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Do knowledge of, perception of, and attitudes toward epilepsy affect the quality of life of Turkish children with epilepsy and their parents?

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ABSTRACT

The main goal of this study was to evaluate knowledge of, perceptions of, and attitudes toward epilepsy and then to correlate knowledge with quality of life and stigmatization of children with epilepsy and their families. Specific questionnaires were administered to children aged 8 to 17 with epilepsy ($n = 220$) and their parents ($n = 313$). Poor school performance, less social support, less self-esteem, higher anxiety, greater stigmatization, and more depressive symptoms were documented in children who were less knowledgeable ($P < 0.05$). Parents were found to be more knowledgeable about the antiepileptic drugs used, understanding both the effects and the side effects of the medications ($P < 0.05$). Family activities were less restricted if they were more knowledgeable and these parents reported worrying less about their children ($P < 0.05$). Knowledge about epilepsy is associated with less perceived stigmatization and social isolation, as well as fewer depressive symptoms and misperceptions.

1. Introduction

Knowledge regarding epilepsy may be important in reducing the impact of seizures, potentially harmful self-management practices, and the emotional impact of both seizures and treatment; increased knowledge may lead to an improvement in quality of life not only for patients but also their families [1–8]. Therefore, knowledge is a vital factor in improving the ability to cope successfully with epilepsy by minimizing its impact on social and psychological functioning [7].

Coping with the child's condition can have significant emotional and social impact, and this burden is reflected in the increased incidence of stress-related illnesses among the families of children with epilepsy [1,5,8]. Therefore, it is not surprising that both the condition and its treatment compromise the quality of life of children with epilepsy [2,4]. For these reasons and many others, there has been an upsurge of interest in devising strategies—beyond antiepileptic drugs—to enhance quality of life for patients and their families [1,5]. Knowledge about epilepsy would be helpful in diminishing the perceived stigmatization, or feelings of social isolation, reported by children who have epilepsy and their families [3]. Researchers and clinicians who wish to develop and implement such strategies must first familiarize themselves with the stigmatization, both actual and perceived, that accompanies epilepsy [6].

The primary objectives of this study were, first, to evaluate knowledge of, perception of, and attitudes toward epilepsy and, second, to correlate this information with quality of life and stigma among children with epilepsy and their families.

2. Methods

2.1. Subjects

The study was performed at the Department of Pediatric Neurology, Gazi University Faculty of Medicine, from January 2006 to December 2007 and involved 220 children with epilepsy (between 8 and 17 years of age) and their parents ($n = 313$).

Patients with epilepsy (having at least two unprovoked seizures) diagnosed by a pediatric neurologist and regularly followed in our pediatric neurology department were included in the study. Children with intellectual impairment, an IQ score lower than 80 on the WISC-R, vision or hearing impairments, and a diagnosis of a progressive neurodegenerative disorder, as well as patients and parents who participated in the pretest, were excluded from the study.

Approval for this study was granted by the Gazi University Faculty of Medicine Ethical Committee. Informed consent was obtained from parents and informed assent from children and their parent(s) before data collection.

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2.2. Development of the questionnaires

Two versions of the questionnaire were administered: one for children and the other for parents. In developing the questionnaires, we reviewed studies on knowledge of, attitudes toward, perception of, and psychosocial impact of childhood epilepsy in the literature and conducted extensive interviews with health care professionals expert in treatment [1,2,4,6–9]. The translations were checked by experts who rated the linguistic accuracy and cultural relevancy. After further review and discussion, a version of each questionnaire was accepted.

These versions were subsequently administered to two pilot groups, one comprising 10 children with epilepsy, and the other, 10 parents. Feedback about the questionnaire's clarity was then solicited, and, based on this feedback, the questionnaires underwent another round of minor changes. One month later, respondents were asked to complete the questionnaire again. Cronbach's α coefficient was assessed to estimate internal consistency reliability, which was determined to be 0.92 for children and 0.94 for parents. Test–retest reliability was good as reflected by κ values of 0.69 for children and 0.71 for parents.

