

# Factors Underlying Stigmatization of Epilepsy: A Comparative Case Study of Suba and Meru Central Districts, Kenya

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## Abstract

Epilepsy is the most common neurological disorder known to mankind. It is shrouded in mystery and associated with supernatural forces resulting in social stigma, systematic discrimination and psychological morbidity to the afflicted. The study was carried out in Suba and Meru central districts in Kenya. The Objective of this study is to determine the factors underlying stigmatization of People with Epilepsy (PWE) in Suba and Meru Central Districts and evaluate the social burden associated with epilepsy. A cross-sectional descriptive study involving the use of a 30-item structured questionnaire, Focus Groups Discussion and key informants. Two hundred and twenty-five (225) household heads, twelve focus group discussions and 30 key informants. A total of 225 households interviewed had male preponderance of 140 (62.2%) to 85 females (37.8%). The level of education for Suba District respondents was higher as 54.3% had secondary and post secondary education compared to 35.2% for Meru Central District. All respondents (100%) in both study cohorts were aware of epilepsy. Thirty four percent (34%) of Suba respondents had some knowledge about epilepsy compared to eleven percent (11%) in the Meru Central District cohort. Statistical relationship between negative attitude and fear of epilepsy overall was significant ( $\chi^2 = 43.69354$ ,  $df=1$ ,  $p<0.05$ ).

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There was no statistical significance in relationship between level of education and fear of epilepsy ( $\chi^2 = 0.15773$ ,  $df=2$ ,  $p=0.092436$ ). However there was statistical significance in relationship with knowledge on epilepsy and fear-for-epilepsy ( $\chi^2 = 7.41663$ ,  $df=1$ ,  $p=0.00646$ ). Occupation of respondents did not influence fear for epilepsy except among Meru Central District female respondents ( $\chi^2 = 6.19763$ ,  $df=2$ ,  $p=0.04510$ ). as a conclusion we can say that in both communities epilepsy was considered a contagious and transferable disease and highly associated with witchcraft. Stigma and discrimination of PWE is amply evident. We recommend a comprehensive community sensitization programme to reverse the negative attitude, myths, beliefs and superstitions surrounding epilepsy.

**Keywords:** Knowledge; Practices; Perception; Fear; Stigma; Contagion; PWE (People with Epilepsy); CORPS (Community Own Resource Persons).

## 1. Introduction

The term 'epilepsy' is derived from a Greek word "epilambanein" which means 'attack', 'grab', 'capture' or 'seize' [1]. It is a ubiquitous disorder known to mankind since antiquity with no racial, religious, class or geographical boundaries. It affects about 50 million people worldwide 10 million of whom live in Sub Saharan Africa [2]. In Kenya it is one of the 12 common diseases identified by local names at family level with a prevalence rate of 18 per 1000[3, 4].

Epilepsy is a chronic condition of the brain characterized by spontaneous recurrent seizures that result from excessive discharge of cerebral neurons. These discharges are unprovoked or provoked by identified cause [5]. The abnormal, excessive electrical discharges are a non-specific response to an insult to the brain causing sudden and transitory phenomena of motor, sensory, autonomic or psychic nature in different measures [6]. These phenomena may result in a diversity of clinical forms of epileptic seizures [7].

History of epilepsy has been riddled with prejudices and counter-prejudices. People with epilepsy have had to face a number of legal restrictions. The Hammurabi code dated 1780 BC dictated that a person with epilepsy could not marry or testify in a court of law and the purchase contract of a slave was considered void if they suffered a seizure in the first three months.

The stigma placed upon PWE by the community in which they live is the greatest problem. In China, PWE are generally withdrawn from the society, denied employment feel isolated and are either overprotected or neglected [8]. Most people would object to their children marrying or even playing with a person with epilepsy. Epilepsy is equated with a mental disorder or insanity. Until recently, compulsory sterilization of PWE was legally permitted in some states in the US. Those who experience seizure in public places faced the risk of being arrested for disorderly conduct or mistaken for being under the influence of alcohol or illicit drugs [9].

