



Who is the bigger stigmatizer?: The loved one or the society

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ABSTRACT

Objective: Epilepsy has long been considered by the society as a dangerous and frightening spiritual possession or even a contagious disease. This results in an unavoidable embarrassment for both the patient and the family leading to social isolation, seclusion, and secretiveness about the diagnosis. The aim of this study was to determine the stigmatizing level of the general Turkish population and to compare these results with the stigmatizing level of the patients' relatives group (PRG).

Methods: This is a substudy of our main study which aimed to develop two scales for the quantification of the stigma level in patients with epilepsy (PWE) and their relatives [Stigma Scale for Epilepsy (SSE) –Self Report (SR) and –Informant Report (IR)]. First-degree relatives of the patients had been included in the main study. For the present study, 202 healthy people who were caregivers and relatives of neurologic patients other than epilepsy were recruited for the control group (CG). A sociodemographic and clinical data form and SSE-IR scale were administered to the CG as well. The relationship between sociodemographic characteristics and SSE-IR scores was evaluated, and a regression analysis was performed in order to analyze sociodemographic factors contributing to SSE-IR scores. Stigmatizing levels were compared between PRG and CG. Statistical analysis was performed using Statistical Package for the Social Sciences version 22.0 software.

Results: Comparison of stigma scores among different sociodemographic strata of the CG showed that there was a statistically significant difference in terms of educational status and occupation ($p < 0.01$). Multivariate linear regression analysis revealed that education accounted for 10.8% and 8.9% of the variance in the SSE-IR scale respectively in the PRG and the CG. Prejudgment scores and total scores of the PRG were significantly higher than those of the CG. There was no statistically significant difference between two groups in terms of discrimination and false beliefs subscales scores. The proportion of highly stigmatizer participants in the PRG was statistically significantly higher than that of the CG.

Discussion/Conclusions: This study showed us that the stigmatization levels in a group of subjects drawn from general population without acquaintance of epilepsy were lower than the relatives of the patients. This result may be partially explained by the ambivalent attitudes of the relatives, as those high scores may stem from not only enacted but also the felt stigma that they were experiencing themselves. It must be a warning sign for both of all the clinicians treating epilepsy and national association against epilepsy, as well as public health officials to increase efforts for awareness raising.

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1. Introduction

Epilepsy is a chronic neurological disease with high stigmatization rate due to the psychosocial consequences of seizures. Scambler theoretically divided the stigma associated with epilepsy as enacted stigma and felt stigma; enacted stigma refers to the feelings of prejudice and behaviors of discrimination against patients with epilepsy (PWE),

and felt stigma refers to the shame and embarrassment of being a person with epilepsy [1–3].

Epilepsy has long been considered by the society as a dangerous and frightening spiritual possession or even a contagious disease [4–10]. Kleinman explained that the moral burden of epilepsy threatens not only the patient but also her family in Chinese culture [11]. This results in an unavoidable embarrassment for both the patient and the family leading to social isolation, seclusion, and secretiveness about the diagnosis.

Our previously reported main study was conducted on 302 patients and 201 relatives. The major objective of the main study was to develop and report two stigma scales that could be used in Turkish PWE and

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their relatives. First scale was developed for PWE, for the purpose of quantifying the feeling of being stigmatized due to being a patient with epilepsy (hence, specific for felt stigma), which we named as Stigma Scale for Epilepsy-Self Report (SSE-SR). The second scale was developed for their relatives, for the purpose of quantifying the feelings of prejudice and discrimination against PWE and false beliefs and misconceptions about epilepsy (hence, specific for enacted stigma), which we renamed as Stigma Scale for Epilepsy-Informant Report (SSE-IR) (Cronbach alpha = 0.892) [10,12] (Table 1). Briefly, the results of the SSE-IR scale as scored by the relatives had shown that 38.8% (n = 78) of informants rated themselves as stigmatizers, 61 of whom were within the moderate and the remaining 17 were in the high stigmatizer range. Males had significantly higher SSE-IR scores as compared with females. The stigma scores of the single and married group were significantly higher, as compared with the other group. Informants with the lowest education and lowest income were found to be more stigmatizers as compared with the informants within other strata [10].

In this present substudy, our objective was to determine the stigmatizing level of the general Turkish population by choosing a group of healthy people who do not have any close person with epilepsy, by using the same SSE-IR scale and to compare these results with the results that had been obtained from the relatives in the previous study.

2. Materials and methods

2.1. Participants

The study protocol was approved by the Ethics Committee of Bakirkoy Prof. Dr. Mazhar Osman Mental Health and Neurological Disorders Training and Research Hospital. A written informed consent was obtained from each participant. The study was conducted in accordance with the principles of the Declaration of Helsinki. First-degree relatives of the patients, who were over the age of 18 years, literate, and accompanied the patients during outpatient visits, had been included in the main study [10]. For the present study, 202 healthy people who were caregivers and relatives of neurologic patients admitted to our hospital with conditions other than epilepsy were recruited. The inclusion criteria

were being over the age of 18 years, being literate, not being a healthcare provider, and not having a relative with epilepsy.

2.2. Procedures

2.2.1. Sociodemographic data form

A sociodemographic and clinical data form, including questions regarding age, sex, marital, and employment status, educational, and income levels, was administered. Income level was classified according to the minimum wage (MW) in January 2015, which was 1201.50 Turkish liras in gross and 949.07 Turkish liras (close to 300 United States dollar) in net. Marital status was divided into three groups: single, married, and other; other denoting divorced and widowed participants, as well as those who were reluctant to disclose their marital status.

2.2.2. Stigma scale for epilepsy informant report

The SSE-IR consists of 20 questions and a 4-point Likert-type answering method and also, three factors according to the factor loading values, which are the following: discrimination, prejudice, and false beliefs (Cronbach alpha = 0.892). The total stigma score was calculated by adding the scores of the individual questions and then converting this total raw score to an adjusted score out of a maximum total score of 100. So, the least possible score is 25, and cutoff for stigmatization is 50. The participants with a score of 25 to 50 were deemed as nonstigmatizers, those with scores between 51 and 75 were moderate stigmatizers, and those with scores between 76 and 100 were high stigmatizers [10].

