Determinants of Quality of Life in Adults Living with Epilepsy

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Abstract

Background: Quality of life (QOL) is a vital outcome measure in people living with epilepsy. The aim of this study is to determine the sociodemographic and clinical factors that predict poor QOL in patients with epilepsy. Materials and Methods: This is a descriptive cross-sectional study that was carried out at the outpatient psychiatric clinic of Abubakar Tafawa Balewa University Teaching Hospital, Bauchi, Nigeria, for 6 months. Seventy-four patients with epilepsy who met the inclusion criteria were recruited to participate in the study. The mental health of these patients and their QOL were assessed using the Mini-International Neuropsychiatric Interview and the short form of the World Health Organization QOL instrument, respectively. Data were analyzed using epi-info version 6.04d, and logistic regression analysis was performed to determine factors that predict poor QOL. Results: Psychiatric disorder was found in 33 (44.6%) of the respondents. The presence of these psychiatric disorders was predictive of poor score on the overall QOL (odds ratio [OR] = 0.382; 95% confidence interval [CI] = 0.145–0.983; P = 0.0046), physical (OR = 0.269; 95% CI = 0.100–1.722; P = 0.009), and psychological health domain (OR = 0.269; 95% CI = 0.102–0.709; P = 0.008). Longer duration of epilepsy was predictive of a poor score on the health satisfaction item (OR = 0.202; 95% CI = 0.06–0.679; P = 0.010) while being single was predictive of poor score on the social relationship domain (OR = 0.177; 95% CI = 0.065–0.482; P = 0.001). Conclusion: The presence of psychiatric disorder, long duration of epilepsy, and being single were predictive of poor QOL. The importance of social relation, prompt seizure control, and efficient collaboration between psychiatrist and other medical professionals in the care of patients with epilepsy cannot be overemphasized.

Keywords: Epilepsy, psychiatric disorder, quality of life, World Health Organization Quality of life-BREF

Résumé

Contexte: La qualité de vie (QV) est une mesure de résultat vitale chez les personnes vivant avec l’épilepsie. Le but de cette étude est de déterminer les facteurs sociodémographiques et cliniques qui prédissent une mauvaise qualité de vie chez les patients épileptiques. Matériel et Méthodes: Cet article est une description étude transversale réalisée à la clinique psychiatrique ambulatoire de l’hôpital universitaire Abubakar Tafawa Balewa, Bauchi, Nigeria, pendant 6 mois. Soixante-quatorze patients épileptiques répondant aux critères d’inclusion ont été recrutés pour participer à l’étude. Le mental la santé de ces patients et leur qualité de vie ont été évaluées à l’aide de l’interview neuropsychiatrique Mini International et de la forme abrégée de World Instrument de qualité de vie de l’Organisation de la santé, respectivement. Les données ont été analysées en utilisant epi-info version 6.04d, et une analyse de régression logistique a été réalisée pour déterminer les facteurs qui prédissent une mauvaise qualité de vie. Résultats: Un trouble psychiatrique a été trouvé dans 33 (44.6%) des répondants. La présence de ces troubles psychiatriques étaient prédic和平 d’un mauvais score sur la QV globale (odds ratio [OR] = 0.382; intervalle de confiance à 95% [IC] = 0.145-0.983; P = 0.0046), physique (OR = 0.269; IC à 95% = 0.100-1.722; P = 0.009) et domaine de la santé psychologique (OR = 0.269; IC à 95% = 0.102-0.709; P = 0.008). Une plus longue durée d’épilepsie était prédictive d’un mauvais score sur l’item de satisfaction pour la santé (OR = 0.202; IC à 95% = 0.06-0.679; P = 0.010) tout en étant célibataire était prédictif d’un mauvais score sur le domaine des relations sociales (OR = 0.177; IC à 95% = 0.065-0.482; P = 0.001). Conclusion: La présence de troubles psychiatriques, la longue durée de l’épilepsie et le fait d’être célibataire étaient prédic和平 d’une mauvaise qualité de vie. L’importance de relation sociale, contrôle rapide des crises et collaboration efficace entre le psychiatre et d’autres professionnels de la santé dans la prise en charge des patients avec l’épilepsie ne peut pas être surestimée.

