Understanding the Barriers and Potential Solutions to Epilepsy Care in Uganda: A Qualitative Study

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Bronwyn Kaiser

Thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Duke Global Health Institute in the Graduate School of Duke University

2018
ABSTRACT
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Abstract

Introduction: Epilepsy is one of the most prevalent neurological diseases in the world. In Sub-Saharan Africa, people with epilepsy frequently seek treatment from traditional or pastoral healers, who are more accessible than biomedical care providers. This is problematic because it often contributes to a time delay preventing patients from obtaining adequate biomedical care. In Uganda, biomedical providers who treat epilepsy are also available, including neurologists and psychiatrists. This study sought to elucidate the barriers to biomedical care for people with epilepsy as well as identify potential solutions to overcome these barriers.

Methods: The study used qualitative research methods. Semi-structured interviews and focus group discussions were conducted with four major groups: patients with epilepsy or family members of patients with epilepsy, neurologists and psychiatrists, pastoral healers, and traditional healers. All interviews and focus group discussions that were in English were audio recorded and transcribed verbatim into English. Those that were not in English were translated live and audio recorded. A translator later translated the audio recording to ensure proper transcription into English. Two independent coders coded the dataset and conducted an inter-rater reliability assessment to ensure reliable coding of the data. Thematic analysis was then performed to elucidate themes from the data and to compare nuances in the themes between each of the study design groups.
Results: Participants in this study discussed several different causes of epilepsy ranging from spiritual to biological causes, but often incorporating elements of both. Common spiritual causes of epilepsy included witchcraft and ancestral spirits. Common biological causes included genetics, fever, malaria, and brain injury. For patients and families, beliefs about the cause of epilepsy often played a role in whom they chose to seek treatment from.

Three major barriers to biomedical care were discussed: practical barriers, barriers relating to medical infrastructure, and barriers related to stigma against people with epilepsy. Practical barriers included logistical barriers such as transportation, cost of medical care, and distance to the nearest healthcare facility. Under medical infrastructure, drug stockouts and lack of access to anti-epileptic drugs were the most consistent problems stated amongst patients. Stigma was heavily discussed and brought up by nearly every participant. Additionally, three significant solutions to improving epilepsy care in Uganda were highlighted by participants: collaboration among treatment providers, community sensitization efforts to address stigma, and building medical infrastructure. Within building infrastructure, all participant types except traditional healers proposed the development of an epilepsy clinic designed to specifically treat epilepsy.

Conclusions: Based on these findings, there are four critical interventions that should be considered for improving epilepsy care in Uganda: collaboration between biomedical
providers and traditional healers, community outreach programs for sensitization, the establishment of epilepsy clinics, and infrastructure building to address medication stockouts.
Dedication

This thesis is dedicated to all the teachers I have had in my life. Thank you for instilling values in me that have cultivated my passion for learning.
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1. Introduction

1.1 Epilepsy Prevalence and Incidence in Uganda and Africa

Epilepsy affects approximately 50 million people worldwide and is one of the most prevalent neurologic diseases in the world (WHO). Lifetime epilepsy prevalence in developed countries is estimated to be 5.7 per 1,000 people, whereas in developing countries, the estimated lifetime epilepsy prevalence is 10.3/1000 in urban settings and 15.4/1000 in rural settings (Ngugi et al., 2010). The estimates of active epilepsy, or those cases that may benefit from treatment, follow a similar pattern. In another meta-analysis, the estimated incidence again showed a discrepancy between high-income countries (45.0/100,000 people per year) and low-income countries (81.7/100,000 people per year) (Ngugi et al., 2011). Although there is a scarcity of epilepsy etiology research in Sub-Saharan Africa, a review concluded that infection in endemic areas of Africa is the leading cause of epilepsy in this region, but that other causes including head injury, perinatal causes, brain tumors, cardiovascular disease, and genetic factors can contribute to the prevalence of epilepsy (Preux & Druet-Cabanaca, 2005).

In a study conducted in the Mukono district of Uganda, epilepsy accounted for 8.5% of the confirmed neurologic illness found (Kaddumukasa, 2016). Ngugi and colleagues (2013) report that Iganga and Mayuge districts in Uganda show an age-standardized prevalence of 6.8 per 1,000 people. This study also identified the youngest age groups (0-5 years and 6-12 years) to have the highest prevalence.
1.2 Epilepsy Treatment in East Africa

1.2.1 Traditional Healers

Traditional healers are often the first line of healthcare received in several African countries because they are more accessible than biomedical providers (Abdullahi, 2011). In Uganda, the ratio of traditional practitioners is estimated to be 1:700, while the ratio of medical doctors to the population is 1: 25,000 (Abdullahi, 2011). For epilepsy patients, this process influences the likelihood and timing of seeking biomedical care. Traditional healers were the most frequently visited healthcare resource for mental distress in sub-Saharan African communities, due to the understanding of mental health as a spiritual, rather than medical problem (Kinyanda et al., 2011). In Tanzania and Uganda, it was found that traditional healers were chosen over biomedical care due to lack of drug stock at local clinics and financial inability to buy drugs (Nnko et al., 2015). For epilepsy treatment in Kenya, traditional healers were preferred due to the flexibility of payment, as traditional healers were more likely to accept loans and barter as payment, even though their fees were often higher than the price of antiepileptic drugs (AEDs) (Kendall-Taylor et al., 2009).

