VOLUME 41, NUMBER 4
April 2024

ISSN 0189 - 160X

WAJM

WEST AFRICAN JOURNAL OF MEDICINE

ORIGINALITY AND EXCELLENCE IN MEDICINE AND SURGERY

OFFICIAL PUBLICATION OF
THE WEST AFRICAN COLLEGE OF PHYSICIANS *AND*
WEST AFRICAN COLLEGE OF SURGEONS

www.wajmed.org

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ORIGINAL ARTICLE

Has Treatment Seeking Behaviour Changed in People Living with Epilepsy? Experience of People Living with Epilepsy Attending Adult Neurology Clinics in Enugu

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ABSTRACT

BACKGROUND: Over the years efforts has been made through public health education to change the knowledge, attitude and practice of epilepsy and seizures among the populace in Nigeria. One surrogate method of reviewing the impact of these educational interventions include changes in treatment seeking behavior of People Living With Epilepsy and the reasons for their choices of treatment.

METHODS: This was a cross-sectional descriptive study. Data were collected from People Living With Epilepsy attending the medical outpatient clinics in two tertiary hospitals in Enugu, Enugu State southeast Nigeria.

RESULTS: A total 276 people living with epilepsy were recruited with a mean age of 30.1 years and a median age of 25 years. After the onset of epilepsy, 76(27.5%) and 70(25.4%) visited general hospitals and teaching hospitals respectively, while prayer houses and traditional healing centers were first visited by 54(19.6%) and 40(14.5%) respectively. As a second choice of care 9(3.3%) and 13(4.7%) visited prayer houses and traditional healing centers. Only 42(15.2%) selected their treatment center because they were confident of getting a cure however, this was highest for those that visited traditional healing centers 11(27.5%). The age of onset of epilepsy positively correlated with selecting orthodox treatment at the choice of care, while occupational status negatively correlated with selecting orthodox care at the same period.

CONCLUSIONS: Health care seeking behaviors among PLWE in Southeast Nigeria might have changed over the years as more people living with epilepsy were more likely to select orthodox treatment compared to non-orthodox means of treatment.

WAJM 2024; 41 (4): 397 - 405.

KEYWORDS: Epilepsy, Health seeking behaviour, Traditional healers, Prayer houses, Orthodox medicine, southeast Nigeria.

RÉSUMÉ

CONTEXTE: Au fil des ans, des efforts ont été déployés par le biais de l'éducation en santé publique pour changer les connaissances, les attitudes et les pratiques concernant l'épilepsie et les crises d'épilepsie parmi la population au Nigeria. Une méthode indirecte pour examiner l'impact de ces interventions éducatives comprend les changements dans le comportement de recherche de traitement des personnes vivant avec l'épilepsie et les raisons de leurs choix de traitement.

MÉTHODES: Il s'agit d'une étude descriptive transversale. Les données ont été collectées auprès de personnes vivant avec l'épilepsie fréquentant les cliniques de consultations externes médicales dans deux hôpitaux tertiaires à Enugu, dans l'État d'Enugu, au sud-est du Nigeria.

RÉSULTATS: Au total, 276 personnes vivant avec l'épilepsie ont été recrutées, avec un âge moyen de 30,1 ans et un âge médian de 25 ans. Après le début de l'épilepsie, 76 (27,5 %) et 70 (25,4 %) ont consulté respectivement des hôpitaux généraux et des hôpitaux universitaires, tandis que les lieux de prière et les centres de guérison traditionnelle ont été les premiers consultés par respectivement 54 (19,6 %) et 40 (14,5 %). Comme deuxième choix de soins, 9 (3,3 %) et 13 (4,7 %) ont consulté des lieux de prière et des centres de guérison traditionnelle. Seuls 42 (15,2 %) ont choisi leur centre de traitement parce qu'ils étaient confiants d'obtenir une guérison, cependant, ce taux était le plus élevé pour ceux qui ont consulté les centres de guérison traditionnelle (11 soit 27,5 %). L'âge de début de l'épilepsie était positivement corrélé avec la sélection d'un traitement orthodoxe comme choix de soins, tandis que le statut professionnel était négativement corrélé avec la sélection de soins orthodoxes au même moment.

CONCLUSIONS: Les comportements de recherche de soins parmi les personnes vivant avec l'épilepsie dans le sud-est du Nigeria ont peut-être changé au fil des ans, car davantage de personnes vivant avec l'épilepsie étaient plus susceptibles de choisir un traitement orthodoxe par rapport aux moyens de traitement non orthodoxes.

WAJM 2024; 41 (4): 397 - 405.

MOTS-CLÉS: Épilepsie, Comportement de recherche de soins, Guérisseurs traditionnels, Lieux de prière, Médecine orthodoxe, sud-est du Nigeria.

