



Relationship between Demographic, Clinical, Psychosocial Factors and Health-related Quality of Life among Persons with Epilepsy in Zaria Northern Nigeria

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Authors' contributions

This work was carried out in collaboration among all authors. Author EUI designed the study, performed the statistical analysis, wrote the protocol and wrote the first draft of the manuscript. Authors ROO and AO managed the literature searches and edited the first draft of the manuscript alongside with author TJI. All authors read and approved the final manuscript.

Article Information

DOI: 10.9734/JAMMR/2020/v32i730453

Editor(s):

(1) Dr. Bhat Sangeetha Govinda, Amrita Vishwa Vidyapeetham, India.

Reviewers:

(1) Rana Choudhary, Wockhardt Hospital, India.

(2) Somsak Tiamkao, Khon Kaen University, Thailand.

Complete Peer review History: <http://www.sdiarticle4.com/review-history/57188>

Original Research Article

Received 12 March 2020

Accepted 19 May 2020

Published 28 May 2020

ABSTRACT

Introduction: There is a growing global interest on the effect of epilepsy on the subjective health-related quality of life (HRQoL) of the sufferers. Several demographic, clinical, and psychosocial factors have been attributed as contributory to the poor HRQoL in patients (persons) with epilepsy (PWE).

Aim: This study evaluated the relationship between demographic, clinical and psychosocial characteristics of PWE and their HRQoL.

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Study Design: A cross-sectional study.

Place and Duration of Study: Study carried out at Neurology clinic of Ahmadu Bello University Teaching Hospital Kaduna State, Nigeria from September 2013 to December 2014.

Methodology: Consecutively presenting PWE on follow-up for at least 1 year, 18 years and above were recruited after obtaining ethical approval and informed consent. Structured questionnaire and the World Health Organization Quality of Life (WHOQOL-Bref) instrument were utilized for the study. The data was analyzed using SPSS version 17 with p-value set at less than 0.05.

Results: The participants were one hundred with median age of 29 years. The factors found to have significant relationship with HRQoL were demographic variables like marital status ($F = 3.250$, $p = 0.025$) and monthly income ($t = -2.883$; $p = 0.005$); psychosocial factors like presence of perceived stigma or discrimination ($\chi^2 = 2.427$, $p = 0.017$), presence of depressive symptom in the preceding month ($\chi^2 = 3.164$, $p = 0.002$) and availability of social support ($\chi^2 = 3.328$, $P = 0.001$). There was no significant relationship found between clinical factors and HRQoL of PWE ($p > 0.05$).

Conclusion: The demographic factors (marital status and monthly income) and psychosocial factors (stigma, depression and social support) had a significant relationship with HRQoL in PWE. There is a need to offer evidence-based and focused care to the sufferers of this illness.

Keywords: Relationship; demographic; clinical; psychosocial; health related quality of life; persons with epilepsy.

1. INTRODUCTION

Epilepsy is one of the most common serious chronic non-communicable disorders of the brain [1]. The hallmark feature is the epileptic seizure, defined as a transient occurrence of symptoms and/or signs due to abnormal excessive or synchronous neuronal activity in the brain [1]. The definition of epilepsy as 'one unprovoked seizure and the probability of further seizures being based on the presence of enduring underlying predisposing factors, revealed by clinical, electroencephalographic (EEG), neuroimaging, genetic or other information' is the most relevant for making a treatment decision [2]. It affects about 70 million people worldwide and accounted for 0.5% of the global burden of disease [3-4]. About 85 % of the burden of the disease is in the developing world like Sub-Saharan Africa and unfortunately, over 60% of the people (persons) with epilepsy (PWE) receive no treatment at all [5].

This illness is a chronic disorder characterized by intermittent, often unpredictable seizures with significant physical, psychological and social consequences for everyday living [6]. PWE report a significant impact of the disease leading to family dysfunction (with attending distortion in the family dynamics), and reduced social and leisure activities. Furthermore, stigmatization and unpredictability of seizure increase the impact on the sufferers [7]. Suicide or deliberate self-harm is common among such patients [7]. Similarly, they are more likely to drop out of school, lose their job or spouse, and (or for the unmarried)

find it difficult to marry based on the wrong socio-cultural perception of the populace about the illness [7].

It is important to consider the total impact of a disease like epilepsy as measured by its effect on a person's quality of life [8]. The World Health Organization (WHO) defined QoL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and about their goals, expectations, standards and concerns" [9]. HRQoL is a subjective concept based on the subject's perspective and experiences and involves physical, psychological, social, and cultural components, all of which contributes to patient's adjustment to his condition and has a significant impact on his life [9].

