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Brief Communication

Perceptions of epilepsy among first-year medical students at Mulago Hospital in Kampala, Uganda

Jeffrey Bigelow [a,*,1], Sawyer Berrett [b], Ivan Kimuli [c], Elly Katabira [c]

[a] Yale-New Haven Hospital, 20 York Street, New Haven, CT 06510, USA
[b] Brigham Young University, Provo, UT 84602, USA
[c] Makerere University School of Medicine, Mulago Hospital, Kawempe, Kampala, Uganda

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ABSTRACT

Epilepsy is associated with stigma throughout the world, which leads to poor treatment of people with epilepsy (PWE). In Uganda, there are more than 75,000 PWE and a large treatment gap. This study evaluated the knowledge, attitudes, and practices regarding epilepsy among first-year medical students at Mulago Hospital. A 22-question survey was developed based on the previous studies of Birbeck et al.'s regarding the stigma of epilepsy in Zambia. This was administered to first-year medical students (96 respondents) at Mulago Hospital in Uganda. More than 80% said that they would not allow their children to marry PWE. Most respondents believed that epilepsy was a mental illness, and many believed that PWE cannot have normal intelligence. Students reported that there was a negative perception and negative treatment of PWE in the community. Some students believed that epilepsy was caused by supernatural causes and was contagious. These misperceptions must be identified and corrected among medical students and other healthcare providers to allow for fair treatment of PWE; this should be incorporated into medical school curriculums in Uganda.

1. Background

Epilepsy is estimated to affect 50 million people, and of these, 80% live in the developing world [1,2]. Throughout the world and different cultures, it has been demonstrated that epilepsy is often associated with stigma that leads to marginalization and poor treatment of people with epilepsy. In Sub-Saharan Africa, Birbeck and colleagues have demonstrated the stigma and incorrect perceptions of epilepsy among different populations in Zambia [3–7]; few studies have been done in other Sub-Saharan African countries.

In Uganda, epilepsy occurs at a rate of 2–5/1000 people with new epilepsy cases occurring in 156 among 100,000 person-years [8]; there are approximately 37.6 million people [9], which would mean that there are at least around 75,000 to 200,000 active cases of people with epilepsy (PWE). Epilepsy has been demonstrated to have a big social impact on PWE and their families in Uganda [10], and improving treatment for these patients has the potential of far-reaching consequences.

Numerous studies have demonstrated that, in developing countries worldwide, there is a large treatment gap and the majority of PWE are not diagnosed and treated; these untreated patients composed up to 95% of PWE in some countries. The epilepsy treatment gap shows a dramatic disparity in the care of epilepsy patients between high-income and low-income countries and between rural and urban settings [2]. There is one reported study in rural Uganda where, among 86 patients with epilepsy, there was a reported treatment gap of 100% [11].

Mulago Hospital is one of two major referral centers in Uganda and the primary teaching hospital for Makerere University, the oldest medical school in East Africa. Their academic curriculum comprised 3 preclinical years and 2 clinical years; the preclinical years include pharmacy and dental students, and an average class has 230 students, about 150 of which are medical students who are completing their clinical years. Students come from rural and urban regions all over the country and, sometimes, from neighboring East African countries. First-year medical students have not been exposed to most medical conditions and come to medical school with a preconceived set of values and beliefs about different disease conditions, representative of their own experience. These perceptions, including knowledge, attitudes, and practices, will presumably impact their interactions with patients and their families, either favorably or negatively. Understanding the first-year medical students' perceptions of epilepsy may be useful in developing medical school curricula and helping improve treatment of PWE.

2. Methods

The researchers developed a questionnaire, which included demographics and a combination of 22 open-ended and closed-ended

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[*] Corresponding author.
E-mail addresses: Jeffrey.bigelow@imail.org (J. Bigelow), sawyerberrett@gmail.com (S. Berrett), ikimuli@yahoo.com (I. Kimuli), katabira@infocom.co.ug (E. Katabira).

