COMBRA

STUDY REPORT

Epilepsy

in the

Districts of Masindi, Kabale and Tororo

A Study carried out

by

Epilepsy Support Association

June 2005

Epilepsy Support Association, Uganda (ESAU)
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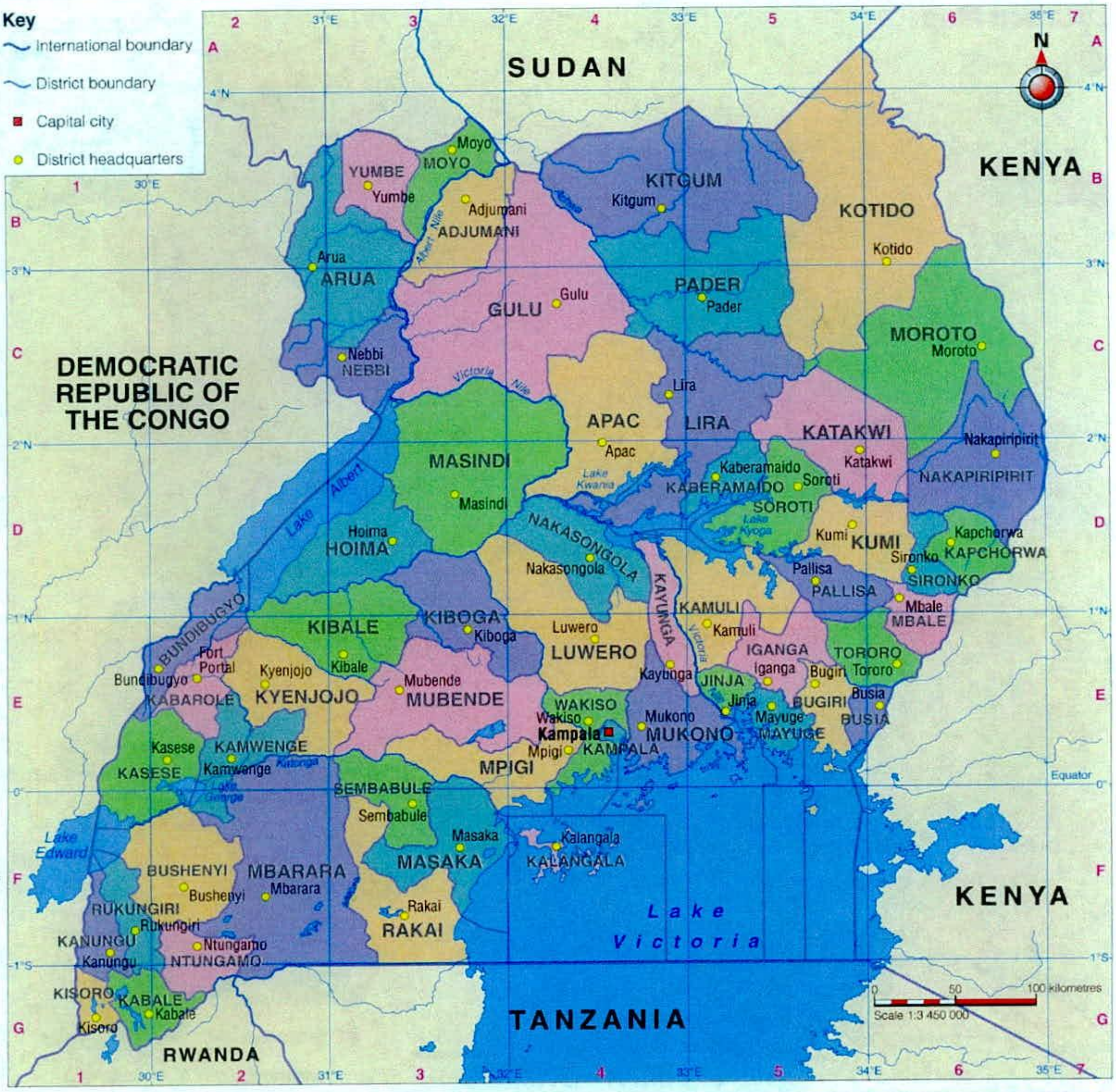


District	Area in km²	Population, 2002
Adjumani	3 083	201 493
Apac	6 506	676 244
Arua	5 611	855 055
Bugiri	5 774	426 522
Bundibugyo	2 236	212 884
Bushenyi	4 310	723 427
Busia	762	228 181
Gulu	11 864	468 407
Hoima	5 853	349 204
Iganga	2 498	716 311
Jinja	722	413 937
Kabale	1 735	471 783
Kabarole	1 819	359 180
Kaberamaido	1 628	122 924
Kalangala	9 038	36 661
Kampala	188	1 208 544
Kamuli	4 265	712 079
Kamwenge	2 458	295 313
Kanungu	1 298	205 095
Kapchorwa	1 735	193 510
Kasese	3 500	532 993
Katakwi	5 038	307 032
Kayunga	1 741	297 081
Kibale	4 252	413 353
Kiboga	4 045	231 718
Kisoro	729	219 427
Kitgum	9 646	286 122
Kotido	13 154	596 130
Kumi	2 849	388 015
Kyenjojo	4 040	380 362
Lira	7 241	757 763
Luwero	5 684	474 627
Masaka	4 757	767 759
Masindi	9 404	469 865
Mayuge	3 409	326 567
Mbale	1 378	720 925
Mbarara	10 183	1 089 051
Moroto	8 441	170 506
Moyo	1 813	199 912
Mpigi	3 602	414 757
Mubende	6 207	706 256
Mukono	13 804	807 923
Nakapiripirit	5 825	153 862
Nakasongola	3 506	125 297
Nebbi	2 917	433 466
Ntungamo	1 876	386 816
Pader	6 777	293 679
Pallisa	1 995	522 254
Rakai	4 828	471 806
Rukungiri	1 525	308 696
Sembabule	2 328	184 178
Sironko	1 091	291 906
Soroti	3 374	371 986
Tororo	1 852	559 528
Wakiso	2 815	957 280
Yumbe	2 278	253 325
Uganda	**241 284 km²**	**24 748 977**
Total land area (excluding water) 197 096 km²		

ACKNOWLEDGEMENT

We are grateful to Danida, who through Danish Epilepsy Association has financed this study as a part of the Project "Bringing Epilepsy in Uganda out of the Shadows". This is also an indicator of the interest the partner associations, Danish Epilepsy Association and Epilepsy Support Association, Uganda has in improving the condition for People Living with Epilepsy in Uganda.

The study provides substantial input to the understanding of the various perceptions and knowledge of; the causes of epilepsy, how it can be controlled – and how people can live with epilepsy, that exist from grassroots- districts, and to government level. This insight will be used to enhance Epilepsy Support Association's work for the betterment of People with Epilepsy's living condition.

Epilepsy Support Association, Uganda would like to appreciate the contribution of the various stakeholders during the preparation, and conducting of the study and production of the report.

The study would not have been possible without the support from the Ministry of Health in particularly from the Department of Mental Health headed by Dr. Sheila Ndyanabangi, whom we thank for her commitment to People with Epilepsy and for her ever inspiring cooperation.

Special thanks goes to the District and Sub-county leaders and officials from Kabale, Masindi and Tororo who gave support and guidance during the study and further showed great interest to learn more about Epilepsy in order to improve the living conditions of People with Epilepsy and strengthen the health services for People Living with Epilepsy.

We also thank our staff who conducted the study and acknowledge the valuable input from various persons.

Last but not least we thank People Living with Epilepsy, their relatives and caregivers for coming out of the "Shadows" and teaching us what living with Epilepsy is about - this study is dedicated to you.

Augustine Mugarura
National Director
Epilepsy Support Association, Uganda

LIST OF ABBREVIATIONS AND ACRYNOMS

ADD	Action on Disability and Development
DDHS	District Director of Health Services
DEA	Danish Epilepsy Association
DPO	Disabled Peoples' Organisations
DRO	District Rehabilitation Office
CAO	Chief Administrative Officer
ESAU	Epilepsy Support Association, Uganda
FGD	Focus Group Discussion
HMIS	Health Management Information System
MHU	Mental Health Uganda
MOES	Ministry of Education and Sports
MOH	Ministry of Health
NMS	National Medical Stores
NUDIPU	National Union of Disabled People in Uganda
NUWODU	National Union of Women with Disabilities of Uganda
PWD	Persons with Disabilities
PWE	People with Epilepsy
UBOS	Uganda Bureau of Statistics
UNAB	Uganda National Association of the Blind
UPACLED	Uganda Parents of Children with Learning Difficulties
USDC	Uganda Society for the Disabled Children
WHO	World Health Organization

LIST OF TABLES AND GRAPHS

EXECUTIVE SUMMARY

The Study, “Epilepsy in the Districts of Masindi, Kabale and Tororo” carried out by Epilepsy Support Association, Uganda, aimed to get a better understanding of how People Living with Epilepsy (PWE) and their community perceive the disease and react to the people with the disease and their families. The purpose of the enhanced understanding is to guide the Epilepsy Support Association in her future interventions.

The Study was designed as both a qualitative and quantitative analysis of PWE’s and their community’s perception of and experiences with the disease; their understanding of treatment; the functioning and easy accessibility to health facilities and lastly to get an indication of the prevalence of PWE. In total 900 people were interviewed using Household Questionnaire, Key Informant Interviews and Focus Group Discussion.

From the results, there is abundant evidence that PWE and / or families looking after PWE are socio-economically isolated and burdened; have poor access to medical care; students / pupils have inadequate access to education / are dropping out. There are reported cases of people who have lost their lives due to epilepsy because of inadequate care. The general attitude to epilepsy is still very negative and many people associate the disease with ancestral spirits. There is regular consultation with traditional healers for treatment of the disease.

There is no evidence of any statistical figures about PWE (at the majority of all district-planning units visited) and this makes it hard for inclusion of epilepsy in the districts’ planning and budgeting.

Responses from stakeholders and service providers, shows that there are limited efforts to re-package and adapt the health system in order for PWE to have easy access to regular anti-epileptic treatment. People living in the villages have to travel a long distance (often by foot or by taxis) to the health centres in order to be medical assessed and diagnosed. When it comes to PWE the distance to the health centres become an extra burden as they are dependant of constant anti-epileptic medication. When the PWE after a exhausting and expensive travel reach the health centres they find that the anti-convulsion drugs are not available. There are inadequate / not regular supplies of anti- convulsion drugs in most health centres especially in rural areas.

However, the difficulties getting medical assessed and regular anti-epileptic medication might improve in the future as the Government is committed to provision of health services to the people including PWE; they have included PWE in the HMIS; they have included anti convulsion drugs in the essential drug kit; and they have set up a series of epilepsy health days.

Among others it is recommended that these opportunities are utilized fully and used effectively to sensitize the public about PWE; the disease, epilepsy and to lobby for inclusion of People living with Epilepsy into the society and mainstream development programs at local and national levels.

TABLE OF CONTENT

1. INTRODUCTION TO - AND OBJECTIVES OF THE STUDY

1.1 The Background of the Study

Epilepsy Support Association, Uganda (ESAU) is a user association for People Living with Epilepsy (PWE) funded among others by its sister association the Danish Epilepsy Association (DEA).

Epilepsy is the most serious neurological disorder across the globe and it is believed that around 50million people live with epilepsy in the world, of these 80% live in developing countries (source: *International Epilepsy News Letter, 2004*).

In 1997, the International League against Epilepsy (ILAE) founded in 1909 and the International Bureau for Epilepsy (IBE) founded in 1961 joined forces with the World Health Organization (WHO) to establish the Global Campaign against Epilepsy in order to address these issues.

The aim of the ILAE/IBE/WHO Global Campaign against Epilepsy is to improve prevention, treatment, care and services for people with epilepsy. It also aims at raising public awareness about the disorder. It is hoped that the end result will be a supportive environment in which people with epilepsy can enjoy a better life.

ESAU and DEA share the above-mentioned aims and have teamed up as partners in the current project, "Bringing Epilepsy in Uganda out of the Shadows" being implemented by ESAU.

Among the key project activities was to carry out a study in selected districts to establish the level and magnitude of the disease, as well as to find out the living conditions of PWE and the services available for them.

1.2 Presentation of Epilepsy Support Association, Uganda (ESAU)

In 1997 ESAU, a user association for PWE was established in Mbarara with the primary objectives of helping PWE to get access to health services and to have their basic human rights as Ugandan citizens observed and respected.

Epilepsy Support Association's main activities include:

- Creating awareness through public education to PWEs, their Parents, Teachers and the Community.
- Capacity building of PWE, their Parents/Guardians and Local Leaders.
- Improve access to health services through encouraging PWEs to go to hospitals for medical treatment for their epilepsy and demanding for sufficient supply of drugs.
- Enabling PWEs to engage in income generating activities to improve on the quality of their lives.
- Providing psychosocial support and counselling to fight stigma.
- Mobilizing PWE to lobby and advocate for their rights including the right to treatment.

The Association facilitates PWE to form groups at local levels from the Sub-county to District level with the aim to build capacity of the members, create awareness about epilepsy and to carry out advocacy and lobbying for the rights of PWE.

ESAU works hand in hand with other development partners both governmental and non-governmental organisations in order to achieve her objectives. These organisations include Mental Health Uganda (MHU), Uganda Society for the Disabled Children (USDC), Action on Disability and Development (ADD), Uganda Parents of Children with Learning Difficulties (UPACLED), and Ministry of Health (MOH), and Ministry of Education (MOE), Blind but Able, National Union of Women with Disabilities in Uganda (NUWODU), Uganda National Association for the Blind (UNAB) and many more others. Further, ESAU is a member of the umbrella organization, National Union of Disabled People in Uganda (NUDIPU).

In 2004, Danida through Danish Epilepsy Association (DEA) granted ESAU funding to carry out the Project "Bringing Epilepsy in Uganda out of the Shadows", which took off 1st April 2004 and is running for 3 years till end of March 2007. Due to this support in addition to support from other donors, ESAU expanded its operations to cover 15 districts, namely Masaka, Mpigi, Luwero, Mbarara, Ntungamo, Kabale, Bushenyi, Jinja, Tororo, Soroti, Masindi, Hoima, Apac, Arua and Moyo.

1.3 A Brief about Epilepsy

Epilepsy, one of the oldest (4500BC) conditions known to mankind is a neurological disorder that affects people in every country throughout the world.

The belief widely held in many countries is that a person with epilepsy is seized by a supernatural force or power. This ancient belief is reflected in the name of the disorder -- the word "epilepsy" being derived from the Greek word "epilambanein" which means "to seize or attack".

Many people world over have associated the disease with the living dead (traditional ancestors) while others think it is witchcraft or people are possessed by the devil (source: *5th AOEC Bangkok epilepsy news report).*

Whatever people may call it, what is known is that epilepsy is a recurrent disorder characterised by outbursts of excessive activity in part or the whole brain, which occurs suddenly, disappears spontaneously and has a tendency to reoccur (source: *Ministry of Health Training Manual*).

This results into occurrence of fits. The diagnosis of epilepsy relies upon the patient's ability to recognise their seizures, seek medical care and be diagnosed (source: *Pierre Jallon et al 2003*).

According to WHO (Fact sheet No 167) anti epilepsy drugs can control seizures (fits) in almost 75%.

Research into epilepsy falls into two main categories: basic and clinical. However, the vast majority of the technology required carrying out this research and the benefits which accrue from the research are only available in developed countries (source: WHO Fact sheet No 167).

1.4 The Study – and the Objectives

Problem Formulation

During the 8 years that ESAU has been working it has gathered vast experiences about epilepsy and envisaged how poor the conditions in Uganda are for People Living with Epilepsy.

In Uganda, epilepsy is estimated to be affecting about 2.5%, which is almost 600,000 people of the total population (source: *The World Health Report on Epilepsy in Developing Countries, 1997*).

Uganda Bureau of Statistics (UBOS) estimate 0,09%, which is almost 21,500 people of the total population (source: *2002 Uganda Population a Housing Census*). This might be greatly underreported due to the stigma attached to the disease.

However, there are no proper records or statistics about the prevalence of PWE living in Uganda. Hopefully, this is going to be improved as the Ministry of Health since June 2005 is able to capture statistics about PWE however, for only those who come for surgery and medication in the Health Units.

ESAU, together with the Ministry of Health note that no national baseline has been carried out to ascertain PWEs' need for anti epileptic treatment and also to know the prevalence in order to plan effectively for the all over support to PWEs.

The public attitude towards Persons Living with Epilepsy both at household and community level is quite negative to the extent that children's right to education in general are not respected and they are not helped to relate well with other children. Adults with epilepsy are hampered in their ability to earn a living and have no right to own property. Children and adults with epilepsy and their families are most of the time socially isolated and stigmatised.

Many people, who are asked about epilepsy, explain the disease from a traditional way of thinking; they perceive it as witch craft, an evil spirit, and a curse. This misunderstanding and lack of knowledge leads to fear for PWE, the disease itself and fear of being contaminated.

No one exactly knows what these people are going through at individual level being stigmatised, denied their human rights and the poorest among the poor. As a result many people with epilepsy have thought of committing suicide to end what they call endless suffering.

Based on ESAU's experiences the assumption is that the majority of the PWE, their family and their community possess lack of knowledge of the causes and the treatment of the disease. Further, we note that valid information to facilitate the public's understanding of epilepsy has not been shared from the central government level to the local levels (the communities) although the Central Government possess in dept knowledge of epilepsy and understanding of the personal and social consequence for children and adults with epilepsy.

However, there are still gaps in our knowledge about epilepsy in Uganda and its impact on the individuals living with epilepsy, households and the community for whom this study is dedicated.

Thus ESAU in conjunction with the Ministry of Health and a team of professionals teamed up to conduct this study but due to financial constraints only three districts were covered.

The Objectives of the Study

The main objective of the study was to collect information about the existing knowledge, perception, attitude, as well as socio economic and health situation for PWE in order to guide future interventions.

