International Journal of Health Science

QUALITY OF LIFE OF ADULTS WITH EPILEPSY: A DESCRIPTIVE ANALYSIS

Maria Fernanda Braga Vilacio Pinto
http://lattes.cnpq.br/6851930715007705

Tatiana Von Hertwing Fernandes de Oliveira
http://lattes.cnpq.br/2804171092103534

Mariana de Oliveira Trintinalha
http://lattes.cnpq.br/9304462679597216

Julia Maria Calisto
http://lattes.cnpq.br/1626808311219260

Giovanna Mafuz Penteado
http://lattes.cnpq.br/7337115843925066

André Luiz Fagundes Avila dos Santos
http://lattes.cnpq.br/9439199733100239

Isabella Cristina Mendes Rossa
http://lattes.cnpq.br/3579489063940830

Carlos Alexandre Twardowschy
http://lattes.cnpq.br/9356482689657819

Abstract: INTRODUCTION: Epilepsy is the most prevalent chronic neurological disease in the world. Treatment is initially pharmacological through anti-epileptic drugs, which include anticonvulsants. The disease negatively impacts quality of life (QoL), and there are standardized scales to measure QoL in Epilepsy, such as QOLIE-31. However, the concept of quality of life is broad and it is necessary to objectively assess which areas of well-being are most impacted by the disease. **OBJECTIVES:** to describe the quality of life of patients with epilepsy under clinical treatment. **METHOD:** descriptive study, carried out through review of medical records and application of the internationally validated QOLIE-31 questionnaire. It took place from June 2021 to June 2022 in patients over 18 years of age diagnosed with epilepsy. RESULTS: Seventeen patients participated in the study, 10 men (58.8%) and 7 women, of different ages (the youngest in the 18-29 age group, and the oldest over 70 years old). The responses to the questionnaire were interpreted using the QOLIE-31 formula, which transformed the subjective responses into scores from 0 (worst QLV) to 100 (best possible QLV), divided into 7 parameters - sociability, calmness during seizures, energy, general quality of life, cognitive function, emotional well-being and adaptation to medication. Each parameter evaluated in the questionnaire had its mean, standard deviation, minimum, maximum and median calculated. **DISCUSSION:** the means of the 7 QOLIE-31 scores demonstrate that the factor with the worst influence on the quality of life of patients with epilepsy is the lack of calmness in having seizures - which is the result of social stigma, insecurity about getting hurt and constant fear of having seizures. The best factor evaluated was the general quality of life, which covered responses that did not depend exclusively on epilepsy. Thus, it can be seen that despite the disease, the patient can present well-being in other areas of life. The other areas evaluated obtained intermediate scores, with averages ranging from 59.5 to 65.4 out of 100 possible points. **CONCLUSION:** the lack of tranquility in having seizures is the worst factor in the QoL of the patient with epilepsy. The care team must address this fear during consultations, in order to train the patient on how to act in the event of a seizure and thus reduce the negative impact of seizures on their QoL.

Keywords: Epilepsy; Quality of Life; QOLIE-31; treatment of epilepsy.

INTRODUCTION

Epilepsy is the most common chronic neurological disease in the world, with an estimated prevalence of 65 million people [1]. According to the ILAE (International League Against Epilepsy), the diagnosis can be defined by two unprovoked seizures that occur more than 24 hours apart. [2]. In 2014, the definition of the disease also included patients with only one unprovoked seizure who have a high risk of recurrence in the next 10 years (such as two provoked seizures), and patients diagnosed with an epileptic syndrome. The ILAE classifies seizures into 3 large groups: focal onset, generalized onset, and unknown onset, as shown in Image 01. Thus, the clinical presentation is quite heterogeneous, ranging from perceptual seizures to generalized tonic-clonic seizures with loss of consciousness[3].

