

# Quality of life in pregnant women with epilepsy versus women with epilepsy

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## ABSTRACT

It is assumed that 25% of patients with epilepsy are women of fertile age and 0.3% to 0.6% of all children are born of mothers with epilepsy. The aim of this study was to evaluate the quality of life on pregnant with epilepsy and compare with non-pregnant women with epilepsy. We evaluated two groups (Experimental Group - 29 pregnant women with epilepsy and Control Group - 30 women with epilepsy); they were attended at the HC/UNICAMP. The patients had three meetings to carry out and implement the anamnesis and the application of QQV-65. There were no significant differences in the measurement of quality of life when comparing both groups. However, when we analyzed individually in the pre- and post-partum periods, we observed significant differences in health aspects ( $p=0.0495$ ), physical ( $p=0.02868$ ) and emotional ( $p=0.0253$ ) dimensions in QQV-65. This study shows that pregnancy could be interpreted as a stressor. In late pregnancy when this stressor was removed, women with epilepsy had improvement in their quality of life. **Key words:** women, pregnancy, quality of life, epilepsy.

## Qualidade de vida em gestantes com epilepsia versus mulheres com epilepsia

## RESUMO

Admite-se que 25% dos pacientes com epilepsia sejam mulheres em idade fértil e que 0,3% a 0,6% de todas as crianças nascidas sejam filhas de mães epiléticas. O objetivo do presente estudo foi avaliar a qualidade de vida em gestantes com epilepsia e compará-la com a de mulheres com epilepsia não grávidas. Foram avaliados dois grupos (Grupo Experimental - 29 gestantes com epilepsia e Grupo Controle - 30 mulheres com epilepsia) atendidos no HC/UNICAMP. As pacientes foram submetidas a três encontros para a realização de anamnese e a aplicação do QQV-65. Não encontramos diferenças significativas na avaliação de qualidade de vida ao comparar ambos os grupos. No entanto quando avaliados individualmente no período pré e pós-natal, observamos diferenças significativas nos aspectos: saúde ( $p=0,0495$ ), físico ( $p=0,02868$ ) e emocional ( $p=0,0253$ ) no QQV-65. Este estudo mostrou que a gravidez pode ser interpretada como um estressor. No final da gravidez, quando este estressor foi removido, mulheres com epilepsia mostraram melhora na qualidade de vida.

**Palavras-chave:** mulheres, gravidez, qualidade de vida, epilepsia.

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The Quality of Life (QoL) was defined by World Health Organization as “the perception of the individual of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns”<sup>1</sup>. This is a concept that embraces and combines the physical, psycho-

logical, level of independence, sociability and relationships with environment<sup>2</sup>.

In chronic diseases, such as, epilepsy, the QoL is recognized as a multifaceted concept, it says the problems experienced the disease condition, which goes beyond its signs and symptoms to refer to the experiential aspects of the subject who fall ill<sup>2</sup>.

It can be defined in terms of satisfaction level of physical needs, psychological, social, marital and structural<sup>3</sup>. Many patients with epilepsy have restrictions in their daily lives and losses that affect their QoL<sup>4,5</sup>.

In pregnant women with epilepsy that impact may be greater, leading to a low QoL, since besides the impact caused by the disease, they still suffer from the stressors related to pregnancy<sup>6,7</sup>. The pregnancy is a period; during the women suffer a variety of social, psychological and somatic changes. Most pregnant women present physical and psychological symptoms, changes in work and activities, and in appearance of body, affectivity, sexuality and relationships<sup>8,9</sup>.

Besides the concerns felt by the disease condition, women with epilepsy have other fears concerning the possibility of them becoming pregnant and how changes of pregnancy will change their lives<sup>7</sup>.

Recent improvements in diagnosis and treatment of epilepsy have allowed many women to lead a normal life; they have the possibility to marry, have children and work. Understand the impact of pregnancy on epilepsy justifies this work. The aim of this study was to evaluate the QoL in pregnant women with epilepsy and to compare with non-pregnant women with epilepsy.

## METHOD

### Patients

Sample was constituted by 59 patients, 29 pregnant with epilepsy (experimental group) and 30 women with epilepsy (control group) from the Clinic of Neurology, University Hospital (UNICAMP, Campinas SP, Brazil). Both groups were aged 17-43 years and presented no obvious psychiatric illness and enough schooling to understand the tests. They suffered from epilepsy, diagnosed according to the criteria of the International League Epilepsy<sup>10</sup>. The epilepsy onset was prior to pregnancy. The antiepileptic drugs (AEDs) were the same during the assessment.

The Committee of Ethics in Medicine of UNICAMP approved this study. Written informed consent was obtained from the patients.

