

ORIGINAL ARTICLE

Frequency and correlates of perceived stigma in a sample of Nigerian people with epilepsy

Michael B FAWALE¹, Mayowa O OWOLABI², Adekunle F MUSTAPHA³,
Morenikeji A KOMOLAFE¹, Adesola OGUNNIYI²

AFFILIATIONS

¹ Neurology Unit
Department of Medicine
College of Health Sciences
Obafemi Awolowo University
Ile-Ife, NIGERIA

² Neurology Unit
Department of Medicine
College of Medicine
University of Ibadan
Ibadan, NIGERIA

³ Neurology Unit
Department of Medicine
College of Health Sciences
Ladoke Akintola University of
Technology, Osogbo, NIGERIA

CORRESPONDING AUTHOR

Michael B FAWALE
Department of Medicine
Faculty of Clinical Sciences
College of Health Sciences
Obafemi Awolowo University
Ile-Ife, NIGERIA

Phone: +234 706 509 3947

Email: bimbofawale@yahoo.com

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ABSTRACT

Background: Adults with epilepsy face a lot of stigma in the various Nigerian settings, mostly based on wrong assumptions on the disease.

Objective: To determine the frequency of perceived stigma and to identify the sociodemographic and clinical factors associated with perceived stigma among adults with epilepsy.

Methodology: The 3-item epilepsy stigma scale was completed by 99 adults with confirmed diagnosis of epilepsy. Socio-demographic and clinical details were, also, obtained.

Results: A total of 99 adults (58 males, 41 females) were recruited for the study. The frequency of perceived stigma was 51 (51.5%) of which, 28 (28.3%) felt severely stigmatized by the disease while 13.1% and 10.1% reported low and moderate levels of perceived stigma, respectively. Logistic regression analysis identified time-to-antiepileptic-drug-treatment and number of AEDs as independently associated with perceived stigma.

Conclusions: The frequency of perceived stigma among our adults with epilepsy is high. Delayed time to AED treatment and number of AEDs may be important correlates of perceived stigma in adults with epilepsy. Further studies are required to ascertain the differential effects of these factors on perceived stigma while controlling for potential psychiatric comorbidities.

Keywords: Acts of discrimination, anti-epileptic drugs, time to treatment, sub-Saharan Africa

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INTRODUCTION

Epilepsy is still a highly stigmatizing disease, particularly in sub-Saharan African cultures.^{1,2} Enacted stigma (actual acts of

discrimination against individuals with epilepsy solely because of their epilepsy) has the potential of eliciting perceived or felt stigma (shame of having epilepsy and fear of

encountering stigma) in people with epilepsy.^{3,4} Perceived stigma has the facility to impair self-esteem, self-efficacy and sense of mastery in adults with epilepsy.^{5,6} Individuals who feel stigmatized due to their epilepsy tend to have higher rates of anxiety, depression and decreased life satisfaction.⁶ Consequently, the stigma associated with epilepsy has profound negative effects on quality of life.⁶

In fact, stigma may be as important as clinical factors such as seizure frequency and anti-epileptic drug (AED) side effects in determining quality of life (QOL) in people with epilepsy (PWE).^{7,8} Perceived stigma also has the propensity of driving people with epilepsy into the shadows, thus, undermining its diagnosis and treatment.⁹

An association, also, exists between perceived stigma and poor drug compliance in those who are on AED treatment.¹⁰ Epilepsy-associated stigma appears to be a global phenomenon cutting across cultures and value systems but reports suggest a higher prevalence and greater significance in resource-poor settings.¹¹

The high prevalence of stigma and its profound influence on QOL provide ample justification for investigations into its predictors as they will be potential targets for preventive and ameliorative interventions.

This study is aimed at determining the burden of perceived stigma among adults with epilepsy and identifying the demographic and disease-related factors associated with it.

METHODOLOGY

Subjects: This cross-sectional study was conducted in the Neurology Unit of Department of Medicine, University College

Hospital (UCH), Ibadan, Nigeria. Consecutive adults aged ≥ 18 years with a diagnosis of epilepsy were recruited for the study. Those who did not give their informed consent were excluded.