2.3. Statistical analysis

Statistical analysis was performed using the SPSS version 22.0 software (SPSS Inc., Chicago, IL, USA). Descriptive data were expressed in mean, standard deviation, median, minimum, maximum, frequency, and percentage. The chi-square and Fischer's exact tests were used to

Table 1
Stigma Scale for Epilepsy-Informant Report.

Discrimination	
Epilepsy is possession. ^a	
I don't want to marry a person with epilepsy.	
I don't want to be the friend of a person with epilepsy.	
I don't want my relatives or children to be friendly with someone with epilepsy.	
If I had a child with epilepsy, I wouldn't want to send him to school.	
People with epilepsy don't contribute to society.	
People with epilepsy have this disease as a punishment from God.	
If I had a relative with epilepsy, I would be ashamed.	
Prejudgments	
Epilepsy is an absolutely untreatable disease.	
People with epilepsy are exposed to discrimination.	
People with epilepsy could not be successful in life.	
People with epilepsy should not be soldiers.	
I don't want to give a job to a person with epilepsy.	
People should not make any decisions alone about their own lives.	
People with epilepsy cannot be self-sufficient.	
False beliefs	
Epilepsy is a contagious disease.	
Epilepsy is a mental disease.	
Epilepsy occurs due to fear.	
Onions, water, cologne are beneficial for stopping convulsions.	
People with epilepsy shouldn't give birth. ^b	

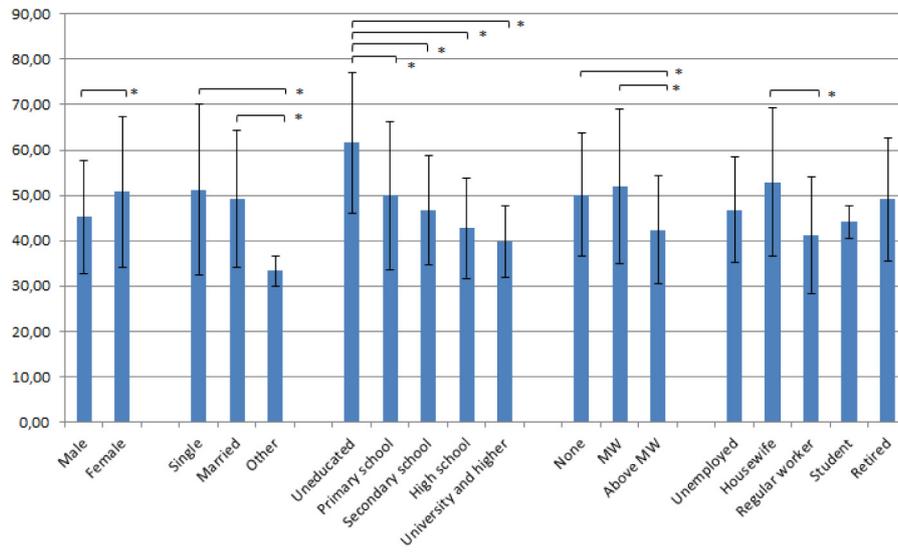
^a Question was included in the discrimination factors, although it was developed as a false belief assessment question.

^b Question was included in the false beliefs factor, although it was developed as a discrimination assessment question.

Table 2
Comparison of the sociodemographic characteristics of patients' relatives and control group.

	Patients' relatives (n = 201)	Control group (n = 202)		t	p
		Mean ± SD (median)	Mean ± SD (median)		
N = 403					
Age	44.48 ± 10.50 (44)	44.66 ± 11.08 (45)		-0.168	0.867
		Patients' relatives (n = 201)	Control group (n = 202)		
		N(%)	N(%)	χ ²	p
+Sex	Female	64(31.8)	78(38.6)	2.025	0.155
	Male	137(68.2)	124(61.4)		
+Marital status	Single	27(13.4)	25(12.4)	1.557	0.459
	Married	168(83.6)	166(82.2)		
	Other	6(3.0)	11(5.4)		
+Educational level	Uneducated	24(11.9)	21(10.4)		
	Primary school	107(53.2)	100(49.5)	1.308	0.860
	Secondary school	21(10.4)	23(11.4)		
	High school	37(18.4)	43(21.3)		
	University and higher	12(6.0)	15(7.4)		
++Occupation	Unemployed	5(2.5)	4(2.0)		
	Housewife	109(54.2)	102(50.5)	6.514	0.162
	Regular worker	50(24.9)	70(34.7)		
	Student	4(2.0)	5(2.5)		
	Retired	33(16.4)	21(10.4)		
+Income level	None	48(24)	44(21.8)		
	MW	101(50)	98(48.5)	0.792	0.851
	Above MW	52(26)	60(29.7)		

Student t-test, + Chi-square, ++ Fisher exact chi-square, SD: standard deviation, MW: Minimum Wage.



Kruskal-Wallis / Mann-Whitney U tests. * $p < 0.05$

Fig. 1. Comparison of stigma scores and sociodemographic characteristics of patients' relatives ($n = 201$). MW: minimum wage. Kruskal–Wallis/Mann–Whitney U tests. * $p < 0.05$.

