Ağrı Tıp Fakültesi Dergisi 2026 4(2):87-94
e-ISSN: 2980-0978

Research Article/ Araştırma Makalesi
DOI: 10.61845/agrimedical.1798384

Evaluation of epilepsy-related knowledge levels and stigma perceptions among parents of children diagnosed with epilepsy: A descriptive study

Epilepsi tanılı çocuğu olan ebeveynlerin epilepsiye ilişkin bilgi düzeyleri ve damgalanma algılarının değerlendirilmesi: Tanımlayıcı bir çalışma

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Gönderilme Tarihi: 08/10/2025
Kabul Tarihi: 22/06/2026
Yayınlanma Tarihi: 30/06/2026

Cite this article:
Sayik D, Yimenicioglu S, Acikgoz A, Yigit D. Evaluation of epilepsy-related knowledge levels and stigma perceptions among parents of children diagnosed with epilepsy: A descriptive study. *Ağrı Med J.* 2026; 4(2):87-94.

ABSTRACT

Aim: Epilepsy is one of the chronic neurological diseases observed in childhood and significantly affects not only the child but also the knowledge levels and perceptions of social stigma among caregiving parents. This study was conducted to determine the levels of epilepsy-related knowledge and stigma perceptions among parents of children diagnosed with epilepsy.

Materials and Methods: This descriptive and cross-sectional study was completed with 55 parents. Data were collected through face-to-face interviews with parents of children attending a pediatric neurology outpatient clinic in a single center in Türkiye. The "Introductory Information Form," "Parental Stigma Scale," and "Parental Epilepsy Knowledge Scale" were used. Statistical significance was accepted as $p<0.05$.

Results: The mean age of children diagnosed with epilepsy was 9.25±3.65 years and the mean time of diagnosis was 42.93±33.90 months. The mean score of the epilepsy knowledge was 11.87±2.49 and the mean score of the stigmatization was 2.57±0.93. As the mean score of the epilepsy knowledge increased, the mean score of the parental stigmatization decreased. A statistically significant negative relationship was found between these two scales ($r=-0.274$, $p<0.05$).

Conclusion: Parents' epilepsy-related knowledge levels and stigma perceptions were found to be moderate. As parents' knowledge levels increased, their perceptions that their children would be stigmatized decreased significantly. Based on these findings, it is recommended that regular and structured educational programs be planned for children diagnosed with epilepsy and their parents, and that comprehensive support approaches addressing the physical, psychological, and social needs of the child and family be developed.

Keywords: *Knowledge, Stigmatization, Parent, Epilepsy, Child*

ÖZ

Amaç: Epilepsi, çocukluk çağında görülen kronik nörolojik hastalıklardan biri olup yalnızca çocuğu değil, bakım veren ebeveynlerin bilgi düzeylerini ve toplumsal damgalanma algılarını da önemli ölçüde etkilemektedir. Bu çalışma, epilepsi tanılı çocuğu olan ebeveynlerin epilepsiye yönelik bilgi düzeyleri ve damgalanma algılarının belirlenmesi amacıyla yapılmıştır.

Gereçler ve Yöntemler: Tanımlayıcı ve kesitsel tipte olan araştırma, 55 ebeveyn ile tamamlanmıştır. Araştırma, Türkiye'de tek merkezde çocuk nöroloji polikliniğine gelen hastaların ebeveynleri ile yüz yüze görüşülerek yapılmıştır. Verilerin toplanmasında "Tanıtıcı Bilgi Formu", "Ebeveyn Damgalanma Ölçeği" ve "Ebeveyn Epilepsi Bilgi Ölçeği" kullanılmıştır. $p<0,05$ istatistiksel olarak anlamlı kabul edilmiştir.

