



## Factors affecting the treatment outcome of epilepsy in resource poor communities of Akwa Ibom State: Analysis of patients at the University of Uyo Teaching Hospital, Uyo

Peters GE PhD<sup>1</sup>, Ononokpono N PhD<sup>2</sup>, Oko NI MSc<sup>3</sup>, Peters EJ FWACP, FRCP (Edin)<sup>4</sup>

<sup>1</sup>Department of Nursing Services, University of Uyo Teaching Hospital, Uyo.

<sup>2</sup>Department of Sociology and Anthropology, Faculty of Social Sciences, University of Uyo, Uyo.

<sup>3</sup>Department of Administration, University of Uyo Teaching Hospital, Uyo.

<sup>4</sup>Department of Internal Medicine, University of Uyo Teaching Hospital, Uyo.

### Abstract

**Background:** The main aim of this study was to investigate the socio-cultural factors affecting the welfare and treatment outcome of patients with epilepsy in Akwa Ibom State.

**Methods:** A cross-sectional data from survey of a total sample of sixty-two (62) respondents comprising of fifty (50) patients diagnosed with epilepsy and 12 medical and nursing personnel in University of Uyo Teaching Hospital were recruited for the study. We analyzed quantitative data using frequency distribution and simple percentages while thematic analysis was used for qualitative narratives.

**Results:** The results of the study indicated that cultural beliefs and the level of education/information/awareness greatly influenced the welfare and treatment outcome of patients with epilepsy.

**Conclusion:** These findings suggest that proper education and awareness are necessary to address the problems associated with the welfare and treatment outcome of people with epilepsy and the attendant health implications.

**Keywords:** Epilepsy, socio-cultural factors, treatment outcome.

### Introduction

Epilepsy is one of the most common and serious brain disorders in the world and it commonly affects young adults in the most productive years of their lives.<sup>1</sup> According to World Health Organization, it is triggered by abnormal electrical activity in the brain resulting in an involuntary change in body movement, function, sensation, awareness and behaviour.<sup>2</sup> The condition is characterized by repeated seizures or brief episodes of involuntary movement. These take many forms ranging from the shortest lapse of attention to severe and frequent convulsions. It is a chronic non communicable

disease of the brain with approximately 50 million people currently living with epilepsy worldwide.<sup>3</sup> Epilepsy is a major health problem in developing countries like Nigeria with a prevailing rate of 8 per 10000 people.<sup>4</sup> However it ranges between 4 to 35 percent in a recent study giving it one of the widest variation in the world.<sup>5</sup> It is also estimated that 80% of people suffering from epilepsy around the world, reside in developing countries in Africa.<sup>6</sup> This is likely due to the increased risk of endemic conditions such as malaria or neurocysticercosis; the higher incidence of road traffic injuries; birth-related injuries; and variations in medical infrastructure, availability of preventative health programmes and accessible care. Also congenital Central Nervous System (CNS) abnormality, tumours, vascular and metabolic disorders are increasingly being reported as causes of epilepsy in adults in the African Region.<sup>7</sup>

Corresponding Author: Dr. Peters GE (PhD)

Department of Nursing Services,  
University of Uyo Teaching Hospital,  
Uyo, Nigeria.  
E-mail: graceepeters@yahoo.com

According to WHO about 100 million people will have at least one epileptic seizure at some time in their lives.<sup>2</sup> Most of the causes of symptomatic epilepsy are preventable and treatable. The condition has serious physical, psychological, social and economic consequences for the concerned persons and their families as persons with epilepsy are at a risk of developing a variety of psychological problems including depression, anxiety and psychosis. Pioneer investigators in Nigeria have also presented a gloomy picture of epilepsy as infectious and disastrous disease in the eyes of the public. As a result, epileptic persons suffer untold social deprivations and discrimination in education, employment, marital life, etc.<sup>8</sup>

In Nigeria, particularly in Akwa Ibom State the welfare and treatment of patients with epilepsy have been greeted with negative cultural and religious beliefs as the illness is believed to be caused by demons, supernatural powers, witchcraft and as such treatment with orthodox medicine is completely ruled out and also lack of proper information/awareness about the disease condition especially in the rural community worsen the situation, hence accessing health facilities becomes the last resort when the damage has already been done.

