

The Quality of life among adult Sudanese patients with epilepsy

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Research Article

Keywords: Epilepsy, QOL

Posted Date: June 24th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-646638/v1>

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Abstract

Introduction: Epilepsy is the most common serious brain disorder worldwide, the impact of it on quality of life can be substantial with far-reaching and life-long consequences despite all this very few studies have been carried out on the QOL in epilepsy.

Objectives: To investigate the quality of life in adult Sudanese patients with epilepsy attending Daoud charity clinic June to July 2018.

Methodology: Thirty six adult Sudanese patients with epilepsy were included in the study, a multi item questionnaire graded scale and check list to explore the demographic characteristics were used to assess the impact of epilepsy on QOL. Respondents were adults aged at least 18 years old with a diagnosis of epilepsy for more than 3 months the unpaired t-test or one way analysis of variances was used to compare means of QOL scores between groups.

Results: Out of 360 patients 190 were males and 170 were females, the mean of age was 34.81. The most frequent type of epilepsy according to the ILAE classification was the generalized tonic clonic (78.4% of patients) .40.5% of patients had < 1 seizure per month during last year while 40.5% had more than 1 seizure per month and 16.2% were free of seizure during last year. The mean total score QOLIE-31 of this study was 43.97_+ 4.78 .Sex, age and marital state did not affect QOL scores. The study showed that type of seizure and duration of epilepsy did appear to be predictive of HRQOL .Adverse effects of antiepileptic drugs (AEDs) have a considerable impact on quality of life and contribute to treatment failure in up to 40% of patients

Conclusion: The decrease in overall score of quality of life in adult Sudanese patients is multifactorial.

Introduction

Epilepsy is a common chronic neurological disease characterized by recurrent unprovoked seizures. Nearly 80% of PWE live in low- and middle-income countries. About three fourths of PWE living in low- and middle- income countries do not get the treatment they need. According to the new operational classification of ILAE 2017, epilepsy is divided into focal, focal to bilateral, generalized, and unknown onset. [1]

Quality of life (QOL) is the overall well-being of individuals and society, and is a negative and positive characteristic of life.

It observes life satisfaction, including everything from: physical health, family, education, employment, religious beliefs, finance and the environment. [2] Quality of life should not be confused with the concept of standard of living, which is based primarily on income. [3] Health-related quality of life (HRQOL) is an assessment of how the individual's well-being may be affected over time by a disease, disability, or disorder. Today, it is mainly collected with the help of patient questionnaires. Most of these

questionnaires are multi-dimensional, including physical, social, emotional, cognitive, work or role aspects, as well as mental aspects and a wide range of disease-related symptoms and side effects. Through treatment and even financial aspects. The impact of medical conditions. The impact of epilepsy on a person's quality of life is usually assessed based on their mental state and the characteristics of their seizures. [2] Both will affect the quality of life and quality of life, but in clinical practice, patients with similar clinical characteristics show the difference between quality of life and health. People with epilepsy (PWE) are more susceptible to physical harm, drug side effects, psychological distress, and general social rights restrictions. Constrained health and technical resources and prevalent cultural misconceptions impart more disadvantages to PWE in developing countries [3]. Also they face many challenges, including having reduced access to insurance, being denied driver's licenses. In many countries legislation reflects centuries of misunderstanding about rejecting and stigmatizing attitudes prevent individuals with epilepsy from seeking medical help and attending rehabilitative programs. Seizures or caring for the patient can cause individual reactions and impair a person's quality of life. This could be an expression of personal coping style, which is the person's typical response when dealing with stressful life-events or smaller problems in daily life. [4]

Justification:

Epilepsy constitutes major health care issue, accounts for 0.6%, of the global burden of disease which impairs all aspects of health related QOL. Better understanding of QOL in people with epilepsy living in different countries is important: a large number of cultural, ethnic, economical differences have their impact on the QOL. There is a need for a lifetime rehabilitation that congruent with the reality of many people with epilepsy in Sudan suffer from co morbid physical or neuropsychiatric disabilities as a consequence of seizure-related injuries or long-standing untreated seizure, while assessing QOL is important to determine the degree of care needed to achieve this goal, few research efforts have been devoted to assess it that's why we concern about this study.

Objectives

To assess the quality of life in adult Sudanese patients with epilepsy attending Banat charity clinic October- November 2017.

Methodology

Study design: descriptive cross sectional study.

Study field: The study was conducted in Daoud charity clinic which was founded in 1985. It commenced as a Neurological clinic in 1995, serving 150-200 epileptic patients per week. The clinic is supervised by a senior consultant neurologist, under which registrars work and medical students attend.. Banat is located in the eastern part of Omdurman, the 2nd largest city in Sudan in terms of population. Omdurman is home for 2.5 million (2010 census) people of different ethnic background. The city has 5 hospitals, with

only 3 specialized neurological clinics. However, Banat clinic is the only charity clinic in the area, hence the high load of patients.

