

Medical Pluralism in Beliefs and Practices Surrounding Epilepsy Care in Uganda

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Abstract

Purpose: In this study, patient and caregiver beliefs about epilepsy etiology and their health-seeking behaviors were investigated as a first step towards exploring a possible basis for collaboration within Uganda's pluralistic health system. We explored differences amongst those with pluralistic versus singular beliefs about causes of epilepsy in a hospital based setting.

Methods: 626 participants were interviewed in three hospitals in Uganda regarding their beliefs about epilepsy and their care-seeking behaviors. Analyses were conducted to determine whether beliefs about epilepsy etiology tended to encompass solely biological explanations or whether they were more pluralistic, drawing upon biological, mystical and spiritual explanations for their conditions. The associations of these beliefs with various demographics and care-seeking behaviors were also investigated.

Results: The findings from this study indicate that people with epilepsy and their caregivers tend to hold multiple, and often simultaneous, understandings of the seizure etiology, with more than two thirds of this sample holding pluralistic beliefs. These pluralistic beliefs tended to be associated with greater delays in seeking biomedical care ($p < 0.005$) and greater likelihood of accessing traditional or pastoral healers for care ($p < 0.1$). People with pluralistic beliefs also tended to be younger ($p < 0.01$), less educated ($p < 0.05$) and have lower incomes ($p < 0.05$) than those with only biological beliefs.

Conclusions: These results suggest reveal the importance of understanding sociocultural beliefs in mediating treatment bottlenecks for epilepsy care associated with medical pluralism. In order to adequately treat patients with epilepsy, there needs to be more inclusive approach to health care delivery that respects pluralistic beliefs.

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1. Introduction

Epilepsy is a common neurological disorder that poses major challenges in global health. As an introduction to epilepsy, **Section 1.1** of this study will present the biology and epidemiology of the disorder as well as introduce the issue of the epilepsy treatment gap. Narrowing the focus to Sub-Saharan Africa, **Section 1.2** will explore the predominant beliefs and treatments for epilepsy, including those related to both biomedicine and traditional medicine. Finally, **Section 1.3** will introduce the current study which examines medical pluralism related to epilepsy beliefs and treatment in Uganda.

1.1 Epilepsy as a Global Health Problem

Epilepsy is a major public health concern that demands coordinated action and attention on a global scale. As one of the most universal of all medical disorders, it affects individuals across all ages, social classes, races, and nations (Sander & Shorvon, 1996; Jallon, 1997). Therefore, all six **World Health Organization (WHO)** regions have recognized epilepsy as a priority and approved resolutions to take coordinated action to address the global burden of the disease (WHO, 2019). The magnitude of epilepsy's widespread impact calls for greater research on understanding the experiences of **people with epilepsy (PWE)** and the barriers they face getting to care.

1.1.1 Biological Basis of Epilepsy

Epilepsy is a chronic neurological disorder characterized by unprovoked and recurrent disruptions in brain electrical activity, called seizures (Fisher et al., 2005). Seizures are brief episodes of involuntary movement that involve part or all of the body and are sometimes accompanied by loss of consciousness and other bodily functions (Sander & Shorvon, 1996). Specifically, an unprovoked, or epileptic, seizure is one that is not due to a known or reversible condition such as substance withdrawal or extremely low blood sugar (El-Hagrassy, Teixeira-Santos & Fregni, 2018).

While up to 10% of people worldwide will experience a single seizure in their lifetime, a patient is only diagnosed with active epilepsy if he or she has experienced two or more unprovoked seizures (Schachter et al., 2013). Both seizure severity and frequency vary drastically amongst patients; while one person may experience less than one seizure per year, another could have multiple per day (Sander & Shorvon, 1996).

Epilepsy is not a single disease entity but rather a class of disorders which reflect abnormal brain activity leading to different types of seizures (Fisher et al., 2005, 2014). This dysfunction may be attributable to a variety of sources, so epilepsy etiology is frequently multifactorial and

challenging to classify. Most often, epileptic seizures are due to traumatic head injury or genetic predisposition to the condition (Frey, 2003; Schachter et al., 2013). Other common causes include parasitic and infectious disease, perinatal complications, brain tumors, and stroke or other vascular diseases (Newton & Garcia, 2012).

1.1.2 Epilepsy Epidemiology

Globally, epilepsy affects almost 69 million people, making it one of the most common chronic neurological disorders in the world (Ngugi et al., 2010). It accounts for nearly 1% of the global disease burden, though the true burden may be underestimated due to high mortality rates and limited prevalence data in rural and isolated regions of the world (Reynolds, 2000; Ngugi et al., 2011). It is especially challenging to determine accurate figures on epilepsy in **low- and middle-income countries (LMICs)**, where figures are often derived from limited cross-sectional surveys (Newton & Garcia, 2012).

Existing studies universally suggest higher prevalence and incidence of epilepsy (**Table 1**) in LMICs than in **high-income countries (HICs)** (Ngugi et al., 2010, 2011; Beghi, 2016). In fact, approximately 85% of epilepsy cases occur in the half of the global population living in LMICs (Kale, 2002; Baingana & Bos, 2006).

Table 1.

Epilepsy incidence and prevalence in LMICs and HICs (Ngugi et al., 2010, 2011)

	Low- and Middle-Income Countries		High Income Countries
Incidence*	81.7		45
	Urban	Rural	
Prevalence**	10.3	15.4	5.8

*Incidence is defined as the number of new cases of epilepsy per 100,000 people per year

**The median lifetime prevalence of epilepsy is the total number of cases per 1,0000 people

The differential incidence of risk factors for epilepsy in LMICs compared with HICs may explain the disproportionate burden of epilepsy on the developing world. On average, risk factors are more widespread in LMICs compared with HICs. Specifically, traumatic brain insults tend to be more common and serious in LMICs due to high rates of violence, falls and road traffic accidents compounded with low biomedical capacity for treatment (De Silva et al., 2009). Further, perinatal and infectious etiology are likely responsible for higher epilepsy prevalence in LMICs, especially in rural areas (Newton & Garcia, 2012; Beghi 2016). For example, the highest incidence of epilepsy reported to date, 215 cases per 100,000, was found in regions of Uganda that are highly endemic to onchocerciasis, a putative risk factor for a variant of epilepsy known as nodding disease (Kaiser et al., 1998; Ngugi et al., 2011).

Moreover, the impact of epilepsy on outcomes can be extreme. Mortality is significantly increased amongst epileptics, with their risk of dying being 1.6-3 times higher than that of the general population (Forsgren et al., 2005). Epidemiological findings also confirm high rates of comorbidity in epilepsy such as psychiatric disorders, learning disabilities, cognitive impairments and abnormal development (Boro & Haut, 2003; Wiebe & Hesdorffer, 2007; Seidenberg, Pusipher, & Hermann, 2009). Furthermore, studies have revealed severe stigma and psychosocial issues related to epilepsy including lower annual income, poor school attendance and performance, and lower quality of life (Scott et al., 2001).

Therefore, this massive disparity in disease burden requires immediate attention. A scale-up of epilepsy interventions is important, not only to address disparities and high mortality, but to ameliorate the contribution of epilepsy to DALYs worldwide.

1.1.3 The Epilepsy Treatment Gap

Despite such a high disease burden worldwide, many **people with epilepsy (PWE)** go untreated. This phenomenon is known as the “**epilepsy treatment gap**”, which is defined as the proportion of PWE who are not receiving biomedical care¹ (Mbuba et al., 2008). This treatment gap includes both (1) PWE who do not or cannot access biomedical facilities and (2) PWE who have accessed biomedical treatment but are not adhering to their prescribed **anti-epileptic drug (AED)** (Newton & Garcia, 2012).

The epilepsy treatment gap in LMICs is staggering; not only do these countries have higher epilepsy incidence and prevalence, but the majority of patients never receive treatment (Jallon, 1997; Pal et al., 2000). The treatment gap for active epilepsy in LMICs ranges from 25% to 100%, compared with approximately 10% in HICs (Mbuba et al., 2008; Meyer et al., 2010; Kpobi et al., 2018). This gap is even greater in rural (versus urban) areas worldwide (Meyer et al., 2010).

It has been suggested that more than 70% of PWE could live seizure-free given proper diagnosis and treatment, yet there are a number of barriers that prevent PWE from ever accessing biomedical care for their epilepsy (Meyer et al., 2010). In LMICs, these barriers typically include inadequate medical supplies, costs of AEDs, lack of skilled health care workers, limited access to health facilities, stigma, cultural beliefs about seizure causation, and use of traditional medicine (Mbuba et al., 2008; Chin, 2012).

Addressing these barriers should be a priority in global health as the first step towards narrowing the epilepsy treatment gap in LMICs. Fortunately, many of these risk factors can be

¹ The typical biomedical management of epilepsy involves identifying the cause, prescribing antiepileptic drugs (AEDs), and addressing any comorbidities (Ba-Diop et al., 2014).

addressed given adequate initiative, resources, and interventions, though cultural beliefs and the use of traditional medicine may pose particular challenges.

1.2 Epilepsy Treatment and Beliefs in Sub-Saharan Africa

In **Sub-Saharan Africa (SSA)**, the epilepsy treatment gap is particularly high, estimated at nearly 95% (Meyer et al., 2010). Comprised of 47 countries south of the Sahara, SSA includes some of the poorest nations in the world, many of which still direct a majority of their health resources towards treating communicable (versus non-communicable) diseases (WHO, 2004).

In the context of this treatment gap and strong cultural beliefs, PWE often consult multiple providers, seeking management of their conditions from a variety of sources. Therefore, in addition to formal health care professionals, epilepsy treatment in SSA also encompasses the care of traditional healers, religious leaders, community health workers, and even friends or family at home (Beckerleg, 1994; Obbo, 1996; Ovuga et al., 1999).

1.2.1 Barriers to Biomedical care

PWE in SSA rarely access biomedical treatment, and those who do will find resources to be limited (Chin, 2012; Beghi, 2016). This is largely due to underfunding in the health care sector. According to 2014 estimates (in USD), countries in SSA spend an average of \$218 per capita on health care compared to \$5221 in HICs (Dieleman et al., 2017).

This may explain the scarcity of specialty services for neurology in SSA, with a mere 0.1 neurologists to every 100,000 people; this is in comparison to a median of 7.1 neurologists per 100,000 people in HICs (WHO, 2017). Furthermore, post graduate programs and specialty training in epilepsy are rarely available, contributing to the lack of expertise (Owolabi et al., 2007). This deficiency also translates into sparse neurological training of the remaining health care workforce, including primary care physicians, clinical officers, nurses, and community health workers (Chin 2012). Thus, in SSA, epilepsy is often managed by mental health and psychiatric services (Kinyanda et al., 2011).