[1] Permanent address: Intermountain Medical Center, 5171 S Cottonwood St, Ste 810, Murray, UT 84107, USA.

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questions (see Appendix A). This was based on previous study tools developed by Birbeck and associates in Zambia regarding PWE [3,4]. This tool was further refined with guidance from Dr. Elly Katabira, faculty neurologist at Mulago Hospital in Uganda. The survey was translated into the most common local language, Luganda, and was approved for accuracy by 3 different Luganda-speaking health-care professionals. Questions were written in both Luganda and English on the survey handouts. The authors obtained an exemption/waiver of approval from the Internal Review Boards at Yale-New Haven Hospital in New Haven, Connecticut, USA and Mulago Hospital in Kampala, Uganda, in order to conduct the survey. This was considered a low-risk questionnaire as identifying information was not used in the survey.

A researcher traveled to Uganda to supervise the completion of surveys. It was the first week of medical school classes at Makerere University at Mulago Hospital for the new first-year medical students. The researcher presented the survey at the beginning of a lecture period to the first-year medical class. This group of students was chosen because they were naïve in their exposure to formal medical training; thus, their perceptions are not yet shaped by curricula. Students were given the survey tool, and these were filled out at that time and then collected as a group at the end of the aisles.

Study participants were given a brief explanation of the purpose of the study, a guarantee of confidentiality, and were told that they could refuse to answer any questions or withdraw their survey at any part of the process. Study participants were not offered any compensation for their participation in the study. By completing a survey, participants were giving their informed consent to take part in the study.

After study completion, surveys were assigned a numerical value, and responses were coded and quantified for analysis. The researchers coded qualitative data into quantifiable values. Several closed-ended answer options were condensed into groups (e.g., for religious affiliation "Catholic" and "Christian" were grouped under "Christian"). Open-ended answers were coded and similarly grouped into categories where appropriate (e.g., responses to a question about general community attitudes towards those with epilepsy similar to "viewed as cursed" or "viewed as insane" were grouped under "negative attitudes"). Percentages were calculated for data comparison purposes. Selected results are presented herein. Of note, in some questions, participants were able to choose more than one response; thus, percentages may add up to more or less than 100.

3. Results

A total of 96 surveys were completed by first-year medical students (Table 1). Around two-thirds of students claimed that they were from an urban as compared to a rural setting. Over 80% of the respondents identified themselves as Christian, with about 10% identifying as Muslim. The average age of medical students was around 20. Over 90% of the students were single. Of note, as reflected in the answered questionnaires, there was generally less than 7% missing data for any single question.

Personal social attitudes are summarized in Table 2. Most students said that they would allow their child to play with someone with epilepsy; however, over 80% said that they would not allow their child to marry someone with epilepsy. Respondents denied that children with epilepsy should never attend school, but many thought that it was situation-dependent. A slight majority of students thought that children with epilepsy could have a normal intelligence. A majority believed that epilepsy is a mental illness.

Respondents were asked about their perceptions as to how patients with epilepsy were treated by their families and communities (Table 3). The students were generally neutral in their perceptions of family treatment, and few believed that families would treat those with epilepsy in a negative fashion. With regard to the community, medical students had a strong perception of negative attitudes in the community and believed that the community treated most people with epilepsy poorly; the most common negative treatment mentioned was isolation of the person with epilepsy. Overall, the belief was that there existed overwhelming negative attitudes and treatments of the community towards those with epilepsy.

The medical students described many examples of poor treatment:

> "They say it is a contagious disease that cannot be cured. They think they are useless to the community."
>
> "They tend to isolate them."
>
> "They are taken as mentally disabled people who cannot go to school and practice day to day work."
>
> "Some fear them."
>
> "They love them as fellow family members but when it attacks the person they keep a distance."
>
> "The community thinks that they're possessed with evil spirits."
>
> "They discriminate them, because at home neighbors used to say our cousin was bewitched."

