



# Evaluation of Epilepsy Awareness and Stigmatization in First-Degree Relatives of Patients Hospitalized in Neurology Service

## Nöroloji Servisinde Yatan Hastaların Birinci Derece Yakınlarında Epilepsi Farkındalığı ve Etiketlemenin Değerlendirilmesi

Ahmet Akpınar,<sup>1</sup> Işıl Kalyoncu Aslan,<sup>2</sup> Çisil İrem Özgenç Biçer<sup>3</sup>

<sup>1</sup>Department of Neurology,  
Kulu State Hospital, Konya,  
Türkiye

<sup>2</sup>Department of Neurology,  
Health Sciences University  
Fatih Sultan Mehmet Training  
and Research Hospital,  
İstanbul, Türkiye

<sup>3</sup>Department of Neurology,  
Niksar State Hospital, Tokat,  
Türkiye

### Cite this article as:

Akpınar A, Kalyoncu Aslan I, Özgenç Biçer Çİ. Evaluation of Epilepsy Awareness and Stigmatization in First-Degree Relatives of Patients Hospitalized in Neurology Service. Bosphorus Med J 2024;11(3):65–72.

Received: 07.04.2024

Revision: 14.07.2024

Accepted: 29.07.2024

### Correspondence:

Dr. Ahmet Akpınar,  
Department of Neurology,  
Kulu State Hospital, Konya,  
Türkiye

Phone:

+90 506 512 69 46

e-mail:

ahmet.akpinar94@gmail.com

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### ABSTRACT

**Objectives:** Epilepsy is a disease with psychological and social aspects; patients suffer not only from seizures but also from social stigma. With this article, we aimed to evaluate society's view of epilepsy patients and the general level of knowledge about epilepsy.

**Methods:** This study is a single-center cross-sectional study, and the study population consists of first-degree relatives of patients who were hospitalized in the neurology service with non-epileptic neurological diagnoses. Questions were asked to evaluate epilepsy awareness and labeling of epilepsy patients. The results were analyzed using statistical methods.

**Results:** It was determined that the mean age of the patients included in the study was 49.25. Of them, 56.6% (n=56) were women. For the question, "Would you hire a patient with epilepsy?" a statistically significant difference was found between the age results (z=2.838, p=0.006). For the question, "What kind of instruction about epilepsy would be more useful for you?" a statistically significant difference was found between the age findings ( $\chi^2=8.548$ , p=0.036).

**Conclusion:** By developing education policies for different age groups and education levels, and increasing the level of knowledge about epilepsy in society, stigmatization can be prevented.

**Keywords:** Awareness; Epilepsy; Stigmatization.

### ÖZET

**Amaç:** Epilepsi, psikolojik ve sosyal yönleri olan bir hastalıktır. Hastalar sadece nöbet geçirmekle kalmaz, aynı zamanda sosyal damgalanmadan da muzdariptir. Bu makale ile toplumun epilepsi hastalarına bakışını ve epilepsi hakkındaki genel bilgi düzeyini değerlendirmeyi amaçladık.

**Yöntem:** Bu çalışma, tek merkezli kesitsel bir çalışma olup, çalışma evrenini epileptik olmayan nörolojik tanımları nöroloji servisinde yatan hastaların birinci derece yakınları oluşturmaktadır. Epilepsi hastalarının epilepsi farkındalığını ve etiketlemelerini değerlendirmeye yönelik sorular soruldu. Sonuçlar istatistiksel yöntemler kullanılarak analiz edildi.

**Bulgular:** Çalışmaya dahil edilen hastaların yaş ortalamasının 49,25 olduğu belirlendi. %56,6'sı (n=56) kadındı. "Epilepsili bir hastayı işe alırmıydınız?" sorusuna verilen cevaplara göre yaş sonuçları arasında istatistiksel olarak anlamlı fark bulunmuştur (z=2,838, p=0,006). "Epilepsi konusunda ne tür bir eğitim sizin için daha yararlı olur?" sorusuna verilen cevaplara göre yaş bulguları arasında istatistiksel olarak anlamlı fark bulunmuştur ( $\chi^2=8.548$ , p=0.036).

**Sonuç:** Farklı yaş gruplarına/eğitim düzeylerine yönelik eğitim politikaları geliştirilerek ve toplumda epilepsi konusundaki bilgi düzeyi artırılarak damgalanma önenebilir.