Traditional healers range in beliefs about epilepsy, with some aligning more with biomedical evidence than others. In Cape Town, South Africa, traditional healers’ beliefs about the etiology of epilepsy include witchcraft, punishment from ancestors, as well as biomedical reasons (Keikelame & Swartz, 2015). Many traditional healers believed that
the disorder is caused by bad omen; Nizard et al. (2016) described Malagasy healers who believed that the disorder was a form of possession and divine punishment. These beliefs may lead to inadequate treatment of patients with epilepsy.

Other beliefs may perpetuate stigma in the community against epileptic patients. Specifically, many healers have the misperception of contagiousness associated with the disorder. A majority of traditional healers from the Ivory Coast endorsed notions that epilepsy is contagious (Francois et al., 2013). Some traditional healers suggested placing the patient in quarantine to prevent spread (Millogo et al., 2004). Despite these differences in the understanding of epilepsy between the biomedicine and traditional perspectives, the healers were willing to collaborate with biomedical providers as long as they were given respect in the relationship (Millogo et al., 2004).

1.2.2 Biomedical Treatment

Those seeking biomedical diagnosis and management for epilepsy in Uganda will find resources to be scarce: with only 0.03 adult neurologists per 100,000 population and two child neurologists for all of Uganda (Wilmshurst et al., 2014). Historically, psychiatrists treat many epilepsy patients in Uganda, with epilepsy diagnosis accounting for more than half of outpatient mental health clinic census at the Psychiatric Butabika National Referral and Teaching Mental Hospital in the country’s capital of Kampala (Birabwa-Oketcho, 2017). A recent study conducted at Mulago National Referral Hospital’s pediatric neurology clinic showed the frequency of multiple AED use
and reported sub-therapeutic blood drug levels despite good adherence to medications (Atugonza et al., 2016).

1.3 Barriers to Biomedical Care

The challenges of treating epilepsy have been previously documented and include stigma, lack of access to clinics, equipment, specialists, and the use of traditional medicine (Wilmshurst et al., 2014). Other challenges identified in Northern Uganda include: cost and process of transaction of medical diagnosis, lab studies, and biomedical medicines; counterfeit generic medicines; distance to care, transportation to care; stigma; access to and cultural norms around consultation of spiritual, herbal, and pastoral healers; and beliefs about epilepsy as a contagious or supernaturally induced condition (Kaddamukasa et al., 2016). This study identified these barriers based on a structured questionnaire given to the general population in Uganda. In order to gain a detailed understanding of these barriers, it is necessary to use qualitative methods and include a variety of views from the epilepsy community in Uganda.

1.4 Rationale and Study Aims

In an effort to build epilepsy care capacity over time, an understanding of the determinants of patterns of epilepsy care seeking behavior is essential. Semi-structured qualitative interviews and focus group discussions will allow us to better understand patterns and determinants of care, which could have an immense impact on future efforts to improve epilepsy care in East Africa.
The main objective of this study is to identify cultural and practical challenges of seeking epilepsy care in Uganda as well as the proposed solutions to addressing these challenges. To accomplish this, this study includes input from various stakeholders in epilepsy care in Uganda: patients and families, psychiatrists and neurologists, traditional healers and pastoral healers. Outcomes from this study can inform specific targets of future interventions that are culturally sensitive.
2. Methods

2.1 Participants

In order to get perspectives of diverse stakeholders involved with epilepsy treatment in Uganda, this study included four major groups. The first group was comprised of patients with epilepsy or family members of patients with epilepsy. All patients and families included in this study were seeking biomedical treatment for their epilepsy from either a neurologist or psychiatrist. The second group of participants included neurologists and psychiatrists treating patients with epilepsy. The third and fourth groups included pastoral healers and traditional healers who stated that they have provided treatment to patients with epilepsy.

2.2 Setting

This study took place in the city of Kampala, Uganda and in rural areas just outside of Kampala. Patients and families were recruited from three public hospitals in Kampala: Mulago National Referral Hospital (MNRH), Kiruddu General Referral Hospital (KGRH), and Butabika National Referral Hospital (BNRH). Psychiatrists were recruited from BNRH, while neurologists were recruited from both MNRH and KGRH. MNRH is the main national referral hospital for the entire country of Uganda, a general hospital for the Kampala metropolitan, and a teaching hospital for Makerere University College of Health Sciences. BNMH is located in the southeastern part of Kampala, and it
is the only national referral mental hospital in Uganda. It is a public hospital and serves as a psychiatric teaching hospital for Makerere University College of Health Sciences.

