

# The Depression and Anxiety Profiles of Mothers Who Have Children with Epilepsy

## Epilepsi Tanılı Çocukları Olan Annelerin Depresyon ve Anksiyete Profilleri

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**ABSTRACT Objective:** Epilepsy has important effects to different extents on children and their families. The purpose of the present study was to evaluate the depression and anxiety scores in order to view the psychological profile of mothers of children with epilepsy. **Material and Methods:** A total of 100 mothers with children having epilepsy were included in the study. The control group consisted of 100 mothers who have children without chronic disease. The Beck depression inventory, the Beck anxiety inventory, the State-Trait anxiety inventory 1 and 2 (STAI 1 ve 2) were used to assess the psychiatric status of the mothers. A statistical software was used to analyze the statistical data. **Results:** There was no statistical difference between the groups in terms of depression ( $p=0.285$ ). Anxiety was found in 55% of the mothers who had epileptic children while the rate in the control group was 46%. There was a significant difference between the groups in terms of the mean Beck anxiety scores ( $p:0.006$ ). There was no statistically significant difference in the mean STAI-1 scores between the groups ( $p=0.06$ ). There was a significant increase in the mean STAI-2 scores in terms of trait anxiety for the study group compared to the controls ( $p=0.001$ ). **Conclusion:** Epilepsy may cause impairment in the quality of life of parents of the affected children. Hence, the awareness of clinicians about the psychosocial consequences for the parents of children with epilepsy may help providing better support and care for such families.

**Key Words:** Epilepsy; mothers; depression; anxiety

**ÖZET Amaç:** Epilepsi çocuklar ve aileleri üzerinde farklı derecelerde önemli etkilere sahiptir. Artan sayıda çalışma epilepsili çocukların ebeveynlerinde depresyon ve anksiyeteye daha fazla yatkınlık olduğuna işaret etmektedir. Bu çalışmanın amacı epilepsili çocuklara sahip annelerin depresyon ve anksiyete skorlarını ölçerek psikososyal profillerini değerlendirmektir. **Gereç ve Yöntemler:** Çalışma grubuna epilepsili çocuğu olan toplam 100 anne alındı. Kontrol grubu kronik hastalığı olmayan çocuğa sahip 100 anneden oluşuyordu. Annelerin psikiyatrik durumlarını değerlendirmek için Beck depresyon envanteri, Beck anksiyete envanteri, State Trait Anxiety 1 ve 2 (STAI-1 ve STAI-2) ölçekleri kullanıldı. İstatistiksel verilerin analizi için istatistik yazılım programı kullanıldı. **Bulgular:** Çalışma ve kontrol grupları arasında depresyon bakımından istatistiksel anlamlı farklılık saptanmadı ( $p:0,285$ ). Anksiyete kontrol grubunda %46 iken epileptik çocuğu olan annelerde %55 bulundu. Çalışma ve kontrol grupları arasında ortalama Beck anksiyete skorları arasında anlamlı farklılık vardı ( $p:0,006$ ). Gruplar arasında ortalama STAI-1 skorları yönünden istatistiksel anlamlı farklılık saptanmadı ( $p:0,06$ ). Çalışma grubu STAI-2 skorlarının kontrol grubundan anlamlı düzeyde yüksek olduğu bulundu ( $p:0,001$ ). **Sonuç:** Epilepsi etkilenen çocukların ebeveynlerinin hayat kalitesinde yetersizliğe sebep olabilir. Bundan dolayı klinisyenlerin epilepsili çocukların ailelerinin psikososyal durumlarının farkında olmaları, böyle aileler için daha iyi destek ve bakım sağlanmasına yardım edebilir.

**Anahtar Kelimeler:** Epilepsi; anneler; depresyon; anksiyete

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Epilepsy is one of the most prevalent disorders, characterized by recurrent seizures and derives mainly from congenital or acquired central nervous system dysfunction.<sup>1</sup> The prevalence of epilepsy is generally between 5 and 10 cases per 1000 people, and the overall incidence is about 50 cases per 100 000 people.<sup>2</sup> It is the most common chronic neurologic disorder during childhood and adolescence periods and mainly has influence on cognitive and behavioral functions of the affected children.<sup>1</sup> However not only the children but also their families are exposed to the functional and psychosocial effects of disease to some extent. The negative aspects of having epilepsy result partially from the unpredictable nature of seizures, their probable effects on academic success of children and the social stigmatization.<sup>3</sup>

