

# Anxiety, depression, sleep disorders and quality of life in parents of children with first unprovoked seizure and epilepsy

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## ABSTRACT

**Background.** Parents of a child with neurological problems such as seizures and epilepsy experience significant mental distress. Little is known about the mental state of parents in such a stressful situation. This study aims to determine the prevalence of self-reported depression, anxiety, sleep disorders, and quality of life in parents of children with epilepsy and first unprovoked seizure.

**Methods.** This cross-sectional study was conducted among the parents of children diagnosed with first unprovoked seizure and epilepsy admitted to the Pediatric Neurology Department, Outpatient Unit of İnönü University Medical Faculty Hospital. Participants filled out a questionnaire investigating demographic variables, Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), Pittsburgh Sleep Quality Index (PSQI), and 36-Item Short-Form Health Survey (SF-36).

**Results.** 113 parents participated in the study. Depression was found in 7%, anxiety in 14%, and sleep quality disorder in 33.3% of parents of children diagnosed with epilepsy on the basis of moderate or higher severity, while depression was found in 8.9%, anxiety in 14.3%, and sleep disorder in 21.4% of parents of children diagnosed with first unprovoked seizure. There was no statistically significant difference between the groups. Mothers were at higher risk for loss of physical function and social functionality. There was a positive correlation between BAI, BDI, and PSQI scores. Quality of life sub-dimension measured by SF-36 was associated with different levels of depression, anxiety, and sleep quality.

**Conclusion.** Addressing parental psychiatric problems by professionals involved in the treatment of children with a history of seizures may have the potential to provide further support for the family and the care of patients.

**Key words:** pediatric epilepsy, parental sleep disorder, depression, anxiety, quality of life.

Epilepsy is the most common neurological problem in childhood and is observed in approximately 0.5-1% of this group.<sup>1</sup> Epilepsy is defined as at least two unprovoked seizures occurring at least 24 hours apart. The first unprovoked seizure occurs in 23-64.1 / 100,000 of the healthy paediatric population without epilepsy risk factors and 30-40% of these children are diagnosed with epilepsy in following periods.<sup>2</sup>

The disease causes severe deterioration in the quality of life of the child and the family due to various psychiatric and cognitive disorders that are often difficult to recognize and cannot be treated.<sup>3</sup> Research has shown that immediately after a long or short seizure, whether febrile or non-febrile, parents are extremely frightened and suffer from anxiety and depression leading to significant impairment in familial, personal and social functions.<sup>3,4</sup>

In addition to these difficulties, many children with epilepsy have most seizures in their sleep and/or have sleep disorders.<sup>5</sup> The presence of sleep disturbance affects the quality of

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life of children with epilepsy as well as their parents.<sup>6</sup> Although population-based data on the prevalence of sleep difficulties in children with epilepsy and their parents are limited, it has been reported that the fear of missing the seizure is frequently experienced even after a febrile seizure, and therefore sleep disturbance is frequently observed in parents due to reasons such as sleeping with the child, increased night checks or sleep problems in the child.<sup>7,8</sup> Although sleep disturbance is an etiological cause in the formation of fatigue, decreased functionality and psychiatric diseases, studies evaluating the effect of parents of children with first unprovoked seizure and epilepsy on mental health and sleep quality are limited in our country.

Childhood epilepsy is not only a disease but also a social problem for children and their parents.<sup>9</sup> Traditional and superstitious approaches such as the disease is a blood or immune system disease, that it can be transmitted to others, and that it is a punishment for previous sins often expose children and families to serious stigmatization and discrimination.<sup>10</sup> Therefore, more attention should be paid to the mental state of the parents during the chronic disease management of the child.

The aim of the present study is to determine anxiety, depression, sleep and quality of life and related factors in parents of children with epilepsy who have been neglected and require further research; to review the psychological changes in families after the first unprovoked seizure and to call for appropriate psychological and social intervention for these parents. In addition, since there is no similar study comparing families of children with epilepsy and families of children with first unprovoked seizure, our study may provide new findings to the literature.

## Material and Methods

This cross-sectional study included parents of children aged 1 month to 17 years, with

normal neurological examination and neurodevelopment diagnosed with first unprovoked seizure and epilepsy, followed at the Pediatric Neurology Department, Outpatient Clinic of İnönü University Medical Faculty Hospital between 2021-2022.

