Epilepsy & Behavior xxx (xxxx) xxx

Contents lists available at ScienceDirect

Epilepsy & Behavior

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

Sociocultural determinants and patterns of healthcare utilization for epilepsy care in Uganda

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ARTICLE INFO

Article history:
Received 13 February 2020
Revised 23 June 2020
Accepted 28 June 2020
Available online xxxx

Keywords:
Healthcare seeking
Determinants
Epilepsy
Uganda
Culture

ABSTRACT

Objective: Epilepsy is a global public health concern, with the majority of cases occurring in lower- and middle-income countries where the treatment gap remains formidable. In this study, we simultaneously explore how beliefs about epilepsy causation, perceived barriers to care, seizure disorder characteristics, and demographics influence the initial choice of healthcare for epilepsy and its impact on attaining biomedical care (BMC).
Methods: This study utilized the baseline sample (n = 626) from a prospective cohort study of people with epilepsy (PWE) attending three public hospitals in Uganda (Mulago National Referral Hospital, Butabika National Referral Mental Hospital, and Mbarara Regional Referral Hospital) for epilepsy care. Patient and household demographics, clinical seizure disorder characteristics, and sociocultural questionnaires were administered. Logistic regression and principal component analyses (PCA) were conducted to examine associations with the choice of primary seizure treatment.
Results: The sample was 49% female, and 24% lived in rural settings. A biomedical health facility was the first point of care for 355 (56.7%) participants, while 229 (36.6%) first sought care from a traditional healer and 42 (6.7%) from a pastoral healer. Preliminary inspection of candidate predictors using relaxed criteria for significance ($p < 0.20$) identified several factors potentially associated with a greater odds of seeking BMC first. Demographic predictors included older caredriver (decision-maker for the participant) age (odds ratio [OR]: 1.01, 95% confidence interval [CI]: [0.99, 1.02], p-value: 0.09), greater caredriver education level (OR = 1.21, 95% CI: [1.07, 1.37], p-value = 0.003), and lower ratio of sick to healthy family members (OR = 0.77 [0.56, 1.05], P = 0.097). For clinical predictors, none of the proposed predictors associated significantly with seeking BMC first. Self-report causation predictors associated with a greater odds of seeking BMC first included higher belief in *biological causes* of epilepsy (OR = 1.31 [0.92, 1.88], P = 0.133) and lower belief in *socio-spiritual causes* of epilepsy

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https://doi.org/10.1016/j.yebeh.2020.107304
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Please cite this article as: D.C. Koltai, T.W. Dunn, P.J. Smith, et al., Sociocultural determinants and patterns of healthcare utilization for epilepsy care in Uganda, Epilepsy & Behavior, https://doi.org/10.1016/j.yebeh.2020.107304

(OR = 0.68 [0.56, 0.84], P < 0.001). In the multivariate model, only higher caredriver education (OR = 1.19 [1.04, 1.36], P = 0.009) and lower belief in *socio-spiritual causes* of epilepsy (OR = 0.69 [0.56, 0.86], P < 0.01) remained as predictors of seeking BMC first. Additionally, PCA revealed a pattern which included high income with low beliefs in nonbiological causes of epilepsy as being associated with seeking BMC first (OR = 1.32 [1.12, 1.55], p = 0.001). Despite reaching some form of care faster, individuals seeking care from traditional or pastoral healers experienced a significant delay to eventual BMC (P < 0.001), with an average delay of more than two years (traditional healer: 2.53 years [1.98, 3.24]; pastoral care: 2.18 [1.21, 3.91]).

Conclusions: Coupled with low economic and educational status, belief in spiritual causation of epilepsy is a dominant determinant of opting for traditional or pastoral healing over BMC, regardless of concurrent belief in biological etiologies. There is a prolonged delay to eventual BMC for PWE who begin their treatment seeking with nonallopathic providers, and although nonallopathic healers provide PWE with benefits not provided by BMC, this notable delay likely prevents earlier administration of evidence-based care with known efficacy. Based on these findings, initiatives to increase public awareness of neurobiological causes of epilepsy and effectiveness of biomedical drug treatments may be effective in preventing delays to care, as would programs designed to facilitate cooperation and referral among traditional, faith-based, and biomedical providers.

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

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1. Introduction

Epilepsy is one of the most common chronic neurological disorders worldwide, affecting almost 69 million people [1]. Unfortunately, a majority of cases with epilepsy occur among those living in lower- and middle-income countries (LMICs), resulting in a massive epilepsy treatment gap (TG) [2], defined as the proportion of people with epilepsy (PWE) who are not receiving biomedical treatment [3]. In Sub-Saharan Africa (SSA), the epilepsy TG is particularly daunting, estimated to be as high as 95% in some regions [4]. Aggravated morbidity and mortality have been demonstrated across numerous reports, including the 2010 and 2016 Global Burden of Disease studies [5–9]. Disability weights for untreated and severe epilepsy are among the highest and are similar to other chronic and severe diseases (e.g., severe stroke, end-stage renal disease, cancer) [8]. But unlike many diseases, epilepsy can be remarkably responsive to treatment.