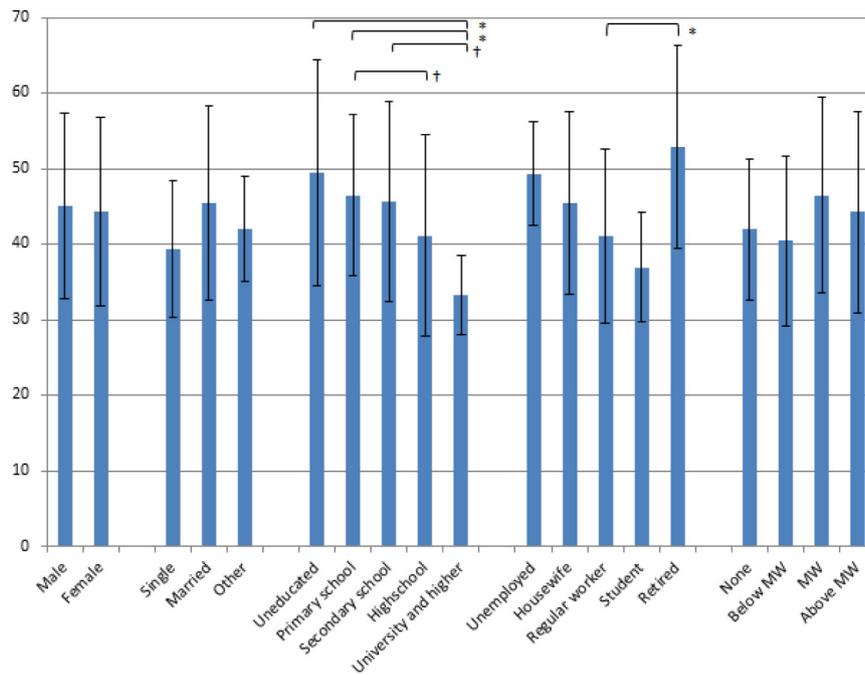
compare the frequencies and percentages. Distribution of variables was measured with the Kolmogorov–Smirnov test. An independent sample t-test and one-way analysis of variance (ANOVA) were used to compare the mean values of normally distributed variables. In the presence of a significant difference in ANOVA, the post-hoc Tukey's Honestly Significant Difference (HSD) test was used for the paired comparison of subgroups. Nonparametric tests, such as the Mann–Whitney U test, Wilcoxon test and Kruskal–Wallis, Bonferroni correction, and Multivariate ANOVA (MANOVA) methods were used, where applicable (depending on the number of subjects and for the homogeneity control). The correlation (Pearson and Spearman) and regression analyses were

performed to determine the correlation between variables and to show the correlations in mathematical relations.

3. Results

The sociodemographic characteristics of patients' relatives group (PRG) and the control group (CG) are summarized and compared in Table 2. There are no statistically significant differences between sociodemographic characteristics of two groups.

The comparisons of SSE-IR total scores among sociodemographic strata in PRG and CG are shown in Figs. 1 and 2, respectively [10].



Student t-test Kruskal Wallis, * $p < 0.001$, † $p = 0.002$

Fig. 2. Comparison of stigma scores and sociodemographic characteristics of the control group ($n = 202$). MW: minimum wage. Student t-test, Kruskal–Wallis, * $p < 0.001$, † $p = 0.002$.

Table 3
Comparison of the SSE-IR total scores and subscores of patients' relatives and control group.

N = 403	Patients' relatives (n = 201)	Control group (n = 202)	Wilks' λ	F	p
	Mean \pm SD (median)	Mean \pm SD (median)			
†Prejudgments	19.49 \pm 7.08 (15)	16.66 \pm 5.78 (16)	0.960**	15.791	<0.001
†False beliefs	12.67 \pm 3.98 (13)	12.07 \pm 3.79 (11)		2.402	0.519
‡Discrimination	16.85 \pm 7.20 (15)	15.87 \pm 4.77 (14)		U	p
‡Total score	49.02 \pm 15.55 (48)	44.61 \pm 12.36 (43)		19,757	0.640
				17,102	0.006**

†One-way MANOVA, ‡Mann–Whitney U, SD: standard deviation.

** $p < 0.01$.

There was a statistically significant difference in terms of educational status and occupation variables in the CG ($p < 0.01$) (Fig. 2). Pairwise comparisons with Bonferroni correction set at $p < 0.005$ showed that in terms of educational status, stigma scores of university and higher education group were lower as compared with those of uneducated, primary school, and secondary school education groups ($p < 0.001$ for the first two and $p = 0.002$ for the last comparison). The stigma scores of high school group were lower than the stigma scores of primary school group ($p = 0.002$). In terms of the occupational status, the only significant difference was between the regular workers and retired participants ($p < 0.001$). No significant correlation was found between the stigma scores and sex, marital status, and income level ($p > 0.05$).

Multivariate linear regression analysis was performed for the factors accounting for the variance in SSE-IR scores in PRG. Using the enter method, a significant model emerged ($p < 0.001$, adjusted R square = 0.167). Significant variables were sex ($\beta = 0.144$, $p = 0.032$), marital status ($\beta = 0.231$, $p = 0.001$), and educational level ($\beta = -0.366$, $p = 0.000$). Using the stepwise method, educational level alone accounts for 10.8% of the variance while the variance explained by the model reaches 15.0% by adding marital status and 17.0% by adding sex. When the other variables were fixed, the increase of one unit in educational level resulted in a decrease of 5.2 units in the SSE-IR scores.

The same analysis was also conducted for the CG. Using the enter method, a significant model emerged ($p < 0.001$, adjusted R square = 0.119). Significant variables were occupation ($\beta = 0.203$, $p = 0.006$) and educational level ($\beta = -0.391$, $p = 0.000$). Using the stepwise method, educational level alone accounts for 8.9% of the variance while the variance explained by the model reaches 11.9% by adding occupational status. When the other variables were fixed the increase of one unit in educational level resulted in a decrease of 3.7 units in the SSE-IR scores.

Multivariate ANOVA with a Bonferroni-corrected p value set at $p < 0.025$ in all comparisons showed that the prejudgment scores of PRG were significantly higher than those of CG ($p < 0.001$), and there was no statistically significant difference between the two groups in terms of false beliefs subscale scores ($p = 0.122$) (Table 3).

Since the data for SSE-IR total scores and discrimination subscale scores did not have a normal distribution, the comparisons between the groups were conducted by using the nonparametric Mann Whitney U test, again with the same Bonferroni-corrected p value. There was no statistically significant difference between two groups in terms of discrimination subscale scores ($p = 0.640$) (Table 3). The total SSE-IR scores of the PRG were significantly higher than that of the CG ($p = 0.006$) (Table 3).

Finally, the proportion of highly stigmatizer participants in the PRG was significantly higher than that of the CG ($p = 0.001$) (Fig. 3).

