

# Knowledge, attitude, and beliefs on epilepsy among adults in Erute South, Lira District, Uganda

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## SUMMARY

**Objective:** To assess the knowledge, attitudes, and beliefs of adults on epilepsy in Erute South County, Lira District, Uganda.

**Methods:** A cross-sectional study was conducted in rural Erute South County. Two hundred seventeen of 220 randomly selected adults 18 years or older participated in the study. A standardized self-administered questionnaire (Attitudes towards persons with Epilepsy “ATPE”) was used for data collection. Protocol approval was sought from International Health Sciences University, and informed consent was obtained from participants at all times.

**Results:** Two hundred seventeen of 220 invited community members completed the study. Females comprised the majority 51.6%. Most of the respondents had a low level of knowledge on epilepsy. The mean ATPE scale knowledge score was 4.57 (standard deviation [SD] = 3.24) of a maximum score of 11. The male respondents almost had mean knowledge scores almost equal to their female counterparts (4.23, SD = 2.48; 4.51, SD = 2.54, respectively). Most respondents had negative attitudes toward epilepsy, with a mean ATPE attitude score of 73.2 (SD = 2.11) of a possible maximum score of 126. The mean attitude scores for the male and female respondents were 58.18 (SD = 4.23) and 86.62 (SD = 5.23), respectively. Most respondents had negative beliefs such as attributing epilepsy to supernatural spirits, heredity, and preference of traditional medicine and healers to conventional medicine as a treatment for epilepsy. A significant number of respondents expressed sympathetic feelings toward people living with epilepsy, specifically tolerance and kindness to those living with epilepsy.

**Significance:** Findings could benefit policymakers, the district health team, researchers, community members, affected families, and people with epilepsy in designing awareness strategies. Knowledge on epilepsy could improve the quality of life and care for people living with epilepsy, through reducing misconceptions and stigmatization in the communities where they live.

**KEY WORDS:** Knowledge, Attitude, Beliefs, Epilepsy, Africa.



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Epilepsy is defined as a disease of the brain characterized by the presence of the following: (1) at least 2 unprovoked seizures occurring >24 h apart; (2) one unprovoked seizure and a probability of further seizures similar to the general recurrence risk of at least 60% after 2 provoked occurring over the next 10 years; (3) diagnosis of an epilepsy syndrome.<sup>1</sup> Epilepsy affects approximately 50 million people worldwide, making it the most common neurological disorder globally.<sup>2</sup> Most people with epilepsy (PWE) live in low- and middle-income countries.<sup>2</sup>

## KEY POINTS

- Knowledge on epilepsy is still low among adults in Uganda
- Epilepsy is still attributed to evil spirits
- Negative attitudes and misconceptions about epilepsy seem to coexist

In the United States, the prevalence of epilepsy is approximately 6 to 8 per 1,000 population, with higher rates among infants and persons older than 60 years of age.<sup>2</sup>

Causes of epilepsy include stroke, head trauma, alcohol, neurodegenerative diseases, encephalopathy, brain tumors, and infection.<sup>2,3</sup>

Epilepsy is a common disorder among adults and in childhood. In children there is an estimated prevalence of 300–600 per 100,000.<sup>2</sup>

According to the International League Against Epilepsy (ILAE), seizure types and epilepsy syndromes are classified based on clinical grounds, biochemical tests, and neurophysiologic and radiographic studies.<sup>4</sup> There are 2 broad categories of seizures: focal (or partial) and generalized seizures.<sup>3,4</sup>

People living with epilepsy (PWE) and their next of kin should have knowledge of the availability of antiseizure drugs, drug-drug interactions, causes of epilepsy, and adverse effects of these management modalities.<sup>3</sup>

Communities and family members are important in providing information on behavioral or environmental factors that trigger seizures among PWE. They can provide information on seizure triggers such as sleep deprivation, alcohol intake, and stress.<sup>5,6</sup> This information is important for the health care team during the assessment of epilepsy.

