilepsy. This comprised of interventions directed towards treatment of

epilepsy and the management of the challenges associated with living with epilepsy. This took various forms including seeking treatment for epilepsy, changing one's style of living, support from friends and family, and being silent over the issue. Coping strategies adopted by participants was described under six sub-themes, namely: problem focused coping, lifestyle changes, social support, faith in God, concealing diagnosis and, thinking and worrying. These sub themes emerged from content analysis of the data.

4.2.2.1 Problem Focused Coping

Direct activities carried out by participants to treat or manage epilepsy were described under the sub theme, problem focused coping. Some participants first sought help from spiritualists and others went to the hospital or the herbalist for help. Those who believed their condition was spiritual sought spiritual help whilst those who did not see it as spiritual sought physical treatment. However, some also combined both physical and spiritual treatment modalities. Problem focused coping activities were in the form of physical treatment, spiritual treatment and response to warning signs.

Physical treatment of epilepsy took the form of taking orthodox medicines and herbal preparations. Participants acquired AEDs from hospitals and clinics. Some of them had free supply of medicines from the facility they attended whilst others were given prescriptions to purchase their own medicines when the health facility runs out of free medicines.

I always come to the hospital for my medicines for free. If they (the health professionals) don't have the medicines, they write it on a prescription form for me to go out and buy – (Rita).

Some participants who sought treatment from health facilities were also referred from one facility to the other for further treatment. Some were referred once; others twice.

I was referred from hospital A to hospital B. Then later, I was referred to this polyclinic.

When I first had seizures I went to hospital A for treatment and then I was referred to hospital B to continue with treatment – (James).

Most participants showed commitment to their treatment regimen. They took their medicines judiciously as prescribed and attended medical reviews regularly.

I take my medicines every morning and evening. That is why the frequency of my seizures has reduced – (Ana).

I just continue taking the medicines – (Peter).

As for the medicines I see to it that I take it regularly ... I take my medicines as prescribed without defaulting – (Ken).

Others tried as much as possible to prevent shortage of their medicines.

I will not allow myself to get short of medicines. When I realise I am running out of medicines, I will come and buy more – (Ana).

I buy the medicines as soon as I realise I am running out to avoid shortage – (Ken).

However, one participant who used to take her medicines regularly stopped taking her medicines because she was not seeing any improvement in her condition.

I used to go to the hospital for medicines. I have been taking these medicines for a long time and have not seen any improvement in my condition so I just stopped taking the medicines – (Mabel).

Herbal medicine was also another form of physical treatment that participants used to treat epilepsy.

He (the herbalist) gave me a kind of herb to boil and drink – (John).

Some used herbal medicines for a while and stopped. One woman used herbal medicines for six months and later stopped and went to the hospital for treatment.

When the seizures started, I began treating it with herbal medicines. I stopped after six months and started attending the psychiatric hospital for treatment – (Mabel).

Others combined herbal medicines with orthodox medicines acquired from various health facilities.

I take his (the herbalist) medicine in the morning and afternoon, and then take the medicine from the hospital in the evening – (John).

Spiritual intervention for epilepsy was carried out through individual prayers whilst others sought prayers from pastors or both. Participants believed that prayers provoked divine healing from God.

All I do is pray or receive prayers from pastors. It is only God who is our helper. He is the only one that is capable of helping me get rid of this disease (epilepsy) – (James).

I always attended prayers at the church every day ... If I am not doing anything at home I go for prayers – (Rita).

As for church, my pastors are aware about it. Because of that they used it as a prayer topic and prayed for me – (Miriam).

Others also prayed for their epilepsy to be sent back to whoever was spiritually afflicting them with the disease.

So when I go to church we do “back to sender”. Thus the pastor asks us to pray so that the sickness (epilepsy) will go back to the person who gave it to us – (Ana).

Prayers were done on daily basis, in church and when one senses a warning sign that he or she was about to have a seizure.

As for me I pray every day ... If I notice a warning sign that I am about to have a seizure attack I pray – (Rose).

Some had to pay huge sums of money or provide livestock as payment to pastors and spiritualists for prayers and spiritual intervention. One woman paid about two million cedis to a pastor and bought a goat for another pastor for spiritual help.

Some time back I went to see a pastor and they took almost two million cedis from me before I was able to see the pastor for prayers. I also went to see a spiritualist and I had to present a goat to them as payment before they attended to me – (Rita).

Other participants were asked to perform certain rituals for spiritual healing. Some were given oil to smear on their bodies before going to sleep, drink soda water and also have water sprinkled on them during a seizure episode.

My pastor told them that when the seizure is about to occur, they should pour water on me. He even gave me oil to smear on my body before going to sleep – (Ana).

Response to warning sign was also described under the sub theme, problem focused coping. This comprised of activities carried out by participants when they sensed that they were about to have a seizure. Participants sat down or lay down when they sensed they were about to have a seizure. These were attempts to avoid any form of injury from a fall and to reduce the severity of the seizure episode.

If I am about going out and I sense that I am about to have a seizure, I just return home and go to sleep – (Peter).

When I realise I am about to have a seizure, I enter into the room and sit down for a while and then it goes away – (Rose).

Now when I notice I am about to have a seizure, I find a place to lie down – (Rita).

Those who found themselves in town sought shelter immediately from people close to them when they noticed they were about to have a seizure episode.

One day I went out to the market to buy a few things and I realised I was going to have a seizure ... So I gave my bag to one woman by the road side and went behind her kiosk to lie down on the ground – (Rita).

I felt dizzy and noticed I was about to have a seizure episode. I was in a hurry looking for someone to help me. I met my sister's husband at the market and he allowed me go under his table and rest – (John).

One male participant said he tried as much as possible to get home if he was not far from home.

When I notice I am about to have a seizure, I hurry home and rest. Because when it happens I only have to rest – (John).

4.2.2.2 Lifestyle Changes

Lifestyle changes emerged as one of the coping strategies adopted by participants to cope with living with epilepsy. These changes in lifestyle were either initiated by the participants themselves or through advice from health care workers, family members or friends. The lifestyle changes were mainly in the form of food restrictions.

Food restrictions included foods that participants believed made them have frequent seizures when they took them. These were mostly sugary and starchy foods.

I took precautions about my eating habit ... I have stopped eating some foods. If I eat rice, I have seizures ... I don't eat okro, eggs, fufu and starchy foods – (Peter).

When I take in sweets like coke I have seizures. So I decided not to eat sweets. Sometimes when I take in porridge I do not add sugar – (John).

4.2.2.3 Social Support

Participants used social support as a way of coping with epilepsy. Social support was derived from family members, friends and church members. Social support received by the participants was in the form of encouragement, reassurance and visitation.

My sister reassured me to have patience and not to bother myself about my epilepsy - (Rita).

Sometimes when I am unable to attend church service, they send some church members to check on me to know why I was not able to make it to church. They then offer me money to buy medicines and they pray for me – (Ana).

Some friends of the participants decided to stick together with the participants as a sign of solidarity and some family members also drew closer to help with treatment.

