QUALITY OF LIFE AMONG PATIENTS WITH EPILEPSY ATTENDING THE NEUROLOGY CLINIC AT KENYATTA NATIONAL HOSPITAL, NAIROBI, KENYA: A COMPARATIVE STUDY.

A DISSERTATION IN PART FULFILMENT OF
THE REQUIREMENTS FOR THE AWARD OF
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NAIROBI.

BY

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DECLARATION

I, Dr. W.D.C Kinyanjui, do hereby declare that this is my original work carried out in part-fulfillment of the requirements for the award of the Degree of Master of Medicine in Psychiatry (MMed. Psych.) of the University of Nairobi, and that I have not presented the same for the award of any other degree or to any other University.

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SUPERVISORS APPROVAL

This dissertation has been submitted for examination with our approval as the University supervisors.

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DEDICATION

For the late Fr. Ndirangu Kinyanjui

'....We are only instruments being played by the master musician,
God the Almighty...."

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ABBREVIATIONS

AEDS	Antiepileptic Drugs
BRFSS	Behavioural Risk Factor Surveillance System
DSM IV - TR -	Diagnostic and Statistical Manual. Fourth Edition.
GTCS	Generalized Tonic Clonic Seizures
HRQOL	Health Related Quality of Life
IBE	International Bureau for Epilepsy
ILAE	International League Against Epilepsy
KAWE	Kenya Association for the Welfare of people living with Epilepsy.
KNH	Kenyatta National Hospital
PLWE	People living with Epilepsy
QOL	Quality of Life
TLE	Temporal Lobe Epilepsy
UON	University of Nairobi
USA	United States of America
WHO	World Health Organisation
WHOQOL -	World Health Organisation Quality of Life

1.0 ABSTRACT

Introduction-. The International League Against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE), together with the World Health Organization (WHO) launched in June 1997 the global campaign against epilepsy (1). The major objective of this campaign is to bring epilepsy "out of the shadows" by improving the diagnosis, treatment, prevention and social acceptability of this worldwide disorder and especially in developing countries. It also aspires to eliminate barriers to a better quality of life with reduction of the treatment gap in those with the disease (2).

Objective: This study explores the subjective evaluation in a cultural, social environmental and even physical context of the perceived quality of life of people living with epilepsy (PLWE) in our nation. It does not provide a means of measuring in a detailed fashion, symptoms, diseases or conditions, but rather the effects of epilepsy, socio-demographic variables and health interventions on quality of life. It also aspires to make evidence-based recommendations with the aim of ultimately improving the quality of life of people with this prejudiced disease.

Methodology: The study design is a cross-sectional descriptive survey of a comparative nature with a sample size of 300 respondents, 150 PLWE and 150 controls, attending the neurology clinic at KNH in Nairobi, Kenya. It began in October 2006 and data was collected over a period of five months, using standardized World Health Organisation Quality of Life-BREF26 (WHOQOL-BREF), seizure burden and characteristics, treatment profile, and socio-demographic questionnaires. Comparison to the DSM IV-TR Global Assessment of Functioning (GAF) was done and cognitive impairment as per the MMSE applied as one of the exclusion criteria.

Results: The study population consisted of 300 subjects, 150 PLWE and 150 NCs accompanying them to the neurology clinic at KNH. In the sample there was no significant ($p > 0.05$) difference in age of the respondents, their religion, area of residence, household size, children had and gender between the two groups. They however differed significantly in other socio-demographic variables: the PLWE showed lower level of education ($p < 0.001$), lower annual income ($p < 0.001$), lower MMSE scores ($p < 0.001$), with most of them unemployed ($p < 0.001$), having unskilled employment ($p = 0.041$) or not married ($p < 0.001$), as compared with the NCs. The mean QOL among PLWE(49.90%) at KNH was significantly($p < 0.01$) lower than that of the NCs(77.60%) accompanying them and significantly impaired as compared to the hypothesized mean of 75+ 2.5%.Factors significantly associated with impairment of QOL among PLWE were lower level of education($p < 0.001$), higher seizure burden($p < 0.001$), lower annual income($p = 0.007$), unemployment($p = 0.004$), unskilled employment($p < 0.001$), living in a rural residence($p = 0.009$), those citing financial difficulties as the reason for non-compliance($p = 0.037$) and in those blaming their illness(epilepsy) as the cause of their unemployment($p < 0.001$).

Conclusions and Recommendations: The mean QOL among PLWE (49.90%) attending the neurology clinic at KNH was significantly lower than that of the NCs accompanying them and significantly impaired as per the hypothesized mean of 75+2.5%.It was therefore recommended that there be established a comprehensive epilepsy management strategy program with the objective of empowering the PLWE through socio-occupational skills training and other alternative forms of training to improve their socio-economic needs. Additionally early psycho-education, de-stigmatization through mass-media, advocacy of routine assessment using the GAF scale, improving their classroom environment, as well as facilitation of further studies among those with chronic disabling illness, including epilepsy, was recommended.

2.0 INTRODUCTION

2.1 BACKGROUND

Myths about epilepsy have been with us for thousands of years but the understanding of the condition did not begin to take root until the 18th and 19th century A.D. "Epilepsy" is a Greek word and means to be taken, seized or attacked (3).

In ancient Indian medicine basic concepts surrounding epilepsy were developed during the Vedic period of 4500-1500 BC. The Ayurvedic literature of Charaka Samhita contains abundant references to all aspects of epilepsy including symptomatology, aetiology, diagnosis and treatment. They described epilepsy as "apasmara" meaning "loss of consciousness" (4).

Ancient Babylonians wrote about the symptoms and causes of epilepsy 3,000 years ago, they thought seizures were caused by demons attacking the person; with different spirits causing different kinds of seizures. A detailed account of epilepsy is on a Babylonian tablet in the British Museum in London (4).

The ancient Greeks believed a cure for epilepsy was eating mistletoe that was picked without using a Sickle, at the time the moon was smallest in the sky; offending the Greek moon goddess (Selene) was thought to result in epilepsy and hence the notion of "Seleniazetai" or "Lunatic" (the Latinized version). However Hippocrates, the father of medicine, disagreed and believed epilepsy was not sacred but a disorder of the brain (5).

Ancient Romans believed epilepsy came from demons and was contagious (by touching and being breathed-on) resulting in segregation and isolation of epileptics. Only during the reign of Emperor Julius Caesar and Petrarch were PLWE thought to be very smart. Other successful and famous PLWE in history include Czar Peter the Great of Russia, Pope Pius IX, the Poet Lord Byron and writer Fedor Dostoevsky (4).

In the Middle Ages in Europe the "three wise men" and St. Valentine were particularly important patrons of PLWE. A special blessed ring was thought to help control and cure seizures as was used by George Washington's daughter Patsy in colonial America. Throughout this time PLWE were viewed with fear, suspicion and misunderstanding and subjected to enormous social stigma, treated as outcasts and even punished. From the late 1600's people with the disorder were locked up in mental asylums but separate from the "mentally-ill" since epilepsy was thought to be contagious (4, 5).

Spiritual healing is common in Nigeria and epilepsy is thought to be related to a visitation by the devil, to witchcraft or to spirits. Belief of the Bini of Nigeria is that epilepsy is a disease where the heart gets blocked by foam, restricting circulation and resulting in a seizure. Treatment includes thrusting the patients' limbs into a fire, rubbing pepper into their eyes and face, and making an unconscious person drink cows' urine (6).

In Cameroon epilepsy is known as "nwaa" (to throw a person on the ground or saturation of the foams in the stomach which overflow and rise to the head, resulting in a seizure), treatment was a special diet assigned to control the foam being produced in the stomach. The Malawians induced emesis using a mixture of roots to rid the stomach of a moving insect thought to cause epilepsy. "Sifosekuwa" (falling disease) or "Sitfuluwane" (lizard movement) is the name given to epilepsy in Swaziland and treatment involved exorcism with induction of vomiting. In Ethiopia spirit specialists in exorcism and sacrifices and associated relentless societal pressures deter PLWE from attending their hospital visits (6).

In northern Uganda the Madi people believed epilepsy is a curse, punishing the sufferer for sins committed by a family member in the current or previous generation. Their fellow countrymen, the Baganda, believed that epilepsy resulted from being born with a lizard in the brain (head) when it moved one convulsed (7).

... "Epilepsy is often thought to be contagious, and witchcraft and ancestral curses appear to play a very definite role - which, of course, explains the secrecy and ostracism which can surround epilepsy in Kenya" .... Stated by Caroline Pickering, one of the founders of the Kenya Association for the Welfare of people living with Epilepsy (KAWE), and emanating from this the association decided to make an informative film depicting a rejected child because of epilepsy. The film is in Kiswahili, and the message is strong and clear - the child's agony, pain and rage has helped improve the knowledge and attitude of many Kenyan people (8).

These beliefs, however, keep 80% of PLWE in Africa from receiving proper treatment, whereas conventional medication may allow more of their people to improve their lifestyles and reduce the treatment gap (6).

In the 19th century the concept of epilepsy as a brain disorder became more widely accepted and helped reduce associated stigma. Potassium bromide (1857), phenobarbitone (1912) and phenytoin (1938) helped reduce frequency and improve control of seizures, but unfortunately supernatural views, social stigma and discrimination still prevails world wide (4).

The International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) have come to consensus on definitions for the terms *epileptic seizure* and *epilepsy.* An epileptic seizure is a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain. Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure (9).

In 1997 the International League Against Epilepsy (ILAE - founded 1909) and the International Bureau for Epilepsy (IBE - founded 1961) joined forces with the World Health Organization (WHO) to establish the Global Campaign against epilepsy. The main objective was to improve prevention, treatment, care services and to raise public awareness about the disorder, achieving a comprehensive approach (4). Quality of Life (QOL) in PLWE is a useful and reliable vehicle in monitoring this objective and providing sound recommendations towards this universal task.

The traditional medical goal in the management of epilepsy has focused almost exclusively on seizure control with minimal or no adverse medication effects. The goal should be to enable the patient to lead a life as free from the medical and psychosocial complications of epilepsy as possible (10). This is clearly an emulation of Engel's biopsychosocial model/concept (11).

Schwartz and Marsh also illustrate this in the four perspectives of looking at psychiatric issues in PLWE. These are: - (a) diseases perspective relating to biological dysfunction in the nervous system, (b) dimensions perspective in recognizing human traits, (e.g. intelligence, personality), vary from individual to individual, (c) behavioural perspective in appreciating "sick-role" and finally the (d) life stories perspective where same life events perception and appraisal vary from one individual to another (12).

WHO and ILAE have estimated that 35 million out of 50 million PLWE in the world live in developing countries and nearly 80% of them are not on treatment. This treatment gap is because either epilepsy is rarely viewed as a medical problem i.e. a treatable brain disorder or the non-existence of services (4). The accessibility of medical services, poor affordability and certain social or cultural beliefs interfere with optimal care for epilepsy in these countries. The benefit of treatment is commonly measured from a caregiver's perspective rather than the impact it has on the life of the patient particularly in the psychosocial realm. However with QOL assessment, the much-needed patient's "point of view" is included together with the physical aspects of the disease (13).

2.2 QUALITY OF LIFE

Consideration of patients opinions concerning their treatment especially in debilitating chronic and incurable illnesses could be useful in the decision making process regarding interventions. The Emphasis being on listening and appreciating the patient's physical, psychosocial and emotional experiences, with empathy, rather than displaying paternalistic and authoritarian roles.

Adjustment to a chronic illness, such as epilepsy is not merely a function of the severity or duration of the disorder or associated treatment adverse outcomes. Response from the family and 'significant others' with associated imbalance between expectations and reality may be more menacing than the illness itself (14).

As such assessment of QOL in PLWE should not only focus on the evaluation of seizures but also other life domains such as cognitive, emotional functioning, role activities and social functioning, health perceptions and general satisfaction with life.

According to the World Health Organization Quality Of Life Group (WHOQOL - Group), QOL can be defined as the; "individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concern" (15). Patient's perspective on QOL is at the core of this definition, requiring his/her personal opinion on physical health status, psychological, social and even environmental status. Or as Rosenbaum (16) put it;

> "… While not ignoring the need to address basic biologic dysfunction in order to improve human well-being, our attention to people's health-related quality of life suggests a redirection of our intervention priorities toward "whole people" and not just to their "broken parts" …"

This subjective evaluation which is embedded in a cultural, social and environmental context is not expected to provide a means of measuring in any detailed fashion symptoms, diseases or conditions but rather the effects of disease and health interventions on quality of life (15). Furthermore a recent study at Yale University contended that screening, diagnosis and treatment of anxiety and depression could be an important contribution to the wellness of PLWE whether or not seizures are controlled; citing 25% of PLWE have symptoms of anxiety and up to 40% are affected by depression (17). The recognition of the multi-dimensional nature of QOL is usually reflected in three to six domains comprising its assessment. In this particular study the physical health, psychological, social relationships and environmental domains will be applied.

Quality of life assessment in PLWE is strongly advocated to identify unobserved need for rehabilitation for the patients' already undergoing treatment and enable revision of allocation of national health resources.

QOL appraisal provides additional "information" for comparisons of different modes of life-prolonging treatment, newer management protocols in chronic illnesses, and is useful in serial assessment of survivors of catastrophic life events. Lastly it can be used as a health "indicator" of a country regarding general life satisfaction and well-being of its citizens.

2.3 JUSTIFICATION OF THE STUDY

Emanating from the above, quality of life is not studied enough. This study determines the quality of life among PLWE as a way of delineating some of the modifiable factors contributing to functional impairment. Epilepsy is the most common neurological condition seen at KNH neurology clinic comprising of 16.6% of all neurological diseases (18). However, the researcher could not find a single study done on quality of life among these patients in our set-up, with consideration that epilepsy is a chronic illness with major psychosocial and economic consequences. This opportunity to study their quality of life should not be ignored.

Availing evidence based recommendations to health service providers and planners especially in primary health care concerning QOL in PLWE may go a long way in revision of national resource allocation and improving outcome, that is, cost effective management of PLWE in our nation. This is where the initiative of the ILAE, 1BE, and WHO 'Global campaign against epilepsy' is directed and its effective development can be achieved by this study.

The study also adds to the scientific knowledge on QOL of PLWE in a non-western setting and contextualizes concepts and instruments used. It is expected that this will, in the future, be invaluable in assessment of outcome after intervention in PLWE.

3.0 LITERATURE REVIEW

3.1 EPILEPSY AND PSYCHIATRIC MORBIDITY.

For psychiatry, epilepsy could possibly be the aetiology for almost any symptoms and as Schwartz states in Psychiatric perspective of epilepsy, "a review of all the psychiatric aspects of epilepsy becomes a review of the practice of psychiatry" (12). Some of the commoner psychiatric presentations of epilepsy include; a schizophrenia-like illness, depression and suicide, manic-like illness and paranoid disorder (7).

One proposed mechanism for psychopathology in epilepsy is based on the observation of forced normalization in which better seizure control and a reduction in interictal epileptiform abnormalities are associated with the emergence of psychotic symptoms or other psychiatric complaints (hypomania and anxiety). The interictal psychiatric symptoms are usually transient with remission of psychiatric dysfunction as seizures return and the electroencephalogram (EEG) again shows interictal disturbances. Depressive symptoms are more frequent and severe in PLWE than in subjects with comparable, chronic neurologic diseases or physical handicap. The author's therefore thought that depression in PLWE does not represent a psychological reaction to a particular cognitive or physical impairment but it is in some way related to the type of epilepsy, more frequent in those with temporal lobe foci and, in particular with temporal left hemisphere lesions (12).

The pathogenetic significance of depression in PLWE is unclear. In addition, some anti-epileptic drugs (AED's) may have psychotropic effects (19) and long term AED therapy is the reality for the majority of patients diagnosed with epilepsy. Drug interaction is a major problem in combination drug therapy and can be avoided by first using the recommended optimal dose, then another member of the same group of drugs, with early proper epilepsy classification being invaluable (20).