Pastoral healers and traditional healers were both recruited from urban areas within Kampala and rural areas just outside of Kampala. Traditional healer focus group discussions occurred in community gathering spaces, and pastoral healer interviews occurred in church spaces.

2.3 Procedures

We conducted semi-structured interviews and focus group discussions with each stakeholder group. Prior to fieldwork, our research team developed semi-structured interview and focus group discussion guides (Appendix A) designed to elicit information from participants about the determinants of treatment-seeking behavior, their beliefs about the cause of epilepsy, barriers to biomedical treatment, and their suggestions for improving epilepsy care in Uganda.

2.3.1 Participant Recruitment and Enrollment

Traditional healers and pastoral healers were recruited into the study by a Makerere University faculty member. Both Makerere University and Duke University faculty members recruited psychiatrists and neurologists into the study. Healthcare assistants who worked at MNRH, KGRH, or BNRH recruited patients and families into the study. Participants were eligible for the study if they were competent to consent to participation in the study and had either experience living with epilepsy or with
providing treatment for epilepsy. Patients were eligible if their medical record indicated that they had a diagnosis of epilepsy. Families or caretakers were included in the study if they had a family member that was diagnosed with epilepsy according to their medical record.

The study was explained to each participant by interviewer or by a translator if the participant did not speak English. Each participant was given sufficient time to read the consent form and ask questions about the study. All participants in this study were compensated with 10,000 Uganda Schillings (~ 2.80 USD). Interviews lasted about 45 minutes, and focus group discussions lasted approximately 75 minutes.

Translators were used during the interview or focus group discussions if participants did not speak English. Interviews and focus group discussions were audio recorded. Translators also reviewed audio files that were not in English afterwards to ensure correct English translation. The files were then transcribed based on this latter translation into English.

### 2.3.2 Ethical Review Board

The Mulago Hospital Research & Ethics Committee and the Duke University Health System Institutional Review Board approved the study protocol.

### 2.4 Analysis

Data transcripts were prepared and analyzed using NVivo 11 Software. The research team first reviewed a subset of transcripts independently to identify themes
and develop them into codes, then convened to collectively decide on final codes.

Transcripts were reviewed until the team met saturation and no new codes were emerging from them. Then, two coders independently coded a subset of the data using this codebook. Inter-rater reliability was calculated for each code on this subset of data. Any codes that had a percent agreement of less than 70% were discussed between the two coders. Both coders decided how these codes should be correctly applied. After all codes reached a percent agreement of at least 70%, the remaining data was dived between the two coders to complete coding the data.

Thematic analysis was then performed to describe each of the themes from the data and to compare nuances in the themes between each of the study design groups: patients and families, neurologists and psychiatrists, pastoral healers, and traditional healers.
3. Results

In total, 20 interviews and nine focus group discussions were included in this study. Of the 20 interviews, six were pastoral healers, 13 were patients and families, and one was a neurologist. Of the nine focus group discussions, five were comprised of traditional healers, two were comprised of patients and families, one was comprised of neurologists, and one was comprised of psychiatrists. Two of the five traditional healer focus group discussions are further described as “town hall” groups because they were larger than focus group discussions and were not as focused as the other focus group discussions in this data set. Traditional healers were not individually interviewed. Pastoral healers were only individually interviewed. Patients and families either participated in an individual interview or focus group discussions. A summary of the participants can be found in Table 1.

The major themes that emerged from the data across all of the groups included the following: beliefs about the cause of epilepsy, perceived barriers to getting patients with epilepsy to biomedical care, and proposed solutions to overcoming these barriers and improving epilepsy care in general.
Table 1: Sample Set Description

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<td>Focus Group Discussion 02</td>
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<tr>
<td>Townhall 02</td>
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<tr>
<td><strong>Pastoral Healers</strong></td>
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<td></td>
</tr>
<tr>
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<td>Urban</td>
</tr>
<tr>
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<td>(n= 6)</td>
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3.1 Beliefs about Causes of Epilepsy

It became evident in data collection that one barrier to biomedical treatment was that many patients initially sought treatment from non-biomedical providers. One psychiatrist estimated that this practice delayed patient treatment in a biomedical facility by 2 years on average. One reason for this is that patients typically believed that the cause of their epilepsy was not biological and therefore did not warrant treatment from a biomedical provider. As a result, it was necessary to understand beliefs about the cause of epilepsy from participants in order to fully appreciate their perceived barriers to biomedical care. Figure 1 illustrates this relationship between beliefs and barriers to biomedical care.

![Conceptual Model](image)

**Figure 1-** Conceptual Model for how beliefs can influence healthcare-seeking behavior, which can be a barrier to biomedical care.
There was large variability in descriptions of causes of epilepsy both between stakeholder groups and within groups. Causes were either spiritual or biological (Figure 2), yet many participants from all groups were likely to support both biological and spiritual causes of epilepsy. Rather than a discrete belief of a biological or spiritual cause of epilepsy, beliefs for many participants fell on a continuum from spiritual to biological (Figure 3).

