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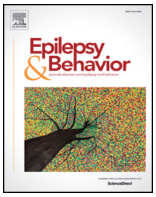

Leveraging the lessons learned from studies on the cultural context of epilepsy care in Uganda: Opportunities and future directions

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ABSTRACT

In this summary paper, we review the body of research contained in this special issue, *The Intersection of Culture, Resources, and Disease: Epilepsy Care in Uganda*, and corollary recommendations for a way forward. We review key findings and conclusions for the studies, which tell a story of culture and care-seeking through discussions and data gleaned from a rich research landscape traversing community village dwellings, shared communal areas, churches, and urban hospitals. The voices and perspectives of over 16,000 study participants inclusive of people living with epilepsy, their neighbors and healthcare workers, traditional healers, and faith leaders are reported. From this, we synthesize findings and prioritize a set of recommendations to advance epilepsy care in Uganda. Progress will require infrastructure strengthening, multilevel educational investments, and an ambitious, extensive program of community sensitization. These proposed priorities and actions outline a way forward through formidable but surmountable challenges but require harmonized efforts by government and other relevant stakeholders, scholars, clinicians, and community leaders.

This article is part of the Special Issue "The Intersection of Culture, Resources, and Disease: Epilepsy Care in Uganda"

1. Introduction

Epilepsy is a disease of the brain characterized by an enduring predisposition to generate epileptic seizures [1], and is one of the oldest, common neurological disorders known to mankind [2]. The estimated number of annual newly diagnosed epilepsy cases exceeds five million globally, with an anticipated rise over the next decade [3]. People with epilepsy (PWE) carry a significantly enhanced risk of premature death compared with that in the general population and have a host of other comorbidities [4]. According to the most recent Global Burden of Disease Study, epilepsy accounted for more than 13 million disability-adjusted life years (DALYs) in 2016 [5]. The DALYs is a summarized calculation that comprises the sum of years of life lost (YLL) due to premature death in the population, and years lived with disability (YLD) due to the disease [6]. Despite showing that overall, the disease burden of epilepsy from 1990 to 2016 had decreased, this change varied across geographical areas with countries from low-income settings like Uganda in sub-Saharan Africa (SSA) noted to have higher age-standardized DALY rates [5].

While epilepsy can be successfully controlled in up to 70% of people using relatively inexpensive and effective antiepileptic drugs (AEDs) [7],

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it is estimated that less than 20% of PWE in Uganda fully benefit from this treatment [8]. The reasons for this discrepancy are complex and have not been clearly elucidated but seem to revolve around major gaps in public awareness, limited human resources and/or diagnostic facilities, and the dominance of nonallopathic treatment choices [8]. Furthermore, there are reports of substantial variations in access to care for PWE because of a multiplicity of unmet needs, such as physicians and other providers having epilepsy treatment expertise, dedicated epilepsy clinics for diagnosis and treatment, and education to alleviate stigma [9].

One of the Ugandan health sector objectives is the goal to produce a healthy and productive nation that effectively contributes to socioeconomic growth through the provision of accessible and quality healthcare to all people in Uganda, including promotive, preventive, curative, palliative, and rehabilitative healthcare [10]. This goal aligns with Sustainable Development Goal (SDG) 3, which includes the targets of reducing premature deaths from noncommunicable diseases and promoting mental health and well-being. The goal also includes the aspiration for universal health coverage with access to quality services and effective, affordable essential medicines [11]. The achievement of SDG3 will not be possible without the investment in the physical and mental health for all people, including those living with epilepsy. Though far from complete, the global fight against epilepsy has made noteworthy strides. The recent adoption of the World Health Assembly (WHA) resolution on epilepsy (WHA68.20) by the Member States [12] underscored the importance of the need for coordinated action at country level through the engagement of governments and civil society to take decisive steps to promote access to care and to protect the rights of PWE.

For Uganda, a great opportunity to put into practice the WHA resolution was created in 2017 out of the partnership between the faculty of the Duke Division of Global Neurosurgery and Neurology (DGNN) and the faculty of Makerere University, Mulago National Referral Hospital, Butabika National Referral Mental Hospital, Mbarara Regional Referral Hospital, and Mbarara University of Science and Technology in Uganda through the execution of several collaborative epilepsy research projects. The primary goal of the initial phase of this partnership was to delineate the key issues, which are paramount to epilepsy care and which could impact the potential effectiveness of establishing epilepsy centers of excellence in Uganda to improve epilepsy care. This research program was facilitated with the generous support of a grant from UCB Societal Responsibility Fund at the King Baudouin Foundation and Duke University BASS Connections grants.

