

Relationships between knowledge, attitudes, stigma, anxiety and depression, and quality of life in epilepsy: A structural equation modeling

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ABSTRACT

Purpose: Epilepsy not only is a medical disorder characterized by seizures, but is also associated with stigma and a neurological disorder that affects quality of life. Insufficient knowledge and misconceptions about epilepsy that causes the development of negative attitudes towards patients with epilepsy increase the stigmatization and psychosocial problems and impact the quality of life. The aim of this study was to examine the relationship between epilepsy knowledge, attitude, stigma, anxiety and depression, and quality of life within the framework of structural equation modeling.

Method: This research was carried out between May 2015 and May 2016 at the Epilepsy Outpatient Clinic of Istanbul University Istanbul Faculty of Medicine. The Epilepsy Knowledge Scale, Epilepsy Attitude Scale, Stigma Scale, Hospital Anxiety and Depression Scale, and Quality of Life in Epilepsy Scale-10 (QOLIE-10) were used. To determine the relationship between the concepts, research hypotheses were created, and structural equation modeling was made.

Results: Two hundred five patients were included in the study, 53.7% were women, and the mean age was 32.5. It was found that 72.2% had generalized seizures, and 46.3% had more than one seizure per month. According to our proposed model, knowledge had a moderate relationship with attitude (including stigma) ($r = 0.50$) that, in turn, had a strong relationship with mental health ($r = -0.62$) while a moderate relationship with quality of life ($r = 0.45$). Our findings revealed that proposed model accounted for 20% of the variance in quality of life and 39% of the variance in mental health (anxiety and depression).

Conclusion: Mental health and quality of life of patient with epilepsy are closely related to the knowledge, attitude, and perceived stigma of the patients. Therefore, educating/supporting patients can help increase the mental health and quality of life.

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1. Introduction

Epilepsy not only is a medical condition characterized by seizures, but also is a neurological disease, which is associated with stigma and which impairs the quality of life. Studies investigating the level of knowledge in patients with epilepsy (PwE) have reported that patients usually do not have sufficient knowledge regarding the disease and have difficulties in the adaptation and management of the disease. Lack of knowledge and worries about the disease result in negative attitudes, and subsequently, patients have difficulties in coping with medical and psychosocial issues. Therefore, patients should be informed about the course of the disease, medical treatment, safety measures, and lifestyle changes [1]. Improving the level of knowledge contributes to the social adaptation and reduces the negative effects of the disease through improvement of the self-

management of the patients [2]. However, it seems that the dynamics of the relationship between the level of knowledge and psychosocial problems has not been sufficiently enlightened. Insufficient knowledge about epilepsy leads to development of negative attitudes, increase in self-stigmatization, psychosocial problems, and impairment in the quality of life [3]. As mentioned below, despite the association between the level of knowledge and perceived stigma or attitude, and also the association between stigma and mental health having been demonstrated, the dynamic relationships between these structures are yet to be studied as a whole. The aim of the present study was to present evidence demonstrating that the association between the level of knowledge about epilepsy and negative or positive mental health indicators were mediated by attitudes towards epilepsy and the level of perceived stigma.

1.1. The association between knowledge, attitude, and perceived stigma

Besides being one of the most common neurological diseases, epilepsy is a disease that brings stigmatization along due to incorrect

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knowledge, misbeliefs, negative conceptions, and negative social attitudes [4,5]. Stigma is divided into two entities, namely “enacted and perceived stigma”, and patients with epilepsy have to cope with the negative outcomes of stigma, namely “perceived/internalized/felt” stigma [6]. When patients do not have sufficient knowledge about the disease, they tend to adopt misbeliefs regarding epilepsy. They conceal their disease, do not comply with their treatment and isolate themselves from social relations [7]. The misbeliefs that epilepsy is a contagious disease and a punishment given by God because of sins, that cognitive functions are poorer than those of others, and that the patient should not participate in social and sports activities, in turn increase the stigma and negatively affect self-management [8–10].