After I developed epilepsy, my family rather drew close to me. Through their support, I got a place to sleep in Accra. Otherwise I would have been moving from the Volta region to Accra all the time for my review ... All my friends who got to know that I had epilepsy never moved away from me – (Michael).

Due to the financial difficulties facing most of the participants, family members provided a great deal of support in terms of financial assistance.

My elder brother is now the one taking care of me and my son ... He gives money to buy my medicines – (Ana).

Every month my junior brother gives me some money from his salary to support me – (Rita).

Church members also provided a great deal of support in terms of financial assistance to some participants who were their church members.

If there is something wrong with me, they (church members) will pay me a visit. Then they offer me money to buy medicines and they pray for me – (Ana).

4.2.2.4 Faith in God

One of the coping strategies adopted by the participants was to have faith by putting their trust in God. The participants through prayers believed that God would heal them.

Everything is in the hands of Jehovah God. I do pray before taking the medicines - (Michael).

Most of them had faith in God for healing. As a result of this, the participants committed their illness to God for healing through prayers. This relieved the stress of worrying about their ill health.

It is God that heals. As for brothers and sisters they will take care of you but, it is only God that cures diseases. So if you commit it to God, He is the one who will heal you - (Ana).

Because of the power of God, I believe it is over ... I believe by God's grace it is well with me - (Ken).

One woman believed that because Jesus was able to heal someone from epilepsy in the Bible, she will continue praying to Him and she believed that He was also going to heal her from her epilepsy.

I'm depending on God ... So I pray to God and I believe that He will heal me because He has done it for others. Even in the Bible, they brought a boy suffering from epilepsy to Him and He was able to heal the boy so, my hope is that God will heal me – (Mabel).

4.2.2.5 Conceal Diagnosis

Concealment of diagnosis also emerged as one of the coping strategies adopted by few of the participants. This strategy was adopted in order to avoid the stigma and discrimination associated with epilepsy. One participant declined to tell his lover about his condition so that she will not leave him.

I did not tell her (lover) about my epilepsy because it is a kind of illness that when I inform anyone, they wouldn't want to come to me (John).

Even among relatives, some participants only kept knowledge about their diagnosis of epilepsy within the nuclear family.

As for my relatives it is only my mother and my father who know about this illness (Miriam).

4.2.2.6 Thinking and Worrying

Thinking and worrying was one of the ways participants responded to the challenges of living with epilepsy. Thinking and worrying was centred on the illness itself and the treatment and cure for the illness.

Sometimes when I have seizures I think a lot – (Peter).

I think so much about this illness to the extent that now I don't know what to do ... The thought of this illness worries me a lot – (Rita).

Some had thoughts centred on how to find cure for their illness.

As for this illness, all that I think about is for it to be cured. If you are sick, the only concern that you have is for the sickness to go ... I usually think about how to get rid of this disease - (James).

One participant however, indicated that he did not worry so much about his illness but, rather thinks about his employment.

I don't worry about this illness ... I don't think about it. All I care is to get some work to do. When I get work to do, I don't even think about this illness at all – (Ken).

4.2.3 Health Outcome

Health outcome represents the successes or failures of coping strategies adopted by PLWE to deal with the challenges associated with living with epilepsy. This theme is also consistent with the CSM. However, the subthemes that emerged from health outcome were as a result of content analysis of the data. These were positive health outcomes, negative health outcomes and adjustment at work.

4.2.3.1 Positive Health Outcomes

Positive health outcomes were in the form of a reduction in the severity and frequency of seizure episodes in response to treatment. Some participants explained how the

seizure episodes used to be frequent but with treatment they now experienced less frequent seizures.

The way it used to happen at first, now it does not happen that way ... I have noticed that the frequency of the seizures has reduced and I believe the seizures will soon stop. At first I can have seizures for about twenty times in a day but, now it happens only once in a month – (Miriam).

The way I used to have the attack at the beginning, now it has changed ... at first I do have the seizures continuously but now it has reduced – (Michael).

I do not have seizures frequently as it used to occur. It has been a long time since I had a seizure - (Ana).

Some of the participants directly attributed the positive outcomes to continuous intake of medicines.

If I take the medicines, I realize that my condition is improving gradually – (Rose).

I have noticed that because of the medicines I am taking, the severity of the seizures has reduced – (Miriam).

Positive outcomes were also described in terms of a reduction in the severity of the signs and symptoms associated with the seizure episodes.

At first I used to fall to the ground or even hit my head against something and get injured most of the time but, now it has reduced – (John).

I do not fall down any more when I have a seizure. I rather become very dizzy and have tremors when I lie down – (Ken).

At first I used to have seizures every night and I soil myself with urine. But now it does not happen every night ... I am grateful to God that the severity of the seizures has reduced - (Rita).

One woman who used to have severe headaches after each seizure episode reported that she did not experience the headaches anymore.

At first after it (seizure episode) happens, I used to have severe headache but, now it has stopped – (Rose).

As a result of this, the negative emotions such as fear and anxiety associated with the seizures were now reducing.

I do not fear anymore – (Rose).

Nowadays when I go out, I don't fear anymore – (John).

Furthermore, certain restrictions that the participants used to place on themselves such as restrictions from social gatherings and restrictions from certain foods that were believed to trigger seizure episodes were now being reduced due to the reduction in the severity and frequency of seizures.

Now I can go anywhere I like. Wherever they are playing some music, I can go over there – (Rita).

I had problems with taking sugary foods. Now when I take a little sugar, I am okay unlike earlier where I used to have seizures after taking sugary foods like coke – (John).

4.2.3.2 Negative Health Outcome

Negative health outcome was in the form of worsening of one's condition. A few of the participants described their seizure episodes as more frequent as compared to how it used to be at first.

I was young when I developed this sickness (epilepsy). At that time it was not as bad as it is now. But after I grew up, the seizures have become more frequent – (James).

4.2.3.3 Adjustment at Work

Adjustment to work emerged as one of the health outcomes associated with living with epilepsy. Adjustment to work evolved from learning how to live with epilepsy. A few of the participants made certain changes with regard to their work situation in order to

make work conducive and safe for them to do. This took the form of resigning to less demanding and easy-to-do jobs.

At the time the illness begun I had my own business. So I realized that, if this sickness becomes serious it will affect me at work ... So I made a kiosk at my place and sold fruits - (Rita).

Others took certain precautions such as avoiding certain situations that may put them at risk of serious injury or death in the event of a seizure episode at work. One participant who was a plumber avoided climbing heights throughout the dispensation of his plumbing duties so as to avoid any severe injury that may arise as a result of falling from a height during a seizure episode at work.

As part of my work I climb heights. When I am up there and I have a seizure I can fall from that height and sustain serious injuries or die. So I stopped climbing – (Ken).

4.3 Summary

In summary, this study employed the Leventhal's CSM to explore the personal experiences of PLWE in the Accra Metropolis and how they coped with the disease. Participants labelled epilepsy as a disgraceful illness. Illness representations were described in terms of beliefs about identity, cause, timeline, consequences, cure and control, illness coherence, and emotional response to epilepsy which were in line with the sub themes of the model. Coping methods included problem focused coping, lifestyle changes and psychosocial support and health outcomes comprised of negative and positive outcomes and adjustment to work. These sub themes under coping methods and health outcomes were derived from content analysis of the data.