Bulgular: Epilepsi tanısı alan çocukların yaş ortalamasının 9,25±3,65, tanı alma zamanlarının 42,93±33,90 ay olduğu belirlenmiştir. Ebeveynlerin Epilepsi Bilgi Ölçeği puan ortalamasının 11,87±2,49, Ebeveyn Damgalanma Ölçeği puan ortalamasının 2,57±0,93 olduğu tespit edilmiştir. Ebeveynlerin epilepsi bilgi ölçeği puan ortalaması arttıkça ebeveyn damgalama ölçeği puan ortalaması azalmıştır. Bu iki ölçek arasında negatif yönde istatistiksel olarak anlamlı bir ilişki bulunmuştur ($r=-0,274$, $p<0,05$).

Sonuç: Çalışmada ebeveynlerin epilepsi bilgi düzeyleri ve epilepsili çocukları ile ilgili damgalanma algıları orta düzeydedir. Ebeveynlerin bilgi düzeyleri arttıkça, çocuklarının damgalanacağı ilişkin algıları anlamlı bir şekilde azalmaktadır. Önerimiz; epilepsi tanısı alan çocuklar ve ebeveynlerine yönelik düzenli ve yapılandırılmış eğitim programlarının planlanması; çocuk ve ailesinin fiziksel, psikolojik ve sosyal gereksinimlerini kapsayan bütüncül destek yaklaşımlarının geliştirilmesi önerilmektedir.

Anahtar Kelimeler: *Bilgi, Damgalama, Ebeveyn, Epilepsi, Çocuk*

INTRODUCTION

Epilepsy is a neurological disease in which abnormal and recurrent seizures occur (1). While the point prevalence of epilepsy is 6.38 per 1000 people, its lifetime prevalence is 7.60 per 1000 people (2). Epilepsy is common in childhood as well as in adults. This disease can negatively affect children and their families physically, psychologically, and socially (3). In order to prevent negative effects on the child's growth and development, early diagnosis and correct treatment should be provided, seizures should be controlled, and the child and family should be supported physically, psychologically, and socially (3-5).

Controlling and treating the symptoms of children diagnosed with epilepsy is a difficult process for the child and the family. Frequent seizures especially negatively affect the child and their family (6-8). In environments outside the home, such as schools and public spaces, the occurrence of seizures may lead to feelings of shame and anxiety among children and their families. Studies indicate that individuals who witness a child having a seizure may display negative reactions toward the child and their family (9–11). These behaviors—such as avoidance, social exclusion, blaming parents for inadequate care, labeling the child as dangerous or incapable, and limiting participation in educational or social activities—can reinforce misconceptions about epilepsy and contribute to stigmatization (6–11).

Stigmatization is therefore recognized as one of the major psychosocial problems experienced by children with epilepsy and their families during the disease and treatment process. Stigmatization refers to society's negative attitudes toward certain patient groups, leading to labeling, discrimination, and social exclusion. Previous studies have shown that stigma related to epilepsy remains widespread and persistent across different societies and cultures (9–13). Families often report feelings of isolation, anxiety, and helplessness as a result of stigmatizing experiences, which may adversely affect treatment adherence and the child's psychosocial development.

The literature suggests that education and psychosocial support play a critical role in reducing stigma and improving attitudes toward epilepsy. Educational interventions targeting families have been shown to increase knowledge about epilepsy, improve seizure management, and reduce fear and misconceptions. However, despite these findings, studies also report that parents of children with epilepsy frequently have insufficient or incorrect knowledge about the disease, its causes, treatment, and prognosis, which may contribute to heightened perceptions of stigma and negative coping strategies (8,14-17). Moreover, the level of stigma experienced by families varies, and the factors influencing this variability particularly parental knowledge level are not yet fully understood.

Although the literature emphasizes education and support as key strategies for addressing stigma, there is limited empirical evidence examining the relationship between parents' knowledge about epilepsy and their perceptions of stigmatization, especially in parents of children diagnosed with epilepsy. Determining whether inadequate knowledge is associated with higher levels of perceived stigma is essential for developing effective, targeted educational and psychosocial interventions.

