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Post-traumatic stress disorder and related psychopathology in parents of children with epilepsy

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Abstract

Mental difficulties and psychiatric illnesses are common in families of children with epilepsy. The aim of this study is to investigate the prevalence and possible risk factors of post-traumatic stress disorder, depression, and anxiety in a sample of parents of children with epilepsy. Parents of children with epilepsy who presented to Turgut Ozal Medical Center Pediatric Neurology Outpatient Treatment Unit between January and March 2023 were invited to this cross-sectional study. Participants filled out a questionnaire examining demographic variables. Depression and anxiety levels were evaluated with the Hospital Anxiety and Depression Scale (HAD-S), and post-traumatic stress levels were evaluated with the Post-Traumatic Stress Disorder short scale (PTSD-short scale). A total of 89 parents, including 47 mothers, and 42 fathers, participated in the study. Of the study participants, 10.11% were at risk for depression and 3.4% for anxiety disorder. 6.7% had PTSD. There was a positive correlation between HAD-S subscale scores and PTSD-short scale scores. According to the linear regression model, PTSD was negatively correlated with having a job and education level, and positively correlated with anxiety and depression. Anxiety and depression were only associated with PTSD. Parents of epileptic children are at risk for PTSD, depression, and anxiety. Clinicians need to identify at-risk parents at an early stage and develop specific assist-oriented intervention programs to provide systematic support.

Keywords: Parents, PTSD, epileptic child

Introduction

Post-Traumatic Stress Disorder (PTSD) is a disorder that manifests itself with traumatic symptoms that can harm the mental and physical integrity of the individual after a traumatic experience, lasting longer than one month [1].

War, violence, terrorist attack, rape, earthquake, flood, etc. while the events are known as traumatic events [2], it is argued that learning that a close person has suffered from a disease such as sudden loss, a chronic or risky neurological disorder, cancer or severe injury in recent years should also be included in this category. A parent learning that their child has a chronic and potentially life-threatening illness has been recognized as a favorable event for the development of PTSD in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) [3,4].

Concordantly, epilepsy is currently one of the appropriate medical conditions to study PTSD in both children and parents, due to its chronic course, uncertainty about when and how severe the seizures will occur, loss of consciousness, tongue biting, injuries, death, and serious consequences [5].

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However, few studies have so far specifically investigated the prevalence of PTSD among parents of children with epilepsy, a chronic disease with potentially dramatic impact that is distressing to parents. In these studies, prevalence of PTSD was reported to be 15.7-31.5% [4,6]. In addition, the traumatic effect of seizures on the patient and family is related to many factors such as gender, income level, education level, knowledge level about epilepsy, family communication and endurance, seizure type, frequency/severity, treatment response, presence of depression and anxiety. It has been shown that it can lead to psychosocial losses that can disrupt dating behaviors. Moreover, it has been emphasized that these psychological symptoms in the parent can be transmitted to the child directly or indirectly through the influence of the parent's mood, fears, behaviors, or narratives, and may seriously impair the child's function and development [7,8].

Therefore, determining the mental problems in the parents and the factors affecting these mental problems while treating children is important in terms of understanding the child, facilitating their adaptation to the new circumstance, and planning the appropriate approach [9].

In this study, it was aimed to determine the relationship between the prevalence of PTSD and depression and anxiety levels, and demographic and clinical variables related to parents and children in a sample of parents of children with epilepsy.

Materials and Methods

This cross-sectional study included the parents of children aged 1-17 years with epilepsy who applied to the Turgut Özal Medical Center Pediatric Neurology Outpatient Treatment Unit between January and March 2023. Participation in the study was voluntary and written and verbal consent was obtained from the participants who agreed to participate. Parents who did not live with the child and/or were not responsible for their treatment, were illiterate, and had active psychiatric or neurological disease and/or mental retardation that would cause cognitive dysfunction were not included in the study. The study was approved by the Inonu University non-interventional ethics committee. (2023/4091)

Sample size

According to the power analysis performed before the study, the margin of error was 0.05, the sample size was 80, and the total number of participants to be included in the study was at least 44 with a power of 0.95 (1-β).

