ORIGINAL ARTICLE

The Quality of Life Among Adult Sudanese Patients with Epilepsy

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Abstract

Introduction: Epilepsy is the most common serious brain disorder worldwide. Its impact on quality of life can be substantial, with far-reaching and life-long consequences. Despite this, very few studies have been carried out on QOL in epilepsy in the Sudanese context. **Objectives:** To investigate the health-related quality of life (HRQoL) in adult Sudanese patients with epilepsy attending Daoud charity clinic from June to July 2022. **Methodology:** Thirty-six (36) adult Sudanese patients with epilepsy were included in this study. The validated QOLIE-31 instrument and a sociodemographic checklist were used to assess the impact of epilepsy on HRQoL. Respondents were adults aged at least 18 years with a confirmed diagnosis of epilepsy for more than 3 months. Unpaired t-test and one-way ANOVA were used to compare QOL scores between groups. **Results:** Of 36 patients, 19 (52.8%) were males and 17 (47.2%) were females; the mean age was 34.81 years. The most frequent seizure type was generalised tonic-clonic (78.4%). The mean total QOLIE-31 composite score was 43.97 ± 4.78, indicating substantially impaired HRQoL. Sex, age, and marital status did not significantly affect QOL scores. Seizure type, seizure frequency, duration of epilepsy, and AED adverse effects were significant predictors of poorer HRQoL. **Conclusion:** Quality of life is substantially impaired among adult Sudanese patients with epilepsy. The decline in HRQoL is multifactorial, with seizure frequency, generalised tonic-clonic seizure type, adverse effects of antiepileptic drugs, and lower educational attainment identified as the principal negative predictors.

1. Introduction

Epilepsy is a common chronic neurological disorder characterised by recurrent unprovoked seizures. Nearly 80% of people with epilepsy (PWE) live in low- and middle-income countries (LMICs), and about three-quarters of PWE in LMICs do not receive the treatment they need. Epilepsy has been classified into focal, focal-to-bilateral generalised, and unknown-onset categories according to the operational classification of the International League Against Epilepsy (ILAE) 2017.[1] Quality of life (QOL) is the general well-being of individuals and societies, encompassing physical health, family, education, employment, religious beliefs, finance, and the environment.[2] Health-related quality of life (HRQoL) is assessed using validated multidimensional patient questionnaires covering physical, social, emotional, cognitive, and role-related domains.[2] People with epilepsy are more prone to physical injury, adverse effects of medication, mental distress, and restrictions in common social rights. Constrained health resources and prevalent cultural misconceptions impart additional disadvantages to PWE in developing countries.[3] Stigma, reduced access to employment, denial of driver's licences, and social isolation contribute substantially to diminished HRQoL.[4]

2. Justification

Epilepsy accounts for 0.6% of the global burden of disease and impairs all aspects of HRQoL. There is a need for Sudan-specific evidence to guide rehabilitation strategies, as many Sudanese PWE suffer from co-morbid physical or neuropsychiatric disabilities as a consequence of seizure-related injuries or long-standing untreated epilepsy. Few research efforts have been devoted to assessing QOL in this population.

3. Objectives

To assess health-related quality of life in adult Sudanese patients with epilepsy attending Daoud charity clinic from June to July 2022.

4. Methodology

Study Design: Descriptive cross-sectional study. Study Setting: Daoud charity clinic, founded in 1985 and operating as a neurological clinic since 1995. The clinic serves 150–200 epileptic patients per week under the supervision of a senior consultant neurologist. It is located in the eastern part of Omdurman (population approximately 2.5 million, 2010 census) and is the only charity neurological clinic in the area.

Inclusion Criteria: Adult Sudanese patients (aged ≥18 years) with a confirmed clinical diagnosis of epilepsy of more than 3 months' duration, attending during the study period, who provided written informed consent. Exclusion Criteria: Non-Sudanese patients; patients aged under 18 years; patients who declined to participate; patients with severe concurrent somatic pathology that would independently impair QOL assessment; patients unable to complete the questionnaire due to significant cognitive impairment. Diagnosis was based on clinical assessment by a consultant neurologist per ILAE 2017 criteria; EEG was performed where clinically indicated. Sampling Method: Consecutive convenience sampling.

Single-centre study; findings should be interpreted in the context of a clinic-attending urban population in Omdurman. Data Collection Tool: The QOLIE-31 (Quality of Life in Epilepsy Inventory-31), a validated epilepsy-specific HRQoL instrument developed by the Epilepsy Foundation, was used. It was translated into Arabic and administered by trained research assistants. The QOLIE-31 contains seven multi-item subscales: • Emotional well-being • Social functioning • Energy/fatigue • Cognitive functioning • Seizure worry • Medication effects • Overall QOL Subscale scores range from 0 to 100 (higher = better HRQoL).

A weighted composite score is derived from the seven subscales, with domains such as seizure worry and cognitive functioning carrying higher weighting in the composite calculation. A sociodemographic checklist captured: age of onset, duration and frequency of seizures, physical injuries, seizure type (ILAE 2017),

and number of AEDs. Statistical Analysis: Data were entered and analysed using SPSS. Results are expressed as frequencies, percentages, means, and standard deviations.

