KNOWLEDGE, ATTITUDES AND PRACTICES OF PARENTS AND GUARDIANS OF CHILDREN WITH EPILEPSY AT KENYATTA NATIONAL HOSPITAL.

MEDICAL LIBRARY
UNIVERSITY OF NAIROBI

"A DISSERTATION PRESENTED IN PART FULFILMENT FOR THE DEGREE OF MASTER OF MEDICINE (PAEDIATRICS) OF THE UNIVERSITY OF NAIROBI, 2000."

MEDICAL LIBRARY
UNIVERSITY OF NAIROBI

BY

DR. CHRISTINE K. MUASYA MB.Ch.B (1989)

University of NAIROBI Library
0390395 2

DECLARATION

This thesis is a result of my original work and has not been presented for a degree in another University.

Signed .....

DR. CHRISTINE MUASYA, MBCHB (NAIROBI)

This thesis has been presented with our approval as supervisors:

Signed .....

PROFESSOR E. M. WAFULA

ASSOCIATE PROFESSOR

DEPARTMENT OF PAEDIATRICS AND CHILD HEATH

UNIVERSITY OF NAIROBI

Signed .....

DR. THOMAS KWASA

SENIOR LECTURER

DEPARTMENT OF INTERNAL MEDICINE

UNIVERSITY OF NAIROBI.

Signed .....

DR. DOROTHY NGACHA

SENIOR LECTURER

DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH

UNIVERSITY OF NAIROBI

DEDICATION

This work is dedicated to my late father ***Jones Muasya*** for the inspiration he gave me in life and his commitment to the education of his children.

IMPORTANT QUOTATION

"Lord have mercy on my son, for he is an epileptic and he suffers terribly". St. Mathew 17:15 (RSV).

THE SUFFERINGS of the epileptic patient, particularly as regards social ostracism and handicaps at school and at work, are great in all countries, but more so in the developing world.

ACKNOWLEDGEMENTS

I would like to express my sincere gratitude and appreciation to the following, to whom I am greatly indebted and without whom this dissertation would not have been possible:-

1. My supervisors Professor E.M. Wafula and Drs. Thomas Kwasa and Dorothy Ngacha for their great concern, invaluable guidance and constructive criticism that realised the present work.
2. Dr. Ruth Nduati for the help she gave me during the formulation of the research proposal.
3. Dr. Louise Aluoch for provision of literature on epilepsy.
4. My friend Dr. Mary Omutsani whose support and encouragement has known no bounds.
5. David Muyodi, Florence Ojiambo, Jane Gwaro and Kimani Mwaura for their untiring support and assistance during data collection.
6. All the parents/guardians who agreed to participate in the study.
7. The nurses and the medical records staff in the Paediatric Neurology Clinic for their co-operation and assistance during the study.
8. Mr. Erastus Muniu of KEMRI for his whole hearted concern, patience and timely assistance in statistical data analysis.
9. Mrs. Nancy Njoroge of KEMRI for her secretarial support.
10. Last but not least to God who provides wisdom, knowledge and strength.

LIST OF CONTENTS

LIST OF TABLES

LIST OF TABLES (Cont.)

LIST OF ABBREVIATIONS

1.	CT scan	-	Computerised Tomography scan
2.	EEG	-	Electroencephalogram
3.	FG	-	Focus Group
4.	FGD	-	Focus Group Discussions
5.	KAP	-	Knowledge, attitudes and practices
6.	KNH	-	Kenyatta National Hospital
7.	PFC	-	Paediatric Filter Clinic
8.	P/G	-	Parents/Guardians
9.	WHO	-	World Health Organization
10.	Yrs	-	Years

SUMMARY

A hospital based descriptive, cross sectional study was carried out, to determine the knowledge, attitudes and practices of parents and guardians of children with epilepsy, regarding the illness. One hundred and sixteen parents and guardians of children with epilepsy, attending the paediatric neurology clinic at Kenyatta National Hospital, were interviewed using a semi-structured questionnaire. Focus group discussions were also carried out on 42 other parents and guardians.

More than 77% of the parents/guardians had some knowledge on the type of illness their children were suffering from, the features of a convulsion, alerting features after convulsion, the type of antiepileptic drug treatment their children were receiving, and the potential hazards to an epileptic child during a convulsion. Many parents/guardians did not know the causes of epilepsy, alerting features prior to a convulsion, and complications of epilepsy.

Two-thirds of the parents/guardians administered some recommended first aid measures to their epileptic children during a fit, but many of them combined these with potentially harmful and harmful first aid measures.

Forty percent of the epileptic children of school going age in this study were not attending school because of problems which should not have interfered with schooling.

Regarding health seeking attitudes and practices, spiritual healing and to a lesser extent traditional herbal medicine were perceived to be important components of therapy for epilepsy when used in conjunction with hospital treatment.

An increased level of education of the parents/guardians had a positive influence on their knowledge, attitudes and practices towards epilepsy.

The findings of the focus group discussions corroborated with those of the questionnaire interviews.

It was recommended that health education should be given at all levels of contact with parents/guardians, to enhance their knowledge attitudes and practices towards epilepsy.

1. INTRODUCTION

1.1 LITERATURE REVIEW

Definition of epilepsy

Epilepsy is defined as two or more afebrile seizures unrelated to acute metabolic disorders or withdrawal of drugs or alcohol. It is characterised by a tendency to recurrent unprovoked seizures which can lead to loss of awareness or consciousness, disturbances of movement, sensation (including vision, hearing and taste), autonomic function, mood and mental function. Patients who have had a seizure within the last 2-5 years, and those on anticonvulsant medication are considered to have active epilepsy.[1,2,3]

Seizures are the result of sudden, usually brief, excessive electrical discharges in a group of neurons in the brain. The clinical manifestations of seizures are, therefore, variable and depend on the site and the function of the neurons involved in the brain.[2,4,5]

Epidemiology

Incidence and prevalence

Epilepsy is a common chronic neurological disorder of considerable public health importance. In 1978, a WHO study group identified epilepsy to be a disorder whose control should receive top priority, in view of its high prevalence in developing countries and potential for severe consequences.[6] Apart from infections affecting the nervous system, epilepsy is the commonest neurological condition among Africans.[7,8] In Kenya and Africa in general, hospital and clinical studies show that epilepsy is the commonest neurological problem seen in children's outpatient clinics.[9,10] It accounts for approximately 61% of the patients seen at the KNH paediatrics neurology out patient clinic.[10] In more than three quarters of the patients with epilepsy, the seizures begin before the age of 18 years.[5] It is estimated that up to 70% of epileptics in Kenya are younger than 25 years of age.[3] Despite this, epilepsy, as with other chronic diseases, generally carries a low priority for health care provision, which tends to be directed to acute infectious and more life threatening conditions.

Prevalence rates of epilepsy both in the first and third worlds have usually been found to lie between 4-10 per 1000 persons in the general population (range 1.5-30/1,000). Most studies report that males are more frequently affected than females. Higher rates of epilepsy have

MEDICAL LIBRARY
UNIVERSITY OF NAIROBI

been found in blacks than in whites and also among lower socio-economic groups. The rates are generally higher in Africa and they are also higher in rural compared to urban areas. The overall prevalence of epilepsies in childhood and adolescence is 4-6 per 1000.[12,13,14] The peak prevalence is in the 1-4 year age range. The prevalence rate of epilepsy in Kenya is estimated at 10.2/1,000 in children under 15 years of age.[15]

Studies done world wide have found incidence rates of 20-100 cases per 100,000 persons in the population per year.[1,5,7] Age is the most important variable affecting incidence figures. In all populations studied, the incidence rates are greatest in the first year of life, remain high in the first decade and then fall to low levels in mid life. In developed countries a second peak of cases occur in late life.[7,11] This second peak is not noticeable in most developing countries because of their demographic structure whereby there's a preponderance of young persons and few in the elderly age group.[5] Studies done in developing countries suggest higher incidence rates than in developed countries.[9] The main reasons for a higher incidence of epilepsy in developing countries are the higher risk of acute and chronic brain infections, pre- and post-natal obstetric complications leading to brain damage and malnutrition.[2]

Aetiology of epilepsy

Epilepsy may develop after a particular identifiable event, in which case it is called symptomatic epilepsy, or it may develop without any identifiable cause and then it is called idiopathic epilepsy.[11] In industrialized countries a specific aetiology for epilepsy is identified in about 60-70% of cases, while a known aetiology is reported for less than 40% of the cases in developing countries. This is because there is often lack of specialised technology (e.g. CT scan and EEG) to investigate epileptics in most of the developing countries, therefore the aetiological diagnosis is often made on clinical grounds and many times may remain obscure.[1,16,17,18]

The causes of symptomatic epilepsy are many and include: infections (e.g. intracranial and extracranial), metabolic conditions (e.g. hypoglycaemia, hypocalcemia, porphyria), trauma (e.g. birth trauma, head injury), circulatory disturbances (e.g. cerebrovascular accidents, sickle cell crisis), congenital malformations (e.g. tuberous sclerosis, neurofibromatosis), and degenerative diseases (e.g. Tay-sach's disease, Niemann-pick disease).[11]

A historic review of beliefs, attitudes and practices towards epilepsy

The oldest detailed account of epilepsy is on a Babylonian tablet obtained from a Babylonian text book of medicine dating as far back as 2000 BC.[2] The tablet emphasizes the supernatural nature of epilepsy, with each seizure type associated with the name of a spirit or god - usually evil. The treatment was therefore largely a spiritual one. It was, and still is, widely believed that a person with epilepsy is seized by a supernatural force or power. This ancient belief is reflected in the name of the disorder: the word "epilepsy" is derived from the Greek word "epilepsia", which means "to take hold of" or "to seize". Hence the common term seizure. This supernatural view was reinforced in the New Testament story of Jesus casting out an evil spirit from a young man with epilepsy (Mark, 9:14-29; Matthew 17:14-20; Luke 9:37-43). The Greek concept of epilepsy (5th century BC) was that of "the sacred disease". The ancient Roman term for epilepsy was "morbus sacer", where "sacer" meant sacred as well as demoniac, cursed and destined to die.[2]

Documented beliefs, attitudes and practices towards epilepsy in a number of African societies (including Kenya)

Beliefs and attitudes

There are several non scientific conceptualizations of the perceived causes of epilepsy which are responsible for the socio-cultural and psychological stigmatization of epileptics and provide the basic rationalization for the prevailing and persistent attitudes of

discrimination against epileptics in Africa.

In Malawi, among the Tumbuka tribe, epilepsy is believed to be caused by something like an insect inside the stomach of the epileptic. A seizure is thought to occur when the insect moves.[19,20] Spirit possession is also commonly perceived to cause epilepsy among the Tumbuka people.[20]

In the Semokwe region of Zimbabwe, epilepsy is believed to be caused by bewitchment, either by the spirits of the ancestors, the fairies or a living person who dislikes the epileptic person.[21]

In Ibadan, Nigeria, the Yoruba people believe that epilepsy is caused by possession of the patient by an evil spirit. [18,22] Black "magic" is another commonly perceived cause of epilepsy among the Yoruba people.[23] They also believe that epilepsy is infectious and can be transmitted from the sufferer to another person through the patient's saliva.[18]

In the rural Grand Bassa county of Liberia, epilepsy is believed to be caused by witchcraft or possession of the patient by evil spirits of the dead. [24,25]

In Southwestern Ethiopia, epilepsy is believed to be caused by possession of the patient by an evil spirit or the devil.[26,27] This belief is also popular in central Ethiopia, where epilepsy is also believed to be caused by a curse or punishment from God.[28] Ethiopians

also believe that epilepsy is contagious by contact with an epileptic person during a convulsive attack.[26-28]

The Baganda tribe of Uganda believe that an epileptic person is born with a lizard in the brain. When the lizard moves, the epileptic is thought to fall in an epileptic fit.[29,30] Bewitchment by the spirits of the ancestors or by fairies is also commonly perceived to cause epilepsy by the Baganda.[29,31,32] The Baganda also believe that epilepsy is contagious by interaction with an epileptic person.[29,30,32]