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INTRODUCTION

Epilepsy is a disease of antiquity which was described in ancient Babylon, Greece, in the Bible and other ancient texts.[1,2] Historically, epilepsy has been associated with spiritual causes because of the dramatic and cyclical nature of the disease. Even in modern times epilepsy is still shrouded in supernatural beliefs and myths which form part of culture of a given community.[3,4] Health and illness are defined, labeled, evaluated, and acted upon in the context of one's culture.[6] Cultural beliefs often exist at an unconscious level but may be modified through "lived experiences."[6,7] The explanatory model of the epileptic phenomenon thus varies widely because of cultural beliefs and may be influenced by adopted religious practices. These beliefs are also reflected in the names given to epilepsy in most languages.[4]

The fact that people do not engage recommended health behaviors is widely known among health workers.[8] This behavior is so common among people with mental health problems as well as in PLWE and has often been linked to sociocultural and religious explanatory models offered to these disorders.[9-12] Understanding health seeking behavior among PLWE may not follow a simple trajectory and goes beyond having adequate knowledge of epilepsy because of the complexity of influences that affects individual's behavior at a given time and place especially in the sub Saharan African context. Most available studies have emphasized 'end point' (utilisation) and few have sought to find the reasons for such choices (illness response, or health seeking behaviour). These studies demonstrate that the decision to engage with a particular medical channel is influenced by a variety of socio-economic variables, sex, age, social status and perceived quality of the service.[13-16] Furthermore, because epilepsy often starts at a younger age, the eventual choice of PLWE may be dependent of the caregivers and factors related to social support. Women with epilepsy (WWE) may be affected by peculiar cultural practices in their locality. They may need the permission of their husbands or male members of their family to seek help.[4,5] Individual religious convictions may also affect health seeking behavior in PLWE. For example, people may subscribe to spiritual causes of epilepsy but will rather visit churches than traditional healers because of their beliefs. There is growing acknowledgement that health care seeking behaviors and local knowledges need to be taken seriously in programs and interventions to promote health in a variety of contexts.[17,18]

In 2009 Sidig et al[19] reported that spiritual and socio-cultural beliefs influence the nature of treatment and care received by people with epilepsy. The experience of Sidig et al[19] is be similar across the continent where consistent poor knowledge and attitude and practice of epilepsy have consistently been reported.

Poor seizure control leads to higher economic and social burden of epilepsy.[20-22] Considering the burden of epilepsy and the cost of treating epilepsy in Nigeria, choice of treatment is very important as it may affect the overall cost of treatment and outcome. Furthermore, visiting hospitals or centers without qualified professional may lead to the same effect as visiting non-orthodox treatment centers.

Treatment seeking behavior among PLWE have been studied several studies.[10,23-25] In India, it was reported that more than 90% PLWE sought healthcare just after the onset of a seizure but the majority opted for allopathic medicine.[23] Factors that affected people's choice of care in that study were ignorance, faith in alternative means of treatments and constraint of money. In Zimbabwe factors that contributed to choice of care included financial constraints, distance and unavailability of anti-seizure medications in government hospitals and the attitude of health care workers.[12] Molla et al reported poor treatment-seeking behavior in 54.6% of rural Ethiopians.[26] The strongest determinant of poor treatment seeking behaviour was poor knowledge of epilepsy (adjusted odds ratio 3.21). In a study in southern Nigeria, Ogunrin et al estimated that out of 342 patients diagnosed with epilepsy, 61.4% sought initial attention at the trado-medical or spiritual homes while the rest (39.6%) sought initial medical attention at orthodox medical institutions. The reasons for their choices were not reported.[27] In Southeast Nigeria, Ojinnaka et al found that 90.2% of children that reported in the Children's neurology clinic had delayed presentation.[11] Use of complementary alternative medicine (39.1%) and lack of knowledge of epilepsy (25.6%) were the two comments reasons given.[11]

Over the years efforts has been made through public health education to change the knowledge, attitude and practice of epilepsy and seizures among the populace in Nigeria. These interventions range from health talks to pregnant women, to community-based outreaches as well as radio and other talk shows. One surrogate method of reviewing the impact of these educational interventions include changes in treatment seeking behavior of PLWE and the reasons for their choices of treatment.[27] Furthermore, studies on treatment seeking behavior will identify areas for further emphasis in public health educational programs. Therefore, this study was conducted to assess treatment choices of PLWE and the reasons for their choices.

MATERIALS AND METHODS

The cross-sectional descriptive study. Data were collected from PLWE attending the medical outpatient clinics in two tertiary hospitals in Enugu, Enugu State southeast Nigeria. The questionnaire was part of the epilepsy register developed by the neurology units

of both hospitals for an epilepsy database. Relevant parts of the register included socio demographic variables, basic characteristics and relevant current and past medical history. The questionnaire was presented with multiple choices answers and options for more answers. Questionnaires were filled in by the key investigator or a resident doctor. All patients gave their consent before recruitment into the data base. We excluded patients with possible psychogenic non-epileptic seizures and single epileptic seizures. Cases of incomplete data or illegible data were few and were excluded. All cases in the data base at the time of the study were analyzed for the index study.

Definition of terms.

A treatment center or center for care refers to the use of any center as the sole source of care. A prayer house is not regarded as a healing center if prayers were offered as part of routine religious service. Prayer houses refers to churches or mosques. Teaching hospital refers to any tertiary institution in Nigeria that offer epilepsy care including pediatric epilepsy care. General hospital, private hospital was defined based on current categorization by the state ministry of health. A traditional healing center was defined as any center that employs traditional healing methods (herbs, libations or religious sacrifices) the cure of epilepsy. Drug store refers to use of pharmacies, chemist shops or open market for self-treatment. All hospitals except teaching hospital were also referred to as Hospitals.

Statistical Methods. The SPSS version 22 (IBM Corporation, New York, USA) was used for database management and statistical analysis. Data were presented in tables. The statistical methods included Student's t-test for unpaired observations and chi-squared test for comparison of categorical data. Mean and median were calculated, and values were presented as graphs where applicable. In all, $p < 0.05$ was regarded as statistically significant. Conclusions were drawn at this level of significance at 95% confidence level.

