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DEVELOPMENT AND VALIDATION OF A QUALITY OF LIFE QUESTIONNAIRE FOR PEOPLE LIVING WITH EPILEPSY IN GHANA

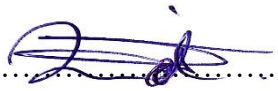
David Atsu Deegbe

A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirement for the degree of Doctor of Philosophy in Nursing

Johannesburg, 2021

DECLARATION

I, David Atsu Deegbe, declare that this research report (Human Ethics Clearance Number M180946) is my own work. It is being submitted for the degree of Doctor of Philosophy in Nursing at the University of Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination in this or any other university.



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Signed at Johannesburg

On the 10th November 2021

DEDICATION

I dedicate this thesis to my father, Ex. WO1 Daniel Cudjoe Deegbe, of blessed memory; my beloved wife, Eno Akyaah Deegbe, and my children, Senyo, Eyram, Aseye and Akorfa.

PUBLICATIONS ARISING FROM THIS RESEARCH PROJECT

1. Deegbe DA, Tshabalala AM, Aziato L, Casteleijn D. Meanings of Quality of Life among People Living with Epilepsy in Ghana; A Qualitative Exploratory Study. Epilepsy Behav. 2021; In Press.

ABSTRACT

Background: A number of epilepsy quality of life (QoL) questionnaires have been developed in Western and European countries which do not necessarily apply to the sociocultural context of countries in other parts of the world. Some countries developed their own questionnaires whilst others adopted and validated existing epilepsy QoL questionnaires to match their sociocultural context. However, no questionnaire was found to accurately assesses the QoL of people living with epilepsy (PLWE) in sub-Saharan African (SSA) countries, including Ghana.

Aim: The aim of this study was to develop and validate a culturally sensitive QoL questionnaire that is best suited for the accurate and consistent assessment of QoL of PLWE in Ghana.

Methodology: The sequential multimethod study design involving nine steps in three phases was employed in this study. Phase one conceptualised the construct of QoL through a scoping and integrative review as well as a qualitative explorative study with PLWE in Ghana. In phase two, the findings from phase one were integrated to generate a pool of items which were used to develop the first and second drafts of the epilepsy QoL questionnaire through consultation with the supervisors and the experts in a nominal group technique, respectively. The content and face validity of the questionnaire were tested in phase three using eight experts and four PLWE.

Findings: A pool of 64 items under 13 domains were generated from the first phase and refined for the first draft questionnaire named the QOLIE-GH and comprising 41 items and 11 domains. After employing the nominal group technique to establish relevance to the sociocultural context of Ghana, an additional 25 items and 2 domains were created. The second draft then had 66 items under 13 domains. Content validity testing led to the elimination of five items, leaving a remainder of 61 items under 13 domains to form the third draft QOLIE-GH with I-CVI ranging from 0.83 to 1. Face validity testing led to no change, and respondents considered all the items to be relevant and easy to understand.

Conclusion: The results from the study showed that the questionnaire is culturally sensitive to PLWE in Ghana, has good content validity appropriate for assessing QoL of PLWE in Ghana. This will help health workers, researchers and policy makers assess the QoL of PLWE and to plan and make informed interventions to promote the QoL and wellbeing of PLWE in Ghana. Future studies should undertake further validation of the QOLIE-GH to make it applicable to countries in SSA.

Key Words: “Epilepsy”, “Quality of Life”, “Questionnaire”, “People Living with Epilepsy”, “Questionnaire Development and Validation”

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LIST OF ABBREVIATIONS

AEDs:	Anti-Epileptic Drugs
CINAHL:	Cumulative Index to Nursing and Allied Health
COVID-19:	Corona Virus Disease - 2019
EQ-5D-3L:	European Quality-of-Life
HRQoL:	Health-Related Quality of Life
I-CVI:	Individual Content Validity Index
IQOL:	Integrated Quality of Life
MAXQDA:	Max Qualitative Data Analysis
NGT:	Nominal Group Technique
PCC:	Population, Concept and Context
PLWE:	People Living with Epilepsy
PRISMA:	Prevention and Recovery Information System for Monitoring and Analysis
QALYs:	Quality-Adjusted Life-Years
QoL:	Quality of Life
QOLIE:	Quality of Life in Epilepsy
QOLIE-10:	10-Item QoL in Epilepsy
QOLIE-31:	31-Item QoL in epilepsy
QOLIE-89:	89-Item QoL in Epilepsy
QOLIE-GH	Quality of Life in Epilepsy questionnaire for Ghana.
S-CVI:	Scale Content Validity Index
SEQOL:	Self evaluated Quality of Life
SF-36:	36-Item Short Form Survey

SSA:	sub-Saharan Africa
WHO:	World Health Organization
WHOQOL GROUP:	World Health Organization Quality of Life Group

CHAPTER ONE: ORIENTATION TO THE STUDY

1.1 INTRODUCTION AND BACKGROUND TO THE STUDY

Epilepsy comprises a group of central nervous system disorders characterised by two or more unprovoked episodes of seizures (Banerjee et al., 2009). Seizures may lead to an altered state of awareness and abnormal somatic sensation or involuntary muscular activity, or both (Deaton & Tortora, 2015; Fisher et al., 2014). Roughly 50 million people globally have epilepsy (WHO, 2017). In addition, an estimated proportion between 4 and 20 per 1,000 people globally have active epilepsy at any given time. About five million people each year across the globe are diagnosed with epilepsy. This ranges from 49 per 1,000 people in high-income countries to 139 per 1,000 people in low- and middle-income countries (World Health Organisation, 2019). Thus, an indication of the vast disparity in health care between low- and middle-income countries. Epilepsy is responsible for about 0.5% of the burden of disease worldwide. Out of this, 80% of the epilepsy disease burden is in developing countries (Newton & Garcia, 2012). North-Western India has a low prevalence of epilepsy, accounting for 1.1 per 1,000 people (Panagariya et al., 2019). The prevalence of epilepsy in the general population in Japan stands at 6.9 per 1000 people (Tanaka et al., 2019).

In Africa, epilepsy directly affects around 10 million people (WHO, 2017). There is a high prevalence of epilepsy in sub-Saharan Africa (SSA) (Ba-Diop et al., 2014; Preux & Druet-Cabanac, 2005), with an estimated 4.4 million people having active epilepsy in the SSA region (Paul et al., 2012). In West Africa, the prevalence of epilepsy among pooled studies stands at 13.14 per 1000 people (Fodjo et al., 2020). According to (Owolabi et al., 2019), eight out of a 1000 people in Nigeria have epilepsy. In Ghana, about 22,171 people have epilepsy (Ministry of Health, 2018); however, most of the cases remain unreported. As a result, the accurate prevalence of epilepsy is unknown and little is known about how epilepsy affects the Quality of Life (QoL) of People Living with Epilepsy (PLWE).

The high prevalence of epilepsy within SSA countries are due to poor health delivery systems, poor sanitation and poverty (Chisholm & Evans, 2007; Deaton & Tortora, 2015). The presence of endemic diseases, including neurocysticercosis and malaria, high incidence of road traffic accidents and its associated head injuries, differences in medical infrastructure, perinatal injuries, lack of preventive health services and lack of easily accessible health care are all contributory factors to the high prevalence of epilepsy in SSA countries (World Health

Organisation, 2019). Meanwhile, the treatment gap in epilepsy is also high in SSA (Mbuba et al., 2012; Sebera et al., 2015; Winkler, 2012). Factors such as inadequately trained personnel, lack of essential Anti-Epileptic Drugs (AEDs) and traditional beliefs and practices affect the health-seeking behaviour of PLWE (Engel et al., 2008; Tanywe et al., 2016). These factors invariably have detrimental effects on the QoL of PLWE in countries within SSA. Higher endemicity of onchocerciasis, before the onchocerciasis control programme for Africa began, and a short period for the control of onchocerciasis were linked to increased prevalence of epilepsy in West Africa (Fodjo et al., 2020).

Indeed, the chronic nature of epilepsy negatively affects the QoL of PLWE (Megari, 2013). Quality of life is a broad term encompassing not just the absence of disease, but an individual's perception of his or her position in life within the perspective of one's culture and value system, goals, expectations, and concerns about health (Blond et al., 2016). Health-Related Quality of Life (HRQoL) is concerned with one's level of functioning and perception of wellbeing in the domains of health - physically, psychologically and socially (Hays & Reeve, 2010). In fact, a number of studies (Beghi, 2016; Blond et al., 2016; Preux & Druet-Cabanac, 2005) show that living with epilepsy has many challenges. The lack of stable jobs, limited social lives, low self-esteem and conflicts with family also worsens their QoL (Beghi, 2016; Gauffin et al., 2015; WHO, 2017). As a result, epilepsy affects QoL in multiple domains (Beghi, 2016), such as physical, psychological, cognitive, social and occupational domains (Blond et al., 2016).

Physically, seizures pose an increased risk of injury and death. The symptoms of epileptic seizures are frightening and horrific to onlookers (Forsgren et al., 2013). Epilepsy often carries limitations on driving (Blond et al., 2016). Both epilepsy and the medications used to treat it are associated with impaired cognition. Drowsiness as a result of AEDs and absenteeism from work and school as a result of the seizures lead to underachievement and low productivity among PLWE.

Psychologically, there is an increased risk of anxiety and depression among PLWE. The unpredictable nature of epilepsy creates some anxiety among PLWE (Jacobs et al., 2009), placing further restrictions on PLWE (Gauffin & Landtblom, 2014). Moreover, the shame and the disgrace associated with living with epilepsy places additional stress and burden on the patient (Deegbe et al., 2020). This impedes their education and career development, resulting in depressive symptoms and, sometimes, suicidal ideations (Jacobs et al., 2009).

Although the seizures only last for a few minutes, the psychological and social problems experienced by patients and their families are enormous. Marked ones such as generalised tonic-clonic seizures (grand mal) are openly noticeable to onlookers. Most patients with generalised tonic-clonic seizures feel embarrassed after a seizure in town, in school, at church, during an occasion or at work. Less marked ones like absence attacks (petit mal) appear to be rather strange to onlookers. This may be wrongly interpreted by others as inattentiveness, rebellion or as mental, emotional or conduct problems. As a result of this, some people mock them, gossip about them, avoid their company and portray them negatively (Beghi, 2016; de Boer et al., 2008; Tanywe et al., 2016). These psychological and social problems arising from the diagnosis of epilepsy (De Boer, 2010) represent a crisis situation that poses a greater challenge to both the victim and their families.

In Africa, epilepsy is believed to be a spiritual, cultural or religious condition rather than a medical condition by the majority of the people (Mpoe Johannah Keikelame & Swartz, 2015; Mugumbate & Zimba, 2018; Watts, 1992). The African traditional religious belief system regards epilepsy as a disease caused by witchcraft and spiritual possession. The Islamic and Christian religious beliefs in African regard epilepsy as a disease caused by evil spirits, demonic attacks, or punishment from God (Mugumbate & Zimba, 2018).

In SSA, spiritual connotations have been attributed to epilepsy, and traditional and faith-based healers also reinforce these in these countries, including Nigeria (Adewumi et al., 2020), Ghana (Deegbe et al., 2019) and the Democratic Republic of Congo (Dolo et al., 2018). For example, the cultural belief that epilepsy is caused by witchcraft, the will of God and other super natural causes have been reported in Nigeria (Adewumi et al., 2020). In Gabon, children with epilepsy are believed to be demon-possessed (Ibinga et al., 2019). In addition, the belief that epilepsy is hereditary and that PLWE are mentally ill exists (Dolo et al., 2018). These traditional and cultural beliefs about epilepsy invariably affect the attitude of people towards PLWE (Ibinga et al., 2019).

Negative attitudes towards PLWE makes epilepsy a stigmatizing condition (Hosseini et al., 2013; Tombini et al., 2019). Due to the nature of the condition, PLWE are treated with contempt and avoided by people around them (Deegbe et al., 2019). People living with epilepsy are not only stigmatised in SSA countries but in some first world countries as well. In Sweden, it was found that immigrants were stigmatised because of their epilepsy and had to deal with

negative self-image about the disease. As such, the immigrants had to put in a lot of effort to be appreciated as a people (Andersson et al., 2021).

The stigma associated with living with epilepsy results in disturbances in their emotions, poor self-esteem and social withdrawal (Hills, 2007). This stigma impinges on their human rights and social integration of PLWE (De Boer, 2010). Persons with epilepsy find it difficult to make life choices such as having children or choosing an education or profession, and most of them are unable to fulfil their normal social roles and obligations (Choi et al., 2011; Gauffin et al., 2011). The family is then burdened with the huge responsibility as the primary social support system for PLWE. The stigma and frustration associated with living with epilepsy are not only limited to the patients but extends to their families as well, with some family members even reporting higher perceived stigma than PLWE (Jada et al., 2020).

In the past two decades, there has been a paradigm shift in studies on epilepsy (Azuma & Akechi, 2014; Chen et al., 2016; Sajobi et al., 2014). More studies are now focusing on patient-reported wellbeing and psychosocial outcomes compared to the traditional clinical health outcomes, such as the effectiveness of antiepileptic medications (Azuma & Akechi, 2014; Chen et al., 2016; Rawlings, Brown, & Reuber, 2017). This is because assessment of QoL promotes communication between patients and health professionals and has the potential to improve upon patient care (King et al., 2016). Quite a number of generic QoL questionnaires have been used to assess the QoL of PLWE in a number of studies, including the 21-item WHO Quality of Life Bref-26 (The WHOQOL GROUP, 1998; Kováts et al., 2017; Santos et al., 2018; Abdelrahim et al., 2015) questionnaire and the 36-Item Short Form Survey questionnaire (SF-36), also referred to as the RAND 36-Item Health Survey (Demirci et al., 2017; Jacoby et al., 2013). Subsequently, more than 20 disease-specific epilepsy QoL questionnaires have been developed. Mostly used ones among them include the 89-item QoL in epilepsy (QOLIE)-89 questionnaire (Devinsky et al., 1995), the 31-item QoL in epilepsy (QOLIE-31) questionnaire (Cramer et al., 1998), and the 10-item QoL in epilepsy (QOLIE-10) questionnaire (Mollaoğlu et al., 2017). These epilepsy-specific questionnaires were developed mostly based on uniqueness of epilepsy as a condition and, the argument that generic questionnaires did not completely address epilepsy specific domains that impact the QoL of PLWE (Blond et al., 2016). Some have fewer domains of QoL (QOLIE-10; QOLIE-31) compared to others (QOLIE-89) (Blond et al., 2016). These epilepsy-specific QoL questionnaires did well to

address the disease-specific concerns about epilepsy and its influence on QoL. However, these questionnaires were developed in some Western and European countries and not SSA.

A preliminary literature review was conducted on questionnaires used in assessing QoL of PLWE. None of the questionnaires used in the 98 studies reviewed were specifically developed to access QoL in PLWE in SSA. Only 4.1% (n=4) of the studies were conducted in SSA. Studies conducted in Uganda (Nabukenay et al., 2014) and South Africa (Ives-Deliperi & Butler, 2017) used the QOLIE-31 and the QOLIE-89 questionnaires respectively. There is, however, no report about the validation of these questionnaires in Uganda and South Africa. Other studies conducted in Sudan (Abdelrahim et al., 2015) and Zambia (Nau et al., 2018) used the generic QoL questionnaire developed by WHO (WHOQOL-Bref). The QOLIE- 31 and 89 questionnaires were developed in the Western and European countries (Devinsky et al., 1995; Cramer et al., 1998) as such, these raise concerns about the appropriateness of use of these questionnaires within the SSA context due to socio-cultural differences.

In fact, culture and values systems have great impact on QoL (WHO as cited in Megari, 2013). The effect of culture on QoL cannot be underestimated however, existing epilepsy QoL questionnaires lack cultural sensitivity to other parts of the world (Blond et al., 2016). Attempts to address cultural sensitivity resulted in the translation of the QOLIE-31 into nine international languages including Dutch, UK-English, Italian, Danish, German, Swedish, French and Canadian French and test them (Cramer et al., 1998). The aim was to adapt them to the culture of these countries but none of these countries were in the sub-Saharan regions. The QOLIE-31 inventory was also adapted to suit the Turkish socio-cultural context (Mollaoğlu et al., 2015). In order to fit into the cultural specific environment within the European context, the European Quality-of-Life (EQ-5D-3L) scale was developed (EuroQol Group, 1990). Due to the sociocultural context with which epilepsy in seen globally and in SSA, and its effect on the QoL of PLWE, it is obvious that these existing questionnaires cannot be considered as fit for assessing QoL for PLWE in SSA. Conversely, they may only, as a temporary measure, be used to evaluate the QoL of PLWE in SSA.

African countries, especially countries within the SSA region have various traditional belief systems and socio-cultural backgrounds that are unique (de Graft Aikins et al., 2012) and different from countries in the West and Europe. The socio-economic situation in SSA is also poor (Deaton & Tortora, 2015) compared to Europe and the West. Invariably, all these have unique influence on the QoL among PLWE in SSA. However, contemporary epilepsy QoL

questionnaires might not be applicable to PLWE in SSA because they are not sensitive of the culture of the sub-region (Blond et al., 2016). Therefore, the development of an epilepsy QoL questionnaire particularly for PLWE in Ghana, within SSA, is imperative due the differences in their culture compared to that of countries in Europe and the West.

1.2 PROBLEM STATEMENT

Like all countries, Ghana has its unique socio-cultural characteristics (Ghana Guide, n.d.). Ghanaians are religious and mostly identify as Muslims, Christians and Traditionalists. The social structures are mainly communal living with links to the extended family system. Traditional folklore and folkways shape our educational system and is reflected in our music, dance and creative spirit. Inherent in this culture is where Ghanaians find meaning in life (Dennis, 2018). Ghana also harbours a high prevalence of PLWE (Ministry of Health, 2018). There is, however, no Ghana specific QoL questionnaire to assess the QoL of PLWE. The use of generic QoL questionnaires such as EQ-5D and the health index in epilepsy has faced criticism for their inability to fully assess the impact of epilepsy and do not address all relevant domains of QoL (Mulhern et al., 2010).

Considering the sociocultural context of existing epilepsy-specific QoL questionnaires, it can be reasonably argued that these questionnaires are best fit for PLWE in the countries of origin of the questionnaires and therefore are not necessarily suitable for other countries, including Ghana. These questionnaires failed to consider the sociocultural context of the lives of people in Ghana. This is obvious in the wording, context and content of some of the items in these questionnaires. This underscores the need to develop an epilepsy specific QoL questionnaire that considers the sociocultural background of people in Ghana due to the significant influence that sociocultural factors have on the QoL of people.

1.3 RESEARCH QUESTION

What will constitute a culturally sensitive QoL questionnaire for accurately and consistently assessing the QoL of PLWE in Ghana?

1.4 PURPOSE OF THE STUDY

The purpose of this study was to develop and validate a culturally sensitive QoL questionnaire that is best suited for accurate and consistent assessment of QoL of PLWE in Ghana.

1.5 OBJECTIVES OF THE STUDY

In order to meet the purpose of the study, the study was undertaken in three phases with the underlisted targeted objectives.

1.5.1 Phase One: Conceptualization phase

1 To explore and synthesize the purpose, concepts, constructs, development process and the scoring systems of questionnaires used in assessing the QoL of PLWE.
2 To ascertain the QoL of PLWE in SSA from a literature perspective.
3 To explore the meaning of QoL from the perspective of PLWE in Ghana.

Outcome: The outcome of phase one helped to appreciate the concept of QoL among PLWE and the content of pre-existing epilepsy QoL questionnaires.

1.5.2 Phase Two: Operationalisation phase

1. To select and generate items for the epilepsy QoL questionnaire for Ghana
2. To draft epilepsy QoL questionnaire for Ghana
3. To develop a scale of measurement and final scoring for the epilepsy QoL questionnaire for Ghana with instructions for use.
4. To conduct an expert review of the draft epilepsy QoL questionnaire for Ghana.

Outcome: The outcome of phase two produced a draft epilepsy QoL questionnaire for Ghana with appropriate items, scale of measurement and scoring.

1.5.3 Phase Three: Validation phase

1. To test the content validity of the draft epilepsy QoL questionnaire for Ghana
2. To test the face validity of the draft epilepsy QoL questionnaire for Ghana

Outcome: The outcome of phase three was an epilepsy QoL questionnaire with good content validity for Ghana and ready to be used in community and clinical settings.

1.6 SIGNIFICANCE OF THE STUDY

The outcome of the study provided a questionnaire for accurate assessment that will help in the provision of quality care for PLWE in Ghana. The qualitative interviews threw more light on the stigma and socio-cultural burden of epilepsy on PLWE in Ghana. The results presumably

will help promote cumulative awareness and understanding of policy makers and the general population on the effect of epilepsy on the QoL of PLWE. This will potentially persuade policy makers and health professionals to make changes in policies and practices, respectively, to improve the QoL of PLWE in Ghana.

The outcome of this study is a QoL questionnaire that is culturally sensitive and fits into the traditional and socio-cultural context of the Ghanaian population. This questionnaire will improve the specificity of information by providing domains and items that are tailored to the QoL of PLWE in Ghana. Hence improving the validity and reliability of future epilepsy QoL studies conducted in Ghana and within the SSA region. Undoubtedly, the outcome of this research will provide direction for future research on the QoL of PLWE in Ghana.

1.7 THEORETICAL FOUNDATIONS OF THE STUDY

1.7.1 Meta-theoretical assumptions

Pragmatism is a philosophical movement that was developed in the early 20th century by William James, Charles Peirce and John Dewey, which dwelt on the practical outcomes of social reality (Kelly & Cordeiro, 2020). Dewey explained that, if studied carefully and methodically, pragmatism could reveal more clearly social realities compared to other philosophical approaches that claim that action and human behaviour exist separate from understanding (Kelly & Cordeiro, 2020).

Pragmatism focuses on what works in a practical sense, and this mainly refers to the pragmatic theory about truth which focuses on addressing practical problems in real life other than dwelling on assumptions about the essence of knowledge (Creswell, 2014). This is concerned with the belief that one needs to focus on what works for a particular situation at a particular time and in a particular context. This helps the researcher to explore practical and useful research methods appropriate for addressing a particular research question. Pragmatists allude to the fact that quantitative and qualitative research approaches are complementary depending on which research method is appropriate for addressing a particular research problem at a particular time (Maarouf, 2019).

In applying both approaches, the qualitative researcher would be interested in detailed descriptions of the meanings of these actions. On the other hand, quantitative studies address the research problem in a rather structured quantitative manner which quantifies the

phenomenon under study into variables and their relationships (Maarouf, 2019). In answering the research question on "What will constitute a culturally sensitive QoL questionnaire for accurately and consistently assessing the QoL of PLWE in Ghana?", there was the need to employ a variety of research approaches that were grounded scientifically and practicable within the research setting. This informed the researcher's decision to use the pragmatic paradigm as the philosophical underpinning for this study (Kelly & Cordeiro, 2020).

Through vast literature review on the questionnaires used in assessing QoL in PLWE worldwide, the researcher gained insight into the content and structure of disease-specific questionnaires used in assessing the QoL of PLWE. The researcher then conducted an integrative review on the QoL among PLWE in SSA. This enabled the researcher to understand the nature of QoL among PLWE in SSA and the significant aspects of QoL among PLWE in the SSA region. Furthermore, a qualitative study was carried out to explore the meaning of QoL among PLWE in Ghana. This gave the researcher the chance to identify specific aspects of life that meant QoL to Ghanaians living with epilepsy. Integration of these studies led to the development of a proposed QoL questionnaire that is pragmatic and appropriate for evaluating the QoL of Ghanaians living with epilepsy (Kelly & Cordeiro, 2020).

1.7.2 Theoretical assumptions

Many theories and concepts of QoL exist and have been applied in many situations and circumstances. Firstly, the socio-economic development concept sees QoL life as economic growth with indicators such as employment, household income, poverty, cost of living, type and quality of job, and accommodation, as well as Gross Domestic Product (GDP) (Sirgy, 2011). However, this does not capture the entire aspects of QoL and the GDP aspect has also been challenged by some researchers. Secondly, the theoretical notion of the personal utility concept of QoL has birthed many QoL indicators. It describes QoL in terms of the extent to which people in a community evaluate their lives positively in terms of their social, family, leisure, spiritual and overall life as well as community conditions and services (Sirgy et al., 2000). Thirdly, the concept of human development is based on the premise that QoL is attained when human needs are satisfied in a hierarchical order. Thus, starting from basic human needs such as health, safety and economic needs as well as higher order needs such as self-esteem and self-actualization (Maslow, 1954). Finally, the concept of individual capabilities and functioning is also used to describe quality of life (Sen, 1987, 1999) and describes indicators such as one's ability to choose freely between various functions. These functions as referred to

as one's capabilities and how these capabilities enable a person to engage in activities and deal with situations that one deems as important to his or her life. There are thus many indicators from theoretical perspectives to study human well-being and QoL.

The integrated QoL theory was deemed the best for this study because it is a combination of several factual theories about QoL. This is in line with the pragmatic approach adopted as the philosophical underpinning of the study. Secondly, the IQOL theory also formed the basis of the development of Danish QoL survey (Ventegodt, 1995, 1997), the SEQOL (Ventegodt et al., 2003), QOL5, and QOL1 (Lindholt et al., 2002) questionnaires. Therefore, it was deemed appropriate for the study.

1.7.3 Integrative quality of life theory

The Integrative Quality of Life (IQOL) theory has within it about eight factual theories found within the subjective existential objective spectrum (Ventegodt et al., 2003). These comprise theories of satisfaction in life, wellbeing, meaning in life, happiness, realising life potential, needs fulfilment, biological view of QoL, and objective factors. These are facets of life in a continuum from the subjective to the objective. The most superficial of all is wellbeing and objective factors. This is because they focus on the superficial ability of man to adapt to his or her culture. Partially deep aspects of QoL have to do with the fulfilment of one's needs and the satisfaction with life. Thus, the relationship between what one expects in life and what life gives to the person. Our deepest existence and human nature are the core of happiness and the realisation of potential in life. Meaning in life, as well as order and disharmony within the biological information system centres on the innermost being of humanity. The IQOL theory by Ventegodt et al. (2003) was adopted for this study because is was found to be the most comprehensive theoretical account of the concept of QoL. Detailed explanation of the integrative QoL theory is presented in chapter two.

1.8 CONCEPTUAL DEFINITION OF TERMS

People living with epilepsy: Adults from 18-60 years of age who have been diagnosed with epilepsy excluding those with comorbid mental retardation and psychiatric problems.

Educated people living with epilepsy: Ghanaians living with epilepsy with at least primary level education and who can speak English or "Twi" (A common vernacular in Ghana).

Health outcome: Changes in knowledge, health related quality of life and coping strategies among PLWE.

Quality of life: The general state of health and functioning of PLWE. These include their mental health (emotional well-being), socio-cultural functioning, felt stigma, general vitality (energy/fatigue), role limitations due to emotional problems, general health perception, physical functioning and role limitations due to physical health problems (Blond et al., 2016).

Quality of care: Sustainable and holistic health care that is safe, timely, equitable, effective and efficient for PLWE and improves upon their overall outcomes including coping strategies and QoL (World Health Organisation, 2017).

Coping: Passive pattern of reaction, actively confronting, and palliative reaction, avoidance, accessing social support, expression of emotions and having reassuring thoughts (Stoilkova et al., 2013).

Sociocultural: Customs, lifestyles and values that are characteristic of a group of people. In this study, socio-cultural refers to the values, customs, traditions, social organizations and lifestyle of people in Ghana.

Sub-Saharan Africa: Sub-Saharan Africa is an area lying south of the Sahara Desert within the continent of Africa. It comprises 49 countries out of the 54 countries in Africa (Kpodo, 2016).

1.9 METHODOLOGICAL ASSUMPTIONS

This refers to the presumptions that the researcher makes regarding the methodological approaches used in any research process (Creswell, 2003). The researcher believes that epilepsy is a chronic and debilitating health problem that invariably affects the QoL of PLWE. As part of managing PLWE, assessing their QoL helps inform particular interventions to help improve upon the health and QoL of PLWE. However, the researcher believes that the extent to which epilepsy affects an individual's QoL depends on the culture of the society in which one lives in as. It is assumed that assessment of QoL of PLWE will therefore require the involvement of PLWE in the development of a culturally sensitive questionnaire that is appropriate for their cultural setting.

Based on the assumptions above the sequential multimethod research design, involving quantitative and qualitative approaches in three phases was found to be suitable and hence

adopted for the study (Hunter & Brewer, 2015). This offers a flexible and practical means for combining research designs, whereby any approach that is appropriate for any stage in the research is applied in order to get the desired results. The multimethod approach also helps cover the weaknesses of individual research designs by combining them in the same study (Hunter & Brewer, 2015). The multimethod research design also supports the development and evaluation of questionnaires. For the purposes of this study, which was to develop a culturally sensitive QoL questionnaire to assess the QoL of PLWE, this approach is most appropriate.

1.10 OVERVIEW OF RESEARCH DESIGN AND METHODS

This study employed a sequential multimethod design to develop an epilepsy specific QoL questionnaire for PLWE in Ghana. To achieve the purpose of developing a QoL questionnaire for PLWE in Ghana, the study was conducted in three phases comprising nine objectives. Table 1.1 presents a summary of the overview of the research design and methods.

Table 1.1: An overview of the research methods applied in the study

PHASE 1 (Conceptualisation Phase) **Articles:** 1. Synthesis of the concepts and constructs of questionnaires used to assess QoL in PLWE 2. Quality of life in PLWE in SSA: An integrative review 3. Meanings of QoL among PLWE in Ghana; A qualitative exploratory study	**Objectives (steps)**	**Design/ Approach**	**Sample and Sampling**	**Data Collection Process**	**Questionnaires**	**Analysis**
	1. To explore and synthesize the purpose, concepts, constructs, the development process and the scoring systems of questionnaires used in assessing the QoL of PLWE worldwide	Integrative literature review (Whittemore & Knafl, 2005)	Peer reviewed and Grey Literature (Qualitative & Quantitative articles)	Desk Top Search Search Engines-CINAHL, PubMed, ScienceDirect, Psych Info & SCOPUS		Meta-synthesis, Thematic and Content Analysis
	2. To ascertain the QoL among PLWE in SSA from a literature perspective.					
	3. To explore the meaning of QoL from the perspective of PLWE in Ghana.	Qualitative exploratory design	PLWE without comorbid mental sub normality (18 years and above) Purposive sampling Sample size: saturation	Face-to-face in-depth interview	Semi-structured interview guide	
PHASE 2 (Operationalisation Phase) **Articles:** 4. The process of developing a QoL questionnaire for PLWE	4. To select and generate items for the epilepsy QoL questionnaire for Ghana					
	5. To draft epilepsy QoL questionnaire for Ghana		Based on Stone (1993)'s recommendations on designing a questionnaire.			
	6. To develop a scale of measurement and scoring for the epilepsy QoL questionnaire for Ghana with instructions for use	Nominal Group Technique (McMillan et al., 2016).	Experts Purposive sampling Sample size: 8 experts (McMillan et al., 2016).			
	7. To conduct an expert review of the draft epilepsy QoL questionnaire for Ghana					
PHASE 3 (Validation Phase) **Articles:** 4.Content validity of epilepsy QoL questionnaire for Ghana	8. To test the content validity of the draft epilepsy QoL questionnaire for Ghana	Methodological design (Grove, Burns, & Gray, 2013, pp. 255)	Experts Purposive sampling Sample size: 8 experts (Health Professionals; Academics; Questionnaire developers)	Email of questionnaire to experts for evaluation	Self-developed content-validity questionnaire	Estimation of Content validity index Summary and description of expert comments
	9. To test the face validity of the draft epilepsy QoL questionnaire for Ghana		Experts Purposive sampling Sample size: 4 experts (PLWE in Ghana)	Email of questionnaire and direct contact with patient to evaluate the questionnaire	Self-developed face-validity questionnaire	Summary and description of scores and expert comments
Dissemination: The epilepsy-specific QoL questionnaire for PLWE in Ghana was included in the thesis submitted to the University of Witwatersrand in fulfilment for the degree of Doctor of Philosophy in Nursing. Research papers will be published in a peer review journal and distributed in soft and hard copies to health educational institutions and nursing organizations across SSA for utilization.						

1.11 ORGANIZATION OF THE THESIS

The thesis is organized into eight chapters. Table 1.2 presents the organization of the these in chapters.

Table 1.2: Structure of the Thesis

PHASE	CHAPTER	DESCRIPTION	
	Chapter 1	Background, Rationale and Theoretical foundation	
	Chapter 2	Conceptual framework and literature Review	
	Chapter 3	Research Methodology	
PHASE ONE: Conceptualization phase	Chapter 4	Integrative literature review one	Purpose, concepts, constructs, development process and scoring systems of questionnaires used in assessing the QoL of PLWE
		Integrative literature review two	Quality of life of PLWE
	Chapter 5	Exploratory qualitative study	Meaning of QoL among PLWE in Ghana
PHASE TWO: Operationalization phase	Chapter 6	Integration of results from chapters 4 and 5 Nominal group technique Development of draft QoL questionnaire for PLWE in Ghana	
PHASE THREE: Validation phase	Chapter 7	Content validity and face validity testing of draft QoL questionnaire for PLWE in Ghana	
	Chapter 8	Summary, Strengths, Limitations, Recommendations and Conclusion	

1.12 SUMMARY

This chapter presented a general overview of the background to the study, the problem statement, purpose, objectives and research questions for the study. Justification of the significance of the study as well as a description of theoretical foundations of the study, conceptual definition of terms for the study in addition to the general overview of the research

methods and the manner in which the rest of the chapters are presented in this chapter. The theoretical framework and literature review are presented in the next chapter.

CHAPTER TWO: LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

2.1 INTRODUCTION

The chapter presents a review of literature on the experience of living with epilepsy. This is followed by a description of the Integrative Quality of Life (IQOL) theory as the framework for this study. The IQOL theory was used to identify key constructs that were examined for the purposes of this study. Furthermore, arranging and grouping the identified concepts provided meaning and direction for the structure and the development process of the Quality of Life (QoL) questionnaire for PLWE in Ghana. The concept of QoL is then explained in the chapter followed by a chapter summary.

2.2 LIVING WITH EPILEPSY

Living with epilepsy influences almost every aspect of one's life. The physical effect of living with epilepsy also affects one's activities of daily living which have an impact on their socioeconomic lives (Akosile et al., 2021; Gauffin et al., 2011). People living with epilepsy also have concerns about public knowledge and perception about the condition (Deegbe et al., 2019; Gauffin et al., 2011; Nurjannah et al., 2020). This also affects them psychologically and emotionally and has a ripple effect on their relationship with others (Deegbe et al., 2019; Fazekas et al., 2021).

2.2.3 Physical effect

There are many physical effects that PLWE experience. Seizures cause migraines and headaches (Fazekas et al., 2021). Fatigue is also a common experience among PLWE (Akosile et al., 2021; Fazekas et al., 2021). This leads to low performance at work and in school as well as love ambition among PLWE (Akosile et al., 2021; Gauffin et al., 2011). An increase in the frequency and severity of seizures contribute in poor QoL among PLWE (Akosile et al., 2021; Gauffin et al., 2011; Kaddumukasa et al., 2019). Increased seizure severity has also been linked to more severe injuries and even abortions among pregnant women with epilepsy (Deegbe et al., 2019). Seizures also occur at night. Having seizures in sleep makes night time very unpleasant for PLWE and raises a lot of concerns for PLWE (Fazekas et al., 2021).

The intake of antiepileptic medication is a necessity for PLWE (Rawlings, Brown, Stone, et al., 2017). The ability of the medication to control the seizures of PLWE makes them happy and cheerful. However, side effects of antiepileptic medications such as heartburns, nausea,

fatigue, memory loss are not uncommon and this makes them even more depressed (Fazekas et al., 2021). In Ghana PLWE sought for traditional and spiritual treatment for their epilepsy either separately or as an addition to their orthodox antiepileptic medications (Deegbe et al., 2020). The seizures and side effects of antiepileptic medications affect activities of daily living of PLWE.

2.2.4 Activities of daily living

The frequency and severity of seizures affect activities of daily living of PLWE. In the UK, and Sweden, PLWE who used to drive had concerns about not being able to drive because of the diagnosis of epilepsy (Gauffin et al., 2011; Kılınç et al., 2017). Studies in Ghana and the UK also shows that PLWE are restricted, either by family or through medical advice, not to stress themselves with house chores such as cooking or bathing without supervision or assistance (Deegbe et al., 2019; Kılınç et al., 2017). These restrictions cause a sense of loss of independence among PLWE(Kılınç et al., 2017) which invariably affects their socioeconomic lives.

2.2.5 Socioeconomic effect

Epilepsy serves as a barrier to progress in life among PLWE. Unlike others, PLWE find it difficult in making plans and setting goals for their lives since all these decisions need to take their seizures into consideration. This results in lifestyle changes and adjustments, many of which are uncomfortable (Gauffin et al., 2011). People living with epilepsy have difficulty with advancement in their education, career choices and progression and family life, including decisions to make children (Gauffin et al., 2011). In Nigeria, PLWE found it difficult to attain tertiary education and had difficulty securing a job (Akosile et al., 2021). In Ghana, PLWE had their work and school activities disrupted by seizures. Those who could not cope unfortunately had to leave school midway (Deegbe et al., 2019). In addition, PLWE feel that they have to expend as much as more than twice the effort that others make in order to achieve academic success, get a good job and move on ahead in life (Gauffin et al., 2011). A commonly expressed goal among PLWE is to live a normal life as any other person without allowing the condition to restrict them. However, feelings of restriction and limitations in the ability to perform responsibilities as adults makes PLWE sad, and disturbed with lowered self-esteem (Gauffin et al., 2011).

The onset of epilepsy has a life-changing effect on PLWE, even to the extent of changing one's identity (Rawlings et al., 2017). Thus, one's perception of who he or she is. Whilst it was mostly detrimental in the lives of many PLWE, it also has a positive effect in the lives of a few PLWE. Epilepsy interferes in the course of people's lives however, a few PLWE are able to cope well by readjusting their goals and future plans because of the diagnosis of epilepsy and were able to move on in life (Kılınç et al., 2017). However, for many people, epilepsy has a negative effect on their personality, an obstacle to their personal development, and changing the way they perceived they would have developed in life (Gauffin et al., 2011). Some had to give up their dreams of advancement in education and career progression. However, persons without already established future plans and those who might have already achieved their goals, in the case of adult onset epilepsy, are easily able to accept and adapt to the condition (Kılınç et al., 2017).

2.2.6 Public knowledge and perception about epilepsy

Concerns about poor public knowledge about epilepsy is very common. This has been reported in studies in Sweden (Gauffin et al., 2011), Indonesia (Nurjannah et al., 2020), UK, Spain, France, Italy, and Germany (Fazekas et al., 2021) and Ghana (Deegbe et al., 2019). In Sweden PLWE could not understand what was happening to them, felt their seizure symptoms were strange and wondered how people would understand them (Gauffin et al., 2011). Epilepsy is actually misunderstood by the public and this is worsened by poor media depiction of the condition, with some even make fun of epilepsy (Fazekas et al., 2021). Due to this, people do not have knowledge on how to give first aid for seizures (Fazekas et al., 2021) as such, they are unable to provide first aid for victims during a seizure episode in public. They end up becoming onlookers rather than active participants in helping PLWE in their crises moments (Gauffin et al., 2011). This makes the lives of PLWE unsafe for them in public, because of the fear of not receiving adequate help during seizures outside home (Gauffin et al., 2011). This is an indication of the psychological and emotional challenges that PLWE face.

2.2.7 Psychological and emotional experiences

Fears and worries about having seizures in public represent an ever present threat lingering in the minds of PLWE and causing undue anxiety in them (Deegbe et al., 2020; Fazekas et al., 2021). The thought of people mocking them, becoming scared of them, or being helpless at the sight of them having seizures in public filled PLWE with dread.

The sudden and unpredictable nature of seizures as well as fears of getting injured during a seizure episode makes PLWE even more anxious (Kılınç et al., 2017). This makes PLWE have a feeling of lack of control over their seizures, which undermines their self-esteem and confidence in carrying out daily activities (Kılınç et al., 2017). They also feel embarrassed and ashamed of having seizures in public (Deegbe et al., 2019; Fazekas et al., 2021). The thought of being labelled crazy or mentally ill, and soiling of self during a seizure episode caused further embarrassment (Deegbe et al., 2019; Fazekas et al., 2021; Gauffin et al., 2011).

People living with epilepsy also experience general loss of memory and can become disoriented with time (Arinzechi et al., 2019; Fazekas et al., 2021; Gauffin et al., 2011). Memory impairment is also attributed to side effects of anti-epileptic medication. Activities of daily living among PLWE is affected by memory decline which sometimes get them into some embarrassing situations (Gauffin et al., 2011). This is one of the reasons PLWE find it difficult to get a good job.

These challenges make PLWE have to do much for little making life difficult for them to live up to their expectations (Gauffin et al., 2011). Frequent and uncontrolled seizures also make them frustrated (Kılınç et al., 2017). As a result of this, PLWE have difficulty with their mental health and often are depressed (Fazekas et al., 2021), which affects their relationship with people.

2.2.8 Relationship with people

Some PLWE end up putting limitations on themselves in order to keep them safe from seizures. These include restrictions from social gatherings and alcohol, and not driving leading to increased social isolation (Fazekas et al., 2021). Persons with epilepsy are also concerned about the strain the condition has on their family and friends. They feel they are a burden on their relations and this makes them feel a sense of guilt, with women becoming particularly concerned about how this would affect their children (Gauffin et al., 2011). Persons living with epilepsy also find it difficult to find and sustain friendships – further increasing their isolation from society (Gauffin et al., 2011).

Inevitably PLWE end up with difficulty in establishing a love relationship although they wish to have a partner to start a family with together (Deegbe et al., 2019; Gauffin et al., 2011). In Ghana some women with epilepsy even end up getting pregnant however, their partners end up not marrying them due to personal fears about the condition or disapproval from their

partner's family members (Deegbe et al., 2019). They end up remaining single or becoming single parents.

Limitations in life placed on them by epilepsy makes PLWE end up becoming dependent on others, particularly parents and family members, for help (Fazekas et al., 2021; Gauffin et al., 2011). However, continual dependence on others for help can become frustrating for PLWE (Gauffin et al., 2011).

Misconceptions about epilepsy lead to stigmatising and discriminatory behaviours towards PLWE (Deegbe et al., 2019; Nurjannah et al., 2020; Rawlings, Brown, Stone, et al., 2017). Friends are no longer in touch as they used to be before the diagnosis of epilepsy (Deegbe et al., 2019; Rawlings, Brown, Stone, et al., 2017). Others now look down upon them and do not regard their opinions as worthy, which contributes in the sorrow and frustrations of PLWE (Gauffin et al., 2011). Increased stigma and discriminatory behaviours towards PLWE are not only reported in Ghana (Adjei et al., 2018; Deegbe et al., 2019) but also in the UK (Rawlings et al., 2017), Sweden PLWE (Gauffin et al., 2011), to mention but, a few. Thus, further complicating their chances of employment and further education (Adjei et al., 2018).

2.3 CONCEPTUAL FRAMEWORK

The current study was guided by IQOL theory developed by Ventegodt et al. (2003). This served as the philosophical and the theoretical framework that guided the development of the Danish QoL survey (Ventegodt, 1995, 1997), the Self evaluated Quality of Life (SEQOL) (Ventegodt et al., 2003), QOL5, and QOL1 (Lindholt et al., 2002) questionnaires. This informed the researcher's decision to adopt this framework for the study. The notions about QoL can be grouped into three aspects of good life namely; Subjective QoL, Existential QoL and Objective QoL. In the IQOL theory, these three aspects of QoL across these three groups are placed in a spectrum with existential QoL at the centre representing the core of the being of humanity (Figure 2.1).

A number of QoL theories are incorporated in the spectrum from the subjective QoL through the existential core to the objective QoL. Quality of life is thus, a complex phenomenon of interacting objective and subjective parts (Lawton, 1991). These include theories of (1) Well Being, (2) Satisfaction with Life, (3) Happiness, (4) Meaning in Life, (5) Biological View of the Quality of Life, (6) Realizing Life Potential, (7) Fulfilment of Needs, and (8) Objective Factors (Ventegodt et al., 2003). The ensuing paragraphs elaborate more on these theories.

