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Research paper

The effect of illness-related fears of parents of children with epilepsy during the COVID-19 period on their children's seizure self-efficacy



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ABSTRACT

Background: Seizure-related self-efficacy is the belief individuals have that they can perform the necessary actions to cope effectively with their seizures. Determining, developing, strengthening, and maintaining the perception of self-efficacy in children with epilepsy facilitates the child's disease management and their ability to cope with it. This study aimed to assess the impact of epilepsy-related parental fears during the COVID-19 period on the seizure self-efficacy of their children.

Methods: A total of 321 children with epilepsy and their parents participated in this descriptive, correlational, and cross-sectional study. Data were collected through the Descriptive Information Form, the Seizure Self-Efficacy Scale for Children (SSES-C), and the Epilepsy-Related Fears in Parents Questionnaire (EFPQ). Descriptive statistics, including frequency, percentage, and mean scores, were used to analyze the characteristics of the children and their parents. The Shapiro–Wilk test was utilized to assess the normality of the scale data. Pearson correlation analysis examined the relationship between parents' epilepsy-related fears and their children's seizure self-efficacy, while multiple regression analysis determined the effect of parental fears on children's seizure self-efficacy.

Results: The mean age of children included in the study was 12.65 ± 2.37 years. Analysis revealed a strong and significant negative correlation between parents' epilepsy-related fears during the COVID-19 period and the seizure self-efficacy of their children. In the model created with regression analysis, the mean scores of parents on the short-term fears of parents about epilepsy of the EFPQ explained 85 % of children's seizure self-efficacy. The mean scores of parents on the long-term fears of parents about epilepsy of the EFPQ explained 85 % of children's seizure self-efficacy. It was determined that all of these variables together explained 85 % of the seizure self-efficacy of children with epilepsy.

Conclusion: The findings of the study underscore the importance of addressing parents' fears regarding epilepsy, emphasizing the need for healthcare professionals to be aware of and provide support for these concerns. Future studies should focus on interventions to enhance the seizure self-efficacy of children with epilepsy.

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Introduction

The new type of coronavirus, severe acute respiratory syndrome coronavirus 2 (SARS CoV-2), and the disease it causes, COVID-19, has spread dramatically across the world, causing unprecedented social

disruption. This disease represents one of the most critical pandemics in human history [1]. It has been reported that the virus does not only involve the lungs or the heart but also has a multisystemic involvement, including the central nervous system and peripheral nervous system, and predominantly affects children with epilepsy and thus the disease management of these children [2–4]. Epilepsy is a chronic disease that is commonly seen in childhood and adolescence, characterized by recurrent seizures, which directly affects both the child with epilepsy and their parents and can cause psychosocial problems

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[5,6]. Disease self-management and seizure-related self-efficacy are very important for children with epilepsy so that they can adjust to the disease and make the necessary life changes [7]. Studies have shown that seizure self-efficacy is important in disease management in children with epilepsy and that seizure self-management increases as the level of self-efficacy increases [8]. It has been reported that children with epilepsy who have a high level of self-efficacy are more successful in taking responsibility for self-care, adjusting to treatment, and controlling their health status [9,10]. It has been determined that children with epilepsy who have low self-efficacy levels have a more negative attitude toward seizure management and experience greater fear of having a seizure, especially during the pandemic [11–13]. In the literature, it is emphasized that one of the factors affecting the seizure self-efficacy of children with epilepsy is parental fear about epilepsy. Parents play a key role in the process of treatment adherence and management of the disease, starting with the acceptance of the child's diagnosis of epilepsy. Therefore, how parents perceive and experience this process is very important [14,15]. Studies have shown that parents experience high levels of fear for various reasons from the time their child is diagnosed, and that particularly the fear of seizures affects the management of epilepsy by parents and children alike [16–18]. Also, parental fear leads to an over-protective attitude, and this process affects the child's adjustment to the illness and treatment adherence [19,20]. Studies have emphasized that these parental fears increased particularly during the pandemic [2,21]. Parents stated that due to restrictions during COVID-19, they experienced difficulties such as not being able to reach health institutions and to access their children's regular medicines and that this situation caused fear [22,23]. It was reported that parental fear of the negative effects of the pandemic on epilepsy-related issues was a risk factor for increased seizures [23,24]. Due to the pandemic, parents avoided taking their children to emergency departments following a seizure and therefore feared that seizures would result in their child's death. Furthermore, cancellation of necessary medical appointments and the closure of pediatric neurology outpatient clinics when the pandemic peaked caused fears in parents that in turn caused fear in children with epilepsy, thereby negatively affecting their seizure self-efficacy [3,25,26]. Although studies conducted before the pandemic on the evaluation of the effect of parental fear levels on self-efficacy are limited, studies performed during the pandemic have shown that parental fear of epilepsy negatively affects their children's self-efficacy [25,27]. There is limited research into the effects of the fears experienced by parents of children with epilepsy during the COVID-19 period on the seizure self-efficacy of these children. We believe that the lack of studies on the parental fears about epilepsy, which directly affects the management of seizures and the disease, is a critical limitation. Tutar Güven et al. (2017) reported that health professionals could provide a more effective treatment process and care by determining and evaluating the seizure self-efficacy levels of children with epilepsy and that they could eventually contribute positively to the child's coping with and management of the disease [28]. In this context, the aim of the present study was to examine the effects of the fears experienced by parents of children with epilepsy during the COVID-19 period on their children's seizure self-efficacy.