Epilepsy has been associated with poor HRQoL and several factors are said to be responsible for this. They include demographic, clinical and psychosocial factors [10-18]. Understanding the unique and complex impact of epilepsy on a person's HRQoL is also increasingly becoming an important component of clinical care. Assessing the HRQoL of these patients will help to identify their other needs aside antiepileptic drug therapy and ultimately optimize epilepsy care. This study evaluated the relationship between HRQoL of PWE and demographic, clinical and psychosocial factors. The findings may also assist in providing evidence-based and focused care to the sufferers of this illness, as well as serve as a template for advocacy for the PWE in Nigeria.

2. MATERIALS AND METHODS

2.1 Study Area and Population

The study was carried out at the Neurology Clinic in the Medical Out-patient Department of Ahmadu Bello University Teaching Hospital (ABUTH), Zaria, Kaduna State, Nigeria from September 2013 to December 2014. This is a specialist clinic that attends to patients with only neurological diseases like stroke, movement disorders, epilepsy etc. It is a major referral centre from all over Northern Nigeria.

2.2 Study Design

A cross-sectional design was employed.

2.3 Sample Size Determination

The sample size of patients was determined using Fisher's formula [19].

$$N = \frac{Z^2 pq}{d^2}$$

Where

N = Minimum sample size

Z = the standard normal deviate at 95% confidence level (1.96)

P = prevalence rate of epilepsy in Nigeria put at 6.2% [20].

d² = degree of accuracy at 0.05

$$N = \frac{1.96 \times 1.96 \times 0.062 \times 0.938}{0.05 \times 0.05}$$

N = 89.36 approximated to N = 90

Attrition rate of 10% of the minimum sample was considered and was approximately 10.

Making it at least a minimum of one hundred (100) PWE.

2.4 Selection Procedure

Consenting consecutively presenting adult PWE diagnosed by the Neurologist were recruited after obtaining informed consent. Those recruited were at least 18 years and have been on routine follow-up for at least 1 year. Epilepsy was diagnosed based on history of at least two unprovoked seizures 24 hours apart corroborated by an eye witness account with

supportive abnormal inter-ictal EEG [21-22]. Patients with a background history of psychiatric illness, cognitive impairment, substance use disorder and clinical history of chronic medical illness such as (hypertension, diabetes mellitus, chronic kidney disease, heart failure, and asthma) were excluded.

2.5 Study Instruments

A structured questionnaire and the World Health Organization Quality Of Life Short version (WHOQOL-BREF) instrument were interviewer-administered to all the participants. The structured questionnaire was used to obtain information on subjects' bio data, relevant clinical information as well as to assess psychosocial variables (presence of a depressive symptom, stigma and social support). The 'two question' simple screening tool for depressive symptom in the preceding one month was used for this study [23]. If one or both of the answers is 'Yes', indicates the presence of depressive symptom. Presence of stigma/discrimination was assessed by asking patients 'do you feel people stigmatize or discriminate against you as a result of this illness?' to which 'Yes' indicates presence of stigma and 'No' implies its absence. Also questions relating to the form(s) and source(s) of stigma/discrimination were sought from them.

The WHOQOL-BREF is a generic questionnaire for assessing HRQoL in epilepsy and it is a short version of the WHOQOL-100 instrument. The instrument is useful in large research studies or clinical trials and has been utilized worldwide. The WHOQOL-BREF questionnaire is reliable, psychometrically and culturally valid and has been validated in Nigeria [9, 18-20].

The WHOQOL-BREF is a 26-item questionnaire made up of domains and facets. Domains are broad groupings of related facets. Each item of the WHOQOL-BREF is rated on a 5-point Likert type scale. Domain scores are scaled in a positive direction (i.e., higher scores denote higher HRQoL). The mean score of items within each domain is used to calculate the mean domain score. After computing the scores, they were transformed linearly to a 0-100 scale using the guidelines by multiplying mean score by 4 to make it comparable to the scores in WHOQOL-100 [21].

2.6 Data Analysis

Data entry and statistical analysis were done using the statistical package for social sciences

(SPSS) software (version 17; SPSS, Chicago, IL, USA). Descriptive statistics were used to compute range, median, mean and standard deviation for quantitative variables as well as frequencies. Chi-square test statistic (χ^2) was used to test the relationship between categorical variables while continuous variables were tested using the independent samples t-test and analysis of variance (ANOVA). A p-value of less than 0.05 was used to determine statistical significance.