Mots-clés: Épilepsie, trouble psychiatrique, qualité de vie, Organisation mondiale de la santé Qualité de vie-BREF

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INTRODUCTION

Quality of life (QOL) measures have become increasingly important in the determinant of the health status of patients with chronic illnesses rather than measures such as frequency and severity of the disease alone.\[^{1,2}\] According to the World Health Organization (WHO), QOL is defined as “an individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns.”\[^{1}\]

Epilepsy is a chronic neurological illness that may adversely affect the QOL of the sufferer. Several factors in epilepsy, such as the clinical characteristics of the seizures, social complication, and the behavioral complications, may impact negatively on the QOL of patients with epilepsy. Report from studies conducted among patients with epilepsy shows that the presence of psychiatric complications, higher seizure frequency, type of seizure and its severity, longer duration of seizure, number of antiepileptic drugs, gender, and a disadvantaged socioeconomic status predicts low score on QOL instrument.\[^{3-5}\]

Various instruments with good psychometric properties have been developed to assess QOL of patients with epilepsy. These include generic instruments like the World Health Organization Quality of life (WHOQOL) questionnaire and 36-Item Short Form Survey (SF-36) and disease-specific instruments like Quality of life in Epilepsy Inventory (QOLIE).\[^{2,3}\] The main purpose of utilizing these instruments in clinical practice is to plan patients’ care toward improving their life satisfaction and general well-being rather than mere symptoms alleviation.\[^{3}\] Researchers using these instruments have reported the negative influence of epilepsy and its sequelae on the QOL of patients, particularly in the developing world.\[^{4-6}\] Report from such research may assist health-care managers in identifying those problem areas and providing necessary interventions to tackle them to boost the QOL of patients with epilepsy.\[^{6}\]

In Nigeria, particularly in the northeastern region of the country, there is a dearth of studies examining the QOL of patients with epilepsy. We aim to determine the predictors of QOL of patients with epilepsy attending the outpatients psychiatric clinic in a tertiary health institution in the northeastern region of Nigeria.

MATERIALS AND METHODS

This is a cross-sectional study carried out in the psychiatric outpatient clinic of Abubakar Tafawa Balewa University Teaching Hospital, Bauchi, from July to December 2014. The hospital is a tertiary health facility that serves not only the people of Bauchi state but also those from neighboring states. The ethics and research committee of the hospital gave approval for the study and informed consent was obtained from the patients after the processes had been explained in detail to them. All consenting consecutive adult patients with the diagnosis of epilepsy based on the International League Against Epilepsy\[^{7}\] criteria using patients’ clinical history, eye-witnessed accounts with or without electroencephalographic findings constituted the study population. Patients were included in the study if they fulfilled the diagnosis of epilepsy and are on anticonvulsant medication for at least 1 year. However, patients with prior history of psychiatric illness before onset of epilepsy, patients with comorbid chronic medical condition or individuals who were too ill to participate were excluded from the study. A total of 74 respondents who presented consecutively and met the inclusion criteria over the 6 months the study was undertaken were enrolled. The sociodemographic and clinical characteristics of the consenting eligible participants were obtained using a pro forma questionnaire designed by the researchers and all study participants were administered Mini-International Neuropsychiatric Interview 6.0\[^{9}\] for the assessment of psychiatric disorder by the Clinic Consultants. The short form of the WHOQOL-BREF questionnaire\[^{9}\] was used to assess the health-related QOL of respondents. This is a 26-item self-administered questionnaire. However, the questions were read out to illiterate patients by a trained research assistant and their responses recorded. The WHOQOL-BREF produces a QOL profile with four domain scores. The four domains are (i) physical health (ii) psychological health, (iii) social relationship, and (iv) environment domains. There are two items that are examined separately: Question 1, which ask about an individual’s overall perception of QOL and question 2, which ask about an individual’s overall perception of their health. The raw scores obtained on each domain were transformed into scores in the range between 0 and 100, with higher scores indicating better QOL. Further categorization was done as “good” or “poor” by first finding the mean score for each domain and each of the 2 items examined separately. A good score is defined as a score equals or greater than the mean while a poor score is defined as a score less than the mean.\[^{10}\]

Data analysis

Data obtained from the study were analyzed using Epi-info version 6.04d. Frequency table was generated, and proportions were compared using Chi-square. The level of statistical significance was set at 5% confidence limit for two-tailed test. A second-stage analysis was performed using logistic regression to determine variables which predict good or poor QOL score in the WHOQOL-BREF domains. Only variables that are statistically significant at the first stage were included in the logistic regression.

