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Determinants of felt stigma in epilepsy

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ABSTRACT

The present study aimed to determine the level of felt stigma, overprotection, concealment, and concerns related to epilepsy in different life domains by using culturally-specific scales for Turkish individuals with epilepsy. Also, it aimed to detect relations among the study variables and to determine the variables which predict felt stigma. For this purpose, felt stigma scale, overprotection scale, concealment of epilepsy scale, and concerns of epilepsy scale were administered to two hundred adult persons with epilepsy (PWE). The results showed that almost half of the participants reported felt stigma, overprotection, concealment of epilepsy, concerns related to future occupation, and concerns related to social life. Almost all the study variables show correlations with each other. Concealment of epilepsy, concerns related to social life, and concerns related to future occupation were found as the predictors of felt stigma.

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1. Introduction

It is now well known that, rather than being just a neurological illness, epilepsy is also a stigmatized condition, which may be more impactful than the physical aspects of the illness [1]. Stigma is defined by Goffman as 'an attribute which is deeply discrediting'[2] [p. 3], and the person who carries this discredit becomes generally undesirable, often resulting in social rejection [3]. Previous research findings, which showed that persons with epilepsy (PWE) had lower marriage rates and higher unemployment and underemployment rates [4,5] than the general population, also support the fact that PWE struggle with felt (the shame of having epilepsy and fear of encountering with enacted stigma) and/or enacted (real episodes of discrimination against a person with epilepsy only on the grounds of his/her epilepsy) stigma [6] in addition to the seizures and restrictions caused by epilepsy. Numerous attempts have aimed to determine the stigma toward individuals with epilepsy, and the level of felt stigma in different cultures [7,8]. Although epilepsy is a stigmatizing condition in almost every culture, the form of stigmatization can vary between cultures, since stigma is a social construction [9]. Therefore, the main aim of the current study was to examine the determinants of felt stigma in Turkish culture by using culturally-specific scales.

The first variable which is hypothesized to predict felt stigma is concealment of epilepsy. Because of the fear of encountering enacted stigma, many PWE prefer to conceal their condition from all except close family members, and it may even be kept secret within the family [10]. Furthermore, clinical features of epilepsy (e.g., seizure frequency, duration of epilepsy, age at onset, and predictability of seizures) have no relation with the willingness to disclose epilepsy [11,12]. Results from a previous study comparing epilepsy and another neurological illness, migraine, showed that epilepsy was concealed by 41% of PWE, but there was no concealment of migraine by the corresponding participant group. Another interesting result of this study was about the duration of concealment; 31% of PWE concealed their epilepsy for an initial period only after their diagnosis, while 69% continued to conceal it. This result indicates that concealment is not caused by an initial shock or ambiguity caused by the diagnosis; on the contrary, it is a long-term strategy [4].

The second variable which was expected to predict stigma was overprotection. Although it is a quite common problem for PWE, overprotection has not received sufficient consideration from researchers in the field. Thomasgard and Metz [13] defined overprotection as parenting which is characterized as follows: (1) supervising and vigilant parenting, (2) having difficulties with separation from the child, (3) discouragement of independent behavior, and (4) highly controlling.

Parental overprotectiveness for a child with epilepsy is reported both in Western countries [14] and in Eastern societies [15]. Regardless of culture, most parents have concerns about their child's safety when not under their direct supervision, such as at school or in a playground. They also have concerns about their child's future, including issues related to marriage, the attitudes of others, education, and finding suitable employment [15,16]. Unfortunately, such well-meant concerns often result in lowered expectations of academic success, and in some cases, withdrawal from education altogether. In the long run, such parental attitudes can reduce PWE's opportunities for finding both employment and also a romantic partner [16]. Therefore, overprotection is usually associated with a greater degree of psychological harm to the

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child than any possible physical injury caused by underprotection [17]. Because of overprotection, Turkish adult PWE consistently report their personal independence as the area of life most affected and impaired in our previous studies [4–18]. On the other hand, PWE from Western countries, in regard to the life limitations, reported driving restrictions, employment-related difficulties, and challenges in everyday activities [19,20], and none of the studies from Western societies, as far as can be ascertained, indicate the continuity of overprotection into adulthood.