CHAPTER FIVE

DISCUSSION

5.0 Introduction

This chapter presents a discussion of the findings presented in the previous chapter. The current study focused on the experiences of living with epilepsy among people in the Accra Metropolis and how they coped with the disease using Leventhal's Common Sense Model (CSM). A critical analysis of the findings and comparison of the findings with existing literature from previous studies have been carried out in this chapter. The discussion was done under the three main themes of the CSM - Illness representations, coping with epilepsy and health outcomes.

5.1 Illness Representations

Study findings on illness representations revealed that epilepsy was labelled as a shameful illness by the PLWE. This is because participants experienced sudden seizure episodes in public places such as church, mosque, market and school in the full glare of the public, including friends and unsuspecting persons. This was shameful and made them feel disgraced. This showed that the discomfort and embarrassment associated with having seizures in the full view of the public was a very shameful and humiliating experience for the participants. Similarly, Hosseini et al. (2013) posited that PLWE feel a sense of indignity and low self-respect when onlookers stare and make contemptuous glances at them when having an epileptic seizure. This makes PLWE have a negative perception about how others think of them - a phenomenon described by Scheff (2003) as shame. Consequently, the shameful experience of having seizures in public was associated with the label given to epilepsy as a shameful illness by the participants.

The negative label attached to epilepsy in this study was a contributory factor to the spoiled identity of PLWE. This made PLWE perceive themselves as unworthy members of the society. This confirms the finding of Ratty et al. (2009) where the identity linked to epilepsy was shame and PLWE felt ashamed of themselves as different. Moreover, the spoiled identity associated with being diagnosed with epilepsy places additional stress and burden on the patient (Renwick, 2013).

As a result of this, the participants felt shy when they met people who saw them having seizures in public. Some participants decided to remain at home for some time due to the shame and embarrassment they felt after having seizures in public. The shame and embarrassment of having seizures in public made the participants lose self-confidence and shy away from others. This is consistent with Kılınç and Campbell (2009) who found that being diagnosed with epilepsy affected one's confidence, making PLWE to remain at home in an attempt to avoid or reduce social contacts so as to avoid the embarrassment of drawing people's attention to themselves during a seizure episode in public. This is also consistent with the findings of Ratty et al. (2009) where PLWE felt so ashamed after having seizures in public to the extent that they refused to visit public places and felt like hiding themselves or becoming invisible. A few of them soiled themselves with urine during seizure episodes. This confirms Brigo et al. (2013) that the sudden loss of control body functions and senses may lead to incontinence due to nature of epilepsy. This caused further shame and embarrassment to PLWE.

The shame of living with epilepsy - a disgraceful illness, was compounded with the stigma associated with epilepsy. According to De Boer (2010), PLWE face stigma and discrimination from the society which is a violation of their human rights, thus preventing them from being properly integrated into the society. In this study, participants experienced various stigmatising attitudes put up towards them by family

members, friends and neighbours. These included disrespect and mockery. This is described by Jacoby (1994) as enacted stigma. This tallies with the findings of Hills (2007) where people mocked, gossiped, avoided the company of PLWE and portrayed them negatively. Others avoided and isolated themselves from the participants due to fear of contracting epilepsy from them. These findings are in agreement with work done by Renwick (2013) who found that some people avoid PLWE for fear of contracting epilepsy from them. According to Engel et al. (2008), this attitude of avoiding PLWE is mainly due to ignorance on the part of the society.

However, some friends and family members of PLWE who were concerned about their condition felt pity and drew closer to help, and this strengthened their relationship. According to Untas et al. (2011), social support for persons suffering from chronic illnesses strengthens relationships and improves upon the person's Quality of Life (QoL). Contrary to this, findings from Wang et al. (2015) revealed that Chinese patients with epilepsy reported less family cohesion and less emotional and instrumental support from their family. However, in Zambia, some Women Living with Epilepsy (WLWE) had supportive families where as others faced extreme rejection from their families. Any of these responses has an effect on one's social and economic wellbeing (Birbeck et al., 2008).

In this study, most participants reportedly became unconscious and fell down during seizure episodes. These types of seizures are usually termed as generalized seizures and is usually accompanied by tonic-clonic movements of the limbs (EF, 2009). Some participants were unaware of the signs and symptoms of seizure they experienced during seizure episodes. They either realised they have had a seizure after waking up to see themselves dirty and bruised or were told by relatives and/ or friends who witnessed these seizure episodes. This shows that the PLWE were not always aware of the seizure

episodes they experienced. This is mainly due to a disturbance of consciousness from the seizures (Blumenfeld & Meador, 2014). This confirms the findings of Hoppe et al. (2007) in Germany where PLWE were unaware of some of their seizure episodes and were unable to give account of all the seizures they had.

Triggers of seizure episodes identified by the participants included being in a bad mood, thinking a lot, eating of sugary foods, having the urge to defecate or urinate and lack of sleep. Apart from sleep deprivation, these triggers are generally different from common triggers or seizures such as intake of alcohol, nicotine, withdrawal from AEDs, stress and infections (Holland, 2014). Participants also experienced palpitations, dizziness and tremors as warning signs of an impending seizure. Although seizure episodes are usually sudden and unannounced (Searson, 2008), PLWE who notice these triggers and signs are those who have lived with the disease for quite some time and are able to tell how their bodies respond to an impending seizure.

A few of the participants attributed their epilepsy to physical causes such as hunger and starvation. These cause malnutrition which may be a cause of epilepsy due to micronutrient deficiency (Johnson, 2001). However, hunger and starvation may actually be consequences of epilepsy due to stigmatizing attitudes against PLWE (Crepin et al., 2007).

Majority of the participants believed that their epilepsy had a spiritual cause. Some consulted spiritualists and pastors who proclaimed that their epilepsy was caused by evil spirits. Whilst others believed that it was someone with evil intentions against them who was indirectly afflicting them with epilepsy spiritually, due to envy for their bright future. This depicts certain Ghanaian traditional and cultural beliefs where chronic illnesses such as epilepsy are attributed to spiritual causes such as acts of witchcraft and

sorcery and evil work of the devil (De Graft Aikins et al., 2012). This situation is common in many ancient and primitive societies, including Africa, where epilepsy is usually seen as a bad omen and is attributed to sin and demonic possession (Engel et al., 2008). This contradicts the findings of Green et al. (2004) where psychological and physical factors such as stress, head injury and heart problems were rather indicated by the participants as causes of their epilepsy.

Some PLWE in this study had no idea about the cause of their epilepsy. As a result of this, they did not really understand how their epilepsy came about. According to Renwick (2013) the causes of most cases of epilepsy are unknown however, it can be caused by head trauma, tumours, inherited conditions, strokes, brain cancer, drug and alcohol misuse, and infection of the central nervous system.