Therefore, it has been stated that while improvement of the level of knowledge of patients gains importance, many studies report that patient education would enable development of positive attitudes and reduce the level of perceived stigma [11–16].

1.2. The association between attitudes, perceived stigma, anxiety and depression, and quality of life

Anxiety and depression are common among patients with epilepsy; the rate varies between 20 and 55%. While the sensation of losing control, reduced self-confidence, excessive protection by the family, and failure in work and education life contribute to depression, negative attitudes that develop because of insufficient knowledge is another major factor [13]. There are many studies reporting that the rate of stigma is higher in patients who have negative attitudes towards the disease and thereby, anxiety and depression rates are also higher in these patients [3,17–20]. The quality of life is severely impaired because of psychosocial problems besides the medical aspects of the disease [21]. Studies conducted with patients with epilepsy in our country have revealed that the quality of life of patients is usually moderate [22,23]. Despite the significant developments in medical and surgical treatment of epilepsy, the quality of life, being at a moderate level, brings out the importance of evaluating the level of knowledge and stigmatization status of the patients. Finding a positive correlation between negative attitudes, perceived stigma, and anxiety and depression and finding a negative correlation between quality of life support the opinion that addressing only the medical aspect of the disease is not sufficient for the quality of life [5,15,18,19,24–28]. While education programs improve the knowledge level, they may enable the development of positive attitudes towards epilepsy, reduce the psychosocial outcomes, enable coping with these outcomes, and render a better quality of life without stigmatization [1,14,29–30].

1.3. Research model and hypotheses

The model composed of knowledge and related factors in PwE has been presented in Fig. 1.

Research hypotheses created based on this research model are as follows:

- H₁**. Knowledge has a statistically significant effect on attitudes in PwE.
- H₂**. Attitude has a statistically significant effect on mental illness in PwE.
- H₃**. Attitude has a statistically significant effect on the quality of life in PwE.
- H₄**. Knowledge has a statistically significant indirect effect on mental illness via attitude.
- H₅**. Knowledge has a statistically significant indirect effect on quality of life via attitude.

2. Material and method

2.1. Participants and procedure

The study was conducted at the Epilepsy Outpatient Clinic of Istanbul University, Istanbul Faculty of Medicine, between May 2015 and May 2016. The inclusion criteria were as follows: being over 18 years of age, having a well-documented diagnosis of epilepsy, taking antiepileptic medications, having at least one seizure within the last two years, being able to understand and speak the Turkish language, and willing to participate in the study. We included all consecutive patients who had seizures within the last two years. The patients were asked about other diseases that may seriously affect the quality of life (such as cognitive disability or major depression), and when they reported comorbidity, they were excluded from the study. We excluded patients when they had a seizure on the day of study inclusion. The data were collected by self-administration of the questionnaires by the patients when they visited the clinic for routine follow-up. The ethical approval was obtained from the Local Ethical Committee before the data collection. Written informed consents were obtained from all participants. To collect data on the personal and disease-related characteristics of the sample, a patient information form was developed by the researchers. To determine the relationship between epilepsy knowledge, attitude, perceived stigma, anxiety and depression, and the quality of life, the validated tools such as the Epilepsy Knowledge Scale, Epilepsy