The last variable investigated for its effects on stigma is the concerns of PWE. It was previously shown that some concerns can cause problems in psychosocial adjustment to epilepsy and increase the risk for psychopathology [19,21,22]. One of our previous findings, which was assessed qualitatively by open-ended questioning, showed that the most reported concern was "having a seizure outdoors" [4]. This result is also in accordance with previous findings [19–21]. Other concerns reported by PWE in the same study were "being alone during a seizure", "seizure related accident/death", "having a child", "future", "antiepileptic drugs", "being a burden to others", "independence", "psychological well-being", and "relations with potential romantic partners" [23]. These results show that PWE are dealing with a wide range of concerns starting from epilepsy-related ones, such as unpredictability of seizures, seizure-related physical harm, or side effects of antiseizure drugs, to concerns caused by social aspects of epilepsy, such as finding a romantic partner and having children, and finally, to concerns related to the future.

Therefore, the aims of the study were: (1) to determine the levels of felt stigma, overprotection, epilepsy-related concerns, and concealment by using culturally-specific scales; (2) to assess the effect of gender, number of seizures, and number of antiseizure medication on felt stigma, overprotection, epilepsy-related concerns, and concealment; (3) to examine the relations among stigma, overprotection, epilepsy-related concerns, and concealment; and finally, (4) to determine the variables which predict felt stigma.

2. Method

2.1. Participants

A total of 200 adult PWE participated in the study from two different sources. The first source used for data collection was Dokuz Eylül University, School of Medicine, Department of Neurology. This group consisted of one hundred and three volunteer PWE, who came for their regular follow-up visits. All procedures were carried out by the second and third authors in face-to-face interviews with this group.

The second source of data collection was the official web site of Turkish Epilepsy Association. Ninety-seven PWE registered with the association completed online version of the scales.

Patients who were illiterate, patients with other impairments (e.g., hearing, seeing, cognitive), and those with other neurological or psychiatric disorders were excluded from the study. Only three patients in face-to-face interviews were excluded from the study because of cognitive impairment.

The current study was approved by the Izmir University of Economics Ethic Board (May 14, 2013, meeting no: 28, page: 66). Additionally, all the participants gave informed consent for their participation in the study.

2.2. The questionnaires

2.2.1. The felt stigma scale

This scale measures the degree of shame caused by epilepsy, and the fear of encountering enacted stigma as defined by Scambler & Hopkins [6] (e.g., I do fear being excluded because of my epilepsy). The reliability and validity of the scale was previously tested [24]. It comprises ten items covering one factor. The scores of the scale range from 5 (completely agree) to 1 (completely disagree), with higher scores representing higher felt stigma. For the current study, the reliability was found as 0.86.

2.2.2. Concealment of epilepsy scale

This scale consists of 17 items which aims to measure the concealment of epilepsy both from family members and others, such as friends, colleagues, and romantic partners (e.g., I do avoid revealing my epilepsy to a boy/girl that I like). The psychometric analysis of the scale revealed one factor [24]. The Cronbach's alpha value for the present study was 0.92. The scores of the scale range from 5 (completely agree) to 1 (completely disagree), with higher scores representing higher levels of concealment.

2.2.3. Epilepsy concern scale

Items of this scale were created based on the open-ended answers of Turkish PWE in regard to limitations, concerns, and most affected life areas caused by epilepsy [4–18]. This scale comprises 20 items covering three factors: (1) concerns related to future occupation—10 items (e.g., I think epilepsy will negatively affect my occupational life in the future); (2) concerns related to social life—7 items (e.g., Epilepsy limits my social activities, such as going out with friends or getting around); and (3) concerns related to marriage and having children—3 items (e.g., I think epilepsy has no effect on having children) [24]. Scores range from 5 (completely agree) to 1 (completely disagree), with higher scores representing higher levels of concerns. The reliability of the factors for the present study was found as 0.89 for factor I, 0.88 for factor II, and 0.66 for factor III.

2.2.4. Overprotection scale

This scale aims to detect the perceived family overprotection of a person with epilepsy (e.g., I believe that my family expects fewer responsibilities from me because of my epilepsy). It consists of ten items, with one factor solution [24]. The internal reliability of the scale for the current study was found as 0.85. Scores range from 5 (completely agree) to 1 (completely disagree), with higher scores indicating a higher level of perceived overprotection.

In addition, the participants were asked to complete an information form regarding their age, gender, marital status, level of education, monthly income, occupational status, duration of epilepsy, number of antiseizure drugs, and number of seizures per month (see Table 1).

Table 1
Demographic and clinical characteristics of the participants.

	Participants (n = 200)
Sex (%)	
Female	60.5
Age (SD)	31.68 (11.17)
Year of education (SD)	10.70 (3.28)
Marital status (%)	
Single	53
Married	42.5
Divorced/widow	4.5
Occupational status (%)	
Employed	35
Unemployed	35
Housewife	8
Student	17
Retired	4.5
Duration of the illness (SD)	13.03 (9.95)
Number of seizures per month (%)	
No seizures	33.9
1–3	38.3
4–5	13.9
6–7 and more	13.9
Number of AEDS (%)	
Monotherapy	46.5
Polytherapy	53.5

Participants completed the information form before receiving the scales in a random order.