Figure 2- Coding Tree for Beliefs about Causes
3.1.1 Traditional Healers

Compared to other groups, traditional healers were more likely to endorse spiritual causes of epilepsy. All focus group discussions and town halls identified spiritual causes of epilepsy, the most common being witchcraft and ancestral spirits. Whenever traditional healers did endorse a biological cause of epilepsy it was often rooted in a spiritual cause. Based on what traditional healers revealed, a proximate cause of epilepsy might be fever; however, the ultimate cause of the fever is spiritual.

Therefore, the ultimate cause of epilepsy is spiritual:

“Still it is the spirits that cause the fever, and in most cases, it is because, for example, someone has failed to perform rituals or for the traditions, and that therefore the spirits bring it as a sort of punishment or reminder.” (Traditional healer, FGD 1)

Given that the cause of epilepsy is believed to be spiritual, traditional healers also often emphasized that only they can treat epilepsy and biomedicine cannot.

3.1.2 Pastoral Healers

Pastoral healers had more variation in their thinking about the cause of epilepsy. All six pastoral healers that were interviewed identified both spiritual and biological
causes of epilepsy. Spiritual causes included the devil or demons, ancestral spirits, and witchcraft, while biological causes included inheritance, malaria, and fever. Two pastoral healers exclusively believed in spiritual causes of epilepsy, stating that it is due to demonic spirits or witchcraft. Unlike the traditional healers, another pastoral healer believed that there were two main causes of epilepsy: those that were due to biological causes such as inheritance, and those that were due to spiritual demonic causes. Still, other pastoral healers shared similar beliefs to traditional healers in that any biological cause of epilepsy was the product of an ultimate spiritual cause. For example, one pastoral healer believed that although disease may be brought through biological inheritance, the bible states that it is ultimately the result of a demon:

“So I came to discover according to the verse that there is also a demon in charge of this disease.” (Pastoral healer, Interview 6)

3.1.3 Patients and Families

Given that patients recruited into this study were already receiving biomedical care, many of them stated biological causes of epilepsy that were consistent with their own diagnosis such as brain injury or genetic inheritance. Despite seeking treatment at biomedical facilities, many patients and families also expressed spiritual causes of epilepsy. Two-thirds of the patient and family participants either believed in spiritual causes themselves or had family members who believed in spiritual causes of epilepsy. Of those who were asked, many people revealed that they had sought treatment from a
traditional healer, suggesting that their belief about epilepsy etiology may have contributed in part to their healthcare-seeking behavior.

One caretaker of a patient highlighted an interesting generational dynamic regarding beliefs about the cause of epilepsy:

“Yes, it is a generational gap, the younger people think of epilepsy as a disease, but the older people think epilepsy is witchcraft or some sort of spiritual origin.”
(Caretaker of patient, Interview 9)

This generational gap has important implications for healthcare seeking. If the older generation of the family has great influence on the healthcare-seeking behavior of the patient, then the patient may be more likely to seek treatment that is consistent with spiritual beliefs of epilepsy, regardless of the patient’s own beliefs.

3.1.4 Neurologists and Psychiatrists

All neurologists and psychiatrists reported biological causes of epilepsy. None of them expressed having beliefs about spiritual causes of epilepsy, but they all recognized that spiritual beliefs are commonly held beliefs amongst their patient population and in the general population. While she did not recognize a spiritual cause of epilepsy, one neurologist also acknowledged that she believed in a spiritual mechanism of healing epilepsy. She noted that God has an ability to heal through medicine, and that many patients held similar beliefs.
Interestingly, one psychiatrist directly made the connection between beliefs and barriers to biomedical care. When asked what she thought the greatest barrier to biomedical care was, she stated,

“It is beliefs. Because many people think bewitched, which is the commonest thing. So they try all those things (traditional healing) before getting to you. And then they see it’s not improving and then eventually they are convinced that this is not subsiding.” (Psychiatrist 2, FGD)

In this statement, she relates how holding spiritual beliefs lead to alternative treatment seeking, which is ultimately a barrier to receiving biomedical care in a timely fashion.

3.2 Barriers to Biomedical Care

When asked what the largest barriers to biomedical care were, participants’ responses fell into three major categories: logistical barriers, stigma against people with epilepsy, and barriers related to medical structure (Figure 3). Of these categories, all groups heavily discussed stigma. The most common stigmatizing belief identified was that epilepsy was contagious.
3.2.1 Traditional Healers

Traditional healers agreed that biomedical care could not treat epilepsy and therefore discussed barriers to getting treatment in general as opposed to biomedical treatment. They specifically only discussed barriers related to stigma, for example:
“Most of the time they are discriminated against. Whenever someone has seizures they see them as disgusting and useless and avoid them, and even within the family if they have a function they would be put into exclusion and cast aside.” (Traditional Healer 3, FGD 2)

Most traditional healers agreed that people with epilepsy face stigma in their communities. They expressed ideas related to discrimination, isolation and contagion, the embarrassment of patients, and bullying.

