THE INFLUENCE OF KNOWLEDGE, ATTITUDES AND PRACTICE OF PEOPLE LIVING WITH EPILEPSY ON SEIZURE CONTROL

A dissertation

presented in part fulfilment for the award of the degree of

Master of Medicine in Internal Medicine.

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My family and friends for encouraging me every step of the way.

Dedication

This book is dedicated to my amazing family that loves and supports me unconditionally.

My parents Hussein and Farida for their patience, faith and encouragement in all that I set out to accomplish. My brothers Ahmed and Nagib, for sacrificing to allow me to succeed. For Ilham, Hussein, Hisham, Muneeb and Waleed who provide a much needed outlet from the stresses of academics.

My husband Manvinder, who always understands me.

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List of Abbreviations

Ach	Acetylcholine
AED	Antiepileptic Drug
ADR	Adverse drug reaction
AED	Antiepileptic drug
AMPA	alpha-amino-2,3-dihydro-5-methyl-3-oxo-4-isoxazolepropanoic acid
Ca	Calcium
CDC	Centers for Disease Control
CT	Computed tomography
DBS	Deep brain stimulation
EEG	Electroencephalography
ESN	Epilepsy specialist nurse
EPQK	Epilepsy Patient Knowledge Questionnaire
GABA	Gammaamino-butyric acid
GGE	Genetic generalised epilepsies
GTCS	Generalised tonic-clonic seizure
HADS-D	Hospital Anxiety Depression Scale Depression sub scale
HR	Hazard ratio
HrQoL	Health-related quality of life
IBE	International Bureau of Epilepsy
ICD-10	International Classification of Diseases, 10th revision
ILAE	International League against Epilepsy
K	Potassium
KEBAS	Kilifi Epilepsy Beliefs and Attitude Scale
KNH	Kenyatta National Hospital
Mg	Magnesium

MOSES	Modular Service Package Epilepsy
Na	Sodium
NCD	Non Communicable Diseases
NMDA	N-methyl-D-aspartate
NDDI-E	Neurological Disorders Depression Inventory for Epilepsy
OR	Odds ratio
PLWE	People Living with Epilepsy
PGES	Prolonged postictal generalised EEG suppression
QoL	Quality of life
RCT	Randomised controlled trial
SUDEP	Sudden unexpected death in epilepsy
UON	University of Nairobi
WHO	World Health Organisation

Abstract

Background

The prevalence of People Living with Epilepsy (PLWE) in developing nations is estimated at 40 million with 13 million reported to reside in Africa. Epilepsy ranks among the non-communicable diseases (NCDs) that contribute to significant morbidity and mortality. A lack of knowledge around the disease process, coupled with stigma and cultural dogma, has been shown to directly influence compliance to medication, reflected in poor seizure control.

Objective

To describe the relationship between the knowledge, attitudes and practice of People Living with Epilepsy and seizure control at the Kenyatta National Hospital.

Study Design/Site

Hospital based cross-sectional descriptive study at KNH Neurology Clinic

Study Subjects

All patients with a seizure disorder on follow up for at least two years at KNH neurology clinic.

Methods

The study was a cross sectional descriptive study done over three months at the KNH outpatient neurology clinic which sees roughly 540 PLWE annually. Data was collected using validated tools; the *Epilepsy Patient Knowledge Questionnaire* (EPKQ), and the *Kilifi Epilepsy Beliefs and Attitude Scale* (KEBAS) for assessing the knowledge, attitudes and practice of PLWE. Poor seizure control was defined as >1 seizure in the previous six months.

Results

A total of 118 attendees of the outpatient Neurology clinic were consecutively screened during the 11 week period. 6 were ineligible while 112 met the study inclusion criteria; of the eligible, 4 declined consent thus 108(91.52 % of total screened) were recruited. The *Epilepsy Patient Knowledge Questionnaire* (EPKQ) revealed patients were well versed in medical knowledge and practice in respect to their illness, with 80.6% (CI, 0.72 – 0.87) of patients having good knowledge and 66.7% (CI, 0.57 – 0.75) having good practice with a cumulative EPQK score

of 91.7% (CI, 0.85 – 0.96).The *Kilifi Epilepsy Beliefs and Attitude Scale* (KEBAS) found patients to have an overall good attitude and belief towards epilepsy with a KEBAS score of 92.6% (CI, 0.86 – 0.96).Poor seizure control was found to be 56.5% (CI, 0.47 – 0.65) 32.4% of respondents reported to regularly failing to take their medication, with 38.2% (CI, 0.29 – 0.47) citing financial difficulties as the reason.

Formal employment was associated with positive beliefs towards epilepsy (p= 0.008).There was an association between level of knowledge and seizure control (OR 6.1).

Conclusion

Despite the fact that a large percentage of the PLWE attending the neurology outpatient clinic had a good background in knowledge and practice as well as a positive attitude towards their disease process, 56.5% of patients had a poor level of seizure control.

Recommendation

We recommend the development of a standardized comprehensive package for medical education around epilepsy for patients and health care providers taking into account factors affecting knowledge, diagnostics to strengthen the pre-existing knowledge base and looking at translating knowledge into practice.

We recommend further studies on other factors that contribute to seizure control.

1.0 Introduction and Literature Review

1.1 Background

Epilepsy was defined by the International League against Epilepsy (ILAE) in 2005 as a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures(1). In 2014 ILAE task force updated the definition such that epilepsy is considered to be a disease of the brain defined by any of the following conditions:

1. At least two unprovoked (or reflex) seizures occurring >24 h apart;
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years;
3. Diagnosis of an epilepsy syndrome.

The prevalence of epilepsy in Kenya estimated at 18.2/1000(2). A locally done study in Kilifi Kenya, found the prevalence at 2.9/ 1000(95% CI 2.6-3.2)(2).WHO estimates that in Africa 80% of PWE do not receive treatment particularly those who are disadvantaged and marginalised despite effective treatment options being available(3). The reasons for which are complex and multi-system including limited resources, poor patient- provider communication and lack of social support. Social and traditional beliefs around epilepsy vary in different countries and may negatively influence health seeking strategies. Social stigma surrounding PLWE may lead to disease denial from the affected and caregivers(4). Previous studies suggest there is a direct relationship between knowledge of disease and patients developing coping mechanisms. Not much is known about how PLWE understand their condition especially in societies where epilepsy is culturally devalued and equated with sacredness or demonic possession. Worldwide studies done in the last two decades have demonstrated that PLWE knew little more and in some cases even less about their disorder than those without epilepsy(5).It has also been shown that by enabling a patient with knowledge and empowering a positive attitude a PLWE can achieve a greater degree of control over his/her seizures, making greater self-management possible(6).

1.2 Literature Review

1.2.1 Definition of Epilepsy

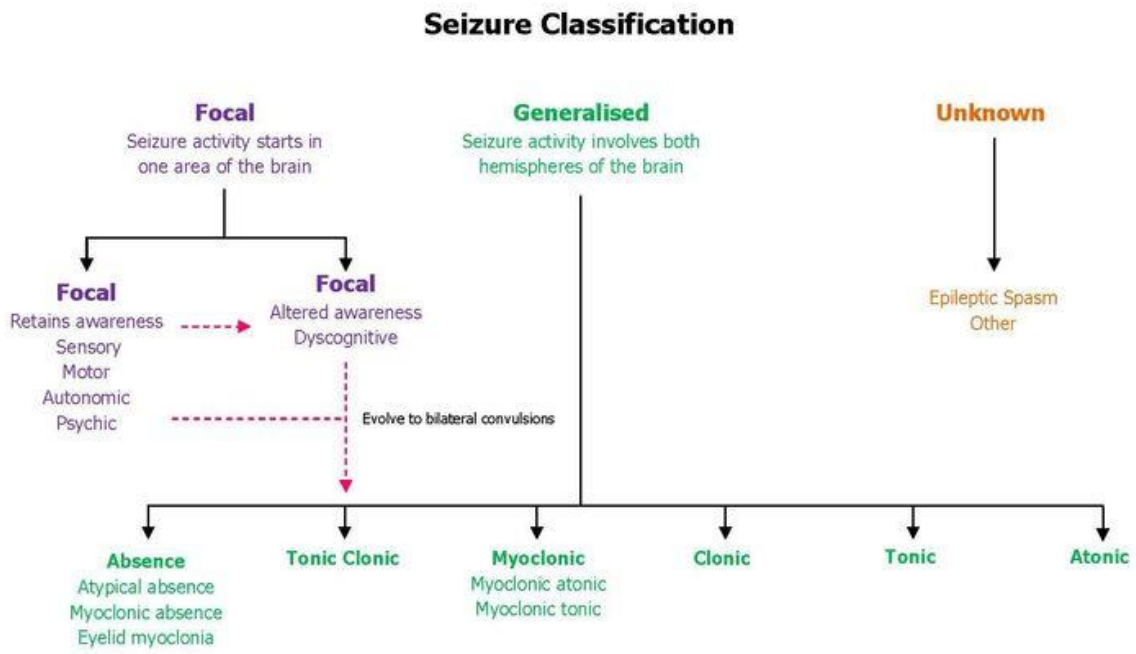
The pathophysiology of seizures was initially proposed by Hughlings Jackson a London neurologist who suggested that seizures were the result of a sudden burst of electrochemical discharges in the brain and that the character of the seizure depended on the location and function of the site of the discharge(7).Now we define a seizure as an episode of neurologic dysfunction in which abnormal neuronal firing is manifested clinically by changes in motor control, sensory perception, behaviour, and/or autonomic function. Epilepsy is the condition of recurrent spontaneous seizures arising from aberrant electrical activity within the brain. While anyone can experience a seizure under the appropriate conditions, epilepsy suggests an enduring alteration of brain function that facilitates seizure recurrence(2).A hyperexcitable state may result from increased excitatory synaptic neurotransmission, decreased inhibitory neurotransmission, an alteration in voltage-gated ion channels, or an alteration of intra- or extra-cellular ion concentrations in favour of membrane depolarization(8).There are many causes of epilepsy, most cases being idiopathic. This was found to be true in 50% of cases presenting at KNH. The presenting age is between 5-20 years with no family history of disease and no prior neurological abnormalities(7).

1.2.2 Classification of Seizures

The International Classification of Epileptic Seizures divides seizures into two group; focal and generalized based on clinical and EEG data. The clinical signs or symptoms of seizures depend on the location of the epileptic discharges in the cerebral cortex, and the extent and pattern of the propagation of the epileptic discharge in the brain. Thus, seizure symptoms are highly variable, but for most patients with 1 focus, the symptoms are usually very stereotypic.

Figure 1: Classification of Seizures

Adapted from International Classification of Epileptic Seizures 2016



1.3 Pathophysiology of Seizures

1.3.1 Neurotransmitters

Neurotransmitters are substances are released by the presynaptic nerve terminal at a synapse and bind to specific postsynaptic receptors for that ligand resulting in channel activation and passage of ions into or out of the cells(8). The major neurotransmitters in the brain are glutamate, gammaamino-butyric acid (GABA), acetylcholine (ACh), norepinephrine, dopamine, serotonin, and histamine.The major excitatory neurotransmitter is the amino acid glutamate. Glutamate receptors can be found post synaptically on excitatory principal cells,inhibitory interneurons, and certain types of glial cells. The ionotropic subclasses allow ion influx upon activation by glutamate(8).All ionotropic glutamate receptors are permeable to Na^+ and K^+, and it is the influx of Na^+ and outflow of K^+ through these channels that contribute to membrane depolarization and generation of the action potential(9). They are classified as

1. AMPA(alpha-amino-2,3-dihydro-5-methyl-3-oxo-4-isoxazolepropanoic acid)receptors
2. Kainate receptors
3. NMDA (N-methyl-D-aspartate) receptors

The NMDA receptor also has a Ca^{2+} channel that is blocked by Mg^{2+} ions in the resting state, but under local membrane depolarization, Mg^{2+} is displaced and the channel becomes permeable to Ca^{2+}; influx of Ca^{2+} tends to further depolarize the cell, and contributes to Ca^{2+} mediated neuronal injury under conditions of excessive neuronal activation potentially leading to cell death, a process termed excitotoxicity. The other major type of glutamate receptor is the metabotropic receptor, which functions by means of receptor-activated signal transduction involving membrane-associated G-proteins(10).

