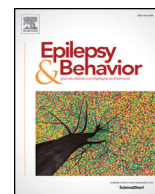




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Barriers to biomedical care for people with epilepsy in Uganda: A cross-sectional study

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ABSTRACT

Objective: Epilepsy, a neurological disorder with effective biomedical treatment, remains largely untreated in Uganda. Potential reasons for this treatment gap (TG) include limited access to trained providers and clinics, social stigmata of seizures, cultural beliefs, or lack of public understanding of epilepsy as a treatable condition. The current study aimed to formally evaluate barriers faced by people with epilepsy (PWE) in Uganda when seeking biomedical care.

Methods: In a cross-sectional study, 435 participants drawn from a community prevalence study were enrolled. We included participants reporting a history of recurrent seizures suggestive of epilepsy, who completed a survey about barriers to obtaining care for their symptoms. Principal axis factor analysis (PFA) using a promax rotation was conducted for data reduction. Frequencies of barrier factors were compared across those who did not seek care for epilepsy ($n = 228$), those who sought care from biomedical facilities ($n = 166$), and those who sought care from a traditional or pastoral healer ($n = 41$).

Results: The PFA yielded a five-factor solution: 1) logistical and actual costs; 2) treatment effectiveness; 3) influence of the opinion of others; 4) doctors' care; and 5) contextual factors impacting decision-making. Variables related to logistical and actual costs were most endorsed. Comparison of groups by care sought did not reveal a difference in endorsement of factors, with the exception that those who sought biomedical care were more likely to endorse factors related to doctors' care compared with those that sought care from traditional or pastoral healers ($P = .005$).

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Conclusions: People with repetitive seizures in Uganda report several barriers to obtaining biomedical care in Uganda, with those related to practical and actual costs endorsed the most. It is imperative that interventions developed to reduce the TG in Uganda consider these practical issues to improve access to effective epilepsy care.

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1. Introduction

Epilepsy is a neurological disorder affecting people of all ages. The global burden of this disease is quite severe, as in addition to seizures, uncontrolled epilepsy leads to both physical and psychological consequences including premature death, bodily injury, and mental health disorders [1]. Worldwide, almost 70 million people are estimated to be living with epilepsy, with approximately 80% residing in low- and middle-income countries (LMICs) [2,3]. In LMICs, the rate of new cases is up to twofold greater when compared with high-income countries [4]. Sub-Saharan Africa (SSA) alone is estimated to have at least 10 million persons with epilepsy (PWEs) [5]. Within SSA, the high incidence of epilepsy may be secondary to higher rates of birth and perinatal insults, traumatic brain injury, and neurological infections such as malaria, cysticercosis, onchocerciasis, and toxocarasis [6].

In these regions, despite advancements in treatment, limited community knowledge regarding epilepsy as well as inherent infrastructural issues pose challenges to effective epilepsy diagnosis and management [7]. Although effective antiepileptic drugs (AEDs) are available to treat epilepsy, as many as 90% of those living in LMICs do not receive the current standard of care, and those residing in rural areas often receive no care at all [8]. Thus, studies in LMICs report a large epilepsy treatment gap (TG)—defined as those not receiving treatment or those receiving inadequate treatment for epilepsy [9]. Because of regional differences in the etiologies of epilepsy and populations of interest, as well as variation in survey methods, the reported size of the epilepsy TG in SSA varies significantly. However, a systematic review by Meyer and colleagues reported a high TG of over 95% in several countries; among them are Uganda, Nigeria, Tanzania, and Zambia [10]. The reasons behind such a pronounced TG are multifactorial, including economic, infrastructural, and social challenges to seeking biomedical care.

From a health systems perspective, barriers may include inadequate medical supplies, cost of AEDs, lack of skilled healthcare workers, and limited access to health facilities [11,12]. There is a scarcity of specialty services for neurology in Africa [13], with SSA having the lowest density of neurologists worldwide [14]. As a result, many PWE are ultimately managed by psychiatrists and general healthcare providers, some of whom may never have had formal or up-to-date epilepsy training [15]. The few neurologists in the region are available exclusively in urban areas and sometimes only in private hospitals, rendering them unavailable to many PWE [16,17] living in rural areas or who have financial restraints. Patients may be required to travel extensive distances to reach medical facilities equipped with experienced providers and diagnostic capabilities [12], further exacerbating the burden of their disease.

