

Limitations in education, employment and relationship amongst persons with epilepsy: the experiences from Benin City, NigeriaFrancis E Odiase,¹ Edith O Kayode-Iyasere²**Abstract**

Background: The persons with epilepsy have higher rates of educational underachievement, unemployment and being unmarried. These socioeconomic consequences of epilepsy can be more difficult to overcome than the seizures. In Nigeria there is a paucity of information on the socioeconomic limitations experienced by persons with epilepsy (PWE). We therefore sought to determine the predictors of these socioeconomic variables amongst PWE in Benin City, Nigeria.

Methods: This was a cross-sectional study, done at the neurology clinics of the University of Benin Teaching Hospital and the Central Hospital, Benin City. Persons on treatment for epilepsy were consecutively recruited. Using a structured questionnaire the demographics, clinical characteristics and socioeconomic experiences with regards to education, employment and relationships were obtained.

Results: One hundred and thirty PWE were recruited. The mean age was 37 ± 10.3 years, range 25 to 55yrs, with 54% being males, while 53.1% have had epilepsy for over 10yrs. About

45% have comorbid conditions, 51% are not adherent to anti-epilepsy drugs, while 49.2% have had stigma experience. Approximately 47% have had more than 10 years of schooling, about 56.2% are employed while 55.4% are in an intimate relationship. Educational underachievement was predicted by stigmatization, while unemployment and not being in a relationship was predicted by stigmatization and longer duration of epilepsy.

Conclusion: The high proportion of the participants with socioeconomic challenges is worrisome. It is hoped that meeting the educational and vocational needs of PWE, in addition to public campaign on epilepsy could reverse the situation.

Keyword. Epilepsy, education, employment, relationship, stigmatization, socio-economics.

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Introduction

Epilepsy is a common neurologic disease affecting over 50 million persons worldwide, and about 80% of these live in the developing countries, with poor infrastructure and limited health manpower. Epilepsy accounts for approximately 1% of global burden of disease according to WHO, and in brain disorders it is amongst the four most important causes of personal and socioeconomic loss.¹

There have been advances in the diagnosis and treatment of epilepsy, but these have not abolished the stigmatization, and psycho-socioeconomic burden of this disease especially in the developing counties. The disease is known to create profound limitations in the lives of sufferers in aspects of schooling, occupation and marriage.^{2,3}

With a prevalence rate of epilepsy in Nigeria ranging from 5.3 to 37 per 1,000 people, there may be between 1 to 7.5million persons with epilepsy (PWE) in Nigeria.³ This is staggering in view of the infrastructural deficits and dearth of expertise that is common in many resource

poor nations.^{2,3}

Epilepsy is characterized clinically by transient or prolonged episodes of recurrent seizures with involuntary movement of any or all parts of the body, sometimes with loss of consciousness. Traditionally clinicians managing individuals with epilepsy may be more concerned with seizure control and minimizing adverse effects of anti-epileptic drugs (AEDs). A person with epilepsy (PWE) is said to have his/her seizure controlled when they are seizure free and there are no or minimal adverse effects from AEDs. These mandates are very fundamental to the care of the PWE, however the PWE may be more worried about the social, psychological and economic issues about epilepsy, including education, employment and marriage. The PWE have been found to have higher rates of educational underachievement, unemployment and been unmarried.^{2,4} These concerns of the PWE are said to affect the quality of life of these individuals and are infrequently assessed in course of routine clinic consultations.

The World Health Organization acknowledges that the social consequences of epilepsy are more difficult to overcome than the seizures themselves.¹ These social health issues focuses on employment, accommodation, transportation, relationship, including friendship, family life and marriage.

In Nigeria there are few studies published on the socioeconomic challenges in persons with epilepsy.^{4,5} So far, to the best of our knowledge we are not aware of any

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study that has been reported on the experiences of persons with epilepsy, regarding education, employment and intimate relationship in the south-south region of Nigeria. Using a logistic regression analysis, this study aimed to determine the predictors and profile the experiences, impediments, limitations and challenges that influence the socioeconomic life of the PWE, especially in respect to schooling, employment and relationship. The findings should bridge the knowledge-gap and aid the health care worker in assisting the PWE in addressing and coping with their socioeconomic challenges.