Participation in the study was voluntary, and all participants gave informed consent to participate in the study. Parents who did not reside with the child and/or were not responsible for their treatment, were illiterate, and had neurological or psychiatric diseases that could cause cognitive loss were not included in the study.

The first unprovoked seizure was defined as a seizure without a history of trauma, fever, intoxication, or acute metabolic and electrolyte disturbances.<sup>2</sup> Epilepsy was defined as patients who had at least two unprovoked seizures with an interval of at least 24 hours and received antiepileptic therapy.<sup>11</sup> Parents of children who had first unprovoked seizure were evaluated at the end of the first month after the seizure.

The İnönü University Faculty of Medicine Non-Invasive Ethics Committee approved the study design (2020/1309).

**Sample Size:** To compare the families of children with first unprovoked seizure and families of children previously diagnosed with epilepsy in terms of anxiety/depression rates, sleep disorder, and quality of life with 95% confidence level ( $\alpha=0.05$ ) and 80% power ( $\beta=0.2$ ). If the impact power of the study was considered 0.33, the total number of participants included in the study should be at least 73.<sup>12</sup>

## Data collection tools

Participants filled out a questionnaire with demographic variables and the child's medical history, age, gender, education, prepared by the researchers. In addition, Beck Depression Inventory (BDI) was used to evaluate depression levels, Beck Anxiety Inventory (BAI) for anxiety levels, Pittsburgh Sleep Quality Index (PSQI) to evaluate sleep quality, and the 36-Item

Short-Form Health Survey (SF-36) was used to evaluate the quality of life.

**Becks Depression Inventory (BDI):** This scale evaluates the level and severity of depressive symptoms in adults and the risk of depression. Beck developed it in 1961, and its Turkish validity and reliability study was done by Hisli et al. in 1989.<sup>13,14</sup> The scale consists of 21 questions, with 10-16 points from the scale accepted as mild depression, 17-24 points as moderate, and 25 and above points as severe depression.<sup>15</sup>

**Beck Anxiety Inventory (BAI):** It is a self-report scale that evaluates the frequency of anxiety symptoms and consists of 21 questions.<sup>16</sup> The Turkish validity and reliability study was done by Ulusoy et al.<sup>17</sup> A total of 8-15 points from the scale are accepted as mild anxiety, 16-25 points as moderate anxiety, and 26-63 points as severe anxiety.<sup>18</sup>

**Pittsburgh Sleep Quality Index (PSQI):** The PSQI is a 24-item scale that provides information on sleep quality, the type, and severity of sleep disturbances in the past month.<sup>19</sup> The scale evaluates 7 sub-dimensions, including subjective sleep quality, latency, duration, habitual sleep efficiency, sleep disturbance, use of sleeping pills, and daytime dysfunction. Each item on the scale scores between 0 (no distress) and -3 (severe distress). The sum of the scores of the seven sub-dimensions gives the total PSQI score. The score of each sub-dimension ranges from 0 to 3. The total PSQI score ranges from 0 to 21. The sleep quality of those with a score of 5 or less is considered "good".<sup>20</sup> The Turkish validity and reliability study of the scale was done by Ağargün et al.<sup>21</sup>

**36-Item Short-Form Health Survey (SF-36):** The study's participants' quality of life was evaluated by the SF-36 scale. The scale was first developed by Ware and Sherbourne in the USA, and its Turkish validity and reliability study was performed by Koçyiğit et al. in 1999.<sup>22,23</sup> SF-36 consists of 36 questions and measures the quality of life in eight areas of health; physical

functioning (PF), general health (GH), role physical (i.e., role limitations due to the physical health problems, RP), bodily pain (BP), social functioning (SF), vitality (VT), role emotional (i.e., role limitations due to emotional problems, RE) and mental health (MH). For each domain, a score ranging from 0 to 100 was assessed with a higher score indicating better health.<sup>24</sup>

### Statistical analysis

Statistical analysis was performed using SPSS 21.0 package program. All parameters were summarized with descriptive statistics. Participants were divided into 2 groups: parents of single-seizure children and parents of children with epilepsy. The compliance of continuous variables to normal distribution was evaluated by Kolmogorov-Smirnov test. The Student t-test or Mann-Whitney U tests were used to compare the continuous parameters between the groups and sleep quality, depression, and anxiety. The Chi-square test was used to compare categorical parameters. The relationship between sleep quality, depression, anxiety and other parameters was evaluated by Pearson correlation test. A p-value less than 0.05 was considered significant.