Caring for a child with a chronic illness can be a significant stressor for parents. Emotional distress is commonly seen particularly during the diagnosis process and exacerbation periods of the disease. Mothers are the primary caregivers and may be more likely than fathers to perceive the negative impact of illness on the family life, possibly placing them under a greater burden of psychosocial problems.<sup>4</sup>

There has been increasing interest in the assessment of the psychological profile of mothers who have epileptic children, as many of these conditions have a significant impact on both the physical and psychosocial functioning of the child and family. Several studies showed more depression and anxiety in parents of children diagnosed with epilepsy.<sup>3,5,6</sup> Parents often have worry for their child when seizure occurs, and they agree that having seizures and using anticonvulsants will result in loss of cognitive function.<sup>6</sup> Chiou and Hesieh reviewed the literature about the effects of epilepsy and other chronic illnesses on families. They stated that parents of children having epilepsy were shown to be much more affected than the parents of other children with different chronic illnesses.<sup>7</sup>

The purpose of the present study was to evaluate the depression and anxiety scores in mothers having children with epilepsy in order to examine their psychological profile.

## MATERIAL AND METHODS

This study was done in the Department of Pediatric Neurology and Department of Psychiatry in Fırat University School of Medicine Hospital. The study group was recruited from the Fırat University School of Medicine Pediatric Neurology Outpatient Clinic and included 100 mothers who had epileptic children. The control group was recruited from the Pediatric Outpatient Clinic of Fırat University School of Medicine where healthy children are admitted. The control group consisted of 100 mothers who had children without any chronic diseases. The control group had similar sociodemographic features with the epilepsy group. Mothers of the children with epilepsy and those of the controls were excluded if they had any known chronic disease or psychiatric disorder. Sociodemographic information regarding educational and economic status of the mothers was drawn by a questionnaire form.

The data related to epilepsy included the age of the onset of disease, the duration of illness, modalities of antiepileptic treatment, intractability to antiepileptic treatment, type of seizures, frequency of seizures and coexistence of motor or mental retardation. Patients who do not achieve seizure control after having tried two or three of antiepileptic drugs were defined as having intractable epilepsy.<sup>8</sup>

Informed consents of all participants were obtained. Beck depression inventory and Beck anxiety inventory was applied to the mothers respectively for depression and anxiety. Their state and trait anxiety evaluation was carried out by using State-trait anxiety inventory 1 and 2 (STAI-1 and STAI-2). In 1961, Beck et al. constructed Beck depression inventory in order to measure the behavioral findings of depression in adolescents and adults.<sup>9</sup> Turkish validity and reliability studies were performed by Hisli in 1988.<sup>10</sup> Beck anxiety inventory is a self assessment scale which is also constructed by Beck et al in 1988 to determine the frequency of anxiety symptoms in adolescents and adults.<sup>11</sup> The reliability and validity studies in Turkey were done by Ulusoy, Sahin and Erkmen in 1998.<sup>12</sup> State-trait anxiety inventory was con-

structed by Spielberger et al. in 1970 to evaluate the feelings of person with anxiety and had been brought into Turkish literature by Oner and Le Compte in 1983.<sup>13,14</sup>

The study was approved by the Firat University Ethics Committee. Informed consents from mothers were taken before the study.

**STATISTICAL ANALYSIS**

A statistical software was used to analyze the statistical data. Kolmogorov-Smirnov test was utilized to assess the normal distribution of the data. For comparison of the parametric and nonparametric data (expressed as the mean ± standard deviation) Student’s t test and Mann-Whitney U test were used, respectively. Correlations for the epilepsy duration, intractable epilepsy, Beck depression and Beck anxiety scores were investigated using the Pearson’s correlation test. A p value below 0.05 was considered statistically significant for evaluation.

**RESULTS**

There was no significant difference with respect to age between two groups; the mean ages of the mothers in the study and control groups were 33.80±6.56 years and 32.39±7.10 years, respectively (p>0.05). Sociodemographic features (education, monthly income level) of the mothers were similar between the two groups (p>0.05, see Table 1).