4. Discussion

In the present study, we aimed to evaluate and compare stigmatization in the relatives of PWE and the society.

We had previously reported that 38.8% ($n = 78$) of the patients' relatives were stigmatizers according to a specifically developed 100-point stigma scale, 61 of whom were in the moderate range and the remaining 17 were high stigmatizers. The stigma scores of the males were significantly higher than the females. The stigma scores of the single and married group were significantly higher compared with the other group. Informants with lowest education and lowest income were found to be more stigma-prone as compared with the informants within other strata. Both minimal income and no income groups were more stigmatizers than the above minimal wage group. The stigma scores of

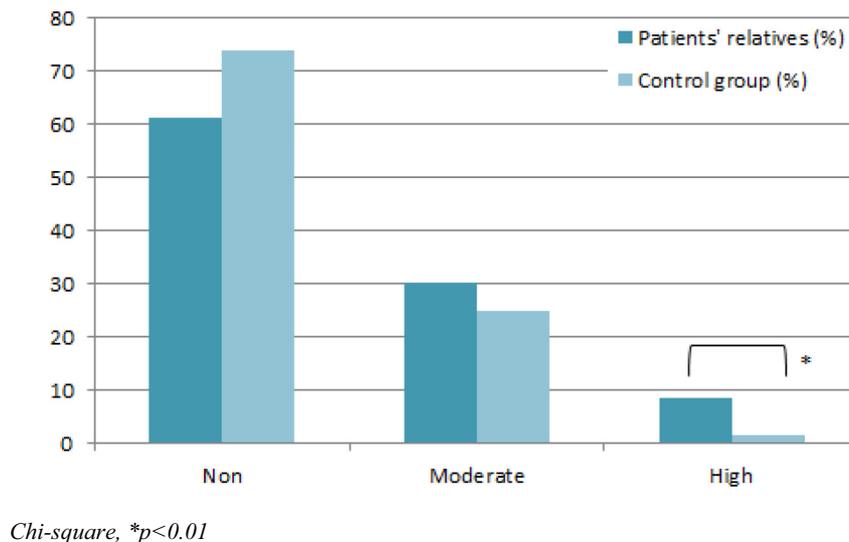


Fig. 3. Comparison of stigmatization severity between patients' relatives ($n = 201$) and control group ($n = 202$). Chi-square, * $p < 0.01$.

Table 4
Some of important similar studies from different countries.

Citation, year, and country	Study sample	Stigma measure(s)	Major stigma-related findings
Austin et al. 2004 [37] USA	Parents of 173 children with epilepsy (CWE) and of 224 children with new-onset seizures. The child scale was tested in the chronic sample.	Parent Stigma Scale (PSS) and Child Stigma Scale (CSS)	<ul style="list-style-type: none"> •Higher scores were associated with greater seizure severity scores. In PSS, lower scores were associated with more positive mood, less worry, and more family leisure activities. In CSS, higher scores were correlated with more negative attitude, greater worry, poorer self-concept, and more depression symptoms. •A significant correlation was found between the child stigma score and the parent stigma score, though it was not strong.
Hansen et al. 2018 [22] USA	136 caregivers of family members with confirmed diagnoses of intractable epilepsy.	A 6-item affiliate stigma scale that was adapted from [54].	<ul style="list-style-type: none"> •75% of the participants reported that people are uncomfortable around their family member, and half believed others avoided and treated them in an inferior manner. •The majority of caregivers felt stigma directed toward themselves. •Affiliate stigma explained 24% of the variation in caregiver burden scores.
Fernandes et al. 2004 [16] Brazil	20 patients with epilepsy (PWE) and 20 relatives	Two questionnaires, one for community had 16 questions and another one for the patient had 4 additional questions [Stigma Scale of Epilepsy (SSE)]	<ul style="list-style-type: none"> •The results were presented by the questionnaires' domains: medical, social, and personal areas. •Medical area: the type of treatment that appeared was medication, exams, surgery, and religious approach; meaning of epilepsy: convulsion, head injury, faint or problem in the brain; the causes of epilepsy were traumas, psychological, and genetic features. •Social area: the social difficulties faced by PWE were related with work, prejudice, school, relationships, driving, freedom, leisure, and memory. •Personal area: the main feelings highlighted by participants about epilepsy were sadness, dependence, inferiority, insecurity, fear, and pity.
Tedrus et al. 2018 [20] Brazil	148 PWE and 90 cohabiting relatives (CR)	Stigma Scale of Epilepsy [16]	<ul style="list-style-type: none"> •CR with depressive disorder perceived more stigma. •Higher perceived stigma by PWE was related to exclusively generalized seizures, longer disease duration, and higher perception of stigma by CR. •Both PWE and CR have high perception of stigma. Higher perceptions of stigma by PWE and CR are associated with worse quality of life (QoL) in PWE.
Giuliano et al. 2019 [38] Bolivia	216 subjects (6 PWE). 133 subjects answered to the questionnaires after the campaign.	SSE [16] was administered to the subjects prior to and one month after an educational campaign.	<ul style="list-style-type: none"> •A significant improvement was recorded in knowledge, attitudes, and practices toward epilepsy, and a significant reduction was found in the mean SSE total score after the educational program. •After the training, PWE stated to experience less depression, memory difficulties, work or social issues, and seizure worry.
Jacoby et al. 2004 [23] United Kingdom	A random sample of >1600 members of the general public	Knowledge of and attitudes toward epilepsy with 16 precoded and two open questions	<ul style="list-style-type: none"> •One-fourth of informants knew someone with epilepsy and one-half had witnessed a seizure. •One-half agreed that PWE are treated differently by others, and themes of exclusion, restriction, and non-normality were commonly cited as reasons for this. •One-fifth agreed with the statement that PWE have more personality problems than others.
Reilly et al. 2018 [39] United Kingdom	Mothers (n = 47) of young CWE, and mothers (n = 48) of children with nonepilepsy-related neurodisability (CWN)	PSS [37]	<ul style="list-style-type: none"> •38% of mothers of CWE scored in the at-risk range on the Total Stress score. Significantly more mothers of CWE scored in the at-risk range on the Parent–Child Dysfunctional Interaction subscale than mothers of CWN. •There was no statistically significant difference in perceived stigma between mothers in both groups. •Mothers of CWE report high levels of parenting stress and higher levels of difficulties with parent–child interaction than mothers of CWN.
Holmes et al. 2019 [40] United Kingdom	An online survey of a stratified quota sample of 3875 adults.	46-item Attitudes and Beliefs about Living with Epilepsy scale	<ul style="list-style-type: none"> •<1% of participants have a very negative attitude, 10% have a negative attitude, 59% have a positive attitude, and 30% have a very positive attitude to epilepsy. •Lower knowledge was associated with more negative attitude, with the exception of risk and safety concerns, where higher knowledge in some areas was associated with higher concerns.
Benson et al. 2016 [41] Ireland	In phase one, 33 CWE and 40 parents participated in qualitative interviews. In phase two, 47 CWE and 72 parents completed a cross-sectional survey.	PSS and CSS [37]	<ul style="list-style-type: none"> •CWE and their parents experience felt and enacted stigma via social exclusion, activity restriction, teasing/bullying, internalized negative feelings to epilepsy, concealment of epilepsy, and parental stigma-coaching. •Higher CWE and parent stigma perceptions were significantly correlated with greater epilepsy concealment and greater negative affect around epilepsy-related communication within the home.
Jansen et al. 2017 [42]	1092 high school students	A questionnaire asking for familiarity, knowledge, and attitudes toward	<ul style="list-style-type: none"> •50% of the respondents knew that people could die from a seizure. 20% thought emotional strain could cause epilepsy.

