ORIGINAL ARTICLE

Orient J Med, Vol. 35, No. 1-2, 2023

Knowledge, Beliefs and Misconceptions about Epilepsy and its Treatment in a Rural Community in South-Eastern Nigeria

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ABSTRACT

Background: Epilepsy is not only one of the oldest known neurological disorder but also one of the most prevalent chronic brain disorder worldwide. The social pathology associated with epilepsy drives the people with epilepsy (PWE) and their families into the shadows and widens epilepsy treatment gap. How much the social aspects of epilepsy and epilepsy care has changed in rural African communities in the globalized world is yet to be fully elucidated. **Objectives:** This study aims to determine the level of knowledge and attitude towards epilepsy and the people living with epilepsy (PWE) by adult inhabitants of a rural south-eastern Nigerian community. **Methodology:** This was a cross sectional door-to-door population survey. Interview on select aspects of knowledge and attitude to epilepsy was conducted using a pretested semi-structured questionnaire. **Results:** Three hundred and seven (90.3%) of the respondents reported awareness of epilepsy, 61(18%) had good knowledge on epilepsy but attitude towards epilepsy was negative. The key source of information on epilepsy for 133 (43.3%) respondents was health workers, while 125 (40.7%) reported that epilepsy was a medical disease. Associations existed between level of knowledge on epilepsy and gender (p=0.0023); marital status (p=0.0012) and educational attainment (p= 0.0476). **Conclusions:** Awareness of epilepsy though high among the rural inhabitants yet a wide gap still exist regarding the knowledge and attitude towards epilepsy. It is hoped that with adequate culturally appropriate educational programs, channelled through the media and health workers in rural communities the existing gap in knowledge and treatment will be bridged.

Keywords: Treatment gap, shadows, rural Nigeria, education

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Article Metrics

Date Submitted:	*10 Feb. 2022*
Date Accepted:	*21 April 2022*
Date Published:	*Jan-June 2023*

Journal Metrics

e- ISSN: *1115-0521*
Website: *www.orientjom.org.ng*
E-mail: *editorojm@gmail.com*

Publisher

cPrint, Nig. Ltd
E-mail: *cprintpublisher@gmail.com*

Access to the article

Website: http://www.orientjom.org.ng
: DOI: 10.5281/zenodo.7293670

How to cite this article

CC Nnebue, EO Nwazor, PO Nwani, CO Ifezulumba, EO Ewa, FE Iwere et al., Knowledge, Beliefs and Misconceptions about Epilepsy and its Treatment in a Rural Community in South-Eastern Nigeria. Orient J Med, 2023;35(1-2):45-55. DOI:10.5281/zenodo.7293670.

INTRODUCTION

Epilepsy is one of the most prevalent chronic brain disorder worldwide. It affects an estimated 50 million people worldwide and about 80% of cases reside in developing countries.[1] The prevalence of epilepsy in Nigeria from community based studies ranges from 4.5 to 37 per 1,000 with a wide regional variation.[2, 3, 4] Epilepsy affects persons of all age groups, tends to be more prevalent in rural communities and localities with endemic proportions of parasitic infections such as neurocysticercosis, onchocerciasis amongst others.[5]

The social consequences of epilepsy leaves the sufferers with varying level of stigmatization and discrimination by the public thus driving them and their families into the shadows.[6] This social consequences stems from the superstitious and socio-cultural beliefs about epilepsy which are based on several unfounded historical connotations.[6,7,9] These superstitious and socio-cultural beliefs also influences the health seeking behaviour and management of PWE in rural African communities and widens epilepsy treatment gap. Studies have shown that majority of people living with epilepsy in the rural communities seek care firstly from unorthodox traditional healers and spiritual homes before orthodox treatments using antiepileptic medications.[9,10]

With the global village paradigm and increasing access to information through the electronic/digital especially social media in almost all aspects of life, how much of these age long superstitious beliefs about epilepsy are still upheld by the adult population in rural Africa communities remains a question to be answered. The increased access to information through the electronic/digital media, also present a new frontier of misinformation from these sources. However, appropriately managed the media will offer a good avenue for appropriate community education regarding epilepsy and care for people living with epilepsy.

