

**UNIVERSITY OF GHANA
COLLEGE OF HUMANITIES
DEPARTMENT OF SOCIAL WORK**

**EXPERIENCES OF PERSONS LIVING WITH EPILEPSY IN ACCRA,
GHANA**

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**THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA,
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DECLARATION

I, Michael Donald Donkor, do hereby declare that the research work presented herein is the result of my own investigation under the supervision of Dr. Mavis Dako-Gyeke and Dr. Cynthia A. Sottie. I declare that this work has not been submitted either in part or in whole anywhere. The sources of the works of other scholars used in this thesis have been acknowledged.

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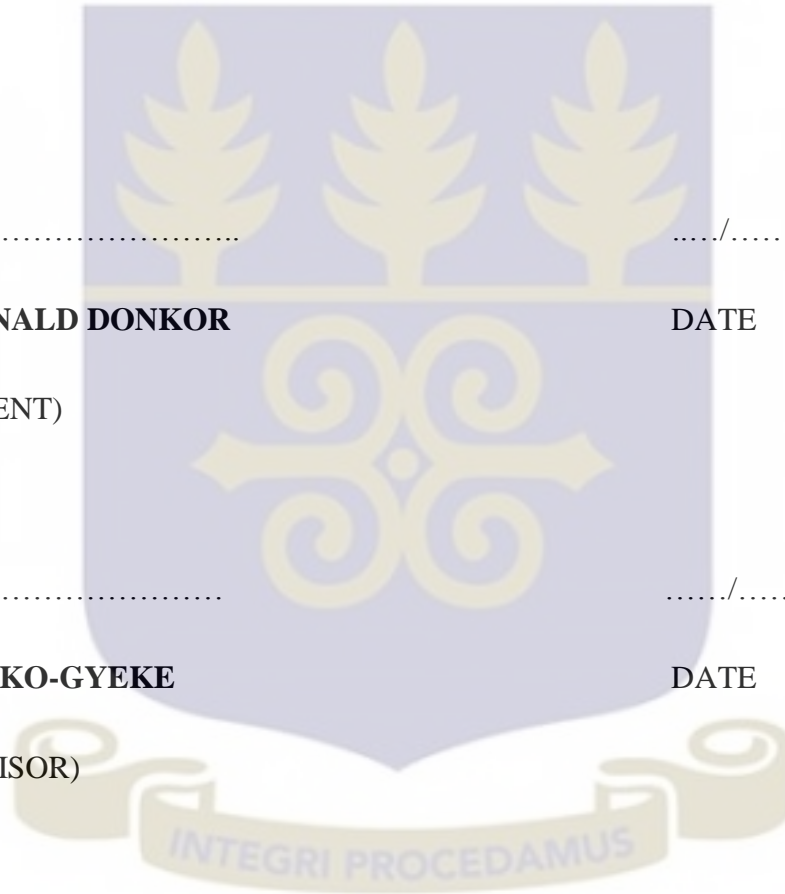
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DEDICATION

This thesis is dedicated to my father, Mr. Harrison Tete-Donkor, Regional Director, Department of Social Development (formerly Department of Social Welfare), Eastern Region for believing in me and urging me to climb higher the educational ladder which has propelled me to this far. Daddy, your contributions in my educational life are immeasurable. I humbly ask God for long life in good health for you.



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LIST OF ABBREVIATIONS AND ACRONYMS

ADEs:	Antiepileptic Drugs
BNG:	BasicNeeds-Ghana
CSOs:	Civil Society Organisations
EST:	Ecological Systems Theory
GHS:	Ghana Health Service
GCAE:	Global Campaign against Epilepsy
ILAE:	International League Against Epilepsy
KPC:	Kaneshie Polyclinic
LEAP:	Livelihood Empowerment Against Poverty
MOH:	Ministry of Health
NHIS:	National Health Insurance Scheme
NGOs:	Non-Government Organisations
PLWE:	Persons Living with Epilepsy
SUDEP:	Sudden Unexpected Death in Epilepsy
WHO:	World Health Organisation

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ABSTRACT

Given that globally, neurological disorders like epilepsy have remained a public health issue, this study explored the experiences of persons living with epilepsy (PLWE) in Accra, Ghana. The study was guided by Bronfenbrenner's (1979) ecological systems theory. The objectives of the study were to: (a) explore the perceptions of PLWE and key informants regarding the disease, (b) identify the challenges faced by PLWE, (c) find out the coping strategies adopted by PLWE and (d) ascertain the kinds of support available to PLWE. A qualitative research design was employed for the study. In-depth individual interviews using interview guides were conducted with twenty participants, comprising of fourteen PLWE and six key informants (two caregivers, two nurses and two officials). Participants were selected using purposive and snow ball sampling techniques. The data was analysed thematically and it was revealed that many PLWE and caregivers perceived epilepsy as a spiritual and curable disease. However, the nurses at Kaneshie Polyclinic and officials of BasicNeeds-Ghana perceived epilepsy as a medical condition. Also, it was found that PLWE faced challenges, such as stigma and discrimination, inability to complete school, unemployment, inadequate healthcare, difficulty finding marriage partners and financial constraints. Moreover, it was found that PLWE coped with the disease by adopting strategies like exclusion and concealment of the disease and involvement in religious activities. Also, evidence showed that there was support available for PLWE through caregivers, government and BasicNeeds-Ghana. Based on the findings of the study, it is recommended that public education on epilepsy be intensified. Furthermore, there is the need to ensure that PLWE have access to improved healthcare. It is also recommended that PLWE are enrolled on the NHIS and LEAP in order to improve their quality of life.

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

Globally, neurological disorders have remained a serious public health concern (World Health Organisation [WHO], 2003). A common, but often neglected neurological condition is epilepsy. It is a neglected disease, particularly in developing and least developed countries as compared to the diseases like malaria, HIV and AIDS, cancer among others (WHO, 2003). As a neurological disorder, epilepsy refers to a group of chronic brain conditions characterised by recurrent epileptic seizures (WHO, 2004). Epileptic seizures are the clinical manifestations (signs and symptoms) of excessive, usually self-limited, abnormal activity of neurons in the brain (WHO, 2004). They epitomise the most common signs and symptoms of brain disorder. Seizures may vary from the briefest lapses or muscle jerks to severe and prolonged convulsions and they may also vary in frequency, from less than one a year to several per day (WHO, 2001). Active epilepsy has been defined as epilepsy that has caused two or more unprovoked seizures on different days in the year prior to the assessment date (WHO, 2004).

The diagnosis of epilepsy requires two elements: a history of at least one seizure and evidence of an enduring alteration in the brain activity (Fisher, Emde Boas, Blume, Elger, Genton, Lee & Engel, 2005). It is not a single disease, but rather an expression of many different brain disorders, and as a consequence investigations and treatment are individualised (Gauffin, 2012). Genetic factors are often likely to play a role, because the underlying cause of epilepsy is primarily genetic (Pandolfo, 2011). Epilepsy is the most common neurological disorder requiring long-term health care contact (Forsgren, 1992). It is a chronic disease that largely influences the

patient's life. Studies from sub-Saharan Africa focus on psychiatry morbidity and factors associated with poor control of epilepsy (Sander & Shorvon, 1996).

One of 21 men and one of 28 women will develop epilepsy during their lifetime (Hesdorffer, Logroscino, Benn, Katri, Cascino & Hauser, 2011). A WHO report estimated that 10 percent of the global burden of brain and mental disorders is caused by epilepsy, calculated in disability-adjusted life years (Global Campaign against Epilepsy [GCAE], 2008). This calculation includes premature deaths and loss of healthy lives due to disability (GCAE, 2008). The WHO noted that while significant, this figure does not include the stigma and social exclusion or the repercussions on the family of PLWE (International League against Epilepsy, 2003).

More than one-third of PLWE continue to have seizures despite treatment (Centers for Disease Control and Prevention [CDC], 2009). Children younger than age two and adults older than age 65 are particularly vulnerable because the risk factors for epilepsy are more common in these age groups (CDC, 2009). About 10 percent of Americans will experience a seizure sometime during their lives (CDC, 2009). In many countries, this disorder is still shrouded in secrecy and patients prefer not to reveal or discuss their condition (Thomas & Nair, 2011).

In many parts of the world, epilepsy continues to be viewed as caused by witchcraft, contagious, and PLWE being possessed by demons and ancestral spirits (Adjei, Akpalu, Laryea, Nkromah, Sottie, Ohene & Osei, 2013; Austin, Shafer & Deering, 2002). In Zambia, much of the population believes that seizures are due to witchcraft and spiritual possession (Birbeck & Rockwell, 2007). Negative social attitudes towards PLWE are often explained in terms of its perceived cause (Sonecha, Noble, Morgan & Ridsdale, 2014). The supernatural element of the aetiology of epilepsy is that it is often viewed as an infectious disease and even a curse from the

gods (Ojinnaka, 2002; Owolabi et al., 2014). In several African countries such as Tanzania, Nigeria and Ghana it is evident that there is reluctance to disclose epilepsy due to fear of stigma and discrimination (Sonecha et al., 2014; Owolabi et al., 2014; Dugbartey & Barimah, 2013).

In Ghana, the issue of public health forms a fundamental approach to health service delivery emphasising primary health care (Twumasi, 2005). Traditional beliefs continue to be central in the way diseases are perceived (Twumasi, 2005). As a result, micro-organisms, malnutrition, and deficiency conditions are not regarded as disease-causing agents (Twumasi, 2005). Rather, causes of many diseases are attributable to acts of antisocial behavior on the part of the patients or close members of their families and witchcraft possession (Twumasi, 2005).

1.2 Statement of the Problem

Despite improved health promotion and some education on neurological disorders like epilepsy, many developing countries, including Ghana are yet to grasp the clinical diagnosis of epilepsy and the experiences of PLWE. World Health Organisation (2003) reported that in both low- and high-income countries, there is history about stigmatisation against PLWE, their families and caregivers. Some of the challenges which limit efforts geared at reducing the burden of epilepsy in developing countries like Ghana are socio-cultural factors which maintain the negative attitudes about the cause and treatment of epilepsy and also reinforce stigma and discrimination (Dugbartey & Barimah, 2013). Traditional medical practices, treatment and consultation with faith and psychic healers are widely accepted in Ghana (Twumasi, 2005). As a result, unrealistic perceptions of causes and treatments for epilepsy could be extremely high (Adjei et al., 2013).

In view of the perceptions about epilepsy, PLWE continue to face challenges in their daily lives in the areas of healthcare, education, employment, marriage and stigma and discrimination.

Many PLWE do not receive adequate medical treatment resulting from lack of medical personnel and medications (WHO, 2005). Persons living with epilepsy have increased medical expenses prior to, and after diagnosis compared to the general population (Jennum, Gyllenberg & Kjellberg, 2011). In Ghana, PLWE are prevented from going to school (Adjei et al., 2013) and those who are in school encounter educational difficulties such learning problems and absenteeism (WHO, 2005). According to Jennum et al. (2011), PLWE have lower rates of employment and those who are employed earn only half of the income of those without epilepsy. Also, PLWE face the challenge of getting married. For instance, in Ghana PLWE are not encouraged to marry for fear of giving birth to children with epilepsy (Adjei et al., 2013) and the married ones face higher rates of divorce (Agarwal, Mehndiratta, Antony, Kumar, Dwivedi, Sharma & Kumar, 2006).

Worldwide, there are more than 50 million of PLWE, 85 percent of whom live in low- and middle- income countries (WHO Ghana, 2015). According to WHO, few of the 34 out of the 50 million PLWE in developing countries receive adequate medical treatment, and an estimated 80 percent to 90 percent receive no treatment (WHO Ghana, 2015). In Ghana, there are over 250,000 PLWE (WHO Ghana, 2015).

Although in Ghana, the exact prevalence of epilepsy is unknown, it is estimated that the prevalence of active convulsive epilepsy is about 102 per 1000 people (Ngugi, Bottomley, Kleinschmidt, Wagner & Kakooza-mwesige, 2013). Nevertheless, it is a major health problem in the country, and the main reason for referral of PLWE for neurological services in the country (Adjei, Akpalu, Nkromah, Song & Nyame, 2011). Almost any brain disorder can cause epilepsy, from inherited causes to post stroke epilepsy (Adjei et al., 2011). In the literature, only 25% to 30% of epilepsy cases have an identifiable cause (Shorvon, 2010).

However, there is paucity of research on the condition in Ghana. Particularly, there are little qualitative studies that capture the voices of PLWE regarding their experiences. This study therefore sought to explore the experiences of PLWE in Accra, Ghana.

1.3 Objectives of the Study

The objectives of the study were to:

1. Explore the perceptions of persons living with epilepsy and key informants regarding the disease in Accra.
2. Identify the challenges faced by persons living with epilepsy in Accra.
3. Find out the coping strategies adopted by persons living with epilepsy in Accra.
4. Ascertain the kinds of support available to persons living with epilepsy in Accra.

1.4 Research Questions

1. What are the perceptions of persons living with epilepsy and key informants regarding the disease in Accra?
2. What are the challenges faced by persons living with epilepsy in Accra?
3. What are the coping strategies adopted by persons living with epilepsy in Accra?
4. What kinds of support are available to persons living with epilepsy in Accra?

1.5 Significance of the Study

It is hoped that, the findings of the study would help policy makers, social workers, school administrators and teachers, Non-Governmental Organisations (NGOs), students and other researchers. The findings will aid policy makers to develop, and implement policies and programmes that will ensure the mainstreaming of PLWE in community and national development. Government will be more abreast with the challenges of PLWE to adequately

resource the psychiatric units where healthcare services are provided. This will help improve the quality of life of PLWE. For NGOs whose areas of interest are geared towards epilepsy issues, the study will provide them with information regarding the problems faced by PLWE in their daily lives. This will help them provide services to assist PLWE in dealing with such challenges to enhance their lives.

The study will help social workers to be well informed on issues of epilepsy. Since they work with communities, the study will help them educate community members on issues pertaining to epilepsy to help change the perceptions and misconceptions people have about the disease and PLWE. It will equip social workers as to how to render psychosocial counselling services to PLWE and their caregivers on the disease to help them cope with the disorder. Also, the study will serve as an advocacy tool for promoting the welfare and interest of PLWE. The study will inform social workers and other human rights activists and NGOs about the challenges faced by PLWE and how they could advocate for their rights in the areas of education, employment, healthcare and marriage to help improve their quality of life.

As part of the stakeholders of PLWE, the study will provide information for school administrators and teachers. This will help them to ensure inclusiveness for PLWE in the educational institutions devoid of stigma and discrimination. This will help PLWE to be able to also complete their levels of education with less difficulty, since they could stay in schools to concentrate on their academic work with support from the school administrator, teachers and their colleague students. Also, the study will provide information for students who are interested in this field. The findings will serve as a guide to researchers and social work students who will undertake similar studies in the field of epilepsy. This will help add up to the scanty research and literature on epilepsy and PLWE in African countries, especially Ghana.

1.6 Definition of Terms

For the purpose of the study, the terms below have been defined for clarity.

Epilepsy: Epilepsy is a neurological disorder characterised by sudden recurrent and unprovoked seizures (Birbeck & Rockwell, 2007).

Seizure: Seizure is what happens to a person living with epilepsy because of abnormal electrical activity in the brain. It is associated with abrupt loss of consciousness, tongue-biting with oral bleeding, loss of control of the bladder or bowel, and sensory or psychic malfunction.

Persons Living with Epilepsy (PLWE): Persons living with epilepsy are people who have recurrent seizures due to an underlying disease of the brain or a brain disorder.

