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PERCEPTION OF EPILEPSY IN TURKEY IN THE LIGHT OF TWO DIFFERENT CITIES

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SUMMARY – The aim of this study was to investigate the perception of epilepsy in Turkey, from west to east, in Kutahya and Yuksekova, two cities of different sociocultural and ethnic status. This was a retrospective comparison study which evaluated the results of two prior studies investigating stigmatization of patients diagnosed with epilepsy and their first-degree relatives in two different cities of Turkey, Kutahya and Yuksekova. The Survey of Epileptic Patient Relatives on the Knowledge, Attitudes, and Behavior Regarding the Disorder was used and included questions on descriptive characteristics, familiarity with epilepsy, attitudes toward epilepsy, and understanding of epilepsy. Data collected by use of the SPSS 15.0 software were analyzed with χ^2-test. In Yuksekova group, 88.5% of first-degree relatives of people with epilepsy felt primarily fear when they heard the diagnosis of epilepsy in their relatives; in Kutahya group, the respective rate was 19.1% ($p<0.05$). The number of participants who objected their child marrying someone with epilepsy was significantly higher in Yuksekova group ($p<0.05$); however, if married, the Yuksekova group significantly stated that they should have a baby, revealing the importance of children as an indicator of power and dignity in the eastern region of Turkey ($p<0.05$). Although understanding of epilepsy was favorable, educating the community about epilepsy and personal contacts are the major strategies against epileptic stigmatization.

Key words: *Epilepsy perception; Understanding epilepsy; Familiarity with epilepsy; Attitudes toward epilepsy; Stigma*

Introduction

Epilepsy is a neurological condition that knows no geographical, social, or racial boundaries, occurring in men and women and affecting people of all ages, though more frequently affecting young people in the first two decades of life and people over the age of 60[1]. It has been estimated that there are at least 50 million people with epilepsy worldwide[2,3]. The predicted prevalence of epilepsy has been reported as 4-10/1000 in the great majority of studies[1,4,5]. It has to be acknowledged that more than 80% of people with epilepsy live in developing countries, where the condition remains largely untreated[7]. According to the results of a limited number of studies including all age groups, the prevalence in Turkey is reported to be 6.1 to 10.2 *per* 1000[7-12].

While epilepsy is a chronic condition itself, the impact of epilepsy rests not only on the individual patient, but also on the family and indirectly on the community. The burden of epilepsy may be due to the

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physical hazards of epilepsy resulting from the unpredictability of seizures; social exclusion as a result of negative attitudes of the others toward people with epilepsy; and stigma, as children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe[13].

Stigmatization ('labeling' or 'marking') encompasses behaviors based on assumptions about particular groups that lead to exclusion of those groups from the wider community. Religions, beliefs, culture, and tradition contribute to this stigmatization. Stigmatization and negative approaches lower the quality of life of individuals in these excluded groups, causing them to live an isolated life and delaying their receipt of assistance[14].

Epilepsy as a hidden disability makes the patients vulnerable in the society. Although the vulnerability of people living with epilepsy may be partly attributed to the disorder itself, the particular stigma associated with epilepsy brings a susceptibility of its own. Stigmatization leads to discrimination, and people with epilepsy have been the target of prejudicial behavior in many spheres of life, over many centuries and in many cultures[13].

In our previous study, we investigated the knowledge and perceptions of epilepsy and preferred treatment options of people with epilepsy (PWE), their first-degree relatives, and healthy individuals in Yuksekova, a city in the south-east region of Turkey. Moreover, we evaluated the behaviors and approaches toward PWE of first-degree relatives of patients and healthy individuals in this region[15].

Currently, our aim was to compare our previous study results with another study on stigmatization and epilepsy performed in Kutahya, a city in the Aegean region of Turkey, which has a different cultural, social, economic and educational status[15,16]. As a consensus among the authors of the study performed in Kutahya, we believed that this comparison would allow us to evaluate the effects of regional, sociocultural and economic differences in the knowledge and perceptions of epilepsy and preferred treatment options in PWE and their first-degree relatives.

Thus, by evaluating epileptic stigmatization in Yuksekova, a south-east city that is underdeveloped and in Kutahya, a modern, developed Aegean city with a higher socioeconomic status, we would be able to analyze regional differences in social stigmatization of epilepsy.