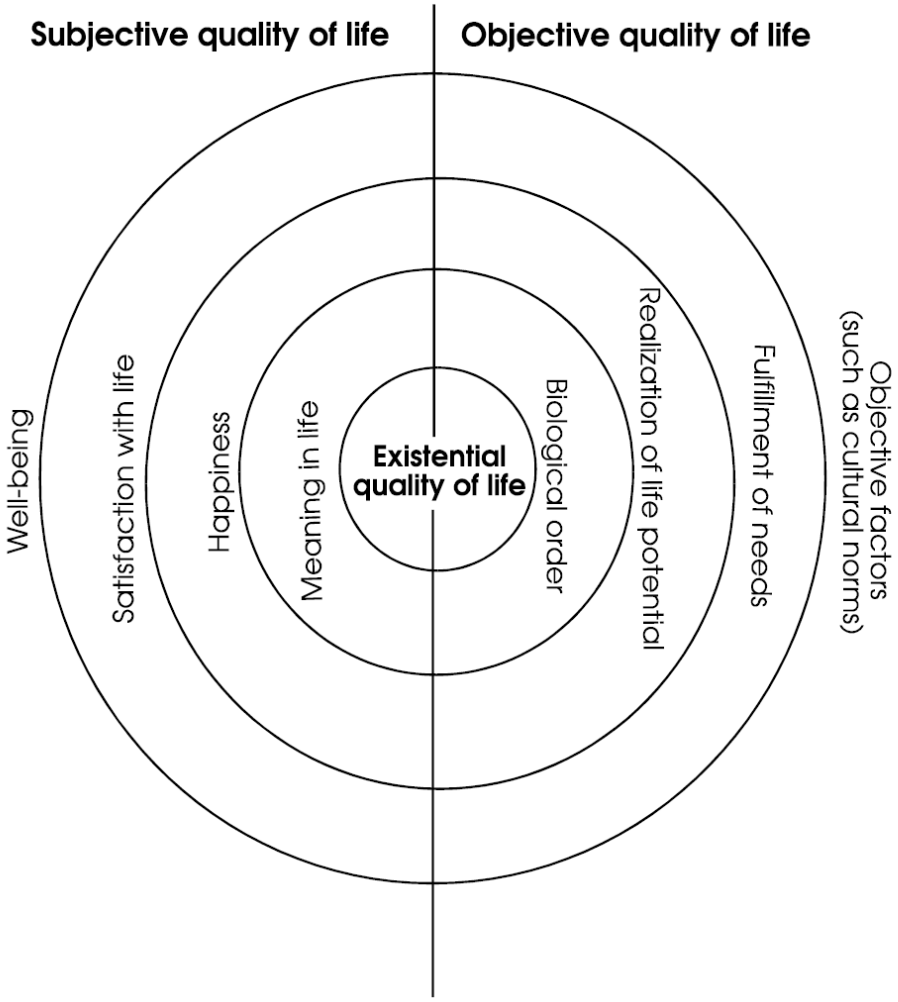

Figure 2.1: The Integrative Quality of Life Model by Søren Ventegodt et al. (2003)

2.3.3 Subjective Quality of Life

Subjective QoL refers to how good one feels about the life that he or she has. Each individual evaluates his or her life in relation to their perception about their life and how they feel about life. People's appraisal of their level of contentment or happiness in life is subjective QoL.

2.3.3.1 Wellbeing

Wellbeing is the most natural aspect of subjective QoL which involves an individual's assessment of his or her own QoL (Cella & Tulsky, 1993). This is elicited in response to the questions "How are you" or "How is life". Such responses do not require any deeper explanation but rather a mere superficial description one's evaluation of QoL.

The response to a question on wellbeing may be followed by an explanation which may be an extension of one's response. For example, "Things are not going too well at home/work" or

"My health is not what is used to be". Thus, an indication that wellbeing is related to one's evaluation of how things function objectively. Therefore, wellbeing is more superficial than meaning in life, self-realisation and the fulfilment of one's needs. However, Cummins et al. (2012) explained that much studies on subjective wellbeing is about people rating their own happiness or satisfaction with socially related factors such as income or events in life.

2.3.3.2 Satisfaction with Life

People most of the time may indicate that something is missing when asked about their satisfaction with life. An individual may feel good but may actually not be very satisfied, or perhaps just be satisfied. In general, people are commonly less satisfied in life compared to their overall state of wellbeing. Satisfaction is a cognitive entity which is realised when one's expectations in life are met. This may be grouped into other aspects including satisfaction with income, health or work (Thieme & Dittrich, 2015).

In order to achieve satisfaction in life, one may either make adjustments in the external world to meet up with their dreams and aspirations or one may alter their dreams and aspirations to be in line with the world they live in. In both ways, satisfaction is realised as dreams and aspirations are met by the external world. However, the two lives are different although satisfaction is met. One life feels umpty and unhappy because their true dreams and aspirations have been given up, although they are satisfied. The other life is lived in true happiness and satisfaction because one finds meaning in life by living up their true dreams and aspirations. Thus, being satisfied in life cannot be equated to finding meaning in life. Therefore, good life is more than merely being satisfied in life (Seligman, 2011).

2.3.3.3 Happiness

Cheerfulness and contentment cannot be equated to happiness in life. The feeling of happiness is very precious, very desirable, but difficult to attain. Happiness is an essence that is deep within an individual and encompasses an individual's entire existence. Happiness also comes along with satisfaction and wellbeing (Seligman, 2011). Although related, happiness is not always about being in harmony with nature such as adapting to culture and its associated factors (Ventegodt, 1995). But, involves being able to achieve deep down what is important to an individual. This is related to nonrational dimensions in life including love, closeness with nature, to mention but a few other than money or the state of one's health.

These concepts of wellbeing, satisfaction in life and happiness, although are described as separate, they also overlap and link up with each other. Happiness is a positive emotion (Seligman, 2011) which is described as a key determinant of wellbeing (Coffey et al., 2015). Moreover, both happiness and wellbeing have positive relationship with satisfaction in life (Cohn & Fredrickson, 2009).

2.3.3.4 Meaning in Life

The theme of classical religion is finding meaning in life. In the quest for meaning in life, people view the value of all aspects of life differently. Finding meaning in life also refers to the attainment of a sense of purpose from something that is bigger than oneself (Steger et al., 2009). People then tend to question the meaningfulness of their relationships with others; question whether there are really doing the right things in life; whether they have got the right job; whether they are using their talents the way they should; and question the truthfulness of their beliefs. In an attempt to find meaning in life, one must accept the meaningfulness and the meaninglessness of life and be ready to make amends for that which is meaningless. This is a deeply personal experience that a few people seek to achieve. A sense of fulfilment is therefore achieved when people find meaning in life (Seligman, 2011).

2.3.4 Existential Quality of Life

One's appraisal of how good life is from deep within is existential QoL. There is an assumption that one has a deeper nature or essence that one lives in harmony with, that needs to be respected. This is a state of an inner depth in humanity or the state of one's soul which is described by thinkers such as Satre, Anotonovsky and Maslow (Lindholt et al., 2002).

2.3.5 Objective Quality of Life

The appraisal of one's life by the outside world is one's objective QoL. This is associated with the culture of people. Objective QoL has little to do with one's personal life but mainly refers to the ability of an individual to adapt to cultural values such as attaining certain social symbols to be a good member of one's society and culture. These are characteristics that can be easily rated by others externally.

2.3.5.1 A Biological View of the Quality of Life: the Biological Information System and the State of Existential Balance

The biological aspect of QoL is the biological constitution of humans. Humans are living organisms. One's physical health is a reflection of the person's biological information system because the cells and organs in the body require correct information in order to function normally and healthy. The link between QoL of illness has deep existential grounding relating to one's state of health and soul and not merely about how good one feels (Ventegodt, 1994, 2003). This implies that if one loses meaning in life, he or she is easily susceptible to ill health without a cause. The relationship between QoL and illness is therefore best demonstrated using the theory of an individual as a biological information system.

2.3.5.2 Realizing Life Potential

Growth and development among humans are a continuous and constant process. This begins with a fertilised egg with enough potential which grows to fulfil this potential in life. Therefore, a key component of QoL is the realization of one's potential in life. Thus, using one's talent to the full, becoming creative, getting a meaningful job, starting a family and reaching one's ultimate goal in life. Seligman (2011) describes this as a drive to achieve a goal for one's own sake. This attribute is however not concerned with the outcome of realizing potential but rather the attitude of perseverance to achieve one's potential or goal in life (Kern et al., 2014).

2.3.5.3 Fulfilment of Needs

This theory posits that one's QoL increases with the fulfilment of needs in life. These needs are a representation of the nature of humans. These are also evident in Maslow's hierarchy of needs theory (Maslow, 1943). These begin from concreate needs such as food, shelter and clothing to more abstract needs such as self-esteem and the need to realise one's self. Fulfilment of needs is a very important stage between the deep existential core of humans and the superficial objective phenomena as illustrated in the IQOL theory spectrum. This need is linked to the satisfaction of having our needs met. The subjective aspect here is satisfaction which is situated between the existential core of one's being and the superficial aspects of life.

The fulfilment of needs is not the same as wellbeing. This is because needs are related to human nature. However, we feel good once our needs have been met. This however, is also not the same as the realisation of life's potential which takes its root from realising one's biological information. This is a complex phenomenon that cannot be reduced to simple actual needs (Ventegodt et al., 2003).

2.3.5.4 Objective Factors

Objective factors of quality of life represent external factors that are easily identifiable (Boelhouwer & Noll, 2014). These include one's health status, marital status, income, and number of daily contacts with people. Usually, people confuse a good life with the kind of life that is general considered as right or rich. Thus, a rich man may be unhappy, but a poor man may be happy. There is also discrepancy in a physician's evaluation of a patient's QoL compared to the patient's self-evaluation of his or her QoL. Objective QoL is linked to one's culture. Thus, the ability of one to adapt to his or her culture reflects one's objective QoL and this is similar to wellbeing (Ventegodt et al., 2003).

2.4 CONCEPT OF QUALITY OF LIFE

Quality of life of PLWE and their families is negatively impacted by epilepsy stigma and the nature of the disease (Deegbe et al., 2020; World Health Organisation, 2019). The epilepsy stigma still remains in many countries till date. Social stigma and discrimination in relation to the misconceptions and fears about epilepsy have been in existence for centuries.

2.4.1 Health Status

According to the WHO, health is "a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity". The main aspects of the WHO definition of health are the incorporation of the concept of social wellbeing as well as their emphases on health beyond the absence of disease. On the other hand, Patrick et al. (1982) defines health as "an individual's level of function", where conclusions about one's "optimum function" are made based on "society's standards of physical and mental well-being" thus, excluding social wellbeing.

2.4.2 Quality of Life

Approaches to how QoL is defined differ (Ferrans, 1990). Some approaches are based on expectations, personal needs, phenomenological viewpoints and subjective wellbeing (Bowling, 2005). Another school of thought on wellbeing attempts to distinguish between approaches based on hedonism, satisfaction of preferences, satisfaction in life and objective lists (Peasgood et al., 2014). Examples of some definitions of QoL are: "a conscious cognitive judgment of satisfaction with one's life" (Rejeski & Mihalko, 2001) and "an individuals' perception of their position in life in the context of the culture and value systems in which they

live and in relation to their goals, expectations, standards and concerns" (Kuyken & Group, 1995).

Although most of these definitions of QoL are mostly focused on the subjective judgements of people others have argued strongly for the inclusion of objective factors in the definition of QoL (Cummins, 2005; Felce & Perry, 1995; Meeberg, 1993). For example, QoL has been defined as "an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values" (Felce & Perry, 1995).

2.4.3 Health-Related Quality of Life

Defining Health-Related Quality of Life (HRQoL) has also been problematic (Bowling & Brazier, 1995). At least mention can be made of four definitions of HRQoL in literature. It is first defined as "how well a person functions in their life and his or her perceived wellbeing in physical, mental, and social domains of health" (Hays & Reeve, 2010). Functioning is described as one's ability to do some pre-fined activities whereas wellbeing is described as an individual's subjective feelings (Hays & Reeve, 2010). Another definition relates HRQoL directly to QoL: "quality of life is an all-inclusive concept incorporating all factors that impact upon an individual's life. Health-related quality of life includes only those factors that are part of an individual's health" (Torrance, 1987). However, aspects of QoL such as political and economic circumstances, that are not health related are not included in the definition of HRQoL(Torrance as cited in Karimi & Brazier, 2016).

The aspects of QoL affected by health are the focus of a third definition of HRQoL. Thus, HRQoL is defined as "those aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment" (Ebrahim, 1995). A narrower version of this definition of HRQoL is where HRQoL "is used to identify the sub-set of the important or most common ways in which health or health care impact upon well-being" (Peasgood et al., 2014).

One last definition of HRQoL is centred on the value of health. For example, HRQoL is referred to as the "values assigned to different health states" (Gold et al., 1996, p. 83). The estimation Quality-Adjusted Life-Years (QALYs) is based on these values in order to determine the benefits accrued form health technologies. These values used in the estimation of QALY are

on a scale of 0 to 1 representing death and full health, respectively (Gold et al., 1996). Values that are lower than one represent a loss of QoL due to ill health (Gold et al., 1996).

2.4.4 Quality of life and health related quality of life

In fact "quality of life is more than health status, clinical symptoms, or functional ability, health is only one dimension of quality of life" (Ferrans, 1990). All of earlier definitions of QoL can be are influenced by non-health related factors including economic and material factors (Guyatt et al., 1993). Although life satisfaction is influenced by health, the status of health explains just a small portion of satisfaction outcomes in life (Michalos, 2004). Thus, an indication that health and QoL are distinct concepts. Earlier definitions of HRQoL are either a sub-set of the definition of health or mirror the value of health. However, the profile associate with one's state of health and not that value associated with the profile is referred to as HRQoL. This underscores the need to assess what typical HRQoL questionnaires actually measure.

Calman explained that "Quality of life must include all areas of life and experience and take into account impact of illness and treatment" (Calman, 1984, p. 124-125). Health related QoL is about the effect that illness and treatment of illness have on one's QoL. Quality of life however, extends beyond illness related factors to include economic status, environment and social interaction/participation/support influence on a person to have a happy life.

In order to understand what literature portrays of QoL of PLWE, an integrative review is presented in the chapter four. Because QoL for PLWE is so important, a number of measures have been developed and these are presented in the form of a scoping review in chapter four.

2.5 SUMMARY

This study is driven by the pragmatic paradigm which is based on the concept of addressing practical problems and this makes no distinction between approaches to research but one that practically addresses a particular research problem at a point in time. The theoretical framework for the study was the IQOL theory. This theory integrated eight quality of life theories including theories of (1) Well Being, (2) Satisfaction with Life, (3) Happiness, (4) Meaning in Life, (5) Biological View of the Quality of Life, (6) Realizing Life Potential, (7) Fulfilment of Needs, and (8) Objective Factors. This served as the theoretical bases for some already existing QoL questionnaires and incorporates the concepts of subjective, existential and objective quality of life. The concept of QoL was also described in this chapter and the

effect that epilepsy has on QoL is also mentioned in this chapter. The following chapter describes the research methods and processes applied to the study.

CHAPTER THREE: METHODOLOGY

3.1 INTRODUCTION

The previous chapter presented a review of literature and the conceptual framework for the study. The overall strategy used in carrying out the study is presented in this chapter. This includes a description of the research design and methods, participant selection process as well as data gathering and analysis. These methods have been linked to the six milestones of design and development to develop the epilepsy QoL questionnaire for PLWE in Ghana.

3.2 RESEARCH SETTING

The study was conducted in the Greater Accra Region of Ghana. Ghana is a sub-Saharan country in the west of Africa. The Greater Accra Region lies on the south-eastern part of Ghana. Accra, the capital city of Ghana is located within the Greater Accra Region. The region is bordered by the Eastern Region, Gulf of Guinea, Lake Volta, and the Central Region on the north, south, east and west respectively. The region occupies a total land area of 3,245 sq. km – thus 1.4% of the total land area of Ghana - which makes it the smallest region of the country in terms of land size (Ghana Statistical Service, 2013).

The Greater Accra Region has a population of 5,446,237 people (Ghana Statistical Services, 2021) with16 administrative areas namely: Accra Metropolis, Tema Metropolis, Ashaiman Municipality, Adenta Municipality, Ga East Municipality, La-Nkwantanang Madina Municipality, Ga West Municipality, Ga South Municipality, Ga Central Municipality, Ledzokuku-Krowor Municipality, Dangbe West Municipality, Dangbe East Municipality, Ada West Municipality, La Dade Kotopon Municipality, Kpong Katamanso Municipality, and Ningo Prampram District (Ghana Nation, 2017). These comprise both urban, peri urban and rural areas. However, about 90.5% of the Greater Accra Region is urban.

The Greater Accra Region is mainly inhabited by three ethnic groups: The Akans (39.8%), Ga-Dangme (29.7%) and Ewe (18%). Common languages spoken are “Twi”, “Ga” and “Ewe”. Majority (83%) of the inhabitants of the Greater Accra Region are Christians, followed by Muslims (10.2%) and non-religious persons (4.6%) and traditionalists (1.4%) (Greater Accra Regional Coordinating Council, 2016). With the region being the most populous in Ghana, it has an average household size of 4.6 and an average of 2.4 rooms per household. Majority (70.8%) of people in Accra are economically active. However, unemployment rate is 13.4% compared to the national unemployment rate of 10.4%. Among the economically active, 42%

engaged in sales and service occupational activities whilst 10.8% engage in technical, professional and related works. Retail and wholesale trading activities (30.4%) and manufacturing (16.7%) dominate the industrial sector. Less predominant activities of occupation include forestry, agriculture, animal husbandry, hunting and fishing (9.1%). Most (51.8%) of economically active inhabitants of the Greater Accra Region are self-employed and 32.6% of them are employees. Within the Greater Accra Region, the Accra Metropolis has the highest literary rate of 85.1%. This is followed by the Tema Metropolis with an average literacy rate of 79.8% with the Dangme West and Dangme East districts having the lowest literacy rates of 50% (Greater Accra Regional Coordinating Council, 2016).

3.3 RESEARCH DESIGN

Polit and Beck (2018), defined research design as a complete plan for tackling research objectives, which includes the strategies for enhancing the research integrity. The multi-method design was applied in this study (Hunter & Brewer, 2015). This involved the employment of various methods to collect, analyse and interpret data. This study begun with two integrative reviews on QoL among PLWE in SSA and analysis of content of QoL questionnaires for PLWE. This was followed by an exploratory qualitative study on concept of QoL among PLWE in Ghana and the development and expert review of the QoL questionnaire for PLWE in Ghana.

In the multi-method research design, two or more research methods are applied in one study but in different phases within that study. This may involve the use of both qualitative and quantitative research approaches within one study. Within a multi-method study, there are complete individual methods for specific objectives all within the same study (Byrne & Humble, 2007; Esteves & Pastor, 2003). This allows for both positivist and in-depth approach of inquiry into a single research topic (Byrne & Humble, 2007; Esteves & Pastor, 2003; Power et al., 2016).

Mixed-method design is a subset of the multi-method design (Hunter & Brewer, 2015). This is because the mixed-method design mixes both quantitative and qualitative methods whilst the multi-method design mixes two or more methods which may be either qualitative, quantitative or both.

This study was conducted in three phases and seven steps as outlined in Table 3.1. The various phases of the research stood alone with one phase providing the background, questionnaire or

data for the next phase. The various phases of the study demanded different research methods to meet the research objective. Therefore, this study employed a sequential multi-method design which is situated in the pragmatic paradigm. The order in which the three phases and methods employed in this multimethod study design was in accordance with the six milestones of the research and design methodology by Ellis and Levy (2010) namely: problem identification, defining the objectives, designing and development of the framework (artefact), testing the artefact, evaluating the results, and communicating the results.

3.3.1 Research and design methods

In conducting design and development research, there is the need for certain factors to be present. It is expected that the research is motivated by a research problem that is justified by the kind of research that is being carried out. Secondly, the type of research being conducted must be directed towards answering research questions that are appropriate for the research being conducted. The scope, limitations and assumptions the research is based upon must be acknowledged. This is when obtainable results from the methods applied can be produced by the research.

The research is expected to make conclusions that are supported by the results (Ellis & Levy, 2010). In the process of design and development research, the first step is to define the problem that is motivating the study (Peffers et al., 2007). In order to make some meaningful contribution in design and development research, the research problem must be a type that can be solved through some form of human interaction and creativity.

3.3.1.1 Six milestones for design and development

The six milestones include problem identification, defining the objectives, designing and developing the artefact, testing the artefact, evaluating the results, and communicating the results (Ellis & Levy, 2010).

First, the emergence of a problem can motivate the employment of design and development research to develop a model or a questionnaire to address the problem. Study objectives are also set to define the aspects of the model or questionnaire needed to address the problem and to indicate the need for the research.

(1) Identify the problem motivating the questionnaire development

The first stage of the design and development process is when the researcher clearly defines the problem to be research worthy. It is imperative that the problem is able to drive the design and development process towards the development of a model or a questionnaire to address that particular problem (Ellis & Levy, 2010). In this study, the problem that motivated the development of the QoL questionnaire for PLWE in Ghana was identified a situational analysis of contemporary epilepsy-specific QoL questionnaires used in assessing QoL of PLWE.

(2) Defining the objectives

The research question to be answered by the study is determined by the study objectives. This study answered the research question; 'What will constitute a culturally sensitive QoL instrument for accurately and consistently assessing the QoL of PLWE in Ghana? The situational analysis conducted in the first phase of this study helped identify how to develop an epilepsy-specific QoL questionnaire that is appropriate for evaluating the QoL of PLWE in Ghana (Ellis & Levy, 2010). This comprised a scoping review of the purpose, concepts, constructs, the development process and the scoring systems of contemporary epilepsy QoL questionnaires, an integrative review of QoL among PLWE in SSA and a qualitative study on the meaning of QoL among PLWE in Ghana.

(3) Designing and development of the artefact

The findings from the conceptualisation phase are used to develop the questionnaire at this stage. According to Ellis and Levy (2010), a model is needed to guide the researcher in the development of the questionnaire. The integrative QoL theory was used to guide the design and development of the epilepsy QoL questionnaire.

(4) Testing the artefact

At this stage the questionnaire developed is tested to see is the purpose for which it was developed has been met. The draft epilepsy QoL questionnaire was presented to experts from both academia and the clinical field to assess for relevance, cultural sensitivity, clarity and simplicity during the content validity testing phase.

(5) Evaluating the results

Another group of experts, comprising four PLWE were invited to evaluate the face validity of the QoL questionnaire as part of face validity testing.

(6) Communicating the results

The validated questionnaire as well as other findings from the study have been communicated in the theses presented after the completion of the study.

3.3.2 Aligning the research design methodology with the multimethod design in this study

The link between the sequential multi-method design applied to the development of the epilepsy QoL questionnaire and the design and development process is presented in Table 3.1.

Table 3.3: Six milestones for design and development and research activity

No.	Milestone	Research Activity
1.	Identify the problem motivating the questionnaire development	An overview of the background of the study, the statement of the problem and the literature review sections provided an overview of concept of QoL and questionnaires used in assessing QoL of PLWE. It also outlined the shortcomings of contemporary questionnaires used in assessing QoL of PLWE in SSA.
2.	Describe the objectives of the study	The main objective of the study was to design and develop an epilepsy-specific QoL questionnaire for PLWE in Ghana that is culturally sensitive and is best suited for accurate and consistent assessment of QoL of PLWE in Ghana.
3.	Design and develop the framework	The researcher developed a draft epilepsy-specific QoL questionnaire using the results from phase one (conceptualization phase) of the research. Development of QoL was guided by the integrative QoL theory and Stone (1993)'s recommendations on designing a questionnaire.

No.	Milestone	Research Activity
4.	Testing and evaluation of the questionnaire	Nominal group technique, involving experts in questionnaire development, was used to develop the draft epilepsy-specific QoL questionnaire for PLWE in Ghana. They identified relevant items and domains for the questionnaire in addition to format for scoring of the questionnaire. The draft questionnaire was then sent to experts including four academics and two clinicians, involved in the care of PLWE were made to evaluate the draft questionnaire. They were made to rate the importance of each item in the questionnaire to establish its content validity. Four PLWE were also made to evaluate the questionnaire for face validity testing.
5.	Communication of results	The final validated questionnaire was presented after revising it based on comments made by the experts.

3.4 PHASE ONE: CONCEPTUALISATION

3.4.1 Content of quality of life questionnaires: Scoping review

This integrative review aimed at exploring the concepts and constructs of questionnaires used in assessing QoL of PLWE. This comprised already existing epilepsy-specific QoL questionnaires commonly used in assessing the QoL of PLWE. This is described in detail in chapter four.

3.4.1.1 Review Question

The review question was formulated as: ''*What are the purpose, concepts, constructs, development process and the scoring systems of questionnaires used in assessing the quality of life of people living with epilepsy?"*

3.4.1.2 Sampling Procedures

A purposive sampling was done to identify eligible primary sources of studies that used already existing epilepsy-specific QoL questionnaires. The study had no participants; hence consent was not obtained. The review was conducted following Levac et al. (2010)s recommended steps in conducting scoping reviews. These steps are an improvement of the original framework developed by Arksky and O'Malley (2005) namely: (1) identification of the review question; (2) searching for studies; (3) selection of relevant studies; (4) charting of data; (5) collating, summarising and presentation of results; and (6) consultation (optional) as described in detail in chapter four.

Data search was done in December, 2019 and a data extraction sheet was developed to document the required information from each paper. This information included; the questionnaire and the author, aim of the questionnaire, questionnaire development process, whether questionnaire was validated or not, content and scoring of the questionnaire. The review was conducted under the guidance of the supervisors.

3.4.1.3 Sources of Literature

A comprehensive data search was done in five databases namely; PsychInfo, Scopus, Science Direct, PubMed and CINAHL (Cumulative Index to Nursing and Allied Health).

3.4.1.4 Search terms/keywords

Boolean combination of the key words “Epilepsy”, “Seizure”, “Quality of Life”, “Wellbeing”, “Instrument”, “Questionnaire”, “Inventory”, and “Questionnaire” was employed as search terms in searching for literature.

3.4.1.5 Inclusion and Exclusion Criteria

Only empirical studies published in English that employed epilepsy-specific QoL questionnaires to assess the QoL of PLWE from January, 2015 to December, 2019 qualified for inclusion into the study. Seven articles were included in the review. Studies on minors as well as studies that do not refer to the questionnaires used to assess QoL were excluded from the study.

3.4.1.6 Data Analysis

This scoping review employed the deductive content analysis approach (Polit & Beck, 2012) to analyse the content of epilepsy-specific QoL questionnaires. Details of the analysis process is presented in chapter four.

3.4.2 Quality of life among PLWE: Integrative review

This integrative review aimed at ascertaining the QoL of PLWE in SSA. This comprised studies on the nature and the extent of the QoL of PLWE in SSA. This is described in details in chapter four.

3.4.2.1 Review Question

The review question was formulated as: *'What is the quality of life of PLWE in SSA?'*

3.4.2.2 Sampling Procedure

A purposive sampling was done to identify eligible primary sources of studies that assessed the QoL of PLWE in sub-Sharan Africa. The review was conducted following the five steps developed by Whittemore and Knafl (2005) namely; Problem identification/formulation stage (Question formulation) literature search stage, data evaluation stage, data analysis stage and presentation stage as described in details in chapter four.

Data search was done in December, 2019 and an updated literature search done in June, 2020. A data extraction sheet was developed to document the required information from each paper. This information included; the author and year of publication, purpose of the study, design/ sample, data collection/ analysis and main findings. This review was conducted in consultation with the supervisors.

3.4.2.3 Sources of Literature

A comprehensive data search was done in five databases namely; PsychInfo, Scopus, Science Direct, PubMed and CINAHL (Cumulative Index to Nursing and Allied Health).

3.4.2.4 Search terms/keywords

Boolean combinations of the key words *"Epilepsy", "Seizure", "Quality of Life", "Wellbeing", "sub-Saharan Africa"* was employed as search terms in searching for literature.

3.4.2.5 Inclusion and Exclusion Criteria

Empirical studies on QoL of PLWE and published in English from January, 2015 to December, 2019 (with an update in June, 2020) qualified for inclusion into the study. Studies on minors as well as studies on QoL of PLWE outside SSA were excluded from the study. Literature reviews and letters to editors were also excluded.

3.4.2.6 Data Analysis

This integrative review employed the content analysis approach to analyse the content of epilepsy-specific QoL questionnaires. Details of the analysis process is presented in chapter 5.

3.4.3 Meaning of quality of life among PLWE in Ghana: Exploratory qualitative study

The main objective of study three was explore the meaning of QoL among PLWE in Ghana through face-to-face in-depth interviews.

3.4.3.1 Research Design

The qualitative exploratory research design was used to explore meanings of QoL among PLWE in Ghana. According to Polit and Beck (2013), exploratory designs help one to not only to investigate the full nature of a phenomenon but, also to appreciate the various ways in which a phenomenon manifests itself as it is and the various factors associated with it. In view of the pragmatic philosophy underpinning the entire study, the qualitative exploratory design was deemed appropriate for this study. This is because it served as a practical means of exploring and understanding of rich descriptions of meanings from experiences from the participants (Fain, 2013) on what QoL is to them. The outcome of this study greatly informed the generation of appropriate items that were best suit for a QoL assessment questionnaire for PLWE in Ghana.

3.4.3.2 Study population

The population for this study comprised all PLWE in Ghana (N=22,151). Thus, persons who have been duly diagnosed as living with epilepsy and receiving some form of treatment.

3.4.3.3 Inclusion criteria

The criteria for inclusion comprise PLWE with no comorbid mental illness or mental sub-normality. People living with epilepsy, that are 18 years old and above, with at least basic

formal education, and capable of speaking or writing English and "Twi" were eligible for the study.

3.4.3.4 Exclusion criteria

The criteria for exclusion were PLWE who felt uncomfortable and were unwilling to take part in the study.

3.4.3.5 Sample size and Sampling Method

Due to the qualitative approach adopted for this study, less than 25 PLWE were targeted to take part in the face-to-face interviews in order to ensure satisfactory personal involvement by the researcher (Wood & Ross-Kerr, 2006). However, data saturation was achieved after the 15th participant.

This study adopted the purposive sampling technique to select participants that qualified for inclusion into the study. This was done by consulting community mental health workers in the Greater Accra Region of Ghana. They led the researcher to their clients with epilepsy who fully met the set criteria for inclusion into the study.

3.4.3.6 Data Collection Instrument

A semi-structured interview guide was used for data collection (Appendix D). This included main questions with probes to explore the meanings of QoL among PLWE in Ghana. The main question for the face-to-face in-depth interview was "*What does quality of life mean to you*?"

However, the researcher probed further in the course of each interview in order to obtain in-depth information and clarify aspects related to the meanings of QoL to participants that could inform the development of a QoL questionnaire that is the best suited for them. Participants' demographic data, including age, sex, level of education, marital status, employment status, religion and duration of diagnosis with epilepsy, were taken at the end of the interview.

3.4.3.7 Data Collection Process

Face-to-face in-depth interviews were carried out on PLWE using the semi-structured interview guide. This involved open ended questions with probes where the participants were given the chance to talk about their views and express themselves well on the meaning of QoL to them. Prior to the interviews, prospective participants were invited and given information sheets (Appendix E) to inform them about the study. Those who agreed to participate were given a consent form (Appendix F) to fill and sign as proof of their consent to participate in the study. Each interview was audio recorded. The participants were requested to indicate their

consent to have the interview audio recorded before the recording was done (Appendix F). The interviews lasted an average period of 50 minutes. This ranged from 45 minutes to 60 minutes.

Data saturation was achieved at the 15th participant. Field notes on observations made, researcher reflections and evaluation were taken in addition to the audio recordings. Notes were also taken on the activities carried out to inform the write up of the methodological approach.

3.4.3.8 Data Analysis

In this study, data analysis was done concurrently with on-going interviews. This was to help the researcher to know when data becomes redundant with no new information emerging. The principles of content analysis were employed to develop themes that emerged from the data.

All interviews were transcribed verbatim. Interview transcriptions were then read several times to obtain full understanding of participants' accounts. Content analysis approach was used to analyse data gathered using the MAXQDA qualitative data analysis software. Content analysis had three phases: preparation, organisation and reporting of results (Elo et al., 2014). In the preparation phase, data gathered were read severally to make sense of it and to determine the approach to analysis. The preparation phase involves coding, categorisation and abstraction of data (Elo & Kyngas, 2008 as cited in Elo et al., 2014). Coding was done by the use of words as labels to represent or describe a particular text in the transcript. Categorisation was done in the organisation phase. Categorisation involved the grouping of codes that are related in context or content. In the organization phase, the content of the data were reviewed and coded to represent identified categories in the data deductively (Polit & Beck, 2013). Coding was verified by the primary supervisor and the second supervisor serving as an adjudicator in the event of any discrepancy. Data is deemed valid if the categories actually represent the concept being studied (Schreier, 2012). The results were then described based on the content of the categories that described the phenomenon under study in the reporting phase.

Data from field notes were also analysed using content analysis and added to the results to enhance the meaning of the information gathered. Interpretations from the data were discussed with the supervisor to ensure that themes are fully developed. Segments of the data that appropriately described the themes identified were sorted appropriately and used to support findings of the study.

3.4.3.9 Methodological rigour

The trustworthiness criteria recommended by Lincoln and Guba (1985) as cited in Polit and Beck (2018) were employed in this study in order to ensure methodological rigour. This includes credibility, transferability, dependability and confirmability.

1. Credibility involves the processes to ensure that results can be confirmed by the participants (Polit & Beck, 2013). Data triangulation was done to ensure credibility. This was done by combining the field notes with the transcribed audio recordings during data analysis to add more meaning to the results. Prolonged engagement of participants in the subject matter was also done to ensure that enough probes have been done on the subject matter during each interview. Quotes, codes and themes from the data were perused by the supervisors to arrive at a consensus. Member checking was then carried out by means of taking the final report back to the participants to determine whether they feel that it is accurate and to be sure their views have been currently represented (Creswell & Plano Clark, 2011).
2. Dependability is about the means of ensuring that acceptable procedures and processes have been followed to establish the trustworthiness of the research (Brink et al., 2012). In order to achieve this, the same interview guide was used to guide all the 15 interviews conducted. Detail reporting of the processes involved in the study was also provided. This included (1) a description of the research design and how it was implemented; (2) detail explanation of the data gathering process and (3) explaining what was done on the field (Polit & Beck, 2018). Independent co-coding of data was also done by an experienced qualitative researcher and results compared for analysis.
3. Confirmability comprises ways of ensuring that data collected is true and applicable and support conclusions drawn and recommendations made from the study. This will be met through triangulation of the methods (combination of field notes and interviews) and keeping of audit trail (Polit & Beck, 2018). Creswell and Poth (2018) emphasized the positionality of the researcher in influencing qualitative research studies which is explained through the use of reflexivity (Swaminathan & Mulvihill, 2018). My positionality as the researcher stems from my profession as a registered mental health nurse as well as my previous experience of caring for PLWE. Through my professional life I realised the helplessness and vulnerability of PLWE which consequently, had a negative effect on their QoL. In order to bracket my personal opinions and feelings towards PLWE, I used memos and field notes during the interview process and analysis stage to focus mainly on what participants said and did. This technique assisted me to ensure objectivity and credibility,

and not to allow my views to cloud the data analysis and interpretation process. In the keeping of an audit trail, documents about the research process in addition to detail recording of all activities carried out during the research process was done to aid any independent auditor to scientifically come to logical conclusion about the data and the results of the study. The aim was to clearly demonstrate all the evidence and the scientific processes that led to the results and conclusions made from the study.

4. Transferability refers to the applicability of the study. Thus, "the extent to which the findings can be transferred to other settings'' (Polit & Beck, 2018). This enables the results to be used by other researchers on similar participants in a similar context. To ensure this, detailed descriptions were portrayed exactly as presented by the participants. This comprised sufficient contextual information about the fieldwork so as to enable the reader to make such a transfer. Detail description of the research setting and the calibre of persons participating in the study, and methods involved were also presented.

3.5 PHASE TWO: OPERATIONALISATION

A draft of the proposed epilepsy-specific QoL questionnaire for PLWE in Ghana was developed by integrating results from the three studies done in the conceptualization phase. The operationalisation phase comprises four stages; Item generation, drafting of instrument, development of a scale of measurement and scoring for the instrument and expert review of draft instrument.

3.5.1 Generating items for the Epilepsy Quality of Life Instrument for Ghana

Based on the studies carried out in phase one, the findings from the scoping review of the epilepsy QoL questionnaires, the integrative review on the QoL of PLWE in SSA and the qualitative study on meaning of QoL among PLWE in Ghana were used to generate items for the epilepsy QoL questionnaire for Ghana. This was done by combining items from contents of already existing epilepsy QoL questionnaires, in addition to their scoring from the scoping review. Additional items were added from results from the integrative review on QoL of PLWE in SSA. Lastly, findings from the qualitative exploratory study on the meaning of QoL among Ghanaians living with epilepsy were used to generate additional items for the questionnaire. This led to the production of an item pool comprising 64 items under 13 domains (Table 6.1).

3.5.2 Drafting of Epilepsy Quality of Life Questionnaire for Ghana

After items for the instrument have been identified, a first draft of the questionnaire was developed. The items generated were reviewed to 41 and organized under 11 domains of QoL (Table 6.2) guided by the IQOL theory, from some of the epilepsy-specific QoL questionnaires and also based on recommendations from the supervisors. Relevant and appropriate domains, subscales and items generated and selected were synthesised as one QoL questionnaire based on Stone (1993)'s recommendations on designing a questionnaire. These comprised (1) deciding on the data you need; (2) selection of items to include; (3) designing individual questions; (4) compose wording; (5) designing of layout; (6) thinking about coding; (7) preparing and pretesting of first draft; (8) piloting and evaluating of questionnaire; (9) performing a survey and; (10) starting all over again. However, only the first 8 steps were employed without piloting or pretesting. Twelve items on socio-demographic characteristics and clinical information about respondents was also included in the first draft questionnaire (Table 6.3). This was named QOLIE-GH, in consultation with the supervisors.

3.5.3 Development of scale of measurement and scoring for the Epilepsy Quality of Life Questionnaire for Ghana

A measurement scale and method of scoring was developed for the draft epilepsy QoL instrument. A five-point Likert scale was adopted for the draft questionnaire. This was based on scoring of existing epilepsy QoL questionnaires and in consultation with the supervisors and experts from the Nominal Group Technique.

3.5.4 Expert review

The first draft QOLIE-GH was subjected to an expert group using the Nominal Group Technique (McMillan et al., 2016). The Nominal Group Technique involving a group of experts in questionnaire development was used to review the items and domains in the first draft questionnaire for cultural sensitivity, adequacy of content, and proper wording.

Study Population and Sample

The nominal group comprised a purposive sample of 8 experts (McMillan et al., 2016) in instrument development from Ghana who were contacted (Table 6.4).

Nominal group process

The Nominal Group Technique comprises four key stages namely: silent generation (individual generation of ideas), round robin (ideas sharing among members), clarification (discussion and

clarification of ideas) and voting (rating or ranking of ideas) (Delbecq, van de Ven & Gustafson as cited in McMillan et al., 2016). This was however, expanded to seven steps as described by Lloyd (2011). Thus, by first having a preliminary voting, followed by a discussion of the voting results, before the main voting and lastly listing of prioritized items. Revision of the questionnaire based on suggestion from the experts led to the development of the second draft questionnaire (Table 6.16). Details are presented in chapter 6 section 6.4.

3.6 PHASE THREE: VALIDATION

The validation phase aims at establishing the content validity and face validity of the epilepsy QoL questionnaire.

3.6.1 Research Design

A methodological design was employed to guide this phase. Methodological designs involve the "assessment of content validity, evaluation of the conceptual structure of a scale, construct validity, and assessment of the reliability" (Grove et al., 2013, pp. 255). Only the content validity and face validity of the draft epilepsy QoL questionnaire were established.

3.6.2 Content validity testing

Content validity comprises the appropriateness with which the content of a text is able to assess the construct that it is supposed to assess (Creswell, 2015). Content validity testing was done with the help of a group of 6 experts. The expert review focused on the structure and clarity of each domain, elimination of redundant items and modification of ambiguous wording. Experts' opinions on the scales and the scoring of the scales were also sought.

Population and sample

The population was health care professionals who provide services to PLWE as well as academics. Samples for content validity are usually small and between 5 to 12 experts (McMillan et al., 2016). In this study, six experts were selected purposively to assess the validity of the content of the second draft epilepsy-specific QoL questionnaire.

Data collection procedure

The experts were invited to take part in the content validity testing of the draft epilepsy QoL questionnaire (Appendix J & K). A questionnaire was compiled based on the content of the

questionnaire. Each expert then gave a rating to indicate the relevance, cultural sensitivity, clarity, and simplicity of each item under all domains in the draft questionnaire.

Data analysis

The content validity index and the content validity ratio were used to quantitatively assess content validity. A content validity index of 0.72 is good for eight experts and considered ideal if it is 0.78 more than five specialists (Polit & Beck, 2018). In this study the average individual content validity index (I-CVI/Ave) and average scale content validity index (S-CVI/ Ave) were estimated. Items with scores 0.80 and above were retained. Details have been explained in chapter 7, section 7.1.1. The third draft of the questionnaire was developed after revision based on the results of the content validity test.

3.6.3 Face validity testing

The third draft questionnaire was then presented to four PLWE in Ghana for face validity testing. This was to assess the appropriateness of the questionnaire from the perspective of the patients in addition to their understanding of the questionnaire and willingness to use it.

3.6.3.1 Data collection questionnaire and analysis

Respondents were given a face validity questionnaire in addition to the third draft epilepsy QoL questionnaire to complete. Ratings were collated and their comments summarised for a final review of the questionnaire. Details are presented in chapter seven section 7.1.2.

3.7 ETHICAL PRINCIPLES

The aim of ethics in research is to protect the rights of participants, protect them from any harm that might befall them as a result of research activities and ensure that appropriate channels are followed to obtain institutional permission for the study (Haigh, 2008). After seeking institutional permission for the study, Haigh (2008)'s principles of autonomy, informed consent, beneficence, non-maleficence and dissemination of research findings were applied in this study.

3.7.1 Institutional Permission

Ethical approval was sought from the Postgraduate and Human Research Ethics Committee (Medical) of the University of the Witwatersrand (M180946) (Appendix A). Ethical approval was also sought from the Ghana Health Service Research Ethics Review Committee (GHS-

ERC004/12/18) (Appendix B). Secondly, written permission was sought from the Greater Accra Regional Health Director before reaching out to the community mental health nurses within the Greater Accra Region for their clients with epilepsy to be interviewed (Appendix C). Invitational letters were also sent to respective experts needed for the study (Appendix G, K & P).

3.7.2 Principle of autonomy

The principle of autonomy demands that participants have freedom from coercion and the right to voluntarily decide to take part in the study. In accordance with this principle, information sheets (Appendix E, H, L & Q) were provided for the participants in all the studies and they were told that they reserve the right to refuse to participate in the study or even withdraw from the study anytime. Participants for the qualitative interview were told that voluntary withdrawal from the study would not affect their treatment and relationship with the community mental health nurses (Appendix E).

3.7.3 Respect for free and informed consent

This principle demands that participants are provided adequate and understandable information about the study, which allows them to make informed choices whether to participate or decline participation from the study. This study involved face-to-face interviews and expert reviews. In line with this principle, information sheets (Appendix H, L & Q) explaining the purpose, conduct, risks and benefits of the study was provided and explained to the understanding of each participant. All participants (PLWE and experts) were then asked to voluntarily sign a consent form (Appendices F, I, M & R) as proof of their consent to participate in the study. Participants for the face-to-face in-depth interviews were also asked to indicate their consent for the interviews to be recorded (Appendix F).

3.7.4 Principle of beneficence

The principle of beneficence imposes a duty on the researcher to maximise net benefits of the research for the participants. By so doing, the participants were asked about what QoL means to them as an individual to help develop and validate a culturally sensitive QoL questionnaire that is best suited for accurate and consistent assessment of QoL of PLWE in Ghana.

3.7.5 Principle of non-maleficence

The principle of non-maleficence imposes a duty on the researcher to avoid or minimise harm to the participants. It also includes ensuring that participants have freedom from exploitation and reassurance that information provided were not used against them. To ensure non-maleficence, all participants were treated with respect and courtesy. Data collection during the interviews was done before the COVID-19 pandemic reached Ghana. Permission to record interviews was also sought from the participants. They were asked to sign consent for the interviews to be recorded (Appendix F). The interviews were scheduled at a time and place private and convenient for all participants to ensure privacy.

The nominal group sessions were conducted virtually through zoom cloud meeting in order to avoid risk of contact and possible exposure of experts to the virus. Consent forms were sent to the email of the experts and electronic signatures were taken on the consent forms instead of hard copies and content validity index scoring done using Redcap software in order to avoid any potential exposure to the virus through personal contact. No data was used for other purposes apart from the purpose explained to participants and documented in the information that was presented to the participants.

Pseudonyms were used instead of real names of the participants in order to ensure anonymity. All transcribed data were kept under lock and key and hard copies transcribed data, including softcopies of documents saved on a password protected computer or flash drive. Data were only accessible to the researcher and the supervisors to ensure confidentiality. In case participants felt uncomfortable during the interview, they were allowed to ask for a pause or even discontinue with the interview. The transcripts and audio records would be destroyed two years after publication of the findings.

3.7.6 Dissemination of research findings

This involves the protection of participants' rights during the course of disseminating research findings. In the event of publication of research findings, identities of all participants will be protected. Results will be published in a peer reviewed journal. Information that identifies participants in the study will not be in the journal.

3.7.7 Conflict of interest

The student and supervisors do not have any conflict of interest concerning this study at the time this thesis was submitted.

3.8 SUMMARY

A detailed account and description of the research design, methods and processes employed in this study is presented in this chapter. The design and methods were described into detail relative to the three phases of the study and the research objectives associated with each phase of the study. This illustrates a detailed account of the measures implemented to ensure good quality and a reliable research process in this study. The subsequent chapters present specific research designs and methods in the conceptualisation, development and content validity testing of the draft epilepsy QoL questionnaire in addition to results and discussion for all the objectives, conclusion, limitations and recommendations.

CHAPTER FOUR: SCOPING AND INTEGRATIVE LITERATURE REVIEWS

4.1 INTRODUCTION

As a part of the conceptualisation phase, a scoping review of the concepts and constructs of QoL questionnaires, as well as an integrative review of the QoL among PLWE in SSA was done. The outcome of these studies provided rich background to the development of a new and more appropriate QoL questionnaire for PLWE in Ghana. Detailed accounts of the research design and methods and the results of the two reviews are presented in this chapter.

4.2 CONCEPTS AND CONSTRUCTS OF QUALITY OF LIFE QUESTIONNAIRES: SCOPING REVIEW

4.2.1 Aim of the review

This scoping review aimed to explore and synthesize the purpose, concepts, constructs, the development process and the scoring systems of questionnaires used in assessing the QoL of PLWE. Studies in which epilepsy specific QoL questionnaires have been used to assess the QoL of PLWE were searched and reviewed.

