



Community Members' Perception of Epilepsy and their Attitude towards Persons Living with Epilepsy Disorders in a Rural Community of Bayelsa State, Nigeria

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Authors' contributions

This work was carried out in collaboration between all authors. Author IOJ performed conceptualization of study, literature search and survey, analysis and revision of data, drafting of the article, critical revision of the article and approving the final version. Author AEM managed the literature search, survey and the analyses of the study. Author OO managed the literature search, survey and analysis of data. All authors read and approved the final manuscript.

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ABSTRACT

Aims: Studies on perceptions and attitudes towards people with epilepsy have focused mainly on students/teachers in the south and Northern Nigeria. This study aimed at assessing community members' perceptions and attitudes towards epilepsy and persons living with epilepsy disorders.
Study Design: A cross sectional survey and descriptive design using a convenience sampling technique was used to collect data.
Place and Duration of Study: The study took place in a rural community of Bayelsa State, Nigeria between November 2014 and February 2015.

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Methodology: A pre-tested structured face-face questionnaire was administered to 120 community members that were randomly selected from each of the sixteen compounds in the community (72 men, 48 women, age range 18-41 and above).

Results: Majority (50%) has heard about epilepsy, 13.3% know it as a brain disorder, 32.5% say it is hereditary, 46.7% believe epilepsy can be caused by supernatural powers, 55% thinks epilepsy is a highly contagious disease and transferable, 55.8% will not take a person with epilepsy to the hospital during a seizure attack, 73.3% said it is unwise for parents to send children with epilepsy to school for fear of ridicule by schoolmates, 100% will not marry neither allow their children marry any person with epilepsy and 63.3% will not disclose to their children's spouses before marriage if son/daughter has epilepsy.

Conclusion: Negative perceptions and attitude is strongly upheld in study environment, and may be hindrance to proper treatment and social interactions. Community mobilization campaigns are advocated to improve the quality of life of persons suffering from epilepsy and counteract misconceptions attached to the disorder.

Keywords: Epilepsy; community members; perceptions; attitude; rural.

1. INTRODUCTION

Epilepsy is a chronic disease characterized by the risk of recurrent seizures [1], it is a neurological disorder that affects at least 50 million people of all ages, though more frequently affecting young people in the first two decades of life and people over the age of 60 [2]. Majority of studies on the prevalence of epilepsy have reported rates between 4 and 10 per 1,000 persons. In developed countries, an average of 4 or 5 of every 1,000 people has epilepsy while in developing countries, 6 or 10 of every 1,000 people [2-4]. Lifetime prevalence rates are much higher than rates for active epilepsy; this is even the case in resource-poor countries, where there is a huge treatment gap and unavailability of anti-epileptic drugs [5,2].

It was also reported that as many as 9 of 10 people with epilepsy in Africa go untreated [6]. The non-availability of treatment mostly in developing countries may include: Inadequate health delivery systems, lack of trained personnel, lack of essential drugs, and traditional beliefs and practices that often do not consider epilepsy as a treatable condition [7-8]. This treatment gap greatly increases the burden of epilepsy and disability. According to World Health Organisation [9], the disability caused by epilepsy accounts for about 0.5% of the global burden of the disease measured by disability-adjusted life-years. As a result, epilepsy ranks just after psychiatric disorders. The global health care burden of epilepsy is comparable to that of breast or lung cancer.

Some cultures believe that epilepsy is caused by demonic possession, witchcraft or punishment from the gods [10-15]. Evidence has shown that

these negative societal portrayals of epilepsy may affect the initiation of prompt medical treatment and management of the disorder [16-18]. This has made people with the disorder to have poor self image, low self esteem that compromised their mental health status, such as anxiety, depression, shame and the feeling of guilt. However, the effectiveness of drug therapy as the mainstay of treatment of epilepsy is well established [19-21]. First line treatment for epilepsy is anti-epileptic drug therapy, the aim of treatment is to limit seizure occurrence, adverse drug side effects, maintaining or restoring quality of life [21-22]. Evidence show seizures can be controlled by monotherapy in approximately 60% of patients [19] while others may respond to combination of therapy and sometimes surgery [23].

