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TREATMENT SEEKING BEHAVIOR OF PEOPLE WITH EPILEPSY AT THE UNIVERSITY TEACHING HOSPITAL AND CHAINAMA HILLS HOSPITAL

1, *Ravi Paul, 2Melody Asukile, 3Thankian Kusanthan

¹Department of Psychiatry, School of Medicine, University of Zambia, Lusaka, Zambia

²University Teaching Hospital, Lusaka, Zambia

³Department of Gender Studies, School Humanities and Social Sciences, University of Zambia

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ABSTRACT

Epilepsy is a chronic neurological disorder characterized by recurrent, unprovoked seizures. It is the most common neurological disorder in Sub-Saharan Africa. It has been found that people in developing countries have low levels of access to quality healthcare and appropriate medication. Moreover, these people may seek several kinds of alternative treatments before using conventional medication. Zambia however does not have much information on the health seeking behavior of people with epilepsy. In a condition such as epilepsy, early presentation to a health center plays a vital role in the long term outcome of the condition. However, this research postulates that many people with epilepsy may for months or years use alternative treatment methods before going to a health center. Therefore, it is important to understand the extent of these beliefs and to investigate whether some of these people actually perceive a benefit from alternative treatment which may justify their delayed pursuit for conventional health care. It is also important to know the several types of medication a PWE may be taking that may affect the action of the prescribed drugs on the behavior of PWE bearing in mind that anti-epileptic drugs are associated with several drug interactions and toxicities.

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INTRODUCTION

Epilepsy is a chronic neurological disorder characterized by recurrent, unprovoked seizures. While there are many forms of epilepsy with varying seizure severity, they all represent the most common positive signs and symptoms of brain disturbance. Epilepsy is the most common neurological disorder in Sub-Saharan Africa. It is estimated that 80% of the total numbers of PWE (40 million) live in the developing world (Institute of medicine, Neurological and psychiatric disorders, 2001). The standard treatment for epilepsy is the regular use of one or more chemical substances called anti-epileptic or anti-convulsant drugs. Studies have shown that modern medical treatment of epilepsy with anti-convulsant drugs proves helpful in most people with epilepsy; with two thirds of patients becoming seizure free after treatment (Schmidt & Kramer; 2011). In developing countries, three quarters of people with epilepsy may not receive the treatment they require while about 9 out of 10 people with epilepsy in Africa go untreated (Ministry of Health, 2009).

*Corresponding author: Ravi Paul,

Department of Psychiatry, School of Medicine, University of Zambia,
Lusaka, Zambia.

Many people with epilepsy living in the developing world such as Sub-Saharan Africa have limited access to health care services. This leads them to seek alternative treatment such as traditional healing methods as they may be more readily available and affordable. Aside from that, epilepsy is associated to witchcraft and evil spirits. Due to this, many traditional cultures attribute the cause of illness to psychological conflicts or disturbed social relationships that create an imbalance and thus manifest themselves in physical or mental problems. It is then believed that correcting these imbalances would lead to healing from the illness (Hewson; 1998). However, there are few studies that give us insight into the treatment seeking behavior of people with epilepsy. A study in Nigeria by Danesi and Adetunji 1994 showed that majority of patients with epilepsy had used either traditional medicines, spiritual healing methods or both before accessing medical services. The study also showed that even after commencement of conventional methods of treatment, some patients continued to use alternative treatment methods; thus it was concluded that they perceived some continued benefit from these treatments. This study therefore aims at exploring the perceptions and treatment seeking behavior of PWE and their caregivers (CG) with regard to treatment of epilepsy by

alternative and/or conventional methods. It however also aims at determining the duration between the onset of symptoms and first presentation to a health center for PWE, exploring the reasons for presentation at a clinic or hospital after onset of symptoms in PWE and understanding the perceptions of PWE and their caregivers concerning treatment of epilepsy by alternative and/or conventional treatment methods.

MATERIALS AND METHODS

The study was conducted at the University Teaching Hospital Clinic 6 and Chainama Hills Hospital Clinic. The study tried to ensure that there was adequate representation from both low and high density residential areas. The residential area as well as occupation of the bread winner and level of education was used as a means of estimating socio-economic status. The sampling method used was sampling of typical cases. It involved selecting representative cases from among the people who attended the epilepsy clinics. The inclusion criteria of people diagnosed with epilepsy by a qualified health professional from 2006 to December 2011 were; people responsible for the care of PWE under 16 years of age or a person who cannot recall the details of the disease and should have stayed with the PWE for at least 1 year; should have been taking prescribed anti-epileptic drugs for at least 3 months and should attend a clinic in Lusaka. The exclusion criteria on the other hand involved people with co-existing mental or psychiatric disorders, people in whom there may be an alternative cause for seizures e.g. alcohol, drugs, other medical condition and informants who have not lived with the PWE for at least one year. A semi-structured questionnaire was administered through scheduled interviews to all participants. The questionnaire was administered either to the PWE or the care giver depending on the age of the patient and duration of condition. The questionnaire included open – ended and closed questions.