3.2.2 Pastoral Healers

Like traditional healers, pastoral healers only identified barriers related to stigma. One pastoral healer acknowledged how patients feel in response to stigma in the community:

“People who are epileptic are […] discriminated against, and they don’t have a lot of respect in society. And in most cases they engage in self-isolation, they feel like they don’t fit in society.” (Pastoral healer, Interview 2)

Pastoral healers also shared that the general community discriminated against people with epilepsy and that many people in the community believe epilepsy to be contagious.

3.2.3 Patients and Families

Patients and families also discussed the stigma that they felt as a barrier to biomedical care. One caregiver mentioned that she encouraged the patient to engage in isolation in order to avoid community stigma:

“So even today, I told her not to get out, because you might fall, and people will see you.” (Caretaker of patient, Interview 13)
In this way, stigma not only impacts the quality of life of patients with epilepsy, but it also is a very real factor that may prevent someone from leaving their home to receive care.

In addition to stigma, patients and families also frequently discussed practical barriers to biomedical care. These practical barriers included the cost of medical care, distance to the healthcare facility, and the method of transportation. One patient even described a practical barrier as a source of stress that results in him having additional seizures:

“The truth is the hospital is not as far but I am financially disadvantaged, so I am financially unable to afford transport; there is nothing else, but I stress about a bit about finances so I think that is one of the causes to why I have seizures.”
(Patient, Interview 8)

The most common barrier identified by patients and families was that of medicine stockouts. Most patients reported seeing positive improvement in their symptoms after taking anti-epileptic drugs. However, over half of the patient and family participants indicated that medicine stockouts in the hospitals were the number one barrier impacting their care.

3.2.4 Neurologists and Psychiatrists

Neurologists and psychiatrists also echoed similar sentiments of stigma as the other groups. A psychiatrist uniquely identified a source of stigma related to medication:

“I think for school going students...people think if you are taking [medicine] every day they think it’s HIV positive-anti retrovirus.” (Psychiatrist 1, FGD)
Medication stigma may act as a barrier to biomedical care in that patients may be less likely to adhere to their prescription due to fear of being mislabeled as HIV positive.

Furthermore, neurologists and psychiatrists also brought up barriers related to medical infrastructure. These barriers included having a shortage of resources (such as those needed for electroencephalographs) due to an inadequate budget for healthcare at the government level and a shortage of epilepsy-trained providers. One psychiatrist expressed sentiments of being overburdened:

“If you notice on a typical epilepsy day we may see maybe 100 plus [patients]. You think clinic is over, and you and you go and see another 120. So you can’t give, you can never give a person that much time.” (Psychiatrist 4, FGD)

3.3 Path Forward

After discussing the perceived barriers to biomedical care, all groups were asked what their vision for better epilepsy care in Uganda would look like. Responses to this question resulted in three major divisions: collaboration, sensitization, and building infrastructure (Figure 4). Of note, all groups except for traditional healers consistently brought up the need for a specialty epilepsy clinic.
3.3.1 Traditional Healers

Traditional healers were reluctant to collaborate with other treatment providers. Many expressed sentiments that biomedical providers did not respect their practice.

Illustrating this concern, one traditional healer stated:

“No, they can’t partner... In most cases, western doctor is against our approaches, making it difficult.” (Traditional healer 1, FGD 2)

Traditional healers also hold a firm belief that epilepsy is a spiritual disease and can therefore only be treated by a traditional healer and not a biomedical practitioner. One focus group discussion of traditional healers thought that collaboration with biomedical providers would only be effective if biomedical providers referred epilepsy patients to
them. When asked if they would consider collaborating with pastoral healers, they declined, stating that pastoral healers do not have real healing abilities.

### 3.3.2 Pastoral Healers

Similarly, pastoral healers were reluctant to collaborate with traditional healers, stating that many traditional healers are fraudulent. When asked if they would consider collaborating with biomedical providers, one pastoral healer suggested having an agency for biomedical providers and pastoral healers to collaborate.

Pastoral healers were the first group to suggest having an epilepsy clinic as a method to build medical infrastructure and to reduce stigma against people with epilepsy. Five out of six pastoral healers proposed an epilepsy clinic as a solution. One pastoral healer described his vision for such a clinic:

> “Actually having an exclusive place, a place made for people with epilepsy, just like Butabika is made for people that are schizophrenic. These people would know that that is our place where we have the same condition and there is no one to stigmatize us.” (Pastoral healer, Interview 1)

### 3.3.3 Patients and Families

Yet another way to build infrastructure was resoundingly suggested by patients and families. Over half of the patient interviews identified the need to address the medicine stockout problem. When asked what the most important thing was to improve epilepsy care in Uganda, one caretaker immediately stated:

> “For the medicine to be there in hospitals. That is the answer.” (Caretaker 3, FGD 1)
Another patient again echoed sentiments from other groups by stating the need for an epilepsy clinic. He stated that such a clinic would be particularly useful for patients without caretakers to receive centralized care:

“...So many of them are isolated, others can go to isolated places, you can find them they don’t have caretakers, so they don’t have helpers. Many times they are just picked and dumped here in the hospitals. So there should be one place where all those patients can be taken care of instead of staying scattered in all those places.” (Patient, Interview 12)

Patients and families also touched upon the need for sensitization to improve epilepsy care in Uganda. These suggestions most commonly took the form of community education on where to seek epilepsy treatment and the use of community leaders to help implement this.