The disease has a significant impact on the patient's quality of life (QoL). Among the factors associated with the loss of QoL, the highest frequency of seizures and the side effects of medication stand out. Given this scenario, standardized scales for measuring QoL in epilepsy were created. An internationally recognized scale is the QOLIE-31 (Quality of Life in Epilepsy), developed by Cramer et al in 1998. This consists of a questionnaire with 31
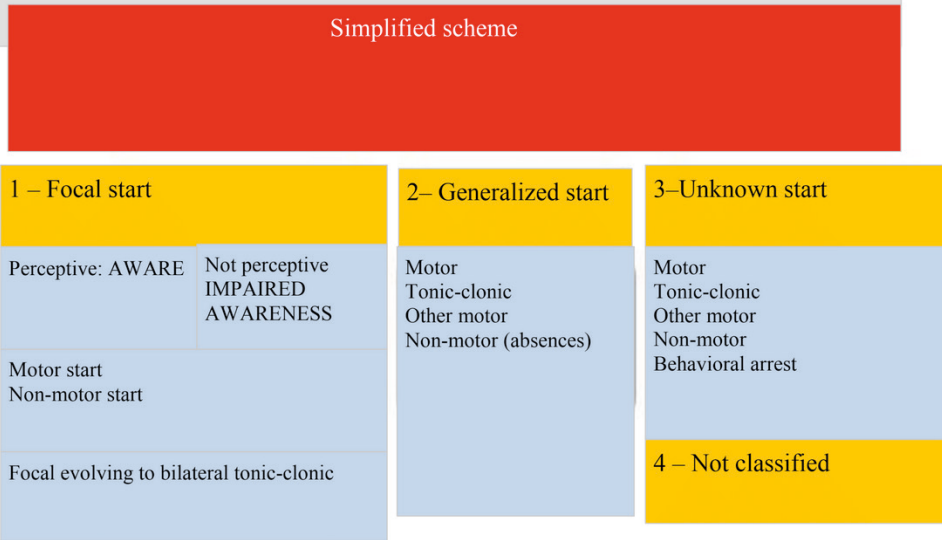
* Figure 01: ILAE seizure classification. Figure 1. ILAE 2017 basic operational classification for seizure types. 1 Definitions, other seizure types, and descriptors are listed in the article and in the glossary of terms that accompanies this article. 2 Due to inadequate information or inability to insert in other categories. https://www.ilae.org/files/ilaeGuideline/OperationalClassification-Fisher2017-Brazil.pdf

questions about memory, mood, leisure, and limitations in daily life, and thus assesses the quality of life of the patient with the disease[4].

The first line of treatment is medication using anti-epileptic drugs (AEDs). However, AEDs are associated with adverse effects such as psychomotor slowing and sedation, and do not provide seizure control for all patients[5].

In a review published in the New England Journal of Medicine, Kwan et al proposes that 22.5% of patients with epilepsy are refractory to medication, which generates a greater risk of injury, early death and lower quality of life[6].

METHODS

The research consists of a descriptive study, with the objective of identifying the quality of life parameters most affected by epilepsy, and has approval from the C.E.P. under CAAE 44763021.4.0000.0020. The study carried out a review of medical records and application of the QOLIE-31 questionnaire to patients with epilepsy at the Hospital Universitário Cajuru (HUC), in Curitiba-PR-Brazil, from June 2021 to June 2022.

The inclusion criterion to participate in the research was to be treated at ``*Hospital Universitário Cajuru*`` with a diagnosis of epilepsy, while the exclusion criterion was to be under 18 years of age. Based on the information in the medical records and application of the QOLIE-31, the quality of life score of each patient was calculated, and thus, the parameters related to the decline in quality of life in patients with epilepsy were described. The QOLIE-31 assesses QOL across 7 major areas: calmness during crises (seizure worry), overall quality of life (overall QOL), emotional well-being (emotional well-being), energy (energy/fatigue), cognitive function (cognitive function), medication effects (medication effects), and sociability (social function). By relating these scores, it presents a formula that calculates the total QOL score (overall score)9.

For each of the 31 questions, the patient must rate how much he or she identifies with the information presented. Each answer corresponds to a value in the QOL, so that each of the 7 areas evaluated results in a score from 0 (poor) to 100 (best possible QOL). Finally, QOLIE-31 presents a final quality of life formula, assigning different weights to each of the 7 major areas, in order to obtain a total QLV value (overall score), also from 0 to 100, with 100 being the best possible value9. The results of the quantitative variables are described by mean, standard deviation, median, minimum value and maximum value. The data were organized and analyzed in an Excel® spreadsheet.

RESULTS

The analysis presented below was performed based on data from 17 patients with epilepsy. The sample included patients of all ages, from 18 to over 70 years old, with the majority being patients aged 18-29 years (29.4%) and 50-59 years (29.4%). The sample was practically homogeneous in terms of gender, with a slight predominance of males (58.8%). Patients were not described qualitatively in terms of their medications, but rather quantitatively – based on how many different AEDs they were using at the time of the study. Regarding comorbidities, participants were assessed for the presence of neurological or psychiatric comorbidities, which could negatively influence QLV scores. Neurological or psychiatric comorbidities (in addition to epilepsy) were considered: generalized anxiety disorder, depression, panic syndrome, cavernoma brain tumor, fibromyalgia, congenital hydrocephalus, and mild mental retardation.