Specific objectives;

1. To understand community perceptions of epilepsy, the causes and the treatment.
2. To get a better understanding of the existence and functioning of Health Services for PWE.
3. To document the impact of epilepsy on the lives of PWE, on their household and on their community.
4. To assess the magnitude of the problem of epilepsy in consideration of prevalence.

1.5 Organization of the Report

This Report is organized into five (5) Chapters.

Chapter 1 gives an introduction which includes the background to the Study, a presentation of Epilepsy Support Association, Uganda and her work, state a brief presentation of epilepsy, formulation of the problems the Study wants to focus on, the objectives and finally the organization of this report.

Chapter 2 presents the literature review including definition of epilepsy, the currently established knowledge and understanding of epilepsy, the need of classification and diagnosis of the various types of epilepsy, the causes of the disease and finally some good advices on how to help a person with fits and how a person can prevent fits.

Chapter 3 covers the methodology with focus on the research team, the research process and the research plan, the selected districts' and the respondents' profile and finally a presentation of the research design, data collection tools, data management and the analysis.

Chapter 4 presents the findings related to the general perception of epilepsy, to the government's and traditional health services, to people living with epilepsy their relations and coping strategies and finally in relation to prevalence.

Chapter 5 covers conclusion of the Study, recommendations and lastly lessons learned from conducting this Study

2. LITERATURE REVIEW

2.1 Definition of Epilepsy

- Uganda's Ministry of Health (MOH) defines Epilepsy as a disorder of the brain characterized by outbursts of excessive activity in part or whole of the brain, which occurs suddenly, disappears spontaneously and has a tendency to reoccur (source: *MOH Training Manual, 2000*).

- World Health Organization (WHO) defines epilepsy as, a disease caused by abnormal functioning of the brain, which may lead to loss of consciousness or abnormal behaviour (source: *WHO Report 1997*).

2.2 Modern Knowledge and Understanding of the Disease

Overall information about epilepsy. Source*: WHO Fact Sheets* *on World Health Organization's web-site* http://www.who.int/topics/epilepsy. Please note that quotations from the Fact sheets are used in analysis of the findings.

Facts sheet no 165 Epilepsy: aetiogy, epidemiology and prognosis, February 2001 provides a clear introduction to various types of epilepsy, prevalence, mortality, the causes, treatment and prognosis of epilepsy.

Facts sheet no 166 Epilepsy: social consequences and economic aspects, February 2001 explain the social and economic negative impact of epilepsy which are (with some minor specific cultural differences) the same all over the world.

Facts sheet no 167 Epilepsy: scientific and medical advances, February 2001 updates about the progress within the various research areas related to epilepsy. Also worth noting is that research of this kind not is possible in the developing countries.

Facts sheet no 168 Epilepsy: historical overview, February 2001 gives a brief about the perception and knowledge of epilepsy from 4500BC and up till 2001. Worth noting is that supernatural belief and proper knowledge of epilepsy for that long time have existed parallel.

Facts sheet no 265 Mental and neurological disorders, December 2001 includes a brief overview about epilepsy.

About Causes of Epilepsy. Source: *Epilepsy Torch by ESAU, the Monitor Publications, July 2005.*

- ➢ The most common cause of epilepsy in tropical countries like Uganda is poorly treated malaria. Infections that affect the brain such as meningitis, HIV/AIDS and severe cases of measles also cause epilepsy.
- ➢ Epilepsy can also be caused by head injuries, strokes and brain tumours.
- ➢ Hereditary and problems in brain development before birth.

- Alcohol and substance abuse may also lead to epilepsy. Excessive consumption of alcohol and intoxicating substances can lead to brain damage and result in epilepsy.
- Birth trauma (injury to an infant during labour).

About Treatment of Epilepsy. Source: http://www.epilepsy.dk.

It is a fact that the large majority, over 70%, of people with epilepsy can be satisfactorily helped by medical treatment, so that they never, or hardly ever, have seizures. 10% of the remaining group can be helped by means of surgical treatment.

Most people with epilepsy are no different from the rest of the population; neither as regards intelligence, nor as far as the ability to carry out a job is concerned. It is therefore important for the patients to visit the medical personnel for examination and treatment. The class of epilepsy will influence the treatment as well as duration.

The common practice is that many people take herbs where the medication progress is quite hard to monitor. Even those who take modern medicine on realizing that they no longer have fits; in most cases abandon the drugs which subsequently bring back the fits. Patients are advised to always visit the Doctors for advice before taking any decision related to medication.

By informing the general population that seizures look more dangerous than they in fact are, and that effective treatment makes seizures more and more unlikely to occur, one can hope that conditions will improve for people with epilepsy.

Today, a large number of clinical phenomena are recognized as epileptic seizures, some of which (e.g., myo-clonic and atomic seizures) are currently poorly understood and might, in fact, reflect neuronal mechanisms that are somewhat different from the path physiologic processes traditionally considered to be "epileptic." A variety of conditions or epilepsies have been categorized and defined not only by the types of seizures they manifest but also by other, associated clinical features.

Classification of Epilepsy is useful; it helps in the treatment and counsel of patients and/or enables medical personnel to understand the basis for a patient's epileptic seizures. Similar ictal behaviour changes can result from different substances in relation to treatment, choice is not as clear as we like to believe. The limitations of seizure classification are that it describes common seizure phenomenology only.

Discrimination is a common practice in family, society and schools against people living with epilepsy. When discrimination arises, it seldom comes from a wish to harm, but because of anxiety and ignorance. It can be difficult for a person with epilepsy to understand why others react so strongly to his seizures. It may be a good idea for the person to see a video recording of seizures. Then they might find it easier to understand the reactions of others.

2.3 Women (with – or without Epilepsy) in Uganda

During the search of relevant literature it has not been possible to get literature that in particular addresses women with epilepsy in Uganda. Though it is difficult to generalize as Uganda is a multi cross cultural country with many tribes and many ways of living including differences in lifestyle between the big cities and the villages there are some trends that might be noted especially in relation to women with epilepsy.

In general the Ugandan culture is patriarchal in terms of; the man own his wife as he has paid for her (bride price), the woman has to obey the man and if she do not it is justified that he beats her, the man owns the property while children and women cannot own land and women are even not supposed to inherit property. A man can marry additional wives and can divorce the wife by sending her back to her father's home. During the last years the Ugandan Parliament have adopted legislation in favour of women's rights however, only in very few cases is it possible for women to get what are their new legal rights. Even in well to do and highly educated families it can be impossible as a reason case in Kampala illustrates; a husband would not share the property when the couple wanted to divorce and in order to avoid this he hired a person to kill his wife. The husband is in prison awaiting the police investigations but a key witness has just been killed.

In order to get some secondary data the following literatures have been chosen. It does not particular address women with epilepsy but it is possible to draw the conclusion that women with epilepsy suffers even more than her "sisters without epilepsy" – and even that to some extent violence against women and children might be the cause for epilepsy.

The issue about battled women is addressed by **Lillian Tibatemwa-Ekirikubinza** (1999) who documents the cultural aspect in domestic violence against women, even pregnant women soon due to deliver.

The issue about rape of disabled women as a general event is addressed in **the Women's Movement in Uganda** – History, Challenges and Prospects (2002)

The issues about women's legal rights are addressed by **Jennifer Okumu Wengi** (1997).

2.4 Good Advises

Uganda Ministry of Health (source: *MOH Training Manual 2000*) recommends people who witness a fit the following:

Keep calm

a. Protect the patient from hurting himself by removing him from the danger for example fire, water, sharp instruments or any of the dangerous environments.
b. Protect the fitting persons head with something soft or your hands.
c. Loosen tight clothing.
d. Position the person/patient in a semi prone position in the breathing and recovery.
e. Stay with the person until he/she has fully recovered.
f. After recovery, re-orientate the patient and if he/she wishes, allow him/her to continue what she/he was doing.
g. Re-assure the patient because he/she may feel embarrassed.
h. In case of injuries wash the wounds with soap and water and cover with clean cloth.
i. Refer the patient to the nearest health centre for medication

http://www.epilepsy.dk/Handbook/Course-of-epilepsy-uk.asp **recommends the following in relation to:**

Toilet and bath: It is not unusual for seizures to occur when one is on the toilet. This is particularly common in people with awakening epilepsy. The toilet or bathroom door should therefore always open outward. Otherwise it may be impossible to get in if a person is lying on the floor, blocking the door. Instead of a lock, an "engaged" sign can be hung on the door. People who have many seizures should take precautions when taking a bath. A shower is safer than a bath in a bathtub. If a bathtub is used, it should not be too full and there should be someone close at hand to help should a seizure occur.

Swimming: When swimming, in an indoor pool or out of doors, there should always be someone present who knows that the person may have seizures, and who can help him/her out of the water if need be. The same applies when fishing. Otherwise PWE should be discouraged from swimming and fishing.

Cycling: Persons who have frequent seizures should not cycle, but most others can. It is rare for seizures to occur when one is cycling, as one is active, and concentrating.

Work: Heavy work should be avoided such as brick laying welding, building, driving, riding, climbing of trees, fetching water alone, cooking alone etc.

The person with epilepsy should tell those at his/her work place that he/she has epilepsy, if there is a risk of seizures occurring at work. If seizures occur only during sleep, it is seldom necessary to tell of it.

Flickering lights: Television sets**,** Video halls, welding lights, water waves etc might cause a fit.

Drinking: Patients with epilepsy should be advised to refrain from drinking.

School: Children with epilepsy can attend school like any other child

The Epilepsy Support Association, Uganda (source: *Epilepsy Torch by ESAU, the Monitor Publication, July 2005*) recommends PWE to keep the following lifestyle recommendations:

Do's	Don'ts
+ Do take your medication everyday at the prescribed time. + Do follow a balanced diet. + Do exercise regularly but avoid exertion. + Do keep accurate records of seizures and their frequency. + Do ask your doctor about drugs for other conditions before you take them. They may not mix too well with anti-epileptic medication. + Do tell someone when you go to swim. Swim with a friend. + Do tell your child's teacher what to do in case the child gets a seizure. + Do talk to your doctor about contra-ceptive pills. + Do tell your doctor about any side effects. + Do get a good night's sleep, every night. + Do get enough medication so that you do not run short. + Do keep your appointments with your doctor.	÷ Don't stop your medication unless your doctor tells you to. ÷ Don't take excessive caffeine (coke-tea-coffee). ÷ Don't lock the bathroom/ toilet door. ÷ Don't smoke, drink Alcohol or take intoxicating substances. ÷ Don't share your medication with others. ÷ Don't drive or operate motorized equipment unless you have been seizure free for two years. ÷ Don't climb trees or work on top of buildings. ÷ Don't cook alone especially where the cooking stands are not properly raised. ÷ Don't watch a flickering television or iridescent situations. ÷ Don't go to fetch water from the well alone. ÷ Avoid fasting if possible.

3. METHODOLOGY

This chapter explain the research processes and procedures followed during the study from planning up to dissemination of research findings. Personnel, Respondents and Professionals involved as well as the tools used in data collection and analysis are all presented.

3.1 Presentation of the Research Team

The Project Officer, ESAU was appointed by ESAU's Management to lead and to carry out this Study. Other staff members were involved at different levels especially during data collection.

A group of Professional Partners were consulted during the research process. The professionals included among others Doctors from MOH and District Health Units for their expertise in terms of medical knowledge in addition to the formers research skills.

Further Research Assistants and Data Clerks were contracted. Research assistants were involved in data collection while Data clerks were contracted to coding and inputting data into the computer.

Finally, a Research Consultant was contracted to provide professional assistance in the methodology and the data analysis.

3.2 Presentation of the Research Process

Steps and Activities	Outputs
1. Planning level Consultations were made with the Group of Professionals and the Research Consultant. Desk studies carried out.	• Roles clearly spelt out. • Professional Partners agreed to participate in the research. • A tentative research plan available.
2. Selection of study areas and respondents Consultations were made with the proposed districts and the MOH. Revised the tentative research plan.	• Three Districts identified (refer to 3.3). • Respondents identified (refer to 3.4). • A revised research plan available (refer to 3.5).
3. Development of research tools Consultations with Professional Partners. Desk studies carried out. Drafting structured questionnaires and the guiding questionnaire	• Agreed research design (refer to 3.6) • Two structured questionnaires available. • A key informant and focus group guiding questionnaire available.

Steps and Activities	Outputs
4. Testing of the questionnaires Three research assistants selected, trained and sent to the field in the out skirts of Kampala to test questionnaires.	• Tested questionnaires available. • Revised and fine-tuned available.
5. Selection and training of research assistants. Consultation with the DRO. Selecting and training 8 research assistants from each of the study districts.	• Agreement with the DRO on which people to select as research assistants. • 24 trained research assistants.
6. Data collection 397 respondents interviewed. 48 focus group (330 people) discussions held. 74 key informants interviewed.	• Raw data was collected from respective districts as planned.
7. Data coding and entry Data coded using computer software, EPI INFO. Data entered into the computer manually for data analysis.	• Data coded. • Data entered.
8. Data analysis Consultations with MOH and the Research Consultant. Data analysed using a computer soft ware SSPS and Microsoft excel. Tables and graphs generated, percentages obtained and interpreted to give meaning to data collected.	• Agreed analysed data available (refer to 3.7). • Analysed data available
9. Drafting Report Consultations with the Professional Partners. Analysed data compiled into a draft report.	• A draft report with professional inputs available
10. Presentation of the draft report Consultations with the CAOs in each of the study districts. Drafted report presented to the study districts, discussed and recommendations provided.	• Plan for presentation of the draft report agreed on. • Views and recommendations available.
11. Finalising Report Integrating views and recommendations. Consultations with the Professional Partners. Proofreading and corrections made.	• Final report available
12. Research dissemination Drafting plan for research dissemination. Identify the recipients Disseminate to the identified recipients.	Final copies disseminated to various stakeholders

3.3 Districts Profile

The study covered the three districts of Masindi in Western Uganda, Kabale in South Western and Tororo in Eastern. Districts were selected based on

- Regional distribution,
- Interventions by ESAU and other Disabled Peoples' Organisations (DPOs)
- Districts where ESAU has operated over a different period of time (Kabale since 1998, Masindi since 2001, and Tororo since 2002).
- Districts perceived by MOH to be having a high number of cases with epilepsy.

Masindi District with a population of 459,490, borders Apac in the East, Gulu in the North, Luwero and Hoima in the south and Lake Albert in the West. The major economic activities in this area include fishing, agriculture and forestry.

Kabale District with a population of 458,318 people, borders Kisoro in the West Rukungiri in the North, Bushenyi in the North East and Rwanda in the South, The area has volcanic soils and people in this area are greatly involved in agriculture with less mining of Tin.

Tororo District with a population of 536,888 people, borders Pallisa in the North, Mbale in the North East, Iganga in the West and Kenya in the East. The source of livelihood of people of Tororo is agriculture and trade.

From each of the study districts, random sampling was used at every stage to select Sub-counties, Parishes and Villages. In each of the districts, three Sub- counties were randomly selected, and three Parishes selected from each of the selected Sub-counties with the exception of Iyolwa Sub-County that has only two parishes.

3.4 Presentation of the Respondents

Three groups of Respondents were selected, namely

(1) Household Respondents from whom the quantitative data were collected. And (2) Key Informants and (3) Focus Groups from whom the qualitative data were collected. Table 1 shows how the groups of respondents are selected in relation to the study Districts.

Table 1: Number of Respondents' by the selected three Districts

Sample Districts	No of Household Respondents		No of Key Informants		No of Focus Groups / People	
	Frequency	%	Frequency	%	Frequency	%
Masindi	129	32.5	25	34	15 / 150	35
Kabale	114	28.7	31	42	15 / 135	31
Tororo	154	38.8	18	24	18 / 144	34
Total	397	100.0	74	100	48 / 429	100

Of the 397 Household Respondents interviewed most respondents from Tororo, namely 39% filled out the questionnaire, in Masindi 33% of the respondents filled out the questionnaire, while Kabale had the least proportion of about twenty (29%) percent.

In total **74 Key Informants** were interviewed from all the three districts to provide qualitative data.

Lastly, **48 Focus Group** Interviews were carried out to cater for qualitative data. On average each group had 10 respondents thus in total 429 people were participating in the Focus Group discussions. They were chosen among Students, Health Professional, Teachers, PWE and People with other disabilities. The reason for grouping people with similar characteristics was to allow respondents to freely express their views.

Finally, the sample distribution is in the same range and therefore comparison by district can be done without fear of over sampling in a particular district.

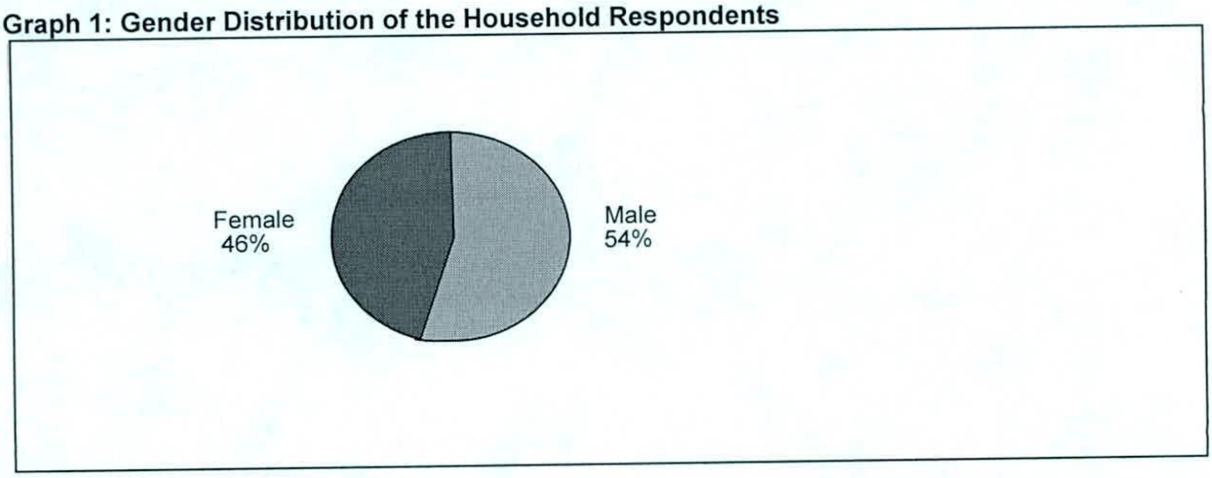
The Household Respondents' Profile

In the following the 397 Household Respondents are presented in relation to sex, age, religion, education, material status, size, headship, education, income, occupation and ownership.

