

Quality of life of patients with epilepsy (Hungarian survey)

JUDIT LÁM[†], MARGIT RÓZSAVÖLGYI[‡], GYÖNGYVÉR SOÓS[§], ZOLTÁN VINCZE[†] & PÉTER RAJNA[¶]

[†]Semmelweis University, University Pharmacy, Institute of Pharmacy Administration, Hungary;

[‡]Central Military Hospital, Hungary; [§]University of Szeged, Department of Clinical Pharmacy, Hungary;

[¶]Semmelweis University, Faculty of General Medicine, Department of Psychiatry and Psychotherapy, Hungary

We assessed the quality of life (QOL) of patients with epilepsy using the Quality of Life in Epilepsy Inventory (QOLIE-31). As the first step we compared our results with the data from an American survey in order to validate the test in Hungary. The results show that the Hungarian values were lower but that they followed the same trends as the American data. There was only one controversial result in the question-group of the 'the effects of treatment', which could be explained by the differences in habits and conventions, opportunities and expectations between Hungarian and American epileptic patients. We found significant differences in many aspects of quality of life with respect to (a) gender (general quality of life, seizure worry), (b) pharmacological treatment form (cognitive functions, medication effects, total score and social and role functioning) and (c) economic activity of patients (cognitive functions, emotional well-being, energy/fatigue, medication effects, overall quality of life, overall scores, seizure worry, social and role functioning). We have tried to explain the differences found by taking either the characteristics of epilepsy or the social background of the epileptic patient into consideration. Based on previous knowledge we have tried to define the situations where the assessment of quality of life for people with epilepsy, may be beneficial to their core.

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Key words: QOLIE-31 inventory; quality of life in epilepsy; gender; economic activity; monotherapy/bitherapy.

INTRODUCTION

Epilepsy is one of the most common chronic neurological diseases, which in the majority of the cases affects patients throughout their life. Doctors usually measure the effects of the complex pharmaco–psycho-social therapy based on the frequency of the seizures and the side effects of the antiepileptic drugs. However, these parameters do not show the exact influence of the illness on the lifestyle and feelings of the patients. This real effect of a complex therapy can only be measured by holistic methods, by changes in the patients' feelings, the change of their mental and physical powers and of their social adaptation. All these complex changes can be mapped by the questionnaire of the quality of life adapted to epileptic disease^{1–11}. The results of these different examinations are not exactly concordant and the opinions of the investigators differ regarding the situations in which the use of the questionnaire of quality of life is recommended in clinical practice^{2, 11–16}.

The aim of this survey was to:

- Find a questionnaire which could be easily completed (QOLIE-31).
- Adapt it for use in our country.
- Validate it.
- Compare the results to those of the US population.
- Evaluate some hypotheses and discuss some interesting data obtained from the first Hungarian survey concerned with QOL in patients with epilepsy.
- Define situations where the application of the QOLIE 31 may be beneficial to the daily routine of patients.

MATERIALS AND METHODS

The study was performed in five Hungarian Epilepsy Centres (SOTE-Clinic of Psychiatry and Psychother-

Table 1: Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
Epilepsy	Diagnosis completed	Uncertain
Age	More than 16 years	Less than 16 years
Gender	Both	
Controls/visits	Regular	Irregular
Other illness	None in the last 6 months	Have had in the last 6 months
Complete the questionnaire	Without help	Only with help
Therapy	No change in last 6 months	Change in last 6 months
Written consent	Yes	No

apy, Central Military Hospital. Budapest; County Hospital, Miskolc; Town Hospital, Miskolc, Neurological Clinic of Medical University, Debrecen) and involved the survey of 185 patients. The QOLIE-31 questionnaire was used. The questionnaire was translated by two colleagues caring for epileptic patients. They compared and interpreted the translation and also asked for the opinion of a third independent expert. Prior to the studies the epileptic population (15 patients) filled in the questionnaire under the control of the attending physician and the opportunity was given to discuss any problems that arose. The Hungarian patients understood the content of all of the questions, therefore no alterations were needed.