In Tanzania, among the Wapogoro tribe, epilepsy is believed to be caused by possession of the patient by an evil spirit.[23,33] The evil spirit is thought to jump from the affected person during a seizure and may affect bystanders. Witchcraft is also commonly perceived to cause epilepsy among the Wapogoro, and in the rural Ulanga district of Tanzania.[17,23] The Wapogoro also believe that epilepsy can be transmitted by coming into contact with the saliva, urine or faeces of an epileptic.[23] In rural Ulanga, epilepsy is believed to be transmitted through physical contact, flatus, breath, excretions and sharing food with an epileptic person.[17]

In Kangundo, Kenya, among the Akamba tribe, epilepsy is primarily believed to be caused by punishment from God.[34] Other common beliefs about the cause of epilepsy among the Akamba include bewitchment, a curse from the ancestors and an animal (e.g a caterpillar) moving in the head. The Akamba also believe that epilepsy can be transmitted by coming

in contact with the body of an epileptic person (including sexual contact), breathing in the air close to an epileptic having a fit, or touching saliva coming out of the mouth of an epileptic during a fit. If a person is hit by an epileptic patient and as a result suffers from a bleeding wound, the Akamba believe that epilepsy can be transmitted via the blood, from the affected person. The above mentioned beliefs and attitudes among the Akamba people may be widely held in Kenya. [35,36] In a community based survey done by Kwasa et al throughout Kenya, the same beliefs and attitudes were found in different districts across the country.[35] In the same study traditional beliefs and attitudes towards epilepsy were least affected by the level of general education of the respondents.[35]

It is consequently noted that in many African countries epilepsy is feared because it is believed to be contagious through excretions (e.g. saliva, urine, faeces, flatus) of an affected person. Due to this fear epileptics suffer social isolation, rejection and neglect. In Tanzania, Ethiopia, Nigeria and Uganda, no one attempts to safeguard or assist an epileptic who is having a fit lest they contract the disease.[18,23,27-29,32,33,37] An epileptic child may have to eat from separate dishes, use a separate wash basin, play separately from others, he/she may not be allowed to start schooling, or having started he/she may be forced to discontinue for fear he/she may contaminate the other children. [8,23,30,32,36,37] In Uganda and Tanzania the epileptic person often lives in a separate hut from the rest of the family.[23,30,32] In Uganda epilepsy is thought to lead to "spoiling" of the brain so that the epileptic becomes foolish and unable to learn, work or take responsibility. He is therefore denied positions of responsibility in life, his normal inheritance and normal burial at death. [30,32] Most chronic

epileptics tend to become outcasts and beggars.[23,26,32] In Ethiopia, the chronic epileptics end up living at the cemetery amongst lepers and other beggars.[26,27]

Health seeking behaviour for epilepsy

In many African communities epilepsy is considered an indigenous disease and therefore one unlikely to be cured by Western medicine. It is widely believed that only the traditional medicineman is capable of unravelling the cause of epilepsy and treating it. In many African communities epilepsy is ascribed to supernatural causes, therefore traditional methods of treatment are frequently tried first, though the frequent ineffectiveness of such traditional methods is recognized even by the patients themselves.[18,20-29,31,32,34, 35, 37-39] The traditional medicineman has not only a medical and healing function, but a spiritual one as well and combines organic medicine with a sort of religious psychotherapy.[21,22]

The traditional methods of treatment used include: herbal drinks which induce purging and vomiting, thus supposedly ridding the body of the cause of epilepsy (Nigeria, Tanzania, Ethiopia, Malawi); fumes for inhalation (Tanzania, Zimbabwe); topical applications (Malawi, Liberia, Tanzania, Nigeria); charms to wear on the arms or neck (Ethiopia, Tanzania); sacrifices to satisfy the spirits e.g. a white chicken (Liberia); rituals performed before and during treatment (Liberia, Nigeria, Tanzania); ingestion of donkey or dog meat (Kenya); shaving of the scalp and applying a horn to suck out the lizard believed to cause epilepsy (Uganda).

In Ethiopia, exorcism of devils and evil spirits may be performed by an orthodox faith healing priest after putting his patients in a trance. In Ethiopia and Liberia, patients may also visit the "holy" waters for the cure of their epilepsy.[24,26-28]

Some of the traditional methods of treatment used are hazardous and at times increase the morbidity and mortality associated with epilepsy.[18,22,38]

Documented studies on knowledge, attitudes and practices towards epilepsy

In studies done on knowledge, attitudes and practices (KAP) towards epilepsy in Tanzania, Ethiopia and Zimbabwe, more than 70%, 90% and 89% of the respondents respectively did not know the cause of epilepsy.[21,28,37] In two studies done on KAP in Kenya, 93% and 60% of the respondents respectively did not know the cause of epilepsy.[34,35] In Kenya, Tanzania and Ethiopia, 68%, 40.6% and 45% of the respondents respectively thought that epilepsy was contagious.[28,34,37] Sixty three percent of the Tanzanian respondents would not allow an epileptic child to go to school for various reasons.[37] In a study done in Kampala (Uganda) only 25% of the 101 epileptic children studied were actually attending school, and even those who continued schooling were liable to drop behind their classmates.[30] Concerning health seeking behaviour for epilepsy, modern drugs were the least favoured form of treatment in various KAP studies done in Ethiopia, Zimbabwe and Kenya.[21,28,34,35]

In studies done on public awareness and attitudes towards epilepsy in Finland and America, the most favourable opinion about epilepsy was found among respondents who had an acquaintance with an epileptic person, the better educated, better employed, young and urban members of the population.[40,41] The KAP of parents and guardians towards epilepsy would probably be influenced by their age, level of education, duration of the illness in their child, their socio-economic status and ethnicity.

1.2 STUDY JUSTIFICATION

This study is justified for the following reasons:

1. Epilepsy is the commonest neurological condition seen in children's outpatient clinics in Kenya, including the KNH paediatrics neurology out patient clinic.[9,10] It is a treatable condition in the majority of patients, yet 74% of our epileptics in Kenya are untreated at any time.[2,35,42] Among the few epileptic patients receiving medical treatment, as many as 55-82% of epileptics in developing countries either default or do not comply with the treatment given.[43-46] Inappropriate knowledge, beliefs and attitudes towards epilepsy have been shown to significantly influence the size of the treatment gap and the level of compliance to treatment.[43-48]

2. Inappropriate KAPs regarding epilepsy have been shown to be associated with increased morbidity and mortality.[18,22,23,26-29,32,33,37,38] So far the information gathered on KAPs towards epilepsy has been on the general community in people not necessarily having epilepsy and those who may not necessarily have taken care of an epileptic person. There's no published data on the KAPs of parents and guardians towards epilepsy in Kenya. These are the primary caretakers of the epileptic children. Their KAP will therefore determine the success of any epilepsy control program in paediatrics. The KAPs of the parents and guardians may be different from those of the general community because they feel ostracized,

discriminated against, isolated, bitter and frustrated. Once their KAPs are known, this can give a baseline from which education policies for parents and guardians and the general population can be based. In this way, reduction of unnecessary morbidity and mortality amongst our epileptic children may be achieved.

1.3 STUDY OBJECTIVES

GENERAL OBJECTIVES

To determine the knowledge, attitudes and practices of the parents and guardians of children with epilepsy.

SPECIFIC OBJECTIVES

1. To determine the knowledge, attitudes and practices of parents and guardians of children with epilepsy attending the paediatric neurology clinic at Kenyatta National Hospital.
2. To determine the type of care given at home to the children with epilepsy during an epileptic fit.
3. To determine the effect of the sociodemographic characteristics of the parents and guardians on their KAP with respect to epilepsy.

2. MATERIALS AND METHODS

2.1 Study design

A descriptive, cross sectional study, using both quantitative and qualitative methods.

2.2 Study area

The study was carried out at the Kenyatta National Hospital which is the national referral centre in Kenya and the teaching hospital for the University of Nairobi. It was conducted at the Paediatric Neurology Clinic which was held every Tuesday afternoon except on public holidays. The average attendance was 45-50 patients per clinic day.

2.3 Study population

All parents and guardians of children with a clinical diagnosis of epilepsy attending Kenyatta National Hospital during the study period were eligible for the study.

2.4 Sampling procedure

The study was conducted in two phases.

In the first phase of the study, every consecutive parent and guardian (P/G)

accompanying a child seen at the Paediatric Neurology Clinic, who satisfied the inclusion criteria and gave consent was recruited for the administration of the questionnaire (quantitative research), until 116 consecutive parents/guardians were recruited.

In the second phase of the study P/G were recruited for Focus group discussions (FGD's) i.e. qualitative research. A similar sampling frame as for the quantitative research group was utilised for the FGD's in order to avoid sampling bias, and to ensure that the composition of the respondents was similar to that of the quantitative research group. Seven FGD's were held on different days.

2.5 Investigation tool

1. A semi-structured questionnaire was used to interview the parents and guardians in Kiswahili or English depending on the language they felt proficient in. The questionnaire was translated from English to Kiswahili and from Kiswahili to English by two independent translators[1] to ensure reproducibility, and to improve its quality. The questionnaire was initially pre-tested on 15 parents and guardians to improve its quality mainly with regard to the range of possible answers and terminologies used by the P/G, rewording of questions, and also to ensure that the responses were objective. Appropriate amendments were made.

[1]Mr. David Muyodi and Miss Nancy Mburu, Registered Clinical Officers (Paediatrics).

2. Focus Group Discussions (FGD) were carried out among parents and guardians (P/G) selected according to the sampling procedure above. The FGD were held in groups of 6 P/G, and were conducted in Kiswahili because this was the language preferred by most of the FGD participants.

2.6 Inclusion criteria

1. Parents and guardians (primary care givers) of children with a clinical diagnosis of epilepsy. The primary care giver of a child may be the biological mother, father, grandmother, or any other relative who lives with and takes care of the child, and has a primary responsibility for the welfare of the child.
2. Informed consent.

2.7 Exclusion criteria

1. Guardians other than the primary care givers of these children were not included in the study. For example househelp (maids), neighbours were excluded.
2. Severe disease requiring emergency/urgent treatment.
3. Children with convulsions associated with fever.

2.8 Investigation procedure

Two undergraduate medical students[2] and three Registered Clinical Officers (Paediatrics)[3] were recruited as research assistants. The medical students had completed their period of clerkship in paediatrics and child health. The principal investigator went through the finalised questionnaire with the research assistants and ensured that they clearly understood the questions, were able to clearly administer them, and correctly record the responses of the parents and guardians. All the research assistants participated in the quantitative research. Only the undergraduate medical students participated in the qualitative research.

The principal investigator and the research assistants reported to the paediatric neurology clinic by 1.30 p.m. every Tuesday afternoon except on public holidays during the study period. The parents and guardians were selected from the attendance list of each clinic. Their children's clinic files were checked through to ensure they met the inclusion criteria. The parents and guardians were then approached while awaiting for their children to be seen at the clinic. The principal investigator first attended to the children of the parents and guardians selected and put them on the appropriate treatment for their illness. Informed consent was then sought from them, and they were interviewed by the principal investigator

---

[2]Miss Jane Gwaro and Mr. Kimani Mwaura

[3]Mr. David Muyodi, Miss Nancy Mburu and Mrs. Florence Ojiambo

or one of the research assistants using the questionnaire. Other P/G who satisfied the inclusion criteria and gave consent participated in the FGD on different Tuesday afternoons at the paediatric neurology clinic.

Focus group discussions were carried out using the standard recommended procedure.[49,50] During the FGD the P/G were asked to sit in a circle with the principal investigator and the research assistants. The principal investigator introduced herself and the research assistants. She then explained the general purpose of the discussion. The personal details of each member of the FGD were recorded (appendix 1), and consent to tape the discussions and take notes was sought. The principal investigator acted as the facilitator of the group. She guided the discussion using a prepared topic guide (appendix 2). The purpose of the FGD was to explore in depth the perceptions, beliefs and attitudes of the P/G towards epilepsy. The members of the FGD were asked to express their views freely, even if they differed from those of the other participants. They were encouraged to interact and stimulate each other to express their perceptions, beliefs and attitudes towards epilepsy. All the respondents were given a fair chance to participate in order to avoid some people talking too much while others were quiet, and to avoid the participants interrupting one another unnecessarily. During the discussion, the principal investigator probed and sought clarification of the answers provided. The research assistants used audio cassette recorders to tape the discussions and took verbatim notes as well.

2.9 Study duration

The study was carried out between 25th August 1998 and 15th December 1998.

