



### Illness Concept among People with Epilepsy and their Caregivers and Preferred Treatment Methods in a Suburban Community in Southeast Nigeria

*Concept de la maladie parmi des personnes présentant une Epilepsie et leurs soignants et les modalités thérapeutiques préférées dans une communauté semi urbaine du sud-est du Nigeria*

P. O. Nwani\*†, E. O. Arinzech‡, A. L. Asomugha‡, K. O. Enwereji‡, M. C. Nwosu‡, A. O. Ogunniyi‡

#### ABSTRACT

**BACKGROUND:** Epilepsy, one of the world's most prevalent chronic diseases is still regarded as a supernatural disease in many parts of the world. These superstitious and cultural beliefs tend to influence treatment seeking behavior of people living with epilepsy (PWE) and their caregivers.

**STUDY DESIGN:** People living with epilepsy in a semi-urban community in Southeast Nigeria were identified in a two phase door-to-door cross-sectional descriptive study. Those identified and their caregivers were further interviewed to determine their concepts of the disease, their treatment (actual and preferred) and what informed treatment.

**RESULTS:** We found 29 cases of active epilepsy, 16 (55.2%) males and 13 (44.8%) females. Witchcraft was held as a major cause of epilepsy in the community accounting for 36.2% (n=17) of the responses. The three major treatment modalities used were spiritual (healing churches), traditional (herbal medicines) and orthodox treatment with antiepileptic drugs. Spiritual treatment was the preferred treatment modality, though most (89.7%) have used traditional (herbal medicine) treatment at one point in the course of the disease. Beliefs on epilepsy and information on the disease obtained mostly from non-medical sources informed treatment.

**CONCLUSION:** The epileptic population studied preferred spiritual treatment though use of traditional treatment was also common. Treatment seeking behavior was greatly influenced by their beliefs and information on the disease obtained mainly from non-medical sources. WAJM 2013; 32(1): 26–30.

**Keywords:** Active epilepsy, Witchcraft, Spiritual treatment, Traditional treatment.

#### RÉSUMÉ

**CONTEXTE:** L'épilepsie, une des maladies chroniques les plus prévalentes au monde est considérée comme surnaturelle dans beaucoup de parties du monde. Ces superstitions et croyances culturelles tendent à influencer l'attitudedes patients vivant avec une épilepsie (PVE) et leurs soignants dans la recherche de traitement.

**SCHÉMA D'ÉTUDE:** Les personnes vivant avec l'épilepsie (PVE) dans une communauté semi urbaine du sud-est du Nigeria ont été identifiées par une étude descriptive transversale en porte à porte à 2 phases. Ceux qui sont identifiés et leurs soignants ont été interviewés pour déterminer leur conception de la maladie, leurs traitements (actuel et préféré) et le traitement communiqué.

**RÉSULTATS:** Nous avons trouvé 29 cas d'épilepsie active, 16 (55,2%) de sexe masculin et 13 (44,8%) de sexe féminin. La sorcellerie était considérée comme la principale cause d'épilepsie dans la communauté soit 36,2% (n=17) des réponses. Les 3 principales modalités thérapeutiques étaient spirituelle (guérisseurs d'église), traditionnelle (plantes médicinales) et le traitement orthodoxe par drogues anti épileptiques. Le traitement spirituel était la modalité préférée, toutefois la plus part (89,7%) avaient utilisé un traitement traditionnel (plantes médicinales) à un moment donné au cours de l'évolution de la maladie. Les croyances sur l'épilepsie et les informations sur la maladie obtenues essentiellement de sources non médicales conditionnaient le traitement.

**CONCLUSION:** La population d'épileptiques étudiées préférait un traitement spirituel bien que le traitement traditionnel était fréquent. L'attitude dans la recherche de traitement était essentiellement influencée par les croyances et les informations sur la maladie obtenues de sources surtout non médicales. WAJM 2013; 32(1): 26–30.

**Mots Clés:** Épilepsie active, Sorcellerie, Traitement Spirituel, Traitement traditionnel.

\*Neurology Unit, Department of Medicine, Nnamdi Azikiwe University Teaching Hospital, Nnewi, Nigeria    †Neurology Unit, Department of Medicine, University College Hospital, Ibadan, Nigeria

\*Correspondence: Nwani Paul O. Department of Medicine, Nnamdi Azikiwe University Teaching Hospital, P.M.B 5025, Nnewi, Anambra State, Nigeria. Tel: +2347082191962 E-mail: paul.nwani@yahoo.com

Abbreviations: PWE, People living with epilepsy

## INTRODUCTION

Epilepsy is one of the world's most prevalent non-communicable diseases that date back to ancient and biblical times.<sup>1</sup> Approximately 10 million people in Africa have epilepsy.<sup>2</sup> In many parts of the developing world epilepsy is still regarded as supernatural disease despite the brain being suggested as the seat of the disease by Hippocrates as far back as the 5<sup>th</sup> century.<sup>1</sup>