Questionnaires: The 3-item Epilepsy Stigma Scale was completed by 99 consecutive patients (58 male, 41 female) with confirmed diagnosis of epilepsy. This scale was adapted from a measure originally designed to assess the perceived stigma of stroke. It consisted of three items requiring a simple "Yes" or "No" response, e.g. "Because of my epilepsy: "I feel that some people are uncomfortable with me". It has a simple scoring system of zero or one for each item; a total score of one represents a low degree, two, moderate degree and three, a high degree of perceived stigma.¹² Sociodemographic data and disease-related variables were obtained.

The subjects were stratified into none, low-moderate and high seizure severity groups based on the number of seizures in the previous 6 months and seizure type (a modification of the criteria for seizure-specific categorization of severity of epilepsy used by Devinsky, *et al*).¹³ On this scheme PWE are stratified into seizure severity categories based on the number of seizures in the previous year and seizure type such that low, moderate and high seizure severity levels for simple partial and absence seizures correspond to 1 - 20, 21 - 100 and 101-200 seizures, respectively, in the previous year.

For complex partial seizures, low, moderate and severe seizure severity corresponded to 1-4, 5-12 and 13-24 seizures, respectively, in the previous year while for generalized tonic-clonic seizures, they corresponded to 1, 2-4 and 5-12 seizures, respectively, in the previous year. In this study, this was modified by obtaining seizure frequency data

in the previous 6 months, therefore, half of the seizure frequencies required were used for categorization into seizure severity groups.

Ethical Clearance: Ethical approval was obtained from the Health Research Ethics Committee of the University of Ibadan/University College Hospital, Ibadan, Nigeria.

Statistical Analyses: To identify factors that predict report of stigma, the subjects were dichotomized into “perceived stigma” and “no perceived stigma” groups. The differences in mean of continuous variables were analyzed using student *t-test* and relationship between report of perceived stigma and categorical variables was tested using the *Chi square test*.

The relationship between level of perceived stigma and these variables was further investigated using one-way *analysis of variance* (ANOVA) for categorical variables and product moment coefficient for continuous variables. One-way ANOVA multiple comparison *post hoc* tests were used to detect where differences between levels of perceived stigma lie. The significance level was set at 0.05. Data were analyzed with the *statistical package for social science* (SPSS) version 16.

RESULTS

Subjects' Demographic and Clinical Characteristics

A total of 99 adults (58 males, 41 females) were recruited for the study, with a mean age of 34.5 ± 14.7 years and a range of 18–75 years. Forty-one (42.3%) had tertiary level education; 76 were in paid employments. About half (49.4%) earned more than 40 dollars monthly.

Complex partial seizures were the most frequent seizure type occurring in 56 (56.6%). Out of the 86 (86.9%) subjects with partial

seizures, 76 (76.8%) had secondary generalization. There was no putative cause or risk factor for epilepsy in 57 (57.4%) of the subjects. The mean age of onset of epilepsy was 21.1 ± 16.4 years with a range of 1–73 years. The mean duration of epilepsy was 14.2 ± 11.3 years while, the mean duration of AED treatment was 9.0 ± 8.9 years. About half of the respondents (47.1%) commenced AED treatment after 5 years of onset of the disease. Ninety (90.9% of respondents) were on AEDs, of these, 64 (64.6%) were on one AED.

Eighteen (18.2%) of the respondents had been seizure-free in the previous 6 months while 50% were in the high seizure severity category. About a quarter (23.3%) of the respondents had exclusively nocturnal seizures, another quarter (24.4%) had exclusively daytime seizures while the remaining half (52.2%) had no specific diurnal seizure pattern (Table 1).

Frequency of Perceived Stigma of Epilepsy

The frequency of report of perceived stigma among the subjects was 51 (51.5%), of these, 28 (28.3%) felt severely stigmatized by the disease while 13.1% and 10.1% reported low and moderate levels of perceived stigma, respectively.

Correlates of Perceived Stigma

Factors Associated with Report of Perceived Stigma:

Participants who reported perceived stigma, compared with those who did not, were more likely to have higher seizure severity levels ($p < .001$), more likely to be on higher numbers of antiepileptic drugs ($p = .003$), and more likely to have earlier-onset of epilepsy ($p = .016$). They were, also, more likely to have longer duration of epilepsy ($p = .009$), and more likely to have commenced AED treatment after 5 years of the onset of recurrent seizures ($p = .001$).