If a person does obtain an epilepsy diagnosis, considerable barriers to treatment persist. Most countries in SSA have insufficient and/or inconsistent AED supplies, leading to ineffective seizure control and often drug resistance (Ba-Diop et al., 2014). Specifically, only about 50% of countries² in the WHO Africa region reported always having at least one anticonvulsant available at the primary care or hospital level (WHO, 2017). When individuals do not respond to the most readily-available AEDs, like phenobarbital, second-line drugs are often not accessible and the patient's epilepsy remains uncontrolled (Birbeck et al., 2007).

² According to a 2017 report, 47% of countries in the WHO Africa region reported always having one anticonvulsant available at the primary care level. 58% reported always having one at the hospital level.

For PWE whose epilepsy is non-responsive to pharmacotherapy, surgery is the only option for cure (Wiebe et al., 2001). However, epilepsy surgery is rarely available in SSA due to high costs, a lack of infrastructure to maintain advanced technology, and the absence of neurosurgeons (Ba-Diop et al., 2014; WHO, 2017).

Finally, any biomedical resources, both human and technological, tend to be concentrated in capital cities, out of reach for a majority of the population (WHO, 2017). The few neurologists in the region are available exclusively in urban areas and sometimes only in private hospitals, rendering them unavailable to most PWE (Birbeck et al., 2007; WHO 2017). The same applies to the already limited supply of diagnostic equipment to aid in the management of epilepsy, including electroencephalography and neuroimaging machines (Wilmhurst et al., 2014). While these services are technically reported to be available in 70-80% of countries in SSA, these technologies are not uniformly available or accessible (WHO, 2004).

Therefore, the biomedical sector of health care is insufficient to render adequate care for epilepsy given the high prevalence in SSA. These shortcomings of the formal medical system, compounded with cultural beliefs rejecting scientific explanations, direct care-seeking outside of the biomedical realm and towards alternative treatments (Birbeck et al., 2007; Chin, 2012).

1.2.2 Traditional and Faith Healing for Epilepsy

Traditional medicine (TM)³ is the oldest form of health care that has stood the test of time. It is an ancient and culture-bound approach to healing that people across the world utilize to cope and deal with various health threats (Abdullahi, 2011). The WHO defines TM as the health practices, approaches, knowledge and beliefs indigenous to different cultures which are employed in the maintenance of health to diagnose, treat and prevent illness (2000).

In SSA, TM is culturally-rooted and absolutely central to health care delivery, with up to 80% of the population relying on it for primary health care provision (WHO, 2002). The popularity of TM can be attributed to its accessibility, affordability, and, most importantly, to its firm embedment within the faith systems of the people (Galabuzi et al., 2009). Compared with modern medicine, the TM sector of health care offers treatment options that tend to be more culturally and conceptually familiar to patients (Abdullahi, 2011). Therefore, TM provides an avenue through which cultural heritages are preserved and respected.

The providers of TM, **traditional and faith healers (TAFHs)**, also tend to occupy influential roles within their communities (Kpobi et al., 2018). The WHO (2000) defines a traditional healer as “a person who is recognised by the community where he or she lives as someone competent to

³ For the purposes of this thesis, TM includes traditional and faith healing systems since both are built on the beliefs, values and customs of their specific communities.

provide health care by using plant, animal and mineral substances and other methods based on social, cultural and religious practices.”

TAFHs are well-known for treating patients holistically and attempting to reconnect the social and emotional equilibrium of patients based on community rules and relationships (Abdullahi, 2011). In many communities, they are regarded as bridging the visible and invisible worlds and serving as mediators to bring sick people back into harmony with ancestors and spirits (Abdullahi, 2011). Herbal medicine is also predominantly used to manage a range of common conditions, including malaria, digestive and respiratory problems, childbirth complications and mental health conditions (De Coninck, 2017). With at least one TAFH for every 500 people,⁴ these alternative health providers constitute a key part of the medical system which is responsible for providing care (Chatora, 2003).

In light of the wide biomedical treatment gap for epilepsy in SSA, the use of traditional and alternative medicine for treating seizures is even more common (Winkler et al., 2010; Keikelame & Swartz, 2015). Given this widespread use, it is important to understand the dominant beliefs around epilepsy which contribute to patient decisions about treatment options and their efficacy (Kpobi et al., 2018).

Ideas about the causes of epilepsy and opinions on treatments tend to be based on predominant beliefs about disease, contagion and sources of unexplained phenomena (Coleman et al., 2012). Previous studies in SSA found that epilepsy is typically considered a spiritual rather than medical affliction, and seizures tend to be attributed to sacred or demonic possession, divine punishment, or witchcraft (Kinyanda et al., 2011; Nizard et al., 2016; Kpobi et al., 2018). Madness and contagion are also frequently affiliated with seizures, contributing to negative attitudes amongst community members and associations of epilepsy with fear, shame, guilt and mysticism (Baskind & Birbeck, 2005; Kpobi et al., 2018).

When patients and families hold these spiritual and mystical beliefs, TAFHs are logically sought to address seizures, since they are considered to mediate supernatural forces (Baskind & Birbeck, 2005). Indeed, it is very common for PWE and their caregivers to seek treatment in the form of TM in place of or prior to seeking care from any formal medical system (Baskind, 2005; Kinyanda et al., 2011; Mushi et al., 2011; Kakooza-Mweisge et al., 2017).

The various treatment regimes recommended by TAFH tend to differ depending on healers’ beliefs about the origins of a person’s seizures (Baskind & Birbeck, 2005). For instance, studies from Tanzania suggest that TAFH tend to focus on pleasing ancestral and evil spirits by offering

⁴ This figure is in comparison to one medical doctor for every 40,000 people on average (Chatora 2003). Of these few physicians, nearly all are concentrated in urban areas, so TAFH remain the primary health providers for millions of people, particularly those in rural areas (Abdullahi 2011).

their patients charms and performing rituals such as slaughtering livestock (Rwiza et al., 1993; Winkler et al., 2010; Mushi et al., 2011). Other treatments may include incantations, deliverance ceremonies and herbal remedies (Danesi & Adetunji, 1994; Nizard et al., 2016). In Uganda, epilepsy is commonly treated with local plants in the form of various preparations including powdered drinks, teas, and inhaled smoke (Tabuti et al., 2003; Okello & Ssegawa, 2007; Nalumansi et al., 2014). Finally, spiritual healing rituals include fasting, group prayers and exorcisms to cast away evil spirits at the root of the seizures (Danesi & Adetunji, 1994; Mushi et al., 2011).

Thus, traditional belief systems are critical to consider for a comprehensive understanding of the epilepsy treatment gap in SSA. Beliefs about epilepsy etiology in particular tend to influence patient and caregiver perceptions about the appropriateness and effectiveness of treatments (van der Watt et al., 2018). Therefore, further studies are needed to investigate how PWE conceptualize their conditions and how these beliefs are related to their care-seeking behaviors. These perceptions and beliefs vary by country and social context and may limit the implementation of strategies to improve the quality of life for PWE (Kaddumukasa et al., 2016).

1.2.3 Medical Pluralism

In SSA in particular, both the biomedical and traditional medical sectors are significant sources of care for patients with a variety of ailments, including epilepsy. Indeed, African health systems are known for being pluralistic, because they involve traditional, religious and allopathic theories and practices (Beckerleg, 1994; Obbo, 1996; Ovuga et al., 1999).

Therefore, the beliefs and health-seeking behaviors of PWE reflect the multiple systems of medical care available which can exacerbate access barriers to health care (Danesi & Adetunji, 1994; Moshabela et al., 2017). This phenomenon is evidenced through practices of **medical pluralism**, which is defined as the tendency to employ beliefs and practices of more than one medical system for health and illness (Leslie, 1980).

In SSA, medical pluralism tends to involve accessing multiple sectors of the health system in search of adequate care (Nyamongo, 2002; Moshabela et al., 2011). In regards to epilepsy, it is well established that patients seek treatment from more than one source, either simultaneously or sequentially (Coleman et al., 2002; Reis, 2002; Mushi et al., 2011; Sebara et al., 2015). In some cases, PWE and caregivers report shopping around with providers until they see improvement in their symptoms (Mushi et al., 2011). Other patients access biomedical care for symptomatic relief while simultaneously turning to traditional healers for cures and explanations about causality (Carter et al., 2012).

Despite evidence of medical pluralism, no country in SSA has an integrated or collaborative health care system which fully recognizes these different approaches to medical provision

(Moshabela et al., 2017). While the traditional medicine has the capacity to complement western-type scientific medicine, plural health care systems usually function in a fragmented and often competitive manner (Moshabela et al., 2017). The degree to which this is the case with epilepsy has not been explicitly explored in the literature.

However, studies involving other illnesses, such as HIV/AIDS, have demonstrated that the utilization of fragmented, plural health systems has been shown to delay treatment access (Moshabela et al., 2017). Therefore, it is important to consider the role of this pluralistic context in shaping patient conceptualizations of illness and influencing care-seeking behaviors.

While the last decade has seen a rise of literature on medical pluralism, few studies have examined the role of medical pluralism as it relates specifically to epileptic patients in SSA. Some studies hint at medical pluralism by revealing that disease attributions for epilepsy range from biological to spiritual to mystical and that PWE tend to access different providers for care (Winkler et al., 2010; Mushi et al., 2011; Carter et al., 2012; Kaddumukasa et al., 2016). None however actually consider the significance of medical pluralism for epilepsy treatment by documenting the frequency of pluralistic beliefs amongst PWE or determining how patients access the health care system when they hold such beliefs about the causes of their seizures.

1.3 Study Goals and Objectives

Therefore, this study will fill a gap in the literature by exploring the manifestations of medical pluralism in PWE experiences and considering the mechanisms through which pluralistic beliefs influence treatment seeking across health care options in Uganda.

To achieve this broader goal, the study has three objectives:

1. Characterize PWE and caregiver beliefs about seizure etiology and determine whether attributions for epilepsy are unitary or pluralistic.
2. Explore characteristics of the study sample that provide insight into the different dimensions of pluralistic versus singular belief systems.
3. Determine how pluralistic beliefs about epilepsy are associated with care-seeking practices and utilize the concept of medical pluralism to explore the reciprocal relationships between patient beliefs and health care decisions.

Thus, this study provides insight into how patients conceptualize epilepsy and navigate their health care landscapes. A clear understanding of these relationships and the complex imbrication between the health care options in Uganda will be crucial for developing culturally-appropriate policies and interventions for maximizing health care delivery for epilepsy and other non-communicable diseases.

