PREVALENCE OF PERCEIVED STIGMA IN PATIENTS WITH EPILEPSY IN LOW INCOME DENSELY POPULATED COMMUNITIES IN NAIROBI

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H58/11108/2018

A Dissertation Submitted in Partial Fulfillment for the Award of the Degree of Master of Medicine, Internal Medicine

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I, **Dr. Nyabuti Winnie Gesare,** do hereby declare that this dissertation is my original work as a requirement for the degree of Masters of Medicine in Internal medicine and has not been presented for a degree to any other university.

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LIST OF ABBREVIATIONS

AED-	Antiepileptic Drugs
CDC-	Center of Disease Control
DALY-	Disability Adjusted Life Years
EEG-	Electroencephalogram
EPKQ-	Epilepsy Patient Knowledge Questionnaire
IBE-	International Bureau for Epilepsy
ILAE-	International League against Epilepsy
KAWE-	Kenya Association for the Welfare of People with Epilepsy
KEBAS-	Kilifi Epilepsy Beliefs and Attitude Scale
NUHDSS-	Nairobi Urban Health and Demographic Surveillance System
PLWE-	People Living with Epilepsy
PQOL-	Patient Quality of Life
QOL-	Quality of Life
SDI-	Socio-Demographic Index
WHO-	World Health Organization
YPWE-	Young People with Epilepsy
SSA-	Sub-Saharan Africa

ABSTRACT

Background: Stigma associated with epilepsy is a global phenomenon that has a direct negative psychosocial influence on people living with epilepsy (PLWE) and indirect negative impact on public health measures instituted to combat the disease. These erode the patients' lives and contributes to morbidity and mortality.(1) Among the different forms of stigma, perceived stigma has been found to have the greatest impact on the quality of life in PLWE. Several factors have been found to contribute to the increase in the level of perceived stigma. Despite being put on treatment to control seizures, PLWE will have to deal with stigma and its consequences unless we address it.

Objectives: To determine the prevalence of perceived stigma and its associated factors in patients with epilepsy in low income densely populated communities in Nairobi.

Study design: This was a descriptive cross-sectional study.

Study site: Kenya Association for the Welfare of People with Epilepsy (KAWE) clinic in Huruma Lion Health Center, Riruta Health Center and Karen Health Centre.

Study population: The study was conducted on individuals who are 14 years or older who are on treatment for epilepsy**.**

Methodology: Simple random sampling method was employed to select participants. Kilifi Stigma Scale score was used to access perceived stigma. A study proforma was used to collect data. The Epilepsy Patient Knowledge Questionnaire (EPKQ) and Kilifi Epilepsy Beliefs and Attitude scale questionnaire (KEBAS) were used to examine factors associated with perceived stigma. Descriptive data was analyzed as percentages and means or medians. Logistic regression model was used to identify factors associated with perceived stigma.

Results:340 patients were enrolled into the study. The mean age of study participants was 30 years with slightly more males than females. Majority had attained primary school education. Most had epilepsy for more than 10 years and on antiepileptic medication (95.6%). Poor seizure control was at 61.5%. The prevalence of perceived stigma in patients living with epilepsy was 33.2%. Difficulty in taking antiepileptic medication (AOR=4.0,95%CI 1.0-16.0), difficulty in attending follow-up clinics (AOD =4.9, 95%CI 1.0-23.0) and Injuries during seizure (AOR=2.1,95%CI 1.2-3.5) were significantly associated with perceived stigma.

Conclusion. In this study, the prevalence of perceived stigma among PLWE was high. Factors significantly associated with perceived sigma were difficulty in taking antiepileptic medication, difficulty attending follow-up clinics and injuries during seizures.

CHAPTER ONE: INTRODUCTION

Epilepsy is a chronic neurological condition of major public health concern worldwide contributing to 0.6% of the global disease burden. (2)The World Health Organization (WHO) estimates that around 50 million people are affected globally and 80 % of these are found in developing countries. In sub-Saharan Africa where most countries are low-income or middle-income countries, the burden is greatest and children constitute the largest group. (3) The prevalence of epilepsy in Kenya is estimated at 18.6 cases in every 1000 people. (4)

Epilepsy definition has evolved over the years. The international league against epilepsy (ILAE) in 2005 defined epilepsy as a neurological disease characterized by a lasting susceptibility to cause seizures. It was later updated in an ILAE 2014 task force to a definition that include the following;(5)

- Two or more unprovoked (or reflex) instances of seizures greater than 24 hours apart in occurrence.
- One unprovoked (or reflex) instance of seizure with a possibility of a recuring risk (estimated at 60%) following two instances of unprovoked seizures, in the next 10 years.
- Epilepsy syndrome diagnosis.

Globally associated with stigma both in developed and developing countries despite their diversity in belief and culture. People with hidden disabilities such as epilepsy are subject to discrimination and vulnerability which arise partly due to the chronicity of the disease process and physical disability .(6)This has great impact on the patients' outcome hindering their social development and lowering their quality of life as well as their families. Weiss and Ramakrishna defined stigma as a social process or related personal experience that is characterized by blame, exclusion, rejection, devaluation resulting from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem.(6),(7) Stigma is inevitable for people living with epilepsy(PLWE) as epilepsy remains a defining feature of their identification. Stigma, in its nature, is diverse and encompasses several factors such as patients' attitude, beliefs and their perception of the social environment. As a result, a large number of factors contribute to stigma making it complex to assess. Factors such as cultural beliefs, seizure control status, age, marital status, duration of illness and level of education all contribute to stigmatization.(7) ,(8)

In full view of these, understanding and eliminating epilepsy-related stigma is cardinal and was included as one of the aims of The International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), in association with the World Health Organization’s (WHO) worldwide advocacy campaign against epilepsy. Their main purpose was to usher epilepsy "out of the shadows" by enhancing the diagnosis, treatment, prevention, and social acceptability of this global disorder more so in low-income countries. (8) ,(9)

Thus, identifying and understanding epilepsy-related stigma and its different forms is the first step to attaining this goal.

Epilepsy-associated stigma can exist in several forms. Therefore, it is well appreciated by the distinguishing of ‘enacted’ and ‘perceived’ stigma. Enacted stigma is discrimination towards people with PLWE basing on social unacceptability, the perceived stigma is the shame felt by PLWE and the fear of anticipated discrimination. Perceived stigma restricts normal participation in society. In this study, we will focus on perceived stigma experienced by PLWE.(10)

CHAPTER TWO: LITERATURE REVIEW

2.1 Background

2.1.1 Definition of Epilepsy.

A seizure can be described as an episode of neurologic dysfunction in which abnormal neuronal firing is manifested clinically by changes in motor control, sensory perception, behavior, and/or autonomic function. The character of a seizure depends on the location and function of the site of the discharge. Epilepsy is known as a having recurrent spontaneous seizures arising from aberrant electrical activity within the brain. Under appropriate conditions anyone can experience a seizure, epilepsy points to an enduring alteration of brain function resulting in the seizure recurring. (4)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(11).There are many causes of epilepsy, most cases being idiopathic.

2.1.2 Classification of Epilepsy

The classification of seizures is important as the etiological diagnosis, treatment and prognostication relies greatly on the accurate identification of the seizure type. The latest ILAE's classification of epileptic seizures has three main types; focal, generalized and epileptic spasms. This is based on clinical data and electroencephalogram (EEG) findings. Focal seizure, previously called partial seizure, shows clinical and EEG findings of onset from a localized region within the cerebral hemisphere. The nature of the symptoms and signs indicate the region of the brain involved. They can be simple focal seizures or complex focal seizures. The difference being the loss of consciousness in complex focal seizures. Generalized seizures arise concurrently from both cerebral hemispheres. Their clinical manifestations are bilateral and this form of seizures is more likely to be associated with a family history.

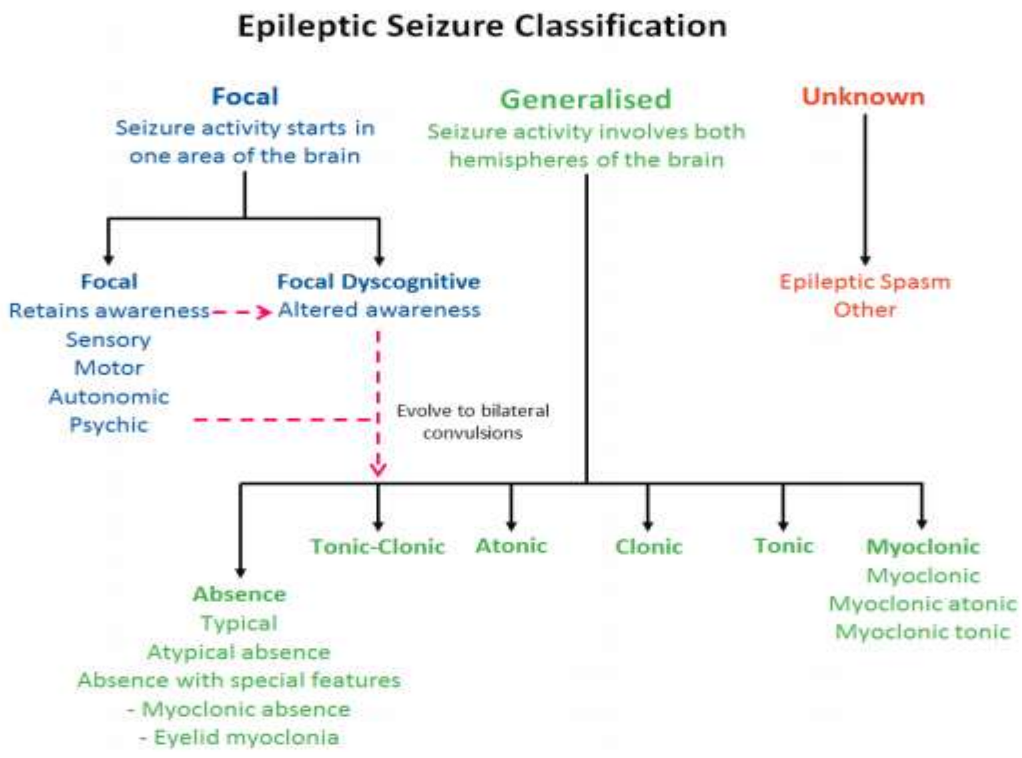

Figure 1: Epileptic Seizure Classification

2.2 Stigma among People Living with Epilepsy (PLWE)

2.2.1 Definition of Stigma

Stigma has been termed by the World Health Organization as a ‘hidden’ burden of disease. It is a major social determinant of morbidity and mortality (12). According to Weiss and Ramakrishna health-related stigma is a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group identified with a particular health problem (6).

Stigma is described using three components which are cognitive, emotional, and behavioral and these can be reflected in attitudes and or experiences. With this broad description, stigma exists in several forms. Perceived stigma which refers to a feeling of fear and possible discrimination as a result of having the disease and anticipated stigma which refers to expectations of future stigma experiences. In addition, internalized stigma refers to a personal understanding of acceptability and stigma application to oneself. Enacted stigma refers to discriminatory behaviors based on the attitude and behavior from society (13).

2.2.2 The Burden of Stigma in Epilepsy

Epilepsy related social stigma harms both the PLWE and their families. This greatly affects their willingness to perform various social activities leading to social isolation, low self-esteem, and low productivity (14).

Studies carried out in the developed parts of the world have shown evidence that stigma contributes heavily to the psychological and social burden caused by of epilepsy. This is also reflected in studies carried out in Africa, this is where the world's burden of epilepsy exists. In sub-Saharan Africa (SSA), in particular rural regions, close family ties, communal living situations, and traditional belief systems undoubtedly influence the expression of stigmatization (15).

Among the several forms of stigma, perceived stigma has a greater impact as it causes strains and limits normal social participation. Fanta et al, in a cross-sectional study in Ethiopia found 31.2 % of PLWE reported presence of perceived stigma with difficulty in attending clinics, injuries related to seizures and contagion beliefs being significantly linked to stigma that is perceived (16).

Another study done by Kirabira et al in South-western Uganda on children and adolescents found perceived stigma to be 34% which was highest in older children. The long duration of antiepileptic drugs (AED) use, injuries related to seizures, and having other defects were linked to a high level of perceived stigma. This was closely similar to a cross-sectional study done in Kilifi by Mbuba et al that found perceived stigma at 33% with high correlation to age and moderate correlation to seizure frequency and physical abuse (17),(18).