1.3.2 Focal Seizure Initiation and Propagation

Seizure initiation is characterized by two concurrent events:

1. High-frequency bursts of action potentials
2. Hyper synchronization of a neuronal population.

The synchronized bursts from a sufficient number of neurons result in a so-called spike discharge on the EEG. At the level of single neurons, epileptiform activity consists of sustained neuronal depolarization resulting in a burst of action potentials, a plateau-like depolarization associated with completion of the action potential burst, and then a rapid repolarization followed by hyperpolarization. This sequence is called the paroxysmal depolarizing shift(11).The bursting activity resulting from the relatively prolonged depolarization of the neuronal membrane is due to influx of extracellular Ca^{2}, which leads to the opening of voltage-dependent Na+ channels, influx of Na+, and generation of repetitive action potentials. The subsequent hyperpolarizing afterpotential is mediated by GABA receptors and Cl− influx, or by K+ efflux, depending on the cell type.

1.3.3 Seizure propagation

The process, by which a focal seizure spreads occurs when there is sufficient activation to recruit surrounding neurons, leading to a loss of surround inhibition and spread of seizure activity into contiguous areas via local cortical connections, and via long association pathways such as the corpus callosum to more distant areas (12).The propagation of bursting activity is normally prevented by intact hyperpolarization and a region of surrounding inhibition created by inhibitory neurons.Repetitive discharges lead to;

1. An increase in extracellular K^+ blunts the extent of hyperpolarizing outward K^+ currents, tending to depolarize neighbouring neurons;
2. Accumulation of Ca^{2+} in presynaptic terminals, leading to enhanced neurotransmitter release
3. Depolarization induced activation of the NMDA subtype of the excitatory amino acid receptor, which causes more Ca^{2+} influx and neuronal activation.

1.4 Knowledge, Attitudes and Practice among PLWE

Due to the decade long initiative titled the Global Campaign against Epilepsy—implemented by the International League against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and the World Health Organization (WHO) concerning both the physical and social implications of epilepsy there has been a trend to increased understanding of the illness.
The result of such campaigns has shown increased awareness in the general population toward PLWE(13). It is well documented that knowledge is a vital factor in the ability to cope successfully with chronic and long term illnesses. Misconceptions and deficits in knowledge have implications not only for psychosocial well-being but also for medical compliance. A study done by Katabalo *et al* looking at determinants of adherence to anticonvulsant therapy at the paediatric epileptic clinic at KNH found that 65.3% had requisite knowledge, while 24% believed that six months of treatment was adequate for complete cure, and 62.5% were unaware of side effects from anticonvulsant use(Participants were parents/guardians of the patients)(14).

A conspicuous challenge is the emerging evidence showing that PWLE themselves appear to know little about epilepsy compared to the general population regardless of their geographical origin(3). Mativo *et al* while studying factors influencing poor seizure control demonstrated that 83% of PLWE attending the KNH outpatient clinic where unaware of the cause of their illness. The study further demonstrated 40% prevalence of poor seizure control, with 22% in

this group using alternative forms of treatment for their seizure disorder(7). An explanation hypothesised for the degree of knowledge among PLWE has been the lack of education among this population. A Quality of life study carried out by Kinyanjui *et al* demonstrated that PLWE attending KNH neurology clinic had attained a significantly lower level of education compared to normal controls with results suggesting the need for enforcement of measures aimed at creating better educational opportunities for PLWE by eliminating stigma and prejudices towards them(15).

Beliefs are derived culturally from previous experiences, education, families, friends and/or storytelling. Attitudes are considered to develop from the evaluation of recurrent experiences within a socio-cultural context(16). Negative beliefs and attitudes toward epilepsy are still prevalent among people living with epilepsy (PLWE), particularly in resource poor countries (RPC) and the general public elsewhere. A community based survey to determine the Knowledge, beliefs and attitudes towards epilepsy in Kenya was carried out by Kwasa *et al* over one year in 1992, at 73 institutions of learning ranging from high school to college students (n=2486) (13). The data showed that 54.4 % had no knowledge as to what epilepsy was. The results further showed that traditional beliefs and attitudes are least affected by general education of the responders, with medical trainees unable to clearly identify the aetiology of epilepsy. The survey identified negative social stigma and lack of scientific understanding as the major problems in demystifying epilepsy(13). Negative attitudes and beliefs may affect the quality of life of PLWE more than seizures themselves. Kinyanjui *et al* also revealed that the mean QOL among PLWE was significantly lower ($p<0.01$) than that of the normal controls accompanying them to clinic(15).

Lack of knowledge coupled with negative attitudes about epilepsy affect the utilization of biomedical services, particularly the use of antiepileptic drugs (AEDs). Non adherence has been associated with increased morbidity and mortality along with increased hospitalization and overall cost of treatment. Studies done in the adult epileptic clinic at KNH by Mativo *et al* showed the rate of non-adherence to be at 40% with the non-adherent population further exhibiting poor seizure control (7). Katabalo *et al* demonstrated similar results when research was done targeting the parents and guardians of children with epilepsy at the paediatric clinic. It is also known that improvement in patient's knowledge may improve symptom control as seen by Faught *et al* (17). Further emphasised by Mativo *et al* when although the study

demonstrated that one of the causes of non-adherence to be the lack of access to anticonvulsants because of cost and availability (7).

Although behaviour during illnesses is often dictated by an individual's socio-cultural identity, the study done by Al- Adawi *et al* suggests that lack of knowledge appears to transcend culture(6). The main findings were that there are widespread misconceptions about epilepsy, its origin, diagnosis, treatment and prognosis. Patients scored slightly better on questions related to the particulars of their own condition rather than general epilepsy-related facts. The researchers suggest that this is due to "a deficit in information transfer from health professionals rather than general lack of interest of engagement". This is further emphasised in the study done by Otieno *et al* at KNH which showed that internal medicine residents engaging with patients at the epileptic clinic where more than competent in their knowledge base but this had not translated into patient knowledge in regards to their disease (18).

1.4.1 Assessing the Knowledge Attitudes and Practice among PLWE

It is well documented that knowledge is a vital factor in coping with epilepsy. The challenge was to develop a standardised validated tool that could be replicated and adapted to various socio cultural settings. In 2000 Long *et al* developed the Epilepsy Patient Knowledge Questionnaire(EPKQ)(19). The three-page, 13-item questionnaire included a variety of multiple-choice, true and false, and "fill in the blank" questions. The questionnaire focused on defining epilepsy (n = l), safety (n = 3), medication compliance (n = 4), social activities (n = 1), and the legal issues of driving (n = 2) and employment (n = 2). A clinical trial of the questionnaire was carried out on newly referred patients at The Ohio State University Medical Centers' Comprehensive Epilepsy Program (n 175); with results showing epilepsy patients referred to the tertiary care centre demonstrating limited knowledge of their disorder. This was true regardless of educational background, number of years with epilepsy, or age(19).
Over time the questionnaire has evolved and modified to accommodate socio-cultural aspects of the society in which it is carried out; the first section elicits demographic information including age, sex, school category, educational level (grade) and religion; while the second part consists of true/ false items (medical knowledge items and social knowledge items) and elicits awareness of existence of epilepsy, knowledge of cause and manifestation, attitude

toward epilepsy, practice in relation to epilepsy, first aid measures and treatment option of epilepsy. The questions are scored and then transformed to a scale of between 0 and 100. A cut off value of 50 is used to categorize knowledge/practice as good knowledge/practice (score≥50) and poor knowledge/practice (<50 score).Clinical trials of the questionnaire indicated that the scale has both good internal reliability and test-retest reliability (70%)(19). It is considered to be objective, sensitive and unambiguous in its assessment of medical knowledge levels in relation to epilepsy and is sensitive to differences in knowledge. The questionnaire has also been used in international studies and, in 2003, was found to be useful in comparing the medical knowledge of PLWE between countries(20).

Table 1: Summary of studies done to assess knowledge and practice in PLWE using the Epilepsy Patient Knowledge Questionnaire (EPQK)

Study	Study Period	Study Design	No. of Patients	Major Findings
Long *et al* (USA 2000)	June-July 2000	Cross sectional Descriptive	220	Patients with epilepsy are not knowledgeable about their disorder, regardless of age, educational background, or number of years with epilepsy.
Al –Adawi *et al* (Oman 2003)	October-December 2002	Cross sectional Descriptive	107	Lack of knowledge of safety and compliance topics.
Jones *et al* (UK 2006)	July 2006	Cross sectional Descriptive	75	Patients with poorly controlled epilepsy had greater belief in their medication but poor knowledge on their disease
Kuriakose *et al*(India 2006)	October-December 2006	Cross sectional Descriptive	105	Patients had a basic understanding of epilepsy, but knowledge in terms of safety measures, social issues and treatment options were poor
Kassie *et al* (Ethiopia 2014)	June-July 2013	Cross sectional Descriptive	180	Knowledge on epilepsy found to be associated with duration on treatment. Majority were well educated on their illness
Obiako *et al* (Nigeria 2014)	January 2011-January 2013	Cross sectional Descriptive	160	Patients who were older and better knowledge on epilepsy were more likely to achieve seizure control
Gilani *et al* (South Africa 2015)	June-August 2014	Cross sectional Descriptive	109	Identified main gaps in knowledge about epilepsy causes, symptoms, diagnosis and treatment

A general take home message from all the studies showed a lack of knowledge, including medical knowledge coupled with stigma and cultural dogma attached to epilepsy has been

shown to directly influence poor medicine regimen compliance, resulting in poor seizure control(3). As a consequence PLWE have a lower quality of life than people with other chronic illnesses. If modifiable factors associated with non-adherence are understood, then it may be possible to intervene to improve adherence and therefore reduce morbidity caused by recurrent seizures.

1.4.2 Developing a quantitative tool for attitude assessment among PLWE

There is a diverse range of beliefs and practice worldwide relating to the causes and treatment of epilepsy. Various models have been used to describe epilepsy worldwide but despite differences between cultures and settings, beliefs about the causes of epilepsy can be grouped into four themes: punishment for sin, bewitchment or possession, a contagious disease, and/or a disease of the brain(21). Understanding cultural beliefs provides an insight into the way people cope with and respond to their experiences with epilepsy. Therefore, it is important for health professionals to be familiar with the community's understanding about the causes and treatment of epilepsy, so that effective communication and treatment can be maintained
Although when using a questionnaire as a form of assessment the limitations of recall bias and self-preservation bias are present, Self-reporting is still the simplest measure of adherence to treatment protocols. George *et al* have found that when a valid questionnaire is used (in this case the survey instrument was a 13-item questionnaire in English, designed to evaluate knowledge, attitudes and practice with respect to epilepsy that had been used in recent studies in Cameroon, South Korea, Brazil, India, Malaysia and Turkey.) the self-report scores are accurate with both sensitivity and specificity of over 70%(17).

The Kilifi Epilepsy Beliefs and Attitude Scale (KEBAS) was developed for use in Africa.The items for the scale were developed in four phases:

1. Formative research and concept development; whereby a literature review to locate instruments designed to measure beliefs and attitudes toward epilepsy was conducted
2. Item development and validity assessment; a pool of 56 items was generated. 28 taken directly or adapted from questions used in previous studies and the remaining items were developed from the qualitative study findings
3. Revising the scale for the main survey;
4. Evaluating the scale.

