



Associação Brasileira de Epilepsia (ABE)
Filiada ao International Bureau for Epilepsy

Quality of Life and the Self-Perception Impact of Epilepsy in Three Different Epilepsy Types

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ABSTRACT

Purpose: This study aimed to evaluate the quality of life (QOL) and verify the domains of greater impact in patients with focal and generalized epilepsies. **Methods:** The sample, composed by 57 subjects from *Hospital São Paulo da Universidade Federal de São Paulo*, was divided into 3 groups, temporal lobe epilepsies (TLE), extra-temporal epilepsies (Extra-TLE) and idiopathic generalized epilepsy (IGE). They answered a preliminary self-reported questionnaire to identify the perception of the most impaired aspects in their lives. The QOL was evaluated through the validated Brazilian version of the Quality of Life Epilepsy Inventory 31 (QOLIE-31). The correlation of the QOLIE-31 domains with epilepsy duration and seizure frequency was defined by dispersion graphics and also Pearson's and Spearman's correlation. **Results:** The most frequently identified impact of epilepsy was related to interpersonal, familial and social relationships mentioned by 13 (22.81%) patients. The seizure frequency per patient in Extra-TLE group was significantly greater ($p = 0.007$) than in the other groups. The *Cognition Functioning* scores were lower for the Extra-TLE group (38.4) when compared with TLE (52.6) and IGE (62.6) ($p = 0.01$). The correlation between epilepsy duration and QOLIE-31 domains did not demonstrate statistical significance; however, seizure frequency was correlated with *Seizures Worry* ($p = 0.0463$, $\alpha = 0.05$) and *Medication Effects* ($p = 0.0476$, $\alpha = 0.05$) domains. **Conclusions:** 1) Interpersonal, familial, and social relationships were the dimension which most impacted daily life; 2) Cognition domain in Extra-TLE group showed the worst scores; 3) QOL scores were similar in the three groups for the majority of the QOLIE-31 domains; 4) The seizure frequency in the Extra-TLE group was significantly greater; 5) Seizure frequency was associated with worse QOLIE-31 scores in the domains *Seizure Worry* and *Medication Effects*.

Key words: quality of life (QOL), QOLIE-31, temporal lobe epilepsy (TLE), extra-temporal lobe epilepsy (extra-TLE), idiopathic generalized epilepsy (IGE), self-perception of epilepsy impact.

RESUMO

Qualidade de vida e percepção sobre impacto em três diferentes tipos de epilepsias

Objetivo: Este estudo teve como objetivo avaliar a qualidade de vida (QV) em três diferentes grupos de epilepsia e verificar a esfera percebida como de maior impacto na vida diária. **Metodologia:** A amostra foi

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Received Apr 24, 2007; accepted May 25, 2007.

composta por 57 pacientes com epilepsias focais e generalizadas do Hospital São Paulo, Universidade Federal de São Paulo, divididos em três grupos, epilepsias do lobo temporal (ELT), extratemporais (Extra-ELT) e generalizadas idiopáticas (EGI). Os pacientes responderam a um questionário preliminar para identificar a percepção sobre os aspectos mais comprometidos em suas vidas. A QV foi avaliada por meio da versão brasileira do *Quality of Life in Epilepsy Inventory 31* (QOLIE-31). A correlação dos domínios do QOLIE-31 com a duração da epilepsia e frequência de crises foi definida pela inspeção dos gráficos de dispersão e pela correlação de Pearson e de Spearman. Foram considerados significantes os valores de $p < 0,05$. **Resultados:** Dificuldades nas relações interpessoais, familiares e sociais foram apontadas como a esfera de maior impacto relacionado à epilepsia, citada por 13 (22,81%) pacientes. O QOLIE-31 mostrou resultado semelhante nos três diferentes tipos de epilepsia, com exceção do domínio *Funcionamento Cognitivo*. Os escores deste domínio foram significativamente menores ($p = 0,01$) no grupo com Extra-ELT (38,4) do que nos grupos ELT (52,6) e EGI (62,6). A duração da epilepsia não influenciou na QOL nesta amostra, porém foi observada uma correlação estatística significativa entre a frequência de crises e os domínios *Efeitos da Medicação* ($p = 0,0476$, $\alpha = 0,05$) e *Preocupação com Crises* ($p = 0,0463$, $\alpha = 0,05$). A frequência de crises mostrou ainda uma diferença estatisticamente significativa ($p = 0,007$) no grupo com Extra-ELT, que apresentou mais crises/paciente, quando comparado aos demais grupos. **Conclusões:** Os pacientes identificaram as relações interpessoais, familiares e sociais como sendo a área mais afetada pela epilepsia. O domínio *Funcionamento Cognitivo* mostrou-se como fator determinante na QOL do grupo Extra-ELT. A frequência de crises influenciou a QOL nos domínios *Preocupação com Crises* e *Efeitos da Medicação* nos três grupos.

