

**AN ASSESSMENT OF THE PREVALENT USE OF
ALTERNATIVE THERAPY, AND THE TYPES OF
ALTERNATIVE THERAPY USED BY PATIENTS LIVING
WITH EPILEPSY WHO ATTEND THE NEUROLOGY
CLINIC AT KENYATTA NATIONAL HOSPITAL.**

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MD(DAR ES SALAAM)**

**A DISSERTATION SUBMITTED IN PART FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF MASTER OF MEDICINE IN INTERNAL
MEDICINE OF THE UNIVERSITY OF NAIROBI.**

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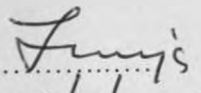
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ABBREVIATIONS

1. AEDS..... Anti-epileptic Drugs
2. HIV..... Human Immunodeficiency Virus
3. KDH..... Kilifi District Hospital
4. KNH Kenyatta National Hospital
5. PI Principal Investigator
6. SPSS..... Statistical Package For Social Scientists
7. TB..... Tuberculosis
8. WHO World Health Organization
9. US..... United States of America
10. UK..... United Kingdom
11. KNH/UON ERC..... Kenyatta National Hospital/University of Nairobi
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ABSTRACT

Background: Epilepsy is the most common neurological disorder worldwide.

There is an increase in prevalence and incidence in the developing world. Use of alternative therapies among patients with epilepsy is high. The use of alternative therapies may have negative impact on the control of seizures. Various factors have been put forward to influence the use of alternative therapies. The magnitude of the problem is unstudied in our setup.

Objective: To determine the magnitude and factors associated with the use of alternative therapy among patients with epilepsy attending neurology clinic at Kenyatta national hospital.

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

Setting: This was done at the Neurology clinic of Kenyatta National Hospital, Nairobi-Kenya

Materials and Methods: Files of patients with epilepsy were examined prior to the beginning of the clinic each day of the clinic. Consecutive sampling method was used to obtain a sample of ten patients with epilepsy every day of the clinic. The selected patients were informed about the study and were requested to sign the informed consent form. Quantitative and qualitative methods using semi-structured questionnaire were used to collect the data. The questionnaire was administered by the interviewer. Patients who reported of using alternative therapies were further subjected for in-depth interviews. The semi-structured open ended questions with probes were administered to the patients individually to ascertain factors for use of alternative therapies and the responses were recorded on the sheet and tape recorded by the interviewer.

Results

One hundred and seventeen patients participated in the study, nineteen (16.2%) were found to be using alternative therapies on top of conventional therapies to treat epilepsy.

Most of the patients who use alternative therapies 79% use local African herbs, 15.8% use spiritual healing and 5.3% use Chinese herbs.

Lack of improvement on conventional treatment of epilepsy was reported to be the main reason for patients to resort to alternative therapies (57.9%)

The decision to use alternative therapies was made by parents in most of the patients (68.4%)

Use of alternative therapies was not significantly associated with socio-demographic factors.

Moreover use of alternative therapies was not significantly associated with seizure type (p-value 0.427)

Conclusion

There is high prevalence of alternative therapy use by patients with epilepsy. Optimization of conventional therapy for epilepsy is paramount to control the seizures and reduce the magnitude of use of alternative therapies.

INTRODUCTION AND LITERATURE REVIEW

1.1 Introduction

Epilepsy is the most common serious neurological disorder worldwide, affecting about 50 million people. In most people with epilepsy, the disorder is clinically benign. However, because of the stigma associated with having epilepsy, which is common to many cultures, there can be a negative effect on the social identity of people with the disorder, particularly for those living in resource-poor countries¹

In developed countries the incidence of epilepsy is around 50/100 000/year. In resource-poor countries, the incidence is likely to be higher due to high prevalence of childhood infections and birth trauma. Prevalence of active epilepsy is in the range of 5-10/1000 in most locations, although it might be higher in some isolates²

The prevalence of active convulsive Epilepsy in Kenya is 4.5/1000³

1.2 The magnitude of use of alternative therapies in management of epilepsy

Various treatment modalities have been attempted by epileptic patients before or after they seek biomedical treatment.

In Nigeria, Danesi et al in 1994 evaluated the use of alternative therapies among epileptic patients before they had sought for hospital care. He found that 47.6% of 265 epileptic patients used African traditional medicine alone. 20.4% used spiritual healing alone and 7.5% used other forms of alternative medicine. Patients used alternative treatments for <1 year to >5 years before seeking hospital treatment, presumably when alternative medicine failed to control seizures. After initiation of hospital treatment, only 14.6% of patients who had earlier used African traditional medicine continued with such treatment⁴

In a community survey Rosalind Coleman et al in Gambia found that 74% of patients with lifetime history of epilepsy had used traditional treatment from more than one source⁵

In the United States, Kaiboriboon et al in 2009 found that 56% of 187 epileptic patients interviewed used herbs and dietary supplements at the time of the study. 71% of these patients reported the use of these products to their physician.⁶

In Ohio US. Peebles et al in 2000 found that 24% of patients with epilepsy attending epilepsy clinic at a tertiary hospital used alternative therapies to treat epilepsy. 31% of alternative therapy users report to their neurologists.⁷

In Great Manchester, Easterford et al in the year 2005 found a prevalence of 34% among patients with epilepsy attending neurology clinic at a tertiary hospital⁸

In India, Tandon et al found a prevalence of 32% among patients with epilepsy attending the neurology clinic and 50% of the patients using alternative therapies reported of being influenced by family members and friends.⁹

1.3 The type of alternative therapies used by epileptic patients

Depending on the perception and belief of epilepsy causation, various alternative treatment modalities have been used, in various places.

In Mexico, Brazil and Bolivia, Francisco Javier Carod-Artal et al found that Kamayura people in Brazil treat epilepsy with two roots tsimo and weweru, kneaded and diluted in water as they perceive that epilepsy is caused by revenge of the spirit (mama`e) of the armadillo killed by a huntsman in Bolivia Chipaya people treat epilepsy with a ritual animal sacrifice called willancha¹⁰

In Nigeria, Danesi et al in 1994, found that the alternative treatment modalities used are African traditional medicine alone, spiritual healing alone, combination of African traditional medicine and spiritual healing or other forms of alternative medicine¹¹.

In Kilifi Kenya, Kendall-Taylor NH et al in 2009 found that people believed epilepsy is caused by three spirits:-

- i. Natural spirit called nyagu, it is treated by removal of the spirit by healer through driving the spirit out using herbal baths, root concoctions or dung that the spirit is known to dislike. The second method for treating nyagu is to entice it out of a person through offerings. Objects offered include incense, herbs, rose water, honey and animal blood.
- ii. When epilepsy is caused by "majini" (malevolent spirits controlled by witches and are blamed for host problems ranging from insomnia to social and economic troubles). Witches are contracted by jealous parties to send majini to specific individuals or families. Majini are sent into two ways: a witch can draw a special

picture in the sand. Once the targeted individual walks over the drawing the curse is cast. A witch may also send majini directly to a person by verbally casting a spell.

- iii. Ancestral spirits (mapepo ya kiasili): these are believed to be the descendants of original mijikenda ancestors. Epilepsy may be transferred between family members if specific rituals are not performed following the death of a member with epilepsy dies. When epileptic dies the family is to bury the individual and must have a traditional healer present to prepare a special herbal mixture that each family member must wash with.¹¹

In 1998 Carod FJ and Vazquez-Cabrera C did a study to analyze traditional anti-epileptic treatment and the basis of the relevant magic in diverse indigenous cultures in central Africa (Cameroon and Tanzania) and central and South America (Paraguay and Chiapas). He found that in traditional Africa epilepsy is linked to the evil eye. He found that wangoni people in Tanzania perform a curative ritual which requires complete shaving of the entire body using glass or banishment of the person causing the evil influence. Bassa and Bambilike people (in Cameroon) believe that burns are common complications and epilepsy is known as disease of people with burns. In Meso-american (Paraguay and Chiapas) culture epilepsy is believed to be caused by some abuse suffered by the animal soul which accompanies the person involved, following a battle between the nagueles or spirits who serve the forces of Good and Evil. Traditional indigenous medicine employs herbal remedies, rituals, spiritual cures or combinations of all these. More than 80% of the epileptic patients of the Third World use only these remedies.¹²

In Togo. Grunitzky et al in 2000 found that epilepsy is treated by forehead scarifications. He found that 80% of 36,000 epileptics had forehead scarifications. When seizures are rare, scarifications are slim, short (1-3mm), near the roots of hair on the forehead and concealed, but when they are frequent, known by many people, scarifications are large, long, and visible on forehead.¹³