RESULTS

Socio-demographic distribution of the patients

A total 276 PLWE were interviewed during the study period. The age and gender distribution are shown in table 1. The cohort was equally distributed by gender and age. Their mean age was 30.1 years with a median of 25 years. The peak age of the participants was 20-29 years. Most of the participants had post-secondary education and were students at the time of the study. Table 1.

Seizure characteristics and treatment seeking behaviours.

Table 2 shows some relevant seizure characteristics. Seizures characteristics obtained showed a mean-age of onset of 18 years (median 12 years with a range of 1-81 years). Epilepsy started about 5 years earlier in males than females 20.1 years in males versus 15.6 years in females. P=0.04. Generally, the peak age-of-onset was below 10 years. It took an average of about 1.2 years (1 year, 2 months) before the first ever hospital visit. This time interval ranged from 0 (same day) to 28 years.

Table 1: Age and socio-demographic characteristics of the study participants.

Gender	Male (%)	Female (%)	Total (%)	p-value
N (%)	149(54)	127(46)	276(100)	0.19
Age (years)				
Mean age (sd)	31.8(18.3)	28.2(15.1)	30.1(17)	0.08
Median age(range)	27(2-88)	24(1-88)	25(1-88)	
Age group				
< 20	33(22.1)	29(22.8)	62(22.5)	
20-29	49(32.9)	59(46.5)	108(39.1)	
30-39	31(20.8)	20(15.7)	51(18.5)	
40-49	11(7.4)	7(5.5)	18(6.5)	
⩾50	25(16.8)	12(9.4)	37(13.4)	0.12
Level of education				
Preschool age	4(2.7)	2(1.6)	6(2.2)	
No education	18(12.1)	5(3.9)	23(8.3)	
Primary	38(25.5)	23(18.1)	61(22.1)	
Secondary school	43(28.9)	46(36.2)	89(32.2)	
Post-secondary school	46(30.9)	51(40.2)	97(35.1)	0.04*
Occupation				
Students	40(26.8)	48(37.8)	88(31.9)	
Employed	36(22.5)	26(20.5)	62(22.5)	
Unemployed	16(10.7)	12(9.4)	28(10.1)	
Retired	13(8.7)	7(5.5)	20(7.2)	
Preschool	4(2.7)	2(1.6)	6(2.2)	
Not indicated	40(26.8)	32(25.2)	72(26.1)	

*Likelihood ratio.

Table 2: Seizure characteristics of the participants

Gender	Male	Female	Total	p-value
Age of onset				
Mean age (sd)	20.1(20.2)	15.6(17)	18.0(15.3)	0.04
Median age (range)	15(0-81)	12(0-80)	12(<1-81)	
Onset to first hospital visit (years)				
Mean age (sd)	0.9(3.4)	1.7(4.8)	1.2(4.1)	0.09
Median (range)	0(0-28)	0(0-21)	0(1-28)	
Age of Onset				
<10	60(40)	60(47.6)	120(43.5)	
10-19	35(23.3)	29(23)	64(23.2)	
20-29	19(12.7)	20(15.9)	39(14.1)	
30-39	11(7.3)	7(5.6)	18(6.5)	
⩾ 40	25(16.7)	10(7.9)	35(12.7)	0.21
Total	149(54)	127(46)	276(100)	

*Mann-Whitney U test.

Table 3: Distribution of Places Patients sought help.

Place Visited	1st Visit	2nd Visit	3rd Visit
General Hospital	76(27.5)	26(9.4)	1(0.4)
Teaching Hospital	70(25.4)	212(76.8)	266(96.4)
Prayer House	54(19.6)	9(3.3)	-
Traditional Medicine	40(14.5)	13(4.7)	5(1.8)
Private Hospital	32(11.6)	8(2.9)	-
Drug store	3(1.1)	2(0.7)	1(0.4)
Psychiatric hospital	1(0.4)	6(2.2)	3(1.1)

Table 4: Reasons given for visiting different treatment centers at different times

Risk factor	*Hospital	Prayer House	Traditional medicine	Drug store	Total
Table 4a. First Treatment center visited.					
No specific reason.	67(61.5)	27(50)	20(50)	2(66.7)	116(42)
Confident of cure.	21(19.3)	9(16.7)	11(27.5)	1(33.3)	42(15.2)
Proximity.	12(11)	6(11.1)	1(2.5)	-	19(6.9)
Spiritual beliefs.	-	6(11.1)	4(10)	-	10(3.6)
Ignorance of teaching. Hospital.	-	3(5.6)	2(5)	-	5(1.8)
Attitude of hospital staff.	4(3.7)	1(1.9)	1(2.5)	-	6(2.3)
Choice of care givers.	3(2.8)	1(1.9)	-	-	4(1.4)
Affordable Cost.	2(1.8)	-	1(2.5)	-	3(1.1)
Fear of Stigma.	-	1(1.9)	-	-	1(0.4)
	**109(39.5)	54(19.6)	40(14.5)	3(1.1)	206(74.6)
Table 4b. Second treatment center					
No specific reason	10(25)	5(55.6)	5(55.6)	2(100)	22(8)
Confident of cure	16(40)	3(33.3)	3(33.3)	-	22(8)
Proximity	6(11)	1(11.1)	1(7.7)	-	8(2.9)
Spiritual beliefs	3(7.5)	-	2(15.4)	-	5((1.8)
Attitude of hospital staff	4(3.7)	-	-	-	4(1.4)
Ignorance of teaching Hospital	2(5)	-	1(7.7)	-	3(1.1)
Cost	1(2.5)	-	1(7.7)	-	2(0.8)
Fear of Stigma	1(2.5)	-	-	-	1(0.4)
	**40(14.5)	9(3.3)	13(4.7)	2(0.7)	67(24.3)
Table 4c. Third treatment center.					
No specific reason		2(50)	5(100)	1(100)	8(2.9)
Confident of cure		1(25)	-	-	1(0.4)
Ignorance of teaching Hospital		1(25)	-	-	1(0.4)
		**4(1.4)	5(1.8)	1(0.4)	10(3.6)

*Psychiatric and Private Hospital.
**percentage of all patients surveyed.

