



Effects of seizure severity and seizure freedom on the health-related quality of life of an African population of people with epilepsy



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ABSTRACT

Purpose: This study aimed at determining the effects of seizure severity and seizure freedom on health-related quality of life (HRQOL) of people with epilepsy (PWE) in the presence of perceived stigma in a sub-Saharan African culture.

Methods: Health-related quality of life was assessed using QOLIE-31 in 93 consecutive adults (56 males and 37 females) with epilepsy. They were stratified into seizure-free, low–moderate seizure severity, and high seizure severity groups based on the seizure type and the number of seizures in the previous 6 months. Other illness variables and sociodemographic variables were also obtained. A 3-item perceived stigma scale was administered. A modified QOLIE-31 (excluding the epilepsy-specific items) was given to 102 age- and sex-matched healthy controls.

Results: There was moderate negative correlation between seizure severity and mean total HRQOL score as well as scores on the Seizure Worry ($p = .000$), Overall Quality of Life ($p = .000$), and Social Function ($p = .001$) subscales of QOLIE-31. Overall, the healthy control subjects had a higher mean HRQOL score compared with the PWE put together (71.0 ± 11.1 vs 64.2 ± 13.6 , $p = .001$). However, there was no difference in the mean HRQOL score between the seizure-free individuals and the healthy controls ($p = .270$). Seizure severity was associated with HRQOL independent of perceived stigma on a multiple regression analysis.

Conclusion: This study provides evidence that seizure severity relates to health-related quality of life in an inverse, graded manner and independent of perceived stigma. Seizure-free people with epilepsy can have quality of life comparable with healthy individuals.

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1. Introduction

The episodic seizures in epilepsy and the accompanying psychosocial comorbidities are capable of impairing quality of life. People with epilepsy tend to have lower quality of life (QOL) compared with matched healthy individuals [1,2]. An inverse relationship also exists between seizure severity and health-related quality of life (HRQOL) in epilepsy [3–5]. There is accumulating evidence that seizure-free individuals may have HRQOL comparable with the general population [1,6]. It does appear then that seizure status is a major determinant of quality of life in epilepsy. Few studies have suggested that significant reduction in HRQOL occurs in a higher proportion of seizure-free individuals (PWE) than would be expected when other factors such as mood disorders, stigma, seizure worry, self-esteem, and self-mastery are considered [7,8]. The relationships between seizure severity and seizure freedom and HRQOL have been widely studied in western cultures but not sufficiently in Africa [9]. Concepts of what constitute health

and QOL vary widely among cultures and value systems [9]. Epilepsy is associated with high levels of stigma in African cultures [10]. Epilepsy-associated stigma may persist even long after seizure remission has been achieved and may have profound impact on the HRQOL of patients with epilepsy [11]. How stigma perception modifies the effects of seizure severity and seizure freedom on HRQOL needs exploration in African cultures as well. Thus, the aim of this study was first to analyze the effect of seizure severity and seizure freedom on the HRQOL of a Nigerian-African population of PWE while controlling for perceived stigma and other determinants of HRQOL. Second, we compared the HRQOL of PWE with age- and sex-matched and socioculturally matched healthy controls.

2. Materials and methods

2.1. Participants and procedures

2.1.1. Group with epilepsy

To study the HRQOL profile of people with epilepsy (PWE), a sample of consecutive adult patients, 18 years and older and with confirmed diagnosis of epilepsy based on the guidelines of the International League Against Epilepsy (ILAE) [12], were recruited at the neurology clinic of

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the University College Hospital, Ibadan, Nigeria. This sample comprised 102 adults (60 males and 42 females) who gave their consent; however, 9 were excluded because of incomplete data. The excluded PWE did not differ from the rest in terms of demographic and clinical characteristics.

2.1.2. Healthy control group

A sample of 102 age- and sex-matched healthy volunteers comprising hospital staff members, students, and visiting relatives of patients with no known somatic or psychiatric illness were recruited to serve as controls.

2.1.3. Assessment of sociodemographic and clinical characteristics

Sociodemographic data such as age, sex, marital status, highest formal educational level, employment status, average monthly income, ethnicity, and religion were obtained. Disease-related variables including seizure frequency and type, etiology and class of epilepsy, duration of epilepsy, duration of treatment, number of AEDs, and treatment modality were also obtained. Classification of epileptic seizures and syndromes was based on the International League Against Epilepsy (ILAE) guidelines [8,13]. The patients' case records were consulted for corroborative purposes.