The burden of stigma in sub-Saharan Africa is higher in the rural regions compared to urban regions. Poor medical services and stigma expose PLWE to physical, psychological and social deprivation. Negative psychological and social consequences are felt more in rural areas with traditional beliefs enhancing the stigma.(19).Justin et al in a cross-sectional study done in rural and urban Nigeria reported the experience of perceived stigma higher in rural residents at 62.2% compared to the urban resident at 31.3% (20).

Caregivers are indirectly affected and experience affiliated stigma as they bear the burden of looking after PLWE. A study done by Hansen et al on 136 caregivers revealed a high level of affiliated stigma on the caregivers with 75% of them reporting people being uncomfortable around members of the family, 51% reported others are uneasy being around them which was associated with higher burden levels (14).

2.2.3 How Perceived Stigma Affects People with Epilepsy

Social stigma affects PLWE in various ways. In a study done by Fisher et al, the marriage rate of people with epilepsy was 51% for men and 48% for women compared to 63% and 59% for men and women respectively without epilepsy in the general American population. This low rate was attributed to social stigma and discrimination matted out on PLWE. It was also reported that PLWE received less education than those without epilepsy with 56% graduating from high school and 15% graduating from college compared to 81.7% graduating from high school and 23.5% graduating from college in the average American population (21).

Perceived stigma may also affect the patients' access to health care services curtailing early diagnosis, treatment, and follow-up. A study done in Britain by Hanif et al on Indian patients with epilepsy revealed reduced access to medical care in this population in an attempt to conceal epilepsy compared to the native population (22).

Moreover, epilepsy-related stigma also contributes to psychosocial stress leading to anxiety, low self-esteem, and in some cases depression. This substantially affects an individual's physical health, psychosocial quality of life (QOL), social relationship and environment. In a local study done in Kenyatta National Hospital in 2007 by Kinyanjui et al, the quality of life in PLWE was reported to be lower when compared to those without epilepsy with factors such as low education level, high burden of seizure, low income annually, lack of employment and residing rural areas significantly associated with impaired QOL (23).

2.2.4 Stigma Impact on the Quality of Life

According to WHO, Quality of Life can be defined as an individual's position in life based on their perception of their goals, expectations and standards in the context of the culture and value systems in which they live (24).

Quality of life in PLWE is adversely affected by illness-related stigma. A local study by Kinyanjui et al among PLWE attending the neurology clinic demonstrated a mean quality of life of 49.9% with a lower education level, high burden of seizure, lower annual income, unskilled employment, past history of head injury, having no religious affiliation, living in rural areas and being unemployed as contributing factors. Some of these factors were attributed to an individual's feeling of being stigmatized due to epilepsy (23).

Another study done in the Netherlands by Suurmeijer et al on the effect of social and psychological functioning on quality of life in PLWE found that stigma perception, psychological affliction, isolation, adaptation and coping among PLWE had a significant impact on the life quality according to patient perspective regardless of the physical status and recommended increased awareness of healthcare workers on the influence of psychosocial functioning on the good quality of life and need of intervention (25).

2.2.5 Stigma Propagation.

People suffering from chronic illness have commonly suffered stigmatization. Public misconceptions regarding epilepsy have contributed greatly to stigma and social disability. According to Krauss et al study, 31% of the English language print stories on epilepsy contained erroneous data mostly in scientific facts (14%), exaggerated treatment claims (9%), overestimated risk of dying during a seizure episode (5%), and information about new antiepileptic medication as curative and without side effect. Some referred to treatment as divine intervention (11%). Seizures were described using demonic imagery in 6% and patients were labelled as epileptic in 45% of the stories (26).

Lack of knowledge of epilepsy among PLWE has been seen to contribute to negative beliefs and social stigma .A study done by Long et al on 175 patients with epilepsy referred to a tertiary health institute who filled a knowledge questionnaire demonstrated limited knowledge of their condition regardless of education level, duration of illness, and age .Misconceptions noted were in 30% who alluded to epilepsy being a mental disorder and contagious and 41% believed in placing something in the mouth of a convulsing individual as acceptable while 25 % thought that women who were pregnant and had epilepsy should discontinue their medication (27).

In a local study conducted by Ahmed et al in Kenyatta National Hospital in 2014 on 118 patients with epilepsy demonstrated an overall good knowledge and attitude towards epilepsy with 91.7% being versed with the disease and treatment and 92.6% having good attitudes and beliefs. However, 56.5% of the patients had poor seizure control. This was attributed to factors such as poor adherence (32.4%), financial constraints (38.2%) (28).

2.2.6 Stigma Interventions

Epilepsy related stigma can be addressed in several ways to improve morbidity and mortality outcomes. Provision of good medical care especially in the initial stages after diagnosis where psychological and social afflictions are closely related to the disease severity has been seen to reduce levels of social stigma (29). Prompt management of stigma in the life of PLWE is crucial. This is to avoid the difficulty experienced in trying to reverse the negative impact of perceived stigma, misconception and low self-esteem after it has persisted in childhood and adolescence.

A study done by Dunn et al on depression in adolescents with epilepsy analyzed the attitude towards epilepsy, nature of family relationships and loss of identity as predictors of depression and found that 23% of adolescents living with epilepsy manifested depression.(30) In addition to early treatment, the center of disease control (CDC) and epilepsy foundation have partnered to develop programs to improve the lives of patients with epilepsy and reduce stigma. Through conducting targeted public education and awareness campaigns, they aim to increase understanding of epilepsy and thereby reduce the level of stigmatization among PLWE. Moreover, they have developed and conducted training for health care workers and members of the community (31).

Self-advocacy is also another tool used to reduce stigmatization. PLWE and caregivers receive counseled sessions as part of their treatment where they establish an appropriate life plan and define realistic expectations. This helps boost their self-esteem and reduce the feeling of helplessness that leads to negative psychosocial effects (30).

The success experienced by most initiates indicate that much can be done to minimize the experience of stigma among PLWE hence reducing the burden.

2.2.7 Stigma and Seizure Control

People with controlled seizures are less likely to experience or perceive social stigma especially if they have been seizure free for six months to more than or equal to two years. In a study done by Ridsdale et al on 283 patients found out that patients who reported epileptic attacks in the prior six months had three times greater chance of feeling stigmatized than those who did not report epileptic attacks in the prior six months and 2 years or more (32).

Another study done by Baker et al on more than 5000 patients living in 15 countries found that reducing the side effects of antiepileptic medication and attaining control of seizures is vital to the betterment of the quality of life and reduction of stigma (33).

Compliance to medication is necessary for the achievement of seizure control. In a study done by Buck et al on factors influencing compliance to AED on 696 patients found a significant relationship between stigmatization and compliance with 66 % of those who reported feeling stigmatized being compliant compared to 74% of those who did not feel stigmatized (34).

2.2.8 Factors Associated with Perceived Stigma

There are several factors associated with epilepsy social stigma leading to the impairment of individuals quality of life. Many studies done globally have reported that several factors associated with perceived stigma such as age, seizure type, amount of medication, age of onset of seizure ,level of income, seizure frequency, low level of knowledge on epilepsy, belief that epilepsy is contagious and duration of illness (35–37). A study on factors associated with perceived stigma done in Turkey by Yeni et al on 194 PLWE where 34% felt stigmatized found that low education level, low income, seizure frequency, early age of onset, lack of psychological support and poor knowledge and attitude towards epilepsy were strikingly associations with high stigma score (35).

The misconceptions, negative attitudes, and beliefs were associated with an increased level of felt stigma and social isolation. A study done by Aydemir et al on predictors of negative and positive attitude towards epilepsy found that as a positive attitude about epilepsy developed there was a decrease in the level of stigma. In addition, another study done by Marie et al on perceived stigma and adherence to treatment found that higher perceived stigma was associated with poor medication adherence, low level of knowledge and poor behavioral skills .(38,39)

In another study done in Southwestern Uganda on perceived stigma and factors associated with stigma reported perceived stigma to be 34% with strong association found in those having epileptic associated defects, other chronic maladies, and long period of antiepileptic medication (17).

2.3 Assessing the Perceived Stigma among PLWE

There has been growing evidence of the negative consequence of stigma on health. Having been seen to affect health in psychological and structural ways several tools have been developed to measure its magnitude. The diverse nature of cultural aspects and beliefs has plagued the development of a standardized validated tool that can be replicated and adapted to assess stigma in various countries. This has led to the development of several tools in developed and developing countries. In 1993 Jacoby et al developed a novel scale to measure perceived stigma. An eight-item tool using the simple 4-point Likert scoring system was developed and the items focused on the important areas in life such as the relationship with partner, close family members and friends, social life activities, work, health, feelings about self, plans and ambitions for the future. Seventy-five patients responded to each item. Responses ranged from 'not at all' (score of 1) to 'a lot' (score of 4). All items were added to get the total impact score (40).

Table 1: Prevalence of stigma and factors Associated with Stigma

Study	**Study period**	**Study design**	**No of patients**	**Major findings**
Tolesa et al (Ethiopia)	May 1ST 2013-May 30TH 2013	Hospital based cross-sectional study	347	Prevalence of stigma was 31.2%. challenges in attending clinic, epilepsy associated injuries and contagious believes were related to stigma[15]
Jack et al (Tanzania)	March 2009-May 2015	Cross-sectional and Case - control study	84YPWE and 79 controls	Perceived stigma was higher in Young People with Epilepsy (YPWE) at 27.4%. Fewer YPWE were educated, employed and in intimate relationships. A good education and employment outcome were predicted by lower level of seizures and high BI score[37]
Joseph et al (Uganda)	February to June 2009	Cross-sectional study	191	Perceived stigma was 34.0%. Epilepsy associated defects, other chronic diseases, low level of education, older age and long duration of AED were linked to high perceived stigma[16]
Berhanu et al (Ethiopia)	January 1st to February 2014	Cross-sectional study	408	Perceived stigma was 71.6% with marital status, duration of illness and seizure frequency associated with perceived stigma.
Justin et al (Nigeria)	April to September 2016	Cross-sectional study	93	The prevalence of perceived stigma and enacted stigma was 46.2% and 67.7% respectively. Correlate of perceived stigma were rural living, lower level of education and long duration of illness.[38]

2.3.1 Developing a Quantitative Tool for Stigma Assessment Among PLWE

Epilepsy influences an individual’s life in various aspects. This includes the psychosocial and physical aspect of life. According to Ann Jacoby et al who did a study on the impact of epilepsy on psychosocial factors such as self-esteem, affect life balance, PQOL, life fulfillment, mastery, anxiety and depression, on 75 patients with epilepsy found that epilepsy profoundly affects the psychosocial variables negatively affecting the lives of PLWE leading to adverse outcomes (40).

The stigma associated with epilepsy is a major social challenge and has been the center of many studies in Sub-Saharan Africa. Epilepsy related stigma is affected by various elements such as cultural practices, traditional beliefs, social environment, and individuals. This has made it complex and challenging to identify a single standardized tool to assess stigma across the globe. Several stigma scales have been developed and tailored to espouse the diverse cultural beliefs and traditional practices to solve this problem (10,39,41).

The Kilifi Stigma Scale is a validated tool developed by Wellcome Trust Kilifi for the evaluation of epilepsy related perceived stigma. It is a 15-item scale with proven reliability and validity. It has been used in East and West Africa for the evaluation of perceived stigma. A rating above 66% shows the existence of perceived instances of stigma.(16,18,39,41).

2.4 Developing a Quantitative Tool for Attitude Assessment in PLWE.

Wrong beliefs combined with a negative attitude from the society are important factors related to stigmatization. Due to cultural diversity, beliefs and attitudes vary from one society to another and culture. However, in underdeveloped countries, a common view defining epilepsy as a punishment of sin, bewitchment, mental illness or contagious disease exists and leads to increased perceived stigma. As a result, there is an increase in social isolation and impaired self-management of epilepsy (42).

Understanding the cultural beliefs provides an insight into the way people cope with and respond to their experiences as PLWE. Negative attitudes and beliefs affect the utilization of biomedical services and impair life quality as compared to seizures.The Kilifi Beliefs and Attitude Scale consists of four main subscales: causes of epilepsy(n=5), biomedical treatment(n=8), cultural treatment of epilepsy(n=9), and risks and safety concerns for people with epilepsy(n=4), and negative attitudes about epilepsy(n=8).