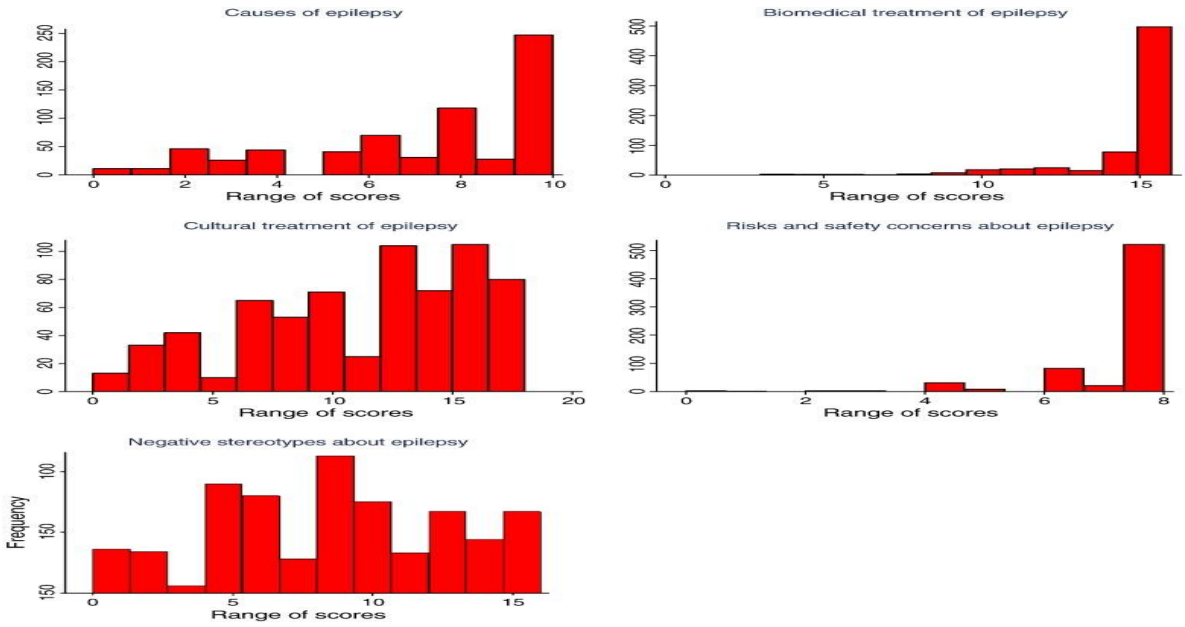
The final scale has 34 items, and the number of items in each subscale is: causes of epilepsy (n = 5); biomedical treatment of epilepsy (n = 8); cultural treatment of epilepsy (n = 9); risks and safety concerns about epilepsy (n = 4); and negative attitudes about epilepsy (n = 8).

The KEBAS also had two methodological strengths that are important in interpreting the findings of acceptable psychometric properties. The first is the large sample size on which the measurement was performed. The second methodological strength is the excellent response rate, which minimized the likelihood that non-responders may be systematically different than responders. This strengthens the generalizability of the findings and potentially increases the stability of the findings(16).

1.4.3 Scoring the Kilifi Epilepsy Beliefs and Attitude Scale

The total score ranges for the five subscales were: causes of epilepsy 0–10; biomedical treatment 0–16; traditional treatment 0–18; risk and safety concerns 0–8; and negative attitudes 0–16. The use of a Likert scale provides a systematic method of gathering information about participants' beliefs and attitudes about epilepsy, shortening the interview time and providing numerical values, which were used to compare participants with high and low scores(22).

Figure 2: Scoring for the five subscales of the Kilifi Epilepsy Beliefs and Attitude Scale



1.5 Seizure Control

Poor Seizure control for the purposes of our study will be defined by >1 seizure in the last six months.This was to allow for comparison with previous studies in the same population at KNH, which used the same measure,(7) Seizure control is multifactorial with some studies showing significant prognostic factors being female sex, age older than 20 years at presentation, secondary and tertiary education attainment, being employed, family support, regular clinic attendance, AED compliance, and generalized epilepsy(7). Potential causes of poorly controlled seizures include incorrect classification of the seizures, inadequate antiepileptic drugs (AED) therapy and biologically intractable seizures (23). Poor adherence may be the most important cause of poorly controlled epilepsy(24). Stanaway *et al* found that 31% of seizures were precipitated by non-adherence to medication(25).Jones *et al* found that patients with poorly controlled epilepsy had beliefs about their epilepsy that were significantly different from those with well controlled epilepsy(26).Both studies sought to look at the impact of knowledge on epilepsy on seizure control.

In 2002 May *et al* conducted a randomised control trial to evaluate the efficacy of the educational program MOSES (Modular Service Package Epilepsy), on 242 epileptic patients on treatment attending follow up at 22 epileptic centres in Germany, Austria and Switzerland. MOSES is an interactive program for people with epilepsy older than 16 years, regardless syndrome, duration, and severity of the epilepsy(27). The aims of which are to improve patients' knowledge about epilepsy, its consequences, and diagnostic and therapeutic measures, and to improve patients' understanding of psychosocial and occupational problems. The MOSES group was found to have significant improvement in seizure frequency compared with the control group and an improvement in contentedness with treatment and the tolerability of AED therapy as well.

In a study done at KNH in 1984, Lisk showed that 70% of literate patients were drug compliant as compared to 44% who were not. Patients on single medication had a' higher degree of compliance". In this study, 60.9% were controlled and 39.1 % uncontrolled(22).

1.5.1 Theoretical and Conceptual Framework

When managing an individual living with epilepsy there are unmodifiable factors such as age of onset, aetiology of seizures and the location of the eliptogenic zone. Despite adequate medication it has been found that seizures will persist in 20-35 percent of cases.(7) It is necessary therefore to identify other modifiable factors that could be explored as avenues to improve seizure control in this patient population. Some of the suggested entry points are Knowledge, Attitudes and Practice of PLWE which may be amenable to an intervention to improve outcome.

Knowledge can be defined as a familiarity, awareness or understanding of facts, information, descriptions, or skills, which is acquired through experience or education by perceiving, discovering, or learning. An attitude is an expression of favour or disfavour toward a person, place, thing, or event which can be formed from a person's past and present experiences. The culmination of knowledge and attitudes results in the practice of the patient which is the actual application or use of an idea, belief, or method as opposed to theories about such application or use. A range of theoretical models have been used to attempt to clarify the relationship between knowledge attitudes and behaviours influencing medical outcomes. Studies suggest that beliefs about medication and illness and can be measured using standardised questionnaires and have been related to adherence in other patient populations.(26)

A community based survey to determine the Knowledge, beliefs and attitudes towards epilepsy in Kenya was carried out by Kwasa *et al* over one year in 1992, at 73 institutions of learning ranging from high school to college students (n=2486). The data showed that 54.4 % had no knowledge as to what epilepsy was. The results further showed that traditional beliefs and attitudes are least affected by general education of the respondees, with medical trainees unable to clearly identify the aetiology of epilepsy. The survey identified negative social stigma and lack of scientific understanding as the major problems in demystifying epilepsy(13). In 1984, Lisk studied 72 patients in the KNH neurology clinic and found that 39.1% of the patients were poorly controlled (22). His study used a questionnaire as the instrument to qualify seizure control. Drug levels were not used to assess drug adherence. Mativo *et al* 20 years later showed no change in the prevalence of control despite the introduction of more potent anticonvulsants (7).

In 2002 May *et al* conducted a randomised control trial to evaluate the efficacy of the educational program MOSES (Modular Service Package Epilepsy), which is an interactive program for people with epilepsy older than 16 years. The aims of which are to improve patients' knowledge about epilepsy, its consequences, and diagnostic and therapeutic measures, and to improve patients' understanding of psychosocial and occupational problems. The MOSES group was found to have significantly improvement in seizure frequency compared with the control group and an improvement in contentedness with treatment and the tolerability of AED therapy as well (27).

Figure 3: Theoretical/Conceptual Framework-Adequacy of Seizure Control

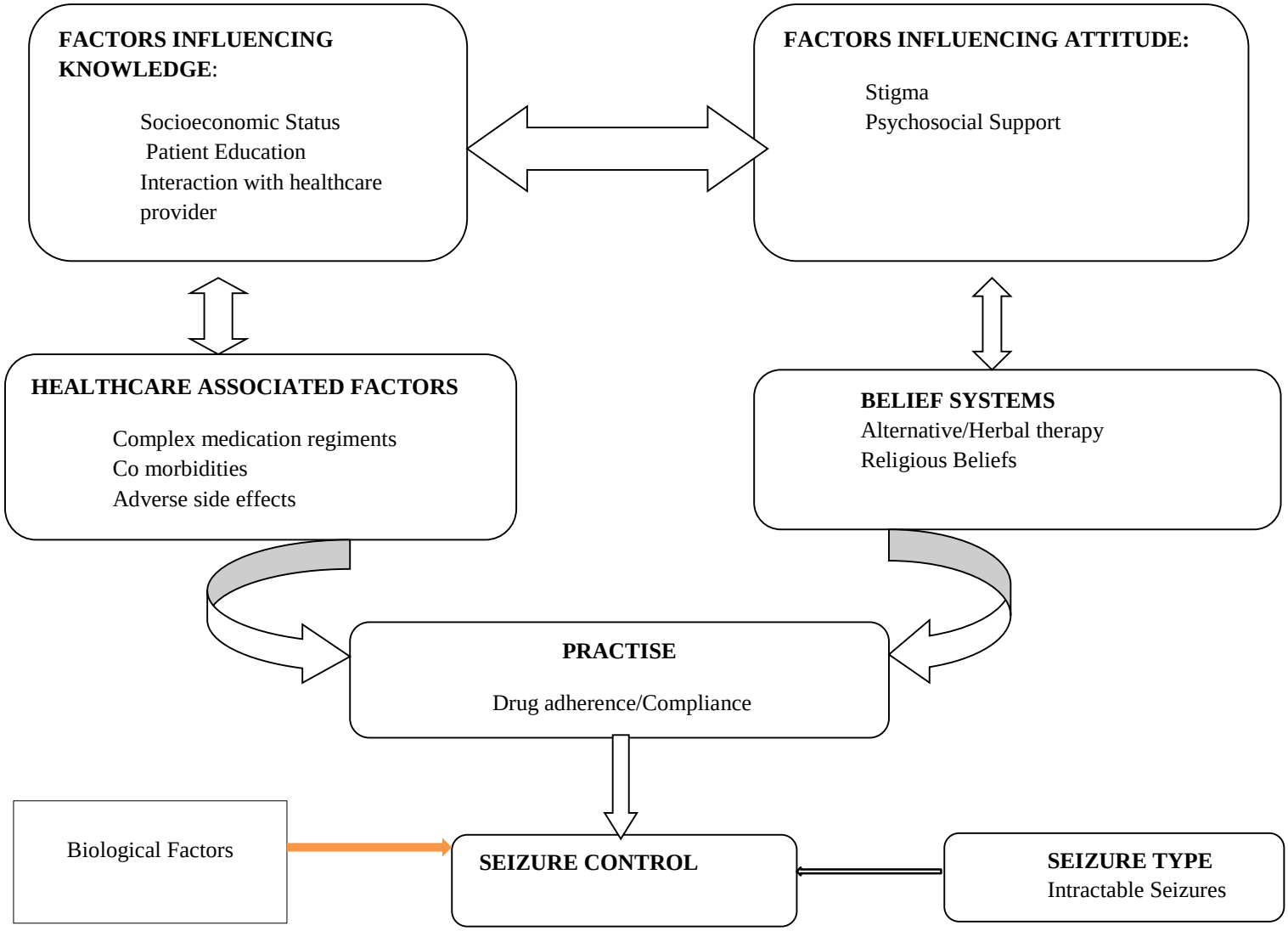


Table 2: Summary of studies done to relate seizure control to knowledge and practice in PLWE

Study	Study Period	Study Design	No. of Patients	Major Findings
Stanaway *et al* (USA 1985)	March 198	Cross sectional Descriptive	95	Compliance with therapy was positively related to perceived benefit of anticonvulsant therapy 31% of seizures due to poor compliance related to poor knowledge
Jones *et al* (UK 2006)	July 2006	Cross sectional Descriptive	75	Patients with poorly controlled epilepsy had greater belief in their medication but poor knowledge on their disease
May *et al* (Germany Austria Switzerland 2002)	Jan-June 2001	Randomised Control trial	242	The MOSES group improved significantly in knowledge and had a decrease in seizure frequency accompanied by an increase in contentedness with treatment as compared to the control group

1.6 Problem Statement

Epilepsy is particularly common in low-income countries, where the prevalence is more than twice that of high-income countries, possibly due to the higher incidence of risk factors. Long *et al* revealed that irrespective of demographic patterns such as age, education and duration of illness PLWE tend to have limited knowledge about their condition(25). The best remedy to negative attitudes to ensure that patients understand exactly what epilepsy is. Without such knowledge PLWE are likely to become the victims of other misconceptions of their disease. Knowledge, attitude, and practice of patients towards a certain disease are important as they greatly determine the outcome especially for those diseases requiring long-term/lifelong therapy. The findings from this study may influence healthcare providers who are in a unique and influential position to enhance medical knowledge as well as dispel misconceptions and myths around epilepsy.