4.2.2 Design and methods

The scoping review framework outlined by Arksky and O'Malley (2005) was employed in this review. Scoping reviews incorporate studies from various paradigms to establish a gap, define or clarify concepts, define the scope of the available evidence, and synthesise evidence available in a subject area. They are either conducted as a foundation for systematic reviews or as independent reviews in which critical appraisal of evidence is not a must (Aveyard, 2014). Compared to systematic reviews, scoping reviews do not necessarily include a critical appraisal; data extraction, inclusion and exclusion criteria may be developed posthoc and the synthesis of evidence is more qualitative (Armstrong et al., 2011; Christmals & Aidam, 2020). Levac et al. (2010) recommended the following steps in conducting scoping reviews to improve the original framework developed by Arksky and O'Malley (2005). Thus, (1) identification of the review question; (2) searching for studies; (3) selection of relevant studies; (4) charting of data; (5) collating, summarising and presentation of results; and (6) consultation (optional). The presentation of the findings were guided by the Prevention and Recovery Information System for Monitoring and Analysis (PRISMA) checklist for reviews (Moher et al., 2010) (Figure 4.1).

4.2.3 Identification of the review question

Several studies have assessed the QOL of PLWE in SSA (Fletcher et al., 2015; Gebre & Haylay, 2018; M. Kaddumukasa et al., 2019; Ogundare et al., 2020). Most of these use different questionnaires in this assessment – both generic (The WHOQOL GROUP, 1998; Kováts *et al.*, 2017; Santos *et al.*, 2018; Abdelrahim *et al.*, 2015) and epilepsy-specific QOL questionnaires (Blond et al., 2016; Cramer et al., 1998; Devinsky et al., 1995). All these questionnaires are essential in assessing the QoL of PLWE, for whom studies have shown that epilepsy has a severe negative impact on one's QoL, including social, psychological and emotional wellbeing (Abadiga et al., 2019; Deegbe et al., 2020; M. Kaddumukasa et al., 2019). None of these questionnaires were developed for African populations. Although they have been used to assess the QoL of PLWE in Africa, it cannot be assumed that the sociocultural aspects of the QoL of PLWE in SSA, and Ghana to be precise, are the same as those outside Africa. Exploring the content of already existing questionnaires for assessing the QoL of PLWE will help develop a more specific and culturally sensitive questionnaire for assessing the QoL of PLWE in Ghana.

The review question was guided by the Population, Concept and Context (PCC) pneumonic of the Joana Brigg's Institute (Peters et al., 2020); thus, the review question '*What are the purpose, concepts, constructs, development process and the scoring systems of questionnaires used in assessing the quality of life of people living with epilepsy?'* guided the review. The population is ‘people living with epilepsy’, the concept under study is 'purpose, development process, concepts, constructs and the scoring systems of epilepsy-specific QoL questionnaires', and the context is worldwide.

4.2.4 Search for studies

Eligible primary studies on the QoL of PLWE were purposively sampled for the study. Only studies that used epilepsy-specific questionnaires to assess the QoL of PLWE were sourced. Five databases: PsychInfo, Scopus, Science Direct, PubMed and CINAHL (Cumulative Index to Nursing and Allied Health) were systematically searched using Boolean combinations of the keywords "Epilepsy", "Seizure", "Quality of Life", "Wellbeing", "Instrument", "Questionnaire", "Questionnaire". Wildcards were also used to ensure variations of words were identified appropriately. The search string for the search in PubMed is presented in Box 1.

Box 1: Search string used in PubMed

((Epilep*[Title] OR Seizure*[Title]) AND (Quality of Life[Title] OR Wellbeing[Title])) AND (Instrument[Title] OR Questionnaire[Title] OR inventory[Title] OR Questionnaire[Title])

Individual hand search was then done to find the papers that reported the process of development of the questionnaires and on the concepts and constructs of the questionnaires.

4.2.5 Selection of relevant studies

Studies were selected based on the inclusion and exclusion criteria.

4.2.5.1 Inclusion criteria

- Studies conducted using epilepsy specific QOL questionnaires
- Studies outlining the development process of epilepsy specific QOL questionnaires
- Studies outlining the content (constructs and concepts) of epilepsy specific QOL questionnaires
- Studies conducted from January 2015 to December, 2019
- Only peer-reviewed studies were included
- Only studies published in English language were considered

4.2.5.2 Exclusion Criteria

All studies that were not explicit on the content and development processes of the questionnaires were excluded. Appraisal of the studies included was not done because the studies only served as a conduit to the epilepsy specific QOL questionnaires – the focus on this review. Secondly, these were already validated epilepsy-specific QoL questionnaires. Therefore, there was no need for critical appraisal of the articles. Full text articles excluded with reasons were presented in Table 4.1.

Studies included

Forty-nine studies were identified from Psych Info, PubMed, Science Direct, SCOPUS and CINAHL and four studies through hand search. After the removal of duplicates, 18 papers were left. Eight of the articles were excluded based on title scan and 10 articles were left. After deep reading of the full-text articles included, three were excluded because two did not use epilepsy specific QoL questionnaires and one questionnaire was not specifically related to QoL

(Table 4.1), leaving seven articles. The details of the inclusion and exclusion are presented on Figure 4.1.

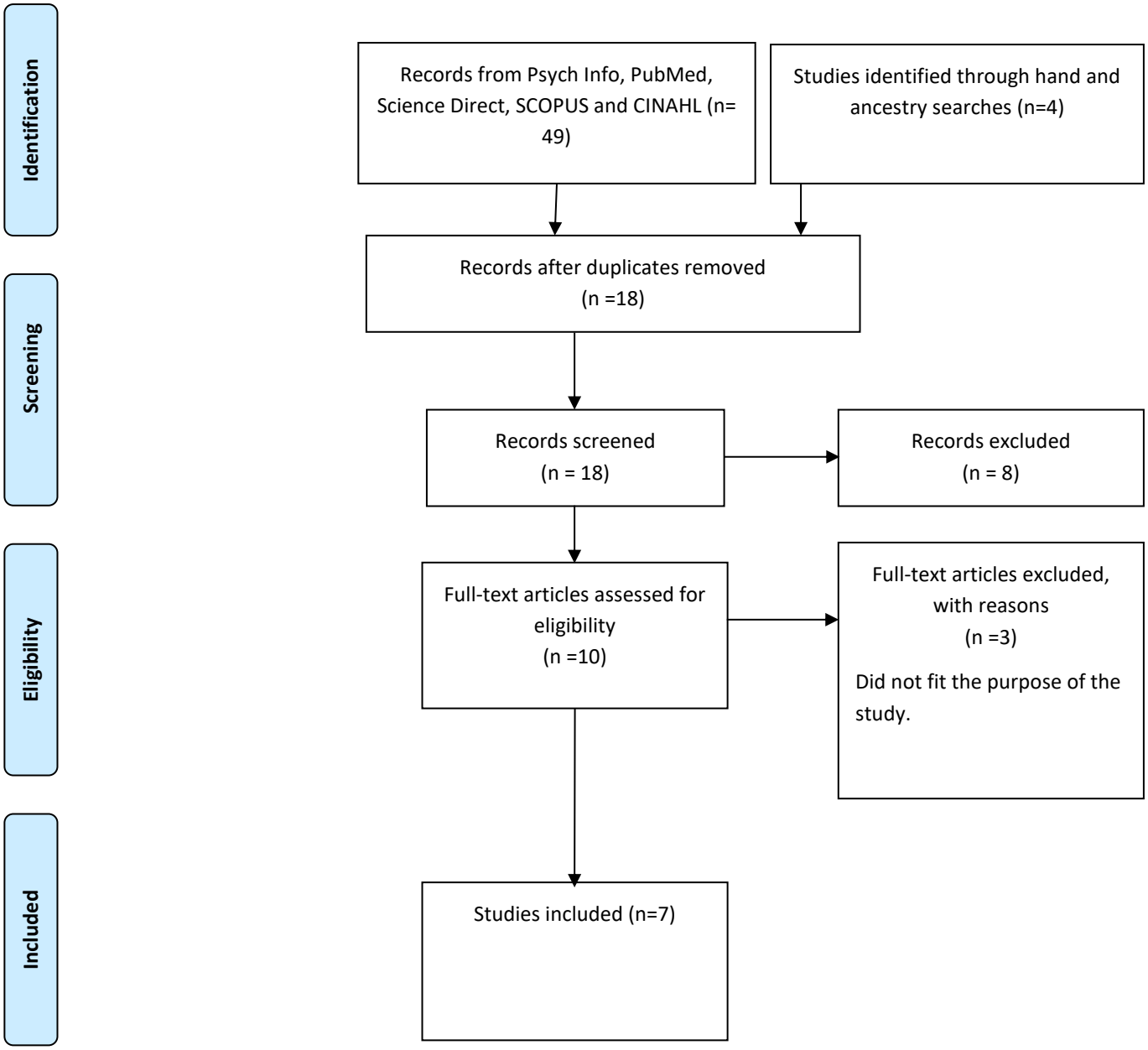

Figure 4.2: PRISMA diagram of the Scoping review

Studies rejected with reasons

From the literature search, three articles were rejected because, after thorough examination of the articles, they were found not to have used epilepsy specific QoL questionnaire. This is presented in Table 4.1.

Table 4.4: Articles rejected with reasons

No	Author & Date	Topic	Reason
1.	(Quintas et al., 2016)	"PARADISE 24 instrument: An observational study on psychosocial difficulties, quality of life, and disability levels in patients with epilepsy"	Did not use an epilepsy-specific QoL questionnaire
2.	(De Marco et al., 2017)	"The relationship between the Neuro-Quality of Life Depression and Anxiety Measures and the Personality Assessment Inventory in persons with epilepsy"	Questionnaires not specifically related to QoL in epilepsy
3.	(Kováts et al., 2017)	"Factors affecting quality of life in Hungarian adults with epilepsy: A comparison of four psychiatric instruments"	Did not use an epilepsy-specific QoL questionnaire

4.2.6 Charting of data

The content of the questionnaires was charted on to a data matrix (Table 4.2), thus: questionnaire (author); the aim of the questionnaire; development process; state of validation; content of the questionnaire; and the measuring (scoring) system used in the questionnaire.

Table 4.5: Summary of studies included

No.	Questionnaire (author)	Aim of the questionnaire	Development process	Validated?	Content of questionnaire/instrument	Scoring
1.	**QOLIE-31** **Studies on development/ Content of questionnaire -** (Asadollahi et al., 2016; Cramer et al., 1998; Leone et al., 2005; Mollaoğlu et al., 2015; Torres et al., 1999) **Studies that used the questionnaire -** (de Vries et al., 2018; Dias et al., 2017; Kováts et al., 2017; Saadi et al., 2016)	To assess the health-related QoL for PLWE who have well to poorly controlled seizures.	The QOLIE-89 was developed from an original 89 items test questionnaire compiled from the various already existing QoL questionnaires in addition to some epilepsy specific questionnaires. An exploratory factor analysis was conducted and items with low factor loadings (4.0 or less) were dropped. Generic contents of the QOLIE- 89 such as items on pain were excluded based on patients' preferences determined by an expert group (QOLIE Development Group). A 31 items questionnaire (QOLIE 31) was developed and evaluated through an empirical study comprising 304 patients. The questionnaire/questionnaire was then translated into "Danish, Dutch, German, Canadian French, French, Italian, Spanish, Swedish, and U.K.-English". A meeting was held between the QOLIE Development Group and the translators to ensure face and content validity.	**Y**	**<u>Seizure worry</u>** "11. Have you worried about having another seizure?" "21. How fearful are you of having a seizure during the next month?" "22.Do you worry about hurting yourself during a seizure?" "23.How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?" "52.Seizures" **<u>Overall quality of life</u>** "1.Overall, how would you rate your quality of life?" "14.Has your health limited your social activities (such as visiting with friends or close relatives)?" **<u>Emotional wellbeing</u>** "3.Have you been a very nervous person?" "4.Have you felt so down in the dumps that nothing could cheer you up?" "5.Have you felt calm and peaceful?" "7.Have you felt downhearted and blue?" "9.Have you been a happy person?" **<u>Energy/ Fatigue</u>** "2.Did you feel full of pep?" "6.Did you have a lot of energy?" "8.Did you feel worn out?" "10.Did you feel tired?"	All pre-coded values in the scale are converted to 0–100-point scores. Higher converted scores represent better QoL. The converted score for each sub-scale is indicated as sub-total score. A total of the converted sub-total scores for all the sub-scale is estimated and divided by the total number of answered items on the whole scale to get the final score. Higher scores reflect better QoL and lower scores reflect worst QoL.

No.	Questionnaire (author)	Aim of the questionnaire	Development process	Validated?	Content of questionnaire/instrument	Scoring
					<u>Cognitive</u> "12.Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?" "15.In the past 4 weeks, have you had any trouble with your memory?" "16.Trouble remembering things people tell you" "17.Trouble concentrating on reading" "18.Trouble concentrating on doing one thing at a time" "26.Memory difficulties" **<u>Medication effects</u>** "24.How worried are you that medications you are taking will be bad for you if taken for a long time?" "29.Physical effects of antiepileptic medication" "30.Mental effects of antiepileptic medication" **<u>Social function</u>** "13.Has your health limited your social activities (such as visiting with friends or close relatives)?" "19.Leisure time (such as hobbies, going out)" "20.Driving" "27.Work limitations" "28.Social limitations"	

No.	Questionnaire (author)	Aim of the questionnaire	Development process	Validated?	Content of questionnaire/instrument	Scoring
2.	**QOLIE-10** **Studies on development/ Content of questionnaire -** (Barranco-Camargo et al., 2019; Leone et al., 2005; Mollaoğlu et al., 2017).	To assess the health-related QoL for PLWE who have well to poorly controlled seizures.	Based on the 89 items and 17 scales from the QOLIE-89 inventory, seven domains deemed very relevant to people with epilepsy were selected by an expert panel. Item-to-scale correlations within these seven domains were examined by the panel. Those with appropriate wording and structure with high item-to-scale correlations were then selected to make the QOLIE-10 instrument. One item each from five out of the seven domains identified from the QOLIE-89 instrument (overall QoL, energy/ fatigue, emotional worry, cognition and seizure worry) was selected for the QOLIE-10 instrument. Three items on work limitations, social and driving were then selected from the social function domain and two items on mental and physical effects of antiepileptic medications were also selected from the medication effect domain of the QOLIE-89 instrument to form ten items to develop the QOLIE-10 instrument.	**Y**	**<u>Epilepsy Effects</u>** "4.During the past 4 weeks, how much have you been bothered by memory difficulties?" "7.During the past 4 weeks, how much have you been bothered by physical effects of antiepileptic medication?" "8.During the past 4 weeks, how much have you been bothered by mental effects of antiepileptic medication?" **<u>Mental Health</u>** "1.During the past 4 weeks, have you had a lot of energy?" "2.During the past 4 weeks, have you felt down-hearted and blue?" "10.During the past 4 weeks, how has the quality of your life been? That is, how have things been going for you?" **<u>Role Functioning</u>** "3.During the past 4 weeks, has your epilepsy or antiepileptic medication caused trouble with driving?" "5.During the past 4 weeks, how much have you been bothered by work limitations?" "6.During the past 4 weeks, how much have you been bothered by social limitations?" "9.How fearful are you of having a seizure during the next month?"	The items numbered 1, 4, 5, 6, 7, 8 and 10 are scored with 1 as the best score. However, items numbered 2, 3 and 9 are reverse scored. The sum of all the scores for each answered question is divided by the total number of items to get the total score for the questionnaire. Low scores mean having least problems.

No.	Questionnaire (author)	Aim of the questionnaire	Development process	Validated?	Content of questionnaire/instrument	Scoring
3.	Liverpool Seizure Severity Scale revisited **Studies on development/ Content of questionnaire-** (Baker et al., 1991; Leone et al., 2005; Scott-Lennox et al., 2001)	To quantify patient's perceptions about seizure severity	Gus A. Bakera, a neurologist, and David W. Chadwicka, a clinical neuropsychologist, devised a 19-item scale subdivided into 2 sub-scales: With the domain perception and control having nine items and the domain ictal and post-ictal effects having 10 items. Questions on the timing of seizures are included in the first section of the sub-scale as well as questions on experiencing an aura and whether patients could predict seizures to minimise its consequences. Questions on losing consciousness and the duration, in addition to confusion after seizures, presence of a fall, incontinence, tongue biting, other injures relating to seizures, perception about overall severity of the seizures and its effect on one's life are captured in the second sub-scale. Patients were then made to rate the items using a four-point Likert scale, based on a four-week recall, with one representing least severe and four representing most severe scores. The test-retest method was used to assess the reliability of the questionnaire by administering it to 35 patients within a space of 2 weeks. The scale's internal consistency was then estimated. Scale validation was carried out by determining its ability to differentiate between the types of seizures in accordance with the ILAE classification of seizures. Caregivers were then made to	**Y**	**<u>Perception subscale</u>** "Timing (specific or any time of the day)" "Ability to predict seizures" "Ability to 'fight off attacks" "Presence of an aura" "Perceived control over attacks" "Clustering or random occurrence" "Seizures in sleep only" "Prevention of normal activities" **<u>Ictal/ Postictal subscale</u>** "Perceived overall severity" "Loss of consciousness" "Degree of postictal confusion" "Duration of postictal confusion" "Failing to the ground" "Postictal headache" "Postictal sleepiness" "Incontinence" "Tongue biting" "Injury other than tongue-biting" "Time to full recovery" "Lip smacking or fidgeting"	In step one, scores are assigned to patients who do not have seizures in the recall period. In the case of no seizures in the four-week period, a 0 ictal score is assigned. However, in case the numbers of seizures are at least one or missing then one moves to the second step. In the second step, answers to questions numbered 1, 3, 4, 6, 7, 8, 9, 10, and 11 are reverse scored. Step three comprises the scoring of the ictal scale. In case four or more questions from question one to twelve are not answered, a missing score is assigned to the ictal scale. However, if one to three questions from question one to twelve are not answered the average score of the answered questions is assigned. Responses to the questions starting one through to question twelve are them reverse coded and summed up. After dividing the score by 40, the product of 100 and the divided is

No.	Questionnaire (author)	Aim of the questionnaire	Development process	Validated?	Content of questionnaire/instrument	Scoring
			complete an abridged version of the questionnaire which had 4 question from both domains as a means to verify the responses of the patients			estimated. Individual ictal scores range from zero to hundred.
4.	NEWQOL **Studies in development/ Content of questionnaire -** (Abetz et al., 2000; Leone et al., 2005; Mulhern et al., 2010)	To assess QoL of patients with new onset seizures from the patient's own perspective	Ann Jacoby, carried out qualitative interviews of 18 PLWE with onset not more than 6 months duration. The interviews were based on problems of PLWE identified through clinical experience and from existing literature. This comprises literature on how seizures are experienced by patients and families, patient worry about the long-term effect of seizures and their concerns about the future, fears about stigma and discrimination, knowledge on epilepsy and seizures, seizure management by both secondary and primary care physicians, the here and noa impact of seizures on patient's activities of daily living. After analysing the data, key themes were identified which served as the domains for the NEWQOL.	Y	**Cognition** "My mind does not work as fast as it should" "I have difficulties in following a book or film" "I have problems finding the correct word" "My thinking has slowed down" "I have difficulty concentrating on the things that I am doing." "I have problems understanding what I read" "I can't concentrate for more than a short period of time" "I get distracted easily" "I sometimes stutter or am unable to find the correct words" "I feel I react too slowly to things that are said to me" **Memory** "Memory problems" "I have difficulties remembering the names of people" "I forget all kinds of things, for example an appointment or where I put an object" "I forget things people have said to me" "I get confused and forget what I was doing" **Depression** "Depression"	The questionnaire developers employed the Likerts method of summated ratings to construct and create a scoring for all the multi-item scales of the NEWQOL. Higher scores represented better functioning for the scales named social activity, worry, and mastery. However, scales named symptoms, hospital depression and anxiety, stigma, neurophysiological assessment and work limitation, higher scores represent poorer functioning.

No.	Questionnaire (author)	Aim of the questionnaire	Development process	Validated?	Content of questionnaire/instrument	Scoring
					"I still enjoy the things I used to enjoy" "I can laugh and see the funny side of things" "I feel cheerful" "I look forward with enjoyment to things" "I can enjoy a good book or radio or TV program" **Control** "There is really no way I can solve some of the problems I have" "I sometimes feel that I am pushed around in my life" "I have little control over things that happen to me" "I often feel helpless in dealing with the problems of life" "There is little I can do to change many of the important things in my life" **Stigmatism** "I feel some people are uncomfortable with me" "I feel some people treat me like an inferior person" "I feel some people would prefer to avoid me" **Worry** "How worried are you about the attacks you have had?" "How worried are you that you might have another attack?"	

4.2.7 Collating, summarising and presentation of results

4.2.7.1 Purpose of the questionnaires

Although the questionnaires have varying purposes, the overarching similarity between them was seeking to describe or measure health-related or perceptions of QoL of people living with various dimensions of epilepsy. The QOLIE-31 (Cramer et al., 1998; Leone et al., 2005; Torres et al., 1999), QOLIE-10 (Leone et al., 2005) and NEWQOL (Abetz et al., 2000) were designed to measure the health related QoL of PLWE whereas the Liverpool Seizure Severity Scale revisited (Baker et al., 1991, 1998) was designed to assess the perception of PLWE about the severity of their seizures.

4.2.7.2 Questionnaire Development process

The development process for the questionnaires included share some similarities and considerable differences and disparities. Both QOLIE-31 (Asadollahi et al., 2016; Cramer et al., 1998; Leone et al., 2005; Mollaoğlu et al., 2015; Torres et al., 1999) and QOLIE-10 (Barranco-Camargo et al., 2019; Leone et al., 2005; Mollaoğlu et al., 2017) were developed through a review and reduction of QOLIE-89 (Cramer et al., 1998). The development process for QOLIE-89, which was the original questionnaire from which both QOLIE-31 and QOLIE-10 were developed, shares similarities with the development of the Liverpool Seizure Severity Scale revisited and the NEWQOL.

The inclusion of an expert group who either select items for inclusion or validate the questionnaire was common to all newly developed questionnaires. Additionally, there is a literature review that sought to explore the existing knowledge on the questionnaire and its content. In the development of the NEWQOL (Abetz et al., 2000; Leone et al., 2005; B Mulhern et al., 2010) and Liverpool Seizure Severity Scale revisited (Baker et al., 1991; Leone et al., 2005; Scott-Lennox et al., 2001), clinical experience of the expert group was central to the selection of the content and the processes that unfold afterwards. In the development of the NEWQOL, literature review was followed by individual interviews with patients. The thematic analysis of the interview data was used to select items for the NEWQOL questionnaire (Abetz et al., 2000; Leone et al., 2005; B Mulhern et al., 2010).

After the selection of items, the questionnaires are validated through pilot testing, statistical analysis and validation. Factor analysis was conducted to ensure that all items were contributing enough to the constructs being measured in the development of the QOLIE-31.

Reliability tests were also conducted using test/ retest research methods for the development of the Liverpool Seizure Severity Scale revisited. In the case of QOLIE-31, an expert group was involved in examining the questionnaire's face validity.

In summary, the processes involved in developing a QoL questionnaire include literature review; interviews, expert panel to select or evaluate items, and validation. Translation also becomes necessary if the questionnaire needs to be used in different countries.

4.2.7.3 Content of the questionnaires

The content of the questionnaires was tabulated (Table 4.3) with their source references under various domains.

Table 4.6: Consolidated content of Epilepsy-specific QOL questionnaires

	ITEMS AND THEIR DOMAINS	SOURCES
SEIZURE WORRY		
1.	"Have you worried about having another seizure?"	QOLIE-31; QOLIE-10; NEWQOL
2.	"How fearful are you of having a seizure during the next month?"	QOLIE-31; QOLIE-10
3.	"How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?"	QOLIE-31; QOLIE-10; Liverpool Seizure Severity Scale revisited; NEWQOL
4.	How much do you bother about seizures?	QOLIE-10
SEIZURE CONTROL		
5.	"How would you rate your ability to predict seizures?"	Liverpool Seizure Severity Scale revisited and NEWQOL
6.	"Perceived control over attacks" OR "To what extent do you think you have your seizures under control?"	Liverpool Seizure Severity Scale revisited and NEWQOL
7.	"How would you rate your ability to 'fight off attacks'?"	Liverpool
EMOTIONAL WELLBEING		
8.	***In the past four weeks …*** "Have you been a very nervous person?"	QOLIE-31
9.	"Have you felt so down in the dumps that nothing could cheer you up?"	QOLIE-31
10.	"Have you felt calm and peaceful?"	QOLIE-31
11.	"Have you felt downhearted and blue?" OR "How sad/ depressed are you about epilepsy?"	QOLIE-31 and QOLIE-10
12.	"Have you been a happy person?"	QOLIE-31

	ITEMS AND THEIR DOMAINS	SOURCES
ENERGY/ FATIGUE		
13.	"Did you feel full of pep? OR Do you feel motivated to face each day?"	QOLIE-31
14.	"Did you have a lot of energy?"	QOLIE-31 and QOLIE-10
15.	"Did you feel worn out?"	QOLIE-31
16.	"Did you feel tired?"	QOLIE-31
COGNITIVE FUNCTION		
17.	"Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?"	QOLIE-31 and NEWQOL
18.	"In the past four weeks, have you had any trouble with your memory?" OR "Rate your general memory performance"	QOLIE-31 and NEWQOL
19.	"Trouble remembering things people tell you"	QOLIE-31 and NEWQOL
20.	"Trouble concentrating on reading"	QOLIE-31 and NEWQOL
21.	"Trouble concentrating on doing one thing at a time"	QOLIE-31
22.	"Memory difficulties" OR "How much are you bothered by memory difficulties?"	QOLIE-31 and NEWQOL
MEDICATION EFFECTS		
23.	"How worried are you that medications you are taking will be bad for you if taken for a long time?"	QOLIE-31
24.	"Physical effects of antiepileptic medication"	QOLIE-31
25.	"Mental effects of antiepileptic medication"	QOLIE-31
SOCIAL FUNCTION		
26.	"Has your health limited your social activities (such as visiting with friends or close relatives)?"	QOLIE-31
27.	"Has epilepsy affected your normal daily activities?"	Liverpool Seizure Severity Scale revisited
28.	"Has your leisure time (such as hobbies, going out) been affected by epilepsy?"	QOLIE-31
29.	"Driving limitations" OR "How mush during the past four weeks has your epilepsy or antiepileptic medication caused trouble with driving?"	QOLIE-31 and QOLIE-10
30.	"Work limitations OR How much do work limitations bother you?"	QOLIE-31 and QOLIE-10
31.	"Social limitations OR How much are you bothered about how epilepsy affect the relationship between you and others?"	QOLIE-31 and QOLIE-10
OVERALL WELL BEING		
32.	"Overall, how would you rate your quality of life?"	QOLIE-31 and QOLIE-10
SEIZURE SEVERITY		
33.	"How often do you have Seizures in sleep only?"	Liverpool Seizure Severity Scale revisited

	ITEMS AND THEIR DOMAINS	SOURCES
INJURY		
34.	"How often do you Fall to the ground during seizures?"	Liverpool Seizure Severity Scale revisited
35.	"Do you worry about hurting yourself during a seizure?"	QOLIE-31 Liverpool

4.2.7.4 Scoring system

The scoring system for all the questionnaires vary. The QOLIE-31 is scored on a 100-point scale with higher scores signifying the better QoL, whereas QOLIE-10 was graded with various scales. Similar to the QOLIE-32, the scores of all the items are calculated. Those with the highest scores have the poorest QoL. The rating in the Liverpool Seizure Severity Scale revisited also vary from seizure or no seizure to a Likert scale in nature similar to that of the NEWQOL. There is no specific way of rating the QoL of PLWE but "yes" or "no" questions and Likert scale ratings are common in the literature.

4.3 QUALITY OF LIFE AMONG PLWE: INTEGRATIVE REVIEW

4.3.1 Aim of the review

This review aimed to ascertain the QoL among PLWE in SSA. Thus, peer-reviewed articles on the QoL of PLWE in SSA from January, 2015 to December, 2019 were reviewed for the study.

4.3.2 Design and methods

Whittemore and Knafl's (2005) integrative review framework was applied in this review. These include (1) problem identification (clearly defining the research question and purpose for the study); (2) literature search (description of the search strategy); (3) data evaluation (determining the quality and authenticity of the studies being included); (4) data analysis (data reduction and display, data comparison, drawing conclusions and verification); and (5) presentation (combination of the findings in a manner that portrays the integration process in addition to its implications and limitations). The integrative review approach was appropriate for this study because it seeks to pool and synthesise studies from various research paradigms on a particular subject (Hopia et al., 2016; Souza et al., 2010). The report was guided by the Prevention and Recovery Information System for Monitoring and Analysis (PRISMA) checklist for reviews (Moher et al., 2010).

4.3.3 Problem identification/ Research Question

Epilepsy is considered a chronic and debilitating disease (Megari, 2013). Sub-Saharan Africa is known to have a high prevalence rate of epilepsy (Ba-Diop *et al.*, 2014; Preux and Druet-Cabanac, 2005). An estimated 4.4 million people are living with epilepsy in SSA which is very high (Paul et al., 2012). Coupled with this is the vast treatment gap among PLWE in SSA (Mbuba et al., 2012; Sebera et al., 2015; Winkler, 2012). This invariably negatively affects the QoL of PLWE in countries within the region.

The chronic nature of epilepsy is known to affect the QoL of PLWE (Megari, 2013). Epilepsy is also known as a stigmatising condition (Deegbe et al., 2019), which also worsens the condition's outcome, making it difficult for them to cope (Deegbe et al., 2020). This affects psychological, physical and cognitive domains as well as the occupational and social lives of PLWE (Blond et al., 2016). This underscores the need for a pooled synthesis of studies on QoL of PLWE in SSA in the form of an integrative review to gain a deeper and more precise understanding of the QoL of PLWE.

This integrative review on the QoL of PLWE in SSA provided background information that guided the situational analysis and conceptualisation of the QoL of PLWE in the sub-region. This was done in conjunction with an exploration of the questionnaires used in assessing the QOL of PLWE to guide the development of a culturally sensitive QoL questionnaire that is specific and fit for measuring the QOL of PLWE in Ghana. The review question '*What is the Quality of Life of people living with epilepsy in sub-Saharan Africa?*' guided this review.

4.3.4 Literature search

A computerised search was reported by various authors (Christmals & Gross, 2017; Whittemore & Knafl, 2005) as the most appropriate form of search. It allows for the use of a combination of search words and delimitations. The following vital strategies were employed to obtain credible information from the regular searches: searching from credible sources for literature, using key words, and considering the inclusion and exclusion criteria and selection process. Despite the importance of computer-assisted search, some articles could be missed by the method. Hand search, ancestry (forward and backwards) searches are two other methods that help mitigate the exclusion of articles that are not picked by the computer-assisted search. These were employed in this review.

A comprehensive computer-assisted literature search was carried out in five databases (PsychInfo, Scopus, Science Direct, PubMed and CINAHL (Cumulative Index to Nursing and Allied Health)) using Boolean combinations of the key words: *"Epilepsy", "Seizure", "Quality of Life", "Wellbeing", "sub-Saharan Africa"*. Wildcards were also used to ensure variations of words were identified appropriately. Sub-Saharan Africa has been substituted with all the 48 countries' names in the sub-region to ensure that no study is unduly excluded. The search string for the search in PubMed is presented in Box 2.

Box 2: Search string used in PubMed

"(Epilep* OR Seizure*) AND ((Quality of Life) OR Wellbeing) AND (sub-Saharan Africa OR Angola OR Benin OR Botswana OR Burkina Faso OR Burundi OR Cameroon OR Cape Verde OR Central African Republic OR Chad OR Comoros OR Congo (Brazzaville) OR Congo (Democratic Republic) OR Côte d'Ivoire OR Djibouti OR Equatorial Guinea OR Eritrea OR Ethiopia OR Gabon OR The Gambia OR Ghana OR Guinea OR Guinea-Bissau OR Kenya OR Lesotho OR Liberia OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Sao Tome and Principe OR Senegal OR Seychelles OR Sierra Leone OR Somalia OR South Africa OR Sudan OR Swaziland OR Tanzania OR Togo OR Uganda OR Western Sahara OR Zambia OR Zimbabwe)"

This search was conducted in January, 2020. However, an updated search was done on 20th June, 2020 to finalise the study.

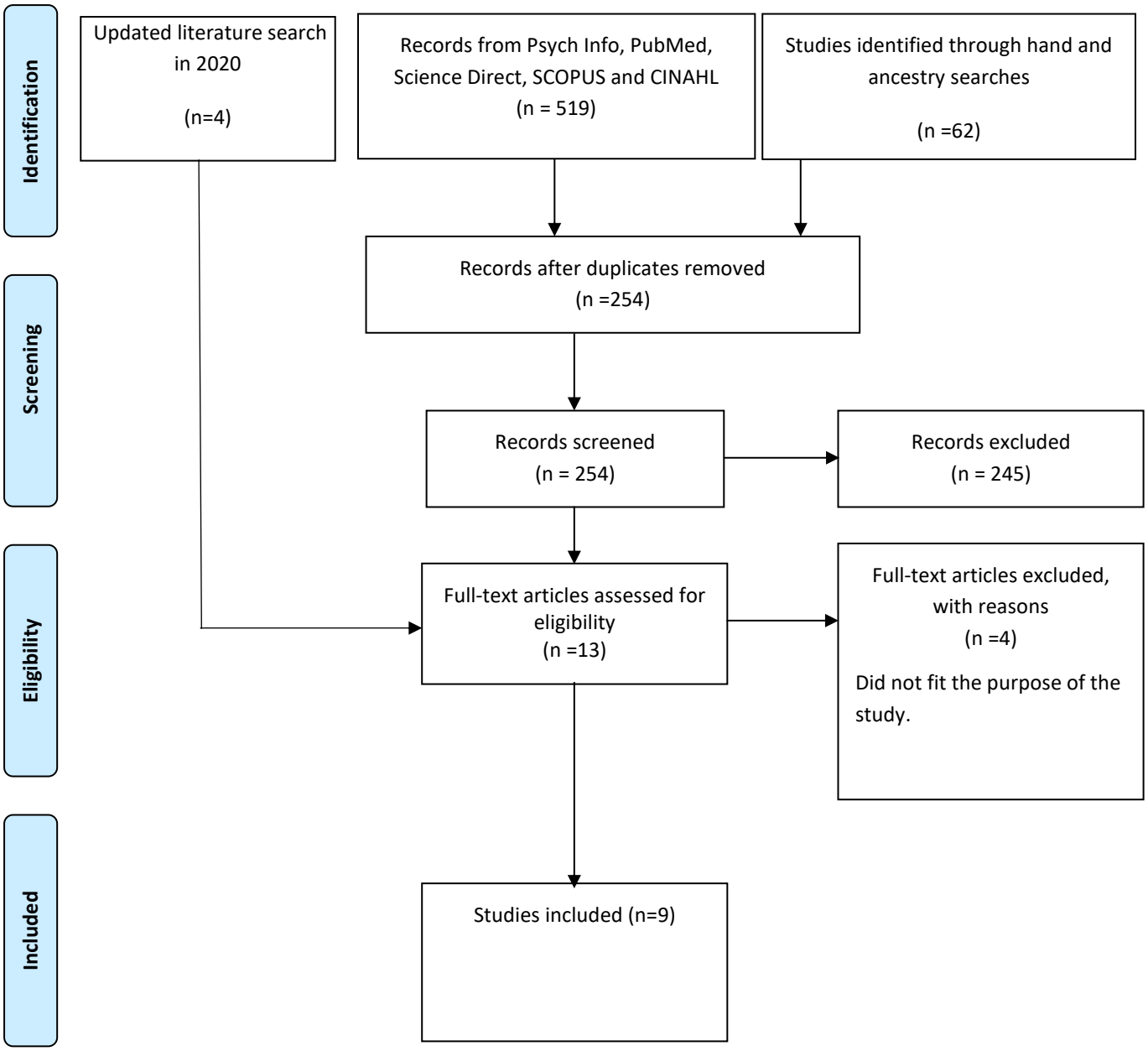

Figure 4.3: PRISMA diagram of Integrative review

4.3.4.1 Inclusion and exclusion criteria

Inclusion criteria

Studies were included if they were peer-reviewed studies on the QoL of PLWE in SSA from January, 2015 to June, 2020. Only studies published in the English language on the QoL of adults with epilepsy were accepted. The titles and abstracts of the articles found during the search were read.

Exclusion criteria

Secondary studies, letters to editors and studies conducted on the QoL of PLWE outside SSA were excluded. The full articles excluded with reasons are presented in Table 4.4.

Table 4.7: Articles rejected with reasons

No	Author & Date	Topic	Reason
4.	(Bashir & Cumber, 2019)	"The QoL and inequalities in health services for epilepsy treatment among patience in the urban cities of Sudan"	Letter to the editor
5.	(Sadr et al., 2018)	"Descriptive epidemiology: prevalence, incidence, sociodemographic factors, socioeconomic domains, and QoL of epilepsy: an update and systematic review"	Systematic review
6.	(Boling et al., 2018)	"Quality of Life and Stigma in Epilepsy, Perspectives from Selected Regions of Asia and Sub-Saharan Africa"	Literature review. Setting is Asia & SSA
7.	(Keikelame et al., 2017)	"Psychosocial challenges affecting the QoL in adults with epilepsy and their carers in Africa: A review of published evidence between 1994 and 2014"	Literature review. Setting is the whole of Africa

4.3.4.2 Studies included

The initial search produced 581 articles, including 62 hand and ancestry searches. After loading the articles into the Mendeley reference manager, a total of 327 duplicates were identified and merged, leaving a total of 254 articles. After scanning the titles of the 254 studies remaining, 245 articles were excluded, leaving nine full-text articles. However, an updated literature search conducted in June 2020 found and added four new peer-reviewed articles on QoL among PLWE in SSA, making 13 articles (Figure 4.2). After critical appraisal and critical reading of the remaining 13 articles, four articles were excluded. Among those excluded were one letter

to the editor and three literature reviews that did not fit the study's purpose. The final number of articles included in the study after the critical appraisal was nine (Figure 4.2) and is presented in the data matrix (Table 4.7).

4.3.4.3 Characteristics of studies included

All of the studies employed a cross-sectional design. Two were explicitly case-control studies. Four publications focused on determinants of QoL among PLWE (Abadiga et al., 2019; Gebre & Haylay, 2018; Kaddumukasa et al., 2019; Tefera et al., 2020) and three focused on comorbid physical and psychosocial disorders and their impact on QoL of PLWE (Mwangala et al., 2018; Nau et al., 2018; Ogundare et al., 2020). In addition to the QoL of PLWE, Fletcher et al. (2015) evaluated stigma and self-esteem among people living with intractable temporal lobe epilepsy. In this study, the findings from the integrative review were presented in this manner: year of publication, the country in which study was conducted, and the quality of the studies conducted**.**

Year of publication

The number of publications per year; starting from 2015 to 2020 have been illustrated in Figure 4.3.

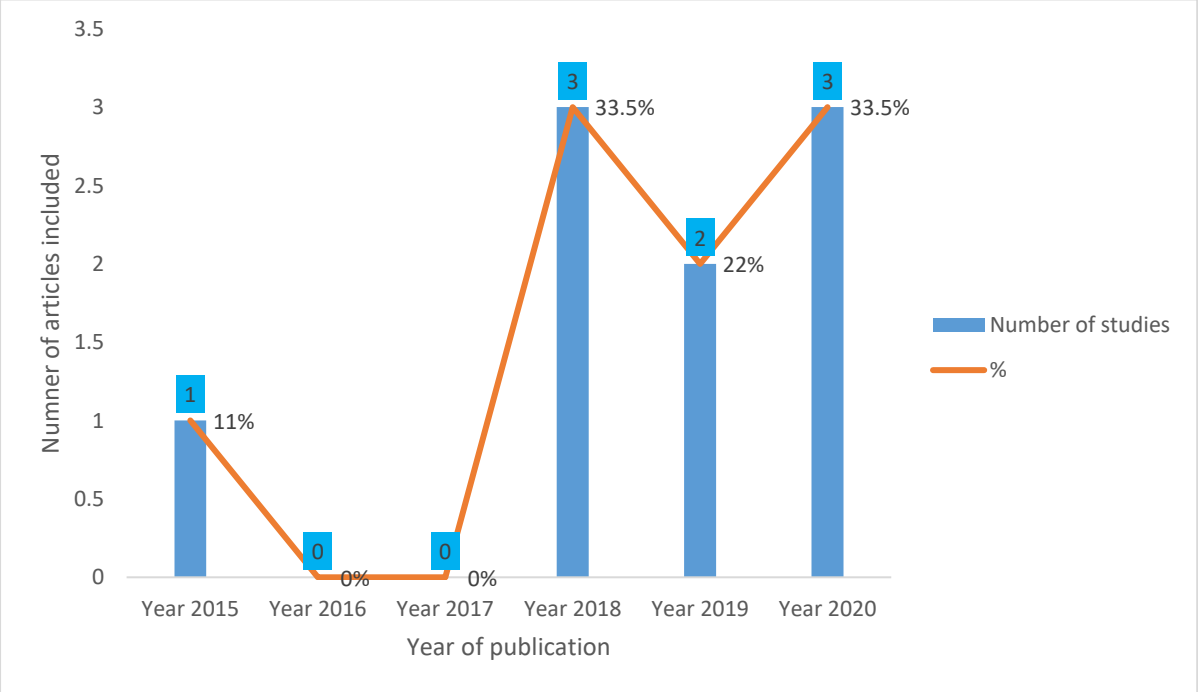

Figure 4.4: Year of publication of journals

The majority of the studies retrieved were published in 2018 and 2020. Thus 3 (33.5%) in each year. However, no studies were found in the years 2016 and 2017.

Country of origin of the study

Table 4.8: Countries from which studies were conducted

Setting	Number of articles published
Ethiopia	4
Uganda	2
Zambia	1
Kenya	1
Nigeria	1

The studies were conducted across five countries in SSA (Table 4.5). Among the nine publications included in this review, four reported findings from research undertaken in Ethiopia (Abadiga et al., 2019; Gebre & Haylay, 2018; Muche et al., 2020; Tefera et al., 2020), and two reported findings from research undertaken in Uganda (Fletcher et al., 2015; Kaddumukasa et al., 2019). One each from the remaining three publications were findings from research conducted in Zambia (Nau et al., 2018), Kenya (Mwangala et al., 2018) and Nigeria (Ogundare et al., 2020). Thus, covering the east, central and western parts of Africa.

The quality of the studies included

The Joana Briggs Institute, Critical Appraisal questionnaires were used to assess the methodological quality of studies included in the review (Table 4.6). Two of the researchers appraised the quality of the studies with a third person serving as an adjudicator. Studies were scored based on the Joana Briggs Institute Critical Appraisal questionnaire that fit the study design. Overall scores were rated in percentages. Articles with appraisal ratings of 75% and above were accepted for inclusion into the review. Articles with quality appraisal scores below 50% were considered as low quality and were not included. There were two case control studies and seven cross-sectional studies. The two case control studies had high scores (90%) and were considered to be of high quality (Mwangala et al., 2018; Nau et al., 2018). Three cross-sectional studies had very high scores (100%) and had very high quality for inclusion (Abadiga et al., 2019; Muche et al., 2020; Tefera et al., 2020). The remaining four cross-sectional studies scored 75% and were considered good quality (Fletcher et al., 2015; Gebre & Haylay, 2018; M. Kaddumukasa et al., 2019; Ogundare et al., 2020). A summary of the scores in percent is

illustrated in Figure 4.4. A detailed description of the individual papers' assessment criteria is presented in Table 4.7.

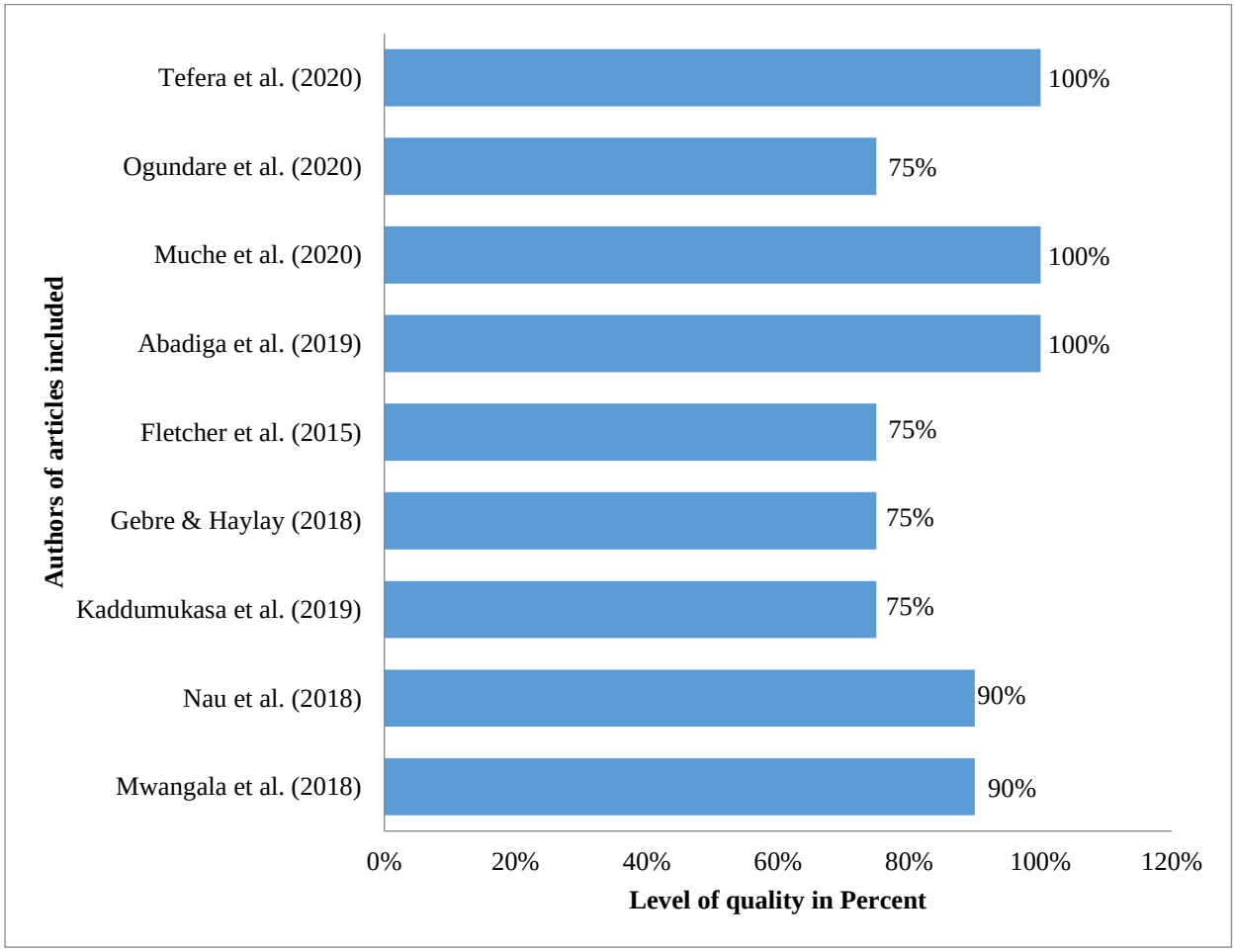

Figure 4.5: Summary of quality of studies included

4.3.5 Data evaluation

Joana Briggs Institute's critical appraisal questionnaires were used to critically appraise the full-text studies retrieved. The data evaluation was done to ensure only quality studies with sound methodology rigour were included. Studies were considered good quality for inclusion if they met at least 75% of the criteria set in the critical appraisal questionnaire. The researcher and the first supervisor independently appraised the studies for inclusion. The appraisal notes were compared and differences reconciled. The second supervisor served as an adjudicator to resolve any disagreement between the student and the first supervisor on the inclusion of any paper. The appraisal process is presented in Table 4.6. In all, nine articles were evaluated. None was excluded based on critical appraisal.

