

Original Article

Social consequences of epilepsy: A study of 231 Nigerian patients

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Abstract

Background: Epilepsy is the commonest neurological disorder and majority of the sufferers are found in the developing countries. It is associated with psychological and social problems. The aim of this study was to determine the social difficulties experienced by epileptic patients and the factors that are associated with these difficulties.

Methods: Two hundred and thirty-one consecutive epileptic patients who were of age 10 years and above, and who had no co-morbid major psychiatric disorder, seen over a 6-month period at the outpatient clinic of Federal Neuropsychiatric Hospital, Kaduna, were interviewed. We used an instrument designed for the purpose of this study, which focused on people's attitudes to epilepsy, relationship/marital, employment and academic problems.

Results: The mean age of the subjects was 28 ± 13.2 years; 59.3% were males; 44.6% said people make negative remarks about their illness; 14.1% have been denied leadership role; 36.4% were irregular at work; 37.3% performed poorly at work; 22.5% have had their marriage proposals rejected; 19.5% have been abandoned by spouse. At least 39.4% had poor academic performance while 19.5% were withdrawn from school because of epilepsy. Short seizure-free period, long duration of seizure disorder and family history of epilepsy were significantly associated with social problems.

Conclusion: Social difficulties are common among epileptics. Effort should be made to educate the society about epilepsy, and physicians treating patients with epilepsy should aim at achieving a good seizure control.

Keywords: Epilepsy, social consequences

Résumé

Arrière-plan: L'épilepsie est la plus courante troubles neurologiques et la majorité des malades se trouvent dans les pays en développement. Elle est associée à des problèmes psychologiques et sociaux. L'objectif de cette étude vise à déterminer les difficultés sociales rencontrées par les patients épileptiques et les facteurs qui sont associés avec ces difficultés.

Méthodes: Patients épileptiques deux cent trente - un consécutives, qui étaient de 10 ans et plus et qui n'avait aucun trouble psychiatrique majeur co-morbid, vu sur une période de 6 mois à la clinique externe de l'hôpital Neuropsychiatrique fédérale, Kaduna ont été interrogés. Nous avons utilisé un instrument conçu aux fins de cette étude qui a mis l'accent sur les attitudes des peuples à l'épilepsie, relation/matrimonial, l'emploi et problèmes académiques.

Résultats: L'âge moyen des sujets a été 28 ± 13.2 ans, 59.3% étaient des hommes, 44.6% dit personnes formuler des remarques négatives sur leur maladie, de 14.1% a été refusé le rôle de leadership, de 36.4% étaient irrégulières au travail, 37.3% effectué mal au travail, 22.5% ont eu leurs demandes en mariage a rejeté, 19.5% ont été abandonnés par les époux, 39.4% au moins eu mauvaise performance académique 19.5% ont été retirés de l'école à cause de l'épilepsie. Courte période sans saisie, longue durée de troubles de saisie et des antécédents familiaux de l'épilepsie ont été considérablement associés avec les problèmes sociaux.

Conclusion: Les difficultés sociales sont communes entre epileptics. Effort, il convient d'informer la société sur l'épilepsie et médecins traitant des patients atteints d'épilepsie devraient viser à réaliser un contrôle de la bonne saisie.

Mots clés: conséquences sociales, l'épilepsie

Introduction

Epilepsy is the most common serious neurological disorder in every country.^[1] About 40 million people worldwide suffer from epilepsy and 80% of them live in the developing countries.^[2,3]

People with Epilepsy (PWE) face social stigma due to negative and incorrect knowledge of the disease^[4,5] and even occasional seizures may have serious personal and societal consequences.^[6,7] In many developing countries, including Nigeria, people are afraid of epilepsy and there is a general misunderstanding that the disease is contagious. Therefore, they run away from patients to avoid contact with the saliva.^[8-11] For the same reason, in some African countries like Uganda, PWE are not allowed to join the communal food pot.^[12] Some children with epilepsy are expelled from school to prevent them from transmitting the disease to others.^[5,13] Furthermore, the day-to-day consequences of epilepsy may also include loss or change of job, a possible reduction in social interaction and productivity^[14,15] and physical effects of frequent seizure makes it difficult to attend school, work or social functions.^[14] Consequently, unemployment and underemployment are more common among PWE.^[12]

In addition, studies have shown that epilepsy affects the intellectual abilities of PWE, which may have a negative effect on the overall school performance,^[16-19] and factors associated with poor intelligence include seizure type;^[16] seizure frequency, long duration of epilepsy, early age of onset of seizure^[17]; and status epilepticus.^[16]

In china, epilepsy diminishes the prospect of marriage, especially for women,^[20] and in China and India it is commonly viewed as a reason for prohibiting and annulling marriages. In the United Kingdom, the law forbidding PWE to marry was repealed only in 1970 and in the past (until 1970) it was legal in the United State of America to deny PWE access to restaurants, theatres, recreation centres and other public buildings.^[12] In England, a patient with epilepsy cannot obtain a driver's license unless he or she has been seizure-free for at least 1 year or seizures occur only when the patient is asleep for up to 3 years with or without medication.^[21] There is generally a dearth of literature on the social complications of epilepsy in Northern Nigeria, and therefore, it is against this background that we conducted this present study to assess the social problems faced by PWE.