Patients With Epilepsy are sometimes more vulnerable to often more disabling psychosocial difficulties. The neurological deficit they may have come to bear on their families who may therefore be hesitant to disclose the illness to neighbours as such information may engender fear and social rejection. Consequently the patients

suffer segregation and exclusion in the society with subsequent stigma.

## **2. Materials and Methods**

The study was carried out in August 2006 Gwasi, Central and Mbita divisions, Suba District and in September 2006 in Nkuene, Mirigamieru West and Abothuguchi Central divisions in Meru Central District. The districts were purposively selected due to contrasting epilepsy care interventions. These varied epilepsy care interventions were noted by the investigators during their involvement in epilepsy care programmes in the two study areas run by Kenya Association for the Welfare of People with Epilepsy (KAWE).

### **2.1 Study Population**

The study population comprised two hundred and twenty-five (225) householdheads, twelve focus discussions and 30 key informants. Only household heads present at the time of the visit and had been residing in the area for at least five years and consented to take part in the study were recruited and interviewed. It excluded non-household heads, household heads that had not lived in the area for at least five years and those who did not consent. Informed consent was verbally obtained from study subjects prior to the interviews and confidentiality was assured.

### **2.2 Study Design**

Cross-sectional Descriptive Study which involved the use of a 30-item structured questionnaire, Focus Group Discussion guidelines and interview schedules for household heads, focused groups and key informants respectively.

### **2.3 Investigation process**

Once in the field further clearance was obtained from respective District Commissioners and District Medical Officers of Health. Multistage sampling was adopted for selection of the division and households. Three divisions in each of the two districts were selected randomly using random numbers. The first sample in each division was determined arbitrarily considering the infrastructure and proximity to urban centres. Systematic random sampling method was used where the heads of every seventh home present at the time of the visit was interviewed face-to-face. The interval of every seventh household was considered appropriate following the fear and stigma attached to epilepsy as revealed from the pilot study where participants considered it an abomination never to be called by name or only discussed in strict confidence. The key informants were served with self-administered questionnaires.

### **2.4 Sample Size Determination**

The sample size was determined by the formula as used by the following formula:

$$n = \frac{Z^2pqD}{d^2}$$

Z = standard normal deviation usually 1.96 at 95% confidence interval

n = is the desired sample size

p = proportion of population estimated to have working knowledge on epilepsy = 0.07

q = 1 – p (1 – 0.2) = 0.93

d = degree of accuracy = 0.05

D = design effect =2

$$n = \frac{1.96 \times 1.96 \times 0.07 \times 0.93 \times 2}{0.05 \times 0.05} = 200$$

However sample size of 119 was selected from Suba District and 106 for Meru Central District were interviewed based on the prevailing environmental and geographical factors.

### 2.5 Data Collection

Data collection was carried out using open and close-ended questionnaires, key informant interviews and focus group discussion guideline which were designed to evaluate the awareness, knowledge, perception, attitude and practices of household heads. Interview schedules were held with the household heads who met the inclusion criteria between 8am and 6pm. Focus Group Discussions (FGDs) were held with youth, women groups, parents, patients and C.B.O. members using FGD guidelines. Key Informant interviews were held with government officials, teachers, religious leaders, traditional healers and health workers which supplemented the interviews held with the household heads. A total of twelve focus group discussions were held and 30 questionnaires were administered to various key informants.

## 3. Results and Discussion

### 3.1 Results

A total of 225 study respondents were recruited and interviewed. Their mean age was 45.5yrs mode of 42yrs and a standard deviation of 14.63yrs and range of 18-98 years. They comprised 140 males (62.2%) and 85 females (37.8%). For Suba District, 96 (80.7%) were males compared to 44 (41.5%) males for Meru Central

District. They were distributed as follows: Mbita, 37(16.4%), Gwasi, 44(19.6%), Central, 38(16.9%), Nkuene, 33 (14.7%), Mirigamieru, 35 (15.6%) and Abothuguchi, 38(16.9%). By occupation, the distribution was: self-employed - 114 (51.6 %); Salaried employees - 57 (25.8 %); unemployed - 50 (22.6%). Upto 54.3% of Suba district respondents had education level of secondary and post secondary level as compared to 35.2% for Meru Central in the same category.