The following were not considered: hypertension, hypothyroidism, dyslipidemia, and HIV. Of the 17 patients, 6 had at least one neuropsychiatric comorbidity (35.2%).

The type of seizure was not assessed, which is considered a limitation of the study. For most patients, there was no information on the type of seizure in the medical records, and the participants did not know how to classify their seizures as focal, generalized, or unknown onset. The current frequency of seizures was measured based on the number of seizures per month. In patients with less than one seizure per month, the number of seizures in the last year was calculated and divided by 12 (12 months). The average number of seizures per month in the sample is between 5 and 6 seizures per month. The other scores evaluated were obtained from the patient's responses to the QOLIE-31 questions. The sample characteristics are presented in Table1.

The different anti-epileptic drugs (AEDs) present in the sample are: carbamazepine, lamotrigine, clobazam, chlorpromazine, valproic acid, topiramate, and clonazepam. The following AEDs were not considered: amlodipine, hydrochlorothiazide, vitamin D, codeine, paracetamol, amitriptyline, zolpidem, fluoxetine, omeprazole, enalapril, metformin, glibenclamide, olmesartan, losartan, levothyroxine, ASA, simvastatin, risperidone, sertraline, quetiapine, rosuvastatin, pantoprazole, mirtazapine, and HIV-ART.

The quality of life scores proposed by QOLIE-31 are: calmness during crises, general quality of life, emotional well-being, energy, cognitive function, adaptation to medication and sociability. The QOLIE-31 questionnaire itself presents a formula to calculate each of these scores based on the patients' responses, and also associates all 7 scores evaluated to form a "total QLV" score. Based on this calculation for each patient, the results of all participants were associated using mean, standard deviation, maximum, minimum and median for each of the 7 scores. The results are shown in Table 01.

SCORE EVALUATED	AVERAGE	STANDARD DEVIATION	MAXIMUM	MINIMUM	MEDIAN
PEACE OF MIND IN CRISES	**49,82**	28,41	91	5	47
OVERALL QUALITY OF LIFE	**68,52**	22,39	100	22,39	68,52
EMOTIONAL WELL-BEING	**65,41**	17,14	92	17,14	65,41
ENERGY	**59,70**	28,42	95	5	70
CONCENTRATION AND MEMORY	**59,57**	28,35	96,66	3,33	59,57
ADAPTATION TO MEDICATION	**62,7**	30,39	100	8,3	62,7
SOCIABILIY	**65,41**	33,16	100	4	75
TOTAL QLV	**62,25**	20,50	83,32	20,50	62,8
FREQUENCY OF CRISES PER MONTH	**5,82**	14,85	60	0	0,33
NUMBER OF DAEs IN USE	**1,94**	0,82	3	0,82	2

Table 1: Description of the characteristics and quality of life scores of the research patients.

Values have been rounded to two decimal places after the decimal point.

DISCUSSION

In the current study, the quality of life of patients with epilepsy was described according to the items of the QOLIE-31: calmness during seizures, general quality of life, emotional well-being, energy, cognitive function, calmness with medication, sociability and total QLV score. Each of the scores has a score from 0 to 100, with 0 being the worst possible score and 100 being the best for all categories evaluated.

Calmness with seizures addresses questions about how much time is spent worrying about having a seizure, how much is the patient worried about getting hurt during a seizure, and about being embarrassed about having a seizure in public. No worry, fear of getting hurt, or embarrassment would total a score of 100. The average score in the sample was 49.82. In other words, less than 50% of what would be expected for a person who, despite having the disease, would be confident if they had a seizure. In this sample, this was the item with the worst score, considering the average scores.

In the item quality of life in general, the patient indicated through images (well-being thermometer and images of emojis graduating levels of happiness and sadness) how he felt about his quality of life "in general", not being an item that depends essentially on the influence of epilepsy. With an average of 68.52 in the sample and the presence of patients with a maximum score (100), this is the item with the best score in the sample. From this, it can be seen that, when epilepsy is not specifically addressed, patients can have a good quality of life in general.

Emotional well-being asked about emotions such as happiness, sadness, nervousness, calmness and exhaustion. This way, it sought to understand the patient's feelings. The average obtained was 65.41 points out of a total of 100 possible points.

As for energy, the questions sought to understand how the patient identifies with regard to tiredness, enthusiasm and exhaustion. The average of 59.7 points shows us less than 60% of the total energy expected for patients.