Therefore, this study was conducted to determine the knowledge levels of parents of children diagnosed with epilepsy and their perceptions of stigma, as well as to examine the relationship between parental knowledge level and stigmatization. Understanding this relationship will contribute to the development of evidence-based educational and support programs aimed at reducing stigma and improving the quality of life of children with epilepsy and their families.

MATERIALS AND METHODS

Study Design and Type

This descriptive study was conducted between April 1 and July 31, 2023, at the pediatric neurology outpatient clinic of the City Hospital in Eskişehir, Turkey**.**

Population and Sample

The population of this study consisted of parents of children diagnosed with epilepsy who applied to the pediatric neurology outpatient clinic of a single center in Türkiye.

The sample was selected using a convenience sampling method and included parents who met the inclusion criteria. The inclusion criteria were the parent's ability to read and write in Turkish, have a child who had been diagnosed with epilepsy at least six months prior, and providing verbal and written informed consent after being informed about the study. Parents who refused to participate and those whose children did not have an epilepsy diagnosis were excluded from the study.

The sample size was determined using power analysis. Based on an effect size of 0.50, a significance level (α) of 0.05, and a statistical power of 90%, it was calculated that a minimum of 55 participants would be sufficient. Accordingly, the study was completed with 55 parents who met the inclusion criteria.

The dependent variables of the study were the parents' levels of knowledge about epilepsy and their perceptions of stigma. The independent variables consisted of the sociodemographic and clinical characteristics of the parents and their children.

Ethical Aspects of the Research

Prior to commencing the study, ethical committee approval (Date: June 3, 2020, Decision: 188) and institutional permission (April 11, 2022) were obtained. The study only included parents who, after being informed, provided both written and verbal consent.

Data Collection Tools

"Introductory Information Form", 'Parental Stigmatization Scale (PSS)' and 'Parental Epilepsy Knowledge Scale (PEKS)' were used to collect the study data.

Introductory Information Form; According to the literature, the researchers created the form (2,4,5,9). This form asks about the parents' and children's sociodemographic traits as well as their awareness of the epilepsy diagnosis.

Parental Stigma Scale (PSS); The scale developed by Austin et al. (17) was developed to determine how parents with children with epilepsy perceive their children with epilepsy compared to other children (17). Turkish validity and reliability was conducted in 2016 and Cronbach's alpha value was found to be 0.87. The scale consists of 5 items and each item is scored from 1 to 5 (1 - Strongly disagree, 2 - Disagree, 3 - Undecided, 4 - Agree, 5 - Strongly agree). The total score of the scale is obtained by dividing the total score of the items by the total number of items (n=5). No cut-off value was given for the scale. As the total score increases, it is understood that parents' stigmatization perceptions about their children with epilepsy are high (18). In this study, Cronbach's alpha was found to be 0.87.

Parental Epilepsy Knowledge Scale (PEKS); The scale was developed by Austin et al. (19) to measure the general knowledge level of parents about epilepsy (19). The Turkish validity and reliability of the scale was conducted by Unal in 2004, and the Cronbach's alpha value was found to be 0.78. The scale consists of 20 items including the cause and complications of seizures, emergency care, cognitive and psychosocial consequences and limitations. Each item is numbered 0 and 1 (0-False, 1-Correct) and the total score of the scale varies between 0-20. No cut-off value was given for the scale. A high total score indicates that families have a high level of knowledge (20). In this study, Cronbach's alpha was found to be 0.80.

Data Collection

Data were collected by the researcher through face-to-face interviews with parents (mother or father) of children diagnosed with epilepsy who applied to the pediatric neurology outpatient clinic of a single center in Türkiye. Participants were approached during their outpatient clinic visits, prior to or following their medical appointments, in a quiet and private area of the clinic to ensure confidentiality. After the parents were informed about the purpose and procedures of the study and provided verbal and written informed consent, data collection was conducted.

The questionnaires were administered by the researcher and completed through structured interviews, which took approximately 15 minutes for each participant. Data collection was carried out over the study period during routine clinic hours (09:00-16:00).