RESULTS

Sociodemographic and clinical characteristics of respondents

Seventy-four consenting patients living with epilepsy who met the inclusion criteria for the study were recruited over the study period of 6 months. Forty-six (62.2%) of the study population were male, 42 (56.8%) were married, and about 32.4% were experiencing some form of discrimination either from relatives, friends, or at work [Table 1].
Table 2 gives information about the clinical characteristics of our respondents. There was a family history of epilepsy in a minority (9.5%), 51 (68.9%) of them had been having epilepsy for over 5 years, about 17% of the recruited patients had being seizure free for a year or more and thirty-three (44.6%) of them met a diagnosis of psychiatric disorder.

### Quality of life of respondents

Table 3 shows that the majority (55.4%) of the respondents scored good in the overall QOL item, whereas 44 (59.5%) scored good in the health satisfaction item. Most of the patients also recorded good in the physical (62.2%) and psychological (56.8%) domain of WHOQOL-BREF instrument, whereas majority recorded a poor score in the social relationships and environmental health domains. The highest mean QOL score of 65.58 ± 15.7 was in domain 2 (psychological health).

In the first-stage (univariate) analysis, among the sociodemographic variables considered, marital status of respondents (\(P < 0.001\)) and the presence of discrimination (\(P = 0.019\)) have a statistically significant relationship with the social and environmental domain of WHOQOL-BREF, respectively. However, among the clinical characteristics, the duration of epilepsy has a statistically significant association with the health satisfaction item of WHOQOL-BREF, while the presence of psychiatric disorder shows a statistically significant relationship with the overall QOL item (\(P = 0.044\), physical domain (\(P = 0.008\)), psychological domain (\(P = 0.007\)), and environmental domain (\(P = 0.026\)).

In the second-stage analysis to determine the predictors of QOL score, only the variables significant in the first stage analysis were included in the logistic regression analysis. The presence of psychiatric disorder was found to be predictive of poor score on the overall QOL item (odds ratio [OR] = 0.382; 95% confidence interval [CI] =0.145–0.983; \(P = 0.046\)), physical health domain (OR = 0.269; 95% CI = 0.100–1.722; \(P = 0.009\)), psychological domain (OR = 0.269; 95% CI = 0.102–0.709; \(P = 0.008\)) but loss it significant on the environmental domain (OR = 0.412; 95% CI = 0.151–1.122; \(P = 0.083\)) of WHOQOL-BREF. The duration of epilepsy of > 5 years was also predictive of poor score on the health satisfaction item (OR = 0.202; 95% CI = 0.06–0.679; \(P = 0.010\)) of WHOQOL-BREF while being single was predictive of poor score on the social domain (OR = 0.177; 95% CI = 0.065–0.482; \(P = 0.001\)) [Table 4].

### Discussion

The psychosocial impact of epilepsy is enormous as demonstrated by several studies on people living with epilepsy. For example, relationship problems, unemployment, discrimination, depression, and anxiety are among the psychosocial factors that may worsen the life satisfaction and QOL of epileptic patients.[3] In addition, clinical variables such

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**Table 1: Sociodemographic characteristics of respondents (n=74)**

| Variables          | Frequency, n (%) |
|--------------------|------------------|
| **Age group**      |                  |
| 18-40              | 61 (82.4)        |
| 41-59              | 11 (14.9)        |
| ≥60                | 2 (2.7)          |
| **Sex**            |                  |
| Male               | 46 (62.2)        |
| Female             | 28 (37.8)        |
| **Religion**       |                  |
| Christianity       | 5 (6.8)          |
| Islam              | 69 (93.2)        |
| **Marital status** |                  |
| Married            | 42 (56.8)        |
| Never married      | 32 (43.2)        |
| **Ethnicity**      |                  |
| Hausa/Fulani       | 59 (79.7)        |
| Others             | 15 (20.3)        |
| **Employment status** |            |
| Employed           | 37 (50.0)        |
| Unemployed         | 37 (50.0)        |
| **Educational status** |            |
| No education/primary | 35 (47.3)  |
| Secondary/tertiary | 39 (52.7)        |
| **Adequate support** |             |
| Yes                | 64 (86.5)        |
| No                 | 10 (13.5)        |
| **Feeling of discrimination** |   |
| Yes                | 24 (32.4)        |
| No                 | 50 (67.6)        |