Methods

This was an observational cross-sectional study, conducted at the neurology clinics of both the University of Benin Teaching Hospital and the Central Hospital Benin City from March 2019 to September 2021. Persons who were managed for epilepsy and who consented to participate in the study were consecutively recruited in the course of their routine follow up clinics. Ethical approval was obtained from the ethics and research committee Central Hospital Benin City.

The participants were aged 25 years and older, since it has been reported in Nigeria, from that age these adults should have completed their secondary schooling, might be employed and may be in a relationship.⁶ Patients with severe neurological or psychiatric disorder and those with serious comorbid medical conditions which would impair responses or affect the quality of life beyond that caused by epilepsy were excluded.

The study instrument was a structured questionnaire, which was designed based on the review of previous studies on epilepsy with regards to education, employment and marriage. The questionnaire was pilot tested on ten persons with epilepsy and minor changes effected. Responses to the questions were both closed and open-ended. Each participant was interviewed face to face by the authors with the survey instrument. The following variables were determined from the conversation, the age, the gender, the duration of the epilepsy, the religion, the educational status, the income per month of sponsors of schooling, housing, transportation, employment status, relationship status, frequency of seizure attacks, adherence to AEDs,⁷ AEDs side effects, experience of unfair treatment (stigmatization), presence of comorbid conditions (confirmed from the medical records). Responses to the open-ended questions were examined, analyzed and thereafter re-grouped/re-classified into categories.

Statistical analysis was done using IBM SPSS version 22 (SPSS Inc., Chicago Illinois). Means, standard deviation, range were used to present continuous variables while frequency and percentages

for categorical variables. Logistic regression analysis was used to examine the effects of eight independent variables on each of the three dependent variables, of educational status, employment status and relationship status. The hypothesis testing was two tailed and significance was $P < 0.05$

Results

One hundred and sixty-four persons with epilepsy (PWE) were approached and invited to participate in the study. Fourteen PWE declined participating, twelve were below the age of 25 years, while eight were too ill to participate. One hundred and thirty PWE who met the inclusion criteria and consented to participate were recruited. The mean age of the participants was 37 ± 10.3 years with a range of 25 to 55 years. Seventy percent of the participants were aged below 40 years. Fifty four percent were males, and over half of the participants (53.1%) have had epilepsy for 10 years or more, while about 47% had 10 years or more of schooling which included completed secondary education and tertiary education. Approximately eighty seven percent of the participants had sponsors of their educational pursuit whose estimated monthly income was $< 100,000$ naira. (Table 1).

About 55% are currently or previously in a relationship, of which 19.2% are married. Regarding employment status, 56.2% are employed. Around 45% of participants had comorbid conditions, including, hypertension, diabetes, migraine, depression and anxiety, while about half (49.2%) of the participants have had the experience of stigmatization. In a period of 6 months, about a third (30.8%) of participant experience only one incident of seizure or none at all with about 51% of the participants not adherent to their AEDs and 56.2% had experienced side effects of AEDs (Table 1).

In the logistic regression analysis the male gender ($P = 0.002$), those with fewer seizure attack ($P = 0.035$), those with AEDs adherence ($P = 0.025$) were more likely to have attained a higher educational status, while those with the experience of stigmatization ($P = 0.0001$) were likely to have attained a lower educational status (Table 2).

Regarding employment status, the participants with higher educational qualification ($P = 0.001$), those with adherence to AEDs ($P = 0.02$), and those with no observed side effects of AEDs ($P = 0.02$), are more likely to be employed, while the males ($P = 0.02$), those with the experience of stigmatization ($P = 0.002$), and those with longer duration of their epilepsy ($P = 0.001$) are more likely to be unemployed (Table 2).

Those more likely to achieve an intimate relationship were males ($P = 0.021$), those with higher education status ($P = 0.001$), those adherent to AEDs ($P =$

0.007), and those with no observed side effects of AEDs ($P= 0.034$). While those with stigmatization experiences ($P= 0.01$) and a longer duration of epilepsy ($P= 0.02$) were less likely to achieve a relationship (Table 2).

