

# Impact of Social Factors on the Quality of Life of Patients with Refractory Epilepsy

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## Abstract-

**Purpose:** To assess the impact of social factors on the quality of life of Bulgarian patients with refractory epilepsy.

**Case Report:** We have studied 70 patients with refractory epilepsy (RE) and 70 patients with pharmacosensitive epilepsy. All of them were between 18 and 65 years of age, without cognitive decline, progressive somatic or neurological disease or recent seizures. All participants were inquired about their education, employment, marital status, and driving. Only the patients with RE completed QOLIE-89.

**Results:** Twenty-five (35.71%) of the participants with RE were not married; 16 (22.86%) of them had an elementary education, 44 (62.86%) - a secondary education, and 10 (14.29%) - a university education. Nineteen (27.4%) participants were employed, 41 (58.57%) were recognized disabled, 10 (14.29%) were unemployed. Two (2.86%) of the patients with RE were drivers. We found out that the marital status did not change the quality of life. The university education correlated with a higher assessment of the "overall health" subscale (50%). The limited or lacking employment had a negative impact on the assessment of the following subscales: "pain", "health discouragement", "sexual relations", "emotional well-being", "memory", "work/driving/social function", "overall health", "overall quality of life" and the overall score of QOLIE-89. The possibility of driving correlated with more worries about adverse events from antiepileptic drugs.

**Conclusion:** The limited or lacking employment has a negative impact on most aspects of the quality of life, while education and driving influence single aspects of the quality of life.

**Key Words:** quality of life, refractory epilepsy, education, employment, driving

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## INTRODUCTION

As early as in 1961 G. Burden announced that no other disease is associated with so many social problems as epilepsy. The negative impact of this disease on all

social aspects (work, driving, interpersonal relations, education) results in low financial status, limited mobility, isolation, disturbed social inclusion and discrimination<sup>(1)</sup>. It is rarely that patients with epilepsy marry and have children<sup>(2-4)</sup>. Children with epilepsy have learning

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problems even in cases without intellectual impairment. The unemployment is more frequent in people with refractory epilepsy (RE) compared to the general epileptic population. It varies from 35% in Sweden to 68% in Spain according to different literature sources<sup>(2,5,6)</sup>. The results from a study of Meza et al. (2002) have proved that driving is very important for 30% of the patients with epilepsy, important for 60%, and not important for only 10% of them<sup>(7)</sup>. The limitation or the suspension of the driving permit is associated with greater safety on one hand, but with mental and social disturbances on the other hand. According to the European legislation seizures during driving are still perceived as extremely dangerous.

Epilepsy has a great influence on the three levels of quality of life (physical, mental and social health), which is exercised directly - by affecting the physical and mental health, and indirectly - by introducing limitations and decreasing the opportunities for taking part in quality of life improving activities. The social functioning has a significant role in obtaining a good quality of life (QOL)<sup>(8-11)</sup>. Sachin et al. (2008) have determined the education as an important factor for behavioral coping strategies which explains its impact on the QOL<sup>(12)</sup>. A number of investigators have confirmed the significance of job finding for the overall assessment of the QOL<sup>(8,13,14)</sup>. People with epilepsy have frequently declared their dissatisfaction with the family and social life and the lack of social support<sup>(8)</sup>. Driving is also an important predictor of some aspects of the QOL like social functioning and seizure worry<sup>(15)</sup>.

Purpose of the study: To assess the impact of some social factors (education, employment, marital status, driving) on the quality of life of Bulgarian patients with refractory epilepsy.

## METHODS

The study was performed with the participation of 176 consecutive patients with RE and 70 consecutive patients with pharmacosensitive epilepsy (PSE) who attended the Clinic of Neurology at the University Hospital in Plovdiv, Bulgaria for a regular examination,

for cases of unsatisfactory seizure control or for adverse events from treatment.

All study procedures were performed after the approval of the Local Ethics Commission at the University of Medicine, Plovdiv. Every patient was introduced to the study design and signed an informed consent form before participating in the study procedures.