Unpaired t-test and one-way ANOVA were used to compare QOL scores across groups. Ethical Considerations: Ethical clearance was obtained from the local Ethics Review Committee. Permission for data collection was granted by the Ministry of Health. Written informed consent was obtained from all participants, who were informed of their right to withdraw at any time.

Confidentiality and data security were maintained throughout.

5. Results

Thirty-six (36) adult patients with epilepsy were interviewed using the Arabic-translated QOLIE-31. Sociodemographic Characteristics: Of 36 patients, 19 (52.8%) were male and 17 (47.2%) were female. The mean age was 34.81 years. Marital status: 45% single, 48% married or cohabiting, 5% separated or divorced, 2% widowed.

Seizure Characteristics: The most frequent seizure type was generalised tonic-clonic (GTCS) in 78.4% of patients. Seizure frequency in the past year: 40.5% had fewer than one seizure per month; 40.5% had more than one seizure per month; 16.2% were seizure-free. Seizure-Related Injuries: Among those with one or more seizures in the past year: 20% reported head injury; 15% reported dental injury; 6% reported a burn or scald; 28% reported other unspecified injuries. AED Treatment: 50% were receiving monotherapy; 40% were receiving two AEDs; 10% were receiving three AEDs.

Thirty percent experienced one or more AED side effects. Functional and Social Impact: Twenty percent were unemployed or had their employment terminated due to epilepsy. Half of all respondents felt stigmatised by their epilepsy. QOLIE-31 Scores: The mean weighted composite QOLIE-31 score was 43.97 ± 4.78, indicating substantially impaired HRQoL.

The highest subscale score was for medication effects (86.2 ± 22.12) and the lowest was for overall QOL (70.97 ± 26.43). Patients with tertiary education demonstrated significantly higher QOL scores (89.52 ± 11.85). Sex, age, and marital status did not significantly affect composite QOL scores. Seizure type (GTCS), seizure frequency, duration of epilepsy, and AED adverse effects were significant predictors of poorer HRQoL.

6. Discussion

This study assessed HRQoL among 36 adult Sudanese patients with epilepsy using the QOLIE-31. The mean composite score of 43.97 ± 4.78 indicates substantially impaired HRQoL, lower than scores reported in studies from Western Europe and North America, [5,6] consistent with the greater burden of uncontrolled epilepsy, limited healthcare access, and socioeconomic disadvantage in LMICs. No significant association was found between sex, age, or marital status and composite HRQoL, unlike an Indian study that found female sex and married status associated with lower QOL scores.[7] This may reflect different cultural dynamics or the overriding impact of seizure-related variables in the Sudanese context. Seizure frequency was the strongest predictor of poor HRQoL, consistent with international literature.[8,9] Patients with GTCS had particularly poor QOL across domains of family relationships, social life, and employment, mirroring findings from a 15-country European study.[8] The unpredictability of seizures leads patients to impose self-restrictions on driving, cooking, and risk-associated activities, further compromising QOL.

Stigma was reported by 50% of respondents, consistent with international literature.[10,11] Despite advances in understanding epilepsy, stigmatisation remains a significant contributor to impaired psychological well-being and HRQoL.[12,13] Seizure-related injuries were common: 20% reported head injuries, 15% dental injuries, 6% burns or scalds, and 28% other injuries, consistent with published international data.[15,16] AED side effects affected 30% of patients. Adverse effects of AEDs are well-documented contributors to treatment failure and HRQoL impairment in up to 40% of patients worldwide.[20,21] Previous work by the Daoud Research Group demonstrated that economic burden, medication adherence, and cosmetic effects of AEDs are significant modulators of QOL in Sudanese epilepsy patients.[22,23] Patients with tertiary education had significantly better QOL scores (89.52 ± 11.85), consistent with the broader literature linking education to health literacy and reduced stigma.[24] Limitations: This study has several limitations. It was conducted at a single charity clinic using convenience sampling, which limits generalisability to the broader Sudanese epilepsy population. Formal cross-cultural psychometric validation of the Arabic QOLIE-31 for the Sudanese population was not performed.

Only univariate statistical tests were employed; multivariate regression analyses are needed in future studies to identify independent HRQoL predictors while adjusting for confounders. EEG was not universally available for diagnostic confirmation. Larger, multicentre studies with prospective data management are needed to generate robust evidence on HRQoL in Sudanese PWE.

7. Conclusion

Quality of life is substantially impaired among adult Sudanese patients with epilepsy attending Daoud charity clinic. The mean QOLIE-31 composite score of 43.97 ± 4.78 reflects markedly reduced HRQoL. The decline is multifactorial: seizure frequency, generalised tonic-clonic seizure type, AED adverse effects, and lower educational attainment are the principal negative predictors. Targeted interventions to improve seizure control, minimise AED side effects, and address stigma are urgently needed.

Larger multicentre studies with validated culturally adapted instruments and multivariate designs are recommended to strengthen the evidence base for epilepsy care in Sudan. References

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