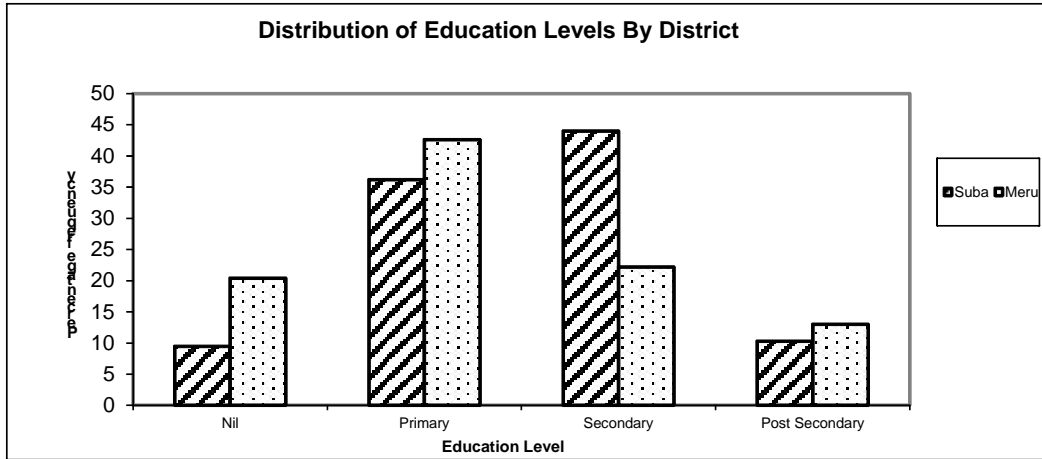


Figure 1: Distribution of study participants by level of education

There was 100% awareness about epilepsy with respondents mentioning schools, CORPS and newspaper as their major sources of information. However, level of knowledge on epilepsy for Suba District respondents 34.2% compared to 11.3% for Meru Central respondents. Consequently 56.9% of respondents of Suba District knew the causes of epilepsy compared to 37.3% for Meru Central District. Upto 51.3% of Suba respondents feared epilepsy as compared to 46.2% of Meru Central respondents. The overall scenario shows that 62.4% of those who feared epilepsy did not know what causes it ( $p < 0.05$ ).

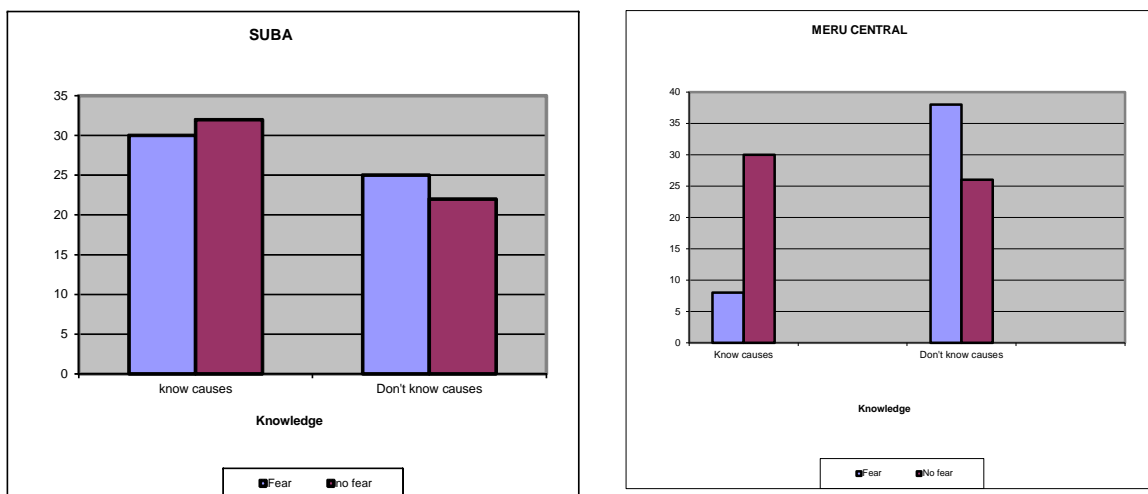


Figure 2: Association between fear and knowledge on causes of epilepsy by Districts