The tool is locally developed and validated for use in Africa. The total score ranges 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 Likert scale will help collect important information about participants' attitudes and beliefs about epilepsy, which will be used to compare participants. The scale has excellent psychometric properties and thus reliable and valid.

2.5 Assessment of Knowledge among PLWE

Knowledge of epilepsy is crucial in the management and reduction of the psychosocial burden of epilepsy. The development of a standardized validated tool that could be replicated in the various sociocultural settings has been a challenge. However, Long et al,.2000 developed the Epilepsy Patient Knowledge Questionnaires (EPKQ) which is a 3 page, 13-item questionnaire that includes multiple choice, true and false and 'fill in the gap' questions.

The questionnaire focuses on defining epilepsy (n=1), safety (n=3), medical compliance (n=4), social activities (n=1) and the legal issues of driving (n=2) and employment (n=2).[24] Furthermore, the questionnaire has evolved to accommodate the diverse socio-cultural aspects experienced in different countries. It has two sections, the first collects demographic information which includes age, sex, education level, school category and religion while the second part consists of medical knowledge items and social knowledge items assessing knowledge on cause and manifestation, attitude towards epilepsy, the practice adopted in relation to epilepsy, first aid measures and treatment options of epilepsy.

The questions are scored on a scale of between 0 and 100.A cut off rate of 50 is categorized as good knowledge/practice and less than 50 score as poor knowledge/practice. The scale has good internal reliability and test re-test reliability. The scale is also considered, objective, unambiguous and sensitive in the assessment of medical knowledge level in epilepsy. The questionnaire has been used in several Sub-Saharan countries and was found useful in comparing the medical knowledge of PLWE in different countries.

2.6 Problem Statement

The psychological and social impact of epilepsy is felt all over the world more so in middle- and low-income countries. According to Nsengiyumva et al, the burden of epilepsy affects individuals with epilepsy, their families, and society at large. PLWE may experience stigmatization and marginalization as a result of their condition hindering them from progressing both socially and economically (43).

The psychosocial factors related to epilepsy stigma greatly impact the quality of life more than clinical variables do in PLWE. Besides, it also contributes to the development of psychiatric co-morbidities such as depression and anxiety (25,44).

A study conducted in Western Kenya revealed that the treatment gap experienced by PLWE has a significant correlation with the perceived stigmatization. The study also revealed that the factors associated with high perceived stigmatization are those related to the treatment gap.(45) This study will help us identify the burden of perceived stigma among PLWE and the factors associated with high levels of perceived stigmatization.

2.7 Study Justification

The stigma associated with epilepsy has been seen to affect the physiological wellbeing, economic status, and social environment far more than the illness resulting in low esteem, withdrawal socially, also self-isolation. Furthermore, it also interferes with timely access to treatment and adherence to medication and lifestyle recommendations (7).

Perceived stigma is usually under-recognized and unattended in most PLWE. This greatly interferes with their quality of life. Scarce data on the rates of prevalence of perceived stigma among the population in urban areas in Kenya hence the need to remove the burden and spread of epilepsy related stigma. The negative perception of epilepsy among health care professionals has interfered with service provision to PLWE. This has resulted in delays in attaining seizure control and improving quality of life. Despite being put on treatment to control seizures patients with epilepsy will have to deal with stigma and its consequences unless we address it.

Through tailored education campaigns and programs such as the WHO's anti-stigma campaigns, self-advocacy that involve individual and family counselling directed against stigma reduction, the psychosocial burden of epilepsy can be reduced and patient's quality of life improved (6,8,46).

2.8 Research Question

What is the burden of stigma in patients living with epilepsy in low income densely populated communities in Nairobi?

2.9 Broad Objective

To determine the prevalence and associated factors of perceived stigma in PLWE in low income densely populated communities in Nairobi.

2.10 Specific Objective

a. To establish the prevalence of perceived stigma in epileptic patients in low-income communities in Nairobi.

2.11Secondary Objective

a. To determine factors associated with perceived stigma in patients with epilepsy
b. To determine the association between the perceived stigma and seizure type.
c. To determine the association between perceived stigma and seizure control.

CHAPTER THREE: METHODOLOGY

3.1 Study Design

A descriptive cross-sectional study.

3.2 Study Population

The study was conducted among individuals who are 14 years or older who are on treatment for epilepsy.

3.3 Study Site

The study site was KAWE clinics based in Huruma Lion Health Center, Riruta Health Center and Karen Health Centre. The KAWE clinics are managed by well-trained clinical officers and nurses. Their catchment population is in the densely populated informal settlements of Korogocho, Viwandani, Kariobangi North and South, Babadogo Kawangware, Kibera and Huruma. The clinics operate on Wednesdays, Thursdays and Fridays. They are run by clinical officers. The Huruma Lion Health Center clinic handles an average of 70 patients in a day with the rest an average of 50 patients in a day.

3.4 Sample Size Calculation

A respective sample was drawn from this population using the Daniel’s formula (1999) for prevalence study:

$$n=\frac{Z^2 *(p)*(1-p)}{c^2}$$

$$\frac{1.96^2*0.33*(1-0.33)}{0.05^2}$$

N=340

Where;

N=sample size

Z= Z value (1.96 for 95% level of confidence)

P=population propotion with the desired characteristics. This will be considered at 33% based on a study done by Mbuba et al in Kilifi.

C=level of confidence, expressed as a decimal

Ina research study carried out by by Mbuba et al found out that the prevalence of perceived stigma in PLWE in Kilifi to be 33.0%. This was selected as the population with the desired characteristic.

3.5 Sampling and Recruitment

The study population was recruited over a period of three months. Simple random sampling method was employed to select participants from the KAWE clinical registry. The patients listed in the registers available in the clinics were used to generate the sampling frame for the study.

The investigator developed a list of patients from the registers and serial numbers assigned as per their registration dates in the clinics. Random numbers were generated from Microsoft Excel spreadsheet then used to select the participants for enrollment. The patients with their serial numbers matching the generated random numbers were sampled for recruitment into the study.

The sampled patients were approached and requested to participate in the study. The recruitment process included screening for eligibility and consenting procedures. The eligible participants were consented by explaining the study procedures, the discomforts, benefits and confidentiality. Those who consented were asked to sign an informed consent form before interviews commence. Protective measure to prevent transmission of COVID-19 was adhered to as instituted by the ministry of health.

3.5.1 Patient Selection

Case definition was based on the ILAE 2014 task force definition using any of the following conditions:(5)

- At least two unprovoked (or reflex) seizures occurring greater than 24 hours apart.
- 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.
- Diagnosis of an epilepsy syndrome.

Poor seizure control in the study is defined as > 1 seizure in the last three months.

3.5.2 Inclusion Criteria

a) Adults and adolescents above 14 years diagnosed with epilepsy for more than three months and attending KAWE clinics.
b) Individuals with signed informed consent.

For patients below 18 years informed assent was obtained from the patient and informed consent obtained from the parent or guardian.

3.5.3 Exclusion Criteria

Major cognitive impairment or severe psychiatric condition

3.6 Flow Chart on Recruitment

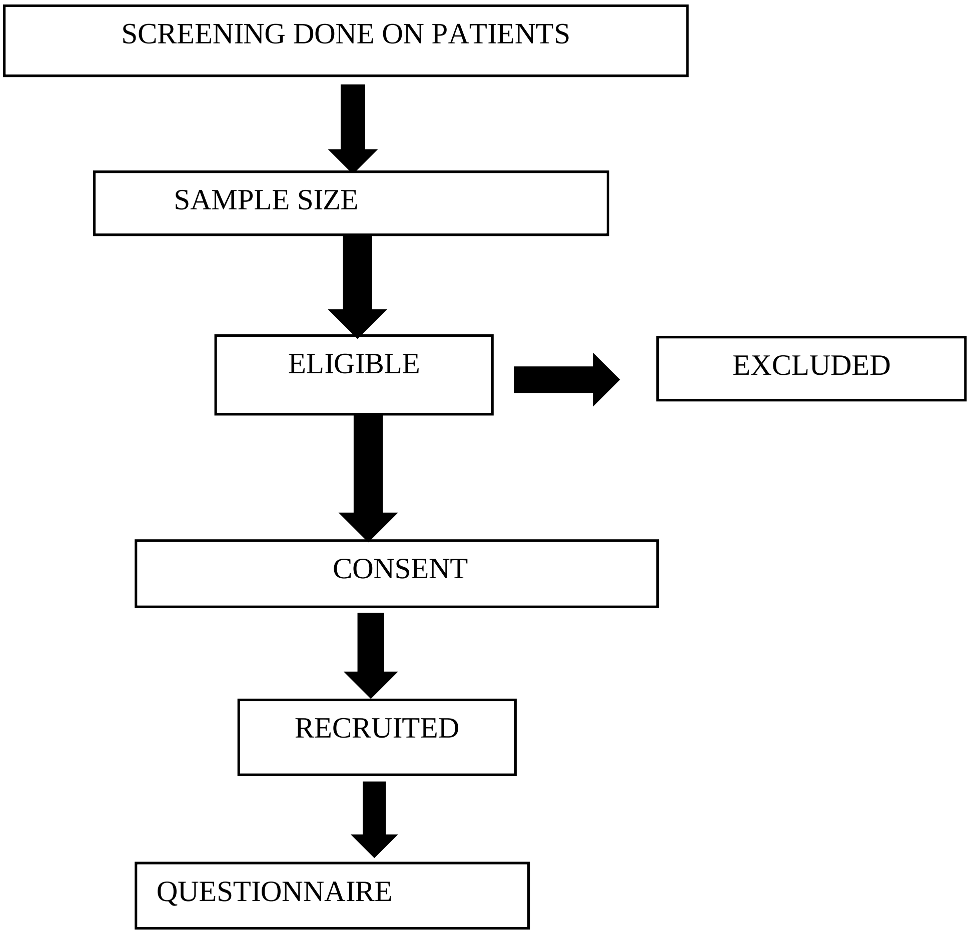

Figure 2: Study Flow Chart on recruitment

3.7 Study Procedure

The PLWE were assessed and consented to take part in the study. The sample selection was selected from the KAWE clinic registry. The principal investigator and the research assistants explained about the objective of study, the procedures, the risks and discomforts, benefits and confidentiality to the participants. Before they can enroll in the study, the clients were asked to give their before taking part in the study. Those who are enrolled in the study were asked to complete structured questionnaires. One set of questionnaires was to collect socio-demographic information of the PLWE and their clinical characteristics. Perceived stigma variables were collected using Kilifi Stigma Scale score tool.

The Kilifi Stigma Scale is a validated and locally developed scale for people with epilepsy. It has a high internal consistency and is easily verifiable (Cronbach's a=0.91). It has an excellent test-retest reliability (r=0.92). This was used to assess the level of perceived stigma.

The Epilepsy Patient Knowledge Questionnaire (EPKQ) which is a 13-item questionnaire entails a set of multiple-choice questions selected by a range of experts with true and false as responses (medical and social knowledge items). This was used to examine the medical knowledge level in relation to epilepsy.

The Kilifi Epilepsy Beliefs and Attitudes tool (KEBAS) was used to assess the attitudes and beliefs of PLWE. It is a locally developed and validated tool that has 34 items with five subscales which represent medical and non-medical beliefs about epilepsy. It is a 4 Likert scoring system with '0 = not at all', '1 = believe a little', '2 = totally believe' and 'missing (.) = don't know'. In each subscale, items are worded in a positive and negative manner to avoid affirmation, acquiescence or bias. All the data tools were self -administered and were translated into Kiswahili and back-translation into English by trained linguists.

3.8 Data Management and Analysis Method

Raw Data was keyed in and cleaned in Microsoft Excel 2016 spreadsheet. Statistical analysis was analyzed in SPSS version 23.0 statistical software. The study population was described using socio-demographic and clinical characteristics by summarizing categorical data into percentages. The continuous data was tested for normality and those with normal distribution summarized into mean with standard deviations while the non-normally distributed data were summarized into median with interquartile ranges.

Kilifi Stigma Scale was analyzed by adding total score of all items to obtain a total score. Total score was categorized such that those above 66% indicates perceived stigma while those below the cut-off being free from stigma. Prevalence of perceived stigma was calculated and presented as a percentage of all the patients studied.

The EPKQ and KEBAS data was scored and then transformed to a scale between 0 and 100. Patients scoring a cut off value of 50 or above were categorized as having good knowledge or positive beliefs or positive attitude towards epilepsy. Knowledge, beliefs and attitudes were summarized and presented as a percentage of the study population.