A few of the participants were unable to tell how long their seizures would last after waiting for a long time without cure. This suggests that with time the reality of the chronic nature of epilepsy tends to dawn on the sufferers which might make some lose hope (Räty & Wilde-Larsson, 2011). On the other hand, most of them /believed that epilepsy was a short term illness. This gave them hope and more expectations for cure. This suggests that PLWE who perceived the illness as a short term illness had more hope for cure where as those who realised it might take longer than expected had less hope. This confirms the finding of Räty et al. (2007) where feelings of despair among PLWE were related to epilepsy as a lifelong illness.

Study findings on beliefs about consequences of epilepsy showed that PLWE experienced various forms of injuries due to fall from seizures. Some fell into gutters and on the ground and sustained bruises and sores whilst others got burnt by fire which was evident by the scars on their bodies. This led to bodily pains and headaches. This

confirms Searson (2008) that seizures occur very suddenly and can cause head or face injuries because they happen so quickly and the person has no warning to protect him or herself from falling. This also confirms the findings of Kariuki et al. (2014) where PLWE in Africa were found to experience burns and head injuries from seizure episodes.

One woman aborted her pregnancies repeatedly as a result of injury from seizures. This may be due to severe physical trauma from falling during seizure episodes. This was also likely to cause fears concerning childbearing. Similarly, Birbeck et al. (2008) noticed fear and ambivalence concerning childbirth among WLWE in Zambia. However, these fears were more than just losing or injuring the unborn child during a seizure episode but also, there were fears of the child being taken away from them after they have given birth.

Due to the nature of the seizures most PLWE were restricted by relatives and friends from cooking or getting close to sources of fire and handling electrical gadgets. These were attempts to protect them from severe injury in the event of a sudden seizure episode. Others were restricted from social gatherings such as parties for fear of having seizures in public. This confirms Gauffin et al. (2011) that seizures impose further restriction on PLWE. A similar response to seizures was reported by Hills (2007) where PLWE became socially withdrawn and avoided taking part in social events.

Repeated seizure episodes at work disrupted the work of some PLWE. Others had to stay at home for treatment and to avoid getting injured at work from seizures. Some were also sacked from work by their employers after they had seizures at work. These revelations are consistent with the findings of Scambler (2011) that PLWE face problems such as being rejected by an employer or discrimination in the form of actual

termination or refusal of employment. As a result of this the participants had financial challenges forcing some of them to rely totally on relatives and others for financial support. This is likely to end up affecting their overall QoL. To buttress this point, Hosseini et al. (2013) posited that epilepsy poses a lot of restriction in the lives of PLWE in many countries. Among these are restrictions to job opportunities and gaining financial security, thereby pushing them to depend on others and become a burden to the family and the community at large.

Frequent seizure episodes also disrupted school activities making some PLWE to stop schooling midway for treatment. Thus some students who have epilepsy may miss classes or may not be able to take part in certain school activities due to their seizures. This confirms O'Dell et al. (2007) that recurrent seizures cause a lot of disruptions which can affect the school activities of PLWE. In a similar finding, Kariuki et al. (2014) noted a lack of education among some PLWE which was more common in children with epilepsy than in adults. Others had their memory affected and could neither learn nor understand anything that was thought in school. This is an indication that their cognitive function had been affected. This can be linked to the finding of Mung'ala-Odera et al. (2008) where most (65%) of children with epilepsy who were neurologically impaired had cognitive impairment. This confirms Scambler (2011) that epilepsy can lead to cognitive impairment.

Consequently, monies that could have been used to pay school fees were rather used to buy AEDs and seek treatment for epilepsy. This is an indication of the huge economic burden that the treatment of epilepsy has on the lives of PLWE and their family (Liu et al., 2013). Using monies intended to pay school fees to buy medicines impedes the education and career development of PLWE (Jacobs et al., 2009).

Epilepsy affected the love relationship of majority of the participants. Two women got impregnated by their lovers but the men refused to marry them. This showed that although the men enjoyed having sexual relationship with the women they were not willing to commit themselves to a marriage relationship with them. The men abandoned the women and their children. This is not different from the situation in Zambia where women with epilepsy found it difficult to have a life partner whilst those who got married were eventually abandoned by their husbands (Birbeck et al., 2008). One woman was maltreated by her in-laws and finally thrown out of her matrimonial home. This can be linked to stigmatizing attitudes against PLWE. This confirms Scambler's (2011) depiction of enacted stigma against PLWE whereby they are displaced or discriminated against due to unacceptable differences placed on them by the society.

With regard to the male participants, their lovers quitted the love relationship after finding out that they had epilepsy. This made some lose hope of ever getting married. This inevitably denied them the opportunity to live their normal lives and fulfil normal social roles. A similar view was expressed by Gauffin et al. (2011) that PLWE find it difficult to make choices in life such as having children and that, most of them are not able to fulfil their normal social roles and obligations. This also affects the QoL of PLWE (Choi et al., 2011). This suggests that PLWE were less likely to be married due to difficulty in finding a life partner or staying in marriage. This is consistent with the findings of Karuiki et al. (2014) that male and female adults living with epilepsy were less likely to be married.

Only two of the participants (one man and one woman) had a positive love relationship and enjoyed a peaceful marriage life despite their epileptic seizures. These were participants whose partners understood and accepted them as people suffering from any normal disease and were able to give them the support they needed. As a result of this,

their epilepsy did not interfere with their relationship with their partners. In a similar finding in the UK by Sarea, Rawnsleyb, Stonemanb and Duncana (2007), most of the participants with epilepsy explained that epilepsy did not interfere with their relationship with their partners. The difference here is between two cultures – Europe and Africa, where most PLWE in Europe do not have their love relationships affected so much by epilepsy where as in Africa, most PLWE have their relationship with their partners affected.

Study findings on beliefs about cure and control of epilepsy showed most of the participants had positive expectations with regard to cure and control of their seizures. They expressed hope and believed in God for cure. Others were confident that their medications had put their seizures in control. This is consistent with the findings of Rätty et al. (2007) where in their quest to illuminate the impact of epilepsy on daily life in young adulthood, participants expressed hope and confidence that as long as they were on AEDs, they felt safe. Only one participant had the opinion that not all sicknesses were curable and as such was not all that concerned about any expectation for total cure. This suggests that he had accepted the fact that his epilepsy had no cure and was ready to go on with treatment to manage the signs and symptoms of his seizures. This can be linked to the finding of Rätty and Wilde-Larsson (2011) where some PLWE tend to accept the condition as part of their daily life and try to live their lives to the fullest.

Fear, anxiety and sadness were some of the emotions expressed by the participants in response to their seizures. They felt anxious about the frequency of their seizures, injuries and having seizures in public. This confirms Mensah et al. (2007) that anxiety and depressed mood often coexist among PLWE and that anxiety is associated with increased seizure activity and seizure severity. Moreover, the unpredictable nature of

the disease also creates some anxiety among PLWE (Jacobs et al., 2009). In addition to that, Wang et al. (2015) also reported higher levels of anxiety and depression among Chinese PLWE.