In this article, we provide a synthesis across the various studies to draw out the high-level learning about culture and behavior that greatly impacts care-seeking for epilepsy: (a) the practical and cultural barriers to epilepsy care; (b) the care-seeking patterns of the patients and their typical care in various health units in the country; (c) and what needs to change to operationalize the vision of creating a culturally sensitive, cost-effective national epilepsy service that will make progress in improving the quality of life of PWE in Uganda. Details about the national community-based, hospital-based, and targeted focus group samples, the research questions and methodologies used, can be found in the manuscripts within this special issue. In this paper, we focus on the findings and future directions that evolved from this work. It is hoped that these lessons are generalizable and serve as a template to similar efforts in other countries, when taking into consideration the understanding of the cultural context of epilepsy care.

2. Our studies: findings and conclusions

2.1. Beliefs about epilepsy, its treatment, its causation, and barriers to care

The study of beliefs and misconceptions across community and hospital samples demonstrated that having limited exposure or experience with PWE greatly impacts one's attitude towards them, beliefs about communicability, considerations of the rights and entitlement of PWE, and ideas about the management of the disease [13]. While there are few similar studies in Africa, negative attitudes and stigma towards PWE resulting from lack of understanding and exposure are a global phenomenon [14,15]. These negative attitudes in our studies may have arisen from the fear of the unknown coupled with unfamiliarity in relating with PWE due to the lack of a personal/emotional experience with them. It is highly likely that in addition to more efforts made to educate the public about epilepsy, more importance should be put on the active involvement of PWE in awareness campaigns or employment of similar patient interest groups in order to build positive attitudes in the public.

The majority of community members in Uganda believe that epilepsy is a communicable, contagious disease [13]. This sociocultural belief has overshadowed the misconceptions about epilepsy in a number of African settings [16–18] with urine, saliva, flatus, or feces implicated as conferring the contagion. These beliefs fuel stigma not only towards PWE in the community but also towards their close associates, and yet evidence-based interventions addressing this issue in the African context are extremely limited. Stigmatized PWE tend to experience more depressive symptoms and social isolation and have poorer psychological health and lower quality of life [19,20] with these effects more pronounced in those from low-income settings. Pragmatic solutions to address these beliefs and reduce the resulting stigma should be made an important priority in Uganda and Africa as a whole. There are several gaps in our understanding of the mechanisms of stigma, reflecting the need to set up culturally responsive multidisciplinary trials of stigma reduction interventions in Africa.

Within communities, the origin of epilepsy is believed to arise from either biological, sociospiritual, or biospiritual factors; however, more than half of this large, randomly selected community sample believed that two or all three of these factors rather than a single one alone could cause the illness [21]. Winkler and colleagues noted similar findings of dual epilepsy causation in Tanzania [22], highlighting the importance of healthcare providers for epilepsy trying to understand and value the existing sociocultural belief systems of their patients before attempting to introduce any intervention. Given that nonbiologic disease perception of epilepsy is still strongly prevalent in Uganda [21], there is a need to appreciate that people hold different cultural beliefs about the illness. Many of these beliefs do not conform to the scientific explanation of illness, and the healthcare providers' failure to communicate effectively can lead to a poorer quality healthcare outcome. Acknowledging this fact and using this knowledge to develop culturally sensitive approaches to gradually empower PWE with the right information are critical.

Beliefs about the cause of illness determine to a great extent the healthcare utilization, treatment uptake, and treatment adherence. In seeking optimal outcomes of epilepsy care, there is a need for the healthcare system in Uganda to develop simple plain language education messages to improve epilepsy literacy. In addition, there is need for awareness programs for the illiterate population through community events using song or drama, or the use of radio and TV messages. Many of the highlighted biological attributions in this paper, such as malaria or birth injury, are preventable. This knowledge could be used in the development of epilepsy prevention messages and could have secondary positive impacts through community efforts to prevent malaria and to seek early interventions during pregnancy and labor.

Higher education and income was associated with a greater likelihood of conceptualizing epilepsy as potentially resulting from biological causes [21]. While this finding reinforces the importance of promoting universal education for all, a system that has been propagated in the Ugandan Education system since January 1997, improved epilepsy health literacy will likely result when better access to foundational education is coupled with decisive proliferation of basic facts about the illness.

Among PWE, several barriers to care are reported, but those related to actual and practical costs associated with obtaining biomedical care are endorsed to the greatest degree [23]. These barriers include the perception of potential monetary costs associated with care, including

AEDs, biomedical tests, and travel, as well as the method and type of payments allowed [23]. Furthermore, indirect costs are oftentimes overlooked, such as reduced productivity of the PWE and their caregivers, the comorbidities, or premature mortality [24]. While these issues are extremely important since they prevent PWE from reaching their full potential in life, there are hardly any studies evaluating the cost implications of epilepsy treatment in a systematic way in low-resource settings.

