



Knowledge of epilepsy among persons with epilepsy in Turkey



Dilek Atakli, Pelin Dogan Ak *, Betül Tekin Guveli, Burcu Yuksel

Bakirkoy Education and Research Hospital for Psychiatry, Neurology and Neurosurgery, Neurology Department, Istanbul, Turkey
 Fatih Sultan Mehmet Education and Research Hospital, Neurology Department, Istanbul, Turkey
 Antalya Education and Research Hospital, Neurology Department, Antalya, Turkey

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ABSTRACT

Purpose: It has been shown in studies that there are knowledge gaps about epilepsy in both developing and developed countries all around the world. Lack of knowledge exists even among people with epilepsy (PWE), and this may affect their lives negatively. This study aimed to evaluate what PWE in Turkey know about their disease.

Method: A self-completed questionnaire consisting of demographic details, an item about perceived stigmatization, and 24 items about general knowledge of medical and social aspects of epilepsy was developed. Applicants were asked to answer 'true', 'false', or 'do not know' to each statement. The scores of the questionnaire were defined as low (<15 point), medium (≥15–20), and high (≥20).

Results: The mean score on the questionnaire was 15.17 ± 3.74 (range, 4–24). One hundred twenty-five PWE (37.9%) scored low, 170 PWE (51.5%) scored medium, and 35 PWE (10.6%) scored high. The education level and household income were highly correlated with the knowledge level. Higher education level ($r: 0.31$) and high income ($r: 0.25$) were correlated with higher mean scores ($p < 0.01$). Lack of information was present particularly in terms of etiology, management of seizures, and medication during pregnancy.

Conclusion: We documented the knowledge deficit of PWE about their disease, a situation that may lead to sub-optimal management and negative attitudes. We concluded that study programs should be organized and more education should be provided to PWE in order to overcome these issues.

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1. Introduction

Epilepsy is one of the major neurological disorders, affecting approximately 50 million people around the world. Although it is widely known in society, knowledge about the disease was shown to be poor [1–11]. Several studies have shown that knowledge gaps exist even among health-care professionals [12–14]. Lack of knowledge has also been reported among people with epilepsy (PWE) [15–21]. Dawkins et al. compared the level of knowledge in PWE with a control group and showed that PWE knew only little more than those without epilepsy [15].

Epilepsy is highly associated with stigmatization in both developing and developed countries [5,11,22–25]. Stigmatization causes discrimination and prejudicial behavior leading to a decrease in quality of life. Persons with epilepsy are less likely to marry, less educated, and more underemployed or unemployed and have lower self-esteem than the healthy population [26–31]. Education has been reported to be negatively correlated with stigma [23,27,30]. Studies have shown that poor knowledge may contribute to increased stigmatization. Without

accurate knowledge, PWE are more prone to misconceptions and negative attitudes.

Doughty et al. assessed the knowledge of 6156 PWE from 10 European countries [18]. Levels of knowledge were different between countries. Overall, they found clear gaps in knowledge, particularly in terms of the cause of disease and medication. In that study, 14% of the respondents were from Turkey, and 88% of those were in the low-scoring group. There have not been any other studies from Turkey evaluating knowledge of PWE about their disease. We aimed to investigate perceived stigma and knowledge gaps among PWE in Turkey and the attitudes that have potential for discrimination and lower quality of life.

2. Material and methods

The study was approved by the Local Ethics Committee and designed as a cross-sectional, descriptive study.

A self-completed, general knowledge assessment of epilepsy questionnaire (GKAEQ), consisting of demographic details, an item about perceived stigmatization, and 24 items about general knowledge of medical and social aspects of epilepsy, was developed. Applicants were asked to answer 'true', 'false', or 'do not know' to each statement. The correct answers were scored as 1, and the wrong and not known ones were scored as 0, leading to a total score between 0 and 24. The scores

* Corresponding author at: Fatih Sultan Mehmet Education and Research Hospital, Neurology Department, Atasehir, Istanbul, Turkey. Tel.: +90 505 638 50 31.
 E-mail address: drpelindogan@hotmail.com (P. Dogan Ak).

of GKAEQ were defined as low (<15 point), medium (≥ 15 –20), and high (≥ 20).