2.1.4. Assessment of seizure severity

Data regarding frequency of seizures were obtained, and the PWE were then stratified into three seizure-specific severity groups (seizure-free, low-moderate seizure severity, and high seizure severity categories) based on the number of seizures in the previous 6 months and seizure type. This was a modification of the criteria for seizure-specific categorization of severity of epilepsy developed by Devinsky et al. [14]. This scheme stratifies patients 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 correspond to 1–4, 5–12, and 13–24 seizures, respectively, in the previous year, while for generalized tonic-clonic seizures, they correspond 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 the seizure frequencies required were used for categorization into seizure severity groups. Also, the low and moderate seizure severity groups were merged because of the small sample size of the low severity group ($n = 5$).

2.1.5. Assessment of HRQOL

The HRQOL of the patients was assessed with Quality of Life in Epilepsy-31 (QOLIE-31) item (version 1.0) inventory. Quality of Life in Epilepsy-31 is an epilepsy-specific QOL inventory that contains seven multi-item scales with a total of 31 items that tap the following health concepts: Overall Quality of Life, Seizure Worry, Emotional Well-being, Energy Fatigue, Cognitive Functioning, Medication Effects, and Social Functioning [15]. A modification of the inventory which excludes the epilepsy-specific items, i.e., seizure worry and medication effects, was administered to the controls. The scoring procedure converts raw precoded numeric values of items to scores of 0–100 where higher scores reflect a better quality of life. An overall score is obtained by using a weighted average of the multi-item scale scores [16]. Quality of Life in Epilepsy-31 has demonstrated robust psychometric properties [17] with modest reliability in Nigerian PWE [18]. The modified QOLIE-31 for controls has demonstrated moderate reliability as well [18].

2.1.6. Assessment of perceived stigma

A 3-item Epilepsy Stigma Scale was used to assess perceived stigma in the PWE. The Epilepsy Stigma Scale was adapted from a measure originally designed to assess the perceived stigma of a stroke and

revised to make it applicable to epilepsy [19]. It has a simple scoring system of zero or one for each item; a score of three represents the perception of being severely stigmatized by the epilepsy. Evidence for its reliability and validity has been well documented [17,20].

2.2. Statistical analysis

Characteristics of the PWE were compared with those of the healthy controls using Student's t -test and χ^2 test. The clinical characteristics of the PWE were also summarized using the Student's t -test and χ^2 test. Mean QOL scores were compared across different seizure severity categories using one-way analysis of variance (ANOVA). Comparison between PWE and controls, between seizure-free individuals and the controls, and between seizure-free PWE and those with persisting seizures was done using the Student's t -test. A stepwise multiple linear regression model was constructed using total QOLIE-31 score as the dependent variable. A 5% statistical significance level was chosen. The Statistical Package for the Social Sciences (SPSS), version 16 (SPSS Inc., Chicago, IL, U.S.A.) was used for all analyses.

2.3. Ethical clearance

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

3. Results

3.1. Demographic characteristics

In the group with epilepsy, the mean age \pm SD was 34.7 ± 14.7 years; 52.9% were single, and 81.3% were in paid employments. The average monthly income was at least 5000 naira (40 dollars) per month in 50% of the patients. Forty-two percent had tertiary level education. There was no significant sociodemographic difference between subjects who had had no seizure in the preceding 6 months and those with persisting seizures (Table 1).

In the control group, the mean age was 34.6 ± 13.7 years; 53.8% were single, and 90.5% were in paid employments. The average monthly income was at least 5000 naira per month in 82.6%, while 74.0% had tertiary level education. The PWE were less likely to be married and more likely to be divorced or separated ($p = 0.16$). They had lower educational attainments ($p < .001$) and earned less income compared with the controls ($p < .001$). While there was no difference in employment status between the PWE and control groups, the PWE were more likely to be in unskilled employments and less likely to be in skilled employments ($p = .001$). Controlling for the attainment of tertiary education, this difference disappeared; however, there was a trend towards PWE who had tertiary education to be in skilled employments compared with the healthy controls ($p = .05$). There were no statistically significant age and gender differences between the group with epilepsy and the control group (Table 1).

3.2. Clinical characteristics of the PWE

Partial seizures were the predominant seizure type in 89 (87.2%) of the cases; of these, complex partial seizures were the most common (55.9% of all cases). There was no identifiable etiology in 57 (55.9%). The mean age of onset of epilepsy was 21.5 ± 16.4 years. The mean duration of the disease was 14.1 ± 11.3 years. Fifty-three (64.8%) had had the disease for more than 10 years, while 22 (26.5%) had been on anti-epileptic drug (AED) treatment for 10 years. Of the 85 (91.4%) study subjects taking AEDs drugs, 4 did not indicate the number of AEDs, and 59 (72.8% of the respondents) were on a single AED. Two of the patients were on traditional remedies only, and 6 were not on any medication (Table 2). There was no significant difference in mean age of

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