2.2. Determinant patterns of healthcare utilization

Our studies afforded us the opportunity to retrospectively examine patterns of healthcare utilization among a sample of PWE who eventually made it to biomedical care. People with epilepsy who first seek care through traditional or pastoral faith healers are delayed from reaching biomedical care by an average of two years [25]. While the impact of this delay has not been studied in this setting, it is known that untreated epilepsy can have devastating consequences on neurocognition and functional outcomes, and the delay further maintains the PWE in the community untreated and symptomatic, subjected to stigma, and at risk of injury, further damaging quality of life outcomes, and death [2]. Belief in sociospiritual or biospiritual causes for epilepsy, combined with lower education of the person in the household directing healthcare decisions, and lower household income, were associated with pursuing nonbiomedical treatment first [25]. When considered together, these factors were more salient than any perceived barriers to care such as cost or distance to the biomedical healthcare facility, suggesting that beliefs about causation are critical to target in large-scale public sensitization to enhance early biomedical care-seeking patterns [25].

2.3. Epilepsy care in major public hospitals

People with epilepsy in Uganda that seek care in public hospitals often have severe forms of epilepsy, and it is possible that those with less severe forms are not seeking treatment at these health units, which may underestimate the epilepsy treatment gap [26]. In an under-resourced healthcare system like in Uganda [27], it will be essential to work towards implementation of a minimum acceptable standard of care for PWE agreed upon by the healthcare providers, based on the standard clinical guidelines already existing.

A number of study participants had neurocognitive deficiencies [26], which was no surprise considering the severity of the disease and the possibility of multidrug therapy. Improvement in the severity of the seizures was noted with biomedical treatment, providing evidence for treatment efficacy and improvement in quality of life [26]. However, these improvements were noted at tertiary teaching hospitals based in urban settings selected for participation in the study. There is a need to spread this benefit throughout the country by developing epilepsy care capacity in lower more rural health facilities.

2.4. Stakeholder views of the challenges and opportunities in epilepsy care in Uganda

Biomedical practitioners managing PWE in Uganda are few and are often overwhelmed with various other responsibilities as they often serve in multiple capacities for the various medical conditions that patients present with to healthcare. In addition, they are underutilized by patients who often have preference for traditional healers who are more accessible, conform to their cause belief model, and are trusted by the community [28]. A possible strategy to alter their misconceptions and harness opportunity may require the exploration of integrating religious, traditional, and indigenous treatments into health systems and developing partnerships with traditional health practitioners [29] to access more PWE.

Infrastructure weaknesses centering on limited human resources and medication sourcing hinder access and cripple care [30]. Willingness to collaborate across allopathic, traditional, and faith communities varies notably, with formidable resistance stemming from concerns about marginalization [28]. The obstacles facing patients to reach and maintain access and faith in biomedical care are numerous and substantive. Importantly, epilepsy care stakeholders prioritized the creation of dedicated epilepsy clinics, infrastructure strengthening to address medication stock-outs, community outreach programs for sensitization, and collaboration between biomedical providers and traditional healers as solutions to improve epilepsy care in Uganda [28].

2.5. Review of stigma reduction interventions

There is no lack of understanding of how pervasive and damaging epilepsy stigma remains. Enacted and perceived stigma against PWE continues unabated globally in spite of a number of attempts that have been made to mitigate this situation in the past. Our systematic review of stigma reduction interventions highlights opportunities for continued development of novel public awareness, patient, school, and public policy interventions [31]. There is also a need to develop valid assessment tools and well-grounded study methods to measure the efficacy of programs, ideally with consensus across researchers to promote comparability of findings. The Personal Impact of Epilepsy Scale (PIES) is one example of a validated tool to monitor health-related quality of life outcomes for PWE and has now been validated in English among patients with epilepsy in Uganda, translated into *Runyankole* and *Luganda*, and has been validated in the latter local language [32].

2.6. Studies conclusion

Our intention in executing this body of work was to enhance our understanding of the cultural context of epilepsy care in Uganda. To accomplish this, we have to holistically consider practical challenges, personal and community sociocultural perspectives, and the realities of each component individually, and the interaction of them in the pluralistic healthcare system of Uganda. It is from this informed perspective that we now outline potential opportunities to advance the care of PWE in Uganda, which will require harmonized efforts including the Ministry of Health (MOH) and relevant stakeholders for prioritization of public policy and fiscal support, scholars to lead training, research, and clinical care programs, and community leaders to execute a broad-reaching sensitization campaign to improve epilepsy health literacy. We next turn to a discussion of these opportunities and much needed future directions.