Gender of the Respondents

Overall gender distribution of respondents was 54% males and 46% females. However, there was no significant difference in gender distribution by district from the overall picture.

Graph 1: Gender Distribution of the Household Respondents



Source: ***Field data April 2005***

Age of Household Respondents

The average age of respondent overall was 40 years, with Tororo having an average of 38 years while Masindi and Kabale having an average of 41 years. According to UBOS 2002 the median age of the Ugandan population is 15.6 years while 56.1 % of the population is less than 18 years.

Religion of Household Respondents

The majority (41%) of the people interviewed revealed that they belong to the African traditional religion; an almost equal proportion (40%) reported belonging to the protestant church while 11% were Christians of the Catholic Church. Others belonged to Muslim, Pentecostal or other religious denominations. There is however no established link/relationship between religion and epilepsy, and therefore irrespective of ones religion, everybody is vulnerable to getting epilepsy.

Table 2: The Household Respondents' Religion

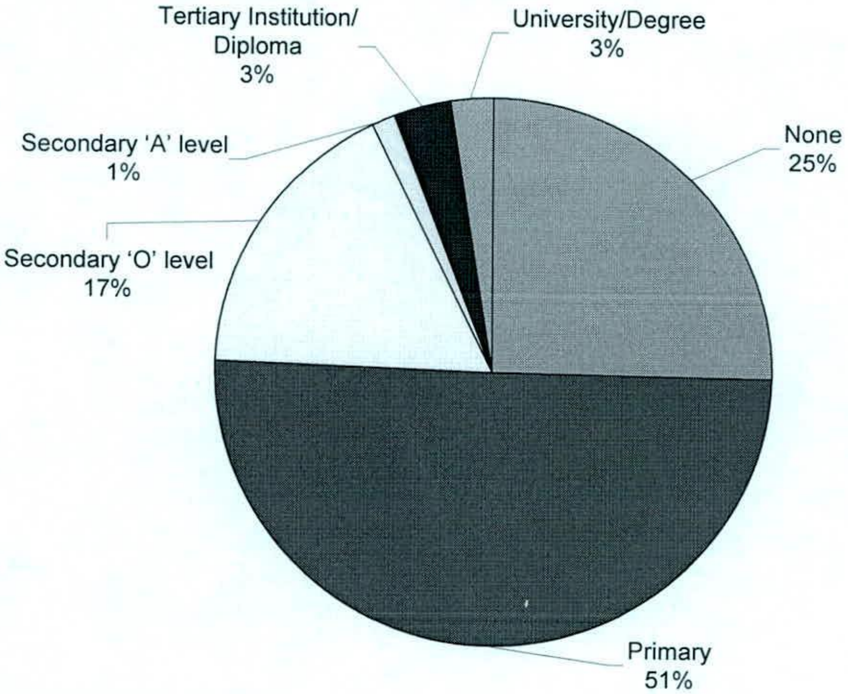
	Frequency	%
Protestant/Church of Uganda	152	38
Catholic	43	10.8
Muslim	5	1.2
Pentecostal	6	1.5
African Traditional Religion	157	39.5
Other religion	18	4.5
Others	9	2
Total	397	100.0

Households Respondents Education

Education levels of respondents in all the districts visited are generally low, with 25% having never gone to school while 50% only have primary level education and close to one fifth (17%) having been to a secondary school but stopped in O-level. The distribution by district follows a similar pattern although with slightly different proportions with the exception of Masindi district, which had about one-third (31%) uneducated. Any interventions towards addressing the issue of epilepsy should seriously consider the low education levels in the communities as a hindrance to successful implementation of any program unless it's given the consideration it deserves. No wonder a sizeable number of respondents think epilepsy is infectious and so have created all sorts of beliefs such as gassing of PWE can cause epilepsy to those around him/her.

The assumption is that the level of education of caregivers may have a relationship with approach to medication and management of epilepsy and PWE.

Graph 2: Education level of Households Respondents



Source: ***Field data April 2005***

Education level of primary caregiver for children is not different from that of the respondents, simply because in most cases respondents were the caregivers for children. About one third (29%) have no education at all, while almost half (45%) had been to a class in secondary school (O-level). The proportion of caregivers who had post secondary school (O-level) combined is very low at 6%.

Table 3: Education of the Household's Primary Caregiver for Family Members

	Frequency	%
None	115	28.9
Primary	46	11.5
Secondary 'O' level	177	44.5
Secondary 'A' level	8	2
Tertiary Institution/ Diploma	4	1
University/Degree	10	2.5
No response	37	9
Total	397	100.0

Household Respondents and Marital Status

About eighty (79%) of respondents were married, 8% were unmarried and 0,5% were widowed while 4% were divorced/separated. Distribution by district is not any different from the general picture except in Kabale where the proportion of widowhood is high (17%) compared to the rest of the districts, which is at about 6%.

Table 4: Marital Status of the Household Respondents

	Frequency	%
Married / cohabitant	307	78.9
Un married / single	31	8.0
Widow / widower	37	9.5
Divorced / separated	14	3.6
No answer	8	2
Total	397	100.0

Household size and Children ever produced

Average household size is 6 people (mean 6.4), although Tororo has a higher size of 7 people. Results show that on average they are five children (mean = 5.60) who have been produced per household in all the districts visited, with no significant differences by district.

Household Headship

Generally, in all the districts households are headed by adults (over 90%), but Kabale district shows a relatively high proportion (8%) of child headed households compared to the other two districts.

The assumption is that a family headed by a child is more vulnerable to health problems including epilepsy as compared to those families headed by adults. Therefore PWE in a family headed by a child is presumed to be in a poorer health state than their counterparts.

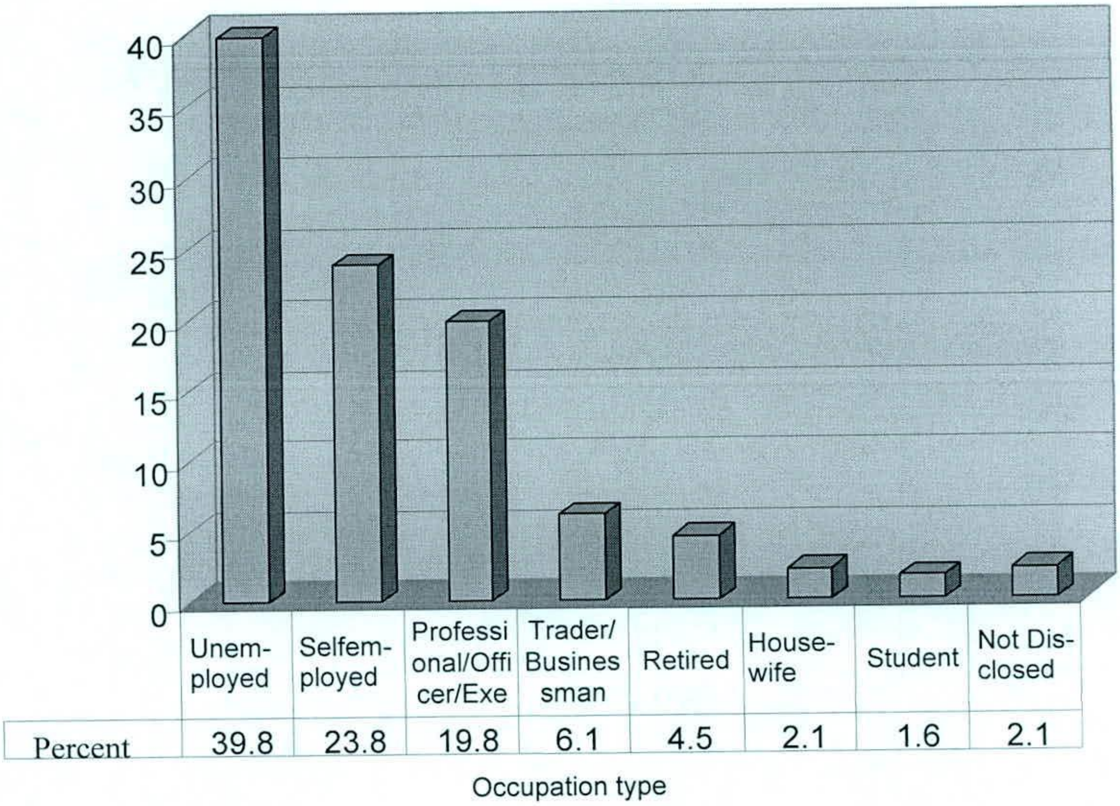
Table 5: Household Headship

	Masindi		Kabale		Tororo	
	Frequency	%	Frequency	%	Frequency	%
Adult headed	127	98.4	97	91.5	150	98.0
Child headed	2	1.6	9	8.5	3	2.0
Total	129	100.0	106	100	153	100

Household Respondents Occupation

Of interest and concern is the high proportion of Peasant farmers in all the districts. Overall 40% were Farmers at the time of the study; the proportion is higher in Masindi district (46%) and lower in Tororo (33%) district. About one quarter (24%) was self-employed, while one fifth are in office related activities (Professional/Officer/Executive) as their type of occupation. Note that Kabale district has a lower proportion of respondents who are self employed. Analysis of occupation by district shows a similar pattern as the overall, the difference being in the proportions by occupation type. The high proportion of peasant farmers is likely to negatively affect people and the communities they belong to because of the likely failure to give support (especially financial) to people with epilepsy in their communities. Addressing this problem would go along way towards having a sustainable solution to the epilepsy disease.

Graph 3. The Household Respondents' Occupation



Source: Field data April 2005

Source of Household Respondents Income

Main source of the Household Respondents' income in the districts visited is crop farming as reported by 76% followed by business/trading (10%). Others depend on fishing, salary and other sources where there is daily income such as Boda boda and tailoring.

Table 6: Main source of income for household

	Frequency	%
Crop farming	276	69.5
Trading/business	38	9.5
Fishing	15	3.7
Animal farming	14	3.5
Salary earner	10	2.5
Pit sawing	1	0.02
Carpentry	4	1
Boda boda (transport)	4	1
Tailor	1	0.02
Others	34	8.5
Total	397	100.0

Household Respondents' Income

Over 80% earn between 0 and 150,000/=, 10% earn 150,000 to 300,000/= while the remaining proportion have a monthly average household income of more than 300,000/=. Note that there is no significant difference in income levels by district. The income distribution is explained by the nature of main source of household income (as seen above). The high proportion of households earning less than 150,000/= coupled with the relatively high household size is likely to significantly affect the household's capacity to cater for any cases of epilepsy which may require monthly on drugs for the disease (which is expensive especially for those who may not have easy access to the free drugs at the defined health service points) in case there is a person affected in the household.

Table 7: Average Monthly Household Income and Ownership

	Frequency	%
0 - 150,000	314	79
151,000 - 300,000	37	9.3
301,000 - 700,000	8	2
701,000 - 1,200,000	2	0.5
Above	2	0.5
No information	34	8.5
Total	397	100.0

Ninety percent of all the respondents interviewed reported staying in own houses, while the 10% rented. This is because the study was conducted in rural areas where most people put up temporal structures.

Table 8: Ownership of house

	Masindi		Kabale		Tororo	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
Owned	113	87.6	96	84.2	139	90.3
Rented	10	7.8	15	13.2	11	7.1
No response	6	4.7	3	2.6	3	1.9
Total	129	100.0	114	100.0	154	100.0

Radios may be vital in accessing health information while bikes ease the movements to – and from the health Units.

Table 9: Ownership of Communication Assets

Items owned	Frequency	%
Radio	237	65.8
Bicycle	195	54.2
Motorcycle	12	3.3
Other assets	27	7.5

Multiple responses

3.5 Revised Research Plan

During the research study, the local leaders expressed interest in having a feedback of the study findings. Various studies were sited where researchers have not provided the district with feedback to enable design appropriate interventions.

Presentation and discussion of the research findings to the district leaders also was seen as an opportunity of raising awareness and sensitizing the district policy makers towards better understanding and management of epilepsy as a public health concern.

3.6 Research Design and Data Collection tools

The study adopted both quantitative and qualitative approach (case study design) where the objective was to capture detailed community and district based information on epilepsy in the sampled districts within a short period of time. In the districts, information was obtained from PWEs themselves and other stakeholders (e.g. community and opinion leaders and professionals offering services to or working with PWEs' organisations).

3.6.1 Randomly Selected Households' Personal Interviews

A semi-structured questionnaire was used to facilitate coverage in all the areas to be researched. The questionnaire comprised of a set of pre-determined and logically related questions. The aim was to obtain information from health institutions and PWEs coping mechanism. The method also helped in analysing people's attitude towards epilepsy. The local languages in the districts visited were the major languages of communication between the respondents and the interviewer, so that all the information could be obtained from the respondent with ease. The types of questions in the questionnaire were both open and close questions, to solicit wider responses. Some of the areas covered include existing knowledge, attitudes, practices, and coping mechanisms adopted by individuals, households and communities.

3.6.2 Key informant Interviews

Key informant interviews were conducted among selected officials at different levels including local council and community leaders, District Rehabilitation Officers and Community Development Officers, Sub-counties' and Districts' Officials and politicians, including selected PWDs representatives in the councils and policy makers. The aim of the tool was to undertake in-depth interviews with informed stakeholders on issues linked to health and epilepsy in general, and among persons living with epilepsy in particular in the study areas. The Interviews were to aid the interviewer get a clear explanation and understanding of the existing knowledge, attitudes, practices, and coping mechanisms. An interview guide was used to collect the required information, and hand written notes taken by the researcher during the interview were later to be transcribed.

3.6.3 Focus Group discussions

This tool targets groups with cross perception of issues related to epilepsy and other disabilities as a measure of obtaining collective views mainly on recommendations with regard to future policy changes towards pro-Epilepsy health reforms. The focus group discussions had an average of 10 persons each, and wherever possible, groups were organised according to gender, disability and age parameters, and specific ones for persons living with epilepsy,

3.7 Data management and analysis

The data entry clerks were identified and oriented in coding and entry of the quantitative data from questionnaires. A comprehensive data entry programme for the household questionnaire was created by the consultant to minimise data entry errors. After the orientation, the clerks coded and captured all the information from the questionnaires into the computer using the EPHNFO software, cleaned and later exported to SPSS for analysis. Statistical methods were used in the analysis of data, the frequencies and cross tabulations were run. Interpretation of the findings was made as a measure of importance and emphasis.

Thematic analysis was used in the analysis of qualitative data. Major themes and sub-themes were identified and key quotations, explanations and insights highlighted. The findings were narrated and interpreted using direct quotations to qualify the findings (Refer to the study findings).

4. STUDY FINDINGS: Knowledge, Attitude and Practices

This chapter presents the study findings clustered into the following 4 themes:

(1) The General Community Perception of Epilepsy
(2) Government / NGO and Alternative Health Services
(3) People Living with Epilepsy, their Relations and Coping Strategies
(4) Perceived Prevalence of Epilepsy in the Study Districts

The themes are in consistence with the hypothesis and the objectives of the study. The data is linked to the themes and analyzed, interpreted and related to both quantitative findings (from Households' interviews) to qualitative findings (from Key Informants and Focus Group interview) and to reviewed literature.

4.1 General Community Perception of Epilepsy

In order to address the above-mentioned theme this sub-chapter presents the findings in relation to;
(1) Peoples' Awareness of the Existence of Epilepsy
(2) People's Description of Epilepsy
(3) Peoples' Perception of the Causes of Epilepsy
- and lastly Key Points are noted

4.1.1 Peoples' Awareness of the Existence of Epilepsy

Have you ever heard about epilepsy?

The quantitative data shows that over 90% of the Households' Respondents in all the three Districts have heard of epilepsy. This is supported by the qualitative data collected from Key Informants interview and FGD.

Table 10: Households' Awareness of the Existence of Epilepsy

	Masindi		Kabale		Tororo	
	Frequency	%	Frequency	%	Frequency	%
Yes	121	93.8	107	93.9	141	91.6
No	3	2.3	2	1.8	6	3.9
No response	5	3.9	5	4.4	7	4.5
Total	129	100.0	114	100.0	154	100.0

From where have your heard about epilepsy?

On average 55% have heard of epilepsy through schools, followed by those who have seen some PWE and / or heard of epilepsy through radio (in total about 30%).

Table 11: Source of information about the disease

	Masindi		Kabale		Tororo	
	Frequency	%	Frequency	%	Frequency	%
Radio	17	13.7	13	11.7	25	17.5
TV	5	4.0	6	5.4	18	12.6
Seminar/workshop	5	4.0	5	4.5	5	3.5
School	82	66.1	65	58.6	62	43.4
By seeing	15	12.1	17	15.3	26	18.2
Word of mouth	-	-	2	1.8	5	3.5
I have it	-	-	3	2.7	2	1.4
Total	124	100.0	111	100.0	143	100.0

School seems to be the main source of information about epilepsy followed by seeing PWE and listening to radio programs. A Sub-county chief in Kabale commented that;

> *"Parents respect their children and whatever they are told at school they tell their families, recently they were told that smoking causes cancer"... "My son told me to stop smoking because I was going to get cancer"... "Now I cannot smoke before him".*

The question if there is a need to ascertain the validity of the information the community receives about epilepsy and PWE. How the community perceives and understands will be dealt with in the next Sub-chapter.

