THE PREVALENCE OF EPILEPSY IN A MALARIA ENDEMIC REGION OF KENYA.

By
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A dissertation submitted in part fulfillment for the degree of Master of Medicine in Internal Medicine, University of Nairobi.

DECLARATION

I certify that this dissertation is my own original work and has not been presented for a degree at any other university.

Dr. G. Muima Munyoki

This dissertation has been submitted with our approval as Supervisors.

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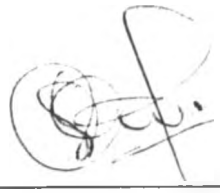

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To Sarah, My wife and best friend; to my daughters, Beth and Mary; My son, Munyoki; and to my late Grandmother, Syokandu. They have been a blessing to my life and have given me so much to pray about and thank the LORD.

Thank you.

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ABBREVIATIONS

ACE Active Convulsive epilepsy

CM Cerebral Malaria

CGMR The Centre for Geographical Medicine Research

EEG Electroencephalogram

EPI-DSS Epidemiologic demographic surveillance system

EQ Epilepsy Questionnaire

ILAE International league against epilepsy

KDH Kilifi District Hospital

KEMRI Kenya Medical research Institute

MS Multiple Seizures

PWE People with Epilepsy

RPC Resource Poor Countries

WHO World health organization

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ABSTRACT

Introduction

Epilepsy is the most common chronic neurological disorder and is one of the world's most prevalent non-communicable disorders. Studies examining the epidemiology of epilepsy in the developing world are scarce. In Africa for instance, the World Health Organization (WHO) estimates that there are 10 million people with epilepsy (PWE) but this estimate is based on little data and the actual burden of epilepsy remains unknown. There are few studies in Kenya. Epilepsy is thought to be more prevalent in Africa, because causes such as birth trauma and infections are common. Recently an association between severe malaria and the development of epilepsy has been documented. However, there are few reports examining the relationship between malaria and epilepsy in endemic areas

Purpose, Methods

My colleagues and I conducted a cross-sectional survey to detect active convulsive epilepsy in an area, with differing malaria transmission in the Kilifi District on the Coast of Kenya. I set out to determine the prevalence and risk factors of active convulsive epilepsy and examine the association between the epilepsy and malaria transmission in this area. Active convulsive epilepsy (ACE) was defined as 2 or more unprovoked convulsions, of which one occurred within the last year, whether or not treatment was being given, since this is the criterion for treatment in Kenya.

Results

The prevalence of epilepsy was 3.5 per 1000 inhabitants at risk, 3.8 per 1000 for males 3.3 per 1000 for females. The highest age-specific prevalence was found for age's 11-20 years. Generalized tonic –clonic seizures were the predominant seizure type and occurred in 70.4% of subjects. However focal seizures accounted for 75.5% of the seizures when second and third seizures were included. History of head trauma, intrapartum and perinatal complications, family history of febrile seizures, history of a widowed mother and family history of seizures in first-degree relatives and also extended family were associated with a risk of developing epilepsy. Drinking alcohol did not add to the risk of developing epilepsy. The prevalence of epilepsy in the low malaria transmission zones was generally higher than in the high transmission zones but logistic regression analysis indicates a statistically significant increased risk of Active Convulsive Epilepsy (ACE) in the later.

Conclusion

The study indicates that the prevalence rate of active epilepsy in our study is comparable to that in other well conducted community based studies in Africa and in the western countries. Strongly independent association between five factors and the risk of epilepsy was noted. Overal the relationship between malaria transmission and epilepsy appears complex and remains unclear.

Introduction and literature review

Epilepsy is one of the most commonly occurring chronic neurological disorders. Globally, WHO estimates that 50 million people have epilepsy, 80% of them live in resource-poor countries (RPCs), of whom 10 million are estimated to live in Africa [1]. However, there are few studies on which to base these estimates, particularly in Africa [2]. The few studies conducted in this region, suggests the prevalence of epilepsy to be significantly higher than that of developed countries, but it is unclear if this is a real difference or caused by differences in methodology. Malaria is also a common condition and severe malaria has been associated with the development of epilepsy (3).There have been no reports that have examined the relationship between epilepsy and malaria transmission in the malaria endemic areas.

Epidemiological studies of epilepsy have a number of methodological considerations. These include difficulties in case definition, ascertainment, classification, definitions and validity of screening instruments. While developed countries utilize medical and service records to provide epidemiological data, these services are often not reliable in the developing world. Single round surveys and key informants have often been used as the alternatives in developing countries, but have a tendency to under estimate the prevalence [2]. Lately, two-phase surveys in which the population is screened with a questionnaire and the diagnoses confirmed by an assessment have been recommended as they appear to be more reliable [4].These methods however depend on both the sensitivity and specificity of the screening questionnaires, which often require careful design and piloting in the target populations. These points are frequently neglected, and some

published questionnaires do not detect all cases. [5]. The cross sectional survey methods can be improved by capture-recapture methods using other sources of information such as key-informants (village elders) and medical records from hospitals and clinics [6].

The reported prevalence and incidence rates of epilepsy are significantly higher in resource-poor countries (RPCs) than it is in the developed world [2]. Reported prevalence in RPCs are often around 10/1000, while in the west, the estimate is 5- 10/1000 [2]. In the West, the annual incidence rate is estimated at 40-70 per 100,000 of the general population [2],whilst in the RPCs the suggested figure is nearly double that at 100 per 100,000 [7].

In Africa, the reported prevalence rates vary from 0.1 to 39/1000 **[Table 1]** [2, 8]. The lowest prevalence having been reported from Tanzania, 0.1/1000 based on countrywide prescriptions for antiepileptic drugs [AED].This method has been discredited in view of the large numbers of patients not receiving treatment [2]. A study in Rift valley, Kenya using the Key informant method found a rate of 3.6/1000 but was 18.2/1000 when a random cluster sample of the population was surveyed by a screening questionnaire (9) Two large general population studies carried out respectively in Nigeria and Ethiopia and which addressed some of the methodological problems, reported rates between 5 and 7/1000 [10,11].

A recent study from rural Tanzania has given an overall rate of 10.2/1000 with rates varying from 5.8-37.1/1000 according to geographic location [12]. In a rural area of Benin, the prevalence of epilepsy determined by the combination of a cross sectional

survey and key-informants (capture-recapture method) was 35/1000 [6]. The highest rates come from Liberia where studies in a small-inbred community suggested rates as high as 39/1000 [13]. Further high prevalence rates have been reported amongst inbred communities in Tanzania (20/1000) [14,15] and in a small survey of a Nigerian village in the immediate environs of the rural branch of a medical school 37/1000[10].

Table 1: Prevalence of Epilepsy in Africa, a review [8].

Country	Year	Population Size	Prevalence Per 1000	95%CI
Benin	2000	3,134	35	22.3-44.3
Ethiopia	1990	60,820	5.2	4.6-5.8
Kenya	1988	2,960	18.2	13.2-23.2
Liberia	1983	4,436	28	23.0-33.0
Nigeria	1987	18,954	5.3	4.2-6.4
Tanzania	1992	18,183	10.2	8.7-11.7

The cause of the high prevalence and incidence of epilepsy in Africa is unknown. Birth trauma and infections are thought to contribute, but the significance of these risk factors for developing epilepsy is not clearly established. The few studies that have been conducted in Africa, have identified family history of epilepsy [16], history of intrapartum complications [16], febrile convulsions [16,17] and head trauma [17].

Genetic factors are thought to contribute to the high prevalence of epilepsy in some areas of Africa; Tanzania [14,15] and Liberia [13] **[Table 2]**.Likewise increased frequency of epilepsy in families of children admitted with malaria and seizures was found in Kilifi [18].

Table 2: Risk factors for epilepsy in Africa, a review [8].

Country	Year	IC* (%)	Fhx (%)	FC. (%)	Inf. (%)	BT (%)	H I (%)
Tanzania	2001	74.7	-	13.4	7.6	1.4	1
Nigeria	1987	60.4	5	23.8	-	2	5.9
Liberia	1983	-	52.8	-	38	2.4	3.3

*IC=Idiopathic; Fhx=Family history of epilepsy; FC=Febrile Convulsions; Inf=Infections; BT=Birth Trauma; HI= Head injury

P.falciparum malaria is a common cause of childhood admissions to District General Hospitals in malaria endemic areas in Kenya, and it is often associated with seizures [19][20-23]. The seizures are associated with a poor outcome in neuro-cognitive damage and epilepsy, with the risk of epilepsy being four and six times following cerebral malaria (CM) and multiple seizures (MS) respectively [3]. Paradoxically, high incidences of severe malaria have been associated with low transmission intensity [24]. Studies on the relationship between entomological inoculation rate (EIR) and the incidence of severe malaria have documented an increase of the latter in sites where insecticide-treated bed nets (ITN) have been used for malaria control [25]. One of the questions that have arisen

from this work is; is *P. falciparum* specifically epileptogenic – does the prevalence of epilepsy vary with transmission. The relationship between epilepsy and malaria can be examined by studying the prevalence of epilepsy in different endemic areas and the effect of previous interventions e.g. ITNs on the development of epilepsy.

Recent studies in Kilifi, Kenya have shown epilepsy to be common. A community survey, which required key informants in the household to report on any members of the household suffering from epilepsy, estimated the prevalence of active epilepsy to be 4/1000 [26] in the population above 5 years. A study based upon histories of epilepsy in relatives of children who acted as controls for study on malaria estimated the prevalence to be 11/1000 [18]. However in both these studies the diagnoses was not confirmed by more detailed histories, taken by clinicians or further assessment, and may either under report the prevalence of epilepsy or include cases that do not have epilepsy. A recent community survey in children aged 6-9 years using the two-phase approach reported a minimum lifetime and active epilepsy prevalence of 41/1000 and 11/1000 [Mung'ala-Odera *et al, Submitted*]. The cause of the high prevalence in this area is unknown, but the contribution of malaria has not been examined.

The purpose of this study therefore was to estimate the prevalence of epilepsy in a malaria endemic area of Kenya, identify the risk factors of active epilepsy and examine the relationship between epilepsy and malaria transmission in this endemic area

2. Justification for the study

Few studies have been done in developing countries on epilepsy. The few studies conducted in this region, have raised a number of questions and been faced with a number of methodological problems. Epilepsy appears to be common in Kilifi, but we do not have any reliable estimates for the prevalence, on which to assess the public health burden. Recognizing the risk factors for epilepsy in the community, will assist us to identify appropriate interventions for epilepsy. There have been no reports that have examined the relationship between malaria and epilepsy in endemic areas.

3. Objectives

3.1 Main objectives

Generally this study attempted to determine the prevalence and risk factors of ACE within a rural malaria endemic area.

3.2 Specific objectives

Specifically, the study aimed to:

(i) Determine the prevalence of ACE in a well-defined community.

(ii) Determine the risk factors for ACE.

(iii) Determine the seizures types.

(iv) Examine the relationship between Epilepsy and Malaria transmission.