Among the Ibibio speaking people of Akwa Ibom State, epilepsy is erroneously believed to be transmitted through contact. This belief system was further corroborated by a study carried out in University of Uyo in Akwa Ibom State, Nigeria by Ekeh and Ekrikpo which showed that there is a very poor knowledge of epilepsy in the state with much stigmatization.<sup>9</sup> Surprisingly, the poor knowledge is seen in all socioeconomic classes.

Sanya and Musa lamented that over the past decades, it has been shown that “the treatment gap” (i.e percentage of patient in a defined population with active epilepsy, not receiving antiepilepsy medication) in the developing countries varies between 60-98 percent.<sup>10</sup> The general practitioners and other health care providers still manage significant number of patients with epilepsy to further bridge the treatment gap.

Furthermore, in recognition of the health implication of epilepsy and in order to close the prevailing treatment gap, the Global Campaign against Epilepsy was jointly launched by the World

Health Organization, the International League Against Epilepsy and the international Bureau of Epilepsy as noted by Diop; De Boer and mandlhate in 1997 to bring epilepsy ‘out of shadows, reduce social and physical burden, educate health personnel, dispel stigma, and support prevention.’<sup>11</sup> Whilst some studies on epilepsy have been done by other scholars, there is limited information and data on how socio-cultural factors militates against the welfare and treatment outcome of patients with epilepsy as well as their health seeking behaviour with focus on Akwa Ibom State.

Despite modernization of society, there are still wrong concepts and ideas about patients with epilepsy, resulting in difficult social environment for the patient. Jacoby, et al argued that some people may have wrong beliefs and stereotypes with negative expectations of patients with epilepsy.<sup>12</sup> A report of the World Health Organization in 2004 indicates that in spite of global advances in diagnosis and treatment in recent years, about eight million people with epilepsy in Africa are not treated with modern antiepileptic drugs. It was also noted that epilepsy is a treatable condition and relatively cheap medication are available, however the treatment gap in developing countries remains very high due to some socio-cultural factors.

Generally, in Nigeria, successive governments have done little in reducing the prevalence of epilepsy in the country as there is no strong fight against it as we have seen in the recent times in diseases like HIV/AIDS, malaria, influenza, measles, cholera, polio and diarrhea. This development has attracted the attention of international health agencies such as the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), World Health Organization (WHO) and the Global Campaign against Epilepsy among others with the aim of reducing the burden caused by epilepsy through the improvement of acceptability, access to services, prevention and quality care.<sup>13</sup>

For Instance, in Akwa Ibom State, the disease has not attracted much attention as there is no known programme in this direction. This poor socio-cultural attitude continues to have a negative impact on the welfare and treatment of epilepsy and contributes to poor prognosis and development of complications. Epilepsy continues to take its toll among the people causing impaired physical,

psychological and social functioning of those affected and equally serious psychological, social and economic consequences for their families. It is against this background that this study seeks to examine the extent to which cultural/religious belief and level of education/information/awareness affect the welfare and treatment outcome of patients with epilepsy in Nigeria.

### Methodology

The research which was survey in design was carried out in Akwa Ibom State, Nigeria. The state is located in the South Eastern angle of the federal republic of Nigeria. It lies between latitude 40 290, and 50 350, North of the equator and between longitudes 70 250 and 80 250 East of the Greenwich Meridian. The state shares a common boundary with Abia State on the North West and West and North. On the East and West it shares boundaries with Cross River State respectively. On the Southern Fringe of Akwa Ibom State has a total landmass of 7,050.637kms and a total population of 3,920,208 (males-2044510 and females 1875698) based on 2006 population census.

The research work was carried out in the University of Uyo Teaching Hospital which is located in Uyo and it is referral centre where cases such as epilepsy are referred for proper treatment. Here, patients from all the local government areas in Akwa Ibom State who need specialist care are referred to.