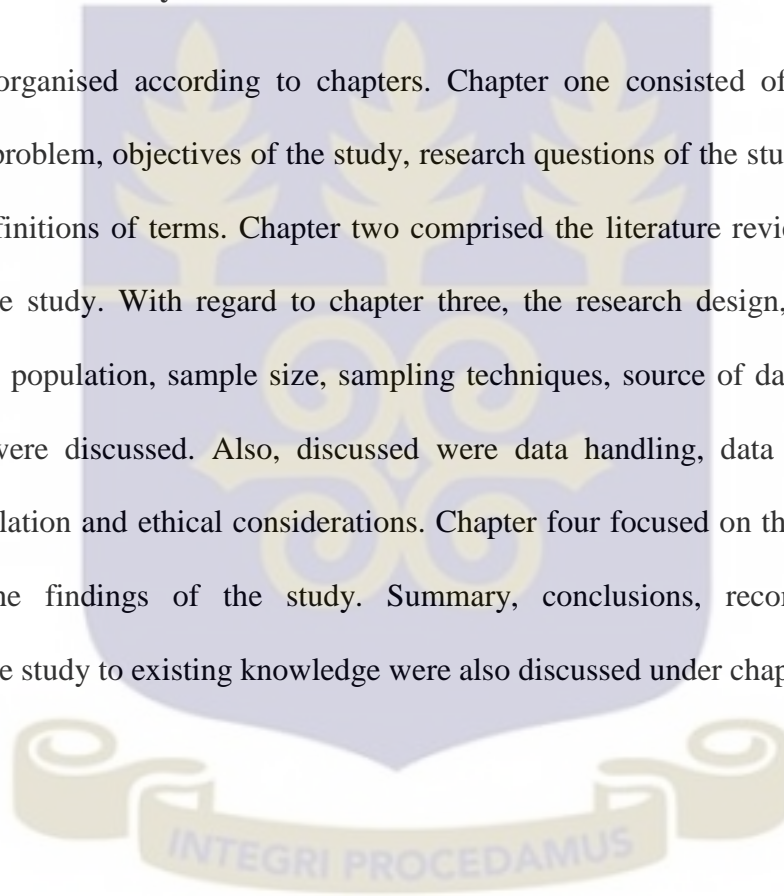
Anti-epileptic drugs (AEDs): They are medications used by PLWE to minimise and manage the occurrences of seizures.

Caregiver:

A caregiver is a person who assists PLWE in certain daily activities related to their situations like going to the hospital for check-ups, taking medications and in cases of experiencing recurrent seizures.

1.7 Organisation of the Study

The thesis was organised according to chapters. Chapter one consisted of the introduction, statement of the problem, objectives of the study, research questions of the study, significance of the study and definitions of terms. Chapter two comprised the literature review and theoretical perspective of the study. With regard to chapter three, the research design, study site, target population, study population, sample size, sampling techniques, source of data and methods of data collection were discussed. Also, discussed were data handling, data analysis, member checking, triangulation and ethical considerations. Chapter four focused on the presentation and discussion of the findings of the study. Summary, conclusions, recommendations and contribution of the study to existing knowledge were also discussed under chapter five.



CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL PERSPECTIVE

2.0 Introduction

This chapter presents the review of relevant literature and the theoretical perspective adopted for the study. Literature was reviewed on the following themes: perceptions about epilepsy; challenges faced by PLWE; coping strategies adopted by PLWE and kinds of support available to PLWE. Also, the ecological systems theory was discussed in this chapter.

2.1 Perceptions about Epilepsy

de Boer (2010) in a review on epilepsy stigma: moving from a global problem to global solutions, reported that because epileptic seizure was involuntary and dramatic gave people reason to believe that it was a mysterious occurrence. While some people considered epilepsy as sacred, others strongly believed that it was a diabolical condition (de Boer, 2010). For instance, Ancient Greek and Latin writings indicated that seizures were related to a hand of sin where the goddess of the moon meted out vengeance on human beings, as punishments (de Boer, 2010). The author further indicated that physicians were of the opinion that seizures were caused by the brain melting as a result of the waxing moon heating the earth. This reinforced the strongly held belief that something spiritual, some supernatural power of the moon, was responsible for epilepsy (de Boer, 2010).

According to de Boer (2010), other scholars posited that epilepsy was not a divine condition but an ordinary hereditary disease that could be treated by drugs and diet. However, the author asserted that this documentation did not gain much prominence in societies, as people were

convinced by the divine or spiritual causation of epilepsy than the hereditary cause. The belief in the general notion or revelation that epilepsy was a condition that had a spiritual, divine, demonic or supernatural background could have played a major role in determining how people reacted toward PLWE.

Studies examining social attitudes towards epilepsy globally uncovered generalisations and beliefs about the condition (Andermann, 2000). In Malaysia, a survey to assess public awareness and knowledge reported that even though there was a high awareness of the condition, many of the participants had negative attitudes and poor knowledge on epilepsy (Ramasundrum, Mohd Hussin & Tan, 2000). In a study, Shorvon and Farmer (1998) found that in developing countries, beliefs about the causation of epilepsy have to do with spiritual, environmental, and psychological causes than the central nervous system.

In most African countries, it is perceived that epilepsy is a spiritual disease (Nyame & Biritwum, 1997). According to Kabir, Iliyasu, Abubakar, Kabir, & Fayinyaro (2005), irrespective of the neurological origin of epilepsy, there seems to be a more social and cultural connotation to the disease, much more than the medical relationship. In a survey of 200 teachers to assess school teachers' knowledge about epilepsy and their attitude towards students living with epilepsy in Northwestern Nigeria, Owolabi, Shehu and Owolabi (2014) found that many of the teachers believed that all epileptic seizures were convulsive. Also, a large number of the teachers believed that epilepsy was caused by demonic possession, evil spirit and was contagious (Owolabi et al., 2014).

In another study conducted among Tanzanian rural inhabitants with 3,256 heads of households, it was found that while 67.7 % of the participants did not know the medical cause of epilepsy, 33.3

% mentioned various causes including heredity, witchcraft, infection of the spinal cord and hernia (Rwiza, Matuja, Kilonzo, Haule, Mbena, Mwang'ombola & Jilek-Aall, 1993). Others (40.6 %) believed epilepsy was infectious and could be contracted through physical contact, flatus, breath, excretions and sharing food. The authors further revealed that 36.8% believed epilepsy could not be cured and 17.1% believed it could not be controlled. Also, 45.3 % believed it could be treated by traditional healers and only 50.8% believed hospital drugs were of any use.

In a study in Tamale, Northern Ghana, 40 participants comprising community nurses, psychiatric nurses and physician assistants were asked to list their perceptions about epilepsy in their communities (Adjei, Akpalu, Laryea, Nkromah, Sottie, Ohene & Osei, 2013). Adjei et al. (2013) found that the perception that epilepsy was a contagious disease was the most often mentioned cause of epilepsy. Adjei and colleagues (2013) further found that taboos, spiritual and/or supernatural forces and punishment for social wrongs were also other frequently mentioned perceived aetiologies for epilepsy. The authors further stated that few responses were attributed to childhood seizures and convulsions as the causes of epilepsy. Regarding treatment methods, the authors found that most suggested treatments appeared inhumane and unrealistic, hence the term extreme treatment methods. For example, PLWE falling in an open fire could be cured and a virgin female patient living with epilepsy could also be healed if an elderly man had sex with her (Adjei et al., 2011).

A cross sectional survey with a total of 380 participants was conducted among government workers and the general public in Accra, Ghana. It was found that the traditional beliefs and attitudes about epilepsy were still held by the working population and that the educational level of the participants was positively related to the responses (Nyame & Biritwum, 1997). While some of the participants did not know about the causes of epilepsy, others believed epilepsy was

inherited. Also, the cause of epilepsy was related to witchcraft and therefore the use of herbs, visits to fetish priests and prayers were considered appropriate treatments methods for PLWE. Moreover, some perceived epilepsy to be caused through contact with PLWE.

In a study with 173 full-time graduate and undergraduate students to assess the traditional beliefs and knowledge base about epilepsy among university students in Ghana, it was found that epilepsy was a poorly understood disorder among the students (Dugbartey & Barimah, 2013). According to the researchers, a more compelling explanation for the restricted knowledge about epilepsy was the seemingly lack of readily accessible and accurate information about the disorder. Dugbartey and colleague (2013) further added that this was typically not the case in many developed countries where the mass media and special interest groups (like the Epilepsy Foundation of America) have made remarkable progress in educating people about epilepsy.

2.2 Challenges Faced by Persons Living with Epilepsy

This theme discusses the challenges that PLWE face in their daily lives. The challenges are: (a) stigma and discrimination, (b) educational challenges, (c) inadequate healthcare, (d) unemployment and (e) difficulty finding marriage partners.

2.2.1 Stigma and Discrimination

Stigma is defined stigma as an attribute that has the potential to discredit an individual, and the possession of which results in the tainting of social identity (Goffman, 1963). The author proposed that people are stigmatised when they possess attributes such as race, class, religion, gender and health condition like living with epilepsy that are undesirable. He identified three broad categories of stigma; (a) tribal stigmas of race and religion; (b) blemishes of individual character; and (c) what he referred to as the abominations of the body. Regardless of how any of

the three categories applies, he argued that those who are stigmatised are seen by others as not quite human. They may be legitimate targets for stigma and social exclusion. Stigmatisation is often triggered by a public crises (Gerhardt, 1985), which in the case of epilepsy could be a seizure in a public place. Individuals are denied access to the benefits of belonging to the general population and are also disempowered (Kai & Crosland, 2001; Samers, 1998).

de Boer (2010) reported how different historical and cultural underpinnings of epilepsy determined the experiences of stigma for PLWE. Stigma and discrimination associated with PLWE is deep-rooted in the history of the neurological health condition and the concept of epilepsy to society (de Boer, 2010). It is also as a result of the lack of knowledge about the neurological condition (Kabir et al., 2005). Epilepsy has had changing names throughout history. It has assumed names such as burning disease, drowning disease or shameful disease and everywhere in the world; it is a hidden disease (de Boer, 2010). In times past, and even today, PLWE are considered as people possessed or chosen by spirits or some deities. Since many people do not know the cause of epilepsy, they are tempted to attribute the disease to some supernatural cause (Kabir et al., 2005).

The work of Scambler (2004) focused on the lived experiences of persons living with epilepsy. The scholar built upon Goffman's theory to address the concepts of felt stigma and enacted stigma. Scambler (2004) described felt stigma as the internalised perception of being devalued by an individual. It also refers to the expectation or fear of enacted stigma or negative reactions to one's disclosure of epilepsy, which also involves feelings of difference and shame. Felt stigma is not necessarily based on personal experiences of enacted stigma, but it is often built upon perceived social responses to epilepsy, and it is as devastating as enacted stigma itself. Enacted stigma, on the other hand, refers to acts of discrimination against PLWE on grounds of their

perceived unacceptability or inferiority. This might include overt discrimination in the workplace or educational institution, neglect, hostility, abuse or what participants termed fair and legitimate discrimination, such as ban on driving or operating heavy machinery (Thomas & Nair, 2011). Enacted stigma is the situational response of others to a visible, overt stigmatising attribute of another (Scambler, 2004).

Stigma and discrimination experienced by PLWE are manifested through or in the attitudes and actions of individuals within society (de Boer, 2010). According to the author, stigma and discrimination might have various justifications like cultural backgrounds which make it difficult to dispel and eliminate. Generally, PLWE who face stigma are disgraced, shamed and denied participation in social gathering or public activities (de Boer, 2010). The author further stated that stigma and discrimination could manifest at the individual, group or the society level. Stigma against PLWE has powers and forces that affect and victimise them. Usually, these practices are persistent and occurring everywhere around the victim (de Boer, 2010). Stigma also devalues the personalities of PLWE and creates attitudes and behaviours of labelling, stereotyping and separating them from the rest of society (de Boer, 2010).

Persons living with epilepsy experience rejection, isolation and have had to endure inhumane treatments and are considered by society as aggressive and violent (de Boer, 2010). The author further stated that the notion that PLWE are aggressive and violent means that they are a threat to society and do not have the full capacity of normal human beings. In times past, PLWE were confined in prisons, lunatic asylums or leprosy colonies (de Boer, 2010). The effect of their isolation from society, according to the author is a symbolic indication that PLWE are not considered as normal human beings. This stigma makes them internalise society's perceptions of

them. The social burdens of PLWE are usually as a result of the social meanings associated with stigma and discrimination (Sonecha et al., 2014).

It could only be a stigma-directed-tendency that would make an employer feels disinclined to employ a PLWE and think that other employees would not feel comfortable or safe around a person living with epilepsy (Parfene, Stewart & King, 2009). According to Parfene and colleagues, to think that co-workers would not feel comfortable or safe around a person living with epilepsy might not be different from the belief that PLWE are violent, unattractive or undesirable. The authors further stated that this argument might be valid because the feelings of discomfort, unsafety, and unindustrious are held because of the epileptic status of the person being employed. Therefore, whether employers use stigma-based beliefs or corporate reasons, PLWE continue to suffer strong disadvantage in the workplace (Parfene et al., 2009)

According to Parfene et al. (2009), workplace stigma on epilepsy might seem to have a strong effect on both PLWE and those who have association with them. Parfene and colleagues asserted that at the workplace, not only do PLWE suffer strong disadvantages, but also people who share some relationship or are associated with PLWE are always likely to suffer similar level of rejection. The authors revealed that individuals who are not themselves members of a stigmatised group may nonetheless stand the chance of becoming subject to the same social rejection and discrimination experienced by those in the stigmatised group by being in some way associated with members of the group, for example, through friendship (Parfene et al., 2009).

Studies have revealed that psychiatric nurses are frequently stigmatised by their peers as being less logical, less skilled, more introverted, and more dependent than nurses from other specialisations, seemingly based on their association with people who have mental illness

(Parfene et al., 2009). This is due to what has been termed as stigma by association or courtesy stigma (Parfene et al., 2009); a situation where a mental perception or stigma developed about someone who has worked with PLWE is similar to the one held against PLWE. In stigma by association, perceivers' mental representations of the stigmatised persons and those closely linked to them have become connected through associative pathways (Parfene et al., 2009).

In a study by Adjei et al. (2013), they found that PLWE experienced social isolation and were discriminated against because they were perceived to be inferior and dangerous. In Northwestern Nigeria, 83% of teachers in a survey felt there was discrimination against students living with epilepsy (Owolabi et al., 2014). The authors further reported that 60% of the teachers believed that students living with epilepsy should be separated from students without epilepsy in the classroom. Same percentage of teachers also opposed to having a child living with epilepsy in their classroom. They further added that the teachers' knowledge about epilepsy was generally poor. Several of the teachers had little or no knowledge about the basics of what an epileptic attack is and the types of seizures.

2.2.2 Educational Challenges

A study carried out in the United Kingdom found that children of average or above average intelligence, who were living with epilepsy, had at least a two-year deficit in reading skills (Aldenkamp, De Krom & Reijs, 2003). In another study among Tanzanian rural inhabitants with 3,256 heads of households, it was reported that 62.7% of the participants would not allow children living with epilepsy to go to school for various reasons, including mental subnormality of 54% and fear that the child living with epilepsy would infect other children with 11.2% and 33.5% would keep away from PLWE when they were having seizures (Rwiza et al., 1993). In

Northern Ghana, PLWE were either not allowed to go to school or withdrawn from school because of epilepsy (Adjei et al., 2013). In addition to the restriction that the disease itself has already placed on them, students living with epilepsy continue to find themselves confronted with social barriers that prevent them from academic achievements (Kankirawatana, 1999).

Underlying brain injuries, epilepsy characteristics, attention disorders, sub-clinical epileptic activity, drug side-effects, cognitive functioning and secondary psychosocial problems are some of the factors associated with epilepsy that could alter a child's learning potentials (WHO, 2005). The WHO (2005) further reported that estimated 25% to 50% of children living with epilepsy had some degree of educational difficulties. Such children could run a greater risk of learning problems and schooling difficulties like absenteeism (WHO, 2005). There are also some effects of medication on cognitive function (Engelbert et al., 2002).

A study carried out in Finland by Sillanpaa (1992) revealed that, despite normal intelligence, students living with epilepsy tended to be one year behind the expected reading level; had variations of over ten points in intelligence quotient (I.Q) scores over four years; tended to repeat grades more often; dropped out of school at higher rates during adolescence; had deficits in language, visual-spatial function, problem-solving and adaptive behaviour and had reduced educational and professional attainment. It was reported from Netherlands that, having epilepsy was found to have negative impact on education and achievement in later life (Shackleton et al., 2003).