The cost of long-term treatment with AEDs for many can be prohibitive to receiving adequate care, and hospital supplies of AEDs are inconsistently available, which can lead to ineffective seizure control and often drug resistance [6]. In a recent 2014 survey of Uganda Hospitals and Health Centre IV facilities, it was found that 84% of the facilities had available carbamazepine, and 80% had phenytoin; however, only 36% had phenobarbital, and 15% had valproate in stock [18]. This lack of consistent access to medication may then lead to the utilization of traditional medicine. For example, a study in Uganda conducted by Kakooza-Mwesige and colleagues in 2017 found that only 21% of PWE reported the use of AEDs, while 49% reported using traditional medicine [5]. At the time of the study, there was a shortage and irregular supply of

AEDs at the referral hospital and none at the lower-level health units, which could have partially contributed to the low AED usage rate [5].

Among patients who choose not to seek biomedical care, poor uptake of medical services may also relate to social stigma and misconceptions about epilepsy. In many parts of Uganda, indigenous traditions, as well as their amalgamation with Judeo-Christian or Islamic doctrines, have influenced community attitudes toward epilepsy [5] and have propagated the idea that epilepsy is caused by supernatural powers rather than having a physiological origin. Epilepsy may then be perceived as unresponsive to biomedical treatment and better managed by a traditional healer via spiritual intervention. Furthermore, many believe that the disease is a result of sin or engaging in taboo behavior, which brings immense guilt and shame to PWE and their families and resultant discrimination within social circles [19]. Such negative attitudes and misconstrued beliefs may lead families to first consult traditional healers, leading to social isolation and delays in seeking medical treatment [6,20]. Thus, the health literacy of the family and knowledge of epilepsy within communities also influences the treatment of epilepsy [21].

Importantly, opportunities to acquire factual biomedical information and subsequently receive appropriate management are lacking in under-resourced healthcare systems. Developing culturally acceptable and effective interventions to improve epilepsy care requires a thorough understanding of the modifiable barriers to biomedical treatment. Thus, this study explored these barriers using a sample of people with suspected epilepsy, as an important step toward improving access to care and reducing the epilepsy TG.

2. Methods

2.1. Institutional review board

This study was approved by the Mulago National Referral Hospital Research Ethics Committee, Uganda National Council for Science and Technology, Duke University School of Medicine Institutional Review Board (IRB), and Duke University IRB.

2.2. Instrument

We developed a Barriers Survey questionnaire, which quantified the study participants' perceptions of barriers to receiving biomedical care for epilepsy. The questionnaire was constructed using barriers reported in the relevant literature (e.g., [11,22]), and additional potential barriers identified through conversations with healthcare providers. Validation of the study questionnaire involved expert review and input by specialists (neurologists, psychiatrists, and a psychologist) in Uganda to ensure cultural and content relevance. Twenty-seven (27) barriers were then set against a 5-point Likert scale, with explicit instructions asking for rating the degree to which each item was or would be considered a barrier to receiving biomedical care (1 = did not matter to 5 = mattered very much).

2.3. Sample

The sample was drawn from adult participants in a national epilepsy prevalence study in Uganda [23], which used a national sampling strategy developed with the Uganda Bureau of Statistics. In this study, 30

households were randomly selected for participation in each of 330 enumeration areas across the country. Of the 9978 households approached, 8819 consented to participate. Every household member was eligible to participate, of which 94.2% enrolled and completed prevalence questionnaires ($n = 35,055$). A two-step screening process for seizures was utilized. The first step employed a 10-question survey tool based upon the validated Limoges questions and other tools used in screening for epilepsy in LMICs [24,25], along with one new question to capture nodding syndrome. The second step used three additional questions developed by our research team to increase specificity by screening out single seizure episodes, febrile seizures, and seizures linked only to severe malaria episodes.

Using this methodology with the national sample, 732 subjects screened positive as having a history of recurring seizures suggestive of epilepsy. Of these, 435 were adults or emancipated minors who also completed additional survey measures, including the Barriers Survey. This sample was further divided by where care was first sought: that that did not seek care for their epilepsy ($n = 228$), those that sought help in a biomedical setting ($n = 166$), and those who reported having sought care from a traditional or pastoral healer ($n = 41$). All participants provided written informed consent before enrollment into the study.