2.10 Sample size calculation

The following formula was used to estimate the minimum required sample size for the study population.

$$n = \frac{z\alpha^2 P(1-P)}{d^2}$$ (Ref 51)

Where:

n is the minimum sample size of the parents and guardians

$z\alpha$ is equal to 1.96 which is the normal standard deviation corresponding to the 95% confidence level.

P is the proportion of parents and guardians with appropriate knowledge regarding epilepsy. P is estimated to be 25% (0.25).

d is the level of absolute precision of 10% i.e. the true value lies between 15-35%

$$n = \frac{(1.96)^2 \times 0.25 (1-0.25)}{(0.1)^2}$$

$$n = \frac{3.8416 \times 0.25 \times 0.75}{(0.01)}$$

$$n = 72.03.$$

2.11 Ethical considerations

1. Approval to carry out the study was sought from the KNH Ethical and Research Committee. The nurse in charge of the Paediatric Neurology clinic KNH was also informed.

2. Verbal consent was obtained from all the respondents.

3. Those parents and guardians found to have inappropriate knowledge, attitudes and practices were given appropriate health education.

4. Personal information obtained during the interview was treated with confidentiality.

2.12 Data Management

The questionnaires used were semi-structured. All open ended questions were coded before data entry. Data was entered into a computer using the SPSS (statistical package for social sciences) programme. Data analysis was done using SPSS/PC^{+} statistical programme. The results are presented in descriptive form, and using frequency tables and cross-tabulation.

The age of the parents/guardians was categorised into < 25 years, 25-34 years and ≥ 35 years. Their education level was categorised into ≤ 8 years (none/primary) 9-12 years (secondary) and > 12 years (post secondary). Their occupation was grouped into small traders, farmers/home makers and professionals.

Statistical significance in response to various KAP variables between groups of sociodemographic variables was assessed using chi-square test (X^2). For more than 2x2 tables X^2 statistic is valid if the number of cells with the expected frequency is less or equal to 20% (≤ 20%) and the minimum expected frequency is greater or equal to 1 (≥ 1). Significant results were considered at $p < 0.05$.

Analysis of the data from the focus group discussions was an on going process. Notes were written during the discussions and cross checked with the tape recorded discussion. Data analysis was carried out by summarising the verbatim report and reviewing its content.

3. RESULTS

A total of 158 parents/guardians were recruited into the study. One hundred and sixteen of these were recruited for the questionnaire administration (quantitative research) and 42 participated in the focus group discussions (FGD) i.e. qualitative research. The sociodemographic characteristics of the parents/guardians and their KAP on various aspects of epilepsy are presented. The characteristics of their children are also presented.

3.1 CHARACTERISTICS OF THE INDEX CHILD

Table 1 shows that over half of the children (57.8%) were males. The median age was 5 years with a standard deviation of 2.9 years, and an age range of 0.9 - 11.9 years. The median age of onset of seizures was 1.9 years with a standard deviation of 2.4 years and an age range of 0 - 10.9 years. The commonest seizure type was generalised tonic clonic seizures (61.2%), followed by simple partial seizures (22.4%) and atonic (akinetic) seizures (11.2%). The majority of children (68.1%) had been on treatment for a period of ≤ 3 years. The median duration of treatment was 2.8 years with a standard deviation of 2.3 years and a range of 0.8 - 11.3 years. The majority of children (81.9%) had good or excellent seizure control.

Table 1: Characteristics of the index child

CHARACTERISTIC	FREQUENCY (N=116)	PERCENTAGE
SEX OF CHILD:		
Male	67	57.8
Female	49	42.2
AGE GROUP:		
≤ 3 years	31	26.7
> 3 - 6 years	51	44.0
> 6 - 9 years	19	16.4
> 9 - 12 years	15	12.9
AGE OF ONSET OF SEIZURES:		
≤ 3 years	93	80.2
> 3 - 6 years	14	12.0
> 6 - 9 years	5	4.4
> 9 - 12 years	4	3.4
* SEIZURE TYPE:		
Generalised tonic clonic seizures	71	61.2
Simple partial seizures	26	22.4
Akinetic (atonic) seizures	13	11.2
Complex partial seizures	11	9.5
Generalised absences (Petit Mal)	9	7.8
Infantile spasms	8	6.8
Myoclonic seizures	6	5.2
DURATION OF TREATMENT:		
≤ 3 years	79	68.1
> 3 - 6 years	25	21.6
> 6 - 9 years	9	7.7
> 9 - 12 years	3	2.6
** LEVEL OF SEIZURE CONTROL:		
Poor	21	18.1
Good	36	31.0
Excellent	59	50.9

* Numbers > 116 due to multiple seizure types in some children

** See Appendix 4 for definition of seizure control

3.2 SOCIO DEMOGRAPHIC CHARACTERISTICS OF THE PARENTS/GUARDIANS

Table 2 shows the distribution of the quantitative research group and the qualitative research group by the sociodemographic characteristics of the parents/guardians.

Majority of the parents/guardians in both groups were mothers (76.7% of the quantitative research group and 90.5% of the qualitative research group) followed by fathers. Others interviewed (8.6% of the quantitative research group) comprised of brothers, aunts and grandmothers.

Most of the parents/guardians (51.7% of the quantitative research group and 64.3% of the qualitative research group) were 25-34 years old. The median age of the parents/guardians was 32.1 years for the quantitative research group and 30.1 years for the qualitative research group.

A significant proportion of the parents/guardians (41.4% of the quantitative research group and 47.6% of the qualitative research group) had ≤ 8 years of education.

Most of the parents/guardians in the quantitative research group were farmers/homemakers (50.0%) while the qualitative research group participants were mainly small traders (47.6%). The primary occupation of the farmers/homakers was home making, but many of

them also had small kitchen gardens or practised peasant farming for feeding their families. The small traders were engaged in small businesses like selling of vegetables or second hand clothes, shopkeepers, carpenters, tailors, hairdressers and mechanics. The professional group comprised of teachers, nurses, accountants, geologists and secretaries.

Majority of the parents/guardians (57.8% of the quantitative research group and 73.8% of the qualitative research group) were of the Kikuyu ethnic group.

There was no statistically significant difference in the distribution of the relationship of the parents/guardians to the child, the age of the parents/guardians and the level of education of the parents/guardians in the quantitative and the qualitative research groups ($p > 0.05$). Only the occupation categories showed a significant difference in distribution between the two groups, with most of the parents/guardians in the quantitative research group being farmers/home makers while most of the qualitative research group participants were small traders ($X^2 = 6.136$, $p = 0.0465$).

Table 2: Sociodemographic characteristics of parents/guardians

CHARACTERISTIC OF THE PARENT/GUARDIAN	QUANTITATIVE RESEARCH GROUP n = 116	QUALITATIVE RESEARCH GROUP n = 42	X^2	P
RELATIONSHIP TO CHILD:				
Mother	89 (76.7%)	38 (90.5%)		
Father	17 (14.7%)	4 (9.5%)	4.960	0.08
Others	10 (8.6%)	———		
AGE GROUP IN YEARS:				
< 25	15 (12.9%)	6 (14.3%)		
25-34	60 (51.7%)	27 (64.3%)	2.813	0.245
≥ 35	41 (35.3%)	9 (21.4%)		
LEVEL OF EDUCATION:				
≤ 8 years	48 (41.4%)	20 (47.6%)		
9-12 years	49 (42.2%)	19 (45.2%)	2.233	0.327
> 12 years	19 (16.4%)	3 (7.1%)		
OCCUPATION/PROFESSION:				
Small trader	33 (28.4%)	20 (47.6%)		
Farmer/Homemaker	58 (50.0%)	18 (42.9%)		
Professionals	25 (21.6%)	4 (9.5%)	6.136	0.0465
*ETHNICITY:				
Kamba	22 (19.0%)	5 (11.9%)		
Kikuyu	67 (57.8%)	31 (73.8%)		
Luo	4 (3.4%)	1 (2.4%)		
Luhya	12 (10.3%)	1 (2.4%)		
Kisii	4 (3.4%)	1 (2.4%)	-	-
Others	7 (6.1%)	3 (7.1%)		

* X^2 not valid

3.3 RESULTS OF THE QUANTITATIVE RESEARCH (QUESTIONNAIRES)

KNOWLEDGE

3.3.1 Knowledge on the type of illness the child was suffering from

Table 3: Terminologies used by the parents/guardians to describe the type of illness.

Terminology	*Frequency	Percentage
Epilepsy	37	31.9
Kifafa	26	22.4
Convulsions	15	12.9
Kukauka	9	7.8
Kuanguka	5	4.3
Fainting spells	5	4.3
Cerebral palsy	4	3.4
Meningitis	1	0.9
Speech disability	1	0.9
Don't know	22	19.0

* Frequencies > 116 due to multiple responses.

Each parent/guardian was asked to mention the type of illness his/her child was suffering from. Thirty two percent of the parents/guardians said that their children had epilepsy, followed in order by *kifafa(22.4%)* and those who did not know (19.0%). *Kifafa* is the Kiswahili word for epilepsy. *Kuanguka* is the Kiswahili term which was used to describe astatic (atonic) seizures, and *kukauka* was the Kiswahili word used to describe generalised tonic seizures (table 3).

The parents/guardians who mentioned epilepsy, convulsions, cerebral palsy, meningitis, speech disability, *kifafa, kuanguka and kukauka* alone or in combination were considered to have appropriate knowledge on the type of illness.(77.6% of the parents/guardians)

The sociodemographic variables of the parents/guardians were cross-tabulated against knowledge on the type of illness (table 4).

Table 4: Distribution of knowledge on the type of illness by the sociodemographic characteristics of parents/guardians

CHARACTERISTIC OF PARENT/ GUARDIAN	KNOWLEDGE ON THE TYPE OF ILLNESS		X^2	P
	Appropriate (n= 90)	Inappropriate (n =26)		
AGE GROUP. < 25 yrs	12.2	15.4		
25-34 yrs	52.2	50.0	0.180	0.914
≥ 35 yrs	35.6	34.6		
LEVEL OF EDUCATION. ≤ 8 yrs	36.7	57.7		
9-12 yrs	46.7	26.9	4.037	0.133
> 12 yrs	16.7	15.4		
OCCUPATION/ PROFESSION . Small Trader	31.1	19.2		
. Farmer / Homemaker	46.7	61.5	1.977	0.372
Professionals	22.2	19.2		

All the figures are in percentages except X^2 and P values.

There was no statistically significant difference in the distribution of knowledge on the type of illness by the sociodemographic characteristics of the parents/guardians. (table 4).

3.3.2 Knowledge on the causes of epilepsy

Table 5: Causes of epilepsy cited by the parents/guardians

Causes of epilepsy	*Frequency	Percentage
Head injury	36	31.0
Perinatal events	37	31.9
Infections	26	22.4
Inherited/familial	16	13.8
Drugs	5	4.3
Circulatory disturbances	4	3.4
Malnutrition	2	1.7
Congenital malformations	2	1.7
Brain tumour	1	0.9
Others: Thinking too much	3	2.6
Evil spirits	7	6.0
Too much cold	2	1.7
Curse	3	2.6
Worms in the stomach	1	0.9
Bewitchment	4	3.4
Don't know	43	37.1

* Frequencies > 116 due to multiple responses.

Thirty seven percent of the parents/guardians said they did not know what causes epilepsy.

The commonest causes of epilepsy mentioned by the others were perinatal events (31.9%)

followed in order by head injury (31.0%) and infections (22.4%). The perinatal events mentioned were birth asphyxia, neonatal jaundice and premature delivery. The infections mentioned were pneumonia, malaria and meningitis. Many of the parents/guardians (59.5%) knew of at least one correct cause of epilepsy (table 5).

The sociodemographic variables of the parents/guardians were cross tabulated against the frequently mentioned causes of epilepsy (tables 6 and 7).

Table 6: distribution of age of the parents/ guardians by the perceived causes of epilepsy

Causes of Epilepsy	< 25 yrs n=15	25-34 yrs n=60	≥ 35 yrs n=41	X^2	P
Head injury	20.0	33.3	31.7	1.010	0.603
Perinatal Events	60.0	33.3	19.5	8.406	0.015
Infections	6.7	21.7	29.3	3.266	0.195
Inherited/ Familial	- -	20.0	9.8	4.906	0.086
Don't know	40.0	33.3	41.5	0.754	0.686

All the figures are in percentages except X^2 and P values.