4.1.2 Peoples' Description of Epilepsy

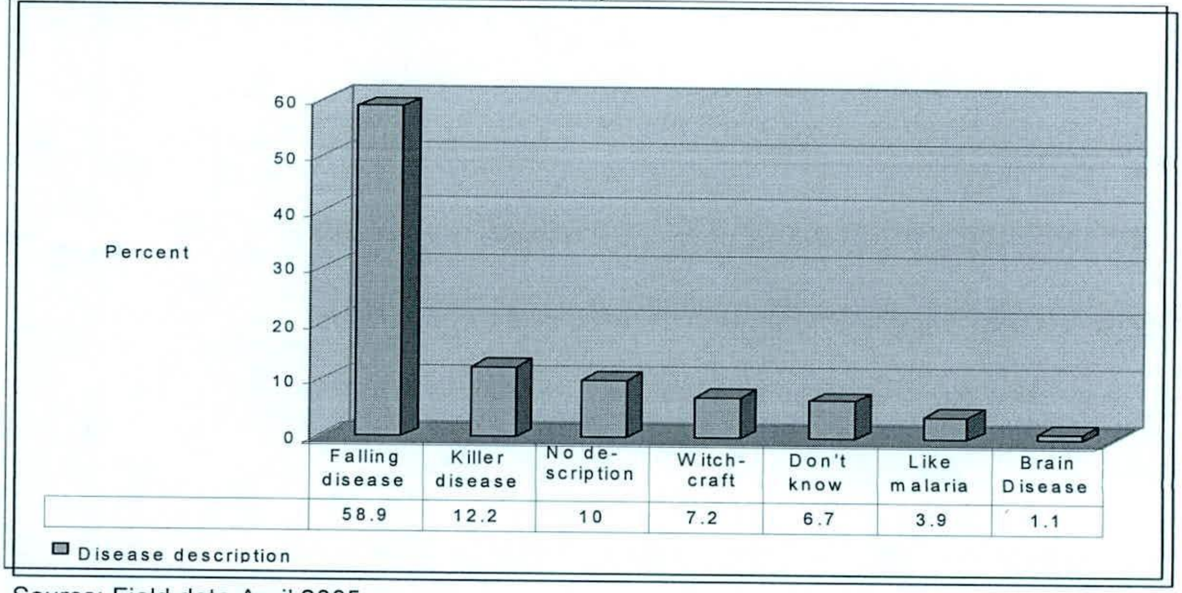
"Epilepsy is the most common of brain disorder. It is characterized by repeated seizures, or "fits", which range from the shortest lapse in attention to severe, frequent convulsions. They can occur several times a day to once every few months. The seizures are caused by burst of excessive electrical activity in the brain." (Source: *WHO Fact sheet No 265*).

Almost 60% of the respondents described the disease as follows;

> *"It is a falling disease that makes somebody first make noise then fall down without prior notice and thereafter the person starts urinating".*

It is worth noting, that only 1.1% of the respondents was aware that epilepsy is a brain disease.

Graph 4: Respondents' Description of Epilepsy.



Source: Field data April 2005

Qualitative results are in agreement with quantitative findings where most of the respondents describe the disease by using its symptoms; calling it a falling disease, characterized by body jerking, loss of conscientiousness, passing flatus and getting froth in the mouth.

4.1.3 Peoples' Perception of the Causes of Epilepsy

"Causes:

- Genetic predisposition;
- Brain damage caused by infections, parasites, alcohol or other toxic substance, and tumors;
- Tapeworm, schistosomiasis, malaria and encephalitis are some of the common infectious causes of epilepsy.

However, in one half of cases, the causes remain unknown." (Source: *WHO Fact sheet No 265).*

Across all the districts studied, the majority of people (46%) perceive malnutrition as a cause of epilepsy. Onchoseasis (River blindness) is the second ranked cause of epilepsy in Kabale, while in Masindi and Tororo; malaria was ranked second cause of the disease.

Table 12: What do you think are the causes of epilepsy in your home/community?

	Masindi		Kabale		Tororo	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
Witchcraft	5	4.1	3	2.7	23	14.2
Evil Spirits	-	-	-	-	1	0.6
Malaria	24	19.8	12	10.9	45	27.8
Jumping over the urine of a PWE	12	9.9	8	7.3	2	1.2
Inheritance	4	3.3	10	9.1	7	4.3
Orchoseasis (River blindness)	14	11.6	13	11.8	17	10.5
Malnutrition	62	51.2	56	50.9	60	37.0
Environment	3	2.7	-	-	-	-
Curse from God	3	2.7	-	-	1	0.6
Nature	2	1.8	-	-	1	0.6
Just attacks	-	-	-	-	2	1.2
Birth related causes	-	-	-	-	1	0.6
Drug abuse	-	-	-	-	2	1.2
Total	121	100	110	100	162	100

Whereas quantitative findings show that people perceive malnutrition as the main cause of epilepsy, qualitative data reveals that malaria, accidents, onchoseasis, brain damage, and inheritance were the common perceived causes of the disease.

In general 44% of respondents showed an accurate understanding of the causes of epilepsy that is to say; malaria, inheritance, Orchoseasis, drug abuse and birth related causes most of which are also identified by the WHO.

The WHO acknowledges that in many cases the causes of epilepsy are not known therefore it might not be appropriate to comment on some of the other causes listed above as to whether they actually lead to epilepsy or not e.g. malnutrition.

Due to traditional beliefs some people believe that even when you jump over urine of a PWE during a fit you will get the disease. This also could explain the reason why many people ran away when a person gets an attack.

During the interview with one opinion leader, he mentioned that people with Syphilis and AIDS were more at risk of getting epilepsy because of the likely damage those disease causes to the brain and especially that epilepsy is a disease associated with brain damage. Also people at more risk include reckless drivers, drunkards, New born babies through prolonged labor, motorcyclists, because of the risk they are exposed to especially when they get accidents (which again is closely associated with epilepsy) *(source: Opinion leader Masindi Municipality)*

Respondents' perception of transmission of epilepsy

Most of the respondents (38%) believe that blood relatives are at a more risk of contracting epilepsy than any other person. This is followed by those who believe that by getting into contact with any PWE one can contract epilepsy.

Table 13: People at more risk of getting epilepsy

	Frequency	%
Blood relatives	138	38.3
Spouse	39	10.8
All people who get into contact with him/her	86	23.9
Don't know	98	27.2

Multiple choices

Of the 147 people that said epilepsy can be transmitted, 88% said it could be transmitted during fitting of the affected person, 23% said through contact with other people, and of significance 16% indicated sexual intercourse as the mode of transmission of the disease.

Table 14: When do you think a person with epilepsy transmit it to others?

Mode of transmission of epilepsy (N=147)	Frequency	%
During a fit	130	88.4
Casual contact with other even when not fitting	34	23.1
During sexual intercourse	24	16.3
Don't know	45	30.6
No response	8	5.4

Multiple choices

This indicates that people in the communities in general are not aware of the causes of epilepsy and that's probably why PWE are isolated.

Respondents' perception on how epilepsy can be transmitted

Close to half (47% with N=397) of respondents believe that epilepsy can be transmitted through particular body products through saliva (69%), urine (60%) and flatus (36%).

Table 15: Which particular body products of a person with Epilepsy are infectious / contaminate?

	Frequency	%
Saliva	128	68.8
Faces	57	30.6
Urine	111	59.7
Gas	66	35.5
Blood	2	1.1
Don't know	2	1.1

Multiple choices

Risk of getting exposed to Epilepsy

Although, epilepsy is almost widely known in the communities, it's very uncommon and so we would expect a very low proportion that thinks about their potential risk of getting epilepsy. Findings however show that 37% (N=397) have already thought about their potential risk, although a similar proportion has not. This proportion is good enough to form a basis for vigorous and regular sensitization programs. The organization should utilize the chance of existing knowledge to increase it even further about the dangers and potential risks of the disease. Such program activities should target service providers such as government, NGOs and the professionals.

Level of risk exposure to Epilepsy

Analysis by district shows no significant difference in terms of risk exposure and pattern of risk distribution. Analysis of qualitative data shows that few people (less than 20%) think are at risk of getting the disease, but think that women are more at risk than any other people. Although in the *prognosis of epilepsy 2003,* in Africa males were reported having more cases of persons living with epilepsy as compared to their female counterparts. Approximately 30% of the respondents gave no response to the question of having a risk of getting epilepsy; this may imply that they are not sure of the causes of the disease.

Table16: Level of risk exposure to be contaminated

Level of risk exposure	Frequency	%
High	85	21.4
Medium	61	15.4
Low	72	18.1
No risk	62	15.6
No response	117	29.5
Total	397	100.0

KEY POINTS

- About 94% of the respondents have heard about epilepsy
- 44% of the respondents have the accurate understanding of the causes of epilepsy
- The sources of information are mainly schools, own experiences and radio programs
- Only 1.1% describes epilepsy as a brain disease
- A high number of the respondents believe that epilepsy is contagious

4.2 Government / NGO and Alternative Health Services

In order to address the above-mentioned this Sub-chapter presents the findings in relation to;

(1) Peoples' Perception of Treatment and the Source for Treatment of Epilepsy
(2) Traditional and Modern Treatment for Epilepsy
(3) Improvement in Health of People Living with Epilepsy
(4) Existence and Functioning of Government and NGO Health Services
- and lastly Key Points are noted.

4.2.1 Peoples' Perception of Treatment and the Source of Treatment of Epilepsy

"Epilepsy therapy aims to prevent seizures and to reintegrate sufferers into community life. Up to 70% of people newly diagnosed with epilepsy can be seizure-free if treated with antiepileptic drugs. Although in most countries the cost of treatment can be as low as US$5".. (appx. equal to UGX10,000/=).."per patient per year, the vast majority of sufferers remain untreated. In Africa, 80% of sufferers receive no treatment." (Source: *WHO Fact sheet No 265*).

The findings shows that almost 70% believe that epilepsy can be treated and almost 60% think that it can be cured. In spite of this it is not clear where one would go for treatment.

Table 17: Perception of the possibility of treatment / cure of Epilepsy

	Yes	No	No Response
Can Epilepsy be treated?	67.3	21.7	11.1
Can Epilepsy be cured?	56.4	32.7	10.8

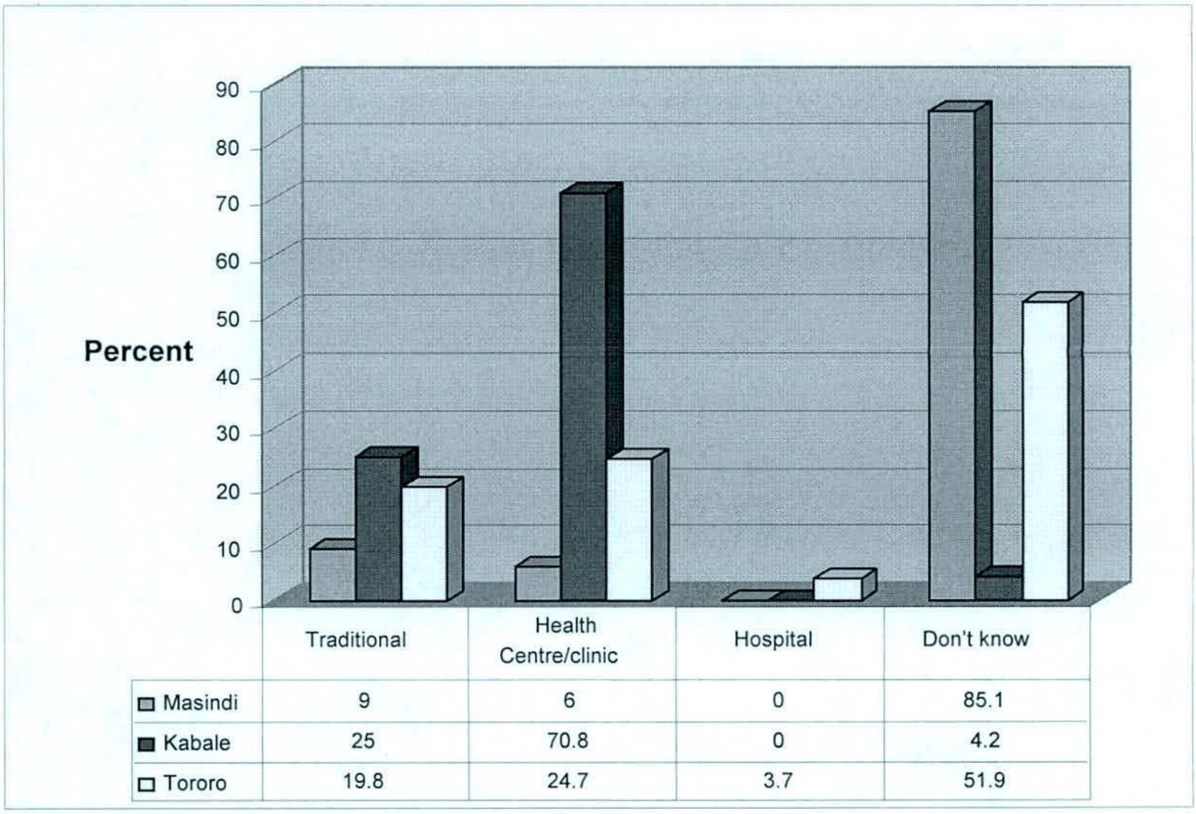
Table 18: Ever gone for treatment?

	Masindi		Kabale		Tororo	
	Frequency	%	Frequency	%	Frequency	%
Yes	67	67.0	48	73.8	81	82.7
No	16	16.0	13	20.0	13	13.3
No response	17	17.0	4	6.2	4	4.1
Total	100	100.0	65	100.0	98	100.0

Although respondents roughly described the disease and its causes, the majority of those who had at least a person in their households or knew of families with PWE or PWEs themselves, reported that three out of every four people who had the disease had sought some kind of treatment. Over all 7% gave no response, probably these are people who seek treatment from the traditional healers and would not wish to regard it as a form of treatment or have not had any medication but did not want to disclose.

Whereas the majority (47%) of respondents did not know where affected persons had gone for treatment of the disease, 34% had visited health centers/clinic for treatment while 18% had gone to traditional doctors for treatment.

Graph 5: Source of Treatment by Districts



Source: Field data April 2005

4.2.2 Traditional and Modern Treatment for Epilepsy

"Misunderstandings about epilepsy combined with the economic and financial barriers to treatment in developing countries play an important role in preventing treatment becoming available to millions of people in developing countries. For example, culturally informed health-seeking strategies often lead the majority of people with epilepsy in developing countries to turn to traditional treatment." (Source: *WHO Fact sheet 166*).

The Government of Uganda has 67 hospitals across the country. Ideally these hospitals are supposed to be offering health services for PWEs but due to lack of anti epileptic drugs and sufficient trained personnel this is not the practice as discussed in the findings below.

Experiences with the sources of treatment

Table 19: Preferred source of treatment

	Masindi		Kabale		Tororo	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
Government health units/hospitals	99	76.7	75	65.8	114	74.0
Traditional doctors	15	11.6	17	14.9	16	10.4
Religious institutions	5	3.9	5	4.4	3	1.9
No where	2	1.6	1	.9	5	3.2
No response	8	6.2	16	14.0	16	10.4
Total	129	100.0	114	100.0	154	100.0

Government Health Units and / or hospitals are seen as the preferred source of treatment for epilepsy. This was reported by 72%, although with slight difference by district. Of significance and concern is the proportion (12%) that would use alternative medicine as their source for treatment for epilepsy. Again this high proportion is a good basis for any out reach programs intended to sensitize the people.

Qualitative data shows that health services for PWE were available although inadequate, and in addition to being far from the patients, needed improvement mainly in the provision of drugs and counseling services. Qualitative findings further show that there were some PWE who were not visiting the Health Centers for treatment, the proportion being put at about 50% although without any justification since these were just people's perception. This points to the existing gap regarding knowledge about the existence of health services for persons living with the disease. Any intervention in this area would be highly appreciated by the communities in general because they are also affected when it comes to provision of support to households and individuals affected but more importantly would be appreciated by people living with epilepsy themselves, because this would create hope among the affected that they can still live a life as others because medication is available.

The adequacy of how and where to get the treatment and the costs involved are not subjects for discussion and analysis at this point, but would probably be areas for further research after this exercise such that intervention programs can be holistic. What should also be of concern is that the 10% of respondents who gave no response may believe there is no treatment for the disease.

Type of medicine/drugs obtained

Different types of medicine/drugs/herbs were given to those who sought medical care depending on the source of their treatment. For example those who visited the traditionalists for treatment were given herbs while those who visited health units were given anti epileptic medication.

Majority indicates that many people have had no anti epileptic drugs at all which may imply that they have possibly not sought modern treatment, or simply because some believe that epilepsy is incurable and so there is no need to go for treatment. The results agree with the secondary data where the majority of the PWE in developing countries do not receive adequate medical treatment and an estimated percent of 80-90% are without any treatment. (Source: *Prognosis of epilepsies 2003.)*

Of interest, qualitative findings indicate that many health workers from the rural Health Units do not know the types of anti epileptic drugs used in treatment of epilepsy.

One thing is to go for modern treatment, another to take the anti epileptic medication as described.

The majority of PWE had spent reasonably long time on medication (53% of household respondents for those who had spent more than two years). This might be due to the interventions by the development partners including ESAU. Analysis by district show significant differences in the proportions for those who had spent less than one year and those of more than one year. For example, in Tororo 60% reported taking drugs for less than one year, while the proportions for Kabale and Masindi for the same period are 39% and 18% respectively. The recent interventions in Tororo by the disability movement might have led to increased awareness and an increased turn up of people for medication. The other way around this might explain why there are few people (37%)

in Tororo who have spent more than two years on medication as compared to Kabale (52%) and Masindi (68%).