Table 1. Comparison of parents' and children's characteristics with PSS and PEKS scores

Variable (N=55)	n (%)	PSS Scores		Statistical analysis*	PEKS Scores		Statistical analysis*
		Median	Min-Max		Median	Min-Max	
Maternal Age (X±SD; 35.76±5.76)							
22-35	26 (47.3)	2.2	1.0-4.0	Z=-0.220	11.0	8.0-15.0	Z=-1.503
36-47	29 (52.7)	2.4	1.0-4.0	p=0.826	13.00	8.0-17.0	p=0.133
Father's Age (X±SD; 39.13±5.44)							
27-40	35 (63.6)	2.2	1.0-4.0	Z=-0.123	11.0	8.0-17.0	Z=-1.276
41-53	20 (36.4)	2.5	1.0-4.0	p=0.902	13.0	8.0-17.0	p=0.202
Mother's education status							
Primary education	27 (49.1)	2.2	1.0-4.0	$\chi2 = 0.006$	12.0	8.0-17.0	$\chi2 = 0.027$
High school	20 (36.4)	2.6	1.0-4.0	p=0.940	11.5	9.0-15.0	p=0.870
University	8 (14.5)	2.3	2.0-4.0		10.0	8.0-15.0	
Father's education status							
Primary education	24 (43.6)	2.2	1.0-4.0	$\chi2 = 0.623$	11.00	8.0-17.0	$\chi2 = 1.606$
High school	21 (38.2)	2.2	1.0-4.0	p=0.430	13.00	9.0-17.0	p=0.205
University	10 (18.2)	3.2	1.0-4.0		12.00	8.0-15.0	
Mother's employment status							
Yes	11 (20.0)	3.2	2.0-4.0	Z=-1.128	10.0	8.0-15.0	Z=-1.460
No	44 (80.0)	2.2	1.0-4.0	p=0.201	12.0	9.0-17.0	p=0.144
Father's employment status							
Yes	49 (89.1)	2.2	1.0-4.0	Z=-1.030	12.0	8.0-17.0	Z=-0.410
No	6 (10.9)	2.2	1.0-3.0	p=0.303	12.0	9.0-15.0	p=0.682
Place of residence							
Village/district	16 (29.1)	2.1	1.0-4.0	Z=-1.367	11.0	8.0-15.0	Z=-1.389
Province	39 (70.9)	2.6	1.0-4.0	p=0.171	13.00	8.0-17.0	p=0.165
Income Status							
Income is less than expenses	17 (30.9)	2.2	1.0-4.0		11.00	8.0-17.0	
Income equals expenses	30 (54.5)	2.2	1.0-4.0	$\chi2 = 1.815$	13.00	8.0-17.0	$\chi2 = 3.707$
Income is more than expense	8 (14.6)	3.2	2.0-4.0	p=0.404	10.00	8.0-14.0	p=0.157
Family type							
Nuclear family	47 (85.5)	2.6	1.0-4.0	Z=-1.702	11.00	8.0-17.0	Z=-0.109
Extended family	8 (14.5)	2.0	2.0-3.0	p=0.089	12.00	9.0-16.0	p=0.913
Child's age (X±SD; 9.25±3.65)							
2-9	30 (54.5)	2.2	1.0-4.0	Z=-1.044	10.00	8.0-17.0	Z=-1.978
10-17	25 (45.5)	2.6	1.0-4.0	p=0.297	13.00	8.0-17.0	**p=0.048**
Gender of the child							
Girl	30 (54.5)	2.2	1.0-4.0	Z=-1.502	12.00	9.0-17.0	Z=-1.112
Male	25 (45.5)	3.0	1.0-4.0	p=0.133	10.00	8.0-17.0	p=0.266
Child's school attendance status							
Yes	47 (85.5)	2.4	1.0-4.0	Z=-0.995	12.00	8.0-17.0	Z=-0.254
No	8 (14.5)	2.1	1.0-3.0	p=0.320	11.00	9.0-14.0	p=0.800

