

## The effects of Epileptic Seizures Upon Quality of Life

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### ABSTRACT

**Objective:** understand the psychological considerations of the relationship between the effect of seizures upon the patients' perception of seizure control, depression, anxiety and quality of life (QoL). **Methods:** 151 adult patients with epilepsy diagnosed for over two years were interviewed and responded the 31-Item Quality of Life in Epilepsy (QOLIE-31), the Trait Form of the State/Trait Anxiety Inventory (STAI II) and the Beck Depression Inventory (BDI). **Results:** 45 patients were depressed (29.8%) and 29 (19.2%) had anxiety. Depression scores ranged from 0 to 49 (M=7.4; SD=8.9) and anxiety scores ranged from 19 to 69 (M=41.5, SD=11.9). Total QoL score was correlated to seizure control ( $p<0.001$ ), perception of epilepsy control ( $p<0.001$ ), anxiety ( $p<0.001$ ), and depression ( $p=0.003$ ). The perception of epilepsy control was correlated to seizure control ( $p<0.001$ ), seizure frequency ( $p=0.001$ ), anxiety ( $p<0.001$ ) and depression ( $p<0.001$ ). Seizure control was associated to anxiety ( $p=0.033$ ) and depression ( $p<0.001$ ). There was co-morbidity between anxiety and depression ( $p<0.001$ ). **Conclusion:** This study highlights the importance of the seizure frequency and control to the evaluation of perception of epilepsy control and shows that anxiety and depression in epilepsy are predicted by seizure-related (seizure frequency and control) and psychosocial aspects (perception of control and QoL) together.

**Key words:** Perception of epilepsy control, epilepsy, depression, anxiety, quality of life, seizure frequency, seizure control.

### RESUMO

#### *Efeito das crises epilépticas na qualidade de vida*

**Objetivo:** Explicar a relação entre o efeito das crises epilépticas na percepção subjetiva de controle do paciente, e nos sintomas de depressão, ansiedade e qualidade de vida (QV). **Métodos:** 151 adultos com epilepsia foram entrevistados e responderam o questionário de qualidade de vida (QOLIE-31), o STAI-II (Traço de Ansiedade) e o inventário de depressão de Beck (BDI). **Resultados:** 45 pacientes (29.8%) apresentaram sintomas de depressão e 29 (19.2%), traço de ansiedade. O escore de depressão variou de 0 a 49 (M=7.4; SD=8.9) e o de ansiedade de 19 a 69 (M=41.5, SD=11.9). O escore total de QV foi associado ao controle de crises ( $p<0.001$ ), percepção de controle da epilepsia ( $p<0.001$ ), ansiedade ( $p<0.001$ ) e depressão ( $p=0.003$ ). A percepção de controle foi associada ao real controle de crises ( $p<0.001$ ), frequência de crises ( $p<0.001$ ), ansiedade ( $p<0.001$ ) e depressão ( $p<0.001$ ). O controle de crises foi associado à ansiedade ( $p=0.033$ ) e depressão ( $p<0.001$ ). Ansiedade e depressão foram correlacionadas ( $p<0.001$ ). **Conclusão:** Este estudo aponta a importância da redução da frequência de crises, assim como o seu controle, na avaliação da percepção de controle da epilepsia e mostra que ansiedade e depressão são resultado de fatores associados ao controle à frequência de crises, assim como à percepção de controle e à QV.

**Unitermos:** Percepção de controle, epilepsia, depressão, ansiedade, frequência de crises, controle de crises.

### INTRODUCTION

There are many studies that determine the relative contributions of psychological, social and seizure-related

variables to quality of life (QoL) scores in epilepsy. Tracy et al.<sup>1</sup> pointed that QoL scores are strongly influenced by depression, and factors such as seizure control exert a more limited effect on the QoL in epilepsy.

Choi-kwon et al.<sup>2</sup> found that the symptom of anxiety was the most important factor in explaining lower QoL in

patients with epilepsy, followed by depression, social life dissatisfaction, activities of daily living dysfunction, and seizure frequency.

Loring et al.<sup>3</sup> demonstrated that, although QoL has multiple determinants, symptoms of depression and seizure worry are the most important factors affecting QoL in patients with intractable epilepsy.

Johnson et al.<sup>4</sup> pointed that frequent, severe, and chronic seizures reduce QoL, but are less powerful predictors of QoL than anxiety and depression. Cramer et al.<sup>5</sup> found clinical depression to be significantly associated with poor QoL among people with all types of seizures.

Hermann<sup>6</sup> developed a model of QoL in which three groups of variables would be responsible for the impact of epilepsy on the patients' daily living activities; variables associated to the characteristics of epilepsy, anti-epileptic drugs and psychosocial variables.

Suurmeijer et al.<sup>7</sup> explored the relative contribution of physical, social and psychological functioning of the patient in their judgment of QoL. They had assumed that the judgment that the person has of its QoL is not directly influenced by a chronic illness, but reflects the problems and concerns induced for the decrease or loss of personal, social and economic resources (for example, for the aggravation of domestic tasks, occupational changes, loss of income, reduction of self-esteem and locus of control).