These superstitious beliefs about epilepsy predominate in Africa and have a large influence on the treatment of epilepsy in Africa. Among the Yoruba in Southwest Nigeria, it is believed that epilepsy is result of visitation of devil<sup>3</sup> while the Shona in Zimbabwe believe epilepsy is caused by the revenge of an aggrieved ancestral spirit.<sup>4</sup> In some parts of Africa people with epilepsy are treated as outcast,<sup>5</sup> but in Senegal, epilepsy is most frequently considered as a religious or magic mental affection.<sup>6</sup>

Apart from supernatural factors, environmental factors like extremes of heat and cold, poverty, are also thought to cause epilepsy in some countries like Kenya and Ecuador.<sup>7</sup> That epilepsy is due to contagion is also believed in places like Nigeria and Tanzania.<sup>3,8,9</sup> These superstitious and cultural beliefs strongly underlies the attitude of people in these areas towards the people living with epilepsy (PWE) and to a great extent is believed to influence the treatment seeking behavior of the PWE and their care-givers.

In Malawi scientific medicine is thought to have no remedies against epilepsy.<sup>10</sup> Among these Malawians epilepsy is treated by "medicine men" who give potion that caused diarrhea and vomiting presumably to expel something moving around the abdomen causing epilepsy.<sup>10</sup> Medicine is given in Shona, Zimbabwe to get rid of the poison imposed by the offended spirit.<sup>4</sup> That these beliefs are erroneous is obvious because these remedies do not produce cure but that they still influence the treatment and treatment seeking behavior of people living with epilepsy (PWE) in Africa cannot be denied.

## SUBJECTS, MATERIAL AND METHODS

**Study Area:** The study was conducted

in Ukpo a suburban community in Southeast Nigeria as part of an ongoing neuroepidemiology program in the district. Ukpo is the headquarters of Dunukofia Local government area and is about 23.3km away from Awka the capital city of Anambra state. Ukpo is inhabited by the Igbo speaking people who predominantly inhabit the eastern part of the country. Dunukofia Local government comprises of five autonomous communities with Ukpo being the largest. The population of Dunukofia Local government according to the 2006 National population census report is 96,517 and it has 20,708 households by ownership status of dwelling units.<sup>11</sup> Farming and trading on farm produce is the occupation of the area. The advent of Christianity in the area led to the majority of the people becoming Christian converts, this also changed some of the traditional practices of the people. However, to a large extent it failed to demystify the beliefs of the traditional religion not only in the minds of the minority adherent but also in those of the Christian converts. Thus oftentimes both Christian converts and traditional religious adherents often participate in some of the ceremonies inherent in the traditional religion. Rudiments of health education have been originally organized in two health centers and two maternity homes in the area. Nnamdi Azikiwe University Teaching Hospital (NAUTH) started overseeing one of these centers since 1997.

**The Survey:** The first phase of the study which was a door-to-door survey was preceded by a census of households in the area. In the first phase eight teams of research assistants, each team comprising of a health attendant (community health worker), two medical students with at least two years of clinical training, and a literate resident of Ukpo. A modified version of the World Health Organisation (WHO) protocol<sup>12</sup> for detecting the presence of neurological diseases in the community which was forth and back translated into the local vernacular of the community was used to detect people with possible epilepsy. This protocol was validated in the area and found to have a sensitivity of 100% and specificity of 65% for active epilepsy.

In the first phase 6800 persons were interviewed. This sample size was obtained from the formula  $n = DZ_{1-\alpha/2}^2 P(1-P)/d^2$  (where n is the minimum sample size, P is the prevalence, D is the design effect,  $Z_{1-\alpha/2}$  is the standard normal deviate and d is the absolute precision).<sup>13,14</sup>

In the second phase all those identified as possibly having epilepsy were evaluated by neurologists and senior residents in neurology and epilepsy was diagnosed based on the International League Against Epilepsy (ILAE) guidelines.<sup>15</sup> Detailed information on patients and caregivers (the primary care giver who takes care of the daily needs of the patient) belief on the cause of epilepsy, preferred treatment, actual treatment received and who prompted the treatment seeking from the onset of illness to the time of survey was obtained by use of an interviewer administered semi-structured questionnaire

Ethical approval for the study was obtained from the Ethical Committee of the Nnamdi Azikiwe University Teaching Hospital Nnewi. The Ministry of Health Anambra State, Nigeria was informed. Informed consent was obtained from the traditional ruler and his council, from household heads and adults subjects and from parents or close family relatives of children. All the subjects gave their consent. Parents or close family members acted as proxy for Children and persons unable to understand and respond to the questions during all the phases of the survey.