4. Design and methodology

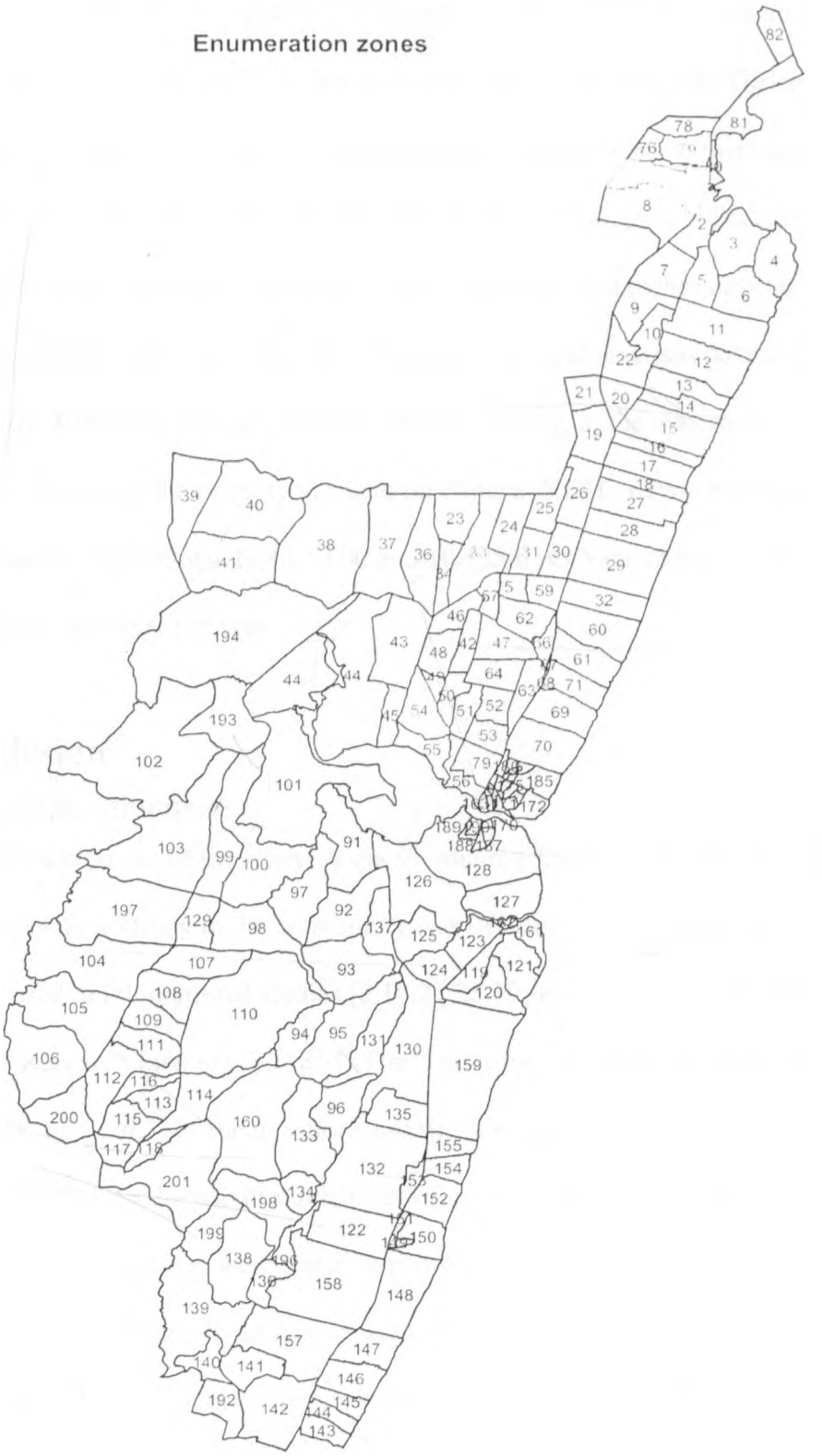
4.1 Study site

The study was conducted in an area surrounding Kilifi District Hospital (KDH) on the Kenya coast. Parts of this area have been undergoing demographic surveillance since 1993 and a larger area has been undergoing intensive surveillance - the Epidemiologic Demographic Surveillance System (EPI-DSS). This is a system with a vital registration which covers 200,000 inhabitants contiguously distributed up the more densely inhabited coastal strip of 15 km width from Junju in the South to Gede in the North. **(Figure 1)**. The entire EPI-DSS area has been mapped using global positioning system (GPS), and further sub-divided into 87 enumeration zones, with digital sketch maps of each zone showing major landmarks, footpaths and homesteads, with their relative positions and survey numbers. The digital sketch maps were used to relocate each household during the household survey.

The malaria transmission varies throughout the area. In particular two sites which have longitudinal entomological data, Ngerenya in the North and Chonyi in the South **(Figure 2)** have entomological inoculation rates (EIR) rates of 1.6 and 52.9 respectively .The EIR is a standard measure o f transmission intensity and is expressed as the number of infective bites per person per unit time (e.g. annually) and calculated by multiplying the human-biting rate by the proportion of sporozote positive mosquitoes.

Figure 1; Study Site

Figure2; Studysite: North [blue]; **South** [white].



4.2 Study population

At beginning of the study, the population of the study area was 228,548 of whom 186,153 were aged 6years and over. The inhabitants are mainly Mijikendas with the Giriama ethnic group predominating. The chosen area consisted of the population that uses the KDH as its main primary care facility. Information on the population is collected by fieldworkers who interview senior members of the households and gather data on residents, births, deaths and migrations three times in a year and a census database updated regularly. Births are also registered in the community, at the maternity department in KDH and at the primary vaccination clinic at KDH. Crude birth and death rates for this area are approximately 40/1,000 and 10/1,000 per year and migration rates are approximately 100/1000 per year

4.3 Study design

4.3.1 Epilepsy Questionnaire

Prior to the commencement of the study, A questionnaire (*Appendix B*) for screening epileptic seizures and epilepsy in the community was developed based upon the questionnaires used in international studies [2,10,27,28,30] and previous work at the Kenya Medical Research institute (KEMRI),The Center for Geographical Medicine research (CGMR) [18,26,31]. The questionnaire was translated into the local vernacular (KiGiriyama) and back to English through a well-developed process to remove any ambiguities. The questionnaires were tested in people attending the neurological and psychiatric clinics at KDH and in an area separate from the proposed study site, to achieve a sensitivity >95% and specificity >90% for detection of generalized clonic

seizures. Minor epilepsies are more difficult to detect in community surveys, and are not subject of this thesis.

4.3.2 The design

This was a cross sectional study which involved a door to door screening of the population to identify people with ACE. In order to make the best possible use of resources the study was linked to the ongoing EPI-DSS census surveys. The survey was conducted in six months from August 2003 to January 2004 in three stages;

Stage 1. Screening of the community during the census

The population in the EPI-DSS was screened by trained field workers, fluent in the local languages, as part of the ongoing census surveys. The fieldworkers interviewed a **senior member** of the household to identify members of the household with epilepsy using **two questions** *(Appendix A)* that have been found to be sensitive for detecting convulsions.

Stage 2. Screening of the community with an epilepsy questionnaire

Within a week, the individuals identified in stage 1 were interviewed about their seizures by another team of fieldworkers. An **Epilepsy Questionnaire (EQ) tool (14-Questions)** *(Appendix B)* which is more specific for epilepsy was administered with the help of the fieldworkers. The fieldworkers also asked about other members of the household who may have epilepsy. The EQ took between 10-20 minutes to administer. In order to determine if this 2-stage process was detecting all individuals with epilepsy, 1% of the

population was randomly chosen from the census database and interviewed with the EQ by 2 fieldworkers not involved in the survey **[Table 4].**

Stage 3. Neurological confirmation at the hospital

All those identified on the Epilepsy Questionnaire as potential ACE cases plus an equal number of those testing negative, matched for age, sex and location were invited to come to KDH for further assessment. With the assistance of a clinician fluent in the local language, I took a full history to confirm the diagnosis *(Appendix C, D, E)* and then performed a thorough neurological examination. *(Appendix F).* Based on the eye-witness account detailed history and the examination, the seizure type was classified as accurately as possible according to International League against Epilepsy (ILAE) criteria but without the benefit of EEG. [32-34].

My neurological supervisors (T.O.K and CN) independently assessed the records and confirmed or disagreed with my classification. Where the neurologists disagreed with my classification and both independently assigned the same alternative classification, the subject was re-assigned. Disagreements between the neurologists were resolved by a panel that included Dr T.O.Kwasa and Professor C.R.J.C. Newton, and Professor BG Neville (Professor of Paediatric Epilepsy, Institute of Child Health, London UK) and Prof JAW Sanders (Professor of Epilepsy, Institute of Neurology, London, UK).**[Fig 3]**

4.3.3 Case Definitions

I used the International League against Epilepsy (ILAE) criteria for the diagnosis and classification of epilepsy (33): On the basis of an eyewitness accounts history,

Active convulsive epilepsy (ACE) was defined as 2 or more unprovoked seizures, of which one occurred within the last year, whether or not treatment was being given. This is the criterion for treatment in Kenya, as recommended by the Ministry of Health (MOH) and the Kenya association for the Welfare of Epileptics (KAWE)

Epilepsy was defined as inactive if there had been no seizure in the previous one year.
Lifetime epilepsy was the sum of active and inactive epilepsy.
Birth trauma was present if there was prolonged labour for more than 12hrs or an estimated apgar score of 7 or less as estimated by the mother.
Problems after delivery was present if there was any history suggestive of neonatal infections, jaundice etc.
Previous hospital admission was any admission outside the neonatal period.

4.3.3.1 Inclusion Criteria

i) All persons aged six years and above with active *convulsive* epilepsy.

ii) A duly signed informed written consent.

4.3.3.2 Exclusion criteria

i) Single seizures or febrile seizures were excluded

ii) Acute symptomatic seizures were also excluded.

4.4 Ethical Considerations

The study was undertaken only after approval by the Department of Internal Medicine, University of Nairobi and as the study was part of a larger study at CGMR-Coast, approval was also obtained from National Ethics Committee of Kenya.

During the survey, individuals found to require additional medical help were helped, either in terms of treatment or further referral.

In accordance with the Helsinki agreement (Bankowski et al 1991) for non-invasive community-based survey work, community consent was sought through informed community leaders. The study was explained to the community leaders in detail before consent was obtained. Thereafter an individual consent was obtained for all more detailed interviews and assessments. See consent form attached *(Appendix F)*. Under no circumstances were subjects offered inducements to participate or coerced into signing the consent form.

5. Data management and analysis

5.1 Data storage

Data was processed and double entered into the computer using the FoxPro VFP 3.0(DPF) data management software. This was done after all the checks and coding had been undertaken.