3. RESULTS

3.1 Demographic Characteristics of PWE and Their Relationship with HRQoL

There were one hundred respondents with median age of 29 years respectively and range of 18-75 years. The relationships of demographic characteristics of PWE with HRQoL are shown in Table 1. This study showed a significantly lower mean HRQoL among separated or divorced patients compared to others (F = 3.250, p = 0.025). Also PWE with monthly income of ₦50,000.00 and above had significantly higher mean HRQoL than those with income of < ₦50,000.00 (t = -2.883, p = 0.005).

3.2 Relationship between Clinical Characteristics (Seizure Types, Seizure Frequency & Duration, the Modality of Treatment) and HRQoL

Table 2 showed no significant relationship between clinical characteristics and mean HRQoL of PWE. Among the patients; 96, 96% were on AEDs monotherapy; 84, 84% were on

Carbamazepine, 7, 7% on Sodium valproate and 5, 5% on Phenytoin. While those on polytherapy were 4, 4%; with Carbamazepine plus Sodium valproate 2, 2% and Sodium valproate plus Phenytoin 2, 2%.

3.3 Relationship between Psychosocial Characteristics of PWE and HRQoL

Majority of the patients, 75 (75.0%) did not feel stigmatized or discriminated and had higher HRQoL than the PWEs 25 (25.0%) who felt stigmatized or discriminated ($\chi^2 = 2.427$, p = 0.017). PWEs without depressive symptoms had significantly higher HRQoL than PWEs with depressive symptoms ($\chi^2 = 3.164$, p = 0.002). Also the majority of the PWEs had social support and also had significantly higher HRQoL than the few without social support ($\chi^2 = 3.328$, p = 0.001) shown in Table 3.

3.4 Sources and Forms of Perceived Stigma Experienced by PWEs

Among the patients who felt stigmatized or discriminated against reported that it occurred 17, (29.8%) of the time at home among relatives, 15 (26.3%) times by their neighbors, 9 (15.8%) times at workplace, 9 (15.8%) at their place of worship, and finally 7 (12.3%) times at school (in the class or hostel).

The forms of discrimination or perceived stigma experienced by the patients included: people avoided them or ran away from them during seizure episode (19, 15.7%), refused to talk to them (18, 14.9%), and were denied leadership role because of the illness (18, 14.9%).

Table 1. Relationship between demographic characteristics and mean HRQoL of PWE

Variable	PWE n = 100	Mean HRQoL	t-test/Anova	P value
15-40 years	70 (70.0)	65.55	0.335	0.738
41 and above	30 (30.0)	64.35		
Male	52 (52.0)	67.05	1.197	0.234
Female	48 (48.0)	63.17		
Single (never married)	55 (55.0)	67.30	3.250	0.025
Married	38 (38.0)	65.02		
Separated/divorced	6 (6.0)	46.00		
Widowed	1 (1.0)	68.24		
Had Formal education	79 (79.0)	65.29	-0.103	0.918
No Formal education	21 (21.0)	64.87		
Employed	40 (40.0)	65.12	-0.046	0.963
Unemployed	60 (60.0)	65.27		
Income of < ₦50,000	*60 (83.3)	62.88	-2.883	0.005
Income of ≥ ₦50,000	*12 (16.7)	76.80		

PWE= Persons with epilepsy; HRQoL= Health related quality of life; n= Number; % = Percentage, * = 18 subjects with no income (students) were excluded

Table 2. Relationship between clinical characteristics and mean HRQoL of PWE

Variable	PWE n=100	Mean HRQoL	t-test	p-value
Focal seizure	48 (48.0)	64.09	0.682	0.497
Generalized seizure	52 (52.0)	66.30		
Seizure frequency (≤1 per Month)	60 (60.0)	67.60	1.764	0.081
Seizure frequency (≥ 2 per month)	40 (40.0)	61.86		
Seizure controlled (over past 12 months)	52 (52.0)	66.10	0.344	0.732
Seizure Uncontrolled (over past 12 months}	48 (48.0)	64.85		
Age at seizure onset (18-40 years)	86 (86.0)	65.15	-0.939	0.077
Age at seizure onset (≥41)	14 (14.0)	65.52		
Seizure duration ≤ 10 years	67 (67.0)	65.28	0.070	0.944
Seizure duration ≥ 11 years	33 (33.0)	65.04		
Monotherapy	96 (96.0)	65.38	0.525	0.600
Polytherapy	4 (4.0)	60.95		
On AED for < 24 months	60 (60.0)	66.86	0.112	0.209
On AED for ≥ 24 months	40 (40.0)	62.69		
Presence of AED side effect	24 (24.0)	63.12	-0.728	0.468
Absence of AED side effect	76 (76.0)	65.87		