Table 4.9: Quality assessment matrix

Case-Control Studies	(Mwangala et al., 2018)	(Nau et al., 2018)	Cross-Sectional Studies	Kaddumukasa et al. (2019)	Gebre & Haylay (2018)	Fletcher et al. (2015)	Abadiga et al. (2019)	Muche et al. (2020)	Ogundare et al. (2020)	Tefera et al. (2020)
1. Were the groups comparable other than the presence of disease in cases or the absence of disease in controls?	Y	Y	1. Were the criteria for inclusion in the sample clearly defined?	Y	Y	Y	Y	Y	Y	Y
2. Were cases and controls matched appropriately?	Y	Y	2. Were the study subjects and the setting described in detail?	Y	Y	Y	Y	Y	Y	Y
3. Were the same criteria used for identification of cases and controls?	Y	Y	3. Was the exposure measured in a valid and reliable way?	Y	Y	Y	Y	Y	Y	Y
4. Was exposure measured in a standard, valid and reliable way?	Y	Y	4. Were objective, standard criteria used for measurement of the condition?	Y	Y	Y	Y	Y	Y	Y
5. Was exposure measured in the same way for cases and controls?	Y	Y	5. Were confounding factors identified?	U	U	U	Y	Y	U	Y
6. Were confounding factors identified?	Y	Y	6. Were strategies to deal with confounding factors stated?	U	U	U	Y	Y	U	Y
7. Were strategies to deal with confounding factors stated?	Y	Y	7. Were the outcomes measured in a valid and reliable way?	Y	Y	Y	Y	Y	Y	Y
8. Were outcomes assessed in a standard, valid and reliable way for cases and controls?	Y	Y	8. Was appropriate statistical analysis used?	Y	Y	Y	Y	Y	Y	Y
9. Was the exposure period of interest long enough to be meaningful?	U	NA								
10. Was appropriate statistical analysis used?	Y	Y								
Total scores (Yes) out of 10 OR 8	9/10	9/10		6/8	6/8	6/8	8/8	8/8	6/8	8/8
No (N)	0	0		0	0	0	0	0	0	0
Unclear (U)	1	0		2	2	2	0	0	2	0
Not applicable (NA)	0	1		0	0	0	0	0	0	0

4.3.6 Data extraction and synthesis

Key findings from the full-text articles included were extracted using a data extraction sheet (Table 4.7). Information extracted from the studies includes author and date; purpose; design and sample; data collection and analysis; and main findings.

Data analysis involves a systematic organisation and data synthesis to generate evidence (Polit & Beck, 2012). Key findings from the papers included in this study were analysed through narrative synthesis as described by the Centre for Reviews and Dissemination (2009). A narrative synthesis was deemed appropriate for the study due to the variety in terms of the outcome measures and settings of the papers included in the study and particularly to answer the review question. Thus, to provide a vivid description of the QoL results of studies one PLWE in SSA. Data analysis was done according to the following steps: data reduction, data display, data comparison, drawing conclusions and verification (Whittemore & Knafl, 2005).

4.3.6.1 Data reduction

Whittemore and Knafl (2005) posited that data could be logically reduced into various sub-groups based on either identified characteristics such as type of design, setting, sample characteristics, or a predetermined conceptual classification of participants. The classified data is then extracted, coded and grouped into a framework in a data matrix or spreadsheet. In this integrative review, data reduction was done by reducing data into designs and settings.

4.3.6.2 Data display

Data display is a critical means of analysis. Seeking the meaning in data is made more accessible by displaying data visually. Tables and matrices are among the means of data display (Whittemore & Knafl, 2005). Following data reduction, data in this study were displayed in a matrix to allow for comparison of findings from primary studies. This enabled identifying patterns and relationships within primary data sources, leading to the development of domains.

4.3.6.3 Data comparison

Data comparison is when one interactively examines the display of data, paying particular attention to the themes or the patterns displayed in the primary data source (Whittemore & Knafl, 2005). In this study, the comparison on data was carried out by grouping similar findings into domains after thoroughly studying the data from the data matrix.

4.3.6.4 Conclusion and drawing verification

In this final phase of data analysis, smaller domains of grouped data that were also similar were classified under main domains (Whittemore & Knafl, 2005). This led to the organising of the data into main domains and sub-domains for easy comparison and drawing of conclusions from the data. Continual review of the data was carried out to ensure that all sources have been captured in the groupings to ensure accuracy and confirmability (Whittemore & Knafl, 2005).

4.3.7 Presentation

This section represents how findings from the integrative review were described. In this study, the results were presented in charts, tables and descriptive narratives. The results are presented under the sub-topics: studies included; characteristics of studies included; physical QoL; psychological QoL; and social QoL of PLWE (Table 4.7).

Table 4.10: Summary of studies included

No	Author(s), Year	Purpose	Design/ Sample	Data collection/ Analysis	Main findings
1.	(Fletcher et al., 2015) UGANDA	To evaluate the QoL, stigma and self-esteem of people living with intractable temporal lobe epilepsy.	Longitudinal survey. Purposive sample of 19 PLWE	Liverpool seizure severity scale, Quality of Life in Epilepsy Scale-31 (QOLIE-31), Child and parent stigma scale, Rosenberg self-esteem scale. Descriptive and inferential statistics	**Physical QOL** Significant higher QoL exists among patients in the surgical treatment group than the nonsurgical patient group (p =.002). Severity of seizure and QoL have significant inverse relationship (P=.0005). **Psychological QOL** Significantly lower perceived stigma exists among patients who are seizure free compared to those who still experience seizures (p=.02). Patients in the surgical treatment group had less perceived stigma than those in the non-surgical treatment group (p = 0.04). Significant positive correlation exists between patients perceived stigma of epilepsy and the severity of seizures (p=.032). **Social QOL** Patients with epilepsy had problems with interpersonal and love relationships. They were unable to marry or to have children. They found it difficult to meet obligations to family and society such as cleaning, cooking, and farming as a result of uncontrolled seizures.
2.	(Gebre & Haylay, 2018) ETHIOPIA	To assess the QoL among PLWE and the factors affecting their QoL in the Makelle city of Northern Ethiopia.	Cross-sectional study design 175 PLWE	Validated version of the QOLIE-31 in Tigrigna. Descriptive and inferential statistics.	**Physical QOL** Patients who had no seizures in the past month had significantly better QoL than those who had some seizures in the past month ($p \leq 0.001$). Significantly moderate negative correlation exists between QoL and number of seizures experienced by the patients (p =0.026). **Psychological QOL** Patients with primary education or less had significantly low QoL compared to those with tertiary level education and above ($p \leq 0.001$). Positive correlation exists between QoL and good level of education among the patients Emotional wellbeing and energy are lowered with increased frequency of seizures.

No	Author(s), Year	Purpose	Design/ Sample	Data collection/ Analysis	Main findings
3.	(Kaddumukasa et al., 2019) UGANDA	To assess the impact of severity of seizures on QOL of PLWE and to ascertain the socio-demographic and clinical determinants of seizure severity.	Descriptive cross-sectional study design. Convenient sampling of 48 PLWE	The Chalfont Seizure Severity Scale (CSSS), QOLIE-31. Descriptive and inferential statistics	**Social QOL** Demographic variables such as age (p=.715), gender (p=.076), onset of epilepsy (p=.659), level of education (P=.735), employment status (p=.322), marital status (p=.500), duration of epilepsy (p=.380) had no significant association with QoL scores of PLWE. Significant inverse relationship exists between seizure severity scores and social function (p=.014) **Psychological QOL** Significant inverse relationship exists between seizure severity scores and total QoL scores (p=.001), seizure worry (p=.030), overall QoL (p=.002) and emotional wellbeing (p=.001). **Physical QOL** Significant inverse relationship exists between seizure severity scores and energy/ fatigue (p=.001). There exists an inverse relationship between seizure frequency and QoL.
4.	(Nau et al., 2018) ZAMBIA	To assess the cognitive performance and QoL of PLWE and the differences in PLWE with or without neurocysticercosis in Zambia.	Community-based cross-sectional case control study. 47 PLWE, 50 healthy controls.	Mini Mental State Examination (MMSE), Digit Span, Selective Reminding Test (SRT), Spatial Recall Test (SPART), Test Battery of Attentional Performance (TAP) and World Health Organization Quality of Life Questionnaire. Descriptive and inferential statistics.	**Psychological QOL** Although there exists no significant correlation between seizure frequency and cognitive impairment of PLWE, increased seizure frequency was significantly associated with lower psychological QoL ($p<0.01$). PLWE had significantly lower cognitive performance compared to healthy controls after "age and education" and "age, education and sex" were controlled ($p<0.05$). PLWE also had significantly lower psychological, social, environmental and overall QoL compared to healthy controls after "age and school years" and "age, school years and sex" were controlled ($p<0.05$). **Physical QOL** PLWE with or without neurocysticercosis had similar QoL domains and had significantly lower QoL than healthy controls ($P<0.05$).

No	Author(s), Year	Purpose	Design/ Sample	Data collection/ Analysis	Main findings
5.	(Mwangala et al., 2018) KENYA	To examine neurocognitive outcomes, depression and psychosocial adjustment of PLWE and their impact on health-related QoL of PLWE in Kilifi, Kenya.	Cross-sectional case control study. 63 PLWE and 83 controls.	Major depression inventory, RAND SF-36 (Quality of Life Questionnaire), neurocognitive function tests (Raven's Standard Progressive Matrices, Digit Span, and Contingency Naming Test). Descriptive and inferential statistics.	**Social QOL** PLWE are significantly more likely to be unemployed than healthy controls (p=0.05). **Psychological QOL** A large number of PLWE have extreme cognitive impairment (34.9%). 27% of the PLWE and 6% of the healthy controls had depression. PLWE have significantly higher levels of depression than healthy controls (p=<0.01) Significantly poorer memory performance exists among PLWE than healthy controls (p<0.001). PLWE who had depression had significantly lower QoL scores in all domains including physical functioning, role functioning, energy/ fatigue, emotional wellbeing and general health (P < 0.05).
6.	(Abadiga et al., 2019) ETHIOPIA	To assess the health-related QoL of PLWE and the factors associated with it among PLWE at public hospitals in Wollega zones in Ethiopia.	Institution-based cross-sectional study design. 392 PLWE	WHO Quality of Life Questionnaire (WHOQOL-BREF) and Hospital Anxiety and Depression Scale (HADS). Descriptive and inferential statistics.	**Physical QoL** The mean score for physical QoL was 17.89 (SD= ± 6.5) ranging from 8 to 32. 46.4% of them have had drug reaction. 41.6% had a seizure weekly and 33.9% had a seizure monthly. Adverse drug reaction (p< 0.001) and frequency of seizures once per week (p= .001) were negatively associated with heath related QoL. **Psychological QoL** The mean score for psychological QoL was 15.33 (SD= ± 6.17) ranging from 7 to 27. 29.6% of them have had comorbid anxiety and 11.7% have had comorbid depression. 79.8% had fear of having seizures and 33.7% experienced perceived stigma. Comorbid anxiety (p< 0.001) was negatively associated with heath related QoL. **Social QoL** The mean score for social QoL was 7.69 (SD= ± 3.24) ranging from 3 to 12. Living alone (p= .007), social stigma (p< 0.001) and monthly income, were negatively associated with heath related QoL.
7.	(Muche et al., 2020) ETHIOPIA	To assess the QoL and the determinants of QoL among PLWE at the University of	Institution-based cross-sectional study design. 354 PLWE	QOLIE-10 Descriptive and inferential statistics.	**Physical QoL** 73.7% of the participants have enough energy most of the time 54.8% of them did not have their antiepileptic drugs affecting their activities of daily living.

No	Author(s), Year	Purpose	Design/ Sample	Data collection/ Analysis	Main findings
		Gondar Referral Hospital, Ethiopia.			**Psychological QoL** 50.85% of the participants were sad for at least some of their time. Patients who perceived their epilepsy was under control had significantly better QoL than those who perceived it had improved, deteriorated or had no change. **Social QoL** Patients who were illiterates, unemployed and earned less than 22USD monthly had significantly lower QoL than their counterparts.
8.	(Ogundare et al., 2020) NIGERIA	To determine the prevalence major depression and its relationship with QoL.	Cross-sectional observational study 270 PLWE	Mini international neuropsychiatric interview (MINI PLUS), Beck's Depression Inventory (2nd edition), QOLIE-31 (version 2). Descriptive and inferential statistics.	**Physical QoL** 33% of the respondents had frequent seizures. Very frequent (P=0.037) and Frequent seizures (P=0.0001) in the past month predicted lower QoL scores. **Psychological QoL** 11.9% of the respondents had MDD. Among them, 21.9% had mild depression, 56.3% had moderate depression, 18.8% had severe depression and 3.1% had extreme depression. Having current MDD (P=0.0001) predicted lower QoL scores. **Social QoL** Patients who were younger, with younger age of onset of epilepsy, single, a student and those with family history of epilepsy had low QoL.
9.	(Tefera et al., 2020) EHIOPIA	To assess health related QoL and its determinants among adults living with epilepsy.	Institution-based cross-sectional study 121 PLWE	WHO Quality of Life Questionnaire (WHOQOL-BREF) Descriptive and inferential statistics	**Physical QoL** Physical health related QoL is negatively affected by co-morbidity ($p<0.0001$), uncontrolled seizures ($p<0.0001$), being widowed ($p=0.011$), and having no formal education ($p=0.001$). **Psychological QoL** Uncontrolled seizures ($p<0.0001$), being divorced ($p=0.002$) strongly predicted low psychological QoL. **Social QoL** Having no formal education ($p=0.001$), absence of polypharmacy ($p=0.003$), being single ($p<0.0001$), and being divorced ($p=0.001$) negatively affected social domain of QoL.

4.3.7.1 Physical quality of life

Conflicting views on the physical QoL of PLWE exist. Abadiga et al. (2019) reported a below-average mean score, thus 17.89 (SD= ± 6.5), on the overall physical QoL of PLWE ranging from 8 to 32. People living with epilepsy have enough physical energy - a key component of physical QoL (Muche et al., 2020). However, there exists a significant negative relationship between energy and the severity of seizures among PLWE (Kaddumukasa et al., 2019).

The frequency and severity of seizures, in addition to comorbid physical and psychological conditions influence physical QoL of PLWE. Uncontrolled seizures have significant negative effect ($p<0.0001$) on the QoL of PLWE (Tefera et al., 2020). Ogundare et al. (2020) found that 33% of patients with clinically diagnosed epilepsy had frequent seizures. Furthermore, Abadiga et al. (2019) reported that weekly seizures were experienced by 41.6% and monthly seizures were experienced by 33.9% of epileptic patients on treatment follow up. Frequent seizures – occurring once a week ($p=0.001$) are negatively associated with health-related QoL. Very low QoL scores has also been predicted by frequent ($p=0.0001$) and very frequent ($p=0.037$) seizures in the past month. Consequently, Gebre and Haylay (2018) found a significantly better QoL among patients with no seizures in the past month than patients who experienced some seizures in the past month. The authors of two studies confirm an inverse relationship between the QoL of PLWE and seizure frequency (Fletcher et al., 2015; Kaddumukasa et al., 2019).

Persons with epilepsy who also have comorbid mental or physical problems have significant negative physical health-related QoL ($P<0.0001$). However, Nau et al. (2018) reported similar life domains among PLWE with or without a diagnosis of neurocysticercosis.

The treatment of epilepsy also affects the physical health-related QoL of PLWE (Abadiga et al., 2019; Fletcher et al., 2015; Muche et al., 2020). Abadiga et al. (2019) reported that about half (46.4%) of PLWE experience some form of drug reaction. Health-related QoL is significantly affected by adverse drug reaction ($p<0.001$) and frequency of seizures of at least once per week ($p=0.001$). However, more than half (54.8%) of PLWE do not have their activities of daily living interrupted by their antiepileptic medications (Muche et al., 2020). Furthermore, (Fletcher et al., 2015) reported a higher QoL is significantly found among PLWE who have had surgical treatment than those who have not had any surgical treatment for their epilepsy.

Moreover, psychosocial factors have also been linked to physical health-related QoL. Being a widow (p=0.011) and having no formal education (p=0.001) also affects physical health-related QoL (Tefera et al., 2020).

4.3.7.2 Psychological quality of life

Psychological QoL among PLWE is reported to be below average. Abadiga et al. (2019) reported an average psychological quality score of 15.33 (SD =± 6.17) within a range of 7 to 27 among PLWE. One significantly strong predictor of low psychological QoL is uncontrolled seizures (p<0.0001) (Tefera et al., 2020). Increased frequency and severity of seizures lower emotional wellbeing (Gebre & Haylay, 2018; Kaddumukasa et al., 2019) and overall psychological QoL of PLWE (Nau et al., 2018). This also increases seizure worry among PLWE (Kaddumukasa et al., 2019). Perceived seizure control among PLWE was associated with significantly better QoL among PLWE compared to those who perceived it remains the same, deteriorated or improved (Muche et al., 2020).

Psychological QoL among PLWE has also been linked to level of education, cognition, perceived stigma and mood disorders (depression and anxiety). There exists a positive correlation between QoL of PLWE and their level of education. According to Gebre and Haylay (2018) PLWE with low level of education, thus, primary level or less have significantly low QoL compared to their counterparts who attain higher levels in education.

Quite a number of PLWE have some form of extreme cognitive impairment. People living with epilepsy have been found to have significantly poorer memory performance compared to healthy controls (Mwangala et al., 2018). Furthermore, compared to healthy controls after controlling for "age and education" and "age, education and sex", Nau et al. (2018) found significantly lower cognitive functions among PLWE (p<0.05). However, they found no significant correlation between cognitive impairment of PLWE and the frequency of seizures.

The authors of two studies reported results that showed that perceived stigma exist among PLWE (Abadiga et al., 2019; Fletcher et al., 2015). Abadiga et al. (2019) reported that 33.7% of PLWE experience perceived stigma. There exists a significant positive correlation between seizure severity and perceived epilepsy stigma. Therefore, PLWE who are seizure free have significantly lower perceived stigma compared to those who experience seizures (p=0.02). Furthermore, PLWE who have had surgical treatment had significantly low perceived stigma compared to those in the non-surgical treatment group (Fletcher et al., 2015).

Mood problems have been found to also contribute to poor psychological QoL in PLWE. More than half (50.85%) of PLWE are reportedly sad for at least some time (Muche et al., 2020). Higher levels of depression are reported among PLWE (Abadiga et al., 2019; Mwangala et al., 2018; Ogundare et al., 2020). Ogundare et al. (2020) found major depressive disorder in 11.9% of PLWE with 21.9%, 56%, 18.8% and 3.1% of those with major depressive disorder having mild, moderate, severe and extremely severe depression, respectively. Similarly, Abadiga et al. (2019) reported 11.7% of PLWE with comorbid depression. Mwangala et al. (2018) found that significantly higher levels of depression exist among PLWE than healthy controls ($p=<0.01$), where 27% of PLWE compared to 6% of healthy controls were found to have depression.

A diagnosis of major depressive disorder predicted lower scores on QoL among PLWE (Ogundare et al., 2020). People living with epilepsy who are diagnosed with depression have significantly lower psychological QoL scores and lower QoL scores in all other domains of QoL (Mwangala et al., 2018). Moreover, 79.8% of PLWE have fear of having seizures. In addition, 29.6% of them suffer comorbid anxiety which is significantly negatively associated with health-related QoL (Abadiga et al., 2019). In addition to mood problems, being a divorcee strongly predicted lower psychological QoL among PLWE ($p=0.002$) (Tefera et al., 2020).

4.3.7.3 The social quality of life

The social QoL among PLWE reportedly had average score of 7.69 (SD=±3.24) thus, ranging from 3 to 12 (Abadiga et al., 2019). Social QoL among PLWE represents their social function, social stigma and, social QoL in relation to demographic variables. Significant inverse relationship is reported between the severity of seizures and social function scores among PLWE ($P=0.014$) (Kaddumukasa et al., 2019). According to Fletcher et al. (2015), PLWE have difficulty with meeting family and society obligations, including farming, cooking and cleaning due to uncontrolled seizures. Two studies found that the monthly income of PLWE had negative association with their health-related QoL (Abadiga et al., 2019; Muche et al., 2020). People living with epilepsy who earned monthly income less than 22USD had significantly lower QoL compared to their counterparts (Muche et al., 2020). Health-related QoL also had significant negative association with the experience of social stigma ($p<0.001$) and living alone ($p=0.007$) among PLWE (Abadiga et al., 2019).

Secondly, demographic characteristics such as education level, employment status, marital status, age and family history of epilepsy represented social QoL of PLWE. Mwangala et al.

(2018) found that PLWE are significantly more likely to be unemployed compared to healthy controls (p=0.05). However, PLWE who are unemployed and illiterate have lower QoL compared to their counterparts (Muche et al., 2020). Having no formal education had significant negative effect on the social domain of quality of PLWE (p=0.001) (Tefera et al., 2020).

Living with epilepsy was accompanied by difficulty in interpersonal and love relationships. Persons with epilepsy found it difficult to marry and were unable to have children (Fletcher et al., 2015). Moreover, not being married had negative consequences on the social domain of QoL of PLWE. Tefera et al. (2020) reported that social domain of quality of PLWE was significantly negatively affected by being divorced (p=0.001). Secondly, being single has significantly negative effect on the social domain of QoL among PLWE (Ogundare et al., 2020; Tefera et al., 2020). In addition, having a younger age of onset of epilepsy, being a student and having a family history of epilepsy was associated with low QoL among PLWE (Ogundare et al., 2020). Contrary to these findings, Kaddumukasa et al. (2019) found no significant association between QoL of PLWE and demographic variables such as gender (p=0.076), age (p=0.715), onset of epilepsy (p=0.659) employment status (p=0.322), level of education (p=0.735), marital status (p=0.500) and duration of epilepsy (p=0.380). In addition, Tefera et al. (2020) found a significant negative effect of the absence of polypharmacy among PLWE on their social domain of QoL.

4.4 DISCUSSION OF SCOPING AND INTEGRATIVE REVIEW

4.4.1 Scoping review

The aim of the scoping review was to examine the concepts and constructs of contemporary epilepsy QoL questionnaires. Among the questionnaires examined were the QOLIE-31 (Cramer et al., 1998), QOLIE-10 (Leone et al., 2005; Mollaoğlu et al., 2017), NEWQOL (Abetz et al., 2000) and the Liverpool Seizure Severity Scale revisited (Baker et al., 1998). The purpose of these questionnaires was to assess the QoL of PLWE which is consistent with other questionnaires developed with the aim of measuring a particular phenomenon or variable. For example, the Occupational Depression Inventory (ODI) (Bianchi & Schonfeld, 2020) which was developed to assess work-related depressive symptoms and the Neurologic Depression Disorders Inventory for Epilepsy (NDDI-E) (Zinchuk et al., 2020) which was developed to determine major depressive episodes among PLWE.

The process of the questionnaire development for all the epilepsy QoL questionnaires in the scoping review was scientific, including the questionnaire validation (Leone et al., 2005). As part of the questionnaire development phase is the inclusion of an expert group (McMillan et al., 2016). This was done in the development of QOLIE-31 (Cramer et al., 1998), QOLIE-10 (Leone et al., 2005; Mollaoğlu et al., 2017), NEWQOL (Abetz et al., 2000) and the Liverpool Seizure Severity Scale revisited (Baker et al., 1998). The aim of including an expert group assisted with the generation of items and selection of items from an already existing item pool as well as refining of the items to suit the sociocultural context of the target population (Mollaoğlu, Durna, & Bolayir, 2015). This implies that the involvement of experts in the development of questionnaires help ensure that the questionnaires are suitable for socio-cultural context of the target population. Therefore, the development of a questionnaire that involved experts from another socio-cultural background may not be culturally sensitive to another population, although it may be relevant in terms of the subject matter it is assessing.

Due to the fact that most of these questionnaires were developed in the West, experts from these areas may not be able to factor in the socio-cultural aspect of PLWE in SSA and Ghana to be precise. In the event of the development of a QoL questionnaire for PLWE, the involvement of experts from Ghana will help fine tune the questionnaire to reflect the culture of Ghanaians in order to make it fit and appropriate for assessing QoL among PLWE in Ghana.

Moreover, as part of the questionnaire development process, qualitative studies were conducted on PLWE in the process of developing the NEWQOL (Abetz et al., 2000). This is important since it allows opportunity for PLWE to contribute to the questionnaire development. This is also reported in the development of the QOLIE-89 in the United States of America (Devinsky et al., 1995).

However, even if a questionnaire has not been developed in a particular country, they are sometimes validated in other countries and revised to fit the sociocultural context of these countries. Adaptation and validation of these epilepsy QoL questionnaires have been done in different parts of the world to ensure that the questionnaire is valid for assessing QoL for PLWE in that particular place. The QOLIE-31 has been validated in Spain (Beghi et al., 2005), Turkey (Mollaoğlu, Durna, & Bolayir, 2015), Italy (Beghi et al., 2005) and Thailand (Asawavichienjinda et al., 2005). Secondly, the QOLIE-10 has been validated in China (Gao et al., 2014) and Turkey (Mollaoğlu et al., 2017). The QOLIE-89 has also been validated in Norway (Stavem et al., 2000), China (Zhao et al., 2007), Portugal and Brazil (Azevedo et al.,

2009). This is to ensure that they could be useful in assessing the QoL of PLWE in these countries although the questionnaires were not originally developed there.

These and many other examples indicate that these questionnaires that were originally developed in the United States of America, have been adapted, refined and validated in different parts of the world because they were not suitable for those countries due to sociocultural differences. However, no study has reported on the adaptation and validation of any of these contemporary epilepsy QoL questionnaires in Ghana or and SSA country. The aim of such validation exercise is to determine its usefulness in a particular population. As a result of that these questionnaires, as of now, are not best suited for assessing QoL among PLWE in Ghana and other SSA countries where they have not been validated.

In addition, Ghana and other SSA countries traditional and religious beliefs about epilepsy (Deegbe et al., 2019; Keikelame & Swartz, 2015; Mugumbate & Zimba, 2018) is known to influence the QoL of PLWE. However, no mention of spirituality, religion or faith is made in the epilepsy QoL questionnaires reviewed in this study. The development of an epilepsy QoL questionnaire that touches on these aspects of spirituality of the Ghanaians is imperative.

4.4.2 Integrative review

Findings from the integrative review showed that physical and psychological QoL among PLWE in SSA was relatively low (Abadiga et al., 2019). This was also reported by Giray et al. (2009) among PLWE in Turkey. The physical and psychological QoL of the PLWE in this review was inversely related to the frequency and severity of seizures (Abadiga et al., 2019; Fletcher et al., 2015; M. Kaddumukasa et al., 2019; Tefera et al., 2020). This explains why patients with perceived seizure control had good psychological QoL (Muche et al., 2020). The negative relationship between seizure frequency, severity and QoL is also reported in studies in China (Lu et al., 2021), UK (Radu et al., 2019), and US (Sajatovic et al., 2017). Persons with epilepsy who experienced relatively no seizures in the past month had significantly high QoL (Gebre & Haylay, 2018).This is worsened by comorbid physical or mental conditions (Nau et al., 2018), poor psychosocial factors (Tefera et al., 2020) and medication side effects (Abadiga et al., 2019). Surgical treatment of epilepsy was however associated with high QoL (Fletcher et al., 2015). Significant improvement in overall QOLIE-31 scores was also found among PLWE after undergoing surgical treatment for their epilepsy (Qiu et al., 2019). This

underscores the need for a multidisciplinary approach to the management of PLWE (Zheng et al., 2019).

Epilepsy is associated with cognitive impairment among victims (Mwangala et al., 2018). Thus, an indication of the deteriorating nature with which seizure have on brain function. Predictors of poor psychological QoL among PLWE were a diagnosis of major depressive disorder and anxiety (Abadiga et al., 2019; Ogundare et al., 2020) as well as poor psychosocial factors (Gebre & Haylay, 2018; Tefera et al., 2020). Depression and its associated poor QoL is also consistently reported in studies in the US (Sajatovic et al., 2017). Similarly, anxiety has been linked to poor QoL among PLWE in China (Lu et al., 2021). In China, a 12-month multidisciplinary intervention program has been found to improve the psychological and emotional wellbeing of PLWE, which is worth emulating (Zheng et al., 2019).

Similar to physical and psychological QoL of PLWE, severe and frequent seizures result in poorer social function (Fletcher et al., 2015; Kaddumukasa et al., 2019). People living with epilepsy are more likely to be unemployed (Mwangala et al., 2018) and with low level of education (Tefera et al., 2020). This explains why social QoL had significantly positive relationship with monthly income (Muche et al., 2020). This is confirmed by a similar review in the US were low income as associated with poor QoL among PLWE (Sajatovic et al., 2017). There was also a significantly negative relationship with epilepsy stigma and living alone (Abadiga et al., 2019). Furthermore, social QoL is worsened by being single (Ogundare et al., 2020). This explains why Giray et al. (2009) found higher QoL scores among married PLWE in Turkey. Having a younger age of onset of epilepsy and a family history of epilepsy also worsened epilepsy QoL among PLWE in SSA (Ogundare et al., 2020; Tefera et al., 2020). In a similar study in China, younger on onset of epilepsy was associated with poorer QoL among PLWE (Lu et al., 2021).

Furthermore, the questionnaires used in assessing QoL among PLWE in SSA comprised both generic QoL questionnaires and epilepsy specific QoL questionnaires. Generic QoL questionnaires used by the studies include the World Health Organization Quality of Life Questionnaire (WHOQOL) (Nau et al., 2018) and the WHOQOL-BREF (Abadiga et al., 2019; Tefera et al., 2020). These questionnaires, although validated, are not epilepsy specific quality of life questionnaires. As such, they are unable to address disease-specific QoL concerns about PLWE (Blond et al., 2016).

On the other hand, epilepsy specific QoL questionnaires used to assess QoL among PLWE in SSA were the QOLIE-31 (Fletcher et al., 2015; Gebre & Haylay, 2018; M. Kaddumukasa et al., 2019; Ogundare et al., 2020), QOLIE-10 (Muche et al., 2020), Liverpool seizure severity scale(Fletcher et al., 2015), and the Chalfont Seizure Severity Scale (CSSS) (M. Kaddumukasa et al., 2019). These epilepsy specific QoL questionnaires are better for assessing the QoL of PLWE since they are able to address epilepsy-specific factors associated with the QoL of PLWE. In addition, socio-cultural factors are very key in relation to the QoL of people (Blond et al., 2016).

Moreover, these epilepsy-specific QoL questionnaires used in this review were originally developed in the United States of America and in the United Kingdom. As a result of that, they take into consideration the sociocultural factors of QoL of the PLWE in the countries where they were developed. However, these questionnaires may not necessarily address sociocultural factors associated with QoL among PLWE in SSA and Ghana in particular due to sociocultural differences in these different parts of the world (Blond et al., 2016). Countries like Spain (Beghi et al., 2005), Turkey (Mollaoğlu, Durna, & Bolayir, 2015), Italy (Beghi et al., 2005), Thailand (Asawavichienjinda et al., 2005), China (Gao et al., 2014), Norway (Stavem et al., 2000), Portugal and Brazil (Azevedo et al., 2009) moved on ahead to adopt and validate some of these questionnaires in order to make them fit within their sociocultural context. However, there is no evidence of any of such adoption and validation of these epilepsy QoL questionnaires in countries in SSA. This might create the opportunity for one to question the authenticity of findings from studies on QoL among PLWE in SSA that used these QoL questionnaires developed in other countries without even trying to adopt and validate these questionnaires to suit the SSA sociocultural context.

4.5 CONCLUSION

This chapter presented two literature reviews; a scoping review of the concepts and constructs of contemporary epilepsy QoL questionnaires globally and an integrative review of the QoL of PLWE in SSA. The scoping review revealed that development of contemporary epilepsy QoL questionnaires was scientific and produced valid and reliable questionnaires. However, these questionnaires were developed mainly in the West, as such were not best fit for PLWE in SSA and Ghana in particular. Most of the questionnaires were adapted and validated in other countries in order to ensure that they could be used to assess QoL of PLWE in other parts of the world but, none of that has been done in Ghana or SSA. The integrative review showed

varying reports on the physical, psychological and social QoL among PLWE in SSA. However, these reports were from data analysed by QoL questionnaires developed from other countries and have not been validated in SSA. These may not be a true reflection of the QoL of PLWE in SSA. The next chapter presents results of qualitative interviews of the meaning of QoL among PLWE in Ghana.

CHAPTER FIVE: QUALITATIVE EXPLORATORY STUDY

5.1 INTRODUCTION

This chapter presents the results from a qualitative exploratory study on the meanings of QoL among PLWE in Ghana. The objective of the study was to explore the concept of QoL from the perspective of people living with epilepsy in Ghana. A description of the methods employed in the qualitative exploratory study is presented in this chapter. Results have been presented in accordance with the themes and sub-themes that emerged from the data and supported by verbatim quotes from participants.

5.2 METHODS

Refer to chapter three, section 3.4.3, for a detailed description of the methodology for the qualitative exploratory study.

5.2.1 Research Design

This study employed the qualitative exploratory design. The exploratory design is often used with research to explore the full meanings and expressions of perceptions and opinions of people living with the condition that is important to the researcher (Polit & Beck. 2013). In this study, the researcher posed the question: "What is the meaning of QoL among PLWE in Ghana?". The design aided the research in gaining an objective understanding of rich descriptions of meanings from experiences from the participants (Fain, 2013).

5.2.2 Study Population and Sample

The study population comprised PLWE in Ghana with no comorbid mental illness or mental sub-normality. People living with epilepsy that are 18 years old and above, with some formal education, and capable of speaking or writing English or "Twi" were eligible for the study. Those who felt uncomfortable and were unwilling to take part were excluded from the study.

Fifteen PLWE took part in the study and which ensured satisfactory involvement of the researcher in the study (Wood & Ross-Kerr, 2006). The purposive sampling technique was used to select participants for the study. This was to ensure that only PLWE that were 18 years old and above and capable of speaking or writing English or "Twi" were identified and purposively selected for the study. The identification and selection of participants was done in consultation with the community mental health workers in the Greater Accra Region of Ghana.

5.2.3 Data Collection

A semi-structured interview guide was designed and used for data collection. Face-to-face in-depth interviews were carried out with each participant. Three main questions were asked with probes “What does quality of life mean to you?”; “In terms of quality of life, what do you expect as an individual living with epilepsy?”; “What else in your view about quality of life, you think it might be helpful for me to know?” (Appendix D). Written consent was sought from participants to conduct the interviews and record the interviews. The interviews lasted 45 to 60 minutes.

5.2.4 Data analysis

Data analysis was done concurrently with on-going interviews. All interviews were transcribed verbatim. Interview transcriptions were then read several times to obtain full understanding of participants’ accounts. The content analysis approach of preparation, organisation and reporting of results (Elo et al., 2014) was used to analyse data gathered using the MAXQDA qualitative data analysis software. As described in chapter 3, coding and categorisation of data (Elo & Kyngas, 2008 as cited in Elo et al., 2014) were then carried out and verified with the supervisors. The results were then described based on the content of the categories that describe the phenomenon under study in the reporting phase. Segments of data that best suited the themes identified were sorted appropriately and used to support findings.

5.2.5 Methodological rigour

The trustworthiness criteria recommended by Lincoln and Guba (1985) as cited in Polit and Beck (2018) were employed in this study in order to ensure methodological rigour. This includes credibility, transferability, dependability and confirmability.

5.3 RESULTS

The results consist of a description of the demographic characteristics of participants and thematic presentation of the findings supported by verbatim quotes. The interviews ended with the fifteenth participant after data saturation was achieved. Identification codes (1F1, 2F2, 3M1, 4M2. 5F3, 6M3, 7M4, 8M5, 9M6, 10M7, 11M8, 12F4, 13F5, 14F6, 15M9) were used, instead of the respondents’ real names, to conceal their identity.

5.3.1 Demographic Characteristic of Participants

The demographic data of the respondents that was taken included age, sex, level of education, marital status, employment status, religion and duration of illness. There were 6 female and 9 male respondents. The age range of the respondents was from 20 to 56 years. Three males and two females had tertiary level education and two participants had basic level education. Two males and one female were self-employed whilst, one male was a private employee. Thirteen of them were Christians and 11 were single. The duration with which the respondents have lived with epilepsy was from 1 to 38 years. Among them eight had lived with epilepsy not more than 10 years and three of them have had epilepsy 22 to 28 years. One male participant who was the oldest among them (56 years old) however has had epilepsy for 38 years (Table 5.1).

Table 5.11: Socio-demographic characteristics of participants (n = 15)

Nº	Code	Sex	Age (Years)	Level of Education	Marital Status	Employment Status	Religion	Duration of Illness (Years)
1.	1F1	Female	42	Secondary	Married	Unemployed	Christian	28
2.	2F2	Female	27	Tertiary	Single	Unemployed	Christian	22
3.	3M1	Male	23	Secondary	Single	Unemployed	Christian	18
4.	4M2	Male	52	Secondary	Married	Self Employed	Christian	13
5.	5F3	Female	41	Basic	Married	Unemployed	Muslim	10
6.	6M3	Male	56	Secondary	Single	Unemployed	Christian	38
7.	7M4	Male	22	Secondary	Single	Private Employee	Christian	22
8.	8M5	Male	21	Tertiary	Single	Student	Christian	8
9.	9M6	Male	35	Tertiary	Married	Unemployed	Christian	8
10.	10M7	Male	20	Tertiary	Single	Student	Muslim	1
11.	11M8	Male	32	Basic	Single	Unemployed	Christian	12
12.	12F4	Female	32	Secondary	Single	Unemployed	Christian	8
13.	13F5	Female	28	Tertiary	Single	Student	Christian	5
14.	14F6	Female	30	Secondary	Single	Self Employed	Christian	8
15.	15M9	Male	32	Secondary	Single	Self Employed	Christian	10

5.3.2 Themes and Categories

Table 5.2 presents the four themes and 14 sub themes emerged from the data analysis.

Table 5.12: Themes and sub-themes

No	THEME	SUB-THEMES
1	SUPPORT	(1) Physical support
		(2) Emotional support
		(3) Financial support
		(4) Spiritual support
2	ACCEPTANCE	(1) Acceptance from partner
		(2) Acceptance by friends
		(3) Acceptance by family
		(4) Acceptance at work
		(5) Acceptance from general population
3	SEIZURE CONTROL	(1) Nature of seizures
		(2) Medication
		(3) Disease outcome
4	SELF-RELIANCE	(1) Economic self-reliance (2) Self-care

5.3.3 Support

The meaning of QoL among PLWE is described in terms of the support they get or expect to get from family, friends and significant others.

5.3.3.1 Physical support

Physical support comprised support provided PLWE during seizures in the form of first aid or assistance to protect them from injury and suffocation. Five participants explained that to have QoL despite epilepsy is when people do not shy away from them but assist by holding them up

and supporting them from falling and getting injured during seizures and to remove dirt from them after the seizures.

> *'People don't have to shy away from me when I get an attack because I might get hurt and if they had helped me, I wouldn't … if it happens to me today, it might happen to them too someday … so they have to help anybody living with epilepsy that gets an attack by holding them up and protect them from getting injured'.* (1F1)
>
> *'I expect the person to hold me when it* (seizure) *happens or help me by removing dirt from my cloths after the attack … That will make me ok, even if it's just one person that assists me out of everybody standing and watching me.'* (13F5)

Having physical support from teachers and colleagues in school also meant QoL for PLWE. This is to help prevent one from feeling bad after a seizure episode.

> *'I would like them to help that person because anybody can get it and when it happens, they have to clear the environment to avoid getting hurt by anything in that area. This will make the person feel ok because he/she has been helped the time of need. If not that person in question will have a dampen spirit in class all the time.'* (1F1)
>
> *'The teachers also have to assist by giving some first aid because during an attack, it is the teacher that will move forward first before the students. If the teacher is standing somewhere, the students will also be afraid to get close until the teacher gets close to provide care.'* (13F5)

One male participant explained how satisfied he was with the way his family was always on the lookout for him and constantly provided physical support and protection for him during seizures.

> *'To my family I'll say they are doing well to me because anytime I get the seizure, they are the people who protect me from injury and hold me up and tell me what happened. They always look out for me so that I will not fall. To me, my family is doing well so that I may not fall and get injured.'* (9M6)

5.3.3.2 Emotional support

Quality of life meant receiving love, a show of concern and emotional warmth from relations and friends. Participants complained of feeling shy after a seizure episode in school and public

places and will like to be comforted. Having the reassurance that someone will be there to provide care or assistance during a seizure episode also gave them some emotional comfort.

> *'After an attack, you feel shy so if the teachers do not get close or make some of the student get close to you, you are always shy. Apart from the shyness, you are also scared that it's going to happen again. So, knowing that someone will care for me when I have a seizure makes me feel ok in class.'* (13F5)

> *'I expect the person to ask me what happened so I explain. That will make me feel ok ... But if no one shows any kind of love or concern, that is very bad.'* (14M6)

Being reassured, counselled, pampered and talked to in a nice and respectable way by their wives meant QoL for two male participants who were married.

> *'Maybe I would like my wife to talk to me nicely or pamper me after the seizure.'* (11M8)

> *Oh, I would want my wife to counsel me and reassure me that everything will be okay and that God will heal me.'* (4M2)

5.3.3.3 Financial support

Financial support for upkeep of self and family and to cater for one's health needs was expressed.

> *'I want help with money so that I can take care of myself.'* (6M3)

> *'Okay for now, all I want is to get someone to support me with money so that I can buy food to eat while taking the medication. … I have certain diet restrictions, so I need money so that I can buy and eat the food that will make me recover from my condition... That's my worry now.'* (5F3)

Quality of life meant getting financial support to take care of children and to pay bills.

> *'Yes. we are four and I have three children and this is my condition. So, I pray that some family or friend gets me some money to cater for them so that I don't get worried every day and feel sad that I couldn't take care of my children. Right now, one of them has completed school and wants to continue but their father complains of having no money.'* (5F3)

Two participants mentioned financial support to buy medicines to treat their epilepsy in the form of sponsorship from government or from any philanthropist.

> *'So, the health issue has to do with our medication and we would plead with government to help us out a bit there with some sponsorship… to help us and perhaps buy some of my drugs'.* (12F4)

> *'I'll be very glad if we get help not only from our family but from others in the form of small funds … Maybe now I'm having financial problems and my mother or father cannot help. So, anyone who can give me money, I will like it.'* (7M4)

5.3.3.4 Spiritual support

Spiritual encouragement and support in terms of prayers were linked to QoL among PLWE. One participant received spiritual support in the form of encouragement from her husband to pray and trust God for healing.

> *'When I go to church, I pray. My husband always encourages me …. So, I am and I'm praying waiting for the day God will actually heal me.*' (1F1)

Other participants indicated that being in a good relationship with God, having a fulfilling spiritual life and being able to pray were satisfying moments that represented QoL. It also served as a means of connection to God for healing.

> *'I think I do have a fulfilling spiritual life… I think that one is a one-on-one relationship with your own God… I can pray to God anywhere at any point, so devoid of people in church and people not in church, I am satisfied that I have a fulfilling life with God.'* (14F6)

> *'My spiritual aspect too is very important. As a human being your spiritual aspect is very important, so that God will help me and through my prayers. God Himself will heal me. That's what I have.'* (3M1)

On the other hand, another participant expressed disbelief about any spiritual link to epilepsy. However, the participant was hopeful that prayers and meditation could contribute to healing.

> *'I don't believe any more about the spiritual aspect of it* (epilepsy) *but I think if you pray and meditate on the Bible God will help. That will be part of the healing. While taking*

the medication, I have to also pray. That will also solve it.' (7M4)

5.3.4 Acceptance

Acceptance has to do with receiving the individual as a person rather than focusing on the disease (epilepsy) The act of accepting one as a person despite epilepsy meant QoL for the PLWE.