Biomedical treatment is highly effective in improving epilepsy outcomes: 60–70% of patients experience a substantial reduction in seizures with antiepileptic drug (AED) intervention, and neurostimulation and surgical options may be considered for patients with drug-resistant epilepsy [10]. Without adequate treatment, PWE are at heightened risk for poorer quality of life, cognitive delay, seizure-related injury, and death [11–13]. Thus, there is a pressing need to identify the relevant factors responsible for the TG to create targeted interventions to address the most pertinent challenges.

Those working in epilepsy care in SSA have recognized the complexity of the overwhelming number of barriers impeding PWE from reaching biomedical care (BMC). These include inadequate medical supplies, costs of AEDs, lack of specialized healthcare workers, limited access to health facilities, stigma, cultural beliefs about seizure causation, and use of traditional medicine [3,14]. Deeply personal and culturally rooted traditional beliefs warrant careful attention.

1.1. Traditional beliefs and healers

Many people in SSA harbor nonbiomedical, spiritual explanations for the origin and nature of epilepsy. The condition is often thought to be caused by active interventions of human (witch or sorcerer), nonhuman (ghost, an ancestor, an evil spirit), or supernatural agents (a deity, powerful being, or the devil) [15]. The belief that epilepsy is caused by witchcraft, evil spirits, or demonic possession can result in fear, shame, and excessive stigma [15]. The stigma and social isolation associated with these beliefs may impact the way patients interact with healthcare [16] and contribute to the huge TG [2,17].

Traditional healers are logically sought out by people with spiritual and supernatural beliefs, as the healers are regarded as bridging the visible and spiritual worlds, serving as mediators to bring sick people back into harmony with the revered ancestors and spirits [18,19]. In Uganda, there is also no clear referral system from one provider system to the next, and patients do not follow any standardized direction as to who (traditional or biomedical practitioner) provides primary or secondary care for epilepsy [20]. Therefore, it is not unusual for even the patients who start in biomedical hospitals to shift to traditional healers or to use both categories of providers at the same time, without collaboration between healthcare providers. However, many traditional healers will not sanction concurrent biomedical treatment [21].

1.2. Biomedical infrastructure

Another important dimension of the epilepsy TG is the underresourced biomedical infrastructure. The Ugandan Ministry of Health reports an estimated ratio of one traditional healer per 200 people, in contrast to one allopathic provider for every 20,000 people [22]. Specialty neurology care is even more scarce, with 11 neurologists practicing in all of Uganda despite a population approaching 41.5 million [23]. Unlike high-income settings where epilepsy is managed as a neurological disorder, in many resource-limited settings, the condition is also managed by mental health practitioners. Hence, with the paucity of neurologists in these settings, the vast majority of PWE are under the care of psychiatrists, medical and psychiatric clinical officers, nurses, general physicians, and nonmedical healthcare workers [24–26]. The lack of human resources and established clinics serving PWE may discourage PWE from seeking care and can lead to suboptimal care for those who do receive biomedical interventions. Limited human resources and clinic overcrowding often constrain clinical encounter times between BMC providers and patients, which can prevent adequate patient education. This in turn may preserve disease misconceptions and impact treatment compliance [26,27].

These challenges are augmented by the inadequate maintenance of AED supplies in Uganda, with clinics and hospital pharmacies often experiencing medication stockouts [21,26,27]. One study in Zambia found that even with good adherence to multiple AED regimens, patients presented with subtherapeutic blood AED levels, raising concerns about the quality of available medication as well [28]. These stockouts and quality concerns present further barriers to adherence for those who pursue BMC, potentially diminishing the effectiveness of AEDs and undermining trust in BMC [29].

1.3. Socioeconomic, education, and seizure disorder characteristics

Families with limited economic and practical resources face even more challenges to receiving BMC for epilepsy [30]. Many resources for epilepsy diagnosis and treatment are beyond the reach of most

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PWE in Uganda, such as costly electroencephalograms, magnetic resonance imaging, newer-generation AEDs, or surgery [14]. Many also remain underserved in relation to access to basic pharmaceutical services [31]. Further costs include those associated with distance of travel to the nearest health centres or pharmacies, as well as the lost work time [32,33]. Not only do people from more isolated and remote areas have further distances to traverse for care, but their communities also tend to have limited epilepsy health literacy [34]. In remote areas, limited access to media and other avenues of sensitization perpetuates misunderstanding of seizure symptomatology.