3.3.4 Neurologists and Psychiatrists

Acknowledging that many patients seek care from traditional healers, neurologists and psychiatrists both recognized the need to collaborate with traditional healers. Psychiatrists suggested that organized workshops take place in order to discourage harmful treatment practices. One such practice that was described by both psychiatrists and traditional healers themselves was the process cutting patients on their bodies and rubbing herbal treatments into these wounds.

Psychiatrists and neurologists also talked about collaborating better with each other. Psychiatrists mentioned feeling overburdened with epilepsy patients and would prefer to refer epilepsy patients to neurologists unless they have comorbid mental health
disorders. Neurologists shared similar sentiments noting that they would refer patients to psychiatrists only if they need treatment for a psychiatric disorder.

In terms of sensitizing the community, a neurologist suggested being creative with dramas and plays for the community, video clips to educate schools, and having a toll-free phone number for community members to call for medical advice.

Lastly, neurologists also highlighted an epilepsy center as one of the best ways to move forward by building infrastructure and reducing stigma. When talking about issues of stigma, one neurologist stated:

“The other way of dealing with this is to, the best way of dealing with these kinds of challenges is to have a specialty center.”

1 Neurologist 03 from Neurologist Focus Group Discussion
4. Discussion

4.1 Causal Thinking Models

Many of the participants described both spiritual and biological causes of epilepsy. Legare and colleagues (2012) describe ways in which natural and supernatural explanations for phenomena can coexist. They categorize causal explanations into three types: integrative thinking, synthetic thinking, and target-dependent thinking. In integrative thinking, two explanations are combined into a single explanation. On the other hand, synthetic thinking combines two explanations without explicit integration of both. In target-dependent thinking two different explanations remain distinct from one another and depend on the context of the explanation.

Many participants in the study displayed integrative thinking in their explanations of the cause of epilepsy. In particular, traditional healers and pastoral healers both explicitly indicated that biological causes were rooted in spiritual causes of epilepsy. Still, other participants described elements of synthetic thinking, stating that the cause of epilepsy could be biological or spiritual. In these instances, there was not any explicit integration of both causes. This was most commonly seen in patients and families, suggesting that traditional and pastoral healers’ beliefs about etiology have a slightly different thinking model. This difference further highlights the nuance in beliefs between participant groups. Understanding these nuances are important for designing future interventions that are culturally sensitive.
4.2 Implications for Interventions at the Health System Level

One of the critical barriers that patients addressed was frequent stockouts of medications at medical facilities. In order to address this problem, future studies should delineate what the major reasons for stockouts in Uganda are. Furthermore, innovative interventions should be designed to address the specific causes of stockouts. One such intervention in Kenya involved healthcare facilities using SMS on mobile phones to report malaria medication stock weekly to district managers (Githinji, 2013). District managers then took steps to prevent stockouts based on this data by redistributing supply. Results of this study showed that facilities utilizing the intervention had a sharp, sustained decline in medication stockouts. Addressing this infrastructural barrier is a critical next step in improving epilepsy care in Uganda. Facilitating access to biomedical care for patients with epilepsy is only worthwhile if medication treatment options are available at biomedical facilities.

A second intervention highlighted by study participants was the need for collaboration between treatment providers. One neurologist alluded to potentially collaborating with traditional healers as was done in previous instances for HIV treatment. South Africa was able to successfully integrate western medical practitioners and traditional healers in the fight against AIDS (Liverpool et al., 2004). The intervention first involved recognition of traditional healers as a vital component in healthcare delivery. The Ministry of Health adopted a policy to include traditional healers in
HIV/AIDS treatment and prevention. An AIDS training program was designed specifically for traditional healers. After the training, over 90% of traditional healers expressed willingness to integrate this education into their practice. Liverpool and colleagues (2004) described that medical students at the Morehouse School of Medicine subsequently delivered a training program to 24 traditional healers. These traditional healers later trained 630 more traditional healers. Several traditional healers provided community education and counseling to patients with HIV. In this example of successful collaboration, the formal recognition of traditional healers by the Ministry of Health was essential to get them to collaborate. Given that traditional healers treating epilepsy in Uganda expressed low willingness to collaborate with biomedical practitioners, it is imperative that future interventions involving traditional healers seek similar methods to increase their readiness to collaborate.