170 completed questionnaires were adequate for analysis. The attending physicians who regularly controlled the patients conveyed the clinical data of each patient to us. The inclusion and exclusion criteria were summarized according to the aspects shown in Table 1. The patients were divided into different groups on the basis of the type and severity of their illness. This classification was similar to that of the original survey performed in the USA¹⁷. The severity was defined by the seizure frequency in the year before the patients were included in the study. The patients were divided into four groups; seizure-free, low, moderate and high frequency of seizures (see Table 2). We had a special group of 18 patients, who were examined after their first epileptic seizure. They were included in the study on the basis of very strict criteria. Only those patients for whom the occurrence of the epileptic seizure could be proved, e.g. the lack of a witness would exclude the patient, could be enrolled. This explains the low number of the patients in this group and therefore statistical analysis was performed separately for this group.

The QOLIE-31 inventory for epileptic patients was used, but some questions were changed in order to survey the patients with new onset epilepsy (see Table 3).

During the analysis of the QOLIE-31 inventory, the values of the individual question-groups as well as the overall score were determined¹⁶. The determination of the factors on the questionnaire that influence the quality of life are carried out with the aid of scales. The patient gives the value—as the answer—which is

nearest to his/her feelings and state. All scale scores were transformed linearly into scales of 0–100, with higher values representing better functioning and well-being. Using this method it is possible to treat the distinct question-groups separately. The QOLIE-31 overall score can be derived by weighting and summing QOLIE-31 scale scores¹⁶.

The data analysis consisted of different aspects; gender, economic activity, therapy-type and severity. The statistical analysis was performed using the Kruskal–Wallis method and the results were qualified at the 95% probability level.

RESULTS

The averages for the Hungarian patients of all question-groups of the QOLIE-31 inventory were compared to the data of the same questionnaire used in the USA¹⁷. Generally, the total scores of the identical question-groups were lower for the Hungarian population than in the USA. The SD (standard deviation) did not show a significant difference between the two assessments, as shown in Table 4. The greatest difference between the two populations was found in the question-group ‘overall quality of life’, and ‘social and role functioning’ (USA: 67.17; H: 55.45; USA: 67.25, H: 56.88).

The averages of the question-group ‘cognitive functions’ were the same (USA: 59.96; H: 59.26). With respect to the results of the question-group ‘effects of medication’ the views of the Hungarian patients were more optimistic (USA: 55.34; H: 57.39). In the other question groups the greatest difference consisted of about 10 points (on average the Hungarian patient scores were 8.19 in the negative direction compared to the US scores). The scale of the differences between these question groups, when compared to the positive difference is important.

We found the same tendency when comparing the results of the QOLIE-31 according to seizure severity. (see Table 5). The results in Table 6 illustrate that the greatest difference was found between the seizure-free groups of Hungary and the USA.

Table 2: The severity of epilepsy according to seizure frequency of different types of seizures¹⁷.

	Seizure-free	Low	Moderate	High
Generalized tonic-clonic	0	1	2–4	<5
Simple- and complex partial	0	1–4	5–12	<13
Other forms	0	1–2	3–12	<13

Table 3: Modification to the wording of the original QOLIE-31 items for the new onset patient group.

No. of items	QOLIE-31	Modified
24	How worried are you that the medications you are taking will be bad for you if taken for a long time?	How worried are you that you will have to take a drug for a prolonged period of time in the future?
29	How bothered are you about the physical effects of antiepileptic medication?	How bothered are you about the recommended observation period and the necessity of control examinations to be performed during this period?
30	How bothered are you about the mental effect of antiepileptic medication?	How bothered are you about the recommended changes to your life style?

To control the reliability of the questionnaire we have chosen two very simple, but in clinical practice very important, conditions as null hypothesis, namely (a) patients on monotherapy, and (b) patients actively working, have a better quality of life. Analysing our data according to the applied therapy, we obtained the following results. The results in Table 7 illustrate that there was a significant difference between the group on monotherapy and the group on bitherapy with respect to 'cognitive function' ($P = 0.0212$), 'social activity' ($P = 0.0007$) and 'overall quality of life' ($P = 0.0073$). We did not find significant differences between the group on bitherapy and the group on polytherapy.