### Results

One hundred and sixty-eight parents were invited to the study. Data from 55 participants who filled out the questionnaires incompletely were excluded from the analysis. The mean age of the 113 participants included in the study was  $35.54 \pm 6.7$  years. Of them, 61 (54%) were mothers, and 52 (46%) were fathers. 52.1% were high school graduates, and .3.5% had a history of epilepsy. The demographic data of the participants are given in Table I.

In the evaluation of the participants' BDI scores, the total BDI score of the parents of children with epilepsy was  $4.19 \pm 0.814$ , while the BDI score of the parents of the children presenting with the first unprovoked seizure was  $3.86 \pm 0.831$ , and there was no statistically significant difference between them ( $p=0.773$ ).

**Table I.** Sociodemographic characteristics of participants.

		Epilepsy	First Seizure
Age (mean±SD)		36.4 ±6.5	34.8±6.8
Parent Type	Mother	31 (27.4)	30 (26.5)
	Father	26 (23.0)	26 (23.0)
Education	Elementary	3 (2.6)	2 (1.7)
	High school	31 (27.4)	28 (24.7)
	University	23 (20.3)	26 (23)
Occupation	Employed	33 (29.2)	33 (29.2)
	Unemployed	24 (21.2)	23 (20.3)
History of chronic disease	Yes	2 (3.5)	0 (0)
History of epilepsy	Yes	2 (3.5)	2 (3.6)
Smoking history	Yes	18 (31.6)	19 (33.9)
History of psychiatric disease	Yes	2 (3.5)	1(1.8)

Data given as n (%) unless indicated otherwise.

The total BAI score of the parents of children with epilepsy was  $7.82 \pm 11.85$ , while the total BAI score of the other group was  $6.71 \pm 9.31$  ( $p=0.662$ ).

According to the sleep quality assessment made with PSQI, sleep quality was impaired in 33.3% of parents of children with epilepsy and 21.4% of parents of children with first unprovoked seizures ( $p=0.156$ ).

The comparison of SF-36 subscale scores showed no statistically significant difference between the two groups ( $p>0.05$ ). The scale scores of the participants are given in Table II. Frequency of parents with moderate to severe levels of depression, anxiety symptoms and sleep disorders across all participants were shown in Table III.

The comparison between the scale scores of the parents of children with epilepsy and the parents of children with first unprovoked seizure revealed that the social functionality scores and physical function scores of mothers of children with the first unprovoked seizure were lower than the fathers ( $p=0.044$ ,  $p=0.017$ ; respectively) whereas the physical function scores of mothers of children with epilepsy were lower than the fathers in the same group ( $p=0.041$ ). The scale scores of parent groups and

the comparative data between them are given in Table IV.

In the correlation analysis conducted between the numerical parameters of the participants and the scale scores, there was a positive correlation between the BAI score and PSQI and a negative correlation with all the SF-36 subscales. A negative correlation was found between BDI score and mental health subscale score, and PUKI and bodily pain and general health subscale scores. The correlation between the scale scores of the participants is given in Table V.

## Discussion

This study extends previous research by further evaluating the relationship between mood, sleep, and quality of life in parents of children with epilepsy and parents of first unprovoked seizures.