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Biological abnormalities associated with epilepsy can also be related to the genesis of psychiatric phenomena e.g. the location of the seizure focus and the presence of gross brain damage (as in head trauma or mental retardation). Furthermore, neurochemical changes related to neuronal excitation and seizure inhibition may also pre-dispose to certain psychiatric phenomena. However, cognitive and temperamental traits, environmental factors and psychosocial issues also contribute to psychiatric disturbance (12).

Muinga's (21) study at KNH neurology clinic revealed that many PLWE were still managed on phenobarbitone the implications of which did not come out in his study. However, further research on the quality of life would embrace the implications in support of evidence based health policy planning. He also found a positive correlation between occupation (50.8% not gainfully employed) and psychopathology. There was thus a possibility that either the psychopathology made it difficult for one to keep a job or PLWE tended to develop more neurotic symptoms if unemployed. However in his symptom profile checklist 94% suffered recurrent headaches, 89% were easily frightened and felt unhappy most of the time, 78% experienced feelings of worthlessness and were easily tired, 72% were worried and tired all the time and 61% experienced suicidal thoughts. Fifty percent of the respondents reported abdominal discomfort, loss of interest in things with tremors occurring frequently, while 17 - 44% had difficulty enjoying life, indecisiveness, cried more than usual, couldn't think clearly, suffered poor digestion and appetites, their work was suffering and had experiences of poor sleep. This appears to correlate even more with QOL domains expressed earlier.

recent postal survey in the USA by Ettinger, involving 1,532 respondents, found that **significantly** more PLWE had symptoms of depression than those with asthma or no chronic medical disorder (36% epilepsy, 27.8% asthma, 11.8% controls, ($p<0.001$). These data support the concept of the higher than expected impact of depression in PLWE, but also **contradicts** the notion that depression is simply a consequence of having any chronic **disorder.** The data unfortunately also revealed that many PLWE were not diagnosed or **treated** for depression. The author thought the problem might have been that patients were **unaware** of the symptoms of depression, assumed it was part of their epilepsy, caused by the **medication** or simply hid the symptoms when with their doctor. Alternatively, doctors may **not have** adequately evaluated symptoms of chronic depression, were unwilling to add **another** medication or had concerns about seizure exacerbation due to an antidepressant (22).

The impact of depression (23) on health related quality of life, self reported seizures severity (24) and health care utilization was further evaluated, by the epilepsy impact project group, in i community sample of PLWE in USA. The conclusion was comorbid depression affected quality of life, seizure severity and health care utilization by PLWE in a significantly negative manner.

Seizure frequency seems to be one of the most relevant determinants of poor quality of life scores and is even worsened by the co-existence of depression. Nevertheless the impact of surgical treatment on QOL of PLWE is positive in all ages, in correlation with Seizure Control (25).

3.2 EPIDEMIOLOGY OF QOL.

A Study done by Kaamugsha and Feksi (1988) in a semi-urban area in Kenya (Nakuru) found an epilepsy prevalence of 18.2 per 1000 population (26). This high prevalence in a chronic illness with our nation's low doctor: patient ratio (physicians per 1,000 people in Kenya 1998 was less than 0.05), means that every medical practitioner will see and manage PLWE at one time or another. Prevalence of epilepsy is higher in developing countries as compared to the developed (27).

In order to find "Some agreed statistic which could form the basis for Comparison", Cummins compared QOL research outcomes of more than 1000 books and articles that were first scanned for normative data on QOL and secondly met a set of definite methodological, statistic and sampling criteria. This resulted in 17 normative data sets (with a diversity of QOL scale) that fulfilled all the normative criteria. Based on this study he hypothesized a range of 75 ± 2.5%, a value that he proposed as a sort of standard in order to evaluate the level of QOL of specific groups (28). This "gold standard" range therefore reflects QOL in western general population, with publications being mainly in the developed countries, rates supposedly different on QOL scales and not having been adequately audited in developing countries. Thus the inevitable need of contextualization of concepts and instruments in QOL studies in developing countries and more so in Africa.

Psychological stress, caused by stigma and worry has an impact on the QOL of PLWE. The increased morbidity associated, both as a result of seizure related accidents and injuries (29) and as an outcome of the effects of AEDS, further increases psychological distress (30). Psychological morbidity has been shown to be substantially higher among PLWE and includes depression, anxiety, social withdrawal and denial, and a reduced sense of mastery and control (31). A particularly stigmatizing area is within employment. Research has documented unfavorable public attitude and negative expectations from informants if they had to work with one with epilepsy (32, 33).

However, since epilepsy's physical manifestations are transient, the individual may conceal their condition but there is the possibility that in the future they may be discovered (witnessed having a seizure). This dilemma inevitably leads them to "manage" information about their condition, deciding what information they will disclose and to whom, needless to say this affects their social interactions and activities with sustained and increased levels of anxiety due to the "secrecy" (34).

Lower rates of marriage (47% single) and employment (25% unemployed), significant impact on activities of daily living with a subjective feeling of being stigmatized among PLWE were the findings in a recent study involving 10 European countries and 6,156 respondents (35).

Behavioral Risk Factor Surveillance System (BRFSS) is an ongoing, state-based, random-digit-dialed telephone survey of the civilian; non-institutionalized people aged > 18 years that tracks the prevalence of key health and safety-related behaviors and characteristics in the United States of America (USA). Analyzed responses to HRQOL questions from 3,355 persons using the BRFSS in Texas (1998) showed that 52 (1.8%) (95% CI = 1.4-2.1) reported having epilepsy and didn't differ in age and sex from those without i.e. 3,290. Results indicated that the epilepsy group reported substantially worse HRQOL than those without epilepsy i.e. 18 (45.9%) respondents with epilepsy as compared with 570 (18.5%) those without epilepsy. (36) The author suggested further studies should be carried out to determine seizure severity, injuries from the seizure, unintended effect of AEDS, anxiety, depression, levels of life fulfillment and their relationship if any to the impaired QOL (36).

Seizure frequency was a significantly inverse predictor of HRQOL across all domains ($P<0.01$ to 0.001) in a 1999 USA multivariate study involving data obtained from 139 adult PLWE from three centers for Health outcomes research. The authors found that men reported poorer physical function than women ($p<0.05$) and patients with a physical comorbid condition had poorer HRQOL in the areas of pain ($p<0.05$) and general health perception ($p<0.01$). Time since last seizure was not related uniquely to HRQOL (37). The author reported that since seizure free adults can have HRQOL levels comparable with those of the general population, HRQOL assessment has potential in evaluating treatment outcomes. As seizure frequency increased, patients reported more impaired HRQOL, regardless of time since their last seizure, gender and comorbid status.

In a 2005 Taiwanese comparative study using the WHOQOL-BREF, it showed that PLWE who had suffered less than 4 attacks during their previous 1 month had a better score in the availability and quality of health and social care in environment domain than healthy subjects ($p<0.05$). They nevertheless had poorer HRQOL than the healthy population in physical, psychological and social domains. The author therefore thought effective control of seizures and thoughtful promotion of positive attitude in community were essential in improving the HRQOL of PLWE (38). After controlling other determinants it appeared that seizure frequency and comorbidity with other diseases were the important factors in predicting HRQOL for PLWE.

Unlike in the USA and Taiwan, psychosocial factors outweighed the physical ones in determining QOL in Korean PLWE. Consecutively identified PLWE attending the outpatient clinic at the National University Hospital were interviewed by two research nurses using standardized questionnaires on QOL (QOLIE-31), seizure characteristics and symptoms of depression and anxiety. In multiple regression analysis, the symptom of anxiety was the most important factor in explaining lower QOL in PLWE, while depression ($p<0.01$), social life dissatisfaction ($p<0.01$), activities of daily life dysfunction ($p<0.05$) and seizure frequency ($p<0.05$) were also significant factors. Recognition of these psychosocial factors led health professionals in Korea to develop different strategies to improve the QOL of these patients. Social prejudice towards PLWE was still pronounced in Korea as was exemplified by this 2003 study (39).

In decreasing order of importance, "psychological distress" ($p - 0.0004$), "loneliness" ($p- 0.01$), "adjustment and coping" ($p - 0.03$) and "stigma perception" ($p - 0.04$) appeared to contribute most significantly to the poor outcome of QOL as judged by the patients themselves, regardless of their physical status. Those were the findings in a 2001 social functioning, psychological functioning and QOL in epilepsy study in the Dutch population. After results of hierarchical regression analysis the authors found a QOL mean rate of 44%. In the final model, none of the clinical variables (seizure frequency, side effects, AED's etc) contributed significantly any more to the patients QOL judgment. The author felt that daily concerns such as employment, driving, medication and side effects, with seizure unpredictability, ran through and manifested themselves in stigma perception, feeling lonely, self efficiency and mood (40).

This had earlier been concluded in the 1999 Beer-Sheva, Israel study on self-efficacy and social support as mediators in the relation between disease severity and QOL in PLWE. Among the Israelites, Mastery (Locus of Control and self-efficacy) was found to mediate the correlation between disease severity and QOL, while social support was found to mediate between disease severity and mastery. The author's suggestion was that QOL among PLWE could be improved by providing social support, counseling and treatment aimed at reinforcing self-efficacy and locus of control (41).

In another study, consecutive 106 adult right-handed Italian patients with a mean age (35.4 ± 9.7) and of equal sex distribution (50% female), having an IQ > 70, with drug resistant unilateral (59% right) TLE (70% hippocampal sclerosis, 30% tumors' or other lesions), underwent a comprehensive non-invasive, pre-surgical protocol (42).They completed the Beck depressive inventory (BDI) and the State form of the Spielberger State - Trait anxiety inventory (STAI), WHOQOL - 100 and disease specific Quality of Life in Epilepsy (QOLIE -31). Multiple linear regression analysis was used to examine the relationship between QOL domains and age, gender, education, side of TLE pathology, duration of epilepsy, seizure frequency and level of depression and anxiety. Results indicated that severity of depression symptoms were significantly associated with and the stronger predictor of lower scores on almost all QOL domains.

Severity of anxiety symptoms was also significantly associated with lower scores across many QOL domains. Independent significant relationships between QOL and socio-demographic or clinical epilepsy variables were limited in number and strength. The authors concluded QOL in TLE might be substantially affected by the presence and severity of depressive symptoms and to a lesser extent, anxiety symptoms. The weaker association between clinical seizure / variables and QOL was thought to be obscured by the absence of seizure free patients in the study (42). Perhaps a possible confounder would have been the "circumstances", such as, awaiting surgery and unsure of surgical intervention outcome; yet again manifesting themselves in depression and anxiety symptoms.

The WHOQOL - 100 Malay version was pilot tested on 300 subjects in Malaysia; 50 healthy controls and 250 ill subjects, suffering from hypertension, diabetes mellitus, both hypertension and ischaemic heart disease (as a comorbid group), epilepsy and schizophrenia. Each group with illness was made up of 50 subjects. The data was analyzed using the EPIINFO 6.Domain facets with Pain and discomfort, energy and fatigue, positive feelings, negative feelings, activity of daily living, dependence on medication, work capacity and sexual activity showed a similar trend in all the ill subjects, which was a compromised QOL. However the comorbid and PLWE subjects seemed to subjectively suffer more negative feelings ($p<0.005$), pain and discomfort ($p<0.00005$) than the other groups. The schizophrenia group subjectively suffered most sexual activity impairment ($p<0.000005$), though PLWE and comorbid groups showed more sexual activity impairment ($p<0.005$, respectively) than the remaining groups. It was interesting to note that even though the authors had tried to match the socio-economic status of the subjects, the hypertensive ($p<0.005$), comorbid and diabetic ($p<0.05$, respectively) groups of patients subjectively rated their financial resources, social support and spirituality better than the healthy or rest of the groups. With the inclusion of the WHOQOL-100 general facet scores, the PLWE group showed the most impaired QOL. The healthy controls subjective ratings showed no statistically significant impairment. The author speculated that the sexual impairment in PLWE and schizophrenia might be influenced by the stigma of their illness as well as far-reaching influence on the self-esteem for epilepsy patients i.e. negative feelings ($p<0.005$)..

Citing significantly impaired social skills such as personal relationships ($p<0.005$) for subjects with schizophrenia as a contributing factor. 'Frequent seizures' was thought to prevent the epilepsy group from doing things they would have liked to do and also increased their worry about pain and discomfort (43).

Researchers revisited a group of 99 adults in Finland, originally from a group of 245 paediatric patients, 30 years after having active epilepsy. Sixty seven percent were in remission and off medication while 14% were still taking AEDS. Those patients still taking long-term AEDS showed higher rates of unemployment and lower socio-economic status, while subjects off medication had results similar to those of the control group. Both groups with epilepsy had lower rates of marriage and having had children than the control group. There was no difference in educational status. The authors' conclusion was childhood onset epilepsy had a long-term adverse effect on QOL and being on medications may be a marker for other adverse effects such as stigma and unemployment (44).

A quasi-experimental research design in which primary care clinics were assigned to enter an intervention or comparison group from 1996 to the year 2000 was carried out in New Mexico. It involved comparing responses to a validated QOL survey after a disease management intervention for 'adult health plan members' with epilepsy. A pre and post analysis utilizing paired t-tests to identify differences in QOL was used. The intervention group patients showed statistically significant positive changes in two QOL domains out of the seven used i.e. seizure worry ($p<0.001$) and emotional well-being ($p<0.05$). One other domain, overall QOL, showed improvement in the interventional group that approached statistical significance ($p<0.06$). The authors' concluded that a well-designed comprehensive disease management program could improve patient empowerment and the coordination of care between patient and provider, subsequently improving the quality of life (45).

A cross-sectional case control study was done in Tunisia in 2002. One hundred and ten PLWE and 120 well subjects' responses, using the short form survey-36 (SF-36) questionnaire, were analyzed. In those unemployed, epilepsy was the cause in 62% of cases. General health (p=0.006), mental health (p=0.05) and social functioning (p=0.05) subscales showed a statistically significant difference, being lower for the PLWE. HRQOL scores of seizure free patients were similar to those of the control group but as seizure frequency increased more impaired HRQOL in physical functioning, physical and emotional role, vitality, General Health, Mental Health and social functioning were noted. As the patients age increased, a poorer HRQOL in the area of physical functioning (p=0.006) and physical role limitations (p=0.009) was found. As AED's side effects increased, patients showed lower scores in HRQOL similar to those with increased seizure frequency. The author noted that seizure severity and frequency appeared to be particularly problematic in impairment of QOL in PLWE living in Europe and North America. Citing previous studies using the SF-36 in Western populations reported significantly lower scores in almost all 8 subscales, whereas only General Health, mental health and social functioning were significantly lower in Tunisian PLWE (46).

Tunisia being an African-Arab country, cross-cultural difference arising from traditions, based on family and social support, cultural and religious beliefs were thought to be major contributors to the difference. She further reported that majority of the population in Tunisia were Muslims and … "in this religion, belief in faith and submission to God's will are very strong. All the events one encounters in life are God's wishes and are thus predestined"... So the PLWE were less demanding and accepted their illness more easily. The author thus concluded seizure frequency was a key factor influencing HRQOL of PLWE everywhere in the world (46). However, that conclusion requires further evaluation considering the paucity of studies on HRQOL in PLWE in the developing countries, where 35 million of the 50 million PLWE in the world currently live.

The level of stigma and prejudice towards PLWE was recently found to be high in a developed country. A USA study explored Kentuckians' attitudes towards children living with epilepsy, asthma, hyperactivity and Acquired Immune Deficiency Syndrome (AIDS). Random digit dialing led to 617 completed interviews; 24% predicted a deterioration of the classroom environment with the addition of a pupil with epilepsy (similar to AIDS at 26%), 41% predicted a lessened QOL at age 21 years (a worse rating than either asthma or hyperactivity). Surprisingly the greatest prejudice was noted among urban residents (the best educated group) (47).