Presence of perceived stigma caused by epilepsy being linked with socio-demographic factors, clinical characteristics, knowledge levels, beliefs and attitudes using chi square test of associations. For the normally distributed data, comparison of means was done using Student's T-test while non-parametric test such as Mann-Whitney U-test was used to compare medians. Factors independently associated with perceived stigma were determined using multiple logistic regression models with controls for confounding variables. 2-tailed statistical tests was used and interpreted at 5% level of significance (P value less or equal to 0.05 was considered to be statistically significant). The results are presented using tables.

3.9 Ethical Consideration

The study was conducted after approval by the Department of Clinical Medicine and Therapeutics, University of Nairobi; Kenyatta National Hospital/University of Nairobi Ethics and Research Review Committee. Before commencing data collection, permission was sought from the relevant county government administration office in order to be allowed to access the facilities in the area. A consent explanation (Appendix) was given to study participants, and eligible subjects who agree to participate signed an informed consent form (Appendix). The participants did not incur any additional costs by participating in the study.

The principal investigator ensured that patient confidentiality was upheld and anonymity ensured. All hard copy data were under lock and key while digital data was password protected. The patients were identified only by study number. All data obtained from this study was used for the sole purpose of meeting the objectives stated in this proposal.

CHAPTER FOUR: RESULTS

4.1 Patient Screening

We did a prospective study between 1st of September to 14th of November 2021 that randomly selected patients with epilepsy attending KAWE clinics in Nairobi. A total of 352 patients were screened. Five did not meet the inclusion criteria for reasons of major cognitive impairment. Five were ineligible for reasons of: barrier in communication (2), lack of guardian (3) and (1) was excluded as he declined to give consent. Two did not complete filling the questionnaire. A total of 340 who meet the inclusion criteria were enrolled in the study after giving consent. This is illustrated in the diagram 4.0

4.2 Flow Diagram of the Enrolled Study Patients

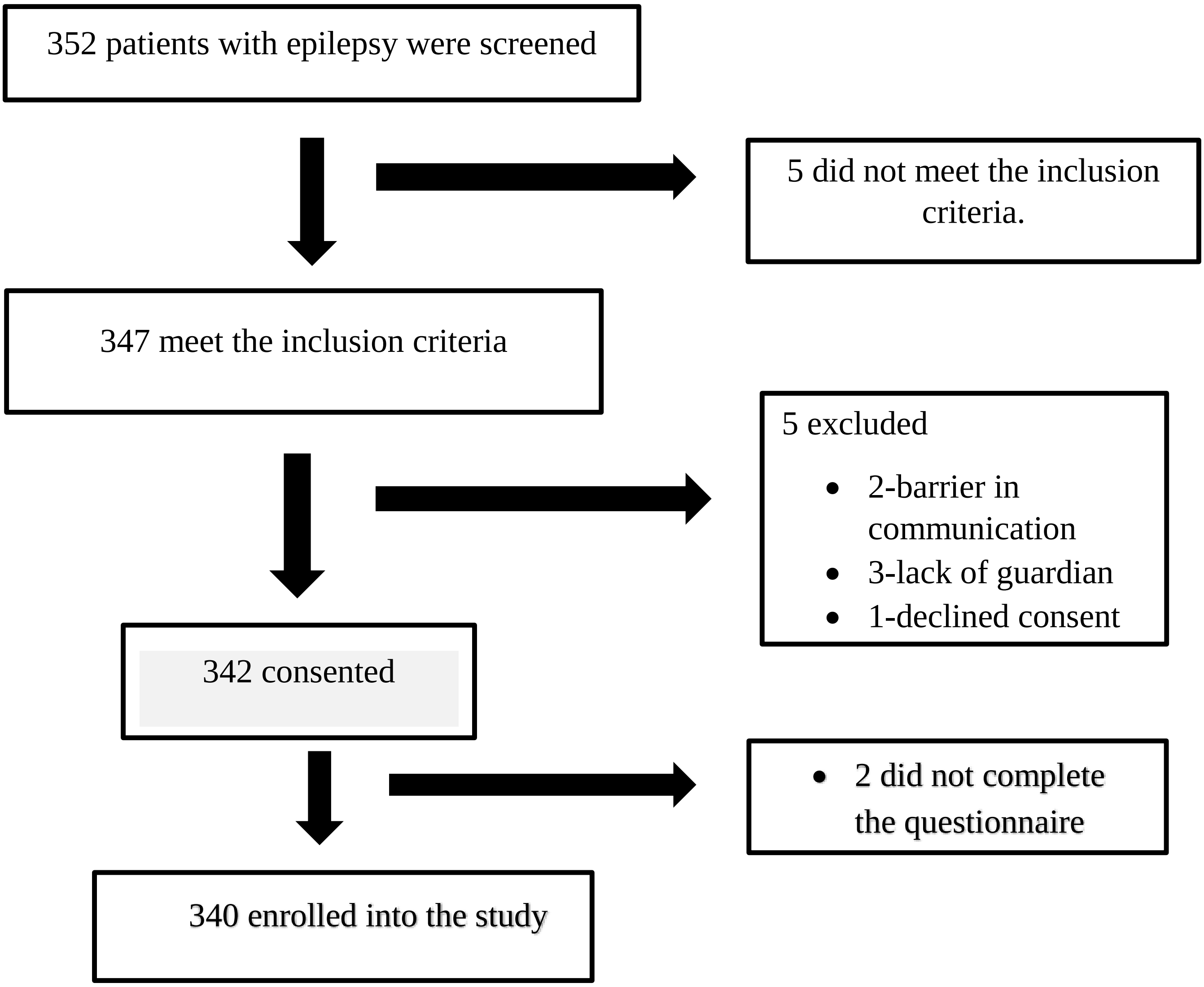

Figure 3: Flow Diagram of the Enrolled Study Patients

4.3 Socio-demographic Characteristic of the Respondents

The study participants mean age is 30.6 ±12.8 SD. Age ranged between 14 and 87 years. The ratio of male to female being 1:1. Many participants in the study were single 63.8%. In terms of level of education, 33.5% had attended primary level and 32.1 % secondary school level. Majority of the respondents were unemployed at 35%. This is shown in table 2.

Table 2: Socio-demographic characteristics of patients with epilepsy at KAWE clinics

Variable	**n=340 Frequency (%)**
Age in years	
Mean (SD)	30.6 (12.8)
Min-Max	14-87
Category, n (%)	
10-19	63(18.5)
20-29	129(37.9)
30-39	67(19.7)
40-49	53(15.6)
50-59	17(5.0)
>60	11(3.2)
Gender	
Male	172 (50.6)
Female	168 (49.4)
Marital Status	
Single	217 (63.8)
Married	99 (29.1)
Separated	15 (4.4)
Divorced	3 (0.9)
Widowed	6 (1.8)
Religion	
Christian	318 (93.5)
Islam	19 (5.6)
Other	3 (0.9)
Level of Education	
Lack of formal education	23 (6.8)
Primary	114 (33.5)
Secondary	109 (32.1)
College/University	94 (27.6)
Occupation Status	
Unemployed	119 (35.0)
Employed	35 (10.3)
Informal sector...e.g. Jua Kali, hawker and self –employed	106 (31.2)
Student	80 (23.5)

4.4 Clinical Characteristics of the Respondents

Majority of the participants had their first seizure at age 10 years and above and 57.1 % had epilepsy for over 10 years. A significant number of the respondents had generalized tonic clonic seizures at 66.2%. Most of the participants,61.5%, reported seizures in the last three months with 80.3% of the participants reporting less than 6 seizures. Injuries during seizures such as burns, bruises and fractures were reported in 52.6%. Majority of the participants in this study 95.9% were on antiepileptic medication and 5.8% had difficulty in taking antiepileptic medication. 5% reported difficulty going for clinics since they feared stigma. As shown in table 3.

Table 3: Clinical characteristics of patients with epilepsy at KAWE clinics

Variable	**n=340 Frequency (%)**
Age of first seizure	
<5	64 (18.8)
5-9	49 (14.4)
10-19	135 (39.7)
20-29	52 (15.3)
30-39	23 (6.8)
40+	17 (5.0)
Disease duration (in years)	
<2	12 (3.5)
2-5	60 (17.6)
6-10	74 (21.8)
>10	194 (57.1)
Type of epilepsy (from file)	
Generalized tonic clonic	225 (66.2)
Simple Focal	22 (6.5)
Complex Focal	55 (16.2)
Others	38 (11.2)
Seizures in the last three months	209 (61.5)
Frequency of seizures in the last three months	
<6times/3months	273 (80.3)
>6times/3 months	67 (19.7)
Have you been prescribed AED's	326 (95.9)
Difficulty in taking AEDs daily due to fear of stigma	19 (5.8)
Follow-up clinics attendance difficulty due to stigma	17 (5.0)
Injuries during seizure	
Yes	179 (52.6)

4.5 Participants Perceived Stigma Scores

Out of the 340 participants recruited, 33.2% met the set criteria for high perceived stigma as measured by the KSSE. This is shown in table 4.

Table 4: Perceived stigma prevalence among epileptic patients

Variable	n=340 Frequency (%)
Kilifi stigma score	
Median (IQR)	39(35-45)
Min-Max	28-68
Perceived stigma	
Present	113 (33.2)
Absent	227 (66.8)

4.6 Association between perceived stigma of epilepsy and socio-demographic factors.

Majority of participants, 44.2%, found to have high perceived stigma were aged 20-29 years. Female respondents were 53.1% and more than two thirds ,69.0%, of respondents were single. A significant number ,94.7%, of participants were Christians. Many of the respondents ,37.2%, had reached primary level of education and 44.2% were unemployed. Perceived stigma was significantly associated with unemployment (p <0.002). This is illustrated in table 5.

Table 5: Association between perceived stigma of epilepsy and socio-demographic factors

Variable	Perceived stigma		OR (95% CI)	Chi square P value
	Present (n=113) n (%)	Absent (n=227) n (%)		
Age				
10-19	24 (21.2)	39 (17.2)	1.0	
20-29	50 (44.2)	79 (34.8)	1.0 (0.6-1.9)	0.929
30-39	22 (19.5)	45 (19.8)	0.8 (0.4-1.6)	0.794
40-49	13 (11.5)	40 (17.6)	0.5 (0.2-1.2)	0.528
50-59	2 (1.8)	15 (6.6)	0.2 (0.04-1.0)	0.217
60+	2 (1.8)	9 (4.0)	0.4 (0.1-1.8)	0.361
Gender				
Male	53 (46.9)	119 (52.4)	0.8 (0.5-1.3)	0.338
Female	60 (53.1)	108 (47.6)	1.0	
Marital Status				
Single	78 (69.0)	139 (61.2)	1.0	
Married	30 (26.5)	69 (30.4)	0.8 (0.5-1.3)	0.327
Separated	4 (3.5)	11 (4.8)	0.6 (0.2-2.1)	0.470
Divorced	0	3 (1.3)	-	0.999
Widowed	1 (0.9)	5 (2.2)	0.4 (0.04-3.1)	0.350
Religion				

Christian	107 (94.7)	211 (93.0)	1.0	
Islam	5 (4.4)	14 (6.2)	0.7 (0.2-2.0)	0.512
Other	1 (0.9)	2 (0.9)	1.0 (0.1-11.0)	0.991
Level of Education				
No formal education	10 (8.8)	13 (5.7)	0.5 (0.2-1.3)	0.145
Primary	42 (37.2)	72 (31.7)	0.7 (0.4-1.2)	0.161
Secondary	35 (31.0)	74 (32.6)	0.8 (0.4-1.5)	0.491
College/University	26 (23.0)	68 (30.0)	1.0	
Occupation status				
Unemployed	50 (44.2)	69 (30.4)	1.0	
Employed	33 (29.2)	108 (47.6)	0.4 (0.2-0.7)	**0.002**
Student	30 (26.5)	50 (22.0)	0.8 (0.5-1.5)	0.524

4.7 Association between perceived stigma of epilepsy and clinical characteristics.

Majority of the participants, 61.1%, with perceived stigma had epilepsy for over 10 years. About 64.6% had generalized tonic clonic seizure. Sixty nine percent (69.0%) reported seizures in the last three months. A significant number ,93.8%, of participants were on antiepileptic medication. Among them 13.2 % had challenged taking antiepileptic medication due to fear being stigmatized. Challenges in follow up clinics attendance due to stigma was identified in 12.4% of participants. A majority of the participants ,63.7%, reported injuries during seizures such as burns, bruises and sometimes fractures. High perceived stigma was strongly associated with age of first seizure(p<0.003), seizure frequency (OR=2.5, p<0.001), difficulty taking antiepileptic medication (OR=8.2, P<0.001), difficulty attending follow-up clinic (OR=10.6, P<0.001) and injuries during seizure (OR=2.0, P<0.004) This is shown in table 6.