Data collection

Participants age, education level, occupation, monthly income, chronic disease (hypertension, coronary artery disease, malignancy, epilepsy) and psychiatric disease history (depression, anxiety, psychotic disorder, bipolar, other), alcohol-substance-cigarette addiction, children's They answered the questions on the Hospital Anxiety and Depression Scale (HAD-S) and the Post Traumatic Stress Disorder Short Scale (PTSD-CS) with a form prepared by the researchers to determine the clinical data about the disease.

Hospital anxiety and depression scale

It is a scale developed by Zigmond and Snaith to determine the risk of anxiety and depression in the patient, to measure its level and change in severity [10]. The scale consists of 14 four-point Likert-type questions and odd numbers measure anxiety and even numbers measure depression. The lowest score that patients can get from both subscales is 0, and the highest score is 21. The Turkish validity and reliability of the form was made by Aydemir. The cut-off points of the Turkish version of the HAD-S were determined as 10 for the anxiety subscale and 7 for the depression subscale. Accordingly, those who score above these points are considered at risk [11].

Post Traumatic Stress Disorder Brief Scale (PTSD-CS)

It is a short nine-item self-report scale developed by LeBeau et al. (2014) that can be used to evaluate PTSD and measure its severity [12]. It can be used both as a screening tool and is consistent with DSM-5 PTSD symptoms. Each question in the scale is evaluated by scoring between 0-4 (never=0, a little=1, medium=2, quite=3, extreme=4). Although the score to be obtained from the scale varies between 0-36, 24 points and above are accepted as a significant value for PTSD. The Turkish validity and reliability study of the scale was performed by Evren et al. (2016), and the Cronbach alpha internal consistency coefficient was found to be 0.87 [13]. In this study, the traumatic event was defined as witnessing the child's epileptic seizure.

Statistical analysis

Analyzes were evaluated in 22 package programs of SPSS (Statistical Package for Social Sciences; SPSS Inc., Chicago, IL). In the study, qualitative data are shown as n and %, and continuous data as mean±standard deviation (Mean±SD). Chi-square analysis (Pearson Chi-square) was used to compare categorical variables between groups. Conformity of continuous variables to normal distribution was evaluated with the Shapiro Wilk test. Pearson Correlation test was used to examine the relationship between continuous variables. The Independent T test was used to determine the variables that could be associated with PTSD, anxiety and depression, and variables with $p < 0.05$ were analyzed using a linear regression model. The statistical significance level in the analyzes was accepted as $p<0.05$.

Results

A total of 89 parents, including 47 (52.8%) mothers and 42 (47.2%) fathers, participated in the study. The mean age of the participants was 38±9 years and 56.2% of them were primary school graduates. While 6.7% of the participants had a history of epilepsy, 5.5% had been treated for a psychiatric disorder. 77.5% of the children of the participants had been diagnosed with epilepsy for more than 6 months, and 17.9% of them were receiving more than 2 anti-epileptic treatments. Demographic

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information of the participants and their children is given in Table 1.

Table 1. Demographic characteristics of the participants

Parents age mean (mean±SD)	38±9
Child age mean (mean±SD)	9.7±5.0
	N (%)
Gender	
Female	47 (52.8)
Male	42 (47.2)
Education	
Primary	50 (56.2)
High school	25 (28.1)
University	14 (15.7)
Occupation	
Abse	52 (58.4)
Monthly income (TL)	
<4000	68 (76.4)
4000-8000	15 (16.9)
>8000	6 (6.7)
Psychiatric disease history	
Positive	5 (5.5)
Children's gender	
Female	44 (49.4)
Male	45 (50.6)
Children age	
Infant	5 (5.6)
Toddler	16 (18)
School age	36 (40.4)
Adolescent	32 (36)
Children's disease duration	
1-6 month	20 (22.5)
6 month-1 year	16 (18)
1-2 year	10 (11.2)
>2 year	43 (48.3)
Children's number of medicine	
1-2	73 (82.1)
>3	16 (17.9)
Seizure type	
Focal	44 (49.4)
Generalize	37 (41.6)
Unclassification	8 (9)
Drug resistance	
Negative	50 (56.2)
Positive	39 (43.8)