The population of this study comprised patients with epilepsy in the University of Uyo Teaching Hospital (100 from hospital statistics 2010-2016) and thirty-five other health personnel who interact with the epileptic patients.

Simple random sampling technique was adopted for the study. All the epileptic patients were asked to pick a number in each of the clinic day and all those who picked even numbers and were willing to take part in the research were selected for the study. A total of sixty-two (62) respondents were selected for the study. Fifty (50) respondents were patients with epilepsy comprising twenty-seven males (27) and twenty-three (23) females and were selected in their different clinic days in University of Uyo Teaching Hospital. Twelve (12) Head of units were also interviewed on the handling of the epilepsy in the hospital.

The major instruments used for data collection were structured questionnaire and interview which were designed according to the objectives of the study. The questionnaire was divided into three sections. Section 'A' had five items which were aimed at collecting information on the demographic data of the respondents. Section 'B' had 9 item four points Likert-type scale to measure cultural and religious variables. Each item required the respondents to indicate the frequency of his/her various responses under strongly agreed, agreed, disagree and strongly disagree. The respondents were required to tick (✓) in the appropriate column for response. The Section 'C' contained open ended questions (Yes or No) on the level of education/information/awareness and welfare/treatment of epilepsy.

The interview section and interview Guide were prepared for the heads of units who the researcher believes can give useful information on the plight of epileptic patient and how they are being handled in the hospital.

A total of fifty (50) respondents with epilepsy were interviewed because of the opportunity offered by the clinic days. Twelve (12) out of 35 heads of clinics were also available for the interview.

The data were collected, collated and analyzed using frequency distribution and percentage and were presented in tables. The interview was analyzed using thematic analysis.

### Results

In this section, data generated from the field were presented. It is pertinent to note that only fifty (50) respondents with epilepsy and twelve (12) heads of units were interviewed and used for analysis.

#### Qualitative analysis

Response by head of selected departments/units in University of Uyo Teaching Hospital, Uyo on treatment of patients with epilepsy in Akwa Ibom State are reported under various themes.

University of Uyo Teaching Hospital and treatment of epilepsy

The result of the study revealed that University of Uyo Teaching Hospital is one of the tertiary institutions in the state where all serious illnesses e.g epilepsy is referred to for proper treatment. Some of the respondents reported that the hospital has a number of specialist doctors including consultant

**Table: 1 Socio-demographic characteristics of respondents with epilepsy in Akwa Ibom State (n-50)**

Variables	Frequency	Percentages
Age group		
10-19	6	12.0
20-29	41	82.0
30-39	2	4.0
40 and above	1	2.0
<b>Total</b>	<b>50</b>	<b>100</b>
Sex		
Male	32	64.0
Female	18	36.0
Total	50	100
Marital Status		
Single	47	95.0
Married	2	4.0
Separated/Divorced	1	1.0
Total	50	100
Level of education		
No formal education	3	6.0
Primary education	20	40.0
Secondary education	25	50.0
Post Secondary education	2	4.0
Total	50	100
Religious Status		
Christianity	48	96
Moslem	2	4
Traditional worshiper	0	0
Total	50	100

The socio-demographic data of the respondents as illustrated in table 1 above shows that a greater number of respondents (82%) were in the age bracket of 20-29 years. Majority of the patients were male 32 (64%) while the 18(36%) were females. The marital status of respondents indicates that, majority (94%) were singles while only 6.6% were married about (50%) of the respondents attained secondary education, while a sizeable percentage (40%) had primary school education. Majority (96%) of the respondents were Christians.