Method

Aim of the study

The study was conducted to evaluate the effects of the fears experienced by parents of children with epilepsy during the COVID-19 period on the seizure self-efficacy of their children. A descriptive, correlational, and cross-sectional design was used.

Setting and time of the study

The study was conducted between March 2021 and March 2022. It included 321 children with epilepsy who were registered at the Pediatric Neurology Outpatient Clinic of a Training and Research Hospital in the western region of Turkey, who agreed to participate in the study voluntarily, and met the inclusion criteria of the study and also included their parents. COVID-19 started in March 2020 in Turkey. The study period covers the two most significant peaks of the COVID pandemic in April 2021 (maximum: 60,000 new cases per day) and February 2022 (100,000 new cases per day). During this period, there were restrictions on interurban travel as well as evening and weekend curfews. Vaccination campaigns began in December 2021 in Turkey [29]. The minimum sample size for the study was calculated as 146 children and their parents on the basis of a regression analysis performed with G-Power 3.0.1 software based on a type 1 error of 0.01, a type 2 error of 0.01 (99 % power), and medium effect size ($f^2=0.15$). A total of 321 children with epilepsy and their parents who met the inclusion criteria were included in the study (Fig. 1). Inclusion criteria were as follows: (a) child aged between 9 and 17 years; (b) having epilepsy for at least 6 months; and (c) child and parents willing to participate in the study. The exclusion criteria of the study were as follows: (a) child with mental disability; (b) communication problems; and (c) other chronic diseases (diabetes, cerebral palsy, etc.).

Data collection tools

The study data were collected using the Descriptive Information Form, the Seizure Self-Efficacy Scale for Children (SSES-C), and the Epilepsy-Related Fears in Parents Questionnaire (EFPQ).

Descriptive information form

The form, which was prepared by the researchers following a review of the literature, consists of 26 questions on the sociodemographic and illness-related characteristics of the child.

Seizure self-efficacy scale for children

The SSES-C is a 15-item, 5-point Likert-type scale. It was developed for children aged 9–17 years, who have had epilepsy for at least 6 months, and have no other chronic diseases (diabetes, cerebral palsy, etc.). The score for each item on the scale varies between 1 and 5. The total scale score is divided by the number of questions on the scale and a score between 1 and 5 is obtained. It was evaluated as a valid and reliable scale that can be used for Turkish samples [30].

Epilepsy-Related fears in parents questionnaire

The EFPQ was developed by Hagemann et al. (2018) to evaluate epilepsy-related fears of parents of children with epilepsy [31]. The Turkish validity and reliability study of the scale was performed by Yalçintuğ and Ayar (2021) [32]. The scale has a 5-point Likert-type structure (1=never, 5=very strong) and consists of 17 items and two sub-dimensions. The first sub-dimension (eight items) is about parents' short-term fears about epilepsy, and the second sub-dimension (nine items) is about long-term fears. High scores on the scale show high levels of fear experienced by parents. Analyses have shown that the scale is a valid and reliable measurement tool for evaluating the epilepsy-related fears of parents [32].