An assessment of PLWE with regard to socio-demographic characteristics, aetiology, EEG results and classification was carried out in a descriptive cohort study from 1997 to 2001 in parirenyatwa group of hospitals in Harare, Zimbabwe. A total of 229 consecutive PLWE were interviewed and data analysed using an SPSS spreadsheet with frequency data compared using X^2 test or Fisher's exact probability test. The results revealed a mean (s.d.) follow-up of 3.2 years with 23.4 years being the mean (s.d.) age of subjects and 56% of them were male. Forty eight percent had attained a secondary level of education, 43.1% unemployed, 25.8% had family history of epilepsy while majority of the subjects suffered generalized tonic clonic seizures (GTCS). The most frequent provoking factors were lack of sleep (7.9%) and emotional disturbance (5.4%) with 51.5% of the subjects experiencing onset of seizures after the age of 20 yrs. Over half of the subjects (52.8%) sought treatment from biomedical drugs, 20.5% first starting with traditional herbs, 20.1% first sought biomedical drugs before resorting to traditional herbs. Over 40% of the subjects were taking phenobarbitol and carbamazepine. The author recommended the use of inexpensive AED's that effectively controlled GTCS such as phenobarbitol and phenytoin, in primary health care centers (48). However, the much needed subjective evaluation of their QOL was not considered and warrant further assessment.

There is evidence to suggest PLWE experience significant impairment in their QOL .The psychological and social domains appear to be particularly problematic, with patients reporting high levels of anxiety and depression, poor self-esteem, and problems with social interaction and involvement. Although inadequate attention has been focused on the QOL of PLWE locally, the preceding reports indicate it imposes a heavy burden on them and often leads to psychiatric morbidity. Seizure burden, treatment profile, pain and discomfort, negative feeling, impaired sexual activity, adjustment and coping, epilepsy type, a longer duration of treatment and associated subjective and objective stigma appear to impact negatively on QOL of PLWE. An assessment of the QOL of PLWE is invaluable in evaluating treatment outcome and making informed recommendations on intervention.

4.0 RESEARCH SCOPE

4.1 RESEARCH QUESTION

What is the QOL among PLWE attending the neurology clinic at KNH, Nairobi, as compared to that of normal controls accompanying them?

4.2 HYPOTHESES

4.2.1 NULL HYPOTHESIS

There is no statistically significant impairment in the QOL, as determined by the WHOQOL-BREF, among PLWE attending the neurology clinic at KNH, Nairobi, as compared to normal controls accompanying them (WHO-BREF score > 75 + 2.5%)(28).

4.2.2 ALTERNATIVE HYPOTHESIS

There is statistically significant impairment in the QOL, as determined by the WHOQOL-BREF, among PLWE attending the neurology clinic at KNH, Nairobi, as compared to normal controls accompanying them (WHO-BREF score < 75 ± 2.5%)(28).

4.3 RESEARCH OBJECTIVES

4.3.1 BROAD OBJECTIVES

(i) To determine the QOL among PLWE as compared to that of accompanying normal controls.

(ii) To determine the mean QOL among PLWE attending the neurology clinic at KNH, Nairobi, as per the hypothesized mean of 75 ± 2.5% (28).

4.3.2 SPECIFIC OBJECTIVES

(i) To determine the relationship between type of epilepsy and QOL among PLWE.

(ii) To determine the relationship between socio-demographic factors and QOL among PLWE.

(iii) To determine the relationship between specific drug therapy and QOL among PLWE.

(iv) To make recommendations as to modifiable factors concerning QOL in PLWE to health service providers and planners.

5.0 METHODOLOGY

5.1 STUDY DESIGN

A comparative, cross-sectional descriptive study, among PLWE and their accompanying normal controls, attending the neurology clinic at KNH, Nairobi. For the purpose of obtaining a mean QOL all consecutive patients, satisfying the inclusion criteria, were recruited. This design was chosen due to lack of data on QOL in our local setting and especially among PLWE.

5.2 STUDY AREA

Location - Kenyatta National Hospital (K.N.H)

K.N.H. is approximately three kilometers southwest of the city centre of Nairobi, which is the capital city of Kenya. It serves as both a referral hospital and teaching hospital. All disciplines in medicine and surgery are well represented with an additional hospice, dental and patient support centre; all manned by both government and University of Nairobi personnel. The adult Neurology out patient clinic is held once a week, on Mondays between 9.00am and 12.00 noon. Patients seen here are referred from the provincial hospitals and other clinics within KNH.

5.3 STUDY POPULATION

The study population consists of PLWE, and their accompanying normal controls, attending the neurology clinic at KNH and fulfilling the inclusion criteria. The clinic has an average total annual attendance of 3,384 neurology patients, with 16.6% comprising PLWE (18).This translates to an average 562 PLWE annually, 47 PLWE monthly and an attendance of 12 PLWE weekly. This is in accordance with the statistics at KNH as of August 2006.

Neurology clinic attendance;

August 2004 to July 2005 -3,155 patients.

August 2005 to July 2006 - 3,612 patients.

5.4 SAMPLE SIZE

QOL is measured as a continuous variable along a continuum of 0-100 %, with higher values indicating a better quality of life. For any new centre not previously involved in either the development or field-testing of the WHOQOL-lOO, the procedure recommended to field test the WHOQOL-BREF should be identical to that used to initially field test the WHOQOL-lOO. The initial testing of the psychometric properties of the 236 proposed items covering 6 domains and 29 facets of QOL in the WHOQOL-lOO involved a pilot study conducted on 4,834 persons in 15 field centers i.e. at least 300 persons, heterogeneous and representative of sick and well people, per center (48,49,50). Epilepsy comprises of 16.6% of all neurological diseases seen at the neurology clinic in KNH (18); with an average total annual attendance of 3,384 patients. This translates to an average monthly attendance of 47 PLWE and an average weekly attendance of 12 PLWE. Within duration of 4 months in a 2004 study, 360 PLWE were interviewed while attending the same neurology clinic (18).Emanating from the above the sample size was 300 subjects, 150 PLWE and 150 NCs.

5.5 INCLUSION CRITERIA

A. Cases

1. PLWE on AED therapy > 2 yrs.
2. Age > 18 years.
3. MMSE score > 22 only for the WHOQOL-BREF since its self administered.
4. Those who gave consent to participate in the study.

B. Normal Controls

1. Accompanying subjects with no illness.
2. Age > 18 years.
3. MMSE score > 22.
4. Those who gave consent to participate in the study.

5.6 EXCLUSION CRITERIA

A. Cases

1. Age< 18 years.
2. PLWE on AED therapy of <2 years.
3. MMSE score <22 only for the WHOQOL-BREF since its self administered.
4. Those who declined to give consent.

B. Normal Controls

1. Age< 18 years.
2. Those with an illness.
3. MMSE<22.
4. Those who declined to give consent.

5.7 STUDY INSTRUMENTS

5.7.1 The WHOQOL-lOO and the WHOQOL-BREF

The WHOQOL-lOO is a comprehensive measure that assesses respondents' perception and subjective evaluation of various aspects of their lives. It was developed through a culturally diverse multi-center project involving a standardized protocol (49).

It was designed using a unique and brilliant methodology, whereby it was developed simultaneously in a wide range of languages involving 15 cross-cultural centers, one of which was from Zimbabwe in Africa. Face and content validity of the facets and domains was reviewed by focus groups consisting of health care professionals and well and unwell individuals from the respective populations. To enable the collaboration to be genuinely international, the 15 field centers were selected worldwide to provide differences in level of industrialization, available health services and other markers relevant to the measurement of quality of life (e.g. role of the family, perception of time, and perception of self dominant religion). The simultaneous development is an enormous strength, because developing an instrument in one culture and translating it for another culture tends to weaken the validity of measures (49, 50, 51).

The WHOQOL-BREF, a short abbreviated form of the WHOQOL-lOO, was developed at a later stage on the basis of data from the above-mentioned 15 sites as well as data from 4 new sites. The generic WHOQOL-BREF hence satisfies the key properties of a QOL questionnaire i.e. reliability, psychometric validity, responsive to clinical change and being culturally valid (52). It is based on a four domain structure and contains a total of 26 questions as illustrated in Table 1 and attached WHOQOL-BREF Questionnaire in Appendix 2A.

Table 1 - WHOQOL-BREF domains

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

5.7.2 Global Assessment of Functioning (GAF)

The multi-axial system of the DSM-IV-TR provides a comprehensive format for communicating and representation of a client's clinical information in different domains or axis i.e.

Axis I - Clinical disorders (other conditions that may be a focus of clinical attention)

Axis II - Personality Disorders / mental retardation.

Axis III - General medical conditions

Axis IV - Psychosocial and environmental problems

Axis V - Global assessment of functioning.

The GAF rating is on a scale of 0-100, which is divided into 10 ranges of functioning, each with a 10 - point range. As indicated in Appendix 2B, intermediate values or picking a single value can be used when appropriate. This represents the clinician's judgment of the individuals overall level of functioning and the scale has two components: the first part covers symptom severity, the second part covers functioning.

The rating always reflects the worse of the two, with respect only to psychological, social and occupational functioning and doesn't include impairment due to physical (or environmental) limitations.

Attached in Appendix 2B

5.7.3 Mini-Mental State Examination (MMSE)

Formal evaluation of cognitive impairment is time-consuming and may require an expert in psychological testing. However, one practical and clinically useful test is the Mini-Mental State Examination (MMSE) which is a

(i) Screening test that can be used during a patient's clinical examination.
(ii) Practical test to track the changes in a patient's cognitive state (53).

Attached Questionnaire in Appendix 2C

5.7.4 Drug and Treatment Profile Questionnaire

Information on compliance, type of AED used, with duration of treatment and any associated reasons for non-compliance was collected. Additional information on alternative therapeutic approach and patients' opinion on the effect of medication in their illness was also collected.

Attached Questionnaire in Appendix 2D

5.7.5 Seizure burden and characteristics questionnaire

Data on clinical features of epilepsy including seizure type and frequency, epilepsy duration and associated trauma was collected. Scoring was according to Engel system that scores seizure frequency and disability on a scale ranging from 0-12 as attached in appendix 2F. *Attached Questionnaire in Appendix 2E*

5.7.6 Socio-demographic questionnaire

Patient's demographic characteristics including age, gender, level of education, occupation, religion, residence and marital status was collected. *Attached Questionnaire in Appendix 2G*

5.8 STUDY IMPLEMENTATION

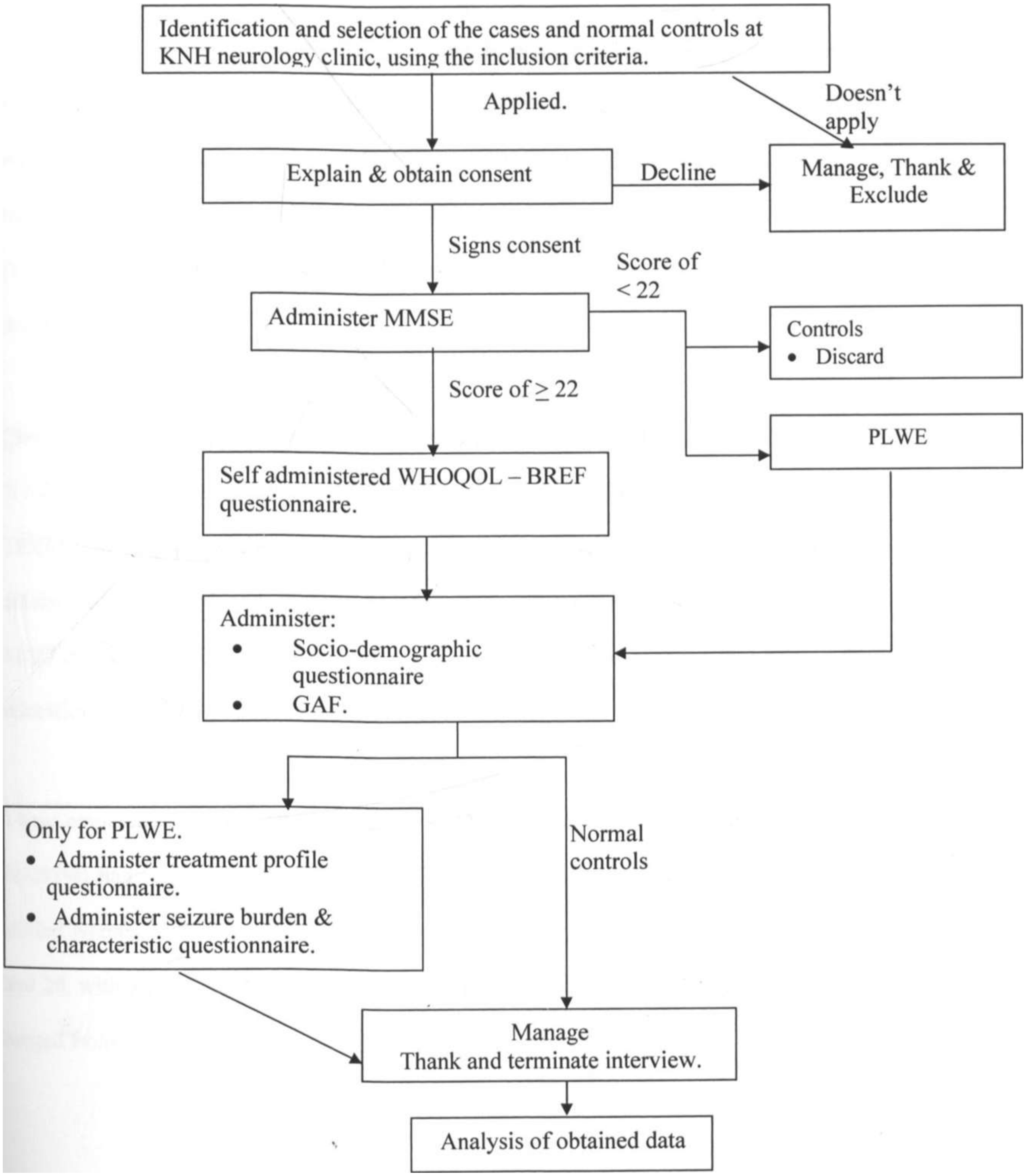
The researcher attended the Monday neurology Clinic at KNH over a period of 20 weeks to conduct 15 interviews a day. This allowed a maximum of 305 interviews, achieving the study objective of 300. Consecutive subjects meeting the inclusion criteria were recruited for the study.

The researcher carried out the study for a period of 5 months, from October 2006 to February 2007, achieving 15 interviews per week. This resulted in the projected 300 interviews; 150 patients with epilepsy and 150 healthy controls, fulfilling the WHOQOL-group requirements stated earlier. The researcher met the patients and their accompanying normal controls at the neurology clinic, KNH each Monday morning. This opportunity was used to scrutinize the files for PLWE and record type of epilepsy, duration of treatment, their age and treatment profile. Consecutive subjects were recruited, after fulfilling the inclusion criteria and obtaining their informed signed consent, to achieve the objective of determining the mean)OL among PLWE.A detailed consent explanation was done before the subjects signed the informed consent. Detailed consent explanation is in Appendix 1. The MMSE was administered to all subjects consenting and normal controls with a score < 22 were to be excluded from the study. Those PLWE with a MMSE score of < 22 were only excluded from the WHOQOL-BREF, since it is self administered. Subjects with a MMSE score of >22 were requested to read and answer all the questions in the WHOQOL-BREF questionnaire. The socio-demographic questionnaire was then administered and a GAF done. Eventually the treatment profile and the seizure burden and characteristics questionnaires were administered to the PLWE. Before termination of the interview the researcher reviewed, managed and thanked the subjects. A detailed sampling methodology is illustrated in the flow chart in 5:10.

5.9 DATA ANALYSIS AND PRESENTATION

Collected data was stored on Computer Media and analyzed using the SPSS Version 12.0 computer program and the WHOQOL-BREF recommended manual scoring and conversion of raw to transformed scores, achieving domain scores. Each domain bears a range of 0 to 100% with higher values denoting better quality of life. The mean QOL was calculated as the mean of the 4 domain scores. Points are presented in the form of tables, charts and descriptive form.