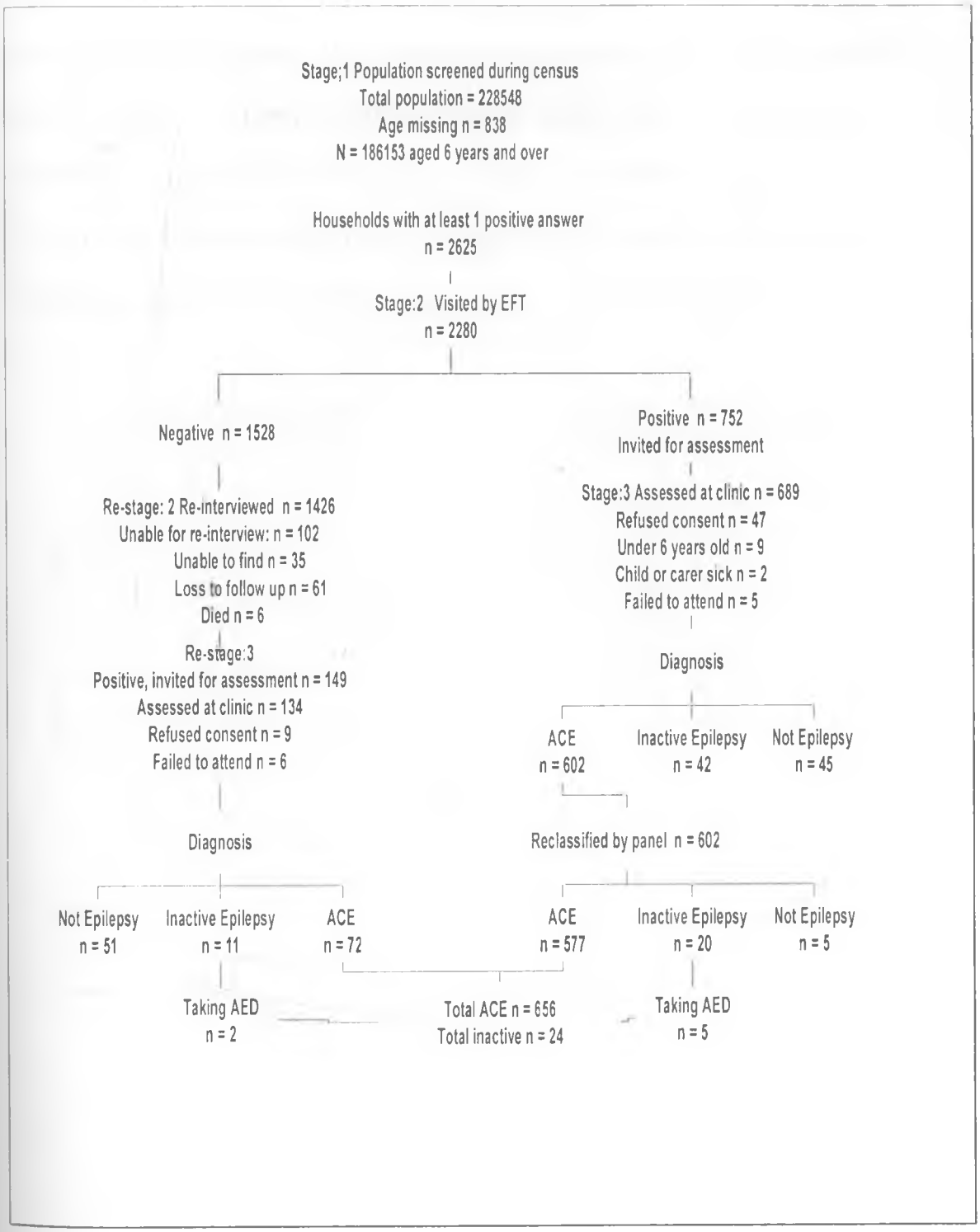
5.2 Data analysis

The survey data was analyzed by means of Stata 8 Software. Overall prevalence estimates for lifetime epilepsy and ACE with 95% Confidence Intervals (CI) are presented along with age-, sex-and area specific estimates. Age-specific prevalence estimates are presented within five year age bands.

The distribution of age and the age onset of seizures of cases of ACE are described along clinical and other important characteristics. The case control data was stratified into two groups; adults (aged 18 years and above) and children (aged 17 years and under) because of the confounding effect of age and investigation of risk factors specific to individuals in the two strata. Logistic regression was used to investigate potential for ACE, both individually and in multivariable model. A step wise building approach was used. To account for the frequency matched design adjustment was made for age, across the five age strata. Confounding effects of potential risk factors were investigated along with interactions between the main exposures of interest. Statistical significance was defined as a p-value from Wald test of less or equal to 0.05.

6. Results

6.1 Outline of the study [Fig 3: flow diagram of the study].



6.2 Demographic details of the population studied

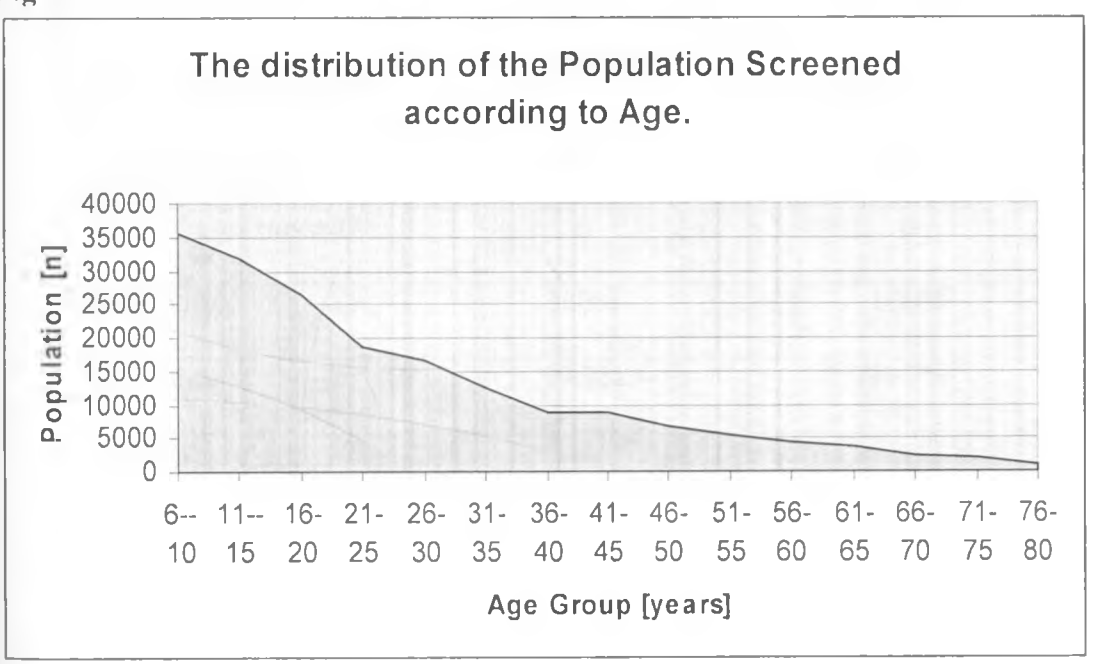
The total population of the study area during this third round of the quarterly censuses was 229,548 inhabitants. The Population aged 6 years and over screened during the census was 186,153 subjects. The distribution of the population according to age and gender is as shown in **Table 3** and **Fig 4**. The age and sex pattern of the population distribution is typical of most developing countries. Approximately fifty one percent (50.7%) of the inhabitants were under the age of 20yrs. No subject(s) in the community refused the screening phase of the survey.

Table 3: The distribution of the population screened according to age and gender

Age/Gender	Male		Female		Total	
	N	%	N	%	N	%
6-10	17,900 (20.9)		17,739 (17.8)		35,639 (**19.3**)	
11-15	16,202 (18.9)		15,692 (15.8)		31,894 (**17.2**)	
16-20	13,201 (15.4)		13,098 (13.2)		26,299 (**14.2**)	
21-25	7,994 (9.3)		10,663 (10.7)		18,657 (**10.1**)	
26-30	6,763 (7.9)		9,737 (9.8)		16,500 (**9.0**)	
31-35	5,259 (6.1)		7,338 (7.0)		12,597(**6.8**)	
36-40	3,785 (4.4)		4,922 (5.0)		8,707 (**4.7**)	
41-45	3,468 (4.0)		5,341(5.4)		8,809 (**4.8**)	
46-50	2,631 (3.1)		4,139 (4.2)		6,770 (**3.7**)	
51-55	2,492 (3.0)		3,100 (3.1)		5,592 (**3.0**)	
56-60	1,964 (2.3)		2,507 (2.5)		4,471 (**2.4**)	
61-65	1,572 (1.8)		2,246 (2.3)		3,818 (**2.1**)	
66-70	1,034 (1.2)		1,330 (1.3)		2,364 (**1.3**)	
71-75	933 (1.1)		1,132 (1.1)		2,065 (**1.1**)	
76-80	464 (0.5)		468 (0.5)		932 (**0.5**)	
Total	**85,662 (100)**		**99,452(100)**		**185,114(100)**	

50.7% of inhabitants under 20yrs.

Fig 4



6.3 Sensitivity and specificity of the 2-EQ and 14-EQ

The total number of those identified by the screening of the community during the census as possibly having convulsions using the two Questions questionnaire(2-EQ) sensitive for convulsion was 2280 subjects. Upon screening the community with the epilepsy questionnaire (14-EQ) which was more specific, 901 persons were identified as possibly having active epilepsy and invited for neurological assessment. All were further evaluated to confirm epilepsy. Both the sensitivity and specificity of the two Questionnaires, the 2-EQ and the 14-EQ, were above Ninety percent (99%) as shown in **Table 4.**

Table 4: Comparison of the 2-EQ and 14-EQ ascertainment methods

	Two convulsive epilepsy questions (2-EQ)	**14-item questionnaire (14-EQ)**
Population Screened	11324	11324
Screen positives	98 (0.9%)	84 (100%)
Examined by Clinician	84 (85.7%)	84 (100%)
Confirmed Active Epilepsy Cases	66	66
Active Cases missed	0	0
Sensitivity	100%	100%
Specificity	99.7%	99.7%

6.4 Prevalence of ACE

6.4.1 Age and Sex Specific prevalence of active epilepsy.

Of the 901cases identified as possibly having epilepsy, 823 persons had neurological assessment and epilepsy was confirmed in 722 cases, 656 as ACE (328 Males and 328 Females) and 66 as inactive epilepsy. The common conditions confused with epilepsy were febrile convulsions, dizziness and syncopal attacks, severe anemia, mental retardation and alcoholic shakes.

The **unadjusted** prevalence of active convulsive epilepsy was 3.5 per1000 with a 95% confidence interval of (3.2.to 3.8) and a life time epilepsy prevalence of 3.9 per1000 (95% CI 3.6 to 4.2). The Age-Specific prevalence was slightly greater among males, 3.8 per 1000 verses 3.3 per 1000 for females; however this difference was not statistically significant. The age and sex-specific rates are shown in **Table 5**.

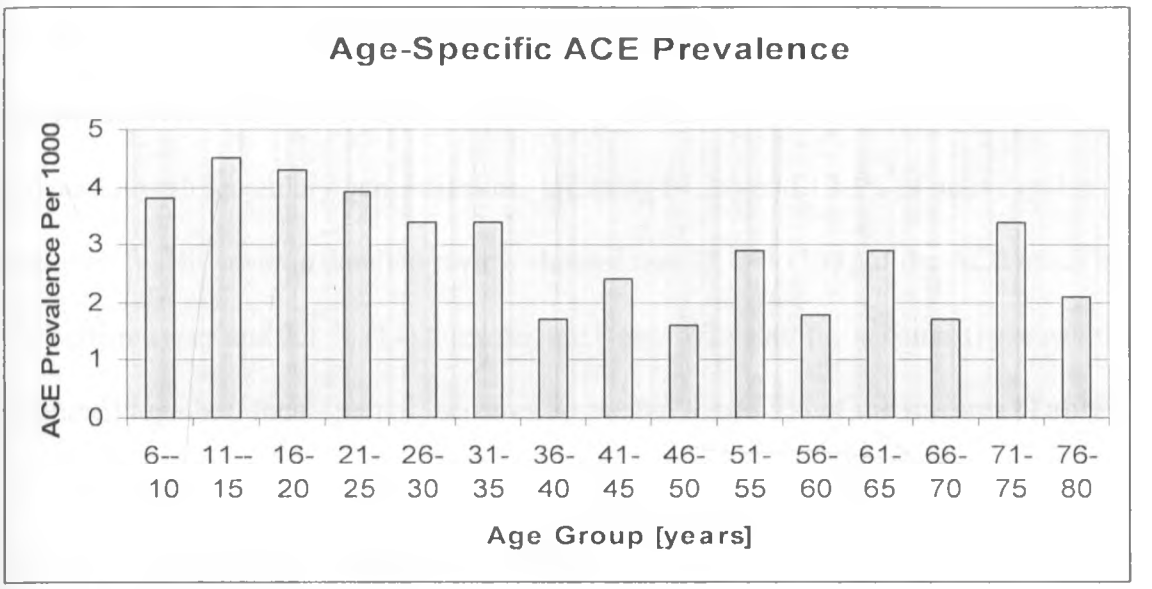
The highest age specific prevalence was found in age group 11-20 years, which constituted 38.9%. Age groups 6-10yrs, 11-15yrs and 16-20yrs constituted 20%, 21% and 17.2% respectively. The median age of people with ACE was 18yrs. Age specific prevalence shows almost a U-shaped pattern with higher rates in children and the elderly than adults **[Fig 4].** The Male ACE Prevalence peaks again in ages 31-35years **[Fig 5]**.