**Anahtar sözcükler:** Epilepsi; Etiketleme; Farkındalık.

Epilepsy is an important public health problem affecting all races, age groups, individuals of different genders, and social status in the world. The majority of the approximately 50 million people diagnosed with epilepsy in the world live in developing countries, and its prevalence is approximately 5–10/1000.<sup>[1]</sup>

Epilepsy is one of the most common and important chronic neurological diseases and affects patients from different age groups.<sup>[2]</sup> Epilepsy is a disease with psychological and social aspects; patients suffer not only from seizures but also from social stigma. Labeling is defined as marginalizing someone because of a certain condition, difference, or situation. This situation causes social inequality and has psychological consequences on patients. Labeling seriously reduces the quality of life.<sup>[3]</sup> Social labeling is mostly associated with low education levels and myths.<sup>[4]</sup>

Stigmatization is associated with low public epilepsy awareness. Successful results can be obtained with training programs targeting low sociocultural groups.<sup>[5]</sup>

The population of our study consisted of first-degree relatives of patients with neurological diagnoses other than epilepsy in the neurology service. This group was chosen because it is the group of people experiencing the issue of neurological disease. It was aimed to evaluate what needs to be done to increase the level of knowledge, epilepsy awareness, and eliminate labeling. We aimed to interpret the knowledge level of the general population about epilepsy and the attitude towards epilepsy patients, with the individuals constituting the study population from different educational and socio-economic segments of society.

## Methods

This single-center, cross-sectional study was conducted with first-degree relatives of patients who were hospitalized with neurological diagnoses other than epilepsy in the neurology service between 01/01/2023 and 01/03/2023. Approval for the study was obtained from the ethics committee of our hospital with the decision number FSM EAH-KAEK 2023/12, dated 26.01.2023. Our study complied with the Declaration of Helsinki and the Good Clinical Practice Guidelines.

Using similar studies in the literature, we prepared a survey consisting of 11 questions to evaluate the general knowledge level, labeling, and information sources about epilepsy (Table 1). As in similar studies in the literature, the answers given to the questions were noted one by one, and it was planned to compare them with the answers in similar studies. Since the answers given to the questions in the questionnaire will be evaluated separately, scoring was not planned. For this reason, a validity study was not sought for the awareness questionnaire. Those who were older than 18 years of age, who did not have epilepsy themselves or in their first-degree relatives, and who were not health workers were included in the study.

The hospital where the study took place provides health care to patients from different regions, as it is a third-level health institution in İstanbul (the most populated and most immigrated city of Türkiye). For this reason, it serves patients and their relatives from different educational and socioeconomic levels. A questionnaire was applied to 101 people selected by a simple random method, who met the inclusion criteria among the first-degree relatives of patients hospitalized in the Neurology Clinic between 01.01.2023 and 01.03.2023. The questions were asked to the participants by the physician in

Table 1. Questions asked to participants

### Chapter 1: General Information on Epilepsy

Have you heard of Epilepsy	Yes	No
Is epilepsy contagious?	Yes	No
Is epilepsy disease genetic?	Yes	No

### Chapter 2: Attitudes Towards Epilepsy Patients

Would you like your children to play with epilepsy patients?	Yes	I would be bothered	No
Would you like your children to marry epilepsy patients?	Yes	I would be bothered	No
Would you hire an epilepsy patient?	Yes	No	

### Chapter 3: Information Resources on Epilepsy

Where did you learn what you know about epilepsy?	Friends	Television	School	Books	Social Media-Internet
Which information would be more useful for you?	TelevisionRadio	Posters and brochures	School	Books	Social Media-Internet

person through a face-to-face interview method, with prior consent. Statistical analysis was performed after all answers were collected.

### Inclusion criteria for the study:

1. Over 18 years old,
2. No diagnosis of epilepsy in themselves and/or their first-degree relatives,
3. Non-health workers will be interviewed,
4. Only one caregiver of each patient will be interviewed.