This concept of QoL corroborates with the Devins et al.<sup>8</sup> concept of "illness intrusiveness", that mentions the interference of the illness in the activities and interests of the person, such as their social, leisure or occupational activities.

Models of QoL in epilepsy always try to associate the patients' subjective characteristics to their physical, social and psychological functioning. In the current article, we aimed to deepen the psychological considerations of the relationship between the effect of seizures upon the patients' perception of epilepsy control, depression, anxiety and QoL, and understand the subjective process of the patient when evaluating himself and his condition.

## METHODS

### Subjects

The subjects of this investigation consisted of 151 consecutive patients from the outpatient clinic of epilepsy at the University Hospital of Campinas, UNICAMP, with temporal lobe epilepsy diagnosed for over two years, older than 17 years and without evident learning disability.

All patients gave their consent for participation in the research, which was approved by the Ethics Committee of UNICAMP (174/2004).

## Measures and Procedure

All patients were individually interviewed and completed an identification card with the following items: age, school level (elementary school/high school/college), employment (yes/no), marital status (single/married), perception of epilepsy control (yes/no), seizure type (partial, partial with secondary generalization), seizure frequency/month, seizure control for over six months (yes/no), epilepsy duration/years and anti-epileptic drugs (AEDs) treatment (quantity of AEDs being used for treatment).

After that, all patients responded to instruments that have been used worldwide and were translated and adapted to the Portuguese language and culture. The QOLIE-31<sup>9</sup> consists of 31 items of QoL scoring from 0 to 100. Higher scores indicate better QoL. The BDI<sup>10</sup> is a 21-item self-report measure and the items are scaled from 1 to 4, according to depression intensity. The STAI<sup>11</sup> consists of 20 self-report questions (trait scale) scoring from 1 to 4. The Trait Scale refers to the stable predisposition of individuals to developing anxiety.

## Data Analysis

The data were analyzed using the SYSTAT for Windows. The Chi-Square and Fisher tests were used for categorical variables. Kruskal-Wallis test was used to compare scores between groups, because of their abnormal distribution. The Pearson coefficients of correlation were used to analyze the association between numerical variables. The significance used was 5% ( $p=0.05$ ).

## RESULTS

The age ranged from 17 to 52 years old ( $M=34.6$ ;  $SD=8.9$ ). Most of the subjects had completed only elementary school ( $n=76$ ; 50.3%), did not work ( $n=99$ ; 65.6%), were single ( $n=89$ ; 58.9%) and perceived epilepsy control ( $n=109$ ; 72.2%).

Epileptic seizures were classified according to the International League Against Epilepsy Classification of Epilepsies and Epileptic Syndromes.<sup>12</sup> The most common seizure type was the partial with secondary generalization ( $n=72$ ; 57.6%) and the mean seizure frequency/month was 10.21 ( $SD=11$ ). Most subjects ( $n=81$ ; 53.6%) had seizure controlled for over six months and epilepsy duration ranged from 4 to 50 years ( $M=24$ ;  $SD=11.2$ ). Most subjects were using two AEDs ( $n=98$ ; 66.7%).

Total QoL scores ranged from 13.9 to 96.4 ( $M=64.3$ ,  $SD=17.4$ ). The QOLIE-31 subscales scored the following: seizure worry ( $M=62.8$ ,  $SD=31.3$ ), overall QoL ( $M=61.9$ ,  $SD=17.5$ ), emotional well-being ( $M=63$ ,  $SD=25.7$ ), energy/fatigue ( $M=64.9$ ,  $SD=27.3$ ), cognitive ( $M=62.5$ ,  $SD=24.8$ ), medication effects ( $M=74.1$ ,  $SD=29.3$ ) and social function ( $M=68.1$ ,  $SD=28$ ).

Forty-five patients were depressed (29.8%) and 29 (19.2%) had anxiety. Depression scores ranged from 0 to 49 ( $M=7.4$ ;  $SD=8.9$ ) and anxiety scores ranged from 19 to 69 ( $M=41.5$ ,  $SD=11.9$ ).

Table 1 lists the demographic and clinical characteristics of subjects.

**Table 1.** Demographic and clinical characteristics of subjects

	Subjects
N	151
Age (mean±SD)	34.6±8.9
<i>School level:</i>	
Elementary school	76 (50.3%)
High School	56 (37.1%)
Start College	19 (12.6%)
<i>Work:</i>	
Employed	52 (34.4%)
Unemployed	99 (65.6%)
<i>Marital State</i>	
Single	89 (58.9%)
Married	62 (41.1%)
<i>Epileptic Seizures:</i>	
Partial seizures	53 (35.1%)
Partial+generalized seizures	72 (47.7%)
Missing data	26 (17.2%)
Seizure frequency (mean±SD)	10.2±11
No seizures/6 months	81 (53.6%)
<i>AEDs treatment</i>	
Monotherapy	38 (25.2%)
Polytherapy	113 (74.8%)
<i>Other characteristics of epilepsy:</i>	
Epilepsy duration/years (mean±SD)	24±11.2
Perception of epilepsy control (Yes/No)	109/41
QoL (mean±SD)	64.3±17.4
Anxiety (Yes/No)	(29/122)
Depression (Yes/No)	(45/106)