Ethics

Patients' information was treated with confidentiality and no form of personal identifiers was disclosed as confidentiality was maintained at all cost on the results obtained from the study. Assistance from the doctors, clinical officers and nurses in charge of the patients was provided as well as the cooperation of the patients.

RESULTS AND DISCUSSION

Results of the study revealed that majority of the participants do seek alternative treatment for several years before resorting to conventional medication. The study also demonstrated that knowledge on epilepsy as an illness still has misguided perceptions concerning its aetiology and classification. Other than that, factors such as level of education, area of residence and occupation play a role in determining perceptions and treatment seeking behavior. Epilepsy is a chronic neurological disorder characterized by recurrent, unprovoked seizures. During the study, it was found that most of the participants had had seizures for more than five years at the time of the interview. Majority however only sought for treatment to the hospital after experiencing symptoms for a year or more

despite the persistence and in some cases worsening of the condition (Figure 1). 78% of all the respondents had sought various forms of alternative treatments first before going to a health centre. Many (40%) admitted to having had sought alternative treatment for more than 2 years prior to visiting a health centre. The most frequent source of alternative medication was a traditional healer, followed by home remedies recommended by family and friends and prayers from a religious leader (Figure 2). According to the results as depicted on Figure 2, most of the participants had first either sought a traditional healer or used home remedies, or both. A few used prayers at home or at church, herbal medicine or no medicine at all. Only 20% of the respondents sought medical advice at the health centre first. Some respondents used a combination of more than one method initially.

Despite years of using alternative treatment, 60% of the respondents who used it said there was absolutely no improvement from the alternative treatment hence concluded that the alternative treatment was not helpful in the treatment of the epilepsy. However, 17.3% of the respondents reported slight reduction in seizure frequency and 2.7% said there was a noticeable improvement (Figure 3). It can be proposed that majority of people believed in the use of alternative treatment initially, but in hindsight, after the use of conventional medication, the alternative treatment had not been very helpful in the treatment of the condition. Majority of the respondents actually reported using hospital medicine exclusively once they started it, and not in combination with alternative methods of treatment¹. The study further showed that people of a lower socio-economic class, judged by the level of education of the caregiver, occupation of the bread winner and residence; were more likely to seek alternative treatment first, and would use this treatment for a longer period than those from a relatively higher class. People living in rural, semi-urban and high density urban areas were more likely to seek alternative treatment first, than the low density urban dwellers.

First Presentation to a Health Centre

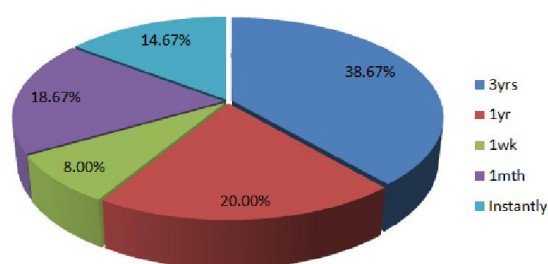


Figure 1. First hospital/clinic visit after onset of illness

In a study conducted in several health centers in Zambia by Birbeck (2004-2005), results showed that 80% of people with epilepsy usually receive treatment from traditional healers rather than conventional medicine and have limited access to standard medical care.

¹ However, it should also be noted that all the respondents interviewed were receiving anti-epilepsy drugs from either Chainama or UTH and as such would not want to exhibit any lack of confidence in the medication they were receiving.