### Statistical Analysis

Number (n) and percentage (%) values were used to show the distribution of individuals in the answers given to the questions about gender and epilepsy. The conformity of the age variable in the study to the normal distribution was evaluated graphically and using the Shapiro-Wilks test. It was determined that the age variable fit the normal distribution. Therefore, mean±standard deviation values were used in the display of descriptive statistics. In addition, median (CIW-Interquartile Width) values were used in descriptive statistics.

Cross tables were created to compare categorical variables by gender, and test statistics of number (n), percentage (%), and chi-square were given.

In the answers given to the questions "Would you like your children to play with epilepsy patients?", "Where did you learn what you know about epilepsy?", and "Which instruction about epilepsy would be more useful for you?", there was no balanced distribution in groups in the comparison of age values of individuals according to more than two categorical variables. Kruskal-Wallis non-parametric analysis of variance was used for this study. In paired comparisons, analysis results were given with Bonferroni correction. For the question "Do you want your children to marry epilepsy patients?", One-Way ANOVA analysis was used to compare the age values of individuals according to the answers given to the question.

For the questions "Have You Heard of Epilepsy?", "Is Epilepsy Contagious?", "Is Epilepsy Genetic?", and "Will you hire an epilepsy patient?", Independent Sample t-test was used to compare the age values of individuals according to the answers given.

IBM SPSS Statistics 21.0 (IBM Corp. Released 2012. IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY: IBM Corp.) and MS-Excel 2007 programs were used for statistical analysis and calculations. Statistical significance level was accepted as  $p < 0.05$ .

### Results

It was determined that the mean age of the individuals participating in the study was  $49.25 \pm 14.87$ , the minimum age was 19, and the maximum age was 78. Of the individuals participating in the study, 56.6% (n=56) were female and 43.4% (n=43) were male. For the question "Have You Heard of Epilepsy?" 93.9% (n=93) of the individuals answered yes, and 6.1% (n=6) answered no. For the question "Is Epilepsy Contagious?" 5.1% (n=5) answered yes, and 94.9% (n=94) answered no. For the question "Is Epilepsy Genetic?" it was determined that 48.5% (n=48) of the individuals answered yes, and 51.5% (n=51) answered no (Table 1).

For the question "Would you like your children to play with epilepsy patients?" 70.7% of the participants said "yes," and for the question "Would you like your children to marry someone with epilepsy?" 32.3% of the participants said "yes" (Table 2).

For the question "Where did you learn what you know about epilepsy?" 46.5% (n=46) of the individuals answered from their

Table 2. Distribution of General Information

	n (%)
Gender	
Female	56 (56.6)
Male	43 (43.4)
Education Level	
Illiterate	7 (7.1)
Primary Education	39 (39.4)
Secondary Education	26 (26.3)
Associate degree	3 (3.0)
High Education	24 (24.2)
Have You Heard of Epilepsy	
Yes	93 (93.9)
No	6 (6.1)
Is Epilepsy Contagious	
Yes	5 (5.1)
No	94 (94.9)
Is Epilepsy Disease Genetic	
Yes	48 (48.5)
No	51 (51.5)

friends, 19.2% (n=19) from books, 13.1% (n=13) from TV, social media, and the internet, and 8.1% (n=8) from school (Table 3).

No statistically significant difference was found in terms of gender distribution according to the answers given to the questions asked about epilepsy ( $p>0.05$ ) (Table 3).

For the question "Would you hire a patient with epilepsy?" the mean age of individuals who answered yes was  $46.81\pm 14.26$ , and the mean age of those who answered no was  $56.12\pm 14.63$ . A statistically significant difference was found between the age values according to the answers given to this question ( $z=2.838$ ,  $p=0.006$ ). For the question "Which instruction about epilepsy would be more useful for you?" a statistically significant difference was found between the age values ( $\chi^2=8.548$ ,  $p=0.036$ ). When we look at the mean age of the answers given to this question, it was determined that the highest mean value was  $52.27\pm 14.73$  in those who answered TV-Radio, and the lowest mean age value was  $32.25\pm 8.65$  in those who answered Information posters and brochures.