$(\chi^2 = 0.24685, df=1, p=0.6193)$        $(\chi^2 = 14.14238, df=1, p=0.00017)$ S

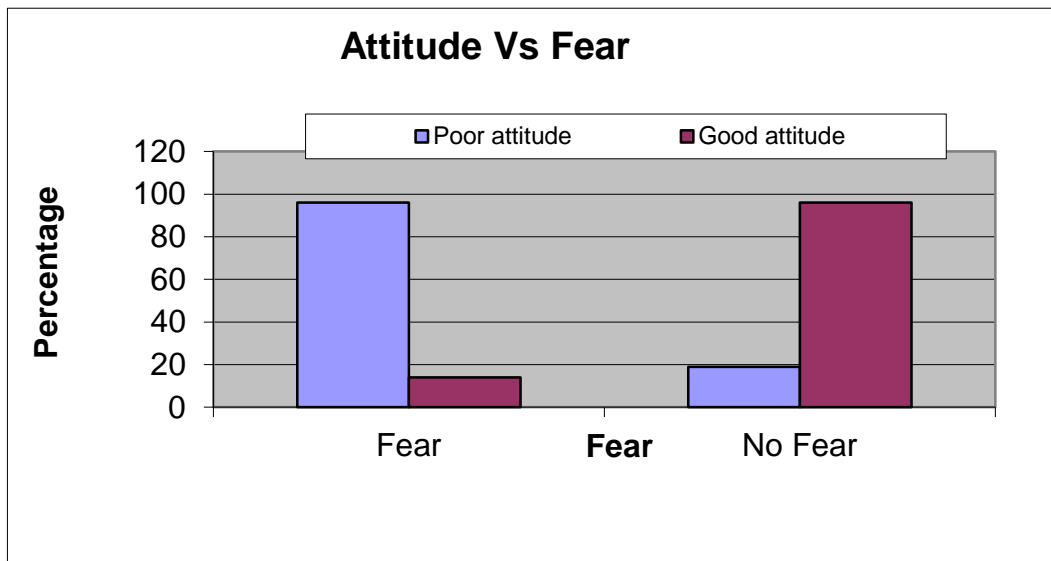
The relationship between fear and knowledge about epilepsy was found to be statistically significant ( $\chi^2=7.41663$ ,  $df=1$ ,  $p=0.00646$ ).

**Table 1:** Education level and fear of epilepsy

|         | No education | Primary    | Secondary  | Total      |
|---------|--------------|------------|------------|------------|
| Fear    | 11 (13.3%)   | 33 (39.8%) | 39 (47.0%) | 83 (49.1%) |
| No fear | 11 (12.8%)   | 32 (37.2%) | 43 (50.0%) | 86 (50.9%) |

( $\chi^2 = 0.15773$ ,  $df=2$ ,  $p=0.092436$ )

For all the respondents in both districts, there was no significant relationship between level of education and fear of epilepsy ( $\chi^2 = 0.1573$ ,  $df=2$ ,  $p=0.92436$ ). Upto 51.1% of all respondents had negative attitude toward PWE but 87.3% of those who fear epilepsy had negative attitude towards PWE while 83.5% of those who did not fear epilepsy had good attitude ( $\chi^2=112.6283$ ,  $df=1$ ,  $p<0.05$ ).