The following inclusion criteria were used: a signed informed consent form; age between 18 and 65 years; a diagnosis of RE or PSE; lack of cognitive impairment based on Evaluation Rapide des Fonctions Cognitives (ERFC; Gil and Toullat, 1986)<sup>(16)</sup> with a score < 47 in patients up to 60 years of age and primary education or < 46 in patients between 60 and 65 years of age and less than a primary education or illiterate; lack of progressive somatic or neurological disease; lack of a simple or complex partial seizure in the last 4 hours; and lack of generalized tonic-clonic seizure in the last 24 hours. Epilepsy was accepted as refractory in cases in which adequate seizure control (at least 50% reduction of seizure frequency) had not been achieved with at least two potentially effective antiepileptic drugs prescribed as mono- or poly-therapy at maximally tolerated doses (based on the Bulgarian consensus for the diagnosis and treatment of epilepsies 2003)<sup>(17)</sup>. After excluding 39 patients with pseudo-refractory epilepsy (in cases with diagnostic, therapeutic errors or poor compliance), 2 patients older than 65 years, 2 patients with progressive neurological disease, 5 patients with a simple or complex partial seizure in the last 4 hours or a generalized tonic-clonic seizure in the last 24 hours, and 58 patients with cognitive impairment, 70 patients with RE and 70 patients with PSE were included in the study. Both groups were similar with respect to age and gender. The response rate for the study was 56.91%.

The data were collected by a trained health professional through an interview on the patients' education, employment, marital status and driving, and examination of the patients' medical documentation. The participants with RE completed QOLIE-89.

QOLIE-89 is the most understandable and the most widely used instrument for QOL assessment in patients

with epilepsy. This scale enables the discrimination of minimally expressed but significant life quality changes in these patients. QOLIE-89 contains 89 items that are distributed in 17 subscales which tap the following health concepts: health perceptions, overall QOL, physical health, role limitations due to physical problems, role limitations due to emotional problems, pain, work/driving/social function, energy/fatigue, emotional well-being, attention/concentration, health discouragement, seizure worry, memory, language, medication effects, social support, social isolation, change in health over the preceding year, satisfaction with sexual relations. The 17 subscales characterize 4 basic factors directed towards epilepsy, physical, mental and social health. QOLIE-89 overall score is calculated in several stages. The so called “T-scores” for each of the 17 subscale final scores and for the overall score are often used. They represent linear transformations of the scores that produce a mean of 50 and a standard deviation of 10 for a cohort of 304 adults with epilepsy. Higher T-scores reflect a more favorable quality of life<sup>(18)</sup>.

In the course of the study, we made a validation of the Bulgarian translation of QOLIE-89 and proved its reliability, internal consistency (the mean of Cronbach’s was  $0.9 \pm 0.0$ ; the coefficient of Spearman-Brown was 0.9; the mean inter-item correlation was 0.3; we calculated a high coefficient of correlation between the subscales scores and the overall score in two completions of the questionnaire [ $r_{xy} = 0.8 - 1.0$ ]), and validity (strong correlations between the overall scores of QOLIE-89 and QOLIE-31 [ $r_{xy} = 0.9$ ] and between their corresponding subscales were found [ $r_{xy} = 0.9 - 1.0$ ])<sup>(19)</sup>.

The collected primary information was checked, encoded, and entered into a computer database for statistical analysis. Data were processed using STATA Version 10 (Stata Corp., College Station, TX, U.S.A.) and SPSS (Statistical Package for the Social Sciences), version 14.0 (SPSS Inc., Chicago, IL, U.S.A.). The results for quantitative variables were expressed as the mean  $\pm$  SE (standard error) and the results for qualitative variables were expressed as percentages. Age, gender, clinical and social findings of the patients with RE and PSE were compared by means of  $\chi^2$  - test. Pearson’s correla-

tion coefficient was used to analyze the correlation between the assessments of the subscales, as well as the overall score of QOLIE-89.