Unitermos: qualidade de vida (QV), QOLIE-31, epilepsia do lobo temporal (ELT), epilepsia extratemporal (extra-ELT), epilepsia generalizada idiopática (EGI), percepção sobre o impacto da epilepsia.

INTRODUCTION

Focal epilepsies present higher prevalence than idiopathic generalized epilepsies (IGE). Among focal epilepsies, mesial temporal lobe epilepsy (TLE) is the epileptic syndrome more frequently diagnosed in adults, ranging between 50 and 75%. From these, 30-40% will not obtain control of the seizures despite appropriate treatment.¹² Because of its lower response to antiepileptic drugs (AEDs), TLE represents 70% to 85% of the epilepsy surgeries.²²

Of all epilepsy types, IGE range from 15.7% to 34.5%. Among them, juvenile myoclonic epilepsy (JME) is the most common type, corresponding to 20% to 27%. Eighty per cent of these patients reach seizure control with valproate, considered a first line drug for the treatment of this syndrome.^{4,13,18}

Epilepsy carries a substantial burden of illness, reflected in poorer quality of life (QOL) and psychosocial function.²⁵ The influence of epilepsy on patient's lives may be quite destructive, with many complains of restrictive daily activities and impaired QOL.⁶ Persons with epilepsy often feel stigmatized by their condition. Emotional distress, social isolation and withdrawal, reduced self-esteem, unemployment or underemployment, are also linked to epilepsy.^{1,6}

The frequency and seizure severity, adverse effects of AEDs, seizure worry, mood status, physical, cognitive and psychosocial limitations, including dependence of caregivers, are determinant aspects frequently assessed by QOL inventories. On the other hand, satisfactory seizure control by AEDs and eligibility to surgical treatment are favorable aspects to the improvement of QOL.²⁴

The Quality of Life in Epilepsy Inventory 31 – QOLIE-31⁷ has been the most frequently used instrument worldwide because of its concise and easy evaluation.

The aim of this study was to evaluate the QOL using the Brazilian version of the QOLIE-31⁸ in three different epilepsy groups: TLE, Extra-TLE and JME and identify in the total sample the most important areas of epilepsy daily impact.

METHODS

The sample was composed by 57 outpatients from *Hospital São Paulo da Universidade Federal de São Paulo* and the data were collected between June and August of 2007. The patients signed a consenting form for a voluntary participation in the study. Patients with neoplasias, psychiatric disturbances and those in post-surgical follow-up or illiterate were excluded of this study.

In a semi structured interview, the clinical data (seizure frequency, duration of epilepsy, medications in use and adverse effects of AEDs) and demographic status (age, sex, schooling, and occupation) were obtained. The data was obtained during the interview as well as in the medical visits.

Subjects were asked to identify in an interview, the three most affected dimensions in their lives in decreasing order of importance. They could choose among the following dimensions: emotional problems; interpersonal, familial and social relationships; work difficulties; treatment and AEDs problems like costs, adverse effects and toxicity; self-sufficiency, co-dependence or dependence; fear of hurting him/herself during a seizure; memory, reasoning and other cognitive impairments. The QOL was evaluated in the same interview through the Brazilian

version of the QOLIE-31, after the application of the preliminary self-reported questionnaire.

The QOLIE-31 is composed by 30 items organized into seven subscales: *Seizure Worry* (5 items), *Overall Quality of Life* (2 items), *Emotional Well-being* (5 items), *Energy-Fatigue* (4 items), *Cognitive Function* (6 items), *Medication Effects* (3 items) and *Social Function* (5 items). The raw scores are rescaled from zero to 100 with higher values reflecting better QOL.