Subjects and Methods

Study groups

This was a retrospective comparison study which evaluated the results of two prior studies evaluating epileptic stigmatization in patients with a new and/or prior diagnosis of epilepsy, and their first-degree relatives[15,16]. Our previous study on stigmatization of PWE and their relatives was conducted at the Yuksekova State Hospital outpatient neurology clinic between November 1, 2008 and January 10, 2009. Yuksekova is a small and underdeveloped city in the south-east region of Turkey. Study group consisted of 130 consecutive patients older than 7 years with a new and/or prior diagnosis of epilepsy that had no other neurologic diseases and their 130 healthy first-degree relatives. Control group included 130 healthy individuals. All participants were informed on the study protocol and gave their written consent before enrolment[15].

Questionnaires

Two different questionnaires were prepared for the patient group and healthy group (relatives and controls). The relatives and controls were healthy people with no chronic diseases. Sociodemographic characteristics were obtained by a structured interview using an open questionnaire completed in person by all participants. There were a total of 16 questions in the patient questionnaire, including 3 questions on familiarity with epilepsy, 6 questions on attitudes toward epilepsy, and 7 questions on understanding of epilepsy. The questionnaire administered to the relatives and controls contained a total of 18 questions[15].

Similar to our previous study, another stigmatization study was carried out in the outpatient neurology clinic of Kutahya Dumlupınar University Medical Faculty. Differing from our study, it was performed in first-degree relatives of PWE and there was no epileptic patient group or control group. Study group consisted of 115 participants including first-degree relatives of PWE. An open questionnaire was administered to all participants in person and sociodemographic characteristics were recorded. There were a total of 18 questions in this questionnaire including 3 questions on familiarity with epilepsy, 8 questions on attitudes toward epilepsy, and 7 questions on understanding of epilepsy[16].

Currently, we retrospectively compared the answers in the questionnaires that were filled out by first-degree relatives of PWE in two previous studies carried out in Yuksekova and Kutahya, the cities of two different ethnic origin, social, cultural, economic and educational status[15, 16].

Statistical analysis

Data were organized in an SPSS Version 15.0 (Statistical Package for Social Sciences for Windows) database. Statistical analyses were performed with the χ^2-test and Fisher exact test. P values <0.05 were considered to indicate statistical significance.

Results

Questionnaires were administered to the first-degree relatives of PWE in the two cities, Yuksekova and Kutahya. In the Yuksekova group, there were 130 participants including 78 (60%) men and 52 (40%) women. The Kutahya group consisted of 115 patients including 61 (53%) men and 54 (47%) women. Mean age in the Yuksekova group was 37.23±13.95 years (range 12-72 years, 95%CI=34.80-39.65). In the Kutahya group, mean age was 38.37±11.11 years (range 13-75 years, 95% CI=36.09-40.64). The sociodemographic characteristics of the patients, their first-degree relatives and controls are summarized in Table 1.

When asked what they felt when their relative was first diagnosed with epilepsy, 88.5% of the Yuksekova group said they felt fear, while this rate was 19.1% in the Kutahya group. There was a statistically significant difference in the answers to this question between the study groups (p<0.05). Ninety-two percent of the Yuksekova group indicated “doctor” as the source of their information about epilepsy, while this rate was 85.7% in the Kutahya group. There was a statistically significant difference between the two groups (p<0.05). Other information sources were found to be used infrequently in both groups. Answers to the questions on familiarity with epilepsy are given in Table 2.

When asked if they would permit their healthy child to marry a person with epilepsy, 15.4% of the participants answered “yes” in the Yuksekova group. The

Table 1. Sociodemographic characteristics of study groups, Kutahya vs. *Yuksekova, 2010*

	Kutahya		Yuksekova		Total		
Sex	n	%*	n	%*	n	%*	p**
Female	54	47.0	52	40.0	106	43.3	0.273
Male	61	53.0	78	60.0	139	56.7	
City							
Kutahya/Yuksekova	100	87.7	124	95.4	224	91.8	0.029
Kutahya/out of Yuksekova	14	12.3	6	4.6	20	8.2	
Marital status							
Married	100	87.0	98	75.4	198	80.8	0.54
Single	13	11.3	30	23.1	43	17.6	
Widowed	2	1.7	2	1.5	4	1.6	
Social guarantee existence							
Yes	104	90.4	127	97.7	231	94.3	**0.01**
No	11	9.6	3	2.3	14	5.7	
Education							
Primary school and lower	71	62.8	78	60.0	149	61.3	0.651
High school and higher	42	37.2	52	40.0	94	38.7	