**Table 3. Distribution of the answers given to the questions "Where did you learn what you know about epilepsy", "Would you like your children to play and marry with epilepsy patients?", "Which instruction would be more useful for you" and "Would you hire an epileptic employee"**

	n (%)
Would you like your children to play with epilepsy patients?	
Yes	70 (70.7)
I would be bothered	19 (19.2)
No	10 (10.1)
Would you like your children to marry epilepsy patients?	
Yes	32 (32.3)
I would be bothered	44 (44.4)
No	23 (23.3)
Where did you learn what you know about epilepsy	
Friends	46 (46.5)
Television	13 (13.1)
School	8 (8.1)
Books	19 (19.2)
Social media and internet	13 (13.1)
Which instruction would be more useful for you	
Television-Radio	30 (30.3)
Posters and Brochures	4 (4)
Social media and internet	24 (24.3)
School	41 (41.4)
Would you hire an epileptic employee	
Yes	73 (73.7)
No	26 (26.3)

Comparison of age values for other variables is summarized in Table 4. According to the comparisons made, a statistically significant difference was found between the answers given to the questions "Would you hire an epileptic employee?" and "Which instruction about epilepsy would be more useful for you?" with age ( $p<0.05$ ).

In terms of age values, a statistically significant difference was found in the pairwise comparison of the answers given to the question "Which information about epilepsy would be more useful for you?" between Information posters and brochures\* in schools and Information posters and brochures\* TV-Radio ( $p=0.018$ ,  $p=0.014$ ) (Table 5).

## Discussion

Although epilepsy is one of the most common neurological diseases, it is associated with misinformation, bad social attitudes, and labeling in society.<sup>[3]</sup> Labeling has serious effects on the quality of life of individuals. It has been reported that appropriate training programs increase the quality of life of patients, especially since labeling decreases as the level of knowledge about the disease increases.<sup>[5]</sup>

In this cross-sectional study, a questionnaire was applied to 101 participants to evaluate general information about epilepsy, attitudes towards patients, and information sources of participants. The relationship between the answers received and demographic information such as age and gender of the patients was examined.

In our study, 93% of the participants answered "yes" to the question "Have you heard of epilepsy?" In a study conducted with 403 participants in Saudi Arabia, 97% answered yes to a similar question.<sup>[6]</sup> In another study conducted by Gzirishvili et al.,<sup>[7]</sup> 90% answered yes.

For the question "Is epilepsy contagious?", 94.9% of the participants answered 'no'. In the study conducted by Abbasi Kangewari et al.,<sup>[8]</sup> 64.1% of the participants answered "No" to the same question, while 27.1% answered "I don't know". On the other hand, in the study by Nagamori et al.,<sup>[9]</sup> 73% answered "No" to the same question, while 27% said "I am not sure". The higher rate of correct answers in our study may be due to the lack of an "I don't know" option in the questionnaire, but still, the rate of incorrect answers seems to be close.

In our study, 48.5% of the participants answered "yes" to the question "Is epilepsy genetic?" In the study conducted

Table 4. Gender distribution according to the answers given to the questions about epilepsy and comparison of the age values of individuals according to the answers given to the questions about epilepsy

	Gender		Test Statistic	
	Female (n=56) n (%)	Male (n=43) n (%)	$\chi^2$	p
Have You Heard of Epilepsy?				
Yes	54 (96.4)	39 (90.7)	1.403	0.223
No	2 (3.6)	4 (9.3)		
Is Epilepsy Contagious?				
Yes	4 (7.1)	1 (2.3)	1.177	0.274
No	52 (92.9)	42 (97.7)		
Is Epilepsy Genetic?				
Yes	28 (50)	20 (46.5)	0.119	0.731
No	28 (50)	23 (53.5)		
Would you like your children to play with epileptic patients?				
Yes	36 (64.3)	34 (79)	2.573	0.276
I would be bothered	13 (23.2)	6 (14)		
No	7 (12.5)	3 (7)		
Would you like your children to marry epileptic patients?				
Yes	16 (28.6)	16 (37.2)	0.849	0.654
I would be bothered	26 (46.4)	18 (41.9)		
No	14 (25.0)	9 (20.9)		
Where did you learn what you know about epilepsy?				
Friends	22 (39.3)	24 (55.8)	7.023	0.135
Television	7 (12.5)	6 (14)		
School	6 (10.7)	2 (4.7)		
Books	15 (26.8)	4 (9.3)		
Social media, internet	6 (10.7)	7 (16.2)		
Which instruction about epilepsy would be more useful for you?				
Television-Radio	16 (28.6)	14 (32.6)	3.371	0.338
Information posters and brochures	4 (7.1)	0 (0)		
Social media, internet	14 (25.0)	10 (23.2)		
School	22 (39.3)	19 (44.2)		
Would you hire an epileptic employee?				
Yes	41 (73.2)	32 (74.4)	0.018	0.893
No	15 (26.8)	11 (25.6)		
	Age		Test Statistics*	
	Mean±SD	Median (QW)	t; F	p
Have You Heard of Epilepsy?				
Yes	49.25±14.86	50 (24)	t=0.014	0.989
No	49.33±16.40	52(18)		
Is Epilepsy Contagious?				
Yes	52.20±8.67	51 (17)	t=0.453	0.651
No	49.10±15.14	50 (23)		
Is Epilepsy Genetic?				
Yes	46.48±15.89	48.5 (29)	t=1.822	0.072
No	51.86±13.47	51 (15)		

