

www.ajbrui.org

Afr. J. Biomed. Res. Vol. 23 (Special Edition 1, July, 2020); 1 - 7

Research Article

The Stigma of Epilepsy Among Nigerian Subjects: A Cross-Sectional Study

Oderinde I.T. and Ogunniyi A.O.

Department of Medicine, College of Medicine, University of Ibadan. Ibadan, Nigeria.

ABSTRACT

Epilepsy is one of the least understood and most feared neurological disorders. It is associated with considerable stigma and discrimination, contributing to the immense psychosocial and emotional burden experienced by people living with epilepsy (PWE) particularly in developing countries. In order to fully understand the extent of this relationship, this study sought to assess the actual experience of discrimination, the degree of internalized stigma, and the perception (knowledge & attitude) of the general public towards epilepsy. Data on sociodemographic variables, internalized stigma and discrimination was collected from two groups of 103 eligible participants presenting at the Neurology and General outpatient clinics of the University College Hospital, Ibadan, using two structured interviewer-administered questionnaires. A high proportion of PWE (n=24, 57.1%) reported severe internalized stigma despite majority (76.9%) reporting not being discriminated against. Thirty-two respondents (56.1%) reported that they would not employ or work with someone known to have epilepsy. A considerable number of people (n=41, 82%) reported that they would help PWE away from danger during a seizure and 46 respondents claimed they were going to call for help, while 15 (of 42 respondents) reported that they would run away. While this study revealed quite a number of positives, it is apparent that there still exists a lot of ignorance and misconceptions about epilepsy and significant improvement is still needed with regards to addressing the stigma of epilepsy and the public attitude towards epilepsy and PWE.

Keywords: *Epilepsy, Stigma, Discrimination, knowledge & attitude.*

*Author for correspondence: Email: aogunniyi53@yahoo.com; Tel: + 234 8038094173

Received: September, 2019; Accepted: March, 2020; Published: July 2020

Abstracted by:

Bioline International, African Journals online (AJOL), Index Copernicus, African Index Medicus (WHO), Excerpta medica (EMBASE), CAB Abstracts, SCOPUS, Global Health Abstracts, Asian Science Index, Index Veterinarius

INTRODUCTION

Epilepsy is a chronic neurological condition characterized by recurrent seizures due to abnormal electrical discharge in the brain. With more than 50 million people living with epilepsy worldwide, it is recognized as a disease of major public health concern by the world health organization (WHO, 2012). An estimated 80% of people living with epilepsy reside in the developing and “economically backwards” countries of the world including Nigeria with a prevalence ranging from 5.3 to 37 per 1000 population (Akinsulore & Adewuya, 2010). Despite being one of the most common neurological disorders, epilepsy is perhaps the least understood and most feared disorder particularly in developing countries (Alem et al, 1999), contributing significantly to the insurmountable myth, prejudice and seemingly inseparable stigma associated with epilepsy. According to a study conducted among more than 5000 patients living in 15 countries in Europe, 51% reported feeling stigmatized and people with epilepsy who experienced

injury during a seizure reported a high feeling of stigma (Baker et al., 2000). However, the extent and manifestations of stigma vary from one locality to another as well as with the clinical context and social status of the individual (Jacoby et al., 1996; Jacoby, 1992; Jacoby, 1994).

Historically, epilepsy was considered a sacred disease resulting from the invasion of the human body by a god. It was thought that “only a god could deprive a healthy man of his senses, throw him to the ground, convulse him, and then rapidly restore him to his former self again” (Reynolds, 1988). In many African countries, epilepsy is also believed to be of spiritual etiology being attributed to witchcraft, demonic possession and poisoning, among many other traditional beliefs. Unfortunately, these beliefs have persisted through several generations and continue to influence public attitude towards epilepsy contributing a great deal to individuals with epilepsy being misunderstood, stigmatized and discriminated against.

Another popularly held belief is the contagiousness of epilepsy, it’s “spread” being believed to be via urine, saliva,

sweat or other bodily excretions produced by persons with epilepsy at all times or during a seizure (Sanya et al., 2005; Tekle-Haimanot et al., 1991; Rwiza et al., 1993). It is also believed to be transmissible via direct contact with/touching individuals with epilepsy. These result in unwillingness to help protect or provide assistance to people with epilepsy during a seizure. It also results in affiliational/courtesy stigma in which relatives, friends and companions of individuals with epilepsy are stigmatized as well. For instance, 20% of mothers reported being stigmatized because of their child's epilepsy (Colaizzi, 1978). Persons with epilepsy and their relatives thus prefer to keep their condition a secret resulting in poor health seeking behavior which together with inadequate access to healthcare, poverty and lack of social support contributes to the high morbidity and poor quality of life of affected individuals.

