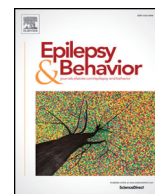




Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Healthcare provider perspectives regarding epilepsy care in Uganda

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ARTICLE INFO

Article history:

Received 13 February 2020

Revised 23 June 2020

Accepted 28 June 2020

Available online xxxx

Keywords:

Providers

Needs

Epilepsy

Uganda

ABSTRACT

Objective: Epilepsy is the most common chronic neurological disorder in the world and imposes a large economic burden on global healthcare systems, especially in low-income settings and rural areas as is found in sub-Saharan Africa (SSA). Despite the high epilepsy prevalence, there are no systematic descriptions of healthcare provider (HCP) perceptions and needs in managing people with epilepsy (PWE) in Uganda. Identifying these perceptions and needs is crucial for understanding community priorities, thereby enhancing the development of culturally sensitive communications, interventions, and research approaches.

Methods: In this qualitative study, we used semistructured interview guides to conduct focus group discussions that explored the perspectives of 32 providers of epilepsy care from health facilities around Mbarara, Uganda. Our sample included nonspecialized general physicians (n = 3), medical residents (n = 8), medical clinical officers (n = 3), psychiatric clinical nurses (n = 6), medical nurses and nursing assistants (n = 9), and other providers (n = 3), who were loosely grouped into discussion groups based on level or type of training. Self-assessed proficiency ratings were also administered to gain a better understanding of participants' confidence in their training, preparedness, and capabilities regarding epilepsy care. Thematic analysis of the focus group transcripts was conducted to ascertain commonly occurring themes about perceptions and challenges in epilepsy care.

Results: Our analyses identified nine major themes that dominated the perspectives of the study participants: care management, medications, diagnostics, HCP training, human resources, location, patient education, social support, and community knowledge and beliefs. Proficiency ratings prioritized areas of confidence as knowledge related to referrals, psychosocial impacts, and seizure neurophysiology. Areas of need were revealed as knowledge of diagnostic tools and antiepileptic drug (AED) regimens.

Conclusions: Our findings delineate the perspectives of providers caring for PWE, with consistent recognition of challenges centering around resource augmentation, infrastructure strengthening, and education. Participants emphasized the urgent need to augment these resources to address limitations in medication types and access, trained human resources, and diagnostic tools. They overwhelmingly recognized the need for infrastructure strengthening to address human, diagnostic, medicinal, and capital resource limitations that place undue burden on patients with epilepsy and physicians. Providers indicated a clear desire to learn more about different diagnostic tools and medical management practices, potentially through continuing education, specialized training, or more intentional in-school diagnostic preparation. They also advocated for the powerful influence of patient and family education and clearly articulated the need for community sensitization and support.

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1. Introduction

1.1. Background and significance

Epilepsy affects approximately 70 million people, making it a leading cause of neurologic disease worldwide [1]. However, the burden of epilepsy falls disproportionately on developing countries, with approximately 80% of people with epilepsy (PWE) residing in low- and middle-income countries where the capacity for diagnosis and treatment is severely limited [1,2]. This phenomenon, known as the epilepsy treatment gap, tends to be even more notable in rural versus urban areas worldwide [2,3].

For countries in sub-Saharan Africa (SSA), the epilepsy treatment gap is estimated in some regions to be as high as 95% [3]. Therefore, studies to advance our understanding of various demographic, practical, and sociocultural barriers to epilepsy care are increasingly urgent and emerging in the literature. For example, a number of relevant factors that impede PWE from accessing care in Kenya have been identified including the cost of medical diagnosis, lab studies, and biomedical medicines; distance and transportation to care; stigma; religious beliefs and cultural norms around the consultation of healers; and beliefs about epilepsy as a contagious or supernaturally induced condition [4,5]. Other studies in SSA report similar findings and identify additional challenges such as the shortage of trained health workers, limited diagnostic capabilities, and insufficient antiepileptic drug (AED) supply [3,6,7]. While these studies inform our understanding of barriers for patients, particularly in terms of reaching biomedical care, it is less clear the degree to which these barriers impact patient care within the treatment setting.