1.7 Study Justification

Epilepsy confers significant morbidity and mortality. There is an increased mortality ratio for PLWE of between 2-3 times the expected(28).Controlled epilepsy has been shown to contribute to better quality of life. Patient education is an effective component of comprehensive care and improving patients' knowledge has been shown to improve their symptoms and prognosis(29). There is a need for educational intervention in this population, particularly related to injury prevention. This can assist in developing a comprehensive standardised package for medical education around epilepsy for patients and health care providers(30). Ultimately this will allow for better communication between healthcare provider and patient and contribute to our strategy on how to deal with poorly controlled patients and resulting in improvement of quality of care for our patients.

2.0 Research Question

What is the knowledge, attitudes and practice of People living with Epilepsy on antiepileptic drug treatment attending the Kenyatta National Hospital outpatient neurology clinic and is there a relationship with their seizure control?

2.1 Broad Objective

To determine the knowledge, attitudes and practice of People living with Epilepsy on antiepileptic drug treatment attending the Kenyatta National Hospital outpatient neurology clinic and describe its relationship with seizure control

2.2 Specific Objectives

1. To assess the medical knowledge and practice of PLWE in terms of causes, symptoms, diagnosis and treatment modalities
2. To assess attitudes of PLWE in terms of positive or negative impact on their lives in relation to their illness
3. To determine the adequacy of seizure control among PLWE attending the neurology clinic
4. To describe the relationship between the knowledge, attitudes and practice of People living with Epilepsy and their seizure control

3.0 Methodology

3.1 Study Design

The study was a questionnaire based cross sectional descriptive study done over three months. The study design was a quantitative approach using a combination of internationally and locally validated tools that can be replicated and adapted to various socio cultural settings for assessing medical knowledge, attitudes and practice of PLWE –,

1. The *Epilepsy Patient Knowledge Profile (EPQK***)** consists of true/ false items (medical knowledge items and social knowledge items) that were selected by a range of experts in the field of epilepsy and is considered to be objective, sensitive and unambiguous in its assessment of medical knowledge levels in relation to epilepsy.
2. The Kilifi Epilepsy Beliefs and Attitudes tool (KEBAS) was developed to be a quantitative assessment of attitudes and belief s in PLWE.

3.2 Study Site

The study site was the Kenyatta National Hospital which is a tertiary, teaching and the main referral hospital for East and Central Africa, with a bed capacity of over 1,800 The outpatient neurology clinic sees 3384 patients annually with 16.6% being PLWE(14) and is held on Mondays, from 8 am to 1pm catering for patients above 14 years. The clinic is run by both consultants (Neurologists) and residents (from Internal Medicine). During the clinic days, health talks run by a nurse are given to new patients, and old patients addressing the need for medication adherence and safety measures. There is no standardised patient education package offered to PLWE.

3.3 Study Population

The study population included all patients 14 years and older with a diagnosis of epilepsy attending the Kenyatta National Hospital outpatient neurology clinic.

3.4 Sample size calculation

According to KNH data from hospital records, an estimated number of 540 PLWE are seen annually with approximately 10-15 patients seen weekly. It is therefore expected that approximately 135 patients will be seen in the clinic during the three month study period. A representative sample was drawn from this population in the period and the sample size calculation was obtained using the formula for finite population (Daniel, 1999). (This sample was based on a similar study done by Stanaway *et al* which had 95 patients as their sample size using the same tool to achieve all previously stated objectives).

The calculation was as follows:

$$n' = \frac{NZ^2P(1-P)}{d^2(N-1)+Z^2P(1-P)}$$

Where

n' = sample size with finite population correction,

N = size of the target population = 135

Z = Z statistic for 95% level of confidence = 1.96

P = Estimated proportion of knowledge, attitudes and practice = 50%

d = margin of error = 5%

$$= \frac{135 \times 1.96^2 \times 0.5 \times 0.5}{0.05^2\,(135-1) + 1.96^2 \times 0.5 \times 0.5}$$

= **100** patients with epilepsy within 5% level of precision.

3.5 Sampling and Recruitment

The target population was estimated at 100 patients who were recruited over a period of 3 months, through consecutive sampling with an average of 10 every Monday clinic visit. This sample size is considered adequate for a small descriptive cross-sectional study to reduce selection bias; all PLWE were invited to participate until the sample size was reached.
Patients were recruited from Kenyatta National Hospital Outpatient neurology clinic by the principal investigator. Patients attending scheduled visits were informed about the study and invited to participate in it. A screening proforma (appendix) was used to assess eligibility to participate in the study.

Patients who fulfilled the inclusion criteria, and were willing to participate in the study were expected to sign a written informed consent form (appendix) and were recruited into the study. Patients with conditions in the exclusion criteria were not enrolled. Files were marked to ensure that patients did not participate more than once.

3.6 Patient Selection

3.6.1 Case Definitions

A case was any epileptic patient as defined by the International League against Epilepsy (ILEA) (1).
Epilepsy is a disease of the brain defined by any of the following conditions;
1. At least two unprovoked (or reflex) seizures occurring >24 h apart
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years
3. Diagnosis of an epilepsy syndrome.

Poor Seizure control for the purposes of our study was defined by >1 seizure in the previous six months.

Compliance was defined as the "readiness on the part of the patient to cooperate with diagnostic and therapeutic measures"(7). Noncompliance was defined as not taking the correct dosage of medicine (too much/too little), failing to follow dosing schedules, not taking medication for the duration specified, or taking non recommended medication.

Patients on treatment were defined as PLWE on AED for minimum of two years attending the neurology clinic.

Patients in remission were defined as patients who have been seizure free for at least one year (for whom AEDs have been stopped and those still on medication).

3.6.2 Inclusion Criteria

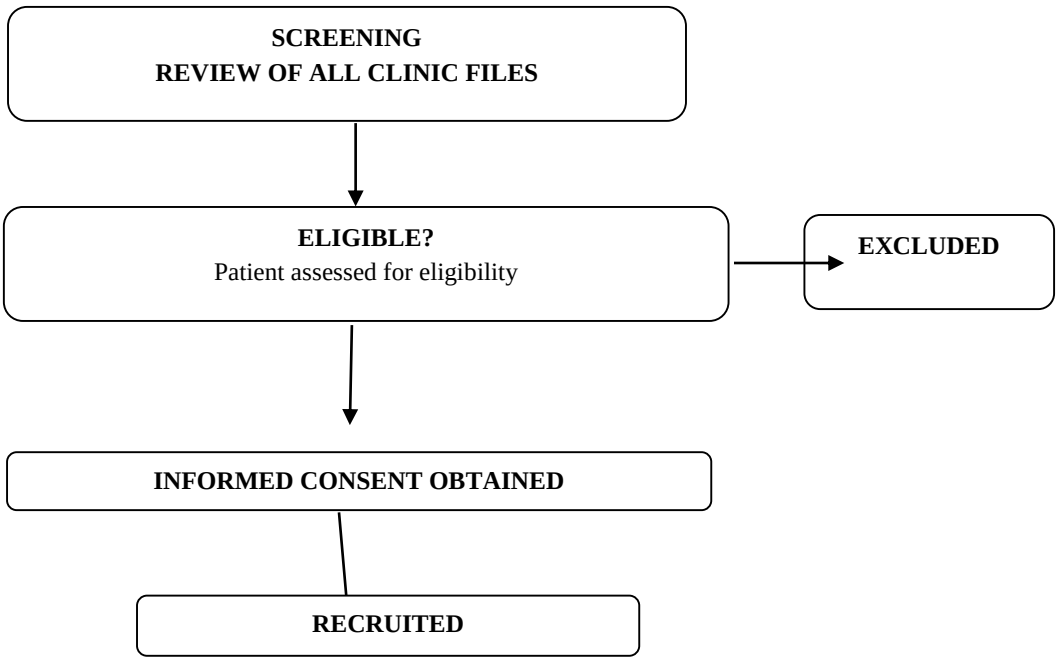
- Adolescents and adults aged >14 years attending the neurology clinic for a minimum of 2 years with a diagnosis of epilepsy.
- Signed informed consent to participate in the study.

For patients aged <18 years, informed assent was obtained from the patient, and informed consent was signed by the parent or legal guardian on behalf of the patient.

3.6.3 Exclusion Criteria

- No documented diagnosis of epilepsy(or epilepsy syndromes)
- Patients with mental retardation or severe psychiatric disorders
- Patients with enrolled in other non-pharmacologic treatment for epilepsy

Figure 4: Flow Chart of Screening & Recruitment



3.7 Study Procedures

After approval from KNH/UoN Ethical Review Committee, the Principal investigator and the research assistant who was a qualified clinical officer with previous experience in data collection and handling underwent a one day training on implementation of the data collection tools, including how to interview the patients and fill in the study proforma under the supervision of the school of public health. The research assistant had the requisite knowledge and credentials to allow access to clinical information while maintaining confidentiality and initially carried out interviews under the supervision of the Principal investigator to ensure adherence to set standards before conducting interviews alone.

Each week, a list of all patients booked for the clinic, with a diagnosis of epilepsy and in the identified age group was drawn up by the Principle Investigator. From the list, consecutive sampling method was used to obtain 8 to 10 patients on each clinic day, until the sample size was reached. The selected patients had the study explained to them, and those who met the inclusion criteria and agreed to participate, were requested to sign the informed consent form. If no consent was given, consecutive sampling was repeated to select further patients for the study. Once the consent had been given, the patients were interviewed as per the proforma after their clinic review. The proforma was administered by the PI and the research assistant. Each of the questions was self-administered in the language best understood by the patient, either English or Kiswahili. The patients' clinical records were reviewed coupled with a brief targeted history to obtain socio-demographic and clinical information including level of education, home language, employment status, age of onset of epilepsy, type of epilepsy, recent seizure frequency and details of prescribed antiepileptic drugs. Poor seizure control was defined as >1 seizure over the last six months.

The data tools are internationally and locally validated questionnaires for assessing medical knowledge, attitudes and practice of PLWE –,

3. The *Epilepsy Patient Knowledge Profile (EPQK* **)**is adapted from Long *et a l*and modified to accommodate socio-cultural aspects (18). It consists of true/ false items (medical knowledge items and social knowledge items) that were selected by a range of experts in the field of epilepsy and is considered to be objective, sensitive and unambiguous in its assessment of medical knowledge levels in relation to epilepsy.

4. The Kilifi Epilepsy Beliefs and Attitudes tool (KEBAS) was developed to be a quantitative assessment of attitudes and belief s in PLWE, through a process employing both quantitative and qualitative analysis(16). A scale of 34 questions is administered with items worded both positively and negatively within the same subscale to avoid acquiescence, affirmation, or agreement bias. Test–retest reliability was acceptable for all the subscales.

Both questionnaires have undergone translation into Kiswahili and back translation into English by trained, independent linguists and finally verified by the principal investigator for authenticity. This is to allow for ease of use among a larger population subset.

3.8 Data management and analysis methods

This study aimed to investigate the extent to which knowledge and practice, measured using a validated self-report questionnaire is associated with seizure control. We also aimed to investigate the relationship between seizure control and beliefs about medication and illness.

Data was collected using a validated data collection tools for assessing the medical knowledge, attitudes and practice of PLWE and analysed descriptively. Data was entered, cleaned and analysed with SPSS version 21.0. Demographic and clinical characteristics were summarized into frequencies and proportions and where applicable median, means and standard deviations were calculated for continuous data.

The Knowledge, attitudes and practice questions were summarized and presented as frequencies and proportions. The questions were scored and then transformed to a scale of between 0 and 100. A cut off value of 50 was used to categorize knowledge/practice as good knowledge/practice (score≥50) and poor knowledge/practice (<50 score). Also, attitude was categorized as positive (≥50) and negative attitude (<50 score). Furthermore, seizure control among patients on antiepileptic drug treatment was determined, and analysed as controlled or not controlled and presented as frequencies and proportions.