1.4. Study aims

To our knowledge, no studies to date have simultaneously included examination of beliefs about epilepsy causation, barriers to care, seizure disorder characteristics, and demographics to elucidate patterns of determinants for the initial choice of healthcare for epilepsy symptomatology and the consequences of that choice to reaching BMC. We hypothesized that complex patterns of interrelated variables would be associated with healthcare choice.

2. Methods

2.1. Institutional Review Board

The Mulago National Referral Hospital (MNRH) Research Ethics Committee, Uganda National Council for Science and Technology, and Duke University School of Medicine Institutional Review Board approved this study.

2.2. Sample

The sample consisted of 626 participants who enrolled in the first wave of a prospective cohort study of PWE attending three public hospitals in Uganda for epilepsy care. Patients and families were recruited from the following public hospitals in Kampala and Mbarara: MNRH, Butabika National Referral Mental Hospital (BNRMH), and Mbarara Regional Referral Hospital (MRRH) as described in Fuller and colleagues in this issue [35].

2.3. Analysis variables and instruments

We collected data on patient and household demographics and clinical seizure characteristics. In addition, we included data for the age and education of the person in the household who made decisions about healthcare, referred to as the "caredriver". Additionally, we added a variable reflecting the ratio of people in the household needing assistance to the number of people in the household able to provide assistance ("assistance ratio"). Healthcare seeking history was ascertained, including time to seek treatment, first-treatment point (government health centre, general hospital, national referral hospital, private clinic, traditional healer, pastoral healer), next-treatment point, and so on, until current care. Participants' scores on sociocultural factors reflecting barriers experienced while seeking BMC derived from the *Barriers to Care Survey* [36] and included the following five barrier factors: logistic barriers, treatment efficacy barriers, influence of others, doctor's care barriers, and contextual barriers. Scores on sociocultural factors reflecting causal attribution for epilepsy derived from the following *Causes of Epilepsy Survey* [37] were also included: biological causes, bio-spiritual causes, and socio-spiritual causes. Scores were created using the average of all items loading onto each factor.

2.4. Data analysis

We used logistic regression to examine which demographic, clinical, and self-reported sociocultural factors (i.e., causes and barriers) were associated with the choice of seeking BMC as the first treatment for seizures. In order to reduce the set of predictors from a larger pool of candidate variables, we conducted preliminary, individual analyses to identify predictors using liberal criteria ($P < 0.20$) for inclusion in a multivariate model. We included all candidate predictors in our multivariate model and subsequently eliminated any variables showing no evidence of association with choice of treatment care ($P > 0.50$) in order to derive a final model. These approaches have been advocated for hypothesis-generating analyses as a means of controlling for type-I error without inadvertently omitting important predictors.

Candidate predictors were taken from demographic, clinical, and self-report domains. Demographic variables included patient and caredriver age, caredriver education, family income, distance from the nearest biomedical healthcare treatment centre, and the assistance ratio. Clinical measures included age of second seizure onset, loss of consciousness (LOC), and frequency of seizures at onset. Self-report measures considered were derived from our analyses of epilepsy causes (biological, bio-spiritual, socio-spiritual) and barriers to BMC (cost, treatment efficacy, influence, doctors, and context).

To eliminate collinearity and consider more global patterns across all predictors, we performed principal component analysis (PCA). For this analysis, we only included complete cases from the hospital sample ($n = 496$). For PCA, we used all predictors except the categorical *urban household* variable, as categorical variables cannot be modeled with standard PCA techniques [38], and binarizing over multiple categories can lead to spurious correlations [39]. The dichotomous variable LOC and all ordinal variables were included as if they were continuous [38]. Before PCA, we standardized each variable to have zero mean and unit variance. Six principal components (PCs) had eigenvalues greater than 1, which were also reflected in a knee in a scree plot (data not shown; [40,41]). The p-values for each PC loading were obtained via a z-test, using the standard error for each loading.

We regressed the binary indicator of care seeking behavior (1 for first seeking BMC, 0 for first seeking traditional or pastoral healers) onto the resulting PC variables to reveal associations between care

Table 1
Characteristics of survey respondents by first treatment sought.