In Uganda, human resources for the biomedical treatment of epilepsy are particularly scarce, which affects the adequacy of medical care that can be provided [8]. This lack of specialty training and limited expertise of the attending health staff has been suggested as another contributing cause to the epilepsy treatment gap in East Africa [9,10]. There are few neurology specialists in Africa, with SSA having the lowest density of neurologists worldwide [11]. In present day Uganda, there are 7 adult and 4 pediatric neurologists [12]. In regions with extreme physician shortages, the majority of trained healthcare providers (HCPs) are clinical officers and nurses, with minimal or little to no training for the diagnosis or treatment of epilepsy [9,13,14]. Epilepsy is also classified as a mental health disorder by the Ministry of Health and is largely treated in the realm of psychiatry [15]. Epilepsy diagnoses account for more than half of the outpatient mental health clinic attendance at Butabika National Referral Mental Hospital in Kampala [16].

In Uganda, where specialty epilepsy providers are rare, health centres with shortages of trained providers and essential drugs must suffice to care for PWE. However, little data are available on the specific knowledge and needs of such health staff from various provider settings. There is also a dearth of studies around identifying the specific resource deficiencies, training gaps, and other relevant barriers to adequate epilepsy care as identified by the care providers themselves. Therefore, identifying the unfulfilled needs and challenges facing providers in Uganda can inform culturally sensitive interventions at the clinic level, which are tailored to providers' needs and priorities.

1.2. Study aim

In 2017, members of this research team conducted a study that explored stakeholder perceptions about epilepsy care in Uganda through interviews with patients and caregivers, traditional healers, pastoral

healers, neurologists, and psychiatrists [17]. That study informed our understanding of the shared and unique challenges that each of these stakeholder groups encounter. While we explored the perspective of biomedical providers, that study included only highly specialized physicians. However, much of epilepsy care in Uganda is provided by nonspecialized HCPs, and there is little known about the perspectives of these providers caring for patients with epilepsy in community- and district-level clinics and hospitals. Such perspectives will be essential to guiding meaningful, educational interventions and capacity-building efforts. Therefore, the purpose of the present study was to identify the perceptions, needs, and perceived proficiencies of nonspecialized biomedical providers who manage epilepsy in Western Uganda, specifically in and around Mbarara.

2. Methods

2.1. Ethics review board

This study protocol was approved by the Mbarara University of Science and Technology Research Ethics Committee and the Duke University Campus Institutional Review Board.

2.2. Participant recruitment and enrollment

Healthcare providers were professionals recruited into the study by email from coauthors at Mbarara Regional Referral Hospital (RM; JN). Potential participants were invited based on recruiters' knowledge of the person or setting being one that typically serves PWE. These participants were recruited from Health Centre II, III, and IV sites, Mbarara Municipal Council, and Mbarara Regional Referral Hospital in the city of Mbarara, Uganda and its surrounding locales. According to the Uganda Health Sector Strategic and Investment Plan, Health Centre II facilities each serve approximately 15,000 people, provide treatment for common diseases, and are usually led by a nurse [18]. Health Centre III sites are larger, mid-level primary care facilities that are typically found in every subcounty in Uganda. They are usually staffed by nurse aids and qualified nurses and led by a clinical officer (physician assistant). Health Centre IV sites are at the next referral level, immediately below district hospitals. They typically serve an entire county and are led by either a physician or senior medical officer. The Mbarara Municipal Council is at the next level and serves as the district hospital with multiple specialized clinics, such as ones for mental health and consult physicians. Mbarara Regional Referral Hospital is at the top of the referral chain in this region and is staffed by many of the most highly trained physicians in the country.

Potential participants responded to the invitation and were assigned a time and central location to come for participation. At this juncture, the study was explained to participants by a Ugandan focus group leader, and each participant was given time to read the consent form and to ask any clarifying questions about the study. Each participant was compensated for their time with 40,000 Ugandan shillings (~10.81 USD) and lunch or tea-time refreshments.

Thirty-two participants enrolled in total. Seven focus group discussions were conducted, with each group containing 4–6 HCPs, loosely grouped based on the level or type of training: general physicians, medical clinical officers, trainees, or nurses. Each focus group discussion lasted approximately 75 min, which were audio recorded and later transcribed verbatim for analysis. After each focus group, participants

completed a short written survey, which included proficiency ratings related to epilepsy care.

2.3. Instruments

2.3.1. Focus group guide

In this study, data were collected through focus group discussions using a semistructured questionnaire designed to elicit information on the challenges and needs in providing epilepsy care. Ten open-ended questions were designed by the research team to broadly gather information about HCP experiences with epilepsy, various strategies for diagnosis and treatment, barriers to care, and suggestions for improving epilepsy care in Uganda.