After item analysis and validation, the final children's version contained 46 items, and the parents' questionnaire, 43 items.

2.2.1. Children's questionnaire

a. The first part of the questionnaire elicited Demographics on the children: age, gender, duration of disease, antiepileptic drugs currently used, schooling, parents' employment status, and number of siblings.

b. The following section contained 12 questions intended to measure General Knowledge of epilepsy. Patients were asked about the definition of the term *epilepsy* and its causes (e.g., neurological, contagious, supernatural, inherited), symptoms (change in consciousness, unusual movements), aggravating factors (e.g., sleepiness, tiredness, some food), help during the seizures, treatment, prognosis, occupational or career choice (e.g., teacher, policeman, pilot, computer engineer), sports (e.g., swimming, cycling, running, basketball), and driving a car. These 12 questions were presented as statements to which the subject was asked to respond on a 4-point Likert scale: (1) yes, (2) no, (3) probably not, (4) I don't know.

c. The remaining 24 questions were devised to gain information on the Impact of Epilepsy on the children. Patients were asked about how epilepsy influenced their attitudes toward and opinions and perceptions of themselves and others. The children were also asked about stigmatization, quality of life, and depression resulting from the disease and about the influence of the disorder on academic performance.

c1. Attitudes: Children were asked if they were concerned over having seizures, if they felt sad after seizures, how did they cope with seizures, did they take their drugs regularly or forget to take medicine, and what were their beliefs on healing.

c2. Perception: Children were asked whether they felt others acted compassionately or cruelly toward them, whether they believed epilepsy is a shameful condition, whether they felt bothered by the difficulty they face in their daily activities, and whether they felt restricted from joining social activities.

c3. Stigmatization: Patients were asked if they hid their disease or spoke to others about it and whether they feel uncomfortable or hesitate to maintain contact with those who know they have epilepsy.

c4. Social Support: The children were asked if they were able to get enough information about their disease from parents, friends, teachers, physicians, psychologists, and psychiatrists and whether any member of their family constantly looks after or protects them?

c5. Self-Esteem: Patients were asked how they felt about their social environment and home, do they feel they were living in a secure and confident environment, do they like living in their home, do they feel they are beautiful or handsome, do they have self-confidence, and how do they perceive the quality of their lifestyle.

c6. School: Children were asked about their attentiveness in school, their exam scores, and their homework.

c7. Depression: Patients were asked if they feel tired or weak; do they experience sleep problems, weight gain, or hair loss; and does feeling sad have a negative effect on their daily life or interfere with their daily activities.

The aforementioned material was presented as statements to which the children were asked to respond on a 5-point Likert scale: (1) nothing, (2) hardly any, (3) a few, (4) more often than not, (5) a lot or often.

2.2.2. Parents' questionnaire

a. As for the children's questionnaire, the first part of the parents' questionnaire elicited Demographics: age, gender, marriage, employee status, and age of their child with epilepsy, date of last follow-up for epilepsy, and antiepileptic drugs currently taken by their children.

b. General Knowledge of epilepsy was the subject of the first 13 questions. Parents were asked about the definition of the term *epilepsy* and its causes; symptoms; factors aggravating seizures; treatment alternatives including antiepileptic drugs, alternative medicine, herbals, and consultation with people who are believed to have spiritual power; and prognosis. Additional questions involved the best way to help someone having a seizure and the effect that epilepsy should have on a child's choice of career or participation in sports. Parents were asked to anwer questions in this section on a 4-point Likert scale: (1) yes, (2) no, (3) probably not, and (4) I don't know.

