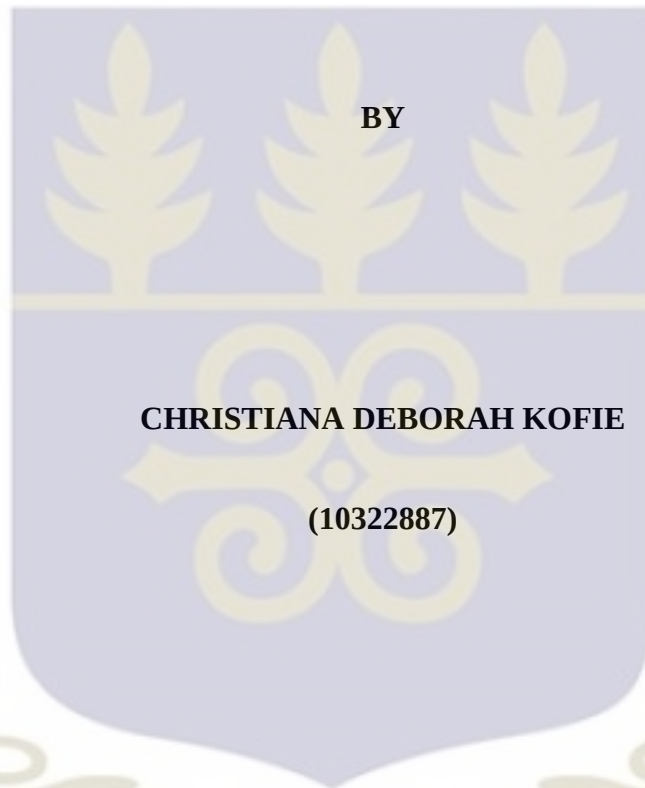


**QUALITY OF LIFE AMONG PATIENTS WITH EPILEPSY ATTENDING THE
KORLE-BU TEACHING HOSPITAL**



**THIS DISSERTATION IS SUBMITTED TO UNIVERSITY OF GHANA, LEGON
IN PARTIAL FULFILMENT OF THE REQUIRMENT FOR THE AWARD OF
MASTER OF PUBLIC HEALTH DEGREE**

JULY, 2015

DECLARATION

I Christiana Deborah Kofie do hereby declare that this dissertation is my own work conducted under supervision of Dr. Emmanuel Asampong. In places where other people's opinions or works have been cited as references, full acknowledgements have been given. This work has never been presented either in whole or in part to any institution for the award of degree, diploma or certificate.

Signature

Date.....

Christiana D. Kofie

(Student)

Signature.....

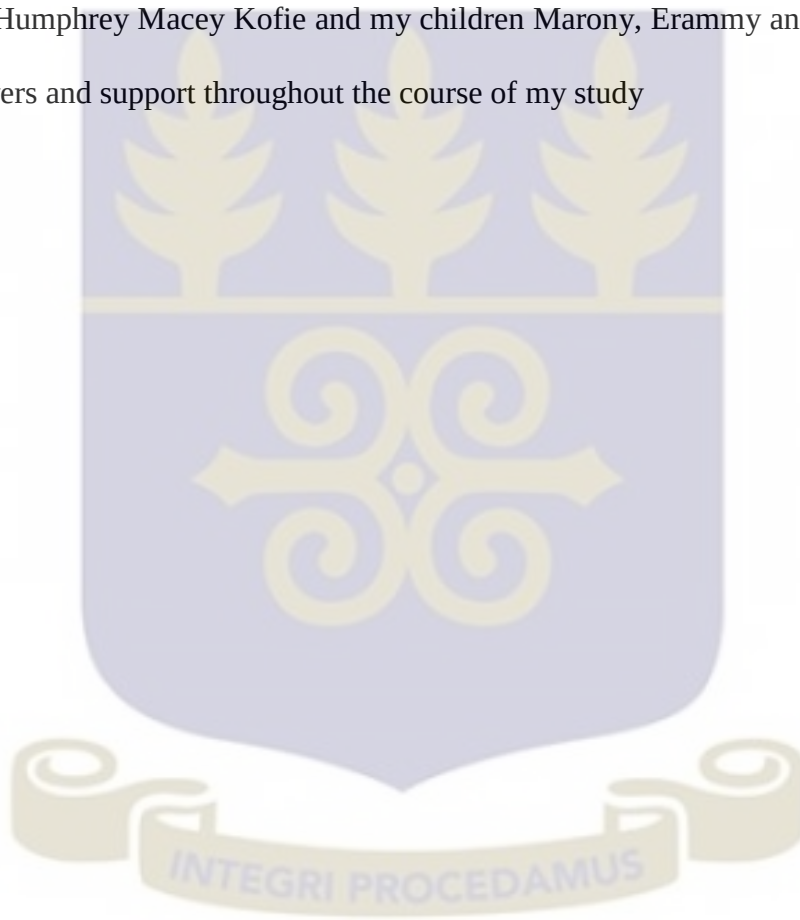
Date.....

Dr. Emmanuel Asampong

(Supervisor)

DEDICATION

I dedicate this work to the Almighty God. He was a constant source of my strength and guidance throughout my academic endeavor. I also dedicate this work to my lovely husband Humphrey Macey Kofie and my children Marony, Erammy and Rylan Kofie for their prayers and support throughout the course of my study



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ABSTRACT

Introduction: Approximately 70 million people worldwide have epilepsy. Epilepsy is seen as highly contagious and shameful disease in the eyes of the public. Those affected are mostly stigmatized and these have great influence on their psychological, physical, environmental and social quality of life. This study sought to assess the level of quality of life of persons living with epilepsy.

Methodology: A cross-sectional descriptive study was employed using quantitative approach. Structured WHO quality of life (WHOQOL) questionnaire was used to obtain information from participant. Eighty-two patients living with epilepsy were selected as study subjects. Data obtained was analyzed using STATA version 12.0

Results: Results obtained showed that in general, majority of the respondents had moderate overall quality of life. Eighty one percent of the participants had moderate physical quality of life (QOL). More than half of the respondents, Sixty one percent had moderate psychological QOL. Participants (58.5%) were found to experience low QOL in their social relationships. More than half of the participants (64.6%) had moderate quality of life for the Environmental domain.

Conclusion: The study showed that on the average, persons living with epilepsy had moderate QOL. However, their social relationships were poor. Their level of education, marital status and gender showed significant association with their quality of life. It is suggested that support systems be created at both community level and clinical areas to better improve upon their quality of life.

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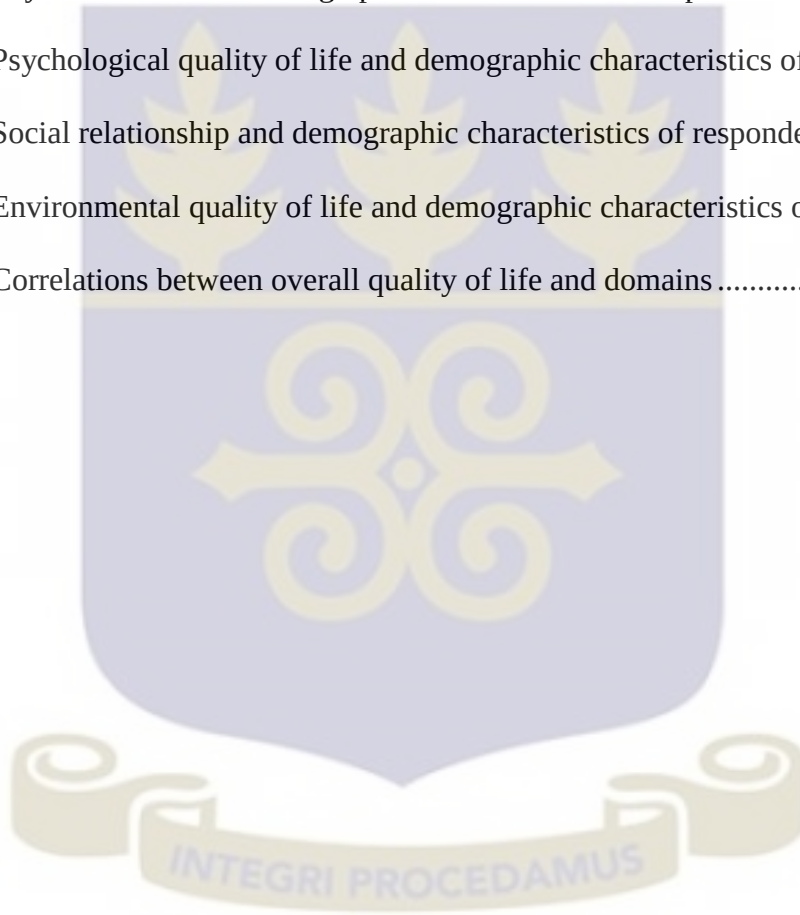
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LIST OF ABBREVIATIONS

AED _s	Antiepileptic Drugs
AE _s	Adverse Effect
HRQOL	Health Related Quality of Life
PLWE	People Living With Epilepsy
QOL	Quality Of Life
SOC	Sense of Coherence
WHO	World Health Organization
WHOQOL	World Health Organization Quality Of Life



DEFINITION OF TERMS

Epilepsy: is not a single disease, but rather an expression of many different brain disorders, and as a consequence investigations and treatment must be individualized.

Quality of Life: The World Health Organization (WHO) defines QOL as an individual's "perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns".

Health Related Quality of Life: It is often referred to as the impact of disease and treatment on QOL. It may be described as the patient's perception of disease impact on well-being, and is used as a subjective measure in population studies.

Seizure: A seizure is an individual episode in which an abrupt discharge of electrical activity in the brain may cause changes in sensation, behavior, and or consciousness (DuLac et al., 1995; Ho-Turner & Bennett, 1999).



CHAPTER ONE

INTRODUCTION

1.1 Background

Epilepsy is a common serious neurological disorder, caused by abnormalities in the electrical activity of the brain (Diop, de Boer, Mandhate, 2003). 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, Boas, Blume *et al.* 2005). Epilepsy is not a single disease, but rather an expression of many different brain disorders, and as a consequence investigations and treatment must be individualized. Genetic factors are often likely to play a role, either because the underlying cause of epilepsy is primarily genetic or because genes modulate susceptibility to an epileptogenic insult (Pandolfo, 2011). Among all neurological disorders, epilepsy requires long-term health care contact (Forsgren, 1992).

Epilepsy is also seen as a chronic disease that largely influence the patient's life. Majority of studies from Sub-Saharan Africa region mainly focus on psychiatry morbidity and factors associated with poor control of epilepsy (Sander & Shorvon, 1996). It is important that the type of seizure and epilepsy is identified and classified in order for healthcare professionals, especially epilepsy nurses, to facilitate ongoing child and family education to optimize long term management, and to promote self-care for young people and appropriate healthy lifestyle choices (Henriksen & Wallace, 2004).

A World Health Organization (WHO) report estimated that 10% of the global burden of brain and mental disorders is caused by epilepsy, calculated in disability-adjusted life years (WHO, 2008). This calculation includes premature deaths and loss of

healthy life due to disability. Forsgren (2004) estimated an age-specific global incidence of 3.5 million people developing epilepsy on an annual basis, 40% are children under 15 years old, 40% young people and adults aged 15-65 years and 20% are elderly. Epilepsy incidence in childhood is higher than in adulthood (Hauser, 1995; Holmes, Mosha & Jones, 2006). The WHO noted that while significant, this figure does not include the stigma and social exclusion or the repercussions on the family of those with epilepsy. As a condition, epilepsy is misunderstood, leading to fear, secrecy, stigmatization and the risk of social discrimination (WHO, 2008). In some patients, the social stigma and impact on quality of life can pose a greater challenge than the clinical severity (Jacoby & Austin, 2007). Worldwide approximately 50 million people have epilepsy (Banerjee, 2009). One in 21 men and 1 in 28 women will develop epilepsy during their lifetime (Hesdorffer *et al.* 2011).

Epilepsy affects about 2 million people in the USA and accounts for \$15.5 billion in direct costs (medical) and indirect costs (lost or reduced earnings and productivity) each year. More than one-third of people with epilepsy continue to have seizures despite treatment. Children younger than age 2 and adults older than age 65 are particularly vulnerable because the risk factors for epilepsy are more common in these age groups. About 10% of Americans will experience a seizure sometime during their lives. About 3% will receive a diagnosis of epilepsy by age 80. In many countries, this disorder is still shrouded in secrecy and patients prefer not to reveal or discuss their condition (Thomas & Nair, 2011). 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 839

respondents had negative attitudes and poor knowledge on epilepsy (Ramasundrum & MohdHussin, 2000).

Previous studies have reported that QOL of people with epilepsy is also influenced by both clinical characteristics (such as frequency, type or presence of seizures, age of onset and treatment) and socio-demographic variables (such as sex, marital status, education and employment) (Guevara, Peña, Corona *et al*, 2005). Epilepsy carries an enormous social stigma and people with epilepsy tend to have lower QOL (Ronen, Streiner& Rosenbaum, 2003). Persons living with epilepsy are prone to have poorer self-esteem, higher levels of anxiety, and depression. They are more likely to be underemployed or unemployed with lower rates of marriage and greater social isolation (Baker, Jacoby *et al*. 1997).

In many parts of the world, epilepsy continues to be viewed as witchcraft, contagious, and possession by devils and ancestral spirits (Austin, Shafer, Deering, 2002). An Indian study reported that 15% of respondents believed epilepsy to be insanity, 40% believed that the child with epilepsy should not go to school or their children should not play with them and 66% objected in their children marrying someone who had epilepsy (Gambhir, Kumar, Singhi, Goel, 1995). Similar observations were found in a study from Taiwan which also reported that 31% of respondents believed that people with epilepsy should not be employed in jobs (Laccheo, Ablah, Heinrichs, Sadler, 2008).

The World Health Organization (WHOQOL–BREF) documents describes four domains of quality of health QOL; physical health, psychological health, social relationships, and environment. Each person has different determinants of QOL and these

determinants are also dependent on if the individual is at good health or suffers from a disease (Bowling, 1995). The World Health Organization (WHO) defines Quality of Life (QOL) as an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns (WHO 1998). The determinants of QOL are also decided by which disease the person is affected by (Bowling, 1996). However, the term QOL is often used in different disciplines and its definition vary depending on which field it is implicated in. Many different instruments have been developed for measuring QOL, and have been used to different extents.

Quality of life refers to an individual's ability to engage in and enjoy normal life activities (Bastiaansen et al., 2005). More specifically, health-related quality of life (HRQL) represents the functional effects of an illness and its subsequent treatment on a patient, as perceived by the individual (Baker, 2001). The determinants of Health Related Quality Of Life (HRQOL) are not only biomedical factors, but also socio-demographic and psychosocial ones. Psychological factors like self-esteem, Sense of Coherence (SOC) and perceived control have been found to relate to HRQOL. In a review of different HRQOL measures, both depression and anxiety were correlated to impaired HRQOL (Taylor et al. 2011). Psychological factors contribute to 30-35% of the variance in HRQOL, while around 20% is explained by seizure-related factors. A study done in USA Florida shows that, depression, driving restrictions and unemployment are pointed out as the most important determinants of QOL (Jehietal, 2011).

Majority of studies from Sub-Saharan regions mainly focus on psychiatry morbidity and factors associated with poor control of epilepsy (Mativo, 2004). However (Muinga, 1986) found a positive correlation between occupation (50.8% not gainfully employed) and psychopathology among persons living with epilepsy (PLWE) in Kenya. A study conducted in Kenya to determine quality of life of persons living with epilepsy reported that 63% of the unemployed PLWE were poorly controlled (Mativo, 2004). One out of 3 teenagers with epilepsy expect their condition to hinder their lives in the future and are especially concerned about employment opportunities, travelling, exploring and education (Baker *et al.* 2008; Jacoby & Baker 2008). The unpredictable nature of epilepsy often causes stress even if the disease is fairly well controlled. If frequent seizures occur this may force persons with epilepsy (PWE) to be absent from ongoing education, which will result in poorer academic achievements (Katzenstein *et al.* 2007).