Demographic data included age, sex and marital status, level of education, employment status, and monthly income. Education level was divided into three categories: (1) primary and secondary school (5–8 years), (2) high school (11 years), and (3) university. When analyzing employment status, subjects were divided into four categories: (1) employed, (2) unemployed, (3) in school, and (4) retired.

Participants consisted of patients who had a well documented diagnosis of epilepsy with clinical and electrophysiological findings and who had been followed at the epilepsy outpatient clinic of our hospital, which is an important tertiary education and research hospital in Istanbul. We excluded patients with suspicious diagnosis or who had nonepileptic seizures.

Patients were requested to complete the questionnaire while they were waiting for their appointments. Patients who were unable to fill in the provided questionnaire without any help were excluded. The study was conducted between 2012 and 2014. For statistical analysis, IBM SPSS Statistics, Version 21.0 was used.

3. Results

Questionnaires were obtained from 330 patients. The demographic data and the items in the questionnaire are shown in [Tables 1 and 2](#).

Of the 330 patients with epilepsy, mean age was 29.05 ± 11.31 years (range: 13–74 years); 64.8% were female, and 35.2% were male.

We correlated the GKAEQ levels (low, medium, and high-scoring) and the mean knowledge scores of PWE with the demographic findings and their feeling of being stigmatized ([Table 1](#)).

The mean score on the GKAEQ for PWE was 15.17 ± 3.74 (range, 4–24). One hundred twenty-five PWE (37.9%) scored low, 170 PWE (51.5%) scored medium, and 35 PWE (10.6%) scored high ([Fig. 1](#)).

Gender ($p: 0.17$, $r: 0.07$), marital status ($p: 0.75$, $r: 0.17$), and employment state ($p: 0.07$, $r: 0.09$) were not significantly correlated with the mean GKAEQ scores.

Table 1
Demographic characteristics of PWE with high/medium and low scores.

	Total percentage	High scorers (≥ 20 –24)	Medium scorers (≥ 15 –20)	Low scorers (0–15)
<i>Gender</i>				
Female	214 (64.8%)	12.2%	53.7%	34.1%
Male	116 (35.2%)	7.8%	47.4%	44.8%
All PWE	330	10.6%	51.5%	37.9%
<i>Feeling stigmatized</i>				
Yes	140 (43.3%)	8.6%	42.1%	49.3% ^a
No	183 (56.7%)	12.0%	58.5%	29.5%
<i>Education</i>				
Primary School	186 (54.5%)	7.0%	44.1%	48.9% ^a
High School	88 (17.8%)	9.1%	63.6%	27.2%
University	56 (13.0%)	25.0%	57.1%	17.9%
<i>Marital status</i>				
Married	143 (43.3%)	11.9%	51.0%	37.1%
Single	187 (56.7%)	9.6%	51.9%	38.5%
<i>Employment</i>				
Employed	132 (40.0%)	14.4%	53.8%	31.8%
Unemployed	146 (44.2%)	10.3%	46.6%	43.1%
Student	48 (14.5%)	2.1%	58.3%	39.6%
Retired	4 (1.2%)	0.0%	75.0%	25.0%
<i>Income</i>				
0–\$300	101 (30.6%)	6.9%	44.6%	48.5% ^a
\$301–\$500	135 (40.9%)	12.6%	45.2%	42.2%
\$501–\$750	61 (18.5%)	11.5%	62.3%	26.2%
\$751–\$1000	20 (6.1%)	5.0%	85.0%	10.0%
\$1001 or more	13 (3.9%)	23.1%	69.2%	7.7%

PWE, people with epilepsy.

^a $p < 0.01$.

Table 2
Items and results of the general knowledge assessment of epilepsy questionnaire (GKAEQ).