In the evaluation based on economic activity, shown in Table 8, it can be seen that the quality of life of patients on disability pension was worse than that of the actively working patients. (Cognitive functions: $P = 0.0010$; emotional well-being: $P = 0.00001$; energy/fatigue: $P = 0.0116$; medication effects: $P = 0.0070$; overall quality of life: $P = 0.0000$; seizure worry: $P = 0.0064$; social and role functioning: $P = 0.0001$).

The results of the evaluation according to gender are shown in Table 9. The perceptions of the women were usually more pessimistic than those of the men in most question-groups, with the exceptions of cognitive functions and social functioning. Significant dif-

ference was found between the genders regarding the averages of 'overall quality of life' ($P = 0.0101$) and 'seizure worry' ($P = 0.0021$).

The population participating in this survey had a very special group, namely the 18 patients who were examined after their first epileptic seizure. They completed the questionnaires after they had been informed about the possible limitations they could expect after the first fit. (These being seizure recurrence and the development of epileptic disease and the transitory restrictions necessary in the year following the seizure, e.g. prohibition of vehicle driving and of the performance of dangerous work.)

We compared the results of the questionnaires of this group with those of the seizure-free patients subjected to continuous antiepileptic treatment. The averages of the question-groups were usually higher in the group of patients after the first seizure, with the exception of 'overall quality of life' and 'social functioning'. As shown in Table 10, significant differences were found in three question-groups; 'cognitive functions' ($P = 0.0130$), 'energy/fatigue' ($P = 0.017$), and 'social functioning', with the greatest difference appearing in the latter. Patients after the first seizure viewed their social activity more negatively than the seizure-free patients ($P = 0.000$).

DISCUSSION

We have carried out a survey aimed at assessing the quality of life of patients in five epilepsy centres in Hungary, using the QOLIE-31 inventory. As the first step we compared our results with data from a survey in the USA (Devinsky *et al.* 1995), in order to validate the questionnaire in our country. Our results have shown that for the QOLIE-31 inventory overall scores in Hungary are generally lower, but that they change in parallel with the American data. The tested population in Hungary perceived their quality of life as worse in all question-groups compared to the population coping with similar disease in the USA. We explain the lower overall score (the negative judgement) by the difference in economic and social status and by the difference in both the social judgement and ability to cope with the disease. The greatest difference was found in two question-groups, namely in the overall

Table 4: Summarized data of the questionnaire collected in the USA and in Hungary according to the groups of questions. QOLIE-31 (USA): $n = 304$; QOLIE-31 (H): $n = 170$; calculated with the Moiser formula.

	Number of questions	Average	
		QOLIE-31 USA (SD)	QOLIE-31 H (SD)
Seizure worry	5	58.29 (± 25.76)	53.95 (± 28.53)
Overall quality of life	2	67.17 (± 18.38)	55.45 (± 19.32)
Emotional well-being	5	67.2 (± 19.28)	58.28 (± 18.48)
Energy/fatigue	4	55.3 (± 21.10)	49.68 (± 17.68)
Medication effects	3	55.34 (± 30.52)	57.39 (± 31.13)
Social & role functioning	5	67.25 (± 26.88)	56.88 (± 23.60)

Table 5: Summarized data of the questionnaire collected in the USA and in Hungary.

	Seizure-free		Low		Moderate		High	
	H	USA	H	USA	H	USA	H	USA
$N(\%) =$	50 (29)	21 (6)	23 (13)	116 (38)	36 (21)	136 (44)	61 (35)	31 (10)
Overall quality of life	62.24	72.00	67.00	68.10	57.66	65.80	56.32	65.90
Seizure worry	53.78	74.90	62.12	61.40	52.22	53.10	52.97	57.40
Emotional well-being	59.92	73.40	61.40	68.50	60.13	64.90	57.54	68.10
Energy/fatigue	47.86	63.00	53.75	53.60	48.44	56.40	53.16	50.50
Cognitive functions	62.10	70.75	60.86	63.90	57.48	59.35	58.13	61.15
Effects of medication	59.58	56.80	60.42	59.80	59.03	52.70	55.41	49.10
Social functioning	65.74	77.70	62.95	73.10	52.63	62.00	52.67	58.20