5.10 FLOW CHART ILLUSTRATING METHODOLOGY



6.0 RESULTS

6.1 Descriptive Statistics

The sample of 300 comprised 154(51.3%) drawn from an urban and 146(48.7%) from a rural community. The age ranged from 18 to 75 years with a mean (sd) of 31.41(10.404) and a median of 29.50.0ne hundred and sixty one (53.7%) were female, while 139(46.3%) were male. Annual income ranged from Kshs.O to 720,000 with a mean (s.d) of 77,325.12 (117,012.384) and median of 36,000; 48.7% lived < 1 U.S dollar per day (Kshs 67.00= 1 U.S. dollar).

One hundred and fifty six (52.0%) were married, 129(43.0%) single and 7(2.3%), 4(1.3%), 3(1.0%), 1(0.3%), living as married, separated, widowed and divorced respectively. Majority, 189(63.0%) were protestants, 108(36.0%) Catholics, 2(0.7%) Muslims while 1(0.3%) was an atheist. One hundred and thirteen (37.7%) had attained secondary level of education, 81(27.0%) tertiary, 79(26.3%) primary, 16(5.3%) university level, 10(3.3%) had no formal education and 1(0.3%) attended special school.

Those employed were 174(58.0%) while 126(42.0%) were unemployed. Of the unemployed 5(1.67%) had retired and 37 (12.33%) were students. Of the employed, 74(42.53%) were skilled whereas 100 (57.47%) had unskilled employment. Household sizes were between 1 and 20, with a mean (s.d) of 3.68 (1.989) and a median of 3.50; the number of children had ranged from 0 to 24, mean (s.d) of 1.60(2.299) and median of 1.00.

6.2 Socio-demographic characteristics of people living with epilepsy and normal controls

The age of the PLWE ranged from 18 to 75 years with a mean (mode) of 31.49(18.0) and median of 28.50.Seventy two (48%) of the PLWE were female, (M: F=l:l), 75(50%) belonged to the urban community while 88(58.7%) were unemployed; 81(54%) single and the majority, 92(61.3%), protestant. Of the unemployed PLWE 4(2.67%) had retired and 23(15.33%) were students, while only 20(32.3%) of the employed had skilled employment. Annual income of PLWE ranged from Kshs.O to 600,000 with a mean (mode) of 47, 538.32 (0.0) and median of 0.0. The household size of the PLWE ranged from 1 to 8 persons with a mean (mode) of 3.74(3.0) and median of 4.0 persons. The number of children had ranged from none to 24 with a mean (mode) of 1.59(0.0) and median of 1.0. Nine (6%) of the PLWE had no formal education while only 26(17.3%) had attained a level equal or higher than tertiary.

In the NC group, the age ranged from 18 to 64 years with a mean (mode) of 31.34 (30.0) and median of 30.0.Eighty nine (59.3%) were female, (M: F=2:3). The NC group was comprised of 79(52.7%) residing in an urban setting with only 38(25.3%) unemployed, 48(32%) single and majority, 97(64.7%), protestant. Of the unemployed NCs 1(0.67%) had retired and 14(9.33%) were students, while 54(48.2%) of the employed were in skilled employment. The annual income of the NC group ranged from Kshs.O to 720,000 with a mean (mode) of 107, 112.00 (0.0) and median of 72,000.The household size of the NCs ranged from 1 to 9 persons with a mean (mode) of 3.63(3.0) and median of 3.0 persons. The number of children had ranged from none to 8 with a mean (mode) of 1.61(0.0) and median of l.O.Only 1 (0.7%) of the NC group had no formal education whereas 71(47.3%) had attained at least a tertiary level of education.

Table 2 below shows the distribution of socio-demographic variables by epilepsy status.

Table 2: Distribution of Socio-demographic Variables by Epilepsy Status

	EPILEPSY STATUS				
VARIABLES	**PLWE n(%)**	**NC n(%)**	**TOTAL n (%)**	**X^2 (df)**	**P**
Gender					
Male	78 (52.0%)	61 (40.7%)	139(46.3%)		
Female	72(48.0%)	89 (59.3%)	161 (53.7%)	3.874(1)	0.064
Residence					
Urban	75 (50.0%)	79 (52.7%)	154 (51.3%)		
Rural	75 (50.0%)	71 (47.3%)	146 (48.7%)	0.213(1)	0.729
Religion					
Protestant	92 (61.3%)	97 (64.7%)	189 (63.0%)		
Catholic	56 (37.3%)	52 (34.7%)	108 (36.0%)		
Others	2(1.4%)	1(0.7%)	3 (1.0%)	0.614(2)	0.736
Level of Education					
No formal	10 (6.7%)	1 (0.7%)	11 (3.7%)		
Primary	53 (35.3%)	26(17.3%)	79 (26.3%)		
Secondary	61 (40.7%)	52 (34.7%)	113(37.7%)		
Tertiary	18(12.0%)	63 (42.0%)	81 (27.0%)		
University	8 (5.3%)	8 (5.3%)	16(5.3%)	44.132 (4)	**<0.001**
Marital Status					
Ever married	69(46.0%)	102(68.0%)	171(57.0%)		
Never married	81(54.0%)	48(32.0%)	129 (43.0%)	14.810(1)	**<0.001**
Employment Status					
Employed	62 (41.3%)	112 (74.7%)	174 (58.0%)		
Unemployed	88 (58.7%)	38 (25.3%)	126 (42.0%)	34.209(1)	**<0.001**
Type of Employment					
Skilled	20 (32.3%)	54 (48.2%)	74 (42.5%)		
Unskilled	42 (67.7%)	58(51.8%)	100 (57.5%)	4.157(1)	**0.041**

As shown in Table 2 the PLWE showed lower level of education ($p < 0.001$), lower mean annual income ($t = -4.552$, $p < 0.001$), lower mean MMSE scores ($t = -5.212$, $p < 0.001$), with most of them unemployed ($p < 0.001$), having unskilled employment ($p = 0.041$) or not married ($p < 0.001$), as compared with the NCs. However, there were more females than males within the NC group that was tending towards significance ($P = 0.064$).

There was no significant ($p > 0.05$) difference in age of the respondents, their religion, area of residence, household size, children had and gender between the two groups.

i

6.3 Clinical characteristics of PLWE

Most of the PLWE, 112 (74.7%) had primary generalized seizures, 35(23.3%) partial and 3(2%) unclassified seizures, 69(46%) were on AED monotherapy while 81 (54%) were managed on polytherapy. Carbamazepine 44(63.8%) was the most commonly used AED monotherapy. Others included phenytoin 12(17.4%), sodium valproate 8(11.6%), phenobarbital 3(4.4%) with 1(1.4%) patient each on either clonazepam or lamotrigine as monotherapy. Seventy-three (54.1%) of the PLWE with a MMSE score of >22 were on polytherapy and 8(53.3%) of those with a MMSE score < 22 were on polytherapy.

The age at onset of epilepsy ranged from birth to 64 years with a mean (s.d) of 21.05(12.052) and median of 19 years. Duration of illness was from 2 to 40, a mean (s.d) of 10.43 (8.952) and median of 7 years, with a follow-up mean (s.d) of 9.55 (8.658) years, 26 (17.3%) of the PLWE had a family history of epilepsy.

Forty one (27.3%) of the PLWE were seizure free, 47(31.3%) had suffered 1 to 3 seizures, 22(14.7%) 4 to 11 seizures and 40(26.7%) had suffered $>$ 12 seizures over the preceding one year. Fifty two (34.7%) of the PLWE were non-compliant to AED treatment, citing financial difficulties, 31(59.61%), forgetting to take their medication, 9(17.3%), side effects, 5(9.61%), inaccessibility, 3(5.76%), unavailability, 2(3.84%), pregnancy and those who thought they were well, 1(1.92%) each, as the reasons for their non-compliance.

Use of alternative modes of therapy was present in 56(37.3%) of the PLWE. Commonly used modes included prayers, 32(57.14%), herbs, 19(33.92%) witchcraft, 4(7.14%) and acupuncture, 1(1.78%). The expectation of AED treatment was a cure in 125(83.3%) with the effect reported as improvement in 139(92.7%), whereas 76(50.7%) of the PLWE reported not knowing the cause of their disease. A few, 29(19.3%) thought it was as a result of excessive stress/thinking, 3(2%) due to witchcraft, 2 (1.3%) believed it was an act of God and 40(26.7%) reported plausible causes of epilepsy (head injury, abnormal nerve function, recurrent childhood febrile illness).

Some, 29(19.3%), had suffered head injury/trauma either as a result of a seizure or as the cause of their illness. Slightly over half 47(53.4%), of the unemployed PLWE blamed the disease as the cause of their unemployment. Fifteen (10.0%) of the PLWE scored < 22 in the MMSE and were therefore excluded from the WHOQOL-Bref questionnaire but their GAF was nevertheless done.

Tables 3A and 3B overleaf show the distribution of PLWE by seizure burden

Table 3A: Distribution of PLWE by seizure burden

	SEIZURE BURDEN					
	No Seizure/yr	**1-3 Seizures/vr**	**4-11 Seizures/yr**	**>12 Seizures/yr**	**x^2 (df)**	**P**
VARIABLE OF PLWE						
Drug Therapy						
Monotherapy **n** = 69 (46.0%)	23(15.3%)	30 (20.0%)	8 (5.3%)	8 (5.3%)		
Polytherapy **n** = 81 (54.0%)	18(12.0%)	17(11.3%)	14(9.3%)	32 (21.3%)	19.406(3)	**<0.001**
Alternative Therapy						
Yes **n** = 56 (37.3%)	10(6.7%)	17(11.3%)	7 (4.7%)	22(14.7%)		
No **n** = 94 (62.7%)	31 (20.7%)	30 (20.0%)	15(10.0%)	18(12.0%)	8.585 (3)	**0.035**
Mode of Alternative Therapy						
Prayers **n** = 32 (21.3%)	5 (3.3%)	13(8.7%)	2(1.3%)	12(8.0%)		
Herbs **n=** 19(12.7%)	4 (2.7%)	3 (2.0%)	5 (3.3%)	7 (4.7%)		
Others **n** = 5 (3.3%)	1 (0.7%)	1 (0.7%)	0 (0.0%)	3 (2.0%)	7.954 (6)	0.241
Marital Status						
Ever married **n** = 69(46.0%)	24(16.0%)	24(16.0%)	10(6.7%)	11 (7.3%)		
Never married **n** = 81 (54.0%)	17(11.3%)	23(15.3%)	12(8.0%)	29(19.3%)	8.593(3)	**0.035**
Compliance						
Yes **n** = 98 (65.3%)	30 (20.0%)	28(18.7%)	15(10.0%)	25(16.7%)		
No **n** = 52 (34.7%)	11 (7.3%)	19(12.7%)	7 (4.7%)	15(10.0%)	2.021 (3)	0.568

As shown in Tables (3A ,3B), there was statistically significant (P0.05) association between higher seizure burden and polytherapy, being single, use of alternative therapy, lower annual income, lower MMSE scores, a longer duration of the illness or past history of head injury and in those with an earlier age at onset of epilepsy.

There was no statistically significant (P>0.05) association between seizure burden and age of the respondent, family history of epilepsy, seizure type, mode of alternative therapy, duration °f treatment, specific monotherapy or non-compliance over the preceding one month.

Table 3B: Distribution of PLWE by seizure burden

	SEIZURE BURDEN					
	No Seizure/yr n=41 (27.3%)	**1-3 Seizures/yr n=47 (31.3%)**	**4-11 Seizures/yr n=22 (14.7%)**	**>12 Seizures/yr n=40 (26.7%)**	**F(df=3)**	**P**
VARIABLE OF PLWE						
Age of Respondent						
Range	18-57	18-75	19-71	18-48		
Mean	**34.34**	**32.77**	**28.73**	**28.58**		
Mode	41.00	24.00	30.00	48.00		
Median	34.00	26.00	26.00	26.00	2.332	0.077
Age at Onset						
Range	0-51	3-64	12-56	0-31		
Mean	**24.78**	**22.61**	**22.04**	**14.85**		
Mode	7.00	9.00	27.00	25.00		
Median	24.00	21.00	19.00	14.50	5.633	**0.001**
Annual Income (Kshs)						
Range	0-300,000	0-600,000	0-360,000	0-156,000		
Mean	**52,193.85**	**74,451.06**	**42,818.18**	**13,740.00**		
Mode	24,000	120,000	60,000	60,000		
Median	**0.00**	**0.00**	**0.00**	**0.00**	3.161	**0.027**
Duration of Illness						
Range	2-36	2-40	2-16	2-36		
Mean	**9.56**	**10.15**	**6.68**	**13.73**		
Mode	34.00	15.00	3.00	23.00		
Median	6.00	7.00	5.00	10.00	3.392	**0.020**
When Suffered Head Injury						
Range	0-16	0-26	0-16	0-36		
Mean	**1.24**	**1.66**	**1.27**	**5.18**		
Mode	**0.00**	**0.00**	3.00	23.00		
Median	**0.00**	**0.00**	**0.00**	**0.00**	3.177	**0.026**
MMSE						
Range	6-30	23-30	0-30	0-30		
Mean	**26.37**	**27.34**	**24.95**	**23.50**		
Mode	27.00	26.00	30.00	28.00		
.Median	28.00	28.00	26.50	26.00	4.029	**0.009**

6.4 Quality of life

Out of the 300 subjects interviewed for the study, 150 (100%) of NC's and 135 (90%) of the PLWE satisfied the inclusion criteria and completed the WHOQOL-Bref questionnaire. The mean QOL of the PLWE was 49.90% while that of the accompanying NCs was 77.60%.

The null hypothesis was tested using the independent samples test (t-test) at 99% confidence interval for the difference in means whereas the comparison between the expected mean QOL and the observed mean QOL was tested using the one sample test.

The mean QOL of PLWE (49.90%) at KNH was significantly (t= -17.694,p<0.01) lower than that of the NCs (77.60%) accompanying them and significantly (t= -18.298,p<0.01) impaired as compared to the hypothesized mean of 75%.The NCs had a significantly (t= 3.148,p<0.01) higher mean QOL as compared to that of the hypothesized mean of 75%.

The null hypothesis was therefore rejected accepting the alternative hypothesis.

The difference between PLWE and NCs in mean domain and facet QOL scores was also tested using the independent samples test (t-test) at 99% confidence interval.

All the four mean domain QOL scores were significantly (p<0.01) lower in PLWE as compared with NC's. The mean physical health QOL score (t = -19.859) differed most, with psychological QOL (t = -18.698), social relationships QOL (t = -12.046) and environmental QOL (t = -9.934) following in order of decreasing difference in mean domain QOL scores.

Figure 1 overleaf shows graphical representation of domains as determinants of mean QOL. All the mean facet QOL scores were significantly ($p<0.01$) lower in PLWE as compared with NCs apart from the subjective evaluation on financial resources. Both groups reported not having enough money to meet their needs (p= 0.625, t= 0.489).

Figures 2 to 5 overleaf show graphical representation of facets as determinants of domain QOL.

As shown in figures 2,mean facet scores determining physical health QOL differed most in the need for daily treatment(t= 29.884),the extent physical pain prevented daily activities(t= 13.782) and satisfaction in their capacity for work(t= -13.423).Those determining psychological QOL(figure 3) differed most in ability to concentrate(t= -14.844),frequent negative feelings(t= 14.179) and the extent life was meaningful(t= -12.389).

The mean facet scores determining social relationships QOL(flgure 4) differed most in satisfaction with their sex life (t= -10.631), personal relationships (t= -10.997) and the support they got from their friends (t= -6.517).Those determining environment QOL(figure 5) differed most in how safe they felt in their daily lives (t= -10.752), satisfaction with access to health services (t= -9.884) and satisfaction with the conditions of the place they lived (t= -7.589).