c. The next section comprised 16 questions on the Medical Aspects of epilepsy in general. Parents were asked to describe their child's seizure type, frequency, severity, predictability, and control of seizures. To determine *seizure severity* parents were asked about bizarre movements, staring, unresponsiveness, injury, confusion, and sleepiness. These answers were regrouped and scored as very mild, mild, moderate, severe, and very severe. *Seizure frequency* was scored as less than one per month, more than one per month but less than one per week, more than one per week, or more than one per day. *Seizure length* was scored as very short, less than 1 minute; short, between 1 and 3 minutes; long, between 3 and 5 minutes; very long, more than 5 minutes. Parents were also questioned about comorbid health conditions associated with epilepsy and about the effects, both beneficial and adverse, of antiepileptic drugs. Because of the wide range of questions, responses to some items were elicited on a 4-point Likert scale. For other items, respondents chose among five options.

d. In the final section of the questionnaire, parents were asked 14 questions that centered on the Day-to-Day Influence of Epilepsy on the child and the entire family.

d1. Negative Effects: Parents were asked if their child's epilepsy has negative effects on relationships between their children and them and their siblings; if they are more protective of their child with epilepsy; if they think there are any negative effects on their other healthy kids; if they feel restricted in planning for the future, and the general impact of epilepsy on their family.

d2. Academic Performance—school attendance, and social activity: Parents were asked about their children's school performance with respect to lessons, homework, exam scores, absences, changes in behavior, physical activities, relationships with peers, and restrictions on social activity.

d3. Happiness or Worry: Parents were asked if they worried about their child, the side effects of the drugs, whether their child would be seizure free, and what would be the effects of the seizures on their child's life, with respect to marriage, employment, and having children.

d4. Support: Parents were questioned about their ability to have their concerns heard and taken seriously by physicians and other health care professionals, and the extent to which they felt "supported" by health care personnel.

Responses to some questions were indicated using a 4-point Likert scale, whereas other items were multiple choice questions with either four or five choices. The items for each group were summed and divided by the number of variables.

2.3. Data analysis

Statistical analysis was performed using the SPSS 11.5 database. Descriptive analyses were conducted, and ages of the patients were expressed as means ± SD.

The Bonferroni correction method was used in multiple comparisons, and continuous variables were used as well.

Spearman correlation coefficients were used to evaluate relationships between demographic variables and other subgroups of the questionnaire, as the continuous variables did not show a normal distribution when a "test of normality" was applied. $P < 0.05$ was considered significant.

3. Results

The mean age was 13.5 ± 3.2 years for children and 38.5 ± 6.8 years for parents. Tables 1 and 2 summarize sociodemographic characteristics of the patients and their parents, respectively.

Table 1
Demographic data on children ($N = 220$)

Age	
8–10	55 (25%)
11–13	76 (34.5%)
14–17	89 (40.5%)
Gender	
Girls	95 (43.2%)
Boys	125 (56.8%)
Time since diagnosis of epilepsy (years)	4.43 ± 3.96
Type of seizures	
Generalized	43 (19.2%)
Secondarily generalized partial epilepsy	46 (20.5%)
Partial epilepsy	131 (60.3%)
Frequency of seizures	
<1 per month	110 (50%)
>1 per month, but <1 per week	45 (20.5%)
>1 per week	32 (14.6%)
>1 per day	23 (10.5%)
Length of seizures (minutes)	
Very short	27 (12.3%)
Short	78 (35.5%)
Long	92 (41.8%)
Very long	23 (10.5%)
Severity of seizures	
Very mild	20 (9.1%)
Mild	72 (32.7%)
Moderate	93 (42.3%)
Severe	20 (9.1%)
Very severe	15 (6.8%)
Current AED therapy	
Monotherapy	108 (49%)
2 AEDs	75 (34%)
3 AEDs	24 (11%)
$\geqslant$4 AEDs	13 (6%)

Table 2
Demographic data on parents ($N = 313$)

Mother	200 (63.8%)
Father	113 (36.2%)
Age	
20–30	85 (27.1%)
31–40	115 (36.7%)
41–50	70 (22.4%)
$\geqslant$51	43 (13.7%)
Job	
Civil servant	200 (63.8%)
Self-employed	65 (20.7%)
Unemployment	48 (15.4%)
Education	
Primary school	104 (33.2%)
High school	110 (35.1%)
College	99 (31.6%)
Family income (monthly)	
$\leqslant$\$700	63 (20.1%)
\$701–1400	161 (51.4%)
$\geqslant$\$1401	89 (28.4%)

3.1. Most notable findings from the children's questionnaire

See Tables 3 and 4.