## RESULTS

Overall, 21 (30%) of the participants with RE were men; the remaining 49 (70%) were women. The mean patient age was  $41.72 \pm 1.08$  years. Most participants (76.6%) were between 30 and 60 years of age. The mean disease duration was  $25.07 \pm 1.32$  years. Of the patients with PSE, 34 (48.57%) were men and 36 (51.43%) were women; their mean age was  $36.70 \pm 1.49$  years. There was no significant difference between both groups regarding their gender ( $P > 0.05$ ,  $\chi^2 = 2.37$ ) and age ( $P > 0.05$ ,  $u = 0.64$ ). The clinical and social findings of the study participants are shown in Table 1. A significant difference was demonstrated between the patients with RE and PSE regarding the type of epilepsy ( $\chi^2 = 26.44$ ,  $P < 0.001$ ), seizures type ( $\chi^2 = 52.71$ ,  $P < 0.001$ ), education ( $\chi^2 = 11.09$ ,  $P < 0.01$ ), employment ( $\chi^2 = 49.76$ ,  $P < 0.001$ ), and driving ( $\chi^2 = 31.76$ ,  $P < 0.001$ ).

The mean overall score of QOLIE-89 given by the patients with RE was  $64.30 \pm 17.06$ . In our data analysis, the T-scores were used for a more explicit comparison with the mean scores of the epileptic population. The obtained scores were accepted as very low ( $\leq 35$ ), low (36 - 45), medium (46 - 55), and high ( $> 55$ ). As a T-score, the mean overall score of QOLIE-89 was lower than the mean of the epileptic population ( $x = 47.80$ ). Low mean scores were obtained for the subscales “health perceptions” ( $x = 39.43$ ), “sexual relations” ( $x = 42.50$ ), and “overall QOL” ( $x = 42.79$ ). The mean scores of all other subscales were close to the mean of the epileptic population.

The subscales of QOLIE-89 were distributed in the following 5 groups: subscales associated with physical health, subscales associated with mental health, subscales associated with social health, subscales associated with epilepsy, and subscales associated with a more general assessment, e.g. “overall health”, “overall QOL”. For the purpose of data analysis, the overall score of QOLIE-89 was also included in the last group.

**Table 1.** Clinical and social findings of the study participants

	RE		PSE		$\chi^2$	P	r <sub>xy</sub>
	N (P % ± SE)		N (P% ± SE)				
Type of epilepsy							
- partial	53 (75.71 ± 5.13)		24 (34.29 ± 5.67)		$\chi^2 = 26.44$	< 0.001	+0.41
- generalized	17 (24.29 ± 5.13)		46 (65.71 ± 5.67)				
Etiology of epilepsy							
- idiopathic	17 (24.29 ± 5.13)		30 (42.86 ± 5.91)		$\chi^2 = 5.41$	> 0.05	-
- symptomatic	28 (40.00 ± 5.86)		21 (30.00 ± 5.48)				
- cryptogenic	25 (35.71 ± 5.73)		19 (27.14 ± 5.31)				
Type of seizures							
- partial	17 (24.29 ± 5.13)		24 (34.29 ± 5.67)		$\chi^2 = 52.71$	< 0.001	+0.42
- generalized	16 (22.86 ± 5.03)		46 (65.71 ± 5.67)				
- polymorphic	37 (52.85 ± 5.97)		-				
Education							
- elementary	16 (22.85 ± 5.02)		3 (4.29 ± -)		$\chi^2 = 11.09$	< 0.01	+0.25
- secondary	44 (62.86 ± 5.76)		50 (71.43 ± 5.40)				
- university	10 (14.29 ± 4.18)		17 (24.28 ± 5.13)				
Employment							
- unemployed	10 (14.29 ± 4.18)		9 (12.86 ± 4.00)		$\chi^2 = 49.76$	< 0.001	-0.41
- employed	19 (27.14 ± 5.31)		57 (81.43 ± 4.65)				
- not working, with recognized disability	41 (58.57 ± 5.89)		4 (5.71 ± -)				
Marital status							
- not married	25 (35.71 ± 5.73)		22 (31.43 ± 5.55)		$\chi^2 = 1.45$	> 0.05	-
- married	38 (54.29 ± 5.95)		44 (62.86 ± 5.76)				
- divorced	7 (10.00 ± 3.59)		4 (5.71 ± -)				
Driving							
- no	68 (97.14 ± 1.99)		40 (57.14 ± 5.91)		$\chi^2 = 31.76$	< 0.001	+0.48
- yes	2 (2.86 ± -)		30 (42.86 ± 5.91)				

No significant difference between the scores given by the patients with a different marital status was found for all subscales and the overall score of QOLIE-89  $P > 0.05$ .