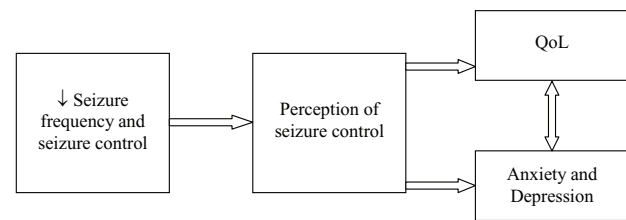
Total QoL score was correlated to seizure control for over six months ( $p<0.001$ ), perception of seizure control ( $p<0.001$ ), anxiety ( $p<0.001$ ), and depression ( $p=0.003$ ).

The perception of seizure control was correlated to seizure control for over six months ( $p<0.001$ ), seizure frequency ( $p=0.001$ ), anxiety ( $p<0.001$ ) and depression ( $p<0.001$ ). Seizure control for over six months was associated to anxiety ( $p=0.033$ ) and depression ( $p<0.001$ ).

There was comorbidity between anxiety and depression ( $p<0.001$ ). Age, school level, work, marital state, AEDs, epilepsy duration and seizure type were not associated to QoL, perception of epilepsy control, seizure control, anxiety and depression.

Figure 1 shows the effect of seizures upon QoL. The seizures remission and even it's the lessen frequency of seizures lead to the perception of epilepsy control, what means that patients perceive control not only when they do

not have any seizures, but also when the seizures decreased in number if compared to the past. When patients perceive epilepsy control, they have a better QoL and fewer symptoms of anxiety and depression. The patients' QoL is by itself correlated to the symptoms of anxiety and depression.



**Figure 1.** Effect of seizures upon QoL.

## DISCUSSION

In the current article, we aimed to deepen the psychological considerations of the relationship between the effect of seizures upon the patients' perception of seizure control, depression, anxiety and QoL, and understand the subjective process of the patient when evaluating himself and his condition.

In a previous study<sup>13</sup> we observed that the perception of seizure control starts the psychological process involved in the subject's evaluation of QoL.

This study highlights the importance of the seizure frequency and control to the evaluation of perception of seizure control. There is a difference between frequency of seizures (real number expressed in days, months, and years according to medical evaluation) and perception of seizure/epilepsy control (subjective evaluation of seizure control).<sup>14</sup> When the subjects evaluate their QoL, they do it according to their subjective evaluation of epilepsy control. However, although subjective, it is supported by the real seizure frequency/control.

The frequency of seizures has the meaning that the person gives to it. His/her self-evaluation of what means to be sick, to have seizures, to use drugs, and to control one's seizures are parameters of well-being.<sup>15,16</sup> Meador<sup>15</sup> has stated that the perception that patients have about their condition affects their QoL more than the condition itself.

The subjects see themselves as sick by evaluating the signs of the disease. The patient perceives his or her disease through the seizures. When the seizures, for whatever reason, decrease in frequency, they feel in control of the disease, even if from the medical perspective, the disease is not considered controlled.

Birbeck et al.<sup>17</sup> pointed that QoL improvement occurs mainly among patients who achieved seizure freedom.

Our study disagrees and highlights the decrease in seizure frequency as a form to perceive epilepsy control and improve QoL. It occurs because when patients feel their seizures have decreased in frequency, they start feeling less interference of the disease in their lives. Epilepsy becomes to be less intrusive in their social, emotional and vocational functioning.

Besides the fact that most of the subjects had epilepsy controlled for over six months and a higher number perceived epilepsy control, most of them did not marry, study much and work. Their social disability shows the impact of epilepsy in their QoL. Although in the moment they were interviewed they were satisfied, with good QoL and feel symptoms of anxiety and depression, epilepsy had already let its signature.

The perception of epilepsy control is a dynamic and continuous process of evaluation of the signs of disease with cognitive structures to modify or to reinforce the representation of the disease as a factor under control or not and, consequently, stressful or not.<sup>13</sup> These interpretations are extremely individualized and affect the patients' QoL.

Besides the perception of epilepsy control, QoL was also affected by mood states (anxiety and depression), what was also found in other studies.<sup>2,18</sup>

Anxiety and depression are separate psychiatric conditions that are often related, according to Cramer et al.<sup>19</sup> and Johnson et al.<sup>20</sup> We also noted the strong association between anxiety and depression.

The prevalence of anxiety and depression in this study was inferior to the prevalence found in our previous study.<sup>13</sup> It may be because of the high number of individuals with epilepsy controlled and even higher number of people with perception of epilepsy control, due to the decrease in seizure frequency.

Our results showed that anxiety and depression in epilepsy are predicted by seizure-related (seizure frequency and control) and psychosocial aspects (perception of control and QoL) together.

The importance of this study is that it shows the psychological process involved in epilepsy, calling attention to the effects of seizure frequency and the subjective perception of seizure control, and its influence in the patients' QoL, anxiety and depression.

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