The Chi-Square test for association and Fisher's exact tests were used to test the relationship between the categorical variables knowledge, attitude and practice towards epilepsy and seizure control. P-values and 95% confidence intervals (CIs) were also calculated where applicable and a P value <0.05 was considered to be statistically significant.

3.9 Ethical Considerations

The study was conducted after approval by Department of Clinical Medicine and Therapeutics, University of Nairobi; Kenyatta National Hospital/University of Nairobi Ethics and Research Review Committee.

A consent explanation (Appendix) was given to study participants, and eligible subjects who agreed to participate were required to sign an informed consent form (Appendix).

The principal investigator ensured that patient confidentiality was strictly observed. Any private information obtained from the patients was not disclosed to any other person or party without the patient's consent. All data obtained from this study was used for the sole purpose of meeting the objectives stated in this proposal.

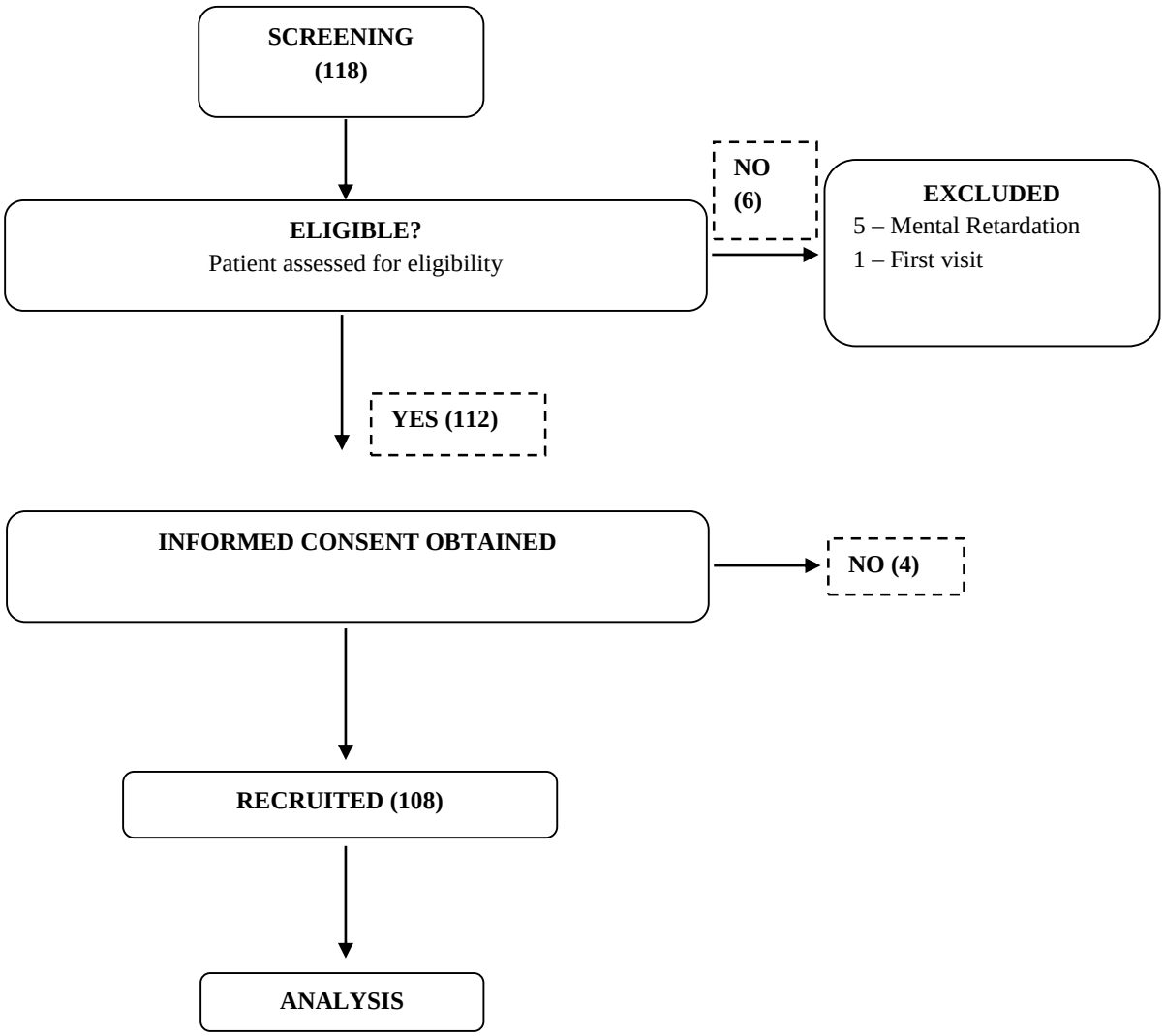
On completion of the study, all data collected was submitted to the department of Clinical Medicine and Therapeutics for possible follow up studies, and can be stored for up to 5 years. Information from the study will also be provided to Kenyatta National Hospital.
Within two months of results presentation, data was disseminated to the healthcare workers in the Outpatient neurology clinic, during a CME session with an aim to determine areas of focus for the said healthcare workers to target during their weekly patient centred morning health talks. This proactive dissemination strategy offers to reach out to multiple audiences and staff to influence attitudes and behaviour change. The healthcare workers will then be tasked of disseminating this information with the goal of educating the patients themselves in an informal setting.

4.0 Results

4.1 Patient Screening

A total of 118 patients were consecutively screened at the outpatient Neurology clinic during the 11 week period; 6 were ineligible for reasons of: severe mental retardation (5) and being a first time clinic attendee (1). 112 met the inclusion criteria; 4 were further excluded because they declined consent thus 108(91.52 % of total screened) were recruited (Figure 5).

Figure 5: Flow Diagram for the enrolled study patients (People living with Epilepsy):



4.2 Demographic Information and Epidemiological Characteristics of the Respondents

The mean age of study subjects was 34.91 (SD17.64) with a range of 13-88 years. Of the 108 recruited 59 (54.6%) were male, and 49 (45.4%) were female, with a male female ratio of 1.2:1; 50.9% of the study subjects were married. 51.9% of respondents were under the age of 18 when first diagnosed with epilepsy while 50 (46.3 %) had been living with epilepsy for 10 years.

Majority of the study participants had attained a minimum of a secondary school education (80.6%), with 28% currently enrolled in full time academics. Approximately 38% had some source of income as they were either self-employed or employed.

The majority of respondents 86 (79.6%) had generalized seizures with 54(50.5%) on monotherapy, while 53 (49.5%) were on polytherapy. Carbamazepine was the most common medication either in monotherapy (67.3%) or polytherapy (94.2%). 32.4% (34) of respondents regularly failed to take their medication, with 38.2 % (13) citing financial difficulties as the reason. while 24% said they routinely forgot to take medication. Majority of the respondents 88 (81.5%) had never sought alternative treatment from a traditional healer.

The demographic distribution and epidemiologic/disease characteristics of the respondents is as depicted in Tables 3-5.

Table 3: Demographic Information of the Respondents

	Frequency N (%)
Age	
< 18	14 (13.0)
18 – 36	57 (52.8)
37 – 55	23 (21.3)
>55	14 (13.0)
Gender	
Male	59 (54.6)
Female	49 (45.4)
Marital Status	
Never married	46 (42.6)
Married	55 (50.9)
Separated/ Divorced /Widowed	7 (6.5)
Education	
No formal education	4 (3.7)
Primary (lower/upper)	28 (25.9)
Secondary	55 (50.9)
College/University	21 (19.4)
Occupation	
Unemployed	36 (33.3)
Employed/Informal Sector/Self	41 (38.0)
Student	31 (28.7)

Table 4: Disease Characteristics of the Respondents

Variable	Frequency N (%)
Disease Characteristics	**Frequency n (%)**
Age at First Seizure	**N=106**
<18	57 (51.9)
18 – 36	34 (31.5)
37 – 55	14 (13.0)
>55	2 (1.9)
Disease Duration (years)	**N=106**
1 – 10	51 (46.3)
11 – 20	28 (25.9)
21-30	27 (24.9)
Seizure Type	**N=108**
Generalized	86 (79.6)
Focal	21 (19.4)
Other	1 (0.9)
Medication Regimen	**N=107**
Monotherapy	55 (50.9)
Polytherapy	52 (48.1)
Type of Drug (Monotherapy)	**N=55**
Carbamazepine	37 (67.3)
Sodium Valproate	8 (14.5)
Phenytoin	5 (9.1)
Phenobarbitone	4 (7.3)
Levetiracetam	1 (1.8)

Table 5: Compliance Characteristics of the Respondents

Variable	Frequency N (%)
Compliance Characteristics	**Frequency n (%)**
Regularly missed medication	**N=108**
Yes	35 (32.4)
No	73 (67.6)
Reasons for missing medication	**N=34**
Financial difficulties	13 (38.2)
Unavailability	3 (8.8)
Just forgetting	8 (23.5)
Side effects	7 (20.6)
Others	3 (8.8)
Treatment from a traditional healer	**N=108**
No	88 (81.5)
Yes	20 (18.5)

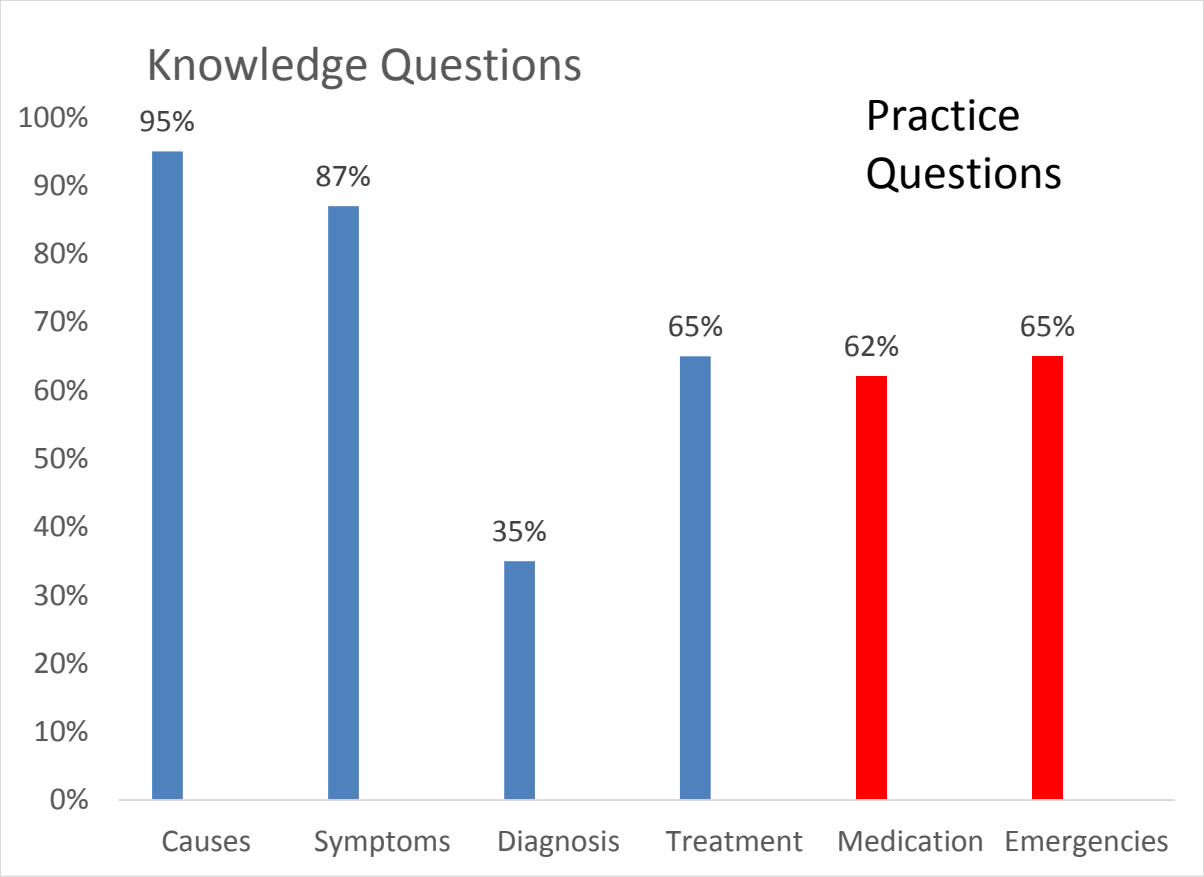
4.3Knowledge, Attitude and Practice Scores (EPQK and KEBAS scores)

Patients answered single response questions, scoring 1(yes) and 0 (no), to questions on their knowledge of epilepsy ranging from causes, symptomatology, diagnosis and treatment modalities to their own daily routines and practice.