T Method of Treatment

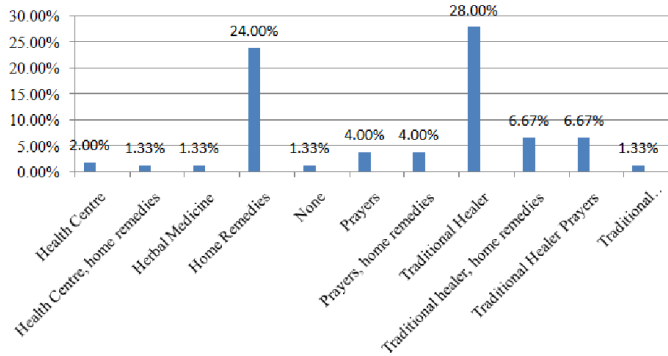


Figure 2. Alternative treatment

Improvement from first Alternative Treatment

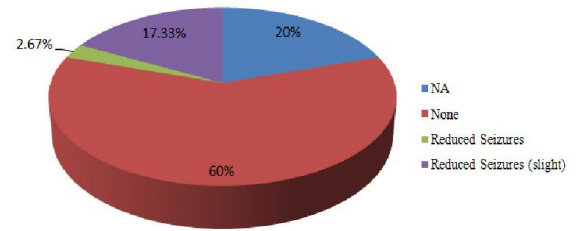
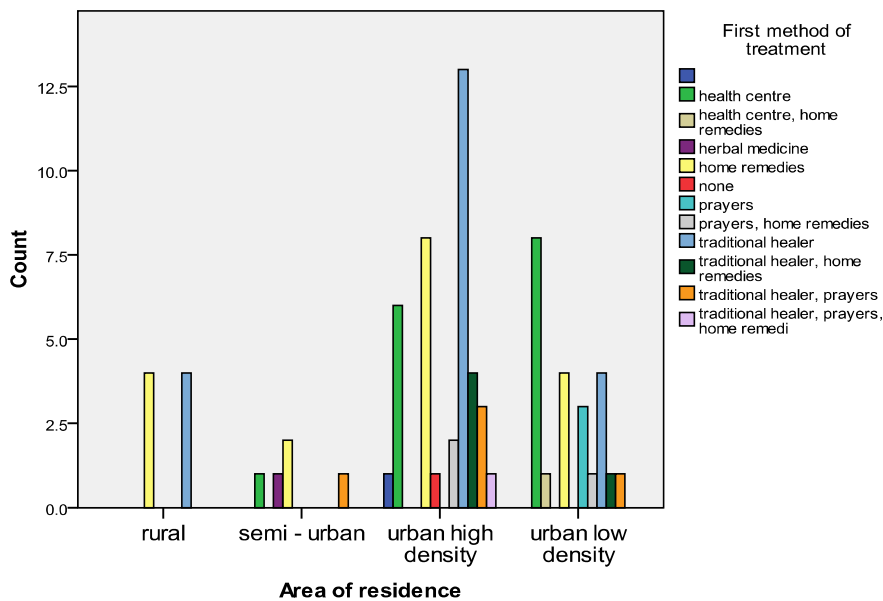


Figure 3. Efficiency of Alternative Treatment

The study also showed that PWE are misunderstood by their families and the community. Many people hold the belief that epilepsy is contagious and that seizures are a sign of demon possession.

Area of residence vs 1st treatment method



Occupation of breadwinner vs duration of 1st tx

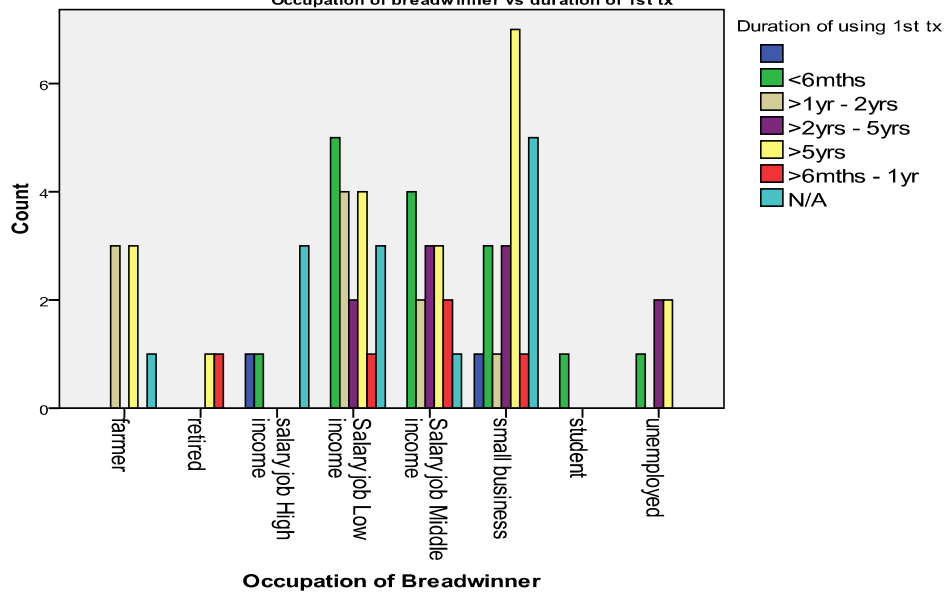


Figure 4i.