Some studies have proved that due to their higher level of education, teachers have some good knowledge about epilepsy. For instance, in Ojinnaka's (2002) study with 125 teachers, 37.6% of whom had university degree, but without any form of health education, specifically for epilepsy,

had 59.2% of correct answers on questions about epilepsy. In a similar study about the perception of teachers' knowledge about epilepsy, Fernandes, Noronha, Araujo, Cabral, Pataro, de Boer, Prilipko, Sander & Li (2007) reported that 43% of teachers claimed to have good knowledge about the disease and 20% had little knowledge, and pointed out that the greatest source of information about this condition were journal articles, television, and school with 53%, 29% and 22%, respectively. However, other studies have reported of poor knowledge of teachers about epilepsy. For example, in the survey of Owolabi, et al. (2014), it was reported that knowledge of teachers about epilepsy was poor. The authors further reported that several of the teachers had little knowledge about the basic manifestations as well as types of epileptic seizure.

2.2.3 Unemployment

Persons living with epilepsy may encounter challenges accessing and maintaining employment because of their health status. Mugumbate and Nyanguru (2013) conducted a study to measure the challenges of PLWE in Harare, Zimbabwe with 60 PLWE. They found that among the life challenges of PLWE was economic, in terms of securing adequate income and finding and maintaining employment. The authors further found that, compared to other life's challenges, economic challenge was the second highest for PLWE. It was also indicated that PLWE would wish to have the opportunity to be employed, to have access to adequate income and to be able to meet other necessities of life such as education and healthcare, but they had difficulties achieving them (Mugumbate & Nyanguru, 2013).

Jennum, Gyllenborg and Kjellberg (2011) conducted a study using records from Danish National Patient Registry between 1998 and 2006 with 64,587 Danish patients with a diagnosis of epilepsy matched with 258,345 patients in a controlled group. The authors found that PLWE had lower employment rates, that is the employment rate among PLWE was only half that of the

control subjects. It was for the equivalent periods up to eight years before the diagnosis was made, at the time of diagnosis and after receiving a diagnosis of epilepsy (Jennum et al., 2011). The researchers further stated that employed PLWE earned only half the income of employed control subjects as indirect costs to PLWE.

Some PLWE have experienced workplace disadvantages. Parfene et al. (2009) have shown evidence that the social devaluation of PLWE is extended to include their work attributes and competencies. The authors further argued that even when PLWE are employed, perceptions about them are always negative and do not promote effective work engagement. The authors added that the high rate of unemployment and under-employment among PLWE is not surprising given that they are often perceived as introverts, unattractive, mentally retarded and undesirable employees. These stigmatising beliefs could make people deny PLWE employment. In a study on employers in the United Kingdom, majority of employers refused to offer employment to PLWE (Parfene et al., 2009). These employers defended their decisions by consistently citing issues regarding social discomfort of co-workers, other employees' safety, and lower productivity capacity of PLWE (Parfene et al., 2009).

In another study in Britain, McLellan (1987) found that PLWE faced difficulties, such as unfair treatment in securing jobs. He argued that since 1980, the level of unemployment in this group was between 25% and 42%. The author argued that a study by the United States in 1978 suggested that approximately 50% of PLWE were in employment positions that did not commensurate their educational attainments. The author further added that it was estimated in 1986 that, between 50,000 and 100,000 people were experiencing moderate or severe difficulties in finding and maintaining a job in Britain because of epilepsy. Persons living with epilepsy have

reduced employment status (Sillanpaa, 1992). They also are likely to be underemployed or unemployed (Hermann, 1992)

Bishop and Allen (2001) conducted a survey in the United States and Puerto Rico, regarding employment concerns of PLWE. They found that the problem associated with employment of PLWE was well known and stated that the unemployment and underemployment of adults with epilepsy continued to be a serious problem. The unemployment rate experienced by PLWE had frequently been higher than that of the general population (Bishop & Allen, 2001). In the United States labour market, the unemployment rate among PLWE who were eligible workers or who were maintaining an active job search was reported to range from 13% to 25% (Bishop & Allen, 2001).

In a similar study in United Kingdom, Collings and Chappell (1994) used a cross-sectional approach with 1,709 participants. They found an unemployment rate of nearly 12% for PLWE compared with nine percent for the general population. In a related study by Jacoby (1995) on a cohort of 494 people with well-controlled epilepsy, it was found that 71% of the people who had attained the working age were employed. Twenty-six percent were unemployed, but other reasons were given as the cause and only three percent cited epilepsy as the reason for not working. However, over 50% unemployment rates have been reported among PLWE who have one or generalised tonic-clonic seizures or complex partial seizures and have been treated in tertiary care centers (Hauser & Hesdorffer, 1990).

Persons living with epilepsy are more likely to be employed in unskilled and menial jobs (Elwes, Marshall, Beattie & Newman, 1991). Problems at work could lead to lack of opportunities for career advancement and ultimately, many PLWE are unable to reach the employment potential

corresponding to their qualification and age (Chaplin, Wester & Tomson, 1998). In his study, Gloag (1985) reported that the rates of unemployment increased among people with frequent seizures and in lower social classes; such people were more likely to live in conditions of poverty. Regarding employment in Central and Eastern Europe, the unemployment rates of PLWE are far worse, as unemployment is high in these countries (International League against Epilepsy [ILAE], 2003). Persons living with epilepsy are more likely to be unemployed or underemployed and have greater social isolation (Jacoby et al., 1996).

Following from the high rate of unemployment of PLWE, they faced financial difficulties. In a study, Ratsepp, Oun, Haldre and Kaasik (2000) examined the impact of epilepsy and its treatment on employment status among 90 patients with epilepsy. The authors found that 59.5% valued their economic and financial status as very good, good or satisfactory and 40.5% described it as bad or very bad. They further found that the 39% were working full-time, 24% were working part-time and 11% were unemployed. However, 63% from those working part-time or unemployed considered their epilepsy to be a significant reason for this. This could explain the 40.5% of the participants who described their economic and financial status as very bad.

2.2.4 Inadequate Healthcare

Access to health care that facilitates accurate diagnosis and effective treatment and management of epilepsy (England, Liverman, Schultz & Strawbridge, 2012) is important for PLWE. The authors further indicated that there has been significant progress made in developing seizure medications with fewer adverse effects, as well as in refining devices and surgical techniques for

specific types of epilepsy. Epilepsy treatment is effective for controlling seizures in 70 percent of all cases (WHO Ghana, 2015).

However, much remains to be done to reduce the sometimes lengthy delays in diagnosis and referral to more advanced levels of care and to improve care for those with refractory epilepsy (England et al., 2012). Earlier studies highlighted a number of areas of particular concern to PLWE (Collings, 1990), who tended to have poorer self-esteem and higher levels of anxiety and depression than people without epilepsy (Chaplin et al., 1992). Major challenges faced by PLWE include inadequate supplies and poor access to antiepileptic medications; lack of primary health workers appropriately trained to diagnose and treat epilepsy; social stigma; misinformation; traditional beliefs and limited opportunities for specialist training in neurology (WHO Ghana, 2015).

According to Jennum et al. (2011), patients living with epilepsy had significantly higher rates of health-related contacts and medications compared with those without epilepsy. They further found that a higher percentage of patients than control subjects were treated with primary care system. Compared with control subjects, a greater proportion of patients took medications and received public support to pay their medications. Medical expenses of patients living with epilepsy were elevated before diagnosis, increased at the time of diagnosis and continued to increase steadily thereafter as a direct cost (outpatient clinic, hospital, primary care and drug costs) to them (Jennum et al., 2011).

It is reported that few PLWE receive adequate medical treatment, and many receive no treatment (WHO, 2005). This is due to lack of medical personnel; non-availability of medications; and lack of information and/or education on epilepsy for both patients and medical staff (WHO, 2005)

and social or cultural beliefs which interfere with optimal care for epilepsy (ILAE, 2003). Persons living with epilepsy are also more likely to be obese and physically inactive, smokers and have a higher risk of experiencing major events that affect their lives. Persons living with epilepsy also have a higher mortality rate (Cockerell et al., 1994; Cockerell, 1996; Cockerell et al., 1997; Lindsten et al., 2000) and a higher risk of committing suicide (Christensen et al., 2007).

Furthermore, studies in the United States of America show that non-white PLWE have lesser chance of accessing specialist care, but have higher rates of emergency cases (Burneo et al., 2009; Kelvin et al., 2007). Evidence suggests that, in the United Kingdom, non-white PLWE form a minority group and are particularly higher consumers of expensive services for their epilepsy (Ridsdale et al., 2013). Persons living with epilepsy experience certain health implications. Per a WHO (2009) report, four out of every ten PLWE suffer from mental disorders such as depression, schizophrenia, intellectual disability and alcohol use disorders. Collings (1990) also argued that PLWE are more likely to experience anxiety, depression and low self-esteem. In respect of active epilepsy, about 30% of PLWE would continue to have seizures despite treatment with AEDs, and most of PLWE would require further specialist follow-up (Brown, Betts, Crawford, Hall, Shorvon & Wallace, 1998).

2.2.5 Difficulty finding Marriage Partners

Persons living with epilepsy are more likely to have lower rates of marriage and greater social isolation (Hermann, 1992). In a study conducted by Agarwal et al. (2006) on 240 patients living with epilepsy in India, it was evident that patients were not only less likely to get married, but also more likely to get divorced, especially women living with epilepsy in comparison with the general population. Also, it was reported that PLWE had lower rate of marriage than persons

without epilepsy (Lechtenberg, 1984). In a study, Adjei et al. (2013) found that in Northern Ghana PLWE were not encouraged to get married, because of the belief that they might give birth to children who would also experience epilepsy.

A study undertaken in India where women were considered unmarriageable if they had epilepsy showed male prevalence to be significantly higher than female recorded cases because female cases might have been concealed (Banerjee, 2009). In some African countries like Ghana, families would either not allow or caution one marrying into or engaging in relationship with someone from a family that has person(s) living with epilepsy (Nyame & Biritwum, 1997). Even parents might not allow their children to either mingle or play with children living with epilepsy. Persons living with epilepsy have reduced likelihood of marriage and childbearing (Sillanpaa, 1992).

In a cross-sectional study with 374 participants, Riasi, Sanati and Ghaemi (2015) found that the marriage rate and the divorce rate among patients with epilepsy were 27.3% and 54.8%, respectively. Riasi and colleagues reported that the higher divorce rate in PLWE might be because of concealment of epilepsy from one's spouse before marriage resulting from fear of unfair discrimination, hence the main cause of divorce. The authors, however, added that PLWE who disclosed their disease before marriage might not suffer from serious social discrimination in conjugal life forever. Also, PLWE who suffer from enacted stigma of epilepsy are more likely to get divorced when compared with other patients (Riasi et al., 2015).

2.3 Coping Strategies Adopted by Persons Living with Epilepsy

Epilepsy is a condition that is responsive to medication: drugs and surgery (Sterman & Egner, 2006). The mild form of epilepsy can be controlled or managed using antiepileptic drugs

(Serman & Egner, 2006). Treating epilepsy can involve either a monotherapy, where there is the administration of one drug; or a combination therapy, which involves two or more different drugs administered together (Moshe, Perucca, Ryvlin & Tomson, 2015). According to Moshe et al. (2015), in instances where the antiepileptic drugs are unsuccessful in managing the condition, surgical treatment is resorted to. They argued that use of destruction or disconnection of epileptic brain tissue and neuro-stimulation are some of the surgical methods employed. The authors further reported that antiepileptic drugs had been found to be age-sensitive, responsive to seizure types and syndrome.

Whether drugs are administered, whether it is a monotherapy or a combination therapy, or a surgical treatment, the side effects, the challenges of treatment and dynamics of the condition would require varying or peculiar coping strategies throughout the period of treatment. Epilepsy exposes its patients to a wide range of unique psycho-social consequences, which sometimes could be more damaging than the medical difficulties with which they deal (Piazzini, Ramaglia, Turner, Chifari, Kiky, Carner & Canevini, 2007). This makes it important to consider the various coping strategies adopted by PLWE as they struggle through life with this neurological condition. Piazzini et al. (2007) categorised the coping strategies into four namely: control, denial, exclusion and social support.

Piazzini et al. (2007) explained that control is the tendency to analyse and re-organise the main elements of the problem to find the best strategy to solve it. In essence, control is a proactive mechanism of confronting the problem and seeking to deal with the effects. Denial is characterised by a clear refusal of difficulties, denying the existence of the problem, or minimising its relevance. Denial, however, is a passive attitude of attempting to avoid recognising the reality of the condition and its effects. It is most probable that PLWE who resort

to denial will refuse to think about the condition and hence push it out of consciousness all together.

Exclusion is the method where patients attempt to separate themselves to avoid a situation considered very stressful to manage. Persons living with epilepsy could not necessarily separate themselves from the fact that they have epilepsy, the best is to separate themselves from the related events such as stigmatising comments and attitudes that could cause stress for them. In such a situation, PLWE could refuse to react to the observable actions and behaviours of other people. They could also decide to avoid the company of people who show attitudes of stigma and discrimination. Social support is considered an approach that looks for others' understanding and support to face difficulties better. Persons living with epilepsy could associate with people who are sensitive to their needs and feelings. Seeking for social support could mean asking for the empathy of other people. It is a way of drawing closer to others for both physical and socio-emotional assistance.

Other people who experience health conditions also adopt religion as a coping strategy. Cummings and Pargament (2010) in their article on medicine for the spirit: religious coping in individuals with medical conditions gave account of the outcomes of investigations of religious coping in samples with medical conditions. The authors reported of the positive and negative outcomes religious coping had on the individual. Some benefited from adopting religious practices such as prayers, attendance at church, reading sacred texts and meditation. In spite of the challenges people with health problems face in participating in public religious activities, sizable proportions of American samples made efforts to do so. For example, with respect to attendance at religious services, between 39% and 51% of HIV/AIDS and cancer patients reported attending services at least once per month. In a similar study with 110 patients with

epilepsy, Tedrus, Fonseca, Magri, & Mendes (2013) found that patients with epilepsy appeared to use positive spiritual/religious coping. However, negative coping was associated with patients with epilepsy with reduced quality of life.

2.4 Support Available to Persons Living with Epilepsy

Persons living with epilepsy receive different kinds of assistance from government, Non-governmental Organisations (NGOs) and caregivers. According to the United Kingdom Epilepsy Society [UNES], (2014), a caregiver might be someone who looks after a family member, partner or friend who needs help because of a health condition like disability, frailty and epilepsy and who would not be able to manage without this support. The society further indicated that all the care the caregivers give is unpaid. The term caregiver does not mean someone who is in paid employment.

Some people are caregivers for a short period of time; others for many years (UNES, 2014). The society further stated that some PLWE do not need any extra care from others to live independent lives. Other PLWE might need a lot of care, some or all of the time. Some PLWE need care only when they have had seizure. Even if they do not have seizure very often, the need for care during or after a seizure might be very urgent. Seizures could be unpredictable; PLWE might be unable to plan as and when they would require help.

According to the United Kingdom Epilepsy Society (2014), some kinds of support caregivers give to PLWE are, but not limited to the following: keeping them safe during a seizure; calling for medical help, or giving first aid or emergency medications; staying with them or seeing them home safely after a seizure and noting any pattern or trigger to their seizures, which might help if they do not recall their seizure. The other help caregivers render to PLWE are helping with their

routine of taking anti-epileptic drugs (AEDs); going with them to appointments, helping to take notes, or providing descriptions of seizure to PLWE and/or their doctor; acting as a representative or advocate for them, with their doctors or others involved in their care; joining in with leisure activities that might pose a safety risk if they were to have a seizure, such as swimming; providing transport if necessary and helping them to adapt to their home or lifestyle to provide a safe living environment.

Lefley (1996) posits that there are 10 burdens of epilepsy to their family and society as a whole; patient economic dependence, disruption of daily routines, behavioral management, times and energy demand required to negotiate the mental health system, confusion or humiliating interaction with service providers. Others are financial costs of illness, deprivation of needs of other family members, curtailment of social activities, impaired relationship with outside world and inability to find satisfactory care settings.