	Biomedical care (n = 355)	Traditional healer (n = 229)	Pastoral healer (n = 42)
Demographics			
Participant age, mean (SD)	35.3 (16.9)	32.9 (16.2)	33.3 (14.0)
Caredriver age	40.6 (12.0)	45.9 (12.2)	42.6 (9.8)
Caredriver education[a]	2.9 (0.5)	2.6 (1.1)	2.6 (1.1)
Household income[b]	42.4 (76.0)	38.3 (58.9)	24.0 (29.7)
Distance to healthcare centre (km)	20.1 (29.4)	18.9 (26.4)	30.6 (48.6)
Assistance ratio	0.81 (0.6)	0.87 (0.5)	0.78 (0.4)
Female gender, n (%)	167 (49%)	126 (54%)	25 (54%)
Urban household			
Urban	78 (23%)	45 (20%)	13 (28%)
Suburban	183 (53%)	111 (48%)	51 (24%)
Rural	82 (24%)	74 (32%)	10 (21%)
Seizure characteristics			
Seizure frequency, #/week	12.9 (30.4)	14.5 (22.7)	12.0 (16.9)
Loss of consciousness, n (%)	316 (92%)	217 (95%)	44 (95%)
Sociocultural factors			
Biomedical cause, mean (SD)	3.2 (0.5)	3.1 (0.4)	3.3 (0.4)
Bio-spiritual cause	2.2 (0.6)	2.2 (0.6)	2.1 (0.6)
Socio-spiritual cause	2.6 (0.8)	2.8 (0.7)	2.8 (0.8)
Cost barrier	2.0 (0.7)	1.9 (0.7)	2.1 (0.8)
Treatment efficacy barrier	1.6 (0.5)	1.6 (0.5)	1.6 (0.6)
Influence barrier	1.3 (0.6)	1.2 (0.5)	1.4 (0.6)
Doctors barrier	1.5 (0.7)	1.4 (0.7)	1.6 (0.8)
Contextual barrier	1.6 (0.7)	1.6 (0.6)	1.8 (0.8)

[a] Average across 6 categorical levels, as described in Kaddumukasa et al. [36].
[b] Weekly income, in units of 1000 Ugandan shilling.

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seeking behavior and the patterns characterizing each PC. To aid visualization of the relationship between income, seizure onset age, beliefs in socio-spiritual causation, and predicted likelihood of seeking BMC first (Fig. 3), we rescaled the data by reconstructing the original set of predictors using each patient's scores on the first 6 significant PCs. We then normalized each of the plotted variables to the range [0, 1] to compensate for changes in absolute baseline of these variables in the reconstructed data.

Finally, in order to characterize the delay to BMC, we conducted an exploratory analysis of all candidate predictors and choice of first treatment (BMC, traditional healer, and pastoral care) as predictors of time to BMC. In order to account for nonlinearity in time to BMC, generalized estimating equations with a negative binomial distribution was used, assuming independence across participants. For all analyses in which predictor variables were missing data (<3%), Markov Chain Monte Carlo multiple imputation was used.

3. Results

3.1. Sample characteristics

Demographic variables, seizure characteristics, and endorsement of sociocultural factors of the sample are illustrated in Table 1.

3.2. Candidate predictors and multivariate prediction of BMC

Preliminary inspection of candidate predictors identified several factors associated with a greater odds of seeking BMC first, using a liberal preliminary inclusion criterion of $P < 0.20$. Demographic predictors included older caredriver age (odds ratio [OR] = 1.01 [0.99, 1.02], P = 0.092), greater caredriver education level (OR = 1.21 [1.07, 1.37], P = 0.003), and lower ratio of sick to healthy family members (OR = 0.77 [0.56, 1.05], P = 0.097). For clinical predictors, none of the proposed predictors associated significantly with seeking BMC first. The self-report causation predictors that were associated with a greater odds of seeking BMC first included greater belief in *biological causes* of epilepsy (OR = 1.31 [0.92, 1.88], P = 0.133) and less belief in *socio-spiritual causes* of epilepsy (OR = 0.68 [0.56, 0.84], $P < 0.001$). None of the self-reported *barriers* were associated with the differential odds of seeking BMC first.

Following our identification of candidate predictors, we examined a multivariate model examining factors independently associated with seeking BMC first ($P < 0.20$). Initial inspection revealed that decision-maker age was no longer associated with choice of seeking BMC first (P = 0.666), falling above our conservative inclusion threshold of ($P > 0.50$) and was therefore removed from the final model. Our final model therefore included caredriver education, the assistance ratio of sick to well family members, *socio-spiritual causes*, and *biological causes*. Results suggested that higher caredriver education (OR = 1.19 [1.04, 1.36], P = 0.009) and lower belief in *socio-spiritual causes* of epilepsy (OR = 0.69 [0.56, 0.86], $P < 0.01$) were the strongest predictors of seeking BMC first. Greater belief in *biological causes* of epilepsy also trended towards a greater odds of seeking BMC first (OR = 1.37 [0.93, 2.01], P = 0.084).

3.3. Analysis of profiles of care seeking

3.3.1. Principal component analysis of predictors

While our regression analysis identified significant associations between BMC seeking behavior and caredriver education and beliefs in *socio-spiritual causes* of epilepsy, we hypothesized that analysis of specific patterns of covariation across the complete dataset could reveal relationships otherwise hidden in the data. In addition, when we assessed the collinearity of predictors included in the multivariate model using the variance inflation factor (VIF), we found high collinearity across the cause variables in the dataset, with VIFs ranging from 11.8 to 21.7.