Study population:

Inclusion criteria: This study included adult (from age of 18 years) Sudanese patients with epilepsy attending Banat charity clinic, and who accepted to participate in the study.

Exclusion criteria: Non Sudanese epileptic patients, with age less than 18 years and those who refused to participate in the study. Patients with severe somatic pathology will be excluded from the study.

Sampling method: Convenient sampling method, Total coverage

Tool of data collection: A full history and proper examination was done by the authors.

(QOLIE-31 questionnaire for adult patients with epilepsy [24] provided by epilepsy foundation [12] which is a multi-item score scale.).

QOLIE-31 questionnaire: Contains seven multi-item scales tap the following health concepts:

- emotional well-being
- social functioning
- energy/fatigue
- cognitive functioning
- seizure worry
- medication effects
- over all QOL

Overall score was obtained using a weighted average of the multi-item scale scores.

Check list, composed of (age of onset, duration & frequency of seizure, physical injury, Type of seizure, number of AEDs).

Data entry and analysis: Collected data was introduced into the computer from a master sheet recording using software program; statistical package program for social science (SPSS). Results were expressed in numbers and percentages (Tables and graphs), represented statistically and then discussed.

Ethical considerations: Ethical clearance was obtained from the local Ethics Review Committee, and permission for data collection was obtained from the Ministry of Health. Informed consent was also obtained for each patient prior to the data collection, privacy was ensured and the safety of participants files and informations were of highest priority. Written consent was taken from participants and a copy was provided with the research. At the middle of data collection the patient has the right to decide whether he/she wants to stop and their sheet was ignored.

Results

360 patients with epilepsy aging 18 years old and above attending Banat neurologic clinic were interviewed using standard and validated version of Quality of Life Scale-31 (QOLIE-31). Out of the 360 patients 190 were males and 170 were females the mean of age was 34.81. Forty-five percent were single, 48% were married or cohabiting, 5% were separated or divorced, and 2% were widowed. The most frequent type of epilepsy according to the ILAE classification was the generalized tonic clonic 78.4% of patients, and 40.5% of patients had <1 seizure per month during last year while 40.5% had more than one attack of seizure per month and 16.2% were free of seizure during last year. Respondents who had had one or more seizures in the past year were asked whether they had had any seizure-related injuries. 20% reported a head injury. 15% reported a dental injury. Six percent reported a burn or scald, and 28% reported some other injury, the precise nature of which was unspecified. Regarding AEDs treatment. Fifty percent were receiving monotherapy, 40% were receiving two AEDs and 10% were receiving 3 drugs. Thirty percent experienced one or more side effect of AEDs. A significant number of respondents reported changing their medication because of side effects or poor control. A significant number of respondents admitted that epilepsy had a negative impact on several aspects of their daily life activities, education and social functioning, 20% were unemployed or had their job terminated because of epilepsy. Half of all respondents felt stigmatized by their epilepsy. The mean total QOLIE-31 score was 43.97_± 4.78 with the highest subscale score for medication effects and the lowest for overall quality of life (QOL) functioning with a score of 86.2 (SD 22.12) and 70.97 (SD 26.43), respectively. Patients with tertiary education and above had shown a significantly high quality of life 89.52 (SD 11.85).

Discussion

Epilepsy is a common chronic neurological disorder which is characterized by recurrent seizures. Epilepsy can cause serious physical, psychological, and social consequences, and can affect a person's quality of life more than other chronic diseases.[4] This study assessed the quality of life among patients with epilepsy who were on antiepileptic medication use. The mean total score QOLIE-31 of this study was 43.97_± 4.78 which is low if we compare it with previous studies of Quality of life in people with epilepsy, performed mostly in Western Europe and North America[5–6].

Out of the 360 patients 190 were males and 170 were females the mean of age was 34.81. Forty-five percent were single, 48% were married or cohabiting, 5% were separated or divorced, and 2% were

widowed. Unlike Indian study, sex, age and marital state did not affect QOL scores. The Indian study, which was done in 2011, revealed that females and married patients had lower QOL scores. [7]

The study showed that type of seizure and duration of epilepsy did appear to be predictive of HRQOL, this similar to what was reported by European study (in 1997) which had been done to assess the impact of epilepsy and its treatment on QOL in PWE in 15 European countries, and it revealed that patients with earlier age of onset of epilepsy and a longer duration are more likely to experience frequent seizures, patients with GTCS had poor QOL in family relationships, social life and ability to work. [8] These patients also had poor perception of overall health, and had no clear ambitions or plans for the future. They also feel that their standard of living is very low, their relationship with friends is very poor, and their self-esteem is very low. Like what was reported by other researchers seizure frequency was the most commonly reported predictor of HRQoL. [9] Seizure frequency was a stronger predictor of poor quality of life, because it is associated with excess fear, unable to work, stigmatization, diminishing hope and future life, impairment in social function, and psychological impairment. People with frequent seizures always feel uncomfortable and don't know when the next seizure will happen. Therefore, they proceeded cautiously and restricted driving, cooking, and high-risk work to avoid seizures at the wrong time. A place or social event that, in turn, may endanger the patient's quality of life.