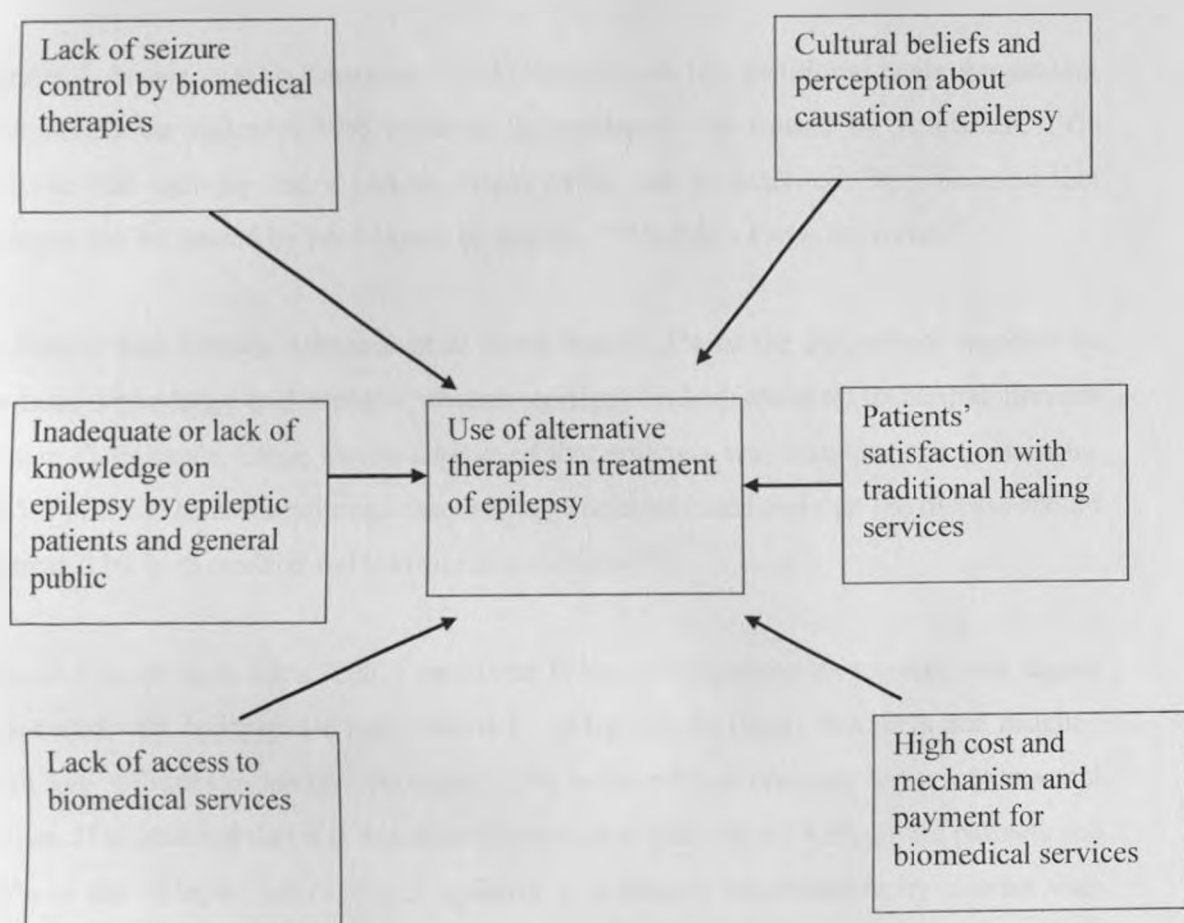
Rosalind Coleman et al in 1997, found that in Gambia, most traditional epilepsy treatment was from healers. The treatment included readings from the Koran, sometimes written down and sewn into cloth or leather amulets (jujus) that had to be worn. Water

with herbs was blessed and given for washing and drinking, sometimes combined with exorcism rituals.⁵

1.4 Factors that are associated with the use of alternative therapies in managing Epilepsy

Studies have demonstrated several factors that contribute to use of alternative therapies for treatment of epilepsy.

Some of the identified factors for alternative therapy use:



1.4.1. Cultural Beliefs and Perception about Epilepsy

Beliefs and perception about epilepsy vary in different cultural settings.

Most of anthropological and psychosocial studies about epilepsy performed in African rural societies have shown that that epilepsy may be caused by evil spirits. Other beliefs include witchcraft and contagion fears from bodily secretions (saliva, stool, or urine) that could potentially transmit seizures to bystanders.

In a study done in Ruaha Tanzania by Louise Jilek – Aall et al in 1994, found that people believed epilepsy to be due to witchcraft, dangerous spirits or a punishment for the sins and that epilepsy is not effectively treatable by modern medicine.¹⁴

Mainen J. Moshi et al in Tanzania (2004) interviewed 100 traditional healers regarding their beliefs on epilepsy. 30% believed that epilepsy was caused by witchcraft, 19% believed that epilepsy has a genetic origin which can be inherited, 24% believed that epilepsy can be caused by head injury or malaria, 27% didn't know the cause.¹⁵

In Burkinafaso (2004), Athanase et al found that 43.2% of the 246 school teachers he assessed knowledge and attitude towards epilepsy linked epilepsy to central nervous system disturbance. Some teachers believed that epilepsy was hereditary or contagious. 56.5% of these teachers believed that epilepsy could be cured and that the disease should be treated by both modern and traditional medicines.¹⁶

Duc-Si Tran et al in Laos (2007) evaluated beliefs about, attitudes towards and stigma associated with epilepsy. He interviewed 83 epileptics, 83 family members and matched with 166 villagers in another province. 42% believed that epilepsy has a supernatural origin, 21% believed that it is due to consumption of pork meat. 14.5% of the patients and 44% of the villagers believed that epilepsy is a disease transmissible by contact with patients saliva. Stigma was high, people thought that they should avoid contact or sharing meals with patients (15% of patients, 62% of family members) and that persons with epilepsy should not get job, get married (29% and 42% respectively) or raise children 42%.¹⁷

1.4.2) Inadequate/ lack of Knowledge on and attitudes towards Epilepsy

It has been found in many studies that there is lack or inadequate knowledge about the disease to both epileptic patients and the general public. This has greatly contributed to the patients seeking for alternative therapies.

Edward Mbewe et al in Zambia (2004) assessed Epilepsy –related knowledge, attitudes, and practice among 200 police officers. He found that 77.1% recognized epilepsy as a brain disorder, 20% blamed spirit possession, 13.9% associated epilepsy with witchcraft, over half of respondents believed that epilepsy is contagious. On what they would do when they get a person with a seizure, 8% reported of taking harmful actions like arrest, detain, handcuff, restrain, 14.3% indicated that people with epilepsy in police custody require quarantine.¹⁸

In Turkey 2010, Yildiz Degirmenci et al found that knowledge on epilepsy among epileptics was low. He found that 95.3% of epileptics interviewed, 89.2% of their relatives interviewed and 63.3% of the control felt primarily fear when they heard diagnosis of epilepsy, Most participants would not let their child marry a person with epilepsy (there was no significant difference between the three groups ($p>0.05$)). It was concluded that patients and their relatives showed similar attitudes and behaviour, perhaps they had common information and experience regarding the disorder.¹⁹

Nguyen Anh Tuan et al in Vietnam (2007) assessed knowledge, attitudes and practice toward epilepsy among adults. Among the 2005 people interviewed, 67% had heard about epilepsy, 52.1% had known someone with seizures and 49.3% had witnessed seizures.

In total 36.3% would object to their children playing with someone with seizures and 82% to their children marrying someone with Epilepsy. Only 32.6% thought that epilepsy patients should be employed in a job as other people, while 10% thought that epilepsy was a form of insanity. He concluded that knowledge of epilepsy among Vietnamese people is limited compared to some Western countries.²⁰

1.4.3) Satisfaction with the traditional healing services

Treatment-seeking for epileptic patients may be facilitated or deterred by the characteristics of available treatment options.

Structural differences between biomedical and alternative treatments have been found to have influence on the treatment choice for epileptic patients.

In Kilifi Kenya (2009), Kendall –Taylor NH et al studied the distinguishing characteristics of services for childhood epilepsy between traditional healers and modern biomedical service providers in Kilifi. Comparing the traditional and biomedical service providers on:

-Explanations of causation and communication style: Patients are more satisfied with traditional healing services than biomedical services, in that traditional healers give explanation with regards to the cause of seizures. They refer to spirits with the occurrence of the seizures and that individuals regain consciousness when spirits depart. Healers accounted for the tremors and shaking associated with seizures as the struggle between the affected individual and the spirit grabbing them. The common looks of surprise or screams prior to seizure onset were rationalized as the individual's reactions to the spirit's sudden appearance. The traditional system offered treatments that directly addressed the assumed causes of the patient's symptoms. Biomedical practitioners and treatments did not address the connection between causation, treatment, and seizure symptoms. The traditional process of diagnosis and treatment involved constant communication between healer and patient over a one- to four-hour period. It was an interactive process between the healer and the patient. In contrast, appointments at clinics and hospitals were brief, and doctor/patient interaction limited. The average length of consultation was less than 20 minutes. Biomedical patients were passive rather than active participants in their care.