3.1.1. Frequency results

When asked about the definition of epilepsy, 65.4% of the children knew that epilepsy was a neurological disorder. However, 22.3% believed that epilepsy was a "disease of the spirit," making this the question most frequently answered incorrectly. The greatest degree of uncertainty was exhibited in response to the question of whether epilepsy could be inherited; 41.4% of the children were not sure.

With respect to seizure symptoms, 39.1% of the patients knew the symptoms; however, 65.9% of the patients were unsure whether a change in consciousness (an absence seizure) was a signal that a seizure was imminent even if no other symptoms were noted.

When patients were asked about factors that might precipitate or exacerbate a seizure, 35.9% of the patients answered all questions correctly. The greatest degree of patient uncertainty or misinformation was in response to the question about whether certain foods might aggravate epilepsy. Nearly 90% of the patients (86.8%) replied that they did not know or that foods could "set off" a seizure.

Although 42% of the patients knew what measures should be taken to help a person having a seizure, another 37.9% "knew" that wrong measures, such as inserting a "spoon," would be helpful.

Most of the children (78.2%) concurred with the statement that "epilepsy is a treatable disease." Another 20%, however, were unsure. Some children (13.6%) believed that epilepsy is a lifelong disease. Many of the children with epilepsy (45.5%) were not sure of which occupation they would have in the future. Among the children, 33.6% indicated that people with epilepsy could not be active in sports, and another 33.5% believed that people with epilepsy could not drive cars.

Notable among the responses to questions on quality of life, almost one-third of the children (29.6%) complained of insufficient support from health care personnel; 20.9% reported not enough support from their own families. A majority of the children, 63.2%, reported that they were bothered by their parents' following them around. Almost 41.2% of the children reported feeling stigmatized by their friends. Epilepsy was perceived to be a "shameful" condition by 20% of the children, and a like number, 19.1%, reported that the disease limited their social activities. Fear of epileptic attacks and sadness following a seizure were reported by 46.8%

Table 3
General knowledge about epilepsy: children's and parent's questionnaires

Answer	Subtest of the questionnaire	Children's questionnaire	Parent's questionnaire
Correct	Neurological disorder	65.4%	82.7%
	Not a contagious disease	81.8%	89.5%
	Not a supernatural disease	76.8%	68.1%
Unsure	An inherited disease	41.4%	31.3%
	A spiritual disease	22.3%	21.1%
	Change in consciousness	65.9%	59.4%
	Foods that "set off" epilepsy	86.8%	51.8%
	Sports	33.1%	32.8%
	Driving a car	33.6%	27.2%
	Choice of occupation	22.8%	43%
Wrong	Lifelong disease	13.6%	18.0%
	How to help during seizure	42.2%	24.8%
	Pull the tongue	36.4%	60.7%
	Put spoon between the teeth	29.5%	49.2%
	Remove the dress	7.7%	12.5%
	Could not do any sports	33.6%	23.2%
	Never could drive	45.5%	12%
	Choice of occupation	19.8%	11%

of the patients. Problems in learning or keeping up with classmates educationally were cited by 31.3%. The percentage reporting symptoms of depression was 19.6%. A permanent lack of self-esteem was reported by 15% of the children who responded.