A study carried out in the Isle of Wight in the UK demonstrated 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). Research has shown that people with epilepsy are more likely to experience problems in identifying a job, than the general population. A study in the UK revealed an unemployment rate of 46% for people with epilepsy, in contrast to 19% for a control group (Elwes, Marshall, Beattie & Newman, 1991). In some European countries there are also legal barriers that restrict people with epilepsy in the workplace. This combination of institutional and social restrictions often results in people with epilepsy underperforming compared with the general population in the workplace (International League against Epilepsy, 2003). Approximately a third of all people with epilepsy are currently living with uncontrolled

seizures despite management with Anti-epileptic Drugs (AEDs). Together with the social stigma that persists in some parts of society, people with epilepsy often feel a sense of social isolation and have an overall reduced quality of life. Social isolation and quality of life have also been shown to be significantly compromised in caregivers of people with epilepsy (Drazkowski, 2007).

The relationship between QOL and different demographic and epilepsy-specific factors has been studied with different results about which predictive factors are the greatest determinants of QOL. There is however evidence that there is an association between seizure severity and QOL even when controlling for depression (Harden et al. 2007; Taylor *et al.* 2011). Ninety-three HRQOL studies reported that increases in seizure frequency, seizure severity, and level of depression, level of anxiety and presence of comorbidity were all correlated to decreased QOL. In view of the above, this study seeks to determine the quality of life of persons living with epilepsy and attending Korle-bu Teaching Hospital.

1.2 Statement of the Problem

The World Health Organization and the International League against Epilepsy have estimated that 34 million out of 40 million people with epilepsy in the world live in developing countries and nearly 80% of them are not on treatment. The inadequacy of medical infrastructure, poor affordability, and certain social or cultural beliefs interfere with optimal care for epilepsy in these countries and these affect their QOL (ILAE, 2003).

Several studies on persons living with epilepsy more often report poor health, unemployment and the inability to work. PLWE more often live in households with the lowest annual income, and have a history of co-occurring disorders (Kobau *et al.* 2008; O'Donoghue *et al.* 1999; Stavem *et al.* 2000; Strine *et al.* 2005; Wiebe *et al.* 1999). PLWE are also more likely to be obese and physically inactive, current epileptic smokers and have a higher risk of experiencing major events that affect their lives significantly. PLWE also have a higher mortality rate compared with other chronic diseases (Cockerell *et al.* 1994; Cockerell 1996; Cockerell *et al.* 1997; Lindsten *et al.* 2000) and even a higher risk of suicide (Christensen *et al.* 2007). People who have experienced a single seizure have been shown to be discriminated against on the labor market (Holland *et al.* 2009).

Several studies have reported low quality of life among persons living with epilepsy. (Heaey *et al.* 2002; Hesdorffer *et al.* 2005; Li *et al.* 2008). Studies from the African continent are less common; Preux and Druet-Carbanac examined the prevalence and incidence of epilepsy in sub-Saharan Africa. (Preux & Carbanac, 2005) The authors found prevalence rates discovered in door-to-door studies of a range of 11.8-20.4 per 1000 and an incidence in the range of 63-158 per 100,000 person years. Lefley (1996) reported on 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, 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. (Lefley, 1996). In Ghana, epilepsy is viewed as a spiritual condition by many tribes and religions. This has led to

stigmatization of PLWE. Such individuals also avoid seeking treatment from hospitals and spent considerable time in prayer camps and herbal clinics. They usually report late to the health facility, and with adverse side effects. In some industries, such individuals are dismissed on the grounds of irregular attendance and lateness. The cost of treatment also turns to impact some level of burden on some of these individuals. The overall impact of these factors is primarily directed towards their quality of life. Documented knowledge on the quality of life of epileptic patients in Ghana is not available and there is little documented evidence of frequent stigmatization of such patients in Ghana.

1.3 Conceptual Framework

The definition of QOL reflects subjective evaluation of one's self which is embedded in culture, social and environmental context. It also looks at the respondents' "perceived" QOL in relation to the effect of disease and health interventions and not the measurement of detailed fashion symptoms disease or condition.

Earlier studies (Cockerell *et al.* 1994; Cockerell 1996; Cockerell *et al.* 1997; Lindsten *et al.* 2000), have established that seizure-related factors exert influence on the QOL of people with epilepsy like duration of seizure, seizure types and number of medications. However, some recent studies by WHO reported on four domains (Physical health, Psychological, Social relationships and Environment) in their WHOQOL-BREF document. In view of the above and for the purpose of this study quality of life of persons living with epilepsy will be the outcome variable while the proposed independent variables will be Physical health, Psychological, Social relationships and the Environment.

The conceptual framework encompasses aspects of QOL that affect health such as psychological, environmental, physical, and social relationship. This conceptual model allows for the measurement of a mix of structural, processes and outcome measures. The framework produces scores relating to particular facets of quality of life (e.g. positive feelings, social support, financial resources), scores relating to larger domains (e.g. physical, psychological, social relationships) and a score relating to overall quality of life and general health.

People with higher levels of well-being judge their life as doing well and feel very healthy and full of energy to take on their daily activities. They are also satisfied, interested, and engaged with their lives and experience a sense of accomplishment from their activities and judge their lives to be meaningful. They are more often content or cheerful than depressed or anxious. People get along with others and experience good social relationships. Personal factors, social circumstances, and community environments also influence their well-being. Below is a conceptual framework of the various domains that contribute to the overall QOL.



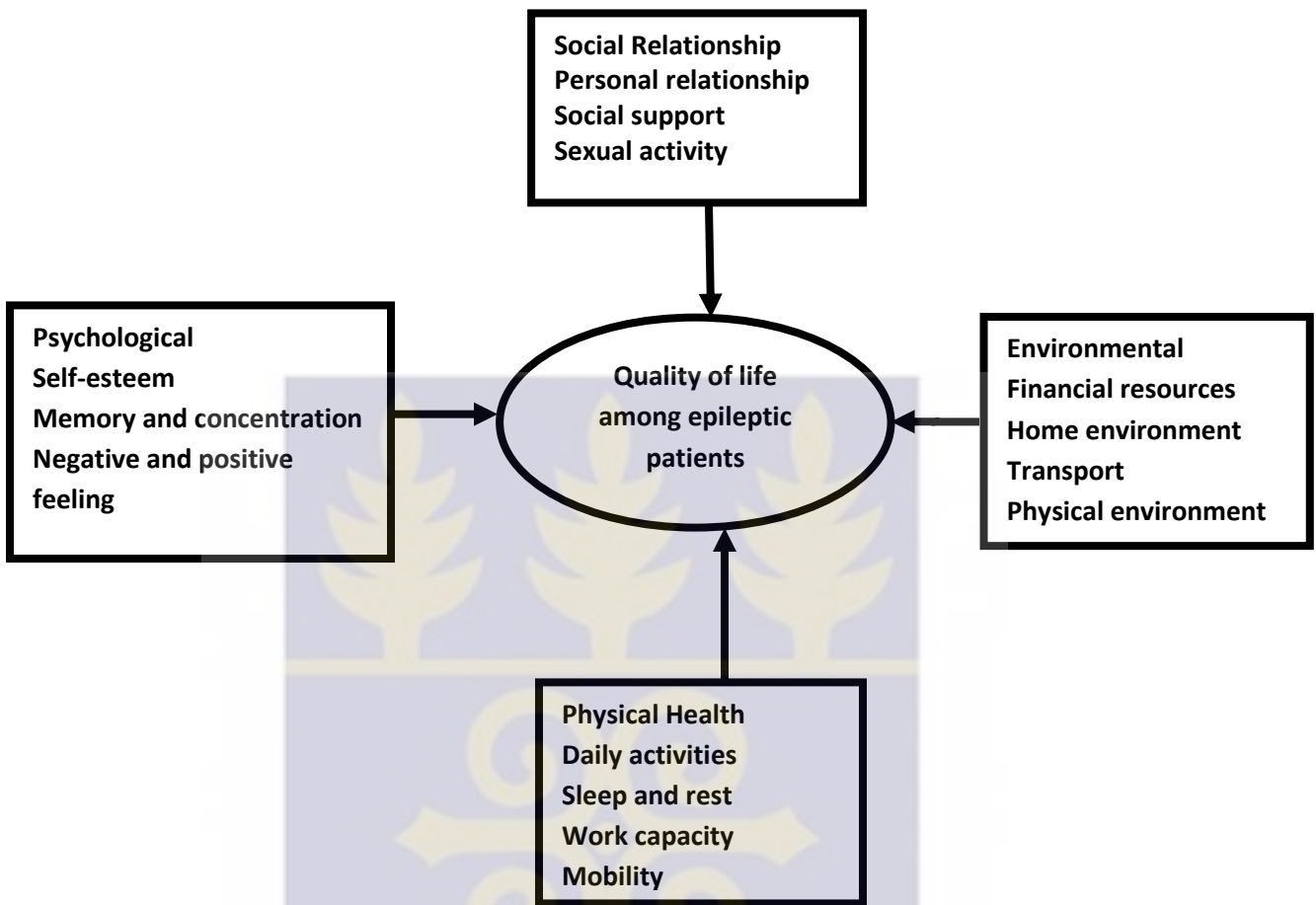


Figure 1: Conceptual Framework of quality of life of persons living with epilepsy

Well-being considers the physical, mental, and social aspects of a person's life. Physical well-being relates to vigor and vitality, feeling very healthy and full of energy mobility absence of pain and discomfort, sleep and rest. Psychological well-being includes being satisfied with one's life; balancing positive and negative emotions; accepting one's self; finding purpose and meaning in one's life; seeking personal growth, autonomy, and competence; believing one's life and circumstances are under one's control; and generally experiencing optimism. Social well-being involves providing and receiving quality support from family, friends, and others as well as sexual activities.

Environment reflects the individual's physical safety, freedom and security, financial resources, opportunity to acquire new information and skills, home environment, leisure activities, accessibility and quality of health care, social care, among others. Demographic characteristics such as age, sex, marital status etc. also impacts on QOL. All these variables discussed above contribute to either good or poor quality of life.

1.4 Justification of Study

Understanding the unique and complex impact of epilepsy on a person's QOL is increasingly recognized as an important component of clinical care and research in this area identifies factors affecting QOL which may lead to strategies that improve the management of PLWE (Bishop and Allen, 2003). Few studies have been carried out on epilepsy in Ghana and none have been published on measurement of QOL among PLWE. According to Brusturean-Bota, Coada and Buzoianu (2013) over the last decades, considerable efforts have been made to develop dedicated quality of life assessment in patients with epilepsy and to assess the impact of demographic, clinical, psychosocial factors and epilepsy-associated comorbidities on their quality of life. In view of the above, this study will provide valuable information on the quality of life of persons living with epilepsy. This information will allow both psychologists and physicians and the general public to assess and treat persons with epilepsy by addressing the factors that are correlated with their health-related quality of life. In addition, this study will shed light on the factors that influence health-related quality of life of PLWE. Information obtained can also be used by other researchers as references to improve on research conducted in this area.

1.5 Objectives

General Objective

The general objective of the study is to examine quality of life among persons living with epilepsy who attend Korle-bu Teaching Hospital.

Specific Objectives

1. To describe the quality of physical health among persons living with epilepsy
2. To examine the quality of psychological health among persons living with epilepsy
3. To find out how the environment and social relationship influences the quality of life of persons living with epilepsy.

1.6 Research Questions

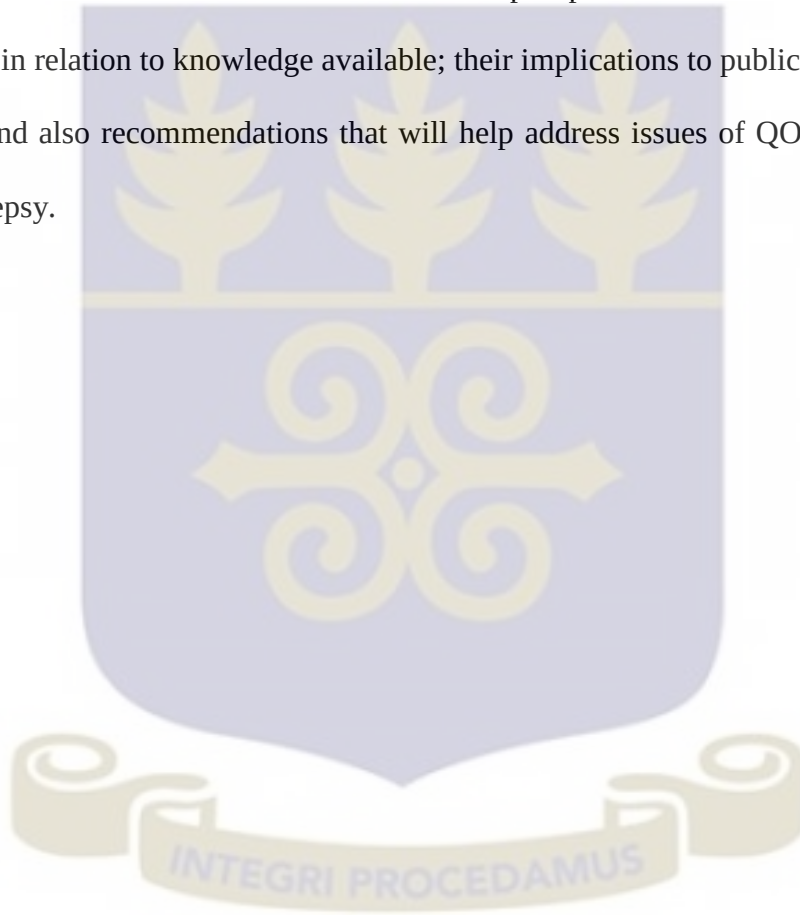
1. What is the QOL of persons living with epilepsy and attending Korle-bu Teaching Hospital?
2. What are the factors that influence the quality of life of persons living with epilepsy and attending Korle-bu Teaching Hospital?

1.7 Organization of work

The dissertation will be organized in the following chapters described;

Chapter one presents the background of the study, problem statement, purpose of the study, research objectives, research questions and significance of the study. Chapter two looks at works and published studies done concerning epilepsy; it looks at the condition

in relation to quality of life and its impact on psychological, physical, environmental and social relationship of the individual .Chapter three describes the methodology and the stepwise method applied to gain access and recruit participants to obtain data. It continues to describe how the data was managed and analysed. The fourth chapter presents the findings of the study. Chapter five focuses on discussion of the findings in accordance with reviewed literature. The last chapter presents the conclusion drawn from the study in relation to knowledge available; their implications to public health practice in general and also recommendations that will help address issues of QOL among persons with epilepsy.



CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This section presents a review of relevant literature in the study area. Search engines such as Google scholar, Hinari, Web of Science, African Journal Online and some books were used in the review. Key phrases such as quality of life, persons living with epilepsy, psychosocial factors, environmental factors, physical factors, incidence and prevalence of epilepsy, were used in the search engine. The literature was reviewed in accordance with the conceptual framework and stated research questions of the study.

2.1 Background

Epileptic seizures can manifest as such symptoms as altered consciousness, involuntary movements, abnormal sensory phenomena, increased autonomic activity or transient disturbances of behavior depending on the localization of the epileptic disorder. In addition to symptoms of the seizures, the pathologic electrical discharges detectable in the electroencephalography (EEG) during the seizures and in the interictal period can also reveal the site of origin of the dysfunction. Although epileptic seizures can be symptoms of a causative brain disease, in the majority of cases of epilepsy the cause is unknown and the diagnosis is solely based on description of seizures and findings in EEG (Engel & Pedley, 1997).