2. Methods

2.1 Study Overview

The study data was collected in 2017 and 2018 as part of work conducted by **Duke Global Neurosurgery and Neuroscience (DGNN)** related to infrastructure strengthening and capacity building for the treatment of epilepsy in Uganda.

2.1.1 Setting

Uganda is a country in East-Central Africa, with a population of approximately 41 million people (CIA, 2018). With almost 20% of its population living under the poverty line, Uganda is classified as a low-income country (World Bank, 2016). Uganda also has a significant shortage of health care professionals, with only one physician for every 10,000 people in urban areas and one for every 50,000 people in rural areas (World Bank, 2003).

Epilepsy prevalence in Uganda is unusually high, as in the rest of Sub-Saharan Africa (Ngugi et al., 2013). The age-adjusted prevalence in the Iganga and Mayuge districts of Uganda is reported to be 6.8 per 1,000 people (Kakooza et al., 2017). The number of new epilepsy cases is exceptionally high in onchocerciasis endemic areas, with rates around 15-20 per 1,000 people in such districts (Ovuga et al., 1992; Kaiser et al., 1998; Ngugi et al., 2011). Additional causative variables are found in parasitic illness, infections with CNS risk, obstetric events, injury, and heredity, but also in barriers to care and non-compliance (Kakooza et al., 2017).

There is a lack of qualified health personnel to manage epilepsy cases in Uganda, with only two child neurologists in the entire country and 0.03 adult neurologists per 100,000 people, compared to 2.96 per 100,000 in HICs (WHO, 2004). In Uganda, psychiatrists also diagnose and treat epilepsy. However, access to this specialty is limited as well, with less than 40 psychiatrists in the country (Paulat, 2016).

2.1.2 Study Sites

The larger DGNN study, within which the current dataset was generated, sought to establish the cultural and practical barriers to PWE seeking **biomedical care (BMC)** in Uganda. Surveys exploring barriers to care, beliefs about epilepsy, and causal attributions were administered across treatment clinics in three referral hospitals in Uganda: Mulago National Referral Hospital, Butabika National Referral Mental Hospital, and Mbarara Regional Referral Hospital.

Mulago National Referral Hospital (MNRH) is a large public hospital in Kampala, Uganda's capital city. With approximately 1500 beds, MNRH serves as a national referral hospital for nearly 1.5 million people (Tran et al., 2015). MNRH provides the most comprehensive specialty services in the country, and nearly all patients with neurosurgical needs are referred to the

hospital for care. It also serves as the teaching hospital for Makerere University College of Health Sciences.

Butabika National Referral Mental Hospital (BNMH) is the second public national referral hospital in Kampala. As noted, epilepsy tends to fall under mental health in Uganda, so many PWE are treated by psychiatrists; epilepsy diagnosis accounts for more than half outpatient mental health clinic census at the BNMH (Birabwa-Oketcho, 2017). This psychiatric hospital serves as the teaching hospital for the Institute of Psychiatric Clinical Officers.

Mbarara Regional Referral Hospital (MRRH) is a smaller hospital with 350 beds to serve a patient population of approximately 4 million. It serves as the teaching hospital for the Mbarara University of Science and Technology. All three hospitals are publicly funded by the Uganda **Ministry of Health (MOH)**, and offer care free of charge.

2.1.3 Ethical Approval

The study was approved by the Duke University School of Medicine Institutional Review Board, the Mulago National Referral Hospital Research Ethics Committee, and the Uganda National Council for Science and Technology. Administrative clearances were obtained from MNRH, BNMH and MRRH.

2.2 Data Collection

The barriers to care survey was part of a larger interview which also asked questions about demographics, clinical seizure characteristics, and attitudes about epilepsy. For this thesis, two areas of focus and their relationship are explored: (1) participant beliefs about the causes of seizures and (2) care-seeking behavior around epilepsy. Therefore, data from these particular sections of the larger survey were used for analysis.

2.2.1 Study Sample

Participants were 626 adults and children (49% males and 51% females) seeking care for epilepsy at MNRH, BNMH, or MRRH. Adult epilepsy patients (aged 18 years or older) who could consent for themselves, and caregivers (for patients who were children or adults who could not consent for themselves) were included in the study. Participants were excluded from the study if it was found that the patient did not have epilepsy. Since participant recruitment occurred only at the National and Regional referral hospitals, it is important to note that this sample consisted entirely of PWE who eventually sought care in a biomedical setting.

2.2.2 Survey Content & Administration

Participants were interviewed one-on-one by research assistants in the language that the participants were most comfortable with (English, Luganda, or Runyankole). The research

assistants conducted the interview orally while manually recording participant responses on a paper questionnaire.

2.2.2.1 Survey Part I: Demographics

Part 1 of the survey contained questions regarding demographics such as age, gender, religion, education, and socioeconomic status [**Appendix A**].

2.2.2.2 Survey Part II: Beliefs about epilepsy etiology

Patients reported their beliefs about the causes of epilepsy in the 'CAUSES' portion of the barriers survey [**Appendix B**]. For this portion of the interview, participants indicated their agreement versus disagreement with 15 proposed causes of seizures (**Table 2**). The 15 causes were selected based on previous research in this area (Mushi et al., 2011; Kaddumukasa et al., 2016,) as well as the DGNN study teams' exposure to cultural beliefs during a previous qualitative arm of the barriers project. After constructing the potential causes, the survey underwent content validity review across experts in the United States and Uganda who were familiar with epilepsy, its treatment, and the local culture.

Table 2.

Causes of epilepsy included in patient survey

1. Brain illness
2. Troubled home
3. High fever
4. Witchcraft or spells
5. Spirits possessing the person
6. Bad medication
7. Malaria
8. Sun heating the brain
9. Injury at birth (like long labor)
10. Punishment by God
11. The blood of the person is abnormal
12. The mother was disrespectful or quarreled during pregnancy
13. Trouble with ancestors
14. Injury to the brain
15. Inherited (passed down to children)

For this portion of the interview, participants were handed a laminated likert scale from 1 to 4 on which to indicate their agreement versus disagreement with the 15 proposed causes of seizures. Implementing an even- rather than odd-numbered likert scale forced the decision toward either agreeing or disagreeing with each cause as being potentially causative. Research assistants requested that participants point to the '1' if they really disagreed with statement, '2' if they somewhat disagreed with the statement, '3' if they somewhat agreed with the statement, or '4' if they really strongly agreed with the statement. Administrators demonstrated this method pointing to the choice on the laminated scale as they gave these instructions.

2.2.2.3 Survey Part III: Health care access variables

In the 'CHARACTERIZATION' section of the interview [**Appendix B**], participants were asked questions about epilepsy and their experiences with the condition. Participants reported whether they sought BMC, and if so, how much time passed between the second seizure and seeing a medical doctor. Time was reported from the second seizure because epilepsy is diagnosed after two or more seizure events. This variable will be discussed as time to medical care.

Another portion of the interview, 'HELP SEEKING HISTORY,' prompted participants to report on who they sought for seizure care. Starting with the first provider, participants reported whether they met with a traditional healer, pastor, or biomedical provider and were asked to elaborate on the services they received from this provider. The interviewer would continue by asking whose help was sought next until the participant reported on their final provider, i.e. a biomedical provider from one of the three study sites.

2.3 Data Analysis

Data analysis was conducted in Microsoft Excel (15.11.2) and SAS (9.4).

2.3.1 Beliefs about the causes of epilepsy

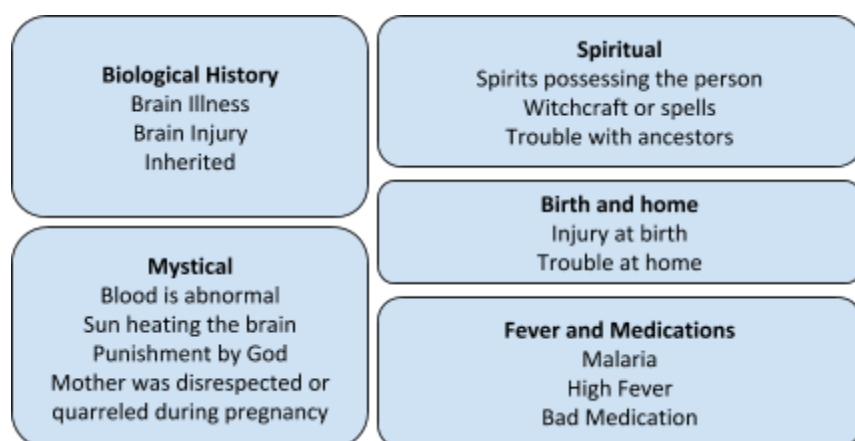
Principal component factor analysis was used to identify item groupings for the 15 causes to be used in subsequent analyses (**Table 3**). The factors were generated using a varimax rotation which reduced the number of variables based on the natural relationships between them. Rotated factor loadings greater than 40 were considered sufficient for a given cause to be included in that factor. If a cause correlated with more than factor, it was loaded into the factor with which it had a better fit, as indicated by a higher factor score.

Table 3.

Rotated factor structure matrix

	Spiritual	Mystical	Fever and Medications	Biological history	Birth and Home
Spiritual possession	93	3	6	1	0
Witchcraft or spells	93	4	4	0	-1
Trouble with ancestors	79	13	-4	18	6
Abnormal blood	1	81	-11	-4	4
Sun heating brain	3	76	13	-18	16
Punishment by God	12	60	9	7	21
Mother disrespectful or quarreled	10	57	-25	10	42
Malaria	2	-8	82	14	-7
High fever	-3	-14	69	34	6
Bad medication	5	29	65	-4	9
Inherited	10	20	-6	74	7
Brain illness	8	-21	37	71	-9
Injury to brain	3	-21	39	64	-17
Injury at birth	-3	16	4	4	80
Troubled home	6	23	3	-16	77

This methodology yielded 5 factors (**Figure 1**). A respondent score for each factor was generated as the mean of the ratings for each of the causes in that factor. The score was considered an endorsement of the factor if it was greater than or equal to 2.5 (on the scale of 1 to 4).

**Figure 1.** Five causal factors for seizures

2.3.2 Combinations of Biological, Spiritual, and Mystical Beliefs

In order to analyze the overarching nature of respondent beliefs, the participants were subsequently sorted into three categories: (1) people with biological beliefs only, (2) people with biological as well as spiritual beliefs and (3) people with biological and mystical beliefs.

For this analysis, participants were considered to hold biological beliefs if they endorsed *any of the three* following factors which can be considered to be largely biological in nature: biological history, birth and home, and fever and medications.

