

Examination of Parents' Knowledge, Attitudes, and Behaviors About Epilepsy

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Abstract

Objective: The aim of our study is to evaluate the knowledge, attitudes, and behaviors of the parents of children diagnosed with epilepsy, regarding the treatment and first aid during seizures.

Methods: Parents of children who applied to Balıkesir University Medical Faculty Pediatric Neurology Outpatient clinic, who were diagnosed with epilepsy, and who had regular controls were included in this cross-sectional study.

Results: In total, 117 patient parents participated in our study. The majority of the attendees were mothers (n=74, 63.2%). The youngest of the participants was 20, the oldest was 70 years old, and their mean age was 37.2. It was found that the parents often learned the information they had about epilepsy only from the doctors (n=69, 59%), and only antiepileptic drugs were used in the treatment of 111 (94.9%) patients and they did not try any other treatment methods. The number of participants who stated that epilepsy could be treated with drugs was 105 (89.7%). Most of the participants stated that they would lay their children down comfortably during the attack (n=113, 96.6%) and that they would keep their mouth and airway open if possible so that they could breathe comfortably after positioning the child (n=104, 88.9%).

Conclusions: In our study, our patients were informed both verbally and in writing about epilepsy and emergent intervention at certain periods before and after treatment and the right approach in the first intervention constituted the majority.

Keywords: Attitude, behavior, epilepsy, information, parent

INTRODUCTION

Although epilepsy can be seen in all age groups, it is more common in children and the elderly.^{1,2} Serdaroğlu et al³ have reported the prevalence of epilepsy in children aged 0-16 in Turkey as 0.8%.³ In epidemiological studies, it has been reported that seizures are more common in the age of 75 and above.^{4,5}

Epilepsy is a disease that requires long-term treatment and follow-up and can negatively affect the physical, emotional, intellectual, and social life of the individual. Psychosocial problems are more common in epilepsy patients compared to the general population.⁶ Nowadays, with the medical developments in the diagnosis, treatment, and follow-up of the disease, the clinical course of the disease is focused on, and the psychosocial and environmental dimensions of the disease are often overlooked.⁷ Ensuring the joint participation of individuals with epilepsy and their families, together with physicians in the treatment and follow-up of the disease, and observing the socio-cultural and special needs of the patients may positively affect the treatment process and quality of life of the patients.⁸ In this sense, it is important that epilepsy patients and their families and/or caregivers have received appropriate information and training about all aspects of the disease and that they can cope with the difficulties that may arise in the process. In studies on epilepsy, insufficient attention has been paid to investigating the knowledge, attitudes, and behaviors of patients, their families, and/or people who take care of them, about the disease, its treatment, and first aid during seizures. Few studies in the literature have focused on the family or relatives of a person with a chronic disease.⁹

The aim of this study is to evaluate the knowledge, attitudes, and behaviors of the parents of children diagnosed with epilepsy, regarding the disease, its treatment, and first aid during seizures.

METHODS

Our study included 117 parents of patients who applied to our tertiary medical faculty Pediatric Neurology Outpatient Clinic between August 2019 and March 2020 and who were diagnosed with epilepsy. A questionnaire was applied after face-to-face interviews were made with the parents of the patients and their written consent was obtained. Participants were asked to fill in questionnaires consisting of 4 separate sections.

In the questionnaire form;

Part 1: Demographic data (gender, age, degree of closeness of the child, degree of social security, education level of parents, employment status of parents, income level of families, where they live, and number of siblings);

Part 2: General information and sources of information that parents have about epilepsy;

Part 3: Parents' attitudes, views, and perceptions about epilepsy;

Part 4: Parents' behaviors regarding epilepsy.

In the 49-question survey, there were options such as filling in the blanks, yes/no, one or more options that can be ticked about the question, and strongly disagree/disagree/undecided/agree/strongly agree. No data on children were used. Approval for our study was obtained from the local Ethics Committee (permission no: 2020/174).

Statistical Analysis

In the study, Statistical Package for the Social Sciences Version 23.0. (IBM SPSS Corp.; Armonk, NY, USA) program was used for the analysis of the data obtained by the survey application. Descriptive statistical data were obtained while analyzing the data. The chi-square test was used to evaluate whether there was a difference between the knowledge, attitudes, and behaviors of the participant mothers and fathers and whether the participants' living in different settlements created a difference in their knowledge, attitudes, and behaviors.