Others felt sorry for themselves and were often unhappy. Most of the time the chronic and disturbing nature of the disease makes PLWE feel demoralised. As a result of this, they have a pessimistic view about life and this affects their mood. This is consistent with Rätty et al. (2007) who found that some PLWE felt sad because they could not maintain the same levels of energy and happiness as others. This also confirms the existence of depressed mood among PLWE (Wang et al., 2015; Mensah et al., 2007).

5.2 Coping with Epilepsy

In an attempt to treat their seizures, some PLWE took orthodox medicines whilst others took herbal preparations. The treatment options selected may be the ones readily available to them or the ones they believed were potent enough to cure their epilepsy. Some of them had free supply of medicines whilst others had to buy their own medicines when there was shortage of free medicines. However, they were committed to their drug regimen. This commitment may be motivated by a strong desire for cure for their epilepsy. This commitment to drug regimen may also be as a result of seeing some form of improvement in their condition (Becker & Maiman as cited in Eatock & Baker, 2007). Contrary to this finding, PLWE in rural Zambia did not show much interest in prescribed AEDs (Birbeck, 2000).

Only one person stopped taking her AEDs because she did not see any improvement in her condition. This might be due to loss of hope in the effectiveness of the AEDs.

According to Packham (2009), the issue of non-compliance to medication occurs among some PLWE is due to the long duration involved in treatment. Usually, patients

who perceive their medications to be effective adhere more to their medications as compared to those who perceive their medications not to be effective (Becker & Maiman as cited in Eatock & Baker, 2007).

In this current study, some PLWE used herbal medicines for a while and stopped. This was after they realised it was no longer working for them. Similarly, Mushi et al. (2011) found that in Tanzania, PLWE sought alternative treatment when they do not see any improvement in the frequency or severity of seizures. However, some PLWE in this study combined herbal medicines with orthodox medicines with the belief that it will work better for them. Others also combined spiritual and physical treatment interventions. This is also similar to the findings of Mushi et al. (2011) where majority (93%) of PLWE in Tanzania sought two or more treatment options for epilepsy, including faith healers (thus prayer groups), traditional healers and modern health facilities. Similar studies in Zambia (Birbeck, 2000) and Sudan (Mohammed & Babikir, 2013) show that in addition to taking AEDs, PLWE also add traditional and spiritual forms of treatment to it.

Most of the participants in this study sought spiritual intervention through individual prayers and seeking prayers from pastors or spiritualists or both. Spiritual intervention was motivated by the belief that prayers provoked divine healing from God. The participants had faith that God would heal them and committed their illness to God through prayers. Similarly, among South Asian communities in the UK, the belief that epilepsy is caused by evil spirits made PLWE seek religious forms of healing, which were mainly in the form of individual prayers or turning to religious healers for help (Ismail et al. 2005).

In their quest for spiritual help, some PLWE in this study had to pay huge sums of money or provide livestock as payment to pastors and spiritualists for prayers and spiritual intervention. A similar observation was also made by Mushi et al. (2011) in Tanzania where all participants who had been to traditional healers had to sell cows, goats, or maize or borrow money from their relatives to meet the cost of services provided by the traditional healers. Some of the PLWE in this study were given oil to smear on their bodies before going to sleep, drink soda water and also have water sprinkled on them during a seizure episode. In similar study by Mohammed and Babikir (2013) in Sudan, spiritual treatment for epilepsy was rather in the form of incantations, spitting cure and the use of incense for rituals. This is an indication of some of the many ways that spiritualists use in healing.

Apart from the direct epilepsy treatment methods being used by the PLWE, they also adopted certain measures to control and reduce the severity of the seizure episode and to avoid any injury. In response to warning signs of an impending seizure episode, the participants sat or lay down to avoid any form of injury from a fall and to reduce the severity of the seizure episode. Others hurried to get home if they were close to their homes. In a similar study, Rätty and Wilde-Larsson (2011) found that in response to an impending seizure PLWE tried to control the situation to avoid injury. This included stopping whatever they were doing and finding a place to lie down. These were behaviours that might have evolved through learning from their epilepsy experience or through advice from health workers.

Furthermore, some participants made certain changes in their lifestyle by avoiding sugary and starchy foods which they believed triggered their seizure episodes. This indicates that these participants were able to identify the triggers of their seizures and tried to avoid them. All these depict concerted efforts directed towards making

adjustments in life to promote one's health. This can be linked to the finding of Kılınc and Campbell (2009) where after learning more about epilepsy through their own epilepsy experiences, the participants tried to avoid certain triggers in order to control their seizures. Furthermore, Rätty and Wilde-Larsson (2011) also found that after identifying situations that can trigger their seizures, PLWE tried to avoid them all in an attempt to control the frequency of their seizures. These changes indicate adaptation on the part of PLWE to their condition.

Moreover, social support from family members, friends and church members in the form of encouragement, reassurance and visitation helped PLWE to cope well. Family and church members also provided financial assistance to the participants. These financial challenges were as a result of lack of employment and poor income (Kobau et al., 2008). Due to the fact that some of them were not working whilst others had less lucrative jobs, financial assistance from family and church members helped them to make ends meet and cope with the financial challenges facing them.

In order to avoid the stigma and discrimination associated with epilepsy, some PLWE kept their diagnosis a secret. By so doing PLWE try to avoid situations in which their condition can be disclosed (Rätty & Wilde-Larsson, 2011). Such strategies adopted by PLWE to conceal their diagnosis rather make them put themselves in a disadvantaged situation termed as felt stigma, which is more disruptive to the lives of PLWE than enacted stigma (Scambler, 2011).

However, a few other PLWE resorted to thinking and worrying about their epilepsy and how to find cure for it. This was because the disruptive and chronic nature of seizures in the lives of PLWE inevitably made them worry so much about ways to free themselves from the disease. This is similar to the findings of Choi et al. (2011) where PLWE

expressed worry over having seizures. Moreover, the spoiled identity associated with being diagnosed with epilepsy places additional stress and burden on PLWE (Renwick, 2013).

5.3 Health Outcome

A reduction in the severity and frequency of seizure episodes was one of the positive treatment outcomes that PLWE experienced. Some also experienced a reduction in the severity of the signs and symptoms associated with the seizures. Some of them associated this with strict adherence to drug regimen. This can be linked to the findings of Green et al. (2004) where PLWE attributed improvement in their condition to their own efforts to manage the condition. This led to a reduction in the fears and anxieties that the PLWE in this study had about their seizures. This confirms the findings of Kılınc and Campbell (2009) that a reduction in seizure frequency appeared to resolve the issue of feeling odd and rejected among PLWE.

In response to a reduction in the frequency and severity of seizure episodes, the participants who restricted themselves from certain foods because they triggered their seizures began eating them without any consequent seizure episodes. Others who avoided social gatherings for fear of having seizures in public felt free to go out. This clearly indicated a significant improvement in the condition of these participants. However, others experienced negative outcomes because their condition rather got worse. Their seizure episodes occurred more frequently as compared to the onset of the illness. This indicates repeated occurrence of their seizures (Heward, 2009).