Participants' PTSD-CS total score was 10.78±7.03, HAD-S anxiety score 3.61±3.06, HAD-S depression score 13.54±2.77. 6.7% had PTSD symptoms, 10.11% had clinical depression and 3.4% had anxiety. The scale mean score and categorical distribution of the participants who are given in Table 2.

Table 2. Scale scores and categorical distribution rates of the participants

		Mean±SD	
PTSD-SS* total		10.78±7.03	
HAD^-Anxiety score		3.61±3.06	
HAD^-Depression score		13.54±2.77	
		n	**%**
Trauma categorical	**Trauma negative**	83	93.3
	Trauma positive	6	6.7
Depression categorical	**0-7**	80	89.9
	8≥	9	10,1
Anxiety categorical	**0-10**	86	96.6
	11≥	3	3.4

*PTSD-SS: post traumatic stress disorder short scale, ^HAD: hospital anxiety and depression scale

According to the analysis to determine the prevalence of participants' post-traumatic stress symptoms (for answers of at least 2 points or more for each question), intrusive thoughts, psychological reactivity, irritability, and hypervigilance were the most common symptoms in the entire sample; Guilt was the least common symptom. The percentages of PTSD symptoms in the total sample are given in Table 3.

Table 3. Prevalence of post-traumatic stress symptoms in parents

	Total n (%)	**PTSD* (+) n (%)**	**PTSD* (-) n (%)**
Flashbacks	25 (28.8)	5 (83.3)	20 (24.1)
Feeling bad emotionally when something reminds you of your stressful experience	34 (38.2)	6 (100)	28 (33.7)
Trying to avoid thoughts, feelings, or physical sensations that remind you of the stressful experience	38 (42.7)	6 (100)	32 (38.5)
Do not think that the stressful event happened because you or someone else did something wrong, or because you didn't do everything possible to prevent it, or because something about you	23 (25.8)	4 (66.6)	19 (22.9)
Being in an extremely negative emotional state after a stressful experience	26 (29.2)	5(83.3)	21 (25.3)
Losing interest in activities you enjoyed doing in the past, after this stressful event	27 (30.3)	5(83.3)	22 (26.5)
Being bed of pins, on the alert, or constantly on the lookout for danger	29 (32.6)	5(83.3)	24 (28.9)
Feeling timid or startled easily when you hear an unexpected noise	32 (36.0)	6 (100)	26 (31.3)
Being so angry or angry that you yell at other people, fight, or hurt something	33 (37.1)	5(83.3)	24 (28.9)

*PTSD: post traumatic stress disorder

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In the correlation analysis between the participants' parametric variables and scale scores:

A positive significant correlation was found between HAD-Depression scores, HAD-Anxiety scores, and PTSD-SS scores ($p<0.01$). The results of correlation analysis between parametric variables and scale scores what are summarized in Table 4.

Variables associated with PTSD, anxiety and depression determined by Student's T test that were analyzed by Linear Regression. PTSD; It was negatively correlated with employment and education level and positively with anxiety and depression. Anxiety and depression were found to be associated only with the presence of PTSD (Table 5).