Multiple seizures occurring in a 24-hour period or an episode of status epilepticus (SE) are considered a single event. Individuals who have had only febrile seizures or only neonatal seizures (seizures in the first 30 days of life), and people with acute symptomatic seizures, (seizures associated with acute systemic illness, intoxication,

substance abuse or withdrawal, or acute neurological insults), and individuals with a single unprovoked seizure, are excluded from this category (Banerjee *et al.* 2009). Broad etiologic categories included idiopathic, symptomatic, and cryptogenic (ILAE, 1989). Idiopathic epilepsies are assumed to have a genetic basis and generally have onset during childhood. Symptomatic epilepsies typically follow an identified brain insult. For cryptogenic epilepsies, the cause of the epilepsy is unknown but many presume that a cause could be identified with sufficient investigation (Banerjee *et al.* 2009).

Epilepsy is one of the oldest neurological conditions that affect mankind at all ages (WHO, 2001). Epilepsy is one of the most prevalent non communicable neurologic conditions and an important cause of disability and mortality (WHO, 2004). It is estimated to affect almost 70 million people worldwide.

The incidence of epilepsy in developed countries is usually quoted as being between 40 and 70 per 100,000 persons per year, and it is usually higher in young children and in older people (Duncan *et al.*, 2006). The incidence in resource-poor countries is usually much higher than in developed countries, often above 120/100,000/year. Poor sanitation, inadequate health delivery systems, and higher risk of brain infections and infestations may contribute to this (Heaney *et al.*, 2002).

The prevalence of epilepsy in low- and middle-income countries (LMIC) is about twice that of high-income countries (HIC) (Ngugi *et al.* 2010). There are relatively few studies of incidence of epilepsy in total populations. In developed countries, the age-adjusted incidence of epilepsy (recurrent unprovoked seizures) ranges from 24 to 53 per 100,000 person-years (Annegers *et al.* 1999; Hauser *et al.* 1993, Oun, Haldre, Magi, 2003). Total population studies reporting the incidence of a first diagnosis of unprovoked seizures (differing from incidence of epilepsy by the inclusion of persons with a single

unprovoked seizure as well as those with recurrent unprovoked seizures) provides estimates of incidence ranging from 26 to 70 per 100,000 person-years (Hauser *et al.* 1996; Jallon *et al.* 1999; Olafsson *et al.* 2005).

Several recent studies provide incidence from developing countries. An incidence of epilepsy that is considerably higher than that reported in industrialized countries (114 per 100,000 person-years) has been reported from a rural area of Chile (Annegers *et al.* 1999). Age-adjusted prevalence in studies that used door-to-door survey methodology ranged from 2.2 in India (Koul *et al.*, 1988) to 41.0 in Nigeria (Osuntokun, 1982). In the North American studies, the age adjusted prevalence was 5.0 in the study conducted (Kelvin *et al.* 2007) in New York and 7.1 per 1000 (Haerer *et al.*, 1986) in Mississippi. In Central and South America, the overall age-adjusted prevalence ranged from 3.7 per 1000 in Argentina (Melcon *et al.*, 2007) to 22.2 per 1000 in Ecuador (Cruz *et al.*, 1985). This study was conducted among a population with a high prevalence of endemic goiter. The South American study most recently completed at the time of this review reports the lowest age-adjusted prevalence of 3.7 (Melcon *et al.*, 2007). In Europe, age-adjusted prevalence was low, 2.7 per 1000 and 3.3 per 1000, respectively in each study conducted in Italy (Reggio *et al.*, 1996; Rocca *et al.*, 2001), when compared to a prevalence of 7.0 per 1000 in the study conducted in the European region of Turkey (Onal *et al.*, 2002). In contrast to the majority of studies conducted in Asia, the age-adjusted prevalence of 10.2 per 1000 in Asian Turkey (Karaagac *et al.*, 1999) was higher than both the age-adjusted prevalence of 6.6 per 1000 and 9.8 per 1000 in the studies conducted in Asian Turkey and Pakistan (Aziz *et al.* 1997). This prevalence was much higher than the age-adjusted prevalence reported in studies conducted in India and China, where prevalence ranged

between 2.2 and 4.4 per 1000 (Koul et. al, 1988; Bharucha et al., 1988; Radhakrishnan et al., 2000; Li et. al, 1985).

Although studies are not in perfect concordance, most reports show a general trend towards an increase in epilepsy prevalence during adolescence or early adulthood (Lavados et al., 1992; Basch et al., 1997; Olafsson and Hauser, 1999; Birbeck and Kalichi, 2004). In developed countries, most studies show the prevalence of epilepsy to be stable in the adult age groups and to increase with age after 50 (Forsgren, 1992; Olafsson & Hauser, 1999). Nevertheless the heavy burden of this condition is not evenly distributed. According to available data age adjusted prevalence in Africa ranges from 3.9 per 1000 in Tunisia and 13.2 per 1000 in Zambia. (Birbeck & Kalichi, 2004). A study in Ethiopia reported an incidence of 64, but this fell to 46 after age adjustment, underscoring the importance of age adjustment if comparisons are to be made (Placencia et al. 1992). Three quarters of affected individuals in the general population become seizure free on anti-epileptic drug (AED) therapy. Prevalence or incidence may be underestimated in areas where the condition is greatly stigmatized and cultural beliefs about the causes of epilepsy or negative attitudes toward those with epilepsy lead to the concealing of symptoms of epilepsy, or its diagnosis (Banerjee et al. 2009).

Unprovoked seizures are those for which no responsible condition is found as an explanation. Acute symptomatic seizures are those that occur in temporal association with for example: brain insult, metabolic derangements, intoxication, drug withdrawal or CNS-infection. Epilepsy is in 2005 defined as a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological and social consequences of this condition. If there is an enduring

predisposition to generate seizures, the diagnosis of epilepsy still requires the occurrence of at least one epileptic seizure.

The classifications of epilepsy and seizures have been changed several times over the years. In Study I and II classification was performed according to ILAE's classification of seizures 1981 (ILAE, 1981) and syndromes 1989 (ILAE, 1989). Since a new classification was proposed in 2010 this was used in papers III and IV (Berg et al. 2010).

In the classification in 1981, partial seizures indicate the initial activation of neurons limited to parts of one cerebral hemisphere. Partial seizures were then classified on the basis of whether consciousness was impaired (complex partial seizures) or not (simple partial seizures). Partial seizures were then grouped into partial seizures with motor signs, autonomic symptoms, somatosensory symptoms or psychiatric symptoms. It may evolve into secondary generalized seizures. In the same classification a seizure was generalized if findings indicated the initial involvement of both hemispheres. Generalized seizures were subdivided into the following categories: absence, myoclonic, clonic, tonic, tonic-clonic and atonic.

According to the recently proposed classification, a focal seizure starts within a network limited to one hemisphere and is either discretely localized or more widely distributed (Berg et al. 2010). Focal seizures can occur with or without impaired conscience, and can progress into bilateral convulsive seizures. A specification of seizure symptoms should follow thereafter. Generalized seizures are defined as those occurring in and rapidly engaging bilaterally distributed networks, and they are subdivided in the

same way as before. If there are no data to determine whether a seizure is focal or generalized, it will be classified as unknown.

2.2 Quality of Life of epileptic patients

During the last few decades, greater attention has been given to the quality of life (QOL) of people with epilepsy (PWE). They have been shown to report a poorer QOL compared to the general population because they are more likely to have poor self-esteem and a high level of anxiety and depression. Social stigma and discrimination of PWE occur in both developed and developing countries (Guekht, Mitrokhina, Lebedeva et al. 2006). QOL has been reported to vary across epileptic patients with different clinical, demographic, and socioeconomic variables. With regard to clinical variables, seizure type and frequency have been found to be significant predictors of QOL scores (Harsono, 2008). Patients with epilepsy are at increased risk for poor health-related quality of life (HRQOL), given the impact of this disorder on psycho-social dimensions that contribute to form the overall perception of an individual's position in life (Jacoby and Baker, 2008).

Many researchers agree that QOL is a multidimensional concept involving one's physical, social and psychological life perceptions (Berto, 2002; Cramer et al. 1998; Bishop et al. 2002; Smith et al. 1991). Previous studies have reported that QOL of PWE is also influenced by both clinical characteristics such as frequency, type or presence of seizures, age of onset and treatment and socio-demographic variables such as sex, marital status, education and employment (Guevara, Peña & Corona et al. 2006).

There is a complex relationship between cognitive functioning, psychological well-being and QOL. For PWE the most evident determinant is having active epilepsy with ongoing seizures, a connection has also been demonstrated by several authors (Baker et al. 1997; Jacoby et al. 1996; Leidy et al. 1999; Senol et al. 2007). More surprising is that PWE who have been seizure-free for a long time still exhibit impaired QOL (Strine et al. 2005); childhood epilepsy still has an impact on the QOL of the adult (Sillanpää et al. 2004).

During the past two decades considerable research has been devoted to developing measures of HRQOL for epilepsy patients (Soria et al. 2007), and to examining the impact of demographic (e.g. age, sex, education, socio-economic status), clinical (e.g. seizure frequency, seizure type, duration of epilepsy, age at onset, type of drugs and number), comorbid psychiatric (e.g. anxiety, depression), and psycho-social (e.g. stigma, social support, self-efficacy) factors on quality of life (Jacoby, Snape, Baker, 2009). Many factors influence the QOL of people with epilepsy, including impact of age and seizures, stigma, social deprivation, fear and anxiety, the presence of cognitive or psychiatric problems, and others (Shafer, 2002). Epilepsy is a complex condition, and many different conditions are known to be risk factors. These vary with age and geographic location. Congenital, developmental, and genetic conditions are associated with developing epilepsy when young. Epilepsy carries an enormous social stigma and people with epilepsy tend to have lower quality of life (QOL) (Ronen, Streiner & Rosenbaum, 2003). They are prone to have poorer self-esteem, higher levels of anxiety, and depression. They are more likely to be underemployed or unemployed with lower

rates of marriage and greater social isolation (Baker, Jacoby, Buck, Stalgis, Monnet, 1997).

Bishop and Allen also concluded from their study that epilepsy has a broad impact on a patient's life, cutting across interpersonal, intrapersonal, and extra personal domains (Bishop and Allen, 2003). People with epilepsy living in Europe or in North America have significant impairment in their QOL. A prospective study was conducted on patients with refractory epilepsy being admitted to an inpatient video-EEG monitoring unit. The impact of clinical variables (age, sex, marital status, seizure frequency, duration and type of seizure disorder, seizure localization, number of AEDs, depression) on QOL was analyzed. This study showed that depression was a powerful predictor of QOL (Boylan *et al.* 2004).

2.2.1 Epileptic patients and their Psychological wellbeing

Epilepsy has many non-medical impacts on the persons living with it. The impacts of epilepsy rest not only on the individual patient, but also on the family and indirectly on the community. The burden of epilepsy may be due to the physical hazards of epilepsy resulting from the unpredictability of seizures; the social exclusion as a result of negative attitudes of others toward people with epilepsy; and the stigma, as children with epilepsy may be banned from school, adults may be banned from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe. Furthermore, epilepsy is a disorder associated with significant psychological consequences, with increased levels of anxiety, depression, and poor self-esteem compared with people without this condition (Baker, 2002).

People with disabilities are among the most vulnerable in any society. This vulnerability is even greater among those with hidden disabilities such as epilepsy and other neurological conditions and intellectual disabilities. Although the vulnerability of people living with epilepsy may be partly attributed to the disorder itself, all chronic medical conditions have an impact on daily life, but the impact of epilepsy is greater; the particular stigma associated with epilepsy brings a susceptibility of its own. Stigmatization leads to discrimination, and people with epilepsy have been the target of prejudicial behavior in many spheres of life, over many centuries and in many cultures (Pahl & Bore, 2005).

There is however evidence that there is an association between seizure severity and QOL even when controlling for depression (Harden *et al.* 2007). In a recent review of 93 HRQOL studies, increases in seizure frequency, seizure severity, level of depression, level of anxiety and presence of comorbidity were all correlated to a decrement in QOL (Taylor *et al.* 2011b). Another large study on therapy-resistant epilepsy stated that adverse effects (AEs) of medication and depressive symptoms were more important predicting factors for HRQOL than were the seizures themselves (Luoni *et al.* 2011).

Throughout history, epilepsy has been considered a stigmatized condition. Unfortunately, this remains true today despite progress in medical science, as the diagnosis of epilepsy can still have a profound social and psychological impact on patients and their families (Fenandes, Cabral, Araujo, Noronha, and Li, 2005). Similarly, a study on clinical factors influencing quality of life in patients with epilepsy, conducted in Korea revealed that, stigma that has been recognized as a burden to patients and their

families was found to adversely affect the quality of life in persons with epilepsy (Youn, Joeng, Kang, Lee, Seo and Hong 2000). In addition, People with epilepsy also have an increased risk of poor self-esteem, depression and suicide. These problems may be as a result of lack of understanding, or discomfort about epilepsy which may lead to cruelty or avoidance by other people (Edward, 2003). Furthermore, the way in which epilepsy is perceived influence the psychological adjustment of persons with epilepsy. In Haiti, epilepsy is considered a “hidden condition” and not openly discussed among community members. Hence people with epilepsy are maligned and feared. Consequently, people living with epilepsy do not disclose their condition to others and avoided contact with friends and family members (Puja, 2006). The social stigma attached to epilepsy affects epileptics more than disabilities associated with seizures and side effects of medications. Perception and attitude of epilepsy by the public play a major role in determining the extent to which people with epilepsy could be integrated into their societies (Edward, 2003).

Although not all people with epilepsy feel stigmatized, studies have shown that 30–51% of participants reported feeling stigmatized, and 18% reported feeling highly stigmatized (Beghi, Roncolato, Visona, 2004; Gilliam *et al.* 2004). Perceived stigma has been found to be significantly associated with higher levels of psychological distress symptoms (Hermann, *et al.* 1990) and lower QOL (Baker *et al.* 2000). Young people who live with epilepsy have a significantly higher incidence of depression related to interpersonal problems, social anxiety, and more obsessive symptoms than do adolescents without epilepsy (Baker *et al.* 2005). However, there are other studies that do not support the notion that epilepsy correlates to low self-esteem (Lee *et al.* 2008; Reeve and Lincoln

2002). Side effects from AEDs also contribute to impaired QOL (Perucca *et al.* 2009). An Indian study reported that 15% of respondents believed epilepsy to be insanity, 40% believed that the child with epilepsy should not go to school or their children should not play with them and 66% objected in their children marrying someone who had epilepsy (Austin, Shafer, Deering, 2003). Depression is associated with internalized or felt stigma at epilepsy onset (Leaffer *et al.* 2011), and results in a greater burden of adverse events at epilepsy onset, even in people who are not taking seizure medications (Perucca *et al.* 2011). Among people with epilepsy, depression is associated with a substantial increased risk for suicide (Christensen *et al.* 2007). In addition to the poor psychosocial outcomes associated with depression in people with epilepsy, depression is also associated with an increased risk for developing epilepsy (Adelow *et al.*, 2012; Forsgren & Nystrom, 1990; Hesdorffer *et al.*, 2000; Hesdorffer *et al.*, 2005; Hesdorffer *et al.*, 2012b) and with poor seizure outcomes.

Cognitive deficits are associated with several forms of epilepsy. Most prominently, temporal lobe epilepsy is associated with deficits in memory function, which are strongly related to the degree of hippocampal atrophy. Recently, cognitive impairments have been studied in individuals with frontal lobe epilepsy (Swartz *et al.* 1996). Deficits in working memory as well as in other frontal executive systems tasks have been found. Primary generalized epilepsies are also associated with specific forms of cognitive deficits (Trimble *et al.* 1992). Even the so-called “benign” epilepsy is now recognized as being associated with neurobehavioral abnormalities (Binnie and Marston, 1992). Memory dysfunction has a strong correlation with lower scores on measures of quality of life (Kendrick and Trimble, 1994).