In order to determine how much variation in mean QOL of PLWE is accounted for by the joint predictive power of the four domains of QOL, further analysis using a stepwise regression model was done.

Table 4: Results of the stepwise regression analysis in the model used

Model	R^2	R^2 Change	SigF Change	beta	t	Sig
1	0.816[a]	0.816	0.000	0.903	1.2E + 08	0.000
2	0.907[b]	0.091	0.000	0.434	LIE + 08	0.000
3	0.972[c]	0.066	0.000	0.357	1.7E + 08	0.000
4	1.000[d]	0.028	0.000	0.260	LIE + 08	0.000

a Predictors: (Constant); Physical heath QOL

b Predictors: (Constant); Physical heath QOL, Environment QOL

c Predictors: (Constant); Physical heath QOL, Environment QOL, Social relationships QOL

d Predictors: (Constant); Physical heath QOL, Environment QOL, Social relationships QOL, Psychological QOL

e Dependent Variable: Mean QOL

As shown in the model, and in decreasing order of importance, physical health, environment, social relationships and psychological health contributed significantly to the outcome, mean QOL (dependent variable).

In the stepwise model, 81.6% of variations in mean QOL was explained by mean physical health QOL, 9.1% by environment, 6.5% by social relationships and 2.8% by mean psychological QOL. Physical health domain (beta= 0.903) showed the most positive relationship with mean QOL in the model.

The residuals plot showed that data met the assumptions of linearity, homoscedasticity and normality in the regression model used.

Figure 1:

Mean Domain scores as determinants of Mean QOL

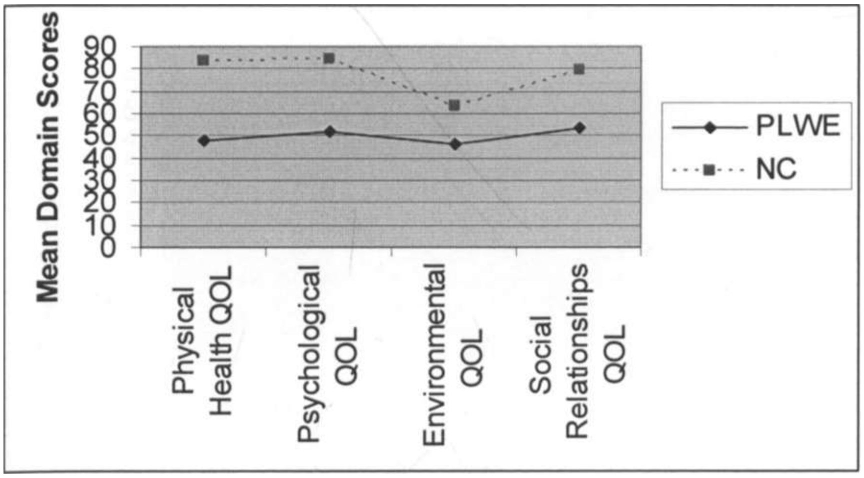


Figure 2:

Facets determining Physical domain QOL

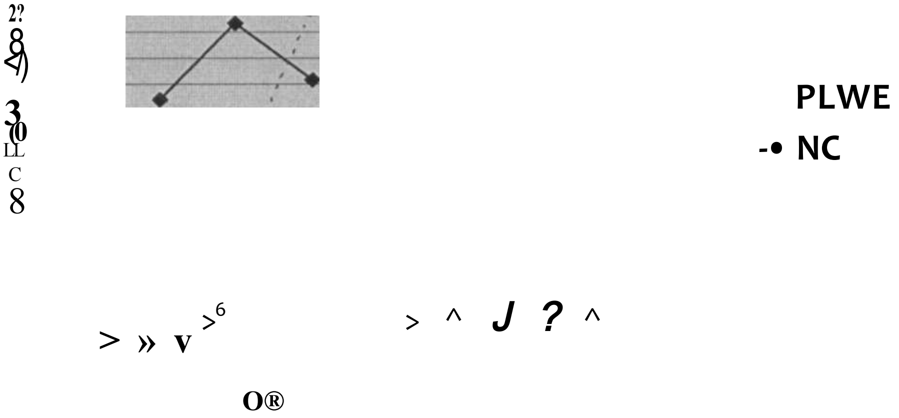


Figure 1:

Facets determining Psychological domain QOL

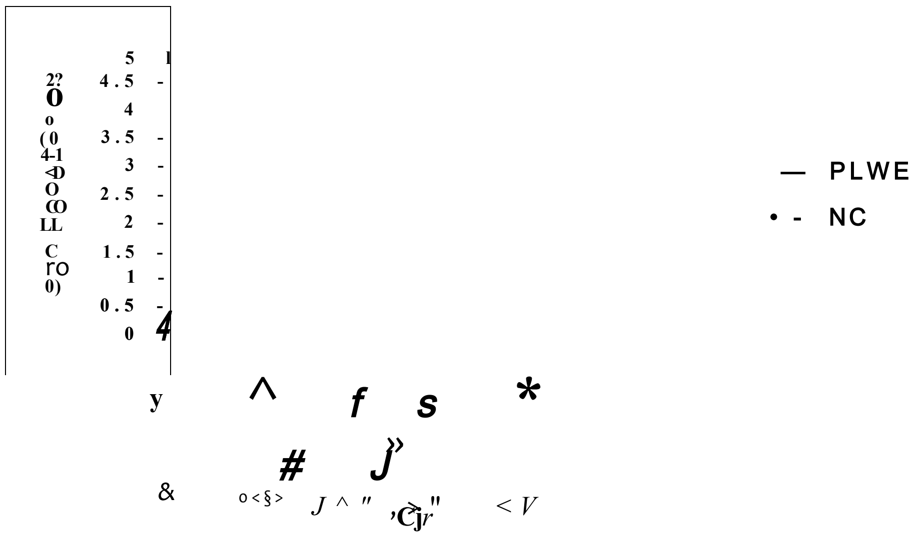


Figure 4:

Facets determining Social relationships domain QOL

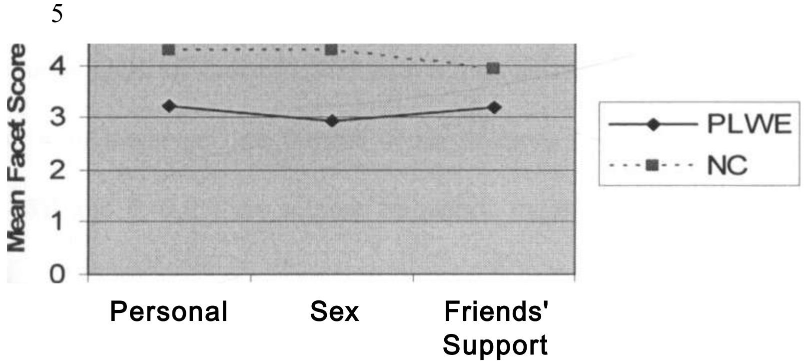
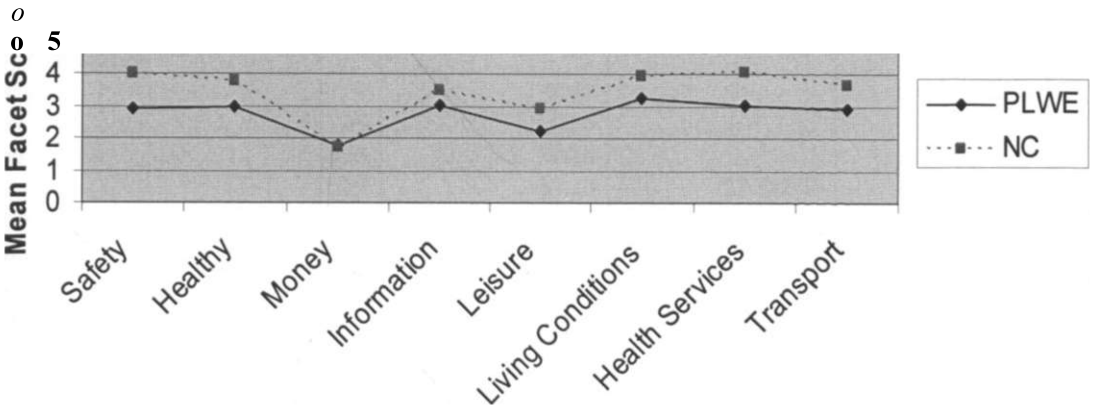


Figure 1:

Facets determining Environmental domain QOL



6.5 QOL and socio-demographic and clinical characteristics of PLWE

A comparison of the mean QOL between groups comprising independent variables was done and statistical significance, showing linearity, determined.

Table 5 overleaf shows the relationship of the variables of PLWE and QOL.

The mean QOL of those PLWE with a high seizure burden was significantly lower than for those with lower seizure burden or no seizures, [F value between groups (linearity) 6.789 (17.88)] and $P<0.05$. As seizure frequency increases, PLWE showed more impaired mean QOL.

Table5: Mean QOL and various variables of PLWE.

VARIABLES	n	MEAN QOL	F(df) • Linearity • Between Groups	P
Residence				
Urban	71	53.29		
Rural	64	46.14	7.079(1)	**0.009**
Level of Education				
No formal	4	48.62		
Primary	45	42.6		
Secondary	58	50.15		
Tertiary	20	61.10	23.752**(1)**	**<0.001**
University	8	61.78	7.022 (4)	**<0.001**
Employment Status				
Employed	60	54.29		
Unemployed	75	46.39	8.656(1)	**0.004**
Type of Employment				
Skilled	19	65.78		
Unskilled	41	48.96	22.290(1)	**<0.001**
Income/Month (kshs.)				
None	75	46.39		
1-22999	8	47.15		
23000-59999	15	49.48		
60000-119999	12	50.77		
120000-179999	13	60.53		
180000-359999	8	58.90	16.700(1)	**<0.001**
360000 or more	4	67.62	3.144 (6)	**0.007**
Seizure Burden				
No Seizures last one year	37	54.28		
1-3 Seizures last one year	47	54.26		
4-11 Seizures last one year	19	46.05	17.880(1)	**<0.001**
>12 Seizures last one year	32	40.72	6.789 (3)	**<0.001**
Reason for Non-Compliance				
Side Effects	5	59.70		
Financial difficulties	30	47.48		
Forgot to take	9	62.72	2.235(1)	0.142
Others	7	59.07	3.057 (3)	**0.037**
Reason for unemployment				
Due to disease	37	39.45		
Not due to disease	12	• 47.39		
Retired	4	49.00	20.385 (1)	**<0.001**
Student	22	57.04	7.100 (3)	**<0.001**

As shown in Table 5, there is statistically significant (P<0.05) relationship between a lower mean QOL and having lower annual income [F value, between groups (linearity) 3.144 (16.7)], lower level of education [F value, between groups (linearity) 7.022 (23.752)], being unemployed [F value, 8.656], unskilled unemployment [F value, 22.290], living in a rural residence [F value, 7.079], and also in those who reported their disease as the cause of being unemployed[F value, between groups(linearity) 7.100(20.385)].

In an effort to determine how much variation in mean QOL is accounted for by the joint predictive power of the variables, the author decided to further analyze the data using a stepwise/forward regression model. To decide which variables to include in the regression analysis, all independent variables were correlated with the dependent variable, mean QOL, using bivariate (Pearson) correlation.

Table 6 below shows the significant correlations of individual variables of PLWE with mean QOL.

Table 6: Bivariate correlations of variables of PLWE with QOL

	MEAN QOL	**PHYSICAL HEALTH**	**PSYCHOLOGICAL**	**SOCIAL RELATIONSHIPS**	**ENVIRONMENTAL**
	Pearson Correlation	**Pearson Correlation**	**Pearson Correlation**	**Pearson Correlation**	**Pearson Correlation**
Residence	• * -0.225	* -0.191	* -0.171	* -0.217	* -0.187
Level of Education	** 0.388	** 0.366	** 0.264	** 0.396	** 0.283
Employment Status	** -0.247	** -0.296	** -0.257	* -0.179	
Type of Employment	** -0.527	• * -0.521	** -0.478	** -0.368	** -0.438
Average Income	** 0.337	*• 0.346	** 0.349	** 0.233	** 0.241
.Reason for Unemployment	** 0.470	** 0.434	** 0.401	** 0.372	** 0.418
J^verage Seizures Last lyr	** -0.344	** -0.277	** -0.305	** -0.342	** -0.247
_Religion__			** -0.226		
-WhenSuffered Head Injury			* -0.179		* -0.206
J^asonfor Non-compliance			* 0.330		

* Correlations significant at the 0.0.5 level
Correlations significant at the 0.01 level

As shown in table 6, the statistically significant variables in the correlation were reason for unemployment, level of education, average seizures over the last 1 year, type of employment, annual average income, employment status and residence. Therefore the author decided to omit the rest of the variables from the regression analysis.

Table 7: Results of the stepwise regression analysis in the model used.

Model	R^2	R^2 Change	SigF Change	beta	t	Sig
1	0.116^{a}	0.116	0.000	0.341	4.414	0.000
2	0.197^{b}	0.081	0.000	-0.285	-3.839	0.000
3	0.247°	0.050	0.000	0.229	3.108	0.002
4	0.292^{d}	0.045	0.000	0.224	3.032	0.003
5	0.315^{e}	0.023	0.000	-0.172	-.2.192	0.030

a Predictors: (Constant) Level of Education.

b Predictors: (Constant) Level of Education, Average Seizures last one year

c Predictors: (Constant) Level of Education, Average Seizures last one year, Reason for unemployment.

d Predictors: (Constant) Level of Education, Average Seizures last one year, Reason for unemployment, Average Income,

e Predictors: (Constant) Level of Education, Average Seizures last one year, Reason for unemployment, Average Income, Type of Employment,

f Dependent Variable: Mean QOL

Table 7 shows the variables (left in the final model after all variables had been entered into analysis according to the specified order) that contribute most and significantly to the outcome, mean QOL (dependent variable).In increasing order of importance these variables are type of employment, average annual income, reason for unemployment, average annual seizures, and the level of education attained by the PLWE.

In the stepwise model, 11.6% of variations in mean QOL was explained by level of education, 8.1% average annual seizures, 5.0% reason for unemployment, 4.5% average annual income, and 2.3% by type of employment. These variables therefore explained 31.5% of the total variation in mean QOL. In the model negative relationships between average annual seizures (beta= -0.285) and type of employment (beta= -0.172) with the mean QOL is shown.

The residuals plot showed that data met the assumptions of linearity, homoscedasticity and normality in the regression model used.

There was no statistically significant (P>0.05) relationship between mean QOL of PLWE and gender, marital status, age, children had, household size, mode and specific type of drug therapy, seizure type, age at onset of epilepsy, duration of illness or duration of treatment.

Table 8: Comparison of mean facet scores by reason for unemployment

	F(df=3)	**P**
Physical Health QOL		
Extent physical pain prevent daily activities	3.459	0.021
Energy for everyday life	4.097	0.010
Ability to get around	5.879	0.001
Satisfaction with ability to perform daily activities	3.136	0.031
Satisfaction with capacity for work	4.864	0.004
Psychological QOL		
How much they enjoy life	3.944	0.012
Satisfaction with self	4.930	0.004
Social Relationships QOL		
^Satisfaction with their sex life	3.503	0.020
Satisfaction with support from friends	3.432	0.021
^Environment **QOL**		
.Enough money to meet needs	3.060	0.034
.Opportunities for leisure activities	8.525	0.000
J>atisfaction with conditions of the place they live	2.992	0.037
J^atisfaction with access to health services	4.259	0.008

6.5.1 Reason for unemployment

The PLWE who reported their illness(epilepsy) as the cause of their unemployment subjectively showed decreased capacity for work(p=0.004), ability to get around(p=0.001),enjoy life(p=0.012),less opportunities for leisure activities(p=0.000) and a decreased ability to perform their daily activities(p=0.031).They also reported not having enough money to meet their needs(p=0.034),dissatisfaction with themselves(p=0.004)and their sex life(p=0.020)with more physical pain preventing them from doing what they needed to do(p=0.021).This group of PLWE was also dissatisfied with their access to health services(p=0.008),the conditions of the place they lived(p=0.037),support from their friends(p=0.021) and reported having less energy for everyday life (p=0.010).