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Table 4 (continued)

Citation, year, and country	Study sample	Stigma measure(s)	Major stigma-related findings
Germany		epilepsy and demographic items.	<ul style="list-style-type: none"> •In case of a seizure, 24% participants would hold the person to the ground, and 19% would put a solid object into the person's mouth. •3% would not like to be friends and 22% would not like to go on a date with a PWE. •Students of a school located nearby a specialized epilepsy center were more familiar with epilepsy and showed better knowledge concerning causes, symptoms, and treatment.
Spat et al. 2005 [25] Austria	A sample of 2128 Austrian adults	A questionnaire for acquaintance with PWE, knowledge about, opinions, and attitudes toward epilepsy	<ul style="list-style-type: none"> •10% of respondents expressed negative attitudes toward PWE. •In addition to being male and of low socioeconomic background, having little theoretical knowledge about epilepsy, misconceptions of epilepsy as a form of insanity, and no personal acquaintance with someone with epilepsy independently predispose to unfavorable attitudes toward epilepsy.
Mendes et al. 2017 [43] Portuguese	CWE and one of their parents were recruited at the pediatric outpatient services.	PSS and CSS [37]	<ul style="list-style-type: none"> •When family cohesion levels were higher, participants reported lower levels of stigma and better QoL. •The severity of epilepsy was positively associated with perceived stigma of parents and negatively associated with family cohesion and QoL of children. •Socioeconomic status was positively associated with family cohesion for all participants and with parents' QoL.
Vodopić & Vujisić 2017 [44] Montenegro	Randomly selected 1000 participants	10-item questionnaire. The questions were taken from a questionnaire previously used in China [55].	<ul style="list-style-type: none"> •91% of the participants had heard about epilepsy. Less than half knew someone with epilepsy, and 31.5% had witnessed a seizure. •One-fifth would object if their child played with a PWE and three-quarters would object if their child married a PWE. •40% believed PWE should be employed in the same way as everybody else. Fewer than 8% thought epilepsy was a form of insanity. •Over 80% favored brain disease as a cause of epilepsy, and 95% chose convulsions to be a major feature of an epileptic attack.
Kampra et al. 2016 [45] Greece	446 teachers from 100 public primary and secondary Greek schools from all districts.	A semistructured anonymous 52-item questionnaire	<ul style="list-style-type: none"> •The sources for the teachers to obtain information about epilepsy were found to be personal experience, internet, and courses. •80.3% of the educators knew what epilepsy is, and 88.1% had the right view about the nature of the illness. •92% of the educators replied that they have not had adequate first aid training.
Guekht et al. 2017 [46] Russia	1167 adults, permanent residents of Moscow, were interviewed.	A 10-item questionnaire (modified from [56]) was used addressing three major domains: familiarity with epilepsy, understanding of epilepsy, and attitude toward the PWE.	<ul style="list-style-type: none"> •60% of respondents believed that epilepsy was a type of mental retardation, and 34% were afraid to stay in the proximity of PWE. •38% considered epilepsy to be curable. The level of understanding of epilepsy was proportional to the level of education of respondents. •Negative attitudes toward PWE were demonstrated in a significant part of the population. •Two-fifths of the respondents ranked epilepsy as the "least preferred" of the six chronic diseases for a colleague.
Aydemir N. 2008 [13] Turkey	Random selected adults (n = 613) from different parts of Istanbul.	Knowledge scale: a 26-item, knowledge of epilepsy scale Attitude scale: a 15-item attitudes toward epilepsy scale	<ul style="list-style-type: none"> •Subjects with more knowledge of epilepsy had more positive attitudes toward epilepsy. As the level of education and income level increased, the level of knowledge increased.
Kartal & Akyildiz 2016 [15] Turkey	500 randomly selected adults	A structured questionnaire comprising 23 questions (adapted from [13])	<ul style="list-style-type: none"> •More than half of all participants reported hearing or reading about epilepsy, 44% knew someone with epilepsy, and 42.2% had witnessed a seizure. The primary source of knowledge was via relatives and friends. •Negative attitudes were about marriage and inability to live alone with epilepsy. •A preconception of epilepsy being a dangerous and lifelong disease was the primary reason for negative attitudes. •Predictors of negative attitudes were female gender, lower educational status, and living in a rural area.
Pazarci et al. 2017 [17] Turkey	33 PWE, 25 of the patients' family members, and 23 people from the community	SSE [16]	<ul style="list-style-type: none"> •The mean scores on the SSE were 57 for patients, 66 for family members, and 65 for the community. •The SSE scores of patients, family members, and the community who believed that PWE are stigmatized or rejected were higher than the SSE scores of those who did not believe it. •There were strong correlation between high SSE scores and poor functionality and Beck Depression Inventory.
Macit et al. 2018 [18] Turkey	219 participants who came to the community pharmacies in Istanbul (47 people with epilepsy and 172 people without epilepsy)	A scale consists of 18 questions about knowledge and awareness of and attitudes (AKA) toward Epilepsy (modified from [57]).	<ul style="list-style-type: none"> •Total AKA level of people with epilepsy was significantly higher than that of people without epilepsy. General knowledge levels of respondents with epilepsy were significantly higher than that of those without epilepsy. •There was no statistically significant difference in awareness levels between groups.