3. Opportunities and future directions

Epilepsy remains a challenge in SSA, particularly in Uganda where PWE suffer with debilitating seizures as well as associated comorbidities, such as depression and neurocognitive delays and deficits. People with epilepsy endure significant isolation and discrimination as a result of pervasive stigma, which dramatically impairs quality of life. Developing feasible, culturally sensitive solutions that focus on the critical barriers of stigma reduction, efficient and affordable supply of AEDs, as well as the distance traveled by patients to the respective health units, is required to address the quality of biomedical care necessary for progress. Importantly, our recommendations emphasize a multipronged approach with a focus on reducing stigma *AND* capacity strengthening. Neither area should be approached in isolation given that a dual focus facilitates synergistic effects that would not be realized otherwise. For instance, solely focusing on a stigma reduction campaign while not attending to the immense shortage of biomedical providers would lead to an infrastructure that would be quickly overwhelmed, causing frustration in PWE and possible reversal to the more readily available traditional and pastoral care providers.

We now outline a structured set of specific interventions (Table 1) that can achieve the goal of improving patient and community health literacy, integrated and collaborative care of PWE, and improved treatment and healthcare outcomes, with coordinated and concerted support across government, provider, and community allies.

3.1. Capacity building for the diagnosis and treatment of epilepsy

Sparse, poorly equipped healthcare facilities to provide epilepsy care coupled with frequent drug stock-outs and lack of adequately trained epilepsy healthcare workforce greatly hinder the provision of effective care. The following recommendations center on necessary components of effective and quality epilepsy care.

3.1.1. Infrastructure strengthening

The most consistent recommendation, recognized across all epilepsy stakeholder groups studied, was the need for specialized epilepsy clinics for the diagnosis and treatment of PWE [28]. It is particularly notable that these groups spontaneously recommended the creation of such treatment hubs. Such clinics are powerful mechanisms in a community as they 1) legitimize epilepsy as a medical condition; 2) direct healthcare seeking to a known site of care; 3) provide a setting for improved care coordination conducive to adherence to AEDs and decreased likelihood of unnecessary regimen changes, and 4) serve as examples of settings where PWE are welcome and stigma is not tolerated.

Table 1
Recommendations to enhance epilepsy understanding, access, and care.

Capacity
Infrastructure strengthening
- Develop specialized epilepsy clinics
- Ensure consistent supply of antiepileptic drugs (AEDs)
- Increase the number of neurology posts
- Augment the nonspecialized healthcare workforce (see below)
- Equip facilities with diagnostic tools (EEG/CT/MRI) and improve access to lab testing
- Develop capacity for local maintenance of equipment
- Build multidisciplinary care capacity
- Integrate technology to facilitate clinical monitoring and access to care

Education and referral coordination
- Develop neurology training program
- Train nonspecialized healthcare providers in local healthcare hospitals and centres to identify, treat, and refer PWE
- Develop local mentorship programs for providers with hands-on training and supervision
- Support development of community medical outreach programs that provide follow-up care in local communities
- Educate stakeholder groups to identify and refer PWE for biomedical care
    - Community health workers
    - Community leaders and elders
    - Educators
    - Faith leaders
    - Traditional healers
- Train and use “epilepsy educators” in community and clinic settings
- Integrate web-based learning and consultation

Community sensitization
Sensitization content
- Epilepsy is not contagious
- Epilepsy is treatable with antiepileptic drugs (AEDs)
- Epilepsy as a biologically based neurological disease
- PWE are not mad or possessed by demons
- Epilepsy is a chronic disease, likely requiring changes in dose or type of AED, or multiple medications
- Healthcare consultation is necessary for all degrees of seizure severity
- A person with well-controlled epilepsy is able to live a fulfilled life

Sensitization mechanisms
- Multimedia campaigns
- Outreach to local government leadership
- Programs in community, school, and clinic settings
- Outreach to public service organizations (e.g., Inter-Religious Council of Uganda)
- Deploy Epilepsy Support Association Uganda (ESAU), Purple Bench Initiative, and other nonprofit groups

Another indispensable recommendation for success is the need to ensure a constant and reliable source of AEDs. Even with AED options being largely limited to first generation medications, improvement in seizure severity is obtainable [26]. A regular supply of AEDs at the health units would sustain treatment engagement, response, and improved quality of life. However, medication stock-outs are ubiquitously named as a major challenge and even as a deterrent to seeking care [23,28,30]. A study conducted at Mulago Regional Referral Hospital [33] documented that two-thirds of their sample of caregivers of children living with epilepsy experienced medication stock-outs during the course of their child's treatment. A 2014 survey of Uganda Hospitals and Health Centre IV facilities showed that 84% of the facilities had carbamazepine available, 80% had phenytoin, but only 36% had phenobarbital and 15% had valproate in stock [34]. Recognizing that some PWE require changes to medication or multiple AEDs to achieve seizure control, limited and interrupted supplies across facilities are problematic. Patients, specialists, and general healthcare workers all recognize interruptions to the availability of AEDs as common and deleterious events [28,30]. Missed doses have a high probability of causing breakthrough seizures, which then fundamentally erode faith in biomedical treatment for patients and observers in the community. Progress made in directing care paths to biomedical care can quickly be undermined with suboptimal treatment resulting in symptoms.