RESULTS**Demographic Data**

Totally 117 patient parents participated in our study. The majority of the respondents were mothers ($n=74$, 63.2%). The youngest of the participants was 20 years old, the oldest was 70 years old, and their mean age was 37.1 ± 8.57 years. Most patients had health insurance ($n=109$, 93.2%). Social Insurance Institution ($n=73$, 62.4%) was the most common health insurance, the second most frequent was the Pension Fund ($n=21$, 18%), and the third was Green Card ($n=10$, 8.5%).

When the education levels of the parents were evaluated, it was seen that most of the mothers were primary school graduates (37.6%, $n=44$), and the fathers had university and postgraduate education (49.5%, $n=58$). When the working conditions are evaluated, it was learned that mothers were mostly housewives ($n=90$, 76.9%) and fathers mostly worked ($n=97$, 82.9%). When the relatives of the patients were asked to describe their income levels, they stated that they were mostly at the middle-income level ($n=83$, 70.9%). It was observed that 113 (96.6%) of the participants were Turkish Republic (TC) nationals, and the number of foreign participants was only 4 (Syria $n=2$, Iran $n=2$), and 41% of the participants lived in the city center ($n=48$) and 59% lived in towns and villages ($n=69$). It was learned that epilepsy patients generally had 2 siblings ($n=66$, 56.4%) and most of them lived with their parents ($n=101$, 86.3%) (Table 1).

Knowledge Levels of Participants

It was determined that the parents often got the information they had about epilepsy only from the doctors ($n=69$, 59%) and that only anti-epileptic drugs were used in the treatment of 111 (94.9%) patients and they did not try any other treatment method. Six (5.1%) participants stated that they used cupping, vinegar, and cold water in addition

Table 1. Demographic Data of Participants ($n=117$)

Female (mother)	74 (63.2%)
Male (father)	43 (36.8)
Mean age (min-max)	37.1 ± 8.57 (20-70)
Number of families with 2 children	66 (56.4%)
Family income level	Very good ($n=2$, 1.7%) Good ($n=23$, 19.7%) Moderate ($n=83$, 70.9%) Poor ($n=7$, 6%) Very bad ($n=2$, 1.7%)
Health insurance	Yes ($n=112$, 93.2%) None ($n=8$, 6.8%)
Education level of mother	Illiterate ($n=4$, 3.4%) Primary school ($n=44$, 37.6%) Secondary school ($n=33$, 28.2%) High school ($n=25$, 21.4%) Undergraduate ($n=11$, 9.4%)
Education level of father	Illiterate ($n=1$, 0.9%) Primary school ($n=42$, 35.9%) Secondary school ($n=16$, 13.7%) Undergraduate-graduate ($n=58$, 49.5%)
Working status of mother	Housewife ($n=90$, 76.9%) Employed ($n=27$, 23.1%)
Working status of father	Not working ($n=20$, 17.1%) Employed ($n=97$, 82.9%)
Place of settlement	Province ($n=48$, 41%) District ($n=37$, 31.6%) Village ($n=32$, 27.4%)

to antiepileptic drugs in the treatment of the disease. When parents' knowledge about the disease is evaluated; the majority of the participants stated that epilepsy can occur at any age ($n=105$, 89.7%), it is contagious ($n=111$, 94.9%), and it is not a psychiatric disease ($n=61$, 52.1%) but a genetic disease ($n=67$, 57.3%).

The number of participants who stated that epilepsy could be treated with drugs was 105 (89.7%), and most of the participants stated that cessation of seizures after drug treatment would not mean that the disease could be cured ($n=87$, 74.4%).

Most of the parents reported that there may be a risk of death during an epileptic seizure ($n=80$, 68.4%) and that frequent epileptic seizures may damage the brain ($n=99$, 84.6%). Again, the majority stated that all children would not lose consciousness during epileptic seizures ($n=77$, 65.8%) and that artificial heart and respiratory massage were not required during epileptic seizures ($n=71$, 60.7%).