quality of life and in social and role functioning, where the difference was greater than 10%. As the study used for comparison did not provide sufficient information we were unable to perform statistical analysis on the data. Thus, only the ratio of the differences could be calculated and used for numerical comparison. Comparing the values according to seizure severity, in the seizure-free group we found more than 10% difference in four question-groups, namely in 'seizure worry', 'emotional well-being', 'energy/fatigue' and in 'social functioning'. In the other groups a greater difference, exceeding 10%, was found in only one question group, the group of low seizure frequency, where the difference with respect to social functioning was 10, 15%. The results shown in Table 6 indicate that in our country the people with seizure free epilepsy suffer more from prejudices than seizure free patients in the USA.

Comparing the data of the Hungarian and American surveys we found an opposite trend, in terms of negative and positive scoring in only one question-group, namely in the judgement of the effects of treatment. The Hungarian patients perceived this more positively. Although when comparing the data we were unable to calculate statistical significance, we felt that this positive difference was worthy of an explanation. This result may be explained by the different mental health expectations, the difference in the expected efficacy of treatment, the confidence in doctors and by the different circumstances and different opportunities open to the two populations. We found a similar trend when comparing the QOLIE-31 survey results of patients

experiencing different seizure severity, but the values were lower than 10% in all cases.

The above-mentioned data may indicate that because of their disease the Hungarian patients, compared with the American study population, judge themselves to be at a greater disadvantage with respect to their social status. This is why they have greater confidence in the doctors and the treatment.

If we compare the two epileptic populations according to the severity of the seizures, we can see that the relative number of the patients in each group is different (see Table 5). In the Hungarian population there are more patients in the seizure-free group (H: 29%, USA: 6%) and in the high frequency seizure group (H: 35%, USA: 10%).

When considering these differences, the more negative perception of their quality of life by the Hungarian epileptic population can be more easily understood. When evaluating data according to gender, we found significant difference in the judgement of 'overall quality of life' and of 'seizure worry' between men and women. Other surveys reported similar results with adolescents suffering from epilepsy. The girls showed more anxiety, less happiness and more negative attitudes towards epilepsy¹⁸. Our results reflect the social judgement and the living conditions of women in Hungary, i.e. women are at a greater disadvantage at their place of employment compared to men. A Hungarian survey, carried out on the normal population, showed similar results¹⁹. The role of women in their work and their family life may be ac-

Table 6: Comparison of the American and Hungarian values of the question-groups from the seizure-free patients. The differences were greater in almost every question-group by more than 10%.

	Seizure-free		Difference (%)
	H (50)	USA (21)	
Seizure worry	53.78	74.90	21.12
Overall quality of life	62.24	72.00	9.76
Emotional well-being	59.92	73.40	13.48
Energy/fatigue	47.76	63.00	15.24
Cognitive functions	62.10	70.75	8.65
Medication effects	59.58	56.80	-2.78
Social and role functioning	65.74	77.70	11.96

Table 7: Comparison of values concerning mono- bi- and polytherapy.

Groups of questions	Monotherapy (SD)	Bithery (SD)	Polytherapy (SD)	Difference between mono- and bithery
<i>N</i> =	89	53	27	
Cognitive functions	62.53 (±19.33)	55.35 (±19.17)	55.56 (±24.19)	7.18 ^a
Emotional well-being	60.14 (±18.10)	55.15 (±17.65)	56.44 (±20.59)	4.99
Energy/fatigue	50.11 (±17.19)	50.29 (±19.59)	47.78 (±13.37)	-0.18
Medication effects	61.85 (±31.36)	49.63 (±28.65)	54.11 (±32.49)	12.22 ^a
Overall quality of life	62.07 (±21.91)	55.48 (±19.64)	52.96 (±24.86)	6.59
Overall score	60.21 (±16.53)	52.88 (±15.33)	53.26 (±19.96)	7.33 ^b
Seizure worry	56.73 (±29.56)	51.14 (±26.18)	47.33 (±29.88)	5.59
Social and role functioning	62.9 (±22.10)	48.98 (±22.78)	53.58 (±26.92)	13.92 ^b