Table 6 : Association between perceived stigma of epilepsy and clinical characteristics

Variable	**Perceived stigma**		**OR (95% CI)**	**Chi square.P value**
	Present (n=113) n (%)	**Absent (n=227) n (%)**		
Age of first seizure				
<5	28 (24.8)	36 (15.9)	3.6 (0.9-13.9)	0.060
5-9	22 (19.5)	27 (11.9)	3.8 (1.0-14.9)	0.056
10-19	40 (35.4)	95 (41.9)	2.0 (0.5-7.2)	0.309
20-29	14 (12.4)	38 (16.7)	1.7 (0.4-6.9)	0.445
30-39	6 (5.3)	17 (7.5)	1.6 (0.3-7.8)	0.530
40+	3 (2.7)	14 (6.2)	1.0	
Disease duration (in years)				
<2	2 (1.8)	10 (4.4)	1.0	
2-5	18 (15.9)	42 (18.5)	2.1 (0.4-10.8)	0.355
6-10	24 (21.2)	50 (22.0)	2.4 (0.5-11.8)	0.282
>10	69 (61.1)	125 (55.1)	2.8 (0.6-13.0)	0.198
Type of epilepsy				
Generalized tonic clonic	73 (64.6)	152 (67.0)	1.0	
Simple Focal	7 (6.2)	15 (6.6)	1.0 (0.4-2.5)	0.952

Complex Focal	23 (20.4)	32 (14.1)	1.5 (0.8-2.7)	0.191
Others	10 (8.8)	28 (12.3)	0.7 (0.3-1.6)	0.453
Seizures in last 3 months				
Yes	78 (69.0)	131 (57.7)	1.6 (1.0-2.6)	**0.043**
Frequency of seizures				
<6 times/3 months	79 (69.9)	194 (85.5)	1.0	
>6 times/3 months	34 (30.1)	33 (14.5)	2.5 (1.5-4.4)	**0.001**
AEDs prescribed				
Yes	106 (93.8)	219 (96.5)	0.6 (0.2-1.6)	0.272
Difficulty taking AEDs daily.				
Yes	14 (13.2)	4 (1.8)	8.2 (2.6-25.5)	**<0.001**
Difficulty attending follow-up clinic				
Yes	14 (12.4)	3 (1.3)	10.6(3.0-37.6)	**<0.001**
Injuries during seizure				
Yes	72 (63.7)	107 (47.1)	2.0 (1.2-3.1)	**0.004**

4.8 Seizure Control

Poor seizure control was identified in 61.5% of the participants. However, a majority of the respondents reported less than six seizures in three months, 80.3%. This is shown in table 3.

4.9 Relationship between perceived stigma and EPQK/KEBAS

A significant number of participants had good knowledge of epilepsy at 97.1%. Respondents with positive beliefs and attitudes were 97.6% while 2.4 % had negative beliefs and attitude. Knowledge, attitudes and beliefs were not to a higher extend linked to with stigma that is perceived

This is shown in table 7 and 8.

Table 7: Epilepsy Patient Knowledge (EPKQ) and Epilepsy beliefs and attitudes scale (KEBAS)

Variable	**n-340 frequency (%)**
Knowledge	
Good knowledge	330(97.1)
Poor knowledge	10(2.9)
Beliefs and attitude	
Positive	332(97.6)
Negative	8(2.4)

Table 8: Associations between perceived Stigma of epilepsy and knowledge levels, beliefs and attitudes

Variable	Perceived stigma		OR (95% CI)	P value
	Present (n=113) n (%)	Absent (n=227) n (%)		
Knowledge				
Good knowledge	110 (97.3)	220 (96.9)	1.2 (0.3-4.6)	1.000
Poor knowledge	3 (2.7)	7 (3.1)	1.0	
Beliefs and attitude				
Positive	110 (97.3)	222 (97.8)	0.8 (0.2-3.5)	1.000
Negative	3 (2.7)	5 (2.2)	1.0	

The model for multiple logistic regression was done considering all factors that could influence stigma. After controlling for occupation status, age of first seizure, seizure frequency several factors showed constant levels these are; difficulty in taking antiepileptic medication (AOR=4.0, P value=0.046), difficulty attending clinics (AOR=4.9, P value=0.043) and injuries during seizure (AOR 2.1, P value=0.008). This is illustrated in table 8.

Table 9: Factors independently associated with perceived stigma (multiple logistic regression model)

	Univariable regression		Multiple regression	
Variable	OR (95% CI)	P value	Adjusted OR (95% CI)	P value
Occupation status				
Unemployed	1.0		1.0	
Employed	0.4 (0.2-0.7)	0.002	0.5 (0.2-0.9)	0.014
Student	0.8 (0.5-1.5)	0.524	1.0 (0.5-1.9)	0.957
Seizures in last 3 months				
Yes	1.6 (1.0-2.6)	0.043	1.0 (0.6-1.8)	0.922
No	1.0		1.0	
Frequency of seizures				
<6 times/3 months	1.0		1.0	
>6 times/3 months	2.5 (1.5-4.4)	0.001	1.8 (0.9-3.3)	0.089
Difficulty taking AEDs daily	8.2 (2.6-25.5)	<0.001	4.0 (1.0-16.0)	0.046
Yes	1.0		1.0	
No				
Difficulty attending follow-up clinics	10.6 (3.0-37.6)	<0.001	4.9 (1.0-23.0)	0.043
Yes	1.0		1.0	
No				
Injuries during seizure				
Yes	2.0 (1.2-3.1)	0.004	2.1 (1.2-3.5)	0.008
No	1.0		1.0	

CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Discussion

The study was carried out to determine the prevalence of perceived stigma, its associated factors in patients with epilepsy in low income densely populated communities in Nairobi. It established that perceived stigma prevalence in epileptic patients in Nairobi, Kenya as 33.2%.

This prevalence of perceived stigma is high and highlights perceived stigma as one of the major social factors affecting PLWE. Perceived stigma has been shown to have enormous economic effects on the patient's status, psychosocial well-being, social interactions, and overall health even greater than the illness itself. Perceived stigma interferes with timely access to healthcare, sticking to treatment and lifestyle change recommendations.

The high levels of perceived stigma in this study is similar to other studies conducted locally and in other African countries. A cross-sectional study done in Kilifi in 2012 while developing and validating the Kilifi stigma scale identified perceived stigma among 673 epileptic patients to be 33.0% (18). Another cross-sectional study conducted in 2017 on 191 patients with epilepsy in rural Southwest Uganda by Kirabira et al found the prevalence to be 34% (17). Similarly, in Ethiopia, a cross-sectional study conducted in 2013 by Fanta et al with a sample size similar to ours found a prevalence of 31.2% (16). All the three studies used the Kilifi stigma scale to assess the level of perceived stigma. This scale has shown to be reliable and was specifically developed to determine perceived stigma in epilepsy, it is culturally appropriate in our setting as it accommodates the cultural beliefs and understands the target population.

The high levels of perceived prevalence of stigma in our study and other African countries demonstrate the diverse problem related to perceived stigma and its major contribution to the global burden of disease.

Previous studies have found a high prevalence of perceived stigma in the rural population compared to the urban population. Justin et al conducted a cross-sectional study in Nigeria (2016) on 93 patients suffering from epilepsy and found a prevalence of perceived stigma of 62.2% in rural residents compared to 31.3% in urban residents. This could be attributed to poor community integration of primary health care providers in sensitizing the community on epilepsy care lead to the propagation of misconceptions and negative beliefs on epilepsy in the rural areas (20).This difference was not noted when comparing our findings to that of rural Kilifi and this could be attributed to community sensitization initiatives that were conducted by KEMRI/wellcome trust research programme before conception of the Kilifi study thereby reducing the level of perceived stigma.

In contrast, Cruz et al in a cross-sectional study done in 2015 in rural and urban areas in Ecuador on 243 patients with epilepsy found a prevalence of 60% in urban areas and 40% in rural areas. The difference noted was attributed to the prevailing lack of community social support noted in urban regions thus making it difficult for persons with epilepsy to achieve community integration and support thereby increasing their level of stigma (47).Our study was conducted among patients who attended the KAWE clinics, a not-for-profit organisation that addresses challenges faced by PLWE through community-based approaches. Their enhancement of community integration among PWE through the use of community support groups and school training programs improves how the community views and addresses epilepsy. The support groups also provide coping strategies, first-hand information about epilepsy and how to maneuver stigma and discrimination to PLWE. This helps reduce the level of perceived stigma.

Further studies done in Africa and globally found a higher level of prevalence in epileptic patients when compared to our study. A cross-sectional study done by Shibre et al in Butarija, Ethiopia in 2004 on 831 patients using the family interview schedule scale found a prevalence of perceived stigma as 81% (48). This scale was initially used to assess the level of stigma and outcome in patients with schizophrenia and this could have contributed to the high prevalence of perceived stigma in the study. The other reasons might be the difference in study setting and socio-cultural characteristics.

Another cross-sectional study done by Justin et al in Nigeria in 2016 on 93 patients, with a mean age of 30 years, using the Jacoby stigma scale found the prevalence of perceived stigma as 46.2%. This discrepancy in prevalence may be attributed to the use of a different stigma scale. The Jacoby stigma scale is a three-item scale developed for use in Western countries. It has been shown to produce disparate results in western and low-income countries due to the difference in cultural perception and attitudes by individuals (20).

Rafael et al in a survey conducted in Beninese rural area on 80 patients with a mean age of 35 years, found a higher prevalence of perceived stigma of 68.7%. This discrepancy could be attributed to the use of Jacoby stigma scale, explanatory model interview catalogue and socio-cultural differences in understanding of stigma (49). This scale has been shown to indicate higher perceived stigma in developing countries as stigma is a cultural construct and tends to vary across cultures.

On the other hand, Goodall et al in a study done in rural Northern Tanzania in 2015, which made use of cross-sectional and case control designs on 112 cases and 113 controls, found a lower prevalence of 27.4%. This variation might be due to the difference in study population which was mainly children aged 6-14 years from rural regions. Another reason could be under-reporting that was noted, as the majority of their questionnaires were completed by relatives rather than the participants who probably were not aware of the perceptions of stigma felt by these participants. Their relatives were likely to socially acceptable answers (41).

The presence of perceived stigma in our study and globally demonstrates that this is a major social factor contributing to the burden of epilepsy. Despite the differences in clinical advances, stigma is experienced everywhere and is an important contributor to the global burden of disease. Therefore, prompt identification and management of stigma in the life of PLWE is crucial to avoid the negative impact of perceived stigma. Further, effective engagement of public health interventions in mitigating and reducing its impact among patients with epilepsy is crucial. This supports the WHO campaign 'out of the shadow 'that advocates for tailored education campaigns and programs that involve individual and family counselling directed against stigma reduction (9).

The nature and level of perceived stigma is influenced by many factors. Being unemployed is highly linked to levels of perceived stigma. Individuals who were unemployed were noted to show higher levels of perceived stigma and this could be attributed to the reduced motivation to work due to social devaluation and discrimination. The participants were less likely to get a job and continue working after disclosing their illness and this would result in low-income levels. This is in line with a cross-sectional study conducted by Goodall et al in Tanzania in 2015 where they reported a significant association between low employment and income and high perceived stigma (41). Low-income level may limit their ability to seek medical care or purchase medication and this further increases the treatment gap.

Age, gender, marital status and level of education of the participants did not show any significant relationship to perceived stigma. Fanta et al, in a cross-sectional study done in 2013 in Ethiopia on 347 participants with epilepsy found no significant correlation between perceived stigma and age, gender, marital status and level of education (16).