Diurnal seizure rhythm was, also, associated significantly with perceived stigma ($p = .008$) such that participants who had exclusively daytime and exclusively nocturnal seizures had significantly less report of perceived stigma compared with those whose seizures had no diurnal seizure pattern.

Controlling for seizure severity, the association between diurnal seizure rhythm only remained significant in the high seizure severity group ($p = .002$). There was no significant association between level of education and report of perceived stigma ($p = .214$), however, when educational level was dichotomized into non-tertiary and tertiary education, the report of stigma perception was significantly higher among participants who had had no tertiary education compared to those with tertiary education ($p = .035$). Other factors were not significantly associated with stigma perception (Table 2).

Logistic regression analysis of all predictors identified on bivariate analysis yielded increasing number of AEDs ($OR = 1.420$, 95% $CI = 1.101$ to 15.549 , $p = .036$) and time to AED treatment above 5 years ($OR = -1.678$, 95% $CI = .056$ to $.621$, $p = .006$) as the only independent correlates of perceived stigma in epilepsy. The odds of stigma perception is 4 times higher with each increase in the number of AEDs, and 5times higher in people who commenced treatment after 5years of the onset of seizures compared to those who commenced 5years and below.

Factors Associated with Increasing Severity of Perceived Stigma:

Higher scores on the stigma scale were associated with lower age of onset of epilepsy ($p=.003$), longer duration of epilepsy ($p= .035$), and increasing severity of epilepsy in the previous six months ($p= .018$).

Other factors include increasing number of AEDs ($p= .036$), and increasing time to AED treatment ($p=.014$) (Table 3). Analysis of strength of association revealed weak to moderate correlation between these variables and perceived stigma score (Table 5).

When time to AED treatment was stratified into ≤ 1 year, >1 year ≤ 5 years and >5 years, there was moderate correlation between level of severity of perceived stigma and time to AED treatment ($rs= .333$, $p=005$). Lack of diurnal seizure pattern was associated with higher scores on the stigma scale as well ($p = .001$).

There was no significant association between the degree of perceived stigma and other variables (Tables 3 and 4).

DISCUSSION

The frequency of report of perceived stigma among PWE in this study was very high; more than half of the subjects reported perception of stigma, while about a third reported feeling severely stigmatized. High as the frequency of perceived stigma in this study might seem, it is unexpectedly low when compared with the relatively high frequencies of perceived stigma reported from previous studies in sub-Saharan Africa (SSA) and when viewed against the background of high level of negative attitudes towards epilepsy in this part of the world.^{13,14,15,16} The burden of perceived stigma among PWE in SSA is consistently reported to be high, mostly above 50%.

Rafael, *et al* in Benin Republic reported a prevalence of 68.7%, while Atadzhanov, *et al* in Zambia reported 89.3% with report of severe perception of stigma in 50% of participants.^{7,17}

Generally, higher frequencies of perceived stigma are reported from developing countries compared to developed countries probably due to the prevailing negative attitudes towards epilepsy driven by ignorance and negative beliefs in developing countries.¹⁷

Time to AED treatment (the interval between the onset of the disease and AED treatment) and the number of anti-epileptic drugs (AED), emerged as independent predictors of perceived stigma in this study. The frequency and severity of perceived stigma increased with the number of years spent with epilepsy before the initiation of AED treatment. About half of our study participants commenced AED treatment after 5 years of the onset. The odds of perceived stigma were 5 times higher in individuals who commenced treatment after 5 years of the onset of epilepsy compared with those who commenced within the first 5 years (Table 2).

We also found that as time to AED treatment increased from ≤ 1 year, >1 year, ≤ 5 years to >5 years, the severity of perceived stigma increased ($p = 005$) (Table 5). While most past studies investigated the relationship between perceived stigma and duration of epilepsy, duration of AED treatment and age of onset of epilepsy, time to AED treatment as it relates to perceived stigma has not been the focus of many studies.^{6,10,14,16} Time to AED treatment may be a more important predictor of stigma perception and determinant of perceived stigma severity as found in this study. The association between time to AED treatment and perceived stigma may be bi-directional.