Personal knowledge regarding cause and contagiousness of epilepsy is summarized in Table 4. Close to half of the respondents thought that

Table 1
Demographics of first year medical students.

	(N = 96)
Average age	20.7
Sex	
Female	44 (46%)
Male	52 (54%)
Marital status	
Married	6 (6%)
Single	86 (90%)
Divorced	1 (1%)
Residence type	
City	63 (66%)
Rural	22 (23%)
Highest education level	
Primary	0 (0%)
Secondary	0 (0%)
College	96 (100%)
Religion	
Christian	81 (84%)
Muslim	10 (10%)
Other	5 (5%)

Table 2
Personal social beliefs of respondents regarding people with epilepsy.

	(N = 96)
Would you allow your child to play with someone with epilepsy?	
Yes	65 (68%)
No	29 (30%)
Would you allow your son or daughter to marry someone with epilepsy?	
Yes	13 (14%)
No	79 (82%)
A child with epilepsy can have a high level of intelligence.	
True	55 (57%)
False	34 (35%)
A child with epilepsy should never attend school.	
True	1 (1%)
False	50 (52%)
Situation-dependent	43 (46%)
Epilepsy is a mental illness.	
True	57 (59%)
False	35 (36%)

Table 3
Respondent perceptions of family and community attitudes towards people with epilepsy.

	(N = 96)
What are the general attitudes of families towards those with epilepsy?[a]	
Positive attitude	28 (29%)
Positive treatment	25 (26%)
Neutral	52 (54%)
Negative attitude	24 (25%)
Negative treatment	3 (3%)
Don't know	3 (3%)
What is the general attitude of the community towards those with epilepsy?[a]	
Positive attitude	9 (9%)
Positive treatment	7 (7%)
Neutral	1 (1%)
Negative attitude	79 (82%)
Negative treatment	48 (50%)
Don't know	3 (3%)

[a] Note: More than one attitude type was expressed by some students.

epilepsy was a brain disease and ran in families. Another common answer is that it was due to a brain or birth injury; many students answered that they did not know. With regard to supernatural causes of epilepsy (witchcraft, curse from God, or spirit possession), 4 respondents thought that it was witchcraft, and 5 believed that it was spirit possession. Participants were asked whether they thought that epilepsy was contagious; 19% of the medical students reported “always” or “sometimes” contagious. The most commonly believed mode of contagion was body contact, most specifically with bodily fluids.

Treatment-seeking behaviors and perceptions of treatment effectiveness were explored in Table 5. The overwhelming majority said that they would seek out biomedical treatment from a doctor for their family or friends. Some respondents were interested in seeking out a church healer, and only a handful said that they would go to a traditional healer. Most respondents believed that hospital or clinical treatment for epilepsy was sometimes or always effective. Despite reporting that they were unlikely to seek care from a traditional healer, a quarter of the students felt that traditional healers were sometimes effective in their treatments. Only around a third of the students felt that traditional healers were ineffective in treating epilepsy.

Table 4
Respondent knowledge regarding cause and contagiousness of epilepsy.

	(N = 96)
What do you think is(are) the cause(s) of epilepsy?[a]	
Madness	0 (0%)
Mental retardation	10 (10%)
Brain disease	43 (45%)
Brain injury	29 (30%)
Runs in families	47 (49%)
Birth injury	16 (17%)
Excessive worry	5 (5%)
Blood disorder	4 (4%)
Witchcraft	4 (4%)
Curse from God	0 (0%)
Spirit possession	5 (5%)
I don't know	21 (22%)
Other	1 (1%)
Epilepsy is a contagious condition.	
Always	3 (3%)
Sometimes	15 (16%)
Never	77 (80%)
If yes, how does someone catch it?	
Contact	2 (2%)
Touching bodily fluid	6 (6%)
Sex	0 (0%)
Genetics	3 (3%)
Air	2 (2%)
Insects	0 (0%)
Brain disease	1 (1%)
Spirit	0 (0%)
God	0 (0%)

[a] Note: Respondents were allowed to answer more than 1 cause.