Some PLWE who were workers managed to adjust to their work situation by avoiding certain situations that may put them at risk of serious injury or death in the event of a seizure episode at work. This is an indication of learning from the experience of living

with epilepsy as described by Kılınc and Campbell (2009). Some participants exhibited this by taking up less demanding and easy-to-do jobs such as store keeping whilst a plumber avoided climbing heights to protect himself from falling from a height during a seizure episode at work. This is an indication of the changes that PLWE make in their lives in order to adapt to the disease condition (Räty et al., 2007).

5.4 Conclusion

The content of this chapter showed that PLWE put up certain measures to cope in response to their health threat – epilepsy. These responses were based on their illness representations of the illness which were all in line with the CSM. Almost all illness representations concerning beliefs about the identity, causes, consequences, timeline, cure and control, illness coherence and emotional response to epilepsy among the participants were similar to findings from previous studies.

Although the coping behaviours and strategies employed, with regard to problem focused coping, were a combination of orthodox, traditional and spiritual interventions, the approaches were sometimes different as compared to findings from previous studies. Health outcomes of the coping behaviours and strategies showed that most of them were successful. There were a few negative health outcomes characterized by worsening of the seizures which was likely to be due to the nature of the seizure condition and not a reflection of poor coping strategies.

CHAPTER SIX

SUMMARY AND CONCLUSION, IMPLICATIONS TO NURSING, LIMITATIONS OF THE STUDY AND RECOMMENDATIONS

6.0 Introduction

This chapter comprises a summary of the whole research and conclusion drawn from the findings of the study. Study implications to nursing practice, education and research have also been outlined. It also includes limitations encountered during the study and recommendations based on the findings of the study.

6.1 Summary

Epilepsy is one of the common chronic neurological disorders worldwide and affects nearly 10 million people in Africa (WHO, 2012). Its prevalence is high in poor countries especially within sub Saharan Africa. The incidence of epilepsy in Ghana is believed to be high however, most of the cases go unreported. Majority of epilepsy syndromes are diagnosed in childhood or adolescence. Living with epilepsy is characterised by a number of challenges. The chronic and unpredictable nature of the disease and the stigma associated with it leads to restricted social life and lowered self-concept. In Ghana, the stigma associated with epilepsy is mainly as a result of traditional belief systems which attribute epilepsy to demon possession and witchcraft including fear of contracting the disease. All these affect the overall QoL of PLWE.

This was a qualitative study with a descriptive-exploratory design that was carried out to explore the personal experiences of PLWE in the Accra Metropolis and how they coped with the disease. The Leventhal's Common Sense Model (CSM) was employed to guide the research. In all, 13 PLWE from 18 to 40 years of age within the Accra Metropolis took part in the study. Face-to-face in-depth interviews were conducted

using a semi-structured interview guide. The interviews were recorded with a digital audio recorder and transcribed verbatim. Using thematic content analysis approach three main themes namely; beliefs about epilepsy, coping with epilepsy and health outcomes were derived from the constructs of the model and sixteen sub themes (seven from the model and nine through content analysis) emerged.

With regard to beliefs about epilepsy, participants labelled epilepsy as a disgraceful illness. Signs and symptoms of seizure episodes were described as falling down unconscious and having uncontrollable body movements. However, most of them were informed about the nature of their seizures by onlookers. Just a few were aware of what went on during their seizure episodes. Epilepsy was attributed to physical and spiritual causes although some participants said they had no idea about the cause of their epilepsy. Most of them believed that epilepsy was a short term illness although all of them have lived with epilepsy for quite a long time. Participants believed that their seizures had caused them to sustain physical injuries and has affected their education, work and relationships. Majority of the participants believed they will be cured however almost all of them lacked understanding about epilepsy. Fear, anxiety and sadness were the common emotions concerning seizures that were expressed by the participants.

Coping methods associated with living with epilepsy took the form of seeking medical, herbal and spiritual treatment. Other coping methods were lifestyle changes, seeking social support, trusting in God, thinking and worrying and concealment of diagnoses of epilepsy. Health outcomes took the form of both positive and negative health outcomes and, adjustment to work. Positive health outcomes were in the form of a reduction in the severity and frequency of seizure episodes in response to treatment; and negative health outcomes were in the form of worsening of one's condition. People living with

epilepsy adjusted to their work situations by ensuring certain safety measures that made the work environment safe and conducive for them.

6.2 Implication to Nursing (Practice, Policy, Education and Research)

Nursing practice: Community psychiatric nurses should collaborate with community health nurses to follow up on PLWE in their respective communities to provide education and counselling services to PLWE. This is because epilepsy is not a psychiatric but a neurological condition which should not be left in the hands of community psychiatric nurses alone for follow up. This will serve as an avenue for PLWE to gain knowledge about their condition and readily available health in their respective communities.

Policy: The Ghana Health Service should develop a policy that would help incorporate herbalists and spiritualists who provide treatment for PLWE into the primary health care programme by recognizing, monitoring and providing them with the necessary assistance in the form of training in first aid management of seizures, follow up and referral to improve upon the care they give to PLWE.

Nursing education: Nurse educators should incorporate on epilepsy into the community health nursing programme to equip community health nurses with the necessary knowledge and skill to attend to PLWE in the community.

Nursing research: The findings in this study revealed that PLWE seek treatment and some even combine orthodox medicines with herbal preparations and spiritual intervention. The findings therefore point to the need for further research into the practices and effectiveness of treatments given by herbalists and spiritualists who claim to have treatment for PLWE. This will help provide greater understanding into their

practices and means by which they can also be incorporated into the primary health care system.

6.3 Limitations

Since most of the interviews were done in “Twi”, the possibility of some slight change in meaning during the process of translating from “Twi” into the English language cannot be completely ruled out. This was addressed by discussing the “Twi” interviews with someone competent in the “Twi”.

Criteria for screening to eliminate PLWE with co-existing mental sub normality was not based on any scientific aptitude test but rather based on previous medical review and appraisal from the community psychiatric nurses. Therefore the possibility of a participant being mildly sub normal which might affect recall of events in his or her report during the interview cannot be entirely ruled out. However, the researcher also interacted with the participants for a while before the interview to ensure that the person did not show any sign of mental sub normality.

6.4 Field Experiences

The experiences the researcher had on the field were interesting however; they were not without some challenges. The researcher never expected the data collection process to take that long, but it did. Getting participants who actually fit into the criteria for inclusion took a rather longer time than expected.

Although most of the interviews were originally intended to be carried out in the homes of the participants, a visit to the homes of some of the participants showed that most of the homes were actually not conducive enough to conduct a successful interview. As a

result of that nine out of the thirteen interviews were carried out at the various offices of the community psychiatric units in the three selected sub metropolis within the Accra Metropolis.

Only three interviews were conducted in the homes of the participants. One interview was conducted at the workplace of one participant who was managing a store on his own. However, this was done in the afternoon where customers less frequently came around, in order to avoid unnecessary interruptions. Tracing of their homes was not difficult because the staff of the selected community psychiatric units accompanied the researcher to the homes of their patients.