%* = column percent; p** = χ^2-test

Table 2. Answers to the section of the questionnaire on familiarity with epilepsy, Kutahya vs. *Yuksekova, 2010*[a]

	Kutahya		Yuksekova		Total		
What did you feel when you/your relative was first diagnosed with epilepsy?	n	%*	n	%**	n	%***	p[b]
Fear	22	19.1	115	88.5	137	55.9	0.0001
Sorrow	115	100.0	78	60.0	193	78.8	0.0001
Thoughtfulness	46	40.0	110	84.6	156	63.7	0.0001
Embarrassment	115	100.0	129	99.2	244	99.6	0.346
Blame	75	65.2	130	100.0	205	83.7	0.0001
Denial	111	95.6	125	96.2	245	96.3	1.000[c]
Anxiety	114	99.1	126	96.9	240	98.0	0.375[c]
How do you define an epileptic seizure?							
Contraction, shake	55	47.8	77	59.2	132	53.8	0.097
Temporary change in behavior	15	13.0	2	1.5	17	6.9	0.0001
Hypersalivation	30	26.1	25	19.2	55	22.4	0.199
Sliding of the eyes	30	26.1	13	10	43	17.6	0.001
Screaming, crying out	7	6.1	1	0.8	8	3.3	0.028[c]
Loss of consciousness	59	51.3	79	60.8	138	56.3	0.136
Memory loss	14	12.2	13	10.0	27	11.0	0.588
Clamping of the teeth	38	33.0	9	6.9	47	19.2	0.0001
Urinary/fecal incontinence	17	14.8	5	3.8	22	9.0	0.003
I don't know	7	6.1	23	17.7	30	12.2	0.006

[a] Participants gave more than one answer to the questions; * = "yes" responder percentage in the Kutahya group; ** = "yes" responder percentage in the Yuksekova group; *** = "yes" responder percentage in total; p[b] = χ^2-test; p[c] = Fisher exact test

rate of the "yes" responders was 22.8% in the Kutahya group. There was a statistically significant difference in the answers to this question between the study groups (p<0.05). The "Should a person with epilepsy have a baby?" question was answered by "yes" in 70% of the Yuksekova group, while the rate of "yes" responders was 46% in the Kutahya group (p<0.05). With respect to giving jobs to PWE, 18.5% of their first-degree relatives in the Yuksekova group said "no", whereas this rate was 7.1% in the Kutahya group (p<0.05).

When asked if they would tell other people that they have a relative with epilepsy, 63.4% of first-degree relatives of PWE in the Kutahya group would tell their "closest friends/relatives only", whereas 80.8% of the Yuksekova group would do so (p<0.05). Answers to the questions on attitudes toward epilepsy section of the questionnaire are listed in Table 3.

When asked what they thought had caused epilepsy, 52.2% of the Kutahya group said they believed that brain was the source of the disease, whereas the rate of this answer was 78.5% in the Yuksekova group (p<0.05). Moreover, 19.5% of the Kutahya group and 2.3% of the Yuksekova group answered this question as "hereditary", yielding a statistically significant difference between the groups (p<0.05).

All participants in the Yuksekova group said that they went other places except doctors for epilepsy treatment (100.0%), while this answer rate was only 7.2% of the Kutahya group (p<0.05). Answers to the questions on their understanding of epilepsy are summarized in Figure 1.

When we analyzed the answers of the two groups to the questions on familiarity with epilepsy, attitudes toward epilepsy, and understanding of epilepsy with respect to sex, marital status, occupation, and educational level, there were no statistically significant differences (p>0.05).