The Ministry of Health (2009) suggests that the immense stigma that PWE experience may discourage people from seeking treatment for symptoms and becoming identified with the disorder. However, despite the stigma associated with epilepsy, most people continued seeking alternative treatment until they finally realized that there was no improvement from the alternative treatment, the condition worsened or other symptoms such as psychotic symptoms and/or disorganized behavior set in. Nevertheless, the most common prompt for seeking medical treatment was when a person with epilepsy has a fit (seizure). Moreover, most people sought medical attention on the advice from family and friends. One respondent reported having gotten information about how the hospital can help from a health television show (Health Matters). Only one person however, reported being referred to a clinic by a traditional healer. No one else reported referrals to health centers by alternative medicine providers despite lack of improvement of the condition.

Perception of cause of epilepsy

Table 2. Perceived cause of illness by PWE and CG

	Perceived cause of Disease									Total
	Demons	Don't Know	Genetic	Head Injury	Illness During Childhood	Other	Witchcraft	Witchcraft, Demons		
CG	1	24	4	0	2	0	5	0		36
PWE	0	18	4	3	0	2	11	1		39
Total	1	42	8	3	2	2	16	1		75

Perception on required Investigations of epilepsy Diagnosis and Monitoring

Table 2. Knowledge statistics on what type of investigations can be conducted to diagnose and monitor epilepsy

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	CT brain	1	1.3	1.3	1.3
	CT brain, EEG	5	6.7	6.7	8.0
	CT brain, FBC	1	1.3	1.3	9.3
	CT brain, FBC, physical exam	1	1.3	1.3	10.7
	CT brain, heart tests	1	1.3	1.3	12.0
	CT brain, MRI, EEG	2	2.7	2.7	14.7
	don't know	42	56.0	56.0	70.7
	EEG	18	24.0	24.0	94.7
	FBC, CXR	1	1.3	1.3	96.0
	HIV, FBC	1	1.3	1.3	97.3
	none	1	1.3	1.3	98.7
	physical exam	1	1.3	1.3	100.0
	Total	75	100.0	100.0	

Perceived best treatment for epilepsy

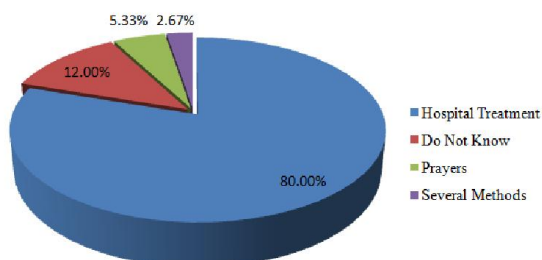


Figure 5. Best perceived method for the treatment of epilepsy

The study further took note of the perceptions of PWE and caregivers on epilepsy and its treatment. According to the Ministry of Health (2009), one of the biggest problems that people with epilepsy face is the stigma placed on them by the

general community. Studies have shown that the attitudes towards sufferers of epilepsy are often negative. It is postulated that some of the negative attitudes may arise from the fact that epilepsy is not considered a “normal medical condition” but a mental disorder, some even equating it to insanity. With reference to Table 1, equal numbers of respondents during the study believed that epilepsy was either a mental illness or a medical one. However, 25% of the respondents said they did not know how to classify it. This therefore shows that most people seeking medical care for epilepsy still do not understand what kind of illness it is. Concerning the cause of epilepsy, most of the respondents simply responded that epilepsy is “just an illness” and this was considered as they did not know what caused it. The second highest majority felt epilepsy is caused by witchcraft (17 respondents) and more PWE rather than CG’s attributed the disease to witchcraft.

Perception of when to seek hospital treatment (AED)

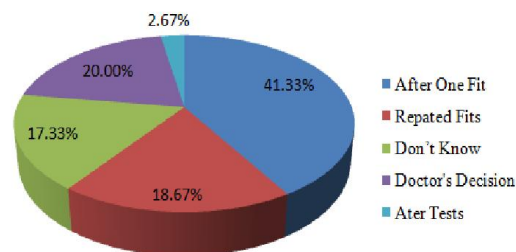


Figure 6. When to seek hospital treatment

There was little knowledge of epilepsy being caused by head injury, childhood brain pathology or as a genetic illness passed down in the family Table 2. Relating to treatment, majority of the respondents perceived improvements in the condition from conventional (hospital) medicines rather than alternative treatment methods.