Creating an infrastructure within Uganda that allows for uninterrupted supply of AEDs for all PWE is an incredibly daunting task. The MOH recognizes drug stock-outs as a critical issue in the health sector that gravely impacts health service delivery [35]. An important initial step would be creation of a mechanism to regularly track stock-outs within the public sector [35]. Such a system would in real-time inform an understanding of the magnitude of stock-outs, and adjustments to AED distribution patterns to facilities could be made. Synergistic to AED stock-out tracking would be added attention to facility-level documentation of AED usage and which AEDs show measurable seizure control for their PWE populations. This harmonious system would provide valuable information to the Ugandan MOH and National Medical Stores to shift national AED requisition patterns and evidence-based alterations to the essential medication list.

Next, there is an absolute need to augment the number of human resources for epilepsy care. Sub-Saharan Africa has the lowest density of neurologists worldwide [36], and Uganda is no exception. At present, there are 11 neurologists in Uganda, located primarily within Kampala city. Coupled with lack of proper referral guidelines, many PWE who require specialist care are missed. The need to augment the number of neurology posts by the MOH is imperative to meet the care required for local cases, absorb complex cases referred from primary care, and to be responsive to consultations from the medical community. In addition, the mental health practitioners including psychiatrists and psychiatric clinical officers that play a critical role in epilepsy care also need additional training to increase their numbers and expertise to serve the large population of PWE. Finally, there is a need to increase the number and expertise of nonspecialized healthcare providers, including physicians, medical clinical officers, and nurses to identify, treat, and refer PWE (see below Section 3.1.2).

It is important that healthcare facilities are equipped with the diagnostic tools needed to accurately diagnose epilepsy. To this end, consistent, reliable access to electroencephalograms (EEG), with a trained health workforce and technical maintenance teams to correctly interpret these diagnostic tests is critical for high-quality care. Additionally, improved laboratories for blood panels are necessary to fully characterize and treat PWE appropriately. Treatment adherence cannot be reliably established in the absence of such studies. Structural imaging tests, specifically computerized tomography (CT) and magnetic resonance imaging (MRI) tests, are needed to identify structural lesions.

Without such imaging capabilities, PWE who would directly benefit from neurosurgical intervention, sometimes curatively, cannot be identified and suffer unnecessary, fully preventable consequences [37–39].

Establishing multidisciplinary teams in and around specialized epilepsy clinics for speech, occupational, and physical therapies has the potential to significantly reduce secondary disability from treatable epilepsy sequelae. Many PWE could benefit from counseling and psychiatric management of secondary sequelae, and social workers and nurses in epilepsy clinics may serve as important “epilepsy educators”, trained to instruct PWE about activities they can embrace and maintain in order to better control their epilepsy, and maximize function and quality of life. Having such a holistic care approach for PWE in Uganda where comorbidities are addressed would reduce morbidity and enhance functional outcomes.

Finally, strengthening support for medical documentation tracking metrics would have numerous favorable effects. Such monitoring would improve clinical care, allow for responsible placement of resources, improve medical accountability, provide clear and measurable targets, and facilitate adaptations to improve service delivery. A better understanding of the treatment gap shall be realized. Essential metrics would include tracking the clinical care decisions and outcomes for PWE longitudinally, availability of AED medications and adherence to AED regimens, and clinic metrics relative to clinic capacity and population ratios. Standardization of documentation using tools like the PIES [32] and the Limoges questionnaire [40] allow collection of data with local, national, and international relevance.

3.1.2. Education and referral coordination

There is a vital need to develop a specialized neurology training partnering with international collaborators to enhance the care of all central nervous system conditions in Uganda. Currently, the development of an East African College of Neurology is underway with the aim of increasing the numbers of trained medical professionals in neurology. An important example of this type of effective partnership has already been demonstrated in Uganda with the creation of the Ugandan College of Surgeons of East, Central and Southern Africa (COSECSA) neurosurgery fellowship program [41–44]. In tandem, installation of specialized epilepsy clinics in strategically placed referral or district hospitals would address and support a referral process and development of specialized epilepsy care.