**Table 2: Respondents view on whether cultural beliefs of the people affect the welfare and treatment of patients with epilepsy in Akwa Ibom State (n-50)**

S/N	STATEMENT	SA	A	D	SD	TOTAL
1	In my culture epilepsy is being caused by evil spirit	8(16%)	19(38%)	17(34%)	6(12%)	50(100%)
2	People run away from epileptic patients during attack because it is contagious	17(34%)	21(42%)	9(18%)	3(6%)	50(100%)
3	Palm kernel oil is used to ward off evil spirit during epilepsy attack	17(34%)	19(38%)	10(20%)	4(8%)	50(100%)
4	In my community traditional healers are consulted to appease the gods as a form of treatment for epilepsy	17(34%)	18(36%)	5(10%)	10(20%)	50(100%)
5	Epilepsy is a disease unlike other disease cannot be treated	19(38%)	20(40%)	8(16%)	3(6%)	50(100%)
6	Hospital sources have healed People with epilepsy in time past.	1(2%)	10(20%)	24(48%)	15(30%)	50(100%)

In Table 2, the result shows that, many of the respondents (38%) affirmed that their culture sees epilepsy as being caused by evil spirit. Majority of the respondents (42%) agreed that people run away from epileptic patients during attacks because it is contagious. Greater percentage of the respondents (38%) confirmed that they use palm kernel oil to ward off evil spirit during epilepsy attack. Over one third of the respondents (36%) agreed that in their community traditional healers are consulted to appease the gods as form of treatment for epilepsy. Most of the respondents (40%) agreed that epilepsy unlike other diseases cannot be treated. Majority of the respondents (48%) disagreed that hospital sources have healed people with epilepsy in time past.

**Table 3: Respondents view on whether religious beliefs of the people affect the welfare and treatment of patients with epilepsy in Akwa Ibom State (n=50).**

S/N	STATEMENT	SA	A	D	SD	TOTAL
1	My religion forbids the taking of drugs of any kind	5(10%)	—	22(44%)	23(46%)	50(100%)
2	Epileptic patients must pass through some spiritual cleansing to get well	8(16%)	24(48%)	4(8%)	14(28%)	50(100%)
3	My religion does not encourage the use of drugs in the treatment of epilepsy	17(34%)	21(42%)	9(18%)	3(6%)	50(100%)

The result in Table 3 reveals that higher percentage of the respondents (46%) strongly disagreed that their religion forbids the taking of drugs of any kind for treatment of epilepsy. Majority of the respondents (48%) agreed that epileptic patients must pass through some spiritual cleaning to get well. Some of the respondents (42%) agreed that their religion does not encourage the use of drugs in the treatment of epilepsy.

neurologists and all it takes to treat epilepsy patients. Narratives from some of the medical personnel are as follows:

The hospital has specialized equipment with Electroencephalogram (EEG) and other sophisticated equipment for the diagnosis and treatment of the condition “(Consultant AAP #1: Male).

The Hospital has been treating these patients since 1997 when it was converted to a Federal Medical Centre” (Medial Doctor GUO: Female).

The treatment of patients in the Hospital results in successful control of the symptom of epilepsy”.

(Consultant #2 BOA: Female).

The respondents pointed out that the hospital has the capabilities and facilities to treated epilepsy. They have been treating these cases for many years now. At present, the total cure for epilepsy has not been achieved but the seizures are well controlled.

Challenges in the treatment of epilepsy

The issue surrounding the misconception about the nature, causes and treatment of epilepsy has exposed the medical personnel to a lot of challenges in the treatment of the condition and the ways of addressing these problems. Some of the respondents



**Table 4: Respondents view on whether level of education/information/awareness of the people affect the welfare and treatment of patients with epilepsy in Akwa Ibom State (n=50).**