Table 4. The relationship between parametric variables and scale scores

Correlations				
		PTSD-SS total	**HAD-anxiety score**	**HAD- depression score**
PTSD-SS total	r	1	.457**	.279**
	p		**.000**	.008
HAD-anxiety score	r	.457**	1	.422**
	p	**.000**		.000
HAD- depression score	r	.279**	.422**	1
	p	**.008**	**.000**	

** Correlation is significant at the 0.01 level (2-tailed), * Only the variables with statistical significance that are included in the table

Table 5. PTSD, anxiety, and depression markers

	Model	**Unstandardized coefficients**		**Standardized coefficients**	**t**	**Sig.**
		B	**p**	**Beta**		
PTSD	**(Constant)**	1.394	.192		7.258	.000
	Treatment response	-.074	.080	-.114	-.929	.355
	Drug resistance epilepsy	.011	.064	.021	.167	.868
	Occupation	-.132	.054	-.259	-2.428	**.017**
	Education	-.074	.036	-.220	-2.064	**.042**
	Age	.002	.003	.068	.621	.536
Anxiety	**(Constant)**	.599	.136		4.406	.000
	Education	-.001	.029	-.006	-.050	.960
	Monthly income	-.041	.038	-.134	-1.078	.284
	Treatment response	.002	.046	.003	.034	.973
	PTSD	.322	.071	.447	4.540	**.000**
	Gender	.034	.037	.093	.904	.369
	Child's gender	.064	.036	.176	1.789	.077
Depression	**(Constant)**	.739	.274		2.694	.009
	Education	-.030	.052	-.075	-.582	.562
	Gender	-.094	.068	-.155	-1.381	.171
	Monthly income	-.010	.068	-.020	-.153	.879
	Treatment response	.052	.081	.066	.645	.521
	Anxiety	-.017	.192	-.010	-.090	.929
	Age	.002	.004	.046	.440	.661
	PTSD	.429	.140	.357	3.070	**.003**

P<0.05

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Discussion

In this study, the prevalence, and predictors of post-traumatic stress symptoms in parents responsible for the care of children with epilepsy were investigated.

Studies have shown that the rates of depression, anxiety and trauma are high in families of epileptic children. For example, Carmassi et al. found a PTSD prevalence of 15.7% in a sample of 166 mothers and 33 fathers of 199 children with epilepsy, while Iseri et al. reported a PTSD 31.5% prevalence of in parents (77 mothers and 3 fathers) of children with primarily tonic-clonic seizures (85%) Omri et al. reported the prevalence of PTSD, depression, and anxiety of 20.7%, 28.9%, and 55.6%, respectively, in 135 parents [4,6,14]. In another study conducted in Italy, the frequency of PTSD was reported as 25% [15].

In our study, it was determined that 6.7% of the participants had PTSD, 10.11% had symptoms of clinical depression and 3.4% had anxiety symptoms. Although our results were consistent with the reported prevalence for anxiety depression and PTSD, they were considerably lower than the studies evaluating the parents of children diagnosed with epilepsy [16]. In another study published recently, which included 99 parents with children with epilepsy, the rate of PTSD was found to be 9% [5].

These differences could be explained by several factors. Firstly, the differences in the scales used for the definition or detection of trauma in the studies, likely affect the prevalence [5]. Secondly; despite the fact that we could not detect a significant relationship between seizure type and psychological exposure levels, our study included parents of children with both generalized and focal and unclassifiable seizures, unlike other studies. Indeed, generalized tonic-clonic seizures present with symptoms that pose a noticeable risk of death at the time of their occurrence, and this is traumatic for individuals experiencing it for the first time and can have lasting psychological effects. On the other hand, behavioral pauses, focal tonic or clonic seizures, absence seizures or seizures with automatism component with more vague or mild symptoms may have caused parenteral reactions such as confusion and inability to understand although they may not have had a severe psychological effect [4,17,18].

Thirdly, most of the participants in these studies are female, and the genders are equal in our country. It has been reported that psychiatric diseases, including PTSD, are 2-3 times more common in women than in men [5,19,20]. This situation has been attributed to the fact that mothers are more responsible for family health in case of general family health concerns and/or when the child has a chronic illness, as well as hormonal variations [21]. It has been reported that particularly mothers of children with epilepsy are exposed to a greater family stress and need to protect their children more than mothers of children with other chronic diseases [9,22]. Therefore, the fact that the genders of our participants were equal in number may have caused us to determine a lower incidence of psychiatric diseases.