Discussion

Epilepsy is one of the most common chronic neurologic disorders affecting people of various cultures

Table 3. Answers to the section of the questionnaire on attitudes toward epilepsy, Kutahya vs. *Yuksekova, 2010*

	Kutahya		Yuksekova		Total		
Would you permit your healthy child to marry a person with epilepsy?	n	%*	n	%*	n	%*	p^b
No	48	42.1	92	70.8	140	57.4	0.0001
Yes	26	22.8	20	15.4	46	18.8	
I don't know	40	35.1	18	13.8	58	23.8	
Should a person with epilepsy have a baby?							
No	23	20.4	14	10.8	37	15.2	0.001
Yes	52	46.0	91	70.0	143	58.8	
I don't know	38	33.6	25	19.2	63	25.9	
Would you give a job to a person with epilepsy?							
No	8	7.1	24	18.5	32	13.2	0.0001
I'd give all kinds of jobs	34	30.1	16	12.3	50	20.6	
I'd give simple jobs	71	62.8	90	69.2	161	66.3	
Would you tell other people that you have a relative with epilepsy?							
I'd hide	9	8.0	21	16.2	30	12.4	0.0001
I'd tell my closest friends/relatives only	71	63.4	105	80.8	176	72.7	
I'd tell everybody	32	28.6	4	3.1	36	14.9	
Which activities make you feel comfortable when you are with your relatives?[†a]							
Social activity	36	34.3	49	37.7	85	36.2	0.589
Daily activities	66	62.9	81	62.3	147	62.6	0.931
Working at the same job	6	5.7	1	0.8	7	3.0	0.047^c
Sports	6	5.7	1	0.8	7	3.0	0.047^c
What kind of difficulties did your illness cause in your social life?[†a]							
None	76	68.5	104	80	180	74.7	0.040
Left school	1	0.9	6	4.6	7	2.9	0.128^c
Had difficulties in school	9	8.1	14	10.8	23	9.5	0.483
Lost job	2	1.8	1	0.8	3	1.2	0.596^c
Divorce	12	10.8	2	1.5	14	5.8	0.002
Exclusion bad behavior	14	12.6	4	3.1	18	7.5	0.005
What would you do if your relative was having a seizure?[†a]							
I'd panic, I couldn't do anything	30	28.0	12	9.2	42	17.7	0.0001
I'd call an ambulance	46	43.4	76	58.5	122	51.7	0.021
I'd tell other people	32	30.2	52	40.0	84	35.6	0.117
How would you intervene when your relative is having a seizure?[†a]							
I'd take him/her to a safer place	49	45.4	83	63.8	132	55.5	0.004
I'd turn him/her to one side	4	3.7	18	13.8	22	9.2	0.007
I'd pull his/her tongue	14	13.0	12	9.2	26	10.9	0.358
I'd make him/her smell something	35	32.4	11	8.5	46	19.3	0.0001
I'd try to open his/her teeth	33	30.6	10	7.7	43	18.1	0.0001
I'd give him/her medicine	10	9.3	5	3.8	15	6.3	0.087
I'd throw water on his/her face	21	19.4	28	21.5	49	20.6	0.691

[a]Participants gave more than one answer to the questions; * = column percentage; † = "yes" responder percentage; p^b = χ^2-test; p^c = Fisher exact test

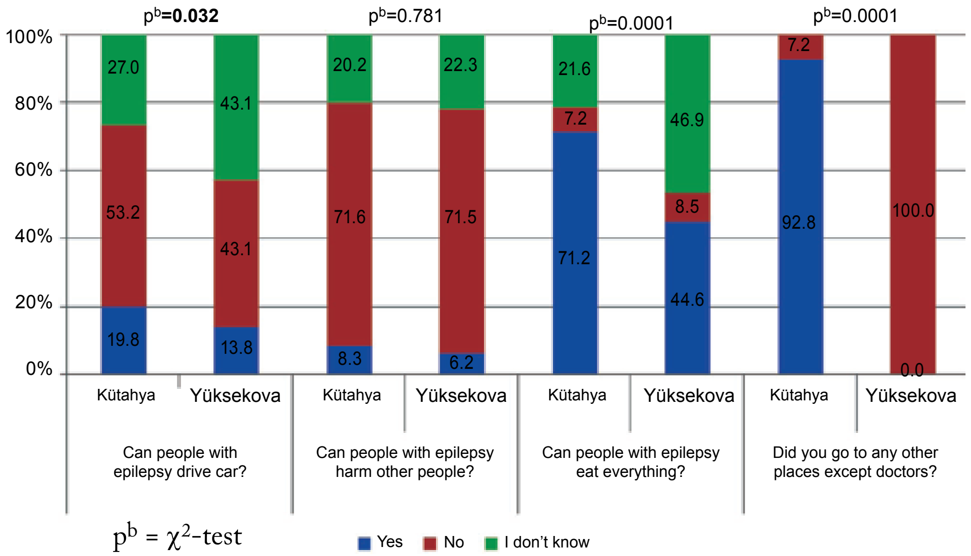

Fig. 1. Answers to the section of the questionnaire on understanding epilepsy, Kutahya vs. *Yuksekova, 2010.*