Variables /response	Number of respondents	Percentage
How did you hear/know about epilepsy?		
Health care providers	10	20
Friends	9	18
Church	3	6
Media	9	18
Witnessing epileptic scene	19	38
<b>Total</b>	<b>50</b>	<b>100</b>
How did you know it could be treated?		
Internet	5	10
Health care providers	32	64
Family/Friends	11	22
TV/Radio	2	4
<b>Total</b>	<b>50</b>	<b>100</b>
Are children with epilepsy allowed to go to school?		
Yes	42	84
No	8	16
<b>Total</b>	<b>50</b>	<b>100</b>
Is there any improvement since you started the treatment		
Yes	39	78
No	11	22
<b>Total</b>	<b>50</b>	<b>100</b>
Is there any special benefit or assistance you are enjoying from government or non-government?		
Yes	3	6
No	41	82
No Response	6	12
<b>Total</b>	<b>50</b>	<b>100</b>
As epileptic patient, are the drugs given to you free?		
Yes	0	0
No	46	92
No Response	4	8
<b>Total</b>	<b>50</b>	<b>100</b>
Is the treatment given to you effective?		
Yes	40	80
No	9	18
No Response	1	2
<b>Total</b>	<b>50</b>	<b>100</b>
Can you now convince another person that the disease could be treated in the hospital?		
Yes	30	60
No	18	36
No Response	2	4
<b>Total</b>	<b>50</b>	<b>100</b>

The result in Table 4 showed that greater percentage of respondents (38%) reported they heard/knew about epilepsy through witnessing epileptic scene. Majority of the respondents (64%) reported that they got to know that epilepsy could be treated through the health workers. Greater number of the respondents (84%) said children with epilepsy in their community were allowed to go to school. Majority of the respondents (78%) affirmed that there has been improvement since they started treatments. Greater percentage of respondents (82%) said they have not enjoyed any special benefit or assistance from government or non-government. Majority of the respondents (92%) said no free drugs have been given them. A greater number of respondents (80%) affirmed that the treatment given to them was effective. Higher percentage of the respondents (60%) agreed that they can now convince other people that the disease could be treated in the hospital.

reported that:

The major challenges faced in the treatment of patient with epilepsy include frequent abscondment and lack of strict compliance to the treatment regime” (Nurse#: Female).

In most cases, patients will default in the treatment resulting in the relapse of symptoms”. (Medical Doctor#1: Male).

The narrative above showed that epileptic patients have limited knowledge about the course of treatment. This indicate that health providers have not done enough advocacy concerning the disease that it is a treatable disease and not curable. Ministry of Health and other stakeholders should create awareness through seminars, public enlightenment programmes/campaigns using both print and electronic media for effective dissemination of information.

Socio-cultural belief and treatment of epilepsy

A question to assess socio-cultural beliefs and treatment of epilepsy was included in the interview guide. The respondents were asked if they were aware of the superstitious belief and myth (e.g that is contagious) surrounding the treatment and how did they tackled the problem.

Some of the respondents narrated:

Yes we are aware of the superstitious belief surrounding this disease. Problems of isolation, discrimination and misconception were tackled through carrying out further advocacy, visiting the family and immediate community of the patient “(Nurse#2 JOA: Male).

We relate with people having this wrong belief during patients’ health education and further counseling about the disease condition”. (Nurse#1 PEA: Female).

The responses from the respondents above showed

that patients with epilepsy suffer untold physical and psychological trauma due to isolation and discrimination from the society and even their immediate family members.

The socio-cultural belief affecting the treatment of epilepsy was addressed through health education and counseling.

### Discussion

The results of the study revealed that socio-cultural beliefs of the people affect the welfare and treatment outcome of patients with epilepsy. For example, a greater number of patients affirmed that their culture sees epilepsy as being caused by evil spirit and as such palm kernel oil was used to ward off evil spirit. Hence, traditional healers were consulted to appease the gods as a form of treatment. This is in-line with the views of Matuja and Rwiza who argued that socio-cultural beliefs influence the nature of treatment and care received by people with epilepsy.<sup>13</sup> According to the authors, many communities in Africa and other developing countries believe that epilepsy results from witchcraft or being possessed by evil spirits and therefore treatment should be through the use of herbs from traditional doctors, fetish priests and religious leaders. This belief system affects the welfare and treatment of patients with epilepsy. Even in deeply different and distant culture such as the Greco-Roman, Judeo-Christian, Islamic, Hindu, and Voodoo traditions, epilepsy has consistently been seen as an infliction possession by a supernatural power, be it a god or a demon.<sup>14</sup>