Of respondents endorsing at least one of those biological factors, they were separated into one of the three categories:

1. **Biological only:** endorsed *at least one* of the three biological factors but did not endorse the spiritual or mystical factor
2. **Spiritual & Biological:** endorsed at least one of the three biological factors as well as the spiritual factor but did not endorse the mystical factor
3. **Mystical & Biological:** endorsed at least one of the three biological factors as well as the mystical factor; may or may not have also endorsed the spiritual factor

Preliminary analysis revealed that most people endorsing the mystical factor also endorsed the spiritual factor, so it would not be possible to meaningfully define an exclusively mystical & biological group due to sample size restraints. By defining the categories as above, the three groups are mutually exclusive. Only one respondent did not fall into any of the three categories.

In subsequent analyses, the participants classified into the 'Spiritual & Biological' and 'Mystical & Biological' belief groups are considered to possess pluralistic beliefs about epilepsy etiology since their beliefs incorporate biological constructs as well as spiritual and/or mystical ones respectively. Participants in the biological only group are considered to have more singular beliefs since their explanations primarily tended to draw from biological constructs only.

2.3.2.1 Demographics

The relationships between demographic variables and the biological, spiritual and mystical groups defined above were evaluated with ANCOVA for continuous variables and logistic regression for categorical variables.

2.3.2.2 Care-seeking behavior

Descriptive statistics were calculated to summarize trends in care-seeking behavior including the types and quantity of providers consulted.

In order to determine how holding pluralistic versus singular beliefs affects care-seeking behavior, the associations between a respondent's belief category and their time to biomedical care and choice of first treatment were analyzed.

Generalized estimating equations with a negative binomial distribution for time were used to model differences in the variance of time to BMC between individuals. This method was used because the responses did not follow a normal distribution and the variation between individuals was clustered and uneven.

For the choice of first treatment, a chi-squared test was conducted, treating the choice as a dichotomous variable with the options being BMC or not BMC.

3. Results

3.1 Sample Description

A total of 626 participants were included in the study. **Table 4** describes the demographics of the sample, including patients and caregivers. Approximately 53% of the interviews were conducted with the patients themselves, while the remainder were conducted with caregivers.

Of the patients in the sample, 36% were pediatric (under 18). The average age of patients in the study was 25.5 years (SD 15), while caregivers tended to be older with a mean age of 46 years (SD 11). The majority of the sample reported early seizure onset with the median age of first seizure being 9 years (IQR 14). Of the 626 patients, 578 (92%) typically lost consciousness during seizures.

Table 4.

Demographics of patients and respondents (n = 626)

PATIENT DATA		
Sex	n	Percentage
Male	306	48.9
Female	318	50.8
Age		
0-17	225	35.9
18-30	256	40.9
30-45	99	15.8
45+	46	7.3
RESPONDENT DATA*		
Relationship to patient		
Patient	331	52.8
Caregiver	294	46.9
Mother	194	31.0
Father	43	6.9
Sibling	21	3.4
Other	36	5.8

Age		
23-30	23	3.7
31-40	82	13.1
41-50	99	15.8
51+	80	12.8
Education		
No school	66	10.5
Completed primary school (1-7)	240	38.3
Completed secondary school (S1-S6)	171	27.3
Higher vocational or university	98	15.6
Household Setting		
Urban	138	22
Suburban	318	50.8
Rural	166	26.5
Religion		
Christian	516	82.4
Muslim	108	17.3
Other	2	0.3

*The respondent is considered to be the person (patient or caregiver) who was interviewed and reported the beliefs that were analyzed in this study

3.2 Beliefs about epilepsy etiology

3.2.1 Causal factors

Following data reduction into five causal factors for seizures, the most commonly endorsed factor was biological history, followed closely by medications and fever (**Figure 2**). The vast majority (94%) of the sample endorsed more than one factor as causative, with the median number of factors endorsed being 3.

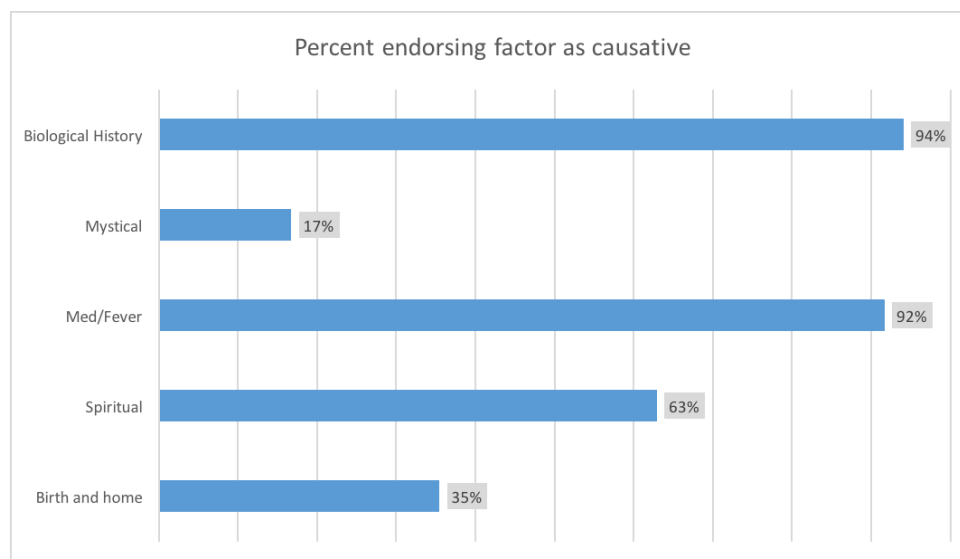


Figure 2. Proportion of interviewees who endorsed each causative factor for seizures (n=626, multiple answers possible)

Of the 626 respondents, none endorsed only the mystical factor, and 4 endorsed only the spiritual factor. Therefore, almost every participant endorsed at least one of the biology factors (i.e. biological history, medications and fever, and birth and home). One third of the sample endorsed all three biological factors.

3.2.2 Belief system groups and associations with demographics

When the sample was sorted into the three belief groups defined in this study, 33% (207/625) fell into the 'Biological only' group, 50% (313/625) into the 'Spiritual & Biological' group and the remaining 17% (105/625) into the 'Mystical & Biological' group. Therefore, a third of the sample fell into the singular beliefs category, while the remaining majority (67%) fell into the pluralistic beliefs groups.

There were several notable differences in demographics between the groups, with most differentiating the 'Biological only' group from the other two (**Table 5**). Respondents in the 'Biological only' group tended to be older ($p < 0.01$) and have higher levels of education ($p < 0.05$) compared with those in the other groups. Finally, the average income of those in the 'Biological only' group was significantly higher than that of respondents in the other groups ($p < 0.05$).

There were few significant differences between the 'Spiritual & Biological' and 'Mystical & Biological' groups. The 'Spiritual & Biological' group had a higher average age ($p < 0.05$) and slightly higher composition of females ($p < 0.1$).

Table 5.

Associations between demographics and etiology belief categories

Variable	Spiritual (n = 309)	Biological Only (n = 201)	Mystical (n = 105)	Biological Only vs. Others	Spiritual vs. Mystical
Patient Age \square	23.2	22.4	23.0	.589	.887
Patient Gender (Female) \square	55%	50%	42%	.693	.056
Age of Seizure Onset	3.0	2.9	2.9	.513	.217
Loss of Consciousness	93%	93%	94%	.597	.653
Distance to Health Center	20.7	21.5	18.0	.458	.443
Caredriver Age	34.1	36.3	30.3	.005	.040
Caredriver Education	2.7	2.9	2.7	.043	.821
Income *	33.3	50.9	36.3	.016	.738
Household Setting (Urban)	72%	78%	68%	.160	.367
Seizure frequency at onset	3.4	3.3	3.4	.210	.123

Symbols denote omnibus group difference: \square $P < .10$, * $P < .05$, ** $P < .01$

3.3 Care-seeking behaviors

3.3.1 Care-seeking history

Since participants were recruited from hospital settings, 100% of the study sample reported consulting BMC for epilepsy treatment. Of these 624 respondents, 301 (48%) also conferred with traditional healers and 105 (17%) with pastors.

The majority of participants, 80% (124/624), consulted more than one provider for epilepsy. For some, 46% (287/624), this meant consulting more than one provider within the biomedical sector. For a few others, it meant seeking the help of multiple traditional healers, 3.5% (22/624), or multiple pastors, 0.5% (3/624).

More than half of the sample, 57% (357/624), accessed more than one **type** of provider (biomedical, traditional, or pastoral). A small portion, 7% (46/624), consulted all three types of providers for their epilepsy.

3.3.2 Associations between belief groups and care-seeking behavior

This study detected differences in care-seeking behaviors amongst participants in the three different belief groups (**Table 6**).

Participants in the 'Biological only' group were more likely to seek BMC as their first source of treatment, compared with those in the 'Spiritual & Biological' and 'Mystical & Biological' groups (χ^2 test, $p < 0.005$). Respondents in the 'Biological only' group also tended to seek BMC more quickly ($p < 0.1$). There were no significant differences in treatment choices or delays detected between the 'Spiritual & Biological' and 'Mystical & Biological' groups.

Table 6.

Care-seeking behaviors and associations with belief groups

Variable	Spiritual (n = 309)	Biological Only (n = 201)	Mystical (n = 105)	Biological vs. Others	Spiritual vs. Mystical
BMC as First Treatment	161 (52%)	129 (65%)	54 (51%)	.003	.170
Time to BMC, mean / median (years)	1.4 / 0.1	0.9 / 0.08	1.2 / 0.08	.061	.634

Symbols denote omnibus group difference: □ $P < .10$, * $P < .05$, ** $P < .01$

4. Discussion

The findings of this study suggest that medical pluralism is common and significant for PWE and caregivers in this sample. Analyses revealed that, while some study participants held etiology beliefs that were mostly biological in nature, a majority held pluralistic beliefs drawing from spiritual and mystical explanations for seizures as well as biological ones. Second, there were detectable differences between these belief groups in terms of age, education and income, but a review of the averages did not reveal marked differences that could strongly predict belief systems. Third, belief systems seemed to impact where care was first sought and whether patients experienced delays to biomedical care. These findings have important implications for understanding the cultural beliefs and practices related to epilepsy that impact health care utilization choices. Any policy changes or infrastructure interventions aimed at improving epilepsy care access, reducing the treatment gap or fostering collaboration across health systems might consider these findings.