### Instruments

Clinical and demographic identification file, with information on age, education, marital status, occupation, and date of onset of illness, type of syndrome, seizure types, duration of the disease, frequency of seizure and medication.

Quality of Life Questionnaire (QQV-65)<sup>2</sup>. This questionnaire was developed from the work of Vickrey et al.<sup>11</sup>, Devinsky et al.<sup>12</sup> and O'Donoghue<sup>13</sup> and shows a high internal consistency. The alpha coefficient Cronbach was 0.897 and ranged from 0.73 to 0.87 in different dimen-

sions<sup>2</sup>. The QVV-65 investigates the QoL of patients with epilepsy through 65 questions in the issues: health perception, physical limitation, and social functioning, locus of control, affective-emotional well-being, self-concept and cognitive functioning. This questionnaire allows in the end of its application, that the patient speak more about some difficulties encouraged by the questions. It was applied in a study center and assistance related to a public university, in order that its scope would enable one to trace the emotional and relational functioning that would justify a psychological referral. It is a self-report and all items are linearly transformed into scales of 0-100 points, such that a higher number reflect a more favorable health state<sup>2</sup>.

## Procedures

Patients answered the Demographic Identification Card and Quality of Life Questionnaire- 65 (QQV-65)<sup>2</sup>. The data on patient's condition was obtained in the medical data assessed by a neurologist (ALCC). The experimental group was evaluated in the third trimester of pregnancy. This time was established according to the authors<sup>14-16</sup>, who suggest that the strongest effect of anxiety in the prenatal period is the first and last quarter. The post test was administered three months after partum.

The application of instruments was performed in the Clinic of Applied Psychology at the University Hospital of Neurology, UNICAMP, Campinas SP, Brazil. Patients completed the questionnaire under the same conditions.

## Statistics analysis

To describe the sample profile according to the study variables, frequency tables with categorical variables with values of absolute frequency (n) and percentage (%) and descriptive statistics (with measurements of position and dispersion - mean, standard deviation, minimum, maximum, median and quartiles) for continuous variables (scores of scales) were performed. To compare numerical variables between two groups, we used the Mann-Whitney test or Qui-Square test. Wilcoxon test was used to compare two different moments: pre- and post-partum. The level of significance for statistical tests was 5% ( $p < 0.05$ ).

## RESULTS

Table 1 presents the characteristics of the sample, containing clinical and demographic data.

Sample was constituted by 59 patients, 29 pregnant with epilepsy aged from 17 to 37 (mean age  $26.4 \pm 6.2$  SD) and 30 non pregnant with epilepsy, aged from 17 to 43 (mean age  $30.1 \pm 7.4$  SD). The statistical analysis showed significant difference in age ( $p = 0.0483$ ) and marital status ( $p = 0.0017$ ) and a slight tendency on the occupation ( $p = 0.0897$ ) between groups.

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

	Experimental group	Control group	p-value
N	29	30	
Age (Mean ±SD)	26.4 ±6.2	30.1 ±7.4	<b>0.0483*</b>
Occupation			
Housewife	7 (11.86%)	13 (22.03%)	
Employee	9 (15.25%)	3 (5.08%)	0.0897**
Unemployee	13 (22.03%)	14 (23.73%)	
School			
Elementary incomplete	10 (16.95%)	11 (18.64%)	
Elementary complete	3 (5.08%)	2 (3.39%)	
College incomplete	2 (3.39%)	4 (6.78%)	
College complete	13 (22.03%)	10 (16.95%)	
Graduation incomplete	0	2 (3.39%)	
Graduation complete	1 (1.69%)	1 (1.69%)	
Marital status			
With partner	24 (40.68%)	13 (22.03%)	<b>0.0017**</b>
Without partner	5 (8.74%)	17 (28.81%)	
Epileptic syndromes			
Temporal lobe epilepsy	22 (37.29%)	26 (44.07%)	
Extra temporal epilepsy	7 (11.77%)	4 (6.78%)	
Seizure types			
Focal seizures	1 (1.68%)	2 (3.39%)	
Generalized seizures	13 (22.03%)	13 (22.03%)	
Focal + generalized seizures	15 (25.42%)	15 (25.42%)	
Frequency			
Controlled seizures	12 (41.37%)	18 (60%)	
No controlled seizures	17 (58.62%)	12 (40%)	
Age at onset of seizures (yrs)			
0 to 5	7 (24.13%)	11 (36.66%)	
6 to 10	9 (31.03%)	9 (30%)	
11 to 15	5 (17.24%)	4 (13.33%)	
Above 16	8 (27.58%)	6 (20%)	
Disease duration (yrs)			
0 to 5	4 (13.79%)	1 (3.33%)	
6 to 10	7 (24.13%)	6 (20%)	
11 to 15	5 (17.24%)	8 (26.66%)	
Above 16	13 (44.82%)	15 (50%)	
AEDs			
One	22 (37.29%)	23 (38.98%)	
Two/three	7 (11.86%)	7 (11.86%)	

\*Value-p referring to the Mann-Whitney test; \*\*Value-p referring to the Qui-Square Test; AEDs: antiepileptic drugs; yrs: years.