2.3. Statistical analysis

For the descriptive, exploratory, and multivariate analyses, SPSS for Windows version 20 was used.

3. Results

3.1. Demographic and clinical characteristics

The age range of the participants varied between 18 and 68 years ($M = 31.68$, SD = 11.17); more than half were female (60.5%), and most were single (53%). There was a high level of unemployment (35%). More than a quarter had no seizures (33.9%), and more than half was on polytherapy (53.5%). In order to detect any possible differences between face-to-face and internet groups, independent sample t-test and X^2 analysis were performed. The results showed no difference in terms of duration of epilepsy ($t(198) = 1.26$, $p > 0.05$), seizure frequency (X^2 (3, $N = 180$) = 8.89, $p > 0.07$) or gender (X^2 (1, $N = 200$) = 0.15, $p > 0.05$). On the other hand, as expected, the internet group was significantly younger ($t(198) = 3.19$, $p < 0.002$), and more educated ($t(196) = -3.83$, $p < 0.001$). The demographic and clinical characteristics of the participants are summarized in Table 1.

3.2. Level of felt stigma, overprotection, concealment of epilepsy, and epilepsy-related concerns

The cutoff points for high and low values were determined according to the median scores for each of the variables. The results showed that almost half of the participants reported high levels of perceived overprotection, felt stigma, concealment of epilepsy, concerns related to social life, and concerns related to future occupation. Finally, almost one-third reported concerns related to marriage and having children (see Table 2).

3.3. Gender, number of seizures, and number of medications

In order to examine whether gender creates a difference among the study variables, independent sample t-test was conducted. The results showed that only concerns related to future occupation showed a significant difference ($t = -2.35$, df = 198, $p < 0.02$), which was higher in male participants.

Additionally, to examine whether the number of seizures and the amount of antiseizure medication created a difference, one-way ANOVA was run. In terms of number of seizures, significant differences were observed in overprotection ($F(3, 175) = 7.36$, $p < 0.00$), concerns related to future occupation ($F(3, 176) = 3.08$, $p < 0.05$), concerns related to social life ($F(3, 176) = 4.37$, $p < 0.00$), and concerns related to marriage and having children ($F(3, 176) = 2.69$, $p < 0.05$). Finally, significant differences were observed in overprotection ($F(3, 189) = 5.02$, $p < 0.00$), stigma ($F(3, 190) = 4.37$, $p < 0.00$), concerns related to future occupation ($F(3190) = 6.33$, $p < 0.00$), and concerns related to social life ($F(3190) = 6.13$, $p < 0.00$) in terms of number of antiseizure medications.

3.4. The relations among the study variables

Overprotection, concerns related to future occupation, and concerns related to social life showed significant correlations with all other variables. Felt stigma was also related to all of the variables except number of seizures. Concealment was also correlated with all of the study variables, except number of seizures and number of medication. Concerns related to marriage and having children were related to all of the other variables, except number of seizures (see Table 3).

3.5. Predictors of felt stigma

A hierarchical multiple regression analysis was conducted to identify the factors related to felt stigma. The total score of the felt stigma scale was entered as a dependent variable. In the first block, demographics (age and gender) and clinical variables (duration of epilepsy, number of seizures, and number of medications) were entered into the analysis. This model was not significant. In the second block, three factors of the epilepsy concern scale (concerns related to future occupation, concerns related to social life, and concerns related to marriage and having children) were entered. At step 2, the total variance explained by the model was 50% ($F(8, 175) = 20.71$; $p < 0.001$). In the last block after the entry of overprotection and concealment of epilepsy, the total variance explained by the model as a whole was 64% ($F(10,175) = 29.15$; $p < 0.001$). In the final model, three predictors were statistically significant, with concealment having a higher beta value ($\beta = .42$, $p < .001$) than concerns related to social life ($\beta = .27$, $p < .001$), and concerns related to future occupation ($\beta = .26$, $p < .001$) (see Table 4).

4. Discussion

The present study aimed to determine the level of epilepsy-related concerns, overprotection, and concealment of epilepsy, and also to examine the determinants of felt stigma in Turkish adult PWE.