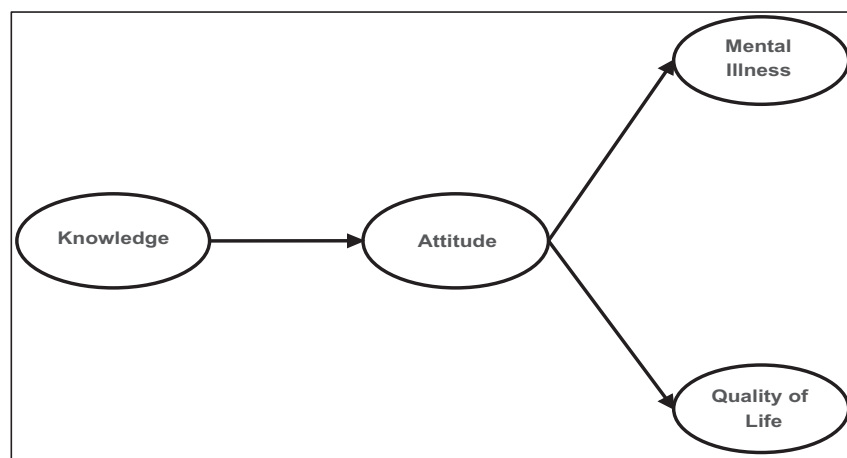


Fig. 1. Conceptual diagram for the proposed model concerning structural relations of the study variables.

Attitude Scale, Stigma Scale, Hospital Anxiety and Depression Scale (HADS), and the Quality of Life in Epilepsy Inventory-10 (QOLIE-10) were used.

2.2. Measures

2.2.1. Patient information form

This form was created by the researchers through review of the literature and includes the sociodemographic and clinical characteristics of the patients.

2.2.2. Epilepsy knowledge scale (EKS)

The Epilepsy Knowledge Scale comprising 16 items was developed by Aydemir [30]. The items in the scale evaluate the knowledge on medical and social dimensions of the disease and the first aid interventions during a seizure. The minimum and maximum scores to be obtained from the scale are 0 and 16, respectively. A higher score indicates a higher level of knowledge. The validity and reliability of the scale were demonstrated, and the Kuder Richardson value was determined as 0.72.

2.2.3. Epilepsy attitude scale

To determine the attitudes towards epilepsy, the Epilepsy Attitude Scale developed by Aydemir was used [30]. The scale comprises 14 five-point Likert-scale items and evaluates the attitudes of participants towards epilepsy. Its score varies between 14 and 70, and high scores express a positive attitude towards epilepsy. The validity and reliability of the scale were demonstrated, and the Cronbach's alpha value was determined as 0.84.

2.2.4. Stigma scale

The stigma scale of Jacoby [31] was used to define the stigma felt by patients with epilepsy. The scale was revised, and the answers were Likert quadruple-like [32]. In the revised stigma scale, a score of 0 indicates no stigma, a score of 1–6 indicates stigma ranging from mild to moderate, and a score between 7 and 9 indicates high stigma. The scale has good internal consistency (0.85) and good concurrent validity.

2.2.5. Hospital anxiety and depression scale

This scale was developed by Zigmond and Snaith [33] to determine the risk of anxiety and depression. Seven of the items evaluate anxiety and seven evaluate depression. The validity and reliability study in Turkish was performed by Aydemir et al. [34]. Cutoff values were reported as 10 for anxiety and 7 for depression in Turkish population. Cronbach's alpha value was found to be 0.85 for anxiety and 0.77 for depression. The correlation coefficients for concurrent validity were 0.75 for anxiety and 0.72 for depression [34].

2.2.6. Quality of Life in Epilepsy Inventory-10 (QOLIE-10)

This scale questions how epilepsy affects the daily activities and the general health of the patients. The scale revised by Cramer et al. [35] consists of 10 items and is a shortened form of a longer quality-of-life scale. The scale consists of three subscales: Epilepsy effects, mental health and role functioning. The validity and reliability of the inventory in Turkish were demonstrated by Mollaoğlu et al. [23] and confirmed a three-factor structure as the original questionnaire. The authors reported good concurrent validity with the Nottingham Health Profile.

2.3. Strategy of analysis

A SEM procedure using the Maximum Likelihood Estimation was used in the present study. Structural equation models consist of measurement and structural models. The measured variables or indicators were created using parcels, sum scores of measures or subfactors for each latent construct. Item parceling is a method that normalizes the distribution of observed variables and increases the reliability of these

indicators. Although there are different kinds of item parceling, the method used in this study creates relatively equivalent indicators by spreading "better" and "worse" items across the different parcels. Indicators as parcels were created for each latent variable by rank-ordering the items by the size of the item-total correlation and summing up of the sets of items to obtain equivalent indicators for those constructs [36, 37].