Anecdotal reports also show that it is commonplace in certain parts of Africa (Nigeria inclusive) to put the leg of individuals with epilepsy in fire during a seizure as this is thought to be the cure for the disorder. This, in addition to injuries sustained during a seizure, contributes to the stigma and consequent low self-esteem experienced by individuals with epilepsy. The nature and degree of stigma has been reported to be influenced by the clinical course, frequency of seizures, drug side effects, age, gender, educational and employment status among many other factors (Achor et al., 2017).

The impact of these misconceptions and stigma on the ability to carry out specific social roles is immense. Unemployment and underemployment rates are higher amongst individuals with epilepsy (WHO, 2001), even in situations when having epilepsy has no direct bearing on their suitability for the jobs. Suicide rates have also been reported to be higher among persons with epilepsy. For instance, between 2003 and 2011, an average of 17 out of 100,000 people with epilepsy, aged 10 years and older, died from suicide each year, compared to 14 out of 100,000 in the general population. Among adults aged 40-49 years, those with epilepsy died more often from suicide (29%) than those without epilepsy (22%) (Tian et al., 2016).

The medical and surgical management of epilepsy has progressed considerably in the recent past with seizure remission possible in as many as 70% of patients with appropriate and timely treatment (Thomas & Nair, 2011). The advent of advanced diagnostic tools such as the video EEG, magnetic resonance imaging and other ancillary investigations have made it possible to identify specific epilepsy syndromes that respond best to surgery (Thomas & Nair, 2011). Despite these scientific advances, there has been little perceptible progress in the rehabilitation of persons with epilepsy particularly with respect to addressing the prevalent social stigma and increasing public awareness. The stigma of epilepsy, although having been significantly explored in developed countries, has not been adequately explored in Nigerian subjects.

This study, necessitated by the immense psychosocial burden of epilepsy and paucity of literature on the Nigerian perspective, therefore set out to assess the degree of stigma experienced by people with epilepsy in Nigeria and possible perpetuating factors of stigma. Data generated from this study

have the potential to develop a framework upon which strategies to combat the stigma of epilepsy in Nigeria can be built and management of the condition improved.

MATERIALS AND METHODS

Study design: The study was hospital-based, incorporating two cross-sectional studies carried out among people with a diagnosis of epilepsy and individuals without epilepsy.

Study population: Study participants included 42 individuals, aged 10-80 years, with a clinical diagnosis of epilepsy and a second set of 61 members of the general public (i.e. people without epilepsy).

Study location: The study was conducted at the Neurology Clinic of the Medical Outpatient's Department as well as the General Outpatient's Department of the University College Hospital, Ibadan, a tertiary Hospital located in Ibadan North Local Government area of Oyo State, Southwestern Nigeria.

Sample Size Determination: The sample size for the study was calculated using the Leslie Kish formula (Kish, 1965) for computing effective sample size. The estimated sample size was 122 (61 people with epilepsy and 61 people without epilepsy) using prevalence of epilepsy of 37% (Akinsolure et al., 2010) at 95% level of confidence and 5% allowable margin of error. Non-response was adjusted for using a 10% non-response rate.

Sampling technique: Consecutive patients with a diagnosis of epilepsy and patients without epilepsy were recruited as they presented in the hospital for routine follow-up. All consenting individuals with a clinical diagnosis of epilepsy aged 10-80 years were recruited for the study. Individuals were required to have active/ongoing epilepsy. Likewise, consenting individuals without epilepsy aged 10-80 years were recruited. Patients with comorbid mental/psychiatric conditions were excluded from the study.

Data collection

Instrument(s) for data collection: Two semi-structured interviewer-administered questionnaires, one for each of the two groups of participants, were used for data collection. The questionnaires were pretested among a select group of patients who were not included in the study. Necessary adjustments were made prior to administration. The questionnaires contained sections on

- **Sociodemographic** (age, sex, marital status, religion, level of education, occupation, and epilepsy characteristics for individuals with epilepsy)
- **Discrimination and Stigma Scale version 12 (DISC-12):** A 32-item instrument for recording the discrimination experienced during the preceding 12 months by individuals with mental illness. It had previously been utilized in the Nigerian environment by Oshodi et al., in 2013. It was used in this study to assess the level of stigma experienced by people with epilepsy.
- **Internalised Stigma of Mental Illness Inventory Scale (ISMI):** A 29-item instrument designed to measure the subjective experience of stigma. It had also been

previously used in the Nigerian setting (Oshodi et al., 2013).

