Evaluation of Quality of Life and Psychiatric Aspects of Children with Epilepsy and Their Families Using Self-assessment Questionnaires

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What is already known on this topic?

- Epilepsy can reduce the quality of life (QoL) by disrupting the psychiatric health of patients and families.
- Children with new-onset epilepsy accompanied by comorbid conditions have a risk of decreased QoL.
- It is important to evaluate children with epilepsy and their families in terms of psychosocial problems in order to provide early intervention.

What this study adds on this topic?

- It was observed that as the KINDL epilepsy QoL dimension scores increase, the scores of all sub-dimensions of the parent KINDL QoL scale increase.
- As the KINDL epilepsy scale treatment satisfaction dimension scores increase, the physical health and emotional health dimensions of the parental SF-36 QoL scale increase.
- In the epilepsy group, the average KINDL parental self-esteem and chronic disease scores were statistically lower in those with comorbidities than those without comorbidities.
- This study suggests that adding self-measuring questionnaires to the extent that the child's mental state permits may be useful in learning the details of the problem.

ABSTRACT

Objective: The aim of this study was to compare sociodemographic characteristics, quality of life, and levels of depression and anxiety of children with epilepsy and their families with a healthy control group.

Materials and Methods: In this study, 60 epileptic children and their families were included. The data of these patients were compared with 51 healthy children and their families. The Children's Depression Inventory, Beck Depression and Anxiety Scale, State–Trait Anxiety Inventory for Children, KINDL General quality of life scale, KINDL–epilepsy module, and short form-36 were used to determine the depression, anxiety, and quality of life levels of children and parents.

Results: Depression and anxiety scale scores of the epilepsy group were statistically higher than the control group ($P < .05$). In the epilepsy group, the emotional well-being dimension on the KINDL parent scale and the total health, emotional well-being, family, and friends dimensions on the KINDL child scale were statistically lower than the healthy control group ($P < .05$). Short form-36 scores of the parents of the epilepsy group were statistically lower than the parents of the control group ($P < .05$). As the KINDL epilepsy quality of life dimension scores increased, the scores of the parental short form-36 quality of life scale scores increased. KINDL parental total scores were statistically lower in those with comorbidities than those without comorbidities.

Conclusion: Monitoring for psychiatric comorbidities and quality of life status for both the child and the parents is recommended. Also, it should be emphasized that it would be more beneficial to use self-answered scales when assessing the quality of life of epileptic children.

Keywords: Children, family, anxiety, depression, epilepsy, quality of life

INTRODUCTION

Epilepsy is one of the most common neurological diseases in children and can cause psychological problems in patients and their families. In children diagnosed with epilepsy, these accompanying psychological problems can adversely affect both the child's and the family's health-related quality of life (HRQL).[1–2] Although the underlying etiology of epilepsy and psychiatric diseases is similar, many psychosocial factors may exacerbate symptoms.[2,3] In addition, studies show that there is a relationship between a family's psychological problems and depression–anxiety in children. These findings underline the importance of reviewing family factors in treating children and adolescents with epilepsy.[4–7]

Quality of life is defined as the way individuals perceive their situation within their culture and value system. It has been demonstrated that epilepsy affects the HRQL of patients and those who take care of them.[8,9]

Many risk factors may affect the prevalence of anxiety and depression in those with epilepsy.[10] Anxiety disorders accompany epilepsy more frequently in adolescence compared to younger age groups.[11] Conflicting results have been reported between depression and gender.[12] Some studies have suggested that there may be a relationship between seizure frequency, polytherapy, antiepileptic drug type, and the duration of the disease.[11,13] Research conducted by Hobdell et al[14] found that the feeling of anger is higher in the families of children diagnosed with a concomitant disease with epilepsy than those without.

This case–control study aimed to compare sociodemographic characteristics as well as depression, anxiety, and QoL levels in children with epilepsy and their families with those of a healthy control group. One of the hypotheses of this study is epileptic children and their parents have more psychiatric disorders and lower QoL than normal children. Another hypothesis is that by using questionnaires that children answer themselves, more information can be gained about their QoL.

MATERIALS AND METHODS

Research Location
The research was conducted in Health Scıences Unıversıty, Dr. Behcet Uz Children's Hospital. Patients with a diagnosis of epilepsy who were followed up in the pediatric neurology outpatient clinic were included in the study. The patients and their families included in the study were referred to the child psychiatry outpatient clinic.

