West African Journal of Pharmacy (2019) 30 (1) 35 - 43

Health related quality of life of people living with epilepsy in a Neuro-Psychiatric Hospital in Northern Nigeria

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ABSTRACT

Background: Epilepsy is a chronic devastating disorder that affects patients' quality of life irrespective of whether anti-epileptic drugs (AEDs) are being used.

Objectives: The objective of the study was to assess the health related quality of life of people living with epilepsy and its determinants in a Neuro-Psychiatric Hospital in Nigeria.

Methods: The cross sectional study involved 182 patients living with epilepsy that are on therapy with AEDs, sampled conveniently and interviewed between March-June 2015. Health Related Quality Of Life (HRQOL) was the primary outcome using items from Quality of Life In Epilepsy inventory (QOLIE-31). The data obtained were analyzed using Statistical Package for Social Sciences (SPSS 19.0). A P-value < 0.05 was considered statistically significant.

Results: Out of 182 patients, who participated in the study, 53.9% were male and 46.1% were female. The average age was 27.6±8.5 years. The overall HRQOL mean QOLIE-31 score of 57.46±14 was low relative to the expected normal value of 60.00±0.0 for people living with epilepsy. The three sub-scales considered normal with scores higher than 60.0 include cognitive functioning (65.67±21.85), social functioning (63.13±23.23) and medication effects (72.4±22.3). The most severely affected domain with sub-optimal scores was physical functioning (36.62±33.02) followed by seizures worry (50.19±20.10) and emotional well-being of 54.77±21.67. Being male was significantly associated with poor overall HRQOL (p-value = 0.021).

Conclusion: The HRQOL of the studied population being managed at the hospital is poor relative to group norm for people living with epilepsy. The most severely affected domain was physical functioning followed by seizures worry. It is important to strengthen the socioeconomic and psychological support in addition to optimal medication utilization to enhance HRQOL of the patients receiving AEDs.

Key words: Epilepsy, HRQOL, Quality of Life in Epilepsy Inventory (QOLIE-31)

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Qualité de vie liée à la santé des personnes atteintes d'épilepsie dans un hôpital neuro-psychiatrique au nord du Nigéria

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RESUME

Contexte : L'épilepsie est un trouble chronique dévastateur qui affecte la qualité de vie des patients, qu'on utilise ou non des médicaments antiépileptiques.

Objectifs : L'objectif de l'étude était d'évaluer la qualité de vie liée à la santé des personnes atteintes d'épilepsie et ses déterminants dans un hôpital neuropsychiatrique au Nigéria.

Méthodes : L'étude transversale portait sur 182 patients atteints d'épilepsie et traités par des DEA, échantillonnés convenablement et interviewés entre mars et juin 2015. La qualité de vie liée à la santé (QVLS) était le résultat principal obtenu à l'aide d'éléments de l'inventaire Qualité de vie dans l'épilepsie (QOLIE-31). Les données obtenues ont été analysées à l'aide du progiciel statistique pour les sciences sociales (SPSS 19.0). Une valeur de $p < 0,05$ était considérée comme statistiquement significative.

Résultats : Sur les 182 patients ayant participé à l'étude, 53,9% étaient des hommes et 46,1% étaient des femmes. L'âge moyen était de 27,6±8,5 ans. Le score QOLIE-31 moyen global de la QVLS correspondant à 57,46±14 était faible par rapport à la valeur normale attendue de 60,00±0,0 pour les personnes vivant avec l'épilepsie. Les trois sous-échelles considérées comme normales avec des scores supérieurs à 60,0 incluent le fonctionnement cognitif (65,67±21,85), le fonctionnement social (63,13±23,23) et les effets des médicaments (72,4±22,3). Le domaine le plus gravement touché avec des résultats sous-optimaux était le fonctionnement physique (36,62±33,02), suivi par les crises épileptiques (50,19±20,10) et le bien-être émotionnel de 54,77±21,67. Le fait d'être un homme était associé de manière significative à une QVLS globale médiocre (valeur $p = 0,021$).

Conclusion : la QVLS de la population étudiée prise en charge à l'hôpital est faible par rapport à la norme de groupe pour les personnes atteintes d'épilepsie. Le domaine le plus gravement touché était le fonctionnement physique, suivi de crises d'épilepsie. Il est important de renforcer le soutien socio-économique et psychologique en plus d'une utilisation optimale des médicaments afin d'améliorer la QVLS des patients recevant des DEA.