**Statistical Analysis:** Data was entered into a pro forma and confidentiality maintained. Data collected was analyzed using Statistical Package for the Social Sciences SPSS version 15 (SPSS Chicago Inc., IL, USA). Relevant percentages and frequencies were calculated and results expressed in tabular forms. The Fisher's exact test was used to compare the relationship between the frequency of ever users of the different treatment modalities and the number of users at the time of survey. Similarly, the relationship between the seizures frequencies among the PWE who preferred spiritual treatment compared to seizure frequency among those who used other treatment modalities was also assessed using the Fisher's exact test. The limit of statistical significance was set at  $P < 0.05$ .

## RESULTS

The 6800 persons screened at first phase of the study included 3249 (47.8%) males and 3551 (52.2%) females. The total number of persons identified by the initial screening as possibly having epilepsy was 76. All were screened in the second phase of the study and 29 persons were found to have active epilepsy. Those with active epilepsy were 16 (55.2%) males with a mean age of  $26.9 \pm 20.8$  and 13 (44.8%) females with a mean age of  $21.7 \pm 13.5$ .

The sources of information on epilepsy are shown in Table 1, while the perceived causes of epilepsy by the PWE and their care givers are shown in Table 2. Non-medical source accounted for 86.1% (n=31) of the source of information on epilepsy illness concept while medical source accounted for 13.9% (n=5). On the perceived cause of epilepsy witchcraft accounted for 36.2% (n=17) of responses while medical (brain) illness accounted for 23.4% (n=11). A hereditary disorder (passed down from generation to generation) 19.1% (n=9), evil spirit possession 8.5% (n=4) and curse from the gods 2.1% (n=1) of responses.

The major modalities used to treat epilepsy were traditional (herbal medicine), spiritual (healing churches), orthodox (antiepileptic drugs) and homeopathy. Various combinations of these modes of treatment were used and overtime patient tend to switch from one mode of treatment to another. Table 3 shows the number of ever users of the major treatment modalities and the number of users at the time of survey. Prior to the survey, 89.7% (n=26) of the PWE had used traditional (herbal medicines) treatment, 79.3% (n=23) spiritual (healing churches) treatment and 62.1% (n=18) orthodox treatment with AEDs. However, at the time of survey only 24.1% (n=7) were on orthodox treatment with antiepileptic drugs (AEDs), 55.2% (n=16) on traditional treatment and 65.5% (n=19) on spiritual treatment. The observed difference between the ever users and users at the time of survey was statistically significant for spiritual and orthodox treatment ( $p<0.05$ ) but not statistically significant for traditional treatment ( $p>0.05$ ) (Table 3). The number of withdrawal from the various treatment modalities were

**Table 1: Sources of Information on Epilepsy**

Source of Information	Number of responses* (%)
<b>Medical</b>	
Doctors	2 (5.5)
Nurses	2 (5.5)
Paramedical	1 (2.8)
<b>Total</b>	<b>5 (13.9)</b>
<b>Non-Medical</b>	
Village Elders/	
Parents	29 (80.5)
Religious gatherings	2 (5.5)
<b>Total</b>	<b>31 (86.1)</b>

\* Multiple responses recorded

spiritual; 17.4% (n=4), traditional; 38.5% (n=10) and orthodox; 61.1% (n=11). Two persons have used homeopathy but had stopped prior to the study.

The initial treatment sourced by the PWE and their caregivers were traditional (herbal medicine) treatment by 65.5% (n=19) of the PWE and their caregivers, spiritual by 24.1(n=7) and orthodox by 10.4% (n=3). At the time of survey when asked what mode of treatment was preferred 41.4% (n=12) answered spiritual treatment, 31% (n=9) traditional treatment while 24.1% (n=7) orthodox treatment. However, there was no statistically significant difference in the frequency of seizures between the patients that preferred spiritual compared to the frequency of seizures in those that preferred the other treatment modalities ( $p>0.05$ ) (Table 4).

