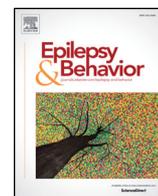




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## Health-related quality of life in adolescents with epilepsy in Montenegro

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## ABSTRACT

**Objective:** The objective of this study was to establish potential risk factors for poor health-related quality of life among adolescents with epilepsy in Montenegro.

**Material and methods:** A sample of 104 adolescents with epilepsy (age: 11–19 years) at a tertiary referral center in Podgorica, Montenegro, completed the validated Serbian version of the QOLIE-AD-48 questionnaire. They were divided into two groups: a group with active epilepsy (60 adolescents) and a group with inactive epilepsy (44 adolescents). Demographic and clinical data were collected.

**Results:** Adolescents with active epilepsy had low quality of life and felt the negative impact of the disease. They also had more cognitive impairments, felt more stigmatized, and had considerably more distorted perception of their health than adolescents with inactive epilepsy ( $p < 0.05$ ). Females reported better social support than males ( $p < 0.05$ ). Older males had lower grades at school ( $p < 0.05$ ) than the younger ones. As expected, adolescents with the highest number of seizures in the past two years had the lowest quality of life ( $p < 0.05$ ).

**Conclusion:** In our study, the quality of life in adolescents with epilepsy was determined by severity of the disease, age, and gender.

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## 1. Introduction

Epilepsy is a complex widespread neurobehavioral and social condition that carries heavy social stigma. In order to achieve a true success in treatment, clinicians need to understand how individuals perceive their disorder and, where possible, to address those factors [1]. The quality of life (QOL) in people with epilepsy is determined primarily by the duration of the disease and the extent of seizure control [2]. QOL in people with epilepsy may be impaired by seizures, side effects of medication, and psychosocial problems. There has been an increasing interest in comparing QOL among people with epilepsy in different cultures [3–6].

Assessing quality of life in pediatric epilepsy is especially important because both cognitive and social skills are developed in childhood. Psychiatric and psychosocial complications and comorbidities are more common in pediatric epilepsy than in other childhood chronic medical illnesses. Epilepsy also requires significant lifestyle adjustment

for both children and their families [7,8]. The severity of comorbid conditions, parental anxiety, seizure control, and number of medications are highly associated with the quality of life for these children [9]. Better definition of the factors causing this vulnerability may create opportunities to improve the long-term psychological health of a child through education, counseling, and support [10–12].

The number of adolescents living with epilepsy is increasing, and therefore, the interest in improving the QOL in this population has grown [13]. Therefore, the interest in measuring the quality of life in adolescents is also increasing [10–13]. The most frequently recommended instrument for measuring health-related quality of life in adolescents with epilepsy is the Quality of Life Epilepsy Inventory for Adolescents (QOLIE-AD-48) [14]. The results with the Serbian version supported the validity and reliability of QOLIE-AD-48 instrument in youths with epilepsy as well [15]. In a study examining potential risk factors for poor health-related QOL among adolescents, Devinsky and colleagues identified that age, increased seizures severity, and neurotoxicity were most consistently associated with poor health-related QOL across domains [16]. Recent study from Brazil using QOLIE-AD-48 indicated that adolescents with epilepsy may present good QOL scores when they themselves consider the disease as being under control [17].

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Based on this background, our objective was to establish potential risk factors for poor health-related quality of life among adolescents with epilepsy in Montenegro.

## 2. Material and methods

The study was carried out at tertiary referral clinics for pediatrics and neurology in Podgorica, Montenegro, among 104 adolescents with epilepsy aged 11 to 19 years.

The diagnosis of epilepsy was based on clinical symptoms, electroencephalography, and the findings of neuroradiological methods such as computerized tomography (CT) and/or magnetic resonance imaging (MRI/MRA) of the brain. The MRI/MRA was performed according to the epilepsy-specific protocol on a Siemens 1.5-T machine. Seizures were classified according to ILAE 1981 [18].

Inclusion criteria were patients with epilepsy aged 11 to 19 years who were taking antiepileptic drugs (AED) for at least 1 year. Subjects were excluded if they had mental retardation or had progressive neurological illness (brain tumor, neurofibromatosis type I, tuberous sclerosis, moyamoya disease).

The participants were divided into two groups: those with active (60 adolescents) and those with inactive epilepsy (44 adolescents). Active epilepsy was defined as the occurrence of epileptic seizures in the previous 2 years despite chronic and adequate AED therapy. The group with inactive epilepsy included adolescents without seizures in the previous 2 years who were taking AEDs [19]. Written informed consent was obtained from potential participants and their parents or guardians prior to inclusion the study.