Table 9: Comparison of mean facet scores by religion

	F(df=2)	P
Psychological QOL		
Acceptance of bodily appearance	3.171	0.045
Satisfaction with self	4.826	0.009
Environment QOL		
Physical safety and security	3.412	0.036

6.5.2 Religion

Those PLWE with religious affiliation showed more acceptance of their bodily appearance (p=0.045) and subjectively felt safer in their daily life (p=0.036).The Protestants were the most satisfied (mean facet score=3.6) with themselves whereas Catholics (mean facet score= 3.05) showed the least satisfaction, even lower than those with no religious affiliation (mean facet score=3.5). This relationship was statistically significant (p=0.009).

Table 10: Comparison of mean facet scores by average annual seizures

	F(df=3)	P
Physical Health QOL		
Ability to get around	2.681	0.050
Satisfaction with sleep	3.926	0.010
Satisfaction with ability to perform daily activities	5.695	0.001
Satisfaction with capacity for work	2.807	0.042
Psychological QOL		
How much they enjoy life	4.492	0.005
Satisfaction with self	3.169	0.027
Frequency of negative feelings (blue mood, despair, anxiety, depression)	2.872	0.039
Social Relationships QOL		
Satisfaction with personal relationships	2.906	0.037
Satisfaction with their sex life	6.213	0.001
Environment QOL		
Availability of information needed in day to day life	3.072	0.030

6.5.3 Seizure burden

PLWE with higher seizure burden showed dissatisfaction with their ability to perform daily activities (p=0.001), their sex life (p=0.001) and enjoyed life less (p=0.005).They also reported decreased satisfaction with their sleep (p=0.010), themselves (p=0.027) and the availability of information they needed in day-to-day life (p=0.030).

Table 11: Comparison of mean facet scores by residence

	F(df=l)	P
Physical Health QOL		
Ability to get around	8.155	0.005
Satisfaction with sleep	5.387	0.022
Satisfaction with ability to perform daily activities	5.221	0.024
Psychological QOL		
Extent life is meaningful	10.549	0.001
Frequency of negative feelings (blue mood, despair, anxiety, depression)	5.081	0.026
Social Relationships QOL		
Satisfaction with their sex life	12.587	0.001
Environment QOL		
Availability of information needed in day to day life	5.990	0.016
Satisfaction with access to health services	4.949	0.028

6.5.4 Residence

Those PLWE residing in a rural community reported lower extents of their life being meaningful (p=0.001), less satisfaction with their sex life (p=0.001), accessibility to health services (p=0.028), sleep (p=0.022) and availability of information they needed in their day-to-day life (p=0.016) than those from an urban community. They also were dissatisfied with their ability to perform their daily activities (p=0.024), get around (p=0.005) and suffered frequent negative feelings (p= 0.026).

Table 12: Comparison of mean facet scores by level of education

	F(df=4)	P
Physical Health QOL		
Need for treatment function in daily life	3.143	0.017
_Energy for everyday life	5.494	0.000
Ability to get around	7.147	0.000
Satisfaction with ability to perform daily activities	3.296	0.013
.Satisfaction with capacity for work	4.826	0.001

Psychological QOL		
Acceptance of bodily appearance	3.933	0.005
Satisfaction with self	3.661	0.007
Social Relationships QOL		
Satisfaction with personal relationships	3.468	0.010
Satisfaction with their sex life	4.635	0.002
Satisfaction with support from friends	2.849	0.026
Environment QOL		
Enough money to meet needs	4.500	0.002
Opportunities for leisure activities	3.141	0.017
Satisfaction with conditions of the place they live	2.456	0.049
Satisfaction with access to health services	3.400	0.011

6.5.5 Level of education

Those PLWE with lower educational levels subjectively reported decreased ability to get around (p=0.000), energy for everyday life (p=0.000) and capacity for work (p=0.001).This group of PLWE felt they did not have enough money to meet their needs (p=0.002), were dissatisfied with themselves (p=0.007) and their sex life (p=0.002) and showing the least acceptance of their bodily appearance (p=0.005).

Tablel3: Comparison of mean facet scores by employment status

	F(df=l)	**P**
Physical Health QOL		
Need for treatment function in daily life	10.264	0.002
Ability to get around	8.546	0.004
Satisfaction with sleep	5.757	0.018
Satisfaction with ability to perform daily activities	8.277	0.005
Satisfaction with capacity for work	7.720	0.006
Psychological QOL		
How much they enjoy life	8.295	0.005
Extent life is meaningful	7.777	0.006
Ability to concentrate	7.374	0.007
Frequency of negative feelings (blue mood, .despair, anxiety, depression)	4.454	0.037
.Social Relationships QOL		
.Satisfaction with their sex life	4.732	0.031

Environment QOL		
Physical safety and security	4.614	0.034
Healthy physical environment		
Enough money to meet needs	9.604	0.002

6.5.6 Employment status

Those PLWE and unemployed reported an increased need for daily treatment (p=0.002), less money to meet their needs (p=0.002), dissatisfaction with their sleep (p=0.004), or ability to perform their daily activities (p=0.005).They also subjectively enjoyed life less (p=0.005) and showed lower extents of life being meaningful (p=0.006).This group of PLWE showed dissatisfaction with their capacity for work (p=0.006).

Table 14: Comparison of mean facet scores by time of head injury

	F(df=3)	**P**
Environment QOL		
Healthy physical environment	3.449	0.019
Availability of information needed in day to day life	4.968	0.003

6.5.7 When suffered head injury

The group of PLWE with a longer duration post suffering head injury subjectively reported increased unavailability of information they needed in their day-to-day life(p=0.003) and felt their environment was unhealthy(p=0.019) despite showing no significant(x^2=0.786, p=0.853), difference in residence with the rest of the PLWE.

v

Table 15: Comparison of mean facet scores by type of employment

	F(df=l)	P
Physical Health QOL		
Need for treatment function in daily life	8.373	0.005
Energy for everyday life	10.018	0.002
Ability to get around	22.278	0.000
Satisfaction with sleep	4.083	0.048
Satisfaction with ability to perform daily activities	12.334	0.001
Satisfaction with capacity for work	13.156	0.001
Psychological QOL		
Ability to concentrate	7.239	0.009
Acceptance of bodily appearance	19.479	0.000
Satisfaction with self	19.259	0.000
Social Relationships QOL		
Satisfaction with personal relationships	5.297	0.025
Satisfaction with support from friends	6.669	0.012
Environment QOL		
Physical safety and security	8.217	0.006
Healthy physical environment	4.532	0.038
Enough money to meet needs	22.851	0.000
Opportunities for leisure activities	4.713	0.034
Satisfaction with their transport	5.916	0.018

6.5.8 Type of employment

Those PLWE with unskilled employment reported more dissatisfaction with their ability to perform daily activities (p=0.001), capacity for work (p=0.001), sleep (p=0.048) and ability to get around (p=0.000) than those with skilled employment. They subjectively felt an increased need for daily treatment to function(p=0.005),reported not having enough money to meet their needs(p=0.000),reduced energy for everyday life(p=0.002),diminished ability to concentrate(p=0.009) and were unwilling to accept their bodily appearance(p=0.000).This group of PLWE was also dissatisfied with their personal relationships(p=0.025), themselves(p=0.000),their transport(p=0.018) and support from their friends(p=0.012).The PLWE with unskilled employment had less opportunities for leisure activities(p=0.034),felt insecure about their safety(p=0.006) and reported their environment as unhealthy(p=0.038).

Table 16: Comparison of mean fact scores by annual income

	F(df=6)	P
Physical Health QOL		
Need for treatment function in daily life	2.586	0.021
Ability to get around	2.299	0.038
Satisfaction with ability to perform daily activities	2.836	0.013
Satisfaction with capacity for work	3.533	0.003
Psychological QOL		
How much they enjoy life	2.265	0.041
Extent life is meaningful	2.191	0.048
Ability to concentrate	3.287	0.005
Acceptance of bodily appearance	2.319	0.037
Environment QOL		
Enough money to meet needs	3.280	0.005
Satisfaction with access to health services	2.795	0.014

6.5.9 Annual income

Those PLWE with lower annual income reported dissatisfaction with their capacity for work (p=0.003), significant impairment in their ability to concentrate (p=0.005) and as expected less money to meet their needs (p=0.005).They were dissatisfied with their ability to perform daily activities (p=0.014) and needed treatment to function in their daily life (p=0.021).They showed reduced acceptance of their bodily appearance (0.037).

6.6 Global Assessment of Functioning (GAF) Score

The GAF scores of PLWE ranged from 30 to 90 with a mean (s.d.) of 68.4 (11.734) and median of 70. However, the GAF scores of those PLWE with a MMSE score of <22 ranged from 30 to 60 with a mean (s.d.) of 48.67 (6.114) and median of 50. Those for the PLWE having a MMSE score of >22 had a range of 50 to 90 with a mean (s.d.) of 70.59 (10.038) and median of 70. Those for the NC's ranged from 65 to 95 with a mean (s.d.) of 87.67 (5.105) and median of 90. As shown in Figure 6 overleaf, this corresponds to varying levels of functioning.

Figure 6: GAF scores and corresponding level of functioning.

NORMAL CONTROLS	90 81	Absent or minimal symptoms (e.g. mild anxiety before an exam)good functioning in all areas interest and involved in a wide range of activities, socially effective, generally satisfied with life, no more than everyday problems or concerns (e.g. an occasional argument with family members)
PLWE with MMSE >22	80 71	If symptoms are present, they are transient and expectable reactions to psychosocial stressors (e.g. difficulty concentrating after family argument); no more than slight impairment in social, occupational ,or school functioning (e.g. temporarily falling behind in schoolwork)
PLWE	70 61	Some mild symptoms (e.g. depressed mood and mild insomnia) OR some difficulty in social, occupational, or school functioning (e.g. occasional truancy, or theft within the household), but generally functioning pretty well, has some meaningful interpersonal relationships.
PLWE with MMSE <22	50 41	Serious symptoms(e.g. suicidal ideation, severe obsess ional rituals, frequent shoplifting) OR any serious impairment in social, occupational, or school functioning (e.g. no friends, unable to keep a job)

Table 17 overleaf shows a comparison of means in GAF scores and QOL for the whole group As shown in table 17, there appears to be a linear trend that is statistically significant. As mean GAF scores increase, the mean QOL increases. The representation in figure 6 can lead to an alluded assumption that PLWE excluded from WHOQOL-Bref had a much lower mean QOL than those included. However, that assumption requires further analysis.

The subjective overall rating in QOL and satisfaction with health was significantly lower and showed unity at lower mean GAF scores. From mean GAF scores of 80 and above there is a significantly higher rating in subjective satisfaction with health as compared with QOL; keeping in mind majority of the NCs ,146(97.3%),mean GAF scores were significantly($p<0.05$) higher (above 80) than those of PLWE,45(30.0%).

Table 17: Comparison of means in GAF scores and QOL

GAF	n	** Mean QOL	*** Overall rating QOL	**** Overall Satisfaction with self health QOL	* P
<50	1	40.75	2.0	2.0	
51-60	40	39.09	2.40	2.28	
61-70	41	48.67	2.54	2.44	
71-80	50	60.28	3.36	3.36	
81-90	135	75.15	3.89	4.10	
>=91	18	89.79	4.50	4.89	<0.000

* P value was similar for mean QOL, overall rating and satisfaction with self.

F between groups(df),linearity(df)

** 91.306(5),451.112(1)

*** 42.223(5), 204.733(1)

**** 67.422(5), 326.137(1)

7.0 DISCUSSION

7.1 Socio-demographic Distribution

The study population consisted of 300 subjects. 150 PLWE and 150 NC's accompanying them to the neurology clinic at KNH, Nairobi. In this sample there was no significant difference in age of the respondents, gender, residence, children had, household size and religion by epilepsy status. This was similar to the findings by Hela et al in a 2002 study (46) even though they found no significant difference in the educational level of the Tunisians.

Distribution of employment status, marital status, the level of education, mean annual income, type of employment and mean MMSE scores differed significantly by epilepsy status.

The NC's were accompanying the PLWE for their clinic visits and interestingly, though not statistically significant, there were more females (59.3%) than males (40.7%) in the NC group. This finding, the author felt, reflects how gender determines the "role played" in our society. It appears the female gender plays a more caring and supportive role in our society.

Majority of the PLWE were single while the NC's were married, yet more of the NC's were living alone and less of the PLWE were living alone(x^2= 10.227, p=0.001), despite showing similar mean household sizes. A plausible explanation would be that the PLWE needed people around to take care of them and even accompany them for their clinic visits. This subjective and objective lack of independence in the living arrangements of PLWE has been reported in other studies (31, 35, 40, 41).

The NC's were better educated with 47.3% attaining tertiary level of education as compared to 17.3% of the PLWE. In the NC's group 74.7% were gainfully employed whereas, only 41.3% were, among the PLWE. Furthermore, of the employed only 20 (32.3%) of the PLWE had skilled employment as compared to 54 (48.2%) of the NC's. This level of unemployment was much higher than that found in earlier studies (35, 46, 48). Muinga in a 1986 study (21) reported a level of 50.8% whereas Mativo in 2004 (18) found a level of 35%. Both studies were carried out in the same locality as the current one. Emanating from the above, the NCs seemed to have a much better earning capacity and hence higher annual income than the PLWE.

The MMSE mean scores for the PLWE were significantly lower than that of the NCs. In fact 15(5%) of the PLWE failed to achieve MMSE scores > 22 to be included in the WHOQOL-Bref assessment as compared to none of the NCs. However to avoid speculation this difference in cognitive ability was further assessed using the GAF in comparison to the mean QOL scores.

7.2 Qol

This study is the first of its kind in Sub-Saharan Africa, as far as could be ascertained by the author, being a comparison of QOL among PLWE and NC's. The mean QOL of PLWE (49.90%) is significantly lower than that of the NC's (77.60%). This observation finds support in earlier studies (36, 38, 40, 43, 46, 47). Comparing the mean QOL with that hypothesized as a 'gold standard' (75 ± 2.5%), this study demonstrated a significantly ($p<0.01$) impaired QOL in PLWE and a significantly ($p<0.01$) higher QOL for the NC's.

The perception of the PLWE, unlike that of the NC's, is that they need treatment to function in their daily lives (PO.Ol), feel physical pain prevents them from achieving what they want in life (PO.Ol) and are not at all satisfied with their capacity for work (PO.Ol). Similar findings have been reported in earlier studies where worry and pain prevented activities of daily living (35, 37, 38) among the PLWE .Other studies (32,33,34) reported dissatisfaction with their capacity for work. Unlike the NC's, they subjectively report a diminished ability to concentrate (PO.Ol), also suffer frequent negative feelings (PO.Ol) and feel life is less meaningful (PO.Ol).

PLWE are also dissatisfied with their sex life (PO.Ol), personal relationships (PO.Ol) and support from friends (PO.Ol). They feel unsafe (PO.Ol), dissatisfied with access to health services ($P<.01$) and despite no significant difference in residence, show dissatisfaction with the conditions of the place they live (PO.Ol).

As discussed above the PLWE, in this study, have lower mean scores in all the 4 domains of QOL; physical health, psychological, social relationships and environment. This level of impairment is similar to earlier western population studies (38, 43, 47) but much higher than that found in a Tunisian study in 2002 (46).

Physical functioning and limitation, emotional role limitation, bodily pains, energy and vitality of the Tunisian PLWE were similar to those of the NC's in a 2002 study (46),unlike in the current study. The Tunisian authors thought major differences based on cultural, religion (Muslims), family and social support between them and western populations could have been the major contributors to the findings. It is however difficult to compare with the current study since they used the SF-36 sub-scales of QOL in their study.