3.1.2. Comparison of subgroups

Older patients demonstrated more knowledge of epilepsy ($P = 0.0001$, $r = 0.294$). Sadly, as age increased, so did reports of perceived stigmatization ($P = 0.0001$, $r = 0.256$) and symptoms of depression ($P = 0.0001$, $r = 0.276$). A longer average duration of seizures was also correlated with more negative attitudes toward the disease ($P = 0.001$, $r = 0.223$).

Patients who demonstrated less knowledge about epilepsy were also patients who perceived themselves as lacking social support ($P = 0.013$, $r = -0.167$) and as being more stigmatized because of their disorder ($P = 0.0008$, $r = -0.180$). On the other hand, children who answered more questions correctly also had more positive attitudes toward epilepsy ($P = 0.034$, $r = -0.143$), better academic performance and fewer learning problems ($P = 0.022$, $r = -0.154$), and fewer symptoms of depression ($P = 0.001$, $r = -0.278$).

The results also indicate that nearly 20% of the parents did not sufficiently inform their children with epilepsy about epilepsy. Both maternal education and maternal employment were correlated with better knowledge of epilepsy ($P = 0.004$) and better school performance ($P = 0.028$), Nevertheless, these children also reported more symptoms of depression ($P = 0.0001$). An increase in perceived stigmatization was reported by children who had at least one unemployed parent ($P = 0.015$).

High scores in perceived stigmatization were associated with greater negativity about epilepsy ($P = 0.004$, $r = 0.195$) and with greater perceived lack of social support ($P = 0.000 < 0.05$ $r = 0.266$). Perceived stigmatization was related to low self-esteem ($P = 0.026 < 0.05$, $r = -0.150$)

Among the children, 19.1% had negative attitudes toward their disease. This negativity was related to poor school performance and learning difficulties ($P = 0.000 < 0.05$, $r = 0.350$), with more symptoms of depression ($P = 0.000 < 0.05$ $r = 0.300$), and with low self-esteem ($P = 0.005 < 0.05$, $r = -0.188$). In fact, the more negative the patient felt about epilepsy, the worse his or her academic performance, and the more depressive symptoms, feelings of isolation, and reduced self-esteem ($P < 0.05$) she or he indicated. In addition, an increase in reported symptoms of depression correlated with ignorance about epilepsy, low self-esteem, and perceived lack of social support ($P < 0.05$).

The more siblings a patient had, the less knowledge about epilepsy he or she was likely to have ($P = 0.018$, $r = -0.160$). Number of siblings was also correlated with perception of insufficient social support ($P = 0.004$, $r = 0.193$), greater anxiety about stigmatization ($P = 0.003$, $r = 0.199$), a more negative attitude toward epilepsy ($P = 0.0001$, $r = 0.396$), and a greater number of symptoms of depression ($P = 0.002$, $r = 0.206$).

3.2. Most notable findings from the parent's questionnaire

See Tables 3 and 5.

Table 4
Correlations between the variables in the children's questionnaire

Variable	Score	Change in score	Affected variable	Effect on variable	r	P
Age	13.5 ± 3.2	Increase	Knowledge	Increase	0.294	0.0001
			Stigmatization	Increase	0.256	0.0001
			Depression	Increase	0.276	0.0001
Knowledge	18.4 ± 7.4	Increase	Positive attitude	Increase	0.143	0.034
			Learning difficulties	Decrease	−0.154	0.022
			Depression	Decrease	−0.278	0.001
		Decrease	Feeling lack of social support	Increase	−0.167	0.013
			Feeling stigmatization	Increase	−0.187	0.008
Feeling stigmatization	6.5 ± 2.2	Increase	Negative perception	Increase	0.195	0.004
			Perceived lack of social support	Increase	0.266	0.000
			Knowledge	Decrease	−0.180	0.008
			Self-esteem	Decrease	−0.150	0.026
Negative perception	10.87 ± 6.05	Increase	Poor school performance	Increase	0.350	0.000
			Depression	Increase	0.300	0.000
			Self-esteem	Decrease	−0.180	0.005
Negative attitude	17 ± 4.5	Increase	Poor school performance	Increase	0.394	0.000
			Depression	Increase	0.451	0.000
			Perceived lack of social support	Increase	0.320	0.000
			Self-esteem	Decrease	−0.0279	0.000
Poor school performance	5.6 ± 2.2	Increase	Depression	Increase	0.554	0.000
			Knowledge	Increase	0.154	0.022
			Perceived lack of social support	Increase	0.247	0.000
			Self-esteem	Decrease	−0.385	0.000