^a $P < 0.05$ and ^b $P < 0.01$.

accompanied by great tension. Although women are not at all equal to men on the manpower market, they all want to work because they feel it is important that they too should earn money (this dates from the tradition of the previous era when it was proclaimed that those who had no working place should not eat). At the same time women working in a city, in trade or in industry, are at a disadvantage as employees. If they are suffering from an incurable disease finding employment is nearly impossible. Those who work in households or in agriculture run counter to social prejudices. It is a further handicap that society and health authorities view this illness to be a special disadvantage in marriage and in the building of a family (the majority of people interviewed were at the reproductive age). So, they have had to cope with all those problems, which cause concern to healthy young people, and they also have to cope with their illness. This period of life is difficult for all women and it is especially difficult for women with epilepsy. The facts described above help us to explain the differences between the two genders found in our study.

To control the efficacy of the QOLIE-31 inventory, we used a null-hypothesis according to which epileptic patients on monotherapy have a better quality of life than those treated with more than one medication. The results of the study confirmed our hypothesis, since we found significant differences between the patients on mono- and on bithery in three question-groups (see

Table 7). A deviation was found in cognitive functions and indicated the adverse effects of the drugs, which appear to increase the more drugs are used. Medication effects were also significantly different between the two groups. This indicates that in these cases the epilepsy of patients was well controlled by monotherapy.

These two facts explain the more positive perception of the quality of life by the patients on monotherapy. Of course the patients well controlled by monotherapy, with less adverse effects, have better cognitive functions and are socially more active and this explains their more positive perception of their 'social and role functioning'²⁰. We also analysed and compared the bithery and polytherapy groups, but no significant differences were found between them^{21,22}.

Another null-hypothesis was used for analysis, according to which the patients conducting an active life can work and have a better quality of life than the disabled ones. Our results showed that after comparing the group of epileptic patients who were employed with those who were disabled, their perceptions of quality of life were very different. In all question-groups we found significant deviations (see Table 8)^{20,23}.

Unfortunately, in our country a problem-solving mechanism is functioning, according to which those epileptic patients who are able to work, do not have the opportunity to work and instead become pensioned

Table 8: Answers to the questions on economic activity.

Groups of questions	Active (SD)	Unemployed (SD)	Disabled (SD)	OAP (SD)	Difference active unemployed	Difference active disabled	Difference active OAP
<i>N</i> =	33	14	62	13			
Cognitive functions	64.71 (±17.42)	66.60 (±19.26)	51.54 (±20.70)	51.58 (±26.76)	-1.89	13.17 ^b	13.13
Emotional well-being	65.36 (±14.67)	64.00 (±15.13)	50.45 (±16.93)	50.15 (±28.12)	1.36	14.91 ^b	15.21
Energy/fatigue	52.55 (±15.67)	55.36 (±15.38)	44.03 (±17.90)	48.85 (±20.12)	-2.81	8.52 ^b	3.7
Medication effects	64.01 (±32.03)	61.70 (±33.45)	49.06 (±28.72)	54.70 (±33.79)	2.31	14.95 ^b	9.31
Overall quality of life	67.13 (±18.61)	65.36 (±20.98)	50.00 (±19.71)	51.15 (±30.70)	1.77	17.13 ^b	15.98
Overall score	62.96 (±12.83)	63.46 (±15.34)	48.46 (±16.24)	51.49 (±22.90)	-0.5	14.5 ^b	11.47
Seizure worry	59.22 (±26.30)	64.19 (±27.68)	44.66 (±29.50)	50.05 (±25.73)	-4.97	14.56 ^b	9.17
Social and role functioning	63.45 (±23.18)	62.36 (±26.18)	45.95 (±21.33)	54.15 (±22.60)	1.09	17.15 ^b	9.3

OAP: old age pensioner.

^b *P* < 0.01.