**Figure 3:** Overall association between fear and attitude towards PWE

In Suba District, 59.6% of those with negative attitude and 57.4% of those with positive attitude had poor perception of behaviour of people with epilepsy ( $p=0.81062$ ). In Meru Central 56.9% of those with poor attitude had poor perception while those with positive attitude had good perception of their behaviour ( $\chi^2 = 4.14216$ ,  $df=1$ ,  $p=0.04183$ ).

### **3.2 Discussion**

Suba and Meru Central Districts are culturally and geographically distinct areas in Kenya. The two districts share limited medical infrastructure, communal living situations and modest education standards especially among the female population. Life in these areas is constrained by high unemployment rate, low income and extended family relationships.

Based on their demographic profile, the study participants were considered mature enough to answer questions appropriately and their age range was representative of the study population. They were evenly distributed in the six divisions to check on selection bias.

The high level of awareness (100%) and relatively low level of knowledge (26%) about epilepsy in the two districts is a strong pointer to the prevailing “wide knowledge gap”. This compares favourably with other authors findings [10]. They found that only 26% of respondents had good knowledge of epilepsy in Nigeria. Respondents with some knowledge on epilepsy mentioned basic clinical signs which included falling down, stiffening, jerking and soiling of clothes. They associate epilepsy with trauma, infections or genetics. Their major sources of information was the media, relatives and personal experiences.

The relatively higher level of knowledge about epilepsy among Suba District participants (34%) could be attributed to their relatively higher education level. The low level of knowledge on epilepsy in Meru Central (11%) where there had been an established community intervention programme was a powerful pointer to the ineffective and inappropriate public education and promotion strategies used by the concerned agency.

The lack of knowledge about the care centres in both districts points to the poor infrastructure about epilepsy care in Kenya. This concurs with WHO standards which observed that very few countries have national plans for epilepsy reinforcing the prevailing wide “treatment gap” [11]. This scenario had direct bearing on the level of care for PWE and a fertile ground for the dissemination of old-age retrogressive beliefs and superstitions which fosters fear of the condition considered an abomination never to be called by name.

The insignificant statistical relationship between level of education and fear of epilepsy was responsible for the widespread negative response among respondents especially during an attack. Running away from the victims represented the maximum expression of fear among respondents regardless of their education level. This implies that many educational curricula in schools in Kenya do not have adequate information on epilepsy and probably other chronic non-communicable diseases.

Epilepsy is portrayed as a mysterious disease whose causality lies in the supernatural world. These belief models are informed by negative cultural heritage passed over generations and therefore entrenched in the culture and traditions of the two communities. It is associated with witchcraft, magical powers and evil spirit where and people fear even to walk in company of PWE. Stigma is due in part to a lack of understanding by people they see every day. Some of these people mistakenly believe that epilepsy is a form of mental illness, a curse or that seizures are something to fear. There is a belief that attributes epilepsy to supernatural rather than medical causes; this belief system is aggravated by lack of adequate facilities in the developing world as noted by

authors in [12].

In Meru Central District, epilepsy causality had ancestral beliefs attributing it to a curse or witchcraft as reported by author in [13]. These authors stated that “though epilepsy is so widespread, it is widely misunderstood leading to stigmatization and the risk of social and legal penalties”. In Suba District, fear of epilepsy was also found to be driven by myths, supernatural beliefs and superstition surrounding its origin and mode of transmission which are considered mysterious.

#### **4. Conclusions and Recommendations**

##### ***4.1 Conclusions***

The pattern of traditional belief systems about epilepsy was similar in both study areas which shaped the expression of stigma as a social burden in both districts. Social stigma and negative attitude towards epilepsy was a common phenomenon. The belief that epilepsy is caused by witchcraft and ancestral curse and thought to be contagious, transmissible and an incurable disease drove families affected to seek treatment from traditional healers who were found to play a major role in their care. This misunderstanding was a major cause social discrimination.

The disconnect between formal education and fear of epilepsy indicates dearth of information about epilepsy in the educational and training curricula. Therefore chronic non-communicable disease like asthma, epilepsy, diabetes and hypertension could be demystified thus increasing the bulk and accuracy of information about them in the school training curricula.