4.1 Beliefs about epilepsy etiology

4.1.1 Spiritual beliefs

This study found that spiritual attributions for epilepsy were common amongst PWE and their caregivers. More than 60% of the sample agreed that seizures could be caused by spiritual forces, including possession, witchcraft and ancestral forces. This finding aligned closely with a recent study of more than 3,500 PWE in the Democratic Republic of Congo that found 55% of their sample considered epilepsy to be of spiritual or religious origin (Bora et al., 2015). Other descriptive studies out of Kenya and Tanzania confirmed that a predominant belief amongst PWE and caregivers was that spiritual and supernatural forces were responsible for seizures (Mushi et al., 2011; Carter et al., 2012).

In contrast, other studies of epilepsy knowledge report lower prevalence of spiritual beliefs than was found in this analysis (Rwiza et al., 1993; Ezeala-Adikaibe et al., 2013; Mustapha & Akande, 2013; Nnko et al., 2015). However, many of these study populations differ from that of the present study. Other samples tended to be composed of specific community groups such as teachers and students, which are likely to have different levels of knowledge and exposure to epilepsy compared with patients and caregivers.

Also contrary to the high frequency of spiritual beliefs in this sample, a recent study in the nearby Mukono district of Uganda reported that none of the 377 community members they interviewed cited supernatural or spiritual causes for epilepsy (Kaddumukasa et al., 2016). Instead, the majority their sample did not know or report any causes of seizures at all, and those who did reported biological explanations. This discrepancy in results may also be attributable to the different study populations. While the sample for this study consists of PWE

and caregivers, the Kaddumukasa et al. (2016) study involved household surveys of community members, the vast majority of which did not have epilepsy. Therefore, it is likely that PWE tend to have stronger and more numerous beliefs about epilepsy etiology than a typical member of the community since the patients have sought explanations and treatments for their conditions.

4.1.2 Biological beliefs

Biological explanations for seizures were also frequent amongst participants in this study, even more so than spiritual and mystical attributions. The results showed that almost every respondent endorsed at least one of the three biological factors as causative in seizures. Therefore, a majority of the sample agreed that seizures could be caused by various illnesses, brain injuries, and genetic factors. This suggests that the study participants generally had some understanding and/or acceptance of scientific and medical explanations for epilepsy.

While previous studies have also found that a significant portion of their sample ascribes epilepsy to biological origins, the frequencies with which they do so tend to be lower than the ones reported here (Winkler et al., 2010; Kaddumukasa et al., 2016). In fact, some studies report that participants ascribe epilepsy to non-medical causes only, rarely citing injury or illness at all (Mushi et al., 2011). This may be due to differences in study populations, as it seems that PWE and their caregivers have more knowledge about epilepsy than the general population. The discrepancy could also be attributable to different survey structures, since this study involved proposing 15 causes to respondents compared with other interview formats which asked open-ended questions and required participants to offer their own explanations (Carter et al., 2012; Keikelame & Swartz, 2015).

The unusually high frequency of biological beliefs in our sample may also reflect the proximity of the study population to the hospitals where the study was conducted and the resultant contribution of these biomedical institutions on education. Since the vast majority of the patients interviewed were in contact with the hospital staff at the study site or had previously accessed biomedical care, it is also likely that our sample had heard biomedical explanations for epilepsy more often than the average PWE.

4.2 Pluralistic beliefs about the causes of epilepsy

As discussed above, this study confirms that both biological and spiritual/mystical attributions for seizures are common. Going beyond previous studies though, this thesis reveals that PWE and caregivers often hold these biological and spiritual beliefs concurrently. In other words, it was common for respondents to report that epilepsy is caused by a combination of spiritual, mystical and biological causes, rather than choosing one explanatory concept.

4.2.1 Frequency of pluralistic etiology beliefs

The majority of participants were found to hold pluralistic beliefs about epilepsy etiology, with 50% endorsing both the spiritual and biological factors and 17% endorsing mystical, spiritual and biological factors. Only about one third of the sample seemed to have a more singular belief system reflected by only endorsing biological factors. These results suggest that there is not a clear dissociation of spiritual, mystical and biological agents in explanatory models of epilepsy etiology.

Furthermore, less than 1% of the sample agreed with only the mystical or the spiritual factor. This suggests that while spiritual and mystical beliefs are prevalent amongst our sample, they are not held instead of biological explanations for seizures.

Our findings are consistent with a similar survey from Northern Tanzania (Winkler et al., 2010). This study concluded that biomedical beliefs about epilepsy were held at least as strongly as traditional ones, and that these supernatural and scientific explanations seemed to coexist. Indeed, while a majority of their sample cited spiritual reasons for epilepsy, more than half also reported that genetic factors and medical disorders could trigger seizures. Since more than half of their sample endorsed biological causes and spiritual causes, the researchers concluded that there must be some overlap in these belief systems, though they did not explore or quantify this overlap any further.

This seems to be a trend in the available literature; many studies conclude that beliefs about seizure etiology include traditional as well as biomedical concepts at the community level, but few demonstrate that these beliefs can be concurrent on an individual level. The only available studies of the sort have been conducted with traditional healers in South Africa and Ghana (Keikelame & Swartz, 2015; Kpobi et al., 2018). These two studies found that traditional healers held explanatory models regarding the origins of epilepsy where both biomedical and supernatural reasons existed side-by-side. While the researchers postulated that patient beliefs would be congruent with those of traditional healers due to their positioning within communities, there have been no studies to date to confirm this (Kpobi et al., 2018).

In alignment with this hypothesis, the present study suggests that patients and caregivers also tend to construct multiple, complex and seemingly contradictory understandings of epilepsy. In doing so, they combine traditional and biological explanations to construct meanings that transcend the discrete belief categories depicted in the literature. These findings point towards the importance of exploring understandings and experiences at the level of the individual.

4.2.2 Demographic associations with pluralistic beliefs

The results of this study suggest that people with pluralistic beliefs tended to be younger than those with biological beliefs alone and have lower incomes and levels of education on average.

Previous studies assessing the associations of age and health care practices tend to be inconclusive. A systematic review of **traditional and complementary medicine (TCAM)** use in SSA summarized a general trend; studies in urban and suburban settings reported TCAM users to be younger, while those conducted in rural settings reported TCAM users to be older (James et al., 2018). Since the majority of our sample is from urban or suburban areas, this could explain the younger average age of the spiritual and mystical groups. However, a review of the means did not show a marked difference in average age across the groups that would meaningfully predict belief systems. Further studies are needed to clarify this relationship, especially as it relates to holding singular versus pluralistic beliefs.

Socioeconomic factors tend to have more consistent associations with the use of medical services (Ahmed et al. 2000; Shih et al., 2010). Many studies report that people with higher **socioeconomic status (SES)** tend to utilize biomedical health services more often than their counterparts (Kang, Chen & Chou 1996; Shih et al., 2010). This may be reflected in our finding that people with only biological beliefs about epilepsy etiology tended to have higher incomes. Other studies from SSA report that TM use is more common in individuals with low SES (Nxumalo et al., 2011; Onyapat, Okoronkwo & Ogbonnaya, 2011; Okoronkwo et al., 2014). This could explain why pluralistic beliefs tend to be associated with lower SES if the same people are accessing TM in addition to biomedical care.

Finally, this study suggests that education is also associated with medical pluralism, with less educated people tending to have more pluralistic beliefs about epilepsy etiology. However, there is an inconsistent pattern observed in the literature related to educational status of TM users (James et al., 2018). More specific to epilepsy, many studies have shown that spiritual beliefs are less frequent amongst students and teachers compared with the general population (Rwiza et al., 1993; Ezeala-Adikaibe et al., 2013; Mustapha & Akande, 2013; Nnko et al., 2015). This may reflect an inverse relationship between education and beliefs in spiritual and mystical causes for epilepsy, as supported by the results of this study. If people with higher levels of education also tend to have fewer supernatural beliefs, then they may be more likely to fall into the singular biological beliefs category defined in this study.

Generally, there are no studies out of SSA which specifically report sociodemographic characteristics associated with adopting medical pluralism. On the other hand, there are many studies out of the United States and South-East Asia that do just that (Mackenzie, Taylor & Bloom 2003; Shih et al., 2010). These findings however tend to be contradictory and inconclusive. It is also difficult to extrapolate from these studies since beliefs and practices are

so culturally- and context-dependent. Therefore, there is a need for future studies to investigate characteristics associated with medical pluralism in SSA.

4.3 Seeking Epilepsy Care in the Uganda Health System

The results of this study regarding beliefs about epilepsy must be considered in the context of a country that relies on traditional and faith healers (TAFH) for explanations of etiology and provision of treatment. In Uganda, TM usage for day-to-day health care is reported to be as high as 80%, with this number being even higher in rural areas (Kamatenesi-Mugisha & Oryem-Origa, 2005). Nationwide, there is at least one TAFH for every 700 people compared with one physician per 25,000 people (Abdullahi, 2011). TAFH are thus appreciated as key and sustainable sources of care and knowledge on disease and illness in Uganda.

This reality was reflected in the results, as 48% and 17% of the sample consulted traditional healers and pastors, respectively, for their epilepsy. This frequency of accessing traditional healers is consistent with findings from Tanzania (Winkler et al., 2010), Nigeria (Danesi & Adetunji, 1994), and Gambia (Coleman et al., 2002). In contrast, few studies report on the rate of PWE seeking care from pastoral healers, but those that do tend to report higher frequencies than found here (Danesi & Adetunji, 1994; Mushi et al., 2011).

In comparison to those of community-based studies, the present sample is unique in that it is entirely composed of PWE and caregivers in biomedical institutions of their volition at the time of data collection. Therefore, any participants who reported consulting TAFHs for care had also seen western-trained medical practitioners, suggesting that pluralistic health-seeking practices were common amongst PWE and caregivers in this particular sample; findings may differ using the same survey in a community sample.

Consistent with this trend, 57% of respondents in this study sought more than one type of care for their epilepsy. Other studies in SSA support this finding and universally demonstrate that PWE tend to seek treatment from more than one source, either simultaneously or sequentially (Coleman et al., 2002; Reis 2002; Mushi et al., 2011; Sebara et al., 2015). In cross-sectional studies in Tanzania (Coleman et al., 2002) and Gambia (Mushi et al., 2011), researchers found that 93% and 74% of PWE respectively sought more than one type of care.

Patients and caregivers seem to access care from different places when they do not see any improvement in the frequency or severity of their systems (Mushi et al., 2011). Therefore, many epileptic patients being treated in hospitals have previously accessed TM before seeking biomedical treatment only once other options had been exhausted (Danesi & Adetunji, 1994). In other cases, PWE access hospitals and clinics for symptomatic relief only while turning to traditional healers for the cure and explanations about the causality (Carter et al., 2012). It is

not clear whether the PWE and caregivers interviewed in the present study were also accessing alternative treatment at the time of their interviews.