Persons with epilepsy have a higher incidence of depression than the general population. Although this relationship is true of all chronic disorders to some extent, depression is more severe among persons with epilepsy than with other conditions. Depression may be directly linked to abnormal metabolic function in the temporal lobes (Victoroff *et al.* 1994). The rate of suicide is high in persons with epilepsy, especially when the left temporal lobe is involved (Rausch *et al.* 1995). Psychosis is associated with epilepsy in several settings. Most commonly, the postictal state can be associated with a transient psychosis. The incidence of postictal psychosis is unknown. Risk factors for postictal psychosis include bilateral focus for temporal lobe seizures, clusters of seizures, and long-term presence of the disease (Devinsky *et al.* 1995).

2.2.2 Epileptic patients and their Social relationship

Epilepsy is associated with a wide range of markers of social and economic disadvantage, including poor academic achievement and low income (Harsono, 2008). Epilepsy can affect the way a person develops healthy relationships and independent living skills (Morgan, Ahmed, Kerr, 2000). Although primary treatment goals focus on the physical complications of epilepsy through seizure control (WHO, 2001; Percca, 2004) people with epilepsy face many other challenges, including problematic psychological manifestations (e.g. poor self-esteem, fear and anxiety) and social complications (e.g. driving restrictions, unemployment and social isolation) (Wagner *et al.* 1999; Bishop *et al.* 2002), all of which can have an impact on quality of life (QOL).

Diagnosis of epilepsy in their child leads to stress in parents, resulting in a higher divorce rate. Focus by parents on the child with epilepsy can result in poor relationships between the child with epilepsy and siblings and psychological difficulties among

siblings. Such focus can also affect family cohesion and relations between the family and their community. It can result in the people with epilepsy growing up to make a poor parent themselves (Devinsky, 2001).

Another factor contributing to QOL is educational level. More years of formal education improve QOL in PWE (Pulsipher *et al.* 2006). A higher prevalence is found in people with epilepsy of learning disabilities and memory problems, often caused by co-morbidities such as brain damage. Attention deficits occur during seizures, especially during absence seizures in school-children. Antiepileptic drug side-effects of drowsiness and short attention span can affect educational achievement, and are commonly exacerbated by polytherapy (Devinsky, 2001).

Elsewhere, objective and subjective stigma with associated high levels of anxiety and depression impaired sexual activities, lower rates of marriage and employment have been reported as some of the effects of epilepsy on QOL (Jenna, 2005). Increased seizure frequency had major effect on the QOL in a study done by (Herodes *et al.* 2009, Guekh *et al.*, 2010) reported that patients with frequent seizures had low social contact and feelings of stigmatization. Many reports suggest that there is a lower marriage rate in individuals with epilepsy compared to the general population (Baker *et al.* 1997). Myeong- Kyu Kim studied marital status in Asian patients with epilepsy and reported high divorce rates in these patients (Kim, 2007). Social isolation and poor social adaptation can result from perceived stigma or over-dependency caused by parental over protection. The people with epilepsy also often fear embarrassment by a seizure, causing reluctance to engage in social interaction, with concomitantly low self- esteem and academic under-achievement.

These can result in a shrunken support network, fewer friends, a lower likelihood of marriage and greater likelihood of anti-social behavior (Buchanan, 2002)

Unemployment is higher among people with epilepsy, by up to 50% in developed countries if seizures are not fully controlled and up to 100% in developing countries. This can be caused by employer prejudice resulting from stigma and a lack of information, a belief that machinery should be avoided by the people with epilepsy, inability to drive, or poorer academic achievement. Disclosure to an employer is therefore a difficult decision. Unemployment commonly results in lower self-esteem, lessened well-being and a lower quality of life (Bisho & Hermann, 2000).

(Djibouti, 2003), also reported an employment rate of 17% among persons living with epilepsy. A study conducted in Jordan on public knowledge and attitude towards epilepsy using standard four set questionnaire on 16,044 respondents, only 11.5% of them would allow their sons to marry an epileptic, 10.6% would allow their daughters to marry an epileptic while 71.4% think epileptics can have children (Daoud, *et al*; 2007). Also, in China, epilepsy diminishes the prospect of marriage, especially for women. A survey of public awareness in 1992 revealed that 72% of patients objected to their children marrying someone with epilepsy (WHO, 2001).

In another study on epilepsy in Hong Kong, attitude towards people with epilepsy showed that 32.2% of respondents would allow their children to marry individuals with epilepsy while 27.5% considered pregnancy to be inappropriate for an individual with epilepsy (Hui & Kwan, 2004). In a comprehensive study that included 15 European countries, the employment of patients ranged from 32% in Spain to 65% in Sweden (Buck *et al*. 1999). A study in Zambia reported that many PWE were feared and rejected

by families or communities (Chomba *et al.* 2007). Cultural beliefs influence attitudes and actions of the community towards PWE and high rates of anxiety, depression, and low self-esteem have been measured in PWE, thus adversely affecting quality of life (Baker, 2002). Satisfactory relations with the other sex require self-esteem. Low self-esteem in a people with epilepsy can result in failure to establish good sexual relationships. Brain damage and/or antiepileptic drugs may also result in anhedonia. Head injury may result in reduced libido and erectile dysfunction. Inadequate sexual functioning may result in depression, marital distress or self-aversion (Cole & Cole, 1999).

Adjustment to a chronic illness, such as epilepsy is not merely a function of the severity or duration of the disorder or associated treatment adverse outcomes. Response from the family and ‘significant others’ with associated imbalance between expectations and reality may be more menacing than the illness itself (Theo, Marieke, Bert, *et al.* 1998). Although primary treatment goals focus on the physical complications of epilepsy through seizure control (WHO, 2001; Devinsky & Penry, 1993), people with epilepsy face many other challenges, including problematic psychological manifestations (e.g. poor self-esteem, fear and anxiety) and social complications (e.g. driving restrictions, unemployment and social isolation), all of which can have an impact on quality of life (QOL) (Berto, 2002; Bishop *et al.* 2002).

2.2.3 Epileptic patients and their Environmental well being

In several studies PLWE more often report poor health, unemployment and the inability to work. PLWE more often live in households with the lowest annual income, and have a history of co-occurring disorders (Kobau *et al.* 2008; O’Donoghue *et al.* 1999;

Stavem *et al.* 2000; Strine *et al.* 2005; Wiebe *et al.* 1999). PWE are also more likely to be obese, physically inactive, current smokers and have a higher risk of experiencing major events that affect their lives significantly. PWE also have a higher mortality rate (Cockerell *et al.* 1994; Cockerell 1996; Cockerell *et al.* 1997; Lindsten *et al.* 2000) and even a higher risk of suicide (Christensen *et al.* 2007). People who have experienced even a single seizure have been shown to be discriminated against on the labor market (Holland *et al.* 2009). A low socioeconomic status has been shown to be a risk factor for developing epilepsy (Heaney *et al.* 2002; Hesdorffer *et al.* 2005) and also to cause more hospital admissions for epilepsy (Li *et al.* 2008). Normal activity limitation in areas in school, work or socialization with family and friends as well as poor social and emotional support are all significant predictors of poor mental health in PLWE (Lu & Elliott, 2012).

More dramatic seizures at work (partial seizures of frontal lobe origin, tonic-clonic seizures) are distressing to watch and upsetting to others in the workplace. After a seizure at work, individuals with epilepsy have often found themselves dismissed, moved to a remote office, or isolated. Numerous surveys have shown high rates of unemployment or underemployment in persons with epilepsy. Patients may feel encouraged to lie to prospective employers because truthfulness undermines their chances of being hired (Chaplin, Wester, Tomson, 1998).

2.2.4 Epileptic patients and their Physical well being

The treatment of epilepsy can be associated with a number of physical symptoms other than just seizures. Furthermore, epilepsy increases the risk for several chronic

health conditions, including heart disease, stroke, arthritis, asthma, severe headaches, lower back pain, neck pain, and cancer (National Health Interview, 2002). People with epilepsy as a group also have worse physical health, more activity limitation, more falls, and less physical activity than the general population (Michigan Behavioral Risk Factor Survey, 2005). Common physical symptoms, some of which may be related to epilepsy and some of which may be medication side effects, includes, headaches, drowsiness, fatigue or weakness, unsteadiness or coordination problems, dizziness, muscle soreness, back and neck pain, weight gain, sleep disturbance and digestive problems (heartburn, nausea, vomiting, constipation, diarrhea).

Wo *et al.* (2014) reported on six main themes as being particularly important in affecting employability among people with uncontrolled seizures, including the ability to work; intention to work; overdependence and protection; life events; and the provision of government and welfare support. Key factors affecting patients' ability to work included education, cognitive and physical functions, their individual capability to continue working after seizures, travel to work and to cope with stress. The study concluded that there were internal and external factors affecting employability among people with uncontrolled seizures both positively and negatively. Positive internal factors such as ability and intention to work require further exploration. Most injuries related to seizures occur because of unfortunate interactions between the seizing patient and the environment. Patients can fall and strike their head or fracture bones (Spitz *et al.* 1998). Burns are common in persons with epilepsy (Spitz *et al.* 1994) and can arise in a number of ways. Complex partial seizures can include automatisms (i.e., senseless repetitive movements). A patient holding a cigarette at the start of a seizure might rub the

burning end into his or her arm without being aware of the pain. In the kitchen, hot objects may be dropped or a hand or arm placed in the fire. In hot climates, patients have developed third-degree burns by lying senseless in a postictal state on hot pavement. During complex partial or tonic clonic seizures, the patient is not reactive to the environment and injuries can occur during driving, climbing ladders, or operating power tools. Patients have drowned while swimming or bathing in tubs (Vickery, 1995).

A low socioeconomic status has been shown to be a risk factor for developing epilepsy (Heaney *et al.* 2002; Hesdorffer *et al.* 2005) and also to cause more hospital admissions for epilepsy (Li *et al.* 2008). Normal activity limitation in areas in school, work or socialization with family and friends as well as poor social and emotional support are all significant predictors of poor mental health in PWE (Lu & Elliott, 2012).

Falling during a seizure can injure head or break a bone. Persons living with epilepsy have 15 to 19 times more risk of drowning while swimming or bathing than the rest of the population because of the possibility of having a seizure while in the water. A seizure that causes either loss of awareness or control can be dangerous during driving of a car or operating other equipment. Many states have driver's license restrictions related to ability to control seizures and impose a minimum amount of time that one has been seizure-free, ranging from months to years, before allowed to drive. Seizures during pregnancy pose dangers to both mother and baby, and certain anti-epileptic medications increase the risk of birth defects.

Most women with epilepsy can become pregnant and have a healthy baby but they need to be carefully monitored throughout pregnancy, and medications may need to be

adjusted. Hence it is very important that the patient works with her doctor to plan the pregnancy.



CHAPTER THREE

METHODOLOGY

3.0 Introduction

This section presents the various techniques and tools that was used to collect data from the participants. It also describes the type of study, study location, variables that was measured, sampling plan and analytical tools that were used to analyze data. Furthermore it presents the ethical considerations and issues of the study.

3.1 Type of Study

A descriptive quantitative design was used. A quantitative design is regarded as an efficient way for investigating health issues in the communities as well as the best method for collecting large information in social and health research (Katzenellenbogen, 1997; Aljeesh, 2003). Due to time and resource constraints, the study adopted the cross sectional survey method of research. Survey is the method of obtaining information about a population by selecting and measuring a sample of the population and generalizing the result of the study to the entire population. In surveys, inferences and generalization are made about the population of study based on sample data obtained (Hoepfl, 2007)

3.2 Study area

The study was conducted at the epilepsy clinic of the Korle-bu teaching hospital (KBTH) in the Greater Accra Region of Ghana. This region was purposively selected because the capital town of the nation where there is a mix of people from all parts of the country who access health services from the facility. In addition, it is a primary health care facility affiliated with the University of Ghana Medical School. The epilepsy clinic can

be found in the same building as the old medical block. It is a special clinic which is held on Mondays only by physician specialists. The KBTH is located in the Nation's capital, Accra, specifically in the Ablekuma Central Sub -metro District and is 0.5 km from the Korle- Lagoon. It covers an area of about 441 acres. The hospital is the premier and leading national referral hospital. It serves as the foremost training facility for healthcare professions within its various branches including the Nursing and Midwifery Training College, the Public Health School, Ophthalmic Nursing School, School of Medical Laboratory Technology, the Medical and Dental School and School of Allied Health Sciences, Radiography Department.

Korle-Bu Teaching Hospital (KBTH) has a bed capacity of 1,700 with staff strength of 3,500 comprising of 390 doctors and dentists, 1035 nurses, 40 pharmacists, a number of health service administrators, laboratory technicians and technologist, and biostatisticians and other categories of staff. KBTH out-patient average daily attendance is 1,000 patients and average admission is 120 patients. It has 17 clinical departments and centers. These are Obstetrics and Gynecology, Surgery, Medicine, Radiology as well as Ear, Nose and Throat departments. The others are Hematology, Microbiology, Eye Clinic, Reconstructive Plastic Surgery and Burns, and National Cardiothoracic Centre. The mission of the Hospital is to provide quality of tertiary health care, teaching, research and outreach services. The epilepsy clinic sees an average of 19 cases in a week and 114 cases in six weeks respectively.

3.3 Variables

3.3.1 Outcome Variables

Quality of Life

3.1.2 Independent Variables

Table 1: Description of domains making up outcome and independent variables

Domain	Facets incorporated within domains
1. Physical health	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work Capacity
2. Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality/ Region/ Personal benefits Thinking, learning, memory and concentration
3. Social relationships	Personal relationships Social support Sexual activity
4. Environment	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation/ leisure activities Physical environment(pollution/noise/ traffic/ climate) Transport

3.4 Study population

Best and Khan (1993) defined a population as a group of individuals that have one or more characteristics in common that are of interest to the researcher. Cardwell (1999) also indicated that the population is a group of people who are the focus of a research study and to which the results would be applied.

The population of this study was all persons living with epilepsy and attending Korle-bu Teaching Hospital. The clinic sees about 19 cases in a week and about 114 cases in 6 weeks respectively. The target population was persons living with epilepsy who are 18 years and above who had agreed to take part in the study and have been on medication for not less than 6 months. This population was chosen because they are adults and will not have to seek consent from their parents/guardian before they take part in the study, also to see if treatment medications have had any influence on their QOL. In addition they have the characteristics needed for the researcher to fulfill the purpose of the study or achieve the set objective.

3.6 Sample size calculation

Kadam and Bhalerao (2010) showed that the sample size is the number of participants in a sample, which is a basic statistical principle with which researchers define the sample size before starting a clinical study so as to avoid misinterpreting results. The estimated minimum sample size for the study was calculated to be 101.

In a related study by Ferrari et al. (2013) the purposive sample size calculation method was used to calculate sample size, non-adherence rate was chosen as the primary endpoint. The sample size calculation for proportions, a 10.7% prevalence of epilepsy as

reported by Ngugi et al. 2013, with a 95% confidence interval and a 5% significance level. This yielded a sample size of 102 patients. This number was scaled up to 105 to compensate for non-response.

Minimum sample size, $n = z^2 (p,q) / E^2$

$$n = 1.96^2 (0.107 * 0.893) / 0.06^2 = 101.3$$

q= estimated proportion of individuals without epilepsy (89.3%)

p= estimated proportion of individuals with epilepsy (10.7%- Ngugi et al. 2013).

e= margin of error= 0.06

z= 95th percentile of the z-score (1.96)

n=Sample size

Using methods used by similar studies conducted by Lua et al. (2012) and the sample size determination used by (Lwanga & Leweshow, 1991; Naing, 2009) this study proposes a minimum sample size of 105 respondents. However, a sample size of 82 giving a response rate of 81 was achieved in this study.