Such information is important in diagnosis and epilepsy treatment.

Misconceptions continue to prevail in communities, which leads to poorly managed epilepsy, and thus many epileptic patients continue to get seizures. This creates a treatment gap that triggers patients and their caretakers to seek alternative sources of treatment such as cannabinoids.<sup>7,8</sup>

The burden of epilepsy in sub-Saharan Africa is high. A study in Kenya reported a lifetime epilepsy prevalence of 20.9 per 1,000 and that of active epilepsy was 11.5 per 1,000.<sup>9</sup> A cross-sectional study conducted among 3,000 adult Ugandans in the rural and urban Mukono district showed that the prevalence of epilepsy was 8.5% from a sub-sample of 98 respondents with confirmed neurological disorders.<sup>10</sup>

Although the causes of stigma toward epilepsy among the population are complex, lack of knowledge has been considered an important determinant of negative attitudes toward PWE. There is a need to ascertain the knowledge, attitude,

and beliefs about epilepsy so as to inform policymakers and service providers on the community's needs with regard to causes, transmission, and treatment of epilepsy. The aim of this study was to assess the knowledge, attitudes, and beliefs of adults with regard to epilepsy.

## METHODOLOGY

### Study design

The study used a cross-sectional design. Data collection was conducted from April to July 2017.

### Study area

The study was conducted in Erute South County, a rural village located in the eastern part of Lira District. Erute South County is one of the 4 counties that form Lira District. Lira District is located in the Lango sub-region in Northern Uganda and is bordered by the districts of Pader, Otuke, Alebtong, and Apac. The setting constitutes part of the region affected by the war against rebels of the Lord's Resistance army in Northern Uganda.

### Study population

The study population was predominantly a rural population comprising of members of the community of Erute South. *Inclusion criteria:* Community members of Erute South, above 18 years, who had lived in the area for more than one year were included in the study. *Exclusion criteria:* community members with major mental illnesses such as schizophrenia were excluded from the study.

### Sampling technique

Simple random sampling techniques were used to select the participants. A list of community members was obtained from the Local Council Authority and this was used as the sampling frame. A list of random numbers was used to select the participants from the sampling frame. This was done until the sample size was reached. A sample size of 220 was required for this study.

The Village Local Council Leaders communicated to the community about the study during village meetings and during village rounds. After selection of the participants, the local leaders contacted the selected participants and gave the researcher directions to their homes. The researcher then administered the questionnaires at the homes of the participants.

### Data collection instruments

A structured questionnaire was developed from Antonak's tool of assessing Attitudes Towards Persons with Epilepsy (ATPE).<sup>11</sup> The final tool consisted of 4 parts. Part 1 assessed sociodemographic variables. Part 2 assessed knowledge regarding epilepsy. Part 3 assessed attitudes toward epilepsy. Part 4 assessed the beliefs toward epilepsy. The tool was pretested among 20 participants and

adjustments were done to the initial tool. The final tool was further validated by 4 experts at International Health Sciences University.

### Data analysis

The questionnaires were checked for completeness immediately after the interview. Data were then entered into Microsoft Excel; this was later exported to Statistical package for Social Scientists (SPSS) Version 20 for analysis. A 95% confidence interval was considered for the study.

### Ethical considerations

The research protocol was approved by the research and ethics committee of the School of Nursing of International Health Sciences University (IHSU). The researcher then introduced the protocol to the local authority with an introductory letter from IHSU for authorization to conduct the study in the area. In addition, informed consent was at all times availed to the participants before the interview and participation in the study was voluntary.

## RESULTS

Two hundred twenty participants were invited to participate; 217 completed the study. Therefore a 98.6% response rate was achieved in this study. Three participants declined to participate in the study. Demographic characteristics of the respondents in the study sample are summarized in Table 1. The median age of the respondents was 25 (18–75 years). Females comprised the majority 51.6%. Most respondents were aged between 26–35 years (49.3%).