**Table 2: Clinical characteristics of respondents (n=74)**

| Variables                      | Frequency, n (%) |
|--------------------------------|------------------|
| **Family history of epilepsy** |                  |
| Yes                            | 7 (9.5)          |
| No                             | 67 (90.5)        |
| **Duration of epilepsy (years)** |                |
| 1-5                            | 23 (31.1)        |
| >5                             | 51 (68.9)        |
| **Frequency of seizure**       |                  |
| Daily                          | 18 (24.3)        |
| Weekly                         | 24 (32.4)        |
| Monthly                        | 24 (32.4)        |
| >Monthly                       | 8 (10.8)         |
| **Seizure-free period (years)** |                |
| <1                             | 57 (77.0)        |
| ≥1                             | 17 (23.0)        |
| **Presence of complication**   |                  |
| Yes                            | 14 (18.9)        |
| No                             | 60 (81.1)        |
| **Presence of psychiatric disorder** |            |
| Yes                            | 33 (44.6)        |
| No                             | 41 (55.4)        |
as type of seizure, seizure frequency, antiepileptic medications, and the severity of seizures are reported to influence QOL scores.\cite{3,5,11,13} However, there are conflicting evidence for the effect of sociodemographic factors on QOL measures.\cite{11} The negative consequences of this illness had informed the need for physician to extend the management of epilepsy, like many other chronic medical conditions, beyond symptoms alleviation but seek also to improve the QOL of patients.\cite{12}

The aim of our study was to determine the effect of sociodemographic, epilepsy-related clinical characteristics, and the presence of psychiatric disorder on the QOL of people living with epilepsy. Among the sociodemographic variables considered, being unmarried was found to be predictive of poor QOL in the study respondents. Our finding is similar to a southern India study among people with epilepsy, in which being unmarried was significantly associated with a low score in WHOQOL-BREF questionnaire, though other sociodemographic variables such as increasing age, no primary education, and low per capita income were also associated with lower QOL among their study respondents.\cite{6} Similarly, Ohaeri \textit{et al.} reported a positive association between QOL score on WHOQOL-BREF with marriage among Sudanese patients with epilepsy.\cite{14} In addition, at the National referral hospitals in Uganda, a cross-sectional study of epileptic patients receiving anti-epileptic drugs by Nabukenya \textit{et al.}, using QOLIE-31 revealed that being unmarried was significantly associated with lower QOL.\cite{15} Our finding is however, in contrast with another study in India using similar instrument among people with epilepsy attending an outpatient department of a community based secondary care hospital were age >30 years, female sex and being married were determinant of poor QOL scores.\cite{15} The plausible explanation for our finding is that marriage provides an opportunity for social interaction and support which are protective factors in helping individuals with epilepsy cope with this chronic debilitating illness.\cite{16}

Since ancient times, epilepsy has been associated with myth and several misconceptions about its causes, which are often linked, particularly in developing countries to spiritual attacks and curses. These misconceptions about the disease result in the experience of discrimination by the patients and as such they might have difficulty with schooling, gaining employment, forming a healthy relationship with people or seeking medical help.\cite{5,16} Although the experience of discrimination in our study respondents was associated with a low QOL score in the environment domain of WHOQOL, it was however, not predictive when subjected to logistic regression analysis. This finding may be likened to a study among epilepsy patients in a multi-ethnic urban population in the USA using QOLIE-31, in which perceived epilepsy stigma was found to be significantly associated with lower QOL score.\cite{17} Similarly, in a study using WHOQOL-BREF questionnaire among people with epilepsy in Addis Ababa, Ethiopia, perceived stigma was found to be significantly associated with poor QOL.\cite{10} It is important that measures to combat discrimination against people living with epilepsy such as public awareness, education about cause and treatability of epilepsy to breakdown misinterpretations and myths surrounding the illness and to increase social acceptability of people with this condition should be put in place, in other to improve their QOL.\cite{3,16}

Researchers from different parts of the world have revealed the negative influence of different clinical variables, including comorbid psychiatric morbidity on the QOL of people with epilepsy.\cite{3,16} Among the clinical characteristics considered in this study, longer duration of epilepsy was predictive of a poor QOL score on the physical health domain. This finding is comparable to that reported by Gülpek \textit{et al.}, using similar QOL instrument in patients with epilepsy in Turkey, where the QOL of patients in the physical health domain was found to be reduced among the respondents with longer duration of the disease.\cite{18} Similarly, Onwuekwe \textit{et al.} found a negative correlation between the psychological well-being of WHOQOL and the duration of epilepsy in their study of