Civil Society Organisations and NGOs who provide healthcare services might or might not be contracted by the state (WHO, 2001). According to WHO (2001), in many cases, these organisations provide assistance to groups otherwise disadvantaged in health service access or assist governments in major treatment campaigns and disease control programmes, in drug distribution, in reaching vulnerable communities, and in fostering innovative approaches to disease control. Also, NGOs contribute to enhance healthcare by providing services in response to community needs and adapted to local conditions; they lobby for equity and pro-poor health policies, often acting as an intermediary between communities and government; reach remote areas poorly served by government facilities; and provide services that might be less expensive and more efficient (WHO, 2001).

Civil Society Organisations also provide technical skills on a range of issues from planning to delivery to services. These organisations contribute to public understanding and enhance public information about health matters. This could build more effective interaction between services and clients and enhancing community control over health interventions. Also, there is great potential for improving public health through systematic collaboration between civil societies and government (WHO, 2001)

2.5 Theoretical Perspective of the Study

2.5.1 Ecological Systems Theory by Urie Bronfenbrenner (1979)

Theories provide a set of explanatory concepts which offer ways of looking at the world which are essential in defining a research problem (Silverman, 1993). The ecological systems theory by Urie Bronfenbrenner (1979) was used as a theoretical perspective for the study.

According to Bronfenbrenner (1979), in order to comprehend human development, it is important to consider the entire ecological system in which growth occurs. The ecological system encompasses an evolving body of theory and research concerned with the processes and conditions that govern the life long course of human development in the actual environments in which human beings live (Bronfenbrenner, 1979). The ecological systems theory proposes three main assumptions:

- a) The individual is an active player and applies substantial force on his or her own environment.
- b) The environment can force an individual to adapt to its restrictions and conditions.
- c) The environment is perceived to comprise of dissimilar size entities that are positioned one inside another.

The theory explains the environment as a system that is composed of five socially organised sub-systems that help support and guide human growth. These systems are the microsystem, mesosystem, exosystem, macrosystem and chronosystem.

2.5.1.1 Microsystem

The microsystem refers to the relationship between a developing person and the immediate environment. The theory explains that, a microsystem is a pattern of activities, social roles, and interpersonal relations experienced by the developing individual in a given face-to-face setting. This happens with particular physical, social, and symbolic features that invite, permit, or inhibit engagement in sustained, progressively more complex interaction with, and activity in the immediate environment (Bronfenbrenner, 1979). Examples of such systems are family, school, peer group, community and workplace. In this study, in identifying the challenges faced by PLWE, the ecological system enabled the researcher to understand how PLWE's relationship with the peers, family, school and community influenced or support the challenges faced by them.

2.5.1.2 Mesosystem

The mesosystem consists of the linkages and processes taking place between two or more settings containing the developing person. For example, the relations between home and school, neighbourhood peer group and school and workplace (Bronfenbrenner, 1979). In this study, an example is the interaction between the parents or the caregivers and the school of PLWE. Also, it could be interactions among PLWE, family, workplace and social networks. The perceptions of these actors about epilepsy in the environment could have negative influence on the perception of PLWE about their own disease. This is because their perceptions of epilepsy would be socially

constructed based on the general perception of these actors who also form part of the larger community.

2.5.1.3 Exosystem

The exosystem consists of the connections and developments taking place between two or more settings, at least one of which does not comprise the developing person, but in which events occur that indirectly influence the development of the individual (Bronfenbrenner, 1979). For example, the relationships between the home, and the workplace of the individual's parents. In this case, the workplace setting does not contain the developing person.

Relating the theory to this study for example, the side effects of medications prescribed for the person living with epilepsy could put undue pressure on both a single mother and the affected. As the affected might be absent from school because of drowsiness or dizziness; the mother might miss work hours due to frequent visits to the hospital with the child for medical review which could eventually lead to loss of job. Similarly, loss of job of the single mother could affect the provision of the nutritional, educational and the health needs of the person living with epilepsy.

2.5.1.4 Macrosystem

The macrosystem includes the principal pattern of micro, meso, and exosystems characteristic of a given culture or subculture, with particular reference to the belief systems, bodies of knowledge, material resources, customs, life-styles, opportunities, structures, hazards, and life course options that are embedded in each of these broader systems (Bronfenbrenner, 1979).

In line with this study, the application of the theory enabled the researcher understand how belief systems, culture and government policies and programmes like NHIS and LEAP and the lack of

such policies and programmes in Ghana for PLWE could positively or negatively influence the experiences of PLWE in their environment.

2.5.1.5 Chronosystem

The EST emphasise that the environment is not static and does not affect people uniformly; rather, it is dynamic and ever changing. The chronosystem encompasses modification over time in the characteristics and the environment in which the individual lives. For example, changes over the life course in family structure, socio-economic status, employment, place of residence and ability in everyday life of the individual (Bronfenbrenner, 1979).

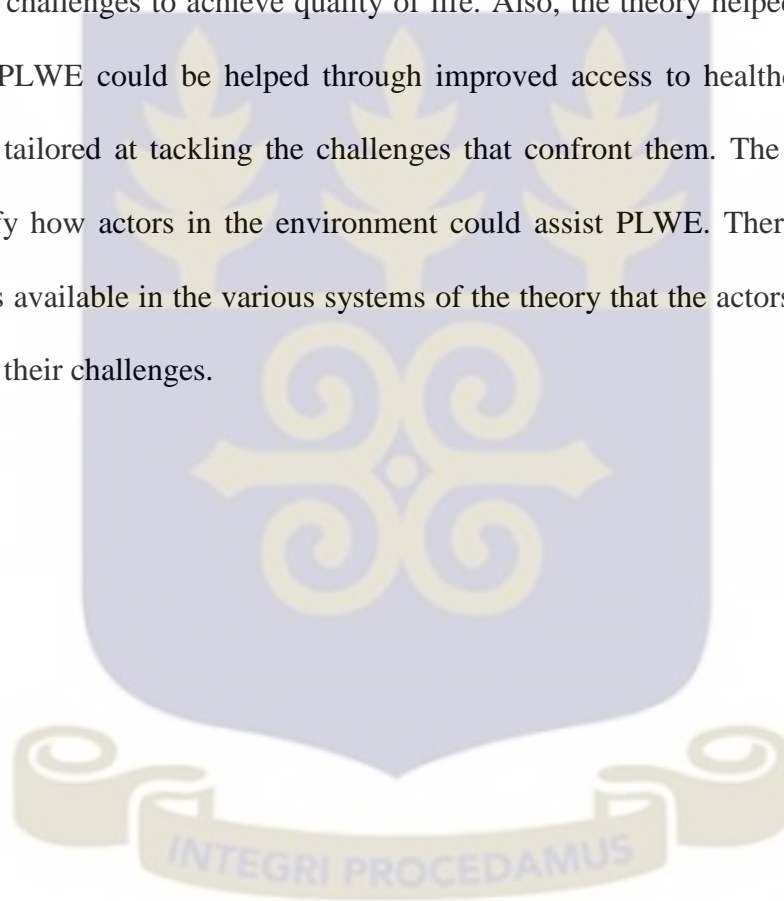
In the context of this study, it is hoped that in the course of time and with intensive public education and awareness creation on epilepsy, society would change their attitudes and perceptions towards epilepsy and PLWE. This would help improve their quality of life of PLWE in respect of employment, marriage, access to health care services, education and eradicate stigma and discrimination being perpetuated against them.

2.5.2 Usefulness of the Theory to the Study

In this study, the environment in which the PLWE, caregivers, nurses and officials stay is very important. The ecological systems theory helped the researcher understand how different actors and factors in the environment influence the experiences of PLWE. The theory provided a framework for understanding the environmental conditions under which PLWE acquire their experiences. It helped to comprehend how PLWE and key informants formed their perceptions about the disease resulting from their interactions with their immediate environment and the larger community. For example, the microsystem which is made up of the activities, social roles,

and interpersonal relations could help create the perceptions people have about epilepsy and PLWE.

It important to add that, various systems of the ecological systems theory helped to provide varied explanatory justifications of the experiences of PLWE. It helped to understand how the various factors helped in either contributing to the challenges of PLWE or helped them in overcoming their challenges to achieve quality of life. Also, the theory helped the researcher to understand how PLWE could be helped through improved access to healthcare and intensive public education tailored at tackling the challenges that confront them. The theory helped the researcher identify how actors in the environment could assist PLWE. Therefore, it helped to identify resources available in the various systems of the theory that the actors could use to help PLWE overcome their challenges.



CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

The chapter discusses the methods that were utilised in undertaking the study. The chapter comprises the research design, study site, target population, study population, sample size and the sampling techniques. The methods employed in data collection and the steps by which data was analysed and interpreted are explained. Finally, the ways by which trustworthiness was ensured are also described in this chapter.

3.1 Research Design

The qualitative research approach was used for this study. Qualitative research design is a research method used extensively by social scientists and researchers studying human behaviours and habits (Krueger, 2000). It was very helpful for the researcher in collecting data from participants who experienced the issue under study (Creswell, 2013). This method was chosen, because this study aimed at exploring the experiences of PLWE, which could best be done within their social environment.

The research sought to explore the life experiences of PLWE. Therefore, the phenomenological approach of qualitative research tradition was more suitable for the study. This is because phenomenology is concerned with the study of experiences of individuals from their own perspectives (Creswell, 2009). It was powerful for understanding subjective experiences, gaining insights into the motivations and actions of PLWE. It is a description-based approach to social science research (Creswell, 2009). Phenomenological methods like interviews and conversations

were particularly effective at bringing to the fore the experiences and perceptions of PLWE and key informants from their own perspectives, and therefore good at challenging structural and normative assumptions in respect of epilepsy issues (Creswell, 2009).

3.2 Study Site

Participants for the study were recruited at BasicNeeds-Ghana. The organisation works with PLWE in their communities in Accra. As a registered Non-Governmental Organisation, it began its operations in Ghana since 2002. Currently, it has programme in the Greater Accra Region covering four sub-metropolitan areas of the Accra metropolis (Ablekuma sub-metro, Ashiedu-Keteke sub-metro, Ayawaso sub-metro and Okaikoi sub-metro). BasicNeeds-Ghana is located in Abelemkpe and it has its headquarters in Tamale. It is a member of the BasicNeeds International Federation and has its headquarters in the United Kingdom, run by the BasicNeeds United Kingdom Trust, and has partners and franchisee in India, Sri Lanka, Vietnam, Uganda, Tanzania, Pakistan, Kenya, Colombia, among others (BasicNeeds-Ghana, 2014).

BasicNeeds-Ghana implements and promotes initiatives to transform the lives of PLWE. This, they do by providing access to integrated healthcare, social and economic services (livelihood support to PLWE and their caregivers) in the communities. In the process, they empower individuals and their families and involve the communities. Also, they partner with government and other organisations to influence public opinion and policy that influence the experiences of PLWE. They support PLWE to live and work successfully in their communities. The organisation works with polyclinics like the Kaneshie Polyclinic from where PLWE receive their healthcare services (BasicNeeds-Ghana, 2014). As at 2014, BasicNeeds-Ghana had reached out to a number of 24,062 PLWE and mental illness and 19,250 of their caregivers.

BasicNeeds-Ghana identifies and renders services to PLWE and caregivers in the areas of healthcare, financial assistance and skills acquisition in various trades. Therefore, it was chosen as the appropriate study site for this research. Also, it helped the researcher in the recruitment of the participants for the study.

3.3 Target Population

The target population of the study was all PLWE and key informants, such as caregivers, nurses at the epilepsy unit of the Kaneshie Polyclinic and officials from BasicNeeds-Ghana.

3.4 Study Population

The study participants were PLWE, caregivers of PLWE, nurses of KPC and officials of BNG. The inclusion criteria for PLWE were (a) aged 18 years and above, (b) had lived with the disease for a year and more, (c) receiving services from BasicNeeds-Ghana and (d) could share their experiences with the researcher.

The caregivers in this study were those who provided care and support for PLWE. They had experiences to share regarding their interactions with PLWE. The nurses at the epilepsy unit of the Kaneshie Polyclinic also had experiences to share in respect of the healthcare services they provided to PLWE. Also, the officials from BasicNeeds-Ghana had knowledge and information about the phenomenon under study to share with the researcher since they worked directly with PLWE and their families. These informants provided information that corroborated with PLWE.

3.5 Sample Size

The sample size consisted of twenty participants and this comprised fourteen PLWE (seven males and seven females), caregivers (two), nurses at the epilepsy unit of the Kaneshie Polyclinic

(two) and officials of BasicNeeds-Ghana (two). In a qualitative research, a sample size of five to twenty-five is appropriate to reach saturation of data (Creswell, 2009).

3.6 Sampling Techniques

Purposive and snow ball sampling techniques were used to select the participants for the study. Purposive sampling was appropriate because, it helped the researcher to select the sample based on their knowledge and the nature of the research objectives (Babbie, 2007). It was also based on certain features relating to specific experiences, behaviours and roles which ensured detailed exploration and understanding of the central themes and puzzles which the researcher studied (Burgess, 1984). Also, purposive sampling was appropriate because the researcher studied a small subset of the population of PLWE (Babbie, 2007). The key informants were people who had worked with, and for PLWE for some years and for that matter had in-depth information on the issues being explored by the researcher and were purposively recruited for the study.

For the caregivers, the researcher recruited two caregivers of PLWE. Regarding PLWE, the participants were purposively recruited from among a group of PLWE. In addition to the purposive sampling method, the snow ball sampling method was used to identify participants who were difficult to reach. Snow ball sampling is normally used in hard-to-reach populations and in studies of sensitive nature (Handcock & Gile, 2011).

The researcher contacted BNG and was given its liaison officer who worked with the leaders of the self-help groups of PLWE in some selected communities in Accra. The liaison officer introduced the researcher to the leaders who then introduced the researcher to some of the group members. Also, the group members introduced the researcher to other members. But the researcher applied the criteria for inclusion in recruiting these participants for the study.

3.7 Source of Data

The study used primary source to gather data.

3.7.1 Primary Data

Interview guides were developed by the researcher and used to collect primary data from PLWE and key informants through in-depth individual interviews. The in-depth individual interviews helped the researcher to probe into issues and provided an insight of the topic through the responses of the participants. It also provided the participants the chance to express their subjective views about issues under discussion. In-depth interviews are appropriate in conducting a comprehensive investigation and when soliciting information on personal experiences on delicate issues (Ritchie & Lewis, 2003).

3.8 Methods of Data Collection

Two interview guides were developed; one for PLWE and the other for key informants. With the interview guides, in-depth individual interviews were conducted to ascertain the lived experiences of the participants with regard to the problem under study. In-depth interviews helped the researcher to solicit the views of the participants in their communities. It allowed the researcher to analysis participants' responses for further clarification. The interview questions were constructed in English, but interviews were conducted in English and Twi. Each interview lasted approximately 45 minutes. The interviews were conducted at the stores/shops, homes and offices of the participants at their own convenient time. With the permission of the participants, the interviews were recorded with audio-recorder and notes were taken as well.

3.9 Data Handling and Analysis

3.9.1 Data Handling

The audio-recorded data was kept on a computer and copies of such on a compact disc to serve as backup. Then, the recorded files were transcribed verbatim in English language from audio to a text format using Microsoft Office Word application 2010 version. For easy analysis, the transcripts were grouped based on the objectives of the study.

3.9.2 Data Analysis

In analysing the data, Creswell's (2009) six steps method of qualitative data analysis was adopted. The first step of this method involved data transcription. At this stage, the researcher listened to the voices over and over again to familiarise with them and all the relevant parts of the audio-recorded data were transcribed to text format. The data were transcribed verbatim from Twi to English using Microsoft Word 2010. The second step was familiarisation. With this step, the researcher read through all the data over and over again. This helped the researcher to get a general sense of the overall meaning of the data from the perspectives of the participants. This exercise provided the cornerstone for the identification of codes and themes.