Table 9: Comparison of the values, calculated on the basis of the distribution according to gender.

	Male (SD)	Female (SD)	Difference
Group of questions	90	80	
Cognitive functions	59.21 (±21.01)	59.31 (±19.47)	-0.1
Emotional well-being	60.72 (±18.60)	55.60 (±18.08)	5.12
Energy/fatigue	50.54 (±17.82)	47.48 (±17.43)	3.92
Medication effects	60.93 (±28.94)	53.50 (±33.12)	7.43
Overall quality of life	63.31 (±20.74)	54.26 (±22.47)	9.05 ^a
Overall scores	58.72 (±17.77)	55.24 (±16.04)	3.48
Seizure worry	60.26 (±28.44)	47.03 (±27.16)	13.23 ^a
Social and role functioning	56.88 (±24.26)	58.04 (±23.94)	-1.16

^a *P* < 0.01.

Table 10: Comparison the values of the seizure-free and first seizure groups.

	Seizure-free (SD)	First seizure	Difference
<i>N</i> =	50	18	
Seizure worry	53.78 (±23.10)	57.33 (±23.37)	-3.50
Overall quality of life	62.24 (±21.19)	60.14 (±19.73)	+2.1
Emotional well-being	59.92 (±15.99)	66.44 (±17.52)	-6.52
Energy/fatigue	47.86 (±16.68)	59.17 (±17.17)	-11.31 ^a
Cognitive functions	62.10 (±19.58)	75.65 (±14.01)	-15.73 ^a
Medication effects	59.58 (±30.63)	62.96 (±19.73)	-3.38
Social and role functioning	65.74 (±22.47)	34.99 (±14.97)	+30.75 ^a

^a *P* < 0.01.

off, disabled, contrary to European practice²⁴. This incites us to work against this solution and fight for the possibility that active epileptic patients obtain employment and conduct an active life.

A special question is raised in our work: what does the first epileptic seizure mean for the patient? We would like to know how the patients perceive the impact of the seizure on their quality of life. Although the number of patients in the group was low, we feel the differences found are important. Comparing the averages of the test performed on the seizure free group with those obtained after the first seizure, we found a significant difference between the two groups in 'cognitive functions' and in 'social functioning'. Of course, after the first seizure the patients perception of their cognitive functions was better, because they

had not been on medication and therefore no side effects had manifested themselves^{21,22}. The values obtained in the question group of 'social functioning' were very low for patients after the first seizure. These results highlight the fact that the occurrence of the first epileptic seizure constitutes a considerable psychological problem for the patients. Uncertainty (the observation time), and the fear of reoccurrence of the seizure may cause deterioration of their quality of life. It appears that after the first epileptic seizure we have to apply a short psycho-educational or psychotherapeutic treatment in order to maintain the quality of life^{22,24}. In the initial phase of epilepsy and the case of isolated seizures the quality of life evaluation of patients also appears to be important in order to confirm the obtained data.

The survey of the patients' actual life-situation and of the medical and social outcome made it possible to assess the information obtained by the use of the QOLIE-31 inventory in the care of epileptic patients.

In the following we list those life-situations in which a short evaluation of quality of life may be important for planning the optimal therapy and provide useful information for the attending physicians:

- At the beginning of the disease (see data of the patients after the first seizure).
- During continuous therapy, when the patient is in steady state, the overall score of the questionnaire may provide information on the patient's capacity to cope with the disease.
- When changing the therapy, in order to measure the effect of the new therapy.
- In the special biological situations of life (puberty, pregnancy, menopause), to obtain information about their impact on our patients.
- We can measure the effects of positive or negative situations of life (finishing school, beginning an independent life, child birth, marriage, travelling, and conversely: unemployment, divorce, death in the family etc.).
- For the perception of the different problems of epilepsy we may be able to answer some questions: what we have to do, e.g. in case of therapy-resistance, seizure-caused lesion, before and after epilepsy surgery, etc.^{10,18}

On the basis of our preliminary investigation, the QOLIE-31 inventory and its modified version for testing patients with epilepsy and after the first epileptic seizure, may help us in achieving the mentioned goal.

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