The majority of patients 99 (91.7%), (CI, 0.85 – 0.96) had good levels of knowledge and practice, scoring in the 80th percentile for knowledge (80.6%), (CI, 0.72 – 0.87) and 60th percentile for practice. (66.7%), (CI, 0.57 – 0.75) (Figure 6). Patients were noted to score poorly on questions related to diagnosis which mainly revolved around EEG (35%).

Figure 6: Chart showing knowledge and practice scores as per categories

Patients had higher scores on question themes related to knowledge as compared with practice



Questions on Epilepsy

The KEBAS score is a Likert scale with subscales scoring 0-3 on beliefs/attitudes towards causes, treatment and living with epilepsy .The majority of respondents were revealed to have positive attitudes and beliefs scoring in the 90th percentile (92.6%), (CI, 0.86 – 0.96).Of the 8 patients with negative attitudes their responses were found to be revolving around themes of resentment and fear of rejection by their families and community at large. In response to the impact the disease process had on their lives; patients were fully aware of the restrictions that epilepsy and anti-epileptic medications impose on their day to day activities especially in terms of employment they could undertake but did not feel that epilepsy should limit them from living a normal life.

The EPQK and KEBAS scores are illustrated in Tables 13.

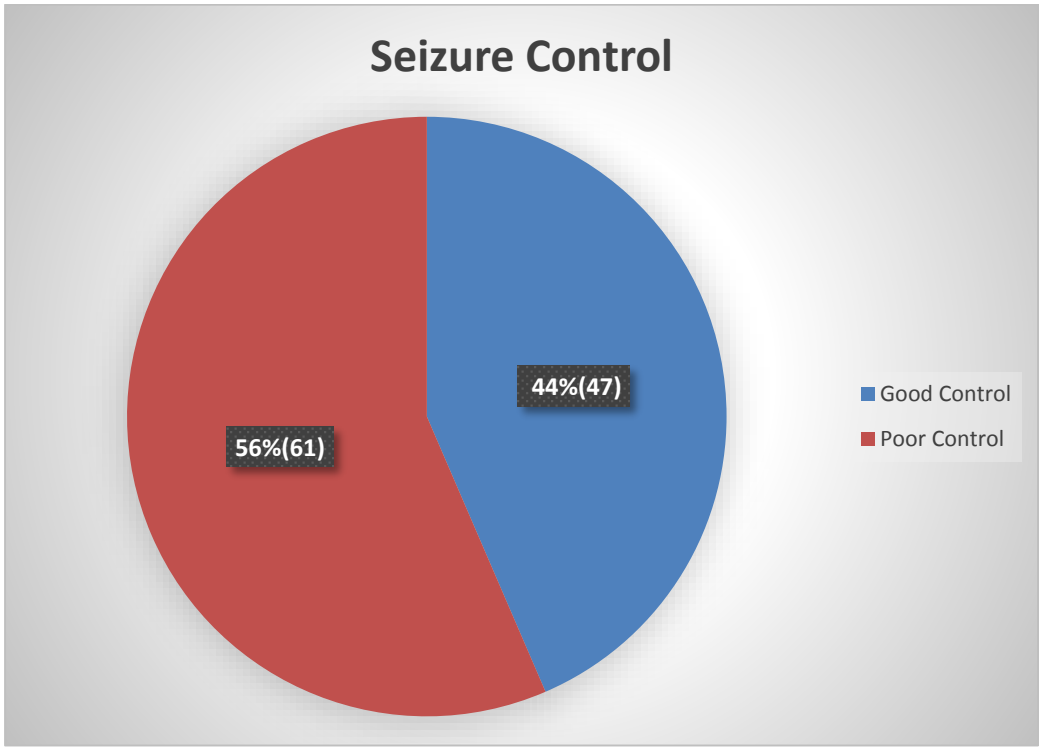
Table 6: Distribution of respondents by Knowledge, Attitude and Practise scores

Scores	**N=108(%)**
Knowledge Score	
Poor knowledge	21 (19.4)
Good knowledge	87 (80.6)
Practice Score	**N=108**
Poor practice	36 (33.3)
Good practice	72 (66.7)
Overall EPQK(KP) Score	**N=108**
Poor KP	9 (8.3)
Good KP	99 (91.7)
Attitude Score	**N=108**
Negative Attitude	8 (7.4)
Positive Attitude	100 (92.6)

4.3.1 Seizure Control

Poor seizure control was defined as >1 seizure in the previous six months. As depicted in Figure 7 approximately 61 (56.5%) (CI, 0.47 – 0.65) of the participants had poor seizure control, while 47 (43.5%) (CI, 0.35 – 0.53) had good seizure control. Poor seizure control was higher in patients who were students (64.5%) or unemployed (58.5%). 32.4% (CI, 0.58 – 0.76) of respondents reported to regularly failing to take their medication, with 38.2% (CI, 0.29 – 0.47) citing financial difficulties as the reason, though using a univariate analysis there was not statistically significant difference between failure to take medication and adequacy of seizure control.

Figure 7: Seizure Control of respondents



4.3.2 Relationship between baseline characteristics, EPQK/KEBAS and Seizure Control

Male and female patients scored equally in the EPQK (81.3%:80.1%), while females had higher KEBAS scores (95.9% vs. 89.8%). Only one patient with no formal education was found to score poorly on the EPQK but subsequently scored well on the KEBAS. Employed respondents scored 78% (CI, 0.69 – 0.85) on EPQK compared to 77.5% (CI, 0.69 – 0.85) for unemployed responders with students scoring the highest (88%), unemployed respondents had the positive attitudes/belief at 100%. Patients who had been epileptic for less than10years scored higher for knowledge and practice (82% vs. 46.3%) but had poorer KEBAS scores compared with those with disease for longer duration (50.9% vs.92.7%).

The only statistical significance observed was between occupation and attitude, with employed respondents having a more positive attitude, (p=0.0080). Overall patients who were male, educated, in gainful employment and had disease duration of less than ten years were more likely to have better knowledge and more positive attitudes although it was not statistically significant.

The relationships between baseline characteristics and KAP/Seizure Control are depicted in Table 7

Table 7: Relationship between baseline characteristics and KAP

Baseline Characteristics	**EPQK Score**			**KEBAS Score**		
	Good N (%)	**Poor N (%)**	**p-value**	**Good N (%)**	**Poor N (%)**	**p-value**
Gender						
Male	48 (81.4)	11(18.6)	**0.999**	53(89.8)	6(10.2)	**0.288**
Female	39 (66.1)	10(33.9)		47(95.9)	2 (4.1)	
Education						
No formal education	3(75)	1(25)	**0.999**	4(100)	0(0)	**0.999**
Formal education	84(80.8)	20(19.2)		96(92.3)	8(7.7)	
Occupation						
Unemployed	28(77.8)	8(22.2)	**0.552**	36(100)	0(0)	**0.008**
Formally employed	32(78)	9(22)		39(95.1)	2(4.9)	
Student	27(87.1)	4(12.9)		25(80.6.)	6(19.4)	
Disease duration						
1-10 years	41(82)	9(18)	**0.165**	47(95.9)	3(4.1)	**0.299**
11-20 years	22(78.6)	6(21.4)		24(85.7)	4(14.3)	
>30 years	22(81.5)	5(18.5)		27(100)	0(0)	

4.3.3 Relationship between KAP and Seizure Control

As illustrated in Table 8, out of the 99 respondents with good knowledge scores on the EPQK, 53(53.6%) (CI, 0.44 – 0.63) had poor seizure control. However, patients with good knowledge were 6 times more likely to have good seizure control (OR 6.1). There was

similar representation seen with KEBAS scores, patients with a good attitude had poor seizure control at 56.7% (56) (CI, 0.47 – 0.66).

Nearly all patients with poor EPQK scores had poor seizure control 88.9 % (CI, 0.57 – 0.98), and a majority of patients with poor KEBAS scores also had poor seizure control 62.5% (CI, 0.31 – 0.86). There was no statistically significant difference between the level of KAP in PLWE and the level of seizure control.

Table 8: Relationship between KAP and Seizure Control

		Seizure control		p-value
		Good N (%)	**Poor N (%)**	
Knowledge/Practice Score	Good knowledge	46(47.6)	53(53.6)	0.074
	Poor knowledge	1(10.1)	8(89.9)	
Attitude Score	Positive attitude	44(43.3)	56(56.7)	0.999
	Negative attitude	3(37.5)	5(62.5)	

5 .0 Discussion

The basis of this study was to assess the knowledge, attitude and practice of people living with epilepsy attending the outpatient neurology clinic at the Kenyatta National Hospital, using validated data collection tools namely the *Epilepsy Patient Knowledge Questionnaire* (EPKQ) and the *Kilifi Epilepsy Beliefs and Attitude Scale* (KEBAS), to assess the adequacy of seizure control and ultimately describe the relationship between KAP and seizure control in the same population. Multiple studies have shown that knowledge is a vital factor in coping with epilepsy, (5) while belief systems greatly influence regimen compliance in turn affecting seizure control. Knowledge Practice and Attitude Scores as performance measures have allowed for the development of standardized tools for assessment and can pinpoint to areas of intervention (19).

The demographic characteristics were similar to previous studies done on the same population in terms of age, gender and marital status (7, 15). Our study revealed that 86 (79.6%) had generalized seizures, this may be explained by the more recognizable features associated with GTC allowing for earlier health seeking behaviour and interventions.

Kinyanjui *et al* carried out a Quality of life study among PLWE attending KNH neurology clinic and demonstrated that patients had attained a significantly lower level of education compared to normal controls with results suggesting the need for enforcement of measures aimed at creating better educational opportunities at the time (15).However, our study population had achieved higher levels of formal education; 80.6% attaining a minimum of secondary education. This was significant in that it may have contributed to a better understanding of the health education topics offered in the clinic eventually leading to a marked improvement in medical knowledge and practice among PLWE attending the outpatient neurology clinic compared with the population studied by Mativo *et al* at the same clinic. Using the EPQK Gilani *et al* in South Africa, while studying 199 PLWE attending an urban clinic in KwaZulu-Natal with general low level of schooling and high unemployment rates found good knowledge around causes, symptoms, diagnosis and treatment but significant gaps in knowledge affecting morbidity and mortality(3) and Kuriakose *et al* in India found that their patients had a basic understanding of epilepsy, but knowledge in terms of safety measures, social issues and treatment options were poor (20).Our patients were found to be knowledgeable about causes, symptoms and treatment in regards to epilepsy but scored poorer in terms of diagnosis with patients unclear on the use of EEG, although majority had had at least one done during their follow up. The KNH outpatient clinic has patient oriented

educational sessions tackling various aspects of epilepsy conducted before the actual clinic appointment run by respective nurses. These are interactive sessions where patients and caregivers can participate, ask questions and share experiences. This may have contributed towards bridging the knowledge gap in our study population; Patients were also noted to have more access to the internet and would search out information regarding their disease process and drug side effect profile. This is further in keeping with the hypothesis that people with higher education would be more knowledgeable about their disease process and influence their belief patterns but is in contrast with a study amongst black African university students in South Africa, which showed no association between a higher level of education and correct knowledge about epilepsy (25). The bidirectional relationship between education and health literacy cannot be overlooked and innovative strategies for disseminating healthcare information to patients with no formal education such as role play must be considered to bridge gaps.

Using the KEBAS scoring system the majority of respondents were revealed to have positive attitudes and beliefs in all respects to their disease process scoring in the 90^{th} percentile (92.6%), (CI, 0.86 – 0.96).Ibinda *et al* conducted an interventional study in Kilifi, Kenya on 581 PLWE. The patients completed the KEBAS questionnaires before an educational intervention and 1 year later, (the non-intervention group received the educational intervention after the second assessment) (31). In the intervention group, there was a significant reduction in the beliefs about cultural treatment and negative perceptions of PWE ($p < 0.001$), but not in KEBAS scores for the causes, biomedical treatment, and risks of having epilepsy. In response to the impact the disease process had on their lives; patients were fully aware of the restrictions that epilepsy and anti-epileptic medications impose on their day to day activities especially in terms of employment they could undertake but did not feel that epilepsy should limit them from living a normal life.