A significantly higher proportion of the parents/guardians less than 25 years of age (60.0%) recognised perinatal events as causes of epilepsy compared to the older parents/guardians (p = 0.015). (table 6).

There was no statistically significant difference in the distribution of age of the parents/guardians by the other causes of epilepsy that were cited.

Table 7: Distribution of education level of the parents/guardians by the perceived causes of epilepsy

Causes of Epilepsy	≤ 8 yrs Education n = 48	9-12 yrs education n=49	> 12 yrs education n=19	X^2	P
Head injury	16.7	34.7	57.9	11.34	0.0035
Perinatal Events	22.9	34.7	47.4	4.05	0.132
Infections	12.5	26.5	36.8	5.46	0.065
Inherited/ Familial	8.3	18.4	15.8	2.13	0.345
Don't know	50.0	32.7	15.8	7.54	0.023

All the figures are in percentages except X^2 and P values.

Parents/guardians with post secondary school education (57.9%) were more likely to know of head injury as a cause of epilepsy compared to those with secondary school education and below (34.7 % and 16.7% respectively). (P = 0.0035).

A significantly higher proportion of the parents/guardians with primary school education and below (50.0%) did not know the causes of epilepsy compared to the better educated parents/guardians (P = 0.023). (table 7).

There was no statistically significant difference in the distribution of the education level of the parents/guardians by the other causes of epilepsy mentioned.

There was no statistically significant difference in the distribution of the occupation categories by the perceived causes of epilepsy.

3.3.3 Knowledge on whether epilepsy can be transmitted from one person to another

The parents/guardians were asked whether epilepsy can be transmitted from one person to another. Seventy seven percent said it can not be transmitted, 27.6% said they did not know, and 6% said that it can be transmitted from one person to another. The methods of transmission mentioned by the latter group of parents/guardians included sharing of utensils (33.3%), inherited/familial (16.7%), airborne (16.7%), touching of an epileptic during a fit (16.7%), contact with the urine or stool of an epileptic person (16.7%), and contact with the saliva of an epileptic (16.7%).

The parents/guardians who said that epilepsy can not be transmitted from one person to another were considered to have appropriate knowledge on transmission of epilepsy. Those who said it can be transmitted and those who did not know were considered to have inappropriate knowledge on the transmission of epilepsy.

The sociodemographic characteristics of the parents/guardians were cross-tabulated against knowledge on the transmission of epilepsy (table 8).

TABLE 8: Distribution of knowledge on transmission of epilepsy by the sociodemographic characteristics of parents/guardians

CHARACTERISTIC OF PARENT/ GUARDIAN	KNOWLEDGE ON TRANSMISSION OF EPILEPSY		X^2	P
	Appropriate (n= 77)	Inappropriate (n =39)		
AGE GROUP. < 25 yrs	80.0	20.0	2.480	0.289
25-34 yrs	68.3	31.7		
≥ 35 yrs	58.5	41.5		
LEVEL OF EDUCATION. ≤ 8 yrs	56.3	43.7	5.820	0.213
9-12 yrs	71.4	28.6		
> 12 yrs	78.9	21.1		
OCCUPATION/ PROFESSION . Small Trader	66.7	33.3	0.050	0.975
. Farmer / Homemaker	65.5	34.5		
Professionals	68.0	32.0		

All the figures are in percentages except X^2 and P values.

There was no statistically significant difference in the distribution of knowledge on transmission of epilepsy by the socio-demographic characteristics of the parents/guardians.

3.3.4 Knowledge on the alerting features prior to a convulsion

Table 9: The recognised alerting features prior to a convulsion.

Alerting feature prior to a convulsion	*Frequency	Percentage
Dizziness	9	7.8
Headache	6	5.2
Irritability	27	23.3
Weakness	15	12.9
Dullness	17	14.7
Sweating/fast heart beat	5	4.3
Abdominal pains	8	6.9
Mood fluctuations	6	5.2
Incoherent talk	2	1.7
Hyperactivity	5	4.3
Hallucinations	2	1.7
Lack of sleep	4	3.4
Fear	3	2.6
Aggressive behaviour	2	1.7
Vomiting	1	0.9
Others:Staring into space	7	6.0
Screaming/whistling noise	8	6.9
Jerky limb movements	5	4.3
Red/yellow eyes	3	2.6
Upward rolling of eyes	1	0.9
Gnashing of teeth	2	1.7
Don't know	44	37.9

*Frequencies > 116 due to multiple responses.

The commonest recognised alerting feature prior to a convulsion was irritability (23.3%), followed in order by dullness (14.7%) and weakness (12.9%) (table 9). Many of the parents/guardians (47.4%) either said they did not know of any alerting features prior to a convulsion (37.9%) or cited incorrect alerting features prior to a convulsion (9.5%)

When the socio-demographic characteristics of the parents/guardians were cross-tabulated against the frequently recognised alerting features prior to a convulsion, there were no statistically significant differences in the distribution.

3.3.5 Knowledge on the features of a convulsion

Table 10: Features of a convulsion recognised by the parents/guardians

Features of a convulsion	*Frequency	Percentage
Jerky limb movements	85	73.3
Upward rolling of eyes	50	43.1
Loss of consciousness	37	31.9
Urine/stool incontinence	18	15.5
Frothing/drooling of saliva	16	13.8
Stiffening of the limbs	48	41.4
Staring gaze	14	12.1
Closing of the eyes	4	3.4
Child falls to the ground	20	17.2
Biting of the tongue	7	6.0
Sweating a lot	2	1.7
Twitching of the eyes	2	1.7
Twitching of the mouth	1	0.9
Falls asleep	4	3.4
Staggering gait	1	0.9
Gnashing of teeth	4	3.4
Weakness	3	2.6
Aggressiveness	1	0.9
Don't know	1	0.9

*Frequencies >116 due to multiple responses.

The parents/guardians were asked to mention the features which made them recognise that their child was having a convulsion. Majority of the parents/guardians (73.3%) recognised jerky movements of the limbs as a feature of a convulsion. followed in order by upward rolling of the eyes (43.1%) and stiffening of the limbs (41.4%) (table 10). Ninety nine percent of the parents/guardians knew of at least one feature of a convulsion.

The sociodemographic variables of the parents/guardians were cross-tabulated against the frequently recognised features of a convulsion.

Table 11: Distribution of age of the parents/guardians by the recognised features of a convulsion.

Features of a convulsion	< 25 yrs n = 48	25-34 yrs n=60	≥ 35 yrs n=41	X^2	P
Jerky limb movements	66.7	68.3	82.9	3.033	0.219
Rolling of eyes	26.7	55.0	31.7	7.286	0.0262
Loss of consciousness	6.7	38.3	31.7	5.541	0.063
Biting of tongue	6.7	8.3	2.4	*	.
Urine/stool incontinence	6.7	13.3	22.0	2.409	0.299
Frothing/ Drooling of saliva	6.7	13.3	17.1	1.022	0.599
Stiffening of limbs	66.7	43.3	29.3	6.528	0.038
Staring gaze	-	16.7	9.8	*	
Child falls to the ground	13.3	16.7	19.5	0.323	0.851

All the figures are in percentages except X^2 and P values.

*X^2 not valid

A significantly higher proportion of parents/guardians in the age range 25-34 years recognised upward rolling of the eyes (55%) as a feature of a convulsion compared to the

younger and the older parents/guardians (P = 0.0262).

The younger parents/guardians less than 25 years of age were more likely to recognise stiffening of the limbs (66.7%) as a feature of a convulsion compared to the older parents/guardians (P = 0.038) (table 11).

There were no statistically significant differences in the distribution of the level of education of the parents/guardians or their occupation categories by the recognised features of a convulsion. (P values > 0.05).

3.3.6 Knowledge on the alerting features after a convulsion

Table 12: The recognised alerting features after a convulsion.

Features after a convulsion	*Frequency	Percentage
Sleeps heavily	44	37.9
Fatigue/weakness	43	37.1
Irritability	13	11.2
Bruises	5	4.3
Bleeding/biting of tongue	4	3.4
Inability to talk	4	3.4
Confusion	6	5.2
Urine/stool incontinence	7	6.0
Mood fluctuation	7	6.0
Headache	6	5.2
Loss of memory	2	1.7
Drooling/frothing of saliva	1	0.9
Loss of appetite	3	2.6
Drowsy	3	2.6
Red eyes	3	2.6
Fearfulness	1	0.9
Others: gnashing of teeth	1	0.9
Makes noise	1	0.9
Thirst	1	0.9
Ringing sound in the ear	1	0.9
Hyperventilation	1	0.9
Don't know	3	2.6

* Frequencies > 116 due to multiple responses.

The parents/guardians were asked to mention the features which make them recognise that their child has had a convulsion. Many of the parents/guardians (37.9%) noted that their children slept heavily after a convulsion followed in order by fatigue/weakness (37.1%) and irritability (11.2%). A few of the parents/guardians (2.6%) did not recognise any features to alert them that their children had had a convulsion. (table 12). Majority of the parents/guardians (93.1%) knew of at least one correct alerting feature after a convulsion.

When the sociodemographic variables of the parents/guardians were cross tabulated against the frequently recognised alerting features after a convulsion, there were no statistically significant differences in the distribution.

3.3.7 Knowledge on the child's current antiepileptic drug treatment

Table 13: Knowledge on the current antiepileptic drug treatment.

Antiepileptic drug	*Frequency	Percentage
Phenobarbitone	54	46.6
Phenytoin (Epanutin)	17	14.7
Carbamazepine (Tegretol)	38	32.8
Clonazepam (Rivotril)	13	11.2
Ethosuximide (Zarontin)	1	0.9
Valproate (Epilim)	3	2.6
Lamotrigine (Lamictal)	1	0.9
Don't know/incorrect drugs cited	23	19.8

* Frequencies > 116 due to multiple responses.

The parents/guardians were asked to mention the antiepileptic drugs their children were receiving at the time of the interview. The commonest reported drug was phenobarbitone (46.6%) followed in order by carbamazepine (32.8%) and phenytoin (14.7%). Twenty percent of the parents/guardians either cited incorrect drugs or did not know any of the antiepileptic drugs their children were receiving (table 13). The type of antiepileptic drug mentioned was confirmed by checking what was indicated in the patient's clinic file.

All the parents/guardians who knew of at least one antiepileptic drug that their child was

receiving at the time of the interview were considered to have appropriate knowledge on the antiepileptic drug treatment (80.2% of the parents/guardians). Those who cited incorrect drugs or did not know any of the drugs that their children were receiving were considered to have inappropriate knowledge on the antiepileptic drug treatment (19.8%).

Table 14: Distribution of knowledge on the antiepileptic drug treatment by the sociodemographic characteristics of the parents/guardians.

CHARACTERISTIC OF PARENT/ GUARDIAN		KNOWLEDGE ON ANTIEPILEPTIC DRUG TREATMENT		X^2	P
		Appropriate (n= 93)	Inappropriate (n =23)		
AGE GROUP.	< 25 yrs	80.0	20.0	2.144	0.342
	25-34 yrs	85.0	15.0		
	≥35 yrs	73.2	26.8		
LEVEL OF EDUCATION.	≤ 8 yrs	60.4	39.6	20.678	0.00003
	9-12 yrs	91.8	8.2		
	> 12 yrs	100.0			
OCCUPATION/ PROFESSION	. Small Trader	87.9	12.1	6.714	0.035
	. Farmer / Homemaker	70.7	29.3		
	Professionals	92.0	8.0		

All the figures are in percentages except X^2 and P values.

All the parents/guardians with post secondary school education (> 12 years of education) knew of at least one antiepileptic drug that their child was receiving compared to 91.8% of parents/guardians with secondary school education and 60.4% of those with primary school

education and below. This difference was statistically significant (P = 0.00003) (table 14).

A significantly higher proportion of the professional group of parents/guardians had appropriate knowledge on the antiepileptic drug treatment (92.0%) compared with the other occupation categories (P = 0.035).

3.3.8 Knowledge on potential hazards to an epileptic child during a convulsion.

The parents/guardians were asked to mention all the potential hazards that their epileptic children should be protected from during a convulsion. The commonest reported potential hazard during a convulsion was fire (81.9%), followed in order by pools/water (59.5%) and heights (37.1%). 13.8% of the parents/guardians did not know of any potential hazards they should protect their epileptic children from during a fit. Majority of the parents/guardians (83.6%) knew of at least one potential hazard during a convulsion (table 15).