With regard to marital status, most respondents were married (52.5%). Most respondents reported that they were unemployed (55.3%). Most respondents had attained a certificate in education (43.3%), whereas with regard to religion, most of the respondents were Christians. The Acholi constituted the majority tribe (52%).

Most respondents reported that they never had a family relative with epilepsy. Those who had a family member with epilepsy mostly reported that a male child or sibling had epilepsy (Table 1).

### Knowledge on epilepsy

All respondents had at least ever heard of epilepsy, primarily from a family member (32.7%) or friends (25.3%). The most common cause of epilepsy reported included evil spirits (40.2%) and inherited disease (30.2%). Other causes reported by the participants included mental retardation, mental illness, and other causes. The majority reported that they had never taken care of a person with epilepsy (Table 2).

Generally, the majority of the respondents had a low level of knowledge on epilepsy. The mean ATPE knowledge score was 4.57 (SD = 3.24) of a maximum score of 11. The male respondents almost had mean knowledge scores equal

to the female counterparts (4.23, SD = 2.48; 4.51, SD = 2.54, respectively).

### Attitude toward epilepsy

The mean ATPE scale attitude score for the entire sample was 73.2 (SD = 2.11) of a possible maximum score of 126. The mean attitude scores for the male and female respondents were 58.18 (SD = 4.23) and 86.62 (SD = 5.23), respectively. The majority of the respondents had wrong attitude toward staying with a person with epilepsy; they reported that staying with PWE is not good (61.7%). However, most respondents reported that PWE should not be discriminated in society (96.3%). Most participants reported that they wouldn't help a person with epilepsy during a seizure, whereas the majority agreed that PWE should also have a family (Table 3).

### Beliefs on epilepsy among respondents

With regard to beliefs toward epilepsy, most of the respondents reported that they believed that PWE have good capabilities (50.7%). Indeed, the majority believed that PWE are allowed to associate with others in the society (94%) (Table 4).

More than a half of the respondents had a negative belief toward the marital plight of PWE. They reported that they couldn't accept a close relative marrying a person with epilepsy (86.6%,  $n = 188$ ). On the other hand, most believed that persons with epilepsy should have children (56.2%).

Socially, most respondents (86.1%) had a positive belief toward associating with persons living with epilepsy during social gatherings. More than half (88.9%) of the respondents reported that they could change their beliefs and attitude toward epilepsy with proper acquaintance of knowledge on epilepsy. The majority (89.4%) believed that they could have a person with epilepsy as a close friend.

The majority of the families harbored negative beliefs such as intolerance, attributing epilepsy to possession by spirits, and preferred to treat epilepsy with the help of traditional healers and herbal medicine. Heredity was also identified as one of the causes of epilepsy (Table 4).

On the other hand, most of the respondents had sympathy, tolerance, and kindness towards PWE. Forty-five percent of the respondents were sympathetic toward the plight of persons with epilepsy, with females showing more inclination for sympathy compared to their male counterparts. The female respondents, however, tended to be more fearful and suspicious and to avoid the persons with epilepsy more than their male counterparts did (Table 4).

## DISCUSSION

This study provides important information on the knowledge, attitude, and beliefs on epilepsy among an adult sample from a war-affected area in Northern Uganda. The study setting is a rural village with many of its members having

**Table 1. Demographic characteristics of the respondents in Erute South County, Lira District, Uganda (N = 217)**

Characteristics	Frequency (n)	Percentage (%)
Age in years		
18–25	80	36.8
26–35	107	49.3
Above 35	30	13.9
Gender		
Male	105	48.4
Female	112	51.6
Marital status		
Single	57	26.3
Married	114	52.5
Widowed	12	5.5
Separated	15	7.0
Divorced	19	8.7
Employment status		
Employed	97	44.7
Unemployed	120	55.3
Level of education		
None	30	13.8
Certificate	94	43.3
Diploma	70	32.2
Degree	23	10.7
Religion		
Muslim	20	9.2
Traditionalist	10	4.6
Christian	172	79.3
Other	15	6.9
Tribe		
Langi	74	34.1
Acholi	113	52.0
Other	30	13.9
Had a family member affected by epilepsy		
Yes	20	9.2
No	197	90.8
Relationship with family member with epilepsy		
Mother	2	10
Father	4	20
Sister	4	25
Brother or male relative	6	20
Other	5	25