2.3.2. Proficiency ratings

Following the focus group discussions, we administered a short rating scale to gain a more thorough understanding of perceptions of self-proficiencies related to 10 areas of epilepsy care. A 5-point Likert scale spanning from low proficiency 'not at all' (1) to 'highly proficient' (5) was used. Areas of epilepsy care covered included knowledge of neurophysiology, seizure classifications, treatment regimens, diagnosis, and outcomes.

2.4. Analysis

Transcripts were reviewed independently by three research team members (CS, GC, OR) using content analysis to identify themes and develop codes to describe these trends. Researchers then convened until consensus was reached on a master code list, with consultation of members of the broader research team, and these were then applied across all transcripts. Frequencies of theme responses were tabulated. Proficiency ratings were summarized descriptively.

3. Results

3.1. Sample

The sample of 32 HCPs had a mean age of 36 years (range: 26–62) and had been in practice for an average of 10 years (range: 3–30). Table 1 shows the facilities in which participants practice as well as their disciplines. Notably, 28% of the sample practiced in psychiatry. The remainder most often came from medical and nursing backgrounds. The 'Other' category for provider level was composed of a midwife, an occupational therapist, and a psychiatric clinical officer.

3.2. Perceptions of proficiencies

Most often, the sample rated their proficiency as 'somewhat proficient' (3), 'very proficient' (4), or 'highly proficient' (5). Less than 3% of responses were rated 'not proficient at all' (1), and less than 9%

were rated 'not very proficient' (2). Table 2 details the mean ratings in each area of epilepsy care. Participants were most confident about their knowledge related to referrals, psychosocial impacts, and the neurophysiology of seizures. As a group, HCPs were least confident in their knowledge of diagnostic tools and their use in epilepsy diagnosis and treatment, as well as the use of mono- and polytherapy and when to make medication regimen changes.

3.3. Focus group discussion content analysis

From the content analysis across focus groups, nine major themes emerged. Table 3 details these themes, their descriptions, the secondary themes within each, and the frequency with which statements related to theme were made.

3.3.1. Care management

There was consensus among HCPs that epilepsy is a complex, multifaceted condition that requires longitudinal care and the cooperation of health professionals from various disciplines. The challenges and impediments to effectively managing epilepsy over the entire course of treatment were the most common themes to arise.

When describing current patient care, HCPs described a lack of integration between various clinics and medical personnel. The following quote expresses the importance of involving personnel across disciplines in managing patients with epilepsy:

"Really the management is multidisciplinary. On top of deciding the drugs you're going to give, yes you can give it, but you have to involve social workers. You have to involve other people. Especially therapists and neurologists, sometimes, also have to come. Actually the majority of the time the neurologists have to come to admit the patient and see if the cause of the disease can be reversed or not. So that's — it's really multidisciplinary."

Healthcare providers also explained that it was common for caregivers and family members to be involved in managing a patient's epilepsy. They agreed that collaboration outside of the healthcare sector was important in addition to the biomedical management of the condition:

"So we need to first come up with a sustainable plan and also involvement with all stakeholders who include, okay, the family, the community, the spiritual leaders in the community, and everyone who takes care of these children."

Table 1

Focus group participants' disciplines and practice areas (n = 32).

Facilities	
Healthcare Centre II	4
Healthcare Centre III	3
Healthcare Centre IV	7
District hospital	1
Regional hospital	17
Provider level	
General physician	3
Medical clinical officer	3
Medical nurse	7
Clinical psychiatric nurse	6
Resident (pediatric, psychiatric, unspecified)	8
Nursing assistant	2
Other	3

Table 2

Participant proficiency ratings.

	Mean ratings
Knowledge of when/where to refer the patient for additional care when symptoms do not improve	4.2
Knowledge about the impact of epilepsy on social, academic, and functional outcomes	4.0
Knowledge about the neurophysiology of seizures (e.g., identification of seizure signs and symptoms)	3.8
Overall knowledge and proficiency in managing patients with epilepsy	3.6
Knowledge about seizure classifications (e.g., type of seizure diagnosis)	3.5
Knowledge about types of AEDs and their side effects	3.5
Knowledge about expected outcomes (seizure frequency, duration, and severity) with treatment	3.5
Knowledge of the uses of mono- and polytherapy and when to make medication regimen changes	3.4
Knowledge about diagnostic tools	3.2
Knowledge about the use of diagnostic studies in diagnosis and treatment of epilepsy	3.0

Table 3
Content analysis results.