Lack of appropriate information, low literacy level which are all common in rural communities have all been reported to negatively impact on the care of people with epilepsy.[11,12,13] Adequate knowledge of epilepsy in the rural communities will improve the attitude towards epilepsy and care of people living with epilepsy. To achieve this accurate documentation of the extent of the problem in rural communities where most people with epilepsy live will be the first step followed by the development of comprehensive culturally appropriate educational plans and policies to bridge the gap. The present study therefore aimed to determine the knowledge and attitude of a rural South-eastern Nigerian community dwellers to epilepsy and its treatment.

METHODOLOGY

Study Area: This study was conducted in Ogbaku a rural community in Mbaitoli Local Government Area of Imo State, Southeast Nigeria between June 2021 and December 2021. Ogbaku is located at about 14km from Owerri, the capital of Imo State and has an area of $84km^2$ and a projected total population of 164,425 persons with a 2011 population density projected at 2004.5 persons per sq. km.[14] The Southeast Nigeria is home for the Igbo speaking people of Nigeria with their numerous traditional religious beliefs and practices that held sway before the introduction of the Christian religion. Though many households in Ogbaku community now practice Christianity there are still a few loyalist of the traditional African religion and some Muslims in the community. The residents are mainly traders, farmers and artisans with a few civil servants working in the schools in the community and the health centre. The town hosts the comprehensive Primary Health Centre of the department of Community Medicine, Imo State University.

Study Design: This was a community-based cross-sectional descriptive study.

Study Population: This study was conducted among adult members of households that were resident in Ogbaku, Imo state.

Sample Size Estimation: The minimum sample size was calculated using the Cochran formula $n = z^2pq/d^2$, where; n=minimum sample size, Z= standard normal deviate corresponding to 95% confidence interval = 1.96, p= proportion of the target population that had positive or good attitude relating to epilepsy, d = tolerable error of margin, set at 0.05. From a study conducted by Akpan, et al.[15], in Akwa Ibom State, South-South Nigeria, p= 0.28 for attitude towards epilepsy (16), $q = 1 \; p$ ($q = 0.72$), so that the estimated sample size n= 310 households. However, to make up for attrition, the unadjusted sample size was divided by (1-0.1) i.e. 0.9 for non-response rate is taken as 10% giving us a total of 340 `households.

***Sampling Technique**:* Multi stage sampling technique was used to select participants. In the first stage, stratified sampling technique was used to split the rural community studied into four according to the four zones. The second stage involved the selection of the villages studied under the four selected zones by simple random sampling. Each select village was regarded as a cluster. The sample size calculated was proportionately allotted to each cluster. Thirdly, a central place in each area was located (market/village hall) and an empty bottle was spun on the ground (the bottle made a minimum of three complete turns before stopping). When it ceased to move, the direction of the neck of the bottle was taken as the starting point. The researchers walked in a line then began again, for the inclusive households. Then systematic sampling technique was used through consecutive enrolment of households to select eligible (head of households or their nominee) and consenting participants from each household within the select village in the respective zones. When the selected participant was absent, the next eligible and available was enrolled.

Data Collection: Interviewer-assisted community-based door-to-door data collection using semi-structured questionnaire, was done. The questionnaires were administered using face-to-face interviews, by four PHC workers (community health extension workers) who were recruited and trained as research assistants. This questionnaire was adapted from tools used in previous epilepsy surveys and were found useful.[16,17,18] The questionnaire comprised four sections namely: (a) socio demographic characteristics of respondents, (b) awareness and knowledge of epilepsy, (c) attitude towards epilepsy and (d) relationship between socio-demographics and level of knowledge of epilepsy. To ensure data quality, training of data collection team, field monitoring and day end reviews were conducted.