5.3.4.1 Acceptance from partner

According to the participants, not being rejected but instead receiving unconditional acceptance, getting attention from a partner and experiencing a loving and intimate relationship with a partner was QoL to them.

> *'To me quality of life is when the person* (partner) *is not rejecting me when I come to her because of the situation I am in... and that the person would accept my love proposal. That's what I have to say.'* (10M7)

> *'It's not a good thing because sometimes you feel rejected or feel worthless for a relationship. Not every lady will accept us. And that's very bad. So, they have to see us normal like everybody … I think the person* (partner) *should love and treat me well like people without epilepsy. They* (prospective love partner) *shouldn't rather reject us but rather get close to us and rather help us.'* (7M4)

To one male participant who was a single father, QoL meant having a partner who would accept him and live with him whilst raising children together.

> *'All I want is to have my partner so that we can stay together happily. Although I have a child, I'll be glad if I'm staying with my lovely partner and living together with our children.'* (15M9)

In addition, being accepted by the family of the partner or being able to marry was satisfying for PLWE and represented QoL for them.

> *'I have been dating for close to three years now and my husband to be is scared to sit his mum down and say this is what my wife to be is going through; and it's scary … She might even decide, okay if that's the issue then there's no way - you're not going to be a part of this family. I've heard of a lot of marriages that didn't work because one partner was suffering from this* (epilepsy) *and so most of the time people shy away from it.* (12F4)

'It's nice and satisfying to marry. If you stayed all your life and you didn't marry it will be very uncomfortable.' (6M3)

5.3.4.2 Acceptance by friends

Participants expressed deep concerns about avoidance and rejection from friends. They expressed frustration and heartbreak at instances where people withdraw from them because of their condition (epilepsy).

'... And it is heart breaking to know that because somebody knows this is what is wrong with you, they have withdrawn from you.' (2F2)

This prevented some from making many friends for fear of rejection.

'Interestingly, with friends, I don't have a lot of them because then you might have to sit somebody down and explain, this is what is wrong with me and you don't know how the person would take it.' (14F6)

Being welcomed and accepted by friends despite epilepsy was QoL to the PLWE.

'Quality of life is that I would get close to my friends and they will not deny me ... I mean whenever my friends see me, they will not shy away from me because of the fear of they also contracting epilepsy.' (3M1)

'Despite my state, I want them to come around me because the more they come around me, the more I feel that I am at home.' (8M5)

5.3.4.3 Acceptance by family

To the participants, QoL also meant having a family that cares, recognizes and accepts one as a family member irrespective of the diagnosis of epilepsy.

'Okay, if you say quality of life, to me it means all the family showing you love by accepting you as you are anywhere you go. And if you are accepted as you are, you are free of everything. That's what I think quality of life is ... If my own family members do not accept me the way I am due to this illness and anyone out there sees it, they could also shy away from me because my own family does not even accept me.' (12F4)

'Oh, as for me quality of life is that the family treat me well. They care about me. They call to know how I am doing.' (4M2)

The participants expect family members to draw closer to them and also help them with the challenges they face as PLWE and not to abuse or neglect them. Quality of life meant not being regarded as a burden to the family because of epilepsy but, rather to live in harmony with ones' family.

> *'Oh, as I said I don't want my family to neglect me as if I am not a human being. In the past when I have seizures people think that I am bad or burden to the family. The family members start to neglect me. But I am praying that this will not happen anymore. I should be living in harmony with my family.'* (8M5)

5.3.4.4 Acceptance at work

Participants raised concerns about negative perceptions and attitudes that colleagues and employers had about them at work because of their epilepsy. They recounted instances of being dismissed from work, disrespected and disregarded for one's contribution to issues at work because one has epilepsy.

> *'I learnt decoration and my aunty made me go work with a friend of hers that owns a gift shop and I got an attack. At the time, the owner herself was not around but some of the workers were there. When I came the next day, she paid me off when the month had not even ended and told me she was travelling abroad to go buy goods so she will call me back when she returns. But to me I knew she was trying to ask me to leave. So, to me I think that is not a quality of life.'* (1F1)

> *'In the past when we go for meetings at work, the suggestions that I will give, they think it is bogus because of this attack I've been having so they don't give me any respect. And whenever I give an advice or say anything, they don't take it.'* (14F6)

Participants, particularly those working, perceived QoL as being able to get along with colleagues at work and employers listening to them and trying to understand their condition in order to provide them with the needed support to be productive at work.

> *'Quality of life is that I can be able to chat with my colleague workers and play games with them.'* (11M8)

> *'They* (colleagues and employers) *should treat me as every other normal person without fear because, there is nothing to be afraid of at the end of the day. Just treat me as you would treat somebody who is not living with epilepsy.'* (2F2)

5.3.4.5 Acceptance from general population

Participants raised concerns about people not accepting them but rather running away from them during seizure episodes due to lack of awareness about epilepsy and the fear of contagion. They stressed the need for more education on epilepsy to the general public in order for them to understand and get closer to PLWE.

> *'The problem is, because people think it is contagious, that's why most people don't help but I feel that if awareness is created that it is not contagious people living with it will be helped when they get the attack.'* (1F1)

Quality of life meant being in a state where one needs not bother about when or where a seizure episode might occur in public without fear of being stigmatized.

> *'Quality of life would be having to live without looking over your shoulder, knowing that you can have a seizure anywhere and nobody would use it against you and there would be no stigma…'* (14F6)

Quality of life meant the general public accepting PLWE and not staying away from them because of their condition, but rather relate with them well just like any other person.

> *'All that I want to say is that people should see us as normal people and shouldn't underrate us. They should not think that because we have this disease* (epilepsy) *we cannot do what other people do. So that's all I want to say. They shouldn't underrate us or stay away from us because of this disease.'* (7M4)

5.3.5 Seizure control

Control of seizures comprised control of the frequency and severity of the seizures, having access to quality medications for the treatment of seizures in addition to the control or cure of seizures.

5.3.5.1 Nature of seizures

Nature of seizures was described in terms of frequency, severity and injuries resulting from seizures. Some of the PLWE recounted severe and frequent seizures that disrupted their lives and activities of daily living.

> "*Okay, the attack comes differently for everybody. For me, when we first got married, I used to get attacks*

> *about ten times a day … I could not do anything. But things are okay and now I could go about two to three months before getting an attack*". (1F1)

This made some become frustrated and wondered why they would suffer such a condition.

> "*Almost every time, every day I have this problem – why?"* (11M8)

What QoL meant to the participants was to have less severe seizures and less frequent seizures of not more than 6 times in a year.

> "*I'm okay if it comes at least ones every two or three months."* (2F2)
>
> "*Okay, I think the attack going away for about three, four to five months for me to see that it's fading away is what will really make me happy*." (1F1)

Others expressed satisfaction with the reduced severity and frequency of the seizures they were experiencing due to the antiepileptic medications they were taking.

> "*Now I would say it's okay for me because of the medication. It was very rough like I said but due to the medication, it's okay and the frequency as well as severity has subsided and I'm very happy about it*". (5F3)

The participants explained that QoL meant having milder seizures without any injuries despite epilepsy. They expressed satisfaction with seizures with minimal or no falls.

> "*I want it come such that I will not fall down and hurt myself. Not falling down and getting injured*." (12F4)

This motivated them to comply with drug regimen to avoid severe seizures with consequent injuries that may disrupt their daily lives.

> "*Formerly, I could just fall but as I'm taking the medication, the falls have reduced and my condition is also better than before. I am now happy about it. That's the reason why I want to take the drugs consistently*". (5F3)

5.3.5.2 Medication

Quality of life meant having access to quality medication for the treatment of epilepsy. Quite a few of them reiterated they will be happier and more satisfied if they had continuous access to antiepileptic medicines that were also affordable.

> "*Well, I don't think there's anything worse than not being able to afford your medication."* (2F2)
>
> "*I always want to have access to the medicine. If every day I get access to it and take it every day as prescribed by the doctor, I think it will help*." (7M4)

However, access to antiepileptic medicines for the PLWE was affected by lack of money unaffordable antiepileptic medications and poor health insurance cover for antiepileptic medications.

> "*When the medications get finished, I don't get money outright to buy another one. When this happens, it worries me a lot*." (5F3)
>
> "*…but sometime the prescribed medications are not covered by the National Health Insurance Scheme which you will have to pay for and they are expensive*." (1F1)

Not only access to medicines, but also, access to quality antiepileptic medication meant QoL to the participants. To them, access to antiepileptic medicines that can effectively control their seizures or cure them from their seizures meant QoL to them.

> "*For me I want just medication that I can live on that can take away this sickness. That's one major thing I want in my life. Because I have been taking all this medicines and other things in my life and this keep occurring. So, it doesn't, make me comfortable in life*." (9M6)

To others QoL meant having access to quality antiepileptic medication with minimal or less side effects.

> "*I think finding a medication that is suitable and has a very minimal side effect for this condition will be satisfying for me. … So, if we know of medications that have really, really low side effects, especially for the female body … that will be good for me."* (2F2)

5.3.5.3 Disease outcome

Quality of life in terms of disease outcome among PLWE was described as expectations for cure from seizures and the reassurance of no risk of transmission of epilepsy to their children.

> "*I want to be healed. I have been taking the medications for a long time now, both traditional and orthodox medicines but the disease still comes. If I could get healed, I'll be very happy*." (6M3)

> *'I will be happy that my children to be born will not carry the illness … Yes, that my future children will not have the same attack … That's all I have to say.'* (3M1)

To one participant, being free from seizures meant more to of QoL, happiness and satisfaction to him than to become rich.

> "*As for money, it is not my main concern. What is the use of money when you're not healthy? You can never be happy. So, I want to be healed. That's what I want to make me satisfied."* (6M3)

Quality of life meant being physically fit and seizures not interrupting with work and academic activities among PLWE.

> *'I expect that I will live a healthy life where I will not have this epilepsy again because this is the reason, I am not able to advance in my education… One thing I also have to say is that, I want to be strong, healthy and be able to work. That's what I have to say.'* (3M1)

> *'I was a student and came home because of the epilepsy. So, all I want is a hospital that can treat me well and cure me so that I go back to school and join my colleagues.'* (9M6)

Physical fitness was also described in terms of general health, energy and vitality. To have QoL, PLWE expected to be strong and energetic.

> "*As for me, the first thing I want is to have energy*." (6M3)

> "*For me, I want to be strong and enjoy every food that when I eat, it would not give me attacks*." (3M1)

5.3.6 Self-reliance

To be self-reliant was perceived as QoL for the participants. Thus, being independent, a state where one is gainfully employed and is able to work and financially support the family without relying on others for financial assistance. To be self-reliant also meant a state in which one is able to carry out physical selfcare activities independently and also be able to protect self from injury during seizures without assistance from others. The sub-themes under self-reliance were economic self-reliance and self-care.

5.3.6.1 Economic self-reliance

People living with epilepsy expected to be in a state of financial sufficiency. This is a form of financial wellbeing where one is able to take care of personal financial demands. Quality of life in terms of economic self-reliance meant gainful employment, less stressful work and the ability to work, take care of personal financial needs and be able to contribute to the family financially.

> "*So, …. I will be satisfied to work and make money to take care of myself as well as being able to work like every other, excuse me to say, "human being" and be part of them too*." (1F1)

> "*So, you having a stable job, something that pays or you're self-employed and it's good for you, that is the reality I want to experience."* (2F2)

One male participant wished to be able to work and pay school fees on his own to further his education.

> "*I wish that I would get a job to do to take care of myself and further my education."* (3M1)

Apart from being gainfully employed, being in the position to provide for one's family's financial needs was seen as a fulfilling state of quality life for PLWE.

> "*I would love that I could work and bring money home but, with my condition I couldn't… I want to work and bring me some income to help the family*." (1F1)

On the other hand, participants were also concerned about the stressful nature of the work they wanted to do. To them, QoL meant doing a tolerable and a less stressful work that would not affect their health.

> "*Personally, stress doesn't work for me, stress just doesn't work for me in anyway. So, I've never done a long day, like 08:00 o'clock to 05:00 job. I've never done any of that. So, I go to work maybe 08:00 am and then I tell my employer that I would like to close at 03:00 or 03:30 so I can go home and get some rest."* (2F2)

> "*I don't need to stress myself too much with work to prevent it* (seizures) *from occurring. So, this limits us to the type of work we have to be doing. …Our employers should provide suitable and less stressful environment to prevent it from occurring or reduce the severity*." (7M4)

5.3.6.2 Self-care

Participants described QoL as being able to carry out activities of daily living independently, and to be able to move around alone without the need for an escort or someone watching out for the person.

> "*At first, I couldn't go out alone to buy something without anybody escorting me but now, I am happy I can do things on my own. I can take the children even to Kumasi or Cape Coast* (cities far away from Accra - the place of the interview) *just by myself."* (1F1)

> "*Now I am able to go to places I couldn't go on my own so I would say it is good for me*." (2F2)

Secondly, QoL in terms of self-care represented self-control over the seizures. Having some form of self-control where one is able to avoid or minimize injury during seizures made the participants feel satisfied about their condition. This includes being able to sense any impending seizure and taking the necessary precautions independently to reduce the severity of the seizure and to avoid any injury getting to a safe place before the seizures begin.

> "*This is when before an attack, I can tell and be able to control it… Like I can control myself during an attack and know when to stand or sit somewhere safe*." (3M1).

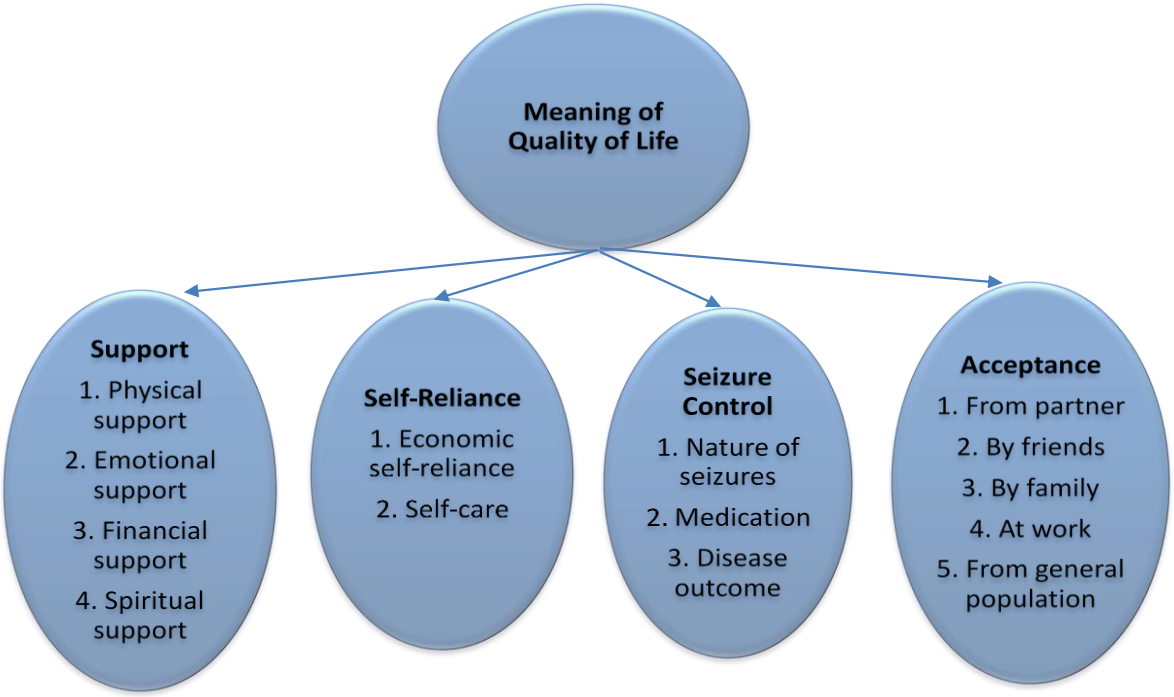

Figure 5.6: Meaning of quality of life among people living with epilepsy

5.4 DISCUSSION

The discussion in this section revolves around support for PLWE, acceptance, seizure control and self-reliance among PLWE.

5.4.1 Support

Physical, emotional, financial, and spiritual support were considered as positively contributing to the QoL of PLWE. Participants indicated the need for physical support by receiving some first aid from bystanders in the form of physically holding up and protecting one from injury and suffocation during a seizure. Injuries are sometimes associated with seizures as some PLWE fall unconscious and injure themselves in the process (Deegbe et al., 2019). Therefore, participants preferred to have a life where people would rather protect them from injuries and assist in cleaning them up after a seizure episode in public. In the absence of any physical support, Deegbe et al. (2020) found that PLWE who had the wherewithal made changes at their workplace to guarantee their safety.

Participants who are students perceived QoL in the school environment to be a situation where teachers served as role models in protecting them from injury and preserving their dignity. This is because in school, teachers and administrators wield powerful influence to change the way

classmates treat another with epilepsy (Fayed et al., 2021). This could help avoid any form of embarrassment of students or school pupils with epilepsy after a seizure episode in school. This is because seizures are unpredictable and their occurrence in public places such as schools and in the presence of unsuspecting persons causes a lot of embarrassment to PLWE (Deegbe et al., 2019).

Due to the anxiety and embarrassment associated with seizures, the PLWE become sad and would prefer to be comforted by a loved one. The reassurance of having someone around to provide some care and assistance during a seizure episode gave the participants some emotional comfort. This is likely to lighten their mood and prevent them from getting depressed hence promoting their QoL. This is because depression is known to be a singular predictor of poor QoL among PLWE (Campos-Fernández et al., 2020; Ogundare et al., 2020). Emotional support in the form of counselling, reassurance and the expression of love and continual support from spouses and family members despite epilepsy meant QoL for the participants. Similarly, Lu et al. (2021) found that the show of love and emotional warmth for PLWE give them peace of mind, makes them less anxious and improves their QoL.

Participants in the current study who were unemployed indicated that receiving some financial assistance from family and friends would make them live a meaningful life. This is to help them meet personal financial demands such as personal upkeep, payment of hospital bills, purchase of antiepileptic medicines as well as enable them to support their family's financially, where necessary. In a similar qualitative exploratory study in Ghana, Deegbe et al. (2020) found that church members and family members played active role in supporting PLWE financially in order for them to survive. This underscores the importance of financial stability to QoL of PLWE.

There are indications of various perceptions about the causes of epilepsy including physical, spiritual and unknown causes among the Ghanaians living with epilepsy (Deegbe et al., 2019). This explains why some participants in the current study perceived spiritual support in terms of prayers and the hope in God for healing as QoL. The result from this study can be linked to a similar study in Ghana in which seeking for healing through prayers and the belief in God for healing were coping strategies adopted by PLWE (Deegbe et al., 2020). Thus, an indication of the belief that epilepsy has a spiritual cause –is common in Ghana and in sub-Saharan Africa (SSA) as a whole (Deegbe et al., 2019; Muchada et al., 2021; Mugumbate & Zimba, 2018).

Therefore, trusting in the divine for protection and deliverance from evil spirits and demonic possession, as well as receiving forgiveness of sins from God, was QoL for the PLWE.

5.4.2 Acceptance

Participants in this study preferred to be seen and accepted as a person and not seen as a diseased person. Quality of life was explained as being accepted unconditionally by a partner, and by the partner's family, irrespective one's situation as a person living with epilepsy. As a result, participants in the current study had trouble establishing a stable love relationship due to the history of epilepsy. Difficulty in establishing a true love relationship negatively affects their mood and further contributing to low QoL (Ogundare et al., 2020).

These negative behaviours by potential partners are as a result of the stigma associated with epilepsy, not only among Ghanaians (Deegbe et al., 2019) but, in other SSA countries (Anguzu et al., 2021; Mbelesso et al., 2019; Menon et al., 2019). Consequently, PLWE remain single, or even lose their marriage later if they were married (Deegbe et al., 2019). These unfortunately contribute to poor QoL among Ghanaians with epilepsy. On the contrary, in Canada, romantic relationships had a formative effect on the lives of PLWE which positively contributed to their QoL although some PLWE had doubts about their partners willingness to fully accept them (Fayed et al., 2021).

Furthermore, the expectation of QoL among participants in this study was that, family members should accept them, get close to them, show concern about their health and help them to deal with the challenges associated with living with epilepsy without seeing them as a family burden. Perceiving PLWE as a family burden is likely to perpetuate the stigma associated with epilepsy (Deegbe et al., 2019) and subsequently affect the QoL of PLWE. Acceptance by family members has significant positive effect on the QoL of PLWE. This however, depends on the knowledge of family members about epilepsy and their willingness to understand their relatives living with epilepsy (Fayed et al., 2021). Participants in the current study were also concerned about acceptance from their friends. Not being accepted by friends because of epilepsy resulted in feelings of frustration and heartache which had negative consequences on their QoL. According to Fayed et al. (2021), these negative social experiences cause negative identity and further social isolation of PLWE (Fayed et al., 2021).

In this current study, PLWE complained of not being accepted at work, disrespected and in some instances, laid off from work. Similarly, an earlier study in Ghana established there was

evidence of stigma and discrimination among PLWE at the workplace (Deegbe et al., 2019). Rejection at the workplace may be linked to disruptions that seizure episodes may cause in their work environment and to their work output (Deegbe et al., 2019). Instead of treating PLWE badly and laying them off from work, employees and co-workers should rather create a warm welcoming environment for PLWE and show some interest in their treatment to improve their QoL.

These behaviours of people disassociating themselves from PLWE mirror misconceptions and myths around epilepsy in Ghana and other SSA countries (Deegbe et al., 2019; Kaddumukasa et al., 2018; Kpobi et al., 2018). In response to this, PLWE are likely to conceal their diagnosis as a way of protecting themselves and preventing themselves from being stigmatized by the family, friends and the general population (Deegbe et al., 2020). Participants therefore dreamt of a society that understands epilepsy to the extent that PLWE are not stigmatized, do not bother about having seizures in public and, are recognised as persons and not as epileptic patients. Unfortunately, people without epilepsy were found to have worse imagined QoL with epilepsy compared to actual reports of PLWE which is a recipe for the perpetuation of stigma against PLWE (Braga, 2021). This underscores the need for more and intensified education campaigns on epilepsy to the Ghanaian population, in SSA and beyond, to make the world a better place for PLWE.

People living with epilepsy are likely to conceal their diagnosis as a way of protecting and preventing themselves from being stigmatized by the family, friends and the general population (Deegbe et al., 2020). In fact, acceptance is an essential component of adaptation among PLWE which is required by PLWE in order to attain good QoL (Fayed et al., 2021). This underscores the importance of acceptance as an important contributor to QoL among PLWE. Unfortunately, existing epilepsy specific QoL questionnaires do not have acceptance as a main construct.

5.4.3 Seizure control

Severe and frequent seizures experienced by some participants affected their daily lives. In their qualitative study in Ghana, Deegbe et al. (2019) found similar results where seizure severity affected work, schooling and general daily activities of PLWE. Seizure severity and seizure impact have also been reported to have significantly negative correlation with QoL of PLWE in most SSA countries (Akosile et al., 2021; Jang et al., 2018; Kaddumukasa et al., 2019). This made some participants in the current study frustrated and wondered why they

would suffer such a condition. This result is also reported by Deegbe et al. (2020) where some PLWE in Ghana worried about how to find a cure for their illness.

Some participants were of the view that QoL is having the frequency and severity of their seizures under control. Deegbe et al. (2020) posited that to achieve this requires strict adherence and commitment to antiepileptic treatment regimen. The ease of access to quality antiepileptic medication was considered as QoL by PLWE. Access to quality antiepileptic medications was however affected by financial constraints and inadequate insurance cover for antiepileptic medications. The low health insurance cover is likely to increase out of pocket hospital expenditure which is known to reduce QoL (Lekoubou et al., 2020). Failed epilepsy treatments take a toll on PLWE by reducing their QoL (Fayed et al., 2021). To others QoL meant having antiepileptic medication with minimal or less side effects. This is because side effects of antiepileptic medications have negative effect on the QoL of PLWE (Fayed et al., 2021; Lozano-García et al., 2021).

The expectation to be physically healthy, and not experience seizures any longer, was QoL for PLWE. This confirms findings of Deegbe et al. (2019) that PLWE in Ghana have expectations for cure. However, some of these hopes get shuttered along the line due to no significant improvement in seizure control after long periods of treatment. To be free from seizures represented a happier and satisfying quality life than to be rich. In their qualitative study on disease outcomes and coping strategies among PLWE in Ghana, Deegbe et al. (2020) found that achievement of seizure control elicited feelings of happiness and less anxiety.

However, seizures are known to interfere with work, schooling and activities of daily living whilst engendering negative emotions among PLWE (Deegbe et al., 2019; Jang et al., 2018). Undoubtedly, seizures pose a lot of challenge to thinking and memory problems which are likely to interrupt with patient work or schooling (Fayed et al., 2021). This also affects the QoL of PLWE. In the current study, participants expected their seizures to be under control so that it does not affect their work, schooling, and other activities.

In addition, participants were concerned about the possibility of transmitting epilepsy to their unborn children, and complied with any treatment regimen they had. Treatment of epilepsy in Ghana commonly involves a combination of both orthodox and traditional medicines (Deegbe et al., 2020; Kpobi et al., 2018). The demand for traditional medical treatment for epilepsy is first due to the huge treatment gap, which is estimated to be about 75% among PLWE in low-

and middle-income countries, including Ghana (Meyer et al., 2010). Secondly, traditional and cultural beliefs about epilepsy account for the preference for traditional medicine for treatment of epilepsy (Musyimi et al., 2016). This is mainly because these traditional and faith-based healing systems are founded on the traditional values and beliefs of Ghanaians (Deegbe et al., 2019; World Health Organisation, 2013). This underscores the importance of traditional medicine in the treatment of epilepsy in Ghana.

5.4.4 Self-reliance

In this study, participants opined that, to be self-reliant, thus, being able to meet financial demands and self-care satisfactorily, was QoL. This finding is similar to that of a study in Canada where the desire to be employed and become independent was also shared by youth living with epilepsy and their families (Fayed et al., 2021). Fulfilling the need to be able to also provide for one's family was QoL for the participants. However, these desires are hampered by negative attitudes that have contributed to unemployment among PLWE in many SSA countries including Ghana (Diby et al., 2021) and Nigeria (Okoye et al., 2016). Increased employment status of PLWE can be linked to the widely prevalent state of stigma and discrimination among PLWE in SSA (Kaddumukasa et al., 2018) which invariably affects the QoL of PLWE.

One aspect of QoL desired by the participants was their ability to carry out selfcare activities independently. Participants would rather wish that, all things being equal, they are also able to move about freely like any other person (Deegbe et al., 2020). Participants therefore wished that being able to have some form of control over their seizures on their own would amount to improving their QoL. Being able to sense an impending seizure and taking some precaution to protect self from injury in the event of a seizure made the participants feel okay about their condition. In a related qualitative study in Ghana, Deegbe et al. (2020) found that PLWE in an attempt to protect themselves from injury during seizure episodes, lay or sat down immediately they sensed a seizure was imminent.

Findings from this study on aspects of life including support, acceptance, seizure control and self-reliance that are affected by seizures have implications for assessing the QoL of PLWE. From accounts of participants in this current study, the facets of acceptance (partner, family, friends, work, general population) suggest that the theme acceptance could be a main construct in the assessment of QoL among PLWE in Ghana in SSA. The information here can be used

in the development of the QoL questionnaire which presents the living experience of PLWE in Ghana. This supports the significance of this study with the overall aim to develop a QoL questionnaire for PLWE that fits into the sociocultural context of PLWE in Ghana.

5.5 CONCLUSION

The aim of this study was to explore meaning of QoL among PLWE in Ghana. Being accepted and receiving support from relations and the community members meant QoL to PLWE. This includes unconditional acceptance from family, friends, acquaintances at home, school, and work and by the public despite epilepsy. Expectations of support were in the form of protection from injury during a seizure, financial assistance to meet individual and family demands, emotional warmth, and spiritual support through prayers and encouragement. Achievement of control over seizures was a sign of quality life to the PLWE. This includes easy and regular access to quality and effective antiepileptic medications with less side effects, and a reduction in the severity and frequency of the seizures if not a complete cure from seizures. Being self-reliant in terms of selfcare and daily activities without undue assistance from others in addition to having some form of financial independence was QoL for the PLWE. The findings have contributed to meaning of QoL among PLWE in Ghana. It has also contributed to the development of a context specific QoL questionnaire to assess the QoL of PLWE in Ghana, which is described in the next chapter.

CHAPTER SIX: QUESTIONNAIRE DEVELOPMENT

6.1 INTRODUCTION

The second phase of the thesis, termed operational phase, comprises the questionnaire development process. This process begun from phase one - conceptualization phase – where one scoping and one integrative review were conducted. The scoping review examined the concepts and constructs of QoL questionnaires for PLWE worldwide. The integrative review focused on the QoL of PLWE in sub-Saharan Africa. This was followed by a qualitative exploratory study to explore meanings of QoL from the perspective of people living with epilepsy in Ghana. This helped to acknowledge the QoL among PLWE in sub-Saharan Africa and the content of QoL questionnaires for epilepsy that are already in existence. The operationalisation phase involves the integration of findings from chapters four and five to generate a list of items and domains. The nominal group process in which these items and domains are finalised by an expert group to develop a draft epilepsy specific QoL questionnaire for PLWE in Ghana is also described in this chapter. The outcome of phase two is a draft epilepsy QoL questionnaire for Ghana with appropriate items, scale of measurement and scoring.

6.2 INTEGRATION OF FINDINGS FROM CHAPTERS FOUR AND FIVE

Integration of the findings from the three studies in the conceptualisation were used to identify items and possible domains for the epilepsy QoL questionnaire for Ghana. This was done by combining items from contents of existing QoL questionnaires from the scoping review on the content of existing epilepsy-specific QoL questionnaires. Additional items were added from results of the integrative review on QoL of PLWE in sub-Saharan Africa. Lastly, items on QoL specific to PLWE in Ghana were added from the qualitative exploratory study on the meaning of QoL among Ghanaians living with epilepsy. This section comprises two steps: (1) A description of the item generation process and; (2) Construction of the epilepsy-specific QoL questionnaire for PLWE in Ghana.

6.2.1 Item generation

Results from the scoping review on the concepts and constructs of epilepsy-specific QoL questionnaires were used to derive an initial number of 35 items for the questionnaire. These were questions and statements about QoL of PLWE that were directly selected from the existing questionnaires. Twenty-three items came from the QOLIE-31, four items from the

QOLIE-10 and eight items from the Liverpool Seizure severity scale. These items were selected based on their relevance, clarity of the wording and common representation across the questionnaires. Twenty-three items were selected from the integrative review on QoL among PLWE in sub-Saharan Africa and added to the pool of items and which were placed under the selected common domains from the existing questionnaires.

From the qualitative exploratory study on meaning of QoL among PLWE in Ghana, 41 items on QoL of PLWE were also generated and added to the pool of items. These were items with culturally specific relevance to the Ghanaian context. In addition, a new domain – "Acceptance" – was discovered from the qualitative exploratory study that was not a concept or construct in the existing QoL questionnaires and from the integrative review on QoL among PLWE in sub-Saharan Africa. Out of the 99 items generated from the conceptualisation phase, 35 of them were a repeated in either two or all three of the studies. Therefore, a total of 64 distinct items were identified at the first attempt. The first pool of items had 13 domains namely: seizure worry, seizure control, emotional wellbeing, energy/ fatigue, cognitive function, medication effects, social function, overall wellbeing, seizure severity, injury, acceptance, employment and, self-reliance. This is presented in Table 6.1.

Table 6.13: Pool of items generated at first attempt

	Items and their domains	**Existing questionna.**	**Reviews**	**Interviews**
SEIZURE WORRY				
36.	Have you worried about having another seizure?	✓	✓	✓
37.	How fearful are you of having a seizure during the next month?	✓	✓	✓
38.	To what extent are you bothered about transferring epilepsy to your unborn children?			✓
39.	How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	✓		✓
40.	How much do you bother about seizures?	✓	✓	✓
SEIZURE CONTROL				
41.	How would you rate your ability to predict seizures	✓		
42.	Perceived control over attacks OR To what extent do you think you have your seizures under control?	✓		
43.	How would you rate your ability to 'fight off attacks'	✓		
EMOTIONAL WELLBEING				
44.	***In the past four weeks …*** Have you been a very nervous person?	✓		

	Items and their domains	Existing questionna	Reviews	Interviews
45.	Have you felt so down in the dumps that nothing could cheer you up?	✓	✓	
46.	Have you felt calm and peaceful?	✓		
47.	Have you felt downhearted and blue? OR How sad/ depressed are you about epilepsy?	✓	✓	
48.	Have you been a happy person?	✓	✓	
49.	To what extent do you feel comforted by family and friends?			✓
50.	How often do you get encouragement from others?			✓
ENERGY/ FATIGUE				
51.	Did you feel full of pep? OR Do you feel motivated to face each day?	✓		
52.	Did you have a lot of energy?	✓		
53.	Did you feel worn out?	✓		
54.	Did you feel tired?	✓		
COGNITIVE FUNCTION				
55.	Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?	✓		
56.	In the past 4 weeks, have you had any trouble with your memory? OR Rate your general memory performance	✓	✓	✓
57.	Trouble remembering things people tell you	✓		✓
58.	Trouble concentrating on reading	✓		✓
59.	Trouble concentrating on doing one thing at a time	✓		✓
60.	Memory difficulties OR How much are you bothered by memory difficulties?	✓	✓	✓
MEDICATION EFFECTS				
61.	How worried are you that medications you are taking will be bad for you if taken for a long time?	✓	✓	✓
62.	Physical effects of antiepileptic medication	✓	✓	✓
63.	Mental effects of antiepileptic medication	✓	✓	✓
64.	To what extent do you have access to antiepileptic medicines that can effectively manage seizures?			✓
SOCIAL FUNCTION				
65.	Has your health limited your social activities (such as visiting with friends or close relatives)?	✓		
66.	Has epilepsy affected your normal daily activities?	✓		
67.	Has your leisure time (such as hobbies, going out) been affected by epilepsy?	✓		
68.	Do you live alone?		✓	
69.	Driving limitations OR How much during the past four weeks has your epilepsy or antiepileptic medication caused trouble with driving?	✓		
70.	Work limitations OR How much do work limitations bother you?	✓		✓

	Items and their domains	Existing questionna.	Reviews	Interviews
71.	Social limitations OR How much are you bothered about how epilepsy affect the relationship between you and others?	✓		✓
72.	To that extent has epilepsy affected your love relationship? OR Are you married or in a stable relationship?		✓	✓
73.	Are you gainfully employed?		✓	✓
74.	Level of education		✓	✓
75.	To what extent do people look down upon you or treat you badly?		✓	✓
76.	How much do people show concern about you?			✓
77.	To what extent do people maintain good relationship with you after getting to know you have epilepsy?			✓
OVERALL WELL BEING				
78.	Overall, how would you rate your quality of life?	✓		
79.	How often do you get financial support?			✓
80.	How will you rate your spiritual life?			✓
SEIZURE SEVERITY				
81.	Have you had any surgery as treatment for epilepsy?		✓	
82.	How would you rate the severity of your seizures?		✓	✓
83.	How would you rate the frequency of your seizures?		✓	✓
84.	How often do you have Seizures in sleep only	✓		
85.	The presence of comorbid physical problems		✓	
INJURY				
86.	How often do you Fall to the ground during seizures?	✓		
87.	Do you worry about hurting yourself during a seizure?	✓		✓
ACCEPTANCE				
88.	To what extent do your family members continue to accept you despite epilepsy?			✓
89.	To what extent do your friends continue to accept you after getting to know you have epilepsy?			✓
90.	To what extent are you accepted at work after getting to know you have epilepsy?			✓
91.	To what extent do others accept you after getting to know you have epilepsy?			✓
EMPLOYMENT				
92.	Employers listening, understanding their condition and providing a conducive working environment			✓
93.	To what extent has epilepsy affected your work/ schooling activities?		✓	✓
94.	Gainful employment			✓
95.	How tolerable is your work? OR How stressful is your work?			✓
SELF-RELIANCE *In the past 4 weeks, to what extent have you been able to …*				

	Items and their domains	Existing questionna.	Reviews	Interviews
96.	Meet personal financial demands?		✓	✓
97.	Provide for one's family's financial needs		✓	✓
98.	Carry out activities of daily living independently?			✓
99.	Move around alone without the need for an escort?			✓

6.2.2 Construction of the epilepsy-specific QoL questionnaire for PLWE in Ghana

The 64 items and their domains were reviewed by the two supervisors and the researcher. This was to check the wording and clarity of the items, appropriateness of the items, organisation of the items in the questionnaire and also under each of the domains, and to decide on a suitable scoring method for the items. Comments from the supervisors led to a revision of the initially generated items.

As a result, the wording of some of the items from the existing questionnaires was revised in order to fit into the local context. Some statements were changed into questions and some questions were rewritten to make it complete and unambiguous. For example, items 12 and 16 in Table 6.1 were changed from "Have you felt downhearted and blue?"; "Did you feel full of pep?" to "I am a happy person"; "I feel motivated to face each day" - items eight and nine in Table 6.2. Those that were redundant and those that did not fit into the local context were deleted.

Because the questionnaire is a self-report questionnaire, the wording of the items was revised to singular first-person pronouns in order to make it easier for the respondents to identify with it and respond appropriately. For example, items one and four in Table 6.1 were revised from "Have you worried about having another seizure?"; "How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?" to "I am worried about having another seizure"; "I am worried about embarrassment resulting from having a seizure in the presence of other people" representing items one and two in Table 6.2.

Secondly, some of the items were merged. Any two or three items that were similar were compared and the best option among them selected or a better one revised to represent all the three. Items one, two and five in Table 6.1 merged to item one in Table 6.2; items nine and 11

in Table 6.1 merged to item seven in Table 6.2; items 10 and 12 in Table 6.1 merged to item eight in Table 6.2; items 21, 22 and 25 in Table 6.1 merged to item 14 in Table 6.2. Some domains that were found to be redundant were removed and their items merged with or placed under other domains that best describes them. These were overall wellbeing, injury, and employment. The tone of the statement of the questions, either positive or negative, were revised first to make it fit for any suitable scoring method and second, to make scoring of the items easy and less complicated. Item 45 under overall wellbeing in Table 6.1 was placed under the new domain, "spiritual life", in Table 6.2.

A total of 41 items were generated for the first draft questionnaire. The items were arranged in 11 domains namely: seizure worry, seizure control, emotional wellbeing, energy/ fatigue, cognitive function, medication effects, social function, seizure severity, acceptance, self-reliance, and spiritual life. This is shown in Table 6.1. The process of the development of the first draft questionnaire is illustrated in Figure 6.1.

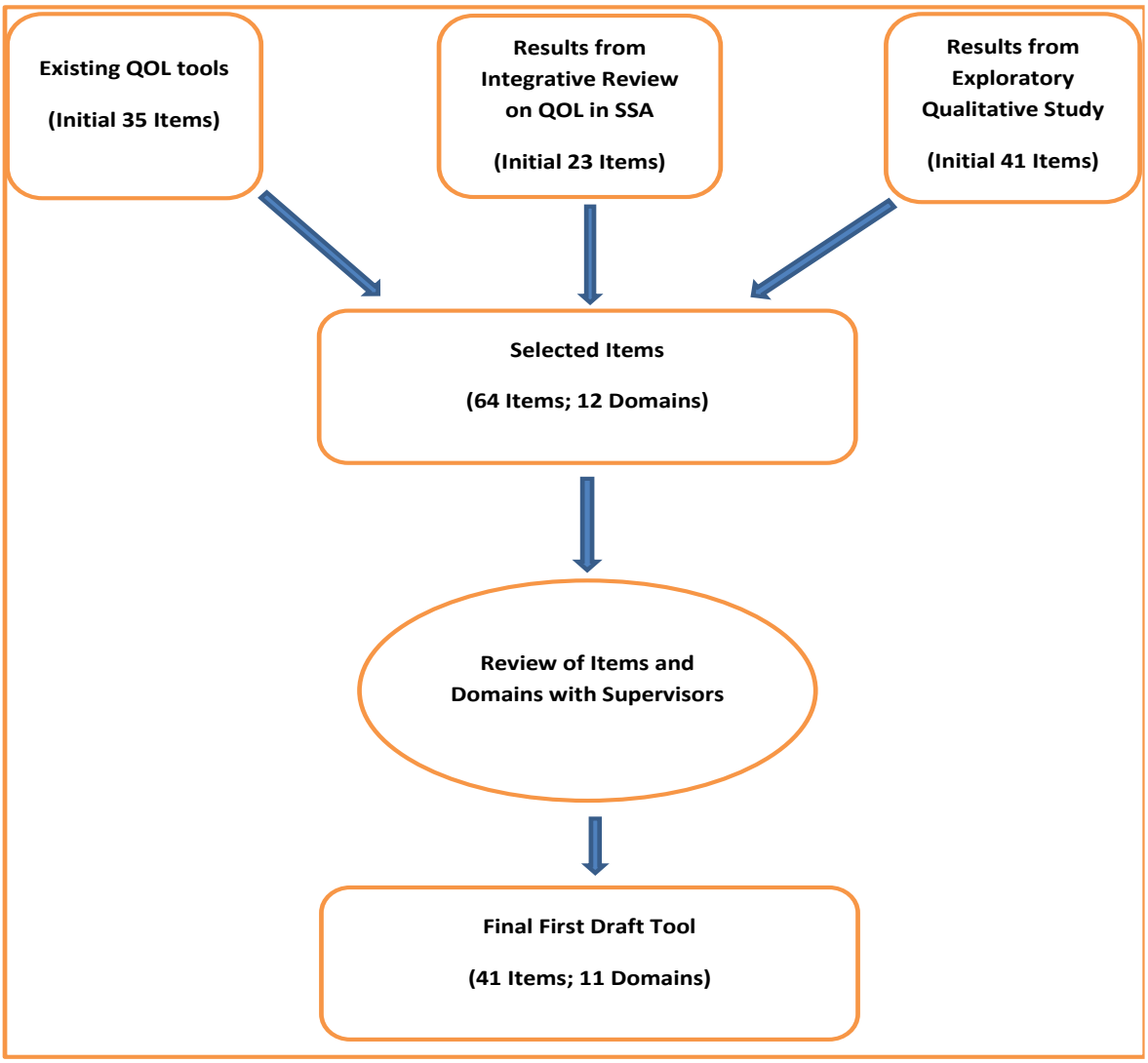

Figure 6.7: Generation of items for the first draft of epilepsy-specific Quality of Life Questionnaire for people living with epilepsy in Ghana

Table 6.14: First draft Quality-of-Life questionnaire for people with epilepsy

Items and domains	**Measurement scale**			
SEIZURE WORRY *To what extent do you agree with the following statements about your worries about having a seizure?*	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
1. I am worried about having another seizure				
2. I am worried about embarrassment resulting from having a seizure in the presence of other people				
3. I am worried about injury resulting from having another seizure				

SEIZURE CONTROL *To what extent do you agree with the following statements about your control over seizures?*	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
4. I am able to predict seizures				
5. I am able to 'fight off attacks'				
6. In general, I have control over my seizures				
EMOTIONAL WELLBEING *How often do you experience these feelings?*	**Never**	**Sometimes**	**Mostly**	**Always**
7. I feel calm and peaceful				
8. I am a happy person				
ENERGY/ FATIGUE *To what extent do you agree with the following statements about your physical strength or energy?*	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
9. I feel motivated to face each day				
10. I have a lot of energy OR I do not get tired easily				
11. I am able to work or learn with little stress				
12. I am able to meet demands at work/ school				
COGNITIVE FUNCTION *How often do you experience the following?*	**Never**	**Sometimes**	**Mostly**	**Always**
13. I have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)				
14. I have trouble remembering things people tell me				
15. I have trouble concentrating or reading				
16. I have trouble doing one thing at a time				
MEDICATION EFFECTS *To what extent do you agree with the following statements about your antiepileptic medicine(s)?*	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
17. My antiepileptic medication(s) affect me physically				
18. My antiepileptic medication(s) affect me mentally				
19. Taking antiepileptic medication(s) for a long time has/have been bad for me				
20. My antiepileptic medicine(s) is/are NOT able to control my seizures				

SOCIAL FUNCTION *To what extent do you agree with the following statements about your social function?*	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
21. I am NOT able to go out and visit my friends and relatives				
22. I am NOT able to enjoy my hobbies and/ or leisure time				
23. Epilepsy has negatively affected my marriage/ love relationship(s)				
24. Epilepsy has negatively affected my education/ schooling				
25. Epilepsy has negatively affected my work/ job				
SEIZURE SEVERITY *How often do you experience the following?*	**Never**	**Sometimes**	**Mostly**	**Always**
26. I have seizures in sleep				
27. I fall to the ground during a seizure				
28. I get injured during a seizure				
29. I have severe seizures				
ACCEPTANCE *To what extent do you agree with the following statements about how people accept you after getting to know you have epilepsy?*	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
30. My family members continue to accept me despite epilepsy				
31. My friends continue to accept me after getting to know I have epilepsy				
32. I feel comforted by family and friends				
33. I am accepted at work after co-workers and employers get to know I have epilepsy				
34. I am accepted by others after they get to know I have epilepsy				
35. I get encouragement from others				
SELF-RELIANCE *To what extent do you agree with the following statements about how your ability to do things on your own?*	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
36. I carry out daily activities such as mouth care, bathing, grooming and feeding and washing on my own				
37. I move around alone without the need for an escort				
38. I am satisfied with the pay I get from work				
39. I am able to meet personal financial demands				
40. I am able to provide for my family's financial needs				
SPIRITUAL LIFE *To what extent do you agree with the following statements about how your spiritual life?*	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
41. My spiritual life is good				

6.2.3 Respondents' characteristics

Characteristics of respondents were accessed from existing QoL questionnaires for PLWE. Additional characteristics were accessed from the integrative review on QoL of PLWE in sub-Saharan Africa and the qualitative exploratory study on meaning of QoL of PLWE in Ghana. These characteristics have been grouped into two sections. The first is socio-demographic characteristics and the second is clinical information on respondents. This is presented in Table 6.3.