Table 1. Demographics and clinical characteristics of participants (130 persons with epilepsy)

Variable	n%
Age categories	
< 40years	91 (70%)
≥ 40years	39 (30%)
Gender	
Female	60 (46.2%)
Male	70 (53.8%)
Educational status(duration)	
Primary up to junior secondary < 10yrs	69 (53.1%)
Senior sec to tertiary ≥ 10yrs	61 (46.9%)
Income/ month of education sponsor	
< 100,000 naira	113 (86.9%)
≥ 100, 000 naira	17 (13.1%)
Intimate relationship	72 (55.4%)
Married	25 (19.2%)
Separated	11 (8.5%)
Divorced	9 (6.9%)
Engaged but not married	13 (10%)
Co-habiting	10 (7.7%)
Widow/Widower	4 (3.1%)
Never in a relationship	58 (44.6%)
Employment status	
Unemployed	57 (43.8%)
Employed	73 (56.2%)
Co-morbidity	
Present	58 (44.6%)
Absent	72 (55.4%)
Experience stigmatization	
No	66 (50.8%)
Yes	64 (49.2%)
Average number of seizures in 6 months	
≥ 3 seizures	38 (29.2%)
2 seizures	52 (40.0%)
≤ 1 seizure	40 (30.8%)
Adherence to AEDs	
Non adherent	66 (50.8%)
Adherent	64 (49.2%)
Side effects of AEDs	
Yes	73 (56.2%)
No	57 (43.8%)
Duration of epilepsy	
< 10years	61 (46.9%)
≥ 10years	69 (53.1%)

Discussion

We found that the males with epilepsy were more likely to attain higher educational status. This may reflect the cultural practices where the male child is preferentially cared for than the female.⁸ There have been divergent views regarding the association between gender and schooling.^{9,10}

This study also revealed that males are more likely to be unemployed and more likely to be in a relationship. It might be a furtherance of the same cultural practices where the male individual is provided for and suitors are arranged for them.⁸ In contrast the difficulty experienced in establishing an intimate relationship by the females with epilepsy is well known.^{5,9,11} It is hoped that these cultural practice be changed.

Over half of PWE had the junior secondary education as their highest educational attainment, which means majority of PWE may not be sufficiently educated to face the demands of living with a chronic condition as in epilepsy. There is agreement from other studies indicating poor educational attainments amongst PWE, with less than 50% achieving higher education.^{4,9,10} This educational underachievement observed in PWE could be due to recurrent seizure attacks, post seizure confusion, AEDs somnolence, cognitive slowing, absenteeism, frequent hospital admission and stigmatization.

The majority of the sponsors (87%) of participants' education had limited funds, which is in keeping with other studies that found epilepsy commoner amongst the socio-economically disadvantaged groups.¹⁴ The low socioeconomic class are burdened with important conditions that may increase the risk for developing epilepsy. PWE should be supported by the communities and government in the funding of their education.

A significant proportion of PWE (53%) have had epilepsy for a long time and were less likely to be employed and to have a relationship. Early age of onset or a longer duration of epilepsy have been observed to affect the quality of life of PWE.¹²

Fewer seizure attacks in our participants was associated with higher educational status. This has also been observed in other studies.¹³ Fewer attacks leads to focused educational pursuit, fulfilment in work and relationships.

Comorbid conditions were noted in the medical records of 45% of our participants. Comorbid conditions have been observed in other studies with up to sixty percent of PWE having depression and over forty percent with anxiety symptoms, and these are known to affect the quality of life of the PWE.^{2,4,14} These comorbid conditions should be identified and managed.