The level of poor seizure control was found to be 56.5% (CI, 0.47 – 0.65) which was an increase from 40% found by Mativo *et al* (7) and 39.1% by Lisk *et al* in 1984(22). Studies in western countries have shown very high rate of control reaching up to 75% and over at 2 years (29). This suggests a disproportionate increase in poor seizure control, despite a perceived increase in good knowledge/ practice and positive attitudes towards their disease process. Ibinda *et al* further demonstrated that an improvement in KEBAS had no ultimate influence on adherence/compliance to medication (30). A randomized controlled trial of the Modular Service Package Epilepsy (MOSES) in Europe found that patient education improved

knowledge about epilepsy, coping strategies, and seizure outcome, but did not investigate improvement in adherence (27).Jones *et al* found that patients with poorly controlled epilepsy had poor knowledge on their disease (26). Stanaway *et al* found that compliance with therapy was positively related to perceived benefit of anticonvulsant therapy (24).Hypothesised factors that could have contributed to poor seizure control are prescription patterns, poor adherence to medication and alternative modalities of treatment.

Our patients were found to be predominantly on monotherapy 54 (50.5%). This differs slightly from the study done by Otieno *et al* at the same neurology clinic where the prescription patterns favoured monotherapy at 61% (18). However these results may have been skewed due to the study population being females of reproductive age. Carbamazepine was the commonest monotherapy prescribed at 67%. In the US there is increased use of lamotrigine (upto36 %) and levetiracetam as monotherapies. in our setting these medications may be less likely to be monotherapy due to cost and availability (We had a single patient on Levetiracetam). Polytherapy significantly increases AED toxicity, drug interactions, comorbid depression, and risk of sudden unexplained death in epilepsy patients (SUDEP). The large patient volume at the neurology clinic limits the patient-doctor time. This may translate to prescription renewal as the main focus of care.

The finding from a previous study done locally by Mugaya *et al* revealed that 13.7% of our patients with epilepsy seek alternative therapies(32) .Our study found that 20 (18.5%) had visited a traditional healer at one time in their illness, though none were reported to be currently under alternative treatment. This increases the likelihood of receiving conflicting advice or diluting the evidence-based information provided by the health care practitioner. Patients who had regularly failed to take their AEDs indicated financial difficulties as the reason (32%), Mativo *et al* found a similar prevalence of 35% (7). Economic factors still play a significant role in access to medication for our population. The implementation of pill counts, phone messaging applications and direct observed treatment may assist patients who report to routinely forget taking their medication.

6.0 Conclusion

In conclusion, among PLWE attending the neurology clinic we found a high level of poor seizure control in a relatively well educated population inspite having good levels of knowledge and practise with positive attitude and belief system. Therefore KAP, although important cannot be ascribed as a single factor influencing seizure control.

7.0 Study Limitations

Our study relied on questionnaires which is subjective since it is based on patient's answers and recall.

Drug levels were not tested to definitively determine drug compliance.

Other factors such as drug choice, cost, and drug adherence, type of seizure, seizure responsiveness and comorbidities which influence seizure control were not investigated

8.0 Recommendations

We recommend the development of a standardized comprehensive package for medical education around epilepsy for patients and health care providers taking into account factors affecting knowledge, diagnostics to strengthen the pre-existing knowledge base and looking at translating knowledge into practice.

We recommend further studies on other factors that contribute to seizure control.

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Appendices

Appendix I: Consent form

A. ENGLISH:

Appendix 1- patient consent explanation form

Introduction

My name is Dr. Shamsa H. Ahmed. I am a qualified doctor, registered by the Kenya Medical Practitioners and Dentists Board. I am currently pursuing a Masters degree in Internal Medicine at the University of Nairobi. I would like to recruit you into my research which is to study whether patients with epilepsy attending the Kenyatta National Hospital are knowledgeable about their illness and if this affects their seizure control.

We will keep all your test results in confidence and keep you informed of the results and what they mean. Treatment does not depend on your participation in this study. We will offer appropriate treatment for any condition that we find from assessing you and from your test results.

Procedures involved

This survey will take approximately 30-40 minutes. The study will include reviewing your prescriptions and answering to a study proforma.Information to collect includes your demographic data, current medications, and your knowledge, attitudes and practises in relation to epilepsy.

Your rights as a participant in this study

Your participation in this study is voluntary.

Whether you choose to participate or not will not affect your medical care.

You are free to terminate the interview and withdraw from the study at any time.

You are free to ask questions before signing the consent form and during the study.

Confidentiality will be maintained at all times.

Risks of participation

There are no risks that you will experience.

Benefits of participation

At the end of the study, I will hand over the findings to the Internal Medicine department of UoN. Any useful information that will improve the quality of care will be shared with the caregivers for appropriate action.

Confidentiality

All information gathered during the study will be kept confidential. Only researchers have access to personal information which. Information gathered will be documented and analysed anonymously.

If you have any question during the course of the study, you may contact the following:

1. DR. SHAMSA H AHMED, UNIVERSITY OF NAIROBI,
   DEPARTMENT OF CLINICAL MEDICINE AND THERAPUTICS,
   Mobile: 0722-811357. ***OR***
2. CHAIRPERSON, KNH/UON ETHICAL REVIEW COMMITTEE,
   TEL: 020-2726300/0722829500/0733606400/EXT 44102. P.O. Box 20723, Nairobi.

Before I involve you in my study, I kindly ask you to sign the attached consent form below. This consent form will not be linked to your answers.

Appendix 2: Consent /assent form-patients

STUDY NO……..DATE……TIME……

I hereby give my written and informed consent to allow myself or my…… participate in this study on **THE INFLUENCE OF KNOWLEDGE, ATTITUDES AND PRACTICE OF PEOPLE LIVING WITH EPILEPSY ON SEIZURE CONTROL**.

I have been adequately explained to about the study by Dr. Shamsa Ahmed/her assistant. I do this with the full understanding of the purpose of the study and procedures involved which include review of my prescriptions and answering to a proforma which have been explained to me. I understand that my rights will be respected, and confidentiality maintained at all times.

I also understand that the consent is voluntary, and I am at liberty to withdraw from the study without my care being affected.

I will not be required to pay for any part of the assessments done for the purposes of this study.

Patient's signature……..

Patient's Name……

INVESTIGATOR'S STATEMENT:

I, the Principal Investigator, have fully educated the research participant on the purpose and implication of this study.

Signed…… Date……..

For any further clarification, you may contact

Dr. Shamsa Ahmed, at Tel No: 0722-811357.

Or: KNH/ERC (Kenyatta National Hospital/Ethics & Review Committee)

TEL: 020-2726300/0722829500/0733606400/EXT 44102. P.O. Box 20723, Nairobi

This study has been approved by the Institutional Research and Ethics Committee (IREC) ofUniversity of Nairobi and the Kenyatta National Hospital.

YOUR CONSENT:

Patientsbelow 18 years of age

I have been adequately informed that my son/daughter is being recruited in a study to find out his/her level of knowledge of epilepsy and their seizure control. The investigator has also informed me that his/her participation in this study is voluntary and will not exclude him/her from their routine care even if he/she were to opt out. She has also informed me that I will not be required to pay for any part of the assessments done for the purposes of this study.

PATIENT'S PARENT/GUARDIAN:

Sign: …….

Name: …….

Date: …….

B. KISWAHILI:

KIAMBATISHO 1- FOMU INAYOELEZA IDHINI

UTANGULIZI Mimi niDkt. Shamsa Ahmed, kutoka Chuo Kikuu cha Nairobi. KwasasanasomeauzamilikatikaTibayaNdani. Kama sehemuyamasomoyanguyauzamifu, nahitajikakufanyamradiwautafiti. NinafanyauchunguzikuhusuKifafakatikaHospitaliKuuya Kenyatta.

TaratibuzitakazohusishwaUpimiohuuutachukuatakribanidakika 30-40. Utafitihuuutahusishakuangaliamaagizoyadaktarinakujibumaswalikatikafomu. Habarizitakazokusanywazitahusu data kuhusuhaliyako, dawaambazounatumiakwasasa, matumiziyanjiayakupangauzazinaufahamuwamaswalayaWanawakewalionakifafa.

HakiyakokamamshirikikatikautafitihuuUshirikiwakokatikautafitihuuniwakujitolea.Hataukichagua kushiriki au ukataekushirikihaitaathirimatibabuyako. Unauhuruwakujiondoakatikamahojianonakatikautafitihuuwakatiwowote. Unauhuruwakuulizamaswalikablayakutiasahihikatikafomuyaidhininawakatiwautafiti. Maswalayoteyatahifadhiwakwasiriwakatiwote.

Hasarazaushiriki

Hakunahasarayoyoteutakayopitia au kupata.

Manufaayakushiriki

Mwishonimwautafitihuu, nitawasilishamatokeoyautafitikatikaidarayaTibayaNdanikatika Chuo Kikuu cha Nairobi. Habarizozotemuhimuzitakazotokananautafitinaambazozitafanyamalezikuwa bora, waleziwatafahamishwailihatuamwafakaichukuliwe.

Siri

Habarizotezitakazokusanywawakatiwautafitizitahifadhiwakwasiri. Ni watafitipekeendiowanaowezakufikiahabarizakibinafsi.

Habarizitakazokusanywazitaandikwanakuainishwabilakutajawashiriki.

Ikiwaunaswalilolotewakatiwautafiti, unawezakuwasilianawafuatao:

1. DKT. SHAMSA HUSSEIN AHMED, CHUO KIKUU CHA NAIROBI,

   IDARA YA MAFUNDISHO YA UDAKTARI NA MATIBABU YA MAGONJWA, Simuyamkono: 0722-984722. ***AU***

2. MWENYEKITI, KNH/UON KAMATI INAYOSHUGHULIKIA MAADILI,

   Nambariyasimu: 020-2726300/0722829500/0733606400/EXT 44102. P.O. Box 20723, Nairobi.

Kablasijakuhusishakatikautafitiwangu, Naombautiesahihikatikafomuyaidhiniiliyopohapochini. Fomuhiiyaidhinihaitahusishwanamajibuyako.

KIAMBATISHO 2: FOMU YA IDHINI /KUBALI- WAGONJWA

NAMBARI YA UCHUNGUZI……TAREHE……WAKATI……

Natoaidhiniandishinaninayoifahamuilikuniruhusu au ……wangukushirikikatikautafitihuukuhusuKifafa, katikaHospitaliKuuya Kenyatta.

NimepewamaelezoyanayofaakuhusuutafitiwaDkt. Shamsa Ahmed /msaidizi wake. Ninafanyahivikwa vile naelewalengokuu la utafitihuunataratibuzitakazohusishwakama vile kuangaliwakwamaagizoyadaktarinakujibumaswalikatikafomuambayonimepewamaelezoyake.

Ninaelewakuwahakizanguzitaheshimiwa, nasuala la kuhifadhiutambuziwanguutadumishwawakatiwote.

Pianinaelewakuwaidhiniyakushirikiniyakujitolea, naninauhuruwakujiondoakatikautafitihuubilamaleziyangukuathiriwa.

SahihiyaMgonjwa……..

Jina la Mgonjwa……

<u>KAULI YA MCHUNGUZI:</u>

Mimi, MchunguziMkuu, nimemuelimishamshirikiwautafitikuhusulengokuu la utafitinakinachodokezwanautafitihuu.

Sihihi…… Tarehe……..

Appendix 3: Data Collection Tools

STUDY PROFORMA

SECTION A

General Information:

Study Number ☐ Date ☐

Patient Number ☐ Contact (Tel No) ☐

Date of Birth ☐ Age in years ☐

SOCIAL-DEMOGRAPHIC DATA(Tick where appropriate)

Marital Status

(1) Never Married ☐ (2) Married ☐ (3) Separated ☐

(4) Divorced ☐ (5) Widowed ☐

Level of Education.