Table 5: Age and sex-specific epilepsy prevalence (per 1000)

Age Group (yrs)	Age specific Population	Prevalence per 1000 Male [n]*	Female [n]	Age specific Prev.[n]	[95% CI]
6-10	35,639	**4.2**[75]	**3.4**[60]	**3.8** [135]	[3.2-4.5]
11-15	31,894	**4.6**[74]	**4.3**[68]	**4.5** [142]	[3.8-5.2]
16-20	26,299	**4.1**[54]	**4.5**[59]	**4.3** [113]	[3.6-5.2]
21-25	18,657	**4.0**[32]	**3.8**[40]	**3.9** [72]	[3.0-4.9]
26-30	16,500	**4.6**[31]	**2.6**[25]	**3.4** [56]	[2.6-4.4]
31-35	12,597	**4.8**[25]	**2.5**[18]	**3.4** [43]	[2.5-4.6]
36-40	8,707	**1.8**[7]	**1.6**[8]	**1.7** [15]	[1.0-2.8]
41-45	8,809	**1.2**[4]	**3.2**[17]	**2.4** [21]	[1.5-3.6]
46-50	6,770	**1.9** [5]	**1.4**[6]	**1.6** [11]	[0.8-3.5]
51-55	5,592	**3.2**[8]	**2.6**[8]	**2.9** [16]	[1.6-4.6]
56-60	4,471	**2.0**[4]	**1.6**[4)	**1.8** [8]	[0.8-3.5]
61-65	3,818	**1.9**[3]	**3.6**[8]	**2.9** [11]	[1.4-5.1]
66-70	2,364	**1.9**[2]	**1.5**[2]	**1.7** [4]	[0.5-4.3]
71-75	2,065	**3.2**[3]	**3.5**[4]	**3.4** [7]	[1.4-7.0]
76-80	932	**2.2**[1]	**2.1**[1]	**2.1** [2]	[0.3-7.7]
Total/Overall	185,114	**3.8**[328]	**3.3**[328)	3.5[328]	[3.2-3.8)

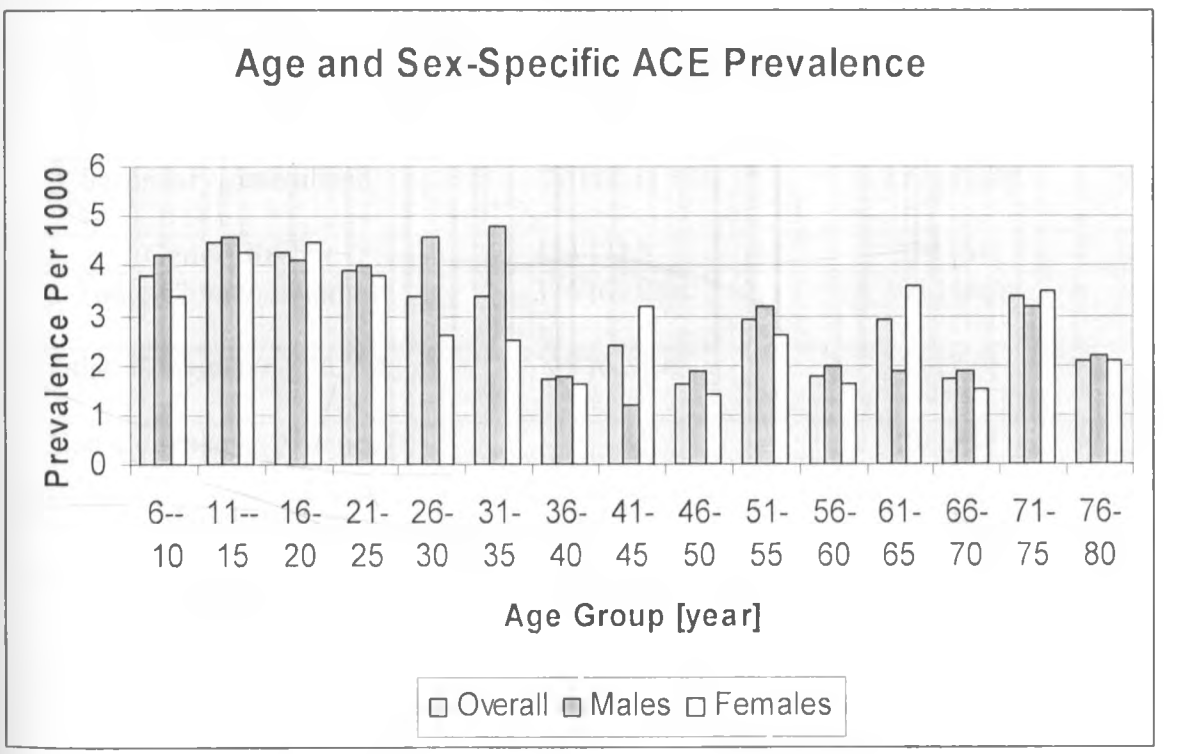
*Actual number of PWE in parentheses

Fig 4 **Age -specific epilepsy prevalence (per 1000)**



Age group 11-20yrs constituted 38.9%, the highest age-specific Prevalence. Two peaks in children and the elderly.

Fig 5. **Age and Sex-Specific epilepsy prevalence (per 1000)**



A Male ACE Prevalence Peak at age group 31-35 years.

6.5 Clinical characteristics of ACE

6.5.1 Seizure types classification

The **predominant** seizure types were primary generalized tonic-clonic seizure (GTCS) and partial with secondary generalization, affecting 64.2% and 12.3% of active epilepsy respectively. However, a detailed review showed that 23.6 % (155) of the ACE cases had two seizure types and 2.1 % (14) three seizure types. When **all** the seizures types were combined together, focal (partial) seizures accounted for 75.5% of the seizures **[Table 6]**

Table 6 Classification of the Seizure Types

Seizure type	No. of Cases (%) (Predominant SZ)	No. of Cases (%) (Multiple SZs Combined)
Partial	**145 [24.8]**	**496 [75.5]**
Simple partial	17 [2.9]	79 (12)
Complex partial	56 [9.6]	139 [21.2]
Secondary generalized	72 [12.3]	277 [42.2]
Generalized	**424 [72.8]**	**337 [51]**
Tonic-Clonic/grandmal	376 [64.2]	303 [46.2]
Other Convulsive [TA,AA]	38 [6.5]	13 [2.0]
Non-Convulsive(Absences)	11 [1.9]	20 [3.0]
Myoclonic	1 [0.2]	1[0.2]
Unclassifiable	**15 [2.6]**	**4 [0.6]**

Pred.SZ: Generalized Seiz.**72.8%,** Partial **24.8%,** and Unclassifiable **2.6%**
Combined seizure Occurrence: Partial **75.5%,** Generalized **51%**

6.5.2 Status epilepticus

Detailed information collected about seizures shows that, of the 656 ACE cases 216 (32.9%) had experienced previous status epilepticus and 164 (25.0%) had experienced previous status epilepticus associated with fever.

6.5.3 Age of onset of seizure and Duration of epilepsy

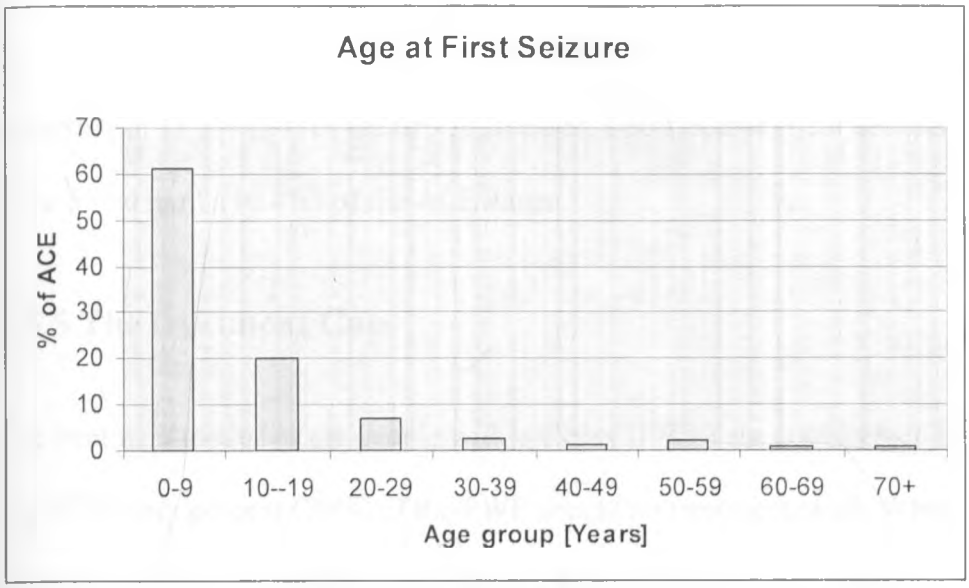
Age at first seizure and the duration of epilepsy was known for 630cases with ACE and is shown in **Table 7**.The first seizure occurred before age 10 years in 61.3%.

The interval from first seizure to the identification of a person with active epilepsy in the study was predominantly between 6 and 20 years (51.7%). (Fig 6)

Table 7 Age at first seizure and duration of epilepsy in 630 PWE

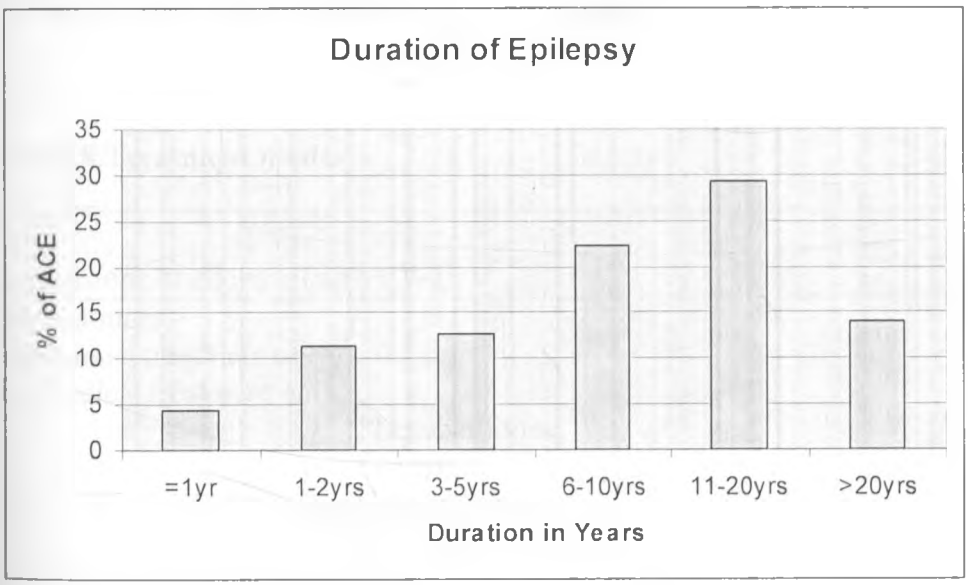
Age at first seizure(Yrs)	No. ACE	%	Duration of epilepsy	No. ACE	%
0-9	369	61.3	**=1yr**	28	4.4
10-19	122	20.3	**1-2yrs**	71	11.3
20-29	43	7.1	**3-5yrs**	80	12.7
30-39	15	2.5	**6-10yrs**	174	22.4
40-49	8	1.3	**11-20yrs**	188	29.3
50-59	12	2.0	**>20yrs**	89	14.1
60-69	6	1.0			
70+	5	0.8			
	No information on 26cases			No Information on 26 cases	
	(Information on 96%))			**(Information on 96%)**	

Fig 6a; **Age at first seizure in 630 PWE**



Age at first seizure; 61.3% before age 10years.Duration of ACE; 30% b/w 11-20yrs

Fig 6b; **Duration of ACE in 630 PWE**



Duration of ACE; 30% b/w 11-20yrs

6.5.4 Associated Neurological disorders

Severe cognitive impairment was the commonest associated neurological disorder occurring in 11.3% (74) of the 656 ACE cases. Focal neurological deficits were found in 68 (10.4%) of the ACE cases.