3.7 Sampling procedure

In this study, due to the low incidence of epilepsy at the KBTH after a pilot study done in the same hospital. Results from the pilot study showed that 19 new cases are seen every week at the clinic. All persons living with epilepsy and are 18years and above, have been on medication for at least 6 months and attending the Epilepsy Clinic during the study period of six (6) weeks were used for the study.

The researcher purposively recruited persons who met the inclusion criteria (all persons living with epilepsy and are 18years and above, have been on medication for at least 6 months and attending the Epilepsy Clinic) and consented to the study at the Epilepsy

Clinic. The researcher explained the purpose of the study to the patients and after they have signed an informed consent they were recruited. The nurses and researcher used their experience and knowledge to recruit respondents who consent to take part in the study. The data was collected over a period of 6 weeks.

3.8 Data Collection Tool

A structured questionnaire designed by WHOQOL-BREF was used for data collection. The first part of the questionnaire section contained demographic data of respondents which included age, gender, marital status and educational level, the second section is on physical health, third section psychological, fourth section is on social relationships and the final section on the environment

3.9 Scoring of the WHOQOL-BREF

WHO-BREF provides a QOL profile and it has four domain scores. Here two items are examined separately; firstly individual overall perception of their QOL and secondly an individual overall perception of their health. The four domain scores denote an individual perception of their QOL in each particular domain.

The domain scores are scaled in a positive direction (i.e. higher score denotes higher QOL.) The mean score of items within each domain is used to calculate the domain score. The mean score is then multiplied by 4 in order to make domain score comparable with the scores used in the WHOQOL-100. The first transformation method converts scores to be in range of 4-20, comparable with the WHOQOL-100. The second transformation method converts domain scores to a 0-100 scale.

3.10 Quality Control

Three research assistants were recruited and trained to help with data collection entry and analysis. Training included interpretation of questionnaire into the local dilate for those who have low level of education. Research assistants were supervised during data collection. Filled in questionnaires were checked for completeness before giving to the respondents. WHOQO-BREF questionnaires were used because it contains the four domains which would be used to measure quality of life.

3.11 Pilot

To reduce error in the main study, questionnaire was pre-tested at the Accra Psychiatric Hospital and gaps that were identified were rectified before the actual study began. A cronbacks alpha of 0.856 was obtained for the reliability and validity test.

3.12 Statistical analysis

The data collected was entered and cleaned using Microsoft Excel spread sheet stored in a computer with password. The data was imported into STATA version 12.0 for coding and further checks. Data were summarized as frequencies, percentages, means and standard deviation. Association between outcome variable (quality of life) and independent variables (Physical health, Psychological health, environmental and social relationship) was determined using the Pearson's chi-square test (X^2). Ordinal regression analysis was performed to determine the effect of selected characteristics on the overall quality of life and the four domains. A p-value <0.05 will be considered as statistically significant.

3.13 Limitations

The study is limited by the use of non-probability sampling method. This limits its generalizability.

The use of questionnaires as data collection tool may have also introduced recall bias.

The cut off age of 18 years may also introduce selection bias.

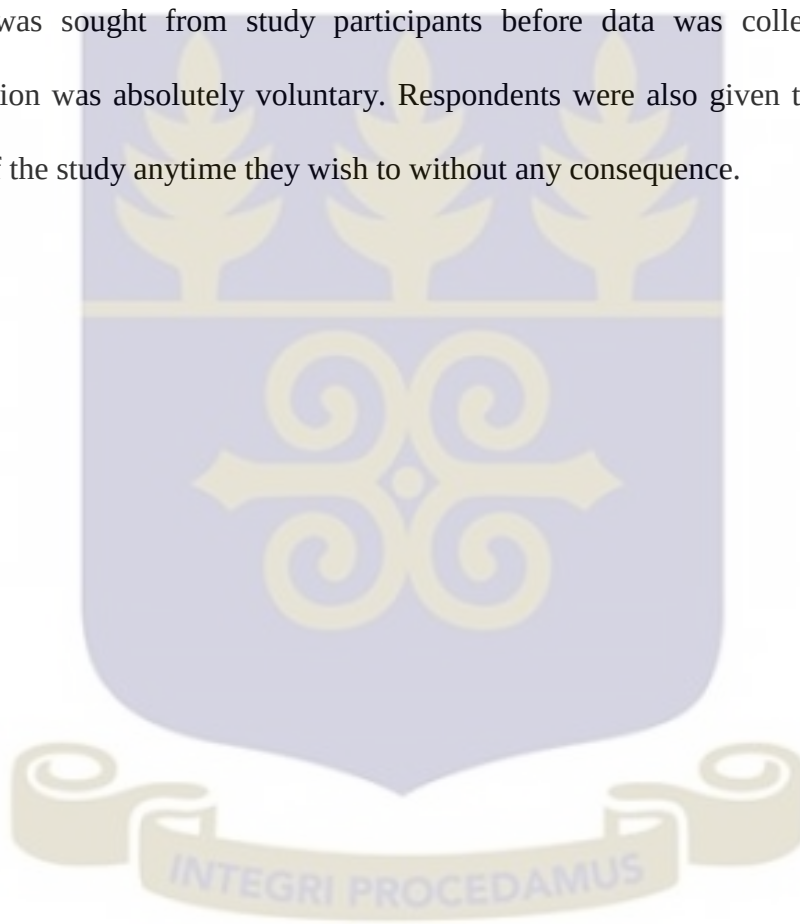
There was a public holiday which fell on a Monday and that affected the number of respondents obtained. Since the clinic is only held once in a week on Mondays.

3.14 Ethical consideration/issues

Before the commencement of data collection, ethical approval for the study was sought from the Ghana Health Service Ethical Review Committee. Permission and approval was sought from the Korle – Bu Teaching Hospital administration and the Epilepsy Clinic before data was collected. The study populations were persons living with epilepsy who are eighteen years and above and have been on medication for at least 6 months. Research participants were made aware of the fact that the research would cause some psychological discomfort, during the answering of some parts of the questionnaire. A psychologist was placed on standby to deal with such situations if the need arose. However, the level of psychological distress would be minimal. The study is envisaged, to be beneficial to the study population, psychologist, physicians and the general public. They were also made to understand that the research would help them assess and treat persons living with epilepsy, by addressing the factors that are correlated with their health– related quality of life. Information obtained can also be used by other researchers as references to improve on research conducted in this area.

The identity and privacy of the patients were protected by assigning codes to them. They were made to understand that no compensation will be given to them for participating in the research; however their inputs will be recognized and appreciated.

The data collected was entered using Microsoft Word and Excel and stored with a password, then the questionnaires would be destroyed after a five year period. Written consent was sought from study participants before data was collected from them. Participation was absolutely voluntary. Respondents were also given the opportunity to opt out of the study anytime they wish to without any consequence.



CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the results of the study. It presents the socio-demographic characteristics of the respondents, the quality of physical health, psychological health, environment, and social relationship among persons living with epilepsy. It also covers the association between the demographic variables and physical health, psychological, environmental and social relationship. The results are presented in tables and slots, and they are summarized as frequencies and percentages and domain scores are also computed.

4.2 Demographic characteristics

The study sampled 82 respondents due to time constraints and low response rate with a mean age of 35 ± 18.9 years. The youngest person was 18 years while the eldest was 75 years. Most respondents 39% in the study were in age group 18-24 years, 18.3% 25-34 years while the least were in age group ≥ 55 years. More than half of the respondents 56.1% were females and almost all the respondents 91.55 were Christians. Most respondents 36.6% had tertiary level education, 28% SHS while 34.5% were below SHS level of education. More than half of the respondent 63.4% were single while 32.9% were married. More than half of the respondents 56.1% were employed with 37.8% working in skilled employments. This is shown in Table 2.

Table 2: Demographic characteristics of respondents

Demographic variable	Frequency (n)	Percent (%)
Age group		
18-24	32	39.0
25-34	15	18.3
35-44	11	13.4
45-54	12	14.6
55 and above	12	14.6
Total	82	100
Gender		
Male	36	43.9
Female	46	56.1
Total	82	100
Religion		
Christian	75	91.5
Moslem	5	6.1
Traditional	2	2.4
Total	82	100
Level of education		
None	7	8.5
Primary	3	3.7
JHS	19	23.2
SHS	23	28.0
Tertiary	30	36.6
Total	82	100
Marital status		
Single	52	63.4
Married	27	32.9
Divorced	2	2.4
Separated	1	1.2
Total	82	100
Employment		
Employed	46	56.1
Unemployed	36	43.9
Total	82	100
Type of employment		
NA	36	43.9
Skilled	31	37.8
Unskilled	15	18.3
Total	82	100

4.3 Quality of life of PLWE

In Table 3, majority of respondents 81.7% have moderate quality of life while only 3.7% had high quality of life for the physical health. More than half of the respondents, i.e. 61% had moderate quality of life for psychological health with 35% having low quality of life. Social relationship was the worse domain as 58.5% had low quality of life with only 11% having high quality of life. More than half of the respondents 64.6% had moderate quality of life for the Environmental domain with 26.8% having low quality of life. Overall, Majority of the respondents 69.5% had moderate quality of life. However, a quarter 24.4% of the respondents had low quality of life.

Table 3: Respondents level of quality of life among the domains

Domains	Low n (%)	Moderate n (%)	High n (%)
Physical Health	12 (14.6)	67 (81.7)	3 (3.7)
Psychological quality of life	29 (35.4)	50 (61.0)	3 (3.7)
Social Relationship	48 (58.5)	25 (30.5)	9 (11.0)
Environmental quality of life	22 (26.8)	53 (64.6)	7 (8.5)
Overall Quality of life	20 (24.4)	57 (69.5)	5 (6.1)

4.4 Associations between overall quality of life and demographic characteristics

The study showed significant associations between level of education of respondents and overall quality of life ($p=0.041$). Age group, marital status, gender, religion, and employment type were not significantly associated with overall quality of life ($p>0.05$). Respondents in age group 25-34 years had a higher proportion of those with low quality of life compared with the other age groups. More females 28.3% had low overall quality of life compared with males. Higher proportions of Christians 26.7% had low quality of life compared with Muslims and traditional worshipers. Low overall quality of life was predominant among those with higher level of education and those unemployed also had low overall quality of life compared with those employed (Table 4).

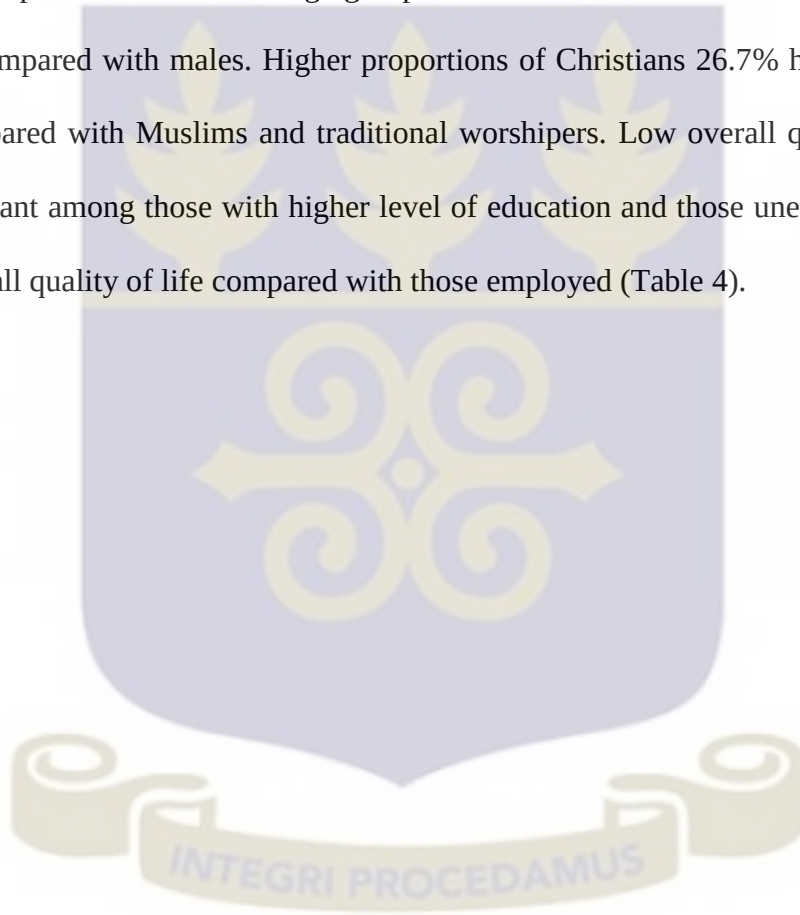


Table 4: Overall quality of life and demographic characteristics of respondents

Overall quality of life					
Demographic variable	Low	Moderate	High	χ^2	p-value
Age group					
18-24	10 (31.2)	18 (56.2)	4 (12.5)	9.561	0.297
25-34	5 (33.3)	9 (60.0)	1 (6.7)		
35-44	2 (18.2)	9 (81.8)	0 (0.0)		
45-54	2 (16.7)	10 (83.3)	0 (0.0)		
55 and above	1 (8.3)	11 (91.7)	0 (0.0)		
Gender					
Male	7 (19.4)	26 (72.2)	3 (8.3)	1.246	0.539
Female	13 (28.3)	31 (67.4)	2 (4.3)		
Religion					
Christian	20 (26.7)	51 (68.0)	4 (5.3)	5.209	0.404
Moslem	0 (0.0)	4 (80.0)	1 (20.0)		
Traditional	0 (0.0)	2 (100.0)	0 (0.0)		
Level of education					
None	0 (0.0)	7 (100.0)	0 (0.0)	16.443	0.041*
Primary	0 (0.0)	3 (100.0)	0 (0.0)		
JHS	8 (42.1)	11 (57.9)	0 (0.0)		
SHS	7 (30.4)	12 (52.2)	4 (17.4)		
Tertiary	5 (16.7)	24 (80.0)	1 (3.3)		
Marital status					
Single	16 (14.8)	32 (81.5)	4 (3.7)	4.701	0.583
Married	4 (14.8)	22 (81.5)	1 (3.7)		
Divorced	0 (0.0)	2 (100.)	0 (0.0)		
Separated	0 (0.0)	1 (100.0)	0 (0.0)		
Employment					
Employed	11 (23.9)	32 (69.6)	3 (6.5)	0.041	0.981
Unemployed	9 (25.0)	25 (69.4)	2 (5.6)		
Type of employment					
NA	9 (25.0)	25 (69.4)	2 (5.6)	0.138	0.998
Skilled	7 (22.6)	22 (71.0)	2 (6.5)		
Unskilled	4 (26.7)	10 (66.7)	1 (6.7)		

*Significant at 0.05

4.5 Associations between Physical health and demographic characteristics

The study showed no significant associations between all demographic characteristics and physical quality of life ($p>0.05$). Respondents in age group 18-24 had a higher proportion of those with low quality of life compared with the other age groups. More males 19.4% had low physical quality of life compared with females. Higher proportions of traditional worshipers 50.0% had low physical quality of life compared with other worshipers. Low physical quality of life was predominant among those with higher level of education and those married had low physical quality of life compared to single respondents. Higher proportions of those employed had low physical quality of life compared with those unemployed. Those with unskilled employed showed low physical quality of life compared with those with skilled employment (Table 5).