Table 5
Treatment seeking behaviors and perceptions of effectiveness among respondents.

	(N = 96)
If you had a friend or relative with epilepsy, what kind of treatment(s) would you suggest?[a]	
See a doctor	82 (85%)
See a traditional healer	5 (5%)
See a church healing session	19 (20%)
Nothing—there is no treatment	1 (1%)
I don't know	9 (9%)
How effective is the clinic/hospital treatment for epilepsy?	
Not effective	5 (5%)
Sometimes effective	40 (42%)
Always effective	17 (18%)
Curative	4 (4%)
I don't know	28 (29%)
Unanswered	2 (2%)
How effective is the traditional healer treatment for epilepsy?	
Not effective	34 (35%)
Sometimes effective	24 (25%)
Always effective	3 (3%)
Curative	0 (0%)
I don't know	33 (34%)
Unanswered	2 (2%)

[a] Note: Respondents are allowed to choose more than 1 treatment type.

4. Discussion

This paper discusses knowledge, attitudes, and beliefs, specifically of first-year medical students in Uganda. Social beliefs seemed to vary according to the risk/impact associated with the questioned behavior. Most respondents would allow their child to play with a child who had epilepsy (low-risk); however, allowing their child to marry someone with epilepsy (high-risk) was more decisively viewed as unacceptable. Many students also believed that epilepsy is a mental illness. These stigmatized social beliefs and prejudices lead to negative treatments; people with epilepsy are viewed as being different, and thus, different social rules exist.

Stigma is also evident among medical students regarding their beliefs of the causes and contagiousness of epilepsy. Many students selected medically accepted causes of epilepsy (e.g., brain disease, genetic inheritance, birth injury); however, among a handful of respondents, there was a belief in supernatural causes of epilepsy (witchcraft, spirit possession, and curse from God). These beliefs about the origin of the disease have an influence on the way people with epilepsy are perceived and, also, on what treatments are sought (traditional versus biomedical treatment options); some medical students said that they would seek a church healer and/or a traditional healer to care for someone having seizures. One would surmise that if supernatural beliefs exist among a highly educated population, then, these beliefs would be much more common in the less educated population of Uganda [12].

Approximately 1 in 5 first-year medical students believed that epilepsy could be contagious, often thought to be due to contact with bodily fluids. The belief that epilepsy is contagious has been repeatedly demonstrated in other African countries [3–7,13–15]. This belief greatly impacts people with epilepsy and their safety during a seizure because bodily fluids (saliva, sweat, urination) are common during a seizure, and if someone believes that they may “catch” epilepsy, they will be less likely to help a patient in need. This belief can directly harm people with epilepsy and needs to be eradicated, especially among medical professionals, such as the medical students in training.

This study was limited as it was a selected demographic. First-year medical students were young and unexperienced and may have different beliefs in comparison to medical students in their clinical years. Compared to the general population in Uganda, these students were more urban, more educated, and more often Christian [16–19]. It would be interesting to survey more specific groups of medical professionals, including students in their clinical years, nurses, trained physicians, and other health care workers to see if stigma persists among these other care-providing groups. Future studies could be considered among different Ugandan populations, including urban and rural populations; it would be interesting to compare different levels of education and study how this impacts beliefs.

In conclusion, stigmatized beliefs and practices do exist among first-year medical students. Some students held beliefs that include discrimination against those with epilepsy and wrong perceptions regarding the disease, e.g., that epilepsy is sometimes caused by supernatural causes and that epilepsy is contagious. Medical school curricula must understand the beliefs and perceptions of their incoming students and need to specifically educate their students about stigma and misperceptions of epilepsy.