Clearly, the few specialty neurology and psychiatry clinics in the major national referral and regional referral hospitals cannot alone meet the treatment needs of the population with epilepsy that seek healthcare in the public sector in Uganda. The current population of Uganda is approaching 41.5 million people [45], about half of which rely on the public health sector for care [46]. Thus, there must be capacity strengthening for treatment at the local level. Currently, because of differences in the total number of healthcare providers and specialty-specific national training programs in Uganda, epilepsy is most often managed within psychiatric hospitals and clinics. Neurologists, thus, are only able to care for PWE at the highest levels within the public healthcare infrastructure, while psychiatric clinic officers and nurses are regularly available at lower levels such as health centre IIIs. As such, training and supporting healthcare providers in these centres to make a diagnosis, interpret EEG, and initiate appropriate treatment is essential. Ideally, such educational programs would be systematic, applied nationally, and would utilize continuing education (CE) mechanisms and incentives.

The effectiveness of educating nonspecialized healthcare providers would be incrementally augmented with a coordinated mentorship system run by specialists, with hands-on training and access to consultation for these providers, resulting in an increased workforce and transfer of skills and knowledge. Ideally, a coordinated referral system between health centres, hospitals, and specialty clinics would not only allow for patients to be easily referred for specialist care if and when needed but also be triaged to local care once diagnosis is made and maintenance therapy is established.

Concurrently, there is an urgent need to empower community medical outreach programs that bring follow-up care directly to patients, to reposition care from overcrowded clinics and increase adherence. For instance, community healthcare workers (CHWs) in local villages could be trained to track basic seizure occurrence and symptoms and provide PWE with either their monthly AED regimen or encourage clinic or hospital-level follow-up. This would decompress specialty clinics, allowing for an increase in capacity to serve new patients, and would further keep patients closer to home for maintenance care [30]. Reducing distance and the cost of care in such a manner may effectively enhance treatment adherence as well [23,47].

There is also value in engaging stakeholder groups to identify symptoms of seizures and refer people for biomedical evaluation, and these include CHW, community leaders and elders, educators from primary to university levels, and faith leaders and traditional healers. Here, the goal is to engage these groups to identify PWE and get them to proven biomedical treatment, while respecting and coordinating complementary roles. Many of these important community members can in turn be empowered as “epilepsy educators” in their respective settings, to provide information, support, and resource referrals, as an epilepsy nurse in a clinic would. A program with a demonstrated reduction in the treatment gap was implemented in Mozambique, and involved broad training of nonspecialized health providers and important community members, including community health activists, faith leaders, teachers, and traditional healers, among others [48].

With the steady annual increase in numbers of estimated internet subscribers in Uganda, the use of digitalization as an avenue for adult learning on epilepsy through online web-based learning courses and video-teleconferencing could be incorporated as a viable vehicle for information dissemination, as it has been in neurosurgical training in Africa [44]. In addition, these opportunities could also be explored as feasible and cost-effective avenues for improving neurological care to underserved populations [49]. These innovative learning and care modalities have the potential of bringing research and care networks together and also may serve as a means to engage the youth in epilepsy-related activities.

3.2. Community sensitization

Misconceptions regarding epilepsy prevail within communities, and successful resolution of such misconceptions and stigma requires a multipronged approach involving patients with epilepsy, healthcare providers, epilepsy support organizations, policy makers, and communities.

The findings of Mbuba and colleagues [47] strongly suggest that education targeting negative attitudes about PWE and their basic rights, and providing free AEDs in facilities near to patients could favorably impact biomedical treatment seeking. Our work additionally identifies belief in biospiritual or sociospiritual causes of epilepsy to be an important risk factor for not seeking biomedical healthcare [25].

Our study confirms prolific misconceptions about epilepsy, its origins, and its treatment in community settings [13]. Those with limited exposure or experience with epilepsy are the most likely to maintain that epilepsy is communicable and to limit the rights of PWE [13]. Therefore, there is a need for culturally appropriate community engagement campaigns utilizing PWE as “epilepsy champions” and trusted leaders to raise awareness and promote positive attitudes to allay the stigma and isolation conferred to these patients. In developing sensitization programs, it is essential to deliver culturally relevant programs with culturally competent providers who will respect prevailing belief systems, which are most often pluralistic [21]. Finally, patterns of healthcare utilization can be considered as a multifaceted gestalt, and interventions should respect and cater to this complexity [25].

3.2.1. Essential content of sensitization campaigns

It is absolutely vital to educate the public that epilepsy is not an infectious disease. Among the greater community population, the dominant belief is that epilepsy is contagious through touching PWE (during or in the absence of an active seizure), contact with secretions, and inhalation of exhaled air or flatus [50,51]. Such fear is corrosive, driving stigma and discrimination. Because they are viewed as conveying a contagion, PWE are separated and isolated, or may isolate themselves to avoid persecution. This type of isolation manifests in various ways ranging from keeping children with epilepsy away from the educational system or the children actively refusing to attend school and adults never getting married. It is reasonable to anticipate that if the perception of personal threat is diminished, so too would the need for discriminatory behavior.