The dominant views were that the disease may not progress with the same findings in all children ($n=99$, 84.6%), the intelligence level will not be lower than other children ($n=52$, 44.4%) but they may have learning difficulties ($n=59$, 50.4%), and there is no harm in being vaccinated according to the normal vaccination schedule ($n=82$, 70.1%) (Table 2). While the opinion between the parents that their children's intelligence level would generally be lower than other children was statistically significant ($P=.019$), there was no statistical difference between the knowledge levels about the disease when the other answers were compared ($P>.05$). Similarly, there was no difference between the participants living in different settlements in terms of knowledge levels ($P>.05$).

Table 2. Knowledge Levels of Participants (n=117)

	Absolutely Agree/Agree, %	Undecided, %	Disagree/Absolutely Disagree, %	P
Epilepsy attacks can occur at any age	89.7 (n=105)	7.7 (n=9)	2.6 (n=3)	
Epilepsy is a contagious disease	2.6 (n=3)	2.6 (n=3)	94.9 (n=111)	
Epilepsy is not a psychiatric illness	52.1 (n=61)	16.2 (n=19)	31.6 (n=37)	
Epilepsy is a genetic (hereditary) disease	57.3 (n=67)	22.2 (n=26)	20.5 (n=24)	
Epilepsy can be treated with epilepsy drugs	89.7 (n=105)	6.8 (n=8)	3.4 (n=4)	
Cessation of seizures after drug treatment started for epilepsy does not mean that the disease is cured	74.4 (n=87)	17.1 (n=20)	8.5 (n=10)	
There may be danger of death during the epilepsy seizure	68.4 (n=80)	17.1 (n=20)	14.5 (n=17)	
Frequent epileptic seizures damage the brain	84.6 (n=99)	13.7 (n=16)	1.7 (n=2)	
Not all children may lose consciousness during a seizure	65.8 (n=77)	22.2 (n=26)	12 (n=14)	
There is no need for artificial respiration and heart massage during epilepsy	60.7 (n=71)	25.6 (n=30)	13.7 (n=16)	
Not all children with epilepsy have the same findings	84.6 (n=99)	8.5 (n=10)	6.8 (n=8)	
Children with epilepsy are generally less intelligent than other children	42.7 (n=50)	12.8 (n=15)	44.4 (n=52)	.019*
Mother*	26.4 (n=31)	4.2 (n=5)	32.4 (n=38)	
Father	16.3 (n=19)	8.6 (n=10)	12 (n=14)	
Children with epilepsy may have learning difficulties	50.4 (n=59)	6.8 (n=8)	42.7 (n=50)	
There is no harm in vaccinating children with epilepsy according to the normal vaccination schedule	70.1 (n=82)	22.2 (n=26)	7.7 (n=9)	

*Chi-square test, $P < .05$.

Thoughts and Perceptions of Participants

Most of the parents stated that they thought that other people did not treat their children differently because they had epilepsy (n=65, 55.6%) and they wanted their family and friends to know that their child had epilepsy (n=95, 81.2%). While most of the parents believed that their children would be successful in education and business life in the future (n=96, 82.1%), they were concerned about their ability to make friends (n=66, 56.4%). Parents who stated that they received sufficient support from the environment (n=80, 68.4%) regarding their children and that they had time to ensure their children's participation in games and social activities were in the majority (n=103, 88%). Most of the participants stated that they could intervene with their children during an epileptic seizure (n=93, 79.5%) and that they had the level of knowledge to intervene with people who had a seizure in the environment (n=77, 65.8%) (Table 3). Thoughts and perceptions about the disease were not statistically different between participating mothers and fathers and participants living in different settlements ($P > .05$).

Behaviors and Attitudes of Participants

Totally 47.9% (n=56) of the parents stated that their children had seizures before, and 33.1% (n=27) stated that there were people who had other seizures in their families. While 94% (n=110) of the participants stated that they would take the child to a safe place during the attack, all of them (100%, n=117) stated that they would remove sharp or hard objects that could injure them during the attack. Most of the participants stated that they would lie down their children comfortably during the attack (n=113, 96.6%), would keep their mouth and airway open if possible so that they can breathe easily after positioning the child (n=104, 88.9%), would try to loosen tight clothing (n=115, 98.3%) removing accessories such as necklaces and belts, if any, and would immediately inform 112 (n=91, 77.8%). Again, most of the participants stated that they would not try to put anything in their children's mouth to keep their airway open during an epileptic seizure (n=74, 63.2%), would not spill water or cologne on their face (n=82, 70.1%) and would not let their children smell onions (n=91, 77.8%).