Table 5: Reasons for selecting different types of hospitals as their first choice

	Teaching Hospital	Other Hospitals	Total
No specific reason.	65(92.9)	67(61.5)	132(73.7)
Confident of cure.	-	21(19.3)	21(11.7)
Proximity.	-	12(11)	12(6.7)
Attitude of hospital staff.	5(7.1)	4(3.7)	9(5)
Choice of care givers.	-	3(2.8)	3(1.7)
Affordable Cost.	-	2(1.8)	2(1.1)
	70(39.1)	109(60.9)	179(100)

Table 6: Correlates of selecting orthodox medicine (coded as 1) and non-orthodox medicine (coded as 0) while selecting 1st and 2nd places of care.

Variable	1st choice r(p-value)	2nd choice r(p-value)
*Age	0.06(0.32)	-0.08(0.17)
*Age of onset	**0.12(0.05)α**	-0.06(0.33)
**Gender (female 0, male 1)	-0.07(0.28)	0.05(0.44)
**Level of Education	-0.02(0.81)	-0.09(0.14)
**Occupational status	-0.12(0.08)	**-0.15(0.01)α**

** Pearson Correlation*
*** Spearman Correlation ion*
α Significant correlates

Choice of treatment

Table 3 shows the places where the PLWE visited for treatment after the onset of epilepsy. The first column shows that most patients 76(27.5%) were taken to the general hospital after the onset of epilepsy. This was closely followed by teaching hospitals 70(25.4%). Prayer houses and traditional healing centers (traditional healers) were first visited by 54(19.6%) and 40(14.5%) of the patients. The second column shows patients' second choices of care. The proportion that visited prayer houses and traditional healing centers dropped to 9(3.3%) and 13(4.7%) respectively. Six people (2.2%) were also seen in psychiatric hospitals. About 10 patients also visited a third center before coming to the teaching hospital, most of whom visited a traditional center 5(1.8%) and a psychiatric hospital 1(1.1%) (third column).

Table 4 (4a-4c) lists the reason for selecting specific places of care. Apart from those that came to the teaching hospital at the onset of epilepsy, most of the patients (116(42%)) did not give any specific reasons for their choice of care, while 42(15.2%) did so because there were confident of getting a cure. The place of care with the highest number of those who were confident of cure was traditional healers 11(27.5%). The reasons given for selecting different treatment centers is shown in table 4a-c. In choosing their first place of care, proximity 19(6.9%), spiritual beliefs 10(3.6%) and cost 2(0.8%) were not presented as strong reasons.

The second most important reason given by the patients was confident of cure 42(15.2%) which was highest in those who chose traditional healing centers 11(27%). Cost was only a consideration for a small minority of the patients. Proximity was the reason for choice of place of first care in 19(6.9%) while cost was the reason 3(1.1%).