- **Rosenberg Self-esteem Questionnaire:** A 10-item instrument that assesses the self-esteem and current feelings of respondents. It was used in this study to assess and compare the self-esteem of both PWE and people without epilepsy.
- **5. General Health Questionnaire (GHQ-12):** An instrument used to identify psychological distress among adults. It comprises of 12 items, each item accompanied by four possible responses. It has been validated (Gureje & Obikoya, 1990) and adapted for use in the Nigerian environment (Yussuf et al., 2013; Issa et al., 2014).
- **6. Stigma scale of epilepsy (SSE):** It is a 5-item instrument that was modified and adapted for use in assessing the views and possible misconceptions of people without epilepsy about epilepsy. A pretest was carried out to ascertain its usefulness in the Nigerian environment.

Data Collection Procedure: Participants were approached on their routine visit to the outpatient Neurology Clinic as well as the General Outpatient Department (GOPD) of the University College Hospital, prior to and/or after consultation. A written informed consent was obtained after adequate information about the study had been given. The questionnaires were administered with the investigator and assistants available to provide clarifications and guidance as required.

Data Entry & Analysis: Data collected was cleaned and completeness ensured. Data entry and analysis was done using the 23rd version of the statistical package for social sciences software (SPSS Inc., Chicago, IL). Categorical variables like age, sex, etc. were summarized and frequencies and cross-tabulations of variables were generated. The Pearson's Chi-square test and Fischer's exact was used to test association between stigma and possible contributing factors. Statistical significance was set at p-value <0.05.

Ethical consideration: Ethical Approval was obtained from the UI/UCH ethics committee. Approval was also sought from the GOPD and Neurology Outpatient Department. Informed consent was obtained from the participants after clearly explaining the voluntary and confidential nature of the study. Names of respondents were not used in order to maintain confidentiality. In addition, the participants were informed of the relatively insignificant risk associated with the study and the ability to pull out of the study anytime they deemed fit.

RESULTS

Sociodemographic Characteristics of Participants: A total of 103 individuals took part in the study, with males (59.5%) constituting the majority of people with epilepsy. Among individuals without epilepsy, 52.5% were female and 47.5% were male.

Table 1.
Sociodemographic characteristics of participants

Characteristics	People with Epilepsy	People Without Epilepsy
Sex		
Male	25 (59.5%)	29 (47.5%)
Female	17 (40.5%)	32 (52.5%)
Age (years)		
Mean ± S.D	33 ± 13.7	31.4 ± 12.0
Median	29	28.5
Range	13-67	14-70
Interquartile Range	22.3	14.8
Marital Status		
Single	25 (62.5%)	37 (60.7%)
Married	15 (37.5%)	24 (39.3%)
Level of Education		
Primary	3 (7.3%)	3 (5.1%)
Secondary	18 (43.9%)	14 (23.7%)
Tertiary	19 (46.3%)	42 (71.2%)
No Formal Education	1 (2.4%)	
Occupation		
Teacher	3 (7.9%)	3 (5.3%)
Civil Servant	4 (10.5%)	17 (29.8%)
Trader	4 (10.5%)	11 (19.3%)
Self-employed	11 (28.9%)	10 (17.5%)
Unemployed	4 (10.5%)	5 (8.8%)
Others	12 (31.6%)	11 (19.3%)
Religion		
Christianity	29 (61%)	46 (76.7%)
Islam	13 (39%)	14 (23.3%)

The mean age of participants with epilepsy was 33 ± 13.7 years while people without epilepsy had a mean age of 31.4 ± 12.0 years. Single individuals were relatively more in both groups of participants (62.5% in People with epilepsy and 60.7% in people without epilepsy). Majority of participants in both groups had tertiary level of education (46.3% of PWE and 71.2% of people without epilepsy). Details of the sociodemographic characteristics of the participants are summarized in Table 1.