Major themes	Description	Secondary themes	Frequency
Care management	Management over the whole course of treatment including coordination with multiple healthcare personnel and follow-up systems	<ul style="list-style-type: none"> > Follow-up > Caregivers > Family involvement > Multidisciplinary care 	241
Medications	Role of medications in epilepsy treatment in terms of medication use and access	<ul style="list-style-type: none"> > Medication access > Cost > Types of drugs > Treatment strategies 	204
Diagnostics	Typical diagnostic approaches and practices as well as the various challenges to diagnosing epilepsy	<ul style="list-style-type: none"> > History-taking > Technology and equipment > Types of epilepsy 	193
Community knowledge and beliefs	Descriptions of typical beliefs and perceptions about epilepsy in the community and how these beliefs affect epilepsy care	<ul style="list-style-type: none"> > Stigma > Isolation > Contagion > Witchcraft > Need for sensitization 	148
Healthcare provider training	The importance of training courses and materials for healthcare providers related specifically to epilepsy	<ul style="list-style-type: none"> > Refresher courses or continuing education > Educational materials > Specialty training 	138
Human resources	Number of healthcare providers available to care for PWE	<ul style="list-style-type: none"> > Shortage of health providers > Need for specialists 	100
Patient education	Educating patients and families about epilepsy as an important component of treatment	<ul style="list-style-type: none"> > Psychoeducation > Family and caregiver education 	46
Social support	Providing care for the psychosocial needs of patients with epilepsy through support mechanisms in and beyond the clinic	<ul style="list-style-type: none"> > Psychosocial needs > Caregiver involvement > Group therapy 	39
Location	Proximity of healthcare centres to communities and ability of patients to access care across such distances	<ul style="list-style-type: none"> > Distance > Lack of transportation > Cost of transit > Isolated and rural areas 	26

3.3.2. Medications

Another major area of concern was related to the availability of medications for treating epilepsy. Healthcare providers uniformly agreed that epilepsy should be managed with medications but that drug supplies were limited and unreliable in Uganda. Many participants cited this lack of a sustainable drug supply as their number one concern.

Healthcare providers described how often treatment decisions were guided by the types of epilepsy drugs that are available, which are typically first-line AEDs, rather than the best agent for the patient. The following quote elaborates on this situation:

“Our resources are minimal. Yes, even when you, even when you feel you should prescribe a particular drug, you may not actually go in for that and only settle for whatever is available. Because in the end, it does no sense if you prescribe a drug and the patient doesn't get it, so you have at least the ones you can start with. So at times, we are forced to write whatever is available and leave out what cannot be accessed by the patients.”

Participants also highlighted how the inconsistent drug supply disrupts treatment adherence and treatment efficacy:

“There are not drugs. We find that this route, this quarter, they are brought phenytoin. Now, those ones who are using carbamazepine, they are going to be sad. They will start to buy another which are not affordable for everyone. So those ones will miss and now the fits will increase. Then the other quarter they will bring carbamazepine and phenytoin now will not be brought.”

When medications are unavailable because of stock-outs, patients are sometimes given prescriptions to take to local pharmacies. However, the cost of the drug is often prohibitive for them, which may result in patients defaulting on their antiepileptic treatment. These medication

stock-outs and associated costs can also affect patients' desires to adhere:

“Poor services, health services. If he comes to the hospital and he doesn't get the medicine that he expected, would he come back next time?”

Patients may be discouraged from seeking biomedical care if they believe that there will be no medications for them when they arrive.

3.3.3. Diagnostics

Another common theme was how difficult accurate diagnosis of epilepsy was in these settings. Healthcare providers described how the challenge of differential diagnosis between epilepsy and other neurologic etiologies is exacerbated by the lack of diagnostic tools in their facilities. Likewise, they noted the additional challenge of accurately delineating the type of epilepsy without such instruments. One provider explained his experience diagnosing epilepsy:

“Epilepsy is a condition that is mimicked by other conditions, so you need to have sufficient information to distinguish from other similar conditions. Regarding the postclinical, postimaging. So you may be able to take a good history and clinically conclude that this is epilepsy, but when it comes to other investigations that you'd need to really make a definitive diagnosis, you may be limited in that area.”