Seizure frequency which is an indicator of degree of severity of illness was showed great association with perceived stigma. Shibre et al in a cross-sectional study done in Butajira, Ethiopia in 2004 on 831 participants with epilepsy reported significant association of seizure activity and higher perception of stigma(48). Yeni et al in a cross-sectional study done in 2014 in Turkey on 194 participants also reported significant association between seizure frequency and high perceived stigma (35). This could be due to the physical consequences such as bruises, burns and fractures that result from uncontrolled disease and the risk of disclosure of their illness to the public. This informs the need of early and appropriate treatment of epilepsy with antiepileptic medication to achieve acceptable seizure control that will allow individuals to live near-normal lives.

Long periods of antiepileptic medication was not associated with perceived stigma which is in line with a cross-sectional study done in rural and urban areas of Ecuador by Jaime et al in 2015 (47). This was in contrast to a cross-sectional study done in south west Uganda by Kirabira et al in 2017 that found an link time use of antiepileptic medication use and high perceived stigma. This leads to an increase in using medication will contribute to the perceived burden of epilepsy. Personal beliefs and the community misinformation about using medication for prolonged periods as well as incurability of such illnesses could also cause the discrepancies (17).

Participants reporting difficulty in taking antiepileptic medication daily because of fear of stigma were more likely to have perceived stigma in comparison to those with no difficulty in taking antiepileptic medication due to stigmatization. It was statistically significant. In addition, participants who had had challenges in going for follow-up clinics due to stigmatization or perceived stigma and this was statistically significant. This finding was similar to a cross-sectional study done by Fanta et al in Ethiopia. Possibly because of fear of enacted stigma that could occur if the community was aware that they are on follow up for epilepsy (16). Moreover, this may affect patient’s adherence to antiepileptic treatment and overall control of epilepsy. Addressing such concerns during adherence counselling will help mitigate the negative impact of perceived stigma on clinical factors.

Presence of epilepsy related injuries was significantly linked to stigma in the study. This was a relation to similar conclusions in a cross-sectional study done by Fanta et al in Ethiopia in 2013 on 347 patients where they found injuries related to stigma and deformities were significantly associated with high levels of stigma(16). Kirabira et al in a cross-sectional study done in South Western Uganda in 2017 found a high correlation between injuries related to seizure and perceived stigma(17). Baker et al, in a study done in 15 European countries in 1997 on 5211 patients reported significant association between perceived stigma and seizure related injuries (33) .This could be because injuries could expose their condition further enhacning stigma such as enacted stigma. Further, epilepsy-related injuries may also be attributed to untreated or inadequately treated epilepsy. Many obstacles to treatment access exist for epilepsy in Kenya. This may range from intermittent availability of medications in health centers, inability to pay for medications and limited health care providers with the expertise to diagnose and treat epilepsy. This delays accesses to treatment and increases the risk of physical injuries. These findings indicate the necessity to incorporate measures that will reduce these barriers and help improve management of epilepsy.

Age of first seizure, duration of epilepsy and Seizure type were not linked to perceived stigma. Majority of our participants had epilepsy for over 10 years and may have developed coping strategies on how to manoeuvre stigma.

Misconceptions and negative beliefs about epilepsy have been associated with high levels of perceived stigma. Using the KEBAS and EPKQ scoring systems, the participants were noted to have good knowledge, attitudes and beliefs about epilepsy. Educating patients on epilepsy improves their coping strategies and overall attitude thereby reducing the feeling of stigmatization. KAWE clinics offer continuous awareness programs on epilepsy by trained nurses on clinic days that aim at dispelling superstitions and misunderstandings such as contagious beliefs on the disease. This could have contributed to the low level of perceived stigma reported. Atadzhanov et al in a cross-sectional study done in Zambia in 2005 found contagious beliefs from communities and community disclosure were related with perceived stigma(50).A study in Ethiopia by Fanta et al in 2013 found contagious beliefs about epilepsy are significantly linked to high levels of perceived stigma(16).

The multivariate analysis, occupation status and seizure control were not highly linked to perceived stigma.

5.2 Conclusion

In this study, perceived stigma prevalence among PLWE was high. Factors significantly associated with perceived sigma were difficulty in taking antiepileptic medication, difficulty attending follow-up clinics and injuries during seizures.

5.3 Limitation

This study strongly angled on the ability of an individual to remember their experiences. This may lead to recall bias which might have impacted on the outcomes of the study.

5.4 Recommendation

There is a need for development of programs to reduce the burden of perceived stigma in patients with epilepsy.

Further studies may build on this study to look into urban and rural impact on stigma and evaluation of the differences in perceived stigma.

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APPENDICES

Appendix I: Patient Consent Explanation Form (English)

Introduction

My name is Dr Nyabuti Winnie Gesare. I am a qualified doctor, registered by the Kenya Medical Practitioners and Dentists Board. I am currently pursuing a Master's 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 experience perceived stigma and what are the factors associated with it. 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 40-60 minutes. The study will include answering to a study proforma. Information to collect includes your demographic data, clinical data, stigma level and your knowledge, attitudes and practices 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. 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. Information gathered will be documented and analyzed anonymously.

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

Principal Investigator:

Dr. Nyabuti Winnie Gesare,
University of Nairobi,
Department of Clinical Medicine and Theraputics,
Mobile: 0713-653820.

Supervisors:

Dr. Thomas Kwasa
Consultant Physician and N Dr

Department of Clinical Medicine & Therapeutics
University of Nairobi

Prof. Erastus Amayo.
Professor of medicine
M.B.CH. B, M.MED, FRCP, FAAN
Department of Clinical Medicine & Therapeutics
University of Nairobi

Dr. Osman Miyanji
Consultant Paediatrician and Paediatric Neurologist
MB.CH.B(Mak), M.MED(Paed)(Nbi), D.P.N.P(Vienna)
Chairman-Board of Directors (KAWE)

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 II: Consent Form (English)

Study No…………………………Date…………………Time…………

I hereby give my written and informed consent to allow myself or my………………………

participate in this study on "**THE PREVALENCE OF PERCEIVED STIGMA IN PATIENTS LIVING WITH EPILEPSY IN LOW INCOME DENSELY POPULATED COMMUNITIES IN NAIROBI"**

I have been adequately explained to about the study by Dr. Nyabuti Winnie Gesare /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.

Signature…………………………… Date…………………………….

For any further clarification, you may contact

Dr. Nyabuti Winnie Gesare, at Tel No: 0713-653820.

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) of University of Nairobi and the Kenyatta National Hospital.

Appendix III: Assent form (Patients below 18 years of age)

I, (parent/guardian) ……………………...of…………………hereby give consent my child/relative to participate in this study. I have been adequately informed that my son/daughter is being recruited in a study to find out The prevalence of perceived stigma and factors associated with it. 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: …………………………………………………………………………………

Appendix IV: Patient Consent Explanation Form (Kiswahili)

Kiambatisho 1- Fomu Inayoeleza Idhini

Utangulizi

Mimi ni Dkt. Nyabuti Winnie Gesare, kutoka Chuo Kikuu cha Nairobi. Kwasa sana somea uzamili katika Tiba ya Ndani. Kama sehemu ya masomo yangu yauzamifu,nahitajika kufanya mradi wautafiti.Ninafanya uchunguzi kuhusu Kifafa katika mtaa wa Viwandani na Korogocho.

Taratibu zitakazo husishwa

Upimio huu utachukua takribani dakika 30-40.Utafiti huu utahusisha kuangalia maagizo ya daktari na kujibu maswali katika fomu. Habari zitakazo kusanywa zitahusu data kuhusu hali yako,dawa ambazo unatumia kwa sasa,matumizi ya njia ya kupanga uzazi na ufahamu wa maswala ya Wanawake walio na kifafa.

Haki yako kama mshiriki katika utafiti huu

Ushiriki wako kati kauta fiti huu ni wa kujitolea. Hata ukichagua kushiriki au ukatae kushiriki haita athiri matibabu yako. Unauhuru wa kujiondoa katika mahojiano na katika utafiti huu wakati wowote. Unauhuru wa kuuliza maswali kabla ya kutia sahihi katika fomu ya idhini na wakati wa utafiti. Maswala yote yatahifadhiwa kwa siri wakati wote.

Hasara za ushiriki

Hakuna hasara yoyote utakayo pitia au kupata.

Manufaa ya kushiriki

Mwishoni mwa utafiti huu, nitawasilisha matokeo ya utafiti katika idaraya Tiba ya Ndani katika Chuo Kikuu cha Nairobi. Habari zozote muhimu zitakazotokana na utafiti naambazo zitafanya malezi kuwa bora, walezi watafahamishwa ilihatua mwafaka ichukuliwe.

Siri

Habari zote zitakazo kusanywa wakati wa utafiti zitahifadhiwa kwa siri.Ni watafiti pekee ndio wanaoweza kufikia Habari zakibinafsi.Habari zitakazo kusanywa zitaandikwa na kuainishwa bila kutajawashiriki.

Ikiwa unaswali lolote wakati wa utafiti, unaweza kuwasiliana na wafuatao:

Mtafiti Mkuu:

Dkt. Nyabuti Winnie Gesare,
Chuo Kikuu Cha Nairobi,
Idara ya Mafundisho ya Udaktari na Matibabu ya Magonjwa,
Simu 0713 653 820.

Wasimamizi:

Dr. Thomas Kwasa
Consultant Physician and Neurologist
MB.CH.B, M.MED
Department of Clinical Medicine & Therapeutics
University of Nairobi

Prof. Erastus Amayo.
Professor of medicine
M.B.CH. B, M.MED, FRCP, FAAN
Department of Clinical Medicine & Therapeutics
University of Nairobi

Dr. Osman Miyanji
Consultant Paediatrician and Paediatric Neurologist
MB.CH.B(Mak), M.MED(Paed)(Nbi), D.P.N.P(Vienna)
Chairman-Board of Directors (KAWE)

Mwenyekiti, KNH/UON Kamati Inayoshughulikia Maadili, Nambari ya simu: 020-2726300/0722829500/0733606400/EXT 44102. P.O. Box 20723,Nairobi.

Kabla sijakuhusisha katika utafiti wangu, Naomba utie sahihi katika fomu ya idhini iliyopo hapo chini. Fomu hii ya idhini haitahusishwa na majibu yako

Appendix V: Consent Form (Kiswahili)

Kiambatisho : Fomu Ya Idhini /Kubali- Wagonjwa

Nambari ya Uchunguzi………………Tarehe…………………Wakati…………

Natoa idhini andishi na ninayoifahamu ili kuniruhusu au ……………………… wangu kushiriki katika utafiti huu kuhusu Kifafa, katika Viwandani na korogosho.

Nimepewa maelezo yanayofaa kuhusu utafiti wa Dkt. Nyabuti Winnie Gesare /msaidizi wake. Ninafanya hivi kwa vile naelewa lengo kuu la utafiti huu nataratibu zitakazo husishwa kama vile kuangaliwa kwa maagizo ya daktarin na kujibu maswali katika fomu ambayo nimepewa maelezo yake. Ninaelewa kuwa haki zangu zitaheshimiwa, na suala la kuhifadhi utambuzi wangu utadumishwa wakati wote. Pia ninaelewa kuwa idhini ya kushiriki niyakujitolea, na ninauhuru wakujiondoa katika utafiti huu bila malezi yangu kuathiriwa.

Sahihi ya Mgonjwa……………………………………..

Jina la Mgonjwa………………………………………………

Kauli Ya Mchunguzi:

Mimi, Mchunguzi Mkuu, nimemuelimisha mshiriki wa utafiti kuhusu lengo kuu la utafiti na kinachodokezwa na utafiti huu.

Sihihi……………………………		Tarehe……………………………..

Appendix VI: Study Proforma

Section A

General Information:

Study Number…………..… Date:…………….. Contact (Tel No): ……………

Date of Birth…………………………….. Age in years: …………………………….