Table 20: Duration taking anti epileptic drug

	Masindi		Kabale		Tororo	
	Frequency	%	Frequency	%	Frequency	%
Six months ago	7	11.7	3	6.5	17	23.6
Less than one year ago	4	6.7	15	32.6	26	36.1
More than two years	41	68.3	24	52.2	27	37.5
Don't know	8	13.3	4	8.6	2	2.8
Total	60	100.0	46	100.0	72	100.0

Frequency of taking drugs

Overall, 50% of those who said they were taking drugs were taking the drugs daily. A very significant percent for both Masindi (30%) and Kabale (26%) reported taking drugs only after a fit, the average for all the districts being 22%. The high proportion for Masindi and Kabale for those who take drugs after fits is a sign of lack of understanding on how to manage the anti epileptic drugs. The implication is that the medication does not have the desired effect to control the frequency of fits. This further indicates that even if anti epileptic drugs were available; the inappropriate drug management by PWE would not help them to improve their health. What can be seen is a need for health personnel to sensitize PWE on drug management.

An average of 15% of respondents either did not know the frequency of taking the drugs or never wanted anyone to know how they are taking their drugs.

Table 21: Frequency of taking anti epileptic drugs

	Masindi		Kabale		Tororo	
	Frequency	%	Frequency	%	Frequency	%
Daily	30	50.0	14	30.4	49	68.1
After a fit	18	30.0	12	26.1	6	8.3
When I have the drugs	1	1.7	6	13.0	5	6.9
Don't know	6	10.0	13	28.3	4	5.6
No response	5	8.3	1	2.2	8	11.1
Total	60	100.0	46	100.0	72	100.0

Frequency of fits

The rate at which PWE get fits seems to be high assuming they take the anti epileptic drugs as prescribed. For instance, in Masindi, 28% reported fitting daily compared to Kabale and Tororo districts with 10% each in the same category. Overall 56% gets fits weekly. 10% over all either did not know how often they fit or never wanted anyone to know because of the stigma associated with the disease.

Table 22: Frequency of fits

	Masindi		Kabale		Tororo	
	Frequency	%	Frequency	%	Frequency	%
Daily	19	27.5	5	10.0	7	8.8
Weekly	36	52.2	22	44.0	59	73.8
Monthly	5	7.2	11	22.0	3	3.8
Yearly	2	2.9	3	6.0	-	-
Don't know	7	10.1	9	18.0	11	13.8
Total	69	100.0	50	100.0	80	100.0

According to medical recommendations anti epileptic drugs can control the occurrence of fits in about 70-80% of PWE. The existence of regular fitting therefore could be due to poor management of the drugs as seen in the previous table.

Perceived Competent Personnel to handle PWE

Responses regarding persons capable of treating epilepsy show that it was mainly trained Health Workers and trained Community Volunteers, that were believed to be capable to handle PWE together with their parents as parents are expected to know much regarding treatment of their children.

Table 23: Persons who are perceived capable of treating epilepsy

	Masindi		Kabale		Tororo	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
General Health Workers	49	31	47	31.9	53	33.5
Psychiatric Nurses	39	24.6	34	23.1	42	26.5
Parents/Guardians	53	36.5	55	37.4	49	31
Others	17	10.7	11	7.4	14	8.8
Total	158	100	147	100	158	100

(N=463)

Unfortunately, most districts have no specialized trained officers for example Psychiatric Clinical Officers. This perhaps has put the lives of PWE at risk due to poor medical attention. Uganda is among many countries in Africa that has very few professionals specialized within treatment of epilepsy for example by 2003; there were only three Neurosurgeons in Uganda with no professional means of neuro–diagnosis. (Source: *Prognosis of Epilepsies 2003.)*

4.2.3 Improvement in Health of PWE

Table 24: Improvement in health of PWE

	Masindi		Kabale		Tororo	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
Yes	49	38.0	34	29.8	60	39.0
No	27	20.9	22	19.3	14	9.1
No response	53	41.1	58	50.9	80	51.9
Total	129	100.0	114	100.0	154	100.0

About one-third (36%) feel there has been a general improvement in the state of health of PWE after taking anti epileptic medication.

This low proportion is probably as a result of poor drug use and management (due to the frequency of fits as seen before where 22% take drugs after a fit).

Over all 52% gave no response, there is a likelihood that they may have had no improvement or their lives could probably be deteriorating but also may have never attended to medication. There is positive relationship when compared to the respondents of about the source of treatment, 48% said didn't know where people go for treatment.

4.2.4 Existence and functioning of Government and NGO Health Services

Government hospitals are distributed in almost all the districts of the country. Drugs are supplied through National Medical Stores and the Ministry of Health. This section tries to explore whether people living with epilepsy are aware of their existence and having access to these services.

Existence of anti epileptic drugs for the disease

Irrespective of whether the respondent had epilepsy or not, findings show that over 50% think there are formal drugs for the disease, with differences in proportion by district. This average proportion forms good basis for intervention especially regarding sensitization on acceptance and use of the drugs, because of the existing positive thinking.

Table 25: Existence of anti epileptic drugs

	Masindi		Kabale		Tororo	
	Frequency	%	Frequency	%	Frequency	%
Yes	73	56.6	60	52.6	101	65.6
No	40	31.0	31	27.2	29	18.8
No response	16	12.4	23	20.2	24	15.6
Total	129	100.0	114	100.0	154	100.0

Emphasis should also be put on people who don't think there are formal drugs because for them the situation is even worse because they may never seek medication and probably still believe in traditional methods. A significant proportion of 15% gave no response but most likely believes that there are no formal drugs or are not sure whether the drugs can be of help to patients.

There are also many NGOs involved in procurement and distribution of anti epileptic drugs to PWE in the Districts of Study, especially Tororo and Masindi. This might probably be a reason why many people believe in the existence of anti epileptic drugs for epilepsy.

Anti epileptic drugs commonly used in treatment of PWE

- Carbamazepine
- Phenobarbital
- Phenytoin

Source of the anti epileptic drugs

Government Health Centers have two main sources of drug supply;

(1) The Local Government's (Districts') Medical Service Department.
This department provides drugs for Primary Health Care targeting malaria, measles, and tuberculosis among others. These drugs are provided for in the District's budget and drugs are procured from the NMS.

(2) The Central Government.
This is also called "the credit line". Under this system the Government have identified 70 essential drugs and the Health Units are requested to make a list of the drugs they need to up to a maximum of an allocated amount by the Government. This amount is paid to NMS to supply the drugs listed by the Health Units.
However, inadequate supply characterizes both sources of drug supply for anti epileptic drugs and sometimes only a third of the requested drugs are supplied.

For the individual PWE, sources of drugs include Health Centers, Private Clinics and/or pharmacies/ drug shops.

NGOs either receive drugs from the international donors or procure them through NMS.

> *"Its not adequate, drugs are not enough, many come and go without drugs. In most cases we receive ¼ of the requested drugs from authorities". (KI Medical/Health officer).*

According to Mr. David Bagonza of (Head of stores, operations and marketing) National Medical Stores (NMS), only two anti epileptic drugs (Phenobarbital and Phenytoin) are part of 70 most essential drug items identified by MOH. Other drugs are procured according to demand basing on past consumption. The biggest problem is that even when demand is indicated at the Health Unit levels, most of these drugs are not put on the list to the National Medical Stores for procurement for one reason or the other. Most of them say they are constrained by the budget. This implies that less will be imported and subsequently cause serious shortage in supply at Health Units as commented by Joyce (not a true name)

> *"In most cases we don't get the drugs, they normally tell us that drugs have not yet come, I have now spent three months without drugs and you know they are very expensive... a tablet is at 100 shillings I cannot manage".*

Mr. David Bagonza also noted that medical supplies are short of the budget by 50%, it would therefore call for serious pressure on the government to be able to include the drugs on the list of supplies and the government will always measure the consequences to determine whether to purchase or not.

According to the NMS's inventory reading as by June 22nd 2005 there were only 189 tins of Carbamazepine, 53 tins of Phenytoin, and 1772 tins of Phenobarbital. Although NMS would subsequently place an order for more drugs, the available tins are significantly very few to serve the entire country with 67 National Hospitals and various Health Units. There is also a need to consider the time lag between placing an order and time of delivery. When compared with other drugs, anti epileptic drugs constituted only 1% of the total NMS's turnover at that time.

KEY POINTS

- 67% of the respondents believe that epilepsy can be treated
- 34% of PWE seek modern treatment either at Health Centers/Clinics or Hospitals
- Overall 47% of the PWEs take anti epileptic medication daily and 20% takes it only after a fit
- 35% the PWEs have experienced improvement in their health
- Availability of anti epileptic drugs is not constant
- 72,3% of PWEs prefer Government Health Units/Hospitals as source of treatment

4.3. People Living with Epilepsy their relations, and coping strategies

In order to address the above-mentioned theme this Sub-chapter presents the findings in relation to;

(1) The Person with Epilepsy and Cooping Strategies at Individual level.
(2) Relation between PWE and their Households - and Cooping Strategies at Household Level.
(3) Relation between PWE and their Communities - and Cooping Strategies at Community Level
- and finally Key Points are noted.

4.3.1 The Person with Epilepsy and his/her Cooping Strategies

"Fear, misunderstanding and the resulting social stigma and discrimination surrounding epilepsy often force people with this disorder "into the shadows". The social effects may vary from country to country and culture to culture, but it is clear that all over the world the social consequences of epilepsy are often more difficult to overcome than the seizures themselves.

Significant problems are often experienced by people with epilepsy in the areas of personal relationship and, sometimes, legislation. These problems may in turn undermine the treatment of epilepsy." (Source: WHO Fact sheet no 166).

During the qualitative interviews the respondents listed up a number of Psycho-social problems faced by persons living with epilepsy:

- Psychological trauma and neglect
- Denied basic needs and rights like education
- Women are sexually harassed
- Not able to look after themselves.
- Strains the income.

With regards to the sexual harassment of disabled women Ms. Janet Nambi, Head of the Department of Psychology at Makerere University wrote: "It is not uncommon for disabled women to experience rape or to be taken advantage of sexually by men, especially able-bodied men who take no responsibility for the consequences of their actions, e.g., pregnancy."

It might be assumed that this only relates to women with physical impairments, however, this is not the case as one incident from Mpigi some month ago showed; a woman with epilepsy was raped during her fit.

Men on the other hand might suffer most from the stigma related to "not able to look after themselves" and "strains the income" as men traditionally are expected to be the main bred winners for their families.

Most respondents (33%) mentioned that PWEs often get involved in accidents. Although less than a third indicates that lack of drugs has had a big effect on the lives of PWE. It is a common understanding that PWE are faced with problems; of low-income, poor health and poor feeding.

Table 26: Effect of Epilepsy on the PWE

	Frequency	%
Accidents	108	33.8
Lack of drugs	76	23.8
Cannot do any work at home	64	20.0
Poor feeding	59	18.4
Low income	51	15.9
Poor health	47	14.7
Causes fear especially during fits	36	11.3
They are not employed	34	10.6
Death	29	9.1
Get malaria	21	6.6
Loss of energy after fits	15	4.7
Normally get wounds	14	4.4

Multiple responses so percentage doesn't add up to 100%

Cooping Strategies at individual level

Findings indicate that family members (20%) provide assistance to and close supervision of PWE. There is common understanding that most of PWE first drop out of school, then stay at home and finally start on treatment instead of the other way around. These cooping strategies seem not to be a result of reflections and decision-making based on knowledge of the disease, its treatment and prognosis on the other hand it seems more or less to be desperate actions in terms of leaving something unbearable to something that also in the long run turns up to be unbearable.

Some 7% of the respondents believed that most PWE become dependants. This is probably true given that most of them are not engaged in income generating activities where they would get some income to be able to live an economically independent life or at least to contribute to the home and thereby get some appreciation in return.

Table 27: Individual coping strategies

	Frequency	%
Family members provide basic needs	55	20.1
Close supervision	54	19.8
Stay at home	34	12.5
Drop out of School	33	12.1
Availing drugs for treatment	32	11.7
Begging	20	7.3
They feed on what is available	17	6.2
Just leave coz it does not cure	15	5.5
Refraining PWE from fetching water or cooking	14	5.1

Multiple responses so percentage doesn't add up to 100%

About three quarters (74%) had never participated in epilepsy awareness activities e.g. a march, rally or in a meeting around epilepsy awareness, while just 18% had participated. Also, over three quarters (78%) had not been involved in the organization of such a meeting or gathering around epilepsy awareness.

Table 28: Involvement in epilepsy awareness activities

	Yes	No	Don't know	No Response
Have you ever participated in a match, rally or meeting around epilepsy awareness?	17.9	73.8	0.5	7.9
Have you ever been involved in the organization of such a meeting or gathering?	13.1	78.1	0.8	8.1

Multiple responses so percentage doesn't add up to 100%

Constraints that are not managed by the selected coping strategies at individual level

The findings indicate that most health centers/services are far from people (17%) This partly explains why there is also a complaint about the cost of transport to reach health centers for medication (10%). Of significance to note is the proportion of respondents who believe that many people living with epilepsy over depend on their relatives for survival (12%). 9% of respondents indicate shortage of drugs while 13% confirm inadequate supply of food to people living with epilepsy.

Table 29: Constraints to the individual coping strategies

	Frequency	%
Health units are far	42	17.2
Shortage of food and shelter	33	13.5
Over dependence on relatives	31	12.7
Inadequate transport to the health centers	25	10.3
No drugs	24	9.8
Unpredictable fits	21	8.6
Affected by famine	9	3.7
No free drugs	9	3.7
Ignorance	8	3.3
Schools are few within easy reach for PWE	8	3.3
Patients do not take drugs as prescribed	8	3.3
Patients become disabled	8	3.3
Employment	8	3.3

Multiple responses so percentage doesn't add up to 100%

"Unemployment and underemployment exist worldwide, but more so with people with epilepsy. The misunderstandings and stigma mentioned previously are usually to blame for this" ... "Epilepsy commonly affects young people in the most productive years of their lives, often leading to avoidable unemployment." (Source: *WHO Fact sheet No 166*).

Table 29 shows that most PWE are not employed (3%) and it can be assumed that due to this they belong to the group of the poorest.

At the end of the Key Informant Interview and the Focus Groups Discussion respondents were requested to suggest some most suitable coping strategies that could help the individual PWE dealing with his/her epilepsy. The respondents suggested the following:

- Government should provide drugs (27%)
- Sensitize caregivers (23.1%)
- Go for medical treatment (13.3%)
- Bring health services near to people (8.6%)

- Seek treatment from traditional doctors (7.3%)
- Keep patients away from fire (3.6%)
- Patients to go for the medical assessment (3.3%)

4.3.2 Relations between PWE and their household and cooping strategies at household level

Respondents listed the following as social and economic impact of epilepsy on the Household:

- Low income (32.2%)
- Low food production (15.7%)
- Poverty (15.7%)
- Low levels of education (14.3%)
- Brings worry to the affected family (13.6%)
- Psychological discomfort (8.4%)
- Loss of labor (6.3%)
- Loss of jobs (6.3%)
- Discrimination within the community (5.9%)
- No employment (4.9%)
- Death (4.9%)
- Destruction of household property by affected person (4.2%)

Others include:

- Morale decreases. There is increased fear
- No peace during attack
- Unlimited attacks occur any time
- Treating and nursing epilepsy even at old age
- Rejection, dissertation
- Affected person becomes a public nuisance
- Divorce in marriages
- Torture to the family
- Effects most on women as primary caregivers
- Husbands ignore them, while neighbors isolate them

Findings show that 50% of respondents hadn't discussed issues of epilepsy with their children or other family members.

Table 30: Discussed issues of epilepsy with children/family members

	Masindi		Kabale		Tororo	
	Frequency	%	Frequency	%	Frequency	%
Yes	52	40.3	42	36.8	50	32.5
No	67	51.9	52	45.6	83	53.9
No response	8	6.2	14	12.3	14	9.1

The proportion of families that had discussed about epilepsy was at 36% (about one third) of all the respondents. This seriously affects the awareness about the disease as well as its treatment for households that may be having an affected person(s).

School going children need to be aware of the causes of the disease, the appropriate source of treatment and the Do's and Don'ts so they not only know about the disease but also how to relate with children living with epilepsy in schools. There is likelihood that those who gave no response equally had never held any discussion with their family members.

People with Epilepsy and marriages

"In many countries a legislation affecting person with epilepsy has reflected centuries of suspicion and misunderstanding about epilepsy. For example, people with epilepsy are often prevented from marrying or having children." (Source: *WHO Fact sheet No 166*).

In all focus group discussions and key informant interviews, marriage to a PWE was largely unacceptable. Although some said that it would be acceptable as long as they loved each other. The refusal to marry PWE was because of the fear of the risk of transmitting epilepsy to the children.

Table 31: Marital problems experienced as result of epilepsy

	Frequency	%
Neglect	44	11.1
Physical harassment	51	12.8
Marital infidelity	5	1.3
Other Problems	140	35.3
No response	157	39.6
Total	397	100.0

While analysis by district shows that for the districts of Masindi and Kabale, there is more of neglect (14%) as a result of epilepsy in the households, than Tororo district (7%). However, physical harassment is more frequent in Tororo (16%) than in other districts (12% for Kabale and 9% for Masindi). Over all 40% could not commit themselves as to whether there was any mistreatment of the people living with epilepsy in families.

Questions about marital problems are sensitive also in a Ugandan context. An average of 12.8% physical harassment might be taken as the "true picture" when keeping in mind that beating up the wife if she does not obey is widely accepted by both men and women.

Likewise the Marital Infidelity where the average is 1.3% seems a bit on the low side knowing that e.g. polygamy is widely practiced in the Ugandan society.

Overall, one in every ten people who were interviewed said that they had ever been threatened to divorce on grounds that one of the partners had epilepsy. The proportion of respondents in Masindi who said their spouses had ever threatened to divorce because of epilepsy is double (16%) that of other districts. However the distribution of responses across district is the same. 40% of the respondents could not commit themselves.