Data Collection Method
The study included 60 children with epilepsy and their parents (epilepsy group) between the ages of 7 and17 and was followed up for at least 6 months in the pediatric neurology department. Data of these patients were compared with 51 healthy children with equivalent age and gender of normal intelligence and their families (control group). The control group consisted of patients from the outpatient polyclinic of healthy children. Informed consent was obtained from both the patient and control groups to administer depression, anxiety, and QoL scales.

Case Report Form
Information related to each patient's demographic data, electroencephalogram, brain magnetic resonance imaging (MRI), etiology of epilepsy, epilepsy onset age, epilepsy duration, drug discontinuation, and seizure recurrence was obtained from their medical records. The 2017 International League Against Epilepsy classification was used for the etiology of epilepsy classification.[15] In-house radiologists evaluated the brain MRI images, and neuroradiology consultations were scheduled for any suspicious ones.

Psychiatric Evaluation
Pediatric psychiatrists examined the psychiatric health of all patients. The Wechsler Intelligence Scale for Children-Revised intelligence test was applied to determine their intelligence level. Mental retardation was accepted as general cognitive abilities (IQ) < 70. Patients with mental retardation were excluded from the study. Questionnaire forms were administered to the families and children by the assistant investigators. The completed questionnaires were collected and evaluated by the same researcher.

Questionnaires
Depression levels of the included patients were evaluated using the Children's Depression Inventory and Beck depression scales. Anxiety levels were assessed with the State–Trait Anxiety Inventory for Children. The Beck depression scale and Beck anxiety scale (BAI) were used to determining the depression and anxiety levels of the parents. The children's QoL was measured with the KINDL general QoL scale and the KINDL-epilepsy module and that of the parents was determined with the "short-form 36."

State–Trait Anxiety Scale for Children
This scale developed by Spielberger[16] has 2 multiple-choice subscales with 20 questions each for state and trait anxiety. The validity and reliability of the scale for Turkey were confirmed by Özusta.[17] Each item is scored as 1, 2, or 3 according to the severity of the symptom. The lowest score that can be obtained on the scale is 20, and the highest total score is 60. State anxiety defines the anxiety felt by an individual at a certain time and under certain conditions and may vary according to external factors. Trait anxiety defines what an individual generally feels and reflects the general tendency of the individual to anxiety. Adaptation studies of the scale show its applicability in the 9–16 age group.

Children's Depression Scale
On this 27-item self-report scale developed by Kovacs et al.[18] each item gets 0, 1, or 2 points depending on the severity of the symptom. The maximum score is 54. The higher the score, the more severe the depression. This scale is acceptable for use in children aged 6-17. Turkish validity and reliability study of this scale was performed by Öy et al[19] and the cut-off point was determined as 19 points.

Beck Depression Inventory
The Beck depression inventory is a 21-item scale filled in by the participant that measures the physical, emotional, cognitive, and motivational symptoms seen in depression. Each item is scored with increasing severity from 0 to 3 and a total score of 17 and above indicates "depression requiring clinical attention."[20] Turkish validity and reliability were performed by Hisli et al.[21]

Beck Anxiety Scale
First developed by Beck et al.[22] the BAI is a self-assessment scale used to determine the frequency of anxiety symptoms experienced by individuals. Turkish validity and reliability were performed by Ulusoy et al.[23] It uses a Likert-type scale consisting of 21 items that are scored between 0 and 3. The score range is 0-63, and a high total score indicates the severity of the individual's anxiety.

Short-Form 36 (SF-36)
The short-form 36, developed by the Rand Corporation in 1992,[24] has a generic scale feature and provides wide-angle

measurement among the QoL scales. The aim when developing this scale was for it to be short, easy to apply, and have a wide range of uses. Initially, 149 items were set out. Then, in studies with more than 22 000 people, the 20-item form, SF-20, was prepared by factor analysis. However, to increase the psychometric properties and scope, the SF-36 was created with 36 items. Turkish validity and reliability studies were performed by Koçyiğit et al.[25] Evaluation is made with a Likert-type scale, except for some health items, and the status of the patients in the last 4 weeks is taken into account. Subscales evaluate health between 0 and 100, and the higher the score, the better the quality of life is interpreted, that is a score of 0 is equivalent to maximum disability and a score of 100 is equivalent to no disability.

Kid-KINDL General QoL Scale

The Kid-KINDL is a general-purpose (generic) QoL scale developed for children consisting of 24 items and 6 dimensions (physical well-being, emotional well-being, self-esteem, family, friends, and school). The original version of the scale is German, and there are versions adapted to different languages.[26] Counting the scores given to the items for each dimension, converting them to scale between 0-100, and summarizing the score is calculated. Scores are positively oriented. The higher the score, the better the perceived QoL. Turkish validity and reliability work was performed by Eser et al.[27] There are 3 versions edited on a declarative basis. Those are Kiddy-KINDL for children aged 4-6 (the version administered through interviewer); Kid-KINDL for 7-13 year olds; and Kiddo-KINDL for adolescents aged 14-17 years. There are 2 "parent forms" in which children can be evaluated indirectly by their families.