The third step involved coding in respect of which the researcher organised the material into segments to bring meaning to the information. These segments were labelled with codes that described the data at different levels with emerged themes. The fourth step was to develop themes. The researcher developed themes which appeared as major findings and were used to create headings and subheadings in the presentation and discussions of data. In respect of the last but one step, data was described. That is meanings and clarifications were made from the data in respect of the subject matter; epilepsy.

At the final step, the researcher interpreted the meaning of the themes in line with the objectives of the study. The researcher also compared these findings with the information gleaned from the literature to draw conclusions. This method was useful because it helped the researcher to validate the accuracy of the information received from the participants (Creswell, 2009).

3.10 Member Checking

With member checking, the researcher went back to the participants to double check the information given to be sure it was same recorded. Member checking provided an opportunity to the researcher to seek clarification and confirmation on the data solicited during data collection. It also ensured that collected data was credible and trustworthy (Morse, Barrett, Mayan & Olson, 2008).

3.11 Triangulation

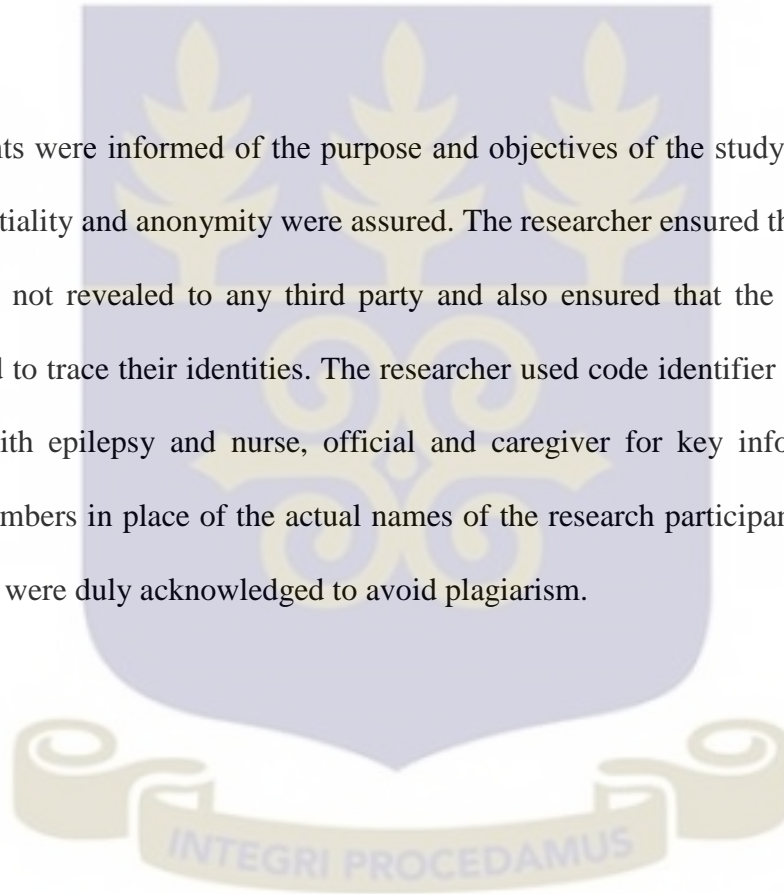
Triangulation is a strategy for ensuring credibility and trustworthiness of research findings by incorporating several viewpoints in a social science research (Yeasmin & Rahman, 2012). With regard to triangulation, viewpoints on the subject matter were sought from PLWE and key informants whose interests and activities were related to the issues of epilepsy. The different perspectives of the participants supported each other to ensure credibility and trustworthiness of the findings of this research.

3.12 Ethical Considerations

The researcher adhered to ethical requirements in conducting a social science research. With introductory letter from the Department of Social Work, University of Ghana, Legon; the researcher sought permission from BasicNeeds-Ghana in order to get access to PLWE and its

officials. The researcher also sought permission from the medical superintendent of the Kaneshie Polyclinic who then directed the head of the psychiatric unit to select two nurses for the study. These nurses who met the researcher's criteria for inclusion were interviewed. Participation in the study was voluntary and participants were assured that they could opt out of the study at any stage. Participants were given consent forms to sign as evidence of their approval to be part of the research. The researcher sought permission from participants before their voices were audio-recorded.

All the participants were informed of the purpose and objectives of the study. The participants' privacy, confidentiality and anonymity were assured. The researcher ensured that the identities of participants were not revealed to any third party and also ensured that the information given could not be used to trace their identities. The researcher used code identifier such as PLWE for persons living with epilepsy and nurse, official and caregiver for key informants with their corresponding numbers in place of the actual names of the research participants. The authors of all used literature were duly acknowledged to avoid plagiarism.



CHAPTER FOUR

PRESENTATION OF FINDINGS AND DISCUSSION

4.0 Introduction

The chapter presents the findings of the study in terms of the demographic characteristics of participants, perceptions of persons living with epilepsy (PLWE) and key informants regarding the disease and the challenges faced by PLWE. Also, presented in this chapter are coping strategies adopted by PLWE and the kinds of support available to PLWE. Moreover, the chapter discusses the findings of the study. The researcher used code identifiers like PLWE, caregiver, nurse and official to conceal the identities of the participants to ensure confidentiality and anonymity.

4.1 Presentation of the Findings

4.1.1 Demographic Characteristics of Participants

The demographic characteristics of participants living with epilepsy comprised age, marital status, religious background, educational level, employment status and the number of years lived with the disease. The ages of PLWE ranged between 20 and 55 years. Four of them were between the ages of 20 to 30 years and five were between the ages of 31 and 40 years. Also, two of PLWE were between the ages of 41 and 50 and the remaining three were between the ages of 51 and 55 years. The age categories implied that most of the participants living with epilepsy were youthful. With regard to the age range, it enabled the researcher to receive diverse views concerning their experiences about the disease.

Regarding the sex of PLWE, they were seven males and seven females who participated in the study. It was evident from the study that, the disease had affected both women and men. The marital status of participants was explored. The study found that the PLWE who were single, divorced and widowed were 10, three and one, respectively. The researcher sought to find out the religious status of participants. It was revealed that 13 PLWE were Christians and one was a Muslim. Many PLWE had had basic school education and few of them had secondary school and form four education. But most of them could not complete their various levels of education because of frequent seizures. The researcher found that seven of the participants were self-employed, six were unemployed and one was employed. Those who were self-employed were engaged in petty trading and menial jobs. All PLWE were experiencing generalised seizure type and had lived with the disease for 20 years and above.

The key informants were 30 years and above. The caregivers had been providing support for PLWE since they were diagnosed of epilepsy, thus 20 years and above. The nurses and officials had been practicing and working in their various fields in the interest of PLWE for more than five years.

4.1.2 Perceptions of Persons Living with Epilepsy and Key Informants about the Disease

It was evident from the study that epilepsy was perceived differently by both PLWE and key informants. From the findings, four perspectives about the disease emerged. These perspectives were: (a) epilepsy as a spiritual disease and (b) epilepsy as a curable disease espoused by many PLWE and caregivers who also revealed that community members perceived; (c) epilepsy as a contagious disease. The fourth perspective: (d) epilepsy as a medical condition was opined by nurses and officials of Kaneshie Polyclinic and BasicNeeds-Ghana and few PLWE.

4.1.2.1 Epilepsy as a Spiritual Disease

For some PLWE and caregivers, epilepsy was a spiritual condition caused by family, community members and as a punishment for the atonement of sins. For example, a participant who perceived the extended family to have given him the disease said that,

I think my grandfather afflicted me with this shameful disease to stop me from becoming the great person I was meant to be in my family. Everybody tells me that this is a spiritual sickness ... given to me by my extended family. Sometime ago, my grandfather; a traditional herbalist (healer) asked my parents to bring me to him to cure within a year which they declined. I was not surprised at his request ... I knew he gave me this disease ... he would have made it worse with more seizures if I had gone (PLWE 13).

Another participant revealed that some community members spiritually afflicted him with the disease:

I think it is a spiritual disease that some people in this community have afflicted me with it to prevent me from succeeding in life. I think they envy my family's good image. Look, look at me do I look like somebody who has epilepsy? No! I do not. They saw my brighter future and decided to give me this disgraceful disease which has no cure until one day, you die (PLWE 3).

With regard to the atonement of sins, a participant explained:

I think I am being used to pay for certain sins my father might have committed when he was a chief before he died. I also think I am paying for the sins of my grandmother who, my mother told me, refused to show appreciation to the gods when they gave her a child

upon her request. I think the gods should have visited their anger on her and not me
(PLWE 4).

A caregiver also was of the view that there was a spiritual force behind the disease for which reason it had not been cured for all these years, in spite of the medications:

I think it is a spiritual disease. If not I do not understand why as at now the disease has not been cured, despite the consultations with traditional healers and spiritual churches in the early stages and now being put on medications for all these years. I am sure there is a spiritual force behind this disease such that it is only God who can be of help
(Caregiver 1).

4.1.2.2 Epilepsy as a Curable Disease

Another perception held by PLWE and caregivers was that the disease was curable. As a form of treatment to cure the disease, most persons living with epilepsy and their caregivers consulted traditional healers and spiritual churches. Regarding treatment from a traditional healer, a participant indicated that,

Yes, since the inception of this disease we have visited a lot of traditional herbalists in the name of looking for healing but all have proofed futile. We visited Kwahu, Mankessim and somewhere in Akwapem area. We just wasted our monies on them without getting cure for him (Caregiver 1).

For a participant, the spiritual church was an option:

When I was in the village, my mother took me to a pastor who told me that epilepsy was a spiritual disease. He also showed me the person who had afflicted me with this disease which I believed. He then gave us directions; to put coins on my bed and sleep on them, woke up and share the coins to people which I did. Seizure occurrences stopped, but I had a relapse after few months when I was brought to my grandmother in Accra. Here, not sooner than I had started learning a trade and I started to experience recurrent seizures again. I was sent to another pastor for prayers, but the seizures did not stop (PLWE 12).

A participant revealed how persons living with epilepsy consulted a lot of these spiritual churches and only sought medical care when all of that had proofed futile:

Yes, before they are even directed to us at the hospital, they would have gone to consult with these spiritual churches and/or prayer camps. For them, they think it is not a medical condition, but a spiritual condition that needs, of course, spiritual healing. Such perceptions affect early diagnosis and treatment which are very important in the healthcare delivery process for patients living with epilepsy. I think there should be more education on epilepsy as a medical condition (Nurse 2, KPC).

4.1.2.3 Epilepsy as a Contagious Disease

Some PLWE and caregivers revealed that community members perceived epilepsy to be contagious and one could get infected by coming in contact with PLWE. For instance, as regards how PLWE were not assisted in cases of experiencing seizure because of the perceived infectious nature of the disease, a participant indicated that,

Whenever I get an attack, no one around me wants to help me. They think it is infectious for which reason they do not want to come close to me. They say when I salivate in the process of seizure, and they come in contact with it they would be infected with the disease (PLWE 10).

Close relatives also perceived epilepsy to be contagious:

Hmmm, my sisters with whom I stay in this compound house also believe the disease is infectious ... they would not want to associate with me. They would not give me common food to eat and would not have anything to do with me to avoid infection (PLWE 11).

A participant indicated that community members viewed epilepsy to be infectious:

When I am busy and I ask him to sell sachet water to the customers, they refused to buy from him and insist that I sell to them. Sometimes, some people will not allow him to either touch or play with their children. Some people simply do not want him to come close to them. All of these things are happening because people think epilepsy is contagious (Caregiver 1).

Another participant narrated the ordeal of a patient living with epilepsy,

One of my clients was doing petty trading in a school. One day she had a seizure and the school children refused to buy from her for fear of getting infected. At times, her relatives in the house do not want to touch the bowls she uses to eat. Because, they perceive that the stains of saliva on the bowls can infect them with the disease. Now, she is jobless (Nurse 2, KPC).

4.1.2.4 Epilepsy as a Medical Condition

Nurses, officials and few PLWE viewed epilepsy as a medical condition. According to them, the only way to manage the disease was through consistent taking of AEDs. A participant who believed epilepsy was a medical condition and had nothing to do with spiritual forces had this to say,

Whether or not the cause is by any spiritual means, I don't want to go there. I do not believe in spirituality. If you follow this spiritual people you will be misled. In my house we don't believe in such spiritual things. When I went to the hospital, the doctor said it is caused by something in my brain and not any witches and wizards (PLWE 1).

Another participant believed epilepsy to be a medical condition caused by certain predisposing factors:

The cause of epilepsy is really unknown, but we have predisposing factors which contribute to it. These factors are the improper handling of delicate heads of babies at birth by traditional birth attendants (TBAs) either during or right after delivery in the name of reshaping the baby's head. The effect of which is brain injury ... which signs and symptoms can be shown through fits or seizures, hence, epilepsy. Tumor grown in the brain can also cause seizures, sudden withdrawal symptoms from alcohol intake and certain medications can also result in seizures (Nurse 1, KPC).

Epilepsy could be caused by accidents, prolonged labour and fevers; a participant explained:

They are a bit complex. But those that are easily talked of are mainly through car accidents, prolonged labour that tends to cause head injuries and damage to the brain of a baby and convulsive fevers through unwell treated malaria (Official 1, BNG).

4.1.3 Challenges Faced by People Living with Epilepsy

Challenges faced by PLWE in their daily lives were explored. The study found that PLWE faced diverse challenges. They were (a) stigma and discrimination, (b) inability to complete school, (c) unemployment, (d) inadequate healthcare (d) difficulty finding marriage partners and (e) financial constraints.

4.1.3.1 Stigma and Discrimination

Stigma and discrimination was identified as one of the challenges faced by PLWE. Many PLWE expressed concern that because of their disease they were laughed and mocked at by some community members because of their experience of seizure in public places. Besides, key informants who worked with PLWE also experienced stigma and discrimination through stigma by association or courtesy stigma. A participant explained how she became a subject of mockery and labelling in the community after a seizure experience:

Sometimes, I get seizure outside home. When I regain consciousness and I am told of how destructive I became, I feel very ashamed of myself. I feel very uncomfortable when I am using the same route of the incident the following day. More to it is that I hear people talk about me and point fingers at me in reference to the incident. Some call me names like “belebele” meaning an insane person in Ga. At church, though I have good

relationship with the church members, I am not sure what members would discuss about me in my absence; they are all the same (PLWE 4).

Another participant who was discriminated against by his siblings revealed that,

Even though my sisters prepare “kenkey” to sell to the public, they would not give me some to eat. One day I had an attack ... people came around to catch a glimpse of what was happening to me. None of my sisters even came around to help me until I regained consciousness. They see me to be an outcast. For me, the stigma and discrimination starts from my own house (PLWE 11).

Other participants believed that the social stigma alone made PLWE to self-discriminate and see themselves worthless and not part of society:

It is a challenge for PLWE to think that they are not who they are; it makes them self-discriminate. The issues of social stigma permeate the other areas of economic, education and marriage. People are not educated on how to manage people living with epilepsy, they stigmatise against them on the grounds of their illness (Official 2, BNG).

Sometimes combination of stigma from family and community re-enforce their own self-stigma to think that they are useless and worthless. Regarding the condition, PLWE think they should not sit in people to avoid attracting attention and for fear of infecting them with the disease. As a result, they begin to live very secluded lives (Official 1, BNG).

For other participants, they were stigmatised by their colleagues and community members through stigma by association or courtesy stigma. For example, a participant explained:

At times when they are at the Out-Patient Department (O.P.D) in a queue to go for review, some of them experience seizures. Then, the general healthcare nurses would call us to come and take care of our people. They would not even provide first aide before we go in to help the situation. This is a form of stigma like your people your people as if they are not their patients too (Nurse 1, KPC).

A participant gave two views on stigma by association:

Yes and no. Yes in the sense that people may think ... they are capable of infecting you with the disease. No, because as a result of our work with them all of these years, people have rather seen that they are a vulnerable group being assisted than they have always thought. Secondly, we have been able to disabuse the minds of people ... as you can see none of the workers of the organisation has been infected. So people now regard us positively than initially ... there are still some doubts (Official 1, BNG).