### Table 3: Distribution of items and domains of the WHO quality of life-BREF among patients with epilepsy

| Variables                        | Mean±SD    | Frequency (%) |
|----------------------------------|------------|---------------|
|                                  |            | Poor QOL | Good QOL |
| Overall QOL                      | 3.46±0.91  | 33 (44.6) | 41 (55.4) |
| Health satisfaction              | 3.55±0.78  | 30 (40.5) | 44 (59.5) |
| Physical domain                  | 60.78±13.44| 28 (37.8) | 46 (62.2) |
| Psychological domain             | 65.58±15.71| 32 (43.2) | 42 (56.8) |
| Social relationships domain      | 58.26±18.51| 38 (51.4) | 36 (48.6) |
| Environmental health domain      | 58.82±13.36| 41 (55.4) | 33 (44.6) |

| QOL: Quality of life, SD: Standard deviation |

### Table 4: Logistic regression for the WHO quality of life-BREF scores and predicting variables

| WHOQOL-BREF | Predicting variables | Coefficient | OR     | 95% CI      | P  |
|-------------|----------------------|-------------|--------|-------------|----|
| Overall QOL | Psychiatric disorder | −0.962      | 0.382  | 0.145-0.983 | 0.046 |
| Health satisfaction | Duration of epilepsy (>5 years/1-5 years) | −1.597 | 0.202 | 0.06-0.679 | 0.010 |
| Domain 1    | Psychiatric disorder | −1.314      | 0.269  | 0.100-1.722 | 0.009 |
| Domain 2    | Psychiatric disorder | −1.313      | 0.269  | 0.102-0.709 | 0.008 |
| Domain 3    | Marital status (married/never married) | −1.729 | 0.177 | 0.065-0.482 | 0.001 |
| Domain 4    | Discrimination (yes/no) | −1.073 | 0.342 | 0.113-1.039 | 0.058 |
|             | Psychiatric disorder (yes/no) | −0.083 | 0.412 | 0.151-1.122 | 0.803 |

OR: Odds ratio, CI: Confidence interval, QOL: Quality of life
patients with epilepsy in the south eastern region of Nigeria. [19]
Furthermore, in other studies among epileptic patients, using QOLIE-31, longer duration of the disease was predictive of a lower QOL scores. [14,20-23]

In contrast to some studies in which frequency of seizures was found to be a very important clinical factor impacting negatively on QOL of patients with epilepsy, this did not show a significant statistical relationship with any of the QOL item and domain of WHOQOL-BREF among our study respondents. [20-23]

About 44.6% of our study population had psychiatric disorders majority of who had depressive illness which is the most commonly diagnosed mental health problem among people with epilepsy. [24,25] Details of the various psychiatric diagnoses and the predictive variables had been described in our earlier publication. [26] The presence of psychiatric disorder in our cohort was predictive of poor QOL scores on overall QOL, physical health, and psychological health domain of the WHOQOL-BREF. This finding is comparable to that reported by Gülpek et al., among patients with epilepsy in Turkey, where a significant negative correlation was found between psychiatric morbidity (anxiety and depressive symptoms) and the physical health, psychological health, social, and environmental domain of WHOQOL-BREF questionnaire. [18]

Also using similar QOL instrument, Rakesh et al. found a statistically significant relationship between the presence of psychiatric symptoms and a low QOL score among people with epilepsy in southern India. [6] Similarly, in other research works among patients with epilepsy using QOLIE-31, the presence of psychiatric disorder was found to be significantly associated with poor QOL. [11,13,22,27,28] A comorbid psychiatric disorder in people living with epilepsy heightened their inability to seek help, worsen medication adherence, increase discrimination and social isolation. It constitutes an additional burden which further worsens their ability to cope with the illness, disrupt their activities of daily living and those of their relatives.

The lack of a control group is a limitation in this study as it is difficult to make a categorical statement on the QOL of patients with epilepsy since there was no comparable group. The result of this study cannot be generalized because it was done among patients with epilepsy attending psychiatric clinic, they may represent the group with more severe symptoms than those attending general or medical outpatients’ clinics. Furthermore, the use of disease specific instruments for measuring QOL would have been more appropriate in this study since it would have measure only attributes that are specific to epilepsy, unlike generic instruments which are appropriate when comparing QOL of patients with different illnesses. [29]

**Conclusion**

This study revealed that being unmarried, long duration of epilepsy, and the presence of psychiatric comorbidity can cause significant damage to the QOL of patients with epilepsy, consequently, measures such as public health campaign to address discrimination and to encourage patients to seek appropriate timely care, as well as early recognition and prompt treatment of psychiatric disorders may improve the life satisfaction and QOL of patients with epilepsy. This study also emphasizes the need for increased collaboration between mental health professionals and other health practitioners involved in epilepsy care.

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**Conflicts of interest**

There are no conflicts of interest.

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