Table 5
Correlations between the variables in the parents' questionnaire

Variable	Score	Change in score	Affected variable	Effect on variables	*r*	*P*
Knowledge	21.1 ± 8.1	Increase	Effects of antiepileptic drugs	Increase	0.145	0.001
			Feeling greater social support	Increase	0.212	0.0001
			Frequency of children's seizures	Decrease	−0.191	0.001
			Family problems	Decrease	−0.125	0.027
			Worry about their children	Decrease	−0.282	0.0001
Worry	23.9 ± 2.7	Increase	Feeling less social support	Decrease	−0.256	0.0001
			Perception of effects of drugs	Decrease	−0.156	0.0006
			School performance	Decrease	−0.129	0.023
Frequency of seizures	1.7 ± 1.23	Increase	Poor school performance of child	Increase	0.217	0.0001
			Restriction of family activities	Increase	0.333	0.0001
Duration of seizures	8.9 ± 24.1	Increase	Poor school performance of child	Increase	0.116	0.04
			Parental worry	Increase	0.120	0.033
			Feeling less social support	Increase	0.226	0.0001
			Stigmatization	Increase	0.112	0.047
			Adverse effects of drugs	Increase	0.18	0.001
Severity of seizures	2.3 ± 1.14	Increase	Poor school performance of child	Increase	0.123	0.029
			Family problems	Increase	0.153	0.007

3.2.1. Frequency results

Among the parents, 66.0% knew that epilepsy is a neurological disorder. As on the children's questionnaire, the question most often answered incorrectly (32.6%) or "I don't know" (31.3%) concerned the heritability of epilepsy.

More than half (52.0%) of the parents recognized the symptoms of an impending seizure. Again, like their children, however, parents were unsure or wrong in thinking (22.9%) that an absence seizure alone indicated the onset of an attack.

All questions about the precipitation or exacerbation of epilepsy were answered correctly by 29.9% of the parents. Parents were most uncertain (29.75%) about the ability of foods to aggravate epilepsy.

Frighteningly, 42% of the parents did not know how they could help or what they could do when their child was seizing. Even more frightening was the finding that 51.5% of the parents "knew" the wrong measures to take.

Most parents (71.2%) thought that epilepsy is treatable, but 21.7% were unsure whether it was. Some parents (17.6%) believed that epilepsy is a lifelong disease. Almost half of the parents (43%) believed that epilepsy limited career choices. A third (33.8%) indicated that epilepsy meant that a child could not be active in sports, and almost as many thought that their children would never be able to drive a car (31.6%).

Because of the criteria for participating in the study, all parents regularly took their children to the doctor. A few (3.5%) reported also having attempted alternative medical treatments: 3.5% of the families used alternative medicine for their children and 13.7% of them visited people who they believed had spiritual power.

Almost one-third of the parents (32.3%) stated that their children were hardly able to understand their lessons or complete their homework after having been diagnosed with epilepsy. Some parents (11.5%) noted that the epilepsy restricted the kinds of activities they would plan for their families. Most parents (65%) reported wondering whether epilepsy would restrict their child's future life in terms of finding a marriage partner, holding down a good job, and enjoying normal activities.