Table 6.15: Socio-demographic characteristics and clinical information about respondents

Section	Question	Coding/Response category
Section 1	**Socio-Demographic Characteristics**	
1.1	Date	……/ ……/ ……..
1.2	Respondent's ID	……..
1.3	How old are you? *(Age as at last birth day)*	…… years
1.4	Sex	1. Male 2. Female
1.5	Marital status	1. Single 2. Married 3. Widowed 4. Separated
1.6	What is your highest level of education?	1. No formal education 2. Primary 3. Secondary 4. Tertiary
1.7	What is your employment status?	1. Unemployed 2. Private sector employee 3. Government sector employee 4. Self-employed
Section 2	**Clinical Information**	
2.1	How many seizures have you had in the past 4 weeks?	…….
2.2	On a scale of 1-4, how would you rate the severity of your seizures?	*(1- meaning slight occasional fainting episode with no injury or fall that goes unnoticed and; 4 - meaning severe frequent convulsions accompanied by injuries)*

Section	Question	Coding/Response category
		……
2.3	Have you had any surgery as treatment for epilepsy?	1. No 2. Yes
2.4	Have you had any complication as a result of seizures?	1. No 2. Yes
2.5	Do you take/ drink alcohol?	1. No 2. Yes

paragraph 2 line 3 insert e word rational and delete the after to

6.3 NAMING OF THE QUESTIONNAIRE

In consultation with the two supervisors, this epilepsy specific QoL questionnaire for Ghana was named as "Quality of Life in Epilepsy questionnaire for Ghana" and abbreviated as QUOLIE-GH. Thus, "QUOLIE" meaning QoL in epilepsy and "GH" meaning Ghana. This is to reflect the rationale for which the questionnaire was developed and also to be in uniformity with international nomenclature for epilepsy QoL questionnaires.

6.4 NOMINAL GROUP TECHNIQUE

The draft questionnaire was subject to expert review through a nominal group technique. A group of eight experts were invited to participate in a nominal group meeting to evaluate the items and domains of the draft epilepsy QoL questionnaire for cultural sensitivity and specificity to the Ghanaian context. The scoring of the questionnaire was also assessed for its appropriateness and revised where necessary. The four main components of the nominal group technique were expanded to seven steps as described by Lloyd (2011) to allow for a discussion of the voting process and a final voting was conducted. The steps involved in the nominal group technique beginning from the first to the last are silent generation, round robin, clarification and voting. Instead of ending with voting, in this particular context, there was a preliminary voting followed by a discussion of the outcome of the preliminary voting process, before a final voting on priorities was done. The nominal group ended with listing and agreement on the prioritized items.

6.4.1 Procedure

At the beginning of the nominal group meeting, members of the expert group were given an oral presentation on the outcome of the conceptualisation phase of questionnaire development

process. They were also briefed on the processes that were taken to derive the first draft of the questionnaire after which they were informed about the steps of the nominal group process and what was expected from them during each phase. Support documents, including a summary of the steps involved in the nominal group process, the draft questionnaire and writing pads were given to them whilst observing all COVID-19 protocols. The entire process is summarised in Table 6.3.

6.4.1.1 Silent generation

During the silent generation phase, a research question - 'What is your opinion about the importance of the items and domains in this draft questionnaire in relation to their cultural sensitivity to accessing the QoL of PLWE within the Ghanaian context?' – was posed to the group of experts in the round table forum. The group of experts were allowed 20 minutes to go through the draft QoL questionnaire, reflect on the question and to identify items and domains in the QoL questionnaire that are relevant and fit into the sociocultural context of Ghana. They were also asked to write down in brief statements or phrases their comments and additional items and domains they deem important to be included in the draft questionnaire with explanation. This step allowed for the experts to work in silence without any interruption and in the presence of others.

6.4.1.2 Round robin

The round robin stage comprises sharing of ideas of each expert among the group members in a round robin fashion. Ideas from expert group members were typed, one after the other, whilst projecting it on a screen for all members to see. They shared their opinion about the items and domains in the draft questionnaire presented to them. Suggestions for addition, removal and modification of some items and domains in the draft questionnaire and the scoring of the questionnaire were also received from the experts and recorded. This was done by calling on the experts to present their ideas about each domain and the items within each domain one at a time. This facilitated equal participation and sharing of ideas equally among the experts. As a result of this, many ideas were shared among the group in short period of time. An idea shared from an expert may also cause another expert to come out with a new idea to be added to the list of ideas being shared. It also provides the opportunity for these ideas to be documented and saved for record purposes. This stage lasted 40 minutes.

6.4.1.3 Clarification

At this stage, there is a serial discussion of ideas shared in the round robin stage. The aim of this stage is to discuss ideas one after other for clarification and to eliminate any form of misunderstanding of the items and domains in the draft QoL questionnaire for PLWE in Ghana. The researcher facilitated this discussion among the experts in a round table manner. The discussion lasted for 60 minutes. This provided opportunity for the experts to deliberate on all the suggestions made by each expert. Reasons for agreement and disagreement with items and domains in the draft questionnaire were presented in a manner devoid of needless argument and differences in opinion were recorded. The format of the questionnaire and the scoring method were also discussed during the nominal group discussion session.

6.4.1.4 Preliminary voting

Based on the discussion of the items, domains, scoring, and suggestions made by experts in the clarification stage, a preliminary voting was done to determine items and domains that should be included in the draft questionnaire. This was done for each of the domains in the draft questionnaire. Experts ranked the items in each domain from the first to the least with number one meaning the most important item and the last number representing the least important and item. With the researcher acting as the moderator, all the ranked scores were entered into the IBM SPSS statistical software (Version 22.2) and computed using the Kendall's coefficient of concordance test statistic (Kendall's W). The Kendall's W test statistic is a non-parametric test statistic that is used to estimate agreement in levels of agreement in rankings or ratings among judges or experts (Legendre, 2010). The Kendall's W scores range from 0-1 with scores closer to one meaning perfect agreement among the rankings and low scores, close to zero meaning disagreement in ranking among the experts.

Mean rank of each item is also provided to help differentiate between the most important and the least important items ranked. This helped in making objective conclusions and determination of the important items and domains that ought to be retained in the draft epilepsy specific QoL questionnaire.

6.4.1.5 Discussion of preliminary voting

A 30-minute discussion of the outcome of the preliminary voting was held. This was to offer a window to examine items that were highly ranked and those that were ranked low in addition to disagreement in ranking. Reasons for items ranked highly or very low were discussed after which the final voting process was conducted.

6.4.1.6 Final voting on priorities

After revising the first draft questionnaire based on the outcome of the discussion and preliminary voting on the items and the domains in the first draft questionnaire, the questionnaire was sent to the experts through their electronic mails and some in person for them to final rank and vote 'Yes' or 'No' to indicate which items they wish to retain and reject respectively, from the questionnaire. Items with a majority vote, thus, in this study, a vote of 80% and beyond, were chosen for further consideration (Wilson, 2013). Items with less than 80% vote were eliminated from the draft questionnaire.

6.4.1.7 Listing and agreement on the prioritized items

A record of the final voting process is kept for the purposes of documentation. Items included after the final voting process were used to produce the second draft of the epilepsy-specific QoL questionnaire for PLWE in Ghana. This was then presented to another group of experts and persons living with epilepsy for content validity testing and face validity testing, respectively. These are described in the next chapter.

6.4.2 Analysis

Analysis done by synthesizing and summarising the comments by experts during the nominal group technique. Direct comments from the experts are in Appendix C. Secondly, the Kendalls' coefficient of concordance (Kendall's W) was used to estimate the strength of agreement in rankings of the items in the domains of the epilepsy QoL questionnaire. A Kendall's W statistic on any item with alpha level ≤ 0.05 was deemed as having significant concordance. Descriptive statistics was used to estimate the frequency and percentages of votes cast to retain each item in the questionnaire with the last phase of the nominal group technique.

6.4.3 Results

6.4.3.1 Demographic characteristics of participants

Table 6.16: Demographic characteristics of respondents

Code	Sex	Age (years)	Educational level	Working area	Specialty
M1	Male	34	Masters	Practice and Academia	Nursing (Tuberculosis control; Model development)
M2	Male	39	Masters	Academia	Nursing (Nursing education)
M3	Male	39	Masters	Academia	Nursing (Public health)
M4	Male	36	PhD	Academia	Psychology (Clinical psychology)
M5	Male	43	PhD	Practice and academia	Nursing (Nursing education)
M6	Male	38	Masters	Academia	Nursing (Family health nursing; Model development)
F1	Female	51	PhD	Academia	Nursing (Nursing education)
F2	Female	43	Masters	Academia	Nursing (Nursing education)

As shown in Table 6.4, eight experts took part in the nominal group technique comprising six males with their ages ranging from 34 to 43 years and two females who were aged 43 and 51 years. Five of them had masters level education out of which four were in academia and only one in both academia and practice area. The three remaining had PhD out of which two were in academia and one in both academia and practice areas. Seven of them were specialised in nursing mainly nursing education and then public health. One however specialised in clinical psychology.

6.4.3.2 Ratings and comments from experts on the items and the domains

Table 6.17: Domain 1: Seizure worry

SEIZURE WORRY *To what extent do you agree with the following statements about your worries about having a seizure?*	**Mean ranking**	**Kendall's W**	**p-value**
1. I am worried about having another seizure	1.25	**.438**	**.030**
2. I am worried about embarrassment resulting from having a seizure in the presence of other people	2.25		
3. I am worried about injury resulting from having another seizure	2.50		

Experts arrived at a significant agreement in their first ranking of items under seizure worry (p= .030). Concerns were raised about the reason for seizure worry, whether it was related to the seizure itself or the outcome or effect of the seizures. Secondly, the experts also suggested additional items for the domain. They also included that the questions should be very specific focused on a particular phenomenon to elicit easy responses. Furthermore, the experts unanimously suggested an increase in the scoring points on the Likert scale to five or more in order to make the questionnaire more statistically robust. Direct comments from the experts have been placed under Appendix C.

Table 6.18: Domain 2: Seizure control

SEIZURE CONTROL *To what extent do you agree with the following statements about your control over seizures?*	**Strongly Disagree Mean ranking**	**Disagree Kendall's W**	**Agree p-value**
4. I am able to predict seizures	1.75	.063	.607
5. I am able to 'fight off attacks'	2.25		
6. In general, I have control over my seizures	2.00		

Experts did not arrive at any significant agreement in their first ranking of items under seizure control (p= .607). Some suggestions for additional items and rewording or existing items were made. For example, they indicated that item four be revised to "I am able to tell when I am about to have a seizure" (Appendix C). Experts were also concerned about terms such as "fight off attacks", "predict seizures" and "control". They suggested more specific items on particular activities undertaken by persons with epilepsy to mean "predict seizures" and "control". The term "fight off attacks" was seen as ambiguous and they suggested it is explained in plain words for ease in comprehension. To the experts, item six should be divided into parts focusing on control before, during and after a seizure. The four-point Likert scale scoring for this domain

was also questioned with suggestions for increment to a five-point Likert scale with the rationale of making the questionnaire more statistically robust.

Table 6.19: Domain 3: Emotional wellbeing

EMOTIONAL WELLBEING *How often do you experience these feelings?*	**Mean ranking**	**Kendall's W**	**p-value**
7. I feel calm and peaceful	1.13	**.563**	**.034**
8. I am a happy person	1.88		

There was a significant agreement in the ranking of items under emotional wellbeing among the experts (p= .034). They suggested that the terms calm and peaceful in item seven should be separated into two items and that one aspect should read as "I feel at peace with myself". Experts raised concerns about the small number of items in the domain and that there should be "a minimum of five items in all of the domains so that after construct validity testing, the few that may not load will leave a reasonable number of validated items for the questionnaire" (Appendix C). They indicated that items in the domain should be both positively and negatively worded. In addition, they opined that items on emotional wellbeing should be worded in the manner in which participants expressed them in the qualitative interviews to capture terms such as "sad, depressed, anxious, disturbed". There were also suggestions for the change of name of the domain to psychological wellbeing. However, the experts later decided to maintain the domain name as "emotional wellbeing". This was because of the realisation of another domain on cognitive function which is also within the context of psychological wellbeing.

Table 6.20: Domain 4: Energy/ Fatigue

ENERGY/ FATIGUE *To what extent do you agree with the following statements about your physical strength or energy?*	**Mean ranking**	**Kendall's W**	**p-value**
9. I feel motivated to face each day	2.25	.325	.05
10. I have a lot of energy OR I do not get tired easily	1.75		
11. I am able to work or learn with little stress	2.50		
12. I am able to meet demands at work/ school	3.50		

Ranking of items under domain four by the experts resulted in a significant agreement (p= .05). Experts suggested items should reflect both energy and fatigue in this domain or the domain is split into two. Secondly, they expressed concerns about terms such as "motivation", "little stress" "…lot of energy" and suggested more simpler and practical terms to represent these attributes. Some were also concerned about the use of "work/school" together since they are

two different settings. Furthermore, the experts preferred the statement "I do not get tired easily" to "I have a lot of energy" for item 10. In addition, they suggested a revision of item 12 to "I am able to meet what is required of me at home, work or school" (Appendix C).

Table 6.21: Domain 5: Cognitive function

COGNITIVE FUNCTION *How often do you experience the following?*	**Mean ranking**	**Kendall's W**	**p-value**
13. I have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)	2.25	.081	.583
14. I have trouble remembering things people tell me	2.13		
15. I have trouble concentrating or reading	2.88		
16. I have trouble doing one thing at a time	2.75		

The experts did not reach a significant agreement with their ranking of items under domain 5 (p= .583). Phrases such as "reasoning and solving problems", "concentrating or reading", were noticed to represent two phenomena and they suggested a split of these into two items. For example, rewording a part of item 15 to "I have trouble concentrating when performing an activity". They also suggested a breakdown of examples in item 13 (making plans, making decisions, learning new things) into different items (Appendix C). Others indicated the need for negative wording of some items to make it easy for respondents to identify with. The suggestion to relate the questions to time, for example, a four-week recall was made in order for respondents to report their experiences within a specific time context for accurate evaluation.

Table 6.22: Domain 6 (Medication effects)

MEDICATION EFFECTS *To what extent do you agree with the following statements about your antiepileptic medicine(s)?*	**Mean ranking**	**Kendall's W**	**p-value**
17. My antiepileptic medication(s) affect me physically	1.13	**.737**	**.001**
18. My antiepileptic medication(s) affect me mentally	2.13		
19. Taking antiepileptic medication(s) for a long time has/have been bad for me	3.13		
20. My antiepileptic medicine(s) is/are NOT able to control my seizures	3.63		

The experts had a significant agreement with their ranking of items under domain 6 (p= .001). The experts mentioned that phrases such as "… affects me mentally", "affects me physically"

were not clear and that more specific examples of physical and mental effects of seizure medications should be used instead. “For example, makes me feel weak, dull, etc” to represent different aspects of “affects me physically” (Appendix C). In addition, the term “antiepileptic medications” was also reworded to “antiseizure medications”. The experts also mentioned that items under this domain assume that all respondents are on orthodox medications for epilepsy treatment, which may not be true in real life. The experts suggested the addition of traditional or herbal medicines to reflect the Ghanaian culture and suggested an option on the scale for a neutral or not applicable response for selection. Suggestions were made for a change of the term “antiepileptic medication” to “seizure medication”. To them, the phrase “long time” was not needed in item 19. They also suggested that item 20 should be positively worded.

Table 6.23: Domain 7: Social function

SOCIAL FUNCTION *To what extent do you agree with the following statements about your social function?*	**Mean ranking**	**Kendall’s W**	**p-value**
21. I am NOT able to go out and visit my friends and relatives	1.38	**.534**	**.002**
22. I am NOT able to enjoy my hobbies and/ or leisure time	2.50		
23. Epilepsy has negatively affected my marriage/ love relationship(s)	3.00		
24. Epilepsy has negatively affected my education/ schooling	3.75		
25. Epilepsy has negatively affected my work/ job	4.38		

The was a significant agreement with the ranking of items under domain 7 by the experts (p= .002). Concerns were raised about negatively worded items, the combination of two different items as one which needed to be separated and the clarity of some items. The naming of the domain was also questioned with suggestions of renaming it as “Social function/Relationship” or splitting it into two. The need for an item on relationship with family members was mentioned by the experts.

Table 6.24: Domain 8: Seizure severity

SEIZURE SEVERITY *How often do you experience the following?*	**Mean ranking**	**Kendall's W**	**p-value**
26. I have seizures in sleep	2.38	**.368**	**.031**
27. I fall to the ground during a seizure	1.50		
28. I get injured during a seizure	2.75		
29. I have severe seizures	3.38		

Table 6.12 shows a significant agreement with the ranking of items under domain eight by the experts (p= .031). Concerns were raised about the need for items on the frequency and duration of seizures. The item on severe seizures (Item 29) was questioned and suggestions were made some more specific items that could help in determining seizure severity. Experts suggested a revision of item 26 to "I have seizures while I am asleep" (Appendix C). They also suggested breaking down item 28 into degrees or types of injury one is likely to sustain in the event of a seizure episode. One expert suggested a five-point Likert scale for scoring this domain.

Table 6.25: Domain 9: Acceptance

ACCEPTANCE *To what extent do you agree with the following statements about how people accept you after getting to know you have epilepsy?*	**Mean ranking**	**Kendall's W**	**p-value**
30. My family members continue to accept me despite epilepsy	1.13	**.820**	**.000**
31. My friends continue to accept me after getting to know I have epilepsy	2.63		
32. I feel comforted by family and friends	2.88		
33. I am accepted at work after co-workers and employers get to know I have epilepsy	3.63		
34. I am accepted by others after they get to know I have epilepsy	4.88		
35. I get encouragement from others	5.88		

Table 6.13 also shows a significant agreement with the ranking of items under domain 9 by the experts (p= .000). The experts suggested a split of this domain into two domains namely "Acceptance" and "Social support". They mentioned that "items 32 and 35 are about social support and not acceptance" (Appendix C). Statements referring to family and friends at the same time were questioned since both were different populations. Experts suggested that statements about acceptance need to be context specific and not general. They suggested a

replacement of the word epilepsy with seizures and a replacement of the term co-workers in item 33 with colleagues (Appendix C).

Table 6.26: Domain 10: Self-reliance

SELF-RELIANCE *To what extent do you agree with the following statements about how your ability to do things on your own?*	**Mean ranking**	**Kendall's W**	**p-value**
36. I carry out daily activities such as mouth care, bathing, grooming and feeding and washing on my own	1.50	**.678**	**.000**
37. I move around alone without the need for an escort	1.88		
38. I am satisfied with the pay I get from work	3.25		
39. I am able to meet personal financial demands	3.75		
40. I am able to provide for my family's financial needs	4.63		

As shown in Table 6.14, a significant agreement was found with the ranking of items under domain 10 by the experts (p= .000). The experts also suggested a split of this domain into two and a complete change of the name of the domain to "Activities of daily living" and the second "Financial independence". For example, placement of items 36 and 37 under the domain "Activities of daily living" and placement of items 38 to 40 under the domain "Financial independence". The need to add more specific items on particular activities of daily living in the context of the Ghanaian culture were also mentioned. For example, additional items such as "going out to the market or shop on my own", "using the bus/ public transport on my own". They also suggested a revision of some of the wording in some of the items. For example, replacing the word "Pay" in item 38, with "income" (Appendix C).

Table 6.27: Domain 11: Spiritual life

SPIRITUAL LIFE *To what extent do you agree with the following statements about how your spiritual life?*	**Mean ranking**	**Kendall's W**	**p-value**
42. My spiritual life is good	N/A		

The domain "Spiritual life" had only one item. As such the Kendall's coefficient of concordance could not be estimated. The experts raised concerns about the number of items under this domain and suggested more items to be added to populate this domain. Suggestions were related to the addition of items of religious activities such as prayers, visits to religious gatherings and spiritual aspects concerning faith and beliefs of the respondents. For example, "I have faith in my God for healing", "I have hope in God that I will be cured from epilepsy"

and “To observe prayers in a congregation”. A concern for the place of persons with no spiritual life in this domain was also raised. For example, “I do not have spiritual life” (Appendix C).

Comments from experts on socio-demographic characteristics and clinical information about respondents

Experts also made comment of the items accessing socio-demographic characteristics and clinical information about respondents (Table 6.3). They suggested addition of the options “divorced”, “cohabitation” and “Others (specify)…” to the item in marital status. Specification of options for the item on education was also suggested. Experts mentioned the need for an item on religion of respondents and an item on duration one has been living with epilepsy. They suggested addition of the option “Others (specify)…” to the options under employment status. They suggested a continuum for respondents to use to answer item 2.2, and specification of common examples of complications from seizures for item 2.4. Age was then suggested to be the last item in the socio-demographic characteristics domain. Type of residence, thus, urban or rural in addition to number of people in a household were suggested as additional items. The experts mentioned that items on clinical information should come before the socio-demographic characteristics subdomain.

6.4.3.3 Determination of scoring for the questionnaire

This is a self-report questionnaire intended for the assessment of the QoL of PLWE in clinical settings and for the purposes of research. A Likert scale was adopted as the yardstick for scoring the items in the draft questionnaire. This informed the wording of the items in the draft questionnaire into Likert-type statements and questions. Likert scales are useful in the measurement of latent variables such as stress, attitude, beliefs, to mention but a few. The decision to adopt a Likert scale was based on similar scoring method adopted by already existing epilepsy-specific QoL questionnaires (Baker et al., 1998; Cramer et al., 1998; Devinsky et al., 1995; Brendan Mulhern et al., 2017) and in consultation with the supervisors and experts from the nominal group session.

In the first draft, a Likert scale with 4 levels was selected for the questionnaire in consultation with the supervisors. This was to avoid any neutral or middle-point value in the assessment so as to appreciate the actual point of view of the respondent. These four levels had two forms depending on the nature and tone of the questions in a particular domain. Domains assessing the degree of affirmation of a statement were rated with the levels one to four namely “Strongly disagree”, “Agree”, “Disagree” and “Strongly agree”. Secondly, domains assessing frequency

of occurrence of a variable were rated with the levels one to four namely “Never”, “Sometimes”, “Mostly” and “Always”. Within this four-point structure of scoring, higher values represent higher QoL. However, domains with negatively worded items are to be reverse scored during the assessment in order to complete the collation of scores for making judgement.

After the nominal group technique, the scoring of the questionnaire was revised to a five-point Likert scale plus and additional column for non-applicable responses. The reason for the five-point Likert scale was to allow for a neutral position – “Neutral” - for respondents who may neither agree nor disagree, thus, feeling indifferent with any of the items in the questionnaire. The additional sixth column – “Not applicable” – was also suggested for responses to items that may not be applicable to respondents. This was to allow room for respondents to indicate where some items in the questionnaire may not be applicable to them. This revision was based on a unanimous decision by all the experts and later concurred by the supervisors after discussing with them.

Items in Domain 1, 2, 4, 6, 7, 9, 10 and 11 are scored using a five-point Likert scale as follows. The “Not applicable” responses are to be ignored and not used in the scoring.

Box 1: Scoring according to strength of agreement

Level	**Point(s)**
Strongly disagree	1
Disagree	2
Neutral	3
Agree	4
Strongly agree	5
Not applicable	0

Items in Domain 3, 5 and 8 are scored using a 5-point Likert scale as follows. The “Not applicable” responses are to be ignored and not used in the scoring.

Box 2: Scoring according to frequency of occurrence

Level	**Point(s)**
Never	1
Rarely	2
Sometimes	3
Mostly	4
Always	5
Not applicable	0

Negatively worded items will be reverse scored. Higher scores represent higher QoL.

6.4.3.4 Second draft of the Quality of Life Questionnaire

The final stage of the nominal group technique is the voting stage. In this context, listing and agreement on the prioritized items was done to finalise conclusions on the draft questionnaire after final voting was done. This led to the development of the second draft of the epilepsy QoL questionnaire based on expert recommendations during the round robin and clarification phases of the nominal group technique and discussion with supervisors. The second draft questionnaire had 66 items divided under 13 domains. The additional two domains resulted in the splitting of the domain self-reliance into two - "Activities of daily living" and the second "Financial independence" – and the splitting of the domain "Acceptance" into two – "Acceptance" and "Social support". In addition, the name of the domain "Social function" was revised to "Social function/ relationship" to reflect items representing social function and interpersonal relationship of respondents in the domain.

With the exception of item five which had one expert voting against its inclusion in the questionnaire, the remaining items had 100% vote from all the experts for them to be retained. The Kendall's W statistic showed significant agreement in ranking of items under 12 domains: Seizure worry (p= .000), seizure control (p= .000), emotional wellbeing (p= .005), energy/fatigue (p= .000), cognitive function (p= .000), social function/ relationship (p= .000), seizure severity (p= .000), acceptance (p= .000), social support (p= .000), activities of daily living (p= .000), financial independence (p= .002) and spiritual life (p= .002). Ranking of items in the medication effects domain by the experts did not achieve significant agreement (p= .154). However, all the experts voted for all the items in the medication effect domain to be retained. Details are shown in Table 6.16.

Table 6.28: Second draft Quality of Life Questionnaire for people living with epilepsy in Ghana

Items and domains	**Measurement scale**					
SEIZURE WORRY *To what extent do you agree with the following statements about your worries about having a seizure?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
1. I am worried about having another seizure	1.63	.625	.000	**8/8**	100%	
2. I am worried about the number of seizures I continue to have	1.75			**8/8**	100%	

Items and domains	**Measurement scale**					
3. I am worried about injury resulting from having a seizure	3.38			**8/8**	100%	
4. I am worried about embarrassment resulting from having a seizure	3.88			**8/8**	100%	
5. I am worried about problems (*memory loss, mental illness, infertility, children having epilepsy*) that may arise from frequent seizures.	4.38			**7/8**	87.5%	
SEIZURE CONTROL *To what extent do you agree with the following statements about your control over seizures?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
6. I am able to tell when I am about to have a seizure	1.88	.641	.000	**8/8**	100%	
7. I am able to move to a safe place before a have a seizure	2.38			**8/8**	100%	
8. I am able to lie or sit down to protect myself from injury during a seizure	2.88			**8/8**	100%	
9. I am able to take care of myself immediately after I awake from a seizure without any assistance	4.25			**8/8**	100%	
10. In general, I think my seizures are under control	4.38			**8/8**	100%	
EMOTIONAL WELLBEING *How often do you experience these feelings?*	**Never**	**Rarely**	**Sometimes**	**Mostly**	**Always**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
11. I feel calm within me	1.75	.463	.005	**8/8**	100%	
12. I feel at peace with myself	2.50			**8/8**	100%	
13. I am a happy person	2.50			**8/8**	100%	
14. I feel sad within me	4.00			**8/8**	100%	
15. I feel disturbed	4.25			**8/8**	100%	
ENERGY/ FATIGUE *To what extent do you agree with the following statements about your physical strength or energy?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
16. I have energy to carry out daily activities	1.00	.963	.000	**8/8**	100%	

Items and domains	**Measurement scale**					
17. I am able to do what is required of me at home, work or school each day	2.00			**8/8**	100%	
18. I get tired easily	3.00			**8/8**	100%	
19. I feel dull	4.25			**8/8**	100%	
20. I find it difficult to work or learn	4.75					
COGNITIVE FUNCTION *How often do you experience the following?*	**Never**	**Rarely**	**Sometimes**	**Mostly**	**Always**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
21. I have difficulty in thinking or reasoning	1.13	.657	.000	**8/8**	100%	
22. I have difficulty making plans	2.75			**8/8**	100%	
23. I have difficulty making decisions	3.38			**8/8**	100%	
24. I have difficulty learning new things	4.00			**8/8**	100%	
25. I have trouble remembering recent things people tell me	5.25			**8/8**	100%	
26. I have trouble concentrating when performing an activity	5.25			**8/8**	100%	
27. I have trouble doing one thing at a time	6.25			**8/8**	100%	
MEDICATION EFFECTS *To what extent do you agree with the following statements about your antiepileptic medicine(s)?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
28. My antiseizure medications make me dull	2.25	.219	.154	**8/8**	100%	
29. My antiseizure medication(s) make me weak	2.38			**8/8**	100%	
30. My antiseizure medication(s) make me sleep during the day	3.38			**8/8**	100%	
31. My antiepileptic medicine(s) is/are able to control my seizures	2.00			**8/8**	100%	
SOCIAL FUNCTION/ RELATIONSHIP *To what extent do you agree with the following statements about your social function?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**

Items and domains	**Measurement scale**					
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
32. I am NOT able to attend social functions such as wedding, party, funerals	2.25	.621	.000	**8/8**	100%	
33. I am NOT able to enjoy my hobbies and/ or leisure time	4.00			**8/8**	100%	
34. Seizures make schooling difficult for me	3.38			**8/8**	100%	
35. Seizures make it difficult for me to get or maintain a job	2.88			**8/8**	100%	
36. Epilepsy made me lose my love relationship/ marriage	4.00			**8/8**	100%	
37. Epilepsy makes it difficult for me to have any committed love relationship/ marriage	4.75			**8/8**	100%	
38. I am NOT able to have a friendly relationship with my friends	7.38			**8/8**	100%	
39. I am NOT able to have a friendly relationship with my family	7.38			**8/8**	100%	
SEIZURE SEVERITY *How often do you experience the following?*	**Never**	**Rarely**	**Sometimes**	**Mostly**	**Always**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
40. Having seizures while I am asleep	1.88	.641	.000	**8/8**	100%	
41. Seizures lasting more than 5 minutes	2.38			**8/8**	100%	
42. Mental confusion after a seizure	2.88			**8/8**	100%	
43. Body pains after a seizure	4.25			**8/8**	100%	
44. Falling to the ground during a seizure	4.38			**8/8**	100%	
45. Bruises after a seizure	5.75			**8/8**	100%	
46. Broken limbs (fracture) after a seizure	6.50			**8/8**	100%	
ACCEPTANCE *To what extent do you agree with the following statements about how people accept you after getting to know you have epilepsy?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
47. My family members continue to accept me despite epilepsy	1.00	1.000	.000	**8/8**	100%	

Items and domains	**Measurement scale**					
48. My friends continue to accept me after getting to know I have epilepsy	2.00			**8/8**	100%	
49. I am accepted by colleagues after getting to know I have epilepsy	3.00			**8/8**	100%	
50. I am accepted in my community after getting to know I have epilepsy	4.00			**8/8**	100%	
SOCIAL SUPPORT *How often do you experience the following?*	**Never**	**Rarely**	**Sometimes**	**Mostly**	**Always**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
51. I am comforted by family after I have a seizure.	1.00	1.000	.000	**8/8**	100%	
52. I am encouraged by my family to achieve my goals in life despite epilepsy.	2.00			**8/8**	100%	
53. My friends comfort me after I have a seizure	3.00			**8/8**	100%	
54. I get encouragement from my friends to achieve my goals in life despite epilepsy	4.00			**8/8**	100%	
55. People comfort me after I have a seizure in public.	5.00			**8/8**	100%	
ACTIVITIES OF DAILY LIVING *To what extent do you agree with the following statements about your ability to do things on your own?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
56. I am able to take care of my personal hygiene (bathing, teeth brushing) on my own	1.00	.731	.000	**8/8**	100%	
57. I wash my own clothing without any help	2.63			**8/8**	100%	
58. I am able to go out to the shop/ market to shop for myself	2.88			**8/8**	100%	
59. I am able to prepare meals for myself on my own	4.13			**8/8**	100%	
60. I move about and use public transport on my own	4.38			**8/8**	100 %	

Items and domains	Measurement scale					
FINANCIAL INDEPENDENCE *To what extent do you agree with the following statements about your financial life?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
61. I am satisfied with my income	1.00	.891	.001	**8/8**	100%	
62. I am able to meet personal financial demands	2.13			**8/8**	100%	
63. I am able to provide for my family's financial needs	2.88			**8/8**	100%	
SPIRITUAL LIFE *To what extent do you agree with the following statements about your spiritual life?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
	Mean ranking	**Kendall's W**	**p-value**	**Vote (n)**	**Vote (%)**	
64. I have faith in my God for healing	1.25	.813	.002	**8/8**	100%	
65. I have hope in God that I will be cured from epilepsy	1.75			**8/8**	100%	
66. I am able to worship in a congregation according to my faith	3.00			**8/8**	100%	

Demographic characteristics of the respondents was also revised based on comments and suggestions from experts in the nominal group technique. Two additional items were added to the clinical information to assess amount of alcohol consumed and duration of living with epilepsy. Two additional items (religion and place of residence) were also added to the socio-demographic characteristics section. Some changes in the organisation of the items and additional options for selection were also done. Details are shown in Table 6.17.

Table 6.29: Revised demographic characteristics of respondents

RESPONDENTS' CHARACTERISTICS **Note:** ***Please write your response in the space provided below or circle the one that best describes your choice of response.***		
Date: ……/ ……/ …….		**Respondent's ID: ……**
Section	**Question**	**Coding/Response category**
Section 1	**Clinical Information**	
1.1	How long have you lived with epilepsy	……. year (s)

1.2	How many seizures have you had in the past 4 weeks?	…….
1.3	On a scale of 1-4, how would you rate the severity of your seizures?	*(1- meaning slight occasional fainting episode with no injury or fall that goes unnoticed and; 4 - meaning severe frequent convulsions accompanied by injuries)* ……
1.4	Have you had any surgery as treatment for epilepsy?	1. No 2. Yes
1.5	Have you had any complication because of seizures?	1. No 2. Yes
1.6	Do you take drink alcohol?	1. No 2. Yes
1.7	If 'Yes" How many bottles do you take in a week?	---------- Bottles
Section 2	**Socio-Demographic Characteristics**	
2.1	Sex	1 Male 2 Female
2.2	Marital status	5. Never married 6. Married 7. Cohabiting 8. Divorced 9. Separated 10. Widowed 11. Other (specify): _____ _____
2.3	What is your highest level of education?	1. No formal education 2. Primary 3. Secondary (JHS/ Middle school education/ SHS) 4. Vocational/commercial/technical education 5. Tertiary
2.4	What is your employment status?	1. Unemployed 2. Private sector employee 3. Government sector employee 4. Self-employed
2.5	What is your religion?	1. Christian 2. Muslim 3. Traditionalist 4. Hindu 5. Buddhist 6. Other (specify): _____ _____
2.6	What type of community do you reside?	1. Urban 2. Rural
2.7	How old are you? *(Age as at last birth day)*	…… years

6.5 DISCUSSION

The aim of this study is to develop an epilepsy specific QoL questionnaire that is sensitive to the Ghanaian culture and appropriate for assessing the QoL of PLWE within the context of Ghana. The second draft of the questionnaire had 13 domains with 66 items in total. Out of these 66 items, 12 items are unique to this newly developed questionnaire. These 12 items are scattered under 5 domains namely: seizure worry, medication effects, acceptance, social support, and spiritual life. The items were exclusively selected from the qualitative exploratory study and was not found among the items in any of the epilepsy specific QoL questionnaires reviewed in the previous chapter. This highlights the genuineness and unique nature of this questionnaire for PLWE in Ghana.

Therefore, the qualitative exploratory study provided the opportunity for the researcher to discover rich meanings of QoL from patients with epilepsy within the Ghanaian cultural context. This led to the discovery of the domain "Acceptance", which solely emanated from desires of patients with epilepsy in the qualitative study to be accepted. The desire to be accepted is a reaction to the stigmatising attitudes such as avoidance and rejection of PLWE which is predominant in Ghana (Deegbe et al., 2019) and other sub-Saharan African countries (Anguzu et al., 2021; Mbelesso et al., 2019; Menon et al., 2019) and has negative implications to the QoL of PLWE (Fayed et al., 2021; Ogundare et al., 2020).

To be accepted as any other ordinary person meant QoL to them within the Ghanaian cultural setting. Although items generated under this unique domain can be linked to the stigma domain of the NEWQOL (Mulhern et al., 2010), the nature, specificity and wording of the items makes this questionnaire genuinely Ghanaian questionnaire. Therefore, the adoption of the construct "Acceptance" as a domain in the QoL questionnaire for PLWE is a strong indication of the uniqueness of this very questionnaire as a QoL questionnaire for the PLWE in Ghana. Moreover, the domain on spiritual life also highlights very key aspects of the culture of Ghanaians including their belief systems about epilepsy (Deegbe et al., 2019), its cause and expectations for cure (Deegbe et al., 2019, 2020; Muchada et al., 2021; Mugumbate & Zimba, 2018).

In addition, the uniqueness of this questionnaire to the Ghanaian setting also stems from the fact that other similar epilepsy specific QoL items that were adopted from other questionnaires have been modified to fit into the Ghanaian context for this particular questionnaire. Similar to the development of the NEWQOL (Mulhern et al., 2010) and the WHO Quality of Life

(WHOQOL) questionnaires (Orley & Kuyken, 1994), new items in this questionnaire were also developed based on the statements of PLWE in Ghana.

Ghanaian scholars who were conversant with the culture of Ghana were invited as experts in the nominal group technique to peruse the items generated and make suggestions for revision of the questionnaire to make it appropriate, clear, easily understandable, and culturally sensitive to the QoL of the Ghanaian living with epilepsy. This procedure was also followed in the development of the WHOQOL (Orley & Kuyken, 1994), QOLIE-10 (Cramer et al., 1996), and Liverpool Seizure Severity Scale (Baker et al., 1998) questionnaires in order to make them appropriate for assessing QoL.

Currently, there is no epilepsy specific QoL questionnaire for Ghana or any of the sub-Saharan African countries. However, other questionnaires have been developed for use in Ghana for other purposes. Dzomeku et al. (2020) developed a questionnaire to measure experiences of Ghanaian women concerning respectful maternity care. Their initial items were adopted from an expert team from Ethiopia; however, these items were reviewed by the Ghanaian authors to ensure that they were unique to Ghana and applicable within the context of Ghana. This review process was also carried out in the nominal group technique that was conducted in the current study, to revise the first draft of the epilepsy specific QoL questionnaire for Ghana to ensure that the items were relevant, clear, simple and culturally sensitive within the Ghanaian context. Similarly, Nii et al. (2017) engaged local experts from government, academia and industry building in the development of an assessment questionnaire for energy efficiency of Ghanaian office buildings. Thus, the development of these Ghana specific questionnaires involved the engagement of local experts with the aim of fine tuning the questionnaire to fit into the Ghanaian context and cultural perspective as demonstrated in the development of the epilepsy specific QoL questionnaire for Ghana.

However, Mohammed and Aboud (2019) adapted the Wechsler Abbreviated Scale of Intelligence-II questionnaire to develop an assessment questionnaire for mental development for Ghana. Wright et al. (2019) also adapted and validated a disease-specific screening questionnaire for nutrition risk in Ghana. Although these questionnaires were made to suit the Ghanaian context, what is missing is the broad consultation with experts in Ghana. These examples highlight the unique nature of the epilepsy specific QoL questionnaire in its appropriateness and cultural sensitivity to the people of Ghana. This is also the first truly Ghanaian epilepsy specific QoL questionnaire to be developed.

Furthermore, changes in the number of items and domains were as a result of the rigorous and broad consultative processes that the questionnaire has undergone. This rigorous process in the form of nominal group technique contributes to the development of pooled ideas (Lloyd, 2011). This explains why the second draft of the questionnaire has 66 items under 13 domains. Thus, an increase in number of items and domains in the first draft from 41 to 66 items and from 11 to 13 domains in the second draft. The increase in the number of items is very important for the subsequent validation that this questionnaire is yet to go through. When a questionnaire in its development stage has a large number of items, it is easier to identify redundant or erratic items in analysis such as factor analysis to establish construct validity. Clark and Watson (1995) suggested that overinclusion of items in developing questionnaires has an advantage as metric analysis can identify weak or duplicated items, but it cannot spot items that should have been included. As such, the end result is expected to be a fully validated epilepsy QoL questionnaire with reasonable number of items and domains that are valid and reliable for assessing the QoL of PLWE in Ghana. Therefore, at this stage, too many items is better than having a few number of items before subjecting the questionnaire for content and construct validity testing (Agarwal, 2011).

The increment in the number of items in the second draft was the result of the rich discussions that occurred in consultation with the experts during the nominal group technique. Apart from making a few very key suggestions of culturally sensitive items to be added to the questionnaire, revisions of the items in the questionnaire led to a splitting of quite a number of the items. The aim was to produce a questionnaire with very specific items and direct examples that speak to individual aspects of QoL under each domain of the questionnaire. As a result of this, two domains had to be split into two – leading to the increase in the number of domains – to allow for domains with only items that relate directly to them. They were honest and shared their own experiences of questionnaire development. Thus, an evidence of the strength of this aspect of the epilepsy QoL questionnaire development process for Ghana (Neergaard et al., 2009). This underscores the importance of involvement of experts in a questionnaire development process (Baker et al., 1998; Cramer et al., 1996; Lloyd, 2011). Consequently, this will help generate positive results in subsequent content and construct validity testing of the questionnaire.

6.6 CHAPTER SUMMARY

This chapter sought to describe the operationalisation phase of the development of the epilepsy QoL questionnaire for PLWE in Ghana. An initial pool of 64 items and 13 domains were generated in relation to the QoL of PLWE in Ghana. This was refined into a first draft questionnaire comprising 41 items and 11 domains on four-point Likert scale. The Questionnaire was named QOLIE-GH to be in tune with international nomenclature of commonly existing QoL questionnaires. Consultation with experts through a nominal group technique resulted in a second draft questionnaire with 66 items and 13 domains. The increment in the number of items and domains was deemed appropriate so that a reasonable number of items may remain after subsequent content and construct validity tests render some items redundant. A five-point Likert scale with an additional column for non-applicable responses was adopted for the second draft of the questionnaire. The next chapter describes the content validity and face validity processes and their results.

CHAPTER SEVEN: THE CONTENT VALIDITY AND FACE VALIDITY OF EPILEPSY QUALITY OF LIFE QUESTIONNAIRE

7.1 INTRODUCTION

The development of the epilepsy Quality of Life Questionnaire for Ghana ended the operationalisation phase of the study. This chapter presents a description of the third phase, the validation phase, which comprises content validity and face validity testing of the new epilepsy QoL questionnaire for Ghana (QOLIE-GH). A discussion and chapter summary, ends this chapter.

7.2 METHODS

Validity of an instrument is the extent to which that measurement instrument demonstrates its ability to measure attributes that it was designed to measure (Robson, 2011). This is usually the first step with experts in the design of the draft questionnaire. This involves the gathering of items and organization of the domains of the questionnaire to reflect the purpose for the design of the questionnaire. In this study, content validity and face validity tests were carried out on the draft epilepsy QoL questionnaire, called the QOLIE-GH. Both content validity and face validity tests offer an opportunity to revise the questionnaire based on comments by experts compared to construct validity testing which only identifies relationship between variables and their latent constructs (Voorhees et al., 2016).

7.2.1 Content validity testing

Content validity refers to the how much items on a questionnaire and the scores of these items adequately represent all questions that could possibly be sought about a particular phenomenon (Creswell, 2015). A number of experts, either theoretical experts or people who are affected by the construct under study are used to critique the items for its relevance. By doing so, the researcher gets a good indication on the adequate number and type of items that is required to assess a particular phenomenon. Content validity testing can be done using five to twelve experts (Lynn, 1986; McMillan et al., 2016). In this study, content validity testing was carried out on the second draft of the QOLIE-GH.

7.2.1.1 Participants and sampling

A total of six experts comprising five nurses and one clinical psychologist took part in the content validity testing process. There were four experts from academia and two from practice area. The purposive sampling technique was used to select these experts from the fields of

academia and professional practice with a minimum of five years of experience in their various fields of work.

7.2.1.2 Measurement of content validity

A questionnaire was designed to measure the content validity of the epilepsy QoL questionnaire for Ghana (Appendix J). The questionnaire had all the items of the second draft of the QOLIE-GH. Each item in the questionnaire was evaluated for relevance to the aim of the questionnaire, cultural sensitivity to the Ghanaian setting, clarity of the question, and simplicity of the question. Existing studies assessed content validity based on four main criteria out of relevance, clarity, simplicity, wording, completeness, ambiguity (Boita et al., 2021; Halek et al., 2017). However, in this study, cultural sensitivity was included in order to ensure that the aim for which the questionnaire was being developed – to produce a culturally sensitive QoL questionnaire for PLWE in Ghana – as a part of the questionnaire development process, is achieved.

The experts assessed each item on the four-point Likert scale. Thus, starting from 1 = not relevant/ not culturally sensitive/ not clear/ not simple to 4= very relevant/ very culturally sensitive/ very clear/ very simple (Table 7.1). A questionnaire on the expertise and demographics of the experts was also administered to the experts (Appendix J).

Table 7.30: Criteria for measuring content validity of the Quality of Life Questionnaire for people living with epilepsy

Relevance (Relevance to the construct)	**Cultural sensitivity** (Sensitivity to the Ghanaian culture)	**Clarity** (Precision)	**Simplicity** (Easy)
1. Not relevant 2. Item needs some revision. 3. Relevant but needs some revision. 4. Very relevant	1. Not culturally sensitive 2. Item needs some revision. 3. Culturally sensitive but needs some revision. 4. Very culturally sensitive	1. Not clear 2. Item needs some revision. 3. Clear but needs minor revision. 4. Very clear	1. Not simple 2. Item needs some revision. 3. Simple but needs minor revision. 4. Very simple

7.2.1.3 Data collection procedure

The expert review focused on the structure of each domain, in addition to the relevance, clarity, simplicity and cultural sensitivity of each item in the draft questionnaire. Experts were contacted by the researcher; some in person and some through a telephone call. After agreeing verbally to take part in the study, the researcher sent them invitation letters, in the form of an email, formally inviting them to take part in the content validity testing of the draft questionnaire (Appendix K). An information sheet explaining this aspect of the study, in addition to a consent form and the content validity questionnaire was attached to the email (Appendix L & M). After a follow up on the experts through calls and emails, they replied with an electronically signed consent form and the completed content validity questionnaire in March, 2020.