Table 3. Opinions and Perceptions of the Participants (n=117)

	Absolutely Agree/Agree, %	Undecided, %	Disagree/Absolutely Disagree, %
I think other people treat my child differently because he has epilepsy	35.9 (n=42)	8.5 (n=10)	55.6 (n=65)
I want my family and friends to know that my child has epilepsy	81.2 (n=95)	7.7 (n=9)	11.1 (n=13)
I believe that my child will be successful in education and business life in the future	82.1 (n=96)	7.7 (n=9)	10.3 (n=12)
I worry about my child's ability to make friends	39.3 (n=46)	4.3 (n=5)	56.4 (n=66)
I have time to engage my child in play and social activities	88 (n=103)	5.1 (n=6)	6.8 (n=8)
I feel that I get enough support from the environment about my child with epilepsy	68.4 (n=80)	12 (n=14)	19.7 (n=23)
I have the level of knowledge to provide first aid when I see someone having an epileptic seizure	65.8 (n=77)	14.5 (n=17)	19.7 (n=23)
I can intervene with my child during the epileptic seizure	79.5 (n=93)	10.3 (n=12)	10.3 (n=12)

Table 4. Behaviors and Attitudes of Participants (n=117)

	Absolutely Agree/Agree, %	Undecided, %	Disagree/Absolutely Disagree, %
I take my child to a safe place during an epileptic seizure.	94 (n=110)	1.7 (n=2)	4.3 (n=5)
I keep sharp or hard objects away from my child that may injure during an epileptic seizure.	100 (n=117)	-	-
During an epileptic seizure, I put my child to bed comfortably.	96.6 (n=113)	0.9 (n=1)	2.6 (n=3)
After positioning my child during seizure, I keep his mouth and airway open, if possible, so that he can breathe comfortably.	88.9 (n=104)	6 (n=7)	5.1 (n=6)
During the epileptic seizure, I take off accessories such as necklaces, belts, and try to loosen tight clothes if there are any.	98.3 (n=115)	1.7 (n=2)	-
During an epileptic seizure, I try to put something in my child's mouth to keep his airway open.	26.5 (n=31)	10.3 (n=12)	63.2 (n=74)
During an epileptic seizure, I pour water and cologne on my child's face.	17.9 (n=21)	12 (n=14)	70.1 (n=82)
I make my child smell onions during an epileptic seizure.	7.7 (n=9)	14.5 (n=17)	77.8 (n=91)
During my child's seizure, I immediately call 112.	77.8 (n=91)	10.3 (n=12)	12 (n=14)
In general, I allow my child to participate in activities he wants.	84.6 (n=99)	7.7 (n=9)	7.7 (n=9)
I let my child play video games.	45.3 (n=53)	12.8 (n=15)	41.9 (n=49)
I let my child to do sports.	84.6 (n=99)	7.7 (n=9)	7.7 (n=9)
I can leave my child on his own.	40.2 (n=47)	16.2 (n=19)	43.6 (n=51)
I let my child to participate in school trips.	66.7 (n=78)	12.0 (n=14)	21.4 (n=25)

It was observed that parents mostly allowed their children to participate in activities they wanted (n=99, 84.6%), to do sports (n=99, 84.6%), and to participate in school trips (n=78, 66.7%). However, their behaviors and attitudes were close to each other in terms of whether to let their children play video games and whether to leave their children on their own. While 45.3% of the parents allowed their children to play video games, 41.9% did not. Similarly, 40.2% of the parents stated that they could leave their children on their own, while 43.6% stated that they could not (Table 4). When the answers given by the participant mothers and fathers to the survey questions were compared, it was seen that there was no statistical difference between the knowledge levels about epilepsy except for 1 question ($P > .05$). There was no difference in behavior and attitudes among the participants living in different settlements ($P > .05$).