Mots-clés : épilepsie, QVLS, qualité de vie dans l'inventaire de l'épilepsie (QOLIE-31)

INTRODUCTION

Epilepsy is a neurological condition-affecting people of all ages, race and social class. An estimated 50 million people are living with epilepsy in the world, out of which up to 75% live in resource-poor countries with little or no access to medical services or treatment .[1, 2, 3]

In general, the incidence of epilepsy in developed countries is taken to be around 50 per 100,000 (range 40−70 per 100,000/year) while in resource-poor countries, it is generally higher in the range of 100−190 per 100,000/year.[4] Active epilepsy was estimated to affect 4.4 million people in Sub–Saharan Africa, whilst lifetime epilepsy was estimated to affect 5.4 million. The prevalence of active epilepsy peaks in the 20–29 age group at 11.5/1000 and again in the 40–49 age group at 8.2/1000.[5] However, a prevalence rate of 5.3-37 per 1000 children has been reported in Nigeria,[5] and it is a common reason for pediatric neurologic consultation in Nigeria[6,7] and other developing countries.[8]

Epilepsy is not always associated with significant morbidity as many patients living with epilepsy (PWE) continue to be highly productive and living somewhat fulfilled lives.[9, 10] However, there is an associated morbidity, which may be significant in some individuals due either to the effects of seizures, their underlying causes and/or treatment.[14.16] Epilepsy may sometimes result in significant disability, social exclusion and stigmatization.[11-16] Global quality of life of people living with epilepsy could be severely impacted by commonly encountered problems in areas such as education, employment, driving, personal development, psychiatric and psychological aspects, social as well as in personal relationships.[11, 12, 14]

Factors influencing incidence and prevalence include gender, age, socioeconomic factors[10,12,14, 17] as well as lower income, which have been reported to be associated with a higher incidence of epilepsy in all ethnic groups.[5, 11] Other probable factors are poor obstetric practices, frequent febrile convulsions, head trauma, meningitis and neurocysticercosis.[17]

In this era of increasing accountability, outcome orientation and dwindling resources, assessing the population's health in terms of improved quality of life (QOL) has become imperative.[15, 16] This is particularly important for chronic conditions such as epilepsy where interventions are directed towards improvement in patient's subjective sense of well-being. QOL is a broad multi-dimensional concept that usually includes subjective evaluations of both positive and negative aspects of life and it integrates physical, mental and social domains.[11, 14, 17, 18] Interest in QOL as the most desirable outcome in therapeutic modalities cannot be overemphasized as implied in Pharmaceutical care concept.[19, 20] The aspect of QOL that is affected by illnesses and its treatment is referred to health related quality of life.[20]

There is paucity of information on quality of life studies in chronic illnesses such as epilepsy in Nigeria. The study was therefore designed to assess health related quality of life (HRQOL) of patients living with epilepsy.

METHODS

Study Setting

The setting for the study was a Federal Neuro-Psychiatric Hospital in northwestern Nigeria, a tertiary mental health institution. The hospital has a current bed capacity of 154 and an annual turnover of about 30,500 patients. It renders a wide range of medical services including in–patients and out-patients mental health clinics, social work services, occupational therapy care, psychological services, drug rehabilitation care, diagnostic laboratory services, other specialized services such as electroencephalography (EEG), electroconvulsive therapy (ECT) and Medical Mental Health Research.

Study population

The study population was ambulatory patients, aged 15 years and above who had been on drug therapy for epilepsy for at least three months prior to the study. The three months cut-off was chosen with an expectation that patients would have gotten a good experience on anti-epilepsy drugs (AEDs) and possibly would knowledgeably describe seizure control features. A sample size of 182 was obtained from an estimated target population of 346 using a sample size calculator at 95% confidence level and 5% confidence interval.[22] Inclusion criteria include diagnosis of epilepsy, currently been managed with AEDs, above 15 years of age and acceptance to participate in the research. Exclusion criteria were non-consenting and mentally retarded patients or those with progressive neurological diseases.