Specifically, the lack of magnetic resonance imaging (MRI) and electroencephalography (EEG) studies was reported as taxing to the diagnostic process. In the very few healthcare facilities where such equipment is available, a secondary challenge reported was that there is rarely anyone available to operate or interpret the technology. In such resource-limited situations, HCPs rely primarily on history-taking

and physical exams. These challenges are evident in the following quote:

"I think the challenge it is all about investigations. How we can get the clear diagnosis by using different investigations like the MRI, the EEG, or what she was talking about, we have that list of questions which may guide you to get the exact type of epilepsy. But if it goes, if you go to investigations, I don't think there is any facility here in Mbarara with those machines which can do investigations and get a clear diagnosis."

3.3.4. Community knowledge and beliefs

Many HCPs spoke of the challenges to effective epilepsy care that result from community misperceptions about epilepsy. Common community beliefs include epilepsy being caused by witchcraft or possession and the idea that epilepsy is contagious. While the participants themselves did not report endorsing such ideas, they explained that some of their colleagues from their respective healthcare sites did. Healthcare providers also explained that these community beliefs influence patients' care-seeking behaviors as shown in the following quote:

"Epilepsy has been associated with witchcraft, so there is a lot of stigma that is associated with epilepsy, even people who should seek health care sit back. They don't want to be labeled as epileptic, so they have always resorted to traditional ways of managing epilepsy. They go to the shrines, even the few who come to hospitals to seek medical care."

Participants highlighted how beliefs of epilepsy as a contagion impacts if and how the community assists a seizing individual and how they may relate to them. The following quote illustrates:

"At times, people think epilepsy is contagious, yet in reality, it is not. Even if someone got an epileptic attack, let's say, they were moving around the road, people will just disperse. Why? They believe if you happen to help, you will get it. So I mean, we are trying to do our best, but there is a very big knowledge gap when it comes to the community. So I believe whichever support that is to be put, we have to put more emphasis such that we close this knowledge gap."

Importantly, participants consistently indicated that these community beliefs were deeply ingrained and will not likely shift without concerted educational outreach and community sensitization programs.

3.3.5. Healthcare provider training

Another commonly cited theme was the need for HCP training. This included specialty training for epilepsy, refresher courses, and continuous medical education. Healthcare providers also expressed a need for educational resources like training booklets and guidelines to stay up to date on diagnostic and treatment approaches. The value of such education is illustrated by this quote:

"Since epilepsy is a chronic illness, if you do not manage it properly, then this child is going to end up with so many complications, so I think it would be good to even train the health workers at all levels of the health centers because these patients seek care from those centers first. So if people could be updated, maybe once or twice a year, so that they get the current guidelines on the management of epilepsy there was a better outcome."

Healthcare providers agreed that physicians, nurses, and other providers should all receive some form of training related specifically to epilepsy. While some of the participants recounted studying epilepsy in school or attending a single conference related to the condition, others expressed that most of their knowledge of epilepsy came from their clinical experience.

3.3.6. Human resources

Among the limited resources that were discussed by the participants, the lack of human resources for patient care emerged as a consistent theme. Participants expressed a need for more medical personnel both in general and for epilepsy care in particular. Addressing the shortage of human resources was a priority for many HCPs, as the volume of patients outnumber the providers in an extraordinary manner. The need for more human resources is explained by the following:

"Need to reduce the burden on institutional care cause when they come to Mbarara. People come from all over and they all converge here, you end up having 300 people in the same day."

The inadequate number of professionals trained in the diagnosis and management of epilepsy, even considering resources across disciplines, is illustrated:

"The biggest resource is the human resource. As much as it has been managed by the mental specialist or mental health workers, still, they are not enough throughout the country to be able to diagnose epilepsy and maybe treat it adequately."

Healthcare providers explained that limitations in human resources are compounded in epilepsy care. Specifically, healthcare centers and clinics are generally understaffed, and, within these clinics, few providers possess the knowledge, experience, or willingness to care for patients with epilepsy. Sometimes, patients are only ever treated by nurses or trainees due to the time restraints of physicians or clinical officers. Without a neurological specialty in Uganda, most patients are seen by providers in general medicine, pediatrics, or psychiatry.