Epilepsy-related Characteristics: Table 2 summarizes the seizure-related characteristics of the participants. Majority of people with epilepsy, 30 (78.9%) were characterized as having focal onset seizures with an average age at onset of 23.5 ± 15.3 years and mean number of years lived with epilepsy of 9.6 ± 8.8 years. All participants were on medical treatment with most (89.7%) reporting to be very regular on medications. Fourteen people with epilepsy (33.5%) reported having sought other treatment modalities other than medical in the past with the use of herbal remedies (16.7%) and spiritual/religious modalities (12%) being the most common.

Table 2.
Epilepsy-related Characteristics

Epilepsy-related Variables	Statistics
Seizure Type	
Partial	30 (78.9%)
Generalized Tonic-Clonic	8 (21.1%)
Age at onset (years)	
Mean ± S.D	23.5 ± 15.3
Childhood	11 (27.5%)
Adolescence	3 (7.5%)

Adulthood	26 (65%)
Age at diagnosis (years)	
Mean ± S.D	24.8 ± 15.2
Childhood	9 (24.3%)
Adolescence	3 (8.1%)
Adulthood	25 (67.6%)
Seizure Duration (years)	
Mean ± S.D	9.6 ± 8.8
Median	7
Range	0-34
Compliance with Medications	
Very Regular	35 (89.7%)
Fairly Regular	3 (7.7%)
Not Regular	1 (2.6%)
Previous Treatment Modalities Sought	
Prayer/Church/spiritual	14 (33.5%)
Herbal Remedies	5 (12%)
Herbs & Prayers	7 (16.7%)
Traditional Healing Home	1 (2.4%)

Internalized Stigma and Experience of Discrimination: Of the 42 individuals with epilepsy, 24 (57.1%) were classified as having severe internalized stigma. The experience of severe internalized stigma was higher among males (58.3%) compared to females (41.7%); however, the observed difference was not statistically significant ($p = 0.856$). Married individuals constituted the minority (43.5%) of PWE with severe internalized stigma compared with single individuals (56.5%). With $p = 0.364$, this difference was not statistically significant. A higher proportion of individuals with partial seizures (86.4%) reported having severe internalized stigma compared with individuals with generalized seizures (13.6%) although this difference did not attain statistical significance ($p = 0.243$). When considering individuals with severe level of internalized stigma, PWE with short duration of disease (47.1%) were more than people with long duration of the disorder (35.3%) but the observed difference was insignificant ($p = 0.604$).

When asked what they thought about society's attitude towards people with epilepsy, 66.7% of people without epilepsy believed PWE were being discriminated against. However, majority of people with epilepsy (76.9%) reported not being discriminated against compared with 23.1% who reported being the subject of discrimination. This was further confirmed by an objective assessment of experienced stigma/discrimination (DISC-12) which revealed that only 7.1% of PWE had experienced high level of discrimination compared with 92.9% who reported low level of experienced stigma/discrimination. For instance, only 7.5% and 7.7% of PWE either agreed or strongly agreed to being unfairly treated in finding and keeping a job respectively while only 7.3% agreed to being avoided/shunned by people who knew they had epilepsy.

Table 3. Severe internalized stigma and sociodemographic and epilepsy-related characteristics.

Severe Internalized Stigma
N= 24 (57.1%)

Demographic & Epilepsy Characteristics	Freq. (N)	%	X ²	p-value
Sex				
Male	14	58.3	0.033	0.856
Female	10	41.7		
Marital Status				
Single	13	56.5	0.825	0.364
Married	10	43.5		
Seizure Type				
Partial	19	86.4		0.243
Generalized	3	13.6		
Seizure Duration (years)				
Short duration (<5)	8	34.8	1.008	0.604
Intermediate (5-10)	7	30.4		
Long Duration (>10)	8	34.8		

Knowledge of Epilepsy & Attitude Towards People with Epilepsy

When asked if they knew anyone with epilepsy, only 27.1 % reported having a friend, relative, or spouse with epilepsy, however, majority (n= 34, 56.7%) reported never having witnessed a seizure. On the contagiousness of epilepsy, only 22 people (41.5%) believed epilepsy to be contagious with contact with bodily fluids of PWE being the most commonly reported mode of transmission (61.8%). Although a high proportion of respondents (84.3%) believed medications to be one of the best treatment options for epilepsy, majority still reported spiritual intervention (77.1%) and herbal remedies (61%) to be the best treatment option for the disorder.