Table 4 (continued)

Citation, year, and country	Study sample	Stigma measure(s)	Major stigma-related findings
Alhalaqa et al. 2018 [47] Jordan	476 university students from three universities in Jordan	A structured 27-item questionnaire that consisted of three parts (Demographics of respondent, knowledge, and attitudes toward epilepsy) was developed.	<ul style="list-style-type: none"> •1.1% of participants had epilepsy, and 9.3% had a family member with epilepsy. The majority of the students were aware of epilepsy. •Nursing students possessed a good knowledge of, and more positive attitudes toward, epilepsy compared with other nonnursing students.
Alhazzani et al. 2016 [48] Saudi Arabia	1044 randomly selected healthy participants	A 14-item questionnaire that assesses familiarity, knowledge, and attitudes toward epilepsy was modified from previous studies.	<ul style="list-style-type: none"> •Knowledge about the etiology and nature of epilepsy was lacking, as 40% thought it was a blood disorder, 21.2% believed it was contagious, and nearly one-third viewed it as due to a mental disorder and emotional stress. •Regarding public attitudes toward PWE, 19.1% would not work with them, 17% would not allow having their child mingle with a CWE, and more than half would not marry a PWE. •When dealing with someone with a seizure; they would force some medicine down the patient's throat (49.3%), use herbal medicine (68.9%), ask a spiritual healer (31.8%), or think it is untreatable (35.6%).
Krishnaiah et al. 2016 [49] South India	Randomly selected 500 participants	A 14-item questionnaire to assess knowledge, attitude, and practice toward epilepsy. Yes/No dichotomous responses	<ul style="list-style-type: none"> •87.7% of the people had heard or read about epilepsy. •Negative attitudes appeared to be reinforced by beliefs that epilepsy is hereditary (23.1%), kind of insanity (22.6%), or as contagious (12.0%). •The knowledge about the clinical characteristics and first aid to a person during a seizure was 25.8%. •36.5% of people think that the society discriminates PWE.
Nagamori et al. 2018 [50] Japan	In 2013 and 2017, randomly selected 2160 people (1080 in each year)	9 questions for knowledge about epilepsy and 5 questions for experiences with epilepsy	<ul style="list-style-type: none"> •Knowledge scores decreased from 2013 to 2017. Participants who had some experience with epilepsy had higher knowledge levels in both 2013 and 2017.
Kanemura et al. 2016 [26] Japan	52 parents of CWE and 10 parents of healthy children were enrolled in the study.	PSS [37]	<ul style="list-style-type: none"> •Parents of CWE showed significantly higher scores on the questionnaire than parents of healthy children. •Greater perceptions of stigma were associated with a seizure frequency. •The presence of prior febrile seizures and family history of epilepsy were associated with lower stigma.
Lee et al. 2017 [51] Korea	227 evangelical Christians and 139 people without religious beliefs as control group	14 item The Public Attitudes Toward Epilepsy [58] scale and Jacoby's Stigma Scale for epilepsy [59]	<ul style="list-style-type: none"> •No differences were found in attitudes toward epilepsy and perception of stigma between people with and without belief in evangelical Christianity in Korea.
Alhagamhmad & Shembesh 2018 [31] Benghazi, Libya	Randomly selected 480 undergraduate students in the University of Benghazi	10-item questionnaire was adopted from an Italian survey conducted by [60] that investigated knowledge and attitudes toward epilepsy.	<ul style="list-style-type: none"> •57.5% of the participants considered epilepsy to be a psychiatric disorder. •37.5% believed in ancient superstitions, such as possession by evil forces, as the underlying cause of the condition, and 31.8% recommended traditional remedies to cure it. •A significantly higher number of Libyan students, compared with Italian students, perceived epilepsy as an important limiting factor in driving, employment, sports, in marriage, and having children. •A significantly higher number of Italian students perceived epilepsy as a mild illness compared with Libyan participants who considered it as a severely disabling disorder.
Dako-Gyeke & Donkor 2018 [32] Accra, Ghana	A total of 20 participants, which comprised 14 PWE, and six key informants (2 caregivers of PWE, 2 nurses from an epilepsy unit, and 2 officials from Basic Needs-Ghana).	Interview with participants	<ul style="list-style-type: none"> •Participants perceived epilepsy as a spiritual, curable, and medical condition. Because of fear of being infected by epilepsy, some people stigmatized and discriminated against PWE. •PWE were stigmatized and discriminated against unemployment and intimate relationships with the incidence of seizures being the major reason. •PWE adopted various strategies (concealment, not responding to demeaning comments made by people, involvement in religious activities, and joining support groups) to manage stigma and discrimination.
Dolo et al. 2018 [33] Democratic Republic of Congo	35 PWE and/or their family members, 60 community leaders, 6 traditional healers, and health professionals.	A total of 14 focus group discussions and 39 semistructured interviews	<ul style="list-style-type: none"> •The clinical signs of convulsive epilepsy were recognized by community members. •A variety of misconceptions about epilepsy were identified including the beliefs that epilepsy is a family-related condition, a contagious disease, is transmitted by insects, saliva or by touching a person of the same sex during seizures, or is caused by evil spirits and witchcraft. The role of traditional healers in spreading these beliefs was revealed. •The study also reported sexual abuse on PWE, stigmatization of PWE, and loss of productivity of PWE and their families. •The lack of training of health providers about epilepsy care, financial barriers in obtaining antiepileptic medication (AEM), and the shortage of AEM at primary health facilities was revealed.