The results of the study also revealed that there is a relationship between religious belief and welfare/treatment of patients with epilepsy. This was confirmed by majority of the respondents who



agreed that epileptic patients must pass through some spiritual cleansing to get well and that their religion does not encourage the use of drugs in the treatment of epilepsy. The finding is in agreement with the views by Komolafe, et al who observed that spiritual treatment often used in conjunction with traditional treatment, usually involves the person participating in some religious activities-usually in the church or mosque depending on the religious context and may reside in the religious building for a period of time as may be prescribed by the 'spiritualist'.<sup>15</sup> Common religious activities include prayer and fasting. Another common practice is the use of the holy water-water over which prayers or incantations have been said.

The person may be required to drink the water, bath with it or have it sprinkled over the body. Some have tried traditional and spiritual methods before presenting the sick for western care and some continued with both traditional and western care thereafter.

According to Carod-Artal and Vazquez-Cabrera in Central and South America epilepsy is believed to be caused by an attack suffered by an animal spirit who accompanies the Person, after a fight between the spirits who serve the forces of good and evil.<sup>16</sup> People with chronic epilepsy are considered witches.

The Level of education/information/awareness affects the welfare and treatment outcome of patients with epilepsy as indicated in the study. A greater percentage of the respondents heard/knew about epilepsy through witnessing an epileptic attack and that they got to know that epilepsy could be treated by health workers and that children with epilepsy in their community were allowed to go to school and also affirmed that there has been improvement since they started treatments as they were effective. Hence, they can now convince other people that the disease could be treated in the hospital. In addition, heads of selected departments/units in University of Uyo Teaching Hospital interviewed admitted that the University of Uyo Teaching Hospital being a tertiary medical institution has all the resources in terms of capabilities and facilities to treat epilepsy. They noted that all challenges associated with the treatment of epilepsy were addressed by strict monitoring and advocacy.

Furthermore, the socio-cultural belief affecting the treatment of epilepsy could be addressed through proper health education and counseling. The finding supports the view of Olubunni et al who maintained that there is need for public health education as intervention to increase general public education and awareness as related to epilepsy knowledge, attitude, and information on treatment options, thereby reducing the level of stigma associated with epilepsy.<sup>17</sup> Cultural and ethnic misconceptions about epilepsy have resulted in increased stigma perceived by people with epilepsy which affects their welfare and treatment negatively. Handy et al maintained that information, awareness and education of the public in general are important in order to enable and empower people to make informed choices when it comes to welfare and treatment of patients with epilepsy.<sup>18</sup> He added that cultural aspects should be studied with regard to patients perceptions, attitudes and practices in relation to epilepsy, as well as their socio-familial relations as they provide the background for appropriate information, education and treatment programmes to be adapted in a holistic way to cultural specificities with a great chance of success in the welfare and treatment of epilepsy.

Among many brain disorders epilepsy stands out not only because of its high prevalence and incidence rates, but in particular because of the myths and beliefs attached to the condition in various cultures.

The high level of prevalence of this disease and their negative health implications is a violation of the right of individual to healthy living given the fact that the general health of an individual is viewed as an important factor in assessing a society's quality of life. Maree, et al observed that epilepsy is associated with increased mortality, including increased risk of sudden unexpected death.<sup>19</sup> It can also result in morbidity which may be physical occurring directly from seizures. The patients can also have cognitive delay, speech difficulties, language difficulties or learning disabilities as well as aggressive behavior or psychosocial issues.

### Conclusion

Based on the findings of the study, it was observed that cultural beliefs, religious beliefs and the level of education/information/awareness greatly affect the

welfare and treatment of patients with epilepsy. Therefore, proper education and creating awareness is necessary to help reduce the problems associated with the welfare and treatment of people with epilepsy and the attendant health implications.

#### Recommendations

It is therefore strongly recommended that: (i) Government should formulate policies and programmes that would help in enlightening the public on the causes, prevention and treatment of epilepsy and (ii) Awareness should be created to educate the populace in our society against the practice and beliefs in certain traditions and culture that are inimical to discoveries in science and technology.

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