Table 15: Recognised potential hazards during a convulsion

Potential hazard	*Frequency	Percentage
Fire	95	81.9
Pools/water	69	59.5
Sharp objects	41	35.3
Heights	43	37.1
Traffic	19	16.4
Child being left alone	7	6.0
Ditches	6	5.2
Electricity	4	3.4
Hard surface	1	0.9
Others: Fever	1	0.9
Hot food	1	0.9
Radio	1	0.9
Don't know	16	13.8

* Frequencies > 116 due to multiple responses.

The frequently recognised potential hazards during a convulsion were cross tabulated against the sociodemographic variables of the parents/guardians.

Table 16: Distribution of age of the parents/guardians by the recognised potential hazards during a convulsion.

Potential hazard during a convulsion	< 25 yrs n = 15	25-34 yrs n=60	≥ 35 yrs n=41	X^2	P
Fire	66.7	86.7	80.5	3.322	0.190
Pools/ Water	33.3	68.3	56.1	6.401	0.041
Sharp objects	20.0	36.7	39.0	1.834	0.400
Heights	33.3	38.3	36.6	0.135	0.935
Traffic	6.7	16.7	19.5	1.331	0.514
Don't know	26.7	10.0	14.6	2.841	0.242

All the figures are in percentages except X^2 and P values.

A statistically significant higher proportion of parents/guardians in the age range 25-34 years recognised pools/water (68.3%) as a potential hazard during a convulsion compared to the younger and the older parents/guardians (P = 0.041) (table 16).

There were no statistically significant differences in the distribution of education level of the parents/guardians or their occupation categories by the recognised potential hazards during a convulsion.

3.3.9 Knowledge on complications of epilepsy

Table 17: Possible complications of epilepsy cited by the parents/guardians

Complications of epilepsy	*Frequency	Percentage
Brain damage	17	14.7
Mental retardation	30	25.9
Injuries after a fall	12	10.3
Delayed Milestones	18	15.5
Death	13	11.2
Paralysis	10	8.6
Speech abnormalities	16	13.8
Deafness	9	7.8
Recurrent sudden movements of the body	1	0.9
Chest infection	1	0.9
Blindness	5	4.3
Seizure recurrence	1	0.9
Depression	2	1.7
Hyperactivity	3	2.6
Generalised weakness	3	2.6
Excessive sleep	1	0.9
Others: Epilepsy	3	2.6
Don't know	42	36.2

* Frequencies > 116 due to multiple responses.

The parents/guardians were asked if they knew of any possible complications of epilepsy. The commonest reported possible complication of epilepsy was mental retardation (25.9%) followed in order by delayed milestones (15.5%), brain damage (14.7%) and speech abnormalities (13.8%). Many of the parents/guardians (36.2%) said they did not know of any possible complications of epilepsy. Most of the parents/guardians (61.2%) knew of at least one possible complication of epilepsy (table 17).

The sociodemographic characteristics of the parents/guardians were cross-tabulated against the frequently reported possible complications of epilepsy.

Table 18: Distribution of education of the parents/guardians by the reported possible complications of epilepsy.

Possible complica-tions of epilepsy	≤ 8 yrs education n = 48	9-12 yrs education n=49	> 12 yrs education n=19	X^2	P
Brain damage	6.3	16.3	31.6	7.172	0.028
Mental retardation	22.9	28.6	26.1	0.407	0.816
Injuries after a fall	12.5	4.1	21.1	*	
Delayed milestones	6.3	18.4	31.6	7.187	0.028
Death	-	16.3	5.3	2.364	0.307
Speech Abnormality	12.5	16.3	10.5	0.503	0.778
Don't know	45.8	30.6	26.3	3.395	0.183

All the figures are in percentages except X^2 and P values.

* X^2 not valid.

MEDICAL LIBRARY
UNIVERSITY OF NAIROBI

A significantly higher proportion of parents/guardians with post secondary school education (31.6%) recognised brain damage (p = 0.028) and delayed milestones (P = 0.028) as possible complications of epilepsy compared to parents/guardians of secondary school education and below (table 18).

There were no statistically significant differences in the distribution of the age of the parents/guardians or their occupation categories by the possible complications of epilepsy mentioned.

PRACTICES

3.3.10 The type of care given to an epileptic child during a fit.

The parents/guardians were asked to list the first aid measures they administered to their children during a fit. Many of the parents/guardians (28.4%) stayed with the child till the convulsion was over, followed in order by removal of all clothes (20.7%), holding the child to avoid falling (19.8%), holding for comfort (14.7%) and removal of harmful objects from around the child during a fit (12.1%). Most of the parents/guardians (62.1%) administered at least one recommended first aid measure (R), but many parents/guardians combined this with unnecessary (U), potentially harmful (PH) and harmful first aid measures (H). (table 19).

Many of the parents/guardians (18.1%) administered no first aid measures to their children during a convulsion. The reasons given for not administering any first aid were parents/guardians who did not know the type of first aid to administer (71.4%) followed in order by parents/guardians who felt that first aid measures were unnecessary because the convulsions were usually very brief (23.8%) and parents/guardians whose children only convulsed at night when they were not near them (4.8%).

Table 19: The type of care given to an epileptic child during a fit.

First aid measure during a fit	*Frequency	Percentage
(H) Put spoon in the mouth	13	11.2
(R) Hold the child to avoid falling	23	19.8
(U) Remove all clothes	24	20.7
(R) Loosen tight clothes	13	11.2
(R) Stay with the child till convulsion is over	33	28.4
(R) Hold the child for comfort	17	14.7
(PH) Hold to restrict movements	9	7.8
(R) Remove harmful objects around the child	14	12.1
(R) Put to lie on the side	8	6.9
(H) Sit child down during a convulsion	2	1.7
(H) Hold child with head downwards	2	1.7
(U) Valium injection	1	0.9
(U) Mouth to mouth resuscitation	2	1.7
(U) Wipe with wet cloth	7	6.0
(PH) Cover with blanket	1	0.9
(R) Support the head with something soft	3	2.6
(R) Put child in a flat position	4	3.4
(PH) Put child to lie on the back	2	1.7
(PH) Put child to lie on the tummy	1	0.9
(H) Give a cold drink	1	0.9
(R) Put to lie on the bed	4	3.4
(PH) No first aid measures	21	18.1

* Frequencies > 116 due to multiple responses.

The frequently practised first aid measures were cross tabulated against the sociodemographic characteristics of the parents/guardians.

There were no statistically significant differences in the distribution of the type of care given during an epileptic fit by the age of the parents/guardians or their occupation categories.

Table 20: Distribution of the type of care given to an epileptic child during a fit by the level of education of parents/guardians.

First aid measure	≤ 8 yrs education n=48	9-12 yrs education n=49	➢ 12 yrs education n=19	X^2	P
Hold to avoid falling	16.7	28.6	5.3	5.194	0.075
Remove all Clothes	20.8	24.5	10.5	1.628	0.443
Stay with The child	20.8	32.7	36.8	2.451	0.294
Hold for Comfort	16.7	6.1	31.6	7.359	0.025
Put to lie On side	8.3	6.1	5.3	*	
No first aid	18.8	18.4	15.8	0.084	0.959

All the figures are in percentages except X^2 and P values.

* X^2 not valid.

A statistically significant higher proportion of parents/guardians with post secondary school education held their children for comfort during a convulsion (31.6%) compared to parents/guardians with secondary school education and below (P = 0.025) (table 20).

When the types of first aid measures practised (i.e. potentially harmful, harmful and recommended first aid measures) were cross tabulated against the sociodemograhic characteristics of the parents/guardians there were no statistically significant differences in the distribution.

3.3.11 Health seeking attitudes and practices

The parents/guardians were asked if they had ever practised other methods of treatment for their epileptic children other than hospital care. The majority (81.8%) said they had only practised hospital treatment while 21 (18.1%) said they had practised a combination of hospital treatment and alternative methods of treatment (table 21).

Table 21: Distribution of the methods of treatment practised by the parents/guardians.

Methods of treatment practised	Frequency	Percentage
Hospital treatment alone	95	81.8
Hospital/ spiritual healing	17	14.7
Hospital/spiritual healing/traditional medicine	3	2.6
Hospital/spiritual healing/traditional medicine/ Witchdoctor	1	0.9
Total	116	100.0

When the methods of treatment practised (i.e. hospital treatment alone versus hospital treatment combined with alternative methods of treatment) were cross tabulated against the socio-demographic characteristics of the parents/guardians there were no statistically significant differences in the distribution.

3.3.12 School attendance by the epileptic children

Out of the 116 children n during the study period, 63 (54.3%) were of below school going age and 53 (45.7%) were of school going age.

Many of the children of school going age (39.6%) were not attending school at the time of the interview because of mental retardation (15/21) and frequent convulsions (6/21). Only 60.4% of the eligible children were attending school at the time of the interview.

3.3.13 Feeding practices of the epileptic children

Majority of the children (90.5%) were being fed using the same utensils as the other family members, while 9.5% were fed with separate utensils from the other family members. The latter group comprised of young children whose utensils were cleaned separately because they were perceived to be more vulnerable to infections compared to the older family members, or young children who required smaller utensils for their feeds compared to the utensils used by the other family members. The feeding of this group of patients with

separate utensils was considered appropriate for the age of the child and in the circumstances given. Hence 100% of the parents/guardians were considered to have appropriate feeding practices for their epileptic children.

3.3.14 Playing habits of the epileptic children

A few of the epileptic children (11.2%) played alone while 88.8% played with other children. The reasons given for those who played alone were children who did not know how to play with other children because of mental retardation (7/13) or because of being very young (5/13), and one child who was often beaten by other children, hence the parents opted for him to play alone. These reasons were considered appropriate in the circumstances given, hence 100% of the children were considered to have appropriate playing habits.

3.4 RESULTS OF THE QUALITATIVE RESEARCH (FOCUS GROUP DISCUSSIONS)

The content of the focus group discussions (FGD's) was largely similar to the responses in the questionnaire interviews. For every question posed, we sought the consensus of the focus group (FG), or gathered the feeling of the majority, while still noting the content of the individual responses.

3.4.1 Perception on the type of illness

All the focus groups (FG's) readily recognised the hypothetical illness described as *kifafa* and epilepsy. In two of the seven FG's vernacular terminologies were also used to describe the illness i.e. "*Cheptolei*" (Kalenjin), "*Mung'athuko*" (Kamba), "*Mung'aro*" and "*Kibaba*" (Kikuyu). In two of the FG's the illness was also described as convulsions, malaria and pneumonia.

The terms *kifafa* ,*kibaba,cheptolei* and *mung'athuko* are the kiswahili and vernacular equaivalents for epilepsy. The term *mung'aro* denotes a generalised tonic seizure in the kikuyu dialect.

One FG participant felt that the hypothetical case described (GTCS) was epilepsy. However, she differentiated this from a condition where a patient "stares into space and appears not to see or hear for a brief period of time, without incontinence of urine/stool or drooling of saliva" (generalised absence seizures), which she said was not epilepsy, but possession of a person by the "angry" spirit of a departed ancestor after whom the person should have been named.

3.4.2 The perceived causes of epilepsy

In all the focus groups perinatal events, head injury and inheritance/ familial were cited as causes of epilepsy. The perinatal events cited were: "*mtoto akikosa hewa wakati wa kuzaliwa*" (If a child lacks air at the time of delivery); "*mtoto akikosa kulia wakati wa kuzaliwa*"(If a child fails to cry at the time of delivery); if the baby's head is compressed at the time of delivery due to " a large head" or following prolonged labour; and neonatal jaundice. It was strongly felt that epilepsy could be passed on from the parents to a child, or it could affect a child who had other relatives with epilepsy even though the parents may be unaffected.

In six of the focus groups infections e.g malaria, pneumonia and meningitis were cited as causes of epilepsy.

In three of the focus groups a curse from the ancestors strongly featured as a cause of epilepsy. It was felt that a curse could cause epilepsy in a child if his/ her father had not

taken all the required dowry to the mother's home, and worse still if the maternal grandparents to the child died before the settlement was done. A curse was also perceived to affect a child if his / her parents failed to name him/ her after a departed ancestor, or if his / her parents had done something wrong to offend the grandparents or the clan.