To eliminate collinearity and consider more global patterns across all predictors, we performed PCA. Principal component analysis uses all predictors to find a new set of perfectly uncorrelated factors that summarize salient patterns of covariance in the data. From the 18 PCs, we separated meaningful sources of covariation from underlying noise using the Guttman–Kaiser criterion (eigenvalues greater than 1), revealing 6 significant PCs explaining 61.3% of the variance in the data.

The PC loadings revealed a diverse set of patterns captured by individual components (Fig. 1). Principal component 1 loaded primarily on each barrier predictor, thus collapsing the observed collinearity of

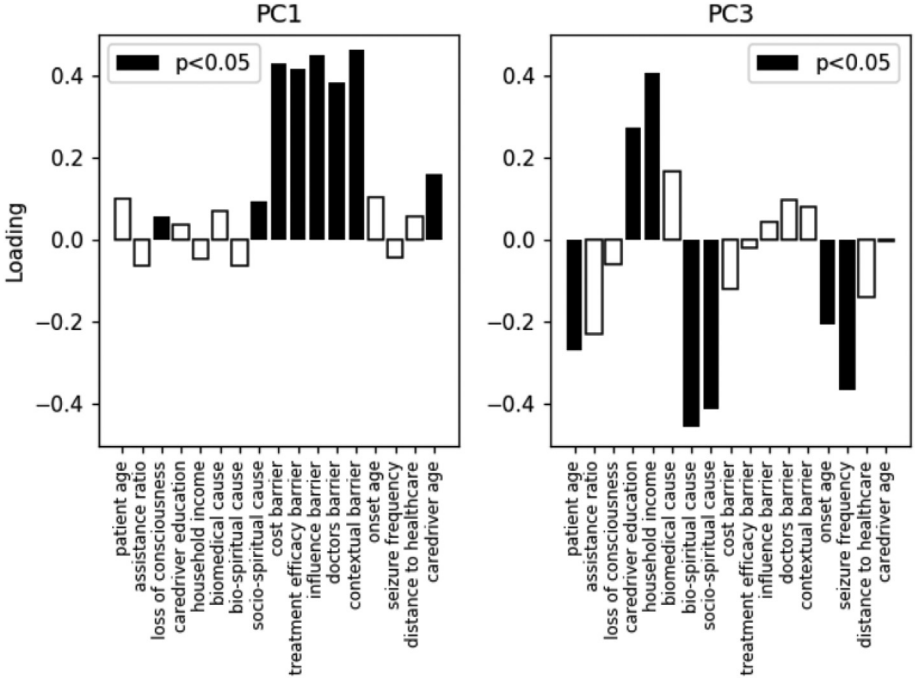

Fig. 1. The loadings of PC1 and PC3 reveal unique patterns of covariation across the sample.

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these predictors into a single variable. In contrast, PC3 summarized a pattern of anticorrelation between family income and caredriver education with many other predictors, including belief in nonbiological causes, age, and seizure onset age and frequency. The other four top PCs represented more complex patterns, with the exception of PC6, which captured an anticorrelation between LOC and most other variables. Fig. 1 illustrates variables of significance within PC1 and PC3.

3.3.2. Logistic regression model to BMC using PCs

We then fit an additional binary logistic regression model of BMC seeking behavior, using projections of the original predictors onto the first 6 PCs as independent variables. The model revealed significant associations only for PC3 (OR = 1.32 [1.12, 1.55], p = 0.001, Table 2).

Considering the coefficients on this component together with the signs of its loadings reveals that a pattern of high income with low beliefs in nonbiological causes of epilepsy predicts seeking BMC first (via PC3). Thus, while our initial inspection of candidate variables suggested no association between household income and BMC seeking behavior, our PCA regression suggests that income, in concert with specific patterns across other variables, is significant. Fig. 2 demonstrates how increases along the PC3 axis (which encompasses the anticorrelation of higher income coupled with lower belief in *socio-spiritual causes*) predict BMC, whereas the correlated barriers composing PC1 do not.

In order to illustrate the complexity of these patterns reflected in PC3, Fig. 3 plots the likelihood of choosing BMC along the dimensions of income, age of seizure onset, and endorsement of *socio-spiritual causes* of epilepsy. Those with higher income, younger age of onset, and less belief in *socio-spiritual causes* were more likely to choose BMC first.