KINDL-Epilepsy Scale

Kid-KINDL Epilepsy is a 36-item QoL scale developed for children with epilepsy (7-13 years old). Ravens-Sieberer et al[26] first developed this scale, and Turkish validity and reliability were performed by Ergin et al.[28] The original KINDL-Epilepsy module comprises 2 dimensions: epilepsy (the first 31 items) and the treatment (items 32, 33, 34, 35, and 36) dimensions. Higher values reflect better QoL. The psychometric properties of the KINDL epilepsy module have not been studied before. The total score was calculated by adding the sub-scale scores transformed to a scale of 100 as per the instructions.

Sample Size

The G Power 3.19.2 program was used to calculate the sample size in this study. It was observed in the literature that sample sizes in epilepsy/control group comparison studies varied between at least 12 and at most 86 participants. The number of patients/control group: 1/1, 95% CI, 0.80 power level, and effect size of 0.52, and the minimum sample size was calculated as 60 for epilepsy, 60 for the control group, and 120 in total.

Statistical Analysis

The Statistical Package for the Social Sciences 18.0 program was used to analyze the data obtained in the study. Categorical variables were presented as percentage and frequency, numerical variables as mean, standard deviation, minimum and maximum values in the descriptive statistics. The comparison of categorical variables was done using the chi-square test. The conformity of the variables to the normal distribution was examined with the Kolmogorov–Smirnov test. The Student's

t-test was used in the analysis of variables with normal distribution, and the Mann–Whitney *U* test was used for variables that did not fit normally. Spearman or Pearson correlation analysis was used to determine the relationship between continuous variables. The significance level was accepted as $P < .05$.

RESULTS

A total of 111 children, 60 of whom had been previously diagnosed with epilepsy and 51 of whom were healthy, and their families were included in the study.

Gender

Approximately half of the patients (48%) were female. There was no statistically significant difference in gender between epilepsy and the control group ($\chi^2 = 0.300$, $P = .584$).

Age

The mean ages of the epilepsy and control groups were similar (n = 60/51; 130.63 ± 26.91 and 136.82 ± 25.93; $t = -1.228$, $P = .222$), (Table 1).

Epilepsy Data

The mean age at onset of epilepsy was 7 years of age, and the mean epilepsy follow-up time was 4.8 years with a median of 4 years. Most of the patients (83.3%) had idiopathic epilepsy and 91.5% of patients were receiving monotherapy. Drug therapy was discontinued in 49% of the patients. Seizure type was generalized in 54.2%, focal in 44.1%, and unknown in 1.7%. A comorbid condition (familial Mediterranean fever, cardiac, renal, and gastrointestinal system disorders) was present in 13 (11.7%) patients.

Sociodemographic Variables in Epileptic and Control Children

There was no statistically significant difference between the epilepsy and the control group in terms of the number of siblings and order of siblings ($\chi^2 = 7.0726$, $P = .124$ and $\chi^2 = 4.451$, $P = .209$, respectively). There was no statistical difference between the groups regarding the mother's age, education level, socio-cultural level, employment status, and physical/psychiatric illness ($P > .05$).

Parent and Child Forms of KINDL QoL Scales

In the epilepsy group, the KINDL emotional well-being dimension on the parent scale and the total health, emotional well-being, family, and friend dimensions on the KINDL children's scale were statistically lower than the control group (Table 2).

Child and Parental Anxiety and Depression Scales between Epilepsy and Control Groups

Children's Depression Inventory scores of epileptic children were statistically higher than healthy children, but this level

Table 1. Demographic and Clinical Variables of Epilepsy and Control Groups

	Epilepsy	Control	Total	P
Female (%)	29 (48.3)	22 (43.1)	51 (45.9)	.584*
Male (%)	31 (51.7)	29 (56.9)	60 (54.1)	
Mean age	130.63 ± 26.91	136.82 ± 25.93		.222**

*Chi-square test, **Student's *t*-test.