Still, our results support the notion that medical pluralism in SSA tends to involving shopping around and switching between multiple modalities of care (Nyamongo, 2002; Moshabela et al., 2011, 2017). Exactly how PWE practice medical pluralism is not well documented in the literature, but studies of patients with HIV/AIDs may serve as models for future investigations into how PWE adopt more than medical system for treatment (Nagata et al., 2011; Moshabela et al., 2011, 2017).

4.4 Intermingling of pluralistic beliefs and behaviors

The present study provides evidence that etiology beliefs are closely tied to treatment choices. Specifically, the results suggest that pluralistic beliefs are associated with accessing non-biomedical providers as a first line of care and with significant delays to BMC. Thus, the adoption of culturally-sensitive interventions in the context of SSA necessitates a better understanding of sociocultural beliefs in mediating treatment bottlenecks for epilepsy care associated with medical pluralism.

4.4.1 The association of beliefs with care-seeking behaviors

The results suggest that participants with singular biological beliefs about seizure causes were more likely to access hospitals and clinics as their first source of treatment. In comparison, respondents with pluralistic beliefs were more likely to access pastoral or traditional healers for their initial consultations about epilepsy. This suggests that beliefs about seizure origin are related to the first choice of care provider.

Such a relationship is universally supported in the literature (Reis, 2002; Carter et al., 2012; Dillip et al., 2012; Abubakar et al., 2013; Kisa et al., 2016). For instance, in her study of PWE and carers in Swaziland, Rita Reis (2002) detected a strong correlation between a patient's suspicions about epilepsy causation and their first choice of treatment. Other studies amongst PWE verify that care-seeking behaviors depend on causal beliefs (Baskind & Birbeck, 2005; Kisa et al., 2016), though none explore how pluralistic beliefs about causes impact treatment access.

Therefore, the present study is unique in that a significant portion of the sample attributes seizures to supernatural as well biological causes, which likely results in unique care-seeking behaviors. This may explain why the results seem to contradict the conclusions of many previous studies amongst PWE. For example, a study in Zambia concluded that care-seeking rarely includes attendance at medical clinics when epilepsy is attributed to supernatural causes (Baskind & Birbeck, 2005). The present data set reveals that this is not universally true, as the majority of this sample cites at least one supernatural cause and yet they all ended up seeking

BMC. This suggests that holding pluralistic beliefs about epilepsy etiology does not prevent PWE from accessing BMC even when these beliefs encompass spiritual and supernatural concepts.

These findings validate those of a cross-sectional study of psychiatric patients in Nigeria which identified a similar trend. Aghukwa (2012) found that even among patients who consulted a general medicine practitioner at the onset of illness, more than half believed in supernatural origins of their conditions. Therefore, it seems that spiritual and supernatural beliefs do not necessarily mean that a PWE will receive their treatment from traditional medicine providers.

This relationship becomes especially important to consider in light of the study's other major finding that pluralistic etiology beliefs tended to be associated with greater delays to epilepsy care. Specifically, the data suggests that respondents with only biological beliefs sought BMC more quickly than those with pluralistic beliefs on average. This particular finding has not been reported before in the epilepsy literature but is consistent with conclusions from studies of care-seeking behavior amongst people with HIV in SSA (Nagata et al., 2011; Moshabela et al., 2011, 2017).

These studies universally suggest that practicing medical pluralism can contribute to delays and interruptions in care because the health system in SSA is fragmented (Moshabela et al., 2011, 2017). Therefore, region-wide interventions and policies are urgently needed to minimize the potential consequences of medical pluralism for all patients whether they suffer from HIV/AIDs or from epilepsy.

4.4.2 Which came first- the belief or the medical care?

Due to the cross-sectional nature of this study, this data is limited in that it only demonstrates an association between participant belief systems and care-seeking behavior, while revealing nothing about the directionality or causality of this relationship. Therefore, it is not clear whether etiology beliefs determine care-seeking behavior or if PWE derive their beliefs systems from the explanations of their health care providers.

4.4.2.1 Beliefs drive treatment decisions

Most studies of care-seeking behaviors in PWE conclude that beliefs about causality drive treatment decisions (Baskind & Birbeck, 2005; Carter et al., 2012; Dillip et al., 2012; Abubakar et al., 2013; Kisa et al., 2016). Such conclusions align with Arthur Kleinman's conceptual model (1980) for analyzing patient behaviors and decisions in the context of culture. Kleinman suggests that beliefs about illness and disease etiology determine the health-seeking behavior of patients and therapeutic options they select (1980). This follows logically from the fact that beliefs about the illness itself are closely tied to beliefs about treatment. Thus, ideas about the

cause of illness are likely linked to perceptions about the efficacy of various treatment options (Kleinman, 1980).

Furthermore, patients who consider their own etiology beliefs to resemble those of their providers tend to regard their provider as more credible and trustworthy, increasing the likelihood of returning to this source for care (Chen & Mak, 2008). In line with this conceptual framework, the results of the present study may suggest that pluralistic etiology beliefs are responsible for the care-seeking behaviors observed in the sample.

4.4.2.2 Explanations for seizures come from a variety of information sources

However, it is also quite possible that the reverse relationship is true, and explanations for seizures could actually be derived from eclectic care-seeking practices. When it comes to epilepsy, many patients report having no idea about seizure etiology when they consult medical providers (Winkler et al., 2010; Carter et al., 2012). Instead, they seek care based on their symptoms and rely on their providers for explanations about causality (Mushi et al., 2011; Carter et al., 2012).

Therefore, the results of this study may reflect the eclecticism⁵ of PWE and caregivers' health seeking practices and suggest that beliefs about the causes of epilepsy are derived from the care-seeking behaviors rather than the other way around. Since PWE tend to access multiple sources for care, this is a plausible explanation for the prevalence of pluralistic beliefs about seizure etiology.

Qualitative studies of care-seeking amongst PWE shine light on how patients access information about their conditions from different sources. Patients seeking care from faith healers report being told that seizures were caused by participation in traditional rituals, seeking care from other providers or possession by evil spirits (Mushi et al., 2011). Conversely, traditional healers told their patients that their epilepsy could be attributed to curses by friends or family, failure to observe traditional rules and trouble with ancestors or spirits (Mushi et al., 2011).

Thus, understandings of epilepsy tend involves a combination of biomedical information gleaned from clinic visits and more traditional beliefs drawn from the community and alternative healers.

4.4.3 Reciprocity in constructing understandings of epilepsy

Considering both of these explanations, it is reasonable to suspect that the results of this study reflect a reciprocal relationship between etiology beliefs and care-seeking behaviors. In other words, patient beliefs tend to be derived from the explanations they receive from various health providers, while these etiology beliefs also guide future health care utilization decisions.

⁵ Eclecticism is the practice of deriving ideas, style or taste from a broad and diverse range of sources

In some cases, patients may already hold beliefs about seizure causality that they acquired from their families and communities prior to seeking treatment, but these beliefs will continue to be shaped by their interactions with care providers moving forward.

Further studies are needed to confirm this hypothesis, but this idea of reciprocity in medical encounters is not unprecedented. In his initial formulation of the explanatory model concept in health care, Kleinman (1980) emphasized that health-related encounters tend to involve negotiations, explicit or otherwise, between patients and providers regarding understandings of illness (1980). Therefore, explanatory models for disease are constantly evolving, so cross-sectional studies like this only capture beliefs systems at a single time point.

Nevertheless, it is crucial to continue pursuing such studies in order to explore how patients ended up in their situations at the time of study. In this investigation in particular, all participants ultimately sought biomedical management of their epilepsy, which tends to be the goal of many interventions. Therefore, it is important to explore how PWE choose one system of beliefs and practices over another in navigating their socio-cultural health care landscapes.

4.5 Implications and future directions

The results of this study suggest that considering medical pluralism in the context of epilepsy is crucial for a comprehensive understanding of patient beliefs and behaviors. These findings suggest that PWE tend to construct complex explanations for their epilepsy, drawing from traditional and biological concepts as they navigate the pluralistic health care system in Uganda, typically accessing multiple sources of care. Since patients and caregivers incorporate explanations and practices from various health systems, it is worth considering the possibilities for collaboration and integration across these systems.

4.5.1 Possibilities for integration and collaboration

Indeed, the findings of this study emphasize the need to engage culturally competent providers in epilepsy care who will respect patient beliefs. By providing care in line with or at least respectful of typical belief systems, providers will have more leverage in treating illness especially where behavior change is needed (Poudyal, Jimba, & Wakai, 2005). Thus, based on the results of this study, it would also be worthwhile to investigate how culturally-sensitive community education programs emphasizing biological etiology could expedite biomedical health seeking.

Furthermore, this study verifies that patients in SSA tend to consider epilepsy as more than a simple medical problem requiring tablets, so typical biomedical management may not be entirely sufficient (Baskind & Birbeck, 2005). Therefore, it is necessary to consider how

collaboration with TM can be fostered in order to present ideas about causation and treatment without disturbing fundamental beliefs and values.

This opinion is reinforced by the WHO which emphasizes the value in integrating health systems (Van Lerberghe, 2008; Akol et al., 2018). Two relevant WHO strategies endorse the involvement of traditional healers in care: the traditional and complementary medicine strategy for 2014-2023 which emphasizes traditional healers as potential solutions to achieving universal health coverage (WHO, 2013b) and the mental health action plan for 2013-2020 which highlights greater collaboration with TAFH to promote mental wellbeing (WHO, 2013a).

The WHO's stance on this issue of pluralistic health systems can be surmised through an address by their Director-General, Dr. Margaret Chan. She stated that:

The systems of traditional and Western medicine need not clash. Within the context of primary health care, they can blend together in a beneficial harmony, using the best features of each system, and compensating for certain weaknesses in each. This is not something that will happen all by itself. Deliberate policy decisions have to be made. But it can be done successfully (2008)

In order to achieve this goal, the WHO highlights the importance of defining the scope of the various health sectors through data on accessing traditional medicine, reasons for using it, popular forms and practices around disclosing TM use (2013b). Thus, studies resembling this thesis will be of critical importance for understanding care seeking behaviors and modalities that will underpin appropriate policies and regulations. Specifically, it is crucial for national governments to explore these health systems and the complex imbrication between them with particular attention to local contexts and cultures.

4.5.2 Global efforts to integrate traditional and biomedical health systems

Globally, countries are recognizing the need to develop a cohesive and integrative approach to health care in order to facilitate treatment access across the various medical sectors. There is emerging evidence that the informal medical sector will be crucial for improving service delivery in the health system by increasing patient accessibility to health services and fostering greater awareness of health promotion and disease prevention (WHO, 2013b). TM of proven quality, safety and efficacy can also contribute to the **Sustainable Development Goal (SDG)** of ensuring that universally people have access to health care (WHO, 2013b).