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Among the PLWE, most (81.6%) of the variations in mean QOL was explained by the physical health domain in the model used. The environmental, social relationships and psychological QOL domains followed in order of decreasing importance. The physical health domain (beta = 0.903) showed the most positive relationship with mean QOL; environment (beta= 0.434), social relationships (beta= 0.357) and psychological (beta = 0.260) QOL domains, followed in order of decreasing nature of the relationship with mean QOL in the model.

Importantly, increasing seizure burden is the only clinical variable significantly associated with impairment of QOL, in all domains, among PLWE in this study. Earlier studies (25, 37, 38, 43, 46) showed that seizure frequency was a significantly inverse predictor of QOL among PLWE in both western and non western populations. This concurs with the findings in the current study.

The other variables significantly associated with impairment of QOL among PLWE in this study include rural residence, unemployment, unskilled employment, lower annual income, lower level of education, and those that blamed their illness (epilepsy) as the cause of their being unemployed.

7.3 Seizure burden related characteristics of PLWE

An appraisal of seizure frequency has been shown to be central to the diagnosis (9), management (22, 25, 29), outcome (37, 38), associated stigmatizing behaviour (34) towards PLWE, and ultimately their QOL. In this study, 26.7% of the PLWE suffered at least one seizure/month while 27.3%, were seizure free over the preceding 1 year. There were more

(34.5%) seizure free and more (28%) with at least one seizure/month in a recent Tunisian study (46) among PLWE.

Distribution of some socio-demographic and clinical variables of PLWE differed significantly by seizure burden. The use of polytherapy, alternative therapy, an earlier age at onset of epilepsy, being single , lower annual income, longer duration of illness or past history of head injury and lower MMSE scores and were significantly associated with higher seizure burden.

The author speculates that the increased seizure burden in those with an earlier age at onset could possibly be as a result of establishment of a seizure focus during active intricate aborization in the brain. This could possibly reduce the seizure threshold and control mechanisms. Other authorities (44) consider childhood onset epilepsy a marker for adverse effect on QOL, including stigma and unemployment.

It appears like the longer the duration of illness or past history of head injury the worse the seizure burden seems to get. Furthermore those with an early age at onset of epilepsy also had a longer duration of illness. This "longer duration", the author speculates, might be responsible for either firm entrenchment of a seizure focus or diminishing seizure control mechanisms. However this warrants further analysis.

The current study found more (37.3%) PLWE were using alternative modes of therapy unlike (22%) in the 2004 local study; 30% were also on polytherapy then as compared to 54% in the current study. The use of alternative therapy, especially herbal treatments, requires further evaluation for possible neurobiological effects on PLWE.

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Unfortunately, the reason for an increase in polytherapy use could not be captured in this study. The socio-economic implications, drug interaction and the significantly higher seizure burden associated, could possible be avoided by first using the recommended optimal dose of monotherapy following thorough early epilepsy classification. Other authorities (19, 20) have suggested similar recommendations. Studies (25) have also shown the impact of surgical intervention on seizure control and QOL, especially in TLE, to be positive in all ages. Assessment for possible neurosurgical intervention of those PLWE with intractable seizures could also be an alternative.

A MMSE score of <22 was also found to be significantly (t=2.125, p=0.035) associated with higher seizure burden A possible explanation would be higher seizure burden leads to cognitive impairment. MMSE scores were however not significantly (t=0.121, p=0.904) associated with AEDs therapy.

This study showed no significant association of seizure burden with age of the respondent, specific drug therapy, family history of epilepsy, seizure type, duration of treatment, non-compliance over the preceding 1 month and modes of alternative therapy used.

The author speculates that a larger sample of PLWE on specific drug therapy or alternative modes of treatment and possibly a longitudinal study design would determine better conclusive findings. A longer duration (>1 month) on non-compliance inquiry would have possibly been more informative.

7.4 Reason for unemployment

Contemporary studies (39, 40, 47) have shown that among PLWE perceived stigma is much greater today than the clear evidence (4, 5, 7, 8) of stigmatizing behaviour in the past. Over half (53.4%) of the unemployed PLWE blamed their disease (epilepsy) as the cause of their unemployment. Similar findings, with higher levels (62%), were reported in a recent Tunisian study (46).

This 'reason', which the author equates to a subjective feeling of being stigmatized, was among the most important factors explaining lower QOL, among PLWE in the current study. This finding was similarly reported in other studies(32,33,34) that showed the unfavourable public attitude towards PLWE and the negative expectations from their workmates, subsequently leads to increased 'secrecy' about their condition . In agreement with the above, the author felt that possibly due to the recurrent and sustained levels of objective stigma towards PLWE, they have internalized it and developed subjective stigma; blaming their disease for unemployment. This may run through and affect their activities of daily living, satisfaction with self or capacity for work, ability to enjoy life, social activities and interactions, income and experimentation with alternative therapy ultimately resulting in increased levels of psychopathology (anxiety and depression).

Interestingly, Muinga (21) found that psychopathology in PLWE was positively correlated with unemployment and another recent local study (18) reported 63% of the unemployed PLWE were poorly controlled. The implication of these findings did not come out in both the studies. However, the necessary selective .exclusion of PLWE from some occupations upon diagnosis may also play a role in initiating this subjective feeling of stigma. The author speculates that early supportive management, from the time of diagnosis, would be invaluable.

7.5 Seizure burden

In this study, seizure frequency was a significantly inverse predictor of QOL, across all domains, among PLWE. In fact, there was significantly better mean QOL for seizure free PLWE, similar to what was found in earlier studies (37, 38, 39, 43, 46), but nevertheless still significantly impaired than that of the NC's. Reduction in seizure burden appears to be the key factor in improving the QOL of PLWE in both western and non-western populations. Avoiding the use of alternative modes of therapy and polytherapy (where possible), and a multidisciplinary approach would enable these achievements.

Importantly, in this study, higher seizure burden was significantly associated with those on polytherapy, alternative therapy use, cognitive impairment, lower annual income, being single, longer duration of illness or past history of head injury and younger age at onset of epilepsy. Indeed, childhood onset epilepsy seems to be a marker for adverse effect on QOL of PLWE (44).

7.6 Level of education

This study found that as the level of education increased, there was a significant increase in mean QOL of PLWE. The level of education attained by PLWE was also the most important factor explaining variations in QOL.

There is the possibility that either the increased seizure burden associated with poorer mean QOL made it difficult for one to achieve highly academically, or their appraisal of the failure to achieve resulted in poorer QOL. However, the NC's achieved significantly higher levels of education than PLWE and hence the former assumption is more acceptable. **Alternatively** those whom attain higher levels of education have better opportunities for **skilled** employment with resultant higher income, better residence, easier aflfordability, availability and accessibility to treatment and information they need and subsequently no need for a reason for being unemployed. This would explain their relatively better QOL than their counterparts with **a** lower level of education.

The low level of educational achievement among **PLWE** could also arise from **reduced** ability to concentrate, school absenteeism from exacerbation of their illness or a high level of stigma and prejudice towards them. A recent Kentuckian study (47) predicted a **deterioration** of the classroom environment with the addition of a pupil with epilepsy. In this study, those **PLWE** with lower levels of educational achievement show decreased ability to get **around** reduced energy for everyday life and diminished capacity for work.

In the global campaign against epilepsy (4), the author suggests research into **alternative** forms of training to improve empowerment and coordination of care between patients and providers hence improving QOL of PLWE. This approach was introduced in New Mexico (45) and showed improvement in the QOL of PLWE.

7.7 Unskilled employment

In the current study only 32.3% of the employed PLWE had skilled employment. An earlier local study (21) found only 0.06% of the PLWE were employed as professionals. The negative expectations of PLWE from their workmates reported in earlier studies (32, 33) could be enhanced and "justified" by this low level of skilled employment among PLWE.

Earlier literature (14) has also shown that, among PLWE, an imbalance between their expectations and reality may be more menacing than the illness itself. The author speculates that those with unskilled employment suffered additional stigmatization and hostility within employment.

Not surprisingly, in this study, those PLWE with unskilled employment report dissatisfaction with themselves, their ability to concentrate, perform daily activities, their capacity for work and support from their friends. They also show dissatisfaction with their sleep. Having unskilled employment seems to run through and manifest in pessimism and may eventually lead to psychopathology (Depression).

Emanating from the above, the author felt that a comprehensive management program for PLWE would enable favourable active coping strategies instead of the more passive submissive approach currently. An improvement in the educational level of PLWE would be invaluable in achieving better employment.

7.8 Income and employment status

In agreement with the studies cited above, concerning unskilled employment and level of education, this study also found that low socio-economic status and specifically low annual income of the PLWE, was associated with significantly poorer QOL. Importantly this showed significant linearity, as their income increased their mean QOL improved. The high level of unemployment among PLWE in this study could be the most plausible explanation for their lower annual income as compared to the NC's.

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Those PLWE with lower annual income report dissatisfaction with their capacity for work, significant impairment in their ability to concentrate, and as expected less money to meet their needs. They are dissatisfied with their ability to perform daily activities, their accessibility to health services and need treatment to function in their daily lives. PLWE with lower annual income also show reduced acceptance of their bodily appearance.

Those PLWE and unemployed report an increased need for daily treatment, less money to meet their needs, dissatisfaction with their sleep and ability to perform their daily activities. They also subjectively feel they enjoy life less and report life to be meaningful at a much lower extent than those employed. This group of PLWE feels dissatisfied with their capacity for work.

7.9 Residence

Despite showing no significant difference in residence among PLWE, (rural: urban residence ratio of 1:1),those from the rural community subjectively report dissatisfaction with their access to health services .This study found they also feel their life is less meaningful, with dissatisfaction in their sex life, ability to get around and availability of information they need in their day-to-day life. This group, of PLWE from the rural residence, is also dissatisfied with their sleep, ability to perform daily activities and subjectively suffer more frequent negative feelings than their urban counterparts.

Earlier studies (4, 15) have shown that inaccessibility of health services interfere with optimal care for PLWE, contributing significantly-to the treatment gap among PLWE in developing countries.

7.10 Non-compliance

This study found that 34.7% of the PLWE are non-compliant to AED's treatment, with varying duration, in the preceding 1 month to the study. Interestingly the reason given for non-compliance was found to be significantly (p=0.037) associated with QOL of PLWE but being non-compliant per se was not.

The conclusion in a 2004 local study (18) was that financial difficulty was the main reason contributing to non-compliance and resulting in poor control of epilepsy. This study concurs with the aforementioned in that the majority (20.7%) of the non-compliant PLWE cited financial constraints as the cause. Interestingly this group shows significantly (p=0.037) poorer mean QOL scores, and in all the 4 domains, than the rest of the non-compliant PLWE.

In this study the reason for non-compliance correlated positively (P=0.018) with the psychological domain of QOL. Those who reported financial difficulties as the reason for non-compliance show significantly (p=0.011) lower extents of life being meaningful than the rest of the non-compliant. This group of PLWE also enjoy life less (p=0.019) and do not have enough money to meet their needs (p=0.000).

7.11 Religion

The numerous religions in our society today directly or indirectly influence our thoughts and behaviour. Religion can be invaluable to both patients and providers in coping with the intangible burden of disease. This was demonstrated in a Tunisian study (46) where Islamic teaching and beliefs enabled the PLWE to be less demanding and show increased acceptance of their illness. In agreement this study found that PLWE who had religious affiliation accepted their bodily appearance most and felt safest as compared to those with no religious affiliations.

The author speculates that the incorporation of positive religious coping in the management of PLWE would greatly enhance their self esteem, improving their QOL.

7.12 GAF

The Global Assessment of Functioning (GAF) is an integral part of the standard multiaxial psychiatric diagnostic system and helps predict the allocation and outcomes of mental health treatment. GAF mean ratings obtained were significantly (PO.Ol) higher for NC's **(81.67)** as compared with PLWE **(68.40).** The NC's showed absence of symptoms, good functioning in all areas, appeared socially effective and generally satisfied with life. The PLWE with a MMSE score of > 22 showed transient expectable reactions to psychosocial stressors with slight impairment in socio-occupational functioning. Those PLWE with a MMSE <22 showed serious symptoms and impairment in socio-occupational functioning and ability to comprehend. Significant (PO.Ol) linearity was shown between GAF mean ratings and mean QOL. As GAF ratings increased the mean QOL, overall rating for QOL and overall satisfaction with self health improved. Emanating from this the author speculated that those PLWE excluded (MMSE <22) from this study may have had more compromised mean QOL than those included (MMSE > 22). Due to the objective nature of the GAF ratings, and the findings above, the author would strongly propose the use of GAF in the routine assessment and follow-up of PLWE.

7.13 Limitations

The following limitations were encountered by the investigator during the study:

- Some of the subjects interviewed also participated in the 2004 study (18) and insisted on getting their blood test results. After reassurance on confidentiality and the collective implementation of any interventions this was resolved.
- Translation of the WHOQOL-Bref from English to the national **language** Kiswahili was not possible due to the short time frame. The author feels that a translation would be able to capture more subjectivity due to **easier** and correct **interpretation** of the questions. The subjective nature also excluded those whom the author **thought** needed the assessment most, were however captured on the GAF.
- Few studies have used the WHOQOL-Bref and GAF in comparing the HRQOL between PLWE and NCs. This made comparison of the study findings difficult.

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8.0 CONCLUSIONS AND RECOMMENDATIONS

8.1 Conclusions

- The mean QOL among PLWE presenting at KNH neurology clinic is 49.90% while that of their accompanying NCs is 77.60%.
- The mean QOL among PLWE attending the neurology clinic at KNH is significantly lower than that of the NCs accompanying them.
- The mean QOL among PLWE attending the neurology clinic at KNH is significantly impaired as compared to the hypothesized "gold standard" of 75+_2.5%.
- Factors associated with impairment of QOL among PLWE at KNH are lower level of education, higher seizure burden, lower annual income, unskilled employment, being unemployed, living in a rural residence, having no religious affiliation, longer duration post head injury, those citing financial constraints as a reason for their non-compliance and in those who blame their illness (epilepsy) as the cause of their unemployment.
- Factors showing no association with impairment of QOL among the PLWE at KNH are gender, marital status, age, children had, household size, specific drug therapy, seizure type and duration of treatment.

8.2 Recommendations

The author recommends the establishment of a comprehensive epilepsy management strategy programmed with the following objectives:

- Improving patient empowerment in management from the time of diagnosis and ^dressing their socio-economic needs through psycho-education and socio-occupational skills training.

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Advocacy of routine assessment using bio-psycho-social functional scales among PLWE, with appropriate interventions to help those showing impairment.

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De-stigmatization of epilepsy through mass-media and other fora, to increase awareness (especially among the youth), improve education and employment opportunities of PLWE and reduced hostility towards those already employed.

Incorporation of epilepsy information to the training of those in the teaching profession, improving educational support for PLWE.

A multidisciplinary approach to those PLWE with intractable seizures, for possible neurosurgical intervention.

Improving accessibility, aflfordability and availability of AEDs especially in the rural areas, to reduce the treatment gap and hence improve the QOL of PLWE.

Facilitate further studies among those with chronic disabling illness, including epilepsy, to assess the outcome of interventions.

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10.0 APPENDICES

APPENDIX 1: CONSENT FORM

INFORMED CONSENT EXPLANATION

To be read and questions answered in a language in which the subject is fluent.

TITLE: QOL among patients with epilepsy attending the neurology clinic at KNH in Nairobi. A comparative study.

INSTITUTION: Department of psychiatry. School of Medicine, College of Health Sciences, University of Nairobi.

INVESTIGATOR: Dr. W.D.C Kinyanjui

SUPERVISORS: 1. Major (Rtd) Dr. D.M. Kathuku

2. Dr. J.M. Mburu

Permission is requested from you for your enrolment in a medical research study.

I wish to inform you that you are required to understand the following general principles, which apply to all in medical research whether well subjects or patient volunteers.