Previous studies report that parents of children with epilepsy are psychologically affected in many areas including parenting stress, and the percentage of parents who scored above the cut-off point in standardized anxiety measures was 9-58%.<sup>25,26</sup> Yong et al. reported that 42% of participants evaluated with The Hospital Anxiety and Depression Scale (HAD) scored in

**Table II.** Comparison of scale scores of participants.

Variables	Epilepsy [n (%)]	First Seizure [n (%)]	p	
PSQI	PSQI ≤ 5	38 (66.67)	44 (78.57)	0.227 <sup>a</sup>
	PSQI > 5	19 (33.33)	12 (21.43)	
BAI	BAI < 16	48 (85.71)	46 (88.46)	0.890 <sup>a</sup>
	BAI ≥ 16	8 (14.29)	6 (11.54)	
BDI	BDI < 17	53 (92.98)	51 (91.07)	0.742 <sup>b</sup>
	BDI ≥ 17	4 (7.02)	5 (8.93)	
BAI total		3(0-10.5)	3.5(0-8)	0.791*
BDI total		2(0-6)	1(0-5)	0.566*
PSQI total		4(3-6)	3(2-5)	0.380*
BP		2(1.5-3)	2.5(1.5-3)	0.791*
RE		2(1.333-2)	1.667(1.333-2)	0.879*
VT		3.41±0.58	3.53±0.81	0.380**
PF		2.8(2.6-3)	2.9(2.6-3)	0.954*
RP		2(1.25-2)	2(1.5-2)	0.703*
GH		3.05±0.56	3.1±0.4	0.616**
MH		3.85±0.48	3.8±0.66	0.702**
SF		3(2.5-3)	3(2.5-3.5)	0.231*

<sup>a</sup>: Yates's correction chi-square test; <sup>b</sup>: Fisher's exact chi square

\*: Mann Whitney U test, \*\*: Independent samples t-test. (Data are given as mean ± standard deviation or median (Q1-Q3) according to normality of distribution)

BAI: Beck Anxiety Inventory, BDI: Beck Depression Inventory, BP: bodily pain, GH: General Health, MH: Mental Health, PF: Physical Functioning, PSQI: Pittsburgh Sleep Quality Index, RE: Role Emotional, RP: Role Physical, SF: Social Functioning, VT: Vitality

**Table III.** Frequency of parents with moderate to severe levels of depression, anxiety symptoms and sleep disorders across all participants (N=113).

	n	%
BAI ≥16	16	14.1
BDI ≥17	9	7.9
PSQI >5	31	27.4

BAI: Beck Anxiety Inventory, BDI: Beck Depression Inventory, PSQI: Pittsburgh Sleep Quality Index

the clinically significant range for depression and 58% scored in the clinically significant range for anxiety, while Shariff et al. reported that 38.7% of parents scored in the clinically significant range for depression and 55% scored in the clinically significant range for anxiety.<sup>27-29</sup> In this study, 7.9% of all participants were found to have depression and 14.1% of all participants were found to have an anxiety disorder based on moderate and above severity levels. These rates are relatively lower than previous studies which may be due to the differences in the evaluation scales used in different studies, and may be explained by the high level of education

in majority of our participants which is often not the case.<sup>26</sup> As a matter of fact, it has been argued in the literature that parents of children with epilepsy are exposed to more stigmatization especially in societies with low education level and this may be an important reason for the high anxiety rates in parents.<sup>30</sup> Similarly, a study conducted in Türkiye showed that individuals with low educational level exhibited a more stigmatizing attitude, and this was presented as a reason for parents of children with epilepsy to become more depressed and anxious over time due to a disruption in search for social support.<sup>31</sup> While the design of our study did not

**Table IV.** Comparison of scale scores of parents according to patient groups.

Variables		Epilepsy Mother	Epilepsy Father	<i>p</i>	First Seizure	First Seizure	<i>p</i>
					Mother [n (%)]	Father [n (%)]	
PSQI	PSQI ≤ 5	24 (77.42)	14 (53.85)	0.110 <sup>a</sup>	24 (80.00)	20 (76.92)	1.0 <sup>a</sup>
	PSQI > 5	7 (22.58)	12 (46.15)		6 (20.00)	6 (23.08)	
BAI total		4(0-11)	0(0-9)	0.168	5(0-10)	2(0-6)	0.158*
BDI total		2(0-6)	1.5(0-6)	0.755	2(0-6)	0(0-2)	0.132*
PSQI total		3(2-5)	5(3-7)	0.103*	4(2-5)	3(2-5)	0.829*
BP		2(1.5-3)	2(1.5-3)	0.556*	3(1.5-3)	1.75(1-2.5)	0.139*
RE		1.667(1.333-2)	2(1.333-2)	0.795*	1.667(1.333-2)	2(1.667-2)	0.114*
VT		3.36±0.6	3.48±0.56	0.487**	3.57±0.79	3.49±0.84	0.721**
PF		2.8(2.5-3)	3(2.7-3)	0.041*	2.7(2.3-2.9)	2.9(2.8-3)	0.014*
RP		1.875(1.25-2)	2(1.5-2)	0.711*	1.75(1.25-2)	2(1.5-2)	0.168*
GH		3.08±0.55	3.02±0.58	0.707**	3.06±0.42	3.15±0.37	0.408**
MH		3.78±0.51	3.93±0.44	0.269**	3.69±0.66	3.92±0.65	0.221**
SF		3(2.5-3)	3(3-3.5)	0.630*	3(3-3.5)	3(2.5-3)	0.017*