6.5.5 The treatment Gap

The treatment modes of the people with epilepsy (PWE) are documented in **Table 8** and Fig 4. Seventy percent (70%) of the PWE sought no treatment at all. When combined with those who only consulted a traditional healer (4%) or mixed traditional and biomedical therapies (1%), the treatment gap was 75%.This rose to 84.9% when detectable therapeutic drug levels of the commonly used AED (phenobarbitone 92%, Phenytoin 3.3%) were assayed.

Table 8.Treatment modes

Treatment choices of the PWE,	n=656 [%]
No treatment,	n=459 [70)]
Traditional treatment only,	n=26 [4]
Biomedical treatment only,	n= 164 [25]
Phenobarbitone	[151 [92]]
Phenytoin	[6[3.3]]
Carbamazepine	[5 [3.0]]
Sodium Vaproate	[2 [1.2]]
Mixed biomedical and traditional,	n= 7 [1]
75% of PWE are not taking AEDs.	

6.6 Risk factors of ACE

6.6.1 Possible aetiologic factors

The possible clinical aetiologic factors for all identified cases of epilepsy are as shown in **Table 9**. In 62.6 % (411) of the ACE, there were no identifiable aetiologic factors. Unspecified CNS infection (12.5%) and cerebral malaria (9.4%) were the leading possible aetiologic factors

Table 9, Possible aetiologic factors

Possible factor (s)	[No. of cases] %
Unknown(none)	306 [62.6]
SAF*	41 [8.4]
Birth Trauma	16 [3.3]
Head injury	10 [2.0]
Brain Tumors(suspected)	7 [1.4]
CVA	2 [0.4]
CNS Infection	61 [12.5]
Cerebral/Malaria (Suspected)	46 [9.4]
*SAF; Seizures associated with fever.	

6.6.2 Risk factors

The results of logistic regression analysis that compared the characteristics of ACE cases and controls are shown for Adults and Children in **Tables 10 &11** and **Tables 12&13** respectively

Five major risk factor were identified in adults and Six in Children. Positive family history of seizures and or febrile seizures, abnormal intrapartum and perinatal history, head injury, use of illicit drugs and even more interestingly children of widowed mothers as compared to married mothers were the major associated risk factors.

6.6.2.1 Adults Risk factors

Table 10. Univariate Logistic regression analysis, in adults.

Risk factors (variable)	AE (n=338)	Controls (n= 319)	Odds ratios	95%CI	p value
Gender					
Male (278)	158	120	1.414	1.034-1.935	0.030
Female (376)	180	196	1		
Area					
Low Endemic (N) (349)	154	195	0.542	0.397-0741	<0.0001*
High Endemic (S) (307)	183	124	1		
FHx of seizures					
First-degree relatives (31)	21	10	2.440	1.120-5.330	0.025
Extended Fhx (145)	103	42	3.030	1.94-4.72	<0.0001
Fhx of febrile seizure(44)	39	5	8.131	3.161-20.92	<0.0001
Head injury					
Yes	31	7	4.529	1.960-10.45	<0.0001
No	307	311			
Drink alcohol					
Yes	43	51	0.783	0.500-1.220	0.277
No	295	268			
Eating raw cassava (331)	133	198	0.382	0.278-0525	<0.0001
Use of illicit drugs					
Yes	20	6	3.271	1.300-8.260	0.012
No.	318	312			

Table 11.Multivariable logistic Regression Analysis, in adults

Parameters	Adjusted OR*(95%CI)	P-Value☹
FHx of Seizure		
No Fhx of seizure	1	
Extended Fhx of Seizure	3.582(2.2.6-5.816)	<0.0001
First-degree Fhx of Sz	2.053 (0.866-4.68)	0.102
Head injury		
No previous head injury	1	
Previous head injury	4.039(1.668-9.781)	0.002
Area		
North Ngerenya	1	
R-Matsangoni-M	0.569(0.284-1.143)	0.113
Tezo	0.427(0.213-0.853)	0.016
Sokoke	0.454(0.171-1.205)	0.113
South chonyi	1.279(0.675-2.421)	0.450
J-Kauma	1.435(0.498-4.136)	0.504
Junju	4.167(0.964-18.022)	0.056
Use of illicit drugs		
No	1	
Yes	5.505(2.034-14.901)	0.001

*Also adjusted for age group;☹ P-value from Wald test.

6.6.2.2 Children Risk factors

Table 12.Univariate Logistic regression analysis, in children (6=>-, <=17).

Risk factors (variable)	AE (n=309)	Controls (n= 318)	Odds ratios	95%CI	p value
Gender					
Male (328)	170	158	1.110	0.824-1.540	0.514
Female (299)	148	151			
Area					
Low Endemic (N) (349)	154	195	0.693	0.397-0741	<0.0001*
High Endemic (S) (307)	183	124	1		
FHx of seizures					
First-degree relatives (35)	26	9	3.644	1.67-7.96	0.001
Extended Fhx (123)	81	42	2.400	1.580-3.630	<0.0001
Fhx of febrile seizure(25)	18	7	2.583	1.060-6.280	0.036
Mother's marital status					
Married(473)	218	255	1		
Separated/divorced (46)	29	17	2.005	1.070-3.750	0.30
Widowed(67)	54	13	5.022	2.660-9.470	<0.0001
Delivery(=Birth Trauma)					
Abnormal (12)	10	2	5.392	1.198-25.496	0.028
Normal (594)	291	303			
Problems After delivery					
Yes (51)	41	10	4.542	2.230-9.250	0.0001
No (562)					
Head injury					
Yes (28)	21	7	2.889	1.200-6.950	0.018
No	294	293			
Previous Hospital admission					
Yes (251)	196	55	7.636	5.248-11.092	< 0.0001
No (373)	121	252			

Table 13.Multivariable logistic Regression Analysis, in Children.

Parameters	Adjusted OR*(95%CI)	P-Value☹
FHx of Seizure		
No Fhx of seizure	1	
Extended Fhx of Seizure	2.755(1.689-4.496)	<0.0001
First-degree Fhx of Sz	3.866(1.636-9.133)	0.002
Mother's marital status		
Married	1	
Separated/Divorced	1.994(0.970-4.100)	0.060
Widowed	4.317(2.140-8.706)	<0.0001
Single mother	0.401(0.137-1.172)	0.095
Head injury		
No previous head injury	1	
Previous head injury	3.466(1.219-9.854)	0.002
Area		
North Ngerenya	1	
R-Matsangoni-M	1.458(0.709-2.996)	0.306
Tezo	1.006(0.502-2.016)	0.987
Sokoke	0.772(0.299-1.990)	0.592
South chonyi	2.406(1.260-4.594)	0.008
J-Kauma	1.936(0.694-5.400)	0.207
Junju	16.924(1.854-154.470)	0.012
Eats raw cassava		
No	1	
Yes	0.441(0.301-0.646)	<0.0001
Problems after delivery		
No.	1	
Yes	4.134(1.781-9.854)	0.001

*Also adjusted for age group
☹ P-value from Wald test

6.7 ACE and malaria

6.7.1 Prevalence and transmission

6.7.1.1 Prevalence of active epilepsy by area.

The prevalence of active convulsive epilepsy was 2.3 per1000 with a 95% confidence interval of (2.1 to 2.6) in Chonyi the best representative area in the high malaria transmission zone (south) and was 4.9 per1000 (95% CI 3.8-6.3) in Ngerenya, a low transmission zone (North) **[Table 14]**. Generally the prevalence of ACE is higher in the north than in the south but after adjustment for the matching variable only, there was no statistically significant evidence of a difference in odds of ACE across areas

Table 14: Prevalence of active epilepsy by area.

Area[EZ]	Area Specific Population	ACE Cases	Area Specific Prev.[95%CI]
South:			
Chonyi	124,647	290	2.3 [2.1-2.6]
Junju	7,213	17	2.4 [1.4-3.8]
Jaribuni-Kauma	7,537	26	3.5 [2.3-5.1]
North:			
Ngerenya	13,589	67	4.9 [3.8-6.3]
RMMida	32,070	114	3.6 [2.9-4.3]
Tezo	32,089	114	3.6 [2.9-4.3]
Sokoke	10,228	26	2.5 [1.6-3.7]

Prev. per 1000; Ngerenya (North) 4.9, Chonyi (South) 2.3.

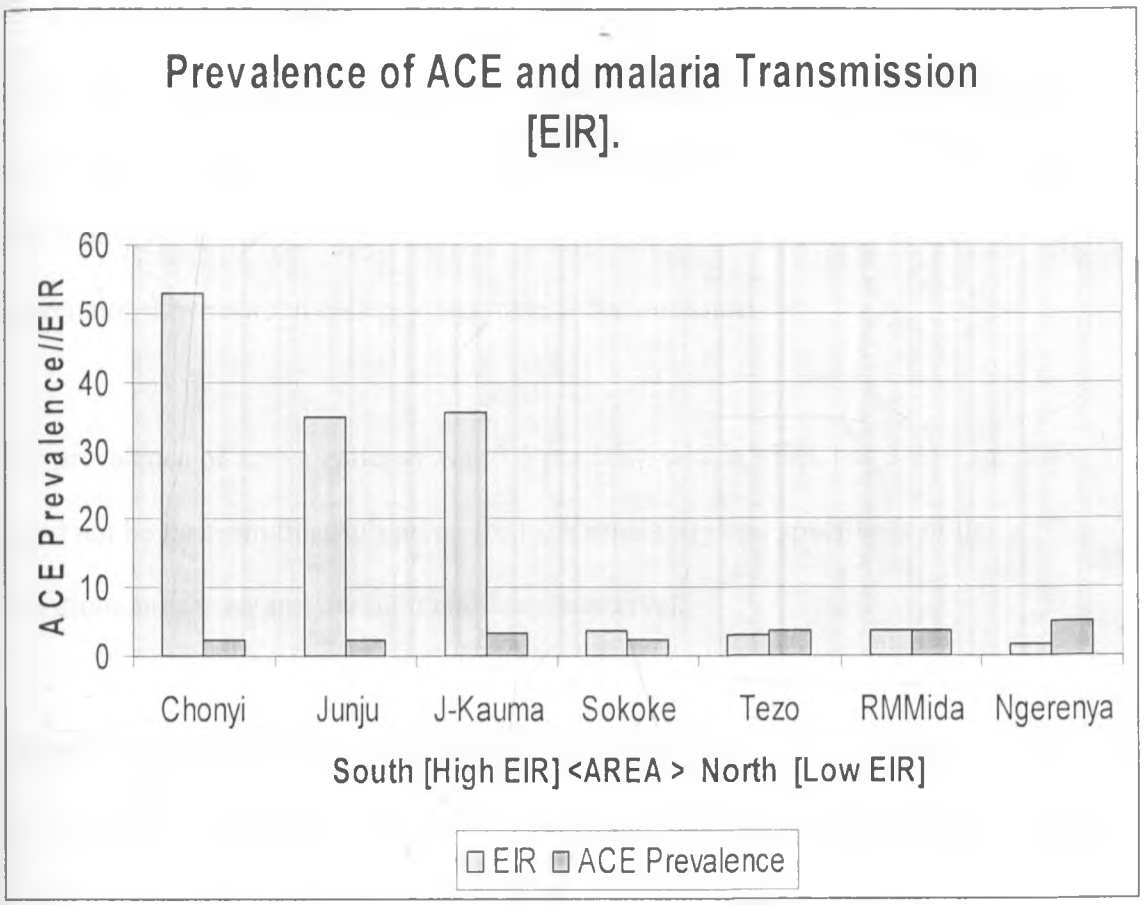
6.7.1.2 Malaria transmission

The northern study areas (Ngerenya) have significantly lower malaria transmission intensities than in the south (Chonyi) as shown by the low annual entomologic inoculation rates (EIR;*infective bites per person per annum*) **[Table 15].** Low area ACE prevalence is associated with a high area EIR, the ACE prevalence then steadily increases slowly as EIR decreases **[fig 7].**

Table 15. EIR and ACE prevalence in the North and southern Areas

Area (EZ)	EIR	Area specific Prevalence [95% CI]
South		
Chonyi	52.9	**2.3 [2.1-2.6]**
Junju	35.0	2.4 [1.4-3.8]
Jaribuni-Kauma	35.4	3.5 [2.3-5.1]
North:		
Ngerenya	1.6	**4.9 [3.8-6.3]**
RMMida	3.8	3.6 [2.9-4.3]
Tezo	3.0	3.6 [2.9-4.3]
Sokoke	3.6	2.5 [1.6-3.7]

Fig 7. EIR and ACE prevalence in the North and southern Areas



Higher EIR in the Southern zones associated with lower ACE Prevalence

7. Discussion.

7.1 The main findings.

To the best of our knowledge this is the largest and most rigorous community –based study on the prevalence of epilepsy in Kenya and in Africa as a whole. Similar studies which have been conducted used smaller population sizes and none has tried to look for the relationship between epilepsy and malaria transmission.