3.3.7. Patient education

Many HCPs also discussed the importance of patient education as a component of effective epilepsy treatment. To them, patient education involved teaching patients, family members, and caregivers about epilepsy and its treatment, including how to best manage their symptoms, maximize their quality of life, and recognize and help other patients in their communities. Providers emphasized the importance of counseling about drug adherence in particular.

Some HCPs considered their ability to educate patients to be a strength of theirs that is essential to successful treatment. The following quotes exemplify participants' ideas of successful treatment outcomes for patients:

"They are able to refer other patients to epilepsy to go for medication... I would take that as successful treatment, and also, when the people who are living epilepsy start maybe educating other people in the community, then I would also consider it as successful treatment."

"So, I have a properly-educated patient, a seizure-free patient, an educated family, and a community that is receptive to the diagnosis, so I would consider that a properly-treated patient."

3.3.8. Social support

Many focus group participants identified social support as another essential element of comprehensive epilepsy care. While some HCPs reported social support mechanisms to be a strength at their health facilities, the majority expressed a need for additional support. The importance of this element of care is exemplified by this quote:

"You also need the social support, because they say the social consequences of epilepsy are worse than the disease. And therefore, the social support, the social management is quite crucial in managing a person with epilepsy."

Multiple participants cited group therapy as an effective form of social support for PWE. Some centres utilize this model, while others have

yet to implement it. The following quotes highlight the regard that the HCPs had for such support, with note that such groups can also result in patients feeling more accepted and less stigmatized.

“Actually, they have an epilepsy association group and it meets every first Wednesday of every month.”

“There should be group creation. These patients should be encouraged to make groups to reduce stigma. Because when they are in the group and when they feel that they are the same, stigma is reduced.”

Other forms of social support mentioned by participants included individual counseling, occupational therapy, and outside support from family, friends, and community members.

3.3.9. Location

The last recurring theme involved the impacts related to location. Healthcare providers explained that distance to healthcare facilities, the lack of transportation, and transportation costs all posed substantial barriers to accessing care. In particular, rural and isolated areas of Uganda are neglected and unable to access epilepsy care in Mbarara. This issue is evident in the following quote:

“Some of them come from as far as 200 kilometers from this facility. And it becomes quite challenging for children who want follow-up frequently after two weeks. Financially they are not able to come.”

These challenges related to location reportedly lead to many patients defaulting from biomedical care because they cannot travel to the clinic for follow-up visits or prescription refills. Because of such barriers, many HCPs advocated for community outreach follow-up initiatives and local community-based care models that would allow for local management of the patient with epilepsy once the patient has been diagnosed and stabilized.

4. Discussion

This study sought to understand the unique perspectives of nonspecialized HCPs treating epilepsy in Western Uganda. Since the majority of patients in Uganda cannot access physician-level care, our focus groups included a range of HCPs, particularly those that PWE are most likely to encounter, such as nurses and clinical officers [12,13]. These perspectives inform capacity building efforts by outlining system weaknesses from those working within the infrastructure and also provide insight into the areas of confidence and need that these HCPs express. The viewpoints and experiences expressed by our participants converged in three broad areas: resources, infrastructure, and education, which collectively shape much of the landscape of epilepsy care. These findings can be utilized to inform educational efforts and resource allocation decisions.

Importantly, one of the most daunting challenges raised by HCPs was the severe lack of resources. Human resources are particularly limited in Uganda with very few trained providers relative to the disease burden. In order to contend with the shortage of providers as well as barriers of distance, the WHO has recommended integrating epilepsy care into primary healthcare [19]. This approach has shown success for mental health, noncommunicable diseases, and human immunodeficiency virus (HIV) in SSA and may address the critical impact of limited continued care resources highlighted in the focus groups [20–22]. Also, currently, there is no consistent system that allows for local management of patients after diagnosis and stabilization, which results in a high patient burden on existing HCPs. Relatedly, many HCPs cited the inadequacies of the current follow-up system as their most pressing concern, because the inability to properly follow-up with patients undermines treatment continuity, education, emergency access, and ultimately adherence. These problems could be addressed by task shifting to nurses or community health workers, which has been shown to be

effective in improving access and retention for epilepsy and other noncommunicable diseases [23–25]. However, even with this approach, a minimum number of specialists are still needed to provide supervision and referral services.