Material and Methods

The study was carried out at the Federal

Neuropsychiatric Hospital, Kaduna, in the north-western part of Nigeria. The hospital is a tertiary health institution which serves as a referral centre for psychiatric patients from virtually all the states in the northern part of the country. It has about 120 inpatient admission beds with outpatient attendees of about 15,000 in a year.

We interviewed all consecutive outpatients with a diagnosis of epilepsy of at least 1 year duration and who were 10 years and above, between March 2008 and September 2008. We excluded all patients who had a comorbid major mental disorder (such as schizophrenia and bipolar affective disorder), cognitive disorder (such as dementia or mental retardation), substance use disorder and serious physical illness (that made it impossible for patient to be interviewed). We arbitrarily chose 10 years because younger subjects may not understand some of the questionnaire items.

The diagnosis of epilepsy was based clinically on information from eye-witness account of two or more unprovoked generalized seizure episodes. Some subjects were diagnosed based on the clinical history and abnormalities found on electro-encephalography (EEG). EEG is a useful tool in diagnosing epilepsy but some patients with epilepsy do not manifest EEG abnormalities while some normal subjects show non-specific EEG findings.^[22,23]

Subjects were interviewed with an instrument designed for the purpose of this study. It has the following sections: sociodemographic/clinical characteristics, peoples' attitude to epilepsy, relationship/marital difficulties, difficulties in securing employment and poor school/academic performance. The reliability of the instrument was determined by interviewing 20 subjects and re-interviewing them 2 weeks later (Cronbach's α and inter-item co-efficient are, respectively, 0.888 and 0.234). These 20 subjects were excluded from the analysis. Using a method of back translation, we translated the instrument to Hausa language^[24] and all the patients who could not understand English were interviewed using the Hausa version by one of the authors (ZTS). All the participants who were 18 years and older gave informed consent while the parents of all those younger than 18 years gave consent on behalf of their children after the objective of the study was explained to them.

The research and ethical committee of the Federal Neuropsychiatric Hospital, Kaduna, gave approval for the study.

Statistical analysis

Data were analyzed using the 13th edition of the Statistical Package for Social Sciences (SPSS-13). Descriptive statistics were calculated for the variables, which included means and standard deviation. Frequency distribution and cross tabulations were generated, *t*-test and chi-square (χ^2) test were used to investigate the association between various types of social difficulty, and continuous and categorical variables, respectively. *P* value of <0.05 was taken as statistically significant.

Results

[Table 1] shows the sociodemographic and clinical characteristics of the subjects. The mean age of all the subjects was 28.0 (SD 13.2) years; the mean age for the male subjects was 27.6 (SD 13.0) years while that of the females was 28.7 (SD 13.5) years. The mean year of education was 8.1 (SD 4.9) while the average income was N6, 974 (SD 10,476). Only 29% were married. The remaining 71% were separated, divorced, widowed or never married. The average duration of seizure disorder was 9.5 years (SD 8.2, range 1–40) while the mean seizure-free period was 26.4 weeks (SD 36.5, range 1–200). One hundred and seventy-six (76.2%) subjects had generalized seizures while 55 (23.8%) had partial seizures.

Approximately, 4% of the subjects reported that neighbors were reluctant to engage them in discussion, 10.8% said people ran away from them especially during episodes of convulsion. Fifty-six subjects have applied for a driver’s license but only 2 (3.6%) were denied [Table 2].

[Table 3] shows the various academic and occupational problems experienced by PWE. About 20% were withdrawn from school either voluntarily by their parents or through compulsory expulsion by the school authorities because of epilepsy. Thirty-six percent of those who were employed had not been regular at work and 37.3% admitted to sub-optimal performance at work.

Further analysis showed a statistically significant association between short seizure-free periods and negative remarks ($t = -2.053$, *P* value = 0.041, 95% CI = -19.308 to -0.398), inability to go to work regularly ($t = -2.636$, *P* value = 0.010, 95% CI = -34.227 to -4.844), poor performance at work ($t = -2.886$, *P* value = 0.005, 95% CI = -35.683 to -6.626), rejection of marriage/relationship proposal ($t = -2.181$, *P* value = 0.031, 95% CI = -30.388 to -1.508), being abandoned by spouse ($t = -2.173$, *P* value = 0.032, 95% CI = -36.205 to -1.684), poor memory ($t = -2.763$, *P* value = 0.006, 95% CI = -33.876 to -5.616) and withdrawal from school ($t = -2.626$, *P* value = 0.045, 95% CI = -27.074 to 0.330).