The impact of employment on the different aspects of QOL is shown in Fig. 1.

Regarding the physical health, employment has an impact on the assessment of the subscales “pain”  $P < 0.01$  ( $\chi^2 = 8.34$ );  $P < 0.05$  ( $r_{xy} = -0.23$ ), “health discouragement”  $P < 0.01$  ( $\chi^2 = 8.97$ );  $r_{xy} = -0.30$ , “sexual relations”  $P < 0.01$  ( $\chi^2 = 8.40$ ). 24.1% of the patients with recognized disability due to epilepsy gave very low

scores for the subscale “pain” as opposed to the employed patients (6.9%). The percentage of the disabled participants with high scores was lower (29.6%) compared to that of the employed patients (55.2%). With regards to the subscale “health discouragement”, only 6.1% of the employed patients gave very low scores for this subscale. 29.8% of the disabled patients were pessimistic about their future physical activities and gave very low scores. Only 12.3% of the disabled participants and much more (36.4%) of the employed patients gave high scores for this subscale. Employment is associated with higher assessments of the subscale “sexual rela-

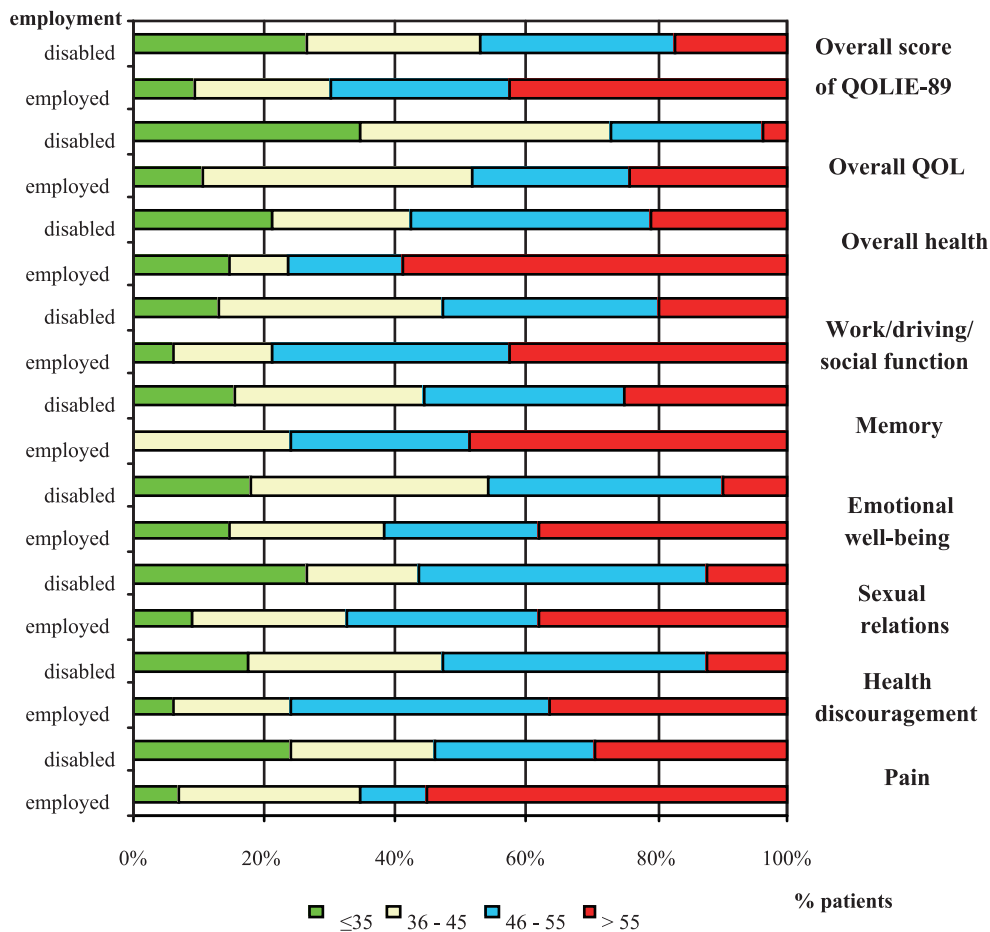


Figure 1. Impact of the employment on the QOL of patients with RE

tions”. This finding could be explained with a higher overall self-esteem, better social contacts, and physical abilities in cases with professional occupation.