Ethics committee approval

Before initiating the study, permission to use the scales was obtained from the scale owners via e-mail. Ethics committee approval (protocol number: 6791-GOA; decision number: 2022/01-05) and institutional permission were obtained from the Non-Interventional Research Ethics Committee. The purpose of the study was

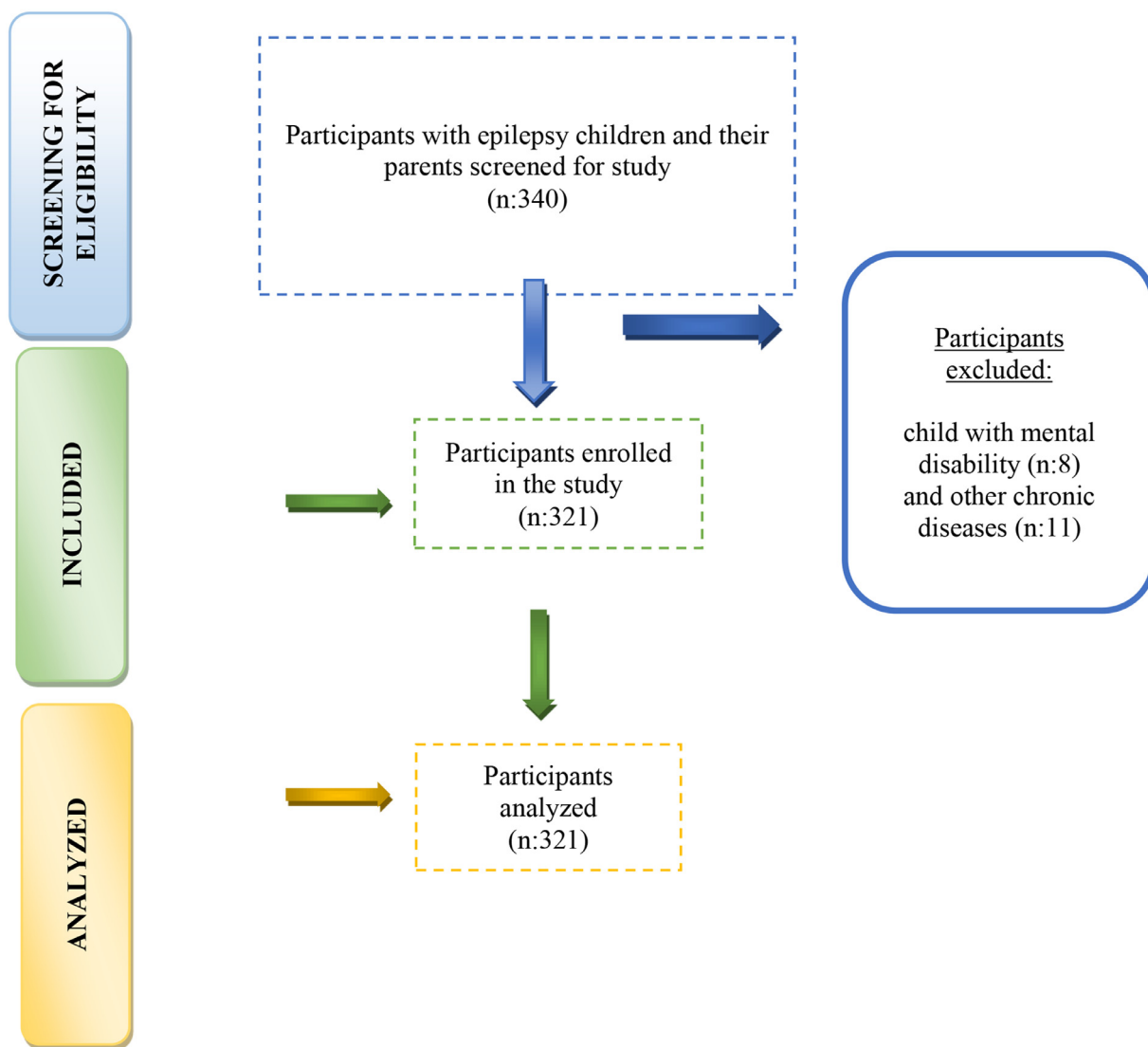


Fig. 1. Study participants flow diagram.

explained to the children included in the study and their parents, and children who voluntarily agreed to participate in the study and delivered a parental consent form as well as their parents were included in the study.