In a few countries, particular aspects of traditional and complementary medicine have been completely integrated into health care services. For instance, in China, TM and conventional medicine are practiced alongside each other at every level of the healthcare system (WHO, 2013). In Vietnam and Korea, TAFHs can provide services in both public and private hospitals or clinics (WHO, 2013). Public and private insurance covers all costs for conventional and

traditional medicine treatments in these three countries, as well as in several others across the world (WHO, 2013).

In the WHO Africa region, progress towards integration of traditional and conventional medicine has been slower but is still promising. The number of countries with national TM policies rose from 8 in 2000 to 39 in 2010, and those with TM strategic plans increased from 0 to 18 in the same time frame (WHO, 2011). Further, many African governments have initiated dialogues with alternative healers to facilitate incorporation of traditional and spiritual healing into the formal medical system through national registration and accreditation programs (WHO, 2013b).

Specifically, South Africa passed legislation to standardize and regulate its 200,000 traditional healers, including herbalists, diviners, and midwives (Tshela, 2015). The recent Traditional Health Practitioners Act established a regulatory council for TM, created a registry for healers, and granted registered healers the authority to issue medical certificates for patients to submit to schools and employers as necessary (Tshela, 2015). This act goes a long way in acknowledging that many people rely on these professionals for their medical needs.

4.5.3 The case for Uganda

Uganda has not yet achieved that degree of integration despite evidence that the TM sector is crucial for health care delivery across the country. As of now, the **Ministry of Health (MOH)** does not recognize or oversee the TM sector of health care, instead relegating these duties to the Ministry of Gender, Labor and Social Development (De Coninck, 2017). However, the MOH has recently drafted a policy on Traditional and Complementary Medicine to regulate the practice, focus on research and development, and encompass the protection and sustainability of traditional medicinal plants (De Coninck, 2017). They have also submitted a new bill for the establishment of the National Council of Indigenous and Complementary Medicine Practitioners, a semi-autonomous body that would support collaboration between the biomedical and TM sectors and regulate the latter (De Coninck, 2017). Though not yet enacted, these initiatives represent important steps towards acknowledging the legitimacy of TM and working towards quality assurance across the health care systems.

In response however, many traditional healers have come out to attack the MOH for trying to moderate and control their practices without offering superior services to the many Ugandans who cannot access expensive biomedical treatments (Kalema, 2019). They also criticize the MOH for efforts to alter TM to fit their agenda without accommodating for or respecting the culturally ingrained beliefs and practices associated with the healing system.

Given the persisting lack of cooperation between different providers in Uganda, an alternative approach would be to direct resources towards the sensitization of biomedical providers. The

results of this study suggest that biomedical providers may benefit from education about the importance and persistence of pluralistic and traditional beliefs, as well as the need to appreciate these beliefs in a sensitive manner in their treatment approaches. This may be challenging in the overburdened biomedical sector, but such sensitization efforts would be invaluable for appreciating and respecting the belief cultures of patients.

Thus, future interventions that utilize concepts and resources from the traditional and biomedical sectors will appeal to larger patient populations and be more sustainable than those that hierarchically preference biomedical providers. Given the poor resources and health infrastructure in Uganda, engaging with all providers across the systems should facilitate each system to contribute and compensate for the limitations of the other.

4.6 Limitations

This study's findings must be interpreted in light of its limitations. Participants were recruited through three major hospitals in Uganda, so the sample is biased towards patients who sought BMC. Since many PWE never access clinics or hospitals for their conditions, these cases are not likely to be representative of the general patient population in the country. A community sample would provide more accurate estimates on the frequencies of pluralistic versus unitary beliefs.⁶ This study is also limited by recall and other social biases inherent to surveys. Beliefs, demographics and care-seeking history were evaluated based on self-reported data from interviews, which may be subject to recall bias and variability in interpretation of questions. It is also possible that self-reported practices may not match actual behaviors, especially since interviews were conducted in a hospital environment. Therefore, social desirability bias may have influenced respondents' willingness to divulge certain information such as health-seeking behavior related to traditional healers. Finally, with this cross-sectional survey, we can only determine associations rather than any causal or temporal relationships between our variables. This study may have been enriched by including qualitative data to expand our scope of understanding beyond pre-existing hypotheses about beliefs and behavior drivers.

⁶ Over the last year, this survey has also been administered to a larger random sample of PWE and caregivers in a community-based study. This data is still being collected, but, in the near future, it will be possible to conduct similar analyses as done in this thesis on the larger sample to acquire more accurate frequency estimates.

5. Conclusions

Patient and caregiver beliefs about epilepsy etiology and their health-seeking behaviors were investigated as a first step towards exploring a possible basis for collaboration within Uganda's pluralistic health system. The findings from this study indicate that people with epilepsy and their caregivers hold multiple, and often simultaneous, understandings of the seizure etiology. These multiple and seemingly contradictory understandings of epilepsy are derived from patients' eclectic health care practices and also tend to determine their care-seeking behaviors. These results suggest reveal the importance of understanding sociocultural beliefs in mediating treatment bottlenecks for epilepsy care associated with medical pluralism. Thus, in order to adequately diagnose patients and link them to treatment, there needs to be more inclusive approach to health care delivery that respects pluralistic beliefs. Understanding the complex imbrications in beliefs, practices and health care systems related to epilepsy will be crucial for making progress towards the WHO's strategic plans for integrating traditional and complementary medicine and for addressing the mental health gap.

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8. Appendices

Appendix A. Demographic portion of the survey

Demographics

1. Date: _____
2. Who is the respondent?
 - Patient
 - Caregiver
3. Name of Patient: _____
4. If respondent is not patient. Name of Caregiver: _____
5. If respondent is not patient. What is the relationship of the caregiver to the patient?
 - Mother
 - Father
 - Sibling
 - Uncle
 - Aunt
 - Other (please specify): _____
6. Phone Number: _____
7. Patient Gender: Male ____ Female ____
8. Caregiver Gender: Male ____ Female ____
9. Age of Patient: _____ years

[Age for babies:
 <3 months = 0
 3- <6 months = 0.25
 6- <9 months = 0.5
 9- <12 months = 0.75
 12-24 months = 1 etc.]
10. If respondent is not patient. Age of Caregiver: _____ years

11. What is the highest educational level that you and the patient has achieved or are currently following?

What is your education level? (note the highest level completed)

- Primary 1-7 (specify grade_____)
- Secondary - O' Level (S.1-S.4) (specify grade_____)
- High School - A' Level (S.5-S.6) (specify grade_____)
- Higher Education
 - Vocational Training (Nursing, Teacher's College, Carpentry, Mechanics, Tailoring, etc)
 - 1 year program (completed_____)
 - 2 year program (completed_____)
 - 3 year program (completed_____)
 - University: diploma sought: _____
 - 2 year program - (completed_____)
 - 3 year program (completed_____)
 - 4 year program (completed_____)
 - 5 year program (completed_____)
 - 6 year program (completed_____)

What is the patient's education level? (note the highest level completed)

- Primary 1-7 (specify grade_____)
- Secondary - O' Level (S.1-S.4) (specify grade_____)
- High School - A' Level (S.5-S.6) (specify grade_____)
- Higher Education
 - Vocational Training (Nursing, Teacher's College, Carpentry, Mechanics, Tailoring, etc)
 - 1 year program (completed_____)
 - 2 year program (completed_____)
 - 3 year program (completed_____)
 - University: diploma sought: _____
 - 2 year program (completed_____)
 - 3 year program (completed_____)
 - 4 year program (completed_____)
 - 5 year program (completed_____)
 - 6 year program (completed_____)

12. Are you able to read and write in any language?

YES NO

13. Is the patient able to read and write in any language?

[For adults and children who are currently learning how to read and write answer: 'No']

YES NO

14. Where are you from? District _____ Town _____

15. What is your primary occupation?
- Unemployed [Currently looking for jobs, retiree's, students]
 - Home maker [Housewives]
 - Domestic helpers [Cleaners, housekeepers, watch guards]
 - Farmer [Herders, agriculture, pastoralist]
 - Self-employed / small-business [Small business owners like: shops, kiosks, food traders]
 - Government employee [Police officer, accountant, teachers, health care workers]
 - Non-government employee [Cooperation managers, NGO-staff]
 - Private sector employee [Company manager, employee]
16. What is the patient's primary occupation?
- Unemployed [Currently looking for jobs, retiree's, students]
 - Home maker [Housewives]
 - Domestic helpers [Cleaners, housekeepers, watch guards]
 - Farmer [Herders, agriculture, pastoralist]
 - Self-employed / small-business [Small business owners like: shops, kiosks, food traders]
 - Government employee [Police officer, accountant, teachers, health care workers]
 - Non-government employee [Cooperation managers, NGO-staff]
 - Private sector employee [Company manager, employee]
17. Are you native to Uganda? [In case of refusal to answer, ask whether the person was born in Uganda]
- Yes No
18. Do you live in an urban/suburban/rural area? (Please Circle One)
- Urban Suburban Rural
19. What is the average weekly income in your household?
- a. What is the primary source of income for your family?
 - b. Who is the primary breadwinner of the family?
20. What is the primary language your family speaks?
- English
 - Luganda
 - Lusoga
 - Swahili
 - Runyankole
 - Ateso
 - Other: _____

21. What is the primary religion/spiritual faith your family practices?

- Christian
- Muslim
- Animistic
- Other

22. In total how many people live in your household? _____

- a. How many people in the household are sick or need help? _____
- b. How many people in the household can provide assistance to the sick or those who need help?

23. How many times have you visited a clinic or hospital, or nurse / medical doctor in the past year?

24. Is there a person in the family that makes the medical decisions?

- Me
- Other
- If other: age _____
- If other: relationship to patient _____

Can the decision maker read? _____

What is the decision maker's education level? (note the highest level completed)

- Primary 1-7 (specify grade _____)
- Secondary - O' Level (S.1-S.4) (specify grade _____)
- High School - A' Level (S.5-S.6) (specify grade _____)
- Higher Education
 - Vocational Training (Nursing, Teacher's College, Carpentry, Mechanics, Tailoring, etc)
 - 1 year program (completed _____)
 - 2 year program (completed _____)
 - 3 year program (completed _____)
 - University: diploma sought: _____
 - 2 year program - (completed _____)
 - 3 year program (completed _____)
 - 4 year program (completed _____)
 - 5 year program (completed _____)
 - 6 year program (completed _____)

25. What is the decision maker's occupation?

- Unemployed [Currently looking for jobs, retiree's, students]
- Home maker [Housewives]
- Domestic helpers [Cleaners, housekeepers, watch guards]
- Farmer [Herders, agriculture, pastoralist]

- Self-employed / small-business [Small business owners like: shops, kiosks, food traders]
- Government employee [Police officer, accountant, teachers, health care workers]
- Non-government employee [Cooperation managers, NGO-staff]
- Private sector employee [Company manager, employee]

26. In your home, is there

Radio:	YES	NO
TV:	YES	NO
Phone:	YES	NO
Electricity	YES	NO
Access to Clean Water:	YES	NO

Appendix B. Complete bass barriers survey

CHARACTERIZATION.