Table 2. Comparison of Parent and Child Forms of KINDL Quality of Life Scales Between Epilepsy and Control Groups

KINDL Parent	Epilepsy (n = 60) Mean ± SD/Median(IR)	Control (n = 51) Mean ± SD/Median(IR)	t*/z**	P
Total	71.33 ± 14.80	74.97 ± 11.73	−1.418*	.159
Physical well-being	70.83 ± 20.28	73.52 ± 21.01	−0.686*	.494
Emotional well-being	**72.91 ± 16.82**	**80.14 ± 14.39**	**−2.409***	**.018**
Self esteem	65.10 ± 18.74	70.58 ± 16.59	−1.619*	.108
Family	76.45 ± 18.46	75.85 ± 17.09	0.177*	.860
Friends	71.56 ± 18.92	74.87 ± 14.38	−1.024*	.298
School	71.14 ± 21.43	74.87 ±17.43	−0.994*	.322
KINDL kids	Epilepsy (n = 60) Mean ± SD/Median(IR)	Control (n = 51) Mean ± SD/Median(IR)	t*/z**	P
Total	**67.06 ± 13.51**	**74.04 ± 12.27**	**−2.826***	**.006**
Physical well-being	71.25 ± 19.53	75.61 ± 17.10	−1.241*	.217
Emotional well-being	**75 (31.25)**	**81.25 (56.25)**	**−3.325****	**.001**
Self esteem	55.10 ± 19.51	62.62 ± 20.89	−1.958*	.053
Family	**72.70 ± 20.19**	**79.65 ± 15.85**	**−1.990***	**.045**
Friends	**75 (31.25)**	**81.25 (18.75)**	**−2.144****	**.032**
School	62.18 ± 17.58	64.70 ± 22.42	−0.663*	.509

SD, standard deviation; IR, interquartile range.
* Student's t-test data and Mann–Whitney U test data. As can be seen from the tables, mean ± SD was used for the t-test data, and median (IR) variables were used for the Mann–Whitney U test. Statistically significant data is marked in bold

was not within pathological limits. The trait anxiety and state anxiety scale scores of the epileptic children were statistically higher than the control group's scale scores. There was no statistically significant difference between the epilepsy and control groups' parents in the scales in which parental levels of depression and anxiety are evaluated (Table 3).

SF-36 Scores Between Patient and Control Groups
When the subscales of the scale in which parents evaluate their QoL are compared, the scores of physical health, emotional difficulties, psychiatric health, and general health subscales of the parents of the epilepsy group were statistically lower than the parents of the healthy controls (Table 4).

Statistical Comparison of Differences Between Study Groups
KINDL parent total scores were statistically lower in those with comorbidities than those without comorbidities. The average KINDL parental self-esteem score of patients with comorbid epilepsy was statistically lower than those without comorbidities (z = −.012, P = .044). In the epilepsy group, the average KINDL parent chronic disease score was statistically lower in

those with comorbidities than those without comorbidities (z=-2.044, P = .041). The mean scores of the SF-36 for physical role difficulty were statistically lower in those with comorbidities than those without comorbidities (z = −2.098, P = .036). The SF-36 viability score averages were statistically lower in those with comorbidities than those without comorbidities (z = −2.324, P = .020).

The mean state anxiety score of children with symptomatic epilepsy was statistically lower than those with idiopathic epilepsy (z = −2.385, P = .017). In the epilepsy group, the mean state anxiety score of children with MRI findings was statistically lower than those without MRI findings (z = −2.141, P = .032). In the group of parents with epileptic children with MRI findings, the Kid-KINDL Epilepsy physical health dimension averages were statistically lower than those without MRI findings (z = −2.018, P = .044).

KINDL parent emotional well-being scores of patients with idiopathic epilepsy were statistically lower than those with healthy control group (z = −2.409, P = .049). In the idiopathic epilepsy group total health, emotional well-being, family, and

Table 3. Comparison of Child and Parental Anxiety and Depression Scales Between Epilepsy and Control Groups

	Epilepsy (n = 60) Mean ± SD/Median (IR)	Control (n = 51) Mean ± SD/Median (IR)	t*/z**	P
Children				
CDI	8 (6)	5 (6)	−3.307**	**.001**
Trait anxiety	34.08 ± 8.39	30.03 ± 6.60	2.776*	**.006**
State anxiety	44.45 ± 6.34	29.37 ± 6.29	12.477*	**<.0001**
Parent				
Beck Depression Inventory	11.5(17.75)	9(11)	−1.864**	.062
Beck Anxiety Scale	6.5(14.75)	6(8)	−0.848**	.396

SD, standard deviation; IR, interquartile range; CDI, Child depression inventory.
*Student's t-test and **Mann–Whitney U test were used istatistically significant data is marked in boldStatistically significant data is marked in boldStatistically significant data is marked in bold

Table 4. Comparison of Parental Quality of Life Scores Between Epilepsy and Control Groups