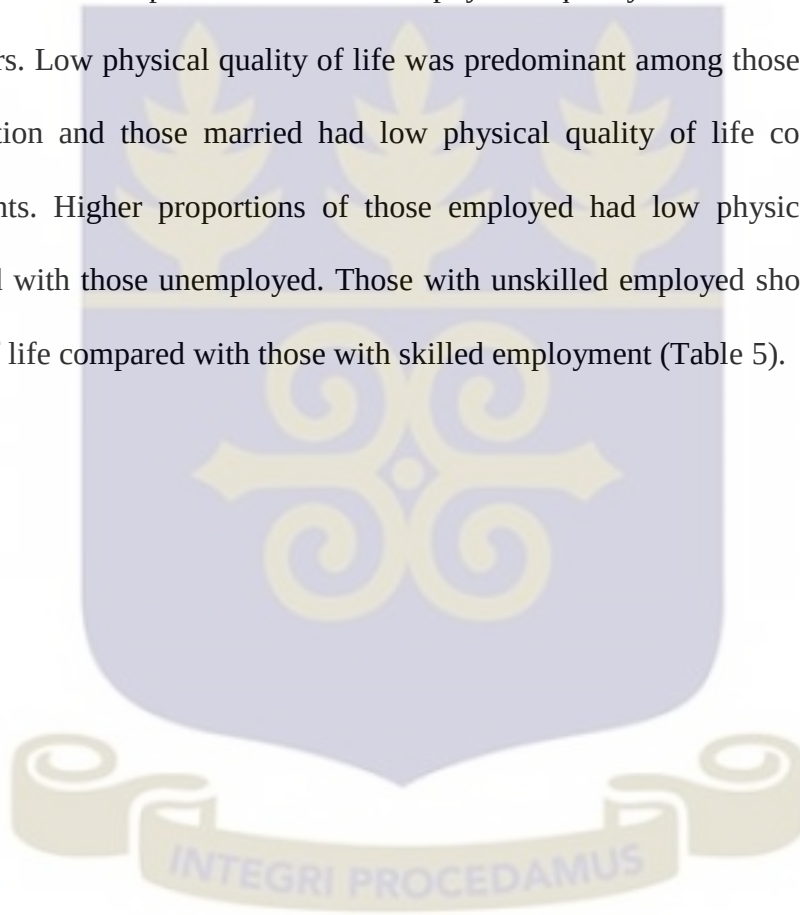


Table 5: Physical health and demographic characteristics of respondents

Physical Health					
Demographic variable	Low	Moderate	High	χ^2	p-value
Age group					
18-24	6 (18.8)	25 (78.1)	1 (3.10)	3.584	0.893
25-34	1 (6.7)	13 (86.7)	1 (6.7)		
35-44	1 (9.1)	9 (81.8)	1 (9.1)		
45-54	2 (16.7)	10 (83.3)	0 (0.0)		
55 and above	2 (16.7)	10 (83.3)	0 (0.0)		
Gender					
Male	7 (19.4)	29 (80.6)	0 (0.0)	3.73	0.185
Female	5 (10.9)	38 (82.6)	3 (6.5)		
Religion					
Christian	11 (14.7)	61 (81.3)	3 (4.0)	3.17	0.529
Moslem	0 (0.0)	5 (100.0)	0 (0.0)		
Traditional	1 (50.0)	1 (50.0)	0 (0.0)		
Level of education					
None	1 (14.3)	6 (85.7)	0 (0.0)	9.771	0.281
Primary	0 (0.0)	3 (100.0)	0 (0.0)		
JHS	2 (10.5)	17 (89.5)	0 (0.0)		
SHS	3 (13.0)	17 (73.9)	3 (13.0)		
Tertiary	6 (20.0)	24 (80.0)	0 (0.0)		
Marital status					
Single	7 (13.5)	43 (82.7)	2 (3.8)	1.582	0.983
Married	5 (18.5)	21 (77.8)	1 (3.7)		
Divorced	0 (0.0)	2 (100.0)	0 (0.0)		
Separated	0 (0.0)	1 (100.0)	0 (0.0)		
Employment					
Employed	8 (17.4)	35 (76.10)	3 (6.5)	3.297	0.192
Unemployed	4 (11.1)	32 (88.9)	0 (0.0)		
Type of employment					
NA	4 (11.1)	32 (88.9)	0 (0.0)	3.423	0.491
Skilled	5 (16.1)	24 (77.4)	2 (6.5)		
Unskilled	3 (20.0)	11 (73.3)	1 (6.7)		

*Significant at 0.05

4.6 Associations between psychological quality of life and demographic characteristics

The study showed significant associations between level of education of respondents and psychological quality of life ($p=0.026$). Age group, marital status, gender, religion, and employment type were not significantly associated with psychological quality of life ($p>0.05$). Respondents in age group 25-34 had a higher proportion of those with low psychological quality of life compared with the other age groups. More females' 45.7.3% had low psychological quality of life compared with males. Higher proportions of traditional worshipers 50.0% had low psychological quality of life compared with Muslims and Christians. Low psychological quality of life was predominant among those with lower level of education and those unemployed also had low psychological quality of life compared with those employment. Low psychological quality of life is predominant among those with unskilled employment compared with those with skilled employment (Table 6).

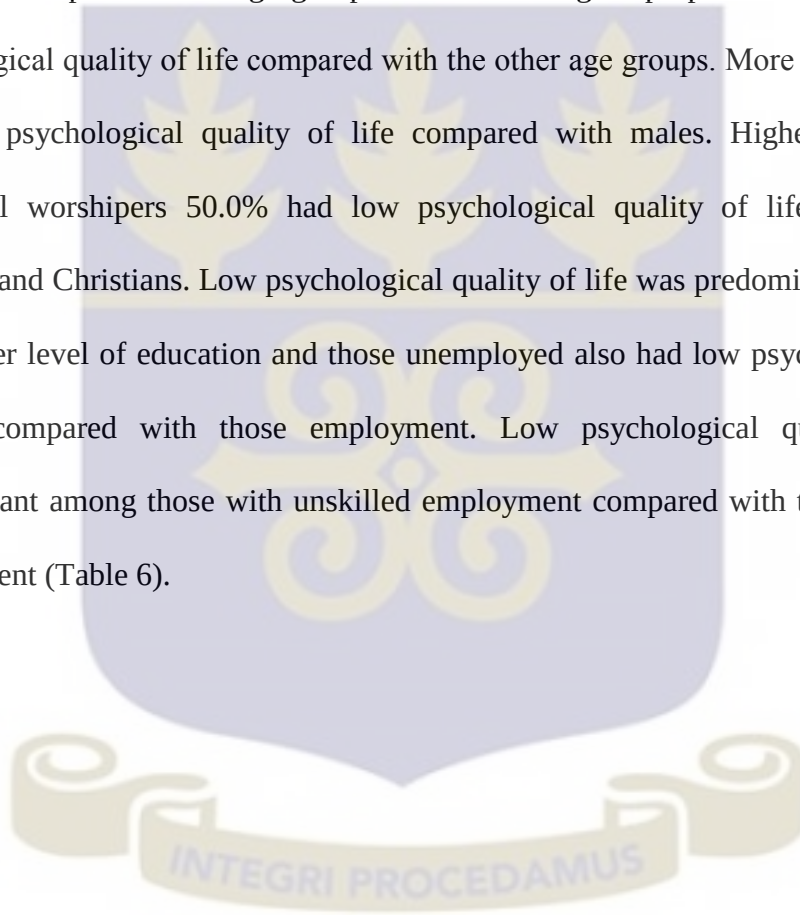


Table 6: Psychological quality of life and demographic characteristics of respondents

Psychological Quality of life					
Demographic variable	Low	Moderate	High	χ^2	p-value
Age group					
18-24	8 (25.0)	21 (65.6)	3 (9.4)	7.076	0.528
25-34	7 (46.7)	8 (53.3)	0 (.0)		
35-44	5 (45.5)	6 (54.5)	0 (0.0)		
45-54	4 (33.3)	8 (66.7)	0 (0.0)		
55 and above	5 (41.7)	7 (58.3)	0 (0.0)		
Gender					
Male	8 (22.2)	26 (72.2)	2 (5.6)	5.097	0.078
Female	21 (45.7)	24 (52.2)	1 (2.2)		
Religion					
Christian	26 (34.7)	47 (62.7)	2 (2.7)	4.22	0.341
Moslem	2 (40.0)	1 (40.0)	1 (20.0)		
Traditional	1 (50.0)	1 (50.0)	0 (0.0)		
Level of education					
None	1 (14.3)	6 (85.7)	0 (0.0)	17.371	0.026*
Primary	3 (100.0)	0 (0.0)	0 (0.0)		
JHS	5 (26.3)	14 (73.7)	0 (0.0)		
SHS	10 (43.5)	20 (66.7)	0 (0.0)		
Tertiary	10 (33.3)	20 (66.7)	0 (0.0)		
Marital status					
Single	15 (28.8)	35 (67.3)	2 (3.8)	3.822	0.701
Married	13 (48.1)	13 (48.1)	1 (3.7)		
Divorced	1 (50.0)	1 (50.0)	0 (0.0)		
Separated	0 (0.0)	1 (100.0)	0 (0.0)		
Employment					
Employed	15 (32.6)	29 (63.0)	2 (4.3)	0.435	0.805
Unemployed	14 (38.9)	21 (58.3)	1 (2.8)		
Type of employment					
NA	13 (36.1)	22 (61.1)	1 (2.8)	0.852	0.931
Skilled	10 (32.3)	20 (64.5)	1 (3.2)		
Unskilled	6 (40.0)	8 (53.3)	3 (3.7)		

*Significant at 0.05

4.7 Associations between Social relationship of life and demographic characteristics

In Table 7 study showed no significant associations between all demographic characteristics and social relationship of respondents ($p>0.05$). Respondents in age group 25-34 had a higher proportion of those with low social quality of life compared with the other age groups. More females 65.2% had higher proportions of respondents with low social quality of life compared with males. Higher proportions of Muslims 60% had low social quality of life compared with Christians and traditional worshipers. Low social quality of life was predominant among those with primary education likewise those employed.

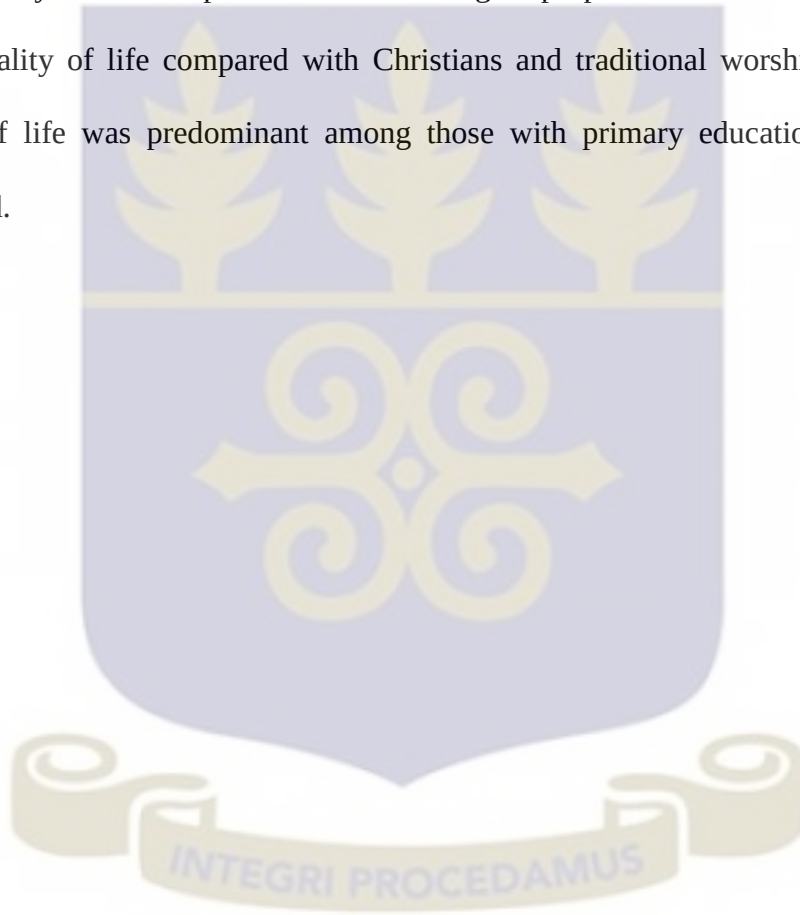


Table 7: Social relationship and demographic characteristics of respondents

Social Relationship					
Demographic variable	Low	Moderate	High	χ^2	p-value
Age group					
18-24	19 (59.4)	8 (25.0)	5 (15.6)	9.732	0.284
25-34	10 (66.7)	2 (13.3)	3 (20.0)		
35-44	7 (63.6)	3 (27.3)	1 (9.1)		
45-54	6 (50.0)	6 (50.0)	0 (0.0)		
55 and above	6 (50.0)	6 (50.0)	0 (0.0)		
Gender					
Male	18 (50.0)	13 (36.1)	5 (13.9)	1.961	0.375
Female	30 (65.2)	12 (26.1)	4 (8.7)		
Religion					
Christian	44 (58.7)	23 (30.7)	8 (10.7)	1.055	0.901
Moslem	3 (60.0)	1 (20.0)	0 (0.0)		
Traditional	1 (50.0)	1 (50.0)	0 (0.0)		
Level of education					
None	4 (57.1)	2 (28.6)	1 (14.3)	7.813	0.452
Primary	2 (66.7)	1 (33.3)	0 (0.0)		
JHS	14 (73.7)	3 (15.8)	2 (10.5)		
SHS	14 (60.9)	5 (21.7)	4 (17.4)		
Tertiary	14 (46.7)	14 (46.7)	2 (6.7)		
Marital status					
Single	35 (67.3)	11 (21.2)	6 (11.5)	7.892	0.269
Married	12 (44.4)	12 (44.4)	3 (11.1)		
Divorced	1 (50.0)	1 (50.0)	0 (0.0)		
Separated	0 (0.0)	1 (100.0)	0 (0.0)		
Employment					
Employed	28 (60.9)	13 (28.3)	5 (10.9)	0.269	0.874
Unemployed	20 (55.6)	12 (33.3)	4 (11.1)		
Type of employment					
NA	20 (55.6)	12 (33.3)	4 (11.1)	0.413	0.981
Skilled	19 (61.3)	9 (29.0)	2 (13.3)		
Unskilled	9 (60.0)	4 (26.7)	2 (13.3)		

4.8 Associations between Environmental quality of life and demographic characteristics

There was not significant association between demographic variables and environmental quality of life ($p > 0.05$). However, more than half of respondents 54.5% in age group 35-44 have low environmental quality of life. In terms of level of education, low quality of life was predominant among respondents with primary education. There were more single respondents with low environmental quality of life compared with married respondents. Those with unskilled employment also had lower environmental quality of life compared with those with skilled employment. This is shown in Table 8.