7.2.1.4 Analysis

Analysis of content validity is usually done by calculating the content validity index (CVI) (Lynn, 1986; Polit & Beck, 2006). The CVI is the proportion of items that received a score of 3 or 4 (see Table 7.1) in each of the attributes for content validity (Lynn, 1986). Both item level content validity index (I-CVI) and the scale level content validity index (S-CVI) were estimated for the items and domains of the draft questionnaire for all the four attributes (Polit & Beck, 2006). Number of experts scoring 3 or 4 divided by the total number of experts was the formular used to estimate the I-CVI. An I-CVI of 0.78 or more is acceptable for content validity involving more than 5 experts (Polit & Beck, 2018). An estimate of the average of the agreements from experts on items from one domain which is the average proportion of items rated 3 or 4 in each domain was done to estimate the S-CVI for each domain (Polit & Beck, 2006). The average I-CVIs for each item (I-CVI/ Ave) and the S-CVI for each domain (S-CVI/ Ave) across all the categories (relevance, cultural sensitivity, clarity and simplicity) were also estimated. In this study, the acceptable criteria for I-CVI/Ave and S-CVI of 0.80 was set as acceptable (Polit & Beck, 2006, 2018; Shrotryia & Dhanda, 2019). A third draft of the QOLIE-GH was then developed after revision of the second draft based on the results of the content validity testing and in consultation with the supervisors.

7.2.2 Face validity testing

Face validity testing was done on the third draft of the epilepsy QoL questionnaire for PLWE in Ghana during the first week in April, 2021. Face validity testing is a widely used form of validity testing which involves evaluation of whether a questionnaire measures the construct it

is intended to measure based on the opinion of a target population (Sangoseni et al., 2013). This is when experts casually examine the items in the questionnaire to determine if the items in each domain relate to the domain and also match the construct it is measuring. The target population for the face validity testing was PLWE in Ghana.

7.2.2.1 Participants and sampling

A total of four PLWE in Ghana were selected for the face validity testing of the epilepsy QoL questionnaire. These were persons 18 years or older with at least primary school education and who could read and write English. These participants, three males and one female, were selected purposively for the study.

7.2.2.2 Data collection questionnaire and procedure

A face validity questionnaire was designed and given to the participants to use to assess the face validity of the third draft QOLIE-GH questionnaire (Table 7.2). This had three statements about the QOLIE-GH which was to be rated on Likert scale with four levels (Strongly disagree, Agree, Disagree, Strongly agree). The last column was a statement requesting respondents to provide comments if they do not strongly agree with any item in the questionnaire. A fourth question which, was an open-ended response, was included for general comments of the respondents on the QOLIE-GH.

All the respondents were contacted through a telephone call and invited to take part in the study. Those who agreed to take part in the study were further contacted to evaluate the third draft QOLIE-GH questionnaire. Two were met in person for the face validity testing and the other two preferred to be given the materials through email to do the face validity testing. All participants were given an invitation letter to take part in the face validity testing of the epilepsy QoL questionnaire in addition to an information sheet explaining the process to them (Appendix P & Q). A consent form was also provided for them to sign either electronically or in person as proof of their consent to take part in the face validity testing of the questionnaire (Appendix R)

The respondents were then given the third draft QOLIE-GH to answer in addition to the face validity questionnaire to assess the QOLIE-GH (Appendices O & S).

Table 7.31: Face validity testing questionnaire

Based on your experience completing the questionnaire on quality of life of people living with epilepsy, please share your opinion based on the statements in the table below. **Key: SD**-Strongly disagree; **D**-Disagree; **A**-Agree; **SA**-Strongly agree.						
Section 2	**Statement**	**SD**	**D**	**A**	**SA**	Provide comments/ suggestions if you do not strongly agree.
2.6	All relevant information on the quality of life of people living with epilepsy has been included in the questionnaire.					
2.7	The questions are clear and easy to understand.					
2.8	I would love to complete this questionnaire as a part of routine assessment at the clinic and in the community.					
2.9	Kindly provide any comments and suggestions you may have on how the questions/ statements, structure and appearance of the questionnaire could be improved.					

7.2.2.3 Analysis

Ratings from the respondents as well as their comments and suggestions on the third draft QOLIE-GH questionnaire from the face validity questionnaire were observed. These ratings were collated and guided the final revision of the item (Table 7.5). Comments and suggestions from the respondents were summarized and used to revise the third draft QOLIE-GH questionnaire.

7.3 RESULTS

7.3.1 Results of content validity index

7.3.1.1 Demographic characteristics of respondents

Table 7.32: Demographic characteristics of respondents

Code	Sex	Age (years)	Educational level	Working area	Specialty
M1	Male	54	PhD	Academia	Nursing (Mental health)
M2	Male	37	Masters	Academia	Nursing (Nursing education/ Research)
M3	Male	56	Masters	Academia	Nursing (Mental health)
F1	Female	42	PhD	Practice	Nursing (Public health)
F2	Female	43	Masters	Academia	Nursing (Mental health)
F3	Female	43	Masters	Practice	Psychology (Clinical psychology)

As shown in Table 7.3, six experts took part in the content validity testing comprising 3 males with their ages ranging from 37 to 56 years and 3 females who were aged 42 to 43 years. Among the males and females, one in each group had a PhD and the remaining two in each group had a master's degree. Four of them were in academia - one with a PhD. They were all nurses with specialty in mental health and public health nursing and one in nursing education and research. The two in the practice area, one with a PhD, specialised in public health nursing and clinical psychology.

7.3.1.2 Individual Content Validity Index and Scale Content Validity Index

Content validity index of individual items (I-CVI) in all four aspects - relevance, cultural sensitivity, clarity and simplicity – ranged from 0.67 to 1. In the seizure worry domain, all five items had good content validity regarding relevance, cultural sensitivity, clarity and simplicity (I-CVI of 0.83 – 1.00) (Appendix N). In the seizure control domain, all five items also had good content validity regarding relevance, cultural sensitivity, clarity and simplicity (I-CVI of 0.83 – 1.00). Among the five items under the domain, emotional wellbeing, four had content validity regarding relevance, cultural sensitivity, clarity and simplicity (I-CVI of 0.83 – 1.00). Item 15 however, had poor content validity with regard to its relevance, cultural sensitivity, clarity and simplicity (I-CVI = 0.67). The average I-CVI was below 0.80 (I-CVI/ Ave = 0.67).

One expert mentioned in a comment that the 5th item under emotional wellbeing was not needed. This item was rejected.

In the domain, energy/fatigue, all five items had good content validity regarding relevance, cultural sensitivity, clarity and simplicity (I-CVI of 0.83 – 1.00). One expert suggested a revision of a phrase in item 16 in this domain to "I have strength" instead of "I have energy". Moreover, in the cognitive function domain, all seven items had good content validity regarding their relevance, cultural sensitivity and clarity (I-CVI of 0.83 – 1.00). However, regarding simplicity, all the items had good content validity (I-CVI of 0.83 – 1.00) expect item 21 which had a poor I-CVI of 0.67. Thus, reducing the average I-CVI of that item to 0.79. One of the experts also suggested that item 21 is not needed because it makes subsequent items a repetition. This item was also rejected.

Furthermore, all four items in the medication effect domain had good content validity regarding relevance, cultural sensitivity, clarity and simplicity (I-CVI of 0.83 – 1.00). Experts raised concerns about the terms "antiseizure" and "antiepileptic" and suggested one term is used to ensure uniformity. One expert suggested a revision of a phrase in item 31 from "control my seizures" to "control or reduce my seizures".

Under social function, the item 36 had poor content validity for relevance (I-CVI= 0.67) but good content validity for cultural sensitivity, simplicity and clarity (I-CVI= 0.83). But it had an average I-CVI of 0.79. One expert also questioned the relevance of item 36 leading to the rejection of this item. The remaining seven items had good content validity regarding relevance, cultural sensitivity, clarity and simplicity (I-CVI of 0.83 – 1.00). However, experts suggested a merger of the items 34 and 35 because they were virtually the same. The experts also mentioned the need to settle on either the term "seizure" or "epilepsy".

All 7 items under seizure severity domain also had good content validity regarding relevance, cultural sensitivity, clarity and simplicity (I-CVI of 0.83 – 1.00). Similarly, all four items under the acceptance domain had good content validity regarding relevance, cultural sensitivity, clarity and simplicity (I-CVI of 0.83 – 1.00).

Under social support, all five items had good content validity regarding relevance, cultural sensitivity, clarity and simplicity (I-CVI of 0.83 – 1.00). The five items under the activities of daily living domain also had good content validity regarding relevance, cultural sensitivity, clarity and simplicity (I-CVI of 0.83 – 1.00).

With regard to the three items under the financial independence, the last two had good content validity regarding all the four aspects (relevance, cultural sensitivity, clarity and simplicity) (I-CVI of 0.83 – 1.00). Item 61 however, had poor content validity score regarding its relevance (I-CVI of 0.67) plus an average I=CVI of 0.78. Therefore, that item was rejected. The domain had poor content validity score with regard to its relevance (S-CVI=0.78), but the average S-CVI score for the domain had good content validity (S-CVI/ Ave = 0.88). Similarly, the first and third items under spiritual life had good content validity for all of the aspects (relevance, cultural sensitivity, clarity and simplicity) (I-CVI of 0.83 – 1.00). The second item had a poor content validity score for relevance (I-CVI of 0.67). However, the average I-CVI for the second item under spiritual life was good (I-CVI/ Ave = 0.88) (Appendix N).

Table 7.33: Scale content validity index (S-CVI)

Domain	Relevance S-CVI	Cultural sensitivity S-CVI	Clarity S-CVI	Simplicity S-CVI	Average S-CVI per domain	Overall S-CVI of Questionnaire	Comments by experts
Seizure worry	0.93	0.97	0.93	0.87	0.93	0.91	
Seizure control	0.97	0.97	0.97	0.93	0.96		
Emotional wellbeing	0.9	0.9	0.9	0.90	0.9		The item "I feel disturbed" is not needed
Energy/ Fatigue	0.93	0.93	0.93	0.90	0.93		Revise item 16 to "I have strength" instead of "I have energy"
Cognitive function	0.93	0.93	0.90	0.88	0.91		Item 21 is not needed here. It's makes subsequent ones a repetition
Medication effect	0.96	0.96	0.96	0.92	0.95		In item 31: Antiseizure or antiepileptic? Choose one. Revise item 31 to "control or reduce my seizures"
Social function	0.94	0.88	0.88	0.88	0.89		Merge items 35 and 34. They are the same thing. Items 35 and 36: Seizure or epilepsy? Choose one. Item 36 is not necessary.
Seizure severity	0.93	0.90	0.90	0.90	0.91		
Acceptance	0.96	0.92	0.92	0.96	0.94		
Social support	0.93	0.87	0.83	0.83	0.87		Item 51: Seizure or epilepsy? Choose one.
Activities of daily living	0.97	0.97	0.97	0.97	0.97		
Financial independence	**0.78**	0.94	0.89	0.89	0.88		
Spiritual life	**0.78**	0.94	0.89	0.83	0.86		

The S-CVI for the 13 domains ranged from 0.78 to 0.97 regarding their relevance, cultural sensitivity, clarity and simplicity. The S-CVI for seizure worry, seizure control, emotional wellbeing, energy/fatigue, cognitive function, medication effect, social function seizure severity, acceptance social support and activities of daily living had good content validity regarding relevance, cultural sensitivity, clarity and simplicity (I-CVI of 0.83 – 0.97). Under the domain, financial independence and spiritual life, there was good content validity regarding cultural sensitivity, clarity and simplicity (I-CVI of 0.86 – 0.94). However, the domain, financial independence and spiritual life, had poor content validity score regarding their relevance (I-CVI of 0.78). Furthermore, the average S-CVI for each domain had good content validity (S-CVI= 0.86 – 0.97). Therefore, no domain was rejected. The overall content validity for the questionnaire was good (S-CVI= 0.91). At the end of the content validity testing, a third draft of the questionnaire was produced after a revision of the second draft epilepsy QoL questionnaire based on ratings and comments from the experts. The third draft had 61 items under 13 domains (Appendix S). Details are shown in Table 7.4. This was then presented for face validity testing among four PLWE.

7.3.2 Results of face validity testing

The socio-demographic characteristics of respondents who took part in the face validity testing is presented in Table 7.5.

7.3.2.1 Demographic characteristics of respondents

Table 7.34: Socio-Demographic Characteristics of respondents (n=4)

Characteristics		**Frequency (%)**
Age	Mean =29.5years	SD= 9.3
Sex	Male	3 (75%)
	Female	1 (25%)
Marital status	Single	3 (75%)
	Married	1 (25%)
Highest level of education	Secondary	2 (50%)
	Tertiary	2 (50%)

The mean age of the respondents was 29.5 years and three out of the four (75%) were males and single (75%). Their level of education was secondary (50%) and tertiary levels (50%).

7.3.2.2 Face validity rating by respondents

Frequency distribution of ratings from the respondents on the face validity testing questionnaire is presented in Table 7.6.

Table 7.35: Results from the face validity testing questionnaire

Item	SD	D	A	SA	Comments
All relevant information on the quality of life of people living with epilepsy has been included in the questionnaire.	0	0	0	4	None
The questions are clear and easy to understand.	0	0	1	3	a. I don't understand what is seizure. All I know is epilepsy but, the questions really speak about my life.
I would love to complete this questionnaire as a part of routine assessment at the clinic and in the community.	0	0	2	2	a. The questions are plenty. b. It takes a long time to answer. That's my problem. But it's nice.
Kindly provide any comments and suggestions you may have on how the questions/ statements, structure and appearance of the questionnaire could be improved.	There many items in here which will take a ling time to complete although they are relevant.				

SA: Strongly agree **A: Agree**
D: Disagree **SD: Strongly disagree**

All the respondents strongly agreed that the epilepsy QoL questionnaire had all information relating to their quality of life. Three out of the four respondents (75%) strongly agreed that the questions were clear and easy to understand. Only one suggestion implied a change of the term seizure to epilepsy would be better and easily understood. Participants also raised

concerns about the large number of items in the questionnaire and the more time it took them to complete the questionnaire although they found it to be nice.

7.4 DISCUSSION

The content validity of the epilepsy QoL questionnaire for PLWE in Ghana was assessed in this study in addition to the face validity of the questionnaire. Apart from other forms of validity testing, content and face validity testing allows experts to make comments that aid in refining the questionnaire to make it better and fit for the purpose for which it was developed (Bolarinwa, 2015; Halek et al., 2017). Content validity testing is a key component of the questionnaire development process as it plays an important role in promoting the construct validity of the questionnaire (Halek et al., 2017; Shrotryia & Dhanda, 2019). In the current study, content validity testing was part of the ongoing process of developing the epilepsy QoL questionnaire which involved the recruitment of experts from both fields of practice and academia to judge and rate the questionnaire. These were persons with expertise in questionnaire development and with experience with management of PLWE. These were also Ghanaians living in the country and could contribute in ensuring that the questionnaire was culturally appropriate for PLWE in Ghana. Such a team of experts is deemed appropriate in ensuring that relevant items are retained in the questionnaire in addition to refining existing items (Sangoseni et al., 2013).

In addition, it is recommended in literature that subjects within the local context for which the questionnaire is being developed assess the face validity of the questionnaire to identify items that are relevant for inclusion into the questionnaire (Sandström & Lundin-Olsson, 2007). In this study, a pool of items for the questionnaire were earlier on generated from existing questionnaires, literature review and from a qualitative exploratory study. However, the involvement of the target population in the evaluation of the face validity of the questionnaire is imperative in confirming the questionnaire (Polit & Beck, 2010). This informed the selection of PLWE in Ghana to assess the epilepsy QoL questionnaire for face validity. This explains why the patients made positive comments about the questionnaire with a few suggestions for improvement. Thus, confirming the facets of quality of life of PLWE in Ghana.

Moreover, patients involved in the face validity testing exercise provided useful comments that enhanced the final revision of the questionnaire in this study. This included a replacement of the word seizure with epilepsy for ease of understanding. It underscores the importance of employing the target population in assessing the face validity of the questionnaire (Connell et

al., 2018). Comments made by patients also indicate that the items in the questionnaire were many and consequently time-consuming, although they expressed willingness to answer the questionnaire as part of routine care in the clinic. Although this is already known to the researcher and also discussed with experts, the questionnaire will be subjected to construct validity testing after this study. Despite the fact that some items have been merged and others eliminated, the remaining items have also been rated as relevant and appropriate for the questionnaire during the content and face validity assessment processes. However, after this study, it is expected that construct validity testing, through more statistically robust testing, will further eliminate some redundant items and reduce the number of items in the questionnaire to a reasonable number that can be quickly completed by patients (Wong et al., 2012). Therefore, it was deemed reasonable to leave the number of items in the questionnaire as is.

In addition, two clinicians and four academics took part in the content validity testing. According to Patrick et al. (2011), the involvement of clinicians in questionnaire validation is key. Expert comments and suggestions helped in the revision of some of the items in the epilepsy QoL questionnaire. They also suggested a merger of items 34 and 35 for the reason that one could either be a student or a worker. Furthermore, they suggested the removal of three items (16, 21 and 36) on account of irrelevance and amounting to a repetition. These items, including item 61, also had I-CVI less than 0.80 supporting the need for their removal from the questionnaire. This also underscores the importance of content validity as imperative in the questionnaire development process (Halek et al., 2017; Shrotryia & Dhanda, 2019).

7.5 CONCLUSION

The epilepsy QoL questionnaire for Ghana was developed for the purpose of producing a culturally sensitive QoL questionnaire that is best fit for assessing QoL of PLWE in Ghana. Content validity testing of the questionnaire proved its relevance, cultural sensitivity, clarity and simplicity. The face validity testing of the questionnaire also provided opportunity for PLWE in Ghana, to peruse, make suggestions for improvement and to confirm the appropriateness of the questionnaire for their use. This led to the production of an instrument with 61 items and good content validity with an S-CVI of 0.91 to be used by PLWE and clinicians.

CHAPTER EIGHT: SUMMARY OF FINDINGS, STRENGTHS AND LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

8.1 INTRODUCTION

A summary of the findings of the study, strengths and limitations of the study, as well as conclusion and recommendations based on the findings from the study are presented in this chapter. This study sought to answer the question "What will constitute a culturally sensitive questionnaire for accurately and consistently assessing the Quality of Life (QoL) of PLWE in Ghana?" This motivated the researcher to develop and validate a culturally sensitive QoL questionnaire that is best suited for accurate and consistent assessment of QoL of PLWE in Ghana. The questionnaire development process was in three phases: conceptualisation, operationalisation and validation phase.

8.2 SUMMARY OF FINDINGS

8.2.1 Phase one: Conceptualisation of the construct of quality of life of people living with epilepsy in Ghana

The conceptualisation phase had three objectives. The first objective was to explore the concepts and constructs in QoL questionnaires for PLWE worldwide. A scoping review of the concepts and constructs of four epilepsy specific QoL questionnaires namely QOLIE-10; QUOLIE-31; NEWQOL and Liverpool Seizure Severity Scale, from seven studies was conducted. Synthesis of the content of the questionnaires led to the extraction of 35 items under 10 domains namely: seizure worry, seizure control, emotional wellbeing, energy/fatigue, cognitive function, medication effects, social function, overall wellbeing, seizure severity and injury.

Secondly, an integrative review was conducted to ascertain the QoL of PLWE in sub-Saharan Africa and included nine studies. Only four of the studies used an epilepsy specific QoL questionnaire to assess the QoL of PLWE (Fletcher et al., 2015; Gebre & Haylay, 2018; Kaddumukasa et al., 2019; Ogundare et al., 2020). Findings from the integrative review were grouped into categories namely: study questionnaire, physical QoL, psychological QoL and social QoL. Studies in the integrative review showed that PLWE in SSA had below-average mean score on the overall physical QoL (Abadiga et al., 2019). Increased seizure frequency and severity contributed to low energy among PLWE (Kaddumukasa et al., 2019) and negatively affected the QoL of PLWE (Tefera et al., 2020; Ogundare et al., 2020; Abadiga et

al., 2019). In addition, the presence of comorbid mental or physical problems and reaction to antiepileptic medications also worsened the QoL of PLWE (Abadiga et al., 2019).

Furthermore, the psychological QoL among PLWE in SSA was below average (Abadiga et al., 2019) which was linked to uncontrolled seizures (Tefera et al., 2020). This affected emotional wellbeing of PLWE (Gebre & Haylay, 2018; Kaddumukasa et al., 2019) and increased their seizure worry (Kaddumukasa et al., 2019). Low level of education was linked to poorer QoL among PLWE (Gebre & Haylay, 2018) whereas significantly low cognitive function was found among PLWE in SSA (Mwangala et al., 2018; Nau et al., 2018). Stigma was associated with frequent seizures (Abadiga et al., 2019; Fletcher et al., 2015) and this had negative implications to their QoL. The PLWE were more depressed and more anxious than healthy controls (Abadiga et al., 2019; Mwangala et al., 2018; Ogundare et al., 2020) with lower QoL scores.

The integrative review revealed that social functions including meeting family and society obligations were affected by frequent seizures (Fletcher et al., 2015) and that PLWE in SSA were avoided in society (Abadiga et al., 2019). Furthermore, they were significantly more likely to be unemployed (Mwangala et al., 2018), with no formal education (Tefera et al., 2020) and low monthly income (Muche et al., 2020), all of which negatively impacted their QoL (Muche et al., 2020). Another aspect that negatively influenced their QoL was poor interpersonal and love relationships, including marriage (Fletcher et al., 2015; Ogundare et al., 2020; Tefera et al., 2020). This contributed to the generation of more items under physical, psychological and social aspects of QoL for the item pool. Two domains, employment and self-reliance, were identified in the integrative review and added to the domains derived from the existing epilepsy specific QoL questionnaires.

The third objective was to explore the meaning of QoL from the perspective of PLWE in Ghana using a qualitative exploratory study. Fifteen PLWE, comprising 6 females and 9 males, in the Accra Metropolis in Ghana were interviewed. Content analysis of the data was done using the MAXQDA qualitative data analysis software. Fourteen sub-themes emerged from the data which were grouped under four themes –support, acceptance, seizure control and self-reliance. The theme acceptance seemed to be unique to the Ghanaian PLWE as it was not found in any of the other QoL questionnaires for PLWE. This finding supported the researcher's need to develop a questionnaire that speaks to the needs of the PLWE in Ghana. The studies in the conceptualisation phase helped in conceptualizing QoL among PLWE and synthesizing the

content of pre-existing epilepsy QoL questionnaires to produce a unique one for PLWE in Ghana.

8.2.2 Phase two: Operationalisation of the Quality of Life Questionnaire

The second phase of the study led to the development of a draft epilepsy QoL questionnaire for Ghana with appropriate items, scale of measurement and scoring. In keeping with the sequential multimethod design for this study, findings from the three studies in the conceptualization phase were integrated to generate a pool of 64 items under 13 domains for the draft questionnaire.

The second objective was to draft the QoL questionnaire. This was done in consultation with the supervisors. Thorough examination of the items in pool was done to remove irrelevant items and duplicates and refine the remaining items for cultural sensitivity, correct wording and grammar. This led to the development of the first draft epilepsy QoL questionnaire comprising 41 items under 11 domains (Table 6.2) which was named QOLIE-GH.

The third objective was to develop a scale of measurement and final scoring for the draft questionnaire with instructions for use. In consultation with the supervisors, an initial four-point Likert scale (Strongly disagree=1; Disagree=2; Agree=3; Strongly agree=4) was designed. A section comprising 12 items was then added to capture socio-demographic characteristics of respondents (7 items) and their clinical information (5 items). The questionnaire was then named QUOLIE-GH, meaning Quality of Life in Epilepsy questionnaire for Ghana.

The fourth objective was to conduct an expert review of the newly developed questionnaire. A nominal group technique involving eight experts was employed to review the first draft questionnaire. The experts suggested a split in some of the domains, for example “Self-reliance” split into two “Activities of daily living” and “Financial independence”, and a split in some of the items, for example “I feel calm and peaceful” to “I feel calm within me” and “I feel at peace with myself”. They also suggested additional items relevant to the Ghanaian context, for example “I feel dull” and “I feel sad within me”. A second draft of the QOLIE-GH questionnaire, with 66 items and 13 domains, was then developed.

The experts suggested a revision of the scoring to a five-point Likert scale with an extra column for non-applicable responses. The socio-demographic and clinical information section was also

revised by the experts. This led to an increase in the items under the clinical information section from five in draft one to seven in the second draft (Table 6.16). The socio-demographic information however, remained at seven items with an addition of a few alternative options for selection under some of the items.

8.2.3 Phase three: Validation of the epilepsy Quality of Life Questionnaire

The validation phase aimed at validating the QOLIE-GH in terms of content validity and face validity. After the content validity testing, four out of the 66 items were eliminated because they did not attain an average I-CVI of 0.80 stipulated as the cut off point for retaining items on the questionnaire. Some items were revised in terms of wording by the experts' comments and two were merged in response to expert recommendation leading to the development of the third draft QOLIE-GH questionnaire (Appendix S). The remaining 61 items in the third draft QOLIE-GH had acceptable I-CVI ranging from 0.83 to 1.

The second objective of this phase was to test the face validity of the third draft QOLIE-GH QoL questionnaire. With regard to the face validity testing, one respondent suggested a replacement of the word seizure with epilepsy. Although two respondents raised concerns about the many number of items, all of them confirmed the relevance of the 61 items in the questionnaire. They all affirmed the use of the QOULIE-GH as a part of routine assessment at the clinic and in the community. Therefore, the third draft QOLIE-GH remained the same as after the content validity testing. Nothing was changed after the face validity testing. The third draft QOLIE-GH questionnaire will be taken for further validation post PhD.

8.3 STRENGTHS OF THE RESEARCH

The use of the multimethod sequential design allowed for the pragmatic use and integration of various methodological approaches suitable at various stages of the study (Hunter & Brewer, 2015). Furthermore, the integration of these methods and the findings helped to achieve the ultimate aim of developing an appropriate epilepsy QoL questionnaire that is culturally sensitive and best fit for assessing the QoL of PLWE in Ghana.

The scoping review of concepts and constructs in existing epilepsy QoL questionnaires and the integrative review of QoL among PLWE in sub-Saharan Africa, provided a good background for the development of a more refined and upgraded epilepsy QoL questionnaire. In addition to these reviews, the exploratory qualitative study provided the opportunity to make inputs

from rich descriptions of meanings of QoL in relation to the socio-cultural aspects of QoL among PLWE in Ghana. This ensured that the questionnaire is actually appropriate, culturally sensitive and best fit for PLWE in Ghana. Similar to the development of the NEWQOL (Mulhern et al., 2010) and the WHO Quality of Life (WHOQOL) questionnaires (Orley & Kuyken, 1994), new items in this questionnaire were also developed based on the statements of PLWE in Ghana. Similar approach was also incorporated in the process of developing the QOLIE-89 epilepsy QoL questionnaire (Devinsky et al., 1995), in the United States of America, which contributes to the validity and reliability of the questionnaire.

The use of NGT in this study was beneficial in producing a structured outcome and organised priorities. Experts engaged in a structured discussion, ranked and voted on the group's decisions, and provided useful suggestions that enhanced the content, structure and format of the QOLIE-GH (Dang, 2015) to produce its second draft. Such rich content and structure in the second draft questionnaire enhanced the content validity of the questionnaire during the content validity testing process.

The methodical approach adopted in the conceptualization, operationalization and validation of the epilepsy QoL questionnaire for PLWE in Ghana (QOLIE-GH), is transparent, clearly outlined and can be easily replicated.

8.4 LIMITATIONS OF THE RESEARCH

The literature search for materials for the scoping and integrative reviews in this study was limited to search engines including PsychInfo, Scopus, Science Direct, PubMed and CINAHL. These are the databases that mostly report on health and QoL issues such as epilepsy however, some might have been missed.

Secondly, the face validity sample could have been extended to a group of 10 PLWE as four people may not be representative of the population.

Finally, this study was conducted to develop an epilepsy QoL questionnaire for the PLWE in Ghana. As a result of this, the questionnaire does not have international relevance since it is only meant for the Ghanaian people living with epilepsy. However, the researcher hopes to carry out construct validity testing to validate this questionnaire to meet international relevance for PLWE in SSA as an extension of this study.

8.5 RECOMMENDATIONS

Based on the findings from this study, the following recommendations were made:

8.5.1 Nursing research

The integrative review revealed that treatment of epilepsy in Ghana includes the use of traditional medicines. There is the need for more research into the efficacy of traditional medicine in the treatment of epilepsy to promote its use. Thus, further research and clinical trials of traditional medicinal preparations for the treatment of epilepsy will help develop upgraded and more refined traditional medicines that are effective for the treatment of PLWE.

Future studies should be carried out to do more assessment and validation of the QOLIE-GH through factor analysis and Rasch analysis to ascertain the validity and reliability of the questionnaire for use in Ghana and other sub-Saharan African countries. This will help to promote the accuracy and the quality of the questionnaire. The QOLIE-GH can also be used by future researchers to collect data on the QoL of PLWE to test hypotheses in their research.

8.5.2 Nursing practice and management

Uncontrolled seizures was found to be a strong predictor of low QoL (Abadiga et al., 2019; Tefera et al., 2020). Nurses need to assess the QoL of PLWE with the QOLIE-GH to understand all the aspects of QoL that is affected by seizures. This will help them employ a holistic approach to the care of PLWE by combining psychological, emotional, social and spiritual aspects of care of PLWE in order to ensure that seizures are relatively under control and promote the QoL of PLWE in Ghana.

Secondly, findings from the integrative review and the qualitative interviews showed that poor access to antiepileptic medications negatively affects the QoL of PLWE. Nurses in collaboration with health service administrators and pharmacists should ensure regular stocking of antiepileptic medications for PLWE since PLWE perceived ready and regular access to antiepileptic medications as QoL.

Moreover, the newly developed QOLIE-GH will be made available for use in clinics and hospitals. Continuous awareness creation on the availability and usefulness of the questionnaire will be done by the researcher to health workers and the public in general through seminars, workshops, radio and television presentations to promote its use. The researcher recommends the use of the QOLIE-GH as a routine QoL assessment questionnaire at health care facilities at

all levels. This will help health workers aspects of QoL of PLWE that are low and the need to carry out informed interventions to address the problem. It will also help them to evaluate the progress of care provided for PLWE and its implication to their QoL objectively.

8.5.3 Community mental health nursing

Results from the integrative review showed that PLWE with comorbid mental health problems have lower QoL. Mood problems, specifically depression and anxiety have been reported among PLWE. Community mental health nurses in collaboration with clinical psychologists and psychiatrists should offer regular psychological assessment, counselling and treatment of any forms of depression and anxiety-related problems. Psychosocial factors have also been linked to poor health-related QoL among PLWE. Mental health professionals, particularly community mental health nurses, who follow up on PLWE in their homes need to screen the PLWE for psychological and social problems using the QOILIE-GH. This will help them offer them the needed psychological support in terms of counselling and the treatment of any mental condition where necessary, and to facilitate social support from family, friends and the community, in addition to offering self to patient to promote their psychosocial QoL.

Secondly, stigma and discrimination among PLWE were found in the integrative review as well as in participant reports from the qualitative interview. In the qualitative interview, PLWE expressed the need to be accepted by family, friends and the community. Community mental health nurses need to rally family and community support for care and acceptance of PLWE as a part of their community mobilization activities to promote the QoL of PLWE in Ghana.

Furthermore, community mental health nurses in collaboration with the media should intensify health education campaigns on epilepsy, whilst involving opinion leaders in the community, to sensitise community embers on the condition whilst debunking myths about epilepsy which perpetuates such stigmatizing the discriminatory behaviours against PLWE. These behaviours make people avoid them hence they have difficulty in establishing social contact, establishing a love relationship, getting married or staying married. Education and counselling of prospective partners of PLWE and spouses of PLWE who are already married will help secure their marriages and love relationships that will promote their QoL.

In addition, community mental health nurses need to engage family members of PLWE and community members in education, first aid training and sensitization programmes on epilepsy in order to create more awareness of the need to support PLWE. This will empower people to

provide first aid for PLWE in the community and protecting them from injury instead of shying away from them and avoiding them when they experience seizures.

Lastly, some PLWE have difficulty with meeting obligations of family and society, including work, cooking and hygiene practices due to uncontrolled seizures. Community mental health nurses in collaboration with community health nurse should facilitate support from family members and friends of PLWE in terms of the needed physical, emotional, financial, and spiritual support to make them peaceful, less anxious and improve their QoL. These interventions can be informed by regular screening of PLWE using the newly developed QUOLIE-GH.

8.5.4 Nursing education

It is established in literature that poor seizure control affects QoL of PLWE. It is recommended that training of nurses should take into consideration physical, psychological, emotional, social and spiritual aspects of care. This will help equip nurses with the knowledge and skill in providing holistic care for PLWE in order to ensure effective seizure control and subsequent improvement in their QoL. Nursing students should be given the opportunity to have more practical experience in the management of PLWE both in the clinic and community setting in order to make them more versatile in the management of PLWE in all settings.

The QOLIE-GH should also be employed in teaching student nurses and students of health professions on assessment of QoL of PLWE. This should be applied at the clinical setting by their preceptors whilst guiding the students to facilitate regular evaluation of QoL of PLWE and to inform appropriate interventions to promote their QoL.

8.5.5 Health policy and implementation

Findings from the integrative review shows a generally poor QoL of PLWE in SSA. The Ghana Health Service in collaboration with non-governmental organisations should make concerted efforts to establish policies that will drive social, health and political interventions to improve upon the lives of PLWE.

There is need for the Ministry of Health and the Ghana Health Service to adopt the QOLIE-GH as a standard questionnaire for assessing QoL of PLWE. This will help provide a standardised and objective means of assessing QoL of PLWE in Ghana and provide evidence which will inform interventions needed to promote the QoL of PLWE in Ghana.

Although this study did not aim at assessing treatment gaps, the findings from the integrative review showed that QoL of PLWE is affected by inability to afford expensive surgeries and sub-optimal treatment. The people of Ghana, and specifically those living with epilepsy, can ill-afford expensive surgery but this study may influence the Ministry of Health to consider surgical treatment at lower rates or if possible free under the national health insurance scheme.

In addition, PLWE considered easy of regular access to their antiepileptic medications as QoL. Ghana Health Service should also procure newer and more effective antiepileptic medications and ensure regular supply of antiepileptic medications to ensure continuous access to antiepileptic medications by PLWE.

Findings from the qualitative interviews showed that PLWE experience stigmatizing and discriminatory behaviours that affect their QoL. The Ministry of Health and the Mental Health Authority need to implement policies on stigma and discriminatory behaviours against PLWE by prosecuting persons found to be engaging in such unlawful acts to serve as deterrent to others from repeating such inhumane acts.

Literature also shows that PLWE are more likely to be unemployed. This is likely to render them dependent on relatives and friends which further impoverishes their QoL. The ministry of local government should establish policies that make easy access to employment opportunities for PLWE including other disadvantaged persons to help them work and live an independent life. This will help improve their self-worth and QoL.

8.6 CONCLUSION

Epilepsy is a known chronic neurological condition. The signs and symptoms of epilepsy are frightening, unexpected and usually associated with embarrassment of the victim. Lack of knowledge about the condition in addition to myths about the causes and associated spiritual and evil causes have fuelled the stigma and discrimination associated with epilepsy. Comparatively, the prevalence of epilepsy globally is high in SSA including Ghana. The problems associated with living with epilepsy inevitably affects the QoL of victims. The purpose of this study was to develop a QoL questionnaire that is appropriate and culturally sensitive to the PLWE in Ghana. The birth of this questionnaire will enhance assessment of QoL of PLWE in Ghana and provide indices that will inform interventions to promote the QoL of PLWE.

The QOLIE-GH questionnaire is a valuable material that will promote quality care of PLWE in Ghana. This is because, the questionnaire would serve as a scientific means of making more objective and appropriate evaluation of the QoL of PLWE in Ghana. First, this could be useful in clinical practice to inform interventions to better the QoL of PLWE in Ghana. This will help health workers monitor the QoL of PLWE and make informed choices of treatment where the need be. Secondly, this could be useful in the conduct of research in Ghana and other sub-Saharan African countries, by collecting data on the QoL of PLWE. Research conducted using the QOLIE-GH could provide more accurate reports on the QoL of PLWE in Ghana and SSA, as evidence-based information that can inform policy revision and interventions to improve the QoL of PLWE.

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APPENDIX A: WITS ETHICS CLEARANCE CERTFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Mr David Atsu Deegbe

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M180946

NAME: (Principal Investigator)	Mr David Atsu Deegbe
DEPARTMENT:	Nursing Education Ghana Regions: Volta, Ashanti, Brong- Ahafo, Eastern, Western, Central, Greater Accra, Northern, Upper East and Upper West Region
PROJECT TITLE:	Development and validation of a quality of life instrument for people living with epilepsy in Ghana
DATE CONSIDERED:	28/09/2019
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr A.M Tshabalala and Prof Daleen Casteleijn
APPROVED BY:	Dr C B Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	19/02/2019

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **September** and will therefore be due in the month of **September** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX B: GHANA HEALTH SERVICE ETHICS CLEARANCE CERTIFICATE

GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

In case of reply the number and date of this Letter should be quoted.



Research & Development Division
Ghana Health Service
P. O. Box MB 190
Accra
Tel: +233-302-681109
Fax + 233-302-685424
Email: ghserc@gmail.com

MyRef. GHS/RDD/ERC/Admin/App 18/468
Your Ref. No.

18th December, 2018

David Atsu Deegbe
University of the Witwaterstand South Africa
P.O. Box AN 8768
Accra - North

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

GHS-ERC Number	**GHS-ERC004/12/18**
Project Title	Development and Validation of Quality of Life Instrument for People Living with Epilepsy in Ghana.
Approval Date	18th December,2018
Expiry Date	17th December, 2019
GHS-ERC Decision	**Approved**

This approval requires the following from the Principal Investigator

Submission of yearly progress report of the study to the Ethics Review Committee (ERC)

Renewal of ethical approval if the study lasts for more than 12 months,

Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.

Submission of a final report after completion of the study

Informing ERC if study cannot be implemented or is discontinued and reasons why

Informing the ERC and your sponsor (where applicable) before any publication of the research findings.

Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED.....
DR. CYNTHIA BANNERMAN
(GHS-ERC CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

APPENDIX C: APPROVAL LETTER FROM GREATER ACCRA REGIONAL HEALTH DIRECTOR

In case of reply the number and date of this letter should be quoted

My Ref. No. ***GHS/GARHD/007/19***

Your Ref. No.



GHANA HEALTH SERVICE
REGIONAL HEALTH DIRECTORATE
GREATER ACCRA
P. O. BOX 184
ACCRA

Tel: +233-0302-234225/226203

E-mail:c_brako@yahoo.com

30th January, 2019

THE METRO DIRECTOR OF HEALTH SERVICES
METRO HEALTH DIRECTORATE
ACCRA

THE DISTRICT DIRECTOR OF HEALTH SERVICES
SHAI OSUDOKU DISTRICT HEALTH DIRECTORATE
DODOWA

RE: REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY INVOLVING PEOPLE LIVING WITH EPILEPSY IN GHANA

Kindly find attached a letter dated 28th January 2019 in connection with the above subject matter which is being forwarded to you for your necessary support.

Thank you.

DR. (MRS.) CHARITY SARPONG
REGIONAL DIRECTOR OF HEALTH SERVICES
ACCRA

APPENDIX D: SEMI-STRUCTURED INTERVIEW GUIDE FOR PEOPLE LIVING WITH EPILEPSY

MEANING OF QUALITY OF LIFE AMONG PLWE IN GHANA

Guiding questions

1. **Please tell me: What does quality of life mean to you?"**

Probes

- Meaning of quality of life since you are living with epilepsy
- General health?
- Access to treatment
- Relationship and support
- Spiritual well- being
- Cultural factors
- Stigma and discrimination
- Assessment of quality of life

2. **In terms of "quality of life", what do you expect as an individual living with epilepsy?**

Probes

- Family
- Friends
- Relationships
- School/ Work

3. **What else in your view about quality of life, you think it might be helpful for me to know?**

APPENDIX E: PARTICIPANT INFORMATION SHEET - FACE-TO-FACE IN-DEPTH INTERVIEW

Title: Development and Validation of Quality of Life Questionnaire for People Living with Epilepsy in Ghana

Hello

My name is David Atsu Deegbe, I am a PhD student from the University of the Witwatersrand, Department of Nursing Education. I would like to request your participation in my study on the quality of life of people living with epilepsy in Ghana. This information leaflet is to let you fully understand what this study is about to help you make an informed decision to take part.

Background

Epilepsy comprises a group of central nervous system disorders characterised by two or more unprovoked episodes of seizures. In Ghana, epilepsy accounts for about 1% of the population however, most of the cases remain unreported. The high incidence of epilepsy raises a lot of concerns about the quality of life of People Living with Epilepsy (PLWE). There is, however, no Ghana specific quality of life instrument to assess the quality of life of PLWE.

What is the purpose of this study?

I will like to know what you understand about quality of life and what quality of life means to you as an individual. This will help me understand the concept of quality of life among Ghanaians living with epilepsy, so as to develop and validate a culturally sensitive quality of life instrument that is best suited for accurate and consistent assessment of quality of life of people living with epilepsy in Ghana.

What do I have to do in this study?

If you agree to take part in the study, you will be asked to sign an informed consent form. This will serve as proof of your consent to take part in the study and permission for me to use the information provided. If you agree, the interview will be recorded with a voice recorder and the conversation will be typed. If you don't agree, then I will take notes instead. I will ask questions about your age, religion, marital, educational and employment status, to know a little about yourself. After that, I will ask questions about what quality of life means to you as an individual. This interview will last for about an hour. In the course of the interview, you may ask me to pause for a while or to discontinue with the interview if you feel uncomfortable.

What are the conditions that qualify me for the study?

You have to be Ghanaian diagnosed with epilepsy without any additional diagnosis of mental disorder and be at least 18 years of age.

What are the risks of taking part in the study?

You may feel sad or upset during the interview. In this happens, you will be referred to an experienced counsellor who will discuss your concerns with you and reassure you about the difficulty you face with living with epilepsy. However, you reserve the right to withdraw from the study anytime and it will not affect your treatment and relationship with the community mental health nurses.

What are the benefits of participating in this study?

The study will hopefully provide basis for proper assessment and the provision of quality care for PLWE in Ghana. It will promote awareness and understanding of policy makers and the general population on the effect of epilepsy on the quality of life of PLWE. This will drive changes in policies and practices, respectively, to improve the quality of life of PLWE in Ghana.

What rights do you have as a participant in this study?

Participation in this study is left to your discretion and is entirely voluntary. You have the right to withdraw from the study at any time without any consequences to you. You also have the right to prevent me from using the information recorded even after the interview. Your personal information and identity will remain anonymous in this study and will not be shared with anyone. However, pseudonyms, thus a different name which is unrelated to your name, will be used instead of your name when referring to the information you shared with me.

Is there reimbursement for taking part in the study?

You will receive no payment to take part and you will not be paid for taking part.

How will confidentiality be maintained?

All information obtained from you will be kept confidential without mention being made of your name or any identifying information about you. A code will be allocated for information provided by each participant and which cannot be linked to your name. With the exception of my supervisors, no one else will have access to this information. Pseudonyms will be used instead of your name when references are being made to the information you provided.

Conflict of interest: There are no conflicts of interest in this study. Data generated from the study will be owned by the researcher. The data will be kept for two years if published and six years if not published, after this period it will be destroyed. Permission will be requested from the Human Research Ethics Committee (Medical) in the event of data sharing with other researchers for academic purposes.

Outcome and feedback: At the end of the study the results will be published in a scientific journal. Information that identifies you as a participant in the study will not be in the journal. Summary of the results will be provided to you as feedback after analysis of data collected.

Who is funding the research study?

Personal funds and funds accessed from the faculty of health sciences research grant will be used to finance this study. The results will therefore not be used for any commercial gain.

Who can I call for enquires?

A copy of the information sheet and consent form will be given to you after it has been signed or thumb-printed to take home. Should you have a concern about the study you can contact me on telephone number +233 243758359 or Email: 2006402@students.wits.ac.za

If you have any concerns over the way the study is being conducted, please contact Hannah Frimpong, the administrator of the Ghana Health Service Research Ethics Committee, on telephone number 0507 041 223

Thank you for taking time to go through this information sheet.

David Atsu Deegbe

APPENDIX F: CONSENT FORM FOR PARTICIPANTS - FACE-TO-FACE IN-DEPTH INTERVIEW

Development and Validation of Quality of Life Questionnaire for People Living with Epilepsy in Ghana

Consent for the interview

I confirm that I have been informed by the researcher about the nature, conduct, benefits and risks of the study. I have read/it was read to me, and I understood the information on the information sheet and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care and legal rights being affected. I also understand that copies of the information sheet and signed consent form will be given to me for my personal records before the interview.

I understand that section of my personal information and what quality of life means to me as an individual may be looked at by the researcher and the supervisors. I am aware that questions on quality of life will be asked. I am aware that data will be reserved for two years if published or six years if not published, after this period the data will be destroyed.

I agree to take part in the above-mentioned study. I hereby give consent for my personal information and information about my disease condition to be used as per above mentioned conditions and for the purpose of research and also to provide information required to develop and validate an epilepsy quality of life instrument for people living with epilepsy in Ghana.

| --- | --- | --- |
| Name and Surname | Signature/ Mark or Thumb | Date |

Consent for audio recording of interview

Do I have your permission to record the interview? Yes [ ] No [ ]

Investigator statement and Signature

I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant has been addressed.