Regarding the mental health, employment has an impact on the subscales “emotional well-being”  $P < 0.05$  ( $\chi^2 = 9.70$ ) and “memory”  $P < 0.05$  ( $\chi^2 = 8.58$ ). 38.2% of the employed patients gave very low and low scores for the subscale “emotional well-being”. The percentage of those with high scores for the same subscale was similar. 54% of the disabled participants gave very low and low scores for this subscale, only in 10% of them the assessments were high. Employment is associated with higher assessments of the “memory” subscale. No one of the employed participants gave very low scores for this subscale, 24.2% gave low scores. Almost half of these

patients gave high scores for this subscale. 44.2% of the disabled patients gave very low and low scores for the “memory” subscale, much less (25%) perceived their memory abilities as intact.

Regarding the social health, the employment has an impact on the assessments of the subscale “work/driving/social function”  $P < 0.05$  ( $\chi^2 = 7.47$ ). 42.4% of the employed patients and much less (20%) of the patients with recognized disability gave high scores for this subscale. Only 6.1% and 15.2% of the employed participants gave very low and low scores as opposed to 12.7% and 34.5% of the disabled patients respectively. The scores of 36.4% of the employed patients and 32.7% of the disabled ones were medium  $P < 0.01$  ( $r_{xy} = -0.29$ ).

An impact of employment on the subscales “overall

health"  $P < 0.01$  ( $\chi^2 = 14.90$ ), "overall QOL"  $P < 0.01$  ( $\chi^2 = 13.25$ ), and the overall score of QOLIE-89 was also found. The lowest percentage of patients with very low and low scores for the subscale "overall health" was that of the employed ones (23%); 25% of the unemployed and 42.2% of the disabled participants gave scores under 45. Only 21.1% of the disabled patients gave high scores as opposed to the employed participants (57.7%) and the unemployed ones (62.5%)  $P < 0.01$  ( $r_{xy} = -0.21$ ). Regarding the subscale "overall QOL", the lowest percentage of patients with very low and low scores was that of the employed ones (50%); 57.1% of the unemployed and 72.7% of the disabled participants gave scores under 45. Only 3.6% of the patients with recognized disability gave high scores in contrast to the employed participants (22.7%) and the unemployed ones (28.6%)  $P < 0.01$  ( $r_{xy} = -0.29$ ).

Regarding the overall score of QOLIE-89, the lowest percentage of patients with very low and low scores was that of the unemployed ones (25%); 32% of the employed and 52.8% of the disabled patients gave scores under 45. Only 17% of the disabled participants gave high scores as opposed to the employed participants (44%) and the unemployed ones (37.5%)  $P > 0.01$  ( $\chi^2 = 2.97$ ). The correlation was weak, and the reverse  $P < 0.01$  ( $r_{xy} = -0.26$ ). In conclusion the temporary or permanent unemployment has a negative influence on the overall health, the overall QOL, and the overall score of QOLIE-89.

A significant difference between the scores given by drivers and non-drivers for the subscale "medication effects" was demonstrated  $P < 0.05$  ( $\chi^2 = 9.18$ ). All three drivers gave low scores. A possible explanation of these results is the presence of worries about the side effects from antiepileptic drugs. Of the non-drivers, 28.6% gave very low and low scores, 27.4% - medium scores, 44% - gave high scores for this subscale  $P < 0.01$  ( $r_{xy} = -0.21$ ). No significant difference between the scores given by drivers and non-drivers for all other subscales was found  $P > 0.05$ .

The level of education has an impact on the subscale "overall health"  $P < 0.01$  ( $\chi^2 = 13.50$ ). The greatest percentage (50.0%) of patients with high scores for this sub-

scale was of those having a university education. Of the participants having a secondary education, 33.33% gave very low and low scores, 31.82% of those having a primary education made similar assessments. Most patients having a primary education (50%) gave very low and low scores for this subscale. In conclusion the higher level of education is associated with higher assessments of the overall health. No significant difference between the scores given by the patients having a different level of education for all other subscales was found  $P > 0.05$ .