Exceptionally from the findings was that some PLWE were able to concentrate on their economic activities without any fear of discrimination. This was because their seizures only came in the night. A participant explained:

As a communication center operator, my customers are not aware of the fact that I have epilepsy, because I do not have seizures in the day time at the workplace. I experience seizures only in the night ... has helped me to do my own work without much difficulty. Though, we are many here at the road side, the people still buy from me (PLWE 2).

4.1.3.2 Inability to Complete School

Some PLWE also faced educational challenges. Persons living with epilepsy experienced low retentive memory, forgetfulness and inability to study for long hours because of the side effects of AEDs. Some experienced frequent seizures which resulted in absenteeism and eventually dropped out of school mid-way. As a result, they were unable to complete school.

A participant who dropped out of school because of frequent seizures indicated that,

The occurrence of seizure became very frequent and my mother asked me to stop schooling. I was always brought home because of seizures which disrupted my academic work. I missed a lot of classes because of absenteeism. I am worried that I was unable to complete school; what at all can I do without education and not able to learn a trade in today's world, hmmm (PLWE 3).

Regarding the side effects of AEDs, a participant said that,

I learn a lot, but whatever I learn does not stay in my head. Though I have completed senior high, I failed in almost all the subjects. During the exams period, I could not remember anything I had studied for the exams ... I forgot everything. I am sure the side effects ... dizziness, drowsiness, loss of concentration ... of the drugs like carbamazepine and the phenytoin I was taking might have partly contributed to this problem (PLWE 7).

Another participant asserted that PLWE were unable to go through normal education:

They may not have the ability to go through normal education to get good qualifications. Some have not been able to go to school and even if they have; they have become drop-outs because of recurrent seizures (Official 2, BNG)

4.1.3.3 Unemployment

Also, the study found unemployment as a challenge faced by PLWE. Those who were able to secure jobs concealed their health condition before they were employed. For example, a participant who had continued to conceal her health status from her employer and colleague employees narrated that,

I did not disclose my health status ... still have not, when I was being employed as a sanitation worker. If I did, they would not have employed me. At the site one day, when I felt like I was going to have a mild seizure I lied down somewhere under a tree. When I felt okay, the supervisor enquired about what was wrong with me. I lied and said I was sick. He then asked one of the truck drivers to bring me home. He would have sacked me immediately if I had told him the truth (PLWE 6).

But when the employers got to know their health status later, they were sacked:

I was working with a university canteen and I had seizure one day. They have medical doctors in the university. So, when I regained consciousness they approached me and told me to my face that I have epilepsy. Although, I lied and told them I did not know about it, they insisted I knew and sacked me immediately. I did not disclose my sickness to anybody for fear of not getting the job until I had the seizure. Prior to getting the job at the canteen, I had moved from one place to another in search of job, but to no avail. Wherever I went, employers denied me a job when there was one because of the disease. Now, I am jobless (PLWE 14).

The inability of PLWE to get employed could be related to lack of right qualification. A participant indicated:

So they do not even have the right qualification to be able to work. Sometimes too it is the system; people are not educated on how to manage people living with epilepsy ... they do not want to employ them (Official 2, BNG).

Other participants explained how they became jobless:

I was working with a man at Kaneshie First Light. One day I experienced seizure. Although, it was not serious and I could concentrate on my work, he sacked me. I have become jobless (PLWE 2).

Eee, working no! I am not working ... anytime I try to get a job the employers do not employ me because of my disease. I think the employers think I would infect my colleague workers with the disease, I would be unable to work up to expectation or I am incompetent because of epilepsy (PLWE 11).

4.1.3.4 Inadequate Healthcare

They study found that persons living with epilepsy had difficult accessing healthcare. Also, they experienced certain health implications because of epilepsy. For instance, a participant who has not received medications from the polyclinic for the past one year had this to say,

For the past one year, we (PLWE) have not been getting drugs from the polyclinic. Whenever we go to the clinic, they say government had not brought some to them yet. It appears they always run out of stock with medications. Hmmm, it is not good for me because when I experience seizure I sustain a lot of injuries (PLWE 14).

A participant recounted PLWE's lack of access to drugs and specialists (neurologists):

Yes, we do not have a permanent neurologist here. He comes from 37 Military Hospital to review our patients monthly ... now, it is twice a year. Also, this condition should not even be under the psychiatric unit as a psychiatric problem. It is a general health condition and should be part of the general healthcare service delivery system ... people living with epilepsy should be able to walk to any health facility for medical care including medications. Sometimes there are shortages in the provision of medications ... patients come to the unit to complain of relapses. We are just hoping and praying that the National Health Insurance Scheme (NHIS) can cover their medications (Nurse 2, KPC).

Participants also experienced other health conditions like physical injuries and language difficulties because of epilepsy. For example, some participants recounted some health effects of epilepsy in their lives:

I experience other conditions like short memory; I am very forgetful. I have injuries on my body and my face as a result of scratching my face on the wall when I get attack in the bathroom. I used to put on weight, but I have reduced in same when I consistently have seizures (PLWE 4).

One day whilst bathing; had seizure ... scratched my face on the floor and sustained a lot of injuries. As you can see, I am really injured. Sometimes too I hit my leg against objects ... I become very destructive too. I cannot use my left hand and leg; they are virtually paralysed because of the disease. Hitherto, I could use both of them to do anything (PLWE 10).

4.1.3.5 Difficult finding Marriage Partners

Difficulty finding marriage partners was also identified as one of the challenges of PLWE. Meeting people and new friends and starting new relationships is an important aspect of human life. However, for PLWE new relationships and marriages became short lived when the other parties realised that they had epilepsy.

A young man would wish to feel loved and appreciated by the opposite sex. But it was not the case for a participant, who busted into laughter and narrated his story when the researcher asked whether or not he would wish to marry one day:

Hahahaha, what lady would decide to marry me with such a burden? I had a girl friend who did not know I had epilepsy. When she got to know, she parted company without even informing me. I do not think I would like to get married in future (PLWE 7).

Those who were fortunate to marry, later in life got divorced or separated when they experienced frequent seizures. A participant narrated her ordeal in the hands of a supposed elder of a church:

The disease has become a padlock to my life's happiness and joy. If not I would have been a married woman going about my normal everyday work. I met an elder of a church; we dated and got married around 2004. There was an issue and we had a child. When he got to know that I had this disease having had a seizure in his presence; he informed the mother who asked him to break up with me which he did (PLWE 14).

Men do not want to marry women living with epilepsy, a participant revealed:

Of course, on the issue of marriage and relationships, it is a great concern. Because of social stigma, no man wants to marry a lady living with epilepsy; no matter how beautiful she is (Official 1, BNG).

Contrary to other findings, the study found that a man did not divorce his wife living with epilepsy because he had a person living with epilepsy in his family. He, therefore, married the woman and supported her until he passed on six years ago as at the time of the interview with the participant who explained her story:

Oh, he married me before I was diagnosed of epilepsy. I started having seizures when I was pregnant with my second child. The seizures were very frequent, but it is better now. My husband upon realising that I had epilepsy had wanted to divorce me, but his mother advised him not to because they also had a family member with epilepsy. He therefore lived with me and we had four children before he passed on. After his death I have decided not to get married again to avoid troubles from any man who might marry me and divorce me later upon realising that I have epilepsy (PLWE 8).

4.1.3.6 Financial Constraints

Persons Living with Epilepsy experienced financial difficulties. They were unable to maintain their children they had had with their partners who had divorced them. They also were unable to purchase their medications. For example, a participant explained his difficulty in purchasing the drugs:

I cannot buy the drugs, if I do not get some from the clinic for free. I do not have money, because people hardly buy from the small table-top-provisions business I am doing. My sisters also do not help me (PLWE 10).

A participant explained the cost of the drug; cheap yet difficulty for PLWE to buy:

There are various types ... the common medication is Carbamazepine. This drug is provided for PLWE by government. When there is shortage we ask them to go and buy it from pharmacies outside. A patient needs GHC 35.00 to buy the medications for a month, yet they complain of financial difficulties ... they cannot buy (Nurse 1, KPC).

Another participant explained the financial difficulty in maintaining her four children:

Unfortunately, two men impregnated me and I have given birth to four children; two for each without marrying any of them because I have epilepsy. One of them does not even bring me money to maintain the children ... now a burden on me, a jobless mother and my family. I and my mother do not have enough money to maintain these children (PLWE 10).

Another participant narrated how her husband abandoned her and two children without financial assistance upon discovering that she had epilepsy:

When my husband realised that I had epilepsy he left me and the children. He totally abandoned me and the children and has never sent money to maintain the children. Since then it has been very difficult taking care of the two to the university level; one has finished and the other one is in the final year. Now, money to buy drugs is also hard to come by. This makes me miss some of my medications some times (PLWE 5).

For a participant consistent taking of the drugs has a financial burden on poor PLWE:

Yes, some really have difficulties; they say the drugs are expensive. When they are on the drugs, they would have to take it every day until such a time that the doctor would diagnose that they are okay. They do not have money, therefore they are unable to buy the required quantity of drugs for the required period of time when they do not get some from the clinic for free (Official 2, BNG).

4.1.4 Coping Strategies Adopted by Persons Living with Epilepsy

In dealing with the challenges of epilepsy, several coping strategies were adopted. These were exclusion and concealment of the disease, involvement in religious activities, engagement in economic activities and social support.

4.1.4.1 Exclusion and Concealment of the disease

By adopting the exclusion style of dealing with the disease, PLWE separated themselves from other stressful events related to the condition and not the disease. They also concealed information about the disease to prevent stress-inducing behaviours and stigmatising and

discriminatory attitudes shown by people. For a participant, to conceal his disease to avoid losing friends and customers was his style of coping:

I think I should not be telling people about my disease, if not they would shun my company and not even buy from my mother's shop again where I get money for my upkeep. If they get to know they would begin to stigmatise and discriminate against me (PLWE 9).

A participant who had refused to react to comments from other people about her health status revealed:

Now, I do not react to comments from people about my disease when I am walking in the community. No matter what you do, they would talk about you and call you names. The least I care about them and their comments, the better for me. If I do not mind them, I think one day they would stop (PLWE 4).

Another participant who believed that withholding his health status was the best mechanism for coping had this to say,

Except the land lady on whose land I do my business, no one is aware of the kind of disease I have. Everybody buys from me. Parents have even asked me to help their children cross the road when they are coming to and from school. If the people around here know about my illness, they would not buy my recharge cards and parents would not allow me to help their children cross the road for fear of infection (PLWE 2).

4.1.4.2 Involvement in Religious Activities

Some of the PLWE coped with the disease by getting involved in religious activities and fellowshiping with brethren in their various churches. This strengthened and kept them moving on in life. A participant whose faith in God and His word helped him to cope explained:

It is God and His word that strengthen me in the face of the disease. Because of the word of God in which I have faith and trust, I do not live in fear. I am able to even go to church at Kasoa and come back to continue my work. I become happy when I meet brethren at church and we share the word of God together as one family (PLWE 2).

Another participant who believed that in the absence of help from the paternal grandfather, a traditional healer, it was only God who could help in him this situation said that,

The attendance at church service and listening to God's word has also been helping me cope with the disease. The almighty God is the creator of the universe and everything within it. So, He knows about my disease and would give me the strength with which to cope, since my grandfather and other traditional healers could not heal me of this disease (PLWE 13).

4.1.4.3 Engagement in Economic Activities

Some of the participants had taken interest in engaging in certain economic activities to cope with the disease. For instance, a participant who sold oranges to cope indicated that,

I love to sell my oranges in front of our house. I go to buy them from the market myself and come to peel them to sell. The business is slow, but it is better than not doing anything at all. I also help my mother to sell water in the house. I become happy and

experience fewer seizures when I am engaged in such economic activities and it also helps me with some little money to help in the purchasing of drugs (PLWE 5).

Another participant recounted how he supplied water to some people in the community for money to help him purchase his medications:

I supply water in a container to some interested members in this community for a fee. The money I get from this economic activity help in the purchasing of my medications and also for my feeding. Although, my parents assist me with some money I also need to work to help myself. I have my customers, so whenever they need water they call me and I supply them (PLWE 13).

4.1.4.4 Social Support as a Coping Strategy

As part of lifestyle management in coping with epilepsy, it was evident from the study that PLWE had self-help groups or social support networks. As members of this support group, PLWE met on monthly basis to share ideas and knowledge regarding the best ways they could cope with the disease to ensure their quality of life.

A participant who depended solely on the self-help group shared his experience and said that,

As I have already indicated, my sisters are not helping me at all. So, apart from the little money I get from my petty trading, I depend on the self-help group through which I get my medications from the polyclinic whenever I run out of it. When we attend meetings, the advice from colleagues gives me hope that all is not lost and I am not alone (PLWE 11).

Another participant agreed to the immense contributions of the group to members and said that,

They share experiences on best practices; especially in the case of the caregivers as to how to give PLWE medicine like those who are totally dependent. Some would even say that for them they put the medicine in their food for them to take. Also, when they meet the PLWE see themselves as not being alone, but are with people who are ready to help them cope with the situation (Official 2, BNG).

4.1.5 Support Available to Persons Living with Epilepsy

There were kinds of support from caregivers, government and NGOs. Persons living with epilepsy alone would be unable to handle these challenges associated with epilepsy and therefore, these kinds of support come to them as a big relief.

4.1.5.1 Support from Caregivers

Some PLWE could not do without the strong support from caregivers in the face of this disease. The caregivers were parents and close family members. They provided PLWE with financial assistance to help in the purchasing of their drugs, emotional assistance by giving them hope for the future and support in their daily activities like washing and cooking.

A participant acknowledged the immense contributions of her family in her life and said that,

My mother has been my saviour; she has been taking care of me and my two children ever since the situation became worse. I do not know what I would have done without her in my life in times like this. Now that my daughters have become matured ladies they also assist my mother in taking care of my drugs. They tell me not to worry ... one day the

disease would go. Though, I cannot rule out certain difficulties sometimes, it is better than without them at all (PLWE 5).

Another participant who provided the necessities of life for her daughter living with epilepsy and the grand-daughters said that,

A lot of assistance in terms of her feeding, items of clothing she would wear, going to the hospital, to church, and taking care of her two kids one of whom she had with one church elder who has shed his responsibility over the child. Have a look ... I bought a uniform for her to go to school on Monday (Caregiver 2).

For a participant, she narrated the assistance she has rendered to her son living with epilepsy:

I wash his clothes when they are dirty. I ensure that he brushes his teeth; if he does not do it well I help him. I make sure that every two weeks he goes to the barbering salon to have his hair cut. I take care of his feeding ... eating a lot of fruits like banana, since I have identified constipation to be a trigger of his frequent seizures. In one of our self-help group meetings, I heard of the story of caregiver whose timely intervention save the grand-daughter whose mother was experiencing seizure and fell on her baby in her sleep. Caregivers, we are important (Caregiver 1).

4.1.5.2 Support from Government

The study found that persons living with epilepsy receive monetary assistance from government through the Accra Metropolitan Assembly (A.M.A). Persons living with epilepsy also received free medications from government through the polyclinics where they accessed their healthcare.

Regarding the assistance received from government, participants explained:

I know the drugs we get from the polyclinic are for free. Government provides the medications for us. But sometimes we (PLWE) do not get some of the drugs. Sometime ago, we had some monies from government through the Accra Metropolitan Assembly (PLWE 11).

Some time ago, we received some money from government through the district assembly common fund. I used the money to engage in an income-generating business which is helping me in providing for the needs of my child. Since then we have not received anything from government again; not that I know of. They say government provides the drugs like phenobarbital, phenytoin and carbamazepine we get from the polyclinic (Caregiver 1).

4.1.5.3 Support from Non-Governmental Organisations (NGOs)

The study revealed that PLWE received monetary assistance from NGOs like BasicNeeds-Ghana. Some also received tools like sawing machines to learn various trades of their choice. In the case of the monetary support, the financial assistance were given to caregivers of PLWE whose conditions would either not allow them to learn a trade or invest the money in any income generating activity.