Section A: Social-Demographic Data (Tick Where Appropriate)

1. Gender

(1) Male ☐

(2) Female ☐

2. Marital Status

(1) single ☐

(2) Married ☐

(3) Separated ☐

(4) Divorced ☐

(5) Widowed ☐

3. Religion:

(1) Christian ☐

(2) Islam ☐

(3) Other ☐

4. Level of Education

(1) No formal education ☐

(2) Primary ☐

(3) Secondary ☐

(4) College/University ☐

5. Occupation Status

(1) Unemployed ☐

(2) Formally employed ☐

(3) Informal sector...e.g. Jua Kali, hawker ☐

(4) Self –employed ☐

(5) Student ☐

Section B: Clinical Factors

6. 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 ☐

7. Number of seizures in the last three months

(1) Yes ☐
(2) No ☐

8. Frequency of seizures in the last three months

(1) <6times/3months ☐
(2) >6times/3 months ☐

Section C: Current Medications (Obtain Information from Prescription)

9. Have you been prescribed AED's

1) Yes ☐
2) No ☐

10. If yes, are you having difficulty in taking AEDs daily because of fear of stigma?

(1) Yes ☐
(2) No ☐

11. Difficulty in attending follow-up because of fear of stigma

(1) Yes ☐
(2) No ☐

12. Injuries during seizure

(1) Yes ☐
(2) No ☐

Appendix VII: Kilifi Stigma Scale (Kiswahili)

Question	Response	Code
Magonjwa /hali tofauti huathiri maisha ya watu katika njia moja hadi njingine. Kwa sababu ya Kifafa:		
1. Unahisi tofauti na watu wengine?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
2. Unahisi kuwa mpweke?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
3. Unahisi aibu?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
4. Unahisi hujaweza kupata ulichotarajia?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
5. Unahisi huwezi kuwa na maisha ya kuridhisha?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
6. Unahisi huwezi kuchangia chochote katika jamii?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
7. Unahisi huwezi kujumuika na wengine hadharani?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
8. Unahisi watu wengine hawana raha kukaa pamoja nawe?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
9. Unahisi watu wengine hawangependa kuandamana nawe kwenye sherehe?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
10. Unahisi watu wengine wanakudhalilisha/kukudunisha?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
11. Unahisi watu wengine wangependa kukuepuka?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
12. Unahisi watu wengine wangependa kuepuka kusalimiana nawe?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
13. Unahisi huhusiani/huelewani vizuri na watu wa familia yako?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
14. Unahisi hukubaliwi na marika yako?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
15. Unahisi unatendewa vibaya na watu wengine?	1. Kila wakati 2. Mara nyingine	[ ]

	3. Hapana	
16. Unahisi watu wengine wanakutenga?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
17. Unahisi watu wanathamini maoni yako?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
18. Unahisi watu wanakuchukulia kama mtu asiyetakiwa?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
19. Wewe huwaambia watu wengine kwamba una kifafa?	1.Ndio 0. La	[ ]
20. Wewe huepuka kuongea na watu wengine kuhusu hali yako?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
21. Wewe hujumuika na watu wengine walio na kifafa?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
22. Watu wengine hufikiri kuwa ni muhimu kuongea na watu wengine walio na kifafa. Je hili ni muhimu kwako kwa kiwango gani?	1. Muhimu sana 2. Muhimu 3. Muhimi kiasi 4. Si muhimi Kabisa	[ ]
23. Katika jamii yako, watu wenye kifafa huchukuliwa vizuri, sawa au vibaya kuliko wale walio na hali nyingine?	1. Huchukuliwa vizuri 2. Huchukuliwa sawa 3. Huchukuliwa vibaya 4. Sina uhakika	[ ]
24. Katika jamii yako, mwanamke aliye na kifafa huchukuliwa vizuri, sawa au vibaya kuliko mwanaume aliye na kifafa?	1. Wanaume huchukuliwa vizuri kuliko wanawake 2. Wanaume huachukuliwa sawa na wanawake 3. wanawake huchukiliwa vibaya kuliko wanaume 4. Wote huchukuliwa sawa 5. Sina uhakika	[ ]
Wakati mwingine watu wanajiapta kuwa waathiriwa wa hali na kujipata katika hali bila msaada. Ukijifikiria wewe mwenyewe:		
25. Umeshawahi kunyanyaswa au kupigwa na mtu yeyote?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]
26. Umewahi kunyanyaswa kijinsia?	1. Kila wakati 2. Mara nyingine 3. Hapana	[ ]

27. Ukifikiria maswali tuliyojadili, unaweza kunieleza vile ilivyo kuishi na kifafa?

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

………………………………………………………………………………………….

28. Unahisi vipi ukiwa na watu wengine?

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

29. Unahisi kuwa watu walio na kifafa wanapewa nafasi sawa katika maisha (kwa mfano ajira, ndoa, shule) ?

…………………………………………………………………………………………

…………………………………………………………………………………………

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30. Jamii yako inafikiria vipi kuhusu watu walio na kifafa?

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

………………………………………………………………………………………….

31. Dini yako inafikiria vipi kuhusu watu walio na kifafa?

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Appendix VIII: Kilifi Stigma Scale (English)

Question	Response	Code
Different diseases impact on people's lives in one way or another. Because of epilepsy:		
1. Do you feel different from other people?	1. Always 2. Sometimes 3. Not at all	[ ]
2. Do you feel lonely?	1. Always 2. Sometimes 3. Not at all	[ ]
3. Do you feel embarrassed?	1. Always 2. Sometimes 3. Not at all	[ ]
4. Do you feel disappointed in yourself?	1. Always 2. Sometimes 3. Not at all	[ ]
5. Do you feel you cannot have a rewarding life?	1. Always 2. Sometimes 3. Not at all	[ ]
6. Do you feel you cannot contribute anything in Society?	1. Always 2. Sometimes 3. Not at all	[ ]
7. Do you feel you cannot join others in public places?	1. Always 2. Sometimes 3. Not at all	[ ]
8. Do you feel other people are uncomfortable with you?	1. Always 2. Sometimes 3. Not at all	[ ]
9. Do you feel other people would not want to go to occasions with you?	1. Always 2. Sometimes 3. Not at all	[ ]
10. Do you feel other people treat you like an inferior person?	1. Always 2. Sometimes 3. Not at all	[ ]
11. Do you feel other people would prefer to avoid you?	1. Always 2. Sometimes 3. Not at all	[ ]
12. Do you feel other people would avoid to exchange greetings with you?	1. Always 2. Sometimes 3. Not at all	[ ]
13. Do you feel you do not relate well with family members?	1. Always 2. Sometimes 3. Not at all	[ ]
14. Do you feel you are not accepted by your peers?	1. Always 2. Sometimes 3. Not at all	[ ]
15. Do you feel you are mistreated by other people?	1. Always 2. Sometimes 3. Not at all	[ ]

16. Do you feel other people discriminate against you?	1. Always 2. Sometimes 3. Not at all	[ ]
17. Do you feel people take you seriously?	1. Always 2. Sometimes 3. Not at all	[ ]
18. Do you feel other people treat you like an outcast?	1. Always 2. Sometimes 3. Not at all	[ ]
19. Do you tell other people you have epilepsy?	1.Yes 0. No	[ ]
20. Do you avoid talking to other people about your condition?	1. Always 2. Sometimes 3. Not at all	[ ]
21. Do you spend time with other people with epilepsy?	1. Always 2. Sometimes 3. Not at all	[ ]
22. Some people think that it is important to talk to other people with epilepsy. How important is it to you?	1. Extremely important 2. Important 3. Somewhat important 4. Not important at all	[ ]
23. In your community, are people with epilepsy treated better, the same, or worse than those who have other conditions?	1. Treated better 2. Treated same 3. Treated worse 4. Don’t know/not sure	[ ]
24. In your community is a female with epilepsy treated better, the same, or worse than a male with epilepsy?	1. Female treated better than male 2. Female treated same as male 3. Female treated worse than male 4. All treated the same 5. Don’t know/not sure	[ ]
Sometimes people fall victim of circumstances and find themselves in a helpless situation. Thinking about yourself:		
25. Have you ever been abused or beaten by anybody?	1. Always 2. Sometimes 3. Not at all	[ ]
26. Have u ever been sexually harassed?	1. Always 2. Sometimes 3. Not at all	[ ]

27. Thinking about some of the questions we have discussed, can you tell me what it is like to live with epilepsy?

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28. How do you feel while in the company of other people?

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29. Do you feel people with epilepsy are given equal opportunities in life (e.g in terms of employment, marriage, school)

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30. What does your community think about people with epilepsy?

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31. What does your religion think about people with epilepsy?

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Appendix IX: 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	YES	NO
34	Put patient on their side		
35	Put patient on their back		
36	Put something in the patients mouth		
37	Prayer		
38	Pour Water on patient		

Appendix X: Kilifi Epilepsy Beliefs and Attitude Scale

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 loses 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.

Hadithi hii inahusu Bahati. Bahati ana kifafa, na huwa anafitika mara moja kwa wiki. Siku 1-2 kabla ya kufitika tabia yake inabadilika. Anaweza kuwa mtukutu wakati mwingine anaweza kumtenga au anaweza kuonekana kuwa na usingizi na anataka kulala. Macho yake yanaweza kuwa mekundu na pia anaweza kulalamika maumivu ya kichwa. Kabla tu ya kufitika anaweza kuhisi moyo wake umepiga kibao na huhisi kuchanganyika(hisia unazoweza kuwa nazo wakati utapoona ghafla jambo la kutisha na lisilotarajiwa- mfano wa maiti). Yeye huanguka chini na kupoteza fahamu, huanza kutikiswa kwa miguu yote 4 huku macho kama yanazunguka juu, ikipinduka pande au wazi kabisa, huuma ulimi na povu kwa takriban dakika 3 kisha yeye hujikojolea na harakati za kuteleza au kufitika zinasimama. Yeye hubaki na fahamu kwa dakika chache kisha huamka akiwa na usingizi na kwenda kulala.

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.

Maximum score [150]

Total score [ ]

Percentage score [ ]

Appendix XI: Epilepsy Beliefs and Attitudes Scale (EBAS)

		Kabisa Amini	Amini kidogo	Hapana kabisa	Sijui	Alama
Causes						
1. I believe that epilepsy can be inherited/be caused by family ancestors **(INHERIT) . Ninaamini kifafa kinaweza kurithiwa / kusababishwa na mababu wa familia (INHERIT)**		3	2	1	0	
2. I believe that a person like Bahati can have epilepsy because he has been bewitched **(BEWITCH) Ninaamini kuwa mtu kama Bahati anaweza kuwa na kifafa kwa sababu amerogwa (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)** . **Ninaamini kuwa jua linapochoma ubongo wa mtu kama Bahati, inaweza kusababisha kifafa**	**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) Ninaamini kuwa mtu kama Bahati ana jeraha la kichwa / akiangukia kichwa kunaweza kusababisha kifafa**		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) Ninaamini kuwa jeraha wakati wa kuzaa linaweza kusababisha mtu kama Bahati kuwa na kifafa (kwa mfano kua na uchungu wa kuzaa kwa muda mrefu)**		3	2	1	0	
6. I believe that when a person takes anti-convulsant medication when not epileptic can result to having the disease **(AEDS)** **Ninaamini kwamba wakati mtu anatumiadawa ya kupunguza kufitika-ikiwa hana kiafafa inaweza kusababisha kuwa na ugonjwa (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)** **Ninaamini kuwa ugonjwa mbaya (kama ugonjwa wa malaria) unaoathiri ubongo wa mtu kama Bahati unaweza kusababisha kifafa(MALARIA**		3	2	1	0	
8. I believe that when a mother uses FPs before conception can make a child like Bahati have epilepsy when born **(FPs)** **Ninaamini kuwa wakati mama hutumia huduma za kupanga uzazi kabla ya kufunga mimba inaweza kumfanya mtoto**	**R**	1	2	3	0	