STATISTICAL ANALYSIS

The correlation between the QOLIE-31 domains with epilepsy duration and seizure frequency was defined by dispersion graphics and also by Pearson and Spearman correlation.

The data distribution in the continuous variables was verified by Shapiro-Wilk test, quartile graphs and quartile interval (25th and 75th percentile). The normal data distribution was expressed by means and standard deviation.

The categorical variables were described by frequencies and percentages of each factor level.

The one-way ANOVA defined the significance of the difference among the three epilepsy types in the different QOLIE-31 domains, and the variable monthly seizure frequency was analyzed by the Kruskal-Wallis and Mann-Whitney test with correction of the significance level given by Bonferroni. For all tests p values < 0.05 were considered statistically significant.

We hypothesized a statistical difference between QOL in JME (IGE) group and focal epilepsies groups (TLE and Extra-TLE), with better scores for the JME group.

RESULTS

This series assessed 57 subjects, 27 (47.4%) male, mean age 33.44 (10.51) yrs. (range, 14-56 yrs). Schooling was classified in four groups: 1 to 4 years of education, n = 9 (15.8%); 5 to 8, n = 14 (24.6%); 9 to 11, n = 24 (42.1%), and more than 11 years of education, n = 10 (17.5%). As employment status, 17 (29.8%) patients were employed full-time, 12 (21.0%) were autonomous and 11 (19.3%) were unemployed. The data are summarized in Table 1.

Of the 57 patients, 39 had focal epilepsies and 18 IGE. In the focal epilepsies group 27 (47.4%) were diagnosed as TLE and 12 (21%) as Extra-TLE, while in the IGE group all the 18 (31.6%) had JME.

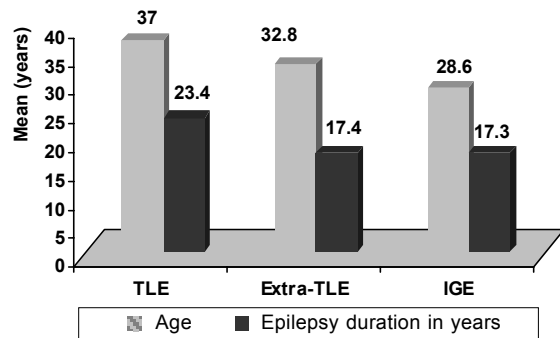
The age of the first seizure ranged from 1 to 38 years of age, mean 13.5 (9.29) and the mean epilepsy duration was 20.2 (10.47) years (Graphic 1).

The seizure frequency of the different samples was 188 seizures in 27 subjects in TLE group; 133.3 seizures in 12 patients in Extra-TLE group and 30.8 seizures in 18 JME (IGE) subjects. TLE seizure frequency (total number seizures) monthly was 4.0 [1.0; 8.5], Extra-TLE, 3.5 [2.3;

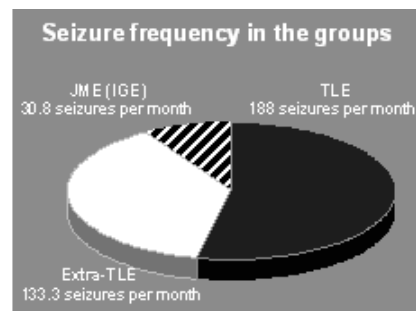
10.5] and JME (IGE), 1.0 [0.0; 3.5]. Seizure frequency per patient was greater in the Extra-TLE group (Graphic 2). There was a statistical significant difference in seizure frequency per patient (p = 0.007) only when Extra-TLE and JME (IGE) groups were compared.

Table 1. Sociodemographic aspects.

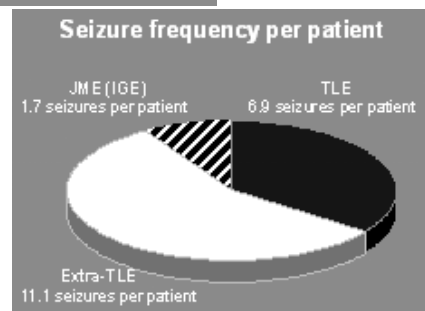
Characteristics	Frequency (%)
<i>Gender</i>	
Female	n = 30 (52.6%)
Male	n = 27 (47.4%)
<i>Schooling</i>	
≤ 4 years of education	n = 9 (15.8%)
≤ 8 years of education	n = 14 (24.6%)
≤ 11 years of education	n = 24 (42.1%)
Higher education	n = 10 (17.5%)
<i>Employment situation</i>	
Employed	n = 17 (29.8%)
Autonomous	n = 12 (21.0%)
Retired due to ill-health/ Government support for illness	n = 7 (12.3%)
Unemployed or jobless	n = 11 (19.3%)
Student and housewife	n = 10 (17.5%)



Graphic 1. Age and epilepsy duration-mean (years).