2.4. Data analysis

Sample means for each barrier were calculated. Empirical data reduction was conducted using principal axis factor analysis with a promax rotation to create summary barrier scores. For the purposes of characterizing differences in the frequency of barriers endorsed, we also examined the frequency that participants scored an average of greater than or equal to 3 (i.e., 'Mattered Some', 'Mattered a lot', or 'Mattered very much' on average) on each factor. Finally, factor scores for each of the five factors were calculated for each subject, and these were compared using least squares (LS) means across groups, specifically comparing those who did not seek care, those who sought care in a medical setting, and those who sought care through a traditional or pastoral healer.

3. Results

3.1. Sample characteristics

The majority of participants attained primary level education (equivalent to elementary grades in the US), and three-quarters of the sample earned 20,000 Ugandan shillings (UGX) or less weekly (about \$5.40 USD) (Table 1).

3.2. Barrier endorsements

Fig. 1 illustrates the mean item endorsement for each barrier. Those involving costs of travel, tests, healthcare visits, and drugs as well as distance and terms of payment were endorsed most frequently.

3.3. Data reduction

Principal axis factor analysis for data reduction yielded a five-factor solution, as illustrated in Table 2. Factor groupings suggested relationships between items having to do with 1) *Cost*: logistical and actual costs (e.g., cost of diagnostic tests, transportation, drugs), payment method inflexibility, and travel distance; 2) *Treatment Effectiveness*: medication efficacy, availability, purity, and side effects, and concerns about physician capacity to treat epilepsy; 3) *Influence*: The impact of the opinions of others, including family decision-makers, family members, community leaders, and friends; 4) *Doctors' Care*: Factors related to the care provided by doctors, such as their understanding, communication, and time; and 5) *Contextual Factors*: Circumstances, such as

symptoms or the setting, such as family support, time from work, or symptom severity, that may impact care-seeking. Examination of the proportion of variance explained by each factor showed that Cost explained the largest portion of variance (33.7%), followed by Treatment Effectiveness (12.7%), Influence (6.4%), Doctors (5.7%), and Contextual Factors (4.2%).

3.4. Association between barriers and demographic variables

Examination of associations between demographic variables and barriers revealed several small but significant associations. Older age was associated with lower Treatment Effectiveness ($r = -0.12$, $P = .015$), Influence ($r = -0.11$, $P = .029$), and Context ($r = -0.10$, $P = .041$) scores. In contrast, higher levels of reported weekly income were associated with greater Influence ($r = 0.13$, $P = .008$) and Context ($r = 0.10$, $P = .035$) scores. We found no significant associations between education or residential setting and the self-reported barrier factors.

3.5. Frequency of barrier factors and their relation to treatment-seeking

To characterize differences in the frequency that each barrier factor was endorsed, we calculated an average factor score for each participant and then tabulated the frequency that this score was equal to or greater than 3 for the sample. All barrier factors were endorsed at this level by some of the sample, but those related to logistical and actual costs were endorsed the most, followed by barriers related to concerns about doctors, treatment efficacy, the influence of others, and contextual variables (Fig. 2).

In order to explore whether the frequency of barrier endorsement differed by what treatment choice was sought, we explored how different care choice groups endorsed the factors. Note that 52.4% of the sample did not seek care, 38.2% reported seeking biomedical care, and 9.4% reported seeking care through a traditional or pastoral healer. Table 3 shows that overall, these groups did not differ significantly in the barriers endorsed, with the single exception that those who sought care from traditional or pastoral healers endorsed barriers related to doctors less frequently than those seeking biomedical care ($P = .005$ for post hoc comparison). Values represent least squares means with associated 95% confidence intervals.

4. Discussion

Formally characterizing the barriers to seeking biomedical care for epilepsy is vital in understanding the cultural context of the disease and in designing focused interventions to improve access to care. These multifactorial barriers can delay or hinder access to biomedical treatment in Uganda and should be urgently addressed in future interventions.

This study was designed to delineate the barriers to epilepsy care in Uganda and revealed five important aspects that may influence the uptake of biomedical care for epilepsy: 1) cost variables (e.g., cost of tests, care, travel, and drugs), travel distance, and payment method; 2) factors related to doctors' care; 3) treatment effectiveness such as medication efficacy, purity, and side effects; 4) influence of the opinions of others; and 5) contextual factors involving symptoms or settings that may impact decision-making. Understanding these barriers to epilepsy care in SSA, particularly Uganda, is needed to improve access through well-informed interventions that target the specific barriers faced by this population.