When those who chose hospitals for their first choice of care were further

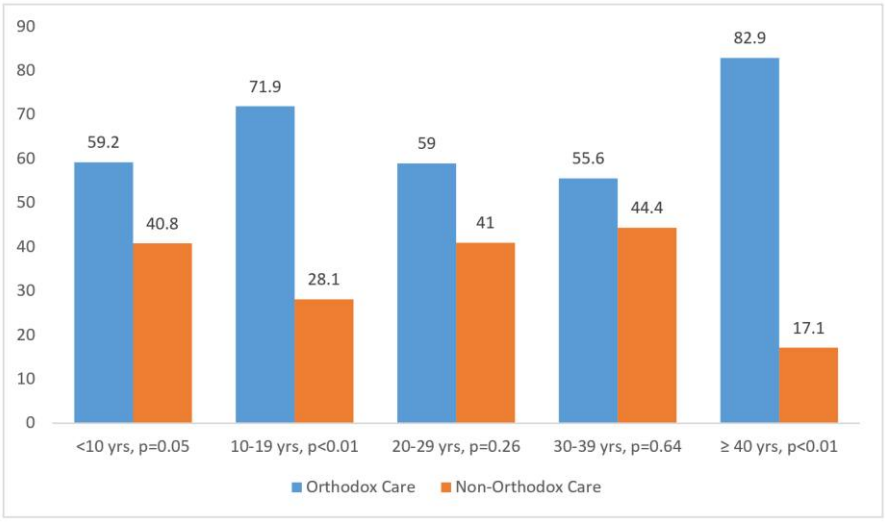

Figure 1: Distribution of choice of care by age of onset

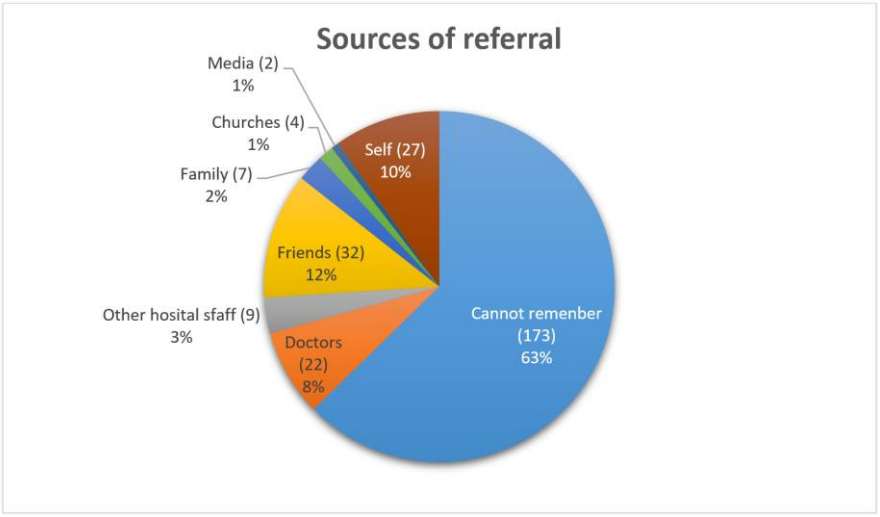

Figure 2: Sources of Referral

analyzed, the majority 132(73.7%), could not say the reason why they chose going to hospitals. Table 5. This proportion was even higher for those who came initially to the teaching hospital 65(92.9%). Proximity was the reason given by 12(6.7%) and cost was given as a reason for 2(1.1%) of the people interviewed. Table 5. Overall, there was no significant difference in selecting orthodox and non-orthodox care depending on the age-of-onset. (P=0.29). However, sub-group analysis showed that in cases where epilepsy started before the age of 20 years and patients with epilepsy onset 40 years and above were much more likely to choose orthodox treatment. Figure 1.

Age of onset of epilepsy positively correlated with selecting orthodox treatment while occupational status (working coded as 1 and not working coded as 0) negatively correlated with selecting orthodox care as second choice of care, Table 6.

Source of referral is shown in Figure 2. Although most people could not state who referred them to the teaching hospital 173(62.7%), however, many were referred by friends and well-wishers (11.6%) followed by self-referral. Only 8% were referred by doctors.

DISCUSSION

Epilepsy is a chronic neurological disease which is integrated into cultural and religious practices in different communities. Interpretations given to the epileptic phenomenon are therefore rooted in cultural beliefs which in turn affects treatment seeking behaviors. Therefore, the practice of epilepsy varies even within the same locality because of cultural and religious differences. Factors such as socio-economic status and religious persuasion influence the trajectory of care in PLWE. Over the years, there has been a big shift in socioeconomic status, availability of health infrastructure and increased awareness of epilepsy in many Nigerian communities.[29] It is possible that long held beliefs might have changed leading to changes in the practice of epilepsy in the community. Unlike many non-communicable diseases, epilepsy often starts before adulthood, thus choice of care is largely influenced by caregivers and members of the community because of its chronicity. Thus, the long held explanatory models of epilepsy in southeast Nigeria might have changed because of the increasing awareness of the disease religious orientations.

The mean age of patients in this study was 30.1±17 years with a median of 25 years. The median number of years taken to go to any hospital at all was less than 1 year. The distribution of the first place for treatment showed that most patients 64.9% were taken to different hospitals including teaching hospitals and 34.1% to unorthodox treatment centers. By the time patients were selecting a second place for treatment, 91.3% were treated in a hospital while 8% were seen in unorthodox centers. Similar reasons were given for selecting different treatment centers although their proportions varied. Irrespective of their choice of first treatment center, 42% said that they had no specific reason for such choices. Confident of getting a cure was the reason for choosing a hospital by 15% of the cohort (19.3% among those who went to hospitals 16.7% among those that sought help in prayer houses and 27.5% among those who used traditional medicine).

Proximity was the reason given by around 11% for selecting prayer houses while religious belief was reported as a reason in 11.1% of those that went to prayer houses and 10% of those that went to traditional centers. Overall, proximity and confident of cure were reasons given by 19(6.9%) and 42(15.2%) of the entire cohort.

Reasons for choosing second treatment centers, showed that more people visited hospitals because they were confident that they would get a cure. At the same time 55.6% of those that visited prayer houses and traditional healing centers had no specific reason. Proximity to treatment centers and belief in spiritual cure for epilepsy were reasons given by 11% in each case. The mean age and gender distribution of the participants in this study is similar to that reported in previous studies and reports[20,28,30]. The peak age of 20-29 years reflects the fact that study was conducted mainly in adult neurology clinics. The distribution of level of education shows that 35.1% had at least had a post-secondary school training. While this does not mean acquiring a university education it shows that many of the patients were preparing for the future in one trade or the other. This is a welcome development considering the high unemployment rates among PLWE. This is supported by the finding that 22.5% were employed and 31.9% were still in formation.

The mean, median and age range of onset of epilepsy reflects the impact of late onset epilepsy due to the growing prevalence of strokes and traumatic brain injuries on the epidemiology of epilepsy in the region. This is also seen in a small peak of age of onset after 39 years.[31,32]

It took an average of about 1.2 years before presenting to any hospital. This ranged from less than a year to 28 years. This contrasts with earlier studies that have shown that PLWE presented very late.[22,33] While late presentation is still a feature among PWE in southeast Nigeria, the index study may suggest a changing trend due to public health educational programs in the country. Another plausible explanation is that most of the patients came from urban areas where most hospitals are located. Nevertheless, 1.2 years still represents a late presentation for epilepsy considering that most of the hospital visited within this time frame may lack adequate expertise in the management of epilepsy.