Z = Mann-Whitney U test, χ^2 = Kruskal-Wallis H test,
PSS = Parental Stigma Scale, PEKS = Parental Epilepsy Knowledge Scale

Statistical Analysis

Statistical analyses were performed using the IBM SPSS Statistics for Windows software package (Version 21.0; IBM Corp., Armonk, NY, USA). Descriptive statistics (frequency, percentage, mean, and standard deviation) were used to summarize the data. The normality of continuous variables was assessed using the Kolmogorov–Smirnov and Shapiro–Wilk tests. Given the sample size, the Shapiro–Wilk test was taken as the primary criterion, and the data were found not to be normally distributed. Accordingly, continuous variables were summarized using median and minimum–maximum values. Accordingly, non-parametric analyses were conducted. The relationship between variables was evaluated using the Spearman correlation test, differences between two independent groups were analyzed using the Mann–Whitney U test, and comparisons among three or more groups were performed using the Kruskal–Wallis H test. A p-value of <0.05 was considered statistically significant.

RESULTS

The mean age of the mothers participating in the study was determined to be 35.76±5.76, the mean age of the fathers was 39.13±5.44, and the mean age of their children was 9.25±3.65. Parents of children aged 2–9 years had lower PEKS scores (median = 10.0, min–max = 8.0–17.0) than parents of children aged 10–17 years (median = 13.0, min–max = 8.0–17.0). A statistically significant difference was found between the child's age and the mean PEKS score ($p<0.05$). No statistically significant difference was found between the other characteristics of the parents and children and the mean PSS and PEKS scores. No statistically significant differences were found in PSS and PEKS scores according to parents' age, education level, employment status, place of residence, income level, and family type, as well as the child's age (for PSS), gender, and school attendance status ($p>0.05$). Table 1 compares the characteristics of the parents and children with the PSS and PEKS scores.

The duration of the children's epilepsy diagnosis was determined to be 42.93±33.90 months. We found that 98.2% of the children regularly used their medications and visited the hospital for check-ups. It was determined that 83.6% of the parents were informed about their child's disease and treatment process, but 69.1% did not know the type of seizure their child was experiencing. No statistically significant difference was found between the characteristics of epilepsy and the mean scores of PSS and PEKS. No statistically significant differences were found in PSS and PEKS scores according to the duration since epilepsy diagnosis, frequency of seizures, seizure status under medication, parental knowledge of seizure type, knowledge about the child's illness and treatment process, difficulty in caregiving, and the impact of epilepsy diagnosis on family relationships ($p>0.05$). Table 2 presents the comparison of epilepsy-related characteristics according to PSS and PEKS scores.

It was determined that the parents' PSS mean score was 2.57±0.93, and the PEKS mean score was 11.87±2.49. A weak, negative but statistically significant correlation was found between PSS and PEKS scores (Spearman $r = -0.274$, $p = 0.043$). Table 3 provides a correlation of the parents' PSS and PEKS mean scores.

Table 2. Comparison of the Characteristics of Epilepsy Disease with PSS and PEKS Scores