(i) Your agreement to enroll is voluntary.

(ii) You may withdraw from the study at any time.

(iii) Refusal to participate will involve no penalty or loss of benefit to which you are otherwise entitled.

(iv) After you read the explanation please feel free to ask any questions that will allow you to understand clearly the nature of the study.

PURPOSE OF THE STUDY: In this project, I am assessing the impairment of QOL among patients with epilepsy attending the neurology clinic at KNH as compared to their accompanying well subjects.

PROCEDURE: I will ask questions concerning your living conditions, treatment, social support, opinion concerning aspects of daily living and level of satisfaction, over the last 4 weeks. These will be in the form of questionnaires and no invasive procedure will be carried out in the course of the study.

BENEFIT: It is hoped that information emanating from this study will enable better intervention and comprehensive care of people with epilepsy in Kenya and hence achieve the "out of the shadow" objective of the WHO/ ILAE / IBE.

RISK: Due to individual varying appraisal of similar circumstances, some subjects may find certain questions distressing. Those subjects found to need treatment or other intervention will be attended to promptly.

CONFIDENTIALITY: All information obtained from this study will be kept confidential and your privacy will be upheld. Your name will not be used in the study or in any resulting publications.

PARTICIPANTS: The expected number of subjects is approximately 300 people, 150 with epilepsy and 150 well subjects, attending the neurology clinic at KNH.

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CONSENT FORM

I, the undersigned do hereby volunteer to participate in this study. The nature and purpose have been fully explained to me by DR.W.D.C. Kinyanjui. I understand that all information gathered will be used for purposes of this study only.

Signed Date

Signed (DR.W.D.C. kinyanjui)....................Date

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

		Not At All	A Little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F 18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very Poor	Poor	Neither Poor Nor Good	Good	Very Good
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last four weeks.

1		Very Dissatisfied	Dissatisfied	Neither Satisfied Nor Dissatisfied	Satisfied	Very Satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily activities?	1	2	3	4	5
18 (F 12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20 (F13.3)	How satisfied are you with your personal relationships	1	2	3	4	5
21 (F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22 (F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23 (F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24 (F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25 (F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following questions refer to **how often** you have felt or experienced certain things in the last four weeks.

–		Never	Seldom	Quite Often	Very Often	fAlwa^**sJI**
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression	1	2	3	4	U

Did someone help you to fill this form?

How long did it take to fill this form out?

Do you have any comments about the assessment?

THANK YOU FOR YOUR HELP

APPENDIX 2-B

DSM IV-TR Global Assessment of Functioning (GAF) Scale

Consider psychological, social, and occupational functioning on a hypothetical continuum of mental health-illness .Do not include impairment in functioning due to physical (or environmental) limitations.

Code (note: Use intermediate codes when appropriate, e.g.45, 68, 72,)

100 91	Superior functioning in a wide range of activities, life's problems never seem to get out of hand, is sought out by others because of his or her many positive qualities .No symptoms_
90 81	Absent or minimal symptoms (e.g. mild anxiety before an exam)good **functioning** in all areas ,interest and involved in a wide range of activities, socially effective, generally satisfied with life, no more than everyday problems or concerns (e.g. an occasional argument with family members)_
80 71	If symptoms are present, they are transient and expectable reactions to psychosocial stressors (e.g. difficulty concentrating after family argument); no more than slight impairment in social, occupational ,or school functioning (e.g. temporarily falling behind in schoolwork)_
70 61	Some mild symptoms (e.g. depressed mood and mild insomnia) OR some difficulty in social, occupational, or school functioning (e.g. occasional truancy, or theft within the household), but generally functioning pretty well, has some **meaningful** interpersonal relationships. _
60 51	Moderate symptoms (e.g. flat affect and circumstantial speech, occasional panic attacks)or moderate difficulty in social occupational, or school functioning (e.g. few friends, conflicts with peers or co-workers) __
50 41	Serious symptoms(e.g. suicidal ideation, severe obsess ional rituals, frequent shoplifting) OR any serious impairment in social, occupational, or school functioning (e.g. no friends, unable to keep a job)
40 31	Some impairment in reality testing or communication (e.g. speech is at times illogical, obscure or irrelevant) OR major impairment in several areas ,such a work school, family relations, judgment, thinking, or mood (e.g. depressed man avoids friends, neglects family, and is unable to work; child frequently beats up younger children, is defiant at home, and is failing at school)
30 21	Behaviour is considerably influenced by delusions or hallucinations OR **impairment** in communication or judgment (e.g. sometimes incoherent, acts grossly in appropriately, suicidal preoccupation)OR inability to function in almost all areas (e.g. stays in bed al day, no job, home, or friends)
20 11	Some danger of hurting self or other (e.g.,suicide attempts without clear expectation of death frequently violent; manic excitement) OR occasionally fails to maintain minimal personal hygiene (e.g. smears faces) OR gross impairment in communication (e.g. largely incoherent or mute
10 *h*	Persistent danger of severely hurting self or others (e.g. recurrent violence) OR persistent inability to maintain minimal personal hygiene or serious suicidal act with clear expectation of death.
0	Inadequate information.

APPENDIX 2-C

MINI-MENTAL STATE EXAMINATION (MMSE) QUESTIONNAIRE

Orientation (Score 1 correct)

Name this area you are in now_

What city are you in now?_

What year is it?_

If the year is divided into 4, what *VA* of the year is it?_

What is the date today?_

Which country are you in?_

What Province is this?_

What floor of the building are you on?_

What day of the week is it?_

What month of the year is it?_

Registration (score 1 for each object correctly repeated)

Cup, table, book - have patient repeat them

Score number repeated by the patient = 3_

Name the three objects several more times if needed for the patient to repeat correctly (record trials)

Attention and Calculation

Subtract 7 from 100 in serial fashion to 65_

Maximum score = 5

r

Recall (score 1 for each object recalled)

Do you recall the three objects named before? = 3

Language tests

Confrontation naming: Watch, pen = 2_

Repetition; "No ifs, ands, or buts" = 1_

Comprehension:

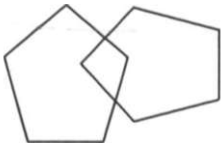
Pick up the paper in your right hand, fold it in half, and set it on the floor = 3

Read and perform the command "Close your eyes" = 1

Write any sentence (Subject, verb, object) = 1_

Construction

Copy the design below = 1_



Total MMSE questionnaire score (maximum = 30)

Ref: Adopted from Folstein MF. Folstein S, Mettugh PR. **Mini**-mental state a **practical** method for **grading** the cognitive state of patients for the clinician

Scoring

<25 - Suggests possible impairment

<20 - Indicates definite impairment

<22 - Exclusion from the study

APPENDIX 2-D

DRUG AND TREATMENT PROFILE QUESTIONNAIRE

Drug	Dosage	Duration
Carbamazepine		
Phenytoin		
Phenobarbitone		
Sodium Valproic		
Benzodiazepine		
Others		

1. What drugs are you currently on?
2. How long have you been on medication?
3. With all medications, we do sometimes forget to take medicine. Do you have any occasions that you forgot to take your medication? a) Yes b) No.
4. If yes in the last month, can you estimate for how many days you may have missed?

5. Are there any factors that caused you to miss medication?
   a) Side effects b) Unavailability c) Financial difficulties d) Inaccessibility
   e) Stopped by a doctor f) Others (Specify)
6. Have you used alternative medications/therapeutic approach a) Yes b) No
7. If yes what form? a) Herbs b) Prayers c) Acupuncture d) Others
8. What in your opinion do you expect the drugs to do? a) Cure b) Improve
   c) No effect d) Do not know
9. What has been the effect of medication on your illness?
   a) Improvement b) No effect c) Worsened

APPENDIX 2-E

SEIZURE BURDEN AND CHARACTERISTICS QUESTIONNAIRE

1. When did you have the first seizure

2. Average seizures over the last one year

3. What in your own opinion do you think is the cause of your illness?

4. Do you have history of head trauma? (a) Yes........(b) No........If Yes, when?

5. Is there any one in your family with similar illness?

a) Yes b) No c) Unknown

If yes who? a) Other siblings b) Parents c) Grandparents d) Cousins

e) Uncles/Auntie 0 Others (specify)

6. Type of epilepsy (from records).

a) Primarily generalized seizure b) Partial seizures c) Unclassified seizures

NB: The classification given above is from the commission on classification and terminology of the International League Against Epilepsy (Appendix 3-A)

APPENDIX 2-F

SEIZURE BURDEN SCORING ACCORDING TO ENGEL SYSTEM

Scores seizure frequency and disability on a quasi-logarithmic scale ranging from 0-12.

Score	**Seizure**
<5	No seizures per year
5	1-3 seizures per year
6	4-11 Seizures, per year
7-12	1 or more Seizures per month

'Seizure freedom'; taken as continuous absence of disabling seizures for more than 12 months.

NB:

1. Non-disabling seizures (aura or brief partial seizures without impairment of consciousness or loss of muscular tone) will be recorded as no seizures.
2. Absence seizures and myoclonic seizures will not be counted for the purpose of seizure frequency (54).

APPENDIX 2-G

SOCIO-DEMOGRAPHIC QUESTIONNAIRE

Date:

Case Number:

OPD Number:

1. Age (years):

2. Sex: a) Male b) Female

3. Residence: a) Urban b) Rural

4. Marital status a) Married b) Living as married c) Single d) Divorced

e) Separated f) Widowed

5. How many children do you have?

6. Religion a) Protestant b) Catholic c) Muslim d) Other (specify)

7. What is the highest level of education you received?

a) No formal education b) Primary c) Secondary d) Tertiary e) university

8. What is your occupation?

9. (i) Are you currently employed? a) Yes b) No

(ii) If yes, which type of employment? a) Skilled b) Unskilled

(iii) What is your average income per month in Kshs?

(iv)If no, in 9(i) above, what is the main reason?

10. Whom are you living with now?

APPENDIX 3: CLASSIFICATIONS

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APPENDIX 3-A:

CLASSIFICATION OF EPILEPTIC SEIZURES: INTERNATIONAL LEAUGE AGAINST EPILEPSY CLASSIFICATION (1989)

1. Partial (focal, local) seizures.
    - (a) Simple partial seizures (consciousness not impaired).
        - (1) With motor signs.
        - (2) With somatosensory or special sensory symptoms.
        - (3) With autonomic symptoms.
        - (4) Compound forms.
    - (b) Complex partial seizures (with impairment of consciousness).
        - (1) Simple partial followed by impairment of consciousness.
        - (2) Impairment of consciousness at onset.
    - (c) Partial seizures with secondary generalization.
2. Generalized seizures (convulsive or nonconvulsive).
    - (a) Tonic-Clonic (grand mal).
    - (b) Petit mal (absence).
    - (c) Atonic (drop attack).
    - (d) Tonic.
    - (e) Clonic.
    - (f) Myoclonic.
3. Unclassified epileptic seizures (with incomplete data).

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APPENDIX 3-B

CLASSIFICATION OF EPILEPSIES AND EPILEPTIC SYNDROMES

The following is an outline of the International Classification of Epilepsies and Epileptic Syndromes.*

1. Localization-related (focal, local, partial) epilepsies and syndromes.

    Idiopathic (with age-related onset).

        Benign childhood epilepsy with Centro temporal spikes.

        Childhood epilepsy with occipital paroxysms

Primary reading epilepsy

Symptomatic

    Chronic progressive epilepsia partialis continua of childhood

(Kojewnikow's syndrome)

syndromes characterized by seizures specific modes of precipitation (for example, reflex epilepsy)

Temporal lobe epilepsies (amygdalohippocampal, lateral)

Frontal lobe epilepsies (supplementary motor, cingulated, anterior frontopolar, orbitalfrontal, dorsolateral, opercular, motor cortex).

Parietal lobe epilepsies

Occipital lobe epilepsies

Cryptogenic

2. Generalized epilepsies and syndromes

Idiopathic (with age-related onset)

Benign neonatal familial convulsions

Benign myoclonic epilepsy in infancy

Childhood absence epilepsy (pyknolepsy)

Juvenile absence epilepsy

Juvenile myoclonic epilepsy (impulsive petit mal)

Epilepsies with grand mal seizures (generalized tonic-clonic seizures) on awakening

Other generalized idiopathic epilepsies not defined above

Epilepsies with seizures precipitated by specific mode of activation

Cryptogenic or symptomatic

West syndrome (infantile spasms, Blitz-nick-Salaam Krampfe)

Lennox-Gastaurt syndrome

Epilepsy with myoclonic-astatic seizures

Epilepsy with myoclonic absence

Symptomatic

Early myoclonic encephalopathy

Early infantile epileptic encephalopathy with suppression-burst

Other symptomatic generalized epilepsies not defined above

Specific syndromes

Epileptic seizures complicating disease states

Epilepsies and syndromes undetermined whether focal or generalized

With both generalized and focal seizures.

Neonatal seizures

Severe myoclonic epilepsy in infancy

Epilepsies with continuous spike-wave activity during slow-wave sleep

Acquired epileptic aphasia **(Lindau**-Kleffner syndrome)

Other undetermined epilepsies not defined above

v

Without unequivocal generalized or focal features

Special syndromes

Situation-related seizures

Febrile convulsions

Isolated seizures or isolated status epilepticus

Seizures occurring only with acute metabolic or toxic event

Adopted from: Commission on Classification and Terminology of the International League Against Epilepsy. Proposal for revised classification of epilepsies and epileptic syndromes. Epilepsia **1989;30:389-99**

APPENDIX 4

STIIDY STTF MAP

A

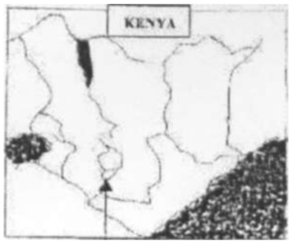
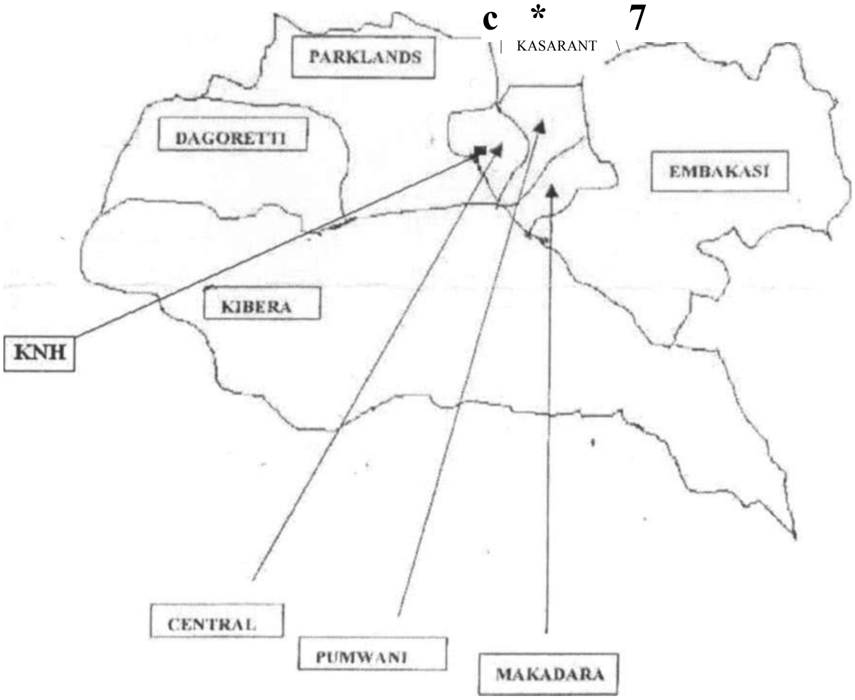


Fig. showing Study site & Div« isions in Nairobi.
Inset:Map of Kenya

NAIROBI PROVINCE



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: KENYATTA NATIONAL HOSPITAL (KNH) NAIROBI (STUDY AREA)