Days for conducting interviews in the offices of the various community psychiatry units were on days where office activities were less busy. Therefore the researcher, with the help of the community psychiatric nurses in the selected areas, had to book appointment to meet with the participants in the office at a particular date and time. Sometimes, interviews were conducted on weekends, where there were no office activities on-going. On some few occasions, the researcher had to wait at the office for participants for long hours before they turned up for the interview. This took the research a longer time to get data to the level of saturation.

6.5 Conclusion

The diagnosis of epilepsy, which represents the health threat in the CSM, was disgraceful to the PLWE. People living with epilepsy had their daily activities (school, work and social life) interrupted by the signs and symptoms of epilepsy. Most of them attributed the disease to unnatural causes which indicated a knowledge gap in the actual causes of epilepsy among them. As a result of this, some PLWE consulted spiritualists

and herbalists for treatment. Coping strategies were adopted by the participants in response to the health threat as indicated in the CSM. In general, coping behaviours and strategies adopted by the participants were good and overall health outcomes were positive. These findings will be of good use when planning measures to reduce stigma in epilepsy, increase treatment coverage and improve the QoL of PLWE. These findings mirror the themes and sub themes of Leventhal's CSM of illness representation. This also confirms that the model is suitable for assessing illness representations among people living with chronic diseases.

6.6 Recommendations

Based on the findings of the study, the following recommendations were made:

1. Health care professionals (nurses and doctors) in collaboration with the media should intensify health education campaigns on epilepsy to demystify traditional concepts about epilepsy and help bring Ghanaians towards a greater understanding and acceptance of PLWE.
2. The Ghana Health Service and the Department of Social Welfare should establish a fund that will help provide support to PLWE in the form of capital or job opportunities in order to make them earn a living and improve upon their QoL.
3. Family members and friends of PLWE should provide them with the support and encouragement they need to be able to deal with the burden of living with epilepsy and the stigma associated with the disease.
4. Due to the stigma associated with epilepsy, nurses should endeavour to be non-judgemental and show open acceptance to PLWE in the community.

5. The Ghana health service should ensure a continuous and well distributed supply of subsidized AEDs all over the country to help promote the use of AEDs and prevent health care workers from losing their clients to herbalists and spiritualists.



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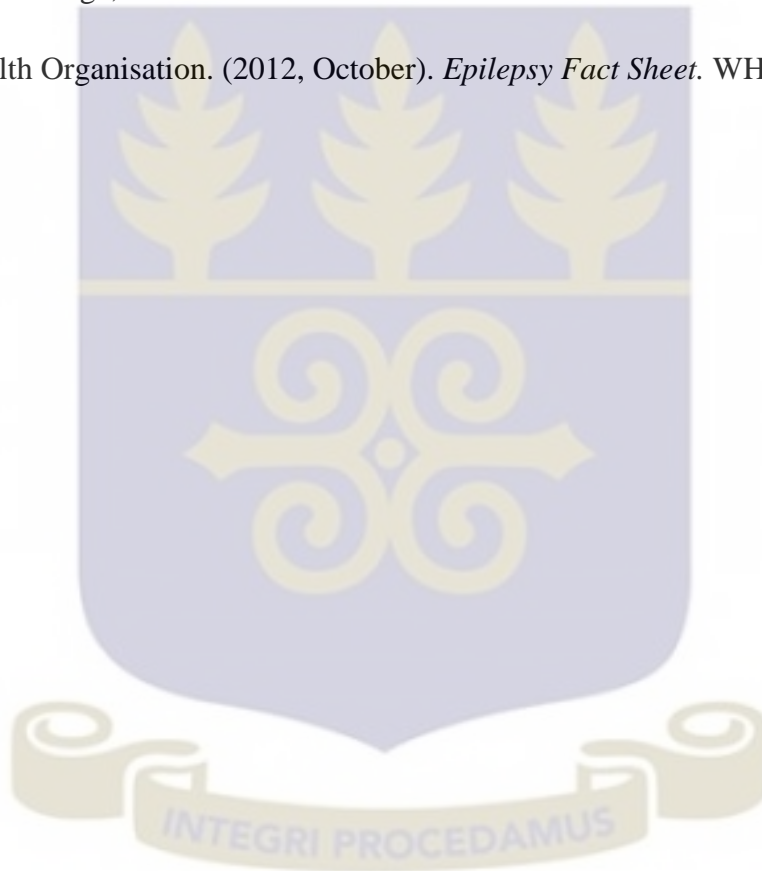
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APPENDIX A: INTRODUCTORY LETTER

**SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA
LEGON**

Telephone: 021-513255 (Dean)
Ext. 6206
021-513250 } Secretary
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P. O. Box LG 43
LEGON, GHANA

Our Ref:.....

Your Ref:.....

9th August, 2014

The Director of Health Service

Accra Metropolis

Accra

Dear Sir,

INTRODUCTORY LETTER

DAVID ATSU DEEGBE

I wish to introduce the above named person who is an M.Phil student of the School of Nursing, University of Ghana, Legon. He is conducting a study on the topic "EXPERIENCES OF PEOPLE LIVING WITH EPILEPSY IN THE ACCRA METROPOLIS". He is seeking your permission to collect data for this research. It will be appreciated if you could give him the needed assistance.

Thank you.

Yours faithfully,

Reverend Alexander Attiogbe
(SUPERVISOR)

Cc: The Nurse In-Charge
Community Psychiatry Unit
Maamobi General Hospital

The Nurse In-Charge
Community Psychiatry Unit
La General Hospital

The Nurse In-Charge
Community Psychiatry Unit
Ussher Polyclinic

APPENDIX B: ETHICAL CLEARANCE CERTIFICATE



UNIVERSITY OF GHANA
ETHICS COMMITTEE FOR THE HUMANITIES (ECH)

P. O. Box LG 74, Legon, Accra, Ghana

My Ref. No.....

20th May, 2014

Mr. David Atsu Deegbe
Department of Nursing
University of Ghana
Legon

Dear Mr. Deegbe,

ECH 079/13-14 EXPERIENCE OF PEOPLE LIVING WITH EPILEPSY AT ASHIEDU KETEKE SUB-METROPOLIS

This is to advise you that the above reference study has been presented to the Ethics Committee for the Humanities and the following actions taken subject to the conditions and explanation provided below:

Expiry Date: 13/11/14
On Agenda for: Initial Submission
Description: 25/04/14
ECH Action: Approved
Reporting: Quarterly



Please accept my congratulations.