experienced some effects of war such as psychological stress and trauma. The demographic characteristics of the sample are similar to those from the recent national population survey in terms of gender, age, level of education, and employment status.<sup>12</sup> Our study demonstrates a low knowledge on epilepsy among adults. The male respondents had mean knowledge scores almost equal to that of their female counterparts. This is lower than that reported among a Ghanaian cohort.<sup>8</sup> Our study demonstrates a need to health educate people on the causes, transmission, and management of epilepsy so as to modify their knowledge on epilepsy.

**Table 2. Awareness on epilepsy among adults in Erute South County, Lira District, Uganda**

Variable	Frequency	Percentage
Ever heard of epilepsy		
Yes	217	100
No	00	0
Source of information		
Friend	55	25.3
Family member	71	32.7
Newspaper	16	7.3
Television	25	11.5
Radio	50	23.0
Causes of epilepsy		
Evil spirits	87	40.2
Mental retardation	15	6.7
Mental illness	10	4.6
Inherited disease	65	30.2
Other	40	18.3
Ever had a member of family with epilepsy		
Yes	22	10.1
No	195	89.9
What was the relationship with member of family with epilepsy (n = 22)**		
Mother	4	18.8
Father	3	13.6
Sister	2	9.09
Brother	6	27.3
Child	7	31.8
Ever taken care of person with epilepsy		
Yes	20	9.2
No	197	90.8

N = 217.  
\*\*Only respondents who reported to have ever had a family member with epilepsy.

Emerging evidence on sources of information on epilepsy from our study findings indicated that family members and friends were the most common sources of evidence on epilepsy. This could ultimately help interventionists to design appropriate strategies of creating awareness on epilepsy.

The most common cause of epilepsy reported included evil spirits and inherited disease. This is similar to findings reported from Winkler's study conducted in a rural community in northern Tanzania. A significant number of respondents (46.7%) reported that epilepsy was due to supernatural causes.<sup>13</sup> A similar study in Kenya also noted that many people associated epilepsy with witchcraft.<sup>12</sup>

The majority reported that they had never taken care of a person with epilepsy. This could be attributed to a lack of knowledge on how to live and care for PWE. On the other hand, misconceptions on the causes of epilepsy such as evil spirits could limit some person from caring for a person with epilepsy. Similar studies conducted in Uganda also reported

**Table 3. Attitudes toward epilepsy among adults in Erute South County, Lira District, Uganda**

Attitude	Frequency (n)	Percentage (%)
Living with a person with epilepsy is not good		
Agree	134	61.7
Disagree	83	38.3
Epilepsy occurs following alcohol/drug abuse.		
Agree	13	6.0
Disagree	204	94.0
Do you think that society should discriminate persons with epilepsy		
Agree	8	3.7
Disagree	209	96.3
Willing to help people with epilepsy during an episode of a seizure		
Agree	22	10.13
Disagree	195	89.87
Persons with epilepsy should have families		
Agree	211	97.2
Disagree	6	2.8
N = 217.		

that respondents had ever heard of epilepsy but attribute it to supernatural causes.<sup>10,14</sup>

### Attitude toward epilepsy

Given the low level of knowledge on epilepsy, it is not surprising that the mean ATPE scale attitude score for the entire sample was moderate. These unfavorable attitudes can in turn lead to neglecting PWE and stigma in the community. Various studies have also reported similar findings from different communities.<sup>13–16</sup> Many organizations including the office of the Prime Minister are working in this area to improve literacy and livelihood of the people living in the war-torn Northern Uganda.<sup>17</sup> Organizations working in the war affected northern region of Uganda could benefit from finding on the level of knowledge, attitude and beliefs of community members on epilepsy.