The prevalence of active epilepsy was 3.5 per 1000 with a 95%CI of 3.2 to 3.8 .This could not be far from the truth given the high sensitivity and specificity of the Questionnaires used and the tight confidence interval.

The *predominant* seizure type was tonic-clonic occurring in 72.8% of the ACE cases, but the co-existence of multiple seizures was remarkable making partial (focal) seizures the overall commonest seizure type in this study.

In majority (62.6%) of the patients seen in this study there was no well defined aetiological factor found. Possible encephalitis (infection/CM) accounted for majority of the possible symptomatic epilepsy. Positive family history of seizures and or febrile seizures, abnormal intrapartum and perinatal history, head injury, use of illicit drugs and even more interestingly children of widowed mothers as compared to married mothers were the major associated risk factors.

The prevalence of epilepsy was high in Ngerenya (4.9 per 1000) a low transmission zone and lower in chonyi (2.3 per 1000) a high transmission zone. However upon logistic regression controlling for Age, Ngerenya appears statistically significantly protected from epilepsy compared to Chonyi.The possibilities are that there exists other aetiologic factors in Chonyi, exposure-cause effects, which are associated with higher mortality or it could be the proximity of the hospital to the Ngerenya residents. Genetic causes with regional differences are also possibilities.

7.2 Comparison of prevalence with other studies

7.2.1 Comparison with other studies including those in the West

The crude Prevalence for ACE of 3.5 per 1000 and a life time prevalence of 3.8 per 1000 is similar to 3.6 per 1000 reported by feski *etal* in Nakuru [9] and is comparable to the figures found in the three well conducted African studies in Nigeria, Ethiopia and Tanzania which found prevalence rates of 5.3, 5.2 and 10.2 per 1000 respectively [10, 11, 12] .A more recent study in South Africa reported a similar prevalence rate of 3.6 per 1000 [35]. Recent reviews of the epidemiology of epilepsy world over [36] and in Africa *(*Munyoki GM *etal, in preparation)* found the prevalence of active epilepsy in the range of 5-10/1000 in most locations, although it might be higher in some isolates. The most recently published review on prevalence of epilepsy in sub-Saharan Africa by *Preux et al* reported a median prevalence, which most likely explains the seemingly high prevalence of 15 per1000 [8].

7.2.2 Discussion about methodology

This study was a community-based study which used the ILAE recommended Two-phase cross-sectional study design with a specially designed and piloted questionnaire for this community. The Questionnaires sensitivity and specificity achieved were almost 100%. A further combination of the door-to-door survey methods and the Capture –Recapture methods made this study the largest most rigorous study. This prevalence rate must therefore be as close to the actual figure as it's possible. The African studies which have found a prevalence of epilepsy exceeding 10 % of the population are based on investigation on either specially selected and or small populations [10, 13]. The results of this study indicate that the prevalence of ACE in the general African population is comparable to that found in the European and USA populations [2].

7.2.3 Prevalence broken down into ages

In this study, the age-specific prevalence rates showed higher rates in children and the Elderly but low in Adults. This follows the pattern found in the West [37] and may be unexpected in the developing countries which have short life expectancy and subsequent lower population in the older age groups. The second peak in the elderly in this study is possibly by a chance occurrence. However this study area has been subjected to many health projects and studies and just may be there is improved life expectancy explaining the peak in the prevalence peak in the elderly. The highest age specific prevalence was found in age group 10-19yrs; this has been found in most studies in developing countries. There was a male predominance over the females. This was also found in the study of Tekle *etal* but not Osuntukun *etal.* No single study has found any statistical gender difference; neither have we found any in this study.

7.2.4 Explanation why there maybe differences

The major difficulties in epilepsy epidemiological studies has been the tools (questionnaires) of ascertainment and case definitions, these have differed frequently and possibly explains much of the differences in these studies. This study used questionnaires which were over 90 % sensitive and specific and neurological review was the utmost. These were stringent measures which most likely provided a true though fairly low prevalence compared to other African studies. Our case definition and exclusion of the under 6years are the most plausible explanations for the lower fingers, most other studies having reported lifetime Prevalence rather than active prevalence.

7.3 Clinical characteristics of the people with ACE

7.3.1 Comparison with other studies//Emphasis on the focal nature

The predominant first seizure was tonic-clonic seizure, also found in most studies in the developing world (11, 12). However none of the African studies had a thorough review by experienced Neurologists as our study. Osuntukun *etal,* in a community-based African study which managed to do EEGs in approximately 20% of cases, reported focal seizures in 55% of the cases, a high focal nature as found in our cumulative seizure reclassification. The fact that status epilepticus was a frequent occurrence in our ACE cases support the increased focal seizures in this study. The epilepsy prognosis in this community surprisingly was good, with the duration of epilepsy in majority having been between 6-20years, a median of 10years.

7.3.2 Risk factors and aetiology

There were no identifiable aetiological factors in 62.6% of the PWE in this study. Idiopathic epilepsy has also predominated in almost all previous epilepsy studies. The only seven studies which reported possible aetiologic factors in Africa found no cause in the range of 60.4-89% [9, 10, 12]. A positive family history of seizures and or febrile seizures, abnormal intrapartum and perinatal history, head injury, use of illicit drugs and children of widowed mother as compared to married mother were identified as the major risk factors in this community. This agrees with many other studies (10, 12, 13), the only interesting finding being the association of a widowed mother with a five times increased risk of epilepsy. There are no previous reports on this finding. Though information on the true biological father needs further clarification, this finding may possibly indicate a genetic predisposition of epilepsy in the community or simply reflect increased mortality. An 'Absent father Syndrome' may be more likely, absence of father contributing to increased infections, malnutrion and child abuse. Emotional factors are possibilities but unlikely given the rigorous seizure reclassification in this study.

7.3.3 The relationship between epilepsy and malaria

The prevalence of epilepsy was generally higher in the Lower malaria transmission zones. This agrees with our hypothesis; of low malaria transmission being associated with increased severe malaria incidence and hence higher epilepsy prevalence and supported by the earlier childhood study which had shown increased odds of developing epilepsy following cerebral or multiple seizures [3]. However the latter was in childhood malaria, no such data is available in adults. The lag time from exposure to seizure is also

unknown, but the fact that most of the seizures (61.3%) in our study occurred before 10yrs of age may still be an indicator that malaria does play a role either directly or otherwise. Unexpectedly the risk of epilepsy in this study is higher in the high malaria endemic zone, it is likely therefore the relationship between epilepsy and malaria is a complex one involving genetic predisposition and other environmental factors interacting with malaria. This could explain the 30% lesser risk seen in the low transmission areas when compared to the south in a logistic regression model. The other environmental factors are possibly associated with high epilepsy mortality in the south (High transmission zone) and hence low prevalence.

8. Limitations

The Questionnaire used was a modification of the Ecuador epilepsy questionnaire and minor epilepsies remained difficult to detect.

Our prevalence of epilepsy most likely represents an underestimate. This is because our exclusion criteria of excluding children less than 6yrs old, to exclude febrile seizures, probably also missed out many epilepsy cases

The active epilepsy definition of two or more unprovoked seizures within the last one years may also explain the slightly lower prevalence rates in this study, as most previous studies have used 2 or more unprovoked seizures in the last 2yrs ,5yrs or in a life time. It's possible that most previous differences in active epilepsy prevalence rates were due to methodological problem; however our study was very rigorous and most likely gives the true picture but lower figures than previous studies.

The lack EEGs Reports most likely affected our seizures classifications

9. Conclusion

The study indicates that the prevalence rate of active epilepsy in our study is comparable to that in other well conducted community based studies in Africa and in the western countries.

Strongly independent association between five factors and the risk of epilepsy was noted; family history of seizures, family history of febrile seizures, intrapartum and perinatal problems, head injury. Children of widowed mothers also had increased risk.

Overall, there was no relationship between malaria transmission and epilepsy.

10. Recommendations

10.1 Public health implications

What this study means for practice is that burden of epilepsy is significant in Kenya and the treatment gap is massive.

Though the prevalence rate is similar to that found in the western world, however the burden may be much greater since the mortality associated with malaria in this setting maybe much higher. A national epilepsy programme may be a worthwhile investment especially aimed at AED provision and prevention of the risk factors, intrapartum complications are potential preventable risk factors.

A question now arises as to how low the EIR should be reduced given the earlier reported increased incidence of severe malaria with decreased EIR and this studies suggestion of possible increase in epilepsy prevalence.

10.2 Need for further research

Further research is necessary on the incidence and mortality of epilepsy to possibly find out why the prevalence of epilepsy in developing countries is comparable to that in the West despite an almost double incidence rates.

Incidence and mortality studies may possibly also explain the protection against epilepsy seen in the North compared to the South despite higher epilepsy prevalence in the former. Higher incidence rates in the south would indicate varied regional aetiologic factors, with the factors in south possibly being associated with higher mortality and hence low prevalence.

A study comparing epilepsy prevalence in highlands (Low endemic areas for long) and lowlands (high endemic areas for long) and also genetic predisposition may possibly give the true epilepsy and malaria transmission correlation.

Further agricultural studies to determine the species of cassava in this area which gives protection against epilepsy, given that other studies have shown the contrary.

The question why children of widowed mothers have an increased risk of epilepsy needs follow, may be the answer to the genetic predisposition in epilepsy.

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13. APPENDICES

APPENDIX A. THE TWO QUESTION QUESTIONAIRE (2-EQ)

QUESTIONS ASKED BY CENSUS TEAM:

- Do you have fits or has someone ever told you that you have fits?
- Do you experience episodes in which your legs or arms have jerking movements or fall to the ground and lose consciousness?

GIRIAMA VERSION:

- Vidze unafitika hedu udzangwe kwambirwa ni mutu yeyosi kala unafitika?
- Vidze nikukala na vipindi ambazho magulugo hedu mikonoyo inasaga hedu kugwa hotsi na kungamikwa ni fahamu?

APPENDIX B; EPILEPSY QUESTIONAIRE (14-EQ)

EPILEPSY SURVEY 2003

SCREENING QUESTIONS

Personal Details

Today's Date.....[__|__]/[__|__]/[__|__|__|__]

EPISURV Number..... [__|__|__|__|__|__]

PID NO:..... [|| || || || || ||]

Name: _____

RESID:..... [__|__|__|__|__|__|__]

DOB: ..... [__|__]/[__|__]/[__|__|__|__]

Age: ..... [__][__]

Sex: ..... [__]

If child is below 10 years.

Mother/ Guardian's Name:

_____

Who will answer questions about the index? ..... [__]

1. Self
2. Self and other
3. The Index's mother
4. The Index's father
5. Index's grandmother
6. Index's sibling
7. Another relative
8. Other.

For children below 10 years/ unable respondents.