3.4. Analysis of time to biomedical care

In order to examine how choice of first care influenced time to eventual BMC, we examined differences in time to BMC across the three primary treatment groups (BMC, traditional healer, and pastoral care), as well as examining differences in time to BMC after adjustment for the predictors in our multivariate model above. In contrast to our logistic models of first BMC, these exploratory analyses also revealed that greater frequency of seizures at onset was strongly associated with a lower time to ultimate BMC, regardless of the initial care sought (B = −0.36 [−0.54, −0.18], P < 0.001). Time to eventual BMC varied widely, with some participants seeking care immediately and others waiting years before finally receiving BMC (range: 0–30 years) with the vast majority of patients (75%) seeking BMC within the first six months after symptom onset. Examination of treatment group differences revealed that on average, those consulting pastoral and traditional healers reached care quicker (0.07 and 0.28 years, respectively) than those who went to BMC first (0.44 years). Despite reaching the initial form of care faster, those individuals seeking care from traditional or pastoral healers experienced a significant delay to eventual BMC (P < 0.001), with an average delay of more than two years (traditional healer: 2.53 years [1.98, 3.24]; pastoral care: 2.18 [1.21, 3.91]). These large group differences remained significant in adjusted analyses of all candidate predictors (P < 0.001), with BMC demonstrating the shortest time (0.42 years [0.32, 0.54]), followed by pastoral care (1.61 [0.84, 3.09]; Table 3). and traditional healers (2.42 [1.88, 3.13]).

Table 2
Binary logistic regression model of BMC seeking using principal components as predictors.

	OR (95% CI)	p-Value
PC1	1.00 (0.92, 1.10)	0.891
PC2	1.03 (0.91, 1.17)	0.591
PC3	1.32 (1.12, 1.55)	0.001
PC4	1.10 (0.93, 1.30)	0.266
PC5	1.12 (0.95, 1.34)	0.178
PC6	1.12 (0.93, 1.34)	0.229

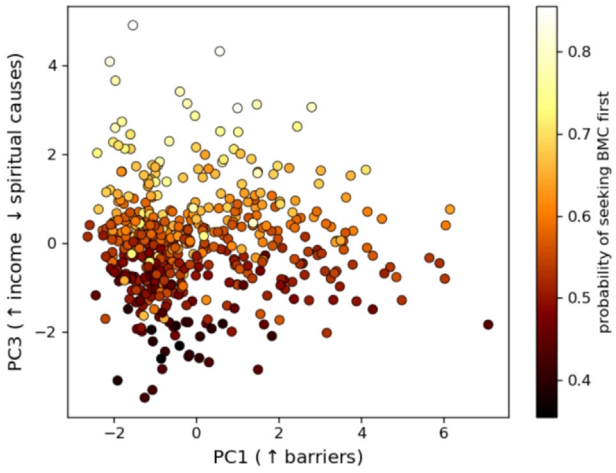

Fig. 2. Relationship between PC1 and PC3 to BMC being sought first.

4. Discussion

Despite the availability of biomedical treatments for epilepsy that ameliorate symptomatology, improve quality of life, and decrease morbidity and mortality, such treatment options are typically out of reach for the vast majority of PWE in SSA. In this setting, untreated epilepsy is widespread [4]. When coupled with community misconceptions and limited healthcare resources, the complex needs and morbidity seen in these individuals are compounded which can lead to poorer health outcomes including injuries, disability, or premature mortality [6,8,9,16,42].

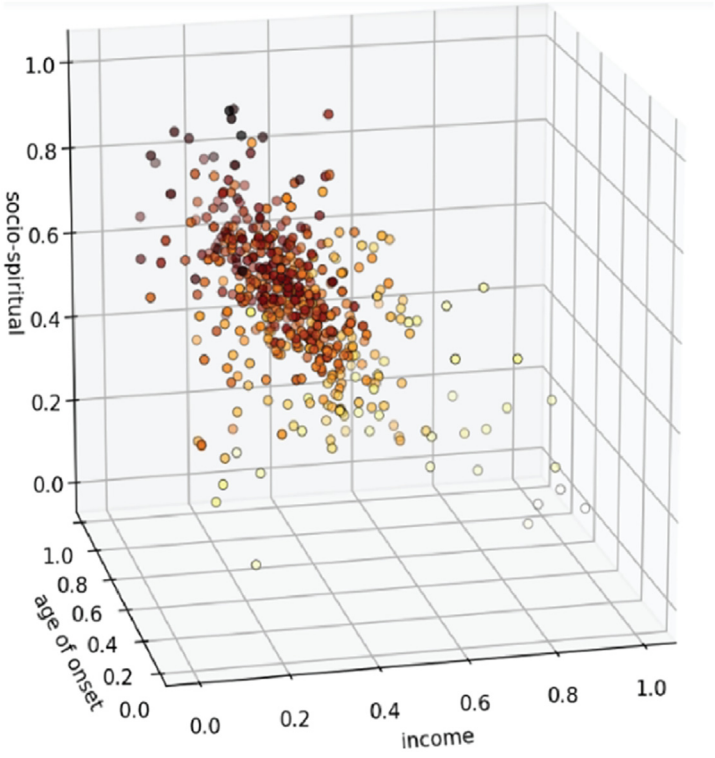

Fig. 3. Relationships between age of onset, income, and belief in socio-spiritual causation to BMC being sought first.