***Inclusion Criteria**:* Any adult member of a household aged between 18 and 65 years who have resided in Ogbaku community for at least one year prior to the time of study qualified to represent the household in the survey.

***Approval for Study**:* Approval for study was obtained from relevant authorities including the Madonna University Ethical Review Board, through the Head Department of Community Medicine, the traditional ruler of Ogbaku community and council of leaders of the community. The survey was preceded by several visits and advocacy meetings with the traditional leaders, religious leaders and family heads in the community. The purpose and objectives of the study were explained to the participants prior to the interview, consent obtained and confidentiality was maintained.

Data Management and Analysis: The data were entered into the computer, cleaning and consistency checks were done. In order to assess the overall distribution for and factors associated with level of knowledge of epilepsy, five knowledge items were generated. First, a score one (1) was assigned for those giving correct answers or having some knowledge about epilepsy and zero (0) if on the contrary. Then a total was obtained from which a percentage score was calculated, ranging from (0% to 100%). Individuals with lower percentage values than the mean percentage score (50%) were considered as having poor knowledge about the condition. Similarly, those with higher percentage values than the mean percentage score were considered as having fair knowledge if 51-70 and good knowledge if 71-100.

All statistical analyses were performed using statistical package for social sciences (SPSS) Windows version 22.0.[19] Descriptive statistics of mean, frequency, and percentages were used to summarize data on socio-demographic variables and knowledge of and attitude to epilepsy. Tests of statistical significance were carried out using Chi square and Fishers tests as appropriate for proportions. A p value of ≤ 0.05 was considered significant.

RESULTS

A total of 340 questionnaires were administered to selected households, all of which were retrieved and analysed, giving a response rate was 100%. Table 1 shows the socio-demographic and household characteristics of the respondents. The modal age group 144 (42.4%) was 21-30 years. Majority of them 240 (60%) were females, *182 (53.5%) not* currently married, while 100 (29.4%) of them had tertiary education.

Table 2 shows the awareness and knowledge of epilepsy among respondents. Three hundred and seven (90.3%) of them reported awareness of epilepsy, with the key sources of information on epilepsy for 133 (43.3%) respondents as Health workers, 90 (29.3%) radio, 87 (28.3%) family members while 71 (23.1%) social media**.**

Out of the 307 that reported awareness of epilepsy, 237 (77.2%) r*eported ever seeing s*omeone suffer an epileptic attack, 156 (50.8%) reported that the commonest cause of epilepsy *is* medical. Two hundred and sixty-nine (79.1%) described epilepsy

Table 1: Socio-demographic and household characteristics of the respondents.

Characteristics	Frequency (n=340)	Percentage (%)
Age(years)		
≤20	29	8.5
21-30	144	42.4
31- 40	107	31.5
41- 50	47	13.8
≥51	13	3.8
Gender		
Male	136	40
Female	204	60
Marital Status		
Married	158	46.5
Not married	135	39.7
Widowed	32	9.4
Separated/Divorced	15	4.4
Religion		
Christianity	326	95.9
Islam	10	2.9
African traditional religion	4	1.2
Highest level of education attained		
No formal education	12	3.5
Primary	51	15.0
Secondary	177	52.1
Tertiary	100	29.4
Occupation		
Trading	60	17.7
Farming	41	12.1
Teaching	34	10
Civil servants	52	15.3
Schooling	55	16.2
Artisans	35	10.3
Unemployed	63	18.5
Ethnicity		
Ibo	327	96.2
Yoruba	7	2