Person explaining Consent

| --- | --- | --- |
| Name and Surname | Signature | Date |

Should you wish to contact me at any stage regarding consent you can contact me at Cell: Cell: +233 243758359/ Email: 2006402@students.wits.ac.za

APPENDIX G: PARTICIPANT INVITATION LETTER - NOMINAL GROUP TECHNIQUE

La-Nkwantanang Madina Municipal Health Directorate
Box, MD 839
Madina.

Dear Sir/Madam,

INVITATION TO PARTICIPATE IN A NOMINAL GROUP SESSION:

DEVELOPMENT AND VALIDATION OF EPILEPSY QUALITY OF LIFE QUESTIONNAIRE FOR PEOPLE LIVING WITH EPILEPSY IN GHANA

I am a PhD Student at the Faculty of Health Sciences, University of the Witwatersrand, South Africa. I am currently conducting a study entitled "Development and validation of Quality of Life Questionnaire for people living with epilepsy in Ghana". This is under the supervision of Dr Amme M. Tshabalala (University of the Witwatersrand, Department of Nursing Education) and Professor D. Casteleijn (University of the Witwatersrand, Department of Occupational Therapy). The aim of the study is to develop and validate an epilepsy quality of life instrument for people living with epilepsy in Ghana.

The study is in three phases: Conceptualization phase, Operationalization phase and Validation phase. The operationalisation phase comprises four stages namely: Item generation, drafting of instrument, development of a scale of measurement and scoring for the instrument and expert review of the draft instrument.

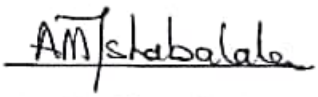
I wish to invite you to take part in the item generation part of the operationalization phase. This will involve a nominal group session meeting with experts for the generation of items for the drafting of the epilepsy Quality of Life Questionnaire for people living with epilepsy in Ghana. You are assured that participation in the review of this instrument is confidential and voluntary. You are free to withdraw your participation at any time.

Thank you in advance for your valuable input and participation.

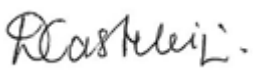
Yours faithfully,



DAVID ATSU DEEGBE
(RESEARCHER)



DR. A.M. TSHABALALA
(SUPERVISOR)



PROFESSOR D. CASTELEIJN
(CO-SUPERVISOR)

APPENDIX H: PARTICIPANT INFORMATION SHEET - NOMINAL GROUP TECHNIQUE

Title: Development and Validation of Quality of Life Questionnaire for People Living with Epilepsy in Ghana

Hello

My name is David Atsu Deegbe, I am a PhD student from the University of the Witwatersrand, Department of Nursing Education. I would like to request your contribution in my study on the quality of life of people living with epilepsy in Ghana. This information leaflet is to let you fully understand what this study is about to help you make an informed decision to take part.

Background

Epilepsy comprises a group of central nervous system disorders characterised by two or more unprovoked episodes of seizures. In Ghana, epilepsy accounts for about 1% of the population however, most of the cases remain unreported. The high incidence of epilepsy raises a lot of concerns about the quality of life of People Living with Epilepsy (PLWE). There is, however, no Ghana specific quality of life instrument to assess the quality of life of PLWE.

What is the purpose of this study?

This study is to help me understand the concept of quality of life among Ghanaians living with epilepsy, so as to develop and validate a culturally sensitive quality of life instrument that is best suited for accurate and consistent assessment of quality of life of people living with epilepsy in Ghana. The study is in three phases: Conceptualization phase, Operationalization phase and Validation phase.

What do I have to do in this study?

I wish to invite you to take part in the item generation part of the operationalization phase. This will involve a nominal group session meeting with experts for the generation of items for the drafting of the epilepsy quality of life instrument for people living with epilepsy in Ghana. You are assured that participation in the review of this instrument is confidential and voluntary.

If you agree to take part in the study, you will be asked to sign an informed consent form. This will serve as proof of your consent to take part in the nominal group session. The Nominal Group Technique comprises four key stages. The first stage, silent generation, comprises individual generation of items for the instrument among a group of experts. The second stage, round robin, is where ideas about these items are sharing among members of the expert group. This is followed by clarification stage involving discussion and clarification of the items generated for the epilepsy quality of life instrument. Voting is the last stage which involves rating or ranking of the items to be included in the instrument. Themes and items identified from the integrative reviews and the qualitative explorative study will be presented to you in advance of the nominal group meeting.

What are the conditions that qualify me for the study?

You have to be Ghanaian scholar who has had some experience in instrument development.

What are the risks of taking part in the study?

You may feel exhausted or upset during the nominal group meeting. In this happens, you have the right to be excused for a while and return to participate. If the need be, you will be referred to an

experienced counsellor who will discuss your concerns with you and reassure you. However, you reserve the right to withdraw your contribution from the study anytime.

What are the benefits of participating in this study?

The study will hopefully provide basis for proper assessment and the provision of quality care for PLWE in Ghana. It will promote awareness and understanding of policy makers and the general population on the effect of epilepsy on the quality of life of PLWE. This will drive changes in policies and practices, respectively, to improve the quality of life of PLWE in Ghana.

What rights do you have as a participant in this study?

Participation in this study is left to your discretion and is entirely voluntary. You have the right to withdraw from the study at any time without any consequences to you. You also have the right to prevent me from using the information provided even after the nominal group meeting.

Is there reimbursement for taking part in the study?

You will receive no payment to take part and you will not be paid for taking part. However, your transportation cost will be catered for.

How will confidentiality be maintained?

All information obtained from you will be kept confidential without mention being made of your name or any identifying information about you. Your personal information and identity will remain anonymous in this study and will not be shared with anyone.

Conflict of interest: There are no conflicts of interest in this study. Data generated from the study will be owned by the researcher. The data will be kept for two years if published and six years if not published, after this period it will be destroyed. Permission will be requested from the Human Research Ethics Committee (Medical) in the event of data sharing with other researchers for academic purposes.

Outcome and feedback: At the end of the study the results will be published in a scientific journal. Final draft of the epilepsy quality of life instrument will be provided to you as feedback.

Who is funding the research study?

Personal funds and funds accessed from the faculty of health sciences research grant will be used to finance this study. The results will therefore not be used for any commercial gain.

Who can I call for enquires?

A copy of the information sheet and consent form will be given to you after it has been signed or thumb-printed to take home. Should you have a concern about the study you can contact me on telephone number +233 243758359 or Email: 2006402@students.wits.ac.za

If you have any concerns over the way the study is being conducted, please contact Hannah Frimpong, the administrator of the Ghana Health Service Research Ethics Committee, on telephone number 0507 041 223

Thank you for taking time to go through this information sheet.

David Atsu Deegbe

APPENDIX I: PARTICIPANT CONSENT FORM - NOMINAL GROUP TECHNIQUE

I, …… (participant's name) hereby confirm that I have read and understood the content of the information sheet inviting me to take part in a nominal group session to generate items for draft of the epilepsy quality of life instrument for People Living with Epilepsy (PLWE) in Ghana.

The process has been explained to me and I also understand the positive outcome to develop an epilepsy quality of life instrument for PLWE in Ghana.

I have had the opportunity to ask questions and seek clarification with regard to concerns that I have about the study in addition to my consent to participating in the nominal group session. I am also aware that a copy of the consent form will be given to you after it has been signed to take home.

Therefore, I freely give my consent to take part in the nominal group session.

…… ……..
Name & Signature of Participant Date

Investigator statement and Signature

I certify that the expert has been duly briefed about the study. All questions and clarifications raised by the participant has been addressed.

---------- ---------- ----------
Name and Surname Signature Date

……. ……..
Name & Signature of Researcher Date

Should you wish to contact me at any stage regarding consent you can contact me at Cell: Cell: +233 243758359/ Email: 2006402@students.wits.ac.za

APPENDIX J: CONTENT VALIDITY TESTING QUESTIONNAIRE

Instructions

The questionnaire is aimed at assessing the content of the draft questionnaire made purposively to assess the quality of life of people living with epilepsy in Ghana. This is to assess the questionnaire for appropriateness and cultural sensitivity to people living with epilepsy in Ghana. Kindly assess each item and each domain for relevance, cultural sensitivity to the Ghanaian context, and for clarity and simplicity. The criteria for this assessment are provided below. Please tick (✓) in the table which aspect of the socio-demographic variables best describes you or write your response in the space provided.

Date: ……/ ……/ ……. **Respondent's ID: …….**

Section	**Question**	**Coding/Response category**
Section 1	**Socio-Demographic Characteristics**	
1.8	How old are you? *(Age as at last birth day)*	…… years
1.9	Sex	3. Male 4. Female
1.10	What is your highest level of education?	5. Bachelor 6. Masters 7. PhD
1.11	What is your working area?	7 Practice 8 Academia
1.12	What is your specialty?	1. Nursing (specify)_____ 2. Medicine (specify) _____ 3. Psychology (specify)_____ 4. Other (specify)_____

Criteria for measuring content validity of the Quality of Life Questionnaire for people living with epilepsy

Relevance	Cultural sensitivity	Clarity	Simplicity
5. Not relevant 6. Item needs some revision. 7. Relevant but needs some revision. 8. Very relevant	5. Not culturally sensitive 6. Item needs some revision. 7. Culturally sensitive but needs some revision. 8. Very culturally sensitive	5. Not clear 6. Item needs some revision. 7. Clear but needs minor revision. 8. Very clear	5. Not simple 6. Item needs some revision. 7. Simple but needs minor revision. 8. Very simple

With reference to the criteria above, kindly assess each of the items and domains of the Quality of Life Questionnaire (NB: Write the number corresponding to your rating in the box)

Items and domains	Relevance	Cultural sensitivity	Clarity	Simplicity
SEIZURE WORRY *To what extent do you agree with the following statements about your worries about having a seizure?*				
43. I am worried about having another seizure				
44. I am worried about the number of seizures I continue to have				
45. I am worried about injury resulting from having a seizure				
46. I am worried about embarrassment resulting from having a seizure				
47. I am worried about problems (*memory loss, mental illness, infertility, children having epilepsy*) that may arise from frequent seizures.				

	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
SEIZURE CONTROL *To what extent do you agree with the following statements about your control over seizures?*				
48. I am able to tell when I am about to have a seizure				
49. I am able to move to a safe place before a have a seizure				
50. I am able to lie or sit down to protect myself from injury during a seizure				
51. I am able to take care of myself immediately after I awake from a seizure without any assistance				
52. In general, I think my seizures are under control				
	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
EMOTIONAL WELLBEING *How often do you experience these feelings?*				
53. I feel calm within me				
54. I feel at peace with myself				
55. I am a happy person				
56. I feel sad within me				
57. I feel disturbed				
	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
ENERGY/ FATIGUE *To what extent do you agree with the following statements about your physical strength or energy?*				
58. I have energy to carry out daily activities				
59. I am able to do what is required of me at home, work or school each day				
60. I get tired easily				
61. I feel dull				
62. I find it difficult to work or learn				

	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
COGNITIVE FUNCTION *How often do you experience the following?*				
63. I have difficulty in thinking or reasoning				
64. I have difficulty making plans				
65. I have difficulty making decisions				
66. I have difficulty learning new things				
67. I have trouble remembering recent things people tell me				
68. I have trouble concentrating when performing an activity				
69. I have trouble doing one thing at a time				
	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
MEDICATION EFFECTS *To what extent do you agree with the following statements about your antiseizure medicine(s)?*				
70. My antiseizure medications make me dull				
71. My antiseizure medication(s) make me weak				
72. My antiseizure medication(s) make me sleep during the day				
73. My antiepileptic medicine(s) is/are able to control my seizures				
	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
SOCIAL FUNCTION/ RELATIONSHIP *To what extent do you agree with the following statements about your social function?*				
74. I am NOT able to attend social functions such as wedding, party, funerals				
75. I am NOT able to enjoy my hobbies and/ or leisure time				
76. Seizures make schooling difficult for me				

77. Seizures make it difficult for me to get or maintain a job				
78. Epilepsy made me lose my love relationship/ marriage				
79. Epilepsy makes it difficult for me to have any committed love relationship/ marriage				
80. I am NOT able to have a friendly relationship with my friends				
81. I am NOT able to have a friendly relationship with my family				
	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
SEIZURE SEVERITY *How often do you experience the following?*				
82. Having seizures while I am asleep				
83. Seizures lasting more than 5 minutes				
84. Mental confusion after a seizure				
85. Body pains after a seizure				
86. Falling to the ground during a seizure				
87. Bruises after a seizure				
88. Broken limbs (fracture) after a seizure				
	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
ACCEPTANCE *To what extent do you agree with the following statements about how people accept you after getting to know you have epilepsy?*				
89. My family members continue to accept me despite epilepsy				
90. My friends continue to accept me after getting to know I have epilepsy				
91. I am accepted by colleagues after getting to know I have epilepsy				
92. I am accepted in my community after getting to know I have epilepsy				

	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
SOCIAL SUPPORT *How often do you experience the following?*				
93. I am comforted by family after I have a seizure.				
94. I am encouraged by my family to achieve my goals in life despite epilepsy.				
95. My friends comfort me after I have a seizure				
96. I get encouragement from my friends to achieve my goals in life despite epilepsy				
97. People comfort me after I have a seizure in public.				
	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
ACTIVITIES OF DAILY LIVING *To what extent do you agree with the following statements about your ability to do things on your own?*				
98. I am able to take care of my personal hygiene (bathing, teeth brushing) on my own				
99. I wash my own clothing without any help				
100. I am able to go out to the shop/ market to shop for myself				
101. I am able to prepare meals for myself on my own				
102. I move about and use public transport on my own				
	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
FINANCIAL INDEPENDENCE *To what extent do you agree with the following statements about your financial life?*				
103. I am satisfied with my income				
104. I am able to meet personal financial demands				

105. I am able to provide for my family's financial needs				
	Relevance	**Cultural sensitivity**	**Clarity**	**Simplicity**
SPIRITUAL LIFE *To what extent do you agree with the following statements about your spiritual life?*				
106. I have faith in my God for healing				
107. I have hope in God that I will be cured from epilepsy				
108. I am able to worship in a congregation according to my faith				

RESPONDENTS' CHARACTERISTICS

Clinical Information		**Relevance**	**Cultural sensitivity**	**Clarity**	**Simplicity**
1.1	How long have you lived with epilepsy? ……. year (s)				
1.2	How many seizures have you had in the past 4 weeks? ……..				
1.3	On a scale of 1-4, how would you rate the severity of your seizures? *(1- meaning slight occasional fainting episode with no injury or fall that goes unnoticed and; 4 - meaning severe frequent convulsions accompanied by injuries)* ……..				
1.4	Have you had any surgery as treatment for epilepsy? 1. No 2. Yes				
1.5	Have you had any complication because of seizures? 1. No 2. Yes				
1.6	Do you take drink alcohol? 1. No 2. Yes				

Clinical Information		Relevance	Cultural sensitivity	Clarity	Simplicity
1.7	If 'Yes" How many bottles do you take in a week? ---------- Bottles				
Socio-Demographic Characteristics		**Relevance**	**Cultural sensitivity**	**Clarity**	**Simplicity**
8.4	Sex 1 Male 2 Female				
8.5	Marital status 1. Never married 2. Married 3. Cohabiting 4. Divorced 5. Separated 6. Widowed 7. Other (specify): _____ _____				
6	What is your highest level of education? 1. No formal education 2. Primary 3. Secondary (JHS/ Middle school education/ SHS) 4. Vocational/commercial/ technical education 5. Tertiary				
7	What is your employment status? 5. Unemployed 6. Private sector employee 7. Government sector employee 8. Self-employed				
8	What is your religion? 7. Christian 8. Muslim 9. Traditionalist 10. Hindu 11. Buddhist 12. Other (specify): _____				
9	What type of community do you reside? 1. Urban				

Clinical Information		Relevance	Cultural sensitivity	Clarity	Simplicity
	2. Rural				
8.10	How old are you? *(Age as at last birth day)* …… years				

APPENDIX K: PARTICIPANT INVITATION LETTER - CONTENT VALIDITY TESTING

School of Nursing and Midwifery

University of Ghana
P.O. Box, LG 43
Legon.

Dear Sir/Madam,

INVITATION TO PARTICIPATE IN CONTENT VALIDITY TESTING OF AN EPILEPSY QUALITY OF LIFE QUESTIONNAIRE FOR PEOPLE LIVING WITH EPILEPSY IN GHANA

I am a PhD Student at the Faculty of Health Sciences, University of the Witwatersrand, South Africa. I am currently conducting a study entitled "Development and validation of Quality of Life Questionnaire for people living with epilepsy in Ghana". This is under the supervision of Dr Amme M. Tshabalala (University of the Witwatersrand, Department of Nursing Education) and Professor D. Casteleijn (University of the Witwatersrand, Department of Occupational Therapy). The aim of the study is to develop an epilepsy quality of life instrument for people living with epilepsy in Ghana.

The study is in three phases: Conceptualization phase, Operationalization phase and Validation phase. The validation phase involves content validity testing of the draft epilepsy Quality of Life Questionnaire for Ghana.

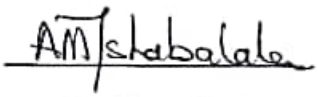
I wish to invite you participate in the validation phase as a member of the expert panel to assess the preliminary version of the epilepsy Quality of Life Questionnaire for content validity. You are assured that participation in the content validity testing of this instrument is confidential and voluntary. You are free to withdraw your participation at any time.

Thank you in advance for your valuable input and participation.

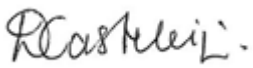
Yours faithfully,



DAVID ATSU DEEGBE
(RESEARCHER)



DR. A.M. TSHABALALA
(SUPERVISOR)



PROFESSOR D. CASTELEIJN
(CO-SUPERVISOR)

APPENDIX L: PARTICIPANT INFORMATION SHEET - CONTENT VALIDITY TESTING

Title: Development and Validation of Quality of Life Questionnaire for People Living with Epilepsy in Ghana

Hello

My name is David Atsu Deegbe, I am a PhD student from the University of the Witwatersrand, Department of Nursing Education. I would like to request your contribution in my study on the quality of life of people living with epilepsy in Ghana. This information leaflet is to let you fully understand what this study is about to help you make an informed decision to take part.

Background

Epilepsy comprises a group of central nervous system disorders characterised by two or more unprovoked episodes of seizures. In Ghana, epilepsy accounts for about 1% of the population however, most of the cases remain unreported. The high incidence of epilepsy raises a lot of concerns about the quality of life of People Living with Epilepsy (PLWE). There is, however, no Ghana specific Quality of Life Questionnaire to assess the quality of life of PLWE.

What is the purpose of this study?

This study is to help me understand the concept of quality of life among Ghanaians living with epilepsy, so as to develop and validate a culturally sensitive Quality of Life Questionnaire that is best suited for accurate and consistent assessment of quality of life of people living with epilepsy in Ghana. The study is in three phases: Conceptualization phase, Operationalization phase and Validation phase.

What do I have to do in this study?

I wish to invite you to take part in the content validity testing of the drafted epilepsy Quality of Life Questionnaire for people living with epilepsy in Ghana. You are assured that participation in this content validity testing process of this questionnaire is confidential and voluntary.

If you agree to take part in the study, you will be asked to sign an informed consent form. This will serve as proof of your consent to take part in the content validity testing session. Each expert will be given a questionnaire based on the content of the questionnaire. Each expert will also be given a rating to indicate the relevance and clarity of each item. After raring the items in the questionnaire, the content validity index and the content validity ratio will be used to quantitatively assess content validity of the questionnaire.

What are the conditions that qualify me for the study?

You have to be a health worker (nurse, clinical psychologist, psychiatrist) with at least 5 years' experience in working with people living with epilepsy.

What are the risks of taking part in the study?

You may feel exhausted or upset during the rating process. In this happens, you have the right to pause for a while and return to rate the final draft instrument. If the need be, you will be referred to an experienced counsellor who will discuss your concerns with you and reassure you. However, you reserve the right to withdraw your contributions at any time.

What are the benefits of participating in this study?

The study will hopefully provide basis for proper assessment and the provision of quality care for PLWE in Ghana. It will promote awareness and understanding of policy makers and the general population on the effect of epilepsy on the quality of life of PLWE. This will drive changes in policies and practices, respectively, to improve the quality of life of PLWE in Ghana.

What rights do you have as a participant in this study?

Participation in the content validity testing process is left to your discretion and is entirely voluntary. You have the right to withdraw from the study at any time without any consequences to you. You also have the right to prevent me from using your ratings even after the content validity testing process.

Is there reimbursement for taking part in the study?

You will receive no payment to take part and you will not be paid for taking part.

How will confidentiality be maintained?

All information obtained from you will be kept confidential without mention being made of your name or any identifying information about you. Your personal information and identity will remain anonymous in this study and will not be shared with anyone.

Conflict of interest: There are no conflicts of interest in this study. Data generated from the study will be owned by the researcher. The data will be kept for two years if published and six years if not published, after this period it will be destroyed. Permission will be requested from the Human Research Ethics Committee (Medical) in the event of data sharing with other researchers for academic purposes.

Outcome and feedback: At the end of the study the results will be published in a scientific journal. Final draft of the epilepsy quality of life instrument will be provided to you as feedback.

Who is funding the research study?

Personal funds and funds accessed from the faculty of health sciences research grant will be used to finance this study. The results will therefore not be used for any commercial gain.

Who can I call for enquires?

A copy of the information sheet and consent form will be given to you after it has been signed or thumb-printed to take home. Should you have a concern about the study you can contact me on telephone number +233 243758359 or Email: 2006402@students.wits.ac.za

If you have any concerns over the way the study is being conducted, please contact Hannah Frimpong, the administrator of the Ghana Health Service Research Ethics Committee, on telephone number 0507 041 223

Thank you for taking time to go through this information sheet.

David Atsu Deegbe

APPENDIX M: PARTICIPANT CONSENT FORM - CONTENT VALIDITY TESTING

I, …… (participant's name) hereby confirm that I have read and understood the content of the information sheet inviting me to take part in the content validity testing of the epilepsy Quality of Life Questionnaire for People Living with Epilepsy (PLWE) in Ghana.

I also understand the process and the positive outcome which is to develop an epilepsy Quality of Life Questionnaire for PLWE in Ghana.

I have had the opportunity to ask questions and seek clarification with regard to concerns that I have about the study in addition to my consent to participating in the content validity assessment of the instrument. I am also aware that a copy of the consent form will be given to you after it has been signed to take home.

Therefore, I freely give my consent to take part in the content validation process.

…… ……..
Name & Signature of Participant Date

Investigator statement and Signature

I certify that the expert has been duly briefed about the study. All questions and clarifications raised by the participant has been addressed.

……. ……..
Name & Signature of Researcher Date

Should you wish to contact me at any stage regarding consent you can contact me at Cell: Cell: +233 243758359/ Email: 2006402@students.wits.ac.za

APPENDIX N: CONTENT VALIDITY INDEX

Item	Relevance		Cultural sensitivity		Clarity		Simplicity		Average I-CVI Per item	Average S-CVI Per domain	Overall S-CVI of Questionnaire
	I-CVI	S-CVI	I-CVI	S-CVI	I-CVI	S-CVI	I-CVI	S-CVI			
SW1	1	0.93	1	0.97	1	0.93	1	0.87	1	0.93	0.91
SW2	0.83		1		0.83		0.83		0.88		
SW3	1		1		1		0.83		0.96		
SW4	1		1		0.83		0.83		0.92		
SW5	0.83		0.83		1		0.83		0.88		
SC6	1	0.97	1	0.97	1	0.97	1	0.93	1	0.96	
SC7	1		1		1		1		1		
SC8	1		1		1		1		1		
SC9	1		1		1		0.83		0.96		
SC10	0.83		0.83		0.83		0.83		0.83		
EW11	1	0.9	1	0.9	1	0.9	1	0.90	1	0.9	
EW12	0.83		0.83		0.83		0.83		0.83		
EW13	1		1		1		1		1		
EW14	1		1		1		1		1		
EW15	**0.67**		**0.67**		**0.67**		**0.67**		**0.67**		
EF16	0.83	0.93	0.83	0.93	1	0.93	0.83	0.90	0.88	0.93	
EF17	1		1		0.83		0.83		0.92		
EF18	1		1		1		1		1		
EF19	0.83		0.83		0.83		0.83		0.83		
EF20	1		1		1		1		1		
CF21	0.83	0.93	0.83	0.93	0.83	0.90	0.67	0.88	**0.79**	0.91	
CF22	1		1		1		1		1		
CF23	1		1		0.83		0.83		0.92		
CF24	1		1		1		1		1		
CF25	1		1		1		1		1		

Item	Relevance		Cultural sensitivity		Clarity		Simplicity		Average I-CVI Per item	Average S-CVI Per domain	Overall S-CVI of Questionnaire
	I-CVI	S-CVI	I-CVI	S-CVI	I-CVI	S-CVI	I-CVI	S-CVI			
CF26	0.83		0.83		0.83		0.83		0.83		
CF27	0.83		0.83		0.83		0.83		0.83		
ME28	0.83	0.96	0.83	0.96	0.83	0.96	0.83	0.92	0.83	0.95	
ME29	1		1		1		1		1		
ME30	1		1		1		1		1		
ME31	1		1		1		0.83		0.96		
SF32	1	0.94	1	0.88	1	0.88	1	0.88	1	0.89	
SF33	1		0.83		0.83		0.83		0.88		
SF34	1		0.83		0.83		0.83		0.88		
SF35	1		0.83		0.83		0.83		0.88		
SF36	**0.67**		0.83		0.83		0.83		**0.79**		
SF37	1		1		1		1		1		
SF38	1		0.83		0.83		0.83		0.88		
SF39	0.83		0.83		0.83		0.83		0.83		
SSE40	1	0.93	1	0.90	1	0.90	1	0.90	1	0.91	
SSE41	1		0.83		0.83		0.83		0.88		
SSE42	1		0.83		1		1		0.96		
SSE43	0.83		1		0.83		0.83		0.88		
SSE44	1		1		1		1		1		
SSE45	0.83		0.83		0.83		0.83		0.83		
SSE46	0.83		0.83		0.83		0.83		0.83		
A47	1	0.96	0.83	0.92	0.83	0.92	1	0.96	0.92	0.94	
A48	1		1		1		1		1		
A49	0.83		0.83		0.83		0.83		0.83		
A50	1		1		1		1		1		
SS51	0.83	0.93	0.83	0.87	0.83	0.83	0.83	0.83	0.83	0.87	
SS52	0.83		0.83		0.83		0.83		0.83		

Item	Relevance		Cultural sensitivity		Clarity		Simplicity		Average I-CVI Per item	Average S-CVI Per domain	Overall S-CVI of Questionnaire
	I-CVI	S-CVI	I-CVI	S-CVI	I-CVI	S-CVI	I-CVI	S-CVI			
SS53	1		1		0.83		0.83		0.92		
SS54	1		0.83		0.83		0.83		0.88		
SS55	1		0.83		0.83		0.83		0.88		
AD56	1	0.97	1	0.97	1	0.97	1	0.97	1	0.97	
AD57	1		1		1		1		1		
AD58	1		1		1		1		1		
AD59	1		1		1		1		1		
AD60	0.83		0.83		0.83		0.83		0.83		
F161	**0.67**	**0.78**	0.83	0.94	0.83	0.89	0.83	0.89	**0.79**	0.88	
FI62	0.83		1		1		1		0.96		
FI63	0.83		1		0.83		0.83		0.88		
SL64	0.83	**0.78**	1	0.94	0.83	0.89	0.83	0.83	0.88	0.86	
SL65	**0.67**		1		1		0.83		0.88		
SL66	0.83		0.83		0.83		0.83		0.83		

APPENDIX O: FACE VALIDITY TESTING QUESTIONNAIRE

Instructions

The purpose of this questionnaire is to assess your opinion about the questionnaire on quality of life of people living with epilepsy that you just completed.

Please tick (✓) in the table which aspect of the socio-demographic variables best describes you or write your response in the space provided.

If you have additional comments and suggestions, please write them below the table.

Date: ……/ ……/ ……. **Respondent's ID: …….**

Section	Question	Coding/Response category
Section 1	**Socio-Demographic Characteristics**	
1.13	How old are you? *(Age as at last birth day)*	…… years
1.14	Sex	5. Male 6. Female
1.15	Marital status	12. Single 13. Married 14. Widowed 15. Separated
1.16	What is your highest level of education?	8. No formal education 9. Primary 10. Secondary 11. Tertiary

Based on your experience completing the questionnaire on quality of life of people living with epilepsy, please share your opinion based on the statements in the table below.

Key: SD-Strongly disagree; **D**-Disagree; **A**-Agree; **SA**-Strongly agree.

Section 2		**SD**	**D**	**A**	**SA**	Provide comments/ suggestions if you do not strongly agree.
6.1	All relevant information on the quality of life of people living with epilepsy has been included in the questionnaire.					
6.2	The questions are clear and easy to understand.					
6.3	I would love to complete this questionnaire as a part of routine assessment at the clinic and in the community.					
6.4	Kindly provide any comments and suggestions you may have on how the questions/ statements, structure and appearance of the questionnaire could be improved.					

Thank you!!!

APPENDIX P: PARTICIPANT INVITATION LETTER - FACE VALIDITY TESTING

School of Nursing and Midwifery

University of Ghana
P.O. Box, LG 43
Legon.

Dear Sir/Madam,

INVITATION TO PARTICIPATE IN FACE VALIDITY TESTING OF AN EPILEPSY QUALITY OF LIFE QUESTIONNAIRE FOR PEOPLE LIVING WITH EPILEPSY IN GHANA

I am a PhD Student at the Faculty of Health Sciences, University of the Witwatersrand, South Africa. I am currently conducting a study entitled "Development and validation of Quality of Life Questionnaire for people living with epilepsy in Ghana". This is under the supervision of Dr Amme M. Tshabalala (University of the Witwatersrand, Department of Nursing Education) and Professor D. Casteleijn (University of the Witwatersrand, Department of Occupational Therapy). The aim of the study is to develop an epilepsy quality of life instrument for people living with epilepsy in Ghana.

The study is in three phases: Conceptualization phase, Operationalization phase and Validation phase. The validation phase involves content and face validity testing of the draft epilepsy Quality of Life Questionnaire for Ghana.

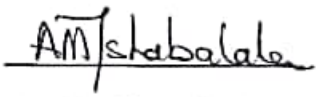
I wish to invite you participate in the validation phase as a potential user to assess the preliminary version of the epilepsy Quality of Life Questionnaire for face validity. You are assured that participation in the face validity testing of this instrument is confidential and voluntary. You are free to withdraw your participation at any time.

Thank you in advance for your valuable input and participation.

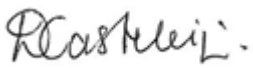
Yours faithfully,



DAVID ATSU DEEGBE
(RESEARCHER)



DR. A.M. TSHABALALA
(SUPERVISOR)



PROFESSOR D. CASTELEIJN
(CO-SUPERVISOR)

APPENDIX Q: PARTICIPANT INFORMATION SHEET - FACE VALIDITY TESTING

Title: Development and Validation of Quality of Life Questionnaire for People Living with Epilepsy in Ghana

Hello

My name is David Atsu Deegbe, I am a PhD student from the University of the Witwatersrand, Department of Nursing Education. I would like to request your contribution in my study on the quality of life of people living with epilepsy in Ghana. This information leaflet is to let you fully understand what this study is about to help you make an informed decision to take part.

Background

Epilepsy comprises a group of central nervous system disorders characterised by two or more unprovoked episodes of seizures. In Ghana, epilepsy accounts for about 1% of the population however, most of the cases remain unreported. The high incidence of epilepsy raises a lot of concerns about the quality of life of People Living with Epilepsy (PLWE). There is, however, no Ghana specific Quality of Life Questionnaire to assess the quality of life of PLWE.

What is the purpose of this study?

This study is to help me understand the concept of quality of life among Ghanaians living with epilepsy, so as to develop and validate a culturally sensitive Quality of Life Questionnaire that is best suited for accurate and consistent assessment of quality of life of people living with epilepsy in Ghana. The study is in three phases: Conceptualization phase, Operationalization phase and Validation phase.

What do I have to do in this study?

I wish to invite you to take part in the face validity testing of the drafted epilepsy Quality of Life Questionnaire for people living with epilepsy in Ghana. You are assured that participation in this face validity testing process of this questionnaire is confidential and voluntary.

If you agree to take part in the study, you will be asked to sign an informed consent form. This will serve as proof of your consent to take part in the face validity testing session. Each expert will be given a questionnaire based on the content of the questionnaire. Each expert will also be given a rating to indicate the relevance, clarity and easily understandable nature of each item. After rating the items in the questionnaire, the scores will be summarised to quantitatively assess face validity of the questionnaire.

What are the conditions that qualify me for the study?

You have to be a matured Ghanaian, 18 years or more, and living with epilepsy.

What are the risks of taking part in the study?

You may feel exhausted or upset during the rating process. In this happens, you have the right to pause for a while and return to rate the final draft instrument. If the need be, you will be referred to an experienced counsellor who will discuss your concerns with you and reassure you. However, you reserve the right to withdraw your contributions at any time.

What are the benefits of participating in this study?

The study will hopefully provide basis for proper assessment and the provision of quality care for PLWE in Ghana. It will promote awareness and understanding of policy makers and the general population on the effect of epilepsy on the quality of life of PLWE. This will drive changes in policies and practices, respectively, to improve the quality of life of PLWE in Ghana.

What rights do you have as a participant in this study?

Participation in the face validity testing process is left to your discretion and is entirely voluntary. You have the right to withdraw from the study at any time without any consequences to you. You also have the right to prevent me from using your ratings even after the face validity testing process.

Is there reimbursement for taking part in the study?

You will receive no payment to take part and you will not be paid for taking part.

How will confidentiality be maintained?

All information obtained from you will be kept confidential without mention being made of your name or any identifying information about you. Your personal information and identity will remain anonymous in this study and will not be shared with anyone.

Conflict of interest: There are no conflicts of interest in this study. Data generated from the study will be owned by the researcher. The data will be kept for two years if published and six years if not published, after this period it will be destroyed. Permission will be requested from the Human Research Ethics Committee (Medical) in the event of data sharing with other researchers for academic purposes.

Outcome and feedback: At the end of the study the results will be published in a scientific journal. Final draft of the epilepsy quality of life instrument will be provided to you as feedback.

Who is funding the research study?

Personal funds and funds accessed from the faculty of health sciences research grant will be used to finance this study. The results will therefore not be used for any commercial gain.

Who can I call for enquires?

A copy of the information sheet and consent form will be given to you after it has been signed or thumb-printed to take home. Should you have a concern about the study you can contact me on telephone number +233 243758359 or Email: 2006402@students.wits.ac.za

If you have any concerns over the way the study is being conducted, please contact Hannah Frimpong, the administrator of the Ghana Health Service Research Ethics Committee, on telephone number 0507 041 223

Thank you for taking time to go through this information sheet.

David Atsu Deegbe

APPENDIX R: PARTICIPANT CONSENT FORM - FACE VALIDITY TESTING

I, …… (participant's name) hereby confirm that I have read and understood the content of the information sheet inviting me to take part in the face validity testing of the epilepsy Quality of Life Questionnaire for People Living with Epilepsy (PLWE) in Ghana.

I also understand the process and the positive outcome which is to develop an epilepsy Quality of Life Questionnaire for PLWE in Ghana.

I have had the opportunity to ask questions and seek clarification with regard to concerns that I have about the study in addition to my consent to participating in the face validity assessment of the questionnaire. I am also aware that a copy of the consent form will be given to you after it has been signed to take home.

Therefore, I freely give my consent to take part in the face validation process.

…… ……..
Name & Signature of Participant Date

Investigator statement and Signature

I certify that the expert has been duly briefed about the study. All questions and clarifications raised by the participant has been addressed.

……. ….……..
Name & Signature of Researcher Date

Should you wish to contact me at any stage regarding consent you can contact me at Cell: Cell: +233 243758359/ Email: 2006402@students.wits.ac.za

APPENDIX S: THIRD DRAFT OF QOLIE-GH QUESTIONNAIRE

Items and domains	**Measurement scale**					
SEIZURE WORRY *To what extent do you agree with the following statements about your worries about having a seizure?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
67. I am worried about having another seizure						
68. I am worried about the number of seizures I continue to have						
69. I am worried about injury resulting from having a seizure						
70. I am worried about embarrassment resulting from having a seizure						
71. I am worried about problems (*memory loss, mental illness, infertility, children having epilepsy*) that may arise from frequent seizures.						
SEIZURE CONTROL *To what extent do you agree with the following statements about your control over seizures?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
72. I am able to tell when I am about to have a seizure						
73. I am able to move to a safe place before I have a seizure						
74. I am able to lie or sit down to protect myself from injury during a seizure						
75. I am able to take care of myself immediately after I awake from a seizure without any assistance						
76. In general, I think my seizures are under control						
EMOTIONAL WELLBEING *How often do you experience these feelings?*	**Never**	**Rarely**	**Sometimes**	**Mostly**	**Always**	**Not Applicable**
77. I feel calm within me						
78. I feel at peace with myself						
79. I am a happy person						
80. I feel sad within me						

ENERGY/ FATIGUE *To what extent do you agree with the following statements about your physical strength or energy?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
81. I have the strength to carry out daily activities						
82. I am able to do what is required of me at home, work or school each day						
83. I get tired easily						
84. I feel dull						
85. I find it difficult to work or learn						
COGNITIVE FUNCTION *How often do you experience the following?*	**Never**	**Rarely**	**Sometimes**	**Mostly**	**Always**	**Not Applicable**
86. I have difficulty making plans						
87. I have difficulty making decisions						
88. I have difficulty learning new things						
89. I have trouble remembering recent things people tell me						
90. I have trouble concentrating when performing an activity						
91. I have trouble doing one thing at a time						
MEDICATION EFFECTS *To what extent do you agree with the following statements about your antiepileptic medicine(s)?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
92. My antiseizure medications make me dull						
93. My antiseizure medication(s) make me weak						
94. My antiseizure medication(s) make me sleep during the day						
95. My antiepileptic medicine(s) is/are able to control or reduce my seizures						
SOCIAL FUNCTION/ RELATIONSHIP *To what extent do you agree with the following statements about your social function?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
96. I am NOT able to attend social functions such as wedding, party, funerals						

97. I am NOT able to enjoy my hobbies and/ or leisure time						
98. Seizures make schooling or working difficult for me						
99. Epilepsy makes it difficult for me to have any committed love relationship/ marriage						
100. I am NOT able to have a friendly relationship with my friends						
101. I am NOT able to have a friendly relationship with my family						
SEIZURE SEVERITY *How often do you experience the following?*	**Never**	**Rarely**	**Sometimes**	**Mostly**	**Always**	**Not Applicable**
102. Having seizures while I am asleep						
103. Seizures lasting more than 2 minutes						
104. Mental confusion after a seizure						
105. Body pains after a seizure						
106. Falling to the ground during a seizure						
107. Bruises after a seizure						
108. Broken limbs (fracture) after a seizure						
ACCEPTANCE *To what extent do you agree with the following statements about how people accept you after getting to know you have epilepsy?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
109. My family members continue to accept me despite epilepsy						
110. My friends continue to accept me after getting to know I have epilepsy						
111. I am accepted by colleagues after getting to know I have epilepsy						
112. I am accepted in my community after getting to know I have epilepsy						
SOCIAL SUPPORT *How often do you experience the following?*	**Never**	**Rarely**	**Sometimes**	**Mostly**	**Always**	**Not Applicable**

113. I am comforted by family after I have a seizure.						
114. I am encouraged by my family to achieve my goals in life despite epilepsy.						
115. My friends comfort me after I have a seizure						
116. I get encouragement from my friends to achieve my goals in life despite epilepsy						
117. People comfort me after I have a seizure in public.						
ACTIVITIES OF DAILY LIVING *To what extent do you agree with the following statements about your ability to do things on your own?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
118. I am able to take care of my personal hygiene (bathing, teeth brushing) on my own						
119. I wash my own clothing without any help						
120. I am able to go out to the shop/ market to shop for myself						
121. I am able to prepare meals for myself on my own when I need to.						
122. I move about and use public transport on my own						
FINANCIAL INDEPENDENCE *To what extent do you agree with the following statements about your financial life?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
123. I am able to meet personal financial demands						
124. I am able to provide for my family's financial needs						
SPIRITUAL LIFE *To what extent do you agree with the following statements about your spiritual life?*	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Not Applicable**
125. I have faith in my God for healing						
126. I have hope in God that I will be cured from epilepsy						
127. I am able to worship in a congregation according to my faith						

DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS

RESPONDENTS' CHARACTERISTICS **Note:** ***Please write your response in the space provided below or circle the one that best describes your choice of response.***		
Date: ……/ ……/ …….		**Respondent's ID: ……**
Section	**Question**	**Coding/Response category**
Section 1	**Clinical Information**	
1.1	How long have you lived with epilepsy	……. year (s)
1.2	How many seizures have you had in the past 4 weeks?	…….
1.3	On a scale of 1-4, how would you rate the severity of your seizures?	*(1- meaning slight occasional fainting episode with no injury or fall that goes unnoticed and; 4 - meaning severe frequent convulsions accompanied by injuries)* ……
1.4	Have you had any surgery as treatment for epilepsy?	3. No 4. Yes
1.5	Have you had any complication because of seizures?	3. No 4. Yes
1.6	Do you drink alcohol?	3. No 4. Yes
1.7	If 'Yes" How many times in a week do you take in alcohol?	---------- times
Section 2	**Socio-Demographic Characteristics**	
2.1	Sex	3 Male 4 Female
2.8	Marital status	16. Never married 17. Married 18. Cohabiting 19. Divorced 20. Separated 21. Widowed 22. Other (specify): _____ _____
2.9	What is your highest level of formal education?	6. No formal education 7. Primary 8. Secondary (JHS/ Middle school education/ SHS) 9. Vocational/commercial/technical education 10. Tertiary
2.10	What is your employment status?	5. Unemployed 6. Private sector employee 7. Government sector employee 8. Self-employed

RESPONDENTS' CHARACTERISTICS **Note:** ***Please write your response in the space provided below or circle the one that best describes your choice of response.***		
Date: ……/ ……/ …….		**Respondent's ID: ……**
Section	**Question**	**Coding/Response category**
2.11	What is your religion?	13. Christian 14. Muslim 15. Traditionalist 16. Hindu 17. Buddhist 18. Other (specify): _____ _____
2.12	What type of community do you reside?	3. Urban 4. Rural
2.13	How old are you? *(Age as at last birthday)*	…… years

APPENDIX T: SAMPLE OF COMMENTS OF EXPERTS FROM NOMINAL GROUP TECHNIQUE

Comments from experts on domain 1 **- Seizure worry**

M1: I think a 5-point scale is better.

You have to consider adding this item; "I am worried the seizure will affect marriage/ chances of getting married"

What about worry about complications? For example, complications with memory.

P4: Reword question 1 to 'I am worried about having another episode'.

Reconsider the phrase "concern about another seizure"

M4: A 5-point scale is better. This is statistically robust and can be used for higher statistical tests.

Is the seizure worry about the consequences of the seizure or the seizure itself?

Embarrassment about a seizure can be experienced either in the presence or absence of people. Reconsider rephrasing it to cover these two aspects.

M5: A 5-point scale or more is better. Increase the points on the scale.

M6: A 5-point scale or more is better. You may even consider a 7-point scale.

Comments from experts on domain 2 **(Seizure control)**

F1: What is the meaning about predict seizures? It should be clearly stated.

The item "Fight off attacks" needs rewording to be understood by everybody.

M1 The scoring should be increased to more than a 4-point Likert scale. Consider arrangement of the ratings.

Revise item 1 to "able to predict seizures before they occur"

"Fight off attacks" – at which point? Revise to "I am able to prevent seizures from occurring".

M2: "Fight off attacks". How possible? This needs further clarification. If not reword it.

P4: "Predict seizures". I suggest you reword to "Identify signs and symptoms before seizures occur"

Revise item 6 - 'In general, I have control over my seizures' - to be more specific.

M4: Change the predict seizure to "I am able to tell when I am about to have a seizure"

The phrase "Fight off attacks" is ambiguous.

The item on control is not comprehensive. Consider control over the phases of seizures. Like the aura, during or after a seizure.

M5: Be more specific with item 6.
Item 5 – “Fight off”. Be specific. Does it mean able to move to a safer place before seizures begin? Consider rewording to this.

F2: Change the terms “predict” and “fight off”. Find more simple way of expressing it.

Comments from experts on domain 3 **(Emotional wellbeing)**

M1: The items are limited. There is the need to add more to the items here.
What is the meaning of calm and peaceful? I suggest you change to “I feel at peace”.

M2: Consider changing the theme to psychological wellbeing

P4: The number of items in the domains are not enough. You should have a minimum of 5 items in all of the domains so that after construct validity testing, the few that may not load will leave a reasonable number of validated items for the questionnaire.
The terms “Calm” and “at peace”. You need to settle on one or you separate them. What about negative emotions? Both positive and negative emotions should be used in here. You need to word the emotional response as it appeared in the qualitative interview. Thus, the direct descriptions of the participants.

M4: Please separate the item with the terms “calm” and “peaceful”
The number of items in the domain is not enough.
Are there no negative emotions? You need to add them. Consider the specifically worded emotions that were presented by the participants during the qualitative interviews.

M5: The number of items in this domain is not enough
Separate the terms “calm” and “peaceful”.
What about items concerning emotional wellbeing such as sad, depressed, anxious, disturbed?

F2: Calm and peaceful at where? You need to be more specific.
Happy? When? You need to come out clearly.

M6: Change the domain emotional wellbeing to psychological wellbeing.
Number of items in the domains are not enough.