Another critical objective of sensitization campaigns is to communicate that epilepsy is treatable with antiepileptic medications and that the majority of patients can achieve symptom improvement or amelioration with AEDs. Information about medication effectiveness should be conveyed in a manner that is sensitive to potentially competing, culturally based beliefs rather than negating them. Finding ways of integrating biomedical solutions while respecting beliefs about the meaning and sources of symptomatology could represent a meaningful compromise between disparate approaches.

A primary objective of sensitization should be dispersal of evidence related to epilepsy as a neurological disorder resulting from brief periods of irregular brain electrical activity. This will be challenging, given that the diversity in epilepsy phenotypes/semiology along with long periods of normal function during interictal periods, defies simple explanation. However, it is imperative, as our data show, that one of the strongest predictors of not choosing biomedical care is belief in spiritual causes of epilepsy, such as witchcraft, possession, or ancestral influence [21]. This attribution of disease does not only occur for PWE, but rather for all medical issues, albeit to varying degrees of conviction. Increasing the population's willingness to consider biologically based explanatory models may favorably impact the number and efficiency of PWE reaching biomedical treatment. Studies have also indicated that there is a substantial need to educate patients and community alike that epilepsy is a treatable but a chronic illness, as many pursue cure rather than symptom control and misunderstand the need to continue medication even when asymptomatic [30,52]. Early communication of the likelihood of the need for medication adjustments involving changes to dosages, medication types, or the number of medications may help manage expectations and increase adherence to the medication regimen and follow-up schedule.

Currently, the majority of PWE remain undiagnosed within communities, and only those with severe forms of seizures seek medical care [26,47]. It is important that symptomatic people seek care regardless of the severity of the epilepsy. Delaying or denying treatment perpetuates symptomatology and its risk for injury and stigmatization. Education on the different types of epilepsy, with an added emphasis on focal seizures and those that do not cause full body convulsions, would promote greater healthcare seeking for those with less severe or nongeneralizing epilepsy.

3.2.2. Proposed mechanisms of community sensitization

It is abundantly clear that there remains a remarkable degree of misinformation about the disease of epilepsy, its origin and consequences, and importantly, its treatment. This fuels stigmatization and impedes PWE from reaching effective biomedical treatments. This misinformation pervades society and can be found in urban communities as well as rural ones, among teachers, educators, and even medical providers. At the highest levels of healthcare information such as the Ugandan MOH and the World Health Organization (WHO), aspects of stigma are inadvertently reinforced by categorizing epilepsy within mental health divisions. Following this structure, epilepsy is evaluated and programmed within the broader framework of mental disorders. An example of this can be seen in the commonly used and effective tool for improving mental healthcare services within low and middle-income countries (LMICs), the WHO Mental Health Gap Action Programme (mhGAP) Intervention Guide 2.0 [53], with an epilepsy module embedded among the broader package of mental health disease modules. In order to shift perspectives, a strategically driven, consistent, and far-reaching multimedia campaign would be ideal recognizing epilepsy as a neurological disease. Coordination with local and national epilepsy support associations within Uganda, such as the Epilepsy Support Association Uganda (ESAU), Epilepsy Fraternity Forum, Patriotic Medics, and Purple Bench Initiative, could greatly facilitate the success and durability of such outreach efforts.

Such a multimedia campaign would include radio and television spots, highly visible interviews with medical professionals, respected community leaders and elders, and local and national governmental leaders. An improved and accurate outlook about epilepsy on the part of the country's educators could serve to model accurate perceptions about epilepsy to students and could also facilitate appropriate treatment of children with epilepsy and reintegration of children with epilepsy into the educational system. Systematically inserting facts to increase epilepsy literacy into educational curricula could be effective, as would be infusing messages in storytelling venues. Simply having more children with treated epilepsy in schools would cause a self-feeding cycle of improved educational attainment for PWE and reduced stigma caused by broader exposure to PWE. Finally, organizations having wide community reach, such as the Inter-Religious Council of Uganda, might be approached for assistance in messaging the necessity of PWE reaching biomedical care.