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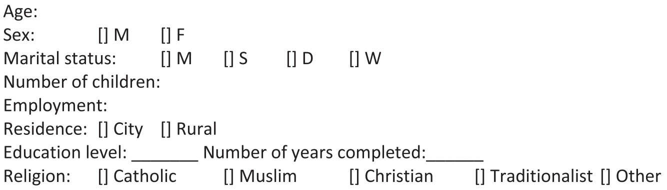
Disclosures

None of the authors have any disclosures or conflicts of interest to report.

Appendix A. Uganda Seizure Perceptions Survey

A.1. Demographics



Age:
Sex: [] M [] F
Marital status: [] M [] S [] D [] W
Number of children:
Employment:
Residence: [] City [] Rural
Education level: ________ Number of years completed:_______
Religion: [] Catholic [] Muslim [] Christian [] Traditionalist [] Other

A.2. Questions

1. Have you ever heard of “epilepsy”? [] Yes [] No
2. Have you ever known anyone with epilepsy? [] Yes [] No
3a. Do you have a family member with epilepsy? [] Yes [] No
3b. If yes, who?
3c. Do they have other disabilities or things special/wrong with them?
4a. Have you ever witnessed a seizure? [] Yes [] No
4b. What did you observe?
1- Shaking/motor activity
2- Falling
3- Loss of consciousness
4- Tongue biting
5- Stiffening
6- Loss of urine/stool
7- Confusion
8- Staring
5. Would you allow your child to play with someone with epilepsy? [] Yes [] No
6a. Would you allow your son or daughter to marry someone with epilepsy? [] Yes [] No
6b. Reason:
7. What do you think is(are) the cause(s) of epilepsy?
1- Madness
2- Mental retardation
3- Brain disease
4- Brain injury
5- Runs in families
6- Birth injury
7- Excessive worry
8- Blood disorder
9- Witchcraft
10- Curse from God
11- Spirit possession
12- I don't know
13- Other
8. A child with epilepsy can have a high level of intelligence. [] True [] False
9a. Epilepsy is a contagious condition.
1- Always
2- Sometimes
3- Never
9b. If yes, how does someone catch it?
10. “A child with epilepsy should never attend school.” [] True [] False [] Situation-dependent
11. “Epilepsy is a mental illness.” [] True [] False
12. How old are people who have epilepsy?
1- Babies/infants (0–3)
2- Children (4–11)
3- Adolescents (12–19)
4- Young adults (20–40)
5- Middle aged adults (41–64)
6- Elderly (65+)
7- Any age
13. What kind of activities is a person with epilepsy able to participate in?
1- Marriage
2- Breastfeeding
3- Dancing
4- Sports
5- Beer or alcohol
6- Job
7- Swim
8- Travel alone
9- Go to healer
10- Drive
11- Cook
12- Work with machines
13- Attend school
14- Climb trees
15- Other
14. What is the general attitude of families towards those with epilepsy?
15. What is the general attitude of the community towards those with epilepsy?
16. If you had a friend or relative with epilepsy, what kind of treatment(s) would you suggest?
1- See a doctor
2- See a traditional healer
3- See a church healing session
4- Nothing—There is no treatment
5- I don't know
17. How effective is the clinic/hospital treatment for epilepsy?
1- Not effective
2- Sometimes effective
3- Always effective

4- Curative
5- I don't know

18. What kind of medicines do clinics/hospitals use to treat epilepsy?
    1- Pills
    2- Rest
    3- Other medical treatment
    4- Counsel
    5- I don't know
19. How effective is the traditional healer treatment for epilepsy?
    1- Not effective
    2- Sometimes effective
    3- Always effective
    4- Curative
    5- I don't know
20. How do traditional healers treat epilepsy?
    1- Herbs
    2- Ritual
    3- Black cloth, etc.
    4- No treatment
    5- I don't know
21. What would you do for a patient who is actively having a seizure?
22. What is the length of time people with epilepsy have the disease?

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