The study used a standard instrument for measuring quality of life of adolescents with epilepsy, QOLIE-AD-48, with the permission of the QOLIE Development Group [14]. The questionnaire contains 48 items divided into 8 subscales: Impact of Epilepsy (12 items), Memory/Concentration (10 items), Attitudes toward Epilepsy (4 items), Physical Functioning (5 items), Stigma (6 items), Social Support (4 items), School Behavior (4 items), and Health Perception (3 items), as well as 3 optional questions. The questionnaire was translated into Serbian [15] and was approved by the QOLIE Development Group [14]. Participants from both groups completed this questionnaire and also a questionnaire for obtaining basic information about age and gender, and questions about epilepsy: the duration in years, type of seizures, frequency of seizures, and type of drug therapy. This study have been approved by Local Ethics committee before data collection.

## 3. Statistical data analysis

Calculation of the total QOLIE-AD-48 scores and of each subscale was performed manually according to the QOLIE-AD-48 scoring instructions [14,15]. For statistical analysis, scale scores were created by averaging items within scales and transforming average raw scores linearly to possible values of 0–100, with higher values indicating better QOL. Missing values were replaced by the mean of the remaining items in the relevant scale unless more than 50% of items in that scale were missing.

The sum and mean values of all subscales were calculated and then multiplied by particular coefficients: “The impact of epilepsy” by 0.31, “Memory/Concentration” by 0.17, “Physical functioning” by 0.09, “Stigma” by 0.13, “Supportive environment” by 0.02, “Behavior at school” by 0.06, “Attitude toward epilepsy” by 0.09, and “Understanding health” by 0.12. The values so obtained were designated as the score for that subscale. The sum of all of eight subscales represented the total score. The maximum possible score was 100, indicating the best QOL, in contrast to 0, the minimum possible score.

The data were analyzed with SPSS version 11.01 using the following methods: mean value, standard deviation, Student's *t*-test, Pearson correlation, and ANOVA. A two-sided *p*-value of <0.05 was considered significant.

**Table 1**  
Descriptive data of adolescents with epilepsy.

Gender	Male	54.8%
	Female	45.2%
Age	11–13 years	48%
	14–16 years	41%
	17–19 years	10.6%
Duration of the disease	<5 years	58.7%
	5–9 years	29%
	>10 years	12.5%
Type of seizures	Primary generalized	37%
	Partial seizures with secondary generalization	36%
	Partial seizures without secondary generalization	27%
Number of seizures in previous 2 years	No seizures	42%
	1–5 seizures	41%
	6–10 seizures	7%
	>10 seizures	10%

## 4. Results

### 4.1. Demographic and clinical characteristics of the patients

The study included 104 participants, 57 male (54.8%) and 47 female (45.2%) aged from 11 to 19 years. Demographic and epilepsy related data of adolescents with epilepsy are shown in Table 1.

The majority of participants (78.8%) were treated with only one AED, while two drugs were used in 22 (21.2%) individuals.

In addition to the neurological status, the brain CT scan and/or MRI/MRA was performed in all participants. The following was observed in 19 participants (18.3%): cerebral ischemia in four patients; status post cerebral hemorrhage, cortical dysplasia type II, and post-traumatic brain injury in two patients each; brain damage after CNS infections in three patients; and perinatal brain damage in six patients.

### 4.2. Scores of QOLIE-AD-48 and its subscales in adolescents with epilepsy

Mean QOLIE AD-48 total score was  $77.94 \pm 10.16$ . Scores ranged from 40.52 to 93.15, with higher value representing better quality of life (Table 2).

### 4.3. Impact of gender

Table 3 shows values of QOLIE-AD-48 and its subscales' mean scores in total study sample in relation to gender.

The only significant difference between male and female adolescents was found for the subscale “Social Support”, in which female adolescents had better score ( $1.51 \pm 0.32$  SD) and better family and community support compared to male adolescents ( $1.32 \pm 0.36$  SD).

**Table 2**  
Values of QOLIE-AD-48 scores and its subscales in the study group.

N = 104				
	MIN	MAX	X	SD
QOLIE-AD-48	40.52	93.15	77.94	10.16
Epilepsy impact	7.11	31	27.13	4.87
Memory/Concentration	5.95	17	13.21	2.74
Physical functioning	4.05	9	8.21	1.05
Stigma	3.61	13	9.96	2.15
Social support	0.38	2	1.41	0.35
School behavior	3	6	5.56	0.62
Attitudes toward epilepsy	0	5.63	2.68	1.58
Health perceptions	5	12	9.73	1.79

N: number of subjects; SD: standard deviation; MIN: minimum; MAX: maximum; X: mean.

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