Table 32: Threatened to divorce due to epilepsy

	Frequency	%
Yes	43	10.8
No	194	48.9
No response	160	40.3
Total	397	100.0

For instances when people were already married, and one of them acquired epilepsy, FGD showed that the majority would not divorce but rather encourage the PWE to continuously take the medication as prescribed.

Other people said they could not cope with the disease and therefore would divorce. Asked whether they knew anybody who had divorced because of the spouse having epilepsy, one Hospital nurse in a FGD said;

> *"One man divorced the woman, saying he would not manage the disease any more".*

In a gender perspective the consequence of divorce is quite different depending if it is a man who divorces his wife or a wife who divorces her husband. The husband can just send the wife back to her parents and still remain with all the household items, the house and the land even the children as they belong to him.

Epilepsy is not contagious

"In Uganda, as in many other countries, epilepsy is thought to be contagious and so people living with epilepsy are not allowed to join the communal food pot for fear of others contracting epilepsy through that person's saliva." (Source*: WHO Fact sheet no 166*).

Table 33: Possibility of family members getting epilepsy from affected member in home

	Masindi		Kabale		Tororo	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
Yes	57	44.2	37	32.5	58	37.7
No	52	40.3	52	45.6	72	46.8
No response	20	15.5	25	21.9	24	15.6
Total	129	100.0	114	100.0	154	100.0

The findings show that fewer people believe that epilepsy is contagious (38%) as compared to those who think epilepsy is not contagious (44%), however with no significant difference. Qualitative findings indicate that many people think that epilepsy can be transmitted through body contact and products.

At least two thirds of the respondents informed that PWE were not given special or unique treatment from the rest of the household members simply because they have epilepsy.

Table 34: Relationship of persons with epilepsy with other household members

	Yes	No	Don't know	No Response
Use own separate room or hut	19.4	67.5	8.3	4.8
Use own eating utensils	21.9	65.7	7.1	5.3
Utensils washed separately	18.1	68.8	7.6	5.5
Eat in a separate place	17.9	70.0	6.8	5.3
Have their own basins for washing	18.4	69.5	6.8	5.3
Their clothes washed separately	18.4	65.7	7.1	8.8

Multiple responses so percentage doesn't add up to 100%

Results show that about one third (32%) of respondents in Masindi, 15% in Kabale and 19% in Tororo reported that persons with epilepsy owned their eating utensils different from the rest of the members in the households. The majority (57% for Masindi, 64% for Kabale and 74% for Tororo) said that they shared them without fear of being infected.

25% of respondents in Masindi, 11% in Kabale and 18% in Tororo mentioned that utensils for PWE were washed separately from the rest that are used by other household members. The majority (64% for Masindi, 66% for Kabale and 75% for Tororo) said that the utensils were washed together with those of other members without fear of contamination because they know that the disease is not contagious.

In some households PWE are isolated from the rest when it comes to eating. For example 24% of respondents in Masindi, 11% in Kabale and 18% in Tororo revealed that PWE were separated from the rest at the time of eating and given their own separate food.

Some households provide separate basins for persons with epilepsy, as was reported by about one fifth (18%) of the respondents. On the other hand 70% did not provide separate basins for affected persons. Distribution by district shows a similar pattern as the overall picture.

Regarding washing of clothes separately for PWE is more pronounced in Masindi (26%) than the rest of the districts (Kabale 10% and Tororo 18%). Two thirds of respondents said that clothes for PWE are not washed separately.

Sending PWE away from their home

PWE were sometimes sent to traditional doctors or health units for treatment because of their sickness and because of fear to infect the rest of the Household's members.

But in other households some PWE were / are sent away from home, normally to; grand parents, friends and relatives - and married women are sent back to their fathers' homes. However, in some instances PWE are just pushed outside the house and then it's up to them to find out where to settle.

The Respondents were requested to suggest the most suitable coping strategies that could help the family to deal with their family members living with epilepsy. The respondents suggested the following:

- Understand the period when a patient gets fits (14.6%)
- Provide patients with basic needs (14.2%)
- Ensure someone is always around to help (10.1%)
- Keeping patients away from fire (9.7%)
- Seek herbs/drugs (9.3%)
- Starting up income generating activities (7.3%)
- Avoiding early marriages (6.9%)
- Continue seeking for advice (6.1%)
- Taking the PWE to the hospital (5.3%)

Table 35: Household coping strategies

	Yes	No	Don't know	No Response
Has the household drawn on savings as a coping strategy during severe epilepsy attacks?	1.8	7.8	7.1	83.4
Has the household sold assets as a coping strategy for medication and survival?	4.0	6.5	6.0	83.4
Has the household received any help in kind or money to supplement their own household efforts?	12.1	17.9	48.4	21.7

Multiple responses so percentage doesn't add up to 100%

Over 80% of the respondents did not respond to whether households affected by epilepsy had either drawn on savings as a copying mechanism during severe epilepsy attacks or sold assets as a coping strategy for medication and survival.

About half (48%) said that they did not know whether epilepsy affected households had received any help to supplement their own household efforts. The high proportions are due to the fact that a sizeable number of respondents were either not PWE or did not have any member with epilepsy in the households and therefore did not have the experience of hardship especially during severe attacks.

However, the few PWE or households with a person with epilepsy who received help mainly got it from relatives, neighbors and friends.

Support to the Household

PWE are economically handicapped and hardly engage in economic activities because of the nature of their condition. As a result they are either helped by their families or seek for help from outside elsewhere.

Responsibilities taken up by the extended family in helping the affected household to cope with reduced income and increased expenditures in terms of treatment

Table 36: Responsibilities taken up by the extended family

	Frequency	Percent
Provide clothes and money	98	27.2
Provide herbs/drugs	38	10.6
Counseling	9	2.5
Provide food	3	0.8
No help	121	33.6
Don't know	28	7.8
Provide domestic labor	11	3.1
Advise to take client to school	7	1.9
Take client to hospital	7	1.9
Help in prayer for recovery	1	0.3
No response	37	10.3

Multiple responses so percentage doesn't add up to 100%

Whereas the majority (34%) of the respondents said that extended families had not played any role in helping affected households cope with reduced income, 27% said that families that attempted to give help provided clothes and some money while 11% said that extended families only provided herbs/drugs.

The implication is that not much support/help is received from extended families because of the likely similar problems faced, and as such affected households should endeavor to have income generating activities to enable households have access to basic necessities.

37% did not want to commit themselves over the role played by the extended family.

Ease of getting help from relatives and friends

Table 37: Ease of getting help from relatives and friends

	Masindi		Kabale		Tororo	
	Frequency	%	Frequency	%	Frequency	%
Very difficult	54	41.9	22	19.3	47	30.5
Very easy	29	22.5	48	42.1	37	24.0
Difficult	15	11.6	5	4.4	15	9.7
No response	31	24.1	39	34.2	55	35.7
Total	129	100.0	114	100.0	154	100.0

30% indicated that obtaining help from relatives was very difficult, while the same proportion said that it was very easy to get help from relatives. On the other hand, 9% said that it was just difficult to get help from relatives. This may not be a surprise as every household is normally faced with its own problems and therefore would not be very willing to give support to someone outside, when there own household issues still are unsolved.

Death and burial of people living with epilepsy

"Epilepsy is associated with an increased risk of mortality. Death may be related to:

- An underlying brain disease, such as a tumor or infection;
- Seizures in dangerous circumstances, leading to drowning, burns or head injury;
- Status epilepticus;
- Sudden and unexplained causes, or a possible respiratory or cardio-respiratory arrest during a seizure;
- Suicide.

Whilst studies on this subject are sparse, epilepsy-related deaths in young adults in the UK, for example, are 3 times higher than standard age-related mortality rates." (Source: *WHO Fact sheet No 165).*

Death of people as a result of epilepsy is not perceived as common, although there are few instances where people are reported to have died of epilepsy. For example during FGD with nurses of Masindi Hospital, they reported only one case and said;

> *"We know only one case, he was found in his house dead "he was a very smart boy; he used to ride boda boda. That boy would tell you that he was about to get an attack and would advise you to jump off the motorcycle immediately and then he would fall the other side. Immediately he gains conscience he would clean himself and get on his motorcycle and go to work"*

Similar, other qualitative data from Masindi revealed 3 cases where PWEs fell in the well while fetching water and died.

In Uganda it is not common practice, as e.g. in the UK to have the dead body inspected by a medical officer in order to issue the death certificate that states the cause of death. It is not possible actually to know the number of people that die of epilepsy in Uganda.

Table 38: Are PWE buried differently

	Masindi		Kabale		Tororo	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
Yes	4	3.1	5	4.4	14	9.1
No	111	86.0	77	67.5	112	72.7
Don't know	8	6.2	10	8.8	9	5.8
No response	6	4.7	22	19.3	19	12.3
Total	129	100.0	114	100.0	154	100.0

In most cases PWE are buried like any other person who did not suffer from epilepsy. However, in a few instances, people who have died of epilepsy are buried with their belongings and a special ritual is performed by the family elders to prevent something bad happening to the family and that the dead PWE does not disturb the family again.

Table 39: Inheriting a person who has died from Epilepsy

	Yes	No	Don't know	No Response
Would you be a heir to a PWE?	73.3	18.6	-	8.1
Would you inherit the property of a dead relative with epilepsy?	67.5	22.2	-	10.3

Multiple responses so percentage doesn't add up to 100%

The findings indicate that most people (73%) would not mind becoming a heir to a PWE. This issue about inheritance can also be seen in a gender related context as it is not yet common practice in Uganda that women and even a widower can inherit on equal terms like a man.

Constraints that can not be overcome by the selected coping strategies at household level:

- No drugs for patients (16.8%)
- Lack of sensitization (15.9%)
- Increase in poverty (14.2%)
- Low income (9.1%)
- Leads to dependence burden (8.2%)
- Unemployment (5.6%)
- Lack of food (5.6%)
- Drugs are expensive (4.3%)
- Discrimination of the affected households (4.3%)
- Low educational levels (4.3%)

At the end of the Key Informant Interview and the Focus Groups Discussion respondents were requested to suggest some most suitable coping strategies that would reduce the suffering by epilepsy at household level:

- Seek for treatment (37.1%)
- Advise people not to stay near rivers (24.1%)
- Government to provide treatment (21.1%)
- Doctors should carry out research to find the cause of epilepsy (6.3%)
- Provide basic needs (4.8%)

- Increase the supply of drugs (4.8%)
- Households should form groups so that they can be assisted (4.8%)
- Encourage pregnant women to deliver from the hospitals (3.7%)

4.3.3 Relation between PWE and their community and coping strategies at community level

Respondents listed the following as social and economic effects of epilepsy on the Community:

- Increased poverty in the household (15.7%)
- Worried of contracting the disease (13.6%)
- Low educational levels (12%)
- PWE don't participate in communal work (10.3%)
- Community neglect (9.1%)
- Reduced household income (8.4%)
- Unemployment (8%)
- Fear to associate with epilepsy patients (7.3%)
- Lack of food (6.9%)
- Psychological torture (6.2%)
- Loss of life (5.8%)
- Drop out of school (4.7%)

Relationship of people with a person with epilepsy in the wider community

Results about the relationship between a person with epilepsy and people in a wider community indicate that people (children and adults) were given the same treatment like any other without discrimination. For example 78% of respondents said children with epilepsy could play with others, 71% said could go to school, 69% said adults could drink with other adults, 70% said they could marry. Three out of every four people revealed that people with epilepsy could also marry like any other, 57% said they could also become leaders, while 56% reported that they could inherit from others. It was however reported by 41% that people with epilepsy could not do heavy work.

Table 40: Relationship between PWE and the wider community

	Yes	No	Don't know	No Response
Can a child play with others?	78.3	13.4	4.3	4.0
Can a child go to school?	71.3	22.7	2.0	4.0
Can an adult drink with others?	69.3	22.4	4.0	4.3
Are the patients expected to do heavy work?	40.6	51.1	4.5	3.8
Can they marry?	70.0	20.4	5.0	4.5
Can they have children?	75.3	15.6	4.5	4.5
Can they become leaders?	57.2	32.7	5.8	4.3
Can they inherit from others?	55.9	30.2	8.8	5.0
If a patient has cured, does some of that social stigmatization still apply?	23.4	52.4	17.4	6.8

Multiple responses so percentage doesn't add up to 100%

Although most respondents from the quantitative data indicate that there is no discrimination of PWE, qualitative findings show that discrimination actually exists. For example FGD carried out in schools indicate isolation of children living with epilepsy similar PWE are not allowed to participate freely in community activities.

Community response to people with epilepsy

Some communities are sympathetic, they feel sorry to have such a "child" in their village but there is no much help, while others have no sympathy at all.

Table 41: Description of what happens after falling

	Frequency	%
People laughed	20	19.8
That person is sick	32	31.7
Person is bewitched	9	8.9
Advised people not to pass near	2	2.0
That epilepsy is the cause	56	55.4
Falling was due to malaria	7	6.9
People got scared	11	10.9
Person is affected by ghosts	1	1.0
Falling was due to dizziness	10	9.9
Person does know the disease he/she is suffering	1	1.0
Don't remember	3	3.0
The person has just fallen down	1	1.0
The person is going to gas	4	4.0
Person got disease from parents	4	4.0
People though he was dead	2	2.0

N=101, percentage don't add up to 100 because of multiple answers

The following is the interpretation of what people say when an epileptic persons falls down; 55% of respondents reported that people say epilepsy is the cause of falling, while 32% said that the person was sick, 20% say that people around just laughed, 11% noted that those around got scared

Access to education

In most cases, all children including those with epilepsy are given the same opportunities including access to education.

However, because of the conditions of the affected children where they get attacks at quite short interval, and every time they get attacks they have to be away from school for some day, besides the psychological torture and stigmatization they get from mainly fellow children, they perform quite poorly as a result of regular absence from school and they subsequently dropout. It was however pointed out clearly that when such children are not having attacks they are quite normal like any other and do all sorts of things other children do.

52% of Household Respondents interviewed reported that once people living with epilepsy have controlled the fits, then no social stigma still applies to the affected person. On the other hand, 23% said that even after the person has controlled the fits, some aspects of social stigmatization still applied. Such aspects of social stigmatization that still apply to the affected persons include;

- Other people doubt those affected persons whether they are normal or not
- No full care given to them from both the household members and the community at large
- They are always a topic for discussion especially after seeing them

- They are isolated
- Fear that they are likely to produce children with epilepsy
- They are denied opportunity to employment
- They fear that they will not marry.

> *"Children with epilepsy are referred to as a dead generation. Parents with many children living with epilepsy appear desperate and care less for their children, while those with few children tend to have special treatment for their epileptic children"(Medical officer Masindi Hospital).*

Although parents / caregivers refer to children living with epilepsy as a dead generation, they have continued sending them to hospital for medication.

The community on the other hand see this as unnecessary a waste of resources and some people have sought of quick solutions to end the problem of epilepsy, for example, in Kigumba there is a family with a young girl living with epilepsy. The girl gets daily attacks. She started on medication six years ago and is taking carbamazapine.

> *"One parent, actually a family friend at one time advised the father to hire someone to come and kill the child, he said; you keep this child? If I were you I would hire somebody to kill her."(Source: KI Kigumba).*

Help from the wider community

Overall, 20% of the respondents revealed that households had asked for help within the last 12 months prior to the study. The low proportion is because of the existing community perceptions and practice of isolating such households, as such affected households fear to ask for any help even when situations get tough. Again mobilization and sensitization of communities to be supportive to such households is critical for any meaningful intervention.

Source of help

The majority (71%) of respondents said that households with PWE asked for help from relatives, followed by about one-third (32%) who asked friends and a significant percent (23%) went to neighbors for assistance. The majority asking for help from relatives is not strange because it may be the only feasible option.

Table 42: Source of help

	Frequency	%
Relatives	58	70.7
Neighbors	19	23.2
Friends	26	31.7
Sub county	6	7.3
Ngo (World Vision)	8	9.8

Multiple responses so percentage doesn't add up to 100%

Of interest and concern, is the involvement of NGOs and government in provision of help to persons with epilepsy. This, points to the need by the government and any other interested parties to start focusing on providing some help in a more official way, than people just storming the offices without knowing whether they will get or not.

Type of help was sought

Findings show that the majority (62%) sought help in terms of money, 46% medical care, clothing (28%) and about one-quarter (27%) sought help in terms of food.

Table 43: Help sought

	Frequency	%
Money	51	62.2
Clothing	23	28.0
Food	22	26.8
Shelter	6	7.3
Medical care	38	46.3

Multiple responses so percentage doesn't add up to 100% (N=82)

The interpretation is that most of the people with epilepsy don't engage in economic activities, as such they have to look for support from wherever they can find it, but most especially money to enable them to buy medicine.

Reason why community helps is not easy to get

Overall, 58% said community help was not forthcoming mainly because of lack of money due to high unemployment rate among the people, while one third (33%) revealed that it was because of fear to associate with families affected with epilepsy that community help could not easily be obtained.

Analysis by district shows, that the distribution is the same as the overall except in Kabale District where the proportion for those who fear to associate with families affected with epilepsy (52%) is greater than those lacking money because of unemployment.

Table 44: Main reasons community help may not be forthcoming

	Masindi		Kabale		Tororo	
	Frequency	%	Frequency	%	Frequency	%
Lack of money due to unemployment	75	66.4	40	40	76	67.9
Fear to associate with families affected with epilepsy	19	16.8	52	52	34	30.4
Not bothered	18	15.9	8	8	2	1.8
Total	112	100.0	100	100.0	112	100.0

At the end of the Key Informant Interview and the Focus Groups Discussion respondents were requested to suggest some suitable coping strategies that could help the community to deal with PWE. The respondents suggested the following:

- Neglect (37%)
- Give help where possible (17.4%)
- Associate with the clients (6.2%)
- Counseling and sensitization (13.4%)
- Advising patients to go for treatment (4.7%)
- Training village health workers (4.7%)
- The community thinks it is the problem of the affected family (4.3%)
- Take the child with epilepsy to school like any other (3.4%)

KEY POINTS

- In addition to living with epilepsy condition, PWE suffer from stigma and psychological torture.
- PWE are faced with a problem of Low income and unemployment
- Family members provide physical care to PWE.
- The common problem affecting PWE is that Health units are not easily accessible in terms of distance and transport.
- There are marital problems facing couples associated with epilepsy in families with people affected with epilepsy.
- Obtaining help from communities and relatives for people living with epilepsy is not easy.
- PWE can easily access to education, however there are many cases of school drop outs linked to PWE.