Parent	Epilepsy (n = 60) Mean ± SD/Median (IR)	Control (n = 51) Mean ± SD/Median (IR)	t*/z**	P
Short–Form 36 physical	**78.23 ± 23.92**	**86.47 ± 15.37**	**−2.188***	**.031***
Physical difficulty	75 (50)	100 (25)	−1.867**	.062**
Pain	76.02 ± 22.76	77.30 ± 21.82	−0.302*	.763*
Viability	65.96 ± 20.13	65.68 ± 19.74	0.74*	.941*
Social function	75.875 ± 22.29	77.00 ± 21.82	−0.270*	.788*
Emotional difficulty	**66.7 (66.7)**	**100 (33.0)**	**−2.434****	**.015****
Mental	**65.13 ± 19.20**	**71.84 ± 14.62**	**−2.042***	**.044***
General health	**62.83 ± 22.10**	**70.88 ± 17.88**	**−2.084***	**.039***

SD, standard deviation; IR, interquartile range.
*Student's *t*-test and **Mann–Whitney *U* test were used. Statistically significant data is marked in bold

friend dimensions on the KINDL children's scale were statistically lower than the healthy controls (z = −2.693, P =.008; z = −3.638, P = .001; z = −2.048, P = .043; z = −2.641, P = .010, respectively).

KINDL children total, emotional well–being, friend scores of epileptic patients without comorbidities were statistically lower those healthy controls (z = −2.731, P = .008; z = −4.006, P = .001; z = −2.757, P = .007, respectively).

Correlation Studies
There was a positive moderate correlation between KINDL Epilepsy QoL dimension scores and the scores of all sub-dimensions of the parent KINDL QoL scale (r = +0.511, P < .0001). There was a positive moderate correlation between KINDL Epilepsy QoL dimension scores and Kid–KINDL QoL total score, physical health score, self–esteem score, and school score (r = +0.356, P = .005; r = +0.323, P = .012; r = +0.478, P = .0001; r = +0.317, P = .014, respectively). There was a negative moderate correlation between Child Depression Scale scores and KINDL Epilepsy QoL dimension scores (r = −0.525, P < .0001). There was a negative moderate correlation between KINDL Epilepsy QoL dimension scores and Child State Anxiety Scale scores (r = −0.456, P < .0001). There were negative moderate correlations between Beck Anxiety and Beck Depression Scale scores and KINDL Epilepsy QoL dimension scores (r = −0.310, P = .016; r = −0.425, P = .001). There was a positive moderate correlation between the physical role difficulty, social function, emotional, mental, and general health dimensions of the parental SF–36 QoL scale and KINDL Epilepsy QoL dimension scores (r = +0.293, P = .023; r = +0.277, P = .032; r = +0.388, P = .002; r = +0.325, P = .011; r = +0.324, P = .012, respectively). There was moderate positive correlation between the physical health and emotional health dimensions of the parental SF–36 QoL scale and KINDL Epilepsy scale treatment satisfaction dimension scores (r = +0.312, P = .015; r = +0.292, P = .023, respectively), (Table 5).

DISCUSSION

It is well known that epilepsy treatment is not limited to treating seizures. Psychiatric comorbidities are common in childhood epilepsies and affect epilepsy treatment and QoL.[1,2] The present study is a novel case–control study in which the psychiatric status and QoL of both children and their families are comprehensively examined. Children with epilepsy were both more depressed and more anxious than healthy children in

accordance with the literature. The physical health, emotional difficulties, psychiatric, and general health of the parents of the epilepsy group were lower than the control group's parents.

Previously, studies have been conducted comparing the QoL of patients with epilepsy and other chronic disease groups such as cardiac diseases or asthma.[29,30] However, it has become popular today to conduct studies by investigating psychiatric comorbidities and QoL in more homogeneous epilepsy groups.[31] To increase the power of this study, all patients who were determined to have the adequate mental capacity to answer the questionnaire were included; however, it is recommended that more advanced studies be performed in specific epilepsy groups.

A variety of tools are available in the form of parent reports and personal reports based on children's HRQL.[32,33] Previous studies have found low to moderate consistency between self and surrogate reports, but few studies have explicitly compared psychometric attributes.[34] In the present study, when the parent and child forms of the KINDL QoL scales were compared between epilepsy and control groups, parents of epileptic children believed that only their children's emotional QoL was lower than the healthy group. Children with epilepsy believed that their overall QoL was lower than healthy ones in the emotional, family, and friends QoL domains. This study suggests that adding self–measuring questionnaires to the extent that the child's mental state permits may be useful in learning the details of the problem.