Drugs of addiction " *madawa ya kulevya*", a "growth" in the brain, and "*damu ikichanganyika na ubongo"* (mixing of blood with the brain) were cited as causes of epilepsy by two of the focus groups. In one FG reduced cerebral blood flow "*ukosefu wa damu katika ubongo"* was cited..

In three of the focus groups, bewitchment by an enemy "*kurogwa"*, or " *mtoto akiangaliwa na jicho mbaya"* (looking at a child with an evil eye) were cited as causes of epilepsy.

3.4.3 Perception on the transmission of epilepsy

In all the focus groups it was strongly felt that epilepsy can not be transmitted from one person to another. However, one or two participants from each FG felt that epilepsy can be transmitted by coming into contact with secretions (e.g. Urine, stool and saliva) of an epileptic person. A few participants from two of the FGs felt that if an epileptic person passed flatus "*mtu mwenye ugonjwa wa kifafa akinyamba"* and another person breathed in the air containing this flatus he could acquire the disease.

A few FG participants felt that epilepsy can be transmitted by sharing a bed or utensils with an epileptic person, or playing with an epileptic child. The other FG participants strongly argued against this because their non epileptic children and themselves had not acquired the disease so far despite sharing a bed/ utensils and playing with the only epileptic child in the family.

One FG participant said that epilepsy can be transmitted by "jumping over a site" where an epileptic person had passed urine. Another participant from a different FG said it can be transmitted via the bite of an epileptic person.

3.4.4 Recommended first aid measures during a convulsion

In all the focus groups it was felt that something should be put in mouth (eg a spoon) to prevent an epileptic from biting him/ her self during a fit. Some FG participants argued against this because they felt that a person would have to struggle to pass a spoon in between clenched teeth during a convulsion, and this could cause more harm to the child. All the focus groups also felt that a child should be put to lie in the lateral position during a fit to prevent inhalation of saliva and choking. A few FG participants felt that a child should be made to sit down during a convulsion, because this prevented injury to the head and limbs by the hard floor. It was generally agreed that tight clothes should be loosened to improve circulation of blood in the body, and that an epileptic should be fanned during a fit to enable him/ her to breath well. All the focus groups recommended that a child should be

left to lie where he/she was during a fit unless he/ she was in danger.

Five of the focus groups recommended that a child should be held to restrict movements during a fit. It was felt that this ensured the convulsions subsided faster. and also prevented the child from hurting him/ herself.

Three of the focus groups recommended that somebody should stay with the child till the convulsion was over.

3.4.5 Recommended health seeking practices

When asked where they would recommend for the parent of an epileptic child to seek help for his/her child's problem, there was a general consensus in all the focus groups that hospital care was the best mode of treatment. It was also felt in all the FG's that prayers were effective in treating epilepsy. It was however noted that prayers needed to be conducted by a "staunch" christian or a spiritual healer and that the parents of the epileptic child needed to have "adequate" faith that the child would get well after being prayed for. Most of the FG participants said that prayers should be used in conjunction with hospital care.

In six of the focus groups, traditional herbal medicine was said to be effective in treating some patients with epilepsy. It was argued that it was worthwhile to try traditional herbal medicine for treating patients who had not improved on long term "modern" medical

treatment. It was however felt that one should not combine traditional herbal medicine with "modern" drugs, and that a patient should be on one or the other at any one given time.

In two of the focus groups, it was felt that epilepsy caused by a curse was best treated by performing traditional rituals. Such rituals involved sacrificing a cow or a goat and traditional beer to "apease" the spirits of the departed ancestors. It was argued that if these rituals were not performed, the ancestral spirits would continue to "haunt" the child and would eventually kill him/her.

In two other focus groups sheep oil was cited as an effective method of treating or preventing epilepsy caused by an "evil eye". Another focus group recommended tying a piece of goat skin around the wrist to prevent or treat epilepsy caused by "an evil eye". In a different focus group it was recommended that epilepsy caused by bewitchment should be treated by a witchdoctor.

In one of the focus groups dog meat was cited as an effective method of treating epilepsy. It was said that one should cook dog meat for an epileptic patient, and inform the patient about it long after he had eaten the meat. It was expected that the patient would get a "major" convulsion - "*atashtuka kabisa*", following which he would be cured of the epilepsy.

4. DISCUSSION

The study population mainly comprised of mothers in the age group 25-34 years. Majority of the parents/guardians had post-primary school education (≥ 9 years of education). The parents/guardians were mainly of the Kikuyu ethnic group followed by Kamba, probably because of the proximity to KNH by these ethnic groups compared to the others.

Most of the epileptic children seen during the study period were males. The median age of the children was 5 years. Majority of the children had onset of seizures before 3 years of age. Most studies report a slight excess of epilepsy among males [1,7,8]. Majority of the children (61.2%) had generalised tonic clonic seizures (GTCS), the commonest reported seizure type in many published reports.[8, 11, 18, 29, 33, 39, 53]

Most of the parents/guardians (59.5%) knew of at least one correct cause of epilepsy. This is better than what was found by Rwiza et al in Tanzania, by Levy in Zimbabwe, Tekle-Haimanot et al in Ethiopia, and by Draat, and Kwasa et al in Kenya, where only 32.3%, <1%, 6%, 46% and 6.9% of the respondents respectively knew of at least one cause of epilepsy.[21, 28, 30, 34, 35] Only 12% of the parents/guardians in this study ascribed epilepsy to supernatural causes e.g. bewitchment, evil spirit or a curse. This is commendable, considering the widely prevalent beliefs and attitudes about the supernatural nature of epilepsy in many published reports in Africa.[17,18, 20-27, 29, 31-34] The findings in this study are comparable to those of Shaba et al in Malawi where the respondents were found to

simultaneously hold medical and traditional beliefs about the cause of epilepsy.[54] Knowledge on the causes of epilepsy has an important preventive function for epilepsy, even for other children that the parent may have in the future. The important causes of epilepsy in developing countries are acute and chronic brain infections, pre- and post-natal obstetric complications, and malnutrition[2]. In a large number of cases epilepsy can be prevented if these are managed in good time, and if the parents/guardians are equipped with the necessary information to deal with them effectively. Health education needs to emphasize the need for proper management of labour and its complications, early treatment of infections e.g. malaria and meningitis, and the need for a balanced diet to avoid malnutrition. A significantly higher proportion of the less educated parents/guardians did not know the causes of epilepsy.

A few of the parents/guardians (6%) thought that epilepsy can be transmitted from one person to another, and 27.6% did not know if it can be transmitted or not. These findings are better than what was found by Tekle-Haimanot et al in Ethiopia, by Draat in Kenya and by Rwiza et al in Tanzania, where 45%, 67% and 41% of the respondents respectively thought that epilepsy was contagious[28, 34, 37] The methods of transmission mentioned by the few parents/guardians in this study who thought that epilepsy can be transmitted included contact with the secretions of an epileptic, touching an epileptic during a fit and sharing of utensils with an epileptic. It is commendable that despite these beliefs and attitudes among a few of our parents/guardians, none of the epileptic children were barred from eating out of the utensils used by the other family members, and the epileptic children

were allowed to play freely with the other children.

Many of the epileptic children of school going age in this study (39.6%) were not attending school at the time of the interview. This is discouraging though it compares favourably with what was found in Uganda and Tanzania. Tamale-Ssali and Billinghurst found that 75% of the eligible epileptic children in Kampala, Uganda were not attending school because of fear that they may transmit the illness to the other children and because of the widely held false belief that epilepsy inevitably led to "spoiling" of the brain, making the epileptic foolish and unable to learn, hence it was believed that the epileptic children would not benefit from schooling [30]. A KAP study done in Tanzania by Rwiza et al revealed that 62.7% of the respondents would not allow an epileptic child to go to school because they believed such children were mentally subnormal or would infect other children [37]. In rural, Tanzania, Jilek also reported that epileptic children were barred from attending school, ate from separate dishes and lived in separate huts from the other family members [23]. It is commendable that our epileptic children are subjected to less social stigma and segregation compared to what has been reported in Uganda and Tanzania. It is however worrying that a large proportion of our epileptic children are not attending school because of problems which need not interfere with schooling. Mentally retarded children can attend special schools to improve their potential in life. However, we did not explore the availability/ affordability of special schools in this study, or if the parents/ guardians were aware of the existence of such schools. With the currently available antiepileptic drugs, majority of the children with frequent convulsions can be rendered seizure free. [2,42] However, there are

instances when epilepsy may be difficult to control, and this can legitimately interfere with schooling.

Only 52.6% of the parents/guardians knew of at least one alerting feature prior to convulsion. Alerting features prior to convulsion may indicate the prodromal phase or the aura phase of a convulsion. The prodromal phase usually begins several days up to a few hours prior to many types of convulsions. The aura occurs a few minutes up to some seconds before a seizure and indicates a high likelihood of an underlying focal structural/pathological aetiology of the seizure. The presence and type of aura (based on the signs and symptoms of the patient) can assist the doctor to localise the focus of the cerebral lesion causing epilepsy, and hence is useful in the management of an epileptic child.[55] Some parents can accurately predict the timing of the next seizure based on the changes in the child's disposition.[56] This is important because the parent can ensure that somebody will be there to watch over the child when the seizure occurs to avoid complications which may occur if the child convulses while alone.

Almost all the parents/guardians (99.1%) recognised at least one feature of a convulsion. The most frequently recognised features were those of a GTCS, the commonest reported seizure type in this study and in many other published reports. Snow et al and Jilek Aall noted that 78% and 53% of the deaths in epileptic patients studied in Kenya and Tanzania respectively, were directly attributable to epileptic seizures.[33, 53] It is therefore important to recognise the features of a convulsion in order to act fast and avoid complications

(including death) which may result from a poorly managed convulsion.

Majority of the parents/guardians 80.2%) knew the antiepileptic drug treatment their children were receiving. A significantly higher proportion of parents/guardians with post secondary school education (> 12 years of education) and the professional group of parents/guardians knew about the type of treatment compared to the less educated parents/guardians and the parents/guardians of the other occupation categories. The commonest drugs used for treatment of epilepsy at KNH are phenobarbitone, carbamazepine and phenytoin. These drugs are indicated for the treatment of GTCS and also for the treatment of partial (focal) seizures, the commonest seizure types seen in our paediatric practice at KNH. These drugs are also more affordable than the other antiepileptic drugs in use. If a patient does not respond to one of these three drugs or their combination, and in-patients where the seizure type requires a different type of drug for control, the other antiepileptic drugs are then used.

In this study, as in many other developing countries, Phenobarbitone was preferred as a "front-line" drug in the treatment of epilepsy. [8,19,20,47] This is because it is much cheaper than Carbamazepine and Phenytoin, though its anticonvulsant efficacy is equivalent to that of the latter two drugs.[47] It is also more suitable for prescription as a single daily dose, and this is associated with improved patient compliance to treatment .[8] With Phenobarbitone treatment alone, 50% of epileptic persons can be rendered seizure free [57] Phenobarbitone frequently causes paradoxical excitement and hyperactivity in children [47]. It is therefore

not much used to treat epilepsy in developed countries where most of the patients can afford equally efficacious or more effective drugs with less side effects.