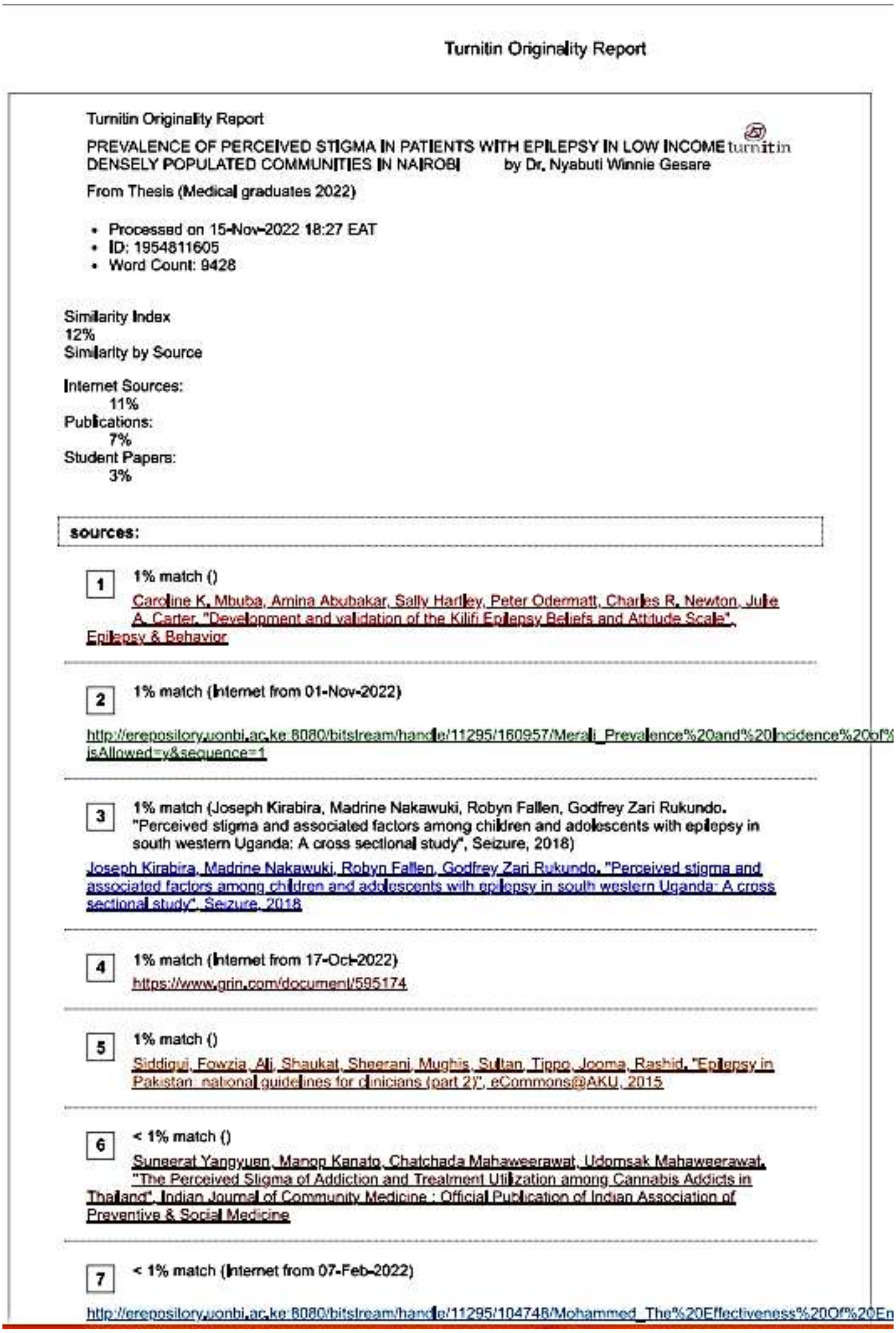
		Kabisa Amini	Amini kidogo	Hapana kabisa	Sijui	Alama
kama Bahati kuwa na kifafa wakati wa kuzaliwa						
9. I believe that when one comes into contact with urine of a fitting person like Bahati can be infected with epilepsy **(URINE)** **Ninaamini kwamba mtu anapogusana na mkojo wa mtu anayefitika kama Bahati anaweza kuambukizwa kifafa**	**R**	1	2	3	0	
10. I believe that after a child like Bahati was born and his faeces did not clear then it may result to epilepsy **(FAECES)** **Ninaamini kuwa baada ya mtoto kama Bahati kuzaliwa na kinyesi hakikusafishwa au kuondolewa basi inaweza kusababisha kifafa**	**R**	1	2	3	0	
11. I believe that a person like Bahati can have epilepsy because part of his brain is damaged **(BRAIN) Ninaamini kuwa mtu kama Bahati anaweza kuwa na kifafa kwa sababu sehemu ya ubongo wake imeharibiwa**		3	2	1	0	
TREATMENT						
12. I believe it is possible to treat a person like Bahati **(TREAT) .** **Ninaamini inawezekana kutibu mtu kama Bahati**		3	2	1	0	
13. I believe that if a person like Bahati is burned, he will never get healed from epilepsy **(BURN)** . **Ninaamini kwamba mtu kama Bahati akichomeka na moto, hatapona kamwe kutoka kwa kifafa**	**R**	1	2	3	0	
14. I believe that nyuni/nyago is treatable but vitsala isn’t **(TNYUNI)** . **Ninaamini kwamba nyuni / nyago inatibika lakini vitsala haitibiki**	**R**	1	2	3	0	
15. I believe that a person like Bahati has to take drugs continuously for them to work **(DRUGS)** **Ninaamini kuwa mtu kama Bahati lazima ameze dawa ndio aweze kufanya kazi**		3	2	1	0	
16. I believe that vitsala is better treated by a mganga than a doctor **(MVITSALA)** **Ninaamini kwamba vitsala inatibiwa bora na mganga kuliko daktari**	**R**	1	2	3	0	
17. I believe there are drugs available that can treat epilepsy **(ADRUGS)** **Ninaamini kuna dawa zinapatikana ambazo zinaweza kutibu kifafa**		3	2	1	0	

18. I believe that pouring water to a person like Bahati when fitting helps treat epilepsy **(WATER)** . **Ninaamini kuwa kumwagia maji kwa mtu kama Bahati wakati anafitika husaidia kutibu kifafa**	**R**	1	2	3	0	
19. I believe that the best person to treat nyuni /nyago is a medical doctor **(DNYUNI) .** **Ninaamini kuwa mtu bora wa kutibu nyuni / nyago ni daktari**		3	2	1	0	
20. I believe smearing rob/paraffin on the body of a person like Bahati when fitting helps treat epilepsy **(PARAFFIN)** **Ninaamini kupaka / mafuta ya taa kwenye mwili wa mtu kama Bahati wakati anafitika husaidia kutibu kifafa**	**R**	1	2	3	0	
21. I believe that epilepsy in a person like Bahati can be treated through fumigation **(FUMIG)**. **Ninaamini kwamba kifafa katika mtu kama Bahati kinaweza kutibiwa kupitia mafusho**	**R**	1	2	3	0	
22. I believe that some types of fits are not suitable for hospital treatment **(HFITS)** **Ninaamini kuwa aina zingine za kufitika hazifai kwa matibabu hospitalini**	**R**	1	2	3	0	
23. I believe that during a fit, it is good to put a stick between the person's teeth to prevent biting one self **(STICK) Ninaamini kuwa wakati wa kifitika, ni vizuri kuweka kijiti kati ya meno ya mtu kuzuia kujiuma mwenyewe**	**R**	1	2	3	0	
24. I believe that during a fit, it is good to straighten the joints of a person like Bahati **(JOINTS).** **Ninaamini kuwa wakati wa kifafa, ni vizuri kunyoosha viungo vya mtu kama Bahati**	**R**	1	2	3	0	
25. I believe that during a fit, it is good to put a person like Bahati in a safe place **(SAFE) .** **Ninaamini kuwa wakati wa kifafa, ni vizuri kumweka mtu kama Bahati mahali salama**		3	2	1	0	
26. I believe that drugs (from hospital) can control seizures **(CDRUGS) .** **Ninaamini kuwa dawa (kutoka hospitali) zinaweza kudhibiti kufitika**		3	2	1	0	
27. I believe that nyuni/ nyago is better treated by a mganga than a medical doctor **(MNYUNI)** . **Ninaamini kuwa nyuni / nyago ni bora kutibiwa na mganga kuliko daktari**	**R**	1	2	3	0	

28. I believe a person like Bahati should only take drugs when he is having a fit **(FITAEDS) .** **Ninaamini mtu kama Bahati anapaswa kutumia tu dawa za kfitika wakati tu ule anafatikia**	**R**	1	2	3	0	
29. I believe that if a person like Bahati misses drugs he/she may fit again **(MISSAEDS) .** **Ninaamini kuwa ikiwa mtu kama Bahati atakosa kutumia madawa anaweza kufitika tena**		3	2	1	0	
30. I believe that the best person to treat vitsala is a medical doctor **(DVITSALA)** **Ninaamini kuwa mtu bora wa kutibu vitsala ni daktari**		3	2	1	0	
31. I believe that drugs for epilepsy can cause side effects such as drowsiness or hyperactivity to a person like Bahati **(SEFFECTS) .** **Ninaamini kuwa dawa za kifafa zinaweza kusababisha athari kama vile kukosa usingizi au kuhangaika au kuwa juu juu kwa mtu kama Bahati**		3	2	1	0	
PREVENTION						
32. I believe that preventing serious diseases like malaria will reduce the number of people with epilepsy **(PDISEASE)** **Ninaamini kwamba kuzuia magonjwa makubwa kama ugonjwa wa malaria kutapunguza idadi ya watu wenye kifafa**		3	2	1	0	
33. I believe that proper medical care during pregnancy and delivery will reduce the number of people with epilepsy **Ninaamini kuwa huduma sahihi ya matibabu wakati wa uja uzito na kujifungua itapunguza idadi ya watu walio na kifafa (PREG)**		3	2	1	0	
Living with epilepsy						
34. There is a belief that people like Bahati cannot marry, what do you think? **(MARRY)** . **Kuna imani kwamba watu kama Bahati hawawezi kuoa/kuolewa, unafikiria kivipi?**	**R**	1	2	3	0	
35. I believe that people like Bahati cannot climb trees or work high up **(TREES)**. **Ninaamini kuwa watu kama Bahati hawawezi kupanda miti au kufanya kazi mahali iko juu**	**R**	1	2	3	0	

36. I believe that children like Bahati cannot go to school **(SCHOOL)** **Ninaamini kuwa watoto kama Bahati hawawezi kwenda shule**	**R**	1	2	3	0	
37. I believe that people like Bahati cannot have a job **(JOB)** **Ninaamini kuwa watu kama Bahati hawawezi kupata kazi**	**R**	1	2	3	0	
38. I believe that people like Bahati cannot do risky jobs (like driving/running machinery) **(DRIVE)**. **Ninaamini kuwa watu kama Bahati hawawezi kufanya kazi hatari (kama mashine ya kuendesha / kuendesha mashine)**		3	2	1	0	
39. I believe that people like Bahati can lead a normal life like other people **(NLIFE)** **Ninaamini kuwa watu kama Bahati wanaweza kuishi maisha ya kawaida kama watu wengine**		3	2	1	0	
40. I believe that people like Bahati should avoid being near fires **(FIRE)** **Ninaamini kuwa watu kama Bahati wanapaswa kujizuia kuwa karibu na moto**		3	2	1	0	
41. I believe that people like Bahati should avoid being near waters (like sea, lake or river water) **(SEA) .** **Ninaamini kuwa watu kama Bahati wanapaswa kuzuia kuwa karibu na maji (kama bahari, ziwa au maji ya mto)**		3	2	1	0	
42. There is a belief that people like Bahati should be kept in isolation, what do you think? **(ISOLATE) .** **Kuna imani kwamba watu kama Bahati wanapaswa kuwekwa peke yao, unafikiariaje?**	**R**	1	2	3	0	
43. There is a belief that people like Bahati should be rejected, what do you think? **(REJECT)** . **Kuna imani kwamba watu kama Bahati wanapaswa kukataliwa, unafikiriaje?**	**R**	1	2	3	0	
44. I believe that parents feel resentful towards their children like Bahati because he/she has epilepsy **(RECENT) .** **Ninaamini kuwa wazazi huhisi uchungu kwa watoto wao kama Bahati kwa sababu ana kifafa**		3	2	1	0	
45. There is a belief that people like Bahati are burdens to their parents, what do you think? **(BURDEN)** .	**R**	1	2	3	0	

Kuna imani kwamba watu kama Bahati ni mzigo kwa wazazi wao, unafikiriaje?						
The effect of epilepsy on development						
46. I believe that continued seizures can damage the brain of a person like Bahati **(DAMAGE).** **Ninaamini kuwa kuendelea kufitika/kuanguka kunaweza kuharibu ubongo wa mtu kama Bahati**		3	2	1	0	
47. I believe that epilepsy can affect the development and behaviour of a person like Bahati **(DEVELOP) . Ninaamini kifafa kinaweza kuathiri kukua na tabia ya mtu kama Bahati**		3	2	1	0	
48. I believe that a child like Bahati often performs poorly in school **(PSCH) .** **Ninaamini kuwa mtoto kama Bahati mara nyingi hupata matokeo duni shuleni**	**R**	1	2	3	0	
49. I believe that people like Bahati are dull **(DULL) Ninaamini kuwa watu kama Bahati sio werevu**	**R**	1	2	3		
50. I believe that people like Bahati are mad **(MAD Ninaamini kuwa watu kama Bahati ni wazimu**	**R**	1	2	3		



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