Data analysis

Frequency, percentage, and mean score analyses were used to evaluate the descriptive data of the children and parents. The Shapiro–Wilk test was used to test the normality of data obtained via the scale. The relationship between parents’ epilepsy-related fears and children’s seizure self-efficacy was evaluated using Pearson correlation analysis. The effect of parents’ epilepsy-related fears on their children’s seizure self-efficacy was evaluated using multiple regression analysis. Four models were created in the study. In the first model, the effects of descriptive data—including children’s age, parents’ education level, duration of the epilepsy diagnosis, family history of epilepsy, and parental fear—on children’s self-efficacy were investigated. In the second model, the relationship between the mean scores of parents on the first sub-dimension (short-term parental fears about epilepsy) of the EFPQ and the seizure self-efficacy of their children was examined. In the third model, the relationship between the mean scores of parents on the second sub-dimension

(long-term fears of parents about epilepsy) of the EFPQ and the seizure self-efficacy of their children was examined. In the fourth model, the relationship between the mean scores of parents on the total EFPQ and the seizure self-efficacy of their children was examined. A multicollinearity test was employed to select the variables to be included in the models. In a multicollinearity test, a variance inflation factor (VIF) value of <10, a tolerance value of >0.2, and a condition index value of <15 are required. The variables in this study were included in the model because they met the desired criteria. The significance level was accepted as $p < 0.001$.

Results

The mean age of children included in the study was 12.65 ± 2.37 years, and 55.1 % ($n = 167$) were girls. It was determined that 73.2 % ($n = 235$) of the children had two or more siblings. Regarding the education level of parents, 38 % ($n = 12$) of mothers had primary school education, and 58.4 % ($n = 187$) of fathers had high school education. Also, 27 % ($n = 87$) of the children included in the study had a family history of epilepsy (mother, father, grandparents). It was found that 92 % ($n = 295$) of children had epilepsy for 5 years or more, and 62 % ($n = 197$) had seizures once or twice a month for the last 6 months. All the children included in the study stated that they used their

medicines regularly, 13 % ($n = 42$) of them managed their medicines themselves, and 83 % ($n = 265$) stated that their mothers managed their medicines. Of the children, 92 % ($n = 295$) reported that they did not forget to take their medication, and only 8 % ($n = 26$) reported that they sometimes skipped their medicines. All of the children had their follow-up regularly, 82.8 % ($n = 266$) did not have enough knowledge about their disease, and 95.4 % ($n = 306$) received support from their families for their disease. In addition, 72 % ($n = 231$) of the children had not been hospitalized due to their illness, but 88 % ($n = 283$) stated that their illness affected their daily needs (Table 1.)

Analysis of the correlation between the fear experienced by parents about epilepsy and the seizure self-efficacy of children with epilepsy showed that there was a strong and significant negative correlation between the epilepsy-related fear experienced by parents and their mean scores on the total EFPQ ($r = -0.924, p < 0.001$) (Fig. 2).

Also, there was a strong and significant negative correlation between the seizure self-efficacy of children and parents' mean scores on the first ($r = -0.921, p < 0.001$) and second ($r = -0.924, p < 0.001$) sub-dimensions of the EFPQ. Four models were established considering the relationships between the study variables and children's seizure self-efficacy. Multiple regression analysis was used to evaluate the models.

In model 1, the effects of the descriptive data—including children's age, parents' education level, duration of the epilepsy diagnosis, family history of epilepsy, and parental fear—on children's self-efficacy were investigated. However, regression analysis results indicated that the descriptive data did not affect children's self-efficacy levels significantly ($p > 0.001$).

In model 2, the mean scores of parents on the first sub-dimension (short-term fears of parents about epilepsy) of the EFPQ explained 85 % of children's seizure self-efficacy ($p < 0.001$). There was a strong and significant negative correlation between parents' mean scores on the first sub-dimension of the EFPQ and the seizure self-efficacy of the children ($\beta = -0.921, p < 0.001$).

In model 3, the mean scores of parents on the second sub-dimension (long-term fears of parents about epilepsy) of the EFPQ explained 85 % of children's seizure self-efficacy ($p < 0.001$). A strong and significant negative correlation was found between parents' mean scores on the second sub-dimension of the EFPQ and the seizure self-efficacy of the children ($\beta = -0.924, p < 0.001$).