Please cite this article as: D.C. Koltai, T.W. Dunn, P.J. Smith, et al., Sociocultural determinants and patterns of healthcare utilization for epilepsy care in Uganda, Epilepsy & Behavior, https://doi.org/10.1016/j.yebeh.2020.107304

Table 3
Time to first choice care and eventual BMC.

	Care sought first			
	BMC (n = 352) Estimated mean (95% CI)	TH (n = 228) Estimated mean (95% CI)	Pastoral (n = 42) Estimated mean (95% CI)	
Time to first care in years	0.44 (0.34, 0.56)	0.28 (0.19, 0.40)	0.07 (0.02, 0.27)	a = 0.003 b = 0.004 c = 0.057
Time to first BMC in years	0.44 (0.34, 0.56)	2.53 (1.98, 3.24)	2.18 (1.21, 3.91)	a < 0.001 b < 0.001 c = 0.645

a = Group differences from negative binomial regression between BMC and traditional healers.
b = Group differences from negative binomial regression between BMC and pastoral care.
c = Group differences from negative binomial regression between TH and pastoral care.

Studies of the TG in SSA have elucidated many obstacles that PWE face in reaching BMC. Notable among these are medical infrastructure weaknesses and pervasive stigma [5,43]. Notwithstanding the impact of shortcomings in the health system and community perceptions of epilepsy, there exist personal and sociocultural drivers which also warranted exploration as potential dominant drivers of healthcare seeking patterns. This study builds on prior work through simultaneous consideration of the potential impact of personal, practical, cultural, and disease-based variables on initial healthcare choice and the consequences of those choices to subsequently reaching biomedical treatment for epilepsy.

One of our most noteworthy findings is that the average delay to BMC, if one first seeks treatment from a traditional or pastoral healer, is about 2 years. Such a serious delay to evidence-based BMC can have grave consequences, including prolonged suffering from stigma, isolation and discrimination, injury from falls and burns, neurocognitive deficits from untreated seizure activity, and increased risk for disability or premature death [8,11,42].

The sum of our findings about the determinants of care highlights that when considered together, demographic, illness, and sociocultural variables are powerful predictors of behavior. Our logistic and multivariate models suggested that of all candidate predictors, the education of the person making healthcare decisions in the household (the "caredriver") and lower endorsement of belief in socio-spiritual causes of epilepsy, such as witchcraft and spells, possession by spirits, and trouble with ancestors, were the strongest predictors of seeking BMC first. These socio-spiritual beliefs closely align with the etiologic belief systems of traditional medicine practitioners [21] who are naturally consulted by PWE to negotiate with the supernatural world [18]. As a result of traditional healers' considerable influence in the community, their teachings and practices greatly affect how epilepsy is treated, interpreted, and regarded in the community [44]. These findings are particularly important to consider in the context of developing countries like Uganda, where traditional medicine is appreciated as a key and sustainable source of care and knowledge on disease and illness [45,46], even among medical professionals and trainees [47].

To our knowledge, this is the first study to empirically identify beliefs about the spiritual causation of epilepsy to be dominant drivers of healthcare utilization and builds upon qualitative studies postulating that beliefs about epilepsy causality play a key role in treatment decisions [19,48]. One of the most elegant studies of BMC use and AED compliance among a defined sample of PWE in Kilifi, Kenya found that attitudes about BMC and religion were important determinants of healthcare seeking practices [30]. In that study, a predictor of not accessing BMC was identifying one's religion as traditional animistic. Our work expands upon this, showing that even among a sample that religiously identifies as Christian or Muslim (>99%; Christian = 516, Muslim = 108, other = 2), belief in spiritual causes of epilepsy are determinants of healthcare seeking. Thus, Christianity/Islam and traditional spiritual beliefs were not mutually exclusive.

We found these spiritually-rooted beliefs about epilepsy causation to be extremely powerful motivators of care choice; endorsing the possibility of spiritual causation has decisive impact. In Uganda, the frequency of pluralistic beliefs in biological and spiritual attributions for epilepsy is high [37]. Taken together, these studies illustrate that many embrace the possibility of witchcraft, possession, and ancestral or supernatural influences despite simultaneous beliefs in biological etiology or their religion and that this impacts care choice.