The majority of the respondents had a wrong attitude toward staying with a person with epilepsy, indicating that it was not good. While most respondents disagreed that that society should discriminate persons with epilepsy. Most participants reported that they wouldn't help a person with epilepsy during a seizure, whereas a majority agreed that persons with epilepsy should have a family. This is right, since persons with epilepsy if properly managed can live a good quality of life.

### Beliefs on epilepsy among respondents

This study unveiled that many people had positive beliefs about the capabilities and social life of PWE. Indeed, people

**Table 4. Beliefs on epilepsy among adults in Erute South County, Lira District, Uganda**

Belief categories	Frequency (n)	Percentage (%)
Capabilities of persons with epilepsy		
Good	110	50.7
Moderate	36	16.5
Poor	71	32.8
Persons with epilepsy allowed to associate with others		
Yes	204	94
No	3	6
Would you object to a person with epilepsy marrying a close relative		
Yes	29	13.4
No	188	86.6
Persons with epilepsy should have children		
Yes	122	56.2
No	40	18.4
Not sure	55	25.4
Associate with persons with epilepsy in social gatherings		
Yes	187	86.1
No	30	13.9
I would change my attitude to an acquaintance with proper knowledge on epilepsy		
Yes	193	88.9
No	24	11.1
I could have a person with epilepsy as a close friend		
Agree	194	89.4
Disagree	23	10.6
What would you prefer as a treatment for epilepsy?		
Medical treatment	104	47.9
Traditional medicine or healers	113	52.1
N = 217.		

with epilepsy have good functional status in the absence of seizures and can perform activities of daily living normally. This finding is similar to that reported in Kolahi's study conducted in a teaching hospital among mothers of children with epilepsy.<sup>16</sup>

On the other hand, negative beliefs existed toward the marital plight of PWE. However, the majority believed that persons with epilepsy should have children. The objection to marrying PWEs could be due to the negative attitudes and low knowledge on epilepsy in the community. This finding is in line with that of Berhe<sup>18</sup> reported about an Ethiopian community.

Most respondents noted they could socialize with PWE during social gatherings and could accept PWE as friends. Ideally, PWE can socialize with others easily in the absence of seizures and are usually not violent.



The fact that more than half of the respondents reported that they could change their beliefs and attitudes toward epilepsy with proper acquaintance of knowledge on epilepsy is a good indicator that interventionists can use to create awareness.

Most respondents expressed sympathy for PWE. Similar findings have been reported in other studies.<sup>15,17,19,20</sup> The female respondents, however, tend to be more fearful. Public beliefs and stigma toward epilepsy may limit patient motivation for treatment and participation in social activities.<sup>21</sup>

The study showed that there is low knowledge, negative attitudes, and misconceptions about the causes, treatment, and other aspects of epilepsy in Uganda. Therefore, there is need to educate the communities on epilepsy. Community awareness campaigns should be directed toward improving knowledge on cause, management, and transmission of epilepsy.

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## DISCLOSURES

The authors declare that they have no competing interests. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

## AUTHORS CONTRIBUTIONS

Both authors took part in conception, design, and the final version of the manuscript. FK was involved in literature review, data analysis, and writing of the manuscript, while ACO was involved in methodology and writing of the manuscript.