(continued on next page)

Table 4 (continued)

Citation, year, and country	Study sample	Stigma measure(s)	Major stigma-related findings
Quereshi et al. 2017 [52] Northern Tanzania	Ten focus group discussions with 35 teachers in Hai schools and semistructured interviews with 19 young PWE and 17 parents.	Focus group discussions and semistructured interviews	<ul style="list-style-type: none"> Behavioral problems and learning difficulties were cited as the main barriers to education for PWE. Other barriers included parental stigmatization, teachers' inadequate seizure management, and limited access to specialist schools. Teachers perceived that parents and PWE believe in spiritual etiology and traditional management for epilepsy. The majority of teachers, parents, and PWE cited biological etiology and management options, although understanding of epilepsy etiology and management could be improved among all groups.
Deresse & Shaweno 2016 [34] South Ethiopia	1320 [660 from rural (RR) and 660 from urban (UR)] randomly selected respondents	20 survey questions designed to evaluate knowledge, attitudes, and practices regarding epilepsy. The questionnaire was adapted from those used in previous studies.	<ul style="list-style-type: none"> The most cited causes of epilepsy were brain disease by UR and evil spirits by RR. More UR than RR believed that epilepsy is contagious. About 39% of RR compared with 7% of UR would not allow their children to associate with a person with epilepsy. 56.7% of RR and 24.8% of UR objected to themselves or their children marrying someone with epilepsy. The majority of the both groups would recommend a medical doctor for the treatment, but herbal medicine and spiritual treatments such as prayers and Holy water were still commonly practiced. UR have more positive attitudes than RR.
Gebrewold et al. 2016 [35] Ethiopia	845 volunteer teachers	A questionnaire evaluates knowledge, attitudes, and practices regarding epilepsy	<ul style="list-style-type: none"> A high percentage of teachers considered epilepsy as a psychiatric illness closely linked to insanity. The most common responses were the following: brain diseases and psychiatric illness from causes, allow my offspring to play with PWE, epilepsy be cured before attendance to school from attitude, protect the subject from injury, seek help from medical doctors, smelling the smoke of struck match and Holy Water treatment from first aid measures and epilepsy treatment suggestions. Level of education was positively associated with biologically plausible responses while teaching experience was negatively correlated with culturally plausible responses.
Mbelesso P et al. 2019 [36] Sub-Saharan Africa	A door-to-door survey with 1023 participants (12 PWE)	Cultural representations toward epilepsy	<ul style="list-style-type: none"> Epilepsy was identified as a supernatural disease related to bad luck (40.4%), witchcraft (31.3%), or a curse (28.3%). 75.9% considered epilepsy as a mental disorder. 75.3% of participants considered epilepsy as a contagious disease. Saliva was mainly mentioned as a means of transmission in 63.8%. More than half of participants preferred or recommended traditional treatments. Only 24.8% believed in the efficacy of medical treatment for epilepsy.
Souza et al. 2018 [53] Multicenter	102 healthy students from Brazil, Argentina, Portugal, United States, and South Africa	Epilepsy Knowledge Questionnaire developed by [61]. A 55-item questionnaire, 34 of which assess knowledge about medical aspects and 21 evaluate social aspects of epilepsy.	<ul style="list-style-type: none"> Portuguese students had significantly higher values than the American ones. Regarding the medical aspects, on average, students hit 63.8% of the questions. The students from Portugal had significantly higher average than the American ones. Regarding the social aspects, there were no differences between the scores of the students of each country. Statements with lower percent of correct answers were about pathophysiology, medication, and treatment. Statements with higher percent of mistakes were about sports practice, labor, proceedings in case of convulsion, and ability to drive vehicles. General knowledge of senior health students about epilepsy was considered low. Regarding the medical aspects, students from Brazil and Portugal exhibited a slightly superior knowledge.

CWE: children with epilepsy, PWE: patients with epilepsy, CSS: Children Stigma Scale, PSS: Parent Stigma Scale, CR: cohabiting relatives, CWN: children with nonepilepsy-related neurodisability, QoL: quality of life, AKA: awareness, knowledge, attitude, RR: rural respondents, UR: urban respondents, AEM: antiepileptic medication.

housewives were significantly higher compared with the regular workers [10].

The present study showed that 26.2% ($n = 53$) of the CG were stigmatizers, 50 of whom were moderate and the remaining 3 were high stigmatizers. Stigma scores were not different in terms of sex, marital status, and income levels. In terms of employment status, only regular workers scored significantly lower than the retired participants. There were no statistically significant differences among other occupational status groups. Stigma scores decreased as the educational level increased, and half of the 10 pairwise comparisons between the 5 educational strata were significantly different in favor of the more educated stratum.

When both groups were compared with subscale scores, prejudgments scores of patients' relatives were higher than the CG. There was no difference for false beliefs and discrimination subscale scores. Total score of SSE-IR and the proportion of highly stigmatizer participants were higher in the PRG than the CG.

When we look through some similar studies made in Turkey, Aydemir et al. developed two separate scales with the purpose of quantifying both the level of knowledge about epilepsy and attitude toward epilepsy in general Turkish population. According to the results of this study, a positive correlation was found between age and knowledge scale while a negative correlation was found between age and attitude scale. As the level of education and income level of the participants

increased, the level of knowledge increased, and as the level of knowledge about epilepsy increased, the negative attitude decreased and also the positive attitude toward epilepsy increased. In our study, it was observed that the levels of stigma for epilepsy decreased both in the PRG and in the CG as the level of education and income level increased [13,14]. Five hundred randomly selected adults enrolled with an adapted version of Aydemir's scale in another study in Turkey; the authors reported high incidence of negative attitudes toward epilepsy and the predictors for these negative attitudes were female gender, lower educational status, and living in a rural area [15]. In a study of validation for the Turkish version of the Stigma Scale of Epilepsy [16], the mean scores of the scale were 66 for family members and 65 for the community, where a score of 0 would suggest no stigma and 100 would indicate maximum stigma [17]. Macit et al. compared 47 PWE and 172 patients without epilepsy about knowledge and awareness of and attitudes (AKA) towards Epilepsy, and they reported that total AKA level and general knowledge levels of PWE were significantly higher than that of patients without epilepsy [18].