The results for unemployment and marriage are in concordance with previous findings from Turkey, which indicate lower rates for PWE compared with that for the general population [4]. In accordance with our clinical observations and our previous studies [4,18], in which Turkish PWE consistently reported “independence” as the most affected area of life, most participants in the current study reported a high level of perceived overprotection by their families. In a recently published Turkish study, although overprotection was measured with only a single item, the results indicate that most adult PWE feel overprotected by families and only two out of 330 of the participants lived alone [25]. These results indicate, therefore, that different from many Western studies, in Turkey, the family overprotection continues beyond childhood and adolescence, throughout the whole life-span.

Compared with our previous studies, in the present study, we found higher level of felt stigma [4,18]. We conclude that the scales that were applied were the major reason for this difference. In our previous studies, we applied the stigma scale of Jacoby [26], which was developed for British PWE, and as stated by Jacoby [27], there is doubt over

Table 2
Descriptive values of overprotection, felt stigma, concealment, and concerns.

Titles	N	*X*	*SD*	Min	Max	Median	High scores (%)[a]
Overprotection	199	29.05	9.05	10.00	50.00	29	49.7
Felt stigma	200	24.24	9.42	10.00	49.00	22.5	46
Concealment	200	33.78	14.08	15.00	70.00	31	49.5
Concerns related to future occupation	200	30.45	10.69	10.00	50.00	31	48
Concerns related to social life	200	16.24	7.63	7.00	35.00	14	49
Concerns related to marriage and having children	200	6.70	3.07	3.00	15.00	7	32

[a] The median values were used as cutoff points to determine the high scores.

Table 3
Correlations among the study variables.

	2	3	4	5	6	7	8
1—Overprotection	.34**	.16*	.43**	.46**	.16*	.25**	.21**
2—Stigma		.64**	.62**	.62**	.43**	.21**	.13
3—Concealment			.37**	.37**	.35**	.04	.03
4—Concerns related to future occupation				.62**	.37**	.27**	.20**
5—Concerns related to social life					.42**	.30**	.24**
6—Concerns related to marriage and having children						.14*	.03
7—Number of antiseizure medications							.36**
8—Number of seizures							

* $p < 0.05$.
** $p < 0.01$.

the cross-cultural applicability of this scale. Because of this, a de novo scale for Turkish PWE was used in the present study, and we received congruent findings with our clinical observations in terms of felt stigma. This finding indicates that, although making cross-cultural comparisons is more difficult, culturally-specific stigma scales which reflect specific forms of stigmatization in a certain culture is the best approach for detecting the stigma in different cultures.

As we expected, most participants reported higher levels of concerns related with social life, and future-occupation , in accordance with our previous research [4,18] and also studies from Western cultures [20]. The sample of this study mainly had well-controlled seizures; nevertheless, their concerns were common with an intractable seizure group.

Table 4
Predictors of felt stigma.

Block	Indicators	R	R^2	R^2 change	B	SE	β	t
1		.23	.05					
	Age				−.05	.07	−.06	−.74
	Gender				.55	1.46	.03	.37
	Duration of epilepsy				.07	.08	.08	.90
	Number of seizures				.59	.74	.06	.80
	Number of medications				1.58	.83	.16	1.89
2		**.71**	**.50*****	**.45*****				
	Age				−.03	.05	−.03	−.52
	Gender				−.02	1.11	−.00	−.02
	Duration of epilepsy				.02	.06	.02	.34
	Number of seizures				−.27	.56	−.03	−.48
	Number of medications				−.05	.63	−.00	−.09
	Concerns related to future				.31	.07	**.35*****	4.71
	Concerns related to social life				.43	.09	**.35*****	4.66
	Concerns related to marriage/having children				.47	.19	**.15****	2.49
3		**.80**	**.64*****	**.14*****				
	Age				−.04	.04	−.05	−.93
	Gender				−.34	.95	−.02	−.36
	Duration of Epilepsy				.03	.05	.03	.51
	Number of Seizures				−.16	.48	−.02	−.35
	Number of Medications				.33	.54	.03	.61
	Concerns related to future				.23	.06	**.26*****	3.94
	Concerns related to social life				.33	.08	**.27*****	3.97
	Concerns related to marriage/having children				.20	.17	.07	1.21
	Overprotection				.02	.06	.02	.34
	Concealment				.28	.04	**.43*****	8.01

** $p < 0.05$.
*** $p < 0.001$.

This finding shows that PWE face a range of concerns in different life domains, as well as seizures, antiseizure medications, and stigma.

When we examine the effects of gender on the study variables, only concerns related to future occupation were observed to be significantly higher in males. This result could be related to the patriarchal nature of Turkish society, as men are widely regarded as the breadwinners of the family.