Many studies have found that the statements of children and families about psychiatric health and well–being are compatible.[35] In the present study, families of healthy children reported higher psychiatric health and well–being than their children, while families of children with chronic diseases reported lower QoLs than their children. No consistent findings were found regarding other potential determinants of parent–child compatibilities, such as the child's age, gender, or socioeconomic variables.[36] Different levels of consistency have been determined in terms of different aspects of HRQL between the family's and the child's reports.[37] These results show that families' evaluations should be interpreted carefully as a potential substitute for self–report evaluations. It has been suggested that proxy reports should be regarded as providing complementary information about young people's mental health and

Table 5. The Relationship of the KINDL Epilepsy Scale with the Quality of Life of Parents and Children and Anxiety and Depression Levels in the Patient Group

	KINDL Epilepsy Quality of Life (n = 60)	KINDL Epilepsy Treatment Satisfaction (n = 60)
Parent KINDL total	r = +0.511 P <.0001*	
Parent KINDL physical	r = +0.498 P <.0001*	
Parent KINDL emotional	r = +0.279 P =.031*	
Parent KINDL self–esteem	r = +0.397 P =.002*	
Parent KINDL family	r = +0.475 P <.0001*	
Parent KINDL friend	r = +0.396 P =.002*	
Parent KINDL school	r = +0.381 P =.003*	
Parent KINDL chronic disease	r = +0.426 P =.001*	
Children KINDL total	r = +0.356 P =.005*	
Children KINDL physical	r = +0.323 P =.012*	
Children KINDL emotional		
Children KINDL self–esteem	r = 0.478 P <.0001*	
Children KINDL family		
Children KINDL family		
Children KINDL school	r = +0.317 P =.014*	
Children KINDL chronic disease		
Child Depression Inventory	r = −0.525 P <.0001*	
State anxiety	r = −0.456 P <.0001*	
Trait anxiety		
Beck anxiety	r = −0.310 P =.016*	
Beck depression	r = −0.425 P =.001*	
Sf36 physical		r = +0.312 P =.015*
Sf36 physical difficulties	r = +0.293 P =.023*	
Sf36 pain		
Sf36 vitality		
Sf36 social function	r = +0.277 P =.032*	
Sf36 emotional	r = +0.388 P =.002*	r = +0.292 P =.023*
Sf36 mental	r = +0.325 P =.011*	
Sf36 general health	r = +0.324 P =.012*	

*Pearson correlation test was used.
Only significant correlations are mentioned.

well–being. Different authors emphasized the importance of personal and family reports as complementary resources in providing information on children's QoL.[36,38] According to these authors, discrepancies between personal reports and reports from families may not indicate inaccuracy or bias. These differences should be considered as data reflecting the perspective of each participant.[39] It is thus believed that conducting both self and family anxiety, depression, and HRQL questionnaires will help reveal coexisting psychiatric problems in the follow–up of children with epilepsy.

Riechmann et al[8] found that QoL in children with symptomatic epilepsy and other comorbid diseases and their families was lower, similar to this study.

Enhart et al[34] found that the parental reports and the children's reports differed slightly according to how each group's perceptions, assessments, and possibly the emotional resonance of the child's own HRQL but were internally consistent. Family reports may help evaluate QoL in younger children because they have more internal consistency.

Puka et al[40] studied adolescents and young adults (AYA) and determined that AYA–family agreement on HRQL was moderate,

but significant differences were observed at the individual level. Adolescents and young adults –family agreement varied according to AYA and parent's age, seizure control, and family environment.

Healy et al[41] reported that adolescents with mental illness had lower HRQL, and clinicians should manage and treat both mental health and seizures with a holistic approach.

One of the limitations of the present study was that after questionnaires were administered and answered, a psychiatric interview was not conducted. If this process was added, it would be possible to diagnose psychiatric disorders and provide a specific treatment. Another factor limiting our study was the minimal sample size of the control group that was calculated as 60 healthy children and parents but the control group of this study includes 51 children and parents. Because we could only reach so many healthy children and their families during the study.

In conclusion, it was found that when the QoL scales based on the self–assessment of children with epilepsy are used, more detailed information is obtained about their QoL than the information provided by their families. As a take–home message, it

is recommended to use the self-reporting Kid–KINDL Epilepsy QoL scale in which the child answers themselves while evaluating the patient in outpatient clinics. The importance of considering the family when evaluating the child's psychiatric condition should also be emphasized. In addition, it was determined that children with epilepsy have more mental problems than healthy children, which reduces both their own and their family's QoL. In future studies, the HRQL questionnaires of epileptic children and their families in conjunction with psychological interviews would be beneficial in revealing coexisting psychiatric problems.