It did appear that age, gender, and marital status were generally found to have no significant association with HRQoL, this is unlike what was reported by researchers in Georgia where female sex was associated with low seizure worry score. A similar observation was reported by researchers in India. [9-10] Similar to what was mentioned in the literature our study showed that half of all respondents felt stigmatized by their epilepsy. [10] Despite advances in the understanding and treatment of epilepsy within the past several decades, people with this disorder continue to be stigmatized by it. Stigma has been conceptualized as "a serious stigmatization attribute." According to reports, the stigmatizing nature of epilepsy and related psychological distress have a significant impact on the quality of life of patients with epilepsy; however, the degree of stigma and its consequences are not the same for all patients with epilepsy. [11] Though attitudes toward people with epilepsy have improved over the years, for many people with epilepsy, stigma continues to adversely impact their psychological well-being and quality of life. The factors influencing the development and maintenance of feelings of stigma are not fully known. [12] Seizure frequency is considered a factor significantly related to felt stigma. The stigma of epilepsy can be linked to a number of factors, including under-resourced medical services, poor seizure control, and inadequate knowledge of epilepsy. [13-14]

Like what was reported in the literature our study showed that respondents who had had one or more seizures in the past year were asked whether they had seizure-related injuries. 20% reported a head injury. 15% reported a dental injury. Six percent reported a burn or scald, and 28% reported some other injury, the precise nature of which was unspecified. [15-16] People with epilepsy and their families often express more fears of injury. Sometimes PWE do need to take extra precautions, especially if their seizures are not well-controlled. However, they may also be told, often erroneously, that they should refrain from doing many activities due to these fears. People may be very vulnerable if they feel confused, alone, or unable

to speak or take care of themselves for a period of time after a seizure. You may need the help of friends, family members or caregivers to make sure they are safe during their recovery. People who are confused after a seizure may enter the danger zone and hurt themselves. [17] They may not realize that they have injured themselves until much later. Injury to the person with epilepsy from other problems, such as side effects of medicines or other neurological problems. For example balance, weakness, fatigue or vision from medicine side effects or other neurological or medical problems can lead to injuries too so don't forget to consider these. [18–19] Although the risk of harm to others is small, accidents may occur and some accidents can be prevented, for example, if a seizure occurs during driving, it will hurt passengers or other people.

Regarding AEDs treatment forty percent of our patients experienced one or more side effects of AEDs, this similar to what was reported by other researchers worldwide. [20–21] Adverse effects of antiepileptic drugs (AEDs) are common, can have a considerable impact on quality of life and contribute to treatment failure in up to 40% of patients. The adverse effect profiles of AEDs differ greatly and are often a determining factor in drug selection because of the similar efficacy rates shown by most AEDs. The most common side effects are dose-dependent and reversible.

In 2014 a Sudanese study was done by Abbashar Hussein and his colleagues at Daoud Research Group aimed to estimate the direct cost of epilepsy among Sudanese patients attending charity clinic in Omdurman, and It revealed that; the economic burden on epilepsy patients is heavy and it affect the quality of life. The contributors to the cost in Sudan have many similar features and some noteworthy differences with that of other countries. [22] The same Group made another study to assess the association of medications adherence with the quality of life and cost of epilepsy among Sudanese epilepsy patients attending the charity clinic and they found that Patients with low adherence to anti-epileptics are more likely to have lower quality of life. [22] In 2015 Abbashar Hussein, and his colleagues studied the cosmetic effect of Antiepileptic drugs among Sudanese patients attending charity clinic in Omdurman and they conclude that their patients prioritize medication intake in spite of the presence of cosmetic effect, and this together with the absence of association between quality of life and the cosmetic effect may be attributed to different Sudanese patients' perception to these cosmetic effects from other populations in addition to the unique Sudanese culture. [23] Like what was mentioned in the literature our study showed that patients with tertiary education and above had shown a significantly high quality of life, education improves the quality of their lives and leads to broad social benefits to individuals and society. [24] Education helps to attain quality of life, educated people have quality better than an uneducated person. Educated people can develop their knowledge and skills through education. Quite a few interviewees admitted that epilepsy will have a negative impact on all aspects of their daily life, education and social functions. Even if controlled, epilepsy will affect a person's daily life. Because it is too unpredictable.

People with epilepsy also can experience feelings of social isolation because they lack control over their body and brain, and worry about what others will think of their seizures. [25]

Declarations

Consent for publication

Not applicable.

Availability of data and materials

The materials datasets used and/or analyzed during this study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Authors' contributions

All authors participated in planning the study, data collection, results and discussion sections.

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