The descriptive analysis and comparisons of QoL assessed by QQV-65 between the experimental group and control group are shown in Table 2. We can observe that both groups show no significant differences with respect to QQV-65. The most affected in the experimental group were the locus of control, cognitive and physical dimen-

sions. The control group showed alterations in locus of control, physical and cognitive aspects. The total score did not differ in both groups.

Table 3 shows descriptive data and comparisons between pre-and post-partum QoL evaluated by the QQV-65<sup>2</sup>, where it is possible to observe a significant difference

**Table 2.** Descriptive analysis and comparisons of Quality of Life between the experimental group and control group were assessed by QV-65.

Group	Aspects	N	Mean	SP	Minimum	Median	Maximum	p-value*
Experimental	Health	29	60.5	16.0	29.8	63.8	93.1	0.3510
	Physical	29	64.2	22.7	11.1	66.7	94.4	0.5889
	Social	29	63.0	13.6	33.3	63.0	87.0	0.4942
	Emotional	29	56.2	16.2	27.8	52.8	91.7	0.9697
	Control Locus	29	78.7	16.4	38.9	83.3	100	0.2491
	SC	29	62.2	18.6	37.5	58.3	100	0.3048
	Cognitive	29	74.7	22.1	16.7	75.0	100	0.2776
	Total	29	65.6	12.8	35.2	64.3	91.2	0.8855
Control	Health	30	63.6	16.5	34.1	65.7	87.6	
	Physical	30	67.0	22.8	11.1	72.2	94.4	
	Social	30	60.5	14.0	31.5	58.3	83.3	
	Emotional	30	56.7	19.5	22.2	51.4	91.7	
	Control Locus	30	72.6	20.6	16.7	72.2	100	
	SC	30	66.5	23.6	20.8	68.8	100	
	Cognitive	30	66.1	27.9	0	70.8	100	
	Total	30	64.7	15.4	36.7	65.8	88.4	

\*Value-p referring to the Mann-Whitney test to compare variables between groups.

**Table 3.** Descriptive analysis and comparisons of QV-65 between pre-and post-partum in the experimental group.

Aspect*	n	Mean	SD	Minimum	Median	Máxim	p-value**
Health	29						
Pre		60.5	16.0	29.8	63.8	93.1	
Post		64.8	14.3	16.7	66.9	85.9	
Difference		4.3	11.2	-17.3	4.5	27.1	<b>0.0495</b>
Physical	29						
Pre		64.2	22.7	11.1	66.7	94.4	
Post		72.8	16.1	38.9	72.2	100	
Difference		8.6	20.3	-33.3	5.6	44.4	<b>0.02868</b>
Social	29						
Pre		63.0	13.6	33.3	63.0	87.0	
Post		66.2	12.4	37.0	64.8	87.0	
Difference		3.3	9.0	-13.0	0.0	25.9	0.0880
Emotional	29						
Pre		56.2	16.2	27.8	52.8	91.7	
Post		62.9	14.1	36.1	61.1	94.4	
Difference		6.7	16.5	-27.8	8.3	36.1	<b>0.0372</b>
Control locus	29						
Pre		78.7	16.4	38.9	83.3	100	
Post		78.4	22.6	16.7	83.3	100	
Difference		-0.4	21.2	-83.3	0.0	33.3	0.6694
Self concept	29						
Pre		62.2	18.6	37.5	58.3	100	
Post		62.4	19.2	16.7	66.7	91.7	
Difference		0.1	18.5	-58.3	0.0	33.3	0.9345
Cognitive	29						
Pre		74.7	22.1	16.7	75.0	100	
Post		69.8	31.5	0.0	75.0	100	
Difference		-4.9	18.8	-58.3	0.0	25.0	0.2222
Total score	29						
Pre		65.6	12.8	35.2	64.3	91.2	
Post		68.2	13.2	33.5	72.1	87.6	
Difference		2.5	9.2	-15.4	2.2	24.6	0.2196

\*Variables that indicate differences relate to the differences, calculated by the value of postpartum subtracting the pre-partum, \*\*Wilcoxon test for related samples.

between the pre-and post-partum in variables related to health aspects ( $p=0.0495$ ), physical ( $p=0.0268$ ) and emotional ( $p=0.0372$ ) dimensions.