REFERENCES

1. Reilly C, Agnew R, Neville BG. Depression and anxiety in childhood epilepsy: a review. *Seizure*. 2011;20(8):589–597. [CrossRef]
2. Kanner AM. 2-Kanner AM. Is it time to train neurologist in the management of mood and anxiety disorders? *Epilepsy Behav*. 2014;34:139–143. [CrossRef]
3. Ott D, Caplan R, Guthrie D, et al. Measures of psychopathology in children with complex partial seizures and primary generalized epilepsy with absence. *J Am Acad Child Adolesc Psychiatry*. 2001;40(8):907–914. [CrossRef]
4. Puka K, Widjaja E, Smith ML. The influence of patient, caregiver, and family factors on symptoms of anxiety and depression in children and adolescents with intractable epilepsy. *Epilepsy Behav*. 2017;67:45–50. [CrossRef]
5. Han SH, Lee SA, Eom S, Kim HD. Family factors contributing to emotional and behavioral problems in Korean adolescents with epilepsy. *Epilepsy Behav*. 2016;56:66–72.
6. Austin JK, DW, Johnson CS, Perkins SM. Behavioral issues involving children and adolescents with epilepsy and the impact of their families: recent research data. *Epilepsy Behav*. 2004;5(suppl 3):S33–S41.
7. Arunkumar G, Wyllie E, Kotagal P, Ong HT, Gilliam F. Parent- and patient-validated content for pediatric epilepsy quality-of-life assessment. *Epilepsia*. 2000;41(11):1474–1484. [CrossRef]
8. Koç G, Bek S, Vurucu S, Gokcil Z, Odabası Z. Maternal and paternal quality of life in children with epilepsy: who is affected more? *Epilepsy Behav*. 2019;92:184–190.
9. Puka K, Ferro MA, Anderson KK, Speechley KN. Health-related quality of life in mothers of children with epilepsy: 10 years after diagnosis. *Qual Life Res*. 2018;27(4):969–977. [CrossRef]
10. Ekinci O, Titus JB, Rodopman AA, Berkem M, Trevathan E. Depression and anxiety in children and adolescents with epilepsy: prevalence, risk factors, and treatment. *Epilepsy Behav*. 2009;14(1):8–18. [CrossRef]
11. Oguz A, Kurul S, Dirik E. Relationship of epilepsy-related factors to anxiety and depression scores in epileptic children. *J Child Neurol*. 2002;17(1):37–40. [CrossRef]
12. Bilgiç A, Yilmaz S, Tiras S, Deda G, Kilic EZ. Depression and anxiety symptom severity in a group of children with epilepsy and related factors. *Turk Psikiyatr Derg*. 2006;17:165–172.
13. Bilgiç A, Yilmaz S, Tiraş S, Deda G, Kiliç EZ. Depression and anxiety symptom severity in a group of children with epilepsy and related factors. *Turk Psikiyatri Derg*. 2006;17(3):165–172.
14. Hobdell EF, Grant ML, Valencia I, et al. Chronic sorrow and coping in families of children with epilepsy. *J Neurosci Nurs*. 2007;39(2):76–82. [CrossRef]
15. Scheffer IE, Berkovic S, Capovilla G, et al.ILAE classification of the epilepsies: position paper of the ILAE Commission for classification and terminology. *Epilepsia*. 2017;58(4):512–521. [CrossRef]
16. Spielberger CD. *State-Trait Anxiety Inventory: a Comprehensive Bibliography*. Palo Alto, CA: Consulting Psychologists Press; 1989.
17. Özusta S. State-Trait Anxiety Inventory for Children: a study of realibility and validity. *Türk Psikhol Derg*. 1995;10:32–44.
18. Kovacs M. Rating scales to assess depression in school-age children. *Acta Paedopsychatr*. 1980;46:305–315.
19. Oy B. Çocuklar için depresyon ölçeği geçerlilik ve güvenilirlik çalışması. *Turk Psikiyatr Derg*. 1991;2:132–137.
20. Beck AT, Ward CH, Mendelson M, Mock JE, Erbaugh JK. An inventory for measuring depression. *Arch Gen Psychiatry*. 1961;4:561–571.
21. Hisli N. Beck Depresyon Envanterinin Geçerliği üzerine bir çalışma. *Türk Psikhol Derg*. 1988;22:118–126.
22. Epstein N, Brown G, Steer RA. 22-Beck AK. *An Inventory Meas Clin Anxiety Psychometric Prop J Consult Clin Psychol*. 1988;56:893–897.
23. Ulusoy N. *Beck Anksiyete Envanteri-geçerlik ve güvenirlik çalışması Bakırköy Ruh ve Sinir Hastalıkları Hastanesi*. İstanbul: Yayınlanmamış uzmanlık tezi; 1993.
24. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care*. 1992;30(6):473–483. [CrossRef]
25. Koçyiğit H, Aydemir Ö, Ölmez N, et al. Kısa Form-36 (KF- 36)'nın Türkçe Versiyonunun Güvenilirliği ve Geçerliliği. *İlaç ve Tedavi Dergisi*. 1999;12:102–106.
26. Ravens-Sieberer U, Bullinger M. Assessing health related quality of life in chronically ill children with the German KINDL: first psychometric and content analytical results. *Qual Life Res*. 1998;7(5):399–407. [CrossRef]
27. Eser E, Yüksel H, Baydur H, et al. Çocuklar İçin Genel Amaçlı Sağlıkla İlgili Yaşam Kalitesi Ölçeği (Kid-KINDL) Türkçe Sürümünün Psikometrik Özellikleri. *Turk J Psychiatry*. 2008;19:409–417.
28. Ergin D, Eser E, Polat M, Yazıcı P. *KINDL Epilepsi Modülünün Türkçe Sürümünün Epilepsili Türk Çocuklarında Psikometrik Özellikleri*. Poster Bildiri. Uluslarası Katılımlı 4. ulusal Pediatri Hemşireliği Kongresi, 22–25 Mayıs 2013, Adıyaman.
29. Wang J, Wang Y, Wang LB, Xu H, Zhang XL. A comparison of quality of life in adolescents with epilepsy or asthma using the Short-Form Health Survey (SF-36). *Epilepsy Res*. 2012;101(1-2):157–165. [CrossRef]. Epub 2012 Apr 16
30. Stavem K, Lossius MI, Kvien TK, Guldvog B. The health-related quality of life of patients with epilepsy compared with angina pectoris, rheumatoid arthritis, asthma and chronic obstructive pulmonary disease. *Qual Life Res*. 2000;9(7):865–871. [CrossRef]
31. Salas-Puig J, Sopelana D, Quintana M. Quality of life in adult patients with idiopathic generalised epilepsy. The EPILAK study. *Rev Neurol*. 2021;72(6):195–202. [CrossRef]