Before the structural models were tested, the measurement model was expected to provide an acceptable fit to the data [36, 37]. Testing of the measurement model was accomplished using indicators for each of four latent variables taken into account in the present study. All latent variables were defined using the sum scores of factors or scales, except for the knowledge-latent variable. The knowledge-latent construct was defined using item-parceling, since the EKS has only one factor. The quality-of-life variable was operationalized by the sum scores of the subfactors, namely the epilepsy effects, mental health, and role functioning. Mental illness- and attitude-latent variables were defined using the sum scores of different scales: the anxiety and depression scores for mental illness and the epilepsy attitude scale and stigma scale scores for the attitude variable. All skewness and kurtosis values were lower than 1, except for 1.37 kurtosis statistics for attitude and 1.06 kurtosis statistics for stigma, indicating that there was no serious problem concerning the normality assumption.

3. Results

3.1. Descriptive results

A total of 205 patients fulfilling the inclusion criteria comprised the sample of the study. Fifty four percent of the patients (Table 1) were female, and the mean age was 32.5 years. Fourteen percent of the patients were unemployed, and 46.3% were single. The mean age at the disease onset was determined as 17.3 ± 10.7 ; 72.2% had generalized seizures; 46.3% experienced more than one seizure monthly, and 51.7% had received polytherapy.

Table 1

Characteristics related to the sociodemographics and the disease process.

Characteristics	N	%
Age (mean, SD, range)	32.5 ± 10.1	18–70
Gender		
Male	95	46.3
Female	110	53.7
Education		
Primary school	87	42.4
High school	71	34.6
University	47	22.9
Employment		
Employed	84	41.0
Housewife	56	27.3
Student	24	11.7
Retired	9	4.4
Unemployed	29	14.1
Others	3	1.5
Marital status		
Single	95	46.3
Married	98	47.8
Divorced/widow	12	5.9
Age of disease onset (mean, range)	17.3 ± 10.7	
Type of seizure		
Focal	57	27.8
Generalized	148	72.2
Use of epilepsy medication		
Monotherapy	99	48.3
Polytherapy	106	51.7
Seizure frequency per month in previous year		
No seizure	29	14.1
Less than one	81	39.5
More than one	95	46.3

3.2. Testing the structural equation model

3.2.1. Test of the measurement model

In the present study, testing of the measurement model was accomplished using indicators for each of four latent variables taken into account. Zero-order correlations, means, and standard deviations of the 10-measured variables or indicators have been presented in Table 2.

An initial test of the measurement model with these indicators or observed variables resulted in a poor fit to the data, $\chi^2(29, N = 205) = 92.03$; Goodness of Fit Index (GFI) = 0.92; Comparative Fit Index (CFI) = 0.88; Standardized Root Mean Square Residual (SRMR) = 0.070; Incremental Fit Index (IFI) = 0.88. An inspection of the modification indices produced by Linear Structural Relations (LISREL) program indicated a strong modification of error covariance between two indicators of Quality of Life, the epilepsy effect and role functioning. Adding the error covariance into the model resulted in a good fit as indicated by the following goodness of statistics: $\chi^2(28, N = 205) = 55.96$; GFI = 0.95; CFI = 0.94; SRMR = 0.061; IFI = 0.94. A chi-square difference test ($\Delta\chi^2 = 36.07, df = 1, p < .01$) showed that the increase in the model fit was statistically significant. All of the loadings of the measured variables on the latent variables were large and statistically significant (Table 3). The standardized values for the revised measurement model ranged from 0.32 to 0.86, mostly over 0.60. Therefore, all of the latent variables appeared to have been adequately operationalized by their respective indicators.