The immense lack of resources related to diagnostic equipment and studies also highlights the fortitude of those working in these environments. With the exception of some larger healthcare facilities, imaging is rarely available for the classification or management of epilepsy in East Africa, and where it is, the cost is typically prohibitive for a majority of the population [26]. With such limited investigative capacity, HCPs in Uganda rely upon clinical history to make complex differential diagnostic decisions as well as care decisions. These classifications and diagnoses determine the subsequent selection of medications and other care interventions. Here too, HCPs desire augmented and updated training to assist their clinical skill maintenance. In rating their own proficiencies, there was a clear desire to learn more about skills related to diagnosis (e.g., the use of diagnostic studies) and medication management (e.g., the use of mono- versus polypharmacy and when to change strategies; AEDs and their expected outcomes on seizure dimensions).

The shortage of resources in Uganda is further illustrated by the fact that HCPs manage with the oldest first-line AEDs, as these remain the primary medicines available in government-supported facilities, despite the existence of newer medications with superior efficacy and better side effect profiles. Public facilities have particularly limited drug supplies compared with private healthcare clinics and hospitals, suggesting that poorer people are particularly disadvantaged in terms of drug access [27,28]. Even at facilities with these medications, the AED supplies are unreliable and are easily depleted (i.e., “stock-outs”), meaning basic treatment becomes disrupted. In Uganda, more than two-thirds of caretakers for children with epilepsy reported that drugs were unavailable on at least one occasion during their child's treatment [29]. In such cases when drug supplies are depleted at clinic or hospital pharmacies, patients are forced to purchase prescriptions from drug shops or private pharmacies at much higher costs [30]. Thus, such shortages, compounded with the work-loss and transportation costs of refilling prescriptions, significantly interfere with medication adherence [6,30], as highlighted by HCPs in the focus group discussions as well. Indeed, AED treatment is reportedly interrupted for most PWE, which results in ineffective seizure control or drug resistance [28]. Because seizures will likely result when medication use is disrupted, confidence in biomedical care of epilepsy is undermined in the families and communities observing this care. Thus, improving access to antiepileptic treatment would mitigate the morbidity and premature mortality associated with epilepsy as well as restore confidence in biomedical approaches.

Many of the other concerns raised about the care of patients with epilepsy were related to the need for infrastructure strengthening. The broader network of diagnosis and care is remarkably limited, with a paucity of multidisciplinary care service networks that could be responsive to individual patient needs. This deficiency limits referrals to specific services, such as occupational or speech therapies, but also speaks to the lack of social work services and community supports. Further, the nonexistence of diagnostic and clinical care capacity in many areas results in large and often prohibitive distances for patients to traverse to reach quality care. The need to travel long distances for proper care has been cited as a primary reason for default from follow-up care for epilepsy [6,31]. Since most specialty care and advanced technology tend to be concentrated in urban areas, such distances exacerbate the disparities already experienced in rural areas of Uganda due to fewer resources and higher levels of stigma and misconceptions about epilepsy [3,10,11]. Strategic placement epilepsy clinics throughout the country to shorten distances to care would be a powerful step towards narrowing the epilepsy treatment gap.

Beyond system and resource limitations, another area of focus for participants was the need for additional medical training programs for managing PWE. This need was strongly expressed by HCPs at all levels

of training, suggesting that such education is not only desired by physicians but by all providers, including nurses and clinical officers. However, there are very few studies evaluating the efficacy of epilepsy training programs in SSA, and there are none from Uganda specifically. A study from Zimbabwe did show that basic workshop-based training for nonphysician HCPs can successfully improve epilepsy care, at least in the short-term [32]. In Cameroon and Kenya, training programs for nurses have been effective for providing care for noncommunicable diseases, including epilepsy, after initial diagnosis by a physician [23,25]. Educational programs involving epilepsy training should be incorporated into prequalification and continuing medical education for physicians and nonphysician providers, and the efficacy of such programs should be empirically evaluated.