The distribution of choices of treatment centers and the reasons for selecting them offers some insight into the health seeking behavior among the populace. At the onset most people came to hospital but did not have any specific reason for that. This suggests that PLWE and their care givers might have followed accepted trends in their local communities (community or cultural influence). Since most cases of new onset of epilepsy are often considered as an emergency by caregivers, they go to hospitals to find out the type of ailments after which they may choose another place. Surprisingly, fewer individuals made their choices based on cost and proximity thus supporting the preceding assumption.

Despite fewer people choosing prayer houses and healing homes as their choices of treatment when compared to hospitals, the proportion is still not acceptable. Delay in the diagnosis and treatment of epilepsy carries with it disastrous consequences especially in children. As with those that went to hospital many did not have any reason for choosing these centers suggesting that they might have gone there for emergency treatment. Nevertheless, a substantial proportion of those who visited healing homes were more confident they would get a cure. This may also be assumed to be related to both religious and cultural explanatory models of epilepsy. The reasons for selecting either a traditional healing center or a prayer house may also be different. Healing homes are often considered to practice rituals which are often contrary to christian beliefs of most people in south-south Nigeria. However, to what extent such beliefs might have affected their choices is difficult to say from the index study. Cost also did not play much role in the selection of both treatment centers at the beginning.

By the time PLWE are considering changing his/her place of care, it is expected that they should be making informed decisions. They must have asked questions and consulted family members. It is therefore a welcome development that at this stage most of our patients were going to hospitals. Nevertheless, about a quarter of them were still not convinced why they did so. Proximity was still a modest factor while spiritual beliefs was a factor in 7.5%. The role of proximity in health choices cannot be overemphasized and may indirectly be related to cost of transportation. At the point of making a second choice, the number of patients visiting prayer houses dropped by almost 6 times and most could not give any specific reason and those visiting traditional healing homes dropped by 3. The reason for these changes may be attributed to people getting informed about the efficacy of anti-epileptic drugs from their family and friends which may be also related to the pattern of referrals reported in the index study. Most people were referred to the teaching hospital by friends and family members. Universally, a large proportion of PLWE has been shown to visit non-orthodox treatment centers.[11,23,26,28]

Factors traditionally considered as key determinants in health seeking behavior in epilepsy such as religious beliefs, cost and proximity did not appear to be very important reasons in the study. Even factors such as stigma and attitude of hospital staff were not so important. While the dwindling role of these factors are welcome considering the cultural context of this study, more public health

education is needed not only to reinforce the good points gained but counter false teachings from traditional health practitioners.

Furthermore, in this study we noticed that people with earlier age of onset and later age of onset were more likely to chose orthodox treatment. Reasons for this may be related to income status. In younger people, the cost of treatment will be likely be borne by parents and family members while in older people are more likely to be working. These notwithstanding, it is outside the scope of the index study to elucidate the reason for these findings.

Some theories have been employed to explain health seeking behavior. These include the Health Belief Model , the theory of Reasoned Action and the Triandis' Theory of Behavior.[8] These theories are encumbered by the heterogeneity in disease types, severity of the disorder as well as patients and socioeconomic variables. In the case of epilepsy, years of public health education on radio and mass media must have affected the health seeking behavior of the populace. However, limitations exist between patients and the eventual action they would take, thus factors such as cost, distance, dependency, and beliefs often play overlapping roles in treatment seeking behavior. Thus, even when a patient has the right knowledge, these limitations may eventually affect the choice. Furthermore, attitudes and social norms determine intentions, which, in turn are presumed to determine behavior.[34,35]

The fact that people do not engage in recommended health behaviors is widely known among health workers.[36-39] In the index study, a small proportion of the respondents cited cost and distance as reasons for selecting their treatment for making their choices. One of the most likely reasons for this would include the urban setting of the study.

This index study not only attempted to find out the places selected for care but also reasons for such. Most available studies have emphasized 'end point' (utilization) and few have sought to find the reasons for such choices (illness response, or health seeking behavior).[11,12,23,25] End point reports often show the tendency for PLWE to visit more of traditional healers and unofficial medical channels rather than orthodox health centers. In mapping out the factors behind such choices other studies have reported factors that act as barriers and facilitators to health seeking behavior.[10] These barriers or determinants of pathway to care vary widely and are also dependent on geographical, social, economic, cultural, and organizational factors.[40]

Because of the diversity of factors affecting health seeking behavior in epilepsy it has been suggested that traditional and religious healers should be incorporated in the wholistic care of PLWE. Despite all the merits proffered for such an approach we think that it will lead to abuse and exploitation of PLWE. There is a large and growing sector of non-qualified practitioners including prayer houses, traditional healing homes and drug dispensers who traffic modern pharmaceuticals. Models that could be applied to other areas of medicine (example the use of traditional birth attendants) may not be suitable in epilepsy.