Table 4. Gender distribution according to the answers given to the questions about epilepsy and comparison of the age values of individuals according to the answers given to the questions about epilepsy

	Age		Test Statistics*	
	Mean±SD	Median (QQW)	t; F	p
Would you like your children to play with epileptic patients?				
Yes	48.17±15.21	49 (23)	=1.476	0.478
I would be bothered	45.91±13.94	55.0 (16)		
No	50.40±14.51	51.5 (23)		
Would you like your children to marry epileptic patients?				
Yes	47.19±15.79	48.5 (24)	F=0.610	0.546
I would be bothered	49.50±13.35	50.5 (17)		
No	51.65±16.49	55.0 (22)		
Where did you learn what you know about epilepsy?				
Friends	48.96±13.84	49 (18.0)	=5.722	0.221
Television	52.77±16.04	55 (27.0)		
School	39.00±12.46	40 (24.0)		
Books	53.16±15.27	53 (25.0)		
Social Media-Internet	47.38±16.66	50 (26.0)		
Which instruction about epilepsy would be more useful for you?				
Television-Radio	52.27±14.73	51.5 (21)	=8.548	0.036
Information posters and brochures	32.25±8.65	34.5 (16)		
Social Media-Internet	44.13±16.70	48.5 (29)		
School	51.71±12.67	50 (16)		
Would you hire an epileptic employee?				
Yes	46.81±14.26	48.0 (22.0)	t=2.838	0.006
No	56.12±14.63	55.5 (18.0)		

t: Independent Sample t Test Statistic;  $\chi^2$ Kruskal Wallis Test Statistic, F:One-Way ANOVA QQW: Quarter-Quarter Width.

Table 5. Which information about epilepsy would be more useful for you? Pairwise Comparisons of Age Values of the Answers to the Question

Which instruction about epilepsy would be more useful for you?	p
Information posters and brochures* Social media and internet	0.716
Information posters and brochures* In schools	0.018
Information posters and brochures* TV-Radio	0.014
Social media and internet* In schools	0.708
Social media and internet* TV-Radio	0.534
TV-Radio* Schools	0.790

\*Bonferroni Corrected p values.

by Ghanean et al.,<sup>[10]</sup> 47.1% of the participants said that epilepsy is a genetic disease.

The answers to these three questions, which were asked to evaluate the general knowledge level about epilepsy, were found to be approximately compatible with the literature.

This situation was thought to demonstrate the validity of our study population.

In our study, 10.1% of the participants answered "No" and 19.2% answered "I would be uncomfortable" to the question "Would you let your children play with epileptic patients?" In a study conducted in Croatia, 6.7% of respondents gave a negative answer to a similar question.<sup>[11]</sup> This difference, though not very high, can be explained by the higher average age of the participants in our study.

The increase in the number of "No" answers given as age increases in response to the question "Would you hire an individual with epilepsy?" may indicate that advanced age is compatible with a negative attitude. However, inconsistent results have been reported in studies on this subject. In the study by Nagamori et al.,<sup>[9]</sup> it was shown that advanced age is associated with better knowledge about epilepsy.

In our study, 32.3% of the participants gave a positive answer to the question "Would you like your children to marry

an individual with epilepsy?" In the study conducted by Guekth et al.,<sup>[12]</sup> 43% gave a positive answer to the question "Will you marry an individual with epilepsy?". Here, too, although the difference is not very large, it is seen that our participants had a more negative attitude towards epilepsy patients.