The mean age of the patients in the study group and mean age of diagnosis were 6.97±4.82

**TABLE 1:** Sociodemographic features of all participants and their mothers.

	Epilepsy (n=100)		Control (n=100)	
Mean age (years ± SD, min-max)				
Children's	6.97 ± 4.82 (1-17)		6.74 ± 4.47 (1-17)	
Mothers'	33.80 ± 6.56 (20-50)		32.39 ± 7.10 (19-48)	
Demographics	n	%	n	%
Patients Sex (Male/Female)	60/40	60/40	58/42	58/42
Education				
Literacy (Yes/No)	92/8	92/8	87/13	87/13
Primary level	74	80.43	70	80.45
High level	15	16.30	12	13.79
University level	3	3.27	5	5.76

**TABLE 2:** Seizure features and related issues of the study group (n=100).

Duration	Mean ± SD (min-max)	
Age of onset of epilepsy (years)	3.84±3.48 (1-13)	
Duration of epilepsy (months)	39.67±40.36 (3-160)	
<b>Epilepsy features</b>		
Type of seizures	n	%
Generalized	75	75
Partial	25	25
<b>Frequency of seizures</b>		
<10/year	48	48
1-2/month	37	37
2-3/week	15	15
<b>Antiepileptic treatment</b>		
Monotherapy	61	61
Polytherapy	39	39
Intractability of seizures (Yes/No)	45/55	45/55
Motor/mental retardation (Yes/No)	81/19	81/19

**TABLE 3:** The mean anxiety and depression scores in both epilepsy and control groups.

	Epilepsy (n=100)	Control (n=100)	p
Beck Depression Inventory (BDI)	15.04±11.08	13.90±10.77	0.285
Beck Anxiety Inventory (BAI)	12.61±10.50	8.17±5.36	0.006*
State-Trait Anxiety Inventory 1 (STAI 1)	42.89±7.95	41.20±7.35	0.060
State-Trait Anxiety Inventory 2 (STAI 2)	50.05±6.93	46.86±6.37	0.001*

\*p<0.05.

years (range:1-17 years) and 3.84±3.48 years (range:1-13 years), respectively. The mean duration of epilepsy was 39.67±40.36 months (range: 3-160 months).

Details of disease and treatment of epileptic children were summarized in Table 2.

As far as depression status of both groups were concerned, the mean Beck depression score was 15.04±11.08, and 60% of mothers had depression (Table 3). The depression levels were classified as having mild, moderate and severe depression and their distribution was as 20 (33.3%), 27 (45%) and 13 (21.6%), respectively (Table 4). However, 40% (n=40) of mothers had no signs of depression. The mean Beck depression score was found to be 13.90±10.77 in control group (Table 3). Besides, 55% of mothers in this group had depression to

some extent which was classified as mild, moderate and severe depression and the distribution of the depression levels were 36 (65.4%), 16 (29.09%), and 3 (5.4%), respectively (Table 4). There was no statistically significant difference between groups in terms of depression ( $p=0.285$ ).

Beck anxiety inventory was used to determine the levels of anxiety of mothers in both groups. In the study group, 55% of the mothers had anxiety whereas 45% of them did not. Twenty-five mothers had mild, sixteen had moderate and fourteen had severe anxiety. On the other hand, in the control group, 46% of the mothers had varying levels of anxiety. Thirty-four mothers had mild and twelve had moderate levels of anxiety. None had severe anxiety in the control group (Table 5). The mean Beck anxiety score of the study group was  $12.61\pm 10.50$  compared to  $8.17\pm 5.36$  in the control group. There was a significant difference between the groups in terms of the anxiety scores ( $p=0.006$ , Table 3).

The state and trait anxiety levels of the mothers were evaluated using State-trait anxiety inventory 1 and 2 (STAI-1 and STAI-2). There was no statistically significant difference in the mean STAI-1 scores between the groups ( $42.89\pm 7.95$  and  $41.20\pm 7.35$ ) for the study and control groups, respectively, ( $p=0.06$ ). However, there was a significant increase in the mean STAI-2 scores in

terms of trait anxiety for the study group compared to controls ( $p=0.001$ ) ( $50.05\pm 6.93$  and  $46.86\pm 6.37$  for the study and control groups, respectively) (Table 3).

The mean duration of epileptic disorder in the study group was  $39.67\pm 40.36$  months (range: 3-160 months). There was no statistically significant relationship between the duration of the disease and the depression or anxiety of the mothers ( $p=0.547$  and  $p=0.064$  respectively).