Table 2: Awar eness and knowledge of epilepsy

Variables	Frequency***	Percentage (%)
Ever heard of epilepsy		
Yes	307	90.3
No	33	9.7
Source of information about epilepsy		
Media (electronic, digital)*	224	41.9
Health workers	133	24.8
Family members (siblings, parents)	87	16.3
Religious organisations**	74	13.8
Books	17	3.2
Reported ever seen someone suffer an epileptic seizure attack (n=307)		
Yes	237	77.2
No	70	22.8
Reported causes of epilepsy		
Medical	156	50.8
Spiritual	110	35.8
Unknown	41	18.4
Reported description of epilepsy		
Brain disorder	269	79.1
Contagious diseases	71	23.1
Reported transmission of epilepsy		
Infectious	158	51.5
Non-infectious	149	48.5
Reported epilepsy can be treated or managed		
Yes	203	66.1
No	104	33.9
Reported that epilepsy can be prevented using local gin		
Yes	55	7.9
No	252	82.1
Overall knowledge of Epilepsy (n=340)		
Poor	217	63.8
Fair	62	18.2
Good	61	18.0

* (Radio=90 (16.8%), Social media=71 (13.3%), television=63 (11.8%) ** (Church=65, Mosque=9),
*** Responses are not mutually exclusive

Table 3: Attitude towards epilepsy

Variables	Frequency (percentage) Yes	No
Would you take persons with epilepsy to hospital?	219 (64.4)	121 (35.6)
Can you associate socially with persons with epilepsy?	257 (75.6)	83 (24.4)
Should persons with epilepsy suffer stigmatization	126 (37.1)	214 (62.9)
Would you marry persons with epilepsy?	20 (5.9)	320 (94.1)
Should persons with epilepsy have children?	252 (74.1)	88 (25.9)
Should persons with epilepsy attend special schools	171 (50.3)	169 (49.7)

Table 4: The relationship between socio- demographics and level of knowledge on epilepsy

Variable	Frequency of overall knowledge grade Poor (%)	Fair (%)	Good (%)	Total (%)	Test statistics	p-value
Gender						
Male	97 (28.5)	25 (7.4)	14 (4.1)	136 (35.9)		
Female	120 (35.3)	37 (10.8)	47 (13.9)	204 (64.1)	8.9768	0.0023*
Total	217 (63.8)	62 (18.2)	61 (18.0)	340 (100.0)		
Marital status						
Currently married	112 (32.9)	4 (1.2)	42 (12.4)	158 (46.5)	14.9267	0.0012**
Not currently married	105 (30.9)	58 (17.1)	19 (5.6)	182 (53.5)		
Total	217 (63.8)	62 (18.2)	61 (18.0)	340 (100.0)		
Religion						
Christianity	212 (62.4)	59 (17.4)	55 (16.2)	326 (95.9)		
Non-Christianity	5 (1.5)	3 (0.9)	6 (1.8)	14 (4.1)	0.8754	0.048**
Total	217 (63.8)	62 (18.2)	61 (18.0)	340 (100.0)		
Highest level of education attained						
At most Secondary	135 (39.7)	56 (16.5)	49 (14.4)	240 (70.6)	3.3865	0.0657
Tertiary	82 (24.1)	6 (1.8)	12 (3.5)	100 (29.4)		
Total	217 (63.8)	62 (18.3)	61 (17.9)	340 (100.0)		
Occupation						
Unemployed	20 (5.8)	31 (9.1)	14 (4.1)	65 (19.2)		
Employed	197 (57.9)	31 (9.1)	47 (12.1)	275 (80.9)	0.7043	0.4013
Total	217 (63.8)	62 (18.2)	61 (18.0)	340 (100.0)		
Ethnicity						
Ibo	211 (62.1)	61 (17.9)	55 (16.2)	327 (96.2)	7.2843	0.0068**
Non-Ibos	6 (1.8)	1(0.3)	6 (1.8)	13 (3.8)		
Total	217 (63.8)	62 (18.2)	61 (18.0)	340 (100.0)		

** Chi-squared test   ** Fisher's exact test.*

as a brain disorder and 71 (23.1%) as a contagious disease. One hundred and fifty-eight (51.5%) reported that epilepsy can be transmitted from person to person, 149 (48.5%) that epilepsy is a non-infectious disease 49 (16%) reported that transmission of epilepsy can be potentiated by malaria and onchocerciasis. Two hundred and three (66.1%) reported that epilepsy can be treated or managed while 55 (7.9%) reported that epilepsy can be prevented using local gin. Only sixty one (18%) respondents had good knowledge on epilepsy.