Study design

The cross sectional study was conducted over a period of four (4) months (March to June, 2015) following ethical approval by Research and Ethics Committee of the Federal Neuro-Psychiatric Hospital, Kaduna. Consenting adults of 18 years and above were enrolled into the study while younger patients (15–17 years) provided assent and consent obtained from an adult caretaker. Data were collected from patients' case notes and quality of life questionnaire which was interviewer-administered.

The adopted instrument was Quality of Life in Epilepsy Inventory (QOLIE-31) version 1.0 which has been previously validated.[11, 15, 18, 23] The QOLIE-31 questionnaire contains 31 items that measure a patient's emotional well-being, general quality of life, seizure worry, level of activities, cognition, medication side effects, and social functioning. The epilepsy-related quality of life instrument is calibrated on a continuum scale of zero (0) (worst-case scenario) to 100 (best-case scenario). However, possible categories or response sets for scoring vary across questions.[23] Examples of response sets used include; (i) 0, 25, 50, 75, 100; (ii) 0, 20, 40, 60, 80, 100; (iii) 0, 33, 67, 100.

Questions on patient socio-demographics were contained in the preliminary section of the questionnaire. Physical functioning was defined to encompass feelings of fatigue or lack of energy to do activities of daily living including taking care of personal hygiene; travel and execution of job related tasks are explored using a set of seven questions. Socio-functioning (i.e. social limitations or withdrawal and feelings of stigma) was measured using six questions aimed at assessing presence of feelings of internalized stigma and the patient's ability to associate or relate with others. Emotional well-being was assessed using six questions on the extent of worry over epilepsy and seizure reoccurrence while the mental functioning was based on question items that explored a patient's ability to reason, memorize important facts or concentrate on key activities. In all subscales, the higher the scores, the better the quality of life but scores less than 60.0 for of the domains are considered poor.[23]

Questionnaires were interviewer administered consecutively to consented respondents. The English version of the instrument was used which was appropriately interpreted to illiterate subjects in local dialect which is being spoken fluently by trained data collectors. Collected data include age, sex, in addition to information on quality of life questionnaire.

Frequencies and corresponding percentages were used to summarize the results including perceived impact of epilepsy on social life/activities and feelings of stigma, among others. To determine the HRQOL of the subjects, the mean and median scores of different items on the QOLIE-31 questionnaire were used. The computation of HRQOL subscale scores (mental, seizure worry, social, medication side effects, physical, psychological functioning as well as emotional wellbeing) was based on the QOLIE-31 manual for summarizing items.[23] The overall HRQOL score was derived using empirical derived weight. All data were then entered into Statistical Package for the Social Sciences (SPSS) version 19.0 and Graph Pad Prism for Windows Instat Version 3 (GraphPad Software San Diego, CA, USA). Chi squared test was used as the test statistics.

RESULTS

Out of 182 patients who participated in the study, 53.9% were male and 46.1% were female. The average age was 27.6±8.5 years and 61.0% were below 30 years. The difference in the age distribution among the gender groups was not statistically significant (See Table 1).

In all subscales, the higher the scores, the better the quality of life but scores less than 60.0 for any of the domains are considered poor. The overall HRQOL mean score of 57.46±13.97 obtained was slightly low relative to published group norms for people living with epilepsy of 60.00 in a multicultural setting.[11, 18, 23] A minimum score of 60.00 is considered normal while any score below that is low. The mean scores of the different HRQOL sub scales scores ranged from the lowest value of 36.62±33.02 for physical functioning involving the use of energy to impressive score of 72.41±22.30 for medication effects, which is much higher than the published norms for the group

Table 1: Demographic characteristics of people with epilepsy

Age group	Female N (%)	Male N (%)	Total	P-value
15 – 19	21 (25.0)	18 (18.4)	39 (21.4)	0.2928
20 – 24	9 (10.7)	16 (16.3)	25 (13.7)	
25 – 29	18 (21.4)	29 (29.6)	47 (25.8)	
>= 30	36 (42.9)	35 (35.7)	71 (39.0)	
Total	84 (100.0)	98 (100.0)	182 (100.0)	

$\chi2$ = 3.724, df =3, p=0.0.2928

Only three sub scales of the scores can be considered normal being higher than 60.00. These include cognitive functioning (65.67±21.85), social functioning (63.13±23.23) and medication effects (72.41±22.30). Among the domains with sub-optimal scores, physical functioning was the most severely affected with a score of 36.62±33.02 followed by seizures worry 50.19±20.10 and emotional well-being of 54.77±21.67. There is statistically significant differences between the physical functioning domain scores and those of emotional well-being, seizures worry, cognitive, social function and medication effects (p=0.0001).