Table 4. Knowledge and beliefs about epilepsy

Variables	Yes n (%)	No n (%)	Total
PWE feel able to control their own epilepsy	16 (29.6)	38 (70.4)	54
Epilepsy is contagious	22 (41.5)	31 (58.5)	53
Mode of transmission			
Touching people with epilepsy	7 (25.9)	20 (74.1)	27
Touching body fluids of PWE	21 (61.8)	13 (38.2)	34
Epilepsy runs in families	34 (59.6)	23 (40.4)	57
Cause of epilepsy			
Demonic possession	23 (44.2)	29 (55.8)	52
Evil spirits	21 (42.9)	28 (57.1)	49
Head injury	30 (61.2)	19 (38.8)	49
Stepping on dead lizards	6 (12.8)	41 (87.2)	47
Ancestral Curse/Sin	17 (38.6)	27 (61.4)	44
Best treatment for epilepsy			
Spiritual Intervention	37 (77.1)	11 (22.9)	48
Drugs	43 (84.3)	8 (15.7)	51
Herbal Remedies	25 (61)	16 (39)	41
Surgery	22 (53.7)	19 (46.3)	41

Regarding attitude towards people with epilepsy, 32 people (56.1%) reported that they would not employ or work with someone known to have epilepsy while a considerable number (n=52, 89.7%) reported that they would not get into a relationship or marry someone with epilepsy. However, a large proportion of participants (68.4%) reported that they would freely associate themselves with someone known to

have epilepsy and 57 (95%) reported never having treated PWE unfairly. See Table 5. for details on attitude towards people with epilepsy.

Figure 1 displays the responses of people without epilepsy when asked what they would do if they were to witness a seizure. A considerable number of people (n=41, 67.2%) reported that they would help people with epilepsy away from danger during a seizure and 46 respondents claimed they were going to call for help, while 15 respondents reported that they would run away. Twenty-eight (60.9%) respondents also reported that they would put a spoon in the mouth of a person having a seizure.

Table 5.
Attitudes towards people with epilepsy

Variables	Yes n (%)	No n (%)	Total
Employ or work with someone with epilepsy	25 (43.9)	32 (56.1)	57
Share transport means with someone with epilepsy	39 (66.1)	20 (33.9)	59

Get into a relationship or marry someone with epilepsy	6 (10.3)	52 (89.7)	58
Consider a divorce if spouse was diagnosed with epilepsy	4 (7)	53 (93)	57
Allow ward befriend someone with epilepsy	39 (66.1)	20 (33.9)	59
Let child marry someone with epilepsy	8 (13.8)	50 (86.2)	58
Associate readily or freely with someone known to have epilepsy	39 (68.4)	18 (31.6)	57
Unfair treatment of someone with epilepsy	3 (5)	57 (95)	60
Children with epilepsy should not attend schools with other children	6 (10)	54 (90)	60
People with epilepsy should stay away from public places	8 (13.8)	50 (86.2)	58