Parents/guardians had good knowledge on the potential hazards to an epileptic child during a convulsion. Health education to the parent of an epileptic child should teach him/her to protect the child in areas where there is a risk of seizures in dangerous circumstances e.g. fires, water, heights, etc. Open fires should have a protective shield around them or they should be raised off the ground so that children can not fall into them during a seizure. The child should always be watched by someone while swimming in case he/she gets a seizure in which case she/he should be immediately removed from the water to avoid drowning. When riding a horse or a bicycle the child should always have a hard hat to protect his/her head in case of a fall. Climbing of trees and ladders should be avoided in case the child gets a seizure at a height with the risk of head injury and other trauma.[11,36]

Only 61.2% of the parents/guardians knew of at least one complication of epilepsy. A statistically significant proportion of parents/guardians with post secondary school education knew of brain damage and delayed milestones as complications of epilepsy compared to parents/guardians with a lower education level. Knowledge on the complications of epilepsy is important because it motivates the parents/guardians to comply with the treatment given, and in so doing there is reduction of unnecessary morbidity and mortality which may be associated with epilepsy. A study done in Michigan by Shope revealed that patient compliance on antiepileptic drug treatment was related to motivation,

the value of illness threat reduction, and the probability that compliant behaviour would reduce the threat.[43]

Most of the parents/guardians (62.1%) administered at least one recommended first aid measure to their epileptic children during a fit. It is however worrying that many of them combined the recommended first aid measures with potentially harmful and harmful first aid measures. The overall effect of such combinations was at times more harmful than useful to the child. These practices, however, were better than what was found by Rwiza et al in Tanzania, and by Tekle-Haimanot et al in Ethiopia where only 35.7% and 11% of the respondents respectively knew of some recommended care to give to an epileptic person during a fit.[28,37]

A significant proportion of the parents/guardians (18.1%) in this study did not administer any first aid measure to their epileptic children during a fit. The majority (70%) of this group of parents/guardians did not administer first aid because they did not know the type of first aid to administer to a convulsing child. This is in contrast to studies done in Tanzania, Ethiopia, Nigeria and Uganda where many people did not attempt to safeguard or assist an epileptic during a fit in fear that they would contract the disease.[18, 23, 27-29, 32, 33, 37]

Majority of the parents/guardians in this study (81.8%) had only used hospital treatment for managing their epileptic children. All the rest (18.2%) combined hospital treatment with spiritual healing, and a few of them also used traditional medicine. It is notable that

spiritual healing was considered an important component of therapy, and traditional medicine to a lesser extent, especially if we consider the findings of the focus group discussions. These findings suggest that many parents/guardians perceived some continuing benefits from alternative methods of treatment, even though they continued to seek "modern" medicine. This is comparable to what was found by Danesi and Adetunji when they followed up a group of epileptic patients attending medical treatment in a university hospital in Nigeria: 14.6% of the patients who had earlier used African traditional medicine continued with such treatment, and more than two thirds of the patients who had earlier used spiritual healing continued with the same as well as being on hospital treatment[58] This observations from Nigeria and those from our study suggest that alternative medicine especially spiritual healing, and to a lesser extent African traditional medicine, can not be considered irrelevant in the management of epilepsy in Africa. Studies done elsewhere revealed exotic traditional methods of treating epilepsy e.g. forcing down the throat of the unconscious epileptic a highly toxic mixture of fresh tobacco juice, gin, alligator pepper and other hot spices (Nigeria) and the use of herbal drinks to induce purging and vomiting, thus supposedly ridding the body of the cause of epilepsy. (Malawi, Tanzania, Ethiopia).[19,22,28,38,48] These traditional methods of treatment were hazardous and many times increased the morbidity and mortality associated with epilepsy. Further investigations are therefore required to determine the efficacy, supportive role and the limitations of alternative medicine in the management of epilepsy in Kenya and other developing countries. Little is known about the safety of most traditional herbal medicines used by our parents/guardians to treat their epileptic children.

The majority of parents/guardians had some knowledge on the type of illness their children were suffering from, the features of a convulsion, alerting features after a convulsion, the type of antiepileptic drug treatment their children were receiving, and the potential hazards to an epileptic child during a convulsion. A significantly higher proportion of parents/guardians with post secondary school education had better knowledge on the causes of epilepsy, the type of antiepileptic drug treatment their children were receiving, and complications of epilepsy, compared to the parents/guardians with secondary school education and below. Other KAP studies done in Kenya by Kamenwa in Baringo district, by Tailor at KNH, by Obimbo in Kibera and by Nyamu at KNH, showed that an increasing level of education of mothers had a positive influence on their KAP towards other childhood illnesses.[59-62] A significantly higher proportion of the professional group of parents/guardians had appropriate knowledge on the type of antiepileptic drug treatment their children were receiving, compared to the other occupation categories. However, the occupation of the parents/guardians did not have a significant influence on the other aspects of KAP towards epilepsy.

This study was carried out in a national referral hospital, in a specialised neurology clinic. In contrast, all the studies quoted in the literature were community based. The difference in KAP between this study and the community based studies done on epilepsy is probably due to the parents/guardians in this study being a select population who have been referred to KNH from another facility and parents/guardians who are nearer KNH, and therefore are more able to access health services than the people previously studied in the community.

The study did not adequately explore cultural factors influencing KAP towards epilepsy due to over-representation of the Kikuyu and the Kamba ethnic groups in this study compared to the other ethnic groups in Kenya.

The study did not adequately explore cultural factors influencing KAP towards epilepsy due to over-representation of the Kikuyu and the Kamba ethnic groups in this study compared to the other ethnic groups in Kenya.

5. CONCLUSIONS

1 .More than 77% of the parents/guardians had some knowledge on:-

a) The type of illness their children were suffering from.

b) The features of a convulsion.

c) Alerting features after a convulsion.

d) The type of antiepileptic drug treatment their children were receiving.

e) The potential hazards to an epileptic child during a convulsion.

2. Over one third of the parents/guardians did not know the causes or the complications of epilepsy.

3. Sixty percent of the parents/guardians administered some recommended first aid measures to their epileptic children during a fit, but many of them combined these with potentially harmful and harmful first aid measures. The overall effect of such combinations was at times more harmful than useful to the child.

4. Spiritual healing and traditional herbal medicine were perceived to be important components of therapy for epilepsy when used in conjunction with hospital treatment.

5. Forty percent of the epileptic children of school going age in this study were not attending school because of problems which should not have interfered with schooling.

6. An increased level of education had a positive influence on KAP towards epilepsy.

6. RECOMMENDATIONS

1. Health education should be given at all levels of contact with the parents/guardians to:-

   a) enhance their knowledge on the causes and complications of epilepsy.

   b) improve their knowledge on the recommended first aid measures during a fit, and emphasize the negative consequences of the potentially harmful and harmful first aid measures.

2. Community based studies on similar aspects of knowledge, attitudes and practices (KAP) among parents/guardians in various ethnic communities are needed to determine more clearly the KAP and different cultural attitudes and practices among the parents/guardians in Kenya.

REFERENCES

1. Senanayake N and Roman G.C. Epidemiology of epilepsy in developing countries. Bull. Wld. Hlth Org.1993; 71(2): 247-258.

2. Bringing epilepsy out of the shadows. Press release Wld Hlth Org, 1997, vol 48.

3. Kwasa T.O. Epilepsy-Myths and misunderstandings. Medicus 1991; 10:3.

4. Meldrum B.S. Anatomy, physiology, and pathology of epilepsy. Lancet. 1990; 336:231-234.

5. Wallace. S.J. In: A textbook of epilepsy. Editors: Laidlaw J., Richens A., Chadwick D. 4th Edition, Churchill Livingstone, Edinburg, 1993.

6. World Health Organization: The application of advances in neurosciences for the control of neurological disorders. Tech. Rep. Ser. Wld Hlth Org. 1978; 629:9.

7. Shorvon S.D. Epidemiology, classification, natural history and genetics of epilepsy. Lancet. 1990; 336: 93-97.

8. Osuntokun B.O. Epilepsy in Africa. Trop. Geog. Med.1978; 30:23-32.

9. World Health Organization: Mental health and psychosocial development. Tech. Rep. Ser. Wld Hlth Org.1977; 613

10. Paediatric neurology clinic returns for the year 1997, Kenyatta National Hospital Records Department, Box 20723, Nairobi.

11. Dekker P.A. Epilepsy: A manual for medical and clinical officers in Kenya, 2nd edition 1994, Kenya Association for the Welfare of Epileptics (KAWE)

12. Ross, E.M., Peckhan C.S. et al. Epilepsy in childhood: findings from the National Child Development Study. Brit. M.J. 1980; 280: 207-210.

13. Doose, H., Sitepu B. Childhood epilepsy in a German city. Neuropediatrics 1983; 14: 220-224

14. Cowan L.D., Bodensteiner J.B. et al. Prevalence of the epilepsies in Childhood and adolescents. Epilepsia. 1989; 30: 94-106

15. Baldwin S., Asindua S., Stanfield P. Survey of childhood disabilities within a community based programme for the rehabilitation of the disabled in Kibwezi division, Kenya, 1990, AMREF/Action Aid.

16. Feksi A.T., Kaamugisha J. et al. Comprehensive primary health care antiepileptic drug treatment programme in rural and semi-urban Kenya. Lancet. 1991; 337:406-409.

17. Rwiza H.T., Kilonzo G.P., Haule J. et al. Prevalence and incidence of epilepsy in Ulanga, a rural Tanzanian district: A community based study. Epilepsia. 1992; 33(6):1051-1056.

18. Osuntokun, B.O. and Odeku E.L. Epilepsy in Ibadan, Nigeria. Afr. J. Med. Sci. 1970; 1: 185-200.

19. Watts A.E. Treating epilepsy in Malawi: Lessons learned. Tropical Doctor. 1990; 20: 52-55.

20. Watts A.E. A model for managing epilepsy in a rural community in Africa. Brit.M.J. 1989; 298: 805-807.

21. Levy, L.F. Epilepsy in Rhodesia, Zambia and Malawi. Afr. J. Med. Sci., 1970; 1: 291-303.

22. Osuntokun B.O. The traditional basis of neuropsychiatric practice among the Yorubas of Nigeria: Epilepsy and convulsive disorders. Trop. Geog. Med. 1975; 27: 422-430.

23. Jilek-Aall and Jilek W.G. Epilepsy and its psychosocial implications in Africa. In: Clinical psychology in Africa (Text book for Universities). Editors: Peltzer. K and Egigbo. P.O. Enugu, University of Nigeria, 1989.

24. Gerrits C. "Conceptions and explanations of sii, epilepsy. A medical-anthropological study among the Bassa and Kpelle in Liberia". CURARE. Zeitschrift für Ethnomedizin und transkulturelle pstchiatrie. 1983; 6: 33-40.

25. Gerrits C. Epilepsy care in a non-clinical setting: Paper for the international seminar on medico social aspects of epilepsy held by the Indian Epilepsy Association on October, 18-19, 1986 in Bangalore, India.

26. Giel R. The epileptic outcast. E. Afr. Med. J. 1968; 45(1): 27-30.

27. Giel R. The problems of epilepsy in Ethiopia. Trop. Geog. Med. 1970; 22:439-442.

28. Tekle - Haimanot R., Abebe M. et al. Attitudes of rural peopie in Central Ethiopia towards epilepsy. Soc. Sci. Med. 1991; 32(2): 203-209.

29. Billington W.R. The problems of the epileptic patient in Uganda. E.Afr. Med. J. 1968; 45(8): 563-569.

30. Tamale-Ssali E.G. and Billinghurst J.R. Schoolchildren with epilepsy: The effect of the psychosocial environment on attitudes to the problem. E. Afr. Med. J.1971;48(8): 406-410.

31. Draat P.J.E.M., Van Luijk, J.N. Smits, H. Epilepsy in Africa. Mimeographed report, Medical Research Centre, Nairobi, 1981.

32. Orley J.H. Culture and mental illness: A study from Uganda. East African Publishing House, Nairobi, Kenya, 1970.

33. Jilek-Aall, L. Thirty year follow up of epilepsy patients in an outpatient clinic in rural Tanzania. Neurology unit, Department of Medicine, Muhimbili University, Dar-es-Salaam, Tanzania, 1990.

34. Draat P.J.E.M. Knowledge, attitude and Practice survey towards epilepsy in a rural population in Kenya. Medical Research Centre, Nairobi, 1981.

35. Kwasa T.O. , Ndungu B.M., Onyango S.H.O. Epilepsy-knowledge, beliefs and attitudes in Kenya. Afr. J. Med. Pract. 1997; 4 (2): 47-50.

36. Pickering C.A. and Otieno P.G. How to help with epilepsy, 1987, The Kenya Association for the Welfare of Epileptics (KAWE).

37. Rwiza H.T., Matuja W.B.. Kilonzo G.P. et al. Knowledge, attitude and practice towards epilepsy among rural Tanzanian residents. Epilepsia. 1993; 34 (6): 1017-1023.

38. Hendrickse R.G. Editorial: Cow's urine poisoning in Nigeria. J. Trop. Med. Hyg. 1976; 79:237-240.

39. Watts, A.E. Managing epilepsy with limited resources. Post graduate doctor Africa. 1991; 13(2): 34-37.

40. Caveness W.F., Merritt H.H. and Gallup G.H. A survey of public attitudes towards epilepsy in 1974 with an indication of trends over the past twenty five years. Epilepsia 1974; 15: 523-536.