Variable (N=55)	n (%)	PSS Scores		Statistical analysis*	PEKS Scores		Statistical analysis*
		Median	Min-Max		Median	Min-Max	
The time the child was diagnosed with epilepsy (months) (X±SD; 42.93±33.90)							
0-12 months	11 (20.0)	2.6	1.0-4.0	$\chi2 = 1.922$ p=0.557	11.0	9.0-15.0	$\chi2 = 0.789$ p=0.852
13-36 months	22 (40.0)	2.4	1.0-4.0		10.5	8.0-17.0	
37-60 months	6 (10.9)	2.2	1.0-3.0		13.0	10.0-15.0	
61 months and above	16 (29.1)	2.8	1.0-4.0		12.0	8.0-15.0	
Frequency of seizures in the child							
At least once a month	4 (7.3)	3.8	3.0-4.0	$\chi2 = 4.164$ p=0.125	12.5	9.0-17.0	$\chi2 = 2.217$ p=0.330
At least once a year	9 (16.4)	3.2	2.0-4.0		10.0	8.0-15.0	
Irregular	29 (52.7)	2.2	1.0-4.0		11.0	8.0-15.0	
No seizures under medication	13 (23.6)	2.2	1.0-4.0		13.0	10.0-17.0	
Parental knowledge of seizure type							
Yes	17 (30.9)	2.2	1.0-4.0	Z=-0.512 p=0.609	12.0	8.0-15.0	Z=-0.369 p=0.712
No	38 (69.1)	2.4	1.0-4.0		11.0	8.0-17.0	
Parents' knowledge of their child's illness and treatment process							
Yes	46 (83.6)	2.2	1.0-4.0	Z=-0.240 p=0.810	11.5	8.0-17.0	Z=-0.254 p=0.800
No	9 (16.4)	3.0	1.0-4.0		13.0	9.0-17.0	
Parental difficulty in caregiving							
Yes	4 (7.3)	2.8	2.0-4.0	Z=-0.374 p=0.708	14.5	10.0-15.0	Z=-1.477 p=0.140
No	51 (92.7)	2.2	1.0-4.0		11.0	8.0-17.0	
Impact of epilepsy diagnosis on family relationships							
Present	4 (7.3)	2.1	2.0-4.0	Z=-0.407 p=0.684	11.5	8.0-15.0	Z=-2.295 p=0.768
Absent	51 (92.7)	2.4	1.0-4.0		12.0	8.0-17.0	
Total	**55 (100)**						

Z = Mann-Whitney U test, χ^2 = Kruskal-Wallis H test

PSS = Parental Stigma Scale, PEKS = Parental Epilepsy Knowledge Scale

Table 3. Correlation Between PSS and PEKS Scores of Parents

	PEKS Score (X±SD; 11.87±2.49)	
	r*	p
PSS Score (X±SD; 2.57±0.93)	-0.274	**0.043**

*r= Spearman correlation coefficient, n = 55
PSS = Parental Stigma Scale, PEKS = Parental Epilepsy Knowledge Scale

DISCUSSION

School attendance represents a critical indicator of disease management, developmental functioning, and social integration in children with epilepsy. A total of fifty-five parents of children with epilepsy participated in this study. According to the findings, 85.5% of the children were attending school. School attendance among children with epilepsy is considered an important indicator of effective disease management, age-appropriate developmental functioning, and social integration. The literature suggests that regular school attendance supports both seizure control and psychosocial adjustment in children with epilepsy (21). However, previous studies have also reported that epilepsy-related seizures and treatment procedures may lead to school absenteeism and negatively affect academic performance (22,23). In this context, seizure frequency and severity are among the key variables influencing children's academic functioning, and the impact of these factors may vary across age groups. The high rate of school attendance observed in this study suggests that disease management may be relatively effective and that children are supported in maintaining their educational engagement. When considered together with parental coping levels and scale scores, this finding highlights the potential interactions between demographic and clinical variables, thereby providing a more meaningful and discussable framework for interpreting the study results.

Seizure frequency and severity are key clinical variables influencing children's academic functioning, and the effects of these factors may vary across age groups. The high rate of school attendance observed in this study suggests relatively effective disease management and sustained educational engagement. When considered together with parental coping levels and scale scores, this finding points to potential interactions between demographic and clinical variables, thereby allowing the study results to be interpreted within a more meaningful and discussable framework. In the present study, parents of children aged 10–17 years demonstrated higher levels of knowledge about epilepsy. Consistent with the literature, parents of children with epilepsy tend to develop greater experience and awareness of the condition over time (24). As children in this age group gain increasing independence, parental involvement in disease management becomes more structured and proactive (25,26). Previous studies indicate that parental awareness of epilepsy increases as children grow older, which positively influences seizure management and adherence to treatment (23,24). The higher knowledge levels observed among parents of older children in this study may therefore be attributed to accumulated caregiving experience and prolonged engagement with epilepsy management processes.