4.4 Prevalence of Epilepsy

In order to address the above-mentioned theme this Sub-chapter presents the findings in relation to;

(1) Prevalence as Perceived by the General Community in the three Study Districts
(2) Prevalence of Epilepsy in Uganda according to Uganda Bureau of Statistics
(3) Prevalence of Epilepsy according to World Health Organization
- and finally Key Points are noted.

4.4.1 Prevalence as Perceived by the Community in the Study Districts

There is not any reliable updated statistics available about the prevalence of PWE (se 4.4.2). In order to understand how the communities perceive the size of PWEs the Respondents were asked about their knowledge of the number of PWEs in their area.

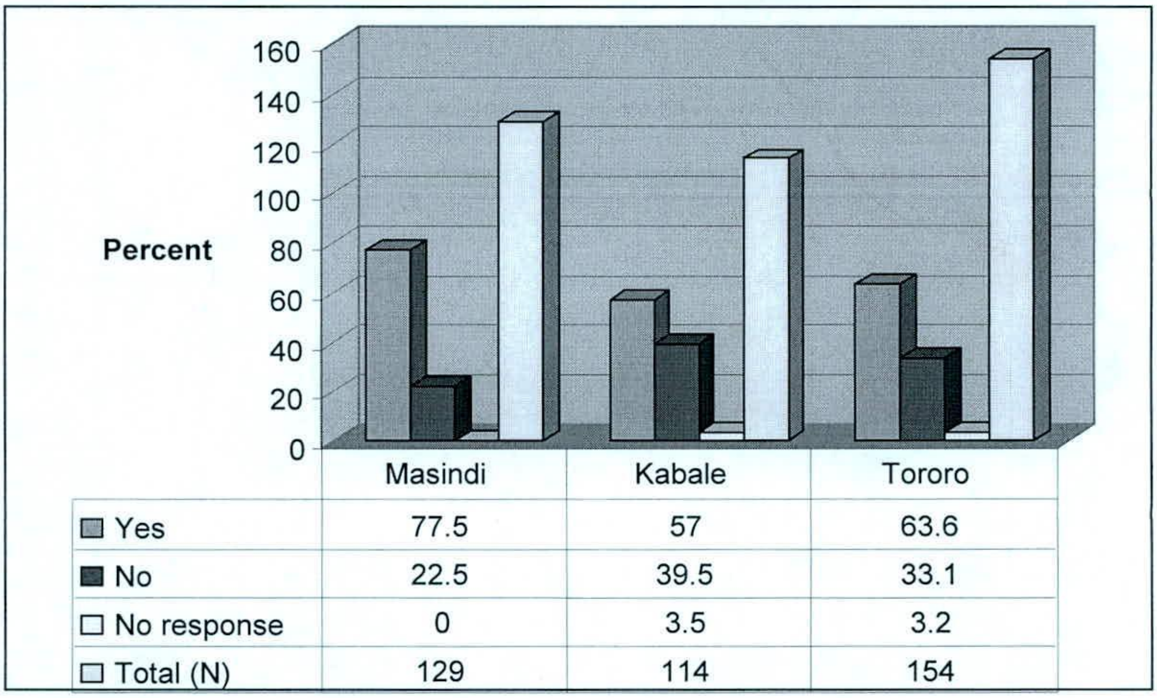
Table 45: Households with at least one Person Living with Epilepsy

	Masindi		Kabale		Tororo	
	Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
Yes	33	25.6	26	22.8	35	22.7
No	96	74.4	75	65.8	114	74.0
No response	-	-	13	11.4	5	3.2
Total	129	100.0	114	100.0	154	100.0

Overall, quantitative findings show that according to the Respondents about one quarter (24%) of their households included at least one PWE.

Respondents were further asked if they knew other families with PWEs. Overall two out of every three (66%) people interviewed knew other families with at least one family member with epilepsy.

Graph 6: Knowledge of other Families having a Family member with epilepsy



	Masindi	Kabale	Tororo
▨ Yes	77.5	57	63.6
■ No	22.5	39.5	33.1
☐ No response	0	3.5	3.2
☐ Total (N)	129	114	154

Source: Field data April 2005

Considering the geographical distance between sampled areas of study and the relationship between the results obtained from different districts, it is likely that there are many cases of PWE in the villages. The percentage of respondents that never responded may imply that they knew of some families with PWE but never wished to disclose them and/or did not know any.

Table 46: Average Number of Families with at least one Family Member Living with Epilepsy

District	Frequency	Mean
Masindi	99	4.99
Kabale	60	2.27
Tororo	92	2.14

On average the respondents knew of three (3) other families living with a family member with epilepsy. In Masindi District even respondents knew on average five (5) other families with PWE. Kabale and Tororo are not very different from each other; their average being two (2) other families.

Health Centre Statistics

At local level many Health Centre / Clinics have tried their best to find out the prevalence of PWE in their area as shown in table 18. However, the Government of Uganda's Health Management Information System (HMIS) did not include Epilepsy as a separate disease, but included it under "Mental Health Problems". This has now been changed as per June 2005 where Epilepsy is categorized as condition number 53.

Table 47: Some of the results showing PWE who would turn up for treatment at Nyantozi Health Centre III. Masindi District

Feb 05	Jan 05	Dec 04	Nov 04	Oct 04	Sep 04	Aug 04	Jul 04	Jun 04	May 04	Apr 04	Mar 04	Feb 04
99	83	60	61	72	39	74	69	50	45	37	50	43

Source: The In Charge Clinical Officer at Nyantozi Health Centre III Bujenje County, 2004-2005.

4.4.2 Prevalence of Epilepsy in Uganda according to Uganda Bureau of Statistics

According to 2002 Uganda Population and Housing Census (March 2005) the total number of PWE in Uganda are 21,342 out of all People with Disability, which is estimated to 844,841 persons.

The Census presents it findings for the total population, but has however clustered the total into the following age groups.

0-17	18-30	31-59	60 and over	Total Frequency
11,762	4,891	3,653	1,018	21,324

4.4.3 Prevalence of Epilepsy according to World Health Organization

According to WHO's Fact sheet No 165 (February 2001); "the prevalence of a disorder is the proportion of a population with that disorder at a given point in time. From many studies around the world it has been estimated that the mean prevalence of active epilepsy (i.e. continuing seizures or the need for treatment) is approximately 8.2 per 1,000 of the general population. However, this may be an underestimate as some studies in developing countries (such as Colombia, Ecuador, India, Liberia, Nigeria, Panama, United Republic of Tanzania and Venezuela) suggest a prevalence of more than 10 per 1,000.

- Thus, it is likely that around 50 million people in the world have epilepsy at any one time. The lifetime prevalence of epilepsy (i.e. the number of people presently in the world who have epilepsy now or have had it in the past or will experience it in the future) is approximately 100 million people."

KEY POINTS

- There are many cases of people known to be living with epilepsy.
- There is an increase of the number of cases of people seeking medication for epilepsy in Government Health units.
- No reliable national statistics available about epilepsy in terms of prevalence, treatment or otherwise

5. CONCLUSION AND RECOMMENDATIONS

The main objective of the study was to collect information about the existing knowledge, perception, attitude, as well as socio economic and health situation for PWE in order to guide future interventions.

Specific objectives;

1. To understand community perceptions of epilepsy, the courses and the treatment.
2. To get a better understanding of the existence and functioning of Health Service for PWE.
3. To document the impact of epilepsy on the lives of PWE, on their household and on their community.
4. To assess the magnitude of the problem of epilepsy in consideration of prevalence, sex, age and illness related information.

The conclusion and recommendations based on the findings are described in 5.1 and in 5.2 the recommendations provided by the respondents and other stakeholders during the presentation of the study are listed.

5.1 Conclusion and Recommendations Based on the Study

Conclusion on community perceptions of epilepsy

It seems very impressive, that about 94% of the respondents have ever heard of epilepsy. It seems also impressive that about 44% of the respondents know one or more of the true courses of epilepsy, though only about 1% describes epilepsy as a brain disease.

However, there seems no transference of the basic knowledge; that epilepsy exists, and what the courses are to where to go for modern treatment and how to live a satisfied life with epilepsy.

- People on the ground believe that the cause of epilepsy is witchcraft and the like
- People on the ground do believe that epilepsy is contagious
- People on the ground refer / seek first to traditional healers for treatment

It is worth noting that schools are recognized as being the primary source of information followed by radio programs and seeing.

Recommendations

The implication derived from the results is that any programs targeting increasing awareness about the disease could focus on using schools as main dissemination points because pupils/students reach a wider section of the community and therefore have a higher multiplier effect because at home they interact with so many people.

Conclusion of the existence and functioning of Health Service for People with Epilepsy

Though about 67% of the respondents believe that epilepsy can be treated, however only 34% of PWE seek modern medical treatment either as Health Centres, Clinics or Hospitals

It is assumed, that PWE first and foremost seek assistance from the alternative healers or even from the witch doctors. The pattern seems to be that PWE first goes to 3 or 4 alternative healers before they approach modern medical institutions.

However, only 47% of those PWE who had been diagnosed and given anti epileptic medication to control their fits do not take it daily. Further, 20% take the anti epileptic medication only after a fit. It is therefore understandable that only 35% of PWE have experienced improvement in their health.

In addition the problem is further enlarged by the function of the Government's Health Services. This goes for the availability of Health Units, for the availability of knowledgably staff and for constant availability of drugs for treatment – as well as for counseling services.

It is worth noting that about 72% of PWE that have gone for treatment prefer the government health units, clinics and hospitals.

Recommendations

- ✓ Sensitize people about the symptoms of epilepsy and the need for as early as possible to go for a modern medical assessment.
- ✓ If the diagnosis is epilepsy start the treatment and then take the medication regular as prescribed.
- ✓ To initiate cooperation with the alternative healers and sensitize / train them about epilepsy.

Conclusion on the impact of epilepsy on PWE, their household and on their community

The physical symptoms cost by epilepsy in terms of fits can be controlled and the person can live a life as all other persons who do not having epilepsy.

The psychological symptoms in terms of depression, low self-esteem, are fare more difficult to "control" or to "cure" as they are caused by stigmatization and exclusion.

Due to what the family, friends and the community has seen and experienced before the PWE had his/her fits controlled by regular medication the social stigmatization starts.

Recommendations:

We should understand the importance of awareness-raising training courses about epilepsy. There must be multidisciplinary and multidimensional approach to reduce the treatment gap in Uganda. The Health workers, Social workers, Traditional Birth Attendance, NGOs, Opinion leaders and other stakeholders should work together to in the fight of stigma and treatment of epilepsy in Uganda. There is a need for the government intervention especially in the provision of drugs and statistics on people living with epilepsy. More anti-epileptic drugs should be included in the essential drug kit and services should be taken closer to people. Management of seizures, pregnancy, and malaria and child health must be given priority in order to control epilepsy.

There is need to sensitize the communities about the causes if any efforts about preventing the disease are to succeed. This should be the major focus of any organization working in this field.

People need to be sensitized that in case any member of the household exhibits some kind of strange behavior in form of sickness, they should immediately seek medical care. The MOH provided guidelines in reference to signs and symptoms of epilepsy and include the following; Sudden loss of conscientiousness, falling of items from the hand, staring at one sport, hearing of voices and seeing of un seen objects by other people for example a lion etc.

Conclusion of the magnitude of the problem of Epilepsy

The prevalence of epilepsy can still only be estimated. WHO have some indicative figures for developing countries as such. It is welcoming that Uganda Bureau of Statistics in March 2005 for the first time has included epilepsy in her statistics, even though the figures might not provide much help in planning of how to address the problem properly.

It is a huge concern that so many children and young people seems to be getting epilepsy. It becomes even more disturbing when WHO states, that early diagnosis and regular medication can suppress the fits and ensure a "normal" life to 80% of those who are affected by epilepsy.

The magnitude of the problem of epilepsy and the problems that follows the disease seems overwhelming especially in the context of Uganda being a developing country, poor, with a lot of demands on her shoulders and not yet having been able to neither assess nor address the problem properly.

Seen in this context Uganda is missing out. Lack of income in form of taxes from employed and healthy medicated People living with Epilepsy and with resources to participate in developing their communities.

Recommendations

Continued research in the magnitude of epilepsy and the causes that in especially Uganda might lead to epilepsy; in the most efficient way to prevent epilepsy (e.g. early treatment for malaria and syphilis, safe delivery for mothers and babies); and also the most efficient way of sensitizing people about the symptoms, the importance of early diagnosis and how to manage the anti-epileptic medication.

5.2 Recommendations from the Respondents and other Stakeholders

During the research (Data collection) most district officials requested that research findings be disseminated at the district levels. The research team later visited the districts and discussed the findings. The district officials came up with the following recommendations to stakeholders:

Addressed to ESAU

ESAU and other stakeholders should continue to work with people affected by epilepsy to ensure their voice is heard. The Association should campaign for improved health-care, better information provision and an end to stigma.

ESAU should continue to promote epilepsy awareness-raising campaign. To achieve this, the Association should embark on producing and distributing booklets: *Guidelines for teachers and pupils/students on how to manage epilepsy* in schools. Information to help teachers/pupils/students know that a pupil/student has or is developing epilepsy should be contained in the booklet.

Addressed to Community Level
Increase awareness through mobilization and sensitization of the people with epilepsy as well as the people in communities they belong to, so that the community can take care of the people living with epilepsy with adequate knowledge. This can easily be done through (Village meetings, House to house visits, Use of posters, local radio programs.

Addressed to Government at Local Level
Trained health workers should attend to epilepsy patients if possible at least weekly compared to the current situation where they are attended to on a monthly basis. In addition, the government should train volunteers and allow them to dispense the drugs on its behalf to persons with epilepsy, as it may not be in position to reach out to all the communities, because some people affected with epilepsy fail to move to collect drugs.

Sensitize mothers to deliver in health centers and avoid self-medication especially pregnant mothers. These can be targeted through antenatal programs.

Addressed to Government at Central Level
As a matter of priority, stakeholders should embark on registration of all persons with epilepsy starting with the districts before rolling out to the entire country. The current HMIS forms do not capture epilepsy and statistics for clients going to health units are kept separately (Disability forms) This creates a planning problem since the actual number of clients visiting health units is not known.

Government intervention through provision of more and better drugs for people closer to the people say at health Centre 11 but also training of health workers in management of epilepsy as a condition and people living with epilepsy.

Carry out a survey on epilepsy in order to come up with reliable statistics to facilitate planning and budgeting. Government, NGOs and Research institutions can do this.

Carry out a research on the relationship between epilepsy and the black flies especially in Masindi and Hoima

There is a need to sensitize the local leaders to take a lead in the community management of epilepsy.

6. FINAL REMARKS

In the final remarks ESAU would like to draw up some lessons learned from having carried out a study as the one presented.

Due to the constraint of funds ESAU chooses to conduct the study with a minimum of consultancy input thus, ESAU's Project Officer was assigned to be the main responsible for the study.

This was an ambitious decision as none of the staff are trained and experienced researchers – and at the same time are very busy conducting training in the field.

However, as the study is neither an evaluation nor a baseline the decision had many advantages - and lessons learned as listed below:

- ESAU's staff learned from the persons on ground how some of them perceive Epilepsy, which can improve on the way the training and sensitizing are conducted on ground.
- Through the study ESAU's staff came closer in contact and build strong linkages with the District and Sub-county leaders and officials, which makes it easier to commit these important stakeholders to include PWE in mainstream development activities.
- The study process in itself became a part of ESAU's advocacy and sensitizing work
- A new method in advocacy and sensitizing have been developed and tested during the study.
- ESAU's staff learned how to conduct a study by doing it.

This study can be seen as a action research process where all involved researchers, respondents, PWE, the community and other stakeholders learned and move a bit further together towards the betterment of the conditions for People Living with Epilepsy.

ANNEXES

Annex 1: List of References.

Annex 2: List of Research Assistants.

Annex 3: The Households' Questionnarie.

Annex 4: The Questionnarie for Health Workers.

Annex 5: The Key Informants' and Focus Groups' Guiding Questionnarie.

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List of Research Assistants

	Names	Districts
1	Kayuko Edith	Masindi
2	Kasangaki Swizen	Masindi
3	Kaahura Bagonza	Masindi
4	Murungi Esther	Masindi
5	Nyantonzi	Masindi
6	Obonyo Peter	Masindi
7	Kasisaki Dison	Masindi
8	Jane Ngabirano	Masindi
9	Masiko Jackson	Kabale
10	Twinomujuni Justine	Kabale
11	Mwesigomwe Jackson	Kabale
12	Swaleh Mawe	Kabale
13	Rukundo Bosco	Kabale
14	Aturinda Phiona	Kabale
15	Tumuhaire Marion	Kabale
16	Bitamazire Arthur	Kabale
17	Karisa John	Kabale
18	Okello Charles William	Tororo
19	Godfrey	Tororo
20	Njalira Herbert	Tororo
21	Oloka Richard	Tororo
22	Ofumbi Nerbat	Tororo
23	Were Paul	Tororo
24	Kiyimba Nicholas	Tororo
25	Janet Musoke	Tororo
26	Musasizi Francis	Tororo

EPILEPSY AND COPING STRATEGIES IN UGANDA
Household Questionnaire

Dear Sir/Madam,
Hello, my name is ______________________ Epilepsy Support Association of Uganda is conducting a national survey on prevalence of epilepsy, its social economic effect on the individual, family, household and community and the coping mechanism. We would like to ask you about some things related to your own life and that of your family. You have been selected for this study on behalf of the community your opinion is very important and all responses will be treated with utmost confidentiality.