Graphic 2. Seizure frequency per month in the three epilepsy groups.



In this study, the most frequently identified impact of epilepsy was related to interpersonal, familial and social relationships expressed by problematic family interactions, difficulties in making friends, feelings of isolation and withdrawal, stigmatization, embarrassment resulting from having a seizure in public, inability to start a conversation in a social group mentioned by 13 (22.81%) patients.

Problems with AEDs were reported by 10 (17.54%) as costs of the drugs, regular time to take the medications, adverse effects as sleepiness, shaky hands, tiredness, loss of energy, fatigue, worry about adverse effects of AEDs if taken for a long time, dependence of the medicines, limitations for leisure time or recreation activities.

Emotional problems as depression, mood swings, sadness, anxiety, fear, irritability, shyness and feelings of failure in life were reported by 9 (15.79%) subjects and work difficulties by 9 (15.79%) expressed in worry about losing the job, unemployment, employment restrictions, limited performing and inability to attain more responsible job as seen in Table 2.

Table 2. Seizure impact* in daily life.

Impact Dimensions	Number = 57	%
Emotional problems	9	15.79
Interpersonal, familial and social relationships	13	22.81
Work difficulties	9	15.79
Treatment and antiepileptic drugs problems	10	17.54
Self-sufficiency, co-dependence or dependence	5	8.77
Fear from hurting him/herself	5	8.77
Cognitive impairments	6	10.53

* Self-perception questionnaire.

The results of QOL assessment obtained through QOLIE-31 were compared among the three groups. The analysis revealed a difference in *Cognition* for Extra-TLE when compared with JME (IGE) group (p = 0.01). The Extra-TLE group showed lower scores, indicating the greatest impact in the *Cognition* domain of QOLIE-31. The QOLIE-31 mean scores were outlined in Table 3.

Table 3. Results of QOLIE-31 domains in the three groups.

QOLIE-31 domains	TLE	Extra-TLE	JME (IGE)
Seizure worry **	53.9 (31.1)	50.9 (33.9)	49.7 (28.0)
Emotional well-being	60.6 (16.8)	60.7 (26.7)	63.5 (16.5)
Energy/Fatigue	60.7 (18.1)	58.8 (18.6)	64.4 (17.0)
Social Function	61.1 (24.1)	63.7 (15.0)	73.4 (21.8)
Cognition	52.6 (23.4)	38.4 (28.4)*	62.6 (18.2)
Medication side-effects **	45.4 (28.6)	29.8 (25.4)	54.3 (31.7)
Overall QOL	62.2 (17.3)	62.6 (22.6)	65.9 (15.6)

* Difference statistically significant (P = 0.01) compared with JME (IGE) group.
 ** (P = 0.05) in correlation with seizure frequency.

The correlation between epilepsy duration and QOLIE-31 domains was expressed in median (25th and 75th percentile); *Seizure worry* 0.07 [-0.20; 0.34], *Emotional Well-being* -0.15 [-0.41; 0.12], *Energy/Fatigue* -0.11 [-0.36; 0.17], *Social Function* -0.20 [-0.45; 0.07], *Cognition* -0.02 [-0.29; 0.25], *Medication side-effects* 0.06 [-0.21; 0.32], and *Overall QOL* -0.04 [-0.30; 0.23]. These results did not demonstrate statistically significant correlations between QOLIE-31 domains.

We found a statistical association between the variable seizure frequency and the QOLIE-31 domains' *Seizure Worry* (p = 0.046) and *Medication Effects* (p = 0.047).

DISCUSSION

The dimensions related to interpersonal, familial and social relationships (22.81%), difficulties with the treatment and medication (17.54%) and emotional problems (15.79%) were mentioned in the interview, with a substantial impact in daily life. Not surprisingly, the patients in our focal group with medically intractable epilepsy had multiple social and psychological disabilities. They described difficulties in social situations, such as schooling and interruption of familial relations.²¹ Other investigations have also found that patients perceive intractable epilepsy as having a devastating effect on the work, social activities and performance in school.⁹ In Brazil the situation is even more dramatic due to the burden of treatment costs (medical visits, expenses with AEDs).