4.1. Logistical and cost barriers

In our sample, the barrier factor related to the actual and logistical costs of seeking biomedical care was the most commonly endorsed barrier, reported by just under half of our sample (49%). Limited financial resources impact care by influencing access to transportation, adherence to purchased medication, and other indirect costs related to care,

Table 1
Characteristics of participants by care sought.

Cohort	No care (n = 228)	Biomedical care (n = 166)	Traditional or pastoral care (n = 41)	Total (n = 435)
Age, mean (SD)	33.2 (14.4)	36.5 (16.2)	26.1 (8.3)	33.8 (15.0)
Male Sex, n (%)	105 (46%)	68 (41%)	17 (41%)	190 (44%)
Education (categorical: 1–6)				
1: None	53 (23%)	35 (21%)	11 (27%)	99 (23%)
2: Primary	136 (60%)	102 (61%)	24 (59%)	262 (60%)
3: Secondary O-level	33 (15%)	23 (14%)	6 (15%)	62 (14%)
4: Secondary A-level	1 (1%)	1 (1%)	–	2 (1%)
5: Vocational Training	4 (2%)	3 (2%)	–	7 (2%)
6: University	–	2 (1%)	–	2 (1%)
Income (categorical: 1–5)				
1: 0–5000 UGX weekly	117 (51%)	72 (43%)	20 (49%)	209 (48%)
2: 5000–20,000 UGX weekly	62 (27%)	52 (31%)	16 (39%)	130 (30%)
3: 20,000–50,000 UGX weekly	23 (10%)	26 (16%)	3 (7%)	52 (12%)
4: 50,000–100,000 UGX weekly	23 (10%)	10 (6%)	1 (2%)	34 (8%)
5: > 100,000 UGX weekly	3 (1%)	6 (4%)	1 (2%)	10 (2%)
Household members, mean (SD)	5.2 (3.0)	5.7 (3.2)	5.2 (2.9)	5.8 (3.1)
Urban household	47 (21%)	39 (23%)	4 (10%)	137 (19%)

such as losing time at work. Furthermore, the relative inflexibility of payment methods when seeking biomedical care was also noted as a barrier. Traditional healers may be preferred over biomedical care because they allow flexible payment methods in installments, at later times, or with bartered goods—all attractive options for families with financial restraints [26].

Among patients who do seek biomedical care, adherence to prescribed AEDs is affected by limited supplies. It is interesting to note that of all the individual barriers studied, “sometimes the amount of epilepsy drugs is not enough” was endorsed often. Patients and caregivers often pursue treatment at great personal cost, only to face common medication shortfalls (i.e., “stock-outs”) in public facilities. These unintentional interruptions in adherence lead to breakthrough seizures [11], which undermine confidence in biomedical treatment and may influence choice of care between traditional and biomedical treatment options.

4.2. Concerns related to doctors' care

About a third of our sample (35%) endorsed the factor indicating concern about aspects of doctors' care. While therapeutic advances in epilepsy care have resulted in meaningful changes in the diagnosis and management of epilepsy [27] and there is clear evidence demonstrating that the majority of PWE become seizure-free with the optimal use of AEDs [28–30], the majority of PWE in SSA still have uncontrolled seizures. Epilepsy expertise and resources are limited, and while nonspecialized healthcare providers are important players in task-shifting and expanding care access, there is still a shortage of human resources [31,32]. Overcrowded clinics then result in long waits and limited time for physician–patient interaction, and the possibility of medication shortages further impacts the treatment interaction [31]. These conditions ultimately contribute to shaping the patient's perception of care or the physician's experience in delivering care.