A participant recounted the kinds of assistance he received from BasicNeeds-Ghana:

I do not have any caregiver in the house, though I stay with my sisters who prepare 'kenkey' to sell to people; they don't even give me some to eat. They do not give me money to buy drugs. My only support is BasicNeeds-Ghana and the self-help group we

have here. The organisation has been helping with the drugs we get for free from the polyclinic (PLWE 11).

Another participant indicated that PLWE were put into apprenticeship training to learn various trades of their choice,

Apart from facilitating the drugs for them, we have put some of them into apprenticeship training in the areas of carpentry, hairdressing, tailoring, and assisting the careers of those whose conditions cannot permit them to learn any trade to engage in economic ventures. This ensures that PLWE in the family are well taken care of (Official 1, BNG).

For a participant, BasicNeeds-Ghana is the only NGO supporting them in healthcare delivery for people living with epilepsy:

As long as I am here, the only organisation I have witnessed their support is BasicNeeds-Ghana. They used to come up with quarterly outreach programmes. But now it is bi-annual that is twice a year. They support us with some few medications to augment the one we get from the central medical store at Korle-Bu Teaching Hospital. We do not get any support from any other organisation, not even a church (Nurse 1, KPC).

4.2 Discussion of the Findings

This part of the study discusses the major findings in line with the reviewed literature and the theoretical perspective for the study. The main focus of this study was to explore the experiences of PLWE in Accra, Ghana. Relating to the perceptions of PLWE and key informants regarding the disease, the study revealed that many PLWE and their caregivers perceived epilepsy as a spiritual disease. These perceptions support the notion of Twumasi (2005) that social wrongs and

punishment from the gods are seen strongly as the cause of diseases in Ghana, rather than microbial or other infectious agents and genetic causes.

The study found that PLWE and their caregivers believed epilepsy was spiritually caused by family, community members and as a punishment for the atonement for the sins of their forefathers. This supports the studies of de Boer (2010) and Andermann (2000) who reported that PLWE are perceived to be possessed, chosen by spirits, bewitched and punished for sinning. Also, PLWE and their caregivers believed that epilepsy was curable. Therefore, they consulted with traditional healers and spiritual churches to find treatment for their illness supporting the study of Nyame and Biritwum (1997) who found traditional beliefs and attitudes about epilepsy among a working population and the use of herbs, visits to fetish priests and prayers as treatments for PLWE.

Persons living with epilepsy and caregivers asserted that community members perceived epilepsy to be infectious. As a result, family and community members would not extend helping hands to PLWE in cases of seizure experiences resulting in PLWE sustaining injuries. This finding is similar to that of Adjei et al. (2013) who found that community members perceived epilepsy as a contagious disease.

Persons living with epilepsy and caregivers had poor knowledge about their own disease which could partly explain their perceptions about the disease. Their perceptions about epilepsy have been influenced by their interactions with the systems in the community and the inability of government and stakeholders like the public health division of Ghana Health Service to provide education on epilepsy affecting the way PLWE judge and perceive the disease as explained by the ecological systems theory (Bronfenbrenner, 1979). As found from this study as well as other

studies by Kabir et al. (2005), Shorvon and Farmer (1998) and Nyame and Biritwum (1997), many people do not know the cause of epilepsy.

The study found that few participants perceived epilepsy as a medical condition which is consistent with the assertion of Diop et al. (2003) who reported epilepsy as a common serious neurological disorder, caused by abnormalities in the electrical activity of the brain. Also, the participants were of the view that the cause of epilepsy was not yet known, but there were predisposing factors like prolonged delivery; head injuries during labour and car accident; poorly treated malaria and convulsive fevers which affect the brain activity and had nothing to do with spirituality. Therefore, they believed that the consistent taking of the antiepileptic drugs (AEDs) would manage epilepsy by minimising the occurrence of seizures for PLWE to be able to attend to their normal daily activities.

Contrary to the educational levels of many PLWE and caregivers who perceived epilepsy to be a spiritual disease, the few PLWE who supported the medical perspective had completed form four and secondary education. Therefore, their perceptions about the disease were influenced by their level of education consistent with the study of Nyame and Biritwum (1997). They found that the educational levels of their working class participants were positively related to the appropriateness of the responses.

The cultural orientations and beliefs about epilepsy as a spiritual and contagious disease in Ghana had made PLWE to face various challenges, especially at the macrosystem level as explained by the ecological systems theory. One major challenge was stigma and discrimination. They encountered stigma and discrimination at their workplaces, schools, churches, communities and even in their families consistent with the study of Thomas and Nair (2011). For example, in

their communities, some PLWE experienced enacted stigma, thus they were called names and mocked at.

As explained by the ecological systems theory, the microsystem and macrosystem influence the development and actions of individuals. Also, found in the study was stigma by association where those who worked with PLWE were stigmatised by their colleague workers and members in the communities in which they worked. Some community members perceived that those who worked with PLWE could also be infected with epilepsy. The findings agree with Parfene et al. (2009) who asserted that people who are not members of a stigmatised group may nevertheless suffer the same scorn and discrimination of the stigmatised group because of their associations with them through friendship or the performance of professional duty.

Contrary to the findings of other studies (Thomas & Nair, 2011; Parfene, 2009), this study found that two participants; one of whom was engaged in the sale of mobile phone cards and the other seasonal poultry farming were active on their jobs without experiencing stigma and discrimination. This was because they experienced seizures only in the night. Community members were did not know about their disease; and patronised their services and products.

The study found that many PLWE were unemployed, thus they had difficulty finding and sustaining jobs. Those who secured jobs could not maintain them, since they were sacked when employers discovered that they had epilepsy. The findings support the studies of Mugumbate and Nyanguru (2013) and Jennum et al. (2011) who found securing adequate income and finding and maintaining employment as a major challenge faced by PLWE who also have lower employment rates. As explained by the ecological systems theory, the inability of government to enforce laws;

thus to effectively implement the Mental Health Act, 2012 (Act 846) portions of which ensure the rights of PLWE to employment, influence the employment challenges faced by PLWE.

It was evident from the study that in the absence of any employment opportunity, PLWE resorted to self-employment in which they were engaged in various menial jobs. Such jobs were supply of water to community members for money; sale of cooking oil and oranges on road side; table top provisions and collection of empty sachet water for sale. They were engaged in these various economic activities partly for the purposes of raising some money to help in purchasing their medications. However, some faced enacted stigma where some community members refused to buy from them because they had experienced seizures at their places of work and there was the fear of infection.

Access to health care that facilitates accurate diagnosis and effective treatment and management of epilepsy (England et al., 2012) is important for PLWE. However, PLWE experienced the challenges of having access to adequate healthcare. Persons living with epilepsy had difficulty accessing medications and specialist care from government polyclinics. They had not received medications from the polyclinics designated to provide such AEDs for the past one year; as at the time of conducting this research agreeing with the report of (WHO, 2005) which indicated that few PLWE receive adequate medical treatment, and most do not receive treatment which is attributable to lack of medical personnel and non-availability of medications.

This problem could be blamed on government's inability to provide the medications and ensure well trained nurses and neurologists to attend to the health needs of PLWE. As explained the ecological systems theory, the macrosystem greatly influence the experiences of PLWE. Persons living with epilepsy also experienced some health implications such as intellectual disability,

dizziness and injuries from seizures and suicidal thoughts. Four out of every ten PLWE suffer from mental disorders such as depression, schizophrenia, intellectual disability and alcohol use disorders (WHO, 2009) and a higher risk of committing suicide (Christensen et al., 2007).

Another challenge experienced by PLWE was their inability to complete school. This was due to seizure disturbances and side effects of medications such as absenteeism and low academic performance agreeing with WHO (2005) that side-effects from medications affect cognitive functioning and result in secondary psychosocial problems and absenteeism. Also, it was revealed that some parents and caregivers would not allow their children to go to school because of frequent seizures supporting the findings of Adjei et al (2013); Rwiza et al. (1993) who reported that most community members would not allow PLWE to go to school. Such educational challenges influenced parents and caregivers' decision to make them drop out of school. Those who managed to continue finished with poor grades.

Besides, the study found difficulty finding marriage partners as another challenge faced by PLWE. Many PLWE faced problems in either starting a relationship or finding a partner to begin a family. Unfortunately, those who married were later divorced resulting from seizures experiences and pressures from men's family. The findings are consistent with Agarwal et al. (2006); Adjei et al. (2013) who found that not only are PLWE less likely to get married, but also more likely to get divorced, especially women living with epilepsy.

Contrary, to the previous findings, the study found that a women living with epilepsy was not divorced by the husband because the partner also had a person living with epilepsy in his family. Although, the man had earlier on threatened to do so, his mother intervened and warned him not to divorce his wife on the grounds of her health condition which they had same in their family.

This could mean that a family may allow their member to be married to a person living with epilepsy only if that family has had experience of having PLWE.

It was evident from the study that PLWE faced financial problems which made it difficult for PLWE; especially women to cater for their children and to purchase their medications. The financial instability of PLWE stemmed from the fact that they were not engaged in any employment and the individual businesses were sometimes being hampered because of stigma and discrimination and frequent seizures. The findings support that of Ratsepp et al. (2000) who found in their study that PLWE described their economic and financial status as bad or very bad.

The challenges faced by PLWE cut across all the four systems (micro, meso, exo and macro systems) in the society as explained by the ecological systems theory. However, with the chronosystem and with time the quality of life of PLWE, knowledge concerning the condition as well as the understanding of the various cultural concepts held both by the wider society and by PLWE themselves, would be addressed and that through continuous action over the next 60 years, the situation with regard to epilepsy stigma will look very different (de Boer, 2010).

Regarding ill health, people adopt different ways of strengthening themselves to cope with the situation. Persons living with epilepsy gave various mechanisms they adopted to cope with the disorder. When the researcher posed the question whether or not they lived in fear, almost all PLWE answered in the affirmative. However, they were of the opinion that they could allay their fears if they were on consistent medications and able to adopt good coping mechanisms. The study found that all PLWE believed that taking AEDs was the first step to managing and coping with epilepsy. The findings support Moshe et al. (2015) who assert that treating epilepsy can

involve either a monotherapy, where there is the administration of one drug; or a combination therapy, which involves two or more different drugs administered together to manage epilepsy.

Apart from the medications, some adopted other coping strategies such as exclusion and concealment of the disease. Some PLWE distant themselves from comments from people that has the potential to dint their personality because of their illness supporting Piazzini et al. (2007). Other PLWE involved themselves in religious activities to cope with epilepsy. They were attending church services and fellowshiping with brethren to renew their Christian faith, praying and reading the bible. The findings support Pargament and Cummings (2010) who assert that in ill health conditions, some benefit from adopting religious practices such as prayers, attendance at church, reading sacred texts and meditation as coping strategies. Some also engaged in economic activities to keep them busy, since idleness sometimes triggered their seizures. Others could not do without their social support groups which met on the monthly basis to share ideas on how best to ensure their quality of life.

With regard to the social support, PLWE associated with people who were sensitive to their needs and feelings. Seeking for social support could mean asking for the empathy of other people. It brings people closer to PLWE for both physical and socio-emotional assistance underscoring the importance of the micro and mesosystems as explained by the ecological systems theory. Studies (GCAE, 2008) have shown increased rates in mortality and morbidity as regards PLWE through SUDEP resulting from sometimes lack of good coping mechanisms for them and feeling of loneliness.

It emerged from the study that there were kinds of support available to PLWE through caregivers, mainly family members; government and NGOs mainly from BasicNeeds-Ghana. In

respect of the caregivers, PLWE receive financial assistance, help in activities of daily living, emotional support, nutritional support and attending to the hospital. The findings concur with United Kingdom Epilepsy Society (2014) which enumerated some kinds of support caregivers provide to PLWE. They were, but not limited to keeping them safe during a seizure, helping with their routine of taking anti-epileptic drugs (AEDs) and accompanying to hospital.

The study found that BasicNeeds-Ghana had provided financial assistance, skill training and medications through self-help groups to PLWE. They collaborate with the Ministry of Health and the Ghana Health Service to assist and facilitate in the provision of AEDs to the polyclinics for onward distribution to PLWE. They organise workshops and training programmes for health professionals and help in the education and awareness creation on epilepsy. They help facilitate with the review of PLWE by a neurologist from 37 Military Hospital. The findings agree with WHO (2001) which asserts that in many cases, these organisations provide disadvantaged people access to healthcare services and often act as an intermediary between communities and government in providing services that may be less expensive and more efficient.

Furthermore, the study found that BasicNeeds-Ghana had assisted caregivers and PLWE financially and put some of PLWE who could learn various trades of their choice into apprenticeship training. BasicNeeds-Ghana also assisted in the passage of the Mental Health Act, 2012 (Act 846) which they continue to advocate for its quick and effective implementation. Non-governmental Organisations contribute to public understanding and enhance public information about health matters. There is great potential for improving public health through systematic collaboration between civil societies and government (WHO, 2001).

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction

This chapter presents the summary of the findings, conclusions drawn from the study, as well as the recommendations. Also, it discusses the implications of the findings for social work practice. Moreover, the chapter concludes with the contribution of the study to existing knowledge.

5.1 Summary of the Findings

This study sought to explore the experiences of persons living with epilepsy in Accra, Ghana. A qualitative study was therefore conducted with four objectives: (a) to explore the perceptions of PLWE and key informants regarding the disease, (b) to identify the challenges faced by PLWE, (c) to find out the coping strategies adopted by PLWE and (d) to ascertain the kinds of support available to PLWE. In-depth individual interviews using interview guides were conducted with twenty participants comprising fourteen PLWE and six key informants; two caregivers of PLWE, two nurses from the psychiatric unit of Kaneshie polyclinic and two officials of BasicNeeds-Ghana.

Many PLWE and caregivers perceived epilepsy as a spiritual and curable disease. As a spiritual disease, they attributed its cause to the family, community members and as a punishment for the atonement for sins. As a result, they consulted with traditional healers and prayer camps some of whom confirmed their spiritual beliefs about the disease and also prescribed treatment methods to cure the disease, but proofed futile. Persons living with epilepsy and caregivers also indicated that community members viewed epilepsy as a contagious disease and so family and community

members would not assist them when they experienced seizures. This made them sustain injuries in the process which worsened their already unstable health condition. On the other hand, nurses and officials perceived epilepsy mainly as a medical condition and considered early diagnosis and treatment as important in managing epilepsy.

The study found that PLWE and key informants faced challenges such as stigma and discrimination, inability to complete school as well as unemployment. Other challenges faced by PLWE were inadequate healthcare, difficulty finding marriage partners and financial constraints. The financial problems made it difficult for PLWE to purchase drugs and to maintain children whose fathers had shed their responsibilities. Some PLWE had their education truncated mid-way because of absenteeism and lack of concentration on academic work resulting from frequent seizures and side effects of medications. Men living with epilepsy were less likely than women to experience more challenges since the latter had more tasks to perform in providing the needs of their children some of whom had been left unmaintained by the men.

The study also found that many PLWE lived in fear. This was attributable to the unpredictability of seizure and sometimes the negative public reactions because of the perceived infectious nature of the disorder. However, PLWE coped with the disease through exclusion and concealment of the disease; involvement in religious activities; engagement in economic activities, and joining social support groups. Above all, participants believed consistent taking of medications which enabled PLWE to manage the disease and to surmount some of these challenges was the first step to coping with the disease. Finally, the findings of the study revealed that caregivers, government and BasicNeeds-Ghana were the sources of support available to PLWE. The study also gave recommendations that would help improve the lives of PLWE.

5.2 Conclusions

Based on the literature reviewed and the findings of the study, the researcher concludes that epilepsy is a social problem that needs to be tackled with the urgency it deserves as any other social issue in Ghana. There should be much emphasis on its perceived nature as a spiritual disease which affects early diagnosis and treatment. Although, it is widely accepted based on most epidemiological studies that epilepsy is a medical condition, it emerged from the study that PLWE and their caregivers continue to perceive the disorder as a spiritual and curable disease. Persons living with epilepsy and their caregivers were of the view that community members perceived epilepsy as a contagious disease as found in the study of Adjei et al. (2013). Such perceptions make them and their caregivers consult with traditional healers and spiritual churches whose perceived treatments in some cases fail to yield positive results. They only seek medical attention when the situation has gotten out of hand and they would have used all their resources both financial and material.