(1) No formal education ☐

(2) Primary a) Lower ☐ b) Upper ☐

(3) Secondary ☐

(4) College/University ☐

Occupation Status

1) Unemployed ☐
2) Formally employed ☐
3) Informal sector...e.g. Jua Kali,hawker ☐
4) Self –employed ☐
5) Student ☐

Reproductive history ☐

1) Parity
2) L.M.P
3) Contraception use

HISTORY OF EPILEPSY

1) Age of first seizure
2) Disease duration(in years)
3) Type of epilepsy (from file)
   1) Generalized tonic clonic
   2) Simple Focal
   3) Complex Focal
   4) Others
4) Number of seizures in the last
   One month
   Three months
   Six months
   One year

CURRENT MEDICATIONS. (Obtain Information from Prescription)

Have you been prescribed AED's 1) Yes
2) No

If yes, are you on 1) Monotherapy
2) Polytherapy

If yes, and on monotherapy, which drug are you on, and the dosage?

Drug	**Dosage**	**Duration of use**
Carbamazepine		
Phenobarbitone		
Sodium Valproate		
Phenytoin		
Clonazepam		
Lamotrigine		
Levetiracetam		
Others(specify)		

If yes, and on Polytherapy, which combinations are you on, and dosage?

Drug combination	Dosage			Duration of use
Carbamazepine/Phenytoin				
Carbamazepine/Phenobarbitone				
Carbamazepine/Valproate				
Valproate/Phenobarbitone				
Carbamazepine/Phenytoin/Phenorbabitone				
Carbamazepine/Valproate/Phenorbabitone				
Others(Specify)				

If no, why?

Never prescribed			
Stopped by physician due to side effects			
Stopped by physician due to remission; If yes how many years in remission.			
Alternative treatment	Herbs	Prayers	Other

DRUG COMPLIANCE

Have you ever failed to take your prescribed AED's 1) Yes

2) No ☐

If yes why?(Tick Response)

Financial difficulties		Inaccessibility		Unavailability	
Just forgetting		Side effects		Others	

EPILEPSY PATIENT KNOWLEDGE QUESTIONNAIRE

	Knowledge of Causes of Epilepsy	**YES**	**NO**
1	Epilepsy is not infectious		
2	Epilepsy is always caused by brain damage		
3	Certain forms of brain damage always causes epilepsy		
4	Epilepsy is a divine process		
5	Epilepsy can be caused by witchcraft		
6	Epilepsy is due to demonic possession		
7	An epileptic seizure can be described as an abnormality in the function of nerve cells of the brain		
8	Too much alcohol make seizures more likely		
9	Stress may cause some seizures		
	Knowledge of Symptoms of Epilepsy	**YES**	**NO**
10	Epilepsy is a symptom of mental illness		
11	All people with epilepsy have similar symptoms		
12	All people with epilepsy lose consciousness during epilepsy		
13	Some seizures may last a matter of seconds and not be noticed by others		
14	Some people get a warning or a feeling just before a seizure		
	Knowledge of Diagnosis of Epilepsy	**YES**	**NO**

15	An EEG can be useful to help diagnose epilepsy		
16	An EEG is designed to detect electrical activity from the brain		
17	If an EEG is abnormal this is a definite sign of epilepsy		
18	A normal EEG means that you do not have epilepsy		
	Knowledge of Treatment of Epilepsy	**YES**	**NO**
19	For most people doctors can treat epilepsy effectively with drugs		
20	All those who start drugs for their epilepsy have to take them for life		
21	Increasing the dose of anti-epileptic drugs increases the chance of side effects		
22	In order for anti-epileptic drugs to be successful, they must be taken regularly		
23	Blood samples can be used to detect the concentration of anti-epileptic drugs in the system		
24	People who are taking a combination of anti-epileptic drugs are more likely to have side effects than those taking only one drug		
25	Most peoples' seizures are well controlled soon after starting regular drug treatment		
26	If seizures stop with anti-epileptic drugs, this means that your epilepsy is cured		
27	Few people with a diagnosis of epilepsy are on anti-epileptic drugs		
	Practice of Patients with epilepsy	**YES**	**NO**
28	It is always helpful to take extra doses of anti-epileptic medication when not feeling well		
29	If you forget to take anti-epileptic drug for a day, it is usually OK to take two doses together		
30	If you have side effects from your medication do you immediately stop taking your medication		
31	Do you talk to your doctor/nurse about side effects from your medication?		
32	If you have side effects do you continue taking your medication?		
33	Have you ever stopped your medicine because you do not need it		
	First aid measures to be taken during epileptic attack		
35	Put patient on their side		
36	Put patient on their back		
37	Put something in the patients mouth		

38	Prayer		
39	Pour Water on patient		

Kilifi Epilepsy Beliefs and Attitude Scale

EPILEPSY **B**ELIEFS AND **A**TTITUDES **S**CALE (**EBAS**)

SECTION I

Please listen to the following story describing a person with a particular type of epilepsy and keep it in your mind while responding to the rest of the Epilepsy Belief Scale.

This story is about Bahati. Bahati has epilepsy, and has one seizure per week. 1-2 days before the seizure, his behaviour changes. He/she may become naughty, sometimes may isolate him/herself or may look sleepy and wants to sleep. His/her eyes may become red and may also complain of headache. Just before the fit, he/she may feel her/his heart has skipped a beat and feels mixed up (a feeling you may have when you suddenly see a scaring and unexpected thing- e.g. a dead body). He/she then falls down and looses consciousness, starts jerking in all 4 limbs with eyes either rolling upwards, deviating to the sides or wide open, bites the tongue and foams for about 3 minutes then he/she urinates and the jerking movements stop. He remains unconscious for a couple of minutes then wakes up drowsy and goes to sleep.

This is about your belief. Only you know what you believe, so if you tell us how you feel, all your answers will be correct.

		Totally Believe	Believe a little	Not at all	Don't know	Score
Causes						
1. I believe that epilepsy can be inherited/be caused by family ancestors **(INHERIT)**		3	2	1	0	
2. I believe that a person like Bahati can have epilepsy because he has been bewitched **(BEWITCH)**	**R**	1	2	3	0	
3. I believe that when the sun heats the brain of a person like Bahati, it may cause epilepsy **(SUN)**	**R**	1	2	3	0	
4. I believe that when a person like Bahati has a head injury/falls on the head can cause epilepsy **(HINJURY)**		3	2	1	0	
5. I believe that an injury at birth can result in a person like Bahati having epilepsy (for example prolonged labour) **(BINJURY)**		3	2	1	0	

		Totally Believe	Believe a little	Not at all	Don't know	Score
6. I believe that when a person takes anti-convulsant medication when not epileptic can result to having the disease **(AEDS)**	**R**	1	2	3	0	
7. I believe that a serious disease (like malaria) affecting the brain of a person like Bahati can cause epilepsy **(MALARIA)**		3	2	1	0	
8. I believe that when a mother uses FPs before conception can make a child likeBahati have epilepsy when born **(FPs)**	**R**	1	2	3	0	
9. I believe that when one comes into contact with urine of a fitting person like Bahati can be infected with epilepsy **(URINE)**	**R**	1	2	3	0	
10. I believe that after a child likeBahati was born and his faeces did not clear then it may result to epilepsy **(FAECES)**	**R**	1	2	3	0	
11. I believe that a person like Bahati can have epilepsy because part of his brain is damaged **(BRAIN)**		3	2	1	0	
Treatment						
12. I believe it is possible to treat a person like Bahati**(TREAT)**		3	2	1	0	
13. I believe that if a person like Bahati is burned, he will never get healed from epilepsy **(BURN)**	**R**	1	2	3	0	
14. I believe that a person like Bahati has to take drugs continuously for them to work **(DRUGS)**		3	2	1	0	
15. I believe that epilepsy is better treated by a mganga than a doctor **(MVITSALA)**	**R**	1	2	3	0	
16. I believe there are drugs available that can treat epilepsy **(ADRUGS)**		3	2	1	0	

		Totally Believe	Believe a little	Not at all	Don't know	Score
17. I believe that pouring water to a person like Bahati when fitting helps treat epilepsy **(WATER)**	**R**	1	2	3	0	
18. I believe that the best person to treat epilepsy is a medical doctor **(DNYUNI)**		3	2	1	0	
19. I believe smearing rob/paraffin on the body of a person like Bahati when fitting helps treat epilepsy **(PARAFFIN)**	**R**	1	2	3	0	
20. I believe that epilepsy in a person like Bahati can be treated through fumigation **(FUMIG)**	**R**	1	2	3	0	
21. I believe that some types of fits are not suitable for hospital treatment **(HFITS)**	**R**	1	2	3	0	
22. I believe that during a fit, it is good to put a stick between the person's teeth to prevent biting one self **(STICK)**	**R**	1	2	3	0	
23. I believe that during a fit, it is good to straighten the joints of a person like Bahati**(JOINTS)**	**R**	1	2	3	0	
24. I believe that during a fit, it is good to put a person like Bahati in a safe place **(SAFE)**		3	2	1	0	
25. I believe that drugs (from hospital) can control seizures **(CDRUGS)**		3	2	1	0	
26. I believe a person like Bahati should only take drugs when he is having a fit **(FITAEDS)**	**R**	1	2	3	0	
27. I believe that if a person like Bahati misses drugs he/she may fit again **(MISSAEDS)**		3	2	1	0	
28. I believe that drugs for epilepsy can cause side effects such as drowsiness or hyperactivity to a person like Bahati**(SEFFECTS)**		3	2	1	0	

		Totally Believe	Believe a little	Not at all	Don't know	Score
Prevention						
29. I believe that preventing serious diseases like malaria will reduce the number of people with epilepsy **(PDISEASE)**		3	2	1	0	
30. I believe that proper medical care during pregnancy and delivery will reduce the number of people with epilepsy **(PREG)**		3	2	1	0	
Living with epilepsy						
31. There is a belief that people like Bahati cannot marry, what do you think? **(MARRY)**	**R**	1	2	3	0	
32. I believe that people like Bahati cannot climb trees or work high up **(TREES)**	**R**	1	2	3	0	
33. I believe that children like Bahati cannot go to school **(SCHOOL)**	**R**	1	2	3	0	
34. I believe that people like Bahati cannot have a job **(JOB)**	**R**	1	2	3	0	
35. I believe that people like Bahati cannot do risky jobs (like driving/running machinery) **(DRIVE)**		3	2	1	0	
36. I believe that people like Bahati can lead a normal life like other people **(NLIFE)**		3	2	1	0	
37. I believe that people like Bahati should avoid being near fires **(FIRE)**		3	2	1	0	
38. I believe that people like Bahati should avoid being near waters (like sea, lake or river water) **(SEA)**		3	2	1	0	
39. There is a belief that people like Bahati should be kept in isolation, what do you think? **(ISOLATE)**	**R**	1	2	3	0	
40. There is a belief that people like Bahati should be rejected, what do you think? **(REJECT)**	**R**	1	2	3	0	

		Totally Believe	Believe a little	Not at all	Don't know	Score
41. I believe that parents feel resentful towards their children like Bahati because he/she has epilepsy **(RECENT)**		3	2	1	0	
42. There is a belief that people like Bahati are burdens to their parents, what do you think? **(BURDEN)**	**R**	1	2	3	0	
The effect of epilepsy on development						
43. I believe that continued seizures can damage the brain of a person like Bahati**(DAMAGE)**		3	2	1	0	
44. I believe that epilepsy can affect the development and behaviour of a person like Bahati**(DEVELOP)**		3	2	1	0	
45. I believe that a child like Bahati often performs poorly in school **(PSCH)**	**R**	1	2	3	0	
46. I believe that people like Bahati are dull **(DULL)**	**R**	1	2	3		
47. I believe that people like Bahati are mad **(MAD)**	**R**	1	2	3		

R: Reverse coded

Maximum score 150

Are you aware of any traditional healer who treats epilepsy? **(TH)Y/N** [ ]
No go to 55

If yes, what is the name of the traditional healer **(NAMETH)**

53. Where does the traditional healer live? **(THLIVE)**

54. Have you ever sought treatment from this traditional healer? **(SEEKTH) Y/N** [ ]

55. Do you have any comments on this questionnaire? **(COMMENT)**