and races worldwide[17]. It is a chronic condition associated with increased social discrimination. People with intractable seizures are at a constant risk of becoming unconscious and of falling and sustaining injuries and, in public, social embarrassment. Whereas epilepsy is a chronic condition, PWE can have demoralization and a negative perspective on life[18].

Insufficient knowledge and false perceptions about the disease make epilepsy a serious and stigmatizing condition on the part of the community. In this respect, epilepsy is considered as a social label, as well as a clinical disease[19]. Moreover, stigmatization leads to discrimination and people with epilepsy have been the target of prejudicial behavior in many spheres of life, over many centuries and in many cultures[20].

Previous studies have reported that perception of epilepsy in the society is commonly negative, leading to difficulties in finding a job, marrying and living a normal life[15,21]. Differences in the perception of stigma may depend on cultural and regional aspects. The understanding of this aspect of epilepsy is important to promote better de-stigmatization campaigns, considering the cultural and social differences[22]. In our study, as an indicator of stigmatization, there was a statistically significant difference in the answers to the question "What did you feel when your relative was first diagnosed with epilepsy?" between the two study groups ($p<0.05$). This difference was due to the Yuksekova group, where most of the participants stated that they felt fear, sorrow and thoughtfulness when their relatives were first diagnosed with epilepsy. This may be due to insufficient information and wrong beliefs and/or perceptions. The high rate of fear, sorrow and thoughtfulness in the Yuksekova group reflects the stigmatization in this rural area which is underdeveloped (Table 2). Similarly, a previous study that was carried out in four different regions of Brazil demonstrated that 28.3% of the respondents felt fear when they saw an epileptic seizure[22].

It is important to emphasize that the rate of correct definition of epilepsy was higher in the Kutahya group. Most of the participants in this group defined epileptic seizure as a temporary change in behavior, sliding of the eyes, screaming, crying out, clamping of the teeth and/or urinary/fecal incontinence. However, most of the participants in the Yuksekova group stated that they did not know the definition of epileptic seizure (Table 2). This statistically significant between-group difference in the definition of epilepsy can be attributed to difference in the level of education between the groups. Higher education and university graduates were more common in the Kutahya group, whereas there was a higher rate of participants unable to read and write in the Yuksekova group.

Epilepsy is considered as a social label leading to numerous problems in marriage, education, social isolation, and employment, especially in developing countries[18]. The burden of epilepsy may be due to the physical hazards of epilepsy resulting from the unpredictability of seizures; social exclusion as a result of negative attitudes of the others toward PWE; and stigma, as children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe[13].

Despite an Austrian study demonstrating that only 15% of the respondents would object to their child marrying a PWE, another previous study revealed that healthy people with relatives with epilepsy would not permit their children to marry individuals with epilepsy[24]. Similarly, in our study, 70% of the participants stated that they would not permit their healthy child to marry a person with epilepsy, while this rate was 42.1% in the Kutahya group (Table 3). This demonstrates stigmatization and false perception that the disease may be infectious or genetically transmitted[15,25]. As a dilemma, the Yuksekova group stated that if married, PWE should have a baby. In order to understand this conflict, it is important to evaluate the sociological structure of the society in this region. Cultural and sociological norms of the region suggest fertility. Moreover, having a child is very important in order to carry on the descent. In this aspect, people if married, should have a baby because children reflect the power and dignity of the family in local community[26]. On the contrary, a previous study revealed that about half of the respondents (43%) were either unsure whether PWE should have children or believed they should not (8%)[27].