PWE= Patients with epilepsy; HRQoL= Health related quality of life; n= Number; % = Percentage, AED = Antiepileptic drug

Table 3. Relationship between psychosocial characteristics and mean HRQoL of PWE

Variables	PWE n=100 n (%)	Mean HRQoL	χ ²	p-value
Presence of perceived stigma/discrimination	25 (25.0)	57.95	2.427	0.017
Absence of perceived stigma/ discrimination	75 (75.0)	66.86		
Presence of depressive symptom	41 (41.0)	59.10	3.164	0.002
Absence of depressive symptom	59 (59.0)	69.26		
Presence of social support	88 (88.0)	67.68	3.328	0.001
Absence of social support	12 (12.0)	52.42		

PWE= Patients with epilepsy; HRQoL= Health related quality of life; N= Number, % = Percentage

Table 4. Sources and forms of perceived stigma experienced by PWE

Sources	*Frequency	Percentage
Relatives	17	29.8
Neighbours	15	26.3
Workplace	9	15.8
Church/Mosque	9	15.8
School	7	12.3
Forms		
Avoidance by people during seizures	19	15.7
Avoidance of people to eat with PWE	14	11.6
Refusal to communicate with PWE	18	14.9
Denied leadership role	18	14.9
Rejection by suitors	12	9.9
Abandonment in marriage by spouse	11	9.1
Job rejection	10	8.3
Job termination	5	4.1
Withdrawal from school	5	4.1

= Multiple responses; PWE = Persons with Epilepsy

Stigmatization also manifested as rejections by suitors (12, 9.9%), people avoided to eat with them (14, 11.6%) and were separated or abandoned by marriage partner (11, 9.1%). Others included: rejected job applications due to knowledge of their illness (10, 8.3%), expelled and/or withdrawn from school (5, 4.1%), and job termination (5, 4.1%). The details are shown in Table 4.

3.5 Sources and Forms of Social Support Experienced by PWEs

Sources of the patients' support during the illness included: relatives (80, 34.5%), doctors and nurses (59, 25.4%), friends (44, 19.0%), neighbours (41, 17.7%), and other epilepsy patients (8, 3.4%). The forms of supportive care received included: assistance during seizure episode (88, 13.6%), being reminded to take drugs (87, 13.4%), being spoken encouraging words to (84, 13.0%), and being accompanied to hospital for epilepsy treatment (81, 12.5%). It also involved paid for/provided their AEDs (78, 12.0%), provided for their feeding or gave them financial assistance (77, 11.9%), and drove or went out with them (55, 8.5%). They were also supported by being given relevant information regarding epilepsy (52, 8.0%), and assisted in activities of daily living (46, 7.1%). Details are shown in Table 5.

4. DISCUSSION

Epilepsy is a chronic disorder major public health concern significantly affecting the lives of those

suffering from it. The demographic characteristics of PWE in this study are similar to what have been reported in some previous HRQoL studies in epilepsy [10-11]. Our finding showed that PWE that were divorced or separated had significantly lower mean HRQoL score. Hence, this study, like those of Ohaeri et al. in Sudan, and Shetty *et al* in India, have demonstrated a positive relationship between being married and HRQoL [12,16]. Conversely, some investigators found no significant relationship between the marital status of PWE and their HRQoL [19,28]. It has been suggested that being married exerts a positive effect on the overall HRQoL of PWE [12,16]. It is believed that marriage has a positive impact on health, by providing greater economic resources, as well as fostering a sense of meaning, promoting healthy behaviour, and improving adherence to medical regimen [29].

The present study also found a significant relationship between the monthly income of PWE and HRQoL. This has been corroborated by a previous study which reported that low annual income was significantly associated with impairment of HRQoL in their cohort [11]. In the presence of poor per capita income, PWE may be unable to pay for their transportation to available health care facility or procure antiepileptic drugs (AEDs) prescribed for them. This could lead to uncontrolled seizures and ultimately worsened HRQoL. There is the need to economically empower PWE by improving their employment opportunities which should be safety friendly.

Table 5. Sources and forms of social support experienced by PWE

Sources	#Frequency	Percentage
Relatives	80	34.5
Health workers	59	25.4
Friends	44	19.0
Neighbours	41	17.7
Other Persons with epilepsy	8	3.4
Forms		
Assist during seizure	88	13.6
Reminds to take medications	87	13.4
Accompanies to hospital	81	12.5
Procures medications	78	12.0
Provides financial assistance	77	11.9
Assists in going out	55	8.5
Gives relevant information	50	8.0
Assists in activities of daily living	46	7.1

= Multiple responses; PWE = Persons with Epilepsy

Apart from marital status and income, other demographic factors like age, sex, level of education, and employment status were not found to have any significant relationship with HRQoL in this study like in some previous reports [16,28]. However, some researchers have reported being a female, level of education, employment status, engaging in high skill occupation to have significant relationship with HRQoL [11-12,30]. These differences in finding may be attributable to differences in study location and socio-cultural setting.