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## REFERENCES

1. Fisher RS, Acevedo C, Arzimanoglou A, et al. ILAE official report: a practical clinical definition of epilepsy. *Epilepsia* 2014;55:475–482.
2. WHO. Epilepsy fact sheet: World Health Organisation, 2017. Available at <http://www.who.int/mediacentre/factsheets/fs999/en/> accessed on 12.11.2017.
3. Schachter S. Overview of management of epilepsy in adults. Upto date. Available at: [https://www.uptodate.com/contents/overview-of-the-management-of-epilepsy-in-adults?search=epilepsy&source=search\\_result&selectedTitle=2-150&usage\\_type=default&display\\_rank=2#H1](https://www.uptodate.com/contents/overview-of-the-management-of-epilepsy-in-adults?search=epilepsy&source=search_result&selectedTitle=2-150&usage_type=default&display_rank=2#H1) accessed on 02.01.2018.
4. Fisher RS, Cross JH, French JA, et al. Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology. *Epilepsia* 2017;58:522–530.
5. Privitera MD, Welty TE, Gidal BE, et al. Generic-to-generic lamotrigine switches in people with epilepsy: the randomised controlled EQUI-GEN trial. *Lancet Neurol* 2016;15:365.
6. Lamberink HJ, Otte WM, Geleijns K, et al. Antiepileptic drug withdrawal in medically and surgically treated patients: a meta-analysis of seizure recurrence and systematic review of its predictors. *Epileptic Disord* 2015;17:211.
7. Friedman D, Devinsky O. Cannabinoids in the treatment of Epilepsy. *Nemj* 2015;373:1048–1058.
8. Dugbartey AT, Barimah KB. Traditional beliefs and knowledge base about epilepsy among university students in Ghana. *Ethn Dis* 2013; 23:1–5.
9. Kind CJ, Newton CRJC, Kariuki SM. Prevalence, risk factors and neurobehavioral comorbidities of epilepsy in Kenyan children. *Epilepsia Open* 2017; 2:388–399.
10. Kaddumukasa M, Mugenyi L, Kaddumukasa MN, et al. Prevalence and incidence of neurological disorders among adult Ugandans in rural and urban Mukono district; a cross-sectional study. *BMC Neurol* 2016;16:227.
11. Uganda Bureau of Statistics. The National Population and Housing Census 2014—Main Report. 2016.
12. Winkler AS, Mayer M, Schnaitmann S, et al. Belief systems of epilepsy and attitudes toward people living with epilepsy in a rural community of northern Tanzania. *Epilepsy Behav* 2010;19:596–601.
13. Nyakwana TDO, Simbauni JA, Jowi JO. Factors underlying stigmatization of epilepsy: A comparative case study of Suba and Meru Central Districts, Kenya. *ASRJETS* 2015; 9:88–105.
14. Bigelow J, Berrett S, Kimuli I, et al. Perceptions of epilepsy among first-year medical students at Mulago Hospital in Kampala, Uganda. *Epilepsy Behav* 2015;51:28–32.
15. Kolahi A, Abbasi-Kangevari M, Bakhshaei P, et al. Knowledge, attitude and practices among mothers of children with epilepsy: A study in a teaching hospital. *Epilepsy Behav* 2017;69:147–152.
16. Gelsdorf K, Maxwell D G, Mazurana D. *Livelihoods, basic services and social protection in Northern Uganda and Karamoja*. London: Secure Livelihoods Research Consortium; Overseas Development Institute; 2012.
17. Berhe T, Yihun B, Abebe E, et al. Knowledge, attitude and practice about epilepsy among teachers at Ethio-National School, Addis Ababa, Ethiopia. *Epilepsy Behav* 2017;70:150–153.
18. Kartal A. Knowledge of perceptions of, attitudes and practices regarding epilepsy among medical students in Turkey. *Epilepsy Behav* 2016;58:115–118.
19. Hijazeen JK, Abu-Helalah MA, Alshraideh HA, et al. Knowledge, attitudes and beliefs about epilepsy and their predictors among university students in Jordan. *Epilepsy Behav* 2014;41:238–243.
20. Maiga Y, Albakaye M, Diallo LL, et al. Current beliefs and attitudes regarding epilepsy in Mali. *Epilepsy Behav* 2014;33:115–121.
21. Antonak RF. Psychometric analysis and validation of the scale of attitudes towards persons with epilepsy. *J Epilepsy* 1990;3:11–1612.