<sup>a</sup>Yates's correction chi-square test, \*Mann Whitney U test, \*\*Independent

Data are given as mean ± standard deviation or median (Q1-Q3) according to normality of distribution.

BAI: Beck Anxiety Inventory, BDI: Beck Depression Inventory, BP: bodily pain, GH: general health, MH: mental health, PF: physical functioning, PSQI: Pittsburgh Sleep Quality Index, RE: role emotional, RP: role physical, SF: social functioning, VT: vitality

examine this effect, the high level of education of our participants may have played a protective role in combating anxiety caused by uncertainty through facilitating access to more accurate information about the disease and its treatment, which may explain the low rates of depression and anxiety for similar reasons. In addition, this result suggests that our clinic, which is a tertiary treatment center, may have contributed to the mental well-being of parents in its programmes for the education of families.

On the other hand, no difference was found between the levels of depression and anxiety among parents of children with both first unprovoked seizure and epilepsy in this study. This result may be an expression of the undeniable burden imposed on parents in childhood seizures and epilepsies regardless of the type of the disease, and it also supports studies showing that the mental adjustment of parents remains constant over time.<sup>32</sup>

Sleep studies have shown that sleep disturbance is frequently observed in parents of children

with epilepsy.<sup>33,34</sup> It has been reported that parents, especially those who think that it is difficult to detect nocturnal seizures and that these may seriously threaten the life of the child, stay awake day and night to meet the needs of the child, wake up seven times more frequently than the healthy population and sleep an average of 4 hours/day.<sup>34,35</sup> Reilly et al. found that 62% of mothers and 44% of fathers of children with epilepsy had "poor quality sleep" on the PSQI.<sup>3</sup> Similarly, in a previous study conducted on 52 mothers of children with intractable epilepsy, 67% of the participants scored in the "poor sleep" range.<sup>33</sup> In this study, the rate of sleep disturbance in all parents was 27.4%. Although the rate of sleep disturbance seemed to be higher in parents of children with epilepsy (33.3%), there were no differences in sleep disturbance between groups or between parents. Sleep disturbance was also associated with increased anxiety, pain and impaired perception of general health. This finding supported the study of Cottrell et al.<sup>36</sup> which showed that parental sleep quality was not only

**Table V.** Relationship between scale scores of participants.

		Age	BDI Total	BAI Total	PSQI Total
Age	r	1	-0.115	0.000	-0.008
	p		0.257	0.996	0.940
BDI Total	r	-0.115	1	-0.105	0.032
	p	0.257		0.269	0.733
BAI Total	r	0.000	-0.105	1	0.330**
	p	0.996	0.269		<b>&lt;0.001</b>
PSQI Total	r	-0.008	0.032	0.330**	1
	p	0.940	0.733	<b>&lt;0.001</b>	
BP	r	0.028	0.067	-0.654**	-0.0247**
	p	0.784	0.481	<b>&lt;0.001</b>	<b>0.008</b>
RE	r	0.085	-0.002	-0.362**	-0.083
	p	0.402	0.986	<b>&lt;0.001</b>	0.382
VT	r	0.028	0.067	-0.654**	-0.247**
	p	0.784	0.481	<b>&lt;0.001</b>	0.008
PF	r	0.197	-0.030	-0.499**	-0.132
	p	0.050	0.756	<b>&lt;0.001</b>	0.162
RP	r	0.057	-0.089	-0.280**	0.032
	p	0.572	0.348	<b>0.003</b>	0.733
GH	r	-0.029	-0.085	-0.560**	-0.211*
	p	0.774	0.370	<b>&lt;0.001</b>	<b>0.025</b>
MH	r	-0.046	-0.193*	-0.616**	-0.183
	p	0.654	<b>0.040</b>	<b>&lt;0.001</b>	0.052
SF	r	0.050	0.089	-0.461**	-0.101
	p	0.620	0.351	<b>&lt;0.001</b>	0.200