4.3 Implications for Interventions at the Community Level

There are several studies that have researched stigma reducing interventions for epilepsy globally, though few have taken place in Sub-Saharan Africa. In Nigeria, Eze and colleagues (2015) implemented a stigma reducing intervention in which teacher trainees were given lectures about epilepsy. While this intervention only targeted teachers, it showed promise as an effective intervention that improves attitudes about epilepsy. A similar study in Ethiopia creatively aimed to improve epilepsy awareness in school children using a comic book (Tekle-Haimanot et al., 2016). Another study in
Zambia aimed to improve self-stigma that people with epilepsy had against themselves by utilizing a peer support group (Elafros et al., 2013). This intervention improved internalized stigma for youth but did not significantly improve internalized stigma for adults.

It is evident that there are many avenues for reducing stigma including general public interventions, school-based interventions, and interventions aimed at people with epilepsy themselves. Future interventions should seek to address both internalized self-stigma for people with epilepsy as well as stigma held by the general community. School-based interventions may be appropriate to target both teachers and children. Interventions should also use validated outcome measures to assess stigma to properly determine intervention efficacy. Additionally, stigma reducing interventions should be monitored and evaluated appropriately to measure efficacy of interventions. It is also worth noting that sensitization efforts are an area where involvement of traditional or pastoral healers could be beneficial given their presence and status in communities.

4.4 Study Limitations

Based on the data we have collected, it appears that beliefs about the cause of epilepsy at least in some way influence how patients and families choose to get treatment. However, these beliefs do not solely influence these treatment decisions. Other factors, such as ease of access to alternative forms of treatment or the flexible payment schemes used by traditional healers likely also play a role in these decisions.
Given that stigma against people with epilepsy is highly prevalent, patients may prefer to see a traditional healer in a rural location to avoid being seen in a public biomedical facility. These supplemental explanations were not well delineated in this study. As such, this study is limited in its ability to say the degree to which beliefs about causes of epilepsy influence healthcare seeking behavior. Therefore, it is difficult to determine how much of an effect beliefs have on barriers to biomedical care. Another ongoing study by our research team is collecting quantitative data from patients to better understand the relationship between beliefs and healthcare seeking patterns.

Additionally, many patients and families were reluctant to first admit that they had sought treatment from traditional healers. This reluctance suggests that there may be an element of social desirability bias in which patients did not want to disagree with what they thought our beliefs about epilepsy were. This may have biased their responses about causes of epilepsy to be more biological than spiritual. For this reason, data that was obtained from traditional healer focus group discussions are more likely to reflect sentiments of those healers who hold the most power. Future studies should seek to gain individual traditional healer perspective in interviews. It is possible that individual perspectives may reveal greater willingness to collaborate with biomedical providers or pastoral healers.

Another limitation is that traditional healers were only recruited into focus group discussions instead of individual interviews due to time constraints. During these
focus group discussions, there was a possibility that power dynamics among the traditional healers may have influenced their responses. In other words, traditional healers may have agreed more with those healers who held more power in the group rather than sharing their true beliefs.

A final limitation of this study is that it recruited a limited sample of patients and families. Our sample of patients and families only included those that were seeking care from a biomedical facility. Since it is estimated that many patients with epilepsy never receive biomedical care in Uganda, it is likely that this study missed perspective from patients that were not seeking care about biomedical treatment. Furthermore, these patients may experience additional barriers that are preventing them from receiving biomedical care. In order to truly understand all barriers to biomedical care, this perspective is essential. To address this limitation, our research team is designing a community-based study to include people with epilepsy who have not sought biomedical treatment.
5. Conclusion

Based on these findings, there are four critical interventions that should be considered for improving epilepsy care in Uganda. The first is collaboration between biomedical providers and traditional healers. This must be done in a culturally sensitive manner given that many traditional healers believe that biomedicine is ineffective and indicated a reluctance to work with biomedical providers. The goal of this intervention would be to get patients to biomedical care sooner, as well as to discourage unsafe traditional methods. Second, community outreach programs for sensitization are necessary. These programs should educate against stigmatizing beliefs (such as contagiousness) and provide communities with information about where to seek epilepsy treatment. A third intervention involves the establishment of epilepsy clinics, as suggested by many stakeholders in this study. Finally, in order to address patients’ largest concern, infrastructure building must occur to reduce medication stockouts.
Appendix A

Focus Group Guide

Patients and Families

Welcome and thank you for volunteering to take part in this focus group. You have been asked to participate as your point of view is important. We know you are busy and appreciate your time.

Introduction: This focus group discussion is designed to assess your current thoughts and feelings about epilepsy. The focus group discussion will take no more than 90 minutes. We will be taping the discussion to be sure that we record everyone’s experience.