Questions	Total	n/%		
		Yes	No	Not know
Did you ever feel yourself different from people without epilepsy?	323	140/43.3%	183/56.7%	
Do you think that a patient can have more than one type of epileptic seizure?	330	256/77.6%	24/7.3%	50/15.2%
Patients become unconscious during every epileptic seizure.	330	133/63.2%	130/39.4%	67/20.3%
Patients fall during every epileptic seizure.	330	155/47.0%	142/43.0%	33/10%
Stress, inadequate sleep and menstrual cycle can cause seizures.	330	222/76.4%	20/6.1%	58/17.6%
Antiepileptic drugs should be taken regularly every day.	330	321/97.3%	3/0.9%	6/1.8%
Seizures of some patients can be controlled with one drug, however seizures of some cannot be controlled with more drugs.	330	234/70.9%	17/5.2%	79/23.9%
Laboratory tests are done regularly to control the complications of drugs.	330	252/76.4%	21/6.4%	57/17.3%
People with epilepsy cannot drink acidic beverages.	330	92/27.9%	121/36.7%	117/35.5%
To have patients sniff an onion during seizures is a very useful method.	330	56/17.0%	179/54.2%	95/28.8%
People with epilepsy cannot work.	330	35/10.6%	256/77.6%	39/11.8%
Epilepsy is related to mental retardation.	330	63/19.1%	199/60.3%	68/20.6%
Epilepsy is just a genetic disease.	330	44/13.3%	214/64.8%	72/21.8%
Seizures can begin by dog biting, or being frightened by anything.	330	91/27.6%	104/31.5%	135/40.9%
Epilepsy is a contagious disease.	330	5/1.5%	307/93.0%	18/5.5%
It is forbidden for people with epilepsy to get married.	330	5/1.5%	287/87.0%	38/11.5%
It is forbidden to give birth for people with epilepsy.	330	14/4.2%	248/75.2%	68/20.6%
People with epilepsy can fast.	330	146/44.2%	118/35.8%	66/20.0%
Epilepsy is a mental disease.	330	100/30.3%	155/47.0%	75/22.7%
People with epilepsy can obtain a driver's license.	330	139/42.1%	116/35.2%	75/22.7%
EEG is a test showing the activity of brain.	330	287/87.0%	3/0.9%	40/12.1%
People with epilepsy can do any kind of job.	330	139/42.1%	149/45.2%	42/12.7%
People with epilepsy can take their drugs regularly when they get pregnant.	330	166/50.3%	18/5.5%	146/44.2%
It is true to put a spoon into the patient's mouth during a seizure.	330	30/9.1%	228/69.1%	72/21.8%

The education level ($p < 0.01$, $r: 0.29$) and household income ($p < 0.01$, $r: 0.21$) were highly correlated with the knowledge level ($p < 0.01$). Higher education ($r: 0.31$) and high income ($r: 0.25$) levels were correlated with higher mean GKAEQ scores ($p < 0.01$).

The question related to stigmatization revealed that 140 of 323 patients (43.3%) had reported feeling stigmatized. We did not find a significant correlation of stigmatization with gender, marital status, or employment status of the respondents but did with education level ($p < 0.01$, $r: 0.18$) ([Table 3](#)).

There was a significantly inverse relation between the mean scores of GKAEQ and the patient's feeling of being stigmatized ($p < 0.01$, $r: 0.15$). High-scoring patients were less stigmatized ($p < 0.01$, $r: 0.18$) ([Fig. 2](#)).

Thirty point three percent of the respondents thought that epilepsy is a mental disease, and 22.7% cited that they did not know if that was true or not; 19.1% of the respondents believed that epilepsy is related to mental retardation, and 20.6% cited that they did not know if that was true or not; 13.3% of them said that epilepsy is just a genetic disease, while 21.8% had no idea about this; and 27.6% of the respondents thought that seizures can be triggered by dog biting or any fearful situation, and 40.9% cited that they did not know if that was true or not.

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