Regarding the number of seizures, the results showed that it caused significant differences on overprotection and concerns related to future occupation, social life, and marriage/having children. Interestingly, the number of seizures creates a significant difference in all concern domains and overprotection, but not in felt stigma and concealment of epilepsy. On the other hand, the number of antiseizure medications makes significant differences on overprotection, stigma, concerns related to future occupation, and concerns related to social life. When the results related to number of seizures and number of medications are evaluated together, it could be stated that these two factors are more likely to create a difference on epilepsy-related concerns, felt stigma, and overprotection. However, neither causes a difference on the concealment. This result could indicate that, rather than being affected by the visible parts of the illness, concealment is more related to just having an illness which is discreditable by its nature [2].

In terms of the relations among the study variables, almost all are correlated to each other. For instance, felt stigma is correlated to overprotection, concealment of epilepsy, all of the concern domains (future occupation, social life, marriage/having children). and number of antiseizure medications, but not with number of seizures. This result is in concordance with the findings of Choi et al. [28], that the concerns are highly related to felt stigma. On the other hand, overprotection was correlated with all of the study variables, except number of medications. These results imply that overprotection is more directly related to seizures. However, stigma is more related to other illness-related variables. In a previous study by Baker et al. [29], felt stigma was related to higher levels of side effects caused by antiseizure medication. Also, in another study from the same group [30] study, seizure frequency was also found to be related to felt stigma. The differences in the results could be caused by the characteristics of the samples and the scales that were applied to measure felt stigma.

Finally, the results showed that the variance in felt stigma was mostly explained with concealment behavior, concerns related to social life, and concerns related to future occupation. Different from previous studies [26,29–31], epilepsy-related variables, such as seizure frequency, number of antiseizure medications, and duration of epilepsy, did not contribute significantly to explaining felt stigma. Contrary to our expectation, overprotection also made no contribution to the variance in felt stigma. Although more than half of the participants reported overprotection, and it is significantly correlated with felt stigma, it does not predict it. This could be due to the collectivist nature of Turkish society [32], which accepts overprotection as a norm and, therefore, is not negatively affected by its existence. In order to see the effects of overprotection clearly, this study should be replicated with adolescent and child groups with epilepsy.

The variables which predict felt stigma were concealment, concerns related to social life, and concerns related to future occupation. Concealment is an important strategy used by PWE to appear to be normal [6], and previous studies also indicate that disclosure of epilepsy, and even whether or not disclosure is voluntary, can predict felt stigma [33]. This situation could be caused by various reasons. First, concealing an illness involves a huge effort, energy, planning, and anxiety [3]. Since a seizure can happen without warning, PWE need to plan some other explanations for a seizure in public, such as low blood pressure or a simple faint. Also, they need to take their antiseizure medication in private or disguise it, for example using a vitamin pill box. All these efforts and stress can create a huge burden on patients; as stated by Kılınç and Campell [34], "epilepsy took over the lives of PWE" which eventually increased felt stigma. Another reason could be that these efforts and related stress to conceal the condition may themselves act as stigma cues, becoming a continuous reminder of an illness which needs to be kept hidden. Eventually, concealing the condition causes negative effects which are as serious as disclosing it and encountering enacted stigma.

The other predictors of felt stigma were concerns related to social life and concerns related to future occupation. There are also previous studies that indicate that concerns and perceived limitations are related to stigma [28,35]. Like the concealment of epilepsy, concerns are also an important part of daily life, which PWE encounter continuously, such as taking the illness into consideration when planning for the future, and limitations on social life which is a constant reminder that PWE are different from "healthy" people, which in turn shows itself as an increase in felt stigma. Although most studies focused on the role of depression, epilepsy-related variables, and anxiety to predict stigma, this study indicates that the concerns, especially related to social life and to future occupation, also should be taken into account when explaining felt stigma.

5. Conclusion

Different from our previous studies, the present study showed that felt stigma was reported by almost half of the participants which is thought to be related to the use of de novo stigma scale for Turkish PWE. Similarly, half of the participants reported overprotection, concealment, and concerns related to future occupation and social life. In terms of the determinants of felt stigma, rather than epilepsy-related variables, concealment and concerns were found as the predictors. Overall, the results again indicate that the effects of epilepsy reach far beyond the effects of a neurological illness.

6. Limitations

By using both patients from a hospital population and from the Turkish Epilepsy Association's web site, it was aimed to increase the representativeness of the sample, however the sample size of the study was the most important limitation of the study. Also, these results cannot be generalized to patients with comorbid neurological and psychiatric conditions and intractable seizures.

Conflict of interest

The authors declare no conflict of interest.

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