32. Riechmann J, Willems LM, Boor R, et al. Quality of life and correlating factors in children, adolescents with epilepsy, and their caregivers: a cross-sectional multicenter study from Germany. *Seizure*. 2019;69:92–98.

33. Hays RD, Vickrey BG, Hermann BP, et al. Agreement between self reports and proxy reports of quality of life in epilepsy patients. *Qual Life Res*. 1995;4(2):159–168. [CrossRef]

34. Erhart M, Ellert U, Kurth BM,Sieberer UR. Measuring adolescents' HRQoL via self-reports and parent proxy reports: an evaluation of the psychometric properties of both versions of the KINDL-R instrument. *Health Qual Life Outcomes*. 2009;7:77.

35. Sillanpää M, Besag F, Aldenkamp A, Caplan R, Dunn DW, Gobbi G. Psychiatric and behavioral disorders in children with epilepsy (ILAE task force report): epidemiology of psychiatric/behavioral disorder in children with epilepsy. *Epileptic Disord*. 2016;18 (Supple.1):S1.

36. Eiser C, Morse R. A review of measures of quality of life for children with chronic illness. *Arch Dis Child*. 2001;84(3):205–211. [CrossRef]

37. Robitail S, Simeoni MC, Ravens-Sieberer U, Bruil J, Auquier P. Children proxies' quality-of-life agreement depended on the country using the European KIDSCREEN-52 questionnaire. *J Clin Epidem*. 2007;60:e1-e469.

38. Eiser C, Morse R. Quality-of-life measures in chronic diseases of childhood. *Health Technol Assess*. 2001;5:55-63.

39. Lawford J, Volavka N, Eiser C. A generic measure of the quality of life for children aged 3-8 years: results of two preliminary studies. *Pediatr Rehabil*. 2001;4(4):197-207. [CrossRef]

40. Puka K, Ferro MA, Camfield CS, et al. Self-reported quality of life and degree of youth-parent agreement: a long-term follow-up of childhood-onset epilepsy. *Epilepsia*. 2020;61(10):2254-2264. [CrossRef]

41. Healy SA, Fantaneanu TA, Whiting S. The importance of mental health in improving quality of life in transition-aged patients with epilepsy. *Epilepsy Behav*. 2020;112:107324.