In model 4, the mean scores of both sub-dimensions of the EFPQ were included in the model. It was determined that all of these variables together explained 85 % of seizure self-efficacy of children with epilepsy. In this model, the most important factors affecting the seizure self-efficacy of children with epilepsy were found to be the mean scores on the second ($\beta = -0.761$) and first sub-dimensions ($\beta = -0.162$) of the EFPQ, respectively. A strong and significant

positive correlation was found between the first (short-term fears of parents about epilepsy) and second sub-dimension (long-term fears of parents about epilepsy) of the EFPQ. The four variables (children's age, parents' education level, duration of the epilepsy diagnosis, family history of epilepsy) in model 1 were included in model 4, but no statistically significant difference was found ($p < 0.001$) (Table 2).

Discussion

The findings of this study show the effect of the fears experienced by parents of children with epilepsy during the COVID-19 period on their children's seizure self-efficacy. Four models were created considering the relationships between study variables and seizure self-efficacy. These models examined the effect of the descriptive data on children's seizure self-efficacy (model 1) and the correlations between the seizure self-efficacy of the children and parents' mean scores on the first (model 2) and second (model 3) sub-dimensions and the total (model 4) EFPQ.

In model 1, the effects of the descriptive data—including children's age, parents' education level, duration of the epilepsy diagnosis, family history of epilepsy, and parental fear—on children's self-efficacy were examined; however, the results of the regression analysis showed that the descriptive data did not affect children's self-efficacy significantly ($p > 0.001$). In similar studies in the literature it was also found that descriptive data, including children's age, parents' education level, duration of the epilepsy diagnosis, and family history of epilepsy, did not affect children's self-efficacy [14,28,13,33].

Model 2 showed that children of parents with high mean scores on the first sub-dimension of the EFPQ had low seizure self-efficacy levels. The first sub-dimension explained 85 % of the variance in the level of self-efficacy. Accordingly, as the parents' short-term fears about epilepsy decreased, their children's seizure self-efficacy levels increased, and parents' belief that their children would show the necessary behavior to cope with their seizures effectively increased. In studies conducted before the pandemic, a moderate and significant negative correlation was found between parents' mean scores on the first sub-dimension (short-term fears of parents about epilepsy) of the EFPQ and the seizure self-efficacy of the children ($\beta = -0.54, p < 0.001$) [33]. In this study conducted during the pandemic, there was a strong and significant negative correlation between parents' mean scores on the first sub-dimension of the EFPQ and the seizure self-efficacy of the children ($\beta = -0.921, p < 0.001$). This shows that the correlation between short-term fears of parents about epilepsy and the seizure self-efficacy of the children increased after the pandemic [23,31,34]. This study found that parents' short-term fears about epilepsy, which is among the factors explaining the seizure self-efficacy of children with epilepsy, had a significant role in seizure self-management. Parents' short-term fears about epilepsy comprise fears that the child may have a seizure outside especially when the parent is away, or may have seizures at any time, that other people may not perform the necessary intervention during the seizure, and that the child can be injured or die due to the seizure [32]. Some studies in the literature have shown that parents have short-term fears about epilepsy and that they were particularly afraid that their children may have a seizure and die during the seizure while under the supervision of other people (at school, sports club) [25]. In the study by Westrehen et al., it was especially emphasized that since parents' short-term fears may affect disease management, it is imperative that pediatric nurses examine parents' fears and how these fears would affect disease management [25]. In addition, the study indicated that age, parents' education level, and the clinical status of the children did not affect the level of parental fear, similar to our study [25].

Model 3 showed that children of parents with high mean scores on the second sub-dimension of the EFPQ had low levels of seizure self-efficacy. It was determined that as the mean score of the second

Table 1
The relationship between mean scores on the total and sub-dimensions of the Seizure Self-Efficacy Scale for Children and stigma perceived regarding seizures.

	1	2	3	4
1. Seizure Self-Efficacy Scale for Children	1.0			
2. Mean scores on the total Epilepsy-Related Fears in Parents Questionnaire	-0.924*	1.0		
3. Mean score on the first sub-dimension of the Epilepsy-Related Fears in Parents Questionnaire (short-term fears of parents about epilepsy)	-0.921*	0.996*	1.0	
4. Mean score on the second sub-dimension of the Epilepsy-Related Fears in Parents Questionnaire (long-term fears of parents about epilepsy)	-0.924*	0.995*	0.994*	1.0

Note. * $p < 0.001$.