Totally 47.9% (n=56) of the parents stated that their children had had seizures before, and 33.1% stated that they had others to have seizures in their families.

DISCUSSION

It is known that 10%-20% of children in society have chronic diseases. One of the most common chronic diseases in this period is epilepsy.¹⁰ In this study, we examined the knowledge, attitudes, behaviors, thoughts, and perceptions of the parents (n=117) of the children we followed up with the diagnosis of epilepsy in our Pediatric Neurology Outpatient Clinic, regarding the disease, its treatment, and first aid during seizures.

It is known that parents are generally aware of their children's illnesses. They can obtain this information from different sources. In the survey conducted by Kurt¹¹ on parents, it was reported that most of the participants were mothers (62.2%), 58.8% of the group had heard about epilepsy, and 26.3% had read about epilepsy. Again, in the survey conducted by Zainy et al¹² on 117 parents (57% of them were mothers), it was found that most of the parents (70%) had knowledge about epilepsy. In a study conducted in Thailand, the rate of familiarity with epilepsy was found to be 80.8%.¹³ In the study of Njamnshi et al¹⁴ with 456 participants, the rate of reading something about epilepsy was found to be 12.3%. Kurt¹¹ stated in his study that the most common sources of information used for epilepsy are television and the

internet.¹¹ Masri et al.¹⁵ on the other hand, reported that parents prefer the treating physician or medical brochures as a source of information. Similarly, in the literature, it is seen that doctors and nurses are the preferred source of information for many parents and caregivers in terms of health.^{16,17} In our study, it was determined that the majority of the participants were mothers (n=74, 63.2%) and that the participants most frequently obtained information about epilepsy from the physicians. Besides the physician, it was observed that the participants also obtained information from sources such as television, radio, newspaper, family and relatives, and the internet.

Epilepsy is a chronic neurological disease that can negatively affect an individual's physical, emotional, intellectual, and social life. Serdaroglu et al³ reported that epilepsy is a neurological disorder with a rate of 65.4% and that epilepsy is a psychiatric disease with a rate of 22.3%.³ It was reported that of the participants in the study, 60.2% in Iran, 68.1% in Serbia, and 90.3% in Jordan, stated that epilepsy is not a contagious disease, and 83% in Iran, 99.5% in Serbia, and 98.5% in Jordan stated that epilepsy is not a psychological disease.^{15,18,19} In our study, the majority of the participants stated that epilepsy is contagious (n=111, 94.9%) and not a psychiatric disease (n=61, 52.1%) but a genetic disease (n=67, 57.3%). It is thought that this difference may be due to the sociodemographic characteristics of other populations, awareness, as well as the difference in education levels and quality of education.

Chronic diseases in childhood can cause various social effects on both the patient and his/her family.²⁰ Stigma is defined as the mark, sign, or label that causes an individual to be rejected, not accepted, viewed as inferior, and excluded by society. Jacoby et al²¹ reported that 62% of patients with epilepsy experience stigma. Epilepsy patients isolate themselves from society because of stigma and fear of having a seizure in public. Along with the decrease in social interaction, friendship relations are also damaged. Internationally, a quarter of parents/caregivers keep their children's epilepsy secret due to fear of discrimination and social stigma.^{22,23} Masri et al¹⁶ reported that nearly half of the parents (48.4%) reported their child's illness to their children's schools. In our study, the majority of parents stated that they thought that other people did not treat their children differently because they had epilepsy (n=65,

55.6%), and they wanted their family and friends to know that their child had epilepsy (n=95, 81.2%). However, most of the parents were concerned about their ability to make friends (n=66, 56.4%). In our study, the majority of parents thought that they received sufficient support from the environment (n=80, 68.4%) regarding their children and that they had time to ensure their children's participation in games and social activities (n=103, 88%).