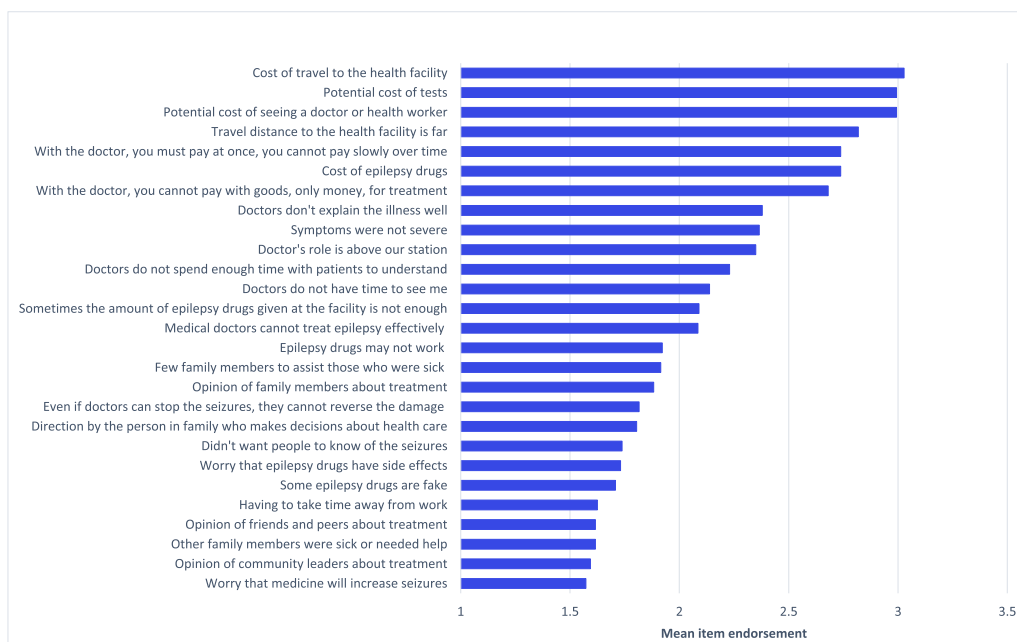


Fig. 1. Mean response frequency for each barrier.

Table 2
Factor loadings.

	Cost	Treatment Effectiveness	Influence	Doctors' Care	Contextual
Potential cost of tests	0.88	0.22	0.13	0.26	0.24
Potential cost of seeing a doctor	0.86	0.23	0.12	0.27	0.23
Cost of epilepsy drugs	0.81	0.31	0.20	0.28	0.24
You must pay at once, not over time	0.81	0.20	0.23	0.37	0.18
You cannot pay with goods, only money	0.80	0.26	0.26	0.42	0.20
Cost of travel to the health facility (HF)	0.74	0.04	0.44	0.32	0.35
Travel distance to the HF is far	0.69	0.01	0.42	0.34	0.41
Doctor's role is far above our station	0.53	0.39	0.28	0.34	0.43
Epilepsy drugs may not work to treat epilepsy	0.20	0.85	0.31	0.35	0.37
Some epilepsy drugs are fake	0.17	0.85	0.36	0.37	0.42
Worry that epilepsy drugs have side effects	0.26	0.78	0.43	0.33	0.42
Worry that the medicine will increase seizures	0.26	0.74	0.49	0.37	0.36
I do not believe medical doctors can treat epilepsy effectively	0.25	0.68	0.43	0.41	0.20
Belief that even if medical doctors stop the seizures, they cannot reverse the damage already there	0.29	0.68	0.49	0.40	0.38
Sometimes the amount of drugs given at the facility is not enough	0.36	0.66	0.33	0.51	0.40
Opinions of friends and peers about treatment	0.23	0.42	0.84	0.25	0.32
Opinions of community leaders about treatment	0.21	0.37	0.83	0.30	0.31
Opinions about family members about treatment	0.17	0.46	0.80	0.23	0.23
Direction by the person in my family who makes decisions about healthcare	0.25	0.54	0.62	0.24	0.21
Doctors do not explain the illness well	0.31	0.38	0.24	0.89	0.21
Doctors do not spend enough time with the patients to understand	0.38	0.42	0.30	0.91	0.27
Doctors do not have time to see me	0.38	0.44	0.27	0.89	0.25
Having to take time away from work	0.13	0.34	0.31	0.23	0.75
Symptoms were not very severe	0.10	0.18	0.12	0.09	0.62
Others in my family were sick or needed help	0.32	0.37	0.22	0.24	0.72
Few family members available to assist those who were sick or needed help	0.36	0.42	0.20	0.21	0.61
I did not want people to know of the seizures	0.22	0.38	0.35	0.22	0.49

Factor loadings in bold denote the dominant factor for the individual item.