Table 2. Logistic regression analysis of predictors of dependent variables

Variables	Education (duration ≥ 10 yrs, OR 95% CI)	P value	Employment Status (employed OR 95%CI)	P value	Intimate relationship* OR 95% CI)	P value
Age						
< 40years	1	0.60	1	0.12	1	0.10
≥ 40 years	0.63 (0.11 to 3.5)		0.19 (0.024 to 1.5)		0.18 (0.022 to 1.3)	
Gender						
Female	1	0.002	1	0.02	1	0.021
Male	7.9 (2.13 to 29.5)		0.16 (0.03 to 0.7)		5.44 (1.29 to 22.8)	
Education (duration)						
< 10yrs	-	-	1	0.001	1	0.001
≥ 10 yrs	-	-	14.0 (3.73 to 52.7)		13.0 (3.84 to 44.2)	
Sponsor of education (income)						
$\geq 100,000$ naira	1	0.13	-	-	-	-
< 100,000 naira	4.18 (0.65 to 27.6)		-	-	-	-
Co-morbidity						
Present	1	0.44	1	0.09	1	0.094
Absent	1.84 (0.39 to 8.7)		0.27 (0.06 to 1.2)		0.29 (0.07 to 1.2)	
Experience of stigmatization						
No	1	0.0001	1	0.002	1	0.011
Yes	0.05 (0.01 to 0.2)		0.05 (0.01 to 0.3)		0.11 (0.02 to 0.6)	
On average Number of seizure in 6mths						
≥ 3 seizures	1		1		1	
2 seizures	4.74(1.36 to 16.5)	0.015	0.82 (0.22 to 3.1)	0.77	0.10 (0.28 to 3.5)	0.10
≤ 1 seizure	6.29 (1.14 to 34.6)	0.035	0.37 (0.05 to 2.6)	0.32	0.35 (0.06 to 2.1)	0.25
Adherence to AEDs						
Non adherence	1	0.025	1	0.02	1	0.007
Adherence	4.58 (1.23 to 17.2)		10.8 (2.47 to 46.8)		6.50 (1.65 to 25.5)	
Side effects of AEDs						
Yes	1	0.87	1	0.021	1	0.034
No	0.89 (0.21 to 3.7))		7.94 (1.37 to 46.0)		5.95 (1.14 to 31.0)	
Duration of epilepsy						
< 10years	1	0.10	1	0.001	1	0.02
≥ 10 years	0.19 (0.03 to 1.3)		0.01 (0.001 to 0.1)		0.03 (0.003 to 0.2)	

The reference variables were age < 40years, female gender, education duration < 10yrs, monthly income of education sponsor $\geq 100,000$ naira, comorbid condition present, no stigmatization, seizure attacks in 6mths ≥ 3 seizures, non-adherence to AEDs. AEDs side effects present, duration of epilepsy < 10years.

*Intimate relationship was defined as any relationship that have resulted in marriage (currently or previously: married, separated, divorced, widow, widower) or may result in marriage according to the opinion of the participant (engaged, co-habiting)

AEDs = anti-epileptic drugs, CI= confidence interval, OR = odds ratio

It was revealed in this study, that about 45% of PWE have never in their life time had any intimate relationship which might lead to marriage. Difficulty in having a friendship is well established amongst PWE and this sorry state is even more in women.^{5,11} With a high proportion of PWE not in a relationship, the main reasons adduced was not being gainfully employed and no suitor coming around. Additionally in some communities, persons are not comfortable with their relations having intimate relations with PWE.

We observed that those who experienced stigmatization were less likely to attain higher

educational status, be employed and achieve an intimate relationship. This has been variously reported.^{2,10,11,13} For many PWE, stigmatization is even more debilitating than the seizure itself. Public campaign on epilepsy could reverse this situation.

Only 49% of our respondents were adherent to their ant-epilepsy drugs, which is similar to other report.^{15,16} Those with AEDs adherence were likely to have higher educational attainment, been employed and having a relationship. Poor AEDs adherence would cause more frequent attacks, with negative socioeconomic implications.

About 44% of our respondents had no side effects of AEDs and they were more likely employed and in a relationship. These side effects may include minor to severe complaints and have been reported to affect the quality of life of PWE.^{16,17} AEDs side effects should be identified and managed accordingly.

A considerable proportion of PWE have never been employed. The high proportion of the unemployed could be a reflection of the level of unemployment in the communities where PWE live, with an unemployment rate in Nigeria at 33% in 2022.¹⁸ Some studies have observed lesser rates of unemployment, some about the same as ours, while others slightly higher figures.^{5,10,17,19} Stigmatization, recurrent seizures, educational underachievement, limited social skills, AEDs side effects have all been associated with unemployment and underemployment.

The limitations of the study included the fact of it being a hospital based study with a modest number of participants. Some of the variables were determined by review of medical records. In determining some variables no instruments was utilized for measurements.

Conclusions

A high proportion of the participants were poorly educated, unemployed and not in a relationship, while stigmatization, and prolonged duration of seizure were amongst the significant predictors of these variables. It is hoped that meeting the educational and vocational needs of PWE, in addition to public campaign on epilepsy could reverse the situation.