Fourthly, it may be the cultural and religious values of societies that determine the fight against diseases (LIT). Value judgments such as “destiny came from God”, unique to our region, which make diseases more easily acceptable, may have contributed to the development of coping strategies for parents to support their children more, and thus to be less traumatized.

Previous studies have shown that factors such as gender, age, family income, educational status, parents' knowledge about epilepsy, the child's seizure type, the child's seizure frequency, the treatment response, and the child's age and gender affect the anxiety levels of parents [9,14,21-26]. Shore and colleagues looked at the anxiety levels of mothers and fathers at 3 and 6 months and found that fathers' stress levels decreased at 6 months, while it remained stable in mothers of epilepsy patients [27]. In a sample of parents of children with persistent epilepsy, parents of children with high seizure severity experienced the most distress [28]. Similarly, another study showed that parents whose children had fewer seizures were the most adaptive [23]. However, our study did not fully support previous studies. Our regression analysis showed that apart from the relationship between unemployment and low education level and PTSD, none of the factors such as parent and child characteristics, seizure type, and treatment resistance affected trauma, depression and anxiety levels. Although this was an interesting result, it was important in that it indicated that it may be important to investigate other factors that pose a risk for developing PTSD, such as family relationships, personality traits, and previous traumatic experiences.

One of the most important results in our study was the positive correlation between depression, anxiety and PTSD. This result was consistent with studies showing that the comorbidity of these disorders is common, and that existing psychiatric illness strongly affects the quality of life, distress and coping strategies of individuals and predisposes them to the development of comorbid psychiatric conditions [28,29]. Considering that epilepsy treatment is a long-term or life-long process that requires certain discipline, this result means that appropriate screening and treatment of depression and anxiety in anxious or depressed parents, individuals with PTSD or vice versa, both parent and child, can be important in protecting mental health, improving adherence to treatment, and improving quality of life [30,31].

This study also illustrated the frequency of PTSD symptoms in participants who scored moderate or higher. All the participants declared that they experienced PTSD symptoms at a sub-syndrome level. Among these symptoms, the most common ones are being angry, avoidance, alertness, or constant vigilance for danger. In a study conducted in our country, it was found that mothers of children with epilepsy had significantly higher anxiety, anger-hostility, and phobic anxiety scores [9]. Although not sufficient to diagnose PTSD, those with these symptoms are likely to become susceptible to psychiatric disorders in the future. Moreover, an excessively anxious or angry attitude can negatively affect a child's behavior and impair his development. However, prospective studies are needed to make a definitive

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judgment [32,33].

Limitations

There are some limitations to this study. The study was conducted on parents of children with epilepsy who presented to our hospital's pediatric neurology clinic and had a small sample size. Therefore, the results obtained may not reflect the entire population. Since participation of the participants in this study was on a voluntary basis, a comparison between the participants and non- participants could not be made. This situation may have prevented the evaluation of parents who may have psychiatric complaints. The cross-sectional nature of the study precludes establishing a definitive causality between the diseases studied and the factors determined. In addition, the fact that the data were obtained from self-report scales may have resulted in a relatively low reliability of the results. Future multicenter, randomized controlled, one-on-one interviews will contribute to eliminate these limitations and to obtain more reliable results.

Conclusions

In this study, it was shown that parents of children with epilepsy are at risk for PTSD, anxiety, and depression. However, it was determined that these psychopathologies were positively correlated with each other, and PTSD was more common in individuals who were unemployed and/or had a low education level. Although they were not at the level of psychopathological diagnosis, most of the participants had trauma symptoms. Considering that epilepsy treatment may impair the success, these results reveal once again that the mental health of parents who take care of epileptic children is at risk, and that health workers should take relevant precautions while treating these children.

Conflict of Interests
The authors declare that there is no conflict of interest in the study.

Financial Disclosure
The authors declare that they have received no financial support for the study.

Ethical Approval
This article was approved by the Ethics Committee of Inonu university. The approved number is 2023/4091.

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