Statistic: Spearman Correlation (r). \*Correlation is significant at the 0.05 level (2-tailed), \*\*Correlation is significant at the 0.01 level (2-tailed).

BAI: Beck Anxiety Inventory, BDI: Beck Depression Inventory, BP: bodily pain, GH: General Health, MH: Mental Health, PF: Physical Functioning, PSQI: Pittsburgh Sleep Quality Index, RE: Role Emotional, RP: Role Physical, SF: Social Functioning, VT: Vitality

associated with the seizure frequency of the child, but also with quality of life factors such as parental depression level, physical health, pain experience, and emotional well-being. Given that sleep disturbances are associated with various unfavourable consequences in adults, including health related problems, declining quality of life and economic expenses, this result once again highlights the prevalence of sleep disturbances among parents whose children are being treated for epilepsy and the need to investigate their current sleep patterns.<sup>37</sup>

In our study, although there was no difference between the groups in terms of quality of life scores measured by SF-36, we observed that

especially mothers were more negatively affected in the areas of physical function and social functioning. Zhang et al.<sup>38</sup> found that the psychological health and quality of life of mothers were affected by their children having epilepsy much more than those of fathers which is consistent with our study. One possible explanation for this is that in our society, mothers are still the primary caregivers of children, both in illness and daily life. Hence, the affinity between mothers and children is generally higher. As a result, mothers are more susceptible to the adverse effects of their children's illnesses than fathers and this may have had a greater impact on their quality of life.

One of the important findings in this study was the negative relationship between depression, anxiety, sleep disturbance and quality of life. In particular, increased anxiety negatively affected almost all subscale parameters of quality of life, while impaired sleep quality led to increased anxiety about pain and poor general health. This result is more important for children with epilepsy who need more support from their parents than their healthy peers. Because the psychological effects occurring in the parents may lead to burnout, anger, deterioration in family relations over time, this may adversely affect the treatment adaptation and development of the children.<sup>39</sup> Therefore, detection of current psychological symptoms in parents of children who are diagnosed with seizure as well as development of measures may provide important benefits in the prognosis of such children in addition to personal benefits.

### **Limitations**

Our study has some limitations. This study included only patients admitted to the pediatric neurology outpatient clinic of our hospital and had a relatively small sample size. Therefore, the results obtained may not reflect the whole population. The relatively low reliability of the data obtained from self-report scales may have affected our results. In addition, the lack of a control group is an important obstacle for the comparison of mental health issues between parents with healthy children and individuals with chronic diseases. Future studies including other clinics, with a larger number of individuals and conducting one-to-one interviews will contribute to overcoming these limitations and obtain more reliable results.

Despite these limitations, our study is the first study to examine depression and anxiety symptoms, sleep and quality of life levels and the relationship between these entities among parents with a first unprovoked seizure and children with epilepsy, and may provide preliminary data for future studies.

In conclusion, our study showed that families of children with first unprovoked seizure and epilepsy diagnosis are at risk for depression and anxiety, especially sleep disorders, and their quality of life is adversely affected. Therefore, health personnel should strengthen the education of parents about their children's disease and provide psychological counselling and support when needed, which may make important contributions to both individuals and public health.

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### **Ethical approval**

This article was approved by the Ethics Committee of İnönü University. The approval number is 2020/1309. All participants gave informed consent to participate in the study.

### **Author contribution**

The authors confirm contribution to the paper as follows: study conception and design: BÖ, NC data collection: BÖ, NC analysis and interpretation of results: BÖ, NC draft manuscript preparation: BÖ, NC All authors reviewed and approved the final version of the manuscript.

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### **Conflict of interest**

The authors declare that there is no conflict of interest.

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