The children were diagnosed with epilepsy at a mean age of 42.93 ± 33.90 months. All children were compliant with their prescribed medication and attended regular hospital follow-up visits. In addition, nearly all parents stated that they were informed about their child's illness and treatment process. However, despite this general awareness, more than half of the parents were unable to identify the specific type of seizure experienced by their child. This finding suggests that parental knowledge may be uneven, with gaps particularly evident in clinically critical areas. The duration of epilepsy prior to diagnosis is a crucial factor for children's neurological and cognitive development, as delays in diagnosis may hinder cognitive functioning and complicate seizure control (26,27). Although regular medication use and follow-up attendance in the present study indicate relatively effective disease management, limited parental knowledge regarding seizure types may negatively affect timely recognition of seizures and appropriate response. Supporting this interpretation, previous research has shown that inadequate follow-up attendance and poor medication adherence are associated with suboptimal disease management in children with epilepsy (24). Taken together, these findings highlight the importance of not only treatment adherence but also comprehensive parental education in achieving optimal clinical outcomes.

In a study by Pellinen et al. (26), more than half of the parents were unaware of the types of seizures their children were experiencing, which made it difficult to provide appropriate interventions in emergency situations. Insufficient knowledge regarding seizure types and their management has been shown to negatively affect children's health outcomes (8,24). Conversely, evidence suggests that disease management improves when parents are well informed about their child's condition and treatment approaches (25). This finding is particularly important, as it underscores the necessity for parents to have a high level of understanding of epilepsy and its clinical course to ensure timely and effective management.

The present study found that nearly all parents reported no difficulties in providing care for their children and that an epilepsy diagnosis did not negatively affect family relationships. Although previous studies have indicated that caring for a child with epilepsy is often a stressful process (28,29), the intensity of this stress appears to be closely related to families' social support systems, knowledge levels, and experience in disease management. While chronic conditions such as epilepsy may influence family dynamics, the direction and magnitude of this effect largely depend on the family's coping capacity (28). Evidence suggests that strong family communication can mitigate the challenges associated with chronic illness and may even contribute to improved family relationships (30). Supporting this perspective, Wei et al. (29) reported that families of children with epilepsy often demonstrate high levels of resilience, which are positively associated with parental psychological well-being and social support. Strong social support plays a protective role in reducing caregiving-related challenges,

highlighting its importance in promoting adaptive family functioning during the disease management process.

The findings of the present study indicate that parents had a moderate level of awareness about epilepsy and experienced a moderate degree of stigma related to their children's condition. Importantly, as parents' knowledge levels increased, their perceptions of stigmatization toward their children decreased. Consistent with these results, Bulduk and Can (31) reported that limited parental knowledge about epilepsy contributes to the intensification of stigma. Previous studies have also shown that parents who receive adequate information about epilepsy are more resilient to societal stereotypes and discriminatory attitudes (32). Pryor and Arjan (33) similarly emphasized that stigma surrounding epilepsy is closely associated with a lack of knowledge, particularly in relation to the psychological effects of social labeling. Furthermore, Rani and Thomas (12) demonstrated that improving parental awareness of epilepsy not only reduces stigma but also enhances children's quality of life and strengthens families' caregiving capacity. Collectively, these findings underscore the critical role of parental education in reducing stigma and promoting more effective disease management and psychosocial outcomes.

Stigma provides a central framework for interpreting the findings of the present study. Consistent with the literature (8,34–36), increases in parents' knowledge about epilepsy are associated with reduced anxiety and lower perceptions of stigma, thereby strengthening resilience against societal misconceptions. Although the overall pattern of the findings aligns with previous evidence, some relationships did not reach statistical significance. This may be related to the limited sample size, the predominantly moderate levels of knowledge and stigma among participants, and the restricted variability within the study population. These findings suggest that the relationship between parental knowledge and stigma is complex and may not be fully captured through quantitative associations alone. While higher knowledge levels appear to contribute to reduced stigma, this effect is likely influenced by additional factors such as cultural context, individual coping mechanisms, and family support structures. Therefore, even in the absence of statistically strong relationships, it can be inferred that parental education plays an important role in shaping stigma-related perceptions. Further studies with larger and more diverse samples may help to clarify the magnitude and mechanisms of this relationship.