The educational needs communicated by HCPs were not limited to their own training, as the importance of psychosocial and cultural aspects of epilepsy care was also strongly highlighted. Healthcare providers clearly detailed the role of patient education in effective care management, which is consistent with other studies from SSA that suggest that improving patient knowledge could narrow the epilepsy treatment gap [33,34]. Recent analysis of care-seeking patterns prompted Rutebemberwa and colleagues to emphasize the need for intensive counseling and adherence support for patients, as pursuit of traditional or faith-based treatment interventions may be related to expectations about outcomes, such as cure seeking [35]. As such, HCPs are responsible for not only treating PWE but also educating patients and caregivers to imbue confidence in their treatments and decrease stigma [36]. It has been suggested that patient and caregiver knowledge is a vital factor in minimizing the impact of epilepsy on social and psychological functioning by reducing fear associated with seizures as well as minimizing potentially harmful self-management practices [37,38]. Therefore, it is ever more crucial that HCPs themselves are adequately informed about epilepsy, as this relaying of knowledge offers potential for better relationships with patients, reduction of stigma, superior treatment compliance and management, and higher quality of life for PWE [37]. Indeed, adherence and outcomes would be improved with patients who understand that epilepsy is treatable and neurological in origin, and the mechanisms of treatment and possible outcomes.

The immense challenges to both HCPs and patients posed by a misinformed public are well established [5,39,40]. To that end, our participants discussed the need both for strengthening social support systems and expanding community sensitization. Indeed, in communities where patient care is highly influenced by tradition and resources, promoting the timely referral of patients to biomedical care can be challenging [41–43]. Perhaps the most damaging misconceptions about epilepsy are that it is contagious and that it is the result of demonic possession. The pervasiveness of such beliefs was reported by HCPs in focus groups and is well established in the literature [44,45]. These two notions fundamentally impede care and prolong suffering. The affiliation of madness and contagion with seizures contributes to negative attitudes among community members and associations of epilepsy with fear, shame, and guilt [43,46]. Because of these convictions, people tend to evade a person experiencing a seizure rather than assist them to reduce injuries, and patients are most often shunned, isolated, and treated with revulsion rather than with empathy.

A limitation of this study is that all participants were recruited from one region, which may have biased perspectives. Also, most of the participants came from the regional hospital, and there was an uneven distribution of HCPs across the various professional levels, both possibly introducing bias. Only one psychiatric clinical officer was enrolled, thus limiting the perspective of this discipline that is primarily charged with caring for PWE in Uganda. Finally, we used self-reported metrics of proficiency; future studies might incorporate a well-validated epilepsy knowledge test or other objective methods to ascertain content mastery.

This study focused on the unique perspectives of HCPs that care for patients with epilepsy. Their rich experiences and perspectives

converged to illustrate focused needs involving augmenting resources, strengthening infrastructure, and education. To provide effective epilepsy diagnosis and care, HCPs delineated the need for the following:

- Augmenting resources
 - 1) Trained human resources;
 - 2) Neurodiagnostic studies (EEG, MRI);
 - 3) Accessibility and quality of medication stock.
- Infrastructure strengthening
 - 1) Integrated and decompressed clinical settings;
 - 2) Increased number and strategic placement of epilepsy clinics to enhance access;
 - 3) Reliable medication sourcing at primary and follow-up treatment sites.
- Providing education, sensitization, and support
 - 1) Training and materials related to epilepsy diagnostics and management;
 - 2) Patient education and social support resources;
 - 3) Community sensitization.

The effect of any of these interventions could be synergistic if executed with harmonized efforts across governmental, community, and healthcare sectors. The challenges require prioritization but remain surmountable.

5. Conclusion

This study sought to understand the perceptions and priorities of HCPs caring for patients with epilepsy in Uganda. Findings revealed the major concerns and challenges raised by HCPs to be broadly grouped into nine major themes: care management, medications, diagnostics, HCP training, human resources, location, patient education, social support, and community knowledge and beliefs. Across these themes, HCPs collectively emphasized the need for greater infrastructural support, resource allocation, and education of both providers and community members. Interventions to reduce the epilepsy treatment gap in Uganda should consider these findings and thus be rooted in a thorough understanding of the needs, beliefs, and priorities of the relevant stakeholders, which they directly affect. Inclusion of HCPs from inception to implementation phases of potential interventions will augment acceptance and effectiveness of such programs.

Funding sources

(1) UCB Societal Responsibility Fund (King Baudouin Foundation) Brussels, Belgium; (2) Duke University BASS Connections. Our funding sources had no involvement in study design, data collection and interpretation, or decision to publish. One coauthor from UCB (DT) provided insights and comments on the manuscript.

Declaration of competing interest

None.

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