Social roles of providers and referral practices: Most of the medical practitioners at KDII were drawn from other parts of the country, generally not members of the communities they treated and were unaware of the daily activities and lives of their patients, nor did they hold much power in community social or political dynamics. Unlike traditional healers who lived in the same communities as their patients, biomedical health workers were largely unaware of other treatments received by their patients. When traditional healer failed to reduce or eliminate symptoms, healer claimed that the offending spirit was too powerful or that they were not proficient at handling the specific spirit responsible for the child's disorder, the healer referred the patient to another healer believed to provide more powerful or specialized treatments,

maintaining hope in an eventual cure within the traditional system. In contrast, no explanation was available for the families of children treated at KDH who continued to have seizures. Although these children may have had their AED regimens modified, there were no further biomedical treatment options¹¹

1.4.4) Lack of access to biomedical services: Lack of access to hospitals and health centers was another factor hindering utilization of biomedical services. Medical services are offered in hospitals and health centers. Patients who live far opted for traditional healing in order to avoid traveling long distances.¹¹

1.4.5. High cost and mechanism of payment for biomedical services: The traditional healers used a flexible payment system. Treatment was provided regardless of the individual's ability to pay and payment was not discussed until after treatment. If the individual was unable to pay, he was expected to return and pay at a later date. The traditional model of payment was also flexible in terms of the type of payment accepted. Each healer accepted livestock, grain, palm wine, cloth, clothing, and labor in lieu of monetary payment. In the biomedical services there was no alternative form of payment, and deferrals or loans were not granted¹¹

Deb K. Pal in his editorial commentary regarding epilepsy control in the 21st century, he underscores the main obstacles for the utilization of biomedical therapies in treatment of epilepsy. He mentions that high cost for biomedical therapy, lack of access, stigma due to social and cultural factors are the main reasons hindering epileptic patients from utilizing biomedical therapies²¹

H. Meinardi et al in his report on treatment gap in epilepsy: the current situation and the ways forward 2001, analyzed factors hindering utilization of biomedical services by epileptic patients. He earmarked factors for epileptics seeking for alternative treatment therapies. He underscores the influence of cultural beliefs, that when people perceive that epilepsy is caused by something not natural or biomedical they seek treatment from traditional or faith healers and compliance with AEDs is difficult. He stresses that high cost of biomedical drugs, lack of access to biomedical services and unreliability of drug supply in hospitals and health centers to be the other factors hindering the utilization of biomedical services. He explains further that due to limited resources in developing countries the available resources are allocated to priority diseases such as HIV, malaria and Tuberculosis. Diseases such as epilepsy are underfinanced²²

Robert A. Scott et al paper on WHO Bulletin 2001 on the treatment of epilepsy in developing countries: where do we go from here. He put forward the factors that hinder the utilization of biomedical therapy among epileptic patients. He mentions that lack of knowledge on the epilepsy causation among epileptics is a main factor that influences people to look for alternative therapies for epilepsy. He further mentions that limited supply of anti-epileptic drugs especially in developing countries was also a contributing factor. He underscores that in resource constrained countries epilepsy is not a priority disease and therefore little resource is allocated for epilepsy control²³

1.4.6. Failure of seizure control by Conventional therapies.

When seizures persist despite use of biomedical therapies, patients and parents of children with epilepsy seek attention from the traditional healers.

El Sharkawy, G. et al in 2006 studied on the effects of attitudes and practices on the epilepsy service utilization, particularly the use of Anti-epileptic drugs among parents with epileptic children in Kilifi Kenya. He found that the parents and epileptic patients reported that when the seizures persist regardless of biomedical treatments, they assume that the disease is incurable by biomedical treatment and therefore opt for alternative treatment modalities²⁴

1.5. EFFECTS OF ALTERNATIVE THERAPIES ON SEIZURES:

Botanicals and herbs have a centuries-old tradition of use by persons with epilepsy, in many cultures around the world. At present, herbal therapies are tried by patients in developing as well as developed countries for control of seizures or for general health maintenance, usually without the knowledge of physicians who prescribe their AEDs. Furthermore, some botanicals and herbs may be pro-convulsant or may alter AED metabolism, hence worsen the seizures²⁵

There is observed induction and inhibition of cytochrome (P450) enzymes by natural products in the presence of a prescribed drug has (among other reasons) led to the general acceptance that natural therapies can have adverse effects, contrary to the popular beliefs in countries where there is an active practice of ethnomedicine. Herbal medicines such as St. John's wort, garlic, piperine, ginseng, and ginkgo, which are freely available over the counter, have given rise to serious clinical interactions when co-administered with prescription medicines²⁶

Herbs may increase the risk for seizures, through intrinsic proconvulsant properties or contamination by heavy metals, as well as via effects on the cytochrome P450 enzymes and P-

glycoproteins, altering antiepileptic drug (AED) disposition. Herb-drug interactions may be difficult to predict, especially since the quality and quantity of active ingredients are often unknown²⁷

2.0 STUDY JUSTIFICATION

Epilepsy remains the most common neurological disease worldwide. Despite the improvement in medical care there remains a treatment gap. Epilepsy is a chronic disorder that is associated with stigma. Evidence elsewhere reveals that alternative treatment methods are used. No local data on the prevalent use of alternative therapy and the types of alternative therapy used by patients living with epilepsy.

The results of this study will form a baseline for interventions to control epilepsy.

3.0 RESEARCH QUESTION

What is the magnitude and associated factors of alternative therapy use among patients with epilepsy attending neurology clinic at Kenyatta National Hospital?

4.0 OBJECTIVES

4.1 Broad Objective

To determine the magnitude and factors associated with the use of alternative therapy among patients with epilepsy attending neurology clinic at Kenyatta National Hospital

4.2 Specific Objectives

1. To determine the proportion of patients with epilepsy who use alternative treatment modalities
2. To determine the types of alternative treatment modalities used by patients with epilepsy
3. To determine the factors associated with the use of alternative therapies
4. To determine the type of seizures associated with use of alternative therapies

5.0 MATERIALS AND METHODS

5.1 Study design

A cross-sectional descriptive study

5.2 Study site

Neurology clinic at Kenyatta National Hospital

5.3 Study population

Patients with epilepsy attending neurology clinic between June 2011 and Aug 2011

5.4 Patient selection

5.4.1 Inclusion criteria

-All patients with epilepsy attending neurology clinic between June and Aug 2011

-Age above 18 years

- A duly signed written informed consent from the patient

5.4.2 Exclusion criteria

-Those patients who declined consent

- Patients with active psychosis, dementia and cognitive impairment

5.5 Case definition

A Seizure is episodes of loss of consciousness, abnormal jerking movements or episodes of being unaware of the surroundings.

Epilepsy is occurrence of two or more episodes of unprovoked seizures

Alternative therapy is the use of any non-biomedical means in treating epilepsy.

Spiritual healing is use of special prayers, holy water or holy oil

Active Epilepsy: occurrence of at least one epileptic seizure in the previous five years

Epilepsy in Remission: No seizures for five or more years with or without treatment

Epileptic patients: Patients with documented file diagnosis of epilepsy attending the clinic

5.6 Screening and Recruitment

The Kenyatta National Hospital runs a neurology clinic every Monday of a week.

Files of all patients with established diagnosis of epilepsy attending the clinic were obtained from the records before start of the clinic. These patients were informed about the study and those who met the inclusion criteria were assigned a number. Consecutive sampling method using a random number table method was used to obtain a sample of ten (10) patients with epilepsy every day of the clinic.

The selected patients were informed about the study and requested to sign the informed consent form.

Once the consent was given, the patients were interviewed as per the questionnaire after being seen by the primary doctor.

Every patient who reported of using or having used alternative therapies was further requested to participate in an in-depth interview.

The structured open ended questions with probes were administered to the patients individually to ascertain factors for use of alternative therapies and the responses were recorded on the sheet and tape recorded by the interviewer.

5.7 Quality Assurance

Research assistants were trained on tool. Pre-testing of the questionnaire was done to ensure that the tool was practical. Everyday of the clinic, the PI had a brief meeting with the research assistants to crosscheck all the filled questionnaires to ensure that they were filled properly and address any matter arising in data collection.

5.8 Questionnaire

A semi structured questionnaire containing open and closed ended questions was used to collect data.

The questionnaire was administered by PI and 2 research assistants. Each of the questions was read and interpreted in a comprehensible manner to each and every recruited patient.

The answers given by the patients were written in the questionnaire in the way they were given by the patients.

Both English and Swahili languages were used and the PI and research assistants interviewed patients in a language best understood by the patient.

In-depth interviews were conducted for patients who reported using alternative therapies to treat epilepsy.

Data for in-depth interviews were collected by recording answers on a sheet and tape recording, later the tape recorded answers were transcribed. Coding was done and later analysis done using qualitative method.

Questions aimed at elucidating the type of alternative therapies, duration of use, probes on reasons for using alternative therapies, information regarding alternative therapies, and the

effects of using alternative therapies to the seizures were used and answers were clarified by more specific follow-up questions, and were analyzed together with any relevant information that surfaced in response to the questions.

Interview conversations were tape recorded and later transcribed verbatim. Interview took an average of 20 minutes.

5.9 Pilot study

The questionnaire was pre-tested for clarity, suitability and practicability through a pilot study of 20 patients at the neurology clinic prior to onset of the project.

5.10 Sample size calculation

Basing on the Gambia study by Rosalind Coleman et al. the prevalence of alternative therapy use among patients with lifetime epilepsy was 74%⁵

Using the Fisher's formula

The minimum sample size,

$$n = \frac{z^2 p (q)}{d^2}$$

n – minimum sample size

z - z score of required confidence interval (95%)

p – Prevalence

q – 1 – p

d - margin of error (8%)

$$\text{Minimum sample size, } n = \frac{(1.96)^2 * 0.74 (1-0.74)}{(0.08)^2}$$

$$n = 115$$

We interviewed 117 patients

5.11 Variables

5.11.1 Independent variables include: Age, sex, marital status, level of education, employment, medical insurance cover, duration of the disease, and type of the seizures

5.11.2 .Dependent variable: Use of alternative therapies

5.12 Data management and analysis

The data collected was verified, cleaned and entered into a Microsoft access database and analysis done using SPSS version 17.0. The continuous variables such as age are presented as mean and standard deviation while categorical variables such as gender, occupation and level of education were analyzed using percentages, with their corresponding confidence intervals.