References

- World Health Organization. Epilepsy: facts Sheet February 2022. Available in: <http://www.WHO.Int/news-room/fact-sheets/detail/epilepsy>.
- Baskind, R., Birbeck, G.L., Epilepsy-associated stigma in sub-Saharan Africa. The social landscape of a disease. *Epilepsy Behav.* 2005; 7(1):68–73. doi:10.1016/j.yebeh.2005.04.009.
- Piere-Marie Preux, Duruet-Cabanac M. Epidemiology and aetiology of epilepsy in sub-Saharan Africa. *Lancet Neurol.* 2005; 4:21-31.
- Nuhu FT, Fawole JO, Babalola OJ, Ayilara OO, Suleiman ZT. Social consequences of epilepsy: a study of 231 Nigerian patients. *Ann of Afri Med.* 2010; 9(3):170-5.
- Komolafe MA, Sunmonu TA, Afolabi OT. The social and economic impacts of epilepsy on women in Nigeria. *Epilepsy Behav.* 2012; 24(1):97–101.
- National Population Commission. Nigeria demographic and health survey 2013. National Population Commission, ICF International; 2013.
- Odiase F.E, Ogbemudia JE. Predictors of non-adherence to antihypertensive medications among stroke survivors in Benin City Nigeria. *Sub-Saharan African Journal of Medicine.* 2019; 6(3):122-128.
- Gabriel E. Idang. African culture and values. *Phronimon.* 2015; 16(2):97-111
- ssHu Y, Shan Y, Du Q, Ding Y, Shen C, Wang S. Gender and Socioeconomic Disparities in Global Burden of Epilepsy: An Analysis of Time Trends From 1990 to 2017. *Front. Neurol.* 2021; 12:643450.
- Goodall J, Salem S, Walker RW, Gray WK, Burton K, Hunter E. Stigma and functional disability in relation to marriage and employment in young people with epilepsy in rural Tanzania. *Seizure.* 2018; 54:27-32. doi: 10.1016/j.seizure.2017.11.016. Epub 2017 Nov 26. PMID: 29195225.
- Quereshi C, Standing HC, Swai A, Hunter E, Walker R, Owens S. Barriers to access to education for young people with epilepsy in Northern Tanzania: a qualitative interview and focus group study involving teachers, parents and young people with epilepsy. *Epilepsy Behav.* 2017; 72:145-149.
- Edefonti V, Bravi F, Turner K, Beghi E, Canevini MP, Ferraroni M. A. Health-related quality of life in adults with epilepsy: the effect of age, age at onset and duration of epilepsy in a multicentre Italian study. *BMC neurol.* 2011; 11(1):1-3.
- McLaughlin DP, Pachana NA, McFarland K. Stigma, seizure frequency and quality of life: the impact of epilepsy in late adulthood. *Seizure.* 2008; 17:281–7.
- Kwon OY, Park SP. What is the role of depressive symptoms among other predictors of quality of life in people with well-controlled epilepsy on monotherapy? *Epilepsy Behav.* 2011; 20(3):528-32.
- Chowdhury S, Phani AK, Das P, Ahammed Z, Kayasthagir PK, Hassanuzzaman M. Adherence to Antiepileptic Drugs and Seizure Control Among Patients with Epilepsy. *Chattagram Maa-O-Shishu Hospital Medical College Journal.* 2020; 19(1):68-73
- Fadare JO, Sunmonu TA, Bankole IA, Adekeye KA, Abubakar SA. Medication adherence and adverse effect profile of antiepileptic drugs in Nigerian patients with epilepsy. *Neurodegenerative Disease Management.* 2018; 8(1):25-36.
- Hovinga CA, Asato MR, Manjunath R, Wheless JW, Phelps SJ, Sheth RD. Association of non-adherence to antiepileptic drugs and seizures, quality of life, and productivity: survey of patients with epilepsy and physicians. *Epilepsy Behav.* 2008; 13(2):316–322.
- National Bureau of Statistics. Nigeria social and economic statistics. 2022.
- Smeets, VM van Lierop, BA Vanhoutvin, JP Aldenkamp, AP and Nijhuis, FJ, Epilepsy and employment: literature review. *Epilepsy Behav.* 2007; 10(3):354-362.