Table 8: Environmental quality of life and demographic characteristics of respondents

Environmental quality of life					
Demographic variable	Low	Moderate	High	χ^2	p-value
Age group					
18-24	10 (31.2)	17 (53.1)	5 (15.6)	14.132	0.078
25-34	2 (13.3)	13 (86.7)	0 (0.0)		
35-44	6 (54.5)	4 (36.4)	1 (9.1)		
45-54	3 (25.0)	9 (75.0)	0 (0.0)		
55 and above	1 (8.3)	10 (83.3)	1 (8.3)		
Gender					
Male	10 (27.8)	23 (63.9)	3 (8.3)	0.031	0.985
Female	12 (26.1)	30 (65.2)	4 (8.7)		
Religion					
Christian	21 (28.0)	49 (65.3)	5 (6.7)	5.855	0.211
Moslem	1 (20.0)	3 (60.0)	1 (20.0)		
Traditional	0 (0.0)	1 (50.0)	1 (50.0)		
Level of education					
None	2 (28.6)	4 (57.1)	1 (14.3)	10.311	0.245
Primary	2 (66.7)	1 (33.3)	0 (0.0)		
JHS	5 (26.3)	14 (73.7)	0 (0.0)		
SHS	8 (34.8)	11 (47.8)	4 (17.4)		
Tertiary	5 (16.7)	23 (64.6)	2 (6.7)		
Marital status					
Single	16 (30.8)	31 (59.6)	5 (9.6)	7.077	0.314
Married	6 (22.2)	20 (74.1)	1 (3.7)		
Divorced	0 (0.0)	1 (50.0)	1 (50.0)		
Separated	0 (0.0)	1 (100.00)	0 (0.00)		
Employment					
Employed	13 (28.3)	28 (60.9)	5 (10.9)	0.973	0.613
Unemployed	9 (25.0)	25 (69.4)	2 (5.6)		
Type of employment					
NA	9 (25.0)	25 (69.4)	2 (5.6)	5.795	0.215
Skilled	7 (22.6)	22 (71.00)	2 (6.5)		
Unskilled	6 (40.0)	6 (40.0)	3 (20.0)		

Ordinal logistic regression did not show any significant effect of demographic characteristics on the overall quality of life of persons living with epilepsy.

4.9 Correlations among overall quality of life and the domains

Pearson correlations showed significant positive correlations between physical health and environment, overall quality of life ($p=0.039$; 0.001) respectively. Psychosocial quality of life also showed significant positive correlation with social quality of life, environment and overall quality of life ($p=0.006$; 0.001 ; 0.001). Social quality of life showed significant association with environmental quality of life and overall quality of life ($p=0.001$; 0.001). Environmental quality of life was also significantly correlated with overall quality of life ($p=0.001$). Overall quality of life was significantly correlated with all four domains. An increase in the levels of the four domains resulted in an increase in the overall quality of life and vice versa.

Table 9: Correlations between overall quality of life and domains

Correlations		Physical	Psycho	Social	Environment	Overall
Physical	Pearson Correlation	1	0.174	0.18	0.229*	0.439**
	p-value		0.117	0.105	0.039	0.001
Psychosocial	Pearson Correlation	0.174	1	.301**	.548**	0.626**
	p-value	0.117		0.006	0.001	0.001
Social	Pearson Correlation	0.18	.301**	1	0.512**	0.857**
	p-value	0.105	0.006		0.001	0.001
Environment	Pearson Correlation	.229*	.548**	.512**	1	0.800**
	p-value	0.039	0.001	0.001		0.001
Overall	Pearson Correlation	.439**	.626**	.857**	.800**	1
	p-value	0.001	0.001	0.001	0.001	

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

CHAPTER FIVE

DISCUSSION

5.1 Introduction

This chapter discusses the findings of the study in relation to literature reviewed in chapter two. The discussions are done in accordance with the stated objectives and research questions.

5.2 Demographic characteristics

This study sought to assess the quality of life of persons living with epilepsy and attending KBTH. Eighty-two respondents were surveyed into the study instead of 102 giving a response rate of 79.6%. Incidence of the condition at KBTH was lower than the rate observed during the pilot study and appointment dates were quite long as well as the reluctance of respondents to be part of the study. The respondents in the study had an average age of 35 years and a standard deviation of 16 years. The standard deviation shows the wide distribution of the condition among a wide range of age groups. However, most respondents in the study were in age group 18-24 years. This may be attributed to the fact that this age group attends clinic more often and those in the older age groups after some time are unwilling to do so. More than half of the respondents 56.1% were females and this distribution seems to agree with the national gender distribution according to the 2010 census. Almost all the respondents were Christians. This is to be expected as majority (85%) of Ghanaians are Christians with about 13% being Muslims. Most respondents 36.6% had tertiary level education, 28% SHS while the least 8.5% had no formal education.

The educational level of respondents seems to be fairly distributed and the fact that most have tertiary level education will impact on their understanding of the study and provide meaningful responses to the questions. More than half of the respondent 63.4% were single, 32.9% were married while 2.4% were divorced as a result of the condition. This distribution is to be expected as society frowns on marriages between those with the condition and those without the condition. Even when an attempt is made by the partners, the families involved may not agree.

A study conducted in Jordan on public knowledge and attitude towards epilepsy using standard four set questionnaire on 16,044 respondents compared to 82 respondents used in this study, only 11.5% of them would allow their sons to marry an epileptic, 10.6% would allow their daughters to marry an epileptic while 71.4% think epileptics can have children with the condition (Daoud, et al; 2007). Also, in China, epilepsy diminishes the prospect of marriage, especially for women. A survey of public awareness in 1992 revealed that 72% of patients objected to their children marrying someone with epilepsy (WHO, 2001). In another study on epilepsy in Hong Kong, attitude towards people with epilepsy showed that 32.2% of respondents would allow their children to marry individuals with epilepsy while 27.5% considered pregnancy to be inappropriate for an individual with epilepsy (Hui and Kwan, 2004). This finding is supported by (Baker, 2002) the burden of epilepsy may be the social exclusion as a result of negative attitudes of others toward people with epilepsy; and the stigma, as children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe.

It was worth noting that more than half of the PLWE 56.1% were employed with 37.8% working in skilled employments. This may probably be due to their educational level or a better understanding of their condition. However, quite a large proportion of them 43% were unemployed. This may be attributed to a number of reasons. Primarily is the age group distribution of the respondents in the study as 39% of the respondents were below 25 years. However, 56% of the respondents were employed.

Stigmatization by society and frequency of seizures prevents them from staying actively in employment. Also, it could be due to their educational level which limits them in gaining employment. In agreement with the above (Elwes, Marshall, Beattie, Newman, 1991), showed that people with epilepsy are more likely to experience problems in identifying a job, than the general population. A study in the UK revealed an unemployment rate of 46% for people with epilepsy, in contrast to 19% for a control group. In some European countries there are also legal barriers that restrict people with epilepsy in the workplace. This combination of institutional and social restrictions often results in people with epilepsy underperforming compared with the general population in the workplace (International League against Epilepsy, 2003). (Djibouti, 2003), also reported an employment rate of 17% among persons living with epilepsy.

5.3 Quality of life of PLWE

This study revealed that PLWE have a moderate overall quality of life. Previous studies have reported that Quality Of Life (QOL) of people with epilepsy is also influenced by socio-demographic variables (such as sex, marital status, education and employment) (Guevara, Peña, Corona *et al*, 2005).

Their physical health was moderate in terms of quality of life. This may be attributed to the fact that these are people attending hospital and are on medication which will minimize their seizures and prevent falling and muscle weakness. More than half of the respondents 61% also had a moderate psychological quality of life. However, less than half of the respondents 35% had low psychological quality of life. This proportion seems to be influenced by educational level of the respondents who may be wondering when their next seizure will occur.

More than half of the respondents in the study had low quality of life in relation to their social relation. This finding is in agreement with distribution of the marital status of the respondents. Most respondents are single and lack any relationship with society. There is no support system in terms of who to discuss issues with where to seek for any form of attention. According to Thomas and Nair (2011), in many countries, epilepsy is still shrouded in secrecy and patients prefer not to reveal or discuss their condition. Respondents in the study also had moderate environmental quality of life. This may be influenced by their educational and skilled employment. The economic status may probably allow them to live in appropriate environmental conditions. A study conducted in Kenya to determine quality of life of persons living with epilepsy reported that 63% of the unemployed PLWE were poorly controlled (Mativo, 2004).

5.4 Associations between overall quality of life and demographic characteristics

In this study, level of education was significantly associated with overall quality of life. Respondents with higher education were seen to have a better overall quality of life. Such people may be well informed and this has an influence on their health and life style choices. In spite of the above finding, information obtained in the study shows that

respondents in age group 25-34 had a higher proportion of those with low overall quality of life compared with the other age groups. This age group forms the youthful workforce of any nation as well as sexually active. Not schooling, working during the age bracket heavily affects the quality of life of such individuals as society stigmatize. This is supported by Shafer (2002), who reported that many factors influence the QOL of people with epilepsy, including impact of age and seizures, stigma, social deprivation, fear and anxiety, the presence of cognitive or psychiatric problems, and others.

More females 28.3% had low overall quality of life compared with males. This may partly be due to how females cope with such health conditions, women with such conditions are normally seen as witches in the society and prevented from marrying and this has a heavy influence on their overall quality of life. Austin, Shafer, Deering (2002) reports that, in many parts of the world, epilepsy continues to be viewed as witchcraft, contagious, and possession by devils and ancestral spirits. An Indian study reported that 15% of respondents believed epilepsy to be insanity, 40% believed that the child with epilepsy should not go to school or their children should not play with them and 66% objected in their children marrying someone who had epilepsy (Gambhir, Kumar, Singhi, Goel, 1995).

Higher proportions of Christians 26.7% had low quality of life compared with Muslims and traditional worshipers. Low overall quality of life was predominant among those with higher level of education and those unemployed also had low overall quality of life compared with those employment. In a related study, Laccheo, Ablah, Heinrichs, Sadler (2008) reported that 31% of respondents believed that people with epilepsy should not be employed in jobs.

5.4.1 Physical health and demographic characteristics

The study showed no significant associations between all demographic characteristics and physical quality of life. Several studies (Cockerell *et al.* 1994; Cockerell, 1996; Cockerels *et al.* 1997; Lindsten *et al.* 2000) have reported that PLWE are also more likely to be obese and physically inactive, current smokers and have a higher risk of experiencing major events that affect their lives significantly. However, respondents in age group 18-25 had a higher proportion of those with low physical quality of life compared with the other age groups. This age group is very active and are primarily concerned about their physical health. This might have influenced their perception on physical quality of life. More males 19.4% had low physical quality of life compared with females. This may be attributed to the fact that males are more active compared with females and as such may be more worried about their mobility in times of seizures. Satisfactory relations with the other sex require self-esteem. Low self-esteem in people with epilepsy can result in failure to establish good sexual relationships. Brain damage and/or antiepileptic drugs may also result in anhedonia. Head injury may result in reduced libido and erectile dysfunction. Inadequate sexual functioning may result in depression, marital distress or self-aversion (Cole & Cole, 1999).

Higher proportions of traditional worshipers 50.0% had low physical quality of life compared with other worshipers. Low physical quality of life was predominant among those with higher level of education and those married had low physical quality of life compared to single respondents. Higher proportions of those employed had low Physical quality of life compared with those unemployed. Those with unskilled

employment showed low physical quality of life compared with those with skilled employment.

5.4.2 Psychological quality of life and demographic characteristics

The study showed significant associations between level of education of respondents and psychological quality of life. Age group, marital status, gender, religion, marital status and employment type were not significantly associated with psychological quality of life. According to Pahl & Bore (2005), stigmatization leads to discrimination, and people with epilepsy have been the target of prejudicial behavior in many spheres of life, over many centuries and in many cultures. Respondents in age group 25-34 had a higher proportion of those with low psychological quality of life compared with the other age groups. Throughout history, epilepsy has been considered a stigmatized condition. Unfortunately, this remains true today despite progress in medical science, as the diagnosis of epilepsy can still have a profound psychological impact on patients and their families (Fenandes, Cabral, Araujo, Noronha, and Li, 2005).

More females had low psychological quality of life compared with males. Higher proportions of traditional worshipers had low psychological quality of life compared with Muslims and Christians. In a related study Puja (2006) reports that the way in which epilepsy is perceived influence the psychological adjustment of persons with epilepsy. In Haiti, epilepsy is considered a “hidden condition” and not openly discussed among community members. Hence people with epilepsy are maligned and feared. Consequently, people living with epilepsy do not disclose their condition to others and avoided contact with friends and family members.

Low psychological quality of life was predominant among those with lower level of education and those unemployed also had low psychological quality of life compared with those employment. Low psychological quality of life is predominant among those with unskilled employment compared with those with skilled employment. According to Jehietal (2011), psychological factors contribute to 30-35% of the variance in HRQOL, while around 20% is explained by seizure-related factors. A study done in USA Florida shows that, depression, driving restrictions and unemployment are pointed out as the most important determinants of QOL. The study showed significant effect of gender and educational level on psychological quality of life. Males have a significant positive effect on psychological quality of life compared with females. Also, secondary level education negatively affected psychological quality of life. Also, although not all people with epilepsy feel stigmatized, studies have shown that 30–51% of participants reported feeling stigmatized, and 18% reported feeling highly stigmatized (Beghi, Roncolato, Visona, 2004; Gilliam *et al.* 2004). Perceived stigma has been found to be significantly associated with higher levels of psychological distress symptoms (Hermann, eta al. 1990) and lower QOL (Baker *et al.* 2000). However, there are other studies that do not support the notion that epilepsy correlates to low self-esteem (Lee *et al.* 2008; Reeve & Lincoln, 2002).

5.4.3 Social relationship and demographic characteristics

The study showed no significant associations between all demographic characteristics and social quality of life of respondents. Social stigma and discrimination of PLWE occur in both developed and developing countries (Guekht, Mitrokhina, Lebedeva *et al.* 2006). Contrary to the findings in the current study, Dratzkowski (2007)

reports that together with the social stigma that persists in some parts of society, people with epilepsy often feel a sense of social isolation and have an overall reduced quality of life. Social isolation and quality of life have also been shown to be significantly compromised in caregivers of people with epilepsy.

Respondents in age group 25-34 had a higher proportion of those with low social quality of life compared with the other age groups. According to Jacoby and Austin (2007), in some patients, the social stigma and impact on quality of life can pose a greater challenge than the clinical severity. More females had higher proportions of respondents with low social quality of life compared with males. The condition makes it difficult for females to find partners and even keep friends. Epilepsy can affect the way a person develops healthy relationships and independent living skills (Morgan, Ahmed, Kerr, 2000). According to Harsono (2008), epilepsy is associated with a wide range of markers of social and economic disadvantage, including poor academic achievement and low income.

More than half of Muslims 60% had low social quality of life compared with Christians and traditional worshipers. Social isolation and poor social adaptation can result from perceived stigma or over-dependency caused by parental overprotection. The people with epilepsy also often fear embarrassment by a seizure, causing reluctance to engage in social interaction, with concomitantly low self- esteem and academic under-achievement. These can result in a shrunken support network, fewer friends, a lower likelihood of marriage and greater likelihood of anti-social behavior (Buchanan, 2002). Low social quality of life was predominant among those with primary education likewise those employed. Another factor contributing to QOL is educational level. More years of

formal education improve QOL in PWE (Pulsipher *et al.* 2006). In a related study by Ronen, Streiner and Rosenbaum (2003), epilepsy carries an enormous social stigma and people with epilepsy tend to have lower quality of life (QOL). Also, other studies (WHO, 2001; Devinsky and Penry, 1993), reports that although primary treatment goals focus on the physical complications of epilepsy through seizure control people with epilepsy face many other challenges such as social complications (driving restrictions, unemployment and social isolation), all of which can impact quality of life (QOL) (Berto, 2002; Bishop *et al.* 2002).

5.4.4 Environmental quality of life and demographic characteristics

There was no significant association between demographic variables and environmental quality of life. This finding is contrary to that of several studies (Kobau *et al.* 2008; O'Donoghue *et al.* 1999; Stavem *et al.* 2000; Strine *et al.* 2005; Wiebe *et al.* 1999), which report that PLWE more often report poor health, unemployment and the inability to work. PWE more often live in households with the lowest annual income, and have a history of co-occurring disorders. However, the current study shows that more than half of the respondents 54.5% in age group 35-44 had low environmental quality of life. In terms of level of education, low environmental quality of life was predominant among respondents with primary education.