Limitations

Like all cross-sectional survey, this study has some inherent limitations. For, respondents were asked to recall events that happened years ago, it is possible that a lot of facts might have been forgotten. Many of the people interviewed started having epilepsy when they were < 10 years old, which might have been the reason why most could not recall who referred them and reasons and why they were referred. As earlier stated, health seeking behavior may be affected by several overlapping factors, hence the associations described may not necessarily be causal. Furthermore, the questionnaires were completed in the hospital which might affect the responses given by the participants. Despite these limitations, this study is the first in southeast Nigeria to explore, the health seeking behavior of PLWE in southeast Nigeria and possible limitations to care. It has provided a set of findings that could be considered as baseline for comparison with future studies and a reason for private health care providers to consider early and timely referrals for PLWE.

Conclusions. Health care seeking behaviors and local knowledges need to be taken seriously in programs and interventions to promote health in a variety of contexts.[17,18] Findings from the index study suggests that more emphasis should be paid on the merits and demerits of choosing treatment centers with qualified personnel. There is also the need to improve integration of private sector providers with public care for easy referrals.

Acknowledgement.

The authors acknowledge our patients who participated in the study as well as all the residents who volunteered during the study.

Funding

There was no external funding for this study.

Summary of findings

Over the decades, studies have shown that people living with epilepsy seek care primarily from unorthodox care givers. This has affected both the morbidity and mortality associated with epilepsy. We sought the explore the treatment seeking behaviour of adult patients seen in two tertiary hospitals in Enugu southeast Nigeria. Our study has shown that:

- The proportion visiting unorthodox healing centers has decreased compared to what was previously reported.
- After their first trial, most patients

will resort to orthodox care. However, there is still a strong belief that unorthodox care will provide cure for epilepsy.

REFERENCES

1. Gross RA. A brief history of epilepsy and its therapy in the Western Hemisphere. Epilepsy Res. 1992 Jul;12(2):65–74.
2. Khalil N, Benbadis S, Robertson D. Ceasing Antiquated Conceptions: A Telling of the Early and Evolving History of Epilepsy. Eur Neurol. 2020 Jul 27;83(3):341–4.
3. Ezeala-Adikaibe BA, Achor JU, Nwabueze AC, Agomoh AO, Chikani M, Ekenze OS, et al. Knowledge, attitude and practice of epilepsy among community residents in Enugu, South East Nigeria. Seizure. 2014 Nov 1;23(10):882–8.
4. World Health Organization. Epilepsy: a public health imperative [Internet]. World Health Organization; 2019 [cited 2023 Aug 3]. 146 p. Available from: https://apps.who.int/iris/handle/10665/325293
5. Baskind R, Birbeck GL. Epilepsy-associated stigma in sub-Saharan Africa: The social landscape of a disease. Epilepsy Behav. 2005 Aug 1;7(1):68–73.
6. Hernandez M, Gibb J K. Culture, Behavior, and Health.Evol Med Public Health. 2020;2020(1):12-13.
7. Sotelo X. The Role of the Unconscious in Culture: A Review Article of New Work by Green and Bainbridge, Radstone, Rustin, and Yates. CLCWeb Comp Lit Cult [Internet]. 2009 Dec 1 [cited 2023 Aug 3];11(4). Available from: https://docs.lib.purdue.edu/clcweb/vol11/iss4/13
8. Lauver D. A theory of care-seeking behavior. Image-- J Nurs Scholarsh. 1992;24(4):281–7.
9. Metta EO. Health-seeking behaviour among adults in the context of the epidemiological transition in Southeastern Tanzania: A focus on malaria and diabetes [Thesis fully internal (DIV)]. [[Groningen]]: University of Groningen; 2016.
10. Banerjee T, Banerjee G. Determinants of help-seeking behaviour in cases of epilepsy attending a teaching hospital in India: an indigenous explanatory model. Int J Soc Psychiatry. 1995;41(3):217–30.
11. Ojinnaka NC, Aronu AE, Ojinnaka GC, Uwaezuoke NA, Bisi-Onyemaechi AI. Health-Seeking Behavior of Care-Givers of Children With Epilepsy in A Resource-Poor Country. 2019; Acta Scientific Neurology 2.1.
12. Mutanana N, Mutara G. Health Seeking Behaviours of People with Epilepsy in a Rural Community of Zimbabwe. Int J Res Humanities Social Studies 2015;2:(12)
13. Tipping G, Segall M. Health care seeking behaviour in developing countries: an annotated bibliography and literature review. In 1995 [cited 2023 Aug 3]. Available from: https://www.semanticscholar.org/paper/Health-care-seeking-behaviour-in-developing-an-and-Tipping-Segall/17f5267a0294903ed15e9c7c460a932ea18d2d5a
14. Latunji OO, Akinyemi OO. Factors Influencing Health-seeking Behaviour Among Civil Servants In Ibadan, Nigeria. Ann Ib Postgrad Med. 2018 Jun;16(1):52–60.
15. Oberoi S, Chaudhary N, Patnaik S, Singh A. Understanding health seeking behavior. J Fam Med Prim Care. 2016;5(2):463–4.
16. Zeng Y, Xu W, Chen L, Chen F, Fang Y. The Influencing Factors of Health-Seeking Preference and Community Health Service Utilization Among Patients in Primary Care Reform in Xiamen, China. Patient Preference Adherence. 2020 Mar 30;14:653–62.
17. Price N. The performance of social marketing in reaching the poor and vulnerable in AIDS control programmes. Health Policy Plan. 2001 Sep 1;16(3):231–9.
18. Runganga AO, Sundby J, Aggleton P. Culture, Identity and Reproductive Failure in Zimbabwe. Sexualities. 2001;4(3):315–32.
19. Sidig A, Ibrahim G, Hussein A, Rahman AA, Yassien F, Hamad A, et al. A study of Knowledge, Attitude, Practice towards Epilepsy among relative of epileptic patients in Khartoum State. Sud J Pub Health 2009 4;(4)
20. Beghi E. The Epidemiology of Epilepsy. Neuroepidemiology. 2020;54 (2):185–91.
21. Behr C, Goltzene MA, Kosmalski G, Hirsch E, Ryvlin P. Epidemiology of epilepsy. Rev Neurol (Paris). 2016 Jan 1;172(1):27–36.
22. Ba-Diop A, Marin B, Druet-Cabanac M, Ngoungou EB, Newton CR, Preux PM. Epidemiology, causes, and treatment of epilepsy in sub-Saharan Africa. Lancet Neurol. 2014 Oct;13(10):1029–44.
23. Sinha A, Mallik S, Sanyal D, Sengupta P, Dasgupta S. Healthcare-seeking behavior of patients with epileptic seizure disorders attending a tertiary care hospital, kolkata. Indian J Community Med Off Publ Indian Assoc Prev Soc Med. 2012 Jan;37(1):25–9.
24. Singh A, Kaur A. Epilepsy in rural Haryana--prevalence and treatment seeking behaviour. J Indian Med Assoc. 1997 Feb;95(2):37–9, 47.
25. Millogo A, Diagana M, Siranyan SA, Preux PM, Dumas M. Health seeking behaviour in epileptic patients in Bobo - Dioulasso (Burkina Faso). Epilepsies. 2003 Jul 1;15(3):153–6.
26. Molla A, Mekuriaw B, Habtamu E, Mareg M. Treatment-Seeking Behavior Towards Epilepsy Among Rural Residents in Ethiopia: A Cross-Sectional Study. Neuropsychiatr Dis Treat. 2020 Feb 13;16:433–9.
27. Li X, Yang H, Wang H, Liu X. Effect of Health Education on Healthcare-seeking Behavior of Migrant Workers in China. Int J Environ Res Public Health 2020. 30;17(7):2344.
28. Ogunrin OA, Adeyekun A, Adudu P. Etiologies of epilepsy and health-seeking itinerary of patients with epilepsy in a resource poor setting: analysis of 342 Nigerian Africans. Seizure. 2013 Sep;22(7):572–6.
29. Federal Republic of Nigeria. National human resources for health strategic plan: 2008 to 2012. : https://www.who.int/workforcealliance/countries/Nigeria_HRHStrategicPlan_2008_2012.pdf
30. Ezeala-Adikaibe B, Onodugo O, Oti B, Ekochin F, Nwazor E, Okoye I, et al. Caregiver reported incidence of status epilepticus in persons with epilepsy in Enugu, Southeast Nigeria: Frequency of prolonged seizures among outpatients. Ethiop Med J [Internet]. 2022 Jan 1 [cited 2023 Jul 10];60(01). Available from: https://www.emjema.org/index.php/EMJ/article/view/1923
31. Onyemaechi N, Nwankwo O, Ezeadawi R. Epidemiology of Injuries Seen in a Nigerian Tertiary Hospital. Niger J Clin Pract. 2018 Jun;21(6):752–7.