The superstitions and belief models compounded by a low knowledge level and dearth of information on epilepsy was responsible for the systematic discrimination of PWE both in employment and social life. They were recommended to undertake low paying jobs under the convenient label of “low risk jobs”. This subjected them to perpetual poverty giving them an identity of stigmatized and downtrodden personality thus contributing to the negative attitudes towards them.

##### ***4.2 Recommendations***

A number of problematic and stigmatizing ideas about epilepsy remained prevalent in Suba and Meru Central Districts. However, the information obtained provides a foundation for the understanding of these problems so that appropriate intervention measures can be put in place. In order to address them the study recommends:

- Well-designed comprehensive community sensitization programme accompanied by audience specific Information, Education and Communication (IEC) materials to disseminate accurate information on epilepsy.
- Review of school and teacher training curricula in order to achieve a reasonable level of technical information to reverse the misunderstanding
- Fostering well designed controlled research to establish tool kits that can be used to monitor attitude and



perception of the public on PWE on a continuous basis

- The provision of accessible and affordable integrated health care of PWE to improve their health outcomes

### Acknowledgement

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**Appendix**

**Appendix 1: QUESTIONNAIRE**

**Introduction**

My name is Tiberry Nyakwana, a student at Kenyatta University in the School of Pure and Applied Sciences. This questionnaire is for a research on factors underlying stigmatization of people with epilepsy in Suba and Meru Central Districts. The findings will be used in the writing of a thesis in partial fulfillment for the requirements for the Degree of Master of Public Health and Epidemiology (MPHE), for which I am studying.

Please answer all questions correctly. All information given will be handled confidentially

| <b>DISTRICT NAME</b> | <b>CODE</b>             | <b>DIVISION NAME</b>   | <b>CODE</b>           |
|----------------------|-------------------------|------------------------|-----------------------|
| _____                | _____                   | _____                  | _____                 |
| Age                  | Occupation              | Education              | Sex                   |
| _____                | _____                   | _____                  | _____                 |
| <u>District Code</u> | <u>Division.Code</u>    | <u>Sex Code</u>        | <u>Education Code</u> |
| 1 = Suba             | 1 = Nkuene              | 1 = Male               | 1=Nil                 |
| 2 = Meru             | 2 = Mirigamieru west    | 2 = Female             | 2=Primary             |
| Central              | 3 = Abothuguchi Central | <u>Occupation Code</u> | 3=Secondary           |
|                      | 4 = Magunga             | 1=Self Employed        | 4=Post Secondary      |
|                      | 5 = Central             | 2=Salaried             |                       |
|                      | 6 = Mbita               | 3=Unemployed           |                       |

|            |       |
|------------|-------|
| Date       | _____ |
| Coding     | _____ |
| Date Entry | _____ |

FORM 1: Household Heads

**I: Knowledge about epilepsy**

1. (a) Have you heard about epilepsy? [ ] Yes [ ] No

b1) If yes what did you hear \_\_\_\_\_

b2) who told you \_\_\_\_\_

c) If no, never? \_\_\_\_\_

2. (a) Have you seen somebody with epilepsy? [ ] Yes [ ] No

(b) If yes how many? \_\_\_\_\_

3. (a) Does any of your family member have epilepsy [ ] Yes [ ] No

(b) If yes who? \_\_\_\_\_

1. Father                      3.Sister

2. Mother                     4. Brother

5. Other specify \_\_\_\_\_

c) If yes, for how long? \_\_\_\_\_

4. (a) Do you know what causes of epilepsy? [ ] Yes [ ] No

(a1) If yes what are the causes:

1=malaria, injury, alcohol,

2=witchcraft, evil spirits, demons

|       |
|-------|
| _____ |
| _____ |

(b) According to you how does one get epilepsy?