A longer duration of seizure disorder was significantly associated with poor memory ($t = 2.958$, *P* value = 0.004, 95% CI = 1.395–7.019) and poor concentration ($t = 2.745$, *P* value = 0.007, 95% CI = 0.998–0.141) while positive family history of epilepsy was significantly associated with rejection of marriage/relationship proposal ($\chi^2 = 5.858$, *d/f* = 1, *P* value = 0.016).

Table 1: Sociodemographic characteristics of the respondents

Variables	Frequency (n)	Percentage
Age (years)		
10–19	69	29.9
20–29	88	38.1
30–39	32	13.9
40–49	20	8.7
50 and above	22	9.5
Sex		
Male	137	59.3
Female	94	40.7
Religion		
Islam	124	53.7
Christianity	107	46.3
Occupation		
Employed	105	45.5
Unemployed	126	54.5
Marital status		
Married	67	29.0
Not married	164	71.0
Education		
Nil	36	15.6
Primary	83	35.9
Secondary	84	36.4
Tertiary	28	12.1
Income		
Nil<N 20,000	115	49.8
N 20,000–N 40,000	99	42.9
>N 40,000	10	4.3
	7	3.0
Family history		
Positive family history of epilepsy	75	32.5
No family history of epilepsy	156	67.5

Table 2: Peoples’ attitude to patients with epilepsy

Variables	Yes n (%)	No n (%)	Total
People don’t talk to me	9 (3.9)	222 (96.1)	231
People run away from me	25 (10.8)	206 (89.2)	231
People don’t eat/drink with me	25 (10.8)	206 (89.2)	231
People make negative remarks	103 (44.6)	128 (55.4)	231
I have been denied leadership roles	31 (35.6)	56 (64.4)	87
I have been denied drivers license	2 (3.6)	54 (96.4)	56
Rejection of marriage proposal	36 (22.5)	124 (75.5)	160
Abandoned by partner	24 (19.5)	99 (80.5)	123

Table 3: Epilepsy and poor academic performance/employment difficulties

Variables	Yes n (%)	No n (%)	Total
I often miss school	91 (39.4)	51 (60.6)	231
I have poor concentration	92 (39.8)	50 (60.2)	231
I have poor memory	106 (45.9)	36 (54.1)	231
Declined academic performance	99 (42.9)	43 (57.1)	231
Expulsion from school	45 (19.5)	97 (80.5)	231
Job application rejected	14 (12.7)	96 (87.3)	110
Termination of appointment	6 (5.5)	104 (94.5)	110
I am irregular at work	40 (36.4)	70 (63.6)	110
I perform poorly at work	41 (37.3)	69 (62.7)	110

We did not find any statistically significant association between social problems and the sociodemographic variables (age, sex, marital status, religion, education, occupation and income; P value >0.05)

Discussion

In this study, there were more males than females. Some epidemiological studies of PWE reported higher prevalence in males^[25] while some found female preponderance.^[26]

About 55% of the subjects were unemployed. In this case, age of the subjects may be a factor as only one out of 45 subjects below the age of 18 years and 3 out of 11 subjects, 60 years and older, were employed. The income level shows that only 7.3% of those who were employed earned more than N20,000 in a month. In fact, 76.6% received less than N10,000 per month. This implies that majority of those who were employed belong to the low-income group. This finding is similar to previous report among epileptics^[12] and this may be related to inability to achieve high level of education, poor intellectual ability or irregularity at work. PWE may thus work as petty traders, attendants, messengers or cleaners rather than occupying the position of a senior staff.

Eleven percent of the subjects reported that people ran away from them especially during episodes of seizure and even family members were neither willing to eat/drink with patients nor share the same cutleries and plates with them. This finding is consistent with previous reports.^[12] There is generally poor understanding and misconception about the nature and etiology of epilepsy among the people especially in the developing countries.^[4,5,10] For instance in Indonesia, epilepsy is often considered as a punishment for unknown dark forces, and in Cameroon, PWE are said to be inhabited by the devil. These same beliefs may explain why in rural areas of India, some patients are tied to the trees, flogged and starved in an attempt to exorcise evil spirits from them.^[12] PWE are also

isolated because of the fear of contact with their saliva which people believe they can be “infected” with the disease.^[8,9]