Instruction: Speak To Any Adult Member (18 years and above) of the Household. But preferably the Household Head.

Name of Interviewer: ____

Date of interview …./………/2005 Time Start ……….. Time end………

SECTION A: IDENTIFICATION			
A1	Name of the District		
A1	Name of Sub county		
A2	Name of Parish		
A3	Name of LC1/Village		
A4	Name of respondent		
A5	Household Status:	1.Adult Headed	2.Child Headed
A6	Relationship of respondent to Household Head	1. Self 2. Son 3. brother 4. others	5. spouse 6. daughter 7. sister
A7	Gender of the Respondent	1. Male	2. Female
A8	Age of respondent in completed years		
A9	Marital status of respondent	1. Married 2. Widow /widower	3. Un married 4. Divorced/separated
A10	How many people normally live in this Household		
A11	What is your occupation?	1. Trader/Businessman 2. Housewife 3. Unemployed 4. Not disclosed 5. Professional/Officer/Executive 6. Self employed 7. Retired 8. Student	
A12	What is your highest level of Education?	1. None 2. Primary 3. Secondary 'O' level 4. Secondary 'A' level 5. Tertiary Institution/ Diploma 6. University/Degree	
A13	What is your religion?	1. Protestant 2. Catholic 3. Muslim 4. Seventh day Adventist 5. Pentecostal 6. African Traditional Religion 7. Others	

A14	Education level of primary caregiver for children	1. None 2. Primary 3. Secondary 'O' level 4. Secondary 'A' level 5. Tertiary Institution/ Diploma 6. University/Degree
A15	What is the main source of income for your household?	
A16	What is your average monthly household income _______Shs?	1. 0 - 150,000 2. 151,000 - 300,000 3. 301,000 - 700,000 4. 701,000 - 1,200,000 5. Above 1,200,000
A17	Does the household receive any remittances from family elsewhere?	1. Yes 2. No (If NO go to A20)
A18	If yes from whom?	
A19	How much is received per month?	
A20	In the last month, did the household need to borrow money? If yes, how much?	
A21	Could you please tell me whether you live in:	1. Own house 2. Rented house
A22	What is the type of your house	1. Permanent 3. Semi-Permanent 2. Temporary 4. Other
A23	Which of the following items does your household have? **(Multiple responses allowed)**	1. Cows 6. Goats 2. Chicken 7. Sheep 3. Radio 8. Turkey 4. Bicycle 9. Motorcycle 5. Other items
A24	How many children have you had up to now in your life?	
SECTION B: KNOWLEDGE, ATTITUDE AND PRACTICE TOWARDS EPILEPSY		
Epilepsy has become a much more common problem in many communities in Uganda. We would like to understand more about how households like yours are coping with the problem.		
B1	Have you heard about epilepsy?	1. Yes 2. No
B2	Where did you hear it?	1. Radio 2. TV 3. Seminar/workshop 4. Word of mouth 5. Others ....
B3	Could you please describe what epilepsy is?	
B4	What do you think are the causes of epilepsy in your home/community?	1. Witchcraft 2. Accident 3. Malaria 4. Don't know 5. Others (specify)
B5	I don't want to know who, but do you have people in this household with epilepsy?	1. Yes 2. No ***(Go to B8)***
B6	If yes, indicate the number of children suffering from epilepsy below?	1. Boys................ 2. Girls ....
B7	If yes, indicate the number of adults suffering from epilepsy below?	1. Male .... 2. Female ....
B8	Do you know other families housing people living with epilepsy around you?	1. Yes 2. No (If NO go to B17)
B9	If yes, on average how many families?	
B10	Have you/they ever gone for treatment?	1. Yes 2. No

B11	If yes, Where did you/they go for treatment?	1. Traditional 2. Health Centre/clinic 3. Hospital 4. Religious institution 5. None 6. Others specify
B12	What type of medicine/drugs did you/they get?	1. Herbs 4. Urine 2. Injections 5. Tablets 3. Others (specify).........................
B13	How long have you/they been taking this drug?	1. Six months 2. Less than a year 3. More than two years
B14	When do you/they take drugs?	1. Daily 2. After a fit 3. When I have the drugs 4. Others ....
B15	How often do you /they get fits/seizures?	1. Daily 2. Weekly 3. Monthly 4. Yearly 5. Others ....
B16	Do you think there has been some improvement	1. Yes 2. No
B17	Do you think there are formal drugs for this disease?	1. Yes 2. No
B18	If you were given an option to choose where to go/take your patient for treatment, where of these places would you go?	1. Government health units/hospitals 2. Traditional doctors 3. Religious institutions 4. No where
B19	In the past year, have you discussed issues of epilepsy with your children or family members?	1. Yes 2. No 3. No children of ages below 10
B20	Do you think other family members can get epilepsy from one of the family member living with it at home?	1. Yes 2. No
B21	In the last 12 months have you felt like you wanted to do anything to decrease your suffering with epilepsy?	1. Yes 2. No (If NO go to B24) 3. No response given
B22	If YES, What did you try to do? [Do not read out list] Mark all mentioned	1. Sought for medication 2. Talked to my friends about epilepsy 3. Talked to the doctor. 4. Other
B23	How successfully do you feel you were able to change your life in the ways that you wanted?	1. Very successfully 2. Quite successfully 3. Not very successfully 4. Not at all 5. No response
B24	If NO, Why not	1. Hadn't thought about it 2. Don't think it's necessary 3. Find difficult to talk about my situation. 4. Other
B25	Have you ever participated in a march, rally or meeting around epilepsy awareness?	1. Yes 2. No 3. Don't Know 4. No Response
B26	Have you ever been involved in the organization of such a meeting or gathering?	1. Yes 2. No 3. Don't Know 4. No Response
B27	Have you ever thought about your own potential risk of epilepsy?	1. Yes 2. No 3. Don't Know 4. No Response
B28	If you were to consider that question now would you consider yourself at high, medium, low or no risk at all of epilepsy?	1. High 2. Medium 3. Low 4. No risk 5. No response

B29	If you are married, has your spouse ever threatened to divorce you because of epilepsy?	1. Yes 2. No
B30	What other marital problems have you experienced?	1. Neglect 2. Physical harassment 3. Marital infidelity 4. None 5. Other
	How do people relate with persons with epilepsy in their households in this community?	
B31	Do they have their own separate room or hut?	1. Yes 2. No 3. Don't know
B32	Do they have their own eating utensils?	1. Yes 2. No 3. Don't know
B33	Do they have their Utensils washed separately?	1. Yes 2. No 3. Don't know
B34	Do they eat in a separate place?	1. Yes 2. No 3. Don't know
B35	DO they have their own basins?	1. Yes 2. No 3. Don't know
B36	Do they have their clothes washed separately?	1. Yes 2. No 3. Don't know
	How do people relate with a person with epilepsy in the wider community?	
B37	Can a child play with others?	1. Yes 2. No 3. Don't know
B38	Can a child go to school?	1. Yes 2. No 3. Don't know
B39	Can an adult drink with others?	1. Yes 2. No 3. Don't know
B40	Are the patients expected to do heavy work?	1. Yes 2. No 3. Don't know
B41	Can they marry?	1. Yes 2. No 3. Don't know
B42	Can they have children?	1. Yes 2. No 3. Don't know
B43	Can they become leaders?	1. Yes 2. No 3. Don't know
B44	Can they inherit from others?	1. Yes 2. No 3. Don't know
B45	If a patient has cured, does some of that social stigmatization still apply?	1. Yes 2. No 3. Don't know
B46	If yes specify which ones still apply	
B47	If a patient with epilepsy died is he/she buried differently?	1. Yes 2. No 3. Don't know
B48	If yes are they buried with	1. With their belongings 2. Separated place 3. Different rituals 4. Others specify ....
B49	Would you be an heir to an epileptic person?	1. Yes 2. No
B50	Would you inherit the property of a dead Epileptic relative?	1. Yes 2. No 3. Don't know
B51	Do you think epilepsy can be transmitted from a person who has cured?	1. Yes 2. No 3. Don't know
B52	Which other disease condition has a similar social Stigma/discrimination like epilepsy in your community?	
B53	Do you think epilepsy is infectious?	1. Yes 2. No
B54	If Yes, when does a person with Epilepsy transmit it to others?	1. During the fit 2. Casual contact with others even when not fitting 3. Through sexual intercourse 4. I don't know 5. Others specify
B55	Are particular body products of a person with Epilepsy implicated / contaminated?	1. Yes 2. No
B56	If yes which ones?	1. Saliva 2. Urine 3. Faces 4. Gas 5. Others specify. ....
B57	Which people are more at the risk of contracting Epilepsy from a person with it?	1. Blood relatives 2. Spouse 3. All people who get into contact with him/her 4. I don't know

B58	What would you do if you found a patient fitting?	
B59	Can Epilepsy be treated?	1. Yes 2. No
B60	Can Epilepsy be cured?	1. Yes 2. No
B61	Have you/ member(s) of your family ever fallen down for no apparent reason?	1. Yes 2. No
B62	Have you/member(s) of your family ever had sudden loss of consciousness?	1. Yes 2. No
B63	After falling what did people around say about what happened?	
B64	Have you/member(s) ever experienced difficulties remembering what might have happened to you over a period of time say from a few minutes to between one to three hours?	1. Yes 2. No
B65	Is your health and behaviour return to normal between episodes?	1. Yes 2. No
B66	Have your child(ren) ever had repeated episodes of dropping things e.g. plates, cups, food etc.?	1. Yes 2. No
B67	Have the child(ren) ever had repeated periods of staring in space and they are unresponsive (cannot talk)?	1. Yes 2. No
SECTION C: SUPPORT TO THE HOUSEHOLD		
C1	What is the role-played by the extended family in helping affected households cope with reduced income?	
C2	Has the household asked for some help within the last 12 months?	1. Yes 2. No
C3	If yes whom?	1. Relatives 2. Neighbours 3. Freinds
C4	What sort of help was sought?	1. Money 2. Clothing 3. Food 4. Shelter 5. Medical Care
C5	How would you rate the ease of obtaining help from relatives and friends?	1. Very difficult 2. Not easy 3. Very easy
C6	What in your opinion is the main reason community help may not be forthcoming?	1. Lack of money because of unemployment 2. Fear to associate with families affected with Epilepsy.
C7	Are there instances when some household members in an Epilepsy affected households have been sent to stay out of home?	1. Yes 2. No (If not go to C12) 3. Don't know
C8	If yes, where were the members sent?	
C9	Why were the members sent?	
C10	Has the household drawn on savings as a copying mechanism during severe epilepsy attacks?	1. Yes 2. Don't know 3. No
C11	Has the household sold assets as a copying mechanism for medication and survival?	1. Yes 2. Don't know 3. No
C12	Has the household received any help to supplement their own household efforts?	1. Yes 2. Don't know 3. No (If not go to D1)
C13	If Yes From who did they receive this help?	1. Relatives 2. Friends 3. Neighbors

SECTION D: EFFECTS OF AND COPING MECHANISMS TOWARDS EPILEPSY	
	Individual level
D1	What has been the effect of epilepsy to the affected person (probe for effects on feeding, health, psychological comfort, income, employment, participation in society activities, education etc)
D2	How has the individual coped with these effects (identify a coping mechanism for each effect)
D3	What are the gaps/loopholes in the coping mechanisms adopted?
D4	Since epilepsy is still with us, suggest the most suitable coping mechanisms that would reduce the suffering brought by epilepsy at individual level.
	Household level coping
D5	What has been the effect of epilepsy to the household (probe for effects on feeding, health, psychological comfort, income, employment, participation in society activities, education, status in society, etc)
D6	How has the household coped with these effects (identify a coping mechanism for each effect)
D7	What are the gaps/loopholes in the coping mechanisms adopted?
D8	Since epilepsy is still with us, suggest the most suitable coping mechanisms that would reduce the suffering brought by epilepsy at household level
	Community coping
D9	What has been the effect of epilepsy to the community (probe for effects on feeding, health, psychological comfort, income, employment, participation in society activities, education etc)
D10	How has the community coped with these effects (identify a coping mechanism for each effect)
D11	What are the gaps/loopholes in the coping mechanisms adopted?
D12	Since epilepsy is still with us, suggest the most suitable coping mechanisms that would reduce the suffering brought by epilepsy at community level

HEALTH FACILITIES

EPILEPSY AND COPING STRATEGIES IN UGANDA
Health workers Questionnaire

Instruction: Speak To Any Adult professional (18 years and above) of the Health Units

Name of Interviewer: ______________________________

Date of interview: …../…../2005 Time Start ……….. Time end………

Introduction:

Dear Sir/Madam
Hello, my name is ____________________, Epilepsy Support Association of Uganda is conducting a national survey on prevalence of epilepsy and the nature of the health facilities available for persons living with epilepsy. You have been selected for this study on behalf of the community your opinion is very important and all responses will be treated with utmost confidentiality.

SECTION A: IDENTIFICATION		
A1	District	
A2	Name of Sub county	
A3	Name of Parish	
A4	Name of LC1 (village)	
A5	Name of respondent	
A6	Gender of the Respondent	1. Male 2. Female
A7	Age of respondent in completed years	……………………………….
A8	Marital status of respondent	1. Married 2. Un married 3. Widow /widower 4. Divorced/separated
A9	What is your highest level of Education?	1. None 2. Primary 3. Secondary 'O' level 4. Secondary 'A' level 5. Tertiary Institution/ Diploma 6. University/Degree
A10	What is your religion?	1. Protestant 2. Catholic 3. Muslim 4. Seventh day Adventist 5. Pentecostal 6. African Traditional Religion 7. Others

1 Name of the health facility: ______________________________

2 Level of the facility:

a) Health centre II ☐
b) Health centre III ☐
c) Health centre IV ☐
d) Hospital ☐
e) Regional ☐
f) Referral ☐
g) National referral ☐

3 Location:

Region: **District:** **Sub-county:** **Parish:**

4 Who is in charge of the epilepsy program at this facility?

5 What are the facilities for epilepsy in your health facility?

(i) In-patient

(ii) Out Patient

(iii) Community outreach

6 How many persons with epilepsy did you see in the previous 12 months?

(i) In patient

(ii) Out patient

(iii) Community outreach

7 a) Do you see patients with epilepsy in a separate clinic?

Yes ☐ No ☐

b) If no where do you see them?

(i) In patient __________ (ii) Out-patient __________(iii) Outreach __________

c) If yes why? ____

8 What are the sources of your referrals?

a) Village health team	b) Local councils
c) Self referral	d) Fellow patient
e) Family	f) Religious institutions
g) Schools	h) others specify

9 What activities do you offer?

a) Health education	b) counseling
c) Give drugs	d) Home visit
e) Resettlement	f) Training of other health workers
g) Training of village health teams	

10 Do you have diagnostic and treatment guidelines for epilepsy?

Yes: No:

11 a) Have received training in the treatment of epilepsy?

Yes: No:

b) If yes which training did you get?

i) Basic: ii) In-service: iii) Refresher course:

iv) Others specify:

12 Attitudes of the health worker

- (a) Should a child play with others? Yes: No:
- (b) If no why: ____________________
- (c) Should an adult drink with others? Yes: No:
- (d) Should a patient with epilepsy be treated with other general patients? Yes: No:

- (e) Are patients expected to work much? Yes: No:
- (f) Should they marry? Yes: No:
- (g) Should they have children? Yes: No:
- (h) Should they go to school? Yes: No:
- (i) Can they inherit from others? Yes: No:
- (i) Can epilepsy be treated? Yes: No:
- (k) Can epilepsy be cured? Yes: No:

12 i) If no for any of the above reasons why?

13 How would you react/respond if a person with epilepsy got a seizure?

14 Drug treatment

What drugs are used in the treatment of Epilepsy?

Phenobarbitone:
Sodium Valproate:
Carbamazepine:
Ethosuxamide:
Gabapentine:
Diazepam rectol:
Diazepam oral:
Diazepam injectable:
Sodium amytal:
Others specify: ____________________

15 What drugs do you have for the treatment of epilepsy in your hospital?

Phenobarbitone:
Sodium Valproate:
Carbamazepine:
Ethosuxamide:
Gabapentine:
Diazepam rectol:
Diazepam oral:
Diazepam injectable:
Sodium amytal:
Others specify: ____________________

16. How long do you operate when the drugs are out of stock in your facility?

i) 1 week: ii) 2-4 weeks: iii) 5-8 weeks: iv) 9-12weeks: v) 13 weeks +:

17 a. Do you have a budget for epilepsy drugs? Yes ☐ No ☐

17 b. If yes how much?

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17 c. Is that adequate? Yes ☐ No ☐

18. Does your health facility consider anti-epileptics as priority drugs?

Yes ☐ No ☐

19 a. What do you think should be done about epileptic services in your health facility?

a) Should greatly be improved:
b) Should relatively be improved:
c) Should not change:
d) Should be removed:
e) I don't know:

19 b. If the answer is a) what should be done to improve the management of epilepsy?

---

20. Do you have an epileptic register? Yes ☐ No ☐

21a. Do you report in the Health Management information System?

Yes ☐ No ☐

21b). If no why?

....

22. Who should treat people with epilepsy?

a) Physician ☐
b) Psychiatrist ☐
c) Clinical psychiatrist ☐
d) CO ☐
e) MO ☐
f) Psychiatric nurse ☐

FOCUS GROUP DISCUSSION GUIDING TOPICS

- The relationship between Epilepsy and Education
- Community Understanding of Epilepsy
- Community understanding o the causes of epilepsy
- Availability of and access to drugs
- Marriage and epilepsy
- Parents and children with epilepsy
- The relationship between a person living with epilepsy and the family and the community
- Coping strategies of people living with epilepsy and their families
- General recommendations for betterment of lives of people living with epilepsy