As a result of the stigma attached to epilepsy, PWE have a reduction in their educational and employment opportunities with the consequent socio-economic limitations.¹⁸

Additionally, in a bid to reduce the likelihood of encountering enacted stigma, PWEs also tend to conceal their disease status.¹⁷

Furthermore, epilepsy-related stigma is more prevalent in resource-poor settings where access to health care is low; all these reduce the chances of care.^{18,19} Thus, the stigma of epilepsy has the facility to undermine care-seeking and prolong the time spent with epilepsy before treatment initiation.

Time to AED treatment is particularly an important potential outcome predictor requiring investigation in SSA where a large proportion of PWE live without AED treatment.²⁰ The global burden of epilepsy stigma appears to parallel global epilepsy treatment gap as both are higher in resource-poor countries compared to developed countries.^{19,21} In a recent systematic review, the epilepsy treatment gap which is the proportion of people who warrant medical care but are not receiving AEDs, increased as countries' income status increased.²²

In this study, the report of felt stigma also increased as the number of AEDs increased such that subjects who reported feeling stigmatized by their epilepsy took significantly higher number of AEDs compared to those who did not.

The association between AED side effects and perceived stigma is well documented in the stigma literature but the potential influence of the number of anti-epileptic drugs on stigma perception has not been well explored.^{6,22} Lee and colleagues investigated the relationship between the number of AEDs and perceived stigma and, in contrast to our finding, found no significant association between them.²³ Expectedly, the number of AEDs increased with seizure severity in our sample ($r = .258$, $p = .021$) but adjusting for seizure severity did

not significantly modify its independence in predicting perceived stigma.

Scambler and Hopkins proposed witnessed drug-taking as a stigma cue which could lead others to suspect 'undesirable differentness' about the individual with epilepsy.³ Golin, *et al* named necessity of taking frequent medication and uncontrollable side effects as types of stigma cues that make it more difficult to conceal stigma and lessen the degree of control people have over their stigmatized identity.²³

We also found significant association between perceived stigma and disease severity on bivariate analysis. There was also moderate positive correlation between seizure severity and the severity of perceived stigma. There was significant difference in the report of perceived stigma between seizure-free subjects (16.7%) and those with persisting seizures (56.9%). While available data from SSA do not particularly show the effect of disease remission and seizure severity on perceived stigma, studies from outside SSA have consistently shown that individuals in remission are less likely to report perceived stigma compared to those with persisting seizures.^{14,17,24,25}

It is remarkable that seizure freedom for at least 6months could make so much difference in the perception of social wellbeing of individuals with epilepsy. On the other hand, that seizure freedom for at least 6months does not guarantee complete freedom from perceived stigma. This also may suggest that other factors may contribute to the dynamics of epilepsy-associated felt stigma.²³ Report of perceived stigma by participants of all disease severity categories corroborates the argument of Reidpath, *et al* that societies generally stigmatize whole categories of people perceived to have poor social value, rather

than individuals.²⁶ However, seizure freedom appears to minimize stigma perception.²⁷

Information regarding the potential psychosocial implications of the chronobiology of epileptic seizures is scanty in the epilepsy literature.²³ We found a significant association between seizure diurnal pattern and perceived stigma on bivariate analyses (Table 4) which, however, disappeared when other factors were adjusted for. Report of perceived stigma was also associated, but not independently, with earlier age of onset of epilepsy and longer duration of the disease. Older age of onset of epilepsy and longer disease duration have been inconsistently reported as predictors of perceived stigma in epilepsy.^{6,28}

CONCLUSION

The frequency of perceived stigma among our sample of adults with epilepsy is high. The findings of this study suggest that clinical factors might be stronger predictors of perceived stigma compared to demographic factors.

Delayed time to anti-epileptic drug treatment and number of antiepileptic drugs are the strongest correlates of perceived stigma in our sample. Seizure freedom for at least 6months significantly reduces perceived stigma. Seizure diurnal rhythm may modify stigma perception in adults with epilepsy.

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