**Table 2: Perceived cause of Epilepsy**

Perceived cause of Epilepsy	Number of responses* (%)
Witchcraft	17(36.2)
Medical (brain) illness	11(23.4)
Hereditary (passed down from generation to generation)	9(19.1)
Not Sure of cause	5(10.6)
Evil spirit possession	4(8.5)
Curse from the gods	1(2.1)

\* Multiple responses recorded

**Table 3: Major Treatment Modalities used by the People with Epilepsy**

Treatment Modality	Ever users (% of Cases of Active Epilepsy N=29)	Users at the Time of Survey (% of Cases of Active Epilepsy N=29)	P-value*
Spiritual	23 (79.3)	19 (65.5)	0.000
Traditional	26 (89.7)	16 (55.2)	0.078
Orthodox	18 (62.1)	7 (24.1)	0.026

\* Fisher's exact test

**Table 4: Seizure Frequency at the Time of Survey of Patients who Preferred Spiritual Treatment Compared with Seizure Frequency of those who Preferred other Modes of Treatment**

Seizure Frequency	Spiritual Treatment (%)	Other Treatment Modalities (%)	Total (%)
$\leq 1$ per month	1 (3.4)	4 (13.8)	5 (17.2)
>1 per month	11 (37.9)	13 (44.8)	24 (82.8)
<b>Total</b>	<b>12 (41.4)</b>	<b>17 (58.6)</b>	<b>29 (100.0)</b>

Fisher's exact test (2-sided)  $p = 0.370$

## DISCUSSION

The people with epilepsy and their caregivers in our study who believed epilepsy was caused by the art of witchcraft, evil spirit possession and curse from the gods "osenmawu" accounted for 36.2% (n=17), 8.5% (n=4) and 2.1% (n=1) of responses respectively. Though results of studies on what people believe is the cause of epilepsy cannot be strictly compared because of differences in methodology and the populations studied, Awaritefe *et al*<sup>9</sup> studying a population of literate non-epileptic persons in Southern Nigeria reported that 38% of their respondents believed epilepsy is caused by witchcraft. In another study conducted among non-epileptic adult in Northern Nigeria evil spirit possession accounted for 16.3% of responses.<sup>16</sup>

The belief that epilepsy is a medical illness or a hereditary disease passed down from generation to generation accounted for 23.4% and 19.1% of responses respectively. The 19.1% that believed epilepsy is hereditary was less than 45.5% reported by Awaritefe *et al.*<sup>9</sup> Visitation by the devil reported among the Yoruba in Southwest Nigeria<sup>3</sup> was not a perceived cause of epilepsy among the predominantly Igbo speaking people in Southeast Nigeria we studied. Curse from the gods "osenmawu" was rather believed to be the cause of epilepsy by the eldest respondent in our study. These beliefs of our respondents were founded on information obtained mostly from non-medical sources (86.1% of responses).

Three major treatment modalities (traditional, spiritual, orthodox) were used either as lone therapy or in various combinations by the PWE in our study. Overtime in the course of the illness, patients tend to switch from one mode of treatment to another. There was a statistically significant difference ( $p<0.05$ ) in the number of ever users of spiritual and orthodox treatment compared to users at the time of the study. At the time of the study 61.1% (n=11) of previous users of orthodox treatment had withdrawn from orthodox treatment.

Spiritual treatment was preferred by 41.1% (n=12) of the PWE in our study. This is comparable to 47% reported by

Kabir *et al*<sup>16</sup> among non-epileptic adults in Northern Nigeria. The preference for spiritual treatment might not be unconnected with the religious inclination of the people rather than efficacy of spiritual treatment. There was no statistically significant difference ( $p>0.05$ ) in the frequency of seizures between those who preferred spiritual treatment from seizures frequency in those who preferred the other modes of treatment. Previous workers in Nigeria have noted that patients with epilepsy seen at a teaching hospital in Southwest Nigeria though recognising the effectiveness of medical treatment, nevertheless would like to combine this with "native" or "church" healing, indicating their belief in these modes of treatment.<sup>17</sup> While the adverse effects associated with the use of traditional medicines are well documented, these workers however, have suggested that the use of spiritual treatment might not be regarded as completely irrelevant in the management of epilepsy as long as the patients continue taking their antiepileptic drugs in addition.<sup>17</sup>

Traditional treatment was used by 89.7% (n=26) of the PWE in our study. Traditional treatment was the first mode of treatment for most (65.5%) however, at the time of the study only 55.2% were on traditional treatment. In a study in Gambia, Coleman *et al* reported that every person (100%) with a lifetime prevalence of epilepsy found had used traditional treatment prior to the study.<sup>18</sup> Use of traditional treatment might in part be related to the beliefs on the cause of epilepsy. Prior workers have shown that the belief that epilepsy results from supernatural influences led to the use of herbs from traditional doctors, fetish priest and religious leaders.<sup>10, 19</sup>

In conclusion this study demonstrates that in this suburban population where active epilepsy was prevalent, spiritual (healing churches) treatment was preferred. Majority of PWE used traditional treatment while a smaller percentage of PWE used orthodox treatment with AEDs. Beliefs and information on the disease gotten from non-medical sources impacted greatly on treatment seeking behavior.

## Limitations

Persons with epilepsy and their caregivers knowledge on the cause of epilepsy and the source of this knowledge were limited to those who were able to understand or respond. Children, persons with mental retardation and psychosis were excluded from this part of the study.

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