This study was carried out in a rural community in Bayelsa State of Nigeria. The occupations of the people are mainly farming and fishing, the water-way was the dominant route of transportation until recently when a bridge was constructed across the River Num to link the community with the State capital Yenagoa. It has two market days (Tuesdays & Fridays) of each week where they bring their produce mainly fish and plantain for sale. It has a fifteen bedded General Hospital to care for the sick, and critical medical conditions are usually referred to the University Teaching Hospital at Okolobiri or to the Federal Medical Centre in Yenagoa. The community is divided into sixteen compounds usually referred to as "Ama" and each of the Ama is headed by a chief, who acts as the custodian/administrator of traditional rites and customs. These compound chiefs constitute the Council of Chiefs headed by a Paramount Ruler known as "Amananaowei" (King).

Previous studies on knowledge, attitudes, beliefs and treatment of people with epilepsy have focused on students or teachers in the south and Northern Nigeria. Little is known about epilepsy and how persons living with the disorder are perceived in the Niger Delta region of Nigeria. Therefore, this study aims to assess community member's perceptions and attitudes towards epilepsy and persons living with epileptic disorders in a rural community of Bayelsa State, in order to ensure proper management and treatment programme.

2. METHODOLOGY

A cross sectional survey and descriptive design using a convenience sampling technique for data collection to assess community members' perception and attitude towards epilepsy and people living with epileptic disorder. The inclusion criteria were that community members must be 18 years and above and should have a basic primary school education in order for them to comprehend and answer the questions asked. Respondents were identified and then informed about the aim of the study and consent was sought, confidentiality and anonymity was also maintained. A structured questionnaire written in English Language that was developed for the purpose of the study consisting of 3 sections; A, B and C. Section A elicits information on socio-demographic variables of respondents, section B focuses on community members' perceptions of epilepsy while section C deals with the community members' attitude towards persons living with epileptic disorder. Validity of the instrument was ascertained based on previous research works gathered from the literature and experts recommendations on the questionnaire suitability and its applicability for the study. Whereas, the reliability of the instrument was determined through a test-retest method using 20 respondents in a nearby community, who were not part of the main population of the study but having similar attributes of the original population of the study. The scores obtained were subjected to the Pearson Product Moment Correlation Coefficient (PPMC) analysis and the result gives 0.81. The reliability coefficient value of 0.81 was considered as an acceptable reliability value for the study.

2.1 Data Collection and Instrumentation

A pre-tested structured face-face questionnaire was administered to 120 community members

that were randomly selected from each of the sixteen compounds in the community and the questionnaires were retrieved immediately after response. Data collection started in November, 2014 and lasted for a period of six weeks. Data obtained from the field work were analyzed by means of the statistical package for social sciences (SPSS) version 17 Chicago IL, using simple percentage, with descriptive and inferential statistics calculated for demographic, perception and attitude towards epilepsy and persons living with epilepsy disorder.

2.2 Ethical Approval

A letter of introduction was submitted to the paramount ruler of the community "Amananaowei" (King) through the office of the Public Relation Officer (PRO) for permission to conduct the research. The researchers were invited to meet with the Council of Chiefs, all information about the research was explained to them and that all information collected will be treated confidentially. Ethical approval for the study was obtained from the paramount ruler of the community "Amananaowei" through the office of the Public Relation Officer (PRO) after a meeting with the Council of Chiefs to explain the purpose of the study.

3. RESULTS

Table 1 show the social demographic data of respondents 72 (60%) of the respondents are males, while 48 (40%) are females, majority 43 (35.8%) are self employed and 8 (6.7%) with tertiary education.

Table 2 shows that 50% of the study population has heard about epilepsy, 45% of respondents believe epilepsy is not a brain disorder, 32.5% held the view that epilepsy is hereditary, 46.7% say it is caused by supernatural powers. All the respondents held the belief that gods/ancestors can punish someone with epilepsy for a past sin, 90% say epilepsy is contagious and transferable. In the choice of treatment of epilepsy 67% believe faith healers are better than the use of modern drugs. 35% thinks epilepsy can never be treated. 55.8% will not take an epileptic to hospital during an attack, and 80% has no friend/relation with epilepsy.

Table 3 shown that: 92.5% of respondents cannot allow their children play with a child with epilepsy. 92.5% of the respondents cannot hire a person with epilepsy. All the respondents 100% cannot marry or allow their children marry a

person with epilepsy, 26.7% agreed to reveal the epilepsy status of their children before marriage is contracted and 80.8% cannot eat from the same plate with a person with epilepsy.

4. DISCUSSION

The findings show that 60% of our study sample were males, this may reflect the patriarchal role of the male gender in a traditional society, 52.5% are within 31-40 years, 63.3% are married, 70%

are Christians, it compares well with other studies in the southern part of Nigeria where Christianity is the dominant religion [12,14,16], and majority 70% had primary education signifying a low level of education.