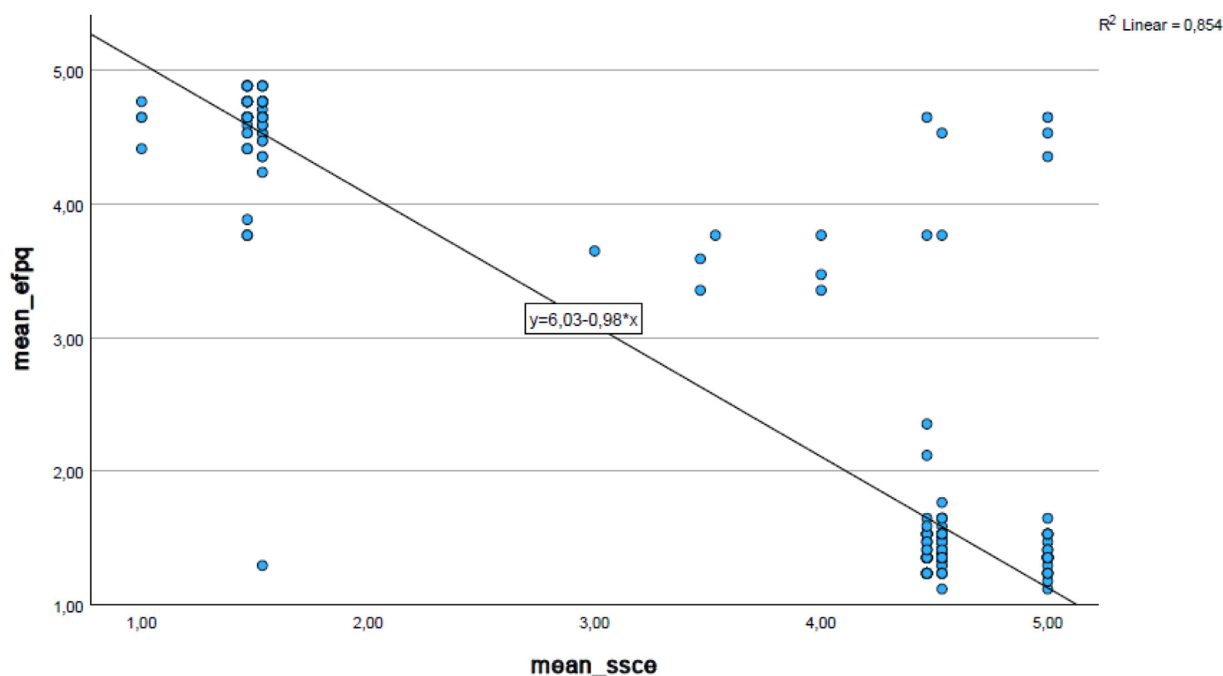


Fig. 2. Total score averages of SSES and EFPQ with children with epilepsy.
SSES: Seizure self-efficacy scale; EFPQ: Epilepsy-related fears in parents questionnaire.

sub-dimension of the EFPQ increased, the seizure self-efficacy level of the children decreased by 85 %. Accordingly, as the parents' long-term fears about epilepsy increased, children's seizure self-efficacy levels decreased, and parents' belief that their children would show the necessary behavior to cope with their seizures effectively decreased. In studies conducted before the pandemic, a moderate and significant negative correlation was found between parents' mean scores on the second sub-dimension (long-term fears of parents about epilepsy) of the EFPQ and the seizure self-efficacy of the children ($\beta = -0.56, p < 0.001$) [32]. In our study conducted during the pandemic, there was a strong and significant negative correlation between parents' mean scores on the second sub-dimension of the EFPQ and the seizure self-efficacy of the children ($\beta = -0.924, p < 0.001$). This shows that the correlation between long-term fears of parents about epilepsy and the seizure self-efficacy of the children increased after the pandemic [23,32,34]. This study indicated that parents' long-term fears about epilepsy, which is among the factors explaining the seizure self-efficacy of children with epilepsy, played a significant role in seizure self-management. Parents' long-term fears about epilepsy comprise fears that the child may experience stigma, that they may need lifelong care due to seizures, that the child's friends can exclude him/her, that the child may be exposed to