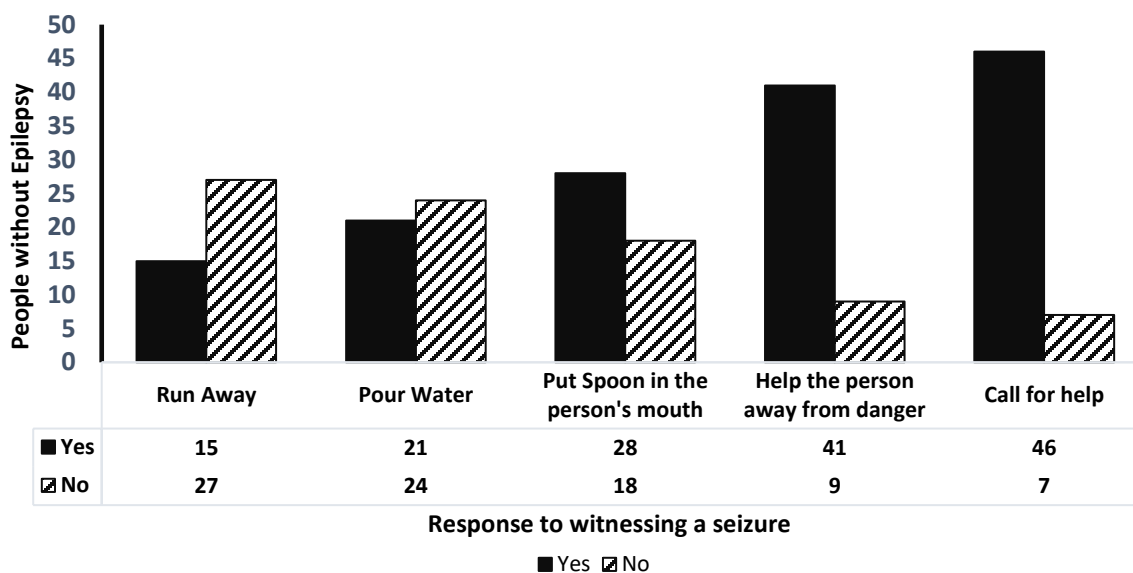


Figure 1.
Responses of people without epilepsy to witnessing a seizure

DISCUSSION

Familiarity with (someone with) epilepsy is thought to improve knowledge and attitude as well as reduce discrimination towards people with epilepsy. In the present study, only 27.1% of People without epilepsy knew someone with epilepsy and 56.7% had never witnessed a seizure. Similar findings were reported in Nigeria with 26% of non-epileptic respondents not knowing someone with epilepsy; however, in the same study, fewer participants (23%) had witnessed a seizure (Adum et al., 2016). Another study in rural Tanzania reported that 32.9% of participants had never witnessed a seizure (Rwiza et al., 1993). This low level of familiarity may reflect a low prevalence of epilepsy or the concealment of the condition by PWE in an attempt to avoid

discrimination. However, with 75.6% of respondents with epilepsy never having concealed their condition, the latter hypothesis was refuted.

This study showed that most participants with epilepsy (57.1%) had severe internalized stigma. Felt/internalized/perceived stigma has been reported by as few as 14% of people with seizures in remission, and as many as 51% of self-help group members (Jacoby, 2002). However, in the above study, felt stigma was associated with seizure frequency and illness trajectory in contradiction to the present study which found no significant association with seizure frequency. Adults with high felt stigma have also been reported to experience potentially greater difficulty with managing treatment regimens and medication adherence

(Izibeloko, 2015). In view of this, although the majority of PWE in this study were regular on antiepileptic medications (AEDs), continued adherence becomes a major concern. Perceived stigma has also been shown to account for more of the variance in quality of life (QOL) scores than clinical variables, hence an important predictor of QOL (Jacoby & Austin, 2002). The observed high level of internalized stigma therefore also raises concern about the negative impact on the quality of life of PWE in Nigeria.

The belief that epilepsy is contagious raises concerns about PWE getting help during a seizure and contributes a great deal to stigma and discrimination. In the present study, 41.5% of respondents (people without epilepsy) believed epilepsy to be a contagious disease. This finding contradicts that from a previous study conducted in Cameroon (Bain et al., 2013), in which a high percentage (65.1%) of the population believed epilepsy to be contagious. In another study conducted in eastern Nigeria, even more individuals (92%) believed epilepsy to be contagious (Adum et al., 2016). This disparity in findings could be due to the more rural setting of these studies compared to the more urban setting of the present study.

In response to questions about the cause(s) of epilepsy, majority of participants said “No” to demonic possession (55.8%), evil spirits (57.1%), ancestral curse/sin (61.4%), and stepping on dead lizards (87.2%) being the cause of epilepsy. Majority of respondents (61.2%) also reported head injury to be a cause of epilepsy and 84.3% believed epilepsy to be best treated with medications. These positive findings could be explained by the relatively high level of education of respondents, with 42 people (71.2%) having at least tertiary level of education. However, a considerable number of respondents also believed spiritual intervention (77.1%) and herbal remedies (61%) to be the best treatment modality for epilepsy. This is evidence that culture and religion still play crucial roles in the interpretation of epilepsy in the Nigerian society.

When asked what they would do if they witnessed a seizure, 49 respondents (82%) said they would be willing to help the individual experiencing the seizure away from danger while only 15 respondents said they would run away. This is in contrast to a study conducted in rural Tanzania which revealed that 33.5% of the respondents would keep away and not touch the person having a seizure (Rwiza et al., 1993). However, a relatively similar finding was reported in a study conducted in Hong-Kong china, with 76% of residents willing to offer help to individuals having a seizure (Fong & Hong, 2002).

Twenty-eight individuals (61%) thought they would need to put a spoon or any other object in the mouth of individuals having a seizure. This is consistent with a study in which 66.5% of participants thought they would need to put an object in the person’s mouth during a seizure (Adum et al., 2016). It is evident that, although mostly out of good intention, this ill-informed and harmful practice still persists in the Nigerian society and poses grave danger to the health of PWE.