Yours Sincerely,

Rev. Prof. J. O. Y. Mante
ECH Chair

CC Director, ISSER

Tel: +233-303933866

Email: ech@isser.edu.gh

APPENDIX C: CONSENT FORM

UNIVERSITY OF GHANA



Official Use only Protocol number

OFFICE OF RESEARCH, INNOVATION AND DEVELOPMENT
Ethics Committee for Humanities (ECH)

PROTOCOL CONSENT FORM

Section A- BACKGROUND INFORMATION

Title of Study:	EXPERIENCES OF PEOPLE LIVING WITH EPILEPSY AT ACCRA METROPOLIS
Principal Investigator:	DAVID ATSU DEEGBE
Certified Protocol Number	

Section B- CONSENT TO PARTICIPATE IN RESEARCH
--

General Information about Research

The purpose of the study is to explore the personal experiences that people who have epilepsy go through whilst living with the disease. This will help me to understand what you think about the disease, some of the difficult situations you go through because of the disease and how you are able to handle these difficult situations. I will have an interview with you concerning your experiences with living with epilepsy. The interview is expected to last for forty five (45) to ninety minutes and it will be recorded. All conversations will be done in English. You will be allowed to sign a consent form before the interview is conducted.

Benefits/Risk of the study

This study may not have any direct benefit to you however, the results may help in the formulation of appropriate policies aimed at addressing the challenges facing people living with epilepsy. It is also hoped that relevant interventions would then be designed with the view of providing support for people living with epilepsy.

This study is not expected to cause any physical, psychological and social harm to you. However, if you experience any discomfort during the interview section, you will be allowed to see a counselor for free counseling.

Confidentiality

You are assured that all the conversations recorded will be kept as private and confidential without access to anyone else except my supervisors. All data including audiotape recordings, field notes of all interviews and other relevant materials will be kept safely under lock. A false name will be used instead of your real name in order to protect your identity and prevent others from tracing any information provided.

Compensation

Your cost of transportation to and from the place of interview will be provided at the end of the interview. You will also be given a snack at the end of the interview.

Withdrawal from Study

Your participation in this study is subject entirely to your own free will. You are not under any mandate to take part in this study. You can opt out of the study anytime you wish to despite signing the consent form. No action will be taken against you for opting out.

You are assured that in case any information becomes available that may be relevant to your willingness to continue participating or withdraw you or your legal representative will be immediately informed.

Your participation in the interview may be terminated in case you become too upset or tired during the interview.

Contact for Additional Information

If you have any other concerns, you can address it to the following;

Reverend Alexander Attiogbe, Lecturer, School of Nursing, University of Ghana

P.O.Box LG 43, Legon

Tel: 0278066255

You can also address the following in case of any research-related harm caused you;

Dr. Lydia Aziato, Senior Lecturer, School of Nursing, University of Ghana

P.O.Box LG 43, Legon

Tel: 0244-719686

Section C- VOLUNTEER AGREEMENT

"I have read or have had someone read all of the above, asked questions, received answers regarding participation in this study, and am willing to give consent for me, my child/ward to participate in this study. I will not have waived any of my rights by signing this consent form. Upon signing this consent form, I will receive a copy for my personal records."

Name of Volunteer

Signature or mark of volunteer

Date

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Name of witness

Signature of witness

Date

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Name of Person who Obtained Consent

Signature of Person Who Obtained Consent

Date

APPENDIX D: INTERVIEW GUIDE**INTERVIEW GUIDE**

You are being invited to take part in a study to explore the personal experiences that people who have epilepsy go through whilst living with the disease. This will help me to understand what you think about the disease, some of the difficult situations you go through because of the disease and how you are able to handle these difficult situations. The interview is expected to last for forty five (45) to ninety (90) minutes and it will be recorded. Thank you.

SECTION A: Demographic Data

1. Age: _____ years
2. Sex Male Female
3. Level of education
 1. No Formal education b. Basic education (Primary/ JHS)
 - c. Secondary education d. Tertiary education
4. Marital Status
 1. Single b. Married c. Divorced
 - d. Widowed e. Cohabiting
5. Employment status
 1. Unemployed b. Self-employed c. Private employee
 - d. Government employee e. Student
6. Religion: Christian Muslim Traditionalist
- Other (specify) _____
7. How long have you lived with the disease? _____ years.

SECTION B: Guiding questions

Beliefs that people living with epilepsy have about the illness

Tell me about this illness from the beginning up till now

What do you think about this illness?

Probe (concern and worries)

In your opinion, what do you think is wrong with you?

What symptoms do you experience?

Probe (severity, frequency)

How will you describe your condition to others?

What do you think is the cause of this illness?

Probe (family history, spiritual, trauma)

How long do you think this condition will last?

Probe (short term or long term)

How do you feel about this illness?

How has this illness affected you?

Probe (physically, education, work, love relationship)

How do people relate to you because of this illness?

Probe (family; friends; general public)

In what aspects of your life has the disease affected?

Probe (education; occupation; marriage)

How will you describe your control over the symptoms of this illness?

What is your belief about whether the condition can be cured or kept under control?

Probe (What role have you played to achieve this?)

Coping with epilepsy

What do you do to treat this illness?

Probe (orthodox treatment; herbal/ traditional treatment; spiritual treatment)

How do you deal with situations whereby people treat you unfairly because of the epilepsy?

Probe (disrespect; rejection; avoidance; denial; intimidation)

What do you think can be done to make you better?

Who or what do you think can help you get better?

Health outcomes of coping strategies adopted by people living with epilepsy

How would you describe the success of the steps you have taken to manage this illness?

Probe (success, failures, expected outcome, actual outcome)

Is there anything else you think it might be helpful for me to know?

Thank you!



APPENDIX E: THEMES AND SUB THEMES

Themes	Sub themes
1. Illness representation (Beliefs about epilepsy)	<ul style="list-style-type: none"> a. Identity b. Causes c. Timeline d. Consequences . e. Cure and control f. Illness coherence g. Emotional response
2. Coping with epilepsy	<ul style="list-style-type: none"> a. Problem focused coping b. Lifestyle changes c. Social support d. Faith in God e. Concealing diagnosis f. Thinking and worrying
3. Health outcomes	<ul style="list-style-type: none"> a. Positive outcomes b. Negative outcomes c. Adjustment to work



APPENDIX F: DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS**[n = 13]**

Label/ Name		Age (Years)	Sex	Education	Marital Status	Employment Status	Religion	Duration of Illness (Years)
1M1	Peter	28	Male	Basic education	Single	Unemployed	Christian	23
2F1	Rose	38	Female	Basic education	Single	Self employed	Christian	18
3F2	Rita	36	Female	Basic education	Divorced	Self employed	Muslim	20
4M2	James	36	Male	Basic education	Single	Self employed	Christian	21
5F3	Ana	29	Female	Basic education	Single	Unemployed	Christian	19
6M3	John	40	Male	Secondary education	Single	Self employed	Christian	36
7F4	Mariam	18	Female	Basic education	Single	Student	Christian	11
8M4	Michael	34	Male	Basic education	Single	Private employee	Christian	11
9F5	Mabel	36	Female	Secondary education	Married	Private employee	Christian	22
10M5	Ken	40	Male	Secondary education	Married	Self employed	Christian	14
11M6	Max	38	Male	Secondary education	Single	Self employed	Christian	30
12M7	Adam	34	Male	Basic education	Single	Unemployed	Christian	32
13F6	Mavis	35	Female	Secondary education	Single	Private employee	Christian	20