Two hundred and nineteen (64.4%) would take persons with epilepsy to hospital, 257 (75%) can associate socially with persons with epilepsy while 126 (37.1%) agree that persons living with epilepsy suffer stigmatization (Table 3). Only 20 (5.9%) respondents agreed they would marry persons with epilepsy, 252 (74.1%) agreed persons with epilepsy should have children while 171 (50.3%) respondents agree persons with epilepsy should attend special schools.

Table 4 shows the relationship between socio-demographic and level of knowledge on epilepsy among respondents. There were statistically significant associations between level of knowledge on epilepsy and these socio- demographic: [gender-males and females (p= 0.0023); marital status-currently married and not currently married (p= 0.0012); religion-Christians and non-Christians (p= 0.048); and ethnicity-Ibos and non-Ibos (p= 0.0068) respectively.

DISCUSSION

The socio-demographics in the present study are consistent with the characteristics in select studies in Africa with higher population of younger adults.[20] In this present study those aged below 40 years of age accounted for 82.4%. This is may be accounted for by the reduced life span in the country due to disease and poverty despite the projected aging of the Nigerian population.[21] This younger age group are the "jet age" group acquainted with the global outburst of information flow through the internet and electronic media howbeit not isolated from the misleading and erroneous information which can also spread through these means. These younger adults will become the older adults of tomorrow so that any meaningful culturally appropriate educational and interventional programs aimed to bring epilepsy out of the shadows in the rural communities should target this subset of the population as well as the older adults and the community leaders.

There was high awareness of epilepsy (90.3%) among the participants in this present study and this is within the range of 73% to 100% reported in previous studies.[18,20,22,23] Previous knowledge and attitude studies among Nigerian urban women, secondary school students and teachers have reported good awareness of epilepsy among the different study populations.[16,24,25]

This current study unlike previous studies revealed the role the electronic/digital media as an increasing source of information of epilepsy especially the digital media. In this present study electronic/digital media accounted for 41.9% of responses on the source of information on epilepsy. In a study among secondary school students in Enugu southeast Nigeria in 2013 Ezeala-Adikaibe et al.[16] reported that electronic media accounted for 36.4% of responses on the source of information on epilepsy while the internet (digital media) accounted for 6.2% of responses. The internet (social media) separately accounted for 13.3% of the responses on the source of information in this present study. The rising access to digital information in Nigeria in the last decade with upgrade to 3G networks in most rural communities in the country is revolutionizing information dissemination even in rural Nigeria. This transformation can be harnessed in bridging epilepsy treatment gap by dissemination of appropriate information on epilepsy through this means. In a study in southern Ethiopia the media accounted for only 12.3% of responses on the source of information on epilepsy.[20] However, despite the ease of accessibility of these sources of information, the information obtained may be entirely unreliable and misleading. The print media (books) only accounted for 5.5% of the responses on the sources of information on epilepsy compared to 10.3% reported among secondary school by Ezeala-Adikaibe *et al*[16,] about nine years ago.

Health workers were a common source of information in this present study accounting for 24.8% of the source of information on epilepsy. This is higher than 20% reported in a community study in southern Ethiopia.[20] Health workers especially community health workers as seen in this present study are a huge source of health information to the rural community dwellers. Efforts at appropriate training and education of these community health workers on epilepsy has been identified as one of the means of bridging epilepsy treatment gaps.[26, 27] Education of the health workers in rural communities on epilepsy is an effective route of disseminating culturally appropriate information about epilepsy in rural communities.[26,27]

Other sources of information on epilepsy in this present study were family sources and religious organizations. The importance of these sources of information on epilepsy lies on the fact that most the old held beliefs on epilepsy driving the misconceptions about the disease are more likely to be transmitted through family sources. On the other hand however, information passed through the religious organisations tend to have great influence on the peoples belief, attitude and practice because of the great devotion to religion in Africa.