bullying, that seizures may cause brain damage, that the child may need to use medicines for life, that epileptic medication may impair the child's health, and that seizures may affect the child's future negatively [4,26,16,35,36]. Parents play a critical role in the disease management of children with epilepsy. Their experiences, perceptions, and fears of the disease affect the child's disease management, especially seizure self-efficacy. Akbarbegloo et al. found that parents' knowledge about their children's fears affected children's self-efficacy levels negatively and significantly [9]. Some studies have shown that the possibility that seizures can occur at unexpected times, in public places, and in a social environment causes the child and parent to be isolated from society and experience fear at the same time, and that the increase in the child's fear levels also negatively affects seizure control, particularly during the pandemic period [13,21].

Model 4, on the other hand, showed that children of parents with high mean scores on the total EFPQ had low levels of seizure self-efficacy. It was found that as the mean score on the total EFPQ increased, the seizure self-efficacy level of the children decreased by 85 %. It was seen that both the short-term and long-term fears of parents had an effect on the seizure self-efficacy of children, but that their long-term fears had a greater effect on the seizure self-efficacy. While seizure-related self-efficacy is the belief that children can show the

Table 2
Prediction of children's seizure self-efficacy by parents' epilepsy-related fears.

Variables	Model 1 β	Model 2 β	Model 3 β	Model 4 β
Child's age	0.009**			0.009
Level of education of the parents	0.002**			0.001
Family history of epilepsy	0.026**			0.026
Duration of epilepsy	-0.014**			-0.011
EFPQ 1st subscale		-0.921*		-0.162
EFPQ 2nd subscale			-0.924*	-0.761*
R		0.921	0.924	0.925
R ²		0.848	0.854	0.853
F		1781.801	1871.394	309.937
p	** $p > 0.001$	<0.001 * $p < 0.001$	<0.001 * $p < 0.001$	<0.001 * $p < 0.001$

EFPQ: Epilepsy-Related Fears in Parents Questionnaire.

necessary behavior to effectively cope with their seizures, some studies emphasize that the development of self-efficacy belief in children is important in controlling the disease and making decisions about it [32]. It is recommended to improve the health behaviors of children with epilepsy and improve their self-efficacy levels for better seizure management [32]. A review of the literature indicated that there is limited research into the direct relationship between the self-efficacy of children with epilepsy and parents' experiences, perceptions, and fears of the disease during the COVID-19 pandemic. Therefore, we believe that the findings of this study contribute additional and novel data for the literature. In addition, another significant finding was that parents' fears of epilepsy explained 86 % of the seizure self-efficacy levels of children with epilepsy. In this study, it was found that the level of self-efficacy was important in the management of the disease for children with epilepsy and that it was effective in increasing the seizure self-efficacy level of children by decreasing parents' epilepsy-related fears.

Limitations of the study

This study has several limitations. The study sample consisted of children with epilepsy and their parents who presented to the pediatric neurology outpatient clinic of a university hospital, which may increase the risk of selection bias, reduce representativeness, and limit the generalizability of the results. The children included in the sample consisted of children who had a diagnosis of epilepsy for 5 years or more, which may show a difference in terms of fear and self-efficacy levels compared to children diagnosed with epilepsy under the age of 5 years.

Conclusion

Disease self-management and seizure-related self-efficacy are very important for children with epilepsy so that they can adjust to the disease and make the necessary life changes [6]. In the literature, it is emphasized that one of the factors affecting the seizure self-efficacy of children with epilepsy is parents' epilepsy-related fears. The investigation of parents' fears related to the disease during the pandemic process, which affects the seizure and disease management of the child by 86 %, will provide an opportunity to establish a more realistic and holistic relationship with the child and the parent, to obtain standard and objective data, and thus to implement effective care. During widespread disease outbreaks, such as the COVID-19 pandemic, healthcare professionals should not ignore parents' fears related to the disease while educating and giving care to the child with epilepsy and the parent. It is very important to raise the awareness of all healthcare professionals about the approach to children with epilepsy and their parents and to address children's self-efficacy and parents' fear of the disease while they are given educational support.

Supplementary appendix 1. Descriptive Information Form

Supplementary appendix 2. Epilepsy-Related Fears in Parents Questionnaire

Supplementary appendix 3. Seizure Self-Efficacy Scale For Children (SSES-C)

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Supplementary materials

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