There were more single respondents with low environmental quality of life compared with married respondents. Many reports suggest that there is a lower marriage rate in individuals with epilepsy compared to the general population (Baker *et al.*, 1997). Myeong- Kyu Kim studied marital status in Asian patients with epilepsy and reported high divorce rates in these patients (Kim, 2007). Those with unskilled employment also

had lower environmental quality of life compared with those with skilled employment. According to Baker, Jacoby et al. (1997), persons living with epilepsy are prone to have poorer self-esteem, higher levels of anxiety, and depression. They are more likely to be under employed or unemployed with lower rates of marriage and greater social isolation. People who have experienced even a single seizure have been shown to be discriminated against on the labor market (Holland et al. 2009).



CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1 Conclusion

This study sought to investigate the quality of physical, environmental, and psychological health as well as the social relationships of persons living with epilepsy attending Korle – Bu teaching hospital and the contribution of these various domains to their overall quality of life. The findings showed that on the average persons living with epilepsy had moderate quality of life. Their social relationship was poor as more than half of them reported low social quality of life. More than a third also had low psychological quality of life. Physical and environmental quality of life was moderate. The level of education of persons living with epilepsy and gender showed some significant association with their quality of life across the various domains.

6.2 Recommendations

From the study the following recommendations are suggested:

The need for a multi-sectorial approach that involves health professionals, religious leaders as well as governmental and non-governmental representatives in all stages of planning and delivery of public health education programmes and other control activities is recommended to ensure better impact, continuity and wider acceptance of the intended health messages.

1. Health education intervention should be intensified, maintained and improved to reduce the perceptions surrounding the disease. Persons living with epilepsy (PLWE) must be adequately educated on how to cope with psychological, physical, environmental

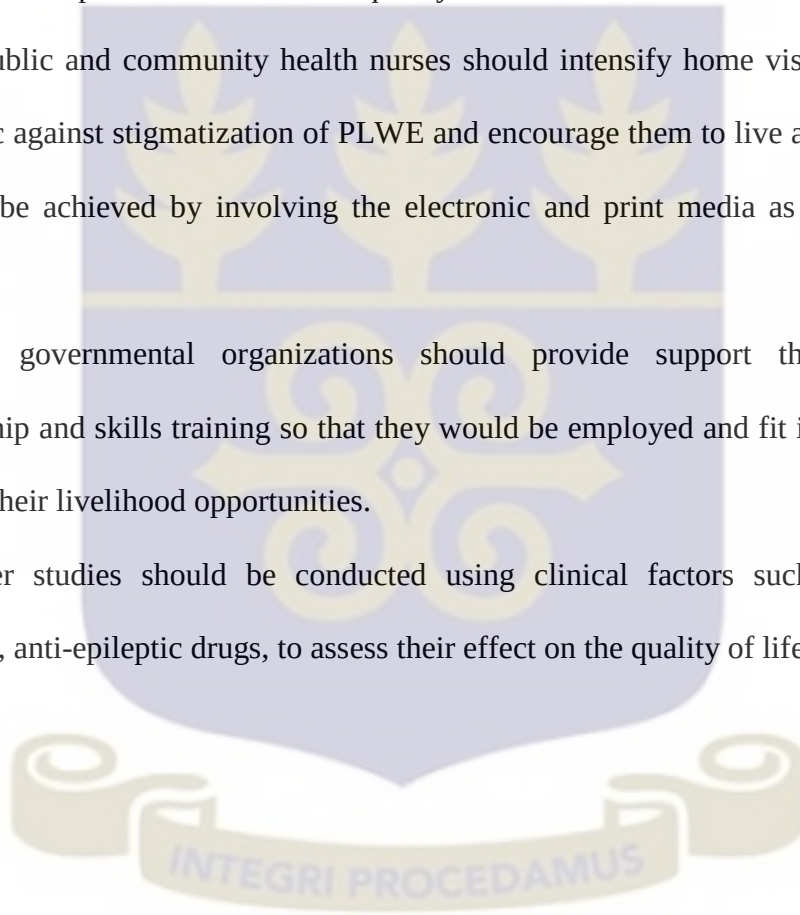
and social stress. This can be done by having a well-planned educational talk each morning at the Out Patient Department by nurses and doctors in the consulting rooms.

2. Epileptic patients should be encouraged to join existing peer support groups to enhance their confidence level. Where there are no such groups, they should be encouraged to form one to enable them access interventions that will minimize their level of stress and improve on their overall quality of life.

3. The public and community health nurses should intensify home visiting and educate the public against stigmatization of PLWE and encourage them to live a normal life. This can also be achieved by involving the electronic and print media as well as religious bodies.

4. Non- governmental organizations should provide support through education sponsorship and skills training so that they would be employed and fit into the society to enhance their livelihood opportunities.

5. Further studies should be conducted using clinical factors such as duration of condition, anti-epileptic drugs, to assess their effect on the quality of life.



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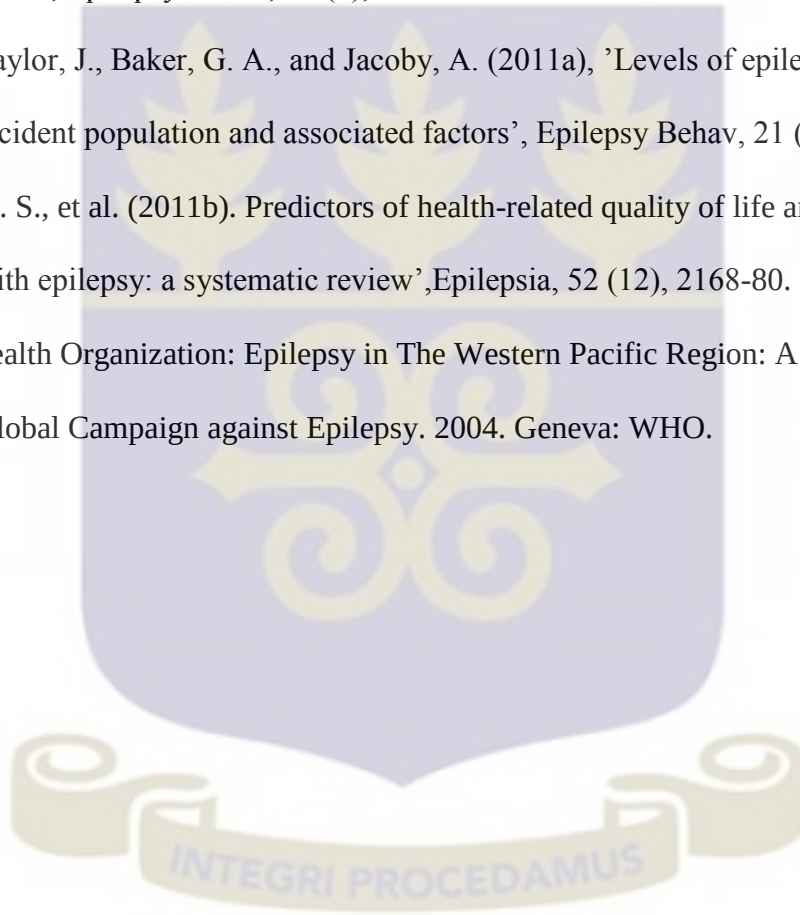
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APPENDICES

APPENDIX I:

QUESTIONNAIRE ON WHO QUALITY OF LIFE

QUESTIONNAIRE

WHOQOL-BREF

My name is Christiana Kofie and a student of School of Public Health. I am currently conducting a research on the quality of life of patients with epilepsy attending the Korlebu Teaching Hospital. The study is solely for academic purposes. I assure you of absolute confidentiality on any information you may provide. This should take about 20 minutes of your time.

The following questions ask how you feel about your quality of life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one (The numbers after responses indicates the scores of the responses).

Please keep in mind your standards, hopes, pleasures, and concerns. We ask that you think about your life in the last four weeks (The overall quality of life and general health facet).

Section A: Demographic Characteristics

Age...

Gender: Male [] Female []

Religion: Christian [] Muslim [] Traditional [] Others []

Level of Education: None [] Primary [] JHS [] SHS [] Tertiary [] Marital Status: Single [] Married [] Divorced [] Separated []

Employment: Employed [] Unemployed [] Type of employment: Skilled [] Unskilled []

Section B: Quality of Life

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks (The overall quality of life and general health facet).

1. How would you rate your quality of life?

Very poor: 1 Poor: 2 Neither poor nor good: 3 Good: 4 Very good: 5

2. How satisfied are you with your health?

Very dissatisfied: 1 Dissatisfied: 2 Neither satisfied nor dissatisfied: 3

Satisfied: 4 Very satisfied: 5

The following questions ask about how much you have experienced certain things in the last four weeks.

3. To what extent do you feel that physical pain prevents you from doing what you need to do?

Not at all: 1

A little: 2 A moderate amount: 3 Very much: 4 An extreme amount: 5

4. How much do you need any medical treatment to function in your daily life?

Not at all: 1 A little: 2 A moderate amount: 3 Very much: 4 An extreme amount: 5

5. How much do you enjoy life?

Not at all: 1 A little: 2 A moderate amount: 3 Very much: 4 An extreme amount: 5

6. To what extent do you feel your life to be meaningful?

Not at all: 1 A little: 2 A moderate amount: 3 Very much: 4 An extreme amount: 5

7. How well are you able to concentrate?

Not at all: 1 A little: 2 A moderate amount: 3 Very much: 4
Extremely: 5

8. How safe do you feel in your daily life?

Not at all: 1 A little: 2 A moderate amount: 3 Very much: 4
Extremely: 5

9. How healthy is your physical environment?

Not at all: 1 A little: 2 A moderate amount: 3 Very much: 4
Extremely: 5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

10. Do you have enough energy for everyday life?

Not at all: 1 A little: 2 Moderately: 3 Mostly: 4 Completely: 5

11. Are you able to accept your bodily appearance?

Not at all: 1 A little: 2 Moderately: 3 Mostly: 4 Completely: 5

12. Have you enough money to meet your needs?

Not at all: 1 A little: 2 Moderately: 3 Mostly: 4 Completely: 5

13. How available to you is the information that you need in your day-to-day life?

Not at all: 1 A little: 2 Moderately: 3 Mostly: 4 Completely: 5

14. To what extent do you have the opportunity for leisure activities?

Not at all: 1 A little: 2 Moderately: 3 Mostly: 4 Completely: 5

15. How well are you able to get around?

Very poor: 1 Poor: 2 Neither poor nor good: 3 Good: 4 Very good: 5

16. How satisfied are you with your sleep?

Very dissatisfied: 1 Dissatisfied: 2 Neither satisfied nor dissatisfied: 3 Satisfied: 4

Very satisfied: 5

17. How satisfied are you with your ability to perform your daily living activities?

Very dissatisfied: 1 Dissatisfied: 2 Neither satisfied nor dissatisfied: 3

Satisfied: 4 Very satisfied: 5

18. How satisfied are you with your capacity for work?

Very dissatisfied: 1 Dissatisfied: 2 Neither satisfied nor dissatisfied: 3 Satisfied: 4

Very satisfied: 5

19. How satisfied are you with yourself?

Very dissatisfied: 1 Dissatisfied: 2 Neither satisfied nor dissatisfied: 3 Satisfied: 4

Very satisfied: 5

20. How satisfied are you with your personal relationships?

Very dissatisfied: 1 Dissatisfied: 2 Neither satisfied nor dissatisfied: 3 Satisfied: 4

Very satisfied: 5

21. How satisfied are you with your sex life?

Very dissatisfied: 1 Dissatisfied: 2 Neither satisfied nor dissatisfied: 3 Satisfied: 4

Very satisfied: 5

22. How satisfied are you with the support you get from your friends?

Very dissatisfied: 1 Dissatisfied: 2 Neither satisfied nor dissatisfied: 3 Satisfied: 4

Very satisfied: 5

23. How satisfied are you with the conditions of your living place?

Very dissatisfied: 1 Dissatisfied: 2 Neither satisfied nor dissatisfied: 3

Satisfied: 4 Very satisfied: 5

24. How satisfied are you with your access to health services?

Very dissatisfied: 1 Dissatisfied: 2 Neither satisfied nor dissatisfied: 3 Satisfied: 4

Very satisfied: 5

25. How satisfied are you with your transport?

Very dissatisfied: 1 Dissatisfied: 2 Neither satisfied nor dissatisfied: 3

Satisfied: 4 Very satisfied: 5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

26. How often do you have negative feelings such as sadness, despair, anxiety, depression?

Never: 1 Seldom: 2 Quite often: 3 Very often: 4 Always: 5

THANK YOU

[Scoring method]

Equations for computing domain raw scores:

Domain 1 (physical) score = Q3 + Q4 + Q10 + Q15 + Q16 + Q17 + Q18

Domain 2 (psychological) score = Q5 + Q6 + Q7 + Q11 + Q19 + Q25

Domain 3 (social) score = Q20 + Q21

Domain 4 (environmental) score = Q8 + Q9 + Q12 + Q13 + Q14 + Q22 + Q23 + Q24

Transformed scores are estimated using the tables for standardizing scores from 0-100 with the lowest score of zero and the highest score of 100.

APPENDIX II:

CONSENT FORM

Title: Quality of life among patients with epilepsy attending to the Krole-bu Teaching Hospital (KBTH).

Principal Investigator: CHRISTIANA DEBORAH KOFIE

Address: School of Public Health, University of Ghana.

Information

Dear Participant, This consent form contains information about the research on Quality of life among patients with epilepsy attending to the Krole-bu Teaching hospital (KBTH). In order to be sure that you are well informed of the research, the researcher is asking you to carefully read (or have it read and explained) to you this Consent Form. You will be asked to sign it or on behalf of your ward and a copy given to you. This consent might contain some words that are unfamiliar to you. Please ask the researcher to explain anything you may not understand.

Why the study

Epilepsy is not a single disease, but rather an expression of many different brain disorders, and as a consequence investigations and treatment must be individualized. Epilepsy is a chronic disease that largely influence the patient's life. In some patients, the social stigma and impact on quality of life can pose a greater challenge than the clinical severity. Epilepsy carries an enormous social stigma and people with epilepsy tend to have lower quality of life (QOL). Persons living with epilepsy are prone to have poorer self-esteem, higher levels of anxiety, and depression. They are more likely to be underemployed or unemployed with lower rates of marriage and greater social isolation. This study seeks to assess the quality of life among patients with epilepsy attending to the Krole-bu Teaching hospital (KBTH).

General Information and your part in the study

For you to qualify to be part of this study, you must be a person who has lived with epilepsy for at least one year. I may contact you by phone if further information is needed.

Possible Risks and Discomforts

The researcher acknowledges that this research will course some psychological discomfort during the answering of some part of the questionnaire. However, the level of psychological distress will be minimal.

Possible Benefits

There are no direct benefits to you; however, findings of this study will help us to suggest improved ways of managing persons living with epilepsy.

Confidentiality/Privacy

Your identity and privacy will be protected; a number will be used to identify you instead of your name on anything that will be written about and the document bearing your name such as the consent form will be handled by the researcher and the supervisors only and these will be kept in safety.

Voluntary Participation and Right to Leave the Research

Your participation in this research is strictly voluntary and so if you don't want to participate you are free to do so. You are not going to lose anything if you decide not to take part. If you participate and in the process you want to stop you will be allowed to do so.

Contacts for Additional Information

If you ever have any questions about the research study or study-related problems, you may contact Miss. Christiana Deborah Kofie School of Public Health, 0244643006 ,ckorowoo@yahoo.com. Dr. Emmanuel Asampong 0244278453-asampong@yahoo.com; ERC administrator Ms Hannah Frimpong 0243235225 or 0507041223

Your rights as a Participant

This research will be reviewed and approved by the Institutional Review Board of the Ghana Health Service. If you have any questions about your rights as a research participant you can contact Mr. Emmanuel Asampong

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title (Quality of life among patients with epilepsy attending to the Krole-bu Teaching Hospital (KBTH) has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

Date

Name and signature or mark of volunteer

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

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

Date

Name and signature of witness

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

Date