The prevalence and the type of alternative therapies are presented as proportions.

Comparisons for continuous data were made using the student -t-test and Man Whitney U test and for categorical data using the Chi-square and Fishers exact tests.

All statistical tests were performed at 5% level of significance (95% confidence interval).

5.13 Qualitative data analysis

Data for in-depth interviews was analyzed qualitatively. The tape recorded data was transcribed into text. The text was coded.

After coding the responses were categorized. The categories were put into themes and inferences are done based on the themes.

6.0 ETHICAL CONSIDERATION

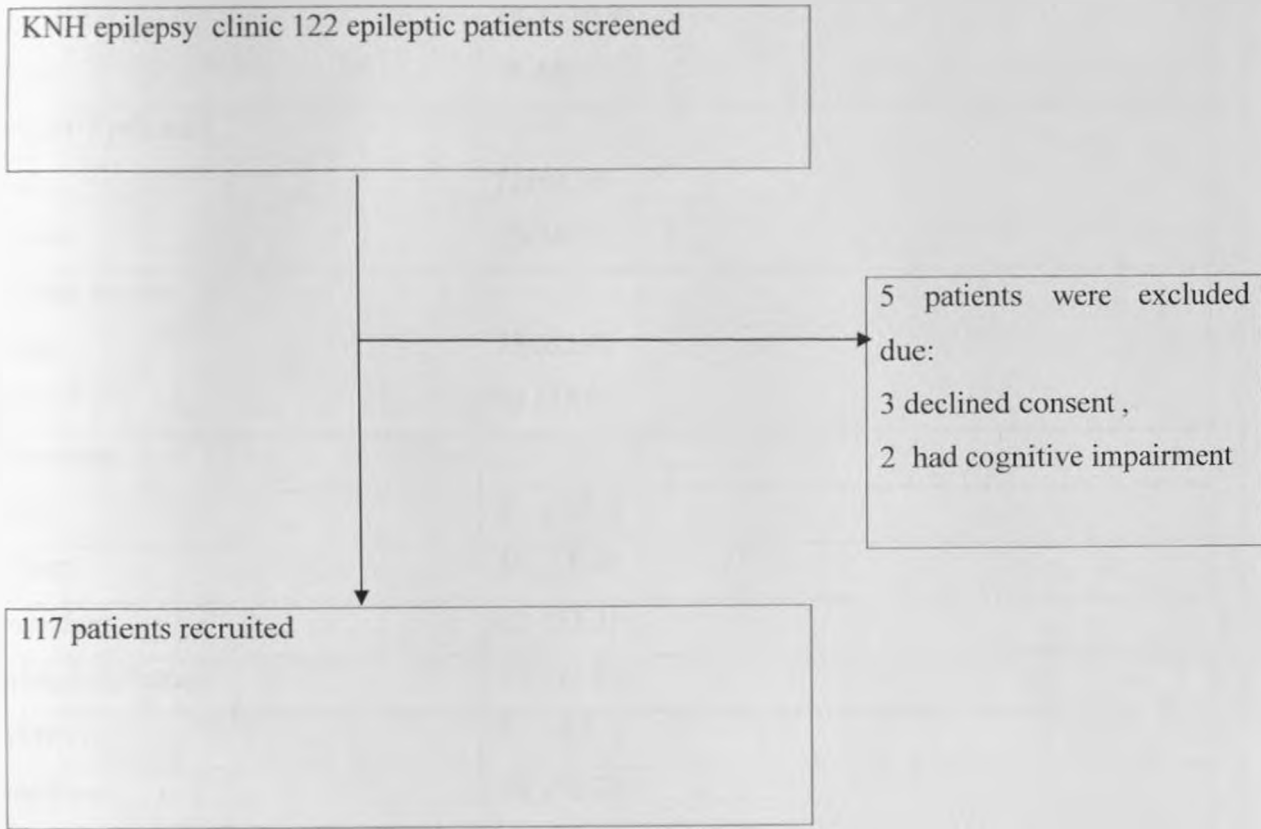
This study was undertaken after approval by the Department of Clinical Medicine and Therapeutics of the University of Nairobi and the Kenyatta National Hospital/University of Nairobi Ethics and Research committee (KNH/UON ERC).

A detailed written and verbal consent explanation was given to the study participants (Appendix 3). All participants signed an informed consent form (Appendix 4)

All patients were educated on epilepsy and on adherence with the prescribed therapy. All issues that arose regarding adherence were communicated to the primary physician

7.0 RESULTS

FIGURE 1: FLOW OF EPILEPTIC PATIENTS INTERVIEWED



The study was conducted between June and August 2011. We screened 122 files, out of which 5 were excluded, of which 3 declined to participate and 2 had cognitive impairment to participate in the interviews.

117 patients were recruited into the study. There were more males representing 61.5% of the study population. The mean age was 29.5 years. The median duration of the disease was 4 years with interquartile range of 9 months to 24 years. The demographic characteristics of the patient population are shown in table 1.

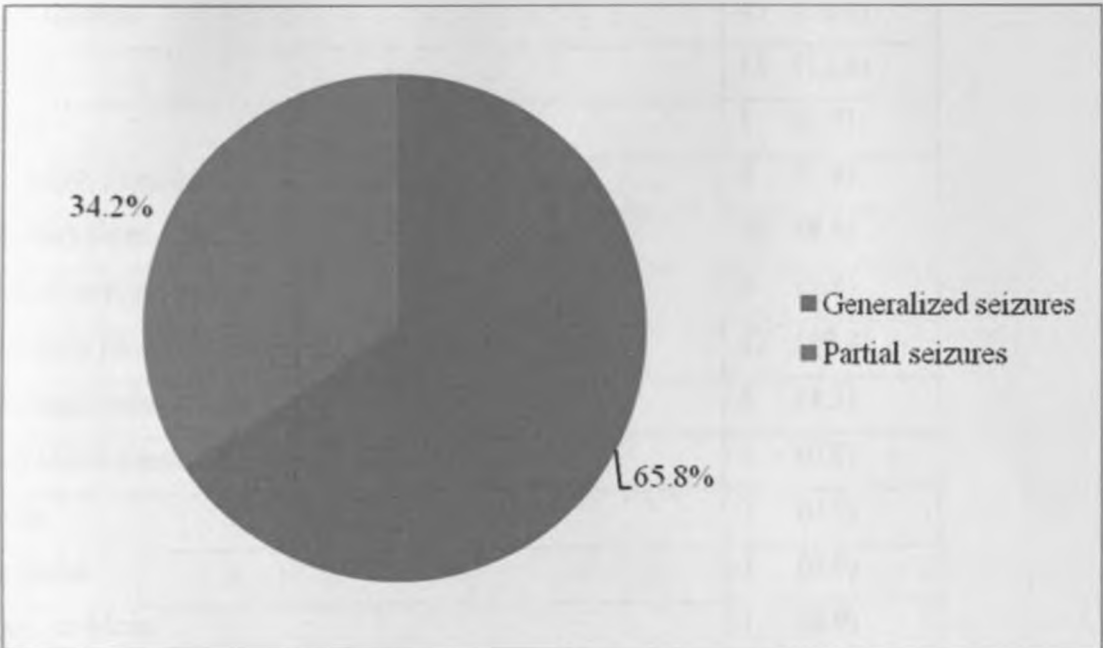
Table 1: Socio-demographic characteristics of the study population

| Variable | Frequency |
|--------------------------------|-------------|
| Age(Years) | |
| Mean(SD) | 29.5 (10.9) |
| Range | 18-60 |
| Sex (M:F)=1.6:1) | |
| Male | 72(61.5) |
| Female | 45(38.5) |
| Marital status | |
| Single | 73 (62.4) |
| married | 44 (37.6) |
| Education | |
| None | 2 (1.7) |
| Primary | 35 (29.9) |
| Secondary | 60 (51.3) |
| College(diploma) | 15 (12.8) |
| University | 5 (4.3) |
| Employed | 40 (43.2) |
| Type of employment | |
| Formal | 26 (65) |
| Self employed | 14 (35) |
| Medical insurance cover | 34 (29.1) |
| Residence | |
| Rural | 40 (34.2) |
| Urban | 77 (65.8) |
| Urban residents (n=77) | |
| Slum dwellers | 9 (11.7) |
| Non-slum dwellers | 68 (88.3) |

Majority of the patients (97.4%) know that they suffer from epilepsy. Only 2.4% don't know the disease they are suffering from.

The median duration of the disease in the study population was four (4) years. The median duration since the last seizure was four (4) months.