Is the informant one who mainly takes care of the Index? (Y/N) ..... [__]

Fieldworker Code..... [__][__]

Answer Yes (Y) or No (N)

1. Do you have fits? [ ]

2. Has someone ever told you that you have fits? [ ]

3. Have you ever been told that you have epilepsy or epileptic fits? [ ]

4. Have you ever had attacks in which you fall to the ground with loss of consciousness? [ ]

5. Have you ever fallen to the ground without a reason and experienced
Twitching [ ]
Shaking of the arms or legs without control [ ]
And wetting yourself [ ]
Biting of the tongue [ ]

6. Has anyone ever noticed that you have episodes of
Shaking, trembling of one arm or one leg without control [ ]
Becoming stiff [ ]
Or moments of losing contact with the surroundings [ ]

7. Have you ever been told by a doctor that you have epilepsy or epileptic fits? [ ]

Interviewer: Answer the question below by ticking the appropriate answer. An individual will only be referred if the answer to any of the above 7 questions is YES.

Should this person be referred for further evaluation? YES [__] NO [__]

If yes to any of the above questions

When did the seizures start? [__][__]/[__][__]/[__][__][__][__]

When was the last seizure? [__][__]/[__][__]/[__][__][__][__]
How many seizures have you had within the last year? [ ][ ]

Did the seizures occur with a febrile illness? [ ]

Did any seizures occur within a febrile illness? [ ]

Family and community seizure information.

Does any other member of the family have seizures? [ ]

If so who?

NAME		RELATIONSHIP		PID NUMBER						

Do you know of anybody with seizures? | |
If so who?

NAME		PLACE	RESIDENCE					
1.								
2.								
3.								
4.								
5.								

APPENDIX C; FAMILY SOCIAL AND PAST MEDICAL HISTORY

FOR 18YEARS AND ABOVE.

EPILEPSY SURVEY 2003

SOCIO-DEMOGRAPHY AND BIRTH HISTORY

FOR 18 YEARS AND ABOVE

Personal Details

Today'sDate :..[__]__]/[__]__]/[__]__]__]__](TDATE)

EPISURV Number: .... [__|__] __] __] __| **(EPISURVNO)**

PID NO:... [ ][ ][ ][ ][ ][ ][ ]**(PID)**

Name: ____

RESID: ....[__[__]__]__]__|__|**(RESID)**

DOB:.. [__|__]/[__]__]/[__|__|__|__ |**(DOB)**

Age:... [__][__]**(AGE)**

Sex: .... |__|**(SEX)**

For the unable respondents, guardian's Name: ______________________________

Who will answer questions about the index? .... |__|**(RESP)**

1. Self
2. Self and other
3. The Index's mother
4. The Index's father
5. Index's grandmother
6. Index's sibling
7. Another relative
8. Other.

Socio-demographic Information

Q1. Marital Status |__|**(MST)**

1. Never married 2. Married 3. Separated 4. Divorced 5. Widowed

Q2. Religious affiliation |__|**(RELA)**

1.Catholic 2. Protestant 3. Islam 4. Traditional 5. None 6. Other (Specify)

Q3. Ethnic Group [__]**(EG)**

1. Giriama 2. Chonyi 3. Kauma 4. Other Mijikendas 5. Luos 6. Others

Q4. Has s/he ever attended school [__](ATTSCH)

1. Yes 2. No

Q5. If Yes, what is highest level of education? [__](LEVEDU)

1. Primary 2. Secondary 3. High school/A-level 4. Post secondary

5. Primary incomplete 6. Secondary incomplete 7. Other (specify)

Q6. Does the s/he do anything to earn cash [__](ECAC)

1. Yes 2. No

Q7. If **Yes**, what does s/he do? [__](OCC)

1. Prof /Technical 2. Adm/Mngt 3. Clerical 4. Agric 5. Production 6. Services

7. Crafts 8. Others (specify)_____

PAST MEDICAL HISTORY

Family seizure history

Q8. Does anyone have seizures (fits) in the family (Y/N) [__](SF)

Q9. If so who?_____

Q10. Has anyone in the family ever had seizures (fits) in the past (Y/N) [__](SFP)

Q11. If so who?_____

Q12. Do any of the brothers or sisters have seizures? (Y/N) [__](BSS)

Q13. Do any of the parents have seizures? (Y/N) [__](PS)

Q14. Does anyone have seizures associated with fevers? (Y/N) [__](SAF)

Please describe

Q15. Have you been admitted to hospital previously? (Y/N) [__](HAP)

Q16. If so when_____

Q17. For what_____ [__](DGS1)

Q18. If so when_____

Q19. For what_____ [__](DGS2)

Q20. If so when_____

Q21. For what_____ [__](DGS3)

Q22. Have you had a head injury? (Y/N) [__](HI)

Q23. If **Yes** did you lose consciousness? (Y/N) [__](HIC)

Q24. Were you admitted to hospital? (Y/N) [__](HIA)

Social History

Q25. Do you often drink alcohol? (Y/N) [__](DA)

Q26. If **Yes**, for how long have you been drinking? (Years)_____

Q27. Do you often eat raw cassava [__](ECAS)

Q28. Have you ever used illicit drugs [__](UDRGS)

Q29. Other relevant history (Y/N) [__](ORH)

Please describe

APPENDIX D; BIRTH HISTORY, FAMILY SOCIAL AND PAST MEDICAL HISTORY FOR UNDER 18 YEARS.

EPILEPSY SURVEY 2003

SOCIO-DEMOGRAPHY, BIRTH AND MEDICAL HISTORY

FOR UNDER 18 YEARS

Personal Details

Today's Date: [__]__]/[__]__]/[__]__]__]__](TDATE)

EPISURV Number: [__|__|__]__|__](EPISURVNO)

PID NO: | || || || || || ||](PID)

Name: _____

RESID: |__|__|_|__|__|__|__](RESID)

DOB: [__|__]/[__]__]/[_]__]__|__](DOB)

Age: [__]| _](AGE)

Sex: [__](SEX)

Does s/he attend school: [__](SCH)

Mother/ Guardian's Name: _____

Who will answer questions about the index? [__](RESP)

5. Self
6. Self and other
7. The Index's mother
8. The Index's father
5. Index's grandmother
6. Index's sibling
7. Another relative
8. Other.

Is the informant one who mainly takes care of the Index ?(Y/N) [__](INFCT)

Fieldworker Code: [__]|__](FWC)

Mother's Socio-demographic Information

Q1. Mother's date of Birth [__][__][__][__][__][__][__][__](**MDOB**)

Q2. Age in completed in year [__] __](**MOMAGE**)

Q3. Mother's religious affiliation [__](**MOMREL**)

1.Catholic 2. Protestant 3. Islam 4. Traditional 5. None 6. Other(Specify)

Q4. Marital Status [__](**MOMMST**)

1. Never married 2. Married 3. Separated 4. Divorced 5. Widowed

Q5. Ethnic Group [__](**MOMEG**)

2. Giriama 2. Chonyi 3. Kauma 4. Other Mijikendas 5. Luos 6. Others

Q6. Has the mother ever attended school [__](**MOMSCH**)

1. Yes 2. No 3. DK

Q7. If Yes, what is the mother's highest level of education? _] (**MOMLEDU**)

2. Primary 2. Secondary 3. High school/A-level 4. Post secondary

5. Primary incomplete 6. Secondary incomplete 7. Other (specify)

Q8. Has the Partner ever attended school [__](**PATSCH**)

1.Yes 2. No 3. DK

Q9. Partner's Level of education [__](**PATLEDU**)

(Use codes in Q7)

Q10. Does the mother do anything to earn cash [__](**MOMECAC**)

1.Yes 2. No 3. DK

Q11. If Yes, What is the mother's occupation? [__](**MOMOCC**)

2. Prof /Technical 2. Adm/Mngt 3. Clerical 4. Agric 5. Production 6.

Services

7. Crafts 8. Others (specify)_____

Q12. Does her partner do anything to earn cash [__|(PATECAC)

1.Yes 2. No 3. DK

Q13. If Yes, What is his occupation? [__|(PATOCC)

(Use codes in Q11)

Q14. Mother's age at first birth [__|__|(AGEBIRTH1)

Q15. Number of children ever born [__|__|(CEB)

Q16. Number of children living with mother [__|__|(CLWM)

Q17. Number of children living elsewhere [__|__|(CLELSE)

Q18. Number of children dead [__|__|(CDEAD)

PAST MEDICAL HISTORY

Family seizure history:

Q19. Does anyone have seizures (fits) in the family (Y/N) [__|(SF)

Q20. If so who?_____

Q21. Has anyone in the family ever had seizures (fits) in the past (Y/N) [__|(SF)

Q22. If so who?_____

Q23. Do any of the brothers or sisters have seizures? (Y/N) [__|(BSS)

Q24. Do any of the parents have seizures? (Y/N) [__|(PS)

Q25. Does anyone else have seizures associated with fevers? (Y/N) [__|(SAF)

Please describe

Obstetric and Perinatal history

Q26. Pregnancy: **N**ormal/**A**bnormal [__](**NP**)

Q27. If abnormal what was the problem:_____

Q28. Delivery at **N**yumbani; **H**ospitali; **C**linic **D**on't know [__](**DL**)

Q29. Delivery: **N**ormal **A**bnormal [__](**NAD**)

Q30. If abnormal what was the problem:_____

Q31. Were there any problems with _____after delivery? (Y/N) [__](**PAD**)

If yes, explain:_____

Q32. Does she been admitted to hospital previously? (Y/N) [__](**HAP**)

Q33. If so when_____

Q34. For what_____ [__](**DGS1**)

Q35. If so when_____

Q36. For what_____ [__](**DGS2**)

Q37. If so when_____

Q38. For what_____ [__](**DGS3**)

Q39. Has s/he ever had a head injury? (Y/N/Dk) |__|(**HI**)

Q40. If **Yes** did s/he lose consciousness? (Y/N/Dk) |__|(**HIC**)

Q41. Was s/he admitted to hospital? (Y/N/Dk) |__|(**HIA**)

Q42. Does she often drink alcohol? (Y/N/Dk) |__|(**DA**)

Q43. If **Yes**, for how long have you been drinking? (Years)_____

Q44. Does she often eat raw cassava? (Y/N/Dk) |__|(**ECAS**)

Q45. Has she ever used illicit drugs? (Y/N/Dk) |__|(**UDRGS**)

Q46. Other relevant history? (Y/N) |__|(**ORH**)

Describe:

APPENDIX E; NEUROLOGICAL ASSESSMENT; EPILEPSY SCREENING QUESTIONAIRE

Name: [_____] [_____] [_____] **Sex:** [ ]

Episurv Number:[ ][ ][ ][ ][ ] **PID:** [ ][ ][ ][ ][ ][ ][ ]

EZHM: [ ][ ][ ][ ][ ][ ] **DOB:** [ ][ ]/[ ][ ]/[ ][ ][ ][ ]

Date of assessment: [ ][ ]/[ ][ ]/[ ][ ][ ][ ] **Clinician:** [ ][ ]

Summary

Does s/he have epilepsy? **Yes/No** [ ]**(HE)**

If Yes is it Active Epilepsy? **Yes/No** [ ]**(AE)**

Does this s/he need an EEG? **(Yes/No)** [ ]**(EEG)**

If Yes, when done? [ ][ ]/[ ][ ]/[ ][ ][ ][ ] **(CTDATE)**

Does s/he have any sickle cell disease? **Yes/No** [ ]**(SCD)**

Diabetes mellitus? **Yes/No** [ ]**(DM)**

Hypertension? **Yes/No** [ ]**(HYP)**

Stroke? **Yes/No** [ ]**(STK)**

Others, specify_____

EPILEPSY RECORD

Answer **Y**es (**Y**) or **N**o (**N**) or **U**nknown (**U**)

Has s/he ever had a fit | |**(CF)**

Has s/he ever had episodes when s/he loses consciousness | |**(CLC)**

Has s/he ever fallen to the ground without a reason | |**(CFG)**

and the arms or legs twitch/shake | |**(ALT)**

and bites the tongue | |**(BT)**

and wets him/herself | |**(WH)**

Have you ever noticed that s/he has episodes of

shaking, trembling of one arm or one leg or the face | |**(ST)**

becoming stiff | |**(BS)**

loses contact with the surroundings | |**(LCS)**

frequent loss memory from a short period of time | |**(FLM)**

jerkings which move up your arm, leg or body | |**(JALB)**

Has s/he had episodes when s/he appears dazed | |**(CD)**

complains of tummy aches | |**(TA)**

smells an odd smell | |**(OS)**

sees something strange | |**(SS)**

Have you ever been told that s/he has had a fit | |**(TCF)**

If response to any of the above questions is Yes, please fill the next section and table on the next page:

Date of onset of seizures: | || |/| || |/| || || || |**(DOS)**

Number of different seizure types | |**(NST)**

When was the last seizure | || |/| || |/| || || || |**(LS)**

How many seizures in the last year | || |**(SY)**

When does s/he have seizures? **D**aytime / **S**leeping/ **B**oth | |**(WS)**

How many seizures has s/he ever had? **0 – 9** or **F**requent (>9) | |**(NS)**

How many times per month? **0 – 9** or **F**requent (>9) | |**(PM)**

How many times per week? **0 – 9** or **F**requent (>9)

How many times per day? **0 – 9** or **F**requent (>9)

Is the seizure provoked?