In this series only 17 (29.81%) patients were full-time employed and difficulties with work dimension was mentioned by 9 (15.79%) in the interview. The problematic employment situation for people with epilepsy is well established. Unemployment rate experience by them has frequently been shown to be higher than of general population.¹¹ It has been suggested that, with respect to unemployment, the type, severity, and frequency of seizures may be relevant. Rates of unemployment have consistently been found to be higher among individuals with more frequent seizures.^{5,16,26} Finally, fear of employer and discrimination or stigmatization at work appears to significantly influence the employment situation.³

The association of QOLIE-31 domains with epilepsy syndromes showed a statistical significance only in the *Cognition Domain*. The Extra-TLE group results were lower as compared with JME scores. The *Cognitive Domain* of the QOLIE-31 consists of questions concerning memory, concentration, and reasoning. It was expected lower scores in *Cognition* for the Extra TLE, in the view of the severity of this type of epilepsy. The type and anatomic location of brain pathology have crucial impact on cognitive deficit.²³

Self-reported memory has been considered as important predictor of QOL, and therefore, correlates with

performance on memory tests, suggesting that memory improvement by specific training may help to improve QOL.^{15,20}

Significant relationships have been found between memory complaints on the questionnaire and objective performance in some neuropsychological tasks.¹⁷ Chronic illness and emotional functioning were strongly related to memory self-perceptions. Other studies also suggested that patients' characteristics may mediate the relationships between subjective and objective memory as mentioned by Helmstaedter and Elger¹⁷ who found that patients with good memory abilities on neuropsychological tests provided more accurate rating of their memory than did patients with poorer memory abilities.

In this series demographic variables, such as duration of epilepsy was not associated with QOLIE-31 scores, maybe because most of the subjects had epilepsy for a long time (mean = 20.2 years). In a Georgian study,¹⁰ the variables that most strongly predicted a lower QOL scores were lower educational level, higher seizure frequency, and long duration of epilepsy.

In this study, we defined the statistical treatment of the seizures frequency through median and quartile interval (25th and 75th percentile) due to irregularity in the data distribution of these variables. Mean and standard deviation were applied in variables with regular parameters in the data distribution. The use of median and quartiles allowed larger robustness and accuracy for interpretation of those data.

The association with seizure frequency and the QOLIE-31 was higher for the domains *Seizure Worry* and *Medication Effects*. The *Seizure Worry* domain consists of items such as worry about future seizures, apprehension over future injury resulting from seizures, trepidation over adverse effects of medication regimens, and social embarrassment over having seizures. In the original paper of the QOLIE-31,⁷ patients with higher seizures frequency scored significantly worse than patients whose seizures were controlled and those with mild seizure frequency. Frequent seizures have been found to be negatively associated with QOL scores, and seizure-free patients have been observed to have a health-related QOL similar to that of general population.^{2,19}

The *Medication Effects* domain of QOLIE-31 has three questions about the medication worry if it is taken for a long time, and the physical and mental possible adverse events. It has been suggested that adverse events are actually a great determinant of QOL.¹⁴ Most of the important toxicity experienced by patients taking AEDs may be sub-clinical and may not reach the attention of the physician. Improvement in medication toxicity was associated with improvement in QOL.¹⁴ Identifying adverse medication effects in outpatients could lead a

better compliance, less AEDs events, and increase the confidence in patient-medical relationship.

These results were limited in exploring the dimensions and variables that may be of crucial impact in QOL. Further investigation will be necessary to understand the complex relationships with different epileptic syndromes and its influence in patients QOL.

CONCLUSION

Overall, the results of this survey concluded: 1) Interpersonal, familial, and social relationships were the dimension which most impact in daily life; 2) Cognition domain in Extra-TLE group showed the worst scores; 3) QOL scores were similar in the three groups for the majority of the QOLIE-31 domains; 4) Seizure frequency in the Extra-TLE group was significantly greater; 5) Seizure frequency was associated with worse QOLIE-31 scores in the domains *Seizure Worry* and *Medication Effects*.

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