Figure 2: Type of seizures experienced by the patients (n=117)



From patients' history and file documents, the patients experienced both generalized and partial seizures. With the generalized seizures mostly experienced at 65.8%. (Fig.2)

Table 2: Responses to the question, what do you think is the cause of your disease (n=117)

| Cause of disease | |
|--|------------------|
| A. Biophysical | Frequency |
| Disconnection in the brain | 2 (1.7) |
| Side effects of abusing illicit drugs alcohol, miraa or cigarettes | 9 (7.7) |
| Brain trauma | 43 (36.8) |
| Stress | 15 (12.8) |
| Shock | 1 (0.9) |
| Too much thinking | 4 (3.4) |
| Inherited from parents | 10 (8.5) |
| Lack of oxygen in the brain | 6 (5.1) |
| Infections like malaria during childhood | 12 (10.3) |
| Prolonged labour | 5 (4.3) |
| High blood pressure | 1 (0.9) |
| Stroke | 1 (0.9) |
| Headache | 1 (0.9) |
| Brain problem | 1 (0.9) |
| B. Supernatural | |
| Spirits | 1 (0.9) |
| Witchcraft | 1 (0.9) |
| Total | 117 (100) |

Majority (36.8%) of the patients reported brain trauma to be the cause of their disease. Stress was mentioned as a second cause at 12.8%. Spirits, witchcraft, stroke, headache, high blood pressure, brain problem were the least mentioned causes at 0.9% each. Other causes are indicated in table 2 above.

CAUSE OF THE DISEASE:

Excerpt 1:

A 19 year old male patient from Umoja, epileptic for four years said, i quote ‘....my disease is caused by disconnection in my brain, that is why I get these episodes of falling’’

Excerpt 2:

A 31 year old male from Kahawa Nairobi ,epileptic for four years said I quote ‘.....my disease is caused by abusing miraa and smoking cigarettes. I have been using miraa and smoke cigarettes for many years’’

Excerpt 3:

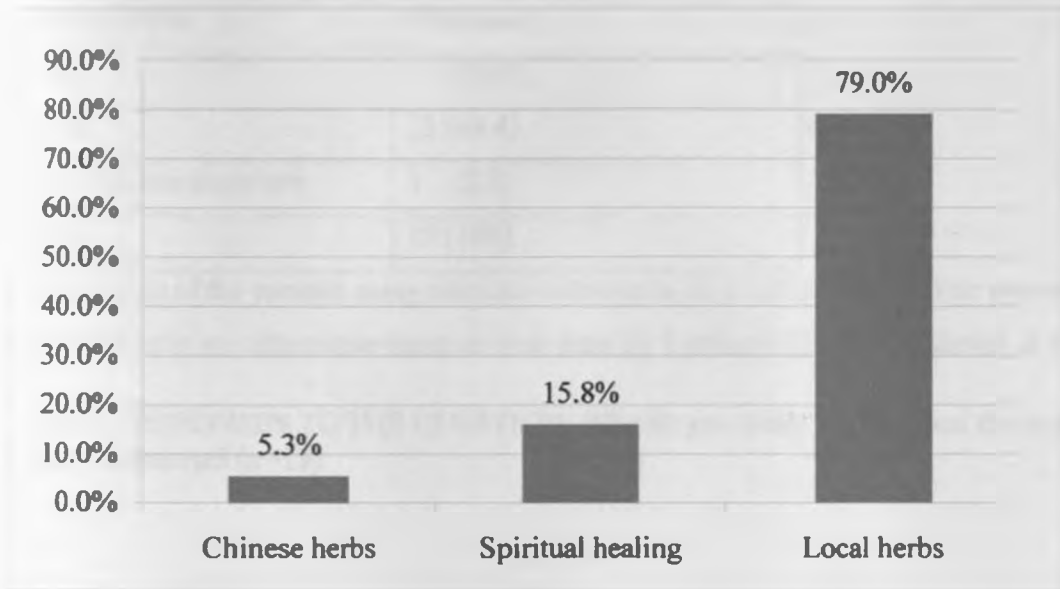
A 31 year old male patient diploma holder from Thika, epileptic for four years said I quote ‘....I think my disease is caused by spirits. I have done the brain CT-scan, but I was told no disease was identified from the scan...’’

Table 3: Type of medication /therapies used by patients with epilepsy (n=117)

| Type of medication/therapies | Frequency |
|--------------------------------------|-----------|
| Hospital drugs and spiritual healing | 3 (2.6) |
| Hospital drugs alone | 98 (83.7) |
| Hospital drugs and Herbs | 16 (13.7) |
| TOTAL | 117 (100) |

Table 3 above shows that inspite of using alternative therapies all patients were on hospital drugs. 83.7% reported that they were exclusively on hospital drugs.13.7 % were using both hospital drugs and herbs.

Figure 3: Alternative treatment modalities used by epileptic patients (n=19)



Local herbs are the most used alternative therapies at 79% (15). Other modalities used are spiritual healing and Chinese herbs. (Fig.3)

Table 4: Source of information regarding alternative therapies (n=19)

| Source of information | Frequency |
|-----------------------|-----------------|
| Neighbor | 1 (5.3) |
| Relatives | 7 (36.8) |
| Friends | 9 (47.4) |
| Church leaders | 2 (10.5) |
| TOTAL | 19 (100) |

Most of patients using alternative therapies got information regarding alternative therapies from friends and relatives at 47.4% (9) and 36.8% (7) respectively. (Table 4)

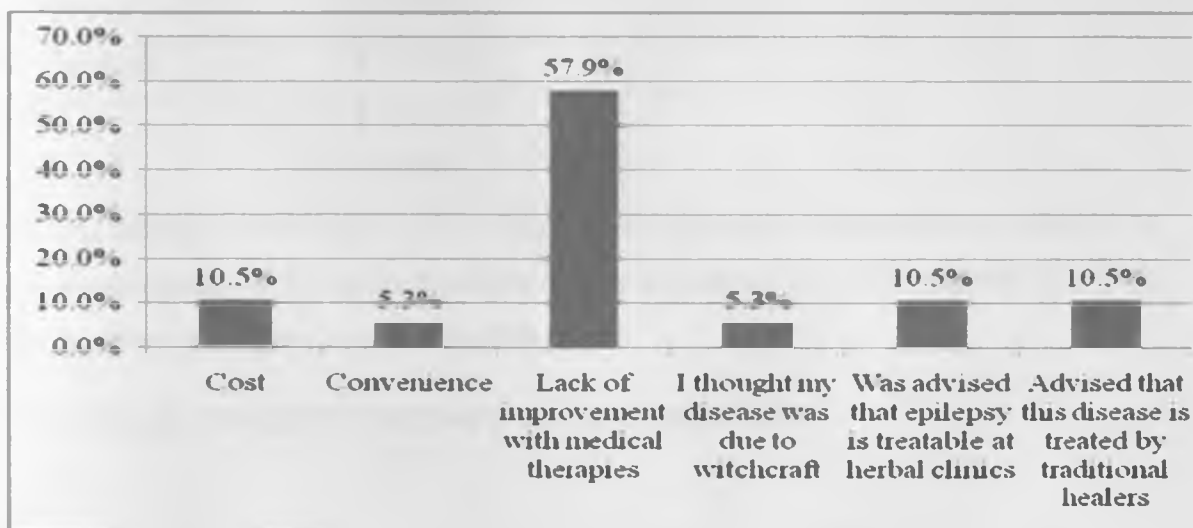
Table 5: Responses to question: who made the decision for you to use alternative therapy? (n=19)

| Decision maker | Frequency |
|-----------------------|-----------|
| Myself | 5 (26.3) |
| Parents | 13 (68.4) |
| Fellow Church members | 1 (5.3) |
| TOTAL | 19 (100) |

Majority (13) of the patients using alternative therapies were influenced by their parents (68.4%).

Self decision to use alternative therapies was done by 5 patients (26.3%) as shown in Table 5.

Figure 4: RESPONSES TO THE QUESTION: Why do you think you use/used the type of therapy mentioned (n=19)



Majority of the patients (11) reported of using alternative therapies due to lack of improvement with conventional medical therapy (57.9%). High cost of conventional therapies, advice that epilepsy is treatable at herbal clinics as well as traditional healers were reported to be the reasons by 10.5% each. Belief that epilepsy is caused by witchcraft and convenience as reasons for opting for alternative therapies were also reported as shown in figure 4.

REASONS FOR USING ALTERNATIVE THERAPY

Excerpt 4:

A 22 year old male patient from Kiambu, epileptic for six years said, I quote ‘... I started using herbs after seeing advertisements in the herbal clinics that they can treat my disease and because I had used hospital drugs without improvement I decided to take herbs’

Excerpt 5:

A 21 year old male patient from Ngong, epileptic for four years, said, i quote ‘...I started using herbal drugs because my father was advised by traditional healers that epilepsy is treatable by traditional healers

Table 6: Responses to the question: what has been the effect of alternative treatment to your illness? (n=19)

| Effect on the seizures | Frequency |
|------------------------|-----------|
| Getting better | 1 (5.3) |
| Remains the same | 9 (47.4) |
| Worsening | 9 (47.4) |
| TOTAL | 19 (100) |

Despite using alternative therapies, 47.4% of the patients reported of their disease remaining the same, no improvement, 47.4% reported of their disease worsening, only 5.3% reported of getting better on alternative therapies, as shown in table 6.