Replacing worries about embarrassment as a measure for feeling of stigma, then 50.2% of respondents would be classified as having stigma. Sixty Two percent of respondents were not able to optimally take care of some personal responsibilities, which involve exertion of energy. Likewise, 58.0% are worried of the occurrence of the next seizure while 64.0% were embarrassed (or concerned about societal attitude towards them) and 75.0% were more worried about seizure-associated injuries. Only about 8.0% of respondents reported having trouble remembering things being told. Overall, 33% of respondents rated their quality of life to be below average. Details are as shown in Table 2.

Table 2: Overall Quality of Life and domain scores

QOL Domain	N	Mean ± SD	95% CI	Scores Range
Overall QOL	182	54.79±17.00	52.32 -57.26	17.50 -95.00
Emotional wellbeing	182	54.77±21.67	51.6 2-57.91	0.00 -100.00
Physical functioning	182	36.62±33.02	31.82 -41.41	0.00 -100.00
Cognitive functioning	182	65.67±21.85	62.49 -68.84	16.00 -100.00
Social functioning	182	63.13±23.23	59.75 -66.50	10.00 -100.00
Seizure worry	182	50.19±20.10	42.27 -53.11	20.00-95.00
Medication effects	182	72.41±22.30	66.17 -75.65	0.00 -100.00
Overall HRQOL	182	57.46±13.97	55.43 -59.49	13.80 -90.12

SD- Standard deviation, CI – Confidence Interval

The gender group is a predictor of HRQOL with a statistically significant better scores (p= 0.0426) for female subjects. Majority of the females (56.0%) had better overall HRQOL using the upper limit mean score of 60 (50.0±10) as a cut-off as compared to 39.8% of male subjects. There was no significant association between age group and HRQOL; however, there was a general increment in the scores as the age increases from 15 to 30 years. On the overall, the proportion of the respondents whose HRQOL are poor was slightly higher than those with good scores. (Table 3)

Table 3: Overall status of Health Related Quality of Life

Variable	Overall HRQOL status Poor overall HRQOL N (%)	 Good Overall HRQOL N (%)	Total N (%)	P value
[a]Gender				
Female	37 (44.0)	47 (56.0)	84 (100.0)	[a]0.0426
Male	59 (60.2)	39 (39.8)	98 (100.0)	
Total	96 (52.7)	86 (47.3)	182 (100.0)	
[b]Age group				
15 – 19	23 (59.0)	16 (41.1)	39 (100.0)	[b]0.7757
20 – 24	14 (56.0)	11 (44.0)	25 (100.0)	
25 – 29	23 (48.9)	24 (51.1)	47 (100.0)	
≥30	36 (50.7)	35 (49.3)	71 (100.0)	
Total	96 (52.7)	86 (47.3)	182 (100.0)	

[a]Femalevs Male:$\chi 2 = 4.111$, df=1, p=0.0.0426; [b]Poor vs Good HRQOL: $\chi 2 = 1.106$, df =3, p=0.7757,
HRQOL: Health Related Quality Of Life

DISCUSSION

The study which evaluated the HRQOL of patients living with epilepsy in various domains including emotional well-being, general quality of life, seizure worry, cognition, medication side effects, and social functioning domains indicated poor health related quality of life among the subjects. The most severely affected domain with sub-optimal score was physical functioning (QOLIE-31 score of 36.62±33.02) followed by seizures worry (QOLIE-31 score of 50.19±20.10) and emotional well-being of QOLIE-31 score of 54.77±21.67).