Because we suspected that there might be more structure in the relationship between predictors and BMC seeking behavior, we analyzed the data using PCA to elucidate meaningful groups, or patterns, of predictors and found that one of these was significantly related to the first choice of care being BMC. This PC was characterized by a pattern of anticorrelation between the caredriver's education and household income versus beliefs in nonbiological causes, age, seizure frequency, and age of seizure onset. Thus, BMC was most likely to be sought when seizure onset was in a younger child in a home with greater economic resources and a more educated decision-maker. Within this pattern, lower seizure frequency prompted care potentially because these households could have a lower threshold for seeking BMC when symptoms emerge, because symptomatology is seen as biological in etiology. This analysis allowed us to demonstrate the complexity of patterns of determinants for healthcare utilization choices. Careful review of the PCA reveals both informative covarying structure across some of these variables, as well as how disparate variable types converge to create a pattern of behavior.

The collinearity of the variables in this study is worthy of particular mention and warrant careful consideration when interventions to change healthcare seeking patterns are designed. It would be erroneous to design programs to address only *the most influential* variable, as once that is eliminated, it is possible that other variables that track in the same manner will remain as key determinants. Instead, the pattern of healthcare utilization must be considered as the multifaceted gestalt that it is and interventions should respect and cater to this complexity.

Further exploration of the impact of individual variables remains warranted nonetheless as identification of important subpatterns of healthcare seeking might be revealed. As an example, Rutebemberwa and colleagues skillfully demonstrated that the seemingly unorganized changes in healthcare type sought by PWE in Uganda persist until satisfactory treatment is secured [20]. In our sample, exploratory comparisons involving seizure frequency showed that compared with those with lower seizure frequency, people with greater seizure frequency at onset had a lower time to ultimate BMC regardless of the initial care sought, suggesting that people with greater seizure frequency rotate through options more quickly, until relief is found.

Please cite this article as: D.C. Koltai, T.W. Dunn, P.J. Smith, et al., Sociocultural determinants and patterns of healthcare utilization for epilepsy care in Uganda, Epilepsy & Behavior, https://doi.org/10.1016/j.yebeh.2020.107304

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Across our sample, people reached care with different speeds depending on which care system was consulted, possibly reflecting convenience in access. Those choosing pastoral care reached care the fastest, followed by traditional medicine consumers, and last by those who went to BMC. However, as noted previously, the average delay to eventual BMC for the first two groups was considerable, likely due in part to the reluctance of some nonallopathic healers to release the patient or allow concurrent biomedical treatment [21]. Additionally, advantages in increased encounter time afforded to PWE by nonallopathic healers [49], along with encouragement from healers themselves to continue treatments or rituals in their care system, may also delay decisions to change care to the biomedical setting. Finally, some PWE may not be able to switch care to biomedical providers because of the additional time and money required to do so.

A strength of this study is that we were able to examine how the initial choice in healthcare type impacted the eventual time to BMC because the sample was drawn from patients seeking epilepsy care in hospital clinics. However, this study is also limited by the exclusive inclusion of only PWE who eventually reached biomedical treatment. It is possible that the barriers to care were not predictive in this sample because it was a sample that overcame these and eventually did reach BMC. It is likely that if the same analysis was conducted among a sample of PWE drawn from a randomly selected community population, some of whom would not have sought BMC at all, the patterns of predictive variables and resulting factors would change. When the validation phase of our prevalence study is complete, we will pursue a better understanding of the determinants of healthcare seeking in this population as well.

5. Conclusion

Two paramount findings arose from this study which simultaneously considered how sociocultural beliefs, seizure disorder characteristics, and demographics together influence the initial choice of healthcare for epilepsy and its impact on attaining BMC. First, related sets of variables which become patterns of sociocultural determinants of healthcare utilization account for the type of care chosen for the treatment of epilepsy symptoms. Coupled with low economic and educational status, belief in the possibility of spiritual causation of epilepsy is a dominant determinant of choosing traditional or pastoral healing rather than BMC, regardless of identified religion or concurrent belief in biological etiologies. Second, when PWE who began their treatment with nonallopathic providers do not experience symptom resolution, there is a prolonged delay to eventual BMC, likely adding to the personal and global disability and risk burden of epilepsy. Interventions should be developed that reflect the complexity of the multifaceted patterns of healthcare seeking. Based on these findings, initiatives to increase public awareness of neurobiological causes and effectiveness of drug treatments would be expected to drive patients to BMC, as would programs designed to respect pluralistic belief systems and facilitate cooperation and referral among traditional, faith-based, and biomedical providers.

Funding sources

Funding sources are as follows: (1) UCB Societal Responsibility Fund (King Baudouin Foundation) Brussels, Belgium and (2) Duke University BASS Connections. Our funding sources were not involved in study design, data collection and interpretation, or decision to publish. One coauthor from UCB (DT) provided insights and comments on the manuscript.

Declaration of competing interest

None.

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