Rutebemberwa and colleagues [52] demonstrated that PWE seek treatment from a host of providers without a clear referral system. Without resolution of symptoms, patients move from one provider to another searching for assistance. Among other recommendations, these authors advocated for engagement of CHW volunteers at the village level and traditional healers as possible agents of perception change given their respected status in many communities. We agree that educating CHW to the basic signs and symptoms of possible epilepsy, using screening instruments such as Limoges screening questionnaire [40] and providing clear information about referral of people with such seizure symptoms to biomedical care for diagnosis and treatment may facilitate more efficient care. Likewise, traditional healers are key in the fundamental management of epilepsy in Uganda; they are more accessible, conform to the cause belief model, and are trusted by the community. Consideration should be made to explore avenues of possible engagement with them. While most interviewed in our study did not indicate an interest in collaborating with biomedical care [28], it is our impression that is at least in part related to previous disharmony and concerns about marginalization. Recently, the Uganda Parliament passed the Traditional and Complementary Medicines Bill [54], which serves to recognize, regulate, and harmonize the work of traditional healers. This recent action holds promise to be an opportunity, a juncture from which collaborative education and practice could be facilitated.

Prevention of epilepsy not only serves as a key priority initiative but also lends itself to a strategic community sensitization mechanism. Discussions of epilepsy prevention have cross-cutting implications for health system development and allow for epilepsy to be embedded within discussions on communicable disease control, maternal and child healthcare, and injury prevention. The prevention of communicable diseases such as cysticercosis, promotion of road safety through the enforcement of traffic and road safety laws, and improvements in maternal and child health are top level national and global health priorities where education on epilepsy can easily be embedded, which ultimately benefits PWE. Another example of such an application would be educational programs targeted at midwives to incorporate material in their prenatal care about maternal infections and birthing complications that are key preventive causes of epilepsy, as well as symptom recognition and direction to biomedical care if seizure symptoms present. This level of integration and desiloization reflects the approach style necessary to truly achieve SDG3 globally.

4. Conclusion

In general, these studies have elucidated the status of epilepsy knowledge and beliefs and how these intersect with healthcare-seeking and healthcare delivery practices in Uganda. The collective voices of the country did not result in a discordant mixture of messages, but instead revealed pivotal interrelated elements, which logically yield an actionable set of recommendations.

Among the many individually important challenges that any PWE may face in their journey of endurance and help-seeking, a few far-reaching elements are essential to appreciate in the landscape of the disease in Uganda. The first is how ingrained belief in potential ancestral, witchcraft, and demonic spiritual determinism is among a majority of the population, to which expert treatment is naturally sought through those known to negotiate between the physical and spiritual worlds, the practitioners of traditional medicine. The signs and symptoms of epilepsy, being most often intermittent, uncontrolled movement, lend themselves particularly well to such etiologic beliefs. This renders PWE vulnerable to ostracism, shame, and isolation, and sets them on a course of seeking treatment that despite its benefits, delays access to effective, evidence-based biomedicine. Another critical element to appreciate is the belief, again by the majority, that epilepsy is a contagion. Categorizing epilepsy as an illness with airborne or contact transmission results in isolation of the affected person, which can be justified as a morally legitimate ethical practice in the service of public health. This further reduces the chances of the PWE from reaching effective biomedical intervention, as the individual is rejected, isolated, and discriminated against. And finally, a third critical element is an under-resourced healthcare workforce and setting, rendering access to diagnosis and an uninterrupted source of AEDs difficult to attain. The numbers of trained allopathic practitioners that could care for PWE are too few and concentrated in urban areas where less than a fifth of the population lives. Ubiquitous medication supply stock-outs persist, which are particularly deleterious in epilepsy as missed doses can result in breakthrough seizures and drug resistance, serving to undermine what is likely already a tenuous engagement with biomedical care. These elements interact to slow progress in public understanding of epilepsy as a treatable biomedical illness and maintain the PWE in a cycle of vulnerability, symptomatology, and isolation.

While these cornerstone challenges are formidable, the corollary recommendations suggest that a vision of creating a culturally sensitive, cost-effective national epilepsy service in Uganda is possible. In line with the WHA Resolution 68.20 [12], it will be necessary to engage the commitment of several stakeholders across all levels of care nationally, regionally, and internationally. Support from government ministries, scholar leaders, and communities will be indispensable. As outlined, first-line priorities should include an ambitious program of culturally relevant community sensitization coupled with infrastructure building to ensure a receptive and accessible workforce and reliable sourcing of AEDs. Strategic placement of epilepsy clinics and mobilization of the existing workforce through epilepsy care training and sensible referral tracks would optimize the use of scant resources. The long-range vision warranting steady attention includes establishing a neurology training program, ancillary expertise in neuropsychology and physical and occupational therapies, as well as neurosurgical capacity for medication-resistant cases.

The proposed platform has been created on which to plan for targeted interventions to improve epilepsy knowledge, beliefs about causation, health-seeking practices, advocate for feasible prevention measures, and to reduce stigma, improve care, and reduce the treatment gap. This knowledge may be useful not only in Uganda but in other low-income countries around the world.

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Declaration of competing interest

None.

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