With 89.7% of non-epileptic respondents having an issue marrying/getting into a relationship with someone known to have epilepsy and 86.2% of respondents reporting “no” to their wards marrying someone with epilepsy, it appears that marriage remains an important facet of life where PWE

continue to experience discrimination. However, with 92.9% of PWE never having been unfairly treated in marriage, it might not pose as much concern as the above finding might suggest. Employment is another important area of concern for PWE as majority (56.1%) of non-epileptic respondents said they would not employ or work with someone with epilepsy. However, majority of PWE in the present study were employed and very few had been unfairly treated in finding or keeping a job. In comparison, a study conducted in rural Bayelsa, Southern Nigeria revealed that all 120 respondents (100%) would not marry nor allow their children marry someone with epilepsy and 92.5% would not hire someone with epilepsy (Izibeloko et al., 2015). This is in stark contrast to a study conducted in New Zealand where only 5% of participants objected to their children marrying someone with epilepsy (Hills & Mckenzie, 2002). In addition, the study reported the knowledge and attitude of New Zealanders towards epilepsy to be very good while attributing the positive findings partly to the intensive education campaigns conducted by the Epilepsy Association of New Zealand since 1960 as well as the deinstitutionalization of people with disabilities over several decades (Hills & Mckenzie, 2002).

While this study revealed quite several positives, it is apparent that there still exists a lot of ignorance and misconceptions about epilepsy and significant improvement is still needed with regards to the public attitude towards epilepsy and PWE. To improve the quality of life of individuals with epilepsy, it is imperative that awareness campaigns and public education/enlightenment through the media and other forms of communication like the social media and interpersonal communication be instituted. Education should particularly focus on the causes, symptoms, treatment options and relevant first aid measures to be implemented in the event of a seizure. Although this study revealed compliance with AEDs to be good, subsidization of AEDs is recommended as this would encourage continued compliance, improve seizure control and ultimately reduce stigma. To combat the high level of internalized stigma observed in this study, it is recommended that clinical psychologists be more involved in the routine management of PWE as psychotherapeutic tools would go a long way in improving the mental and emotional wellbeing of PWE.

A major limitation of the study was the number of participants. The hospital-based setting of this study, in addition, increased the likelihood of exclusion of communities where myths and misconceptions about epilepsy still predominate and stigma is commonplace. A large-scale community-based study would be more representative. The study was also limited by its quantitative nature; the use of interviewer-administered questionnaires did not allow for adequate exploration of the stigma and discrimination experienced by PWE. In-depth interviews and/or focused group discussions would allow for more adequate exploration of experiences of PWE and is recommended for future studies. Although this study did not assess the suicide tendencies of PWE, interaction with PWE during the course of the study revealed quite a number of them to have contemplated suicide in the past. This is an important area which needs further research. Another limitation is the possibility of social desirability bias in responses obtained: informants may have

responded in ways they thought more socially/morally acceptable.

Acknowledgement

This research was supported by funding from the Medical Education Partnership Initiative in Nigeria (MEPIN). Special thanks to all participants, particularly patients with epilepsy, without whose cooperation the study would not have been possible. The authors appreciate the University College Hospital and the Heads of the Neurology Clinic and General Outpatient's Department for approving this study. Deepest gratitude Dr. Jibril Abdulmalik for his assistance with drafting the instruments used for the study.