Only 18% of the participants in this present study have good level of knowledge of epilepsy. Poor knowledge of epilepsy despite high prevalence of awareness of epilepsy as found in this present study has also been reported by other studies in tropical Africa.[15,22,28] This dearth of knowledge about epilepsy has important significance in the fight to bring epilepsy out of the shadows as it affects both the people's attitude towards epilepsy and the health seeking behaviour of people living with epilepsy and their care givers.

Most participants in the study reported that the cause of epilepsy is medical, a finding similar to reports of several previous studies.[16, 28, 29] Similarly, varying proportions of the participants in the present study also described epilepsy as a mental illness or a brain disorder and agreed that epilepsy is transmissible from person to person. The reason for this disturbing combination of false and good ideas about epilepsy found in this study with a higher population of younger adults with relatively high level of education may be explained from the unreliability of information available in the electronic/digital media and also from poorly trained and uninformed health workers which were the major sources of information about epilepsy in this present study. The implication therefore is that any meaningful effort to bring epilepsy out of the shadows in the tropics will require comprehensive culturally adapted educational programs targeted not only on disseminating correct information about epilepsy but also messages that will dissuade the false beliefs about epilepsy in tropical communities.

General attitude towards epilepsy by participants in the present study though poor, the participants demonstrated good attitude towards response to care for persons with epilepsy. About seven in every ten participants in this present study agreed to take persons with epilepsy to hospital. However, a proportions of participants demonstrated negative attitude by agreeing that persons with epilepsy should attend special school (50.3%); persons with epilepsy should suffer stigmatization (37.1%) while only 5.9% of participants agreed to marry persons with epilepsy. These negative attitudes drive high level of stigmatization and social ostracism associated with epilepsy and have been linked to the unreliable informal sources of information about the disease.[13,28,30] Misinformation and traditional belief about epilepsy do not only drive negative attitude towards epilepsy but has also been identified as cause of epilepsy treatment gap.[31]

The present study also examined and found statistically significant associations between participants' level of knowledge on epilepsy and their socio-demographic characteristics like gender, marital status, religion and ethnicity. These findings are consistent with that of Lim *et al.*[32] and Neni *et al.*[33], who reported that the socio-demographic variables have significant association with poor level of knowledge. These findings also derive support from previous researchers, who documented that select socio-cultural and socio-demographic variables such as higher income would play a role in the level of knowledge on epilepsy.[24] Our study may be limited by the cross- sectional design. Thus further studies are needed in this area.

Limitations and strengths of the study: The study design was cross-sectional indicating that the associations found between variables may not necessarily be causal and may not accurately explain a change of knowledge and attitude over time in the target population. Various forms of biases such as reporting bias, social desirability bias and recall bias could result from this study. Also, self -reported practice may not match actual behaviours. These would have been minimized by the anonymity entrenched in data collection and assuring participants of strict confidentiality. Despite these limitations we think that our data increases the understanding of beliefs and misconceptions concerning epilepsy in rural Nigeria. A major strength of this study is the 100% response rate achieved.

CONCLUSION

There was high awareness of epilepsy among participants in this study however the knowledge of epilepsy was poor as well as high negative attitude towards epilepsy. The common sources of information on epilepsy were electronic/digital media and health workers, indicating that policies targeting adequate education of health workers on epilepsy and dissemination of appropriate culturally acceptable information about epilepsy through these routes may contribute greatly to the bridging of the epilepsy knowledge gap in tropical communities.

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