Anonymity: Despite being taped, I would like to assure you that the discussion will be anonymous. The tapes will be kept safely in a locked safe until they are transcribed word for word, then they will be destroyed. The transcribed notes of the focus group will contain no information that would allow individual subjects to be linked to specific statements. You should try to answer and comment today as accurately and truthfully as possible. However, once we leave this group, information must be kept confidential. Please refrain from talking about the comments of other group members outside the focus group. This way we can all be sure our viewpoints are being respected and kept confidential. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Basics
- Restroom locations are…
- Food and drink will be…

Ground rules
- The most important rule is that only one person speaks at a time. There may be a temptation to jump in when someone is talking but please wait until they have finished.
- There are no right or wrong answers
- You do not have to speak in any particular order
- When you do have something to say, please do so. There are many of you in the group and it is important that I obtain the views of each of you
- You do not have to agree with the views of other people in the group. We are not hear to convince each other or reach consensus or opinion
- Please turn off cell phones or put them on vibrate so that there are no distractions to the group.
- We are here just to facilitate the session today and therefore you should feel free to express your thoughts and feelings about our topics without any expectations from me. We are interested in hearing your thoughts and points of view even if it is different from that which others express in the group. I’m going to make every effort to keep the discussion focused and within our time frame. If too much time is being spent on one question or topic, I may park the conversation so that we can move on and cover all of our topics and to ensure that all participants have a chance to give their input. If we have sufficient time, we will revisit parked thoughts at the end.
- Does anyone have any questions? ….Ok, then we are ready to begin. Remember, you are the experts.
Warm up
First, I’d like everyone to introduce themselves. Can you tell us your name (begin around the group)?

Guiding questions
What has been your family’s experience with epilepsy?

Probes:
--Story: who what when
--Duration
--Aura, sx, reactions, c

What are your beliefs about the cause of epilepsy…what is happening?

Probes:
--Source
--Soul and Body

Where have you sought treatment and why?

Probes:
--Sequence
--Timeline
--Drivers

What were the biggest influences directing WHO you saw and WHEN you saw them for consultation?
In what way did your family's background and living situation impact the care of the person with epilepsy?

Describe the barriers to patients seeking biomedical care for epilepsy in Uganda?

Tell me about epilepsy in general and how it impacts people. Describe the typical fate of persons with epilepsy, in their homes and communities.

What is your vision for Better Epilepsy care in Uganda?

Concluding questions
Of all the things we’ve discussed today, what would you say are the most important issues to focus on to facilitate progress in care?

Is there any area that we did not touch upon today that you think is critical for us to understand the experience of having epilepsy in Uganda?
Welcome and thank you for volunteering to take part in this focus group. You have been asked to participate as your point of view is important. We know you are busy and appreciate your time.

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Warm up
First, I'd like everyone to introduce themselves. Can you tell us your name (begin around the group)?

Guiding questions
What is your professional background, medical training, and training in treating epilepsy patients?

Describe your current and historical experience with treating epilepsy patients.

Described your perception of the Health Care Seeking Patterns of epilepsy patients?

What is the typical Diagnostic and subsequent Management process for epilepsy patients you see?

What are your usual Patient Outcomes, and what are the variables that modify these?
Describe the primary referral patterns involving epilepsy patients in Uganda.

Describe the barriers to care that impact the Epilepsy treatment gap in Uganda?

What is your vision for Better Epilepsy care in Uganda?

Concluding questions
Of all the things we’ve discussed today, what would you say are the most important issues to focus on to facilitate progress in care?

Is there any area that we did not touch upon today that you think is critical for us to understand the role biomedical treatment of epilepsy in Uganda?
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- Does anyone have any questions? ....Ok, then we are ready to begin. Remember, you are the experts.
Warm up
First, I'd like everyone to introduce themselves. Can you tell us your name (begin around the group)?

Guiding questions
What is your professional background, training, and training in treating epilepsy patients?

Describe your current and historical experience with treating patients with seizures.

What are your beliefs about the cause of epilepsy…what is happening?

How do you diagnose and treat seizures? How do you decide what the treatment will be?

Has treatment been successful? Please describe a successful treatment. Please describe the BEST outcomes that people can hope for? What are the factors that impact the degree of success of treatment?

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Probes:
-- Formal Schooling
-- Skill acquisition
-- Epilepsy specific training

Probes:
-- Length of time Tx Epilepsy
-- # of patients
-- Current #/week

Probes:
-- Source
-- Soul and Body
-- During and between seizures

Probes:
Method of dx, Frequency, duration of tx

Probes:
-- Sz freq, severity
-- Functional level
-- Management vs Cure
*** If seizures don’t stop, what is the effect on the person’s body and soul?
Tell me about epilepsy in general and how it impacts people. Describe the typical fate of persons with epilepsy, in their homes and communities.

Please explain if and how traditional healing and biomedical care could work together to treat epilepsy patients?

Many patients with epilepsy in Uganda never get treated. Why is that? What are the barriers to care?

What is your vision for Better Epilepsy care in Uganda?

Concluding questions
Of all the things we’ve discussed today, what would you say are the most important issues to focus on to facilitate progress in care for epilepsy patients?

Is there any area that we did not touch upon today that you think is critical for us to understand the experience of the traditional or pastoral healer’s role in treating epilepsy in Uganda?
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