In this study none of the clinical factors such as seizure type, age of onset of first seizure, duration of illness, seizure frequency, time of last seizure, duration on AEDs treatment, and numbers of drugs used (monotherapy or polytherapy) and presence of AED side effect was found to have significant relationship with HRQoL. Our finding is in conformity with the report by Ashwin *et al* which found no significant association between HRQoL and clinical characteristics of the PWE [31].

This study showed that (25.0%) of epilepsy patients admitted to being discriminated against or experienced some perceived stigma as against (11.0%) found by Baker *et al.* [32]. This study also revealed that the presence of discrimination/perceived stigma which was significantly associated with lower HRQoL. Some investigators had demonstrated the negative impact of stigma on HRQoL and epilepsy care [17,32-33]. Thomas *et al.* had noted that epilepsy stigma can interfere with timely access to healthcare, early diagnosis, treatment, adherence to treatment and lifestyle recommendations thereby widening the treatment gap [34].

Similarly, stigma reduces opportunities for marriage and employment for PWE. The implications of epilepsy related stigma on disease burden and HRQoL are difficult to calculate and are certainly of great significance in resource-constrained countries like ours where epilepsy is a major public health problem [35]. A more comprehensive approach must include interventions at the levels of the individual, the family, the health care system (i.e. adequate information and/or training must be provided to caregivers in the medical system), and the community. Medical professionals must be aware of the effects of a diagnosis of epilepsy and take the time to discuss with the patients and

their families the possible psychosocial consequences and how these may be addressed.

Diagnosis of epilepsy could trigger negative perceptions and attitude towards the patients at home [36]. This was demonstrated in the present study where (29.8%) of patients had discrimination or perceived stigma from family relatives. Clinicians should watch out for any misconceptions and misunderstandings about epilepsy and ensure that all members of the family are fully aware of the illness through accurate information and health education.

Presence of depressive symptom in the preceding month among PWE was significantly related to lower HRQoL in this study. Mosaku *et al.* rated depressive symptoms as the single most important factor causing impaired HRQoL [30]. This result supports those of previous researches in which depression was a significant factor in predicting HRQoL in patients with epilepsy, even though these studies used different instruments to measure depression and HRQoL [17,30]. Yet these results provided consistency and strengthened the evidence for the relationship between depressive symptom and HRQoL.

About (41.0%) of the patients had depressive symptoms at presentation, this figure was higher than that of Okubadejo *et al.* which showed a prevalence of (26.0%) in epilepsy patients [37]. Since there is a significant relationship between depression and HRQoL in PWE, early screening and recognition of depressive symptoms in these patients should be of great concern for health care providers. If depression can be identified early; patients can be given antidepressants, referred for psychotherapy or given other forms of mental health interventions that can improve their well-being.

This study found that the patients who received adequate supportive care had significantly higher mean HRQoL score compared to those who did not. Also, a significant number of the PWE agreed that they received adequate social support from relatives, health care personnel, neighbours, friends etc. Social support is defined as the perception that an individual is a member of a network in which one can give and receive help, affection and obligation [38]. Social support is an important component in managing

epilepsy. Greater social support has been linked to better HRQoL in PWE [17]. There is the need to create awareness about the illness and encourage adequate social support for sufferers with epilepsy.

5. CONCLUSION

This study showed that predominantly the psychosocial factors (social support, depressive symptom and perceived stigma/discrimination) and some demographic factors (marital status and monthly income) were significantly related to the HRQoL of PWE in Zaria. This calls for the need by clinicians to pay closer attention to these factors in order to ensure wholistic care for PWE in order to improve their HRQoL.

CONSENT

Informed consent was obtained from all participants in this study. The Hausa version of the consent form was administered to those who had difficulty in understanding English.

ETHICAL APPROVAL

Ethical approval was obtained from Health Research Ethical Committee (HREC) of the institution with reference number ABUTH/HREC/TRG/36 before commencement of the study.

ACKNOWLEDGEMENTS

We sincerely appreciate the contributions of Mrs. J. Odengele and Mr. Akanmen Ikwosio in the analysis and the initial editing of the work.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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