EFFECT OF ALTERNATIVE THERAPY ON THE SEIZURES

Excerpt 6:

A 32 year old male patient from Machakos, epileptic for 8 years said, I quote... ‘...after being on hospital drugs for 8 years with no improvement, I was advised that there is a healer in Loliondo Tanzania, I went to Loliondo in May this year. When I met the healer I was given a solution to drink from the cup, the healer instructed me to stop hospital drugs that I have been cured so I came back and stopped the hospital medications. The last two weeks I got terrible convulsions

that I have never experienced before until I was admitted here and was restarted on hospital drugs. the convulsions have stopped. I thank you doctors”

Excerpt 7:

A 19 year old male patient from Kangundo epileptic for ten years said, I quote ‘.....I was told that this disease is caused by witchcraft that can’t be treated by hospital drugs. I have been on hospital drugs for many years but still getting the convulsions. When I started on herbal drugs I haven’t experienced the seizures for a year now, until last week when I had another episode of a seizure”

Table 7: Factors associated with alternative therapy use:

| Variable | Alternative therapies | | P-value |
|--------------------------------|-----------------------|------------------|---------|
| | Yes | No | |
| Age, mean (SD) | 28.0(10.9) | 29.8(11.0) | 0.524 |
| Sex | | | |
| Male | 14 (73.7) | 58 (59.2) | 0.234 |
| Female | 5 (26.3) | 40 (40.8) | |
| Marital status | | | |
| Single | 11(57.9) | 62 (63.3) | 0.658 |
| Married | 8 (42.1) | 36 (36.7) | |
| Level of education | | | |
| Primary level or less | 7 (36.8) | 30 (30.6) | 0.593 |
| Post primary | 12 (63.2) | 68 (69.4) | |
| Employment | | | |
| Yes | 6 (31.6) | 34 (43.7) | 0.793 |
| Medical insurance | | | |
| Yes | 4 (21.1) | 30 (30.6) | 0.401 |
| Duration of the disease | | | |
| Median (IQR) | 8.0 (5.0-12.0) | 9.0 (3.0 – 13.0) | 0.692 |
| Type of seizures | | | |
| Generalized | 11 (57.9) | 66 (67.3) | 0.427 |
| Partial seizures | 8 (42.1) | 32 (32.7) | |

Socio-demographic characteristics Age, Sex, Marital status, Level of education, employment, medical insurance cover, and duration of disease were not statistically significant associated with the use of alternative therapies to treat epilepsy as shown in Table 7. Also seizure type was not associated with the use of alternative therapies to treat epilepsy (p- value=0.427). This is shown in table 7.

8.0 DISCUSSION

Various studies have been done to address the use of alternative therapies by patients with epilepsy globally. This study was carried out in the neurology medical outpatient clinic at a tertiary hospital. The clinics are run by physicians and medical residents. This study used both quantitative and qualitative methods to explore the magnitude, types of alternative therapies and reasons for using alternative therapies by patients with epilepsy attending the neurology clinic. The mean age of the study population was found to be 29.5 years, this is considered to be a young population, mainly still depending on their parents for guidance for most of their decisions. The age in the study population was similar to the population in other African studies^{28, 4}. Education attainment was mainly secondary at 51.3%, minority had tertiary education at 17.1% and illiteracy level was at 1.7%. This is expected of our study population which is mainly urban. 43.2% were employed, of which 65% had formal employment while 35% were self employed. Only 29.1% had medical insurance cover, however this could not impact on clinic attendance for the patients who are not covered by the scheme as the insurance doesn't cater for outpatients. Most (65%) of our patients resided in urban this is in keeping with the study site and the hospital location. Of the urban residents 88.3% were non-slum dwellers, indicating that socio-economic status of our study population was generally good to be able to afford medical care at the Kenyatta National hospital.

Epilepsy is associated with a lot of stigma in many cultures. This is mainly due to little or lack of knowledge about the disease. Many studies done in various rural areas globally have attributed epilepsy causation with spirits and witchcraft. Studies done in rural Bolivia, Kilifi in Kenya, rural Tanzania and Zambia demonstrated similar findings^{10, 11, 15, 18}. Our study found that most of the patients (36.8%) reported epilepsy to be caused by head injury. Few patients reported of spirits and witchcraft to be the cause of epilepsy. The other causes reported in our study are: disconnection in the brain, abuse of substances (alcohol, cigarettes, miraa) stress, shock, too much thinking, inherited from parents, lack of oxygen in the brain, infections during childhood, prolonged labour, high blood pressure, stroke, headache and brain problem. The discrepancies between our study findings and other studies is perhaps the location of study that our study was done in an urban tertiary hospital among patients who have been attending clinics while other

studies were mainly community based. Most of our study population is educated (attained secondary education) and resided in urban area so they have better understanding of the disease and other things in general than their counterparts in rural areas. To achieve seizure control and drug compliance we need to strengthen health education to our patients and the general public.

The prevalence of alternative therapy use in this study was found to be 16.2%, this is close to what was found in the Nigerian study by Danesi et al who found a prevalence of 14.6% in similar study done in a tertiary hospital¹. In the US Kaiboriboon et al found a prevalence of 56% and 24% by Peebles et al^{6, 7}. In India, Tandon et al 2002, found a prevalence of 32% among epileptics attending neurology clinic in a tertiary hospital⁹. This discrepancy between our findings and the findings in the western countries could be explained by the differences in the whole concept of "alternative therapies". In the western countries alternative therapies are almost exclusively food supplements. While in developing world Africa in particular, alternative therapy means use of non-biomedical means to treat a disease. Therefore in western countries many people use food supplements as alternative therapies not only for epilepsy but even other medical conditions making the magnitude use to be higher than in African countries.

In this study we found that most patients resort to use alternative therapies after failure of control of the seizures by conventional therapies. This is similar to what was found by Danesi et al in Nigeria.⁴ But this differs from what was found by Kaiboriboon in the US and Easterford in the UK that the patients with epilepsy use alternative therapies as food supplements and not because of dissatisfaction with the conventional therapies^{6, 8}. Failure to achieve seizure control by conventional therapies is attributed to by the failure to optimize treatment. In our clinics we are unable to do serum blood levels to ascertain the serum drug concentrations. Various studies have found that most patients with epilepsy are on polypharmacy. The polypharmacy can lead to drug interactions if selection of drugs is not done carefully. In a local study done by Kariuki et al in 2007 among patients with epilepsy attending neurology clinic, he found that 31.9% were on dual therapy, 3.1% on triple therapy and 1.1% were on four drug therapy²⁸. Shorvon et al in 1977 did a study in four European countries and found that patients were on average of 3.2 drugs per patients and 84.3% were anticonvulsants.²⁹ Callaghan et al in 1984 in Scandinavian countries found that 54.3% were on dual therapy, 37.1% were on triple therapy and 8.% were on four drug therapy. He further found that reduction in polypharmacy reduced the seizure frequency by

54^{9,10}. We could optimize our conventional therapies if we had facilities to measure serum drug levels in patients on antiepileptic drugs. If this can be done we can be able to know, the patients who require monotherapy or polypharmacy to achieve seizure control. From our study, it is clear that if we can achieve seizure control by conventional therapies we are likely to significantly reduce the magnitude of alternative therapy use by patients with epilepsy.

Alternative therapies used by patients with epilepsy are the ones which are locally available and perceived to be effective by patients or relatives. Mushrooming of charismatic churches with claims to treat chronic diseases including epilepsy has greatly influenced patients with epilepsy to seek for spiritual healing in those churches. There have been enormous adverts in the media in which the preachers send the message to the public that they have the power to heal epilepsy. Because epilepsy is widely believed to be caused by witchcraft and evil spirits, most patients who consult spiritual healers have faith that healers possess special powers to deal with these forces. In our study we found that most patients who use alternative therapies, use Local African herbs at 79%.Spiritual healing at 15.8% and minority reported of using Chinese herbs at 5.3%.Our findings are consistent with what was found in Nigeria by Danesi et al .He also found that most patients use African herbs .others use spiritual healing by prayers and minority use other modalities like Acupuncture, homeopathy & nature cure)⁴.These differ significantly from what was found in the US and India, the alternative therapies used are herbs/supplements, music therapy, meditation, art therapy, aromatherapy and acupuncture^{6,7,9}. This demonstrates that the alternative therapies used are the ones which are locally available and affordable. The alternative therapies used in African countries are similar but differ from the ones used in the Western countries.

Information with regards to alternative therapies and decision to seek for these therapies can be influenced by various people in the communities. In our study we found that most of the patients who use alternative therapies (68.4%), the decision to use alternative therapies is made by their parents. Individual decision is reported to be made by 26.3% and fellow church members are reported to make decision for 5.3% of the patients who use alternative therapies. Our findings are consistent with the findings by Danesi et al in Nigeria and Tandon et al in India^{1,9}.The study population in our study is young, perhaps still dependant to their parents for the decision on where to seek medical care. Interventions to enhance compliance on conventional epilepsy

treatment should bring on board the parents, relatives and other community members like religious leaders.