1=Contact, sharing clothes, greeting, witchcraft

2= Through diseases or injuries to the head

|       |
|-------|
| _____ |
| _____ |

5. (a) Have you ever lived with a person with epilepsy ? [ ] Yes [ ] No

(b) If yes who? \_\_\_\_\_

c) How did/ does he/ she behave (comment) \_\_\_\_\_

\_\_\_\_\_

|       |
|-------|
| _____ |
| _____ |

(d) Do you like the behaviour? [ ] Yes [ ] No

If yes why? \_\_\_\_\_

If not why not? \_\_\_\_\_

6. Do you think that families where there are people with epilepsy are comfortable living with them? [ ] Yes [ ] No

a) if yes why so? \_\_\_\_\_

b) If no, why not? \_\_\_\_\_

7 (a) Have you ever heard of a cure for epilepsy [ ] Yes [ ] No

(b) If yes which one?

(i) If no, do you think it is curable?  Yes  No

(ii) If yes what is the cure? \_\_\_\_\_

**II: Attitudes toward PWE:**

1 (a) Do you think one can have epilepsy by staying with a person with

epilepsy?  Yes  No

(b) If no, how do you think one can acquire it?

\_\_\_\_\_

2 (a) How do you feel when you meet somebody with epilepsy  bad

Uncomfortable  nervous  different

(b) Do you feel about following?

|                    | 1.Uncomfortable | 1. Indifferent | 1. Good | 2. Bad |
|--------------------|-----------------|----------------|---------|--------|
| Sharing abed       |                 |                |         |        |
| Sharing Utensils   |                 |                |         |        |
| Shaking hands      |                 |                |         |        |
| Sharing clothes    |                 |                |         |        |
| Sharing classrooms |                 |                |         |        |

3. (A) Do you think people with epilepsy should be separated to stay in their own places?

Yes  No

If yes where? \_\_\_\_\_

(b) Do you think they should be hidden to conceal their condition?  Yes  No

If yes why? \_\_\_\_\_

4. (A) have ever seen or heard of someone who has been cured of epilepsy?

Yes  No

If yes who \_\_\_\_\_

(b) If yes, what cure was it? \_\_\_\_\_

(c) Do you think there are other alternative ways of treating it??  Yes  No

If yes which one? \_\_\_\_\_

5. for families with person with epilepsy

(a) Have you ever sought treatment for the patient  Yes  No

(b) If yes where?

If yes which one \_\_1=hospital, clinic, 2= herbalist,

6. A) Do you know of any organization that treats epilepsy

If yes which ones?

(b) What about the government medical services?

Are there any other individual (s) who treats epilepsy?

If yes which ones \_\_\_\_\_

**III. Practice**

1 Do all people like to stay with people of epilepsy? (1=Yes, 2=No)

1a. If no, why?

2. Why would people I not like to associate with people with epilepsy?

3. Which of the following can make you not to associate with people with epilepsy?

| <b>Reasons</b>                   | <b>yes</b> | <b>no</b> |
|----------------------------------|------------|-----------|
| Culture does not allow           | _____      | _____     |
| Parents do not allow             | _____      | _____     |
| People with epilepsy are violent | _____      | _____     |
| They are mad                     | _____      | _____     |

|                                   |       |       |
|-----------------------------------|-------|-------|
| You can contract the disease      | _____ | _____ |
| My children will develop epilepsy | _____ | _____ |

4. Do you think people with epilepsy are discriminated in schools and colleges? (1=Yes, 2=No,)

4. a. If yes, in what ways?

|  |
|--|
|  |
|--|

4.b. If No, why do you think so?

|  |
|--|
|  |
|--|

5. Do you think people with epilepsy behave normally?

(1=Yes, 2=No,)

5. A. If yes, why do you think so?

|  |
|--|
|  |
|--|



5. b. If no, what bad behaviours do they have?

5.c. Do you think such behaviours should be controlled?

6. What do you think should be done to assist people with epilepsy?

THANKS FOR TAKING YOUR TIME TO ANSWER THESE QUESTIONS

Appendix 2: Map of the Study Area