Approximately, 45% of our subjects reported that people made negative remarks about their illness. This usually occurs when there is a quarrel or an argument, when patient is aspiring for a leadership position or when he applies for a job. This attitude is again a reflection of stigma and discrimination against PWE. Many people still treat epileptics as social outcasts and as such PWE are deprived of the opportunity to express their views. In this study, 14.1% of those who aspired for leadership roles such as being a class captain, school prefect, leading prayers as an imam or a pastor, traditional ruler position or elective or political offices were denied. We also found that 22.5% of our subjects who had made proposals for intimate relationship or marriage have had such proposals rejected because of epilepsy. It is common in this country for parents to ask their children if they have investigated the family of their would-be spouses for epilepsy, and if family history of epilepsy is confirmed, the marriage proposal will be turned down for fear of introducing epilepsy into their own family. The possible reason for this attitude is the misconception that PWE are being punished for their ancestral misdeeds. Our findings are in keeping with previous reports.^[12,20] Twenty percent of those who were previously married in this study had been abandoned by their spouses. The general misconception about epilepsy may be a reason for break down in marriage, but it is also possible that the burden of care for a partner with epilepsy may be too high to bear. Another possibility is inability to meet the financial obligation of paying hospital bills and procuring antiepileptic drugs for the partner. Some of our respondents who still live with their spouses reported that their partners are not willing to have sexual intercourse with them probably because they are afraid of contacting the disease or giving birth to an epileptic child, should pregnancy result from such affairs.

It is however surprising that only 2 (3.6%) of those who had applied for a driver’s license were denied. These two cases were peculiar because the first was involved in a road traffic accident and had his request rejected based on the history of accident, while the second subject actually convulsed in the licensing office while waiting to collect his license which had been processed. This may imply that our licensing authorities do not pay attention to medical fitness of the drivers. In the UK, the law stipulates that an epileptic patient can only obtain a driver’s license if he or she has been seizure-free for at least 1 year or seizures occur only during sleep for at least

3 years.^[21] If such a law exists in Nigeria, at all, it is not being enforced!

Epilepsy has been recognized as a cause of absenteeism from school^[16] Among subjects who often missed school in this study, repeated seizure was a cause in some cases while in others the fear of having seizures informed their decision to stay at home. They prefer to have convulsion at home where it can be concealed rather than exposing themselves when fits occur in the school. Those who had poor concentration were probably preoccupied with the fear of having seizures in the class or alternatively the shame and effects of fits they have had in the past. About a half of these subjects have had problems with their memory. Poor concentration, on the one hand, may be responsible for poor recollection of events, while on the other hand, direct effects of repeated seizure may damage the brain and present with cognitive deficit. The possible brain damage may also be an explanation for poor concentration and thus poor memory. Poor academic performance is also common and this is similar to previous findings among PWE.^[17,19] This may be a result of not being regular in school, poor concentration, poor memory, the direct effect of seizure on the brain or a combination of two or more of the above factors. Among those who were asked to withdraw from school, some of them were expelled by the school authorities for fear of infecting other students with their disease or because some parents of those other students threatened to remove their children if the authorities allowed an epileptic child to remain in the school. In some cases the parents of the children with epilepsy asked them to stop going to school to avoid discrimination. The attitudes of the teachers and parents also reflect the poor understanding and wrong perception of the disease epilepsy.^[4,5,10]

Similarly, misconception may be responsible for employer's refusal to give jobs to PWE while frequent seizures; irregularity at work and poor performance may be the reason for loss of job in those who were previously employed.

The findings from this study confirm the reports from other studies that epilepsy has effects on the social, academic and occupational functioning of the affected patients.^[4-20]

A short seizure-free period (indicating frequent seizures) was significantly associated with relationship, academic and occupational difficulties; a long duration of seizure disorder was associated with poor academic performance. Similar observations were made by Sunmonu *et al.*^[17] while family history of epilepsy was associated with rejection of marriage

proposal. Patients who have repeated seizures are unable to go to work (or school) regularly. It is also possible that their confidence and self-esteem are reduced and also the motivation to achieve greater heights. Neighbors and the society in general are also more likely to stigmatize patients who have repeated seizures. A long duration of seizure disorder and an early age of onset have been found to be associated with intellectual impairment^[17,19] and this could be the long-term effect of seizure on the brain.

The absence of association between social difficulties and sociodemographic characteristics of the patients may imply that clinical variables (illness factors) may be more important than sociodemographic variables (patient factors) in determining the social consequences of epilepsy.

In conclusion, social difficulties are common among PWE. These include relationship, marital and employment difficulties as well as poor academic performance. Repeated seizures, early age of onset and family history of epilepsy are associated with various types of problems that PWE face in the course of their life. Therefore, efforts should be made to prevent the occurrence of the disease and physicians who treat PWE should aim at achieving a good seizure control. There should be awareness campaign programs to educate the society about epilepsy.

Limitations

It is a cross-sectional study conducted in one center in Nigeria; a nationwide survey is recommended. The instrument used has not been validated but the internal consistency is good. In addition, the study considered only patients with either generalized or partial seizures, and few subjects with unclassified type of seizure, according to the International League Against Epilepsy (ILAE), could have been missed.

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