The findings show that majority (50%) of the respondents have heard about epilepsy and 13.3% know it as a brain disorder. An emerging view from our study shows epilepsy is a poorly

Table 1. Showing demographic variables of respondents (n=120)

	Variable	Frequency	Percentage (%)
Sex	Male	72	60
	Female	48	40
Age	18-30	36	30
	31-40	63	52.5
	41 and above	21	17.5
Marital status	Single	33	27
	Married	76	63.3
	Separated	11	9.2
Religion	Christian	84	70
	Traditional worship	15	12.5
	Muslim	13	10.8
	Others	8	6.7
Occupation	Self employed	43	35.8
	Farming	27	22.5
	Fishing	24	20
	Civil servants	15	12
	Students	11	9.2
Education	Primary	84	70
	Secondary	28	23.3
	Tertiary	8	6.7

Table 2. Community members' perception about epilepsy (The questions were answered using the following guidelines) Always (0); Often (1); Sometimes (2); Rarely (3) and Never (4)

No	Keys	0%	1%	2%	3%	4%
1	Have you ever heard about Epilepsy?	60 (50)	19 (15.8)	31(25.8)	10 (8.4)	0 (0)
2	Is epilepsy a brain disorder?	16 (13.3)	17 (14.2)	33 (27.5)	0 (0)	54 (45)
3	Do you think epilepsy runs in families (hereditary)?	39 (32.5)	32 (26.7)	30 (25)	12 (10)	7 (5.8)
4	Is epilepsy caused by supernatural powers?	56 (46.7)	23 (19.2)	31 (25.8)	10 (8.3)	0 (0)
5	Can the gods/ancestors punish someone with epilepsy for a past sin?	30 (25)	43 (35.8)	29 (24.2)	18 (15)	0 (0)
6	Is epilepsy contagious and transferable?	66 (55)	42 (35)	0 (0)	12 (10)	0 (0)
7	Are faith healers better than the use of modern drugs for treatment?	51 (42.5)	30 (25)	39 (32.5)	0 (0)	0 (0)
8	Do you think epilepsy can be treated?	34 (28.3)	0 (0)	0 (0)	44 (36.70)	42 (35)
9	During an epileptic attack, will you take the patient to the hospital?	0 (0)	0 (0)	32 (26.7)	21 (17.5)	67(55.8)
10	Do you have friend or relation who has epilepsy?	10 (8.30)	0 (0)	0 (0)	14 (11.7)	96 (80)

Table 3. Shows the attitude of community members towards persons living with epilepsy

S/n	Question	Yes (%)	No (%)
1	Can you allow your children play with a child with epilepsy?	9 (7.5)	111 (92.5)
2	Is it wise for parents to send children with epilepsy to school?	32 (26.7)	88 (73.3)
3	Can you hire a person with epilepsy to work for you?	9 (7.5)	111 (92.5)
4	Can you marry or allow your child marry a person with epilepsy?	- (-)	120 (100)
5	If your son /daughter has epilepsy, will you reveal it to his/her spouse before marriage?	44 (36.7)	76 (63.3)
6	Can you eat from the same plate with a person you know suffer from the disease?	23 (19.3)	97 (80.8)
7	Can you befriend someone you know that has epilepsy?	21 (17.5)	99 (82.5)

understood disorder among community members, this may be due to lack of necessary health information. The finding was similar to a study [10] among university students in Ghana that reported the restricted knowledge about epilepsy in their study sample appears to be the lack of readily accessible and accurate information about the disorder. The lack of knowledge and inadequate information regarding epilepsy by the larger society will continue to uphold negative perceptions.

The study shows that epilepsy is seen as a hereditary disease as reported by majority of the respondents. This finding is consistent with reports from previous studies which show evidence of hereditary as a factor associated with misconception and stigma of epilepsy. In a related study of knowledge, attitudes and perception towards epilepsy amongst Medical Students in Uyo, Southern Nigeria [14] epilepsy was seen as being transmissible by blood (mother to child) and in another study [10], it was reported that 31.8% of their study sample indicated that epilepsy was exclusively inherited.