32. The Prevalence of Stroke Survivors in Urban Slums in Enugu, Nigeria [Internet]. [cited 2023 Aug 3]. Available from: https://www.scirp.org/journal/paperinformation.aspx?paperid=93690
33. Danesi MA, Adetunji JB. Use of Alternative Medicine by Patients with Epilepsy: A Survey of 265 Epileptic Patients in a Developing Country. Epilepsia. 1994;35(2):344–51.
34. KIM MS, HUNTER JE. Relationships Among Attitudes, Behavioral Intentions, and Behavior: A Meta-Analysis of Past Research, Part 2. Commun Res. 1993 Jun 1;20(3):331–64.
35. Hohman ZP, Crano WD, Niedbala EM. Attitude ambivalence, social norms, and behavioral intentions: Developing effective antitobacco persuasive communications. Psychol Addict Behav J Soc Psychol Addict Behav. 2016 Mar;30(2):209–19.
36. Hardcastle SJ, Hancox J, Hattar A, Maxwell-Smith C, Thøgersen-Ntoumani C, Hagger MS. Motivating the unmotivated: how can health behavior be changed in those unwilling to change? Front Psychol. 2015 Jun 16;6:835.
37. Keyworth C, Epton T, Goldthorpe J, Calam R, Armitage CJ. 'It's difficult, I think it's complicated': Health care professionals' barriers and enablers to providing opportunistic behaviour change interventions during routine medical consultations. Br J Health Psychol. 2019 Sep;24(3):571–92.
38. Kelly MP, Barker M. Why is changing health-related behaviour so difficult? Public Health. 2016 Jul 1;136:109–16.
39. Kelly S, Martin S, Kuhn I, Cowan A, Brayne C, Lafortune L. Barriers and Facilitators to the Uptake and Maintenance of Healthy Behaviours by People at Mid-Life: A Rapid Systematic Review. PLOS ONE. 2016 Jan 27;11(1):e0145074.
40. Anderson KK, Fuhrer R, Schmitz N, Malla AK. Determinants of negative pathways to care and their impact on service disengagement in first-episode psychosis. Soc Psychiatry Psychiatr Epidemiol. 2013 Jan;48(1):125–36.