Seizure type has been found to be associated with the use of alternative therapies. In our study we found that most of our patients (65.8%) presented with generalized seizures as picked from patients' history and verified by file diagnosis. Partial seizures accounted for 34.2%. These findings are consistent with what Kariuki found at same hospital in 2007²⁸. Our findings differ from what was found in America. In US it was found that majority of the patients present with Partial seizures⁶. In our study we did not find association of the seizure type with the use of alternative therapies in treating epilepsy. Our results are similar to what Easterford found in the UK, that seizure type and frequency were not associated with the use of alternative therapies to treat epilepsy⁸. In the US Kaiboriboon demonstrated that partial seizures were associated with the use of alternative therapies. That patients with partial seizures were 3.36 times more likely to use alternative therapies compared with patients with Generalized seizures ($p=0.01$)⁶. In our study we didn't demonstrate the association perhaps due to small numbers of patients on alternative therapy. There is a need for larger study.

Demographic characteristics have been found to be associated with use of alternative therapies. Some studies have found that lack or low education significantly influences the use of alternative therapies for treating epilepsy. In our study Age, Sex, marital status, level of education, employment, medical insurance cover and duration of the disease were not associated with the use of alternative therapies. Our findings differ from what Danesi et al found in Nigeria. He found that Lack or low education was associated with the use of alternative therapies to treat epilepsy. He found that 11.3% of the alternative therapy users were illiterates while the non-users only 6.8% were illiterates. Also he found that 5.3% of the alternative therapy users had attained higher degree education as compared with 17.1% of the non-users had higher degree education⁴. In Great Manchester UK, Easterford found that higher education was associated with the use alternative therapies to treat epilepsy. He didn't establish association of age, sex, seizure type & frequency, number of AEDs and dissatisfaction with conventional medicine⁸. In our study we couldn't find association of low education with the use of alternative therapies perhaps due to small number of patients using alternative therapies (n=19). In the US, Kaiboriboon found race to be associated with use of alternative therapies. He found that Caucasian race was 3.55 times

more likely to use alternative therapies as compared to the Hispanics ($p=0.03$)⁴. In our study our study population was black race and hence no comparison race.

9.0 CONCLUSIONS:

- There is high prevalence of alternative therapy use among patients with epilepsy attending neurology clinic at KNH
- Alternative therapies used by patients with epilepsy include local African herbs, spiritual healing and Chinese herbs.
- Most patients with epilepsy opt for using alternative therapies after failing to improve on conventional therapies
- The decision to seek for alternative healing by patients with epilepsy is mainly made by their parents.
- Socio-demographic characteristics and seizure types are not associated with the use alternative therapies to treat epilepsy

10.0 LIMITATION:

This was a hospital based study: findings don't reflect the true picture of patients with epilepsy in the general population e.g. we were unable to study patients who are using alternative therapy exclusively

11.0 RECOMMENDATIONS

- Comprehensive health education programmes on epilepsy are required to the patients with epilepsy and public in general, to allay the misconceptions which surround the disease
- Larger community based study needed to study alternative therapies used and their perceived effectiveness
- There is a great need for better seizure control by optimizing conventional therapies at our clinic to enhance compliance to conventional therapies

13. APPENDICES:

APPENDIX 1: QUESTIONNAIRE FOR THE STUDY ON THE TREATMENT MODALITIES USED BY EPILEPTIC PATIENTS ATTENDING NEUROLOGY CLINIC AT KNH.

Serial Number..... ID Number.....
Hospital Number..... Place of residence.....

Demographic data

1. Date of Birth.....Age in Years.....
2. Sex.....(Male...1 , Female2)
3. Marital status ()
(Single = 1, Married =2, Divorced = 3 Widowed/widower=4)
4. What is your level of education? ()
(None = 1, Primary =2 , Secondary = 3 College (Diploma) = 4 ,University (degree) = 5)
5. Are you employed? ()
(Yes = 1 No= 2)
 - i) If yes are you in formal employment or are self employed?
(Formal =1, Self = 2)
 - ii) If not, what is your source of livelihood.....
6. Do you have a medical insurance cover?(Yes =1, No=2)
 - i) If Yes, does it cover your treatment? Yes.....No.....
 - ii) If No, are you able to afford your treatment ? Yes.....No.....
7. Residence
 - i) Rural1 Urban2

ii) Urban residence Slum1 Non-slum.....2

- 8 What disease do you think you are suffering from?.....
- 9 What do you think is the cause of your disease?.....
10. How long have you suffered from this disease?
11. What kind of medication/therapy have you ever used?.....
12. When did you last experience the seizures
13. How do relatives/friends explain the events when you get an attack of your illness? ()
(Tonic clonic =1, shaking of part of the body = 2, Absence = 3, Others = 4)
If others mention
14. What treatment modalities do you know are available for the disease you are suffering from?
()
(1 =Biomedical drugs , 2 =Herbs , 3 = Spiritual , 4= Others)
If Others mention
15. Some of us have ever used other alternative therapies when we fall sick. Have you ever used or sought alternative therapy for your illness? ()
(Yes=1, No = 2)
16. What are some of the reasons for using the various treatment modalities?()
(Cost =1, Convenience =2 , Lack of improvement =3 ,Others = 4)
If Others (mention).....
17. What are the treatment modalities you have used?
.....
.....
18. Where did you get the information on the above? ()
(Neighbour =1,Relative = 2, Friend= 3 ,Others =4)
If others. mention.....
19. Who made the decision on using traditional medicine? ()
(Myself = 1, Parents = 2, Traditional healer = 3, Others = 4)
If others (mention).....
20. What kind of medication were you given?
.....
21. What is/was the mode of administration?

APPENDIX 2: QUESTIONS FOR IN-DEPTH INTERVIEW

1. You have said that you are using/have used alternative therapies

What type of alternative therapy have you used /you are using ?

.....

How is it / was it used

For how long is it/was it supposed to be used?

.....

2. Why do you think you use/used the type of therapy mentioned above? ()

i) Affordable cost

ii) Advertisements

iii) Convenient to me (how).....

iv) My disease is not cured by biomedical drugs

v) Others (explain).....

3. Where do you get information for the alternative therapy?

i) Traditional healers

ii) Spiritual leaders

iii) Advertisements (explain).....

iv) others (explain).....

4. What has been the effect of the treatment to your illness?

i) Getting better

ii) Remains the same

iii) Worsening

iv) I don't know

v) Others (explain).....

Thanks for participating in this study

KIAMBATANISHO 1: DODOSO KWA AJILI YA YA UTAFITI JUU YA TIBA MBADALA ZINAZOTUMIWA NA WAGONJWA WA KIFAFU WANA OHUDHURIA KLINIKI YA MAGAONJWA YA FAHAMU KATIKA HOSPITALI YA TAIFA KENYATTA

Nambari ya dodoso.....Nambari ya kitambulisho.....
 Nambari ya hospitali.....Unaishi wapi?.....

1. Tarehe ya kuzaliwaUmri (miaka).....
2. Jinsia (...)(mme =1.mke = 2)
3. Hali ya ndoa ()
 Hajaoa/Hajaolewa = 1. Ameoa/Ameolewa = 2
 Ameachika/ametalikiwa = 3, Mjane =4
4. Je kiwango chako cha elimu ni kipi? ()
 (Sijasoma = 1, Elimu ya msingi =2. Elimu ya upili = 3
 Elimu ya chuo (stahada) = 4, Elimu ya chuo kikuu = 5)
5. Je umeajiriwa () (Rasmi =1.Nimejijiri = 2)
 a) Kama umeajiriwa ,je ni ajira rasmi?.....
 b) Kama huna ajira je una mudu vipi maisha yako?.....
6. Je unayo bima ya afya?() (Ndiyo=1.Hapana =2)
 a) Kama ni ndiyo ,je bima inalipia matibabu ya huu ugonjwa wako?
 Ndiyo.....Hapana.....
 b) Kama ni hapana,je una mudu kugharimia matibabu yako?
 Ndiyo.....Hapana.....
7. Aina ya makazi ()
 i) Kijijini = .1
 Mjini = 2
 ii) Mjini
 Mtaa wa mabanda.....1
 Mtaa usio wa mabanda.....2

8. Je unafikiri unaumwa ugonjwa gain? unagonjeka nini?.....
9. Je unafikiri nini kinasababisha ugonjwa wako?.....
10. Je umegonjeka huu ugonjwa kwa kipindi gain?.....
11. Je ni dawa gain umewahi kutumia.....
12. Mara ya mwisho kuanguka kutokana na ugonjwa wako huu ni lini?
.....
13. Je ndugu au rafiki zako wamekueleza unaposhikwa na ugonjwa wako ni nini huwa kinatokca?
(kurusha rusha miguu na mkiono (Tonic Clonic) = 1, schemu moja ya mwili kutingishika = 2
Kuzubaa (absence) = 3, Mengineyo (eleza) = 4)
14. Ni tiba zipi unazifahamu zipo zinatumiwa kutibu ugonjwa ulionao?
(Dawa za hospitali = 1, Dawa za kienyeji = 2, maombi (spiritual) = 3
Nyinginezo (eleza) = 4
Kama ni nyinginezo toa maelezo
15. Baadhi yetu tumewahi kutumia tiba mbadala tunapopata ugonjwa wowote. Je umewahi kutumia tiba yoyote mbadala kutibu ugonjwa wako huu wa Kifafa?.....()
Ndiyo = 1
Hapana = 2
16. Ni sababu zipi zilikuifanya utumie tiba mbadala? ()
Gharama nafuu = 1
Inanifaa = 2
Kutopata nafuu = 3
Nyinginezo (taja) = 4
17. Ni aina zipi za tiba umeshawahi kutumia?.....
.....
18. Ni mahali gani ulipata habari za matumizi ya tiba uliyoitaja hapo juu (17)? ()
Toka kwa jirani = 1

Ndugu yangu =2

Rafiki = 3

Wengineo (taja) =4

19.Nani alikuamulia juu ya kutumia tiba mbadala ? ()

mimi mwenyewe =1

wazazi wangu =2

Mganga wa jadi =3

Wengineo (taja) =4

20.Ni tiba ipi uliyopewa ?.....