The obtained values (QOLIE-31 score of 57.5 ± 14.0 on QOLIE-31 score 0-100 scale) are relatively low as compared to normal average value for the group of 60.0.[11,23] The slightly low overall HRQOL mean score among the subjects is nevertheless significantly higher than obtained values for studies conducted in some West African countries using the same instrument with scores of 49.5 ± 14.4 for Togo and 52.1 ± 33.4 for Benin.[24] Probable reasons could be better health care services and higher standard of living in Nigeria as compared to those less developed West African countries. However, it is less than the global mean QOLIE-31 score of 59.8±8.0 with a range from 42.1±4.1 in the Russian Federation to 82±32.8 in Canada,[11] and a study conducted in Malaysia with a score of QOLIE-31 of 68.9 ± 15.9.[18] Higher QOLIE-31 mean scores in more develpoled countries such as Canada may be due to improved quality of care and higher socio-economic profile. Lower income and poor socio economic profile have been reported to be associated with a higher incidence of epilepsy in all ethnic groups and poorer HRQOL scores.[24, 25, 26] A statistically significant difference in the QOLIE-31 score by world region and income category (p<0.0001) has been previously reported with lower country income level associated with worse QOL (test for trend,).[11]

The severe impairment of physical functioning observed among the patients is of serious concern. Sub-optimal energy driven personal responsibilities and fear of injury from seizure associated falls might be responsible. This call for better medication adherence behaviour, improved pschotherapy and enhanced family support. The family members need special counseling to facilitate optimal support in drug dosage regimen, non-drug therapy as well as in personal responsibility matters. Family support have been demonstrated to improve HRQOL scores of patients with epilepsy.[27]

The implications of worries about seizure occurrence, associated injuries and emotional well-being on HRQOL are overwhelming. Seeming frustration and being worried to some extent is real but with adequate reassurance, optimal medication adherence and regular counseling by specially trained health care professionals, there could be great reduction in negative impact on these domains. Public enlightenment about the need for family and societal support for people with epilepsy is imperative to counter and reduce probable feeling of stigma/embarrassment. It has been observed in many studies among people with epilepsy that excessive stigma could lead to psychopathology [28,29] which should be avoided at all cost. Promulgation of policies by relevant governments and agencies to safeguard employment and fundamental rights of people with epilepsy would also help in this respect.

The relatively normal social and cognitive functioining among the subjects is encouraging and should be maintained and possibly improved upon. The underlining factors responsible for these funtional status should be examined and promoted accoringly during psychotherapy session. Optimal social and mental functing have being reported to be important for overall improvement in HRQOL.[30] Observed impressive score for medication effects subscale is a source of encouragement to the health care service delivery system and should be sustained. The fact that more than 90.0% of the subjects had no problem with memory and subsequent good attitude to medication is consistent. The reason for this need to be elucidated and strenghtened to promote efficient service delivery. The higher incidence of epilepsy among male subjects who also had poorer subjective sense of well being with lower mean overall HRQOL scores supports the earlier findings which associate this gender group with higher epilepsy prevalence.[31] The observed general trend of seeming higher quality of life as the patients become older, until certain age need to be closely examined. The inability of a good proportion of the young and the very old to take proper personal care of themselves, physically, socially and financially in normal life scenario actually make them to be much more disadvantaged with epilepsy. It is important to categorize them as candidates for extra socioeconomic support.

Most respondents had poor overall HRQOL score which suggests the need for better management of people with epilepsy. Studies have shown that treatment with AEDs alone does not significantly improve the social and psychological functioning of people with epilepsy.[32] Other factors that can significantly impact the HRQOL of people with epilepsy include social/family support, marital status, education level and employment status. All these deserve adequate attention and appropriate interventions from stakeholders.[9,33]

Non availability of locally translated version of the validated QOLIE-31questionnaire is a limitation which would probably have facilitated greater understanding of the respondents during the interview. However interpretation of the English version of the tool to the respondents in Hausa reduced error of misinterpretation. In some cases, care takers were asked to interpret the questions to the respondents. In addition, the small sample size though representative of the population and the use of one study center means there is the need to exercise caution in generalizing or extrapolating the findings in this study. Exclusion of patients below 15 years and non stratification of age group above 30 years are also limitations to the applicability of the findings.

CONCLUSION

The HRQOL of the studied population is poor relative to group norm for people living with epilepsy. The most severely affected domain was physical functioning followed by seizures worry. It is important to strengthen the socioeconomic and psychological support inaddition to optimal medication utilization to enhance HRQOL of the patients receiving AEDs.

AKNOWLEDGEMENT

The cooperation and support of the staff and management of the hospital are appreciated.

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