Regarding cognitive function, the questions were about making plans, learning new things, making decisions, memory perceived by the patient and family and concentration in activities such as reading. This topic obtained the second worst average among the parameters, with 59.5 points, being higher only than the lack of tranquility in having seizures.

Adaptation to medication addressed insecurity about short and long-term side effects and also about its effects on reasoning and concentration. The average score was 62.7% of the possible points.

As for sociability, questions were asked about visiting friends and relatives, driving vehicles, work, and interacting with people around them. It is worth noting that this was the parameter with the lowest minimum value, since one of the participants scored only 4 out of 100 points. Even though the average score for sociability is not the lowest in the sample, for this patient the social factor is practically completely impaired by epilepsy.

CONCLUSION

The study aimed to describe the QOLIE-31 scores of patients with epilepsy undergoing clinical treatment. In this scenario, the study concluded that the item with the worst influence on the quality of life of patients with epilepsy is the lack of tranquility when having seizures. This factor is also the only one in the sample with less than 50% of the maximum score (ideal for the best possible QOL).

Meanwhile, the best parameter evaluated through the averages is the QOL in General, as it is an area that assesses the general well-being of the patient, something not necessarily linked to epilepsy.

Therefore, an approach that could enhance the doctor-patient relationship and help in coping with the disease would be to train the patient on what to do when they have seizures, in order to minimize the concern that so affects their quality of life. As well as making them realize that their well-being is not limited exclusively to controlling the disease, but also to different areas of life. New studies that correlate the type of epileptic seizure with the response to treatment and consequent impact on QLV are interesting, since not correlating the epileptic seizure with QLV is a limitation of this study.

REFERENCES

1. Zuberi SM, Symonds JD. Update on diagnosis and management of childhood epilepsies. Jornal de Pediatria. 2015 Nov;91(6): S67–77.

2. Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, et al. ILAE Official Report: A practical clinical definition of epilepsy. Epilepsia [Internet]. 2014 Apr;55(4):475–82. Available from: https://www.ilae.org/files/ilaeGuideline/Definition2014.pdf

3. Fisher R, Cross J, French J, Higurashi N, Hirsch E, Jansen E, et al. Classificação Operacional dos Tipos de Crises Epilépticas pela International League Against Epilepsy: documento da posição da Comissão da ILAE de Classificação e Terminologia [Internet]. Available from: https://www.ilae.org/files/ilaeGuideline/OperationalClassification-Fisher2017-Brazil.pdf

4. Silva, T. I. (2006). Tradução e adaptação cultural do Quality of Life in Epilepsy (QOLIE 31). *J. epilepsy clin. neurophysiol.*

5. Bortolini, L. G. (2009). Efeitos endócrinos e metabólicos das drogas antiepilépticas. *Arq Bras Endocrinol Metab*, 53 (7).

6. Patrick Kwan, M. P. (2011). Drug-Resistant Epilepsy. *The New England Journal of Medicine*, 365:919-926.

7. A.G., B. (2019). Complications after Anterior Temporal Lobectomy for Medically Intractable Epilepsy: A Systematic Review and Meta-Analysis. *Stereotactic and Functional Neurosurgery*, 97:69–82.

8. Samanta D, Ostendorf AP, Willis E, Singh R, Gedela S, Arya R, et al. Underutilization of epilepsy surgery: Part I: A scoping review of barriers. Epilepsy & Behavior. 2021 Apr;117:107837.

9. Silva, T. I. (2006). Tradução e adaptação cultural do Quality of Life in Epilepsy (QOLIE 31). *J. epilepsy clin. neurophysiol.*

10. Faiz Uddin Ahmad 1, M. T. (2007). Health-related quality of life using QOLIE-31: before and after epilepsy surgery a prospective study at a tertiary care cente. *Neurol India*, 55(4):343-8.

11. Georgios A Maragkos, G. G. (2019). Quality of Life After Epilepsy Surgery in Children: A Systematic Review and Meta-Analysis. *Neurosurgery*, 741-749.

12. Liu, S.-Y. M., Yang, X.-L. M., Chen, B. M., Hou, Z. M., An, N. M., Yang, M.-H. M., & Yang, H. M. (2015). Clinical Outcomes and Quality of Life Following Surgical Treatment for Refractory Epilepsy. *Medicine*, Volume 94 - Issue 6 - p e500. Lunshan Xu, M. X. (2010). Epilepsy surgery in China: past, present, and future. *European Journal of Neurology*.