CONCLUSION

The findings of this study indicate that parents are actively involved in managing their children's epilepsy, as reflected by regular follow-up attendance and high school participation rates, which together suggest relatively effective disease management. However, despite this involvement, a substantial proportion of parents lacked knowledge about seizure types, highlighting a critical gap in epilepsy-specific awareness. Importantly, higher parental knowledge was associated with lower perceptions of stigma, demonstrating that knowledge functions as a key protective factor against stigmatizing attitudes.

Based on these findings, targeted educational interventions are warranted to address identified knowledge gaps, particularly regarding seizure recognition and management. Education-focused programs for parents may not only improve clinical management but also contribute to reducing stigma and enhancing psychosocial outcomes for children with epilepsy. In addition, community-based educational initiatives aimed at increasing public awareness may help mitigate societal misconceptions and stigma. Future studies employing interventional designs are recommended to evaluate the effectiveness of structured educational programs on parental knowledge, stigma reduction, and disease management outcomes.

Limitations and strengths

There are several limitations to this study. First, because of the cross-sectional design, dynamic changes in parental knowledge and perceptions of stigma over time could not be assessed. Second, the study was conducted in a single hospital in Eskişehir province with a relatively limited sample size, which may restrict the generalizability of the findings. In addition, parental knowledge and stigma were assessed using self-report measures; therefore, responses may have been influenced by parents' subjective perceptions or social desirability. Another important limitation is that the Parental Stigma Scale was applied without distinguishing between mothers and fathers. Given that caregiving roles and social experiences may differ between mothers and fathers, perceptions of stigma may also vary accordingly. Evaluating parental stigma as a single construct may have obscured potential gender- or role-specific differences. Future multicenter studies, including larger samples and qualitative or longitudinal designs, are recommended to better capture changes in knowledge and stigma over time and to examine potential differences between mothers and fathers.

The strengths of this study include the use of valid and reliable measurement tools and the simultaneous evaluation of parental knowledge and stigma among parents of children with epilepsy within a clinical sample. Assessing these two closely related constructs together provides a more comprehensive understanding of the psychosocial dimensions of epilepsy management. In addition, data were collected through face-to-face interviews, which may have enhanced the accuracy and completeness of the responses by allowing clarification of items and reducing missing data. Conducting the study in a clinical setting also strengthens the relevance of the findings to real-world healthcare practice, as participants were actively engaged in the management of their children's condition.

Ethical Approval

Ethical approval was obtained from the Non-Interventional Clinical Research Ethics Committee of Eskişehir Osmangazi University with decision number 2020 - 188 Karar (25403353-050.99-E.52031), dated June 3, 2020**.**

Conflict of Interest

The authors report no conflict of interest. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

Financial Disclosure
This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Authors' Contributions
D.S.: Conceptualization, Methodology, Software, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - original draft, Writing - review & editing, Visualization, Supervision, Project administration. S.Y.: Conceptualization, Methodology, Writing - original draft, Writing – review & editing, Visualization, Supervision. A. A.: Conceptualization, Methodology, Writing - original draft, Writing – review & editing, Visualization, Supervision. D.Y.: Conceptualization, Methodology, Software, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - original draft, Writing - review & editing, Visualization, Supervision.

Data Sharing Statement
The data that support the findings of this study are available from the corresponding author upon reasonable request.

Declaration of generative AI and AI-assisted technologies in the writing process
The authors declare that no generative AI or AI-assisted technologies were used in the preparation, writing, or editing of this manuscript.

Additional information
An abstract based on this study was presented as an oral presentation at the Mardin Artuklu University Health Sciences Congress (May 8-10, 2025, Mardin, Türkiye) and was published in the congress proceedings book (pp. 37–38).

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