Persons living with epilepsy continue to experience challenges in their daily lives. They encounter challenges regarding stigma and discrimination and in the areas of employment, education, healthcare, marriage as well as financial constraints at the micro, meso, exo and macro levels in society as explained by the ecological systems theory. The financial difficulties of PLWE affect their ability to purchase drugs and to maintain their children whose fathers have divorced them or separated and left the children on them and their family without remitting them. The need for PLWE to identify the best coping strategies to apply and consistently take the medications to help them manage their condition and achieve quality of life cannot be underestimated.

Although, PLWE live in fear due to the unpredictable nature of seizure occurrences, they are able to cope with the disease through exclusion and concealment of the disease; involvement in religious activities; engagement in economic activities, and joining social support groups. Persons living with epilepsy and key informants believe that the most important of the coping mechanisms is the consistent taking of medications which enable PLWE to manage the disease and to surmount some of the challenges they face. Caregivers, government and BasicNeeds-Ghana are important sources of support available to PLWE.

5.3 Recommendations

Since the study found that PLWE and caregivers had poor knowledge about epilepsy, it is recommended that medical doctors, community psychiatric nurses and NGOs that are into health should embark on intensive public and community education on epilepsy as a medical condition that needs early diagnosis and treatment. This would help change the entrenched perception about epilepsy as a spiritual, contagious and infectious disease. Also, it would help reduce stigma and discrimination and other challenges experienced by PLWE in the areas of healthcare, education, employment and marriage would be eliminated.

From the study, it was evident that PLWE did not get access to adequate healthcare regarding medications and neurologists to regularly review PLWE to help them in their treatment. Therefore, there is the need for government to train more health professionals such as neurologists, epileptologists, neuropsychologists, community psychiatric nurses and pediatricians. This would help in the early detection and treatment of epilepsy, since in many cases epilepsy is diagnosed at childhood. The Minister for the Ministry of Health should direct the National Health Insurance Authority to find out the possibility of ensuring that the

medications of PLWE are covered under the scheme. It is also recommended that PLWE consistently take their medications without missing a dose to help manage the disease.

The psychiatric unit of the Kaneshie Polyclinic was found to lack logistics like vehicle and public address system to ensure health professional mobility to communities to undertake community education and awareness creation on epilepsy. Government should provide human and material resource such as vehicles, public address systems and financial assistance to this and other units. This would enable them perform their mandatory roles of reaching out to PLWE and the general public with the educative messages on epilepsy.

Also, the study found that PLWE faced high unemployment rate. The challenges of PLWE could be reduced if they are engaged in economic activities. Therefore, self-help groups of PLWE with the assistance from BasicNeeds-Ghana could access loans with flexible systems of repayment from Macro Finance and Small Loan Centre (MASLOC). This would help PLWE and caregivers to engage in income generating activities to raise income to cater for their basic needs. Also, the LEAP programme should be extended to PLWE to them with the purchase of medications and in meeting other basic needs.

Implications of the Findings for Social Work Practice

Given that, PLWE and their caregivers perceived epilepsy to be caused by spiritual forces, as educators working with communities, social workers could embark on community education and awareness creation on issues of epilepsy. This would help change the mindset of PLWE, their caregivers and community members about epilepsy and professionals who work with PLWE towards perceiving epilepsy as a medical disease that needs early diagnosis and treatment.

Since PLWE experience challenges in their daily lives, social workers as advocates could help in the effective implementation of the Mental Health Act, 2012 (Act 846) portions of which ensure the rights of PLWE. This would compel government to resource the Ministry of Health and the Ghana Health Service to ensure that the needs of PLWE are part of their mainstream plans to improve their conditions. Social workers could also render psychosocial counselling services to PLWE and caregivers on how to cope with the disease.

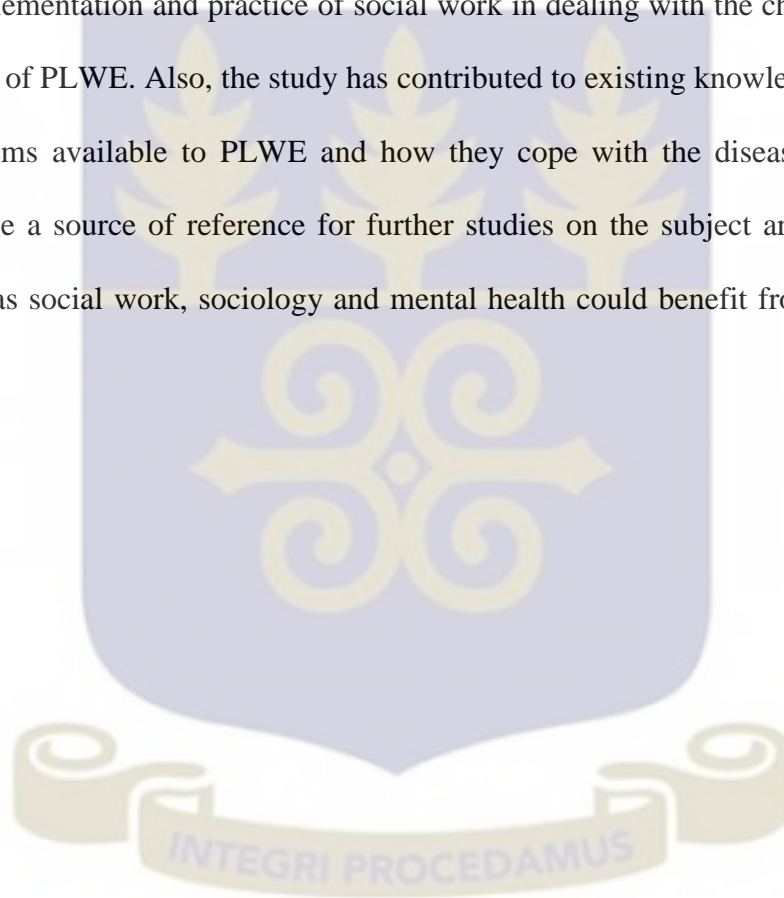
The study found that all PLWE and their caregivers were not beneficiaries of social intervention programmes of the country. Social workers could perform the roles as brokers to link PLWE and their caregivers to services like the Livelihood Empowerment against Poverty (LEAP) programme, the National Health Insurance Scheme (NHIS), Department of Social Welfare and other NGOs that can help improve their living conditions. Therefore, linking them to these programmes would help meet their basic needs and help maintain their children.

In view of the fact the researcher is a social worker, steps could be taken to ensure a collaboration between the Department of Social Development (formerly Department of Social Welfare) and BasicNeeds-Ghana. This would help PLWE who have had children with men who divorced them and are not maintaining the children to seek redress at the department. Therefore, such men would be mandated by law to be responsible towards the maintenance of their children.

Given the fact that, much research has not been done in the area of epilepsy by social workers, it is recommended that social workers should conduct further studies into the issues of epilepsy in Ghana. Future research could focus on exploring the experiences of the caregivers of PLWE. With adequate information based on research, social workers could contribute in helping PLWE to improve their quality of life.

5.4 Contribution of the Study to Existing Knowledge

In Ghana, not many studies have been conducted on epilepsy issues. In respect of this, the findings of the study have added up to the scanty existing knowledge on the perceptions about epilepsy. The study has generated knowledge on the challenges encountered by PLWE in their social, economic, religious, health and educational spheres. These findings could inform policy formulation, implementation and practice of social work in dealing with the challenges to ensure the quality of life of PLWE. Also, the study has contributed to existing knowledge with regard to the support systems available to PLWE and how they cope with the disease. Moreover, this research would be a source of reference for further studies on the subject area. In this regard, disciplines such as social work, sociology and mental health could benefit from the findings of the study.



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APPENDIX I: PARTICIPANTS' CONSENT FORM

DEPARTMENT OF SOCIAL WORK

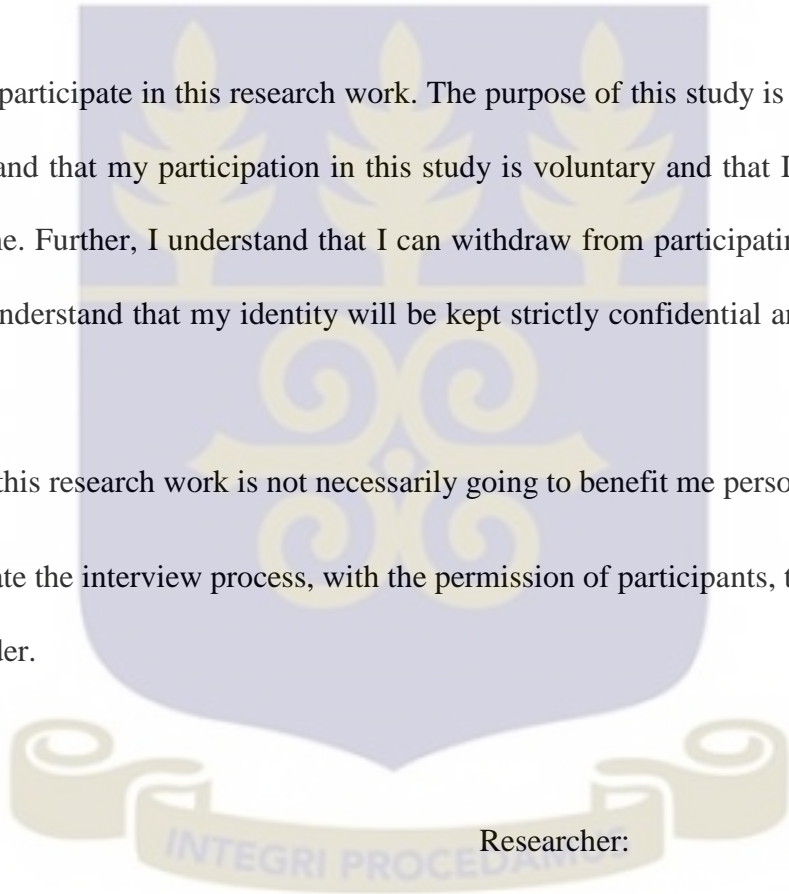
UNIVERSITY OF GHANA

The researcher is an M.Phil. student of the Department of Social Work, University of Ghana, conducting a study on the topic: **Experiences of Persons Living with Epilepsy in Accra, Ghana.**

I hereby agree to participate in this research work. The purpose of this study is fully explained to me and I understand that my participation in this study is voluntary and that I am not forced to participate in same. Further, I understand that I can withdraw from participating in this study at any time. I also understand that my identity will be kept strictly confidential and not revealed to any third party.

I understand that this research work is not necessarily going to benefit me personally.

In order to facilitate the interview process, with the permission of participants, the researcher will use a voice recorder.



Participant:

Researcher:

Signature.....

Signature

Date.....

Date

APPENDIX II

INTERVIEW GUIDE FOR PERSONS LIVING WITH EPILEPSY

DEPARTMENT OF SOCIAL WORK

UNIVERSITY OF GHANA

Topic: Experiences of Persons Living with Epilepsy in Accra, Ghana

The researcher is a student of the University of Ghana conducting this study with the above topic in partial fulfillment of the requirement for the award of a Master of Philosophy Degree in Social Work. I would be very grateful if you would spend some time with me for an interview. The information is for academic purpose. Therefore, names and identities of participants will not be required. It is noted that participation in the study is voluntary and participants can opt out of the study at their free will without any consequence.

1. Personal Information

Please, can you tell me about yourself? (Age, Sex, Marital Status, Religion, Number of children, Level of education, Type of work, Type of epilepsy and Number of years lived with the disease)

2. Perceptions of Persons Living with Epilepsy regarding the disease

What is your Knowledge about epilepsy (Meaning, causes and seizure type and frequency)?

Is epilepsy an infectious disease?

Do other people perceive it to be infectious?

Have you consulted with traditional healers and spiritual in connection with your disease?

3. Challenges faced by Persons Living with Epilepsy

How has life been for you in respect of the disease?

What are some of the difficulties you experience because of epilepsy?

Do you suffer any other conditions because of epilepsy?

Do you have challenges in accessing healthcare, employment, education and engaging in relationships?

Are you able to purchase the medications?

Do you have difficulties in either getting a job or admission to a school?

How are your relationships with your family members, community members, colleagues at work and in school?

4. Coping Mechanisms Adopted Persons Living with Epilepsy

Do you live in fear because of epilepsy and why?

What are some of the things you do to manage the challenges associated with epilepsy?

How do you meet your basic needs (food, healthcare and education)?

5. Kinds of Support Available to Persons Living with Epilepsy

Do you have a caregiver and how does he or she assist you in your daily life?

Do some of your family members help you in meeting your basic needs?

Does any organisation assist you in meeting some of your basic needs?

How does government help you in providing some of your basic needs?

What do you think can be done to improve your quality of life?

APPENDIX III

INTERVIEW GUIDE FOR KEY INFORMANTS-CAREGIVERS

DEPARTMENT OF SOCIAL WORK

UNIVERSITY OF GHANA

Topic: Experiences of Persons Living with Epilepsy in Accra, Ghana

The researcher is conducting this study in partial fulfillment of the requirement for a Master of Philosophy Degree in Social Work. I would be very grateful if you would spend some time with me for an interview. The information is for academic purpose. So, information provided will be strictly confidential and no names or identities will be required.

Questions asked

What is your Knowledge about epilepsy (Meaning, causes and seizure types)?

Is epilepsy an infectious disease?

Have you consulted with traditional healers and spiritual in connection with the disease?

What kinds of assistance do you give to your family member living with epilepsy?

What is the duration of support provided to persons living with epilepsy?

Do you have challenges as a caregiver?

What are the challenges faced by persons living with epilepsy?

INTERVIEW GUIDE FOR KEY INFORMANTS-

BASICNEEDS-GHANA (BNG)

DEPARTMENT OF SOCIAL WORK

UNIVERSITY OF GHANA

Topic: Experiences of Persons Living with Epilepsy in Accra, Ghana

The researcher is conducting this study in partial fulfillment of the requirement for a Master of Philosophy Degree in Social Work. I would be very grateful if you would spend some time with me for an interview. The information is for academic purpose. So, information provided will be strictly confidential and no names or identities will be required.

Questions asked

What is your Knowledge about epilepsy (Meaning, causes and seizure types)?

Is epilepsy an infectious disease?

Do persons living with epilepsy and their caregivers consult with traditional healers and spiritual in connection with the disease?

What are the challenges faced by persons living with epilepsy?

What are the programmes or interventions available for persons living with epilepsy?

What are the challenges faced as an organisation in helping persons living with epilepsy

From your perspective, what are the interventions that can help in decreasing the challenges faced by persons living with epilepsy to help ensure their quality of life in Ghana?

**INTERVIEW GUIDE FOR KEY INFORMANTS-
EPILEPSY UNIT-KANESHIE POLYCLINIC (KPC)
DEPARTMENT OF SOCIAL WORK
UNIVERSITY OF GHANA**

Topic: Experiences of Persons Living with Epilepsy in Accra, Ghana

The researcher is conducting this study in partial fulfillment of the requirement for a Master of Philosophy Degree in Social Work. I would be very grateful if you would spend some time with me for an interview. The information is for academic purpose. So, information provided will be strictly confidential and no names or identities will be required.

Questions asked

What is your Knowledge about epilepsy (Meaning, causes and seizure types)?

Is epilepsy an infectious disease?

Do people perceive it as an infectious disease?

Do persons living with epilepsy and their caregivers consult with traditional healers and spiritual in connection with the disease?

What are the challenges faced by persons living with epilepsy?

What kinds of healthcare services do you render to persons living with epilepsy?

Do you receive complaints of side effects of medications or treatment?

Do you receive complaints of inability to purchase the medications?

Challenges in the delivery of healthcare services to persons living with epilepsy

What do you recommend as ways to improve on service delivery in the unit to help enhance the quality of life of persons living with epilepsy?