3.2.2. Comparisons between subgroups

Employed parents knew more about epilepsy ($P = 0.0001$); unemployed parents reported worrying more about their children with epilepsy ($P = 0.001$). As families in which one parent was unemployed generally had lower incomes, increased worriying was also associated with lack of money ($P = 0.004$). Low family income was also correlated with ignorance about epilepsy ($P = 0.0001$) and perceived lack of social support ($P = 0.001$).

Other marked correlations were found between parental knowledge of epilepsy and other factors. The children of more knowledgeable parents were more likely to have infrequent seizures ($P = 0.001$, $r = –0.191$). Parents who knew about epilepsy also knew the beneficial effects ($P = 0.001$, $r = 0.145$) and adverse effects ($P = 0.010$, $r = 0.145$) of antiepileptic drugs more precisely. Knowledgeable parents also reported less restriction of family activities ($P = 0.027$, $r = –0.125$) and less worry ($P = 0.0001$, $r = –0.282$). Knowledgeable parents also perceived themselves and their children as having greater social support ($P = 0.0001$, $r = 0.212$).

The more frequent a child's seizures, the more likely that child was to be challenged in school ($P = 0.0001$, $r = 0.217$) and the more likely were the parents to restrict family activities ($P = 0.0001$, $r = 0.333$).

Longer seizure length was correlated with more educational problems ($P = 0.04$, $r = 0.116$) and more parental worry ($p = 0.033$, $r = 0.120$), as well as the perception that social support was inadequate ($P = 0.025$, $r = 0.126$). Parents who reported seizure times as longer than the records indicated also reported feeling more worried about their children ($P = 0.0001$, $r = 0.226$) and feeling less social support and more stigmatization in the social environment ($P = 0.047$, $r = 0.112$). The children of these parents were also reported to have greater academic challenges ($P = 0.025$, $r = 0.126$), seizure-related problems ($P = 0.013$, $r = 0.14$), and adverse drug effects ($P = 0.001$, $r = 0.18$).

Severity of seizures was highly correlated with reports of family problems ($P = 0.007$, $r = –0.153$), educational problems ($P = 0.029$, $r = –0.123$), and the perception that seizures lasted longer than they actually did ($P = 0.0001$, $r = 0.477$). Parents who misperceived the duration of seizures also reported greater adverse reactions to antiepileptic drugs ($P = 0.001$, $r = 0.281$) and more serious school problems ($P = 0.0001$, $r = –0.253$).

Children of parents who reported family problems were more likely to have poor academic performance ($P = 0.0001$, $r = 0.201$). High levels of worry were correlated with perceived lack of social support ($P = 0.001$, $r = –0.256$), greater and more numerous adverse reactions to antiepileptic drugs ($p = 0.006$, $r = 0.156$), and educational difficulties ($P = 0.023$, $r = –0.129$).

4. Discussion

Epilepsy is a common neurological condition that affects people of all ages, races, and social status [8,9]. Lack of information has been suggested as causing the perpetuation of stigma, negative attitudes, it appears to be an incomplete thought [1–3,5,8,9]. Furthermore, patients with epilepsy often report that the quality of life is compromised by the disease [1–3,5,8,9].

Knowledge about epilepsy is a vital factor in improving the ability to cope successfully with epilepsy by minimizing its impact on individual, social, and psychological functioning [4,7]. To date, the literature suggests that levels of knowledge of epilepsy are generally poor [3,5,10–13], particularly with respect to certain aspects of epilepsy [10,14,15], etiology of epilepsy, administration of antiepileptic drugs [16], and helpful measures during seizures [17]. In our study, we found clear gaps in knowledge, particularly with respect to medication and the cause of epilepsy: 41.4% of patients were not sure whether epilepsy could be inherited, 65.9% did not know or were not sure that a simple change in consciousness could be a seizure (absence seizures), and 86.8% believed some foods could induce seizures. Among the parents, 42% did not know what they could do to help a seizing person; 51.5% knew the wrong things to do to help the patients during seizures. The most incorrectly answered question (32.6% incorrect, 31.3% unsure) was whether epilepsy could be inherited. Moreover, our study suggests that those who know less about their disease are more likely to be depressed and to have a worse self-concept than those who know more. Social anxiety was also associated with lack of knowledge.