Cognitive disability is one of the most frequently reported problems in epilepsy patients, and these patients may also have learning difficulties. This may negatively affect children's school success.²⁴ Austin et al²⁵ found that children diagnosed with epilepsy had significantly worse results compared to the control group in terms of criteria related to behavior, attention, reaction time, place learning, and academic skills. In the literature, it was a common opinion that children with epilepsy would not be as successful as healthy children.²⁶ Masri et al¹⁵ reported that 40% of parents of epileptic children stated that their children can have normal intelligence and 61.7% of them can continue higher education. On the contrary, McEwan et al²⁷ stated in their study that epilepsy patients can be as intelligent and successful as other children. In our study, most of the participants thought that frequent seizures could damage the brain (n=99, 84.6%) and that children with epilepsy might have learning difficulties (n=59, 50.4%). However, the dominant opinion was that the intelligence level of children with epilepsy would not be lower than other children (n=52, 44.4%) and that their children would be successful in education and business life in the future (n=96, 82.1%).

Parents' behaviors toward children may differ according to education level, economic level, and cultural habits.²⁸ Masri et al¹⁵ reported that parents do not restrict watching television and using computers in children with epilepsy, while such practices were found to be limited for students with epilepsy in some schools. While Gazibara et al¹⁹ reported that parents were in favor of doing sports activities for children with epilepsy, Masri et al¹⁵ found that most of the parents (59.2%) restricted children's sports activities.

Anık et al²⁹ conducted a study on the parents of 223 patients with epilepsy and 57 patients with recurrent febrile convulsions and found that 69.3% of the parents did not receive information about the first intervention. In this study, it was determined that the rate of appropriate positioning of the patients was 39.5%, trying to open a respiratory tract with a foreign body was 23.8%, pouring water was 17.9%, trying to prevent contractions was 14.3%, shaking the child and slapping were 7.2%, and taking the child to the hospital without first aid was 20.6% and they emphasized that they have insufficient, wrong information, and first aid practice on seizure control.²⁹

Education, income, and epilepsy are indicated in the prevention of many problems that parents may encounter regarding seizures and treatments.³⁰ In the study of Zararsız³¹, it was stated that the education given to the parents also reduced anxiety and depression. In some studies in the literature, it was stated that a large number of the students (83.3%) did not know about first aid during the seizure; 83.9% of the teachers knew that side position should be given during the seizure, but only 45.2% of them knew that the locked jaw should be opened; only 45.2% had knowledge about first aid interventions such as removing objects around, protecting their head, or taking them to the hospital during the seizure.³²⁻³⁴

In our study, the number of parents who have the knowledge to provide first aid during an epileptic seizure was 76 (65.5%), the number

of parents who can intervene was 92 (79.3%), and the parents who had knowledge about the correct practices to be made during the intervention [positioning (n=112, %). 95.72), keeping the airway open (n=103, 88.8%), informing 112 (n=90, 77.6%)] constituted the majority of the participants. In our study, it was observed that most of the parents were able to carry out the first aid intervention correctly during the seizure. We think that this is due to the fact that verbal and written information about first aid interventions is given to patients diagnosed with epilepsy and their relatives in our polyclinic, and the high level of education of the participants, especially the fathers, may also play a role.

In Kurt's¹¹ study, 45.7% of parents stated that epilepsy is treatable. It is known that traditional and non-medical treatments can be used by some parents in addition to pharmacological treatment.¹² In our study, the number of participants who stated that epilepsy could be treated with drugs was 105 (89.7%), and most of the participants stated that cessation of seizures after drug treatment would not mean improvement of the disease (n=87, 74.4%). It was determined that 111 (94.9%) patients used only antiepileptic drugs in their treatment and they did not try any other method, and 6 participants stated that they used cupping, vinegar, and cold water in addition to the medicine in the treatment of the disease.

The limitation of our study is the low number of cases due to the coronavirus disease 19 pandemic and the related measures and restrictions.

As a result, although our polyclinic gave verbal and written information to our participants about epilepsy and emergency response, it was seen that there were different opinions among the participants on both the disease and the first aid. In the light of the data obtained from the study, we think that updating the education programs for parents will contribute to preventing the wrong attitudes and behaviors of the parents during the treatment processes, increasing the level of knowledge, and improving the quality of life of the patients.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Balıkesir University Medical Faculty from the local Ethics Committee (Date: October 14, 2020, Decision no: 2020/174).

Informed Consent: All participants in the present study gave informed written consent to participate in this study.

Peer-review: Externally peer-reviewed.

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