## DISCUSSION

Our work showed no significant difference in any of the aspects of QoL studied through QQV-65, when the experimental group compared with the control group.

We postulate that women with epilepsy experience both pregnancy and epilepsy stressors that influenced their well being. In a pilot study, we identified a higher stress index due to pregnancy in epileptic women compared to normal women<sup>8</sup>. During pregnancy, some stressors are specific to women with epilepsy and, these may overburden the personal adaptive mechanisms<sup>8</sup>.

In this sample we estimated that the pregnancy might be a stressor that could make a difference between the groups, which did not happen in this study.

It can be observed more difficulties related to locus of control, physical and cognitive dimensions in this sample of individuals with epilepsy regardless of the condition of pregnancy.

Our results showed the lack of control over the disease and concern for their physical and cognitive functioning were reported as most affected. In modern society, women take on multiple independent roles of their social level. Here we are talking about people with a lower social level, and more difficulties related to this condition. The condition of being employed or not, and whether the women receive support from partner (Table 1), for example may be related to our results. It was not the object of this work relates these variables with QoL, but they deserve to be recognized. From the psychological point of view, worry and anxiety caused by lack of control over their bodies and their physical and cognitive limitations, that epilepsy appeared as a strong stressor.

The condition of being pregnant did not differ between groups, which do not mean it is not a stressor and a burden on individual mechanisms.

The significant difference was found between these two periods particularly in the areas of health, physical and emotional aspects. These findings corroborate the literature data, showing that pregnancy is a time of intense change and physical and emotional difficulties<sup>8,9,15,16</sup>. The pregnancy experience is affected by the variety of roles that women play in their life. The roles demands, and concerns about pregnancy, make a stressful event for someone, because beyond the tensions of the day by day, thoughts about the pregnancy course and childbirth itself, the concerns and expectations about the health of the baby can be considered stressors<sup>8,9,15,16</sup>.

The women experience subtle changes that can alter their ability to perform their habitual functions<sup>16,17</sup>.

This study addresses women who have a chronic illness, so the results found, in the postnatal period show that with the removal of the stressors related worries, such as, having a healthy baby, anxiety about the influence of drugs on fetal development, and the increased seizure frequency during pregnancy, stressors identified by Lunardi<sup>18</sup> we can observe an improvement in the evaluated aspects related to physical and emotional according to Luef<sup>19</sup>.

Lunardi<sup>18</sup> identified on pregnant women who worry about delivering a healthy child or a child with epilepsy were the most frequent stressors with self reported of symptoms of fear, anxiety, irritation, insomnia. An article by Kaneko<sup>7</sup> does not mention the assessment of quality of life, instead reporting that pregnant women who have epilepsy have legitimate worries regarding the effects of antiepileptic drugs on the fetus. Concerns about teratogenic effects indicate a reduced quality of life by Kaneko<sup>7</sup> and confirmed by Lunardi<sup>18</sup>. Costa<sup>20,21</sup> also noted anxiety and fear about medical issues related to pregnancy and epilepsy that impact pregnant women with epilepsy in our center.

This work deserves some methodological considerations. The first concerns the choice of instruments. It was used an inventory of QoL specific to epilepsy that could be used in two groups: experimental and control. The literature presents various instruments recently validated in Brazil (for example, SHE<sup>22</sup>, QOLIE-89<sup>23</sup>, QOLIE-AD-48<sup>24</sup>). The use of QQV-65 aimed mainly that the results allow us to practice interventions related to changes in health care and psychological changes in patients. The QQV-65<sup>2</sup> addresses all issues raised by the QOLIE-89<sup>23</sup> which in turn signals also points for intervention. This questionnaire, although comprehensive, its application is more time consuming. The QOLIE-31<sup>25</sup> is not as comprehensive as the goal of applied research is the immediate assistance. Patients were followed in the Service of Psychology at the end of the study.

However, we know that is important to consider that this study showed significant differences in health aspects, in physical and emotional dimensions in QQV-65 in pregnant women with epilepsy in the end of pregnancy.

The authors suggest further research with different paradigms and greater number of subjects or other instruments.

A number of articles in this area used the term "Quality of Life", but did not address it specifically. Our study objectively measured this variable and calls the attention of health professionals on this topic. Our study shows the first results with women with epilepsy in whom pregnancy could be interpreted as a stressor with impact in their quality of life.

Then, a therapeutic orientation focused on medical

and psychological aspects in that period can provide a decrease in anxiety/stress related to pregnancy as well as an increase in well-being.

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