According to the literature, the negative attitude towards epileptic patients in our population and the increase in labeling with increasing age may be related to the mean age and education level of the participants. Considering that the period of compulsory education was increased to 5 years in 1923, when the republic was declared in Türkiye, 8 years in 1997, and 12 years in 2013, the fact that the education period of the young population is longer than that of the elderly may be related to the increase in awareness and the decrease in labeling in the young population.

In our study, no significant difference was found in the distribution of the answers given to the questions asked to evaluate the level of knowledge and labeling about epilepsy by gender. In a study by Adewumi et al.,<sup>[13]</sup> it was shown that male gender is associated with negative behavioral attitudes towards epilepsy. In another study conducted in Ghana,<sup>[14]</sup> it was not shown that gender difference was associated with epilepsy knowledge level and labeling. This difference in the literature may be related to the number of patients participating in the studies and the unequal number of men and women. Since our study was designed with a free sampling method, it should be aimed to design studies with equal numbers of male and female participants, as the female population was slightly higher.

In our study, it has been shown that negative answers to the question "Would you hire an individual with epilepsy?" increased in older ages. For the other questions asked to assess labeling, no statistically significant differences were obtained.

The information sources of the participants in the study about the disease were also evaluated. According to the results, while 46.5% of the participants cited "friends" as a source of information, only 8.1% mentioned "school." This can be interpreted as a significant portion of the population having ambiguous information about epilepsy. As the most useful source of information, the participants most frequently answered "school" with 41.4%. This indicates that epilepsy should be included in educational curricula to ensure that society obtains accurate information about

the condition. In the study conducted by Brabcova et al.,<sup>[15]</sup> it was observed that the level of knowledge about the disease increased and labeling decreased by having children between the ages of 9-11 watch educational videos. In the article by Herrman et al.,<sup>[16]</sup> studies using lectures and educational videos to increase the level of knowledge about epilepsy were reviewed, and positive results were observed. However, in this study, new generation communication channels that appeal to wider audiences, such as social media and the internet, were not evaluated. In another study, significant results were obtained in an information campaign that used the internet and social media with the participation of physicians, celebrities, and patients.<sup>[17]</sup> As in these examples, it can be said that positive results can be achieved in Türkiye, which has a high proportion of young people, with an information program to be conducted in schools to reduce labeling.

In our study, statistically significant responses were obtained between different age groups in the answers given to the questions asked about information sources. It was observed that the average age of individuals who prefer TV-Radio as an information channel is the highest, while the average age of those who prefer informational posters and banners is the lowest. Considering that the negative response to the question "Would you hire an individual with epilepsy?" obtained in this study increases with age, positive results can be achieved with TV-Radio broadcasts targeting the elderly group, given that older age is associated with labeling.

Weaknesses of our study include the low number of participants, the lack of evaluation of education level, and the unequal gender distribution due to the sequential patient recruitment method. Evaluating the preferred sources of information and examining their relationship with different age groups are the innovative and strong aspects of the study.

## Conclusion

Epilepsy is one of the most common neurological diseases, and it is associated with misinformation, bad social attitudes, and labeling in society. Labeling patients with epilepsy not only impairs their quality of life but also affects their motivation to seek treatment. By developing education policies for different age groups, the level of knowledge in society should be increased, and labeling should be prevented.

## Disclosures

**Ethics Committee Approval:** Approval for the study was obtained from the ethics committee of our hospital, Turkish Republic Ministry of Health Fatih Sultan Mehmet Research and Training Hospital, with the decision number FSM EAH-KAEK 2023/12 dated 26.01.2023. Our research was conducted in accordance with the Declaration of Helsinki and the Guidelines for Good Clinical Practices.

**Peer-review:** Externally peer-reviewed.

**Conflict of Interest:** None declared.

**Use of AI for Writing Assistance:** Not declared.

**Authorship Contributions:** Concept – A.A.; Design – I.K.A.; Supervision – A.A.; Materials – Ç.İ.Ö.B.; Data collection &/or processing – A.A.; Analysis and/or interpretation – A.A.; Literature search – Ç.İ.Ö.B.; Writing – A.A.; Critical review – I.K.A.

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