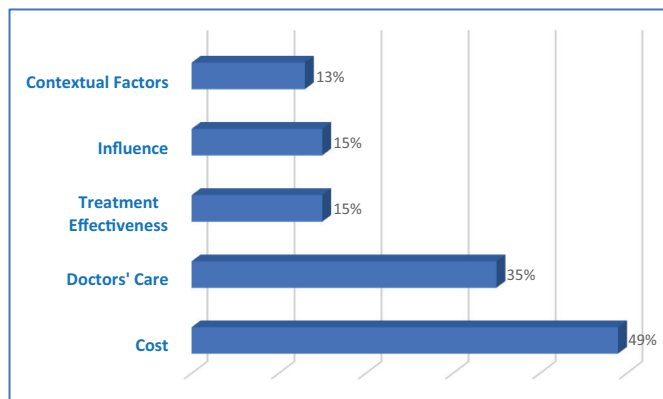


Fig. 2. Percent of sample endorsing each barrier factor.

In contrast, traditional healers are ubiquitous and are most often the more trusted provider of care in SSA [26,32,33]. Typically, the patient is likely to enjoy lengthier individual attention in this setting, with open

communication over a one- to four-hour period [26]. In contrast, while the biomedical setting typically affords less time for the doctor-patient interaction, PWE and their caregivers seeking care in these clinics have more accurate knowledge and perceptions about epilepsy, likely due to the essential psychoeducation that takes place in the context of specialized epilepsy care [31,34]. Discussion and negotiation between patients and healthcare providers establish an important contract of disease management. Decompression of overcrowded clinics with increased access points may improve this valuable exchange.

In this study, few participants reported consulting traditional or pastoral healers in contrast to those who reported seeking biomedical care or not seeking care at all. Rutebemberwa and colleagues also reported a lower than expected rate (11%) of traditional healer consultation as the first provider contact in their sample [35]. These rates differ from others [32,33] and warrant consideration for future studies, as they may reflect some degree of reporting bias. It is interesting to note that in the Masindi sample, a similar portion of people consulted a neighbor rather than a traditional healer, and 34 of those 39 people received herbs from that neighbor [35].

Our work highlights the importance of the quality of the interaction between the patient and the care provider. It is notable that the factor reflecting concern about doctors was endorsed with high frequency in

Table 3
Estimated mean factor scores for each treatment group.

Factor	Not treated	Biomedical care sought	Traditional or pastoral care sought	Omnibus P-value
Cost	2.8 (2.6, 3.0)	2.8 (2.6, 2.9)	3.0 (2.6, 3.4)	.616
Logistical & actual costs, payment flexibility, distance				
Treatment Effectiveness	1.8 (1.7, 1.9)	1.9 (1.8, 2.1)	1.9 (1.6, 2.2)	.357
Medication efficacy, availability, purity & side effects, and physician capacity to treat				
Influence	1.7 (1.6, 1.9)	1.7 (1.5, 1.8)	1.8 (1.5, 2.1)	.719
Opinions of decision makers, family, community leaders & friends				
Doctors' Care	2.2 (2.0, 2.3)	2.5 (2.3, 2.7)	1.8 (1.4, 2.2)	.006
Doctors' understanding, communication & time				
Contextual Factors	1.9 (1.7, 2.0)	1.8 (1.7, 2.0)	1.7 (1.4, 1.9)	.367
Symptom, family & work circumstances that may impact care seeking				

this sample, second only to cost barriers. But perhaps more disquieting is the finding that this factor was endorsed significantly more by those who reported that they had pursued biomedical care. Together, these findings suggest not only general concern about biomedical care and interactions with physicians but also the possibility that some participants may have endorsed some items as critical statements reflective of their experience rather than as barriers in their care-seeking.

4.3. Medication efficacy, purity, side effects, and availability

Concerns related to treatment effectiveness, such as medication efficacy, purity, and side effects were also endorsed by 15% of our sample. While doubts exist about the efficacy of medication in controlling seizures and the ability of physicians to treat the disease, some concern was also related to counterfeit medications and potential drug side effects. Notably, concerns related to persistent neurologic sequelae even with seizure control are also a cause of doubt regarding biomedical treatment. One study in Uganda demonstrated that PWE may miss AED doses because they have been advised to stop medication by either health workers or family members due to a perceived fear of side effects following long duration of treatment [36]. Unfortunately, this poor understanding of the chronicity of epilepsy can undermine adherence. Together, these findings suggest that careful counseling of PWE about treatment efficacy, medication adherence, and side effects is essential.