"I'd like to ask you some questions about epilepsy. It will just take a few minutes."

Who in the household has epilepsy? _____

What is your relation to the person with epilepsy? _____

Are you the primary caregiver of the person with epilepsy? YES NO

How old is the person now? _____

How old were they when seizures began? _____

When did he/she/you first have a seizure? YEAR _____ MONTH _____

When did he/she/you first have the second seizure? YEAR _____ MONTH _____

In the beginning, how often did the seizures occur? _____ x per month

If they have continued, how often do they occur now? _____ x per month

Did the seizures start in the context of a high fever as a child? YES NO

Did the seizures start after an illness like meningitis/encephalitis? YES NO

Did the seizures start after a head injury? YES NO

Does anyone else in the family have epilepsy or seizures? YES NO

Do you/he/she lose consciousness during seizures? YES NO

How long do seizures last? LENGTH OF TIME _____ (seconds or minutes)

When it begins, is there isolated, repetitive movements of the mouth or hands? YES NO

Can you/he/she tell when there will be a seizure before the actual seizure happens? YES NO

if Yes, How _____

Are there triggers for the seizures, such as flashing lights, vigorous exercise, lack of sleep, strong smells, etc.? YES NO Unknown

Are you/he/she confused or tired after the seizure? YES NO If Yes, How long? _____

Does the person with seizures lag behind others in skill/learning ability? For children, lagging by 3 years or more, for adults, needing help in areas where independence is expected YES NO

What do you think causes the seizures? _____

Was a medical doctor ever consulted for the seizures? YES NO

If you have sought medical treatment for the epilepsy, how many months passed between the second seizure and seeing a medical doctor? _____

What health center would you go to for biomedical care for epilepsy? _____

How many kilometers is it from that HC and your home? _____ km

Is the person with epilepsy on anti-epileptic drugs (AEDs)?

If yes, how many AEDs? 1 2 3 4

If yes, how long have you/he/she been taking AEDs? _____ years _____ months

HELP SEEKING HISTORY.

"I'd like to talk to you a bit more about whose help was sought over time."

Let's discuss whose help was sought FIRST about the seizures?

Traditional Healer YES NO

If yes: HERBALIST SPIRITUALIST BOTH UNKNOWN

Pastor YES NO

Biomedical Care YES NO

If yes:

Village Health Clinic I ___ II ___ III ___ IV ___ don't know ___

Regional Hospital _____ National Hospital _____ (Mulago/Butabika)

Who was seen? Doctor _____ If yes, PSYCHIATRIST NEUROLOGIST OTHER DK

Medical Officer _____ Psychiatric Nurse _____ Other _____

Why was care sought here? _____

Did anyone in the family direct that treatment be sought there? _____

How much time was there between the second seizure and this treatment? ___ years ___ months

What was explained about the cause of seizures? _____

What was the suggested treatment? _____

Was this treatment done? YES NO

Did it work? YES NO

Was anyone else consulted during the same time period? YES NO (if yes, fill out next portion for that consultation).

Who was consulted NEXT about the seizures?

Traditional Healer YES NO

If yes: HERBALIST SPIRITUALIST BOTH UNKNOWN

Pastor YES NO

Biomedical Care YES NO

If yes:

Village Health Clinic I ___ II ___ III ___ IV ___ don't know ___

Regional Hospital _____ National Hospital _____ (Mulago/Butabika)

Who was seen? Doctor _____ If yes, PSYCHIATRIST NEUROLOGIST OTHER DK

Medical Officer _____ Psychiatric Nurse _____ Other _____

Why was care sought here? _____

Did anyone in the family direct that treatment be sought there? _____

How much time was there between the second seizure and this treatment? ___ years ___ months

What was explained about the cause of seizures? _____

What was the suggested treatment? _____

Was this treatment done? YES NO

Did it work? YES NO

Was anyone else consulted during the same time period? YES NO (if yes, fill out next portion for that consultation).

Who was consulted NEXT about the seizures?

Traditional Healer YES NO

If yes: HERBALIST SPIRITUALIST BOTH UNKNOWN

Pastor YES NO

Biomedical Care YES NO

If yes:

Village Health Clinic I ____ II ____ III ____ IV ____ don't know ____
Regional Hospital _____ National Hospital ____ (Mulago/Butabika)

Who was seen? Doctor _____ If yes, PSYCHIATRIST NEUROLOGIST OTHER DK
Medical Officer _____ Psychiatric Nurse _____ Other _____

Why was care sought here? _____

Did anyone in the family direct that treatment be sought there? _____

How much time was there between the second seizure and this treatment? ____ years ____ months

What was explained about the cause of seizures? _____

What was the suggested treatment? _____

Was this treatment done? YES NO

Did it work? YES NO

Was anyone else consulted during the same time period? YES NO (if yes, fill out next portion for that consultation).

Who was consulted NEXT about the seizures?

Traditional Healer YES NO

If yes: HERBALIST SPIRITUALIST BOTH UNKNOWN

Pastor YES NO

Biomedical Care YES NO

If yes:

Village Health Clinic I ____ II ____ III ____ IV ____ don't know ____
Regional Hospital _____ National Hospital ____ (Mulago/Butabika)

Who was seen? Doctor _____ If yes, PSYCHIATRIST NEUROLOGIST OTHER DK
Medical Officer _____ Psychiatric Nurse _____ Other _____

Why was care sought here? _____

Did anyone in the family direct that treatment be sought there? _____

How much time was there between the second seizure and this treatment? ____ years ____ months

What was explained about the cause of seizures? _____

What was the suggested treatment? _____

Was this treatment done? YES NO

Did it work? YES NO

Was anyone else consulted during the same time period? YES NO (if yes, fill out next portion for that consultation).

Reflecting on the help seeking history you just provided, how confident are you in the accuracy of the history?

1	2	3	4	5
Not at all confident	A little confident	Average confidence	Strongly confident	Extremely confident

BARRIERS.

“Now I’d like to ask you about what impacted the decision about biomedical care being sought for the person with epilepsy. You may find that you agree or disagree with the item as being true or false, but here we very specifically want to know TO WHAT EXTENT that item INFLUENCED THE DECISION about biomedical care being sought.”

Was biomedical care sought?

YES NO

For those who said YES, they did seek biomedical care: ***“Alright, so I’d like to know to what extent the following items made it difficult to get biomedical treatment”: (may repeat)***

For those who said NO, they did not seek biomedical care: ***“Alright, so I’d like to know to what extent the following items influenced your decision NOT to seek biomedical care”: (may repeat)***

Having to take time away from work

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

I did not think that the symptoms were bad enough to go to the doctor

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Others in my family are sick or need help

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Few family members are able to take care of or help those that are sick

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

I did not want people to know that I was having seizures

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Doctors cost too much

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Cost of doctor's tests

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Cost of medicine

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

They do not give enough epilepsy drugs and the medicine runs out

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Drug medicine does not work to treat epilepsy

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Even if I receive medicine, some of it is fake

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Travel distance to the doctor is far

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Cost of travel to the doctor or health center

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

With doctor, you cannot pay slowly over time for medicine

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

With doctor, you cannot pay with goods, only money, for medicine

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Worry that medicine will make things worse

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

I was directed by the person in my family who makes decisions about health care

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

(Who is that ? _____ Age? _____)***Friends and peers shared their beliefs about treatment with me.***

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

(Who is that ? _____ Age? _____)***I do not believe that medical doctors can heal epilepsy***

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

The belief that even if medical doctors can stop the seizures, they cannot reverse the damage that is already there

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Doctors do not spend enough time with patients to understand

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Doctors do not have time to see me

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

Doctors do not explain the illness well

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

I went to a traditional healer instead

1	2	3	4	5
Did not matter	Mattered a little	Neutral	Mattered	Mattered a lot

CAUSES.

"Now I'd like to talk to you a bit about what might cause these seizures.

Use this guide [hand participant laminated copy of scale] to help you answer the following questions. Answer '1' if you really strongly disagree with the statement [point to 1 on the laminated scale], '2' if you somewhat disagree with the statement [point to 2 on the laminated scale], '3' if you somewhat agree with the statement [point to 3 on the laminated scale], or '4' if you really strongly agree with the statement [point to 4 on the laminated scale]."

Please indicate the extent to which you agree or disagree that the following things can cause seizures?:

Brain illness

1-----2-----3-----4
Strongly Disagree Disagree Agree Strongly Agree

Troubled Home

1-----2-----3-----4
Strongly Disagree Disagree Agree Strongly Agree

High Fever

1-----2-----3-----4
Strongly Disagree Disagree Agree Strongly Agree

Witchcraft or spells

1-----2-----3-----4
Strongly Disagree Disagree Agree Strongly Agree

Spirits possessing the person

1-----2-----3-----4
Strongly Disagree Disagree Agree Strongly Agree

Bad medication

1-----2-----3-----4
Strongly Disagree Disagree Agree Strongly Agree

Malaria

1-----2-----3-----4
 Strongly Disagree Disagree Agree Strongly Agree

Sun heating the brain

1-----2-----3-----4
 Strongly Disagree Disagree Agree Strongly Agree

Injury at Birth (like long labor)

1-----2-----3-----4
 Strongly Disagree Disagree Agree Strongly Agree

Punishment by God

1-----2-----3-----4
 Strongly Disagree Disagree Agree Strongly Agree

The blood of the person is abnormal

1-----2-----3-----4
 Strongly Disagree Disagree Agree Strongly Agree

The mother was disrespectful or quarreled during pregnancy

1-----2-----3-----4
 Strongly Disagree Disagree Agree Strongly Agree

Trouble with ancestors

1-----2-----3-----4
 Strongly Disagree Disagree Agree Strongly Agree

Injury to the brain

1-----2-----3-----4
 Strongly Disagree Disagree Agree Strongly Agree

Inherited (passed down to children)

1-----2-----3-----4
 Strongly Disagree Disagree Agree Strongly Agree