41. Iivanainen M., Uutela A. and Vilkkumaa I. Public awareness and attitudes towards epilepsy in Finland. Epilepsia 1980; 21: 413-423.

42. Pellock J.M. Seizure disorders. Pediatr. Clin. N. Am. 1989; 36(2).

MEDICAL LIBRARY
UNIVERSITY OF NAIROBI

43. Shope J.T. Compliance in children and adults: Review of studies. Epilepsy Res Suppl. 1988; 1:23-47.

44. Mucklow J.C., Dollery C.T. Compliance with anticonvulsant therapy in a hospital clinic and in the community. Br. J. Clin. Pharmacol. 1978; 6(1): 75-9.

45. Iyun A.O., Lukanbi F.A. Drug compliance and serum phenytoin levels in some Ibadan epileptics. W. Afr. J. Med. 1986; 5:169-73.

46. Elechi C.A. Default and non compliance among adult epileptics in Zaria, Nigeria. The need to restructure continued care. Trop. Geogr. Med. 1991; 43(1-2): 42-45.

47. Shorvon S.D., Hart Y.M. et al. The management of epilepsy in developing countries. An ICBERG manual. Royal Society of Medicine Service, 1991, London, New York.

48. Rwiza H.T., Kilonzo G.P., Haule J. et al. The past medical profile of epilepsy patients in an African rural community. J. Trop. Geog. Neurol. 1992; 2(4): 146-150.

49. Varkevisser C.M., Pathmanathan I., Brownlee A. Health Systems Research Training Series: Focus group discussion. A WHO/IDRC publication 1991; 2(1): 173-184.

50. Pathmanathan I. Health Systems Research Training Series: Focus group discussion. A WHO/IDRC publication. 1992; 4:63-64.

51. World Health Organization. Sample size determination: A users' manual. 1986; WHO/HST/ESM/86.1.

52. Callaghan N., Kenny R.A., O'neill B. et al. A prospective study between carbamazepine, phenytoin and sodium valproate as monotherapy in previously untreated and recently diagnosed patients with epilepsy. J. of Neurology, Neurosurgery and psychiatry. 1985;48:639-644.

53. Snow R.W., Williamson J.E., Rogers V.O. et al. The prevalence of epilepsy among a rural Kenyan population: It's association with premature mortality. Trop. Geog. Med. 1994; 46(3): 175-179.

54. Shaba B., MacLachlan M. et al. Palliative versus curative beliefs regarding tropical epilepsy as a function of traditional and medical attributions Centr. Afr. J. Med. 1993;39 (8):165-7.

55. Dichter M.A. The epilepsies and convulsive disorders. In: Harrison's principles of internal medicine. Editors: Isselbacher K.J., Braunwald. E. et al. 13th Edition, Mc Graw-Hill, New York, 1993, Ch. 367, P.2227 - 2233.

56. Haslam R.H. In: Nelson Textbook of Paediatrics. Editors: Behrman R.E., Kiliegman R.M., Arvin M.A. 15th Edition. W.B. Saunders Co., Philadelphia, 1996, Ch. 543, P. 1686-1689.

57. Hosking G. Editorial. Tropical Doctor. 1990; 20(2): 49-51.

58. Danesi M.A. and Adetunji J.B. Use of alternative medicine by patients with epilepsy: A survey of 265 epileptic patients in a developing country. Epilepsia. 1994; 35(2):344-51.

59. Kamenwa R.W. Maternal knowledge, attitudes and practices towards childhood diarrhoea in a rural community. M. Med Thesis. Department of Paediatrics, University of Nairobi, 1990.

60. Tailor A.R. A study of maternal knowledge, attitudes and practices regarding diarrhoea disease in their children presenting at Kenyatta National Hospital. M. Med Thesis. Department of Paediatrics. University of Nairobi, 1988.

61. Obimbo E.A. The knowledge, attitude and practices of mothers, and the knowledge of health care workers regarding care of the umbilical cord of a newborn. M. Med. Thesis. Department of paediatrics. University of Nairobi. 1996.

62. Nyamu M.N. Perception, attitude and practices of parents/guardians of children diagnosed to have asthma at the Kenyatta National Hospital. M. Med. Thesis. Department of Paediatrics. University of Nairobi. 1998.

APPENDIX 1

FOCUS GROUP DISCUSSION RECORD SHEET

Focus group discussion number [ ][ ]

Date of interview (day/month/year) [ ][ ]/[ ][ ]/[ ][ ]

Patient's particulars.

1. Name.....
2. IP Number.....
3. Sex 1=male, 2=Female [ ]
4. Age (indicate date of birth) i.e. month/year [ ][ ]/[ ][ ]

Socio demographic data of parents/guardian

1. Relationship to the patient .....
2. Age of parent/guardian [ ][ ]
3. Level of education of parent/guardian

   (indicate number of completed years of education). [ ][ ]
4. Ethnic group (tribe) of parent/guardian

   .....
5. Profession of parent/guardian

   .....
6. Religion of parent/guardian [ ]

   1=Catholic 2=Moslem 3=Protestant (specify).....

   4=Others (specify) .....

APPENDIX 2

Topic guide for the focus group discussion

The principal investigator described a hypothetical case scenario simulating a patient with Generalized Tonic Clonic Seizures (GTCS), the commonest type of seizures encountered in our clinical practice.[11] The focus group participants were then asked to make a diagnosis. This was followed by a series of probing questions to explore the perceived causes of epilepsy, home care action, health seeking behaviour, and the perceptions, beliefs and attitudes towards epileptic children.

Case scenario

Mary (a pseudonym) is a 30 year old housewife. She is your neighbour and usually seeks advice from you when she has a problem.

She leaves her five year old son, John, playing outside the house, and goes to the kiosk to buy some milk. When she comes back to the house, she finds her son John has fallen on the ground. She tries to wake him up but John is not responding. She touches him to check whether he has a fever, but he doesn't feel hot to touch. She notices that John's eyes are rolled upwards and he has stiffening of the whole body. John then gets repeated jerky movements of both his arms and legs. Mary also notices that John has passed urine on himself, though he usually goes to the toilet when he needs to pass urine or stool. He is also frothing from the mouth. After a few minutes, the jerky movements of the arms and legs stop and John goes to sleep. He wakes up after fifteen minutes complaining of a headache. He does not remember what happened before he went to sleep.

Mary rushes to your house carrying John and tells you what happened. She also informs you that this is the second time that her son John has suffered from this illness.

1. She asks you what illness her son is likely to be suffering from.

2. What causes this illness (probe).

3. Are there any methods by which this illness can be transmitted (or passed on) from one person to another (probe).

4. What first aid measures should she have given to her son John when she found him having the jerky movements on the floor (probe: position, spoon or spatula in the mouth, restraining of movements etc).

5. Where would you recommend for Mary to seek help for her son's illness (probe).

6. Which methods of treatment are effective in the treatment of this illness.

7. Can John's illness be cured?.

APPENDIX 3

QUESTIONNAIRE.

Study Number [ ][ ][ ]

Date of interview (day/month/year) [ ][ ]/[ ][ ]/[ ][ ]

Patient's particulars

1. What is your child's name:.....

2. IP number .....

3. What sex is the child

   1=male, 2=female [ ]

4. When was the child born (indicate the month/year) [ ][ ]/[ ][ ]

5. Seizure type (code 1=Yes, 2=No against seizure type)

   1= Generalized tonic clonic seizures (GTCS) [ ]

   2= Generalized absence seizures (Petit mal) [ ]

   3= Simple partial seizures [ ]

   4= Complex partial seizures (Temporal lobe epilepsy) [ ]

   5= Myoclonic seizures [ ]

   6= Other (specify).....

Socio demographic data of parents/guardians

1. How are you related to this child .....

2. How old are you [ ][ ]

3. What is the level of your education

   (indicate the number of completed years of education) [ ][ ]

4. What tribe are you.....

5. What is your profession.....

6. What is your religion

1=Catholic 2=Moslem 3=Protestant (specify) .....

4=Others (specify) ..... [ ]

Knowledge, attitudes and practices

1. What illness does your child have

.....

.....

2. What causes this illness

.....

.....

3. When did your child get the first convulsion (month/year) [ ] [ ]/[ ] [ ]

4. When was your child started on treatment for this illness

(month / year) [ ] [ ]/[ ] [ ]

5. Can the illness be transmitted (passed on) from one person to another?

1= Yes, 2 =No 3 = Don't know/not sure [ ]

6. If yes to 5, what are the methods of spread

.....

.....

7. a. How many times has your child had a convulsion in the last 3 months? [ ][ ]

b. How many times has your child had a convulsion in the last 6 months? [ ][ ]

8. a. How many times has your child been attended to in Casualty/PFC with a convulsive attack in last 3 months [ ][ ]

b. How many times has your child been attended to in Casualty/PFC with a convulsive attack in the last 6 months [ ][ ]

9. Are there any features which alert you that your child is about to have a convulsion?

(Indicate what the parent / guardian says)

.....

.....

10. Are there any features which alert you that your child is having a convulsion?

(Indicate what the parent / guardian says)

.....

.....

11. Are there any features which alert you that your child has had a convulsions (Indicate what the parent / guardian says)

.....

.....

12. Are there any first aid measures which you administer (give) to your child when he/she gets a convulsion? (Let the parent / guardian explain and indicate)

.....

.....

13. If the answer to question 12 is do nothing, ask why

(let the parent/guardian explain and indicate)

.....

.....

14. What type(s) of drugs is your child on

(code I =Yes, 2=No against the selected drugs)

I=Phenobarbitone [ ]

2=Phenytoin (Epanutin) [ ]

3=Tegretol (Carbamazepine) [ ]

4=Rivotril (Clonazepam) [ ]

5=Other(Specify) [ ]

6=Don't know [ ]

15. Is the treatment continuous or intermittent

I=Continuous 2=Intermittent [ ]

16. If intermittent, ask why (let the parent/guardian explain and indicate)

.....

.....

17. Do you know of any other methods of treatment for this illness other than hospital care? (Ask to be told which ones and indicate)

.....

.....

If the answer to No. 17 is yes go to 18

If the answer to No. 17 is no go to 21

18. Which of these other methods of treatment have you tried

(Ask the parent/guardian to say and indicate)

.....

.....

19. Did any of them work?

1=Yes 2=no, 3=Don't know/not sure [ ]

If the answer to No. 19 is yes go to 20

If the answer to No. 19 is no go to 21

20. Which of these other methods of treatment worked, and how did they help?

(Ask the parent/guardian to say and indicate)

.....

.....

21. Can the child's illness be cured?

I=Yes

2=No

3=Don't know/not sure [ ]

22. Are there any potential hazards (dangers) from which a child with this illness should be protected? (Ask to be told and record)

.....

.....

23. Do you know of any possible complications of this illness?

(Let the parent/guardian say and indicate)

.....

.....

24. What is the source of your information regarding your child's illness?

(Let the parent/guardian say and indicate)

.....

.....

25. Is the child attending school at present?

I=Yes 2=No [ ]

If yes go to question 26 - 28, then 30

If no go to question 29

26. What is the highest class reached at school.....

27. How often does he miss school (per month / per term)

.....

28 Reason why he missed school

.....

29. Why is the child not attending school? (Let the parent/guardian explain and indicate)

.....

.....

30. Does your child use separate utensils or the same utensils used by the other family members (e.g. cup, spoon, dish etc)

1 =Separate utensils

2=Same utensils as the other family members [ ]

If the answer to question 30 is separate utensils, go to 31

If the answer to question 30 is the same utensils as other family members, go to 32

3 1. Why does your child use separate utensils

(let the parent/guardian explain and indicate)

.....

.....

32. Does your child play alone or with other children

1 =alone, 2=with other children. [ ]

If answer to question 32 is alone, go to 33

33. Why does the child play alone (let the parent/guardian explain and indicate)

.....

MEDICAL LIBRARY
UNIVER OF NAIROBI

APPENDIX 4

Seizure control is classified based on the percentage (%) reduction in seizure frequency over a minimum period of three (3) months whereby:

Excellent seizure control	=	Complete freedom from seizures
Good seizure control	=	Greater than or equal to 50% ($\geq$ 50%) but less than 100% reduction in seizure frequency.
Poor seizure control	=	Less than 50% reduction in seizure frequency.

[4] Abstracted from reference Number 52.