As recent studies have demonstrated, children who have epilepsy feel that their parents and physicians do not give them enough information to manage or live at peace with their condition [7]. Similarly, according to our study, nearly 20% of the parents failed to give their children enough information about epilepsy.

In one study that evaluated 1023 individuals with epilepsy, of whom 22% were 18 or younger and had received less education, fear of seizures was the most frequently reported concern [4]. The same study found that the more educated the mother, however, the more symptoms of depression she was likely to exhibit [4]. Children in a family in which at least one parent was unemployed had more anxiety about stigmatization [4]. The findings of our study are strikingly similar. Employed parents demonstrated more knowledge of epilepsy; unemployed parents reported worrying more about their children. In addition, among low-income families, worry was increased whereas knowledge of epilepsy was decreased, compared with families with higher incomes. Inadequate income was also found to be correlated with a perceived lack of social support.

Young people who must live with epilepsy face various challenges [8,18]. They are at greater risk of experiencing unpleasant or embarrassing incidents at school and of performing poorly on examinations and homework [7,8,18]. Later in life, patients who have epilepsy may find obstacles in their path when they decide on a career or seek a spouse [7,8,18]. Throughout their lives, more than 60% of people with epilepsy often feel stigmatized by their disorder, and up to 70% of them feel discriminated against by society [7,8,11,19,20]. This is consistent with our study, in which almost 40% of the children reported stigmatization by their friends; moreover, the higher the score for perceived stigmatization, the more negative the perception of epilepsy as well. Interestingly, we also found that children whose seizures began earlier in life and those who had had seizures for at least a year reported feeling more stigmatized.

Experts assert that quality of life and self-esteem among children with epilepsy can be greatly improved by reducing their stigmatization or anxiety about stigmatization [6,8–10,19,21]. For children in our study, both poorer self-concept and an increase in symptoms of depression were associated with higher levels of perceived stigmatization and perceived lack of social support. Furthermore, our results suggest that those who know less about their disease are more like to be depressed and to have a worse self-concept than those who know more.

Even within the family unit, epilepsy places increased demands on children, their parents, their siblings, and their other relatives [3,5,8]. The strongest association reported by some studies was between parental perceptions of stigmatization and limitations on and problems in family life [6]. It has been reported that parents worry most (65%) about the future of their children with epilepsy with respect to restrictions on activities, marriage, and employment [7,22]. Similarly, in our study, we observed that 60% of the parents reported concern about these issues. Also, young parents, earlier age at onset of epilepsy, and severity and duration of seizures are likewise correlated with the stigmatization perceived by the family.

Alternative medicine may have disadvantages in patients with epilepsy. Herbal medicines and dietary supplements may have adverse effects, may interact with conventional medicines, or have disease state contraindications [4]. All of the parents and children who participated in our study visited physicians regularly, yet 3.5% of the patients were also being treated with alternative medicine. This finding suggests that careful questioning by health care professionals is necessary, so that use of potentially harmful alternative therapies comes to light and treatment can be optimized.

5. Conclusion

To our knowledge, our study is the first in Turkey to investigate both children with epilepsy and their parents with respect to knowledge of, attitudes toward, and perception of epilepsy. Like other studies in this field, our findings strongly support a need for greater education of children who have epilepsy and their parents. Those who learn how the disease affects their lives seem better able to decrease the perceived stigmatization, anxiety, depression, and social isolation associated with epilepsy. Therefore, continuous, repetitive educational efforts are necessary in children with epilepsy and their families to decrease the negative effects of epilepsy.

Additional studies with more comprehensive groups are needed both for validation and for comparison with control groups.

Ethical approval

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Conflict of interest statement

We are not supported by any government agency, private industry, or foundation.

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