Employment is a serious problem for PWE because of stigmatization of the disorder as a disabling disease among healthy people in the community[28]. A previous study about epileptic stigmatization carried out in the USA demonstrated that 42% of the respondents believed that PWE are usually able to work[27]. In our study, 18.5% of the Yuksekova group stated that they would not give a job to PWE, while this rate was 7.1% in the Kutahya group. This demonstrates that discrimination of PWE is more common in Yuksekova than in Kutahya due to stigmatization. Moreover, by answering this question giving all kinds of jobs, the Kutahya group showed that they did not consider epilepsy as a reason of disability.

It is important to emphasize that 78.5% of the Yuksekova group stated that the source of epilepsy was brain, while this answer rate was 52.2% in the Kutahya group. This statistically significant difference on behalf of the Yuksekova study group could be attributed to their direct communication with doctors. However, the participants in the Yuksekova group had lower education. On the contrary, there were a small number of participants in the Yuksekova group defining the source of the disease as "hereditary", yielding a statistically significant difference. This could be explained by the low education level in the Yuksekova group.

Several studies indicated that epileptic seizure is still considered a mystic event, and traditional beliefs along with religion play an important role in shaping the stereotypes, attitudes, and bias of societies with respect to epilepsy. On the basis of culture, philosophy, and religion, persons in underdeveloped and developing countries often consider epilepsy as the result of good or bad spirits. These beliefs are also frequent in Turkey, where people perceive epilepsy as a supernatural event. In order to deal with this mystic event, people frequently go to the hodja, wear an amulet, and participate in religious ceremonies[15,29,30]. A Turkish study revealed that 19% of Turkish PWE sought such treatment. The various nonmedical treatment options included visiting hodjas (17.6%), drinking curative water (1.0%), and consuming homemade medicines (1.0%)[30]. Similarly, in our study, all of the participants in the Yuksekova group stated that they went to other places in addition to doctors. This is compatible with the strong religious beliefs of the local society and indicates that they are in need of searching for alternative therapy along with medical treatments.

In summary, like other chronic diseases, epilepsy has a great impact on everyday life of the patients as well as on their quality of life in different ways. Since the community has a low understanding of epilepsy, stigma will likely continue to be. In our opinion, a combination of personal contacts and educating the community about the etiology of epilepsy and informing them about the nature of the disease are the major strategies against epileptic stigmatization.

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PERCEPCIJA EPILEPSIJE U TURSKOJ U SVJETLU DVAJU GRADOVA

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Cilj istraživanja bio je ispitati percepciju epilepsije u Turskoj, od zapada do istoka, u gradovima Kutahya i Yuksekova različitog sociokulturalnog i etničkog statusa. Istraživanje je provedeno kao retrospektivna, usporedbena studija u kojoj su se procjenjivali rezultati dviju prethodnih studija koje su ispitivale stigmatizaciju bolesnika s dijagnosticiranom epilepsijom i njihovih srodnika prvog stupnja u dva različita turska grada, Kutahya i Yuksekova. Primijenjeno je anketiranje rodbine epileptičnih bolesnika o znanju, stavovima i ponašanju u odnosu na bolest, a obuhvaćena su pitanja o deskriptivnim značajkama, poznavanju epilepsije, stavovima prema epilepsiji i razumijevanju epilepsije. Podaci prikupljeni uz pomoć statističkog programa SPSS 15.0 analizirani su primjenom χ^2-testa. U skupini Yuksekova 88,5% srodnika prvog stupnja osoba s epilepsijom osjetilo je prvenstveno strah kad su čuli za dijagnozu epilepsije postavljenu kod njihovih rođaka, dok je u skupini Kutahya taj postotak bio 19,1% ($p<0,05$). Broj sudionika koji su svom djetetu zamjerali sklapanje braka s nekim tko boluje od epilepsije bio je značajno viši u skupini Yuksekova ($p<0,05$). No kad je takav brak već sklopljen, značajan broj sudionika skupine Yuksekova ustvrdio je kako bi oni trebali imati djecu, što ukazuje na važnost djece u istočnom dijelu Turske kao pokazatelja snage i dostojanstva ($p<0,05$). Iako se razumijevanje epilepsije pokazalo povoljnim, izobrazba lokalne zajednice o epilepsiji i osobni kontakti glavne su strategije protiv stigmatiziranja osoba s epilepsijom.

Ključne riječi: *Percepcija epilepsije; Razumijevanje epilepsije; Poznavanje epilepsije; Stavovi prema epilepsiji; Stigma*