REFERENCES

- Achor J.U, Ezeala-Adikaibe B.A, Obayi O.N, Ezeruigbo C.F.S, Ekenze O.S, and Onodugo O.D, (2017):** The Stigma of Epilepsy among Outpatients in a Tertiary Hospital in South-East Nigeria. *Open Journal of Psychiatry*, 7, 344-364.
- Adum A.N, Ebeze U.V, Ekwugha U.P, Ojiakor O.E. (2016):** Epilepsy, Stigmatization and the Publicity Imperative for Nigeria: An Assessment of NECAP-Rise Clinic Communication Initiative. *Research on Humanities and Social Sciences Vol.6, No.10.*
- Akinsulore A, Adewuya A (2010);** Psychological Aspects of Epilepsy In Nigeria: A Review *Afr. Journal Psychiatry* 2010; 13:351-6
- Alem A, Jacobsson L, Araya M, Kebede D, Kullgren G. (1999):** How are mental disorders seen and where is help sought in a rural Ethiopian community? A key informant study in Butajira, Ethiopia. *Acta Psychiatr. Scand. Suppl* 1999; 397:40-7.
- Bain L.E, Awah P.K, Takougang I, Sigal Y, Ajime T.T. (2013):** Public awareness, knowledge and practice relating to epilepsy amongst adult residents in rural Cameroon - case study of the Fundong health district. *The Pan African Medical Journal*. 2013; 14:32.
- Colaizzi P (1978):** Psychological research as the phenomenologists view it. In: Vale R, King M, editors. *Existential-Phenomenological Alternatives for Psychology*. London: Oxford University Press. 1978. p. 48-71.
- Reynolds E. H. (1988):** "Historical aspects," in *Epilepsy, Behaviour and Cognitive Function*, M. R. Trimble and E. W. Reynolds, Eds., pp. 3-8, John Wiley & Sons, New York, NY, USA, 1988.
- Sanya E. O., T. A. T. Salami, O. O. Goodman, O. I. N. Buhari, and M. O. Araoye (2005):** "Perception and attitude to epilepsy among teachers in primary, secondary and tertiary educational institutions in middle belt Nigeria," *Tropical Doctor*, vol. 35, no. 3, pp. 153-156.
- Fong C.G., Hung A. (2002):** Public Awareness, Attitude, and Understanding of Epilepsy in Hong Kong Special Administrative Region, China. *Epilepsia*, 43(3):311-316.
- Baker G.A., J. Brooks, D. Buck, and A. Jacoby (2000):**, "The stigma of epilepsy: A European Perspective". *Epilepsia*, vol. 41, no. 1, pp. 98-104.
- Rwiza H. T., W. B. P. Matuja, G. P. Kilonzo et al. (1993):** "Knowledge, attitude, and practice toward epilepsy among rural Tanzanian residents," *Epilepsia*, vol. 34, no. 6, pp. 1017-1023.
- Rwiza H. T., W. B. P. Matuja, G. P. Kilonzo, J. Haule, P. Mbena, R. Mwang'ombola, L. Jilek-Aall (1993):** Knowledge, Attitude, and Practice Toward Epilepsy Among Rural Tanzanian Residents. *Epilepsia* 34(6):1017-1023.
- Hills M.D, Mckenzie H.C (2002):**. New Zealand Community Attitude Towards People with Epilepsy. *Epilepsia* 43(12):1583-1589, 2002.
- Izibeloko O. Jack-Ide, Agnes E. Maliki, Olayinka Onasoga (2015):** Community Members' Perception of Epilepsy and their Attitude towards Persons Living with Epilepsy Disorders in a Rural Community of Bayelsa State, Nigeria. *International Neuropsychiatric Disease Journal* 4(4): 161-167.
- Jacoby A, (1992)** Epilepsy and Quality of Everyday Life: Findings from a Study of People with Well-Controlled Epilepsy. *Social Science and Medicine*, 34, 657-666.
- Jacoby A, (1994)** Felt versus Enacted Stigma: A concept Revisited. Evidence from a Study of People with Epilepsy in Remission. *Social Science and Medicine*, 38, 269-274.
- Jacoby A, Austin J.K. (2007)** Social stigma for adults and children with epilepsy. *Epilepsia* 48(9):6-9.
- Jacoby A. (2002)** Stigma, epilepsy and quality of life. *Epilepsy Behav* 3: S10-S20.
- Jacoby, A., Baker G.A., Steen N., Potts P., and Chadwick D.W. (1996)** The Clinical Course of Epilepsy and its Psychological Correlates: Findings from a UK Community Study. *Epilepsia*, 37, 148-161.
- Niu Tian, Wanjun Cui, Matthew Zack, Rosemarie Kobau, Katherine A. Fowler, Dale C. Hesdorffer (2003):**. Suicide among people with epilepsy: A population-based analysis of data from the U.S. National Violent Death Reporting System, 17 states, 2003-2011. *Epilepsy & Behavior*. 2016; 61: 210
- Tekle-Haimanot R., M. Abebe, L. Forsgren et al. (1991):** "Attitudes of rural people in central Ethiopia toward epilepsy," *Social Science & Medicine*, vol. 32, no. 2, pp. 203-209.
- Thomas SV, Nair A (2011):** Confronting the stigma of epilepsy. *Annals of Indian Academy of Neurology*. 2011;14(3):158-163.
- WHO fact sheet (2001):**. World Health Organization fact sheet No 166; Revised Feb. 2001.
- WHO fact sheet (2012):** World Health Organization (WHO) Fact Sheet: No 99, October, 2012. WHO Media Centre Available from: www.who.int/media/centre/en.