A Brazilian group [16] developed a scale including 20 questions, 16 of which were for patients' relatives and additional 4 questions for the PWE. All of the patients' relatives stated that it was more difficult for PWE to be employed. When asked if they would hire a person with epilepsy, 60% of the patients' relatives stated that they would not hire for security reasons. Ninety percent of the patients' relatives stated that PWE should not drive because it is dangerous. The authors reported that the areas where the patients suffered most were professional life, social relations, limitation of activities such as driving, and negative feelings about themselves. The findings were interpreted as epilepsy-associated stigma as it is not only due to dearth of information about it, but also because of the discriminatory attitudes and behaviors of people toward PWE [16]. In our study, 34.8% ($n = 70$) of the patients' relatives and 24.8% ($n = 50$) of the CG stated that they would not want to hire someone with epilepsy. In our study, the reason for this was not questioned, but the same security considerations seem a plausible explanation also for our population.

In another study conducted again in Brazil with PWE and their relatives, the participants stated that they did not know what epilepsy is and how it was treated. It was also reported that the areas where the PWE are most exposed to discrimination were work life and social relations and that a large number of patients' relatives stated that they would not hire a patient with epilepsy. Furthermore, overprotective attitudes of the families on the patients were interpreted as a factor increasing the stigma [19]. Tedrus et al. studied with 148 PWE and 90 cohabiting relatives in Brazil, using the Stigma Scale of Epilepsy [16], and the results showed that higher perceived stigma by PWE was related exclusively to generalized seizures; longer disease duration and higher perception of stigma by cohabiting relatives and higher perceptions of stigma by PWE and cohabiting relatives were associated with worse quality of life (QoL) in PWE [20].

In a study conducted with 758 participants in the United States, it was suggested that there are four factors that determine attitudes about epilepsy [21]. First, negative prejudices reflect people's beliefs about epilepsy. Examples can be listed as PWE should not marry or they are unreliable. Second, risk and safety concerns reflect concerns of people about the possible harm PWE may be exposed to when they participate in social activities. The third factor reflects beliefs that a person with epilepsy cannot succeed in work or social life. The fourth factor is the feeling tense, being frightened, and avoid being in the same environment or staying alone with a person with epilepsy. In this study, it was reported that the participants who were more informed and who had more positive attitudes had higher education and higher levels of income. And Hansen et al. reported that the caregivers of people with intractable epilepsy felt stigma directed toward themselves, and they believed others avoided and treated them in an inferior manner [22]. In a study conducted with 1600 participants in the UK, while the responders conceded that PWE were avoided and that they were excluded

in the society, they also stated that they behaved sometimes likewise because of the unpredictability of the disease and because the patients were "abnormal" [23]. Jacoby mentions two other UK studies' results of which showed that responders of the surveys defined PWE as excitable, aggressive, potentially violent, retarded, antisocial, and physically unattractive [2,24].

In a study conducted in Austria, 15% of the participants reported that they could oppose their child's marriage with a person with epilepsy [25].

A study with 52 parents of children with epilepsy and 10 parents of healthy children in Japan reported that parents of children with epilepsy showed higher stigma scores than parents of healthy children. The presence of prior febrile seizures and family history of epilepsy were associated with lower stigma, and this may show us the important effect of familiarity and knowledge about epilepsy on stigma perception [26].

A number of studies from sub-Saharan Africa reported that male patients were abandoned by their wives because of the nocturnal enuresis due to seizures [27]; females with epilepsy were not preferred because they were not suitable to take care of their children and to cook [28]; PWE with normal intelligence were shown to receive less education than their peers [29]; patients were often enforced to eat from different plates, sleep in a separate place than the rest of the family, and kept hidden from the visitors [30]. Misconceptions about epilepsy (a contagious disease, a psychiatric disease, a spiritual etiology), herbal medicine, and spiritual treatments as epilepsy treatment strategies, refusing to associate with a PWE stand out as common results of the studies in Libya, Accra Ghana, Democratic Republic of Congo, Ethiopia, and sub-Saharan Africa [31–36]. Although these studies are very valuable in terms of explaining the relationship between epilepsy and stigma in a region with very low socioeconomic level, where infectious diseases are frequent, life expectancy is short, and famine periods are experienced, the fact that a scale has not been developed to measure stigma in these countries makes it difficult to compare with the results of other countries.

Some of important similar studies from different countries can be seen in Table 4.

5. Conclusions

This study showed us that the stigmatization levels in a group of subjects drawn from general population without an acquaintance with epilepsy were lower than the patient's relatives. The latter group scored significantly higher in total score and prejudgments subscale score of the specifically designed scale for measuring prejudgments, false beliefs, and discriminatory attitudes among individuals without epilepsy. At first glance, it is somewhat surprising for the relatives of PWE to be more stigmatizing and prejudiced toward PWE than those individuals who do not have any close encounter with epilepsy. This result may be partially explained by the ambivalent attitudes of the relatives, as those high scores may stem from not only enacted but also the felt stigma that they were experiencing themselves. This is also the major limitation of our study, as the SSE-IR scale did not include a separate number of items to specifically question the felt stigma. Nevertheless, these results explicitly show us that the information level in the general population about epilepsy is quite inadequate, surprisingly, it is even more so in people close to these patients. It must be a warning sign for both all the clinicians treating epilepsy and national association against epilepsy to increase efforts for awareness raising; moreover, it is also for the national policy makers to increase measures, such as improving teaching curriculum on health issues and ensuring a safer work environment for people with epilepsy for minimizing discrimination.

Conflict of interest

We have no conflict of interest.

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