## DISCUSSION

Taking care of a child with a chronic disorder is one of the most stressful situations for parents. Emotional distress is frequently seen when the child takes the first diagnosis and during exacerbation periods of the disease. Taking care of children who have chronic disorders is mostly undertaken by their mothers and therefore they are susceptible to the negative effects related to familial situation compared to fathers.<sup>15</sup> A great number of studies examining the psychological and psychosocial effects of chronic childhood disorders on the family lives revealed that parents of children with chronic diseases are at higher risk of emotional distress.<sup>3,15,16</sup> Recent studies have clearly demonstrated that mothers of children with chronic disorders tend to be more susceptible to emotional trauma due to possible stress factors.<sup>3-8</sup> These may have been caused by the unpredictable course of the illness when the child may have been at risk of death during seizures and social stigmatization.<sup>17</sup>

Studies conducted by Shore et al. and Weinstein et al. reported higher rates of stress among families of children with epilepsy.<sup>18,19</sup> Rodenburg et al. pointed out the familial factors and the psychopathologies among parents with epileptic children.<sup>20</sup> Similarly, in another study by Ferro and Speechley, mothers taking care of epileptic children had borderline or higher scores of depression.<sup>21</sup> In addition, a study conducted among Turkish families with epileptic children revealed high rates of post-traumatic stress disorder and major depression in such parents.<sup>22</sup>

**TABLE 4:** Depression severity of the participants.

	Epilepsy (n=100)	Control (n=100)
None	40	45
Mild	20	36
Moderate	27	16
Severe	13	3

**TABLE 5:** Anxiety levels of both groups.

	Epilepsy (n=100)	Control (n=100)
None	45	54
Mild	25	34
Moderate	16	12
Severe	14	0

Akay et al. evaluated the depression and anxiety scores, their parental attitudes and family functions of 50 mothers having children with epilepsy.<sup>3</sup> In the epilepsy group, depression and anxiety scores were found significantly higher than those of the controls. In addition, even higher anxiety levels were found in mothers whose children had intractable epilepsy. Similar to the findings of this study, we found higher anxiety levels in mothers with epileptic children compared to controls. However, there was no significant relationship between the anxiety levels of mothers and the presence of intractable epilepsy. Unlike this study, we found no statistical difference between groups in terms of depression levels of mothers.

In contrast to many other studies in the literature, Baki et al. examined the depression and anxiety levels of 35 epileptic children/adolescents and their mothers.<sup>23</sup> They reported higher depression levels in epileptic children than those of controls. However, there was no difference in anxiety levels of both groups. Moreover, neither the depression nor the anxiety levels of mothers with children having epilepsy were higher than that of controls. Unlikely, we did not evaluate the depression and anxiety levels of epileptic children. Our study findings support the report of Baki et al; although scores of Beck depression scales were higher than those of controls, there was no statistically significant difference between the study and control group. However, the Beck anxiety scale scores and STAI2 levels were significantly higher in the study group compared to control group.

Williams et al. studied the mean anxiety levels of 200 parents (179 mothers and 21 fathers) of children with epilepsy.<sup>6</sup> They reported that the mean anxiety levels were within normal range and did

not correlate with the seizure type or frequency. Similar to these findings, in our study, we could not establish any relationship between anxiety in mothers and intractability of seizures to antiepileptics. In contrast to Williams et al.'s study, we found higher anxiety scores in the study group. Another study conducted, demonstrated that parents of children with epilepsy had higher depression and anxiety levels compared to those with healthy children, using Zund depression scale and Zund anxiety scale.<sup>17</sup> In our study, although depression scale scores were far higher than that of controls, there was no statistical significant difference. We suppose that this is due to the acceptance of disease by the parents as a fate and a fact that cannot be resolved through striving. The differences received in various study populations may be related to the distinct social and medical support systems that are in place.

Parent has to deal with many troublesome issues like unexpected course of seizures and the potential risk of injuries and death during seizures. For instance, a great number of mothers could not maintain their careers. Epilepsy may also affect the relationship among family members and cause restrictions in their social lives. Besides these, economical burden of this chronic disease gives rise to another stressing factor for the family. For all these reasons, childhood epilepsy can easily have a negative impact on parents' physical and/or mental well-being. In conclusion, epilepsy is a chronic condition which may cause impairment in the quality of life of parents of affected children and have a detrimental effect on their psychological profiles. Hence, the awareness of clinicians about the psychosocial consequences for the parents of children with epilepsy may help providing better support and care for such families.

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