Furthermore, 80% of respondents said they perceived hospital medicine as the best treatment for epilepsy, and that it (hospital medicine); rather than alternative treatment was helpful in treating the condition (Figure 5). These results were unlike a study carried out in rural northern Tanzania (Winkler and others, 2010) in which, 44.3% of interviewees believed that traditional healing methods could make an important contribution to the treatment of epilepsy. The fact that many respondents did initially seek help from traditional healers, does indicate that they may have held the same belief earlier, but later changed their minds.

According to the American Academy of Neurology (2010), it is a common belief in medical practice that treatment be started only when the potential for benefit from the treatment exceeds the potential for harm. In epilepsy, it is equally important to weigh the risks of treatment, as AEDs also carry various risks. It is also a challenge as not every person who presents with a first unprovoked seizure will have a recurrence. It is thus vital to ensure all possible causes are ruled out and corrected before initiating AED therapy. Hauser *et al* (1998) reported a seizure recurrence rate of 33% after a single seizure, 73% after a second seizure, and 76% after a third seizure in a population based study. Three clinical trials have shown that treatment after a first seizure reduces the risk of subsequent seizures (American Academy of Neurology, 2010).

Nevertheless, during the study, 41% of the respondents believed that hospital treatment should be initiated after the first seizure (fit), whereas 18.7% believed it should be after more than one seizure. The others either responded by saying they did not know or they would leave it up to the doctor to decide (Figure 6). Despite the majority saying that hospital treatment be initiated after the first seizure, greater than 50% of respondents sought treatment more than one year after the onset of seizures in spite of repeated seizure episodes during that period. Therefore, questions arise on the knowledge of the general community concerning the availability of drugs that can be used to treat epilepsy. The American Academy of Neurology (AAN) has generated an evidence-based guideline for evaluating an apparent unprovoked first seizure in adults. The most appropriate tools considered are electroencephalography (EEG), neuroimaging studies (CT or MRI), laboratory blood tests (blood glucose, full blood count, electrolyte levels), CSF examination (lumbar puncture) and toxicological screening.

However when asked during the study about what investigations were important in diagnosing and monitoring epilepsy, majority of the respondents said they did not know and denied any such tests being performed on them (PWE). Still, 25 people knew about the EEG, which they referred to as a "brain scan". Much fewer people suggested CT of the brain, MRI, ECG and Blood laboratory tests. Nonetheless, none of the participants knew or suggested on the CSF exam via lumbar puncture or Urine and blood toxicology. Some respondents, who said that epilepsy was a mental illness, said "it was impossible to carry out tests for such an illness" (Table 3). It is then important to note that most of the respondents had just attained some level of secondary education at the most and thus this could be a contributing factor to the low level of knowledge in this area.

With regards to how long treatment should be given after initiation, most people said they did not know while another group said they would rely on the doctor's advice on whether they should stop treatment or not. The study despite the successful attainment of data had some challenges. One of the challenges was as regards the collection of data which served as a challenge as it became very tiring in the course of time thus making it difficult to ask the questions thoroughly. This further contributed to the challenge of finding time to collect data during full time academic activities. Additionally, the window of opportunity for data collection was very short as participants were interviewed during the clinic session which was about 2.5 hours long.

Aside from that, the questionnaire was designed in English, but most participants could only speak Bemba or Nyanja. This brought in the issue of language barriers as some questions may have been distorted during attempts to translate. Lastly, very few of the participants recruited in the study had undergone any investigations for their seizure disorders. So it was difficult to know whether other causes of seizures had been ruled out. However, there is need to continue educating the community on epilepsy, what kind of illness it is, the availability of treatment that could render a person seizure free and the importance of seeking medical care early to avoid complications. It is also recommended that there is need to encourage caregivers to allow children with epilepsy to go to school and pursue their ambitions just like anyone else. This however can be possible if PWE and their caregivers receive adequate information from the hospital concerning epilepsy, its aetiology, management and when treatment should be started and stopped. Lastly, the health system should consider collaborating with traditional healers to assess how they can work together in the management of epilepsy.

Conclusion

In this study, most people attending epilepsy clinics at UTH and Chainama sought alternative treatment first before coming to the hospital. And this treatment sought for years before prompts such as worsening condition, lack of improvement or additional symptoms; would compel them to seek medical advice. However, once commenced on conventional anti-epileptic drugs, many neglect alternative treatment methods of epilepsy and rely exclusively on the medicines provided by the hospital. Therefore there was little knowledge on the investigations needed in Epilepsy, but despite this an overwhelming majority perceived conventional (hospital) medication to be the best treatment for epilepsy.

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