Majority of the study sample believe that epilepsy can be caused by supernatural powers and that gods/ancestors can punish an individual with epilepsy for a past sin. In a study [12] on teachers' knowledge and attitudes towards epileptic disorder: A comparative study of urban and rural school teachers in Akwa Ibom State, Nigeria it was reported that 28.8% of urban respondents believe epilepsy is caused by witchcraft and in another related study about knowledge and attitudes of Nigerians toward epilepsy in Northern Nigeria [11] reveal that possession by evil spirits ranked fourth (16.3%) among the perceived causes of epilepsy by the respondents. Although epilepsy arises from a transient dysfunction in the brain, fear and ignorance still lead to feelings of shame and stigma.

The beliefs that epilepsy is a highly contagious disease and transferable was strongly upheld by 55% of our study sample. Similarly, in a study [14] conducted in Southern Nigeria on Medical Students, it was reported that 54.36% of both basic and clinical students believe epilepsy is transmissible, while in another study [13] in Nigeria, it was reported that majority of both urban and rural school teachers (68.2% and 63.6% respectively) of the respondents believed that the foam (saliva) from the mouth of a convulsing person with epileptic disorder is the infecting agent. This may explain the reason why persons with epilepsy usually may not get help while having a seizure in Nigeria.

The study shows that 42.5% of respondents believe faith healers are better than the use of modern drugs in the treatment of epilepsy. This is similar to a study [11] that reported spiritual healing was the most preferred method of treatment for epilepsy in 47% of respondents and people who opted for this method of treatment were mostly those who believed the disorder was a result of affliction by evil spirits. The belief that epilepsy disorder is best treated with traditional medicine is also upheld in other developing countries [8,10,15]. However, there is evidence that anti epileptic drugs are effective for the treatment and control of seizures [20-23]. Therefore societal knowledge of anti epileptic drug therapy, where and how to access medical care service will be advantageous for the treatment, management and control of the disorders.

The study show 96% of respondents reported not having a friend or relative with epilepsy. We believe that most people will not want to reveal family members with the disorder due to negative societal perceptions and the consequences of such disclosures. The concealment of the disorder is in accordance with other studies that people with epilepsy will prefer anonymity for fear of being marginalized or de-valued [14-15].

On marital relationship the entire study sample (100%) indicated that they will neither marry nor allow their children marry any person with epilepsy disorder. This may be linked to the negative belief in this study that epilepsy is hereditary. Similar finding were reported [14], 70% of the respondents indicated that they will not marry any person with epilepsy. We also found that majority (63.3%) of our study sample will not disclose to their children spouses before marriage if their son/daughter have epilepsy. In a similar study of epilepsy among secondary school teachers in Osogbo South-West Nigeria [13] revealed that some of the teachers believe epilepsy could be enough reason to prevent marriage or for divorce. Negative perceptions hinders social acceptance, which in turn drives the affected families to hide the disease, and makes it difficult to increase people's awareness of it.

4.1 Study Limitation

The major limitation of this study is the number of participants. The study was carried out in one rural community in Bayelsa State, Nigeria. We suggest a wider population study to assess perception and attitude towards epilepsy and persons living with the disorders.

4.2 Implication for Policy

Nurses at all levels should provide the public with information and teach the basic facts of epilepsy to dispel local beliefs and misconceptions about the disorder.

There is need for health professionals to work towards improving awareness of the public i.e. that head injury, lack of oxygen at birth, systemic diseases and metabolic disturbances may predispose/cause epilepsy.

That genetics play only a partial role perhaps by increasing a person's susceptibility to seizures that are triggered by an environmental factor and women with epilepsy can safely give birth to children without any adverse effects on the baby.

Government at all levels should allocate more resources to the treatment of epilepsy as is being done for HIV/AIDS.

Special clinics should be set up for proper management and treatment of epilepsy.

Local epilepsy organizations should be set up so that people living with the disorders can always

engage in group psychotherapy and support one another.

Community mobilization campaigns must be encouraged in order to improve the quality of life of persons with epilepsy.

Qualitative research is suggested to understand the lived experiences of persons and families living with the disorder.

5. CONCLUSION

The study reported negative attitude and perceptions towards epilepsy and persons living with the disorder. It will be important to note the difficulties experienced by persons with epilepsy in the study environment has important social implication in that, negative perceptions could be a major hindrance to proper medical care and follow-up, limiting education, work opportunities and social interaction. There is need for community mobilization campaigns in order to improve the quality of life of persons with epilepsy and counteract misconceptions attached to the disorder.

CONSENT

Informed consent to participate in the study was obtained after informing the respondents about the purpose of the study and that confidentiality will be maintained and they are allowed to withdraw from the study at any time if they so wished.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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