## DISCUSSION

The purpose of this study was to assess the impact of some social factors on the QOL of adult patients with RE. The obtained results have proven that the social limitations correlate with lower assessments of some aspects of the QOL. An exception is the marital status which according to our data doesn't have an influence on the QOL. We have found contradictory data about the impact of this social factor in literature. Todorova (2010) and Boylan et al. (2004) has also found that the marital status is not associated with the assessments of QOL<sup>(20,21)</sup>. Zhao et al. (2011) however, have demonstrated that the overall scores of QOLIE-89 given by married patients ( $57.1 \pm 15.3$ ) were lower than those of unmarried patients ( $70.9 \pm 15.7$ )  $P < 0.001$ <sup>(22)</sup>.

The study participants with RE have more frequently a primary education [16 (22.86%)] and have rarely graduated from university [10 (14.29%)] compared to the participants with PSE. In his study Gonzales del Castillo (2005) has found that 68% of the patients with RE have a primary education<sup>(21)</sup>. According to our study results the university education is associated with a higher assessment of the subscale "overall health" - 50% of the patients having a university education, 33.3% of those having a secondary education, and 31.8% of those having a primary education gave high assessments for this subscale. These results correspond to the proven by several studies correlation of a better QOL with a higher level of education<sup>(8,12,20,22,24-26)</sup>. Sachin et al. (2008) have explained this correlation with the more successful formation of coping strategies<sup>(12)</sup>. Djibuti et al. (2003) have

proven the predicting role of the lower level of education, the high seizure frequency, and the greater epilepsy duration for the low overall score of QOLIE-31 and the scores of the subscales “cognitive function”, “social function”, and “overall QOL”<sup>(9)</sup>.

RE restricts the opportunities for a professional realization of the participants in our study - 41 (58.57%) of those with RE are with recognized disability and do not work. Our data are close to the results from the study of Jacoby et al. (2005) according to which the unemployment is higher in people with RE (59%) compared to the general epileptic population (46%)<sup>(6)</sup>. The limited or lacking employment of the disabled patients correlates with worsened assessments of the following subscales: “pain”, “health discouragement”, “sexual relations”, “emotional well-being”, “memory”, “work/driving/social function”, “overall health”, “overall QOL”; and the overall score of QOLIE-89. The negative impact of unemployment on most aspects of the QOL has been confirmed by other studies as well<sup>(8,13,14,20,27)</sup>. Tracy et al. (2007) have determined the employment as one of the predictors for the assessment of the subscales of QOLIE-31 “cognitive function” and “medication effects”<sup>(15)</sup>.

The participants in our study having RE drive much more rarely [2 (2.86%)]. Driving is associated with more worries about the adverse events from drugs - all drivers and 28.6% of the non-drivers gave low assessment for the corresponding subscale. Elsharkawi et al. (2009) have proven a significant correlation of driving with all subscales of QOLIE-31 in patients who have gone through surgery for temporal epilepsy<sup>(24)</sup>. Tracy et al. (2007) have determined the favorable influence of the ability of driving on other aspects of QOL - social functioning and the overall QOL score<sup>(15)</sup>.

## LIMITATIONS

The first limitation of our study is that only patients with refractory epilepsy completed QOLIE-89. To adequately complete QOLIE-89, we excluded patients older than 65 years, as well as those having cognitive impairment, progressive neurological disease, and those with either simple or complex partial seizures in the last 4

hours or generalized tonic-clonic seizures in the last 24 hours. The participation of only those patients that had access to the University Clinic of Neurology, as they usually attended it either for a regular examination or in cases of unsatisfactory seizure control or adverse events from treatment is also a limitation. These limitations do not devalue the results from our study. Further investigations of patients having different demographic, clinical and social characteristics are needed.

In conclusion the demonstration of the social factors role in QOL in patients with epilepsy contributes to the attention that this problem has drawn in Bulgaria, as well as all over the world, and illustrates the necessity of a multidisciplinary approach in dealing with these patients. Being able to address these issues will give the medical community reasons for increasing the role of associations of people with epilepsy, media, improving the education of medical and non-medical staff regarding epilepsy, and petitioning the government to provide additional financial aid for research and to patients and their families.

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