If **Yes** is it by fever?

If **No** what are the precipitating factors

Description of seizure types:	1st		2nd	
Before the episode				
Does s/he know it is going to occur eg. goes to another person		(KO1)		(KO2)
Abnormal behaviour		(AB1)		(AB2)
During the episode				
Becomes unresponsive (not answer questions, disobey commands)		(BU1)		(BU2)
Fall to the ground		(FG1)		(FG2)
Talks nonsense		(TN1)		(TN2)
Does not know where s/he is		(DW1)		(DW2)
Hallucinations; paraesthesiae		(HP1)		(HP2)
Automatisms: swallowing/grimacing/fiddling/gestures/ vocalisations/walking		(AM1)		(AM2)
Other phenomena: fear/weeping/abdominal/déja vu,		(OP1)		(OP2)
Convulsive movements				
Which side: **B**oth; **R**ight; **L**eft; one **S**ide (unsure which)		(CS1)		(CS2)
Which limb: **B**oth; **A**rms; **L**egs		(CM1)		(CM2)
Partial: **F**ace; **L**ips; **H**and		(CP1)		(CP2)
Eyes involved:				
Blank look		(BK1)		(BK2)
Stares ahead		(SA1)		(SA2)
Deviate: **U**pwards; **R**ight; **L**eft; **D**eviate (unsure to which side)		(ED1)		(ED2)
Jerking movements		(JM1)		(JM2)

Lips involved: No, Smacking, Licking		(LI1)		(LI2)
Bites tongue		(BG1)		(BG2)
Wets self		(WE1)		(WE2)
Soils self		(SO1)		(SO2)
Duration (minutes)		(DU1)		(DU2)
After the episode				
Drowsy		(DY1)		(DY2)
Sleeps		(SP1)		(SP2)
Headache		(HE1)		(HE2)
Abnormal behaviour		(AN1)		(AN2)
Paralysis		(PA1)		(PA2)
Disturbance of sleep		(DS1)		(DS2)
Speech and language difficulties (aphasia)		(SL1)		(SL2)
Does s/he remember the episode		(RE1)		(RE2)

Description of seizures:

Current anti-epileptic drugs:
Any Medication ? **Y/N** | |**(AM)**

If Yes which one/s; Phenobarbitone (**PB**); Phenytoin (**PH**); Carbamazepine (**CB**); Sodium valproate (**NN**)

First drug taken: | || |**(AE1)** Second drug taken: | || |**(AE2)**
Dose per day | | | |**(AED1)** | | | |**(AED2)**

Traditional medicine? | |**(CTRM)**

Previous anti-epileptic drug history:
First drug taken: | || |**(AEP1)** Second drug taken: | || |**(AEP2)**
Dose per day

Drug reactions or unacceptable side effects from anti-epileptic **drugs**

(Y/N).....| |**DR**

Describe_____

Traditional medicine? | | **(PTRM)**

APPENDIX F; NEUROLOGICAL ASSESSMENT, EPILEPSY EXAMINATION QUESTIONAIRE.

Name: [_____] [_____] [_____] **Sex:** [ ]

Episurv Number:[ ][ ][ ][ ] **PID:** [ ][ ][ ][ ][ ][ ][ ][ ]

EZHM: [ ][ ][ ][ ][ ][ ] **DOB:** [ ][ ]/[ ][ ]/[ ][ ][ ][ ]

Date of assessment: [ ][ ]/[ ][ ]/[ ][ ][ ][ ] **Clinician:** [ ][ ]

Nutritional Measurements:

Weight |__|__|.|__| Kg **(WT)**

OFC |__|__|.|__| cm **(HC,** head circumference)

MUAC |__|__|.|__| cm **(MUAC)**

Height |__|__|__|.|__| cm **(HT)**

Blood pressure(BP):_____mmhg.

Handedness: **R**ight **L**eft **U**ndetermined [ ]**(HD)**

Facial Appearance: Normal; **D**ysmorphic [ ](FA)

_____

_____

Skin: Any features of neurocutaneous syndromes **(Y/N)** [ ]**(NCS)**

Hands and feet: **N**ormal; **A**bnormal [ ]**(HF)**

Respiratory system: **N**ormal; **A**bnormal [ ]**(RPS)**

Cardiovascular system: **N**ormal; **A**bornomal [ ]**(CDS)**

Mental State exam: Is he oriented to:	Person (Y/N)	|	|**(ORP)**
	Place (Y/N)	|	|**(ORPL)**
	Time (Y/N)	|	|**(ORT)**
Does s/he have any burn marks? (Y/N)		|	|**(ABM)**

If yes, where_____

Examination of Cranial Nerves

Cranial Nerve II III

Visual Acuity	Normal/Abnormal	|	| **(VA)**
Ptosis	Yes/ No	|	| **(PT)**
Pupils	Normal/ Abnormal	|	| **(PU)**

Cranial nerves III, IV and VI; V and VII

Eye movements	**Cranial nerves III, IV and VI**		
Squint?	Yes/ No	|	|**(SQ)**
Which eye?	Right /Left/ Both	|	|**(SWE)**
Nystagmus?	Yes/ No	|	|**(NY)**

The face	**Cranial nerve VII**		
Muscles of facial expression			
Facial weakness?	Yes/ No	|	|**(FW)**
Forehead stronger than lower face	Yes/ No	|	|**(FS)**

Cranial nerves IX and X; XII

The mouth, pharynx and larynx	**Cranial nerves IX, X, XII**		
Pharynx and larynx			
Uvula: is central?	Yes/ No	|	|**(UMC)**
Deviates to:	Right/ Left/ None	|	|**(UD)**

Tongue

Deviation?	Yes/ No	|	|**(TD)**

Motor system:

Arms:

Wasting?	Yes/ No	|	|(AW)
Where?_____			
Tone	Normal Increased or Decreased?	|	|(AT)
Contractures?	Yes/ No	|	|(AC)
Where?_____			
Power (MRC 0-5)	Normal/ Abnormal/ Grossly Abnormal	[	|(AP)

	Right	Left
Upper arm	—	—
Lower arm	—	—
Hand	—	—

Legs:

Wasting?	Yes/ No	|	|(LW)
Where? _____			
Tone	Normal Increased or Decreased?	|	|(LT)
Contractures?	Yes/ No	|	|(LC)
Where? _____			
Power (MRC 0-5)	Normal/ Abnormal/ Grossly abnormal	[	|(LP)

	Right	Left
Upper leg	—	—
Lower leg	—	—
Foot	—	—

Reflexes:

	Right	Left
Biceps	[|(BR)	| |(BL)
Knee	[|(KR)	| |(KL)
Ankle	[|(AR)	| |(AL)
	(Decreased Normal	Increased)
Plantar	[| (PR)	[| (PL)
	(Flexor	Extensor)

Co-ordination:

Finger-nose	Normal/ Abnormal	[	](FN)
Dysdiadochokinesia?	Yes/ No	[	](DDK)

Gait:

Normal/ Abnormal	[	](GN)
Describe gait abnormality		

Eyes

Cataracts	Yes/No		[	](CT)
Which eye?	Right /Left/ Both/None		[	](CWE)
Other abnormality	Yes/No		[	](EAB)
Describe_____				
_____				
Fundoscope examination	Right	Normal/Abnormal/Impossible	[	](FR)
	Left	Normal/Abnormal/Impossible	[	](FL)

Ears

Auroscope examination:	Right	Normal/Abnormal/Wax	[	](UR)
	Left	Normal/Abnormal/Wax	[	] (UL)
Otitis Media	Right	Yes/No/Wax	[	](OMR)
	Left	Yes/No/Wax	[	](OML)
Otitis Externa	Right	Yes/No/Wax	[	](OER)
	Left	Yes/No/Wax	[	](OEL)

Any other Observations and medical history

Summary

Does s/he have evidence of learning difficulties [ ] (ELD)

Does s/he have any neurological deficits? Y/N [ ] (EXND)

Does s/he need a CT scan? Y/N [ ](EXCT)

APPENDIX G; CONSENT FORM

Informed Consent

What is KEMRI?

My name is_____ and I'm from KEMRI. KEMRI is a research institution, which aims to learn more about health issues in Kenya in order to improve prevention and treatment for everybody in the future.

What is the purpose of this study?

As you may have heard from your community leaders, one of KEMRI's current interests is to learn more about the causes, distribution and effects of epilepsy among the different ages groups in Kenya. This is important because although epilepsy is known to be an important problem for citizens, developing appropriate interventions for the country needs far better information about how many people suffer and why. In order to do this, we need the to compare people who do and do not suffer from epilepsy Those without epilepsy are being invited because we want to establish whether individuals with epilepsy have different characteristics compared to those without.

What are we requesting from you?

On the basis of the questions that we have just asked, we believe that a) you might have epilepsy or b) you do not have epilepsy. We are therefore asking you to assist us in learning about the disease by coming/bringing your child to KEMRI where;

1) A clinician will first see you to ask various questions to confirm that there is a possibility that you have epilepsy/to confirm that you do not have epilepsy.
2) If you are suspected to have epilepsy, you will also be examined and a recording will be done from your head using an EEG (show picture of EEG), a machine

that diagnoses and classifies epilepsy and does not cause any discomfort.

3) Whether or not you are believed by the clinician to have epilepsy, a blood sample (5mls) equivalent to one teaspoonful may be taken from you/from your child There is no harm in taking this amount of blood. This blood sample will be used to look for the causes of epilepsy.

Also, we may request a sub-group of those found to have and not have epilepsy to be involved in a more detailed and long-term study on that visit to the hospital.

Benefits of the Study

Individuals found to be suffering from epilepsy would be given medication at no cost for the duration of the study; thereafter an epilepsy clinic will be established at the hospital for the purpose of dispensing drugs at a minimal cost. This study is intended to provide a better understanding of the problem of epilepsy in this community and Kenya in general.

Confidentiality

Results from these investigations will only be used for research purposes only and under no circumstances will they be divulged to any other person apart from you.

Voluntary participation

Your participation in this project is voluntary. You are free to withdraw or withdraw your child from the study at any time without any problem. Feel free to ask any questions regarding the information given to you.

If you are willing to participate in this study, please sign this document to show that you have understood and allowed us to examine you/your child.

Consent Agreement

I_____(Name)

Being above the age 18 and _____(Name of Child)

I have accepted/allowed this child to participate in the Epilepsy Study.

I fully understand the aims of the study, that has been explained to me in_____

a language that I understand most, and have been allowed to ask questions which have been answered. In case of any questions in future you will be able to contact Victor Mung'ala Odera at KEMRI, Kilifi.

I also know that I'm free to withdraw from the study at any given time without any conditions.

Participant's/Parents name _____Date_____

Participant's/Parents sign _____Date_____

Witness's name _____

Witness's sign _____Date_____

Fieldworker's _____