21.Je hiyo tiba ulikuwa unaitumiaje?.....

KIAMBATANISHO 2. Dodoso la mahojiano ya kina (in-depth interview questionnaire)

1. Umesema unatumia/umewahi kutumia tiba mbadala kutibu huu ugonjwa wako.

Je ni tiba zipi mbadala unatumia au umewahi kutumia?.....

.....

.....

Je unaitumiaje ? / Ulikuwa unaitumiaje?

Je hiyo tiba mbadala inatumiwa au inatakiwa itumiwe kwa muda gain?.....

.....

2. Je ni kwa nini unatumia /uliwahi kutumia tiba mbadala?

Ni sababu zipi zinakufanya au zilikufanya utumie tiba mbadala?

- i) Ni gharama nafuu (rahisi)
- ii) Kutokana na matangazo (advertisements)
- iii) Inanifaa /haina taabu
- iv) Ugonjwa wangu hautibiwi na dawa za hospitali
- v) Mengineyo (eleza).....

3. Ni mahali gani unapata taarifa/habari juu ya matumizi ya tiba mbadala?

i) Waganga wa jadi ()

ii) Viongozi wa kiroho (spiritual leaders)..... ()

iii) Matangazo (eleza).....()

iv) Kwingineko (Eleza).....

4. Je unaonaje hali ya ugonjwa wako baada ya kuwa umetumia tiba mbadala?

i) Napata nafuu.....()

ii) Uko vile vile()

iii) Ninazidiwa()

iv) Sijui()

v) Mengineyo (eleza).....

Asante kwa kushiriki kwenye utafiti huu

APPENDIX 3: CONSENT EXPLANATION FORM

My name is Dr. John Mugaya ANDREW. I am a postgraduate student from the department of Internal Medicine, University of Nairobi. I am conducting a study titled:

ASSESSMENT OF ALTERNATIVE THERAPEUTIC MODALITIES USED BY EPILEPTIC PATIENTS ATTENDING NEUROLOGY CLINIC AT KENYATTA NATIONAL HOSPITAL.

Purpose of the study

The study is about getting to know the magnitude and the factors associated with the use of alternative treatment modalities for management of epilepsy among epileptic patients at KNH. The study is being conducted at this hospital with assistance from staff and permission from the hospital administration.

What does the study involve?

If you consent to be included in the study, the following shall be carried out:

1. Filling of a study proforma about socio-demographic
2. A questionnaire about treatment history of your disease.
3. An in-depth interviews for the one who has a history of using alternative treatment in treating epilepsy.
4. Tape recording of the questions and responses for the ones who will participate in the in-depth interviews.

Are there any risks involved?

Absolutely there is no risk.

Will I benefit from this study?

Yes. Once the results of this study are analysed, we will be able to make suggestions on whether there is a need to institute health education packages to our patients at KNH. This will help in epileptic seizure control.

Can I withdraw from the study?

Your participation in this research is voluntary .You are also free to terminate the interview and withdraw from the study at any time.

If you have any questions/clarifications you can contact the following:

Dr. John Mugaya ANDREW

P.O. Box 19676

Nairobi.

Telephone: 0700-898813

Prof. E. Amayo

Department of clinical medicine and therapeutics

University of Nairobi

P.O. Box 19676

Nairobi.

Prof. J. M. Olenja

School of Public Health

University of Nairobi

P.O. Box 19676-00202

Nairobi

The Chairman of the Ethical and Review Committee

Kenyatta National Hospital

020-2726300/0722-829500/0733-606400 ext.44102

KIAMBATANISHO NAMBA 3: FOMU YA MAELEZO YA UFAFANUZI JUU YA KUHUYARI KUSHIRIKI KATIKA UTAFITI

Ninaitwa Dr. John Mugaya ANDREW. Ni mwanafunzi wa shahada ya uzamili katika idara ya magonjwa ya ndani (Internal Medicine) ya chuo kikuu cha Nairobi.

Ninafanya utafiti juu ya: Tiba mbadala zinazotumiwa na wagonjwa wenye kifafa wanaohudhuria kliniki ya magonjwa ya njia za fahamu katika hospitali ya taifa ya Kenyatta.

Dhumuni la utafiti huu:

Ni kutaka kufahamu kiwango cha matumizi ya tiba mbadala pamoja na sababu zinazopelekea wagonjwa wenye kifafa wanaohudhuria kliniki hapa hospitali ya Kenyatta kutumia hizi tiba mbadala. Utafiti huu unafanyika hospitalini hapa baada ya kuruhusiwa na uongozi wa hospitali na katika kufanya utafiti huu tunasaidiwa na watumishi wa hospitali.

Je Utafiti unahusisha nini?

Kama utahiyari kushiriki katika utafiti huu yafuatayo yatafanyika:

1. Kujaza fomu ya taarifa zako za awali juu ya umri, jinsia, kiwango cha elimu na kadhalika.
2. Kujaza dodoso juu ya kumbukumbu zako za matibabu yako ya kifafa.
3. Mahojiano ya kina kwa yule ambaye amweahi au anatumia tiba mbadala katika kutibu kifafa.
4. Kuchukua maelezo kwa njia ya kurekodi (tap recording) kwa yule ambaye atahusika kwenye mahojiano ya kina (in-depth interviews)

Je kuna hatari yoyote katika kushiriki utafiti huu?

Hakuna hatari yoyote katika kushiriki kwenye utafiti huu.

Je nitapata mianufaa yoyote kwenye utafiti huu?

Ndiyo. Baada ya matokeo ya utafiti huu kuchambuliwa, tutaweza kutoa ushauri na mapendekezo kama kuna haja ya kuwa na uboreshaji wa elimu ya afya kwa wagonjwa wetu katika hospitali ya Taifa ya Kenyatta. Hili litasaidia katika tiba ya ugonjwa wa kifafa .

Je ninaweza kujiondoa kutoka kwenye utafiti huu?

Ushiriki wako katika utafiti huu ni wa hiyari. uko huru kujiondoa muda wowote.

Kama una maswali / au una hitaji ufafanuzi zaidi unaweza kuwasiliana na wafuatao:

Dr. John Mugaya ANDREW

S.L.P. 19676

Nairobi

Simu: 0700898813

Prof. E. Amayo

Idara ya Magonjwa ya Ndani na Tiba

Chuo kikuu cha Nairobi

S.L.P 19676

Nairobi

Prof. J. M. Olenja

Shule ya Afya ya Jamii

Chuo Kikuu cha Nairobi

S.L.P.19676-00202

Nairobi

Mwenyekiti.

Kamati ya maadili ya Utafiti

Hospitali ya Taifa ya Kenyatta

020-2726300/0722-829500/0733-606400 ext.44102

APPENDIX 4: CONSENT FORM

Iconsent to participate in the study on the assessment of alternative therapeutic modalities used by epileptic patients. I do this with the full understanding of the purposes of the study and the procedures involved which include filling out a study questionnaire and participating in in-depth interview, all of which have been explained to me by Dr. John Mugaya ANDREW /his assistant.

I understand that I am free to either agree or refuse to participate in the study and this shall not interfere with my medical care.

Having agreed on the above i voluntarily agree to participate in the study.

SIGNED.....

THUMBPRINT.....

WITNESS.....

DATE.....

KIAMBATANISHO NAMBA 6. Fomu ya kuhiyari kushiriki katika utafiti.

Mimi.....nimehiyari

kushiriki katika utafiti juu ya tiba mbadala zinzotumiwa na wagonjwa wenye kifafa katika hospitali ya Taifa ya Kenyatta.

Ninafanya hivi nikijua fika madhumuni ya utafiti huu na taratibu zinazotumika ikiwa ni pamoja na kujaza dodoso.kushiriki katika mahojiano ya kina. kurekodiwa majibu nitakayoyatoa,yote haya nimeelezwa kwa kina na Dr.John Mugaya ANDREW/msaidizi wake.

Ninafahamu fika kuwa niko huru kukubali au kukataa kushiriki katika utafiti huu na kuwa haya yote hayataathiri matibabu yangu.

Baada ya kukubaliana na hayo hapo juu nimekubali kwa hiyari yangu kushiriki katika utafiti huu.

Sahihi.....

Alama ya kidole gumba.....

Shahidi.....

Tarehe.....

Investigator's statement.

I the investigator have educated the research participant on the purpose and implication of this study.

Signed:

Date:

Maelezo ya Mtafiti

Mimi mtafiti nimemwelewesha mshiriki vya kutosha juu ya madhumuni na matarajio ya utafiti huu.

Sahahi.....Tarehe.....

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