Currently, carbamazepine, phenytoin, sodium valproate, lamotrigine, and phenobarbitone are available as first line AEDs at the higher-level government health facilities [37]. Some private retail pharmacies may also carry gabapentin, or other AEDs, though the cost of drug acquisition is beyond the financial reach of most patients [12]. In public facilities, there are frequent interruptions in drug availability, where certain AEDs are not in stock in either the clinic or central hospital pharmacies. Atugonza and colleagues reported that 67% of the caregivers in their sample of children with epilepsy reported experiencing one or more of these interruptions in medication supply [38]. The overall limited selection of AEDs and medication stock-outs can influence seizure control, and may impact patient confidence in biomedical treatment. There is, hence, an urgent need to regularly revise the types and quantities of AEDs in the district-specific essential medicines and health supplies kits supplied by the District Health Office, with representatives from the respective health facilities. This activity is done with technical assistance from the National Medical Stores under the supervision of the Ministry of Health, with the objective of quantifying facility pharmaceutical needs for the next financial year to inform accurate planning and ensure access to essential medicines in the public sector.

4.4. Influence of the opinions of others

In resource limited settings, communities lack information about epilepsy as a chronic, noncommunicable disease, and misconceptions are ubiquitous [34]. Many are unaware of the possibility of treatment and control of the disease, the potential triggers and precipitants of seizures, and the role and side effects of AEDs [39]. Consequently, the customary consultation of influential family members and community leaders may serve to perpetuate misconceptions and delay care. With continued symptomatology, PWE and their families are further isolated and stigmatized [22,40].

Many communities rely on the experience of family decision-makers, community leaders, and elders, particularly when confronted with new and unfamiliar symptoms. In this sample, 15% endorsed the factor reflecting the influence of the opinions of others as barriers to care.

Only a third of the participants who screened positive for repetitive seizures in the sample sought help through a biomedical care provider. In our work with PWE seeking routine care for their epilepsy in hospital settings, almost half reported seeing a traditional or pastoral healer prior to receiving biomedical care, with an average of a two-year delay to biomedical care for those who sought care elsewhere [33]. This study suggests that

the beliefs and opinions of caretakers and the community do have strong influence on healthcare choices of PWE, and when misinformed, these may play a role in delays to biomedical care and the TG.

4.5. Contextual factors

Family support is a crucial variable impacting treatment-seeking behavior, medication adherence, and quality of life [41] and includes accompanying patients to the hospital, reminding them of clinic days, and supervising medication acquisition and adherence. This study shows that contextual variables, such as the ability of family members to provide such support, impacted healthcare seeking for 13% of the sample. Other related contextual variables that could potentially modify treatment-seeking include the need to take time off work, the ratio of family members who need assistance versus those that can provide aid, the severity of symptoms, and concern about public awareness of symptoms. Increased epilepsy health literacy, community awareness and support, and clear referral avenues may help individuals reach care despite these contextual limitations.

Strengths of this study include that its participants were a part of a large national population prevalence study, and thus representative of Ugandans. However, while the sample in this study reflects people who screened positive for symptoms suggestive of repetitive seizures, because clinical validation with electroencephalograms (EEGs) is pending in the national sample, we are not yet able to characterize the sample as definitively having epilepsy or by seizure type. Recall bias or social desirability bias in reporting may have resulted in misreporting, though every effort, through careful probing by well-trained fieldworkers, was made to ensure the collection of accurate data.

5. Conclusion

The current study identifies major barriers to seeking and accessing biomedical care and highlights the urgent need for implementing interventions to effectively reduce the epilepsy TG in Uganda. Barriers to reaching biomedical care include the burden of practical costs of seeking medical care in a population often already lacking in personal resources, individual concerns regarding healthcare delivery by physicians, doubts about treatment effectiveness, and limited community knowledge and support. Based upon our study findings, interventions aimed to specifically improve medication availability, reduce costs of AEDs, and minimize travel distances and other expenses have the most potential to impact access to care. Improving basic health literacy about epilepsy and its treatment may also facilitate more efficient and appropriate treatment care choices. While recognizing the restraints of a resource limited setting, these findings offer straightforward targets for intervention and underscore the need for broad collaboration between patient, community, biomedical provider, and government stakeholder groups to address barriers in managing this treatable disease.

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Declaration of competing interest

None.

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