3.2.2. Test of the structural models

Testing of the structural model using the measurement model tested above resulted in an acceptable fit to the data as indicated by the following goodness of fit statistics: $\chi^2(30, N = 205) = 69.90$; GFI = 0.94; CFI = 0.92; SRMR = 0.079; IFI = 0.92. In order to prove that the proposed model did not fit to the data as a result of a statistical coincidence, we tested an alternative model in which knowledge regarding epilepsy mediated the relationship of attitudes towards epilepsy with mental illness, and the quality of life was tested against the proposed model. The test of this model indicated a poor fit to the data ($\chi^2(30, N = 205) = 83.23$; GFI = 0.92; CFI = 0.88; SRMR = 0.11; IFI = 0.89) and supported the superiority of the proposed model based on the literature. The chi-square difference test ($\Delta\chi^2 = 13.33, df = 0, p < .01$) indeed supported the proposed model against the alternative.

The standardized parameter estimates have been displayed in Fig. 2, supporting the hypotheses of the present study. It is clear that knowledge had a moderate relationship with attitude-latent variables, which in turn had a strong relationship with mental illness, while a moderate relationship with the quality of life. The significance of the indirect effects in the proposed model was evaluated by the estimates produced by LISREL. The estimates regarding the indirect effects of knowledge on both mental illness ($-0.31, SE = 0.09, p < .01$) and quality of life ($0.22, SE = 0.08, p < .01$) were shown to be statistically significant. Finally, it is worth mentioning here that model accounted for 20%

Table 3
Factor Loadings, standard errors, and *t*-values for the measurement model.

Measure and variable	Unstandardized factor loading	SE	<i>t</i>	Standardized factor loading
Quality of life				
Epilepsy effect	9.78	2.39	4.08	0.32
Mental health	15.49	1.52	10.19	0.80
Role functioning	12.65	1.85	6.84	0.50
Attitudes towards epilepsy				
Attitude	3.44	0.82	4.20	0.44
Stigma	0.95	0.24	3.88	0.37
Mental illness				
Depression	3.02	0.24	12.83	0.86
Anxiety	2.69	0.26	10.18	0.69
Knowledge				
Parcel 1	0.82	0.09	9.10	0.66
Parcel 2	0.80	0.08	9.90	0.71
Parcel 3	1.09	0.11	10.39	0.75

Notes. *N* = 205.

of the variance in the quality of life and 39% of the variance in mental illness-latent variables.

4. Discussion

Analyses using the structural equation modeling supported the expected relationships between variables, hence the hypotheses; knowledge was shown to have a statistically significant effect on attitude, while attitude was shown to have a significant effect on both mental illness and the quality of life as indicators of negative and positive mental health, respectively.

The participants' level of knowledge was determined to affect the attitudes towards the disease and perceived stigma level in patients with epilepsy. This finding is consistent with the earlier findings showing that negative attitudes were determined to develop in patients who had incorrect knowledge and misbelief; this condition was determined to increase stigmatization [3,15,18,38]. The knowledge level of the community is as important as the knowledge level of the patients for increased stigmatization. Patients are isolated in communities that have incorrect knowledge and beliefs, and this condition leads the patients to feel stigma to a higher extent. Therefore, educating both the patients and the community has great importance in the prevention and reduction of stigma [39–44].

Negative attitudes and perceived stigma in epilepsy were determined to be among the factors that affect the mental health of the patients. Anxiety and depression are among the most common comorbidities in patients with epilepsy and 46.9% of patients with epilepsy in Turkey were reported to have depressive symptoms, and depression was found to be associated with perceived stigma [45]. Self-management is impacted when the patients feel stigmatized; the disease management and coping with the negative outcomes impair, the

Table 2
Means, standard deviations, and intercorrelations of observed variables.

Observed variables	M	SD	1	2	3	4	5	6	7	8	9
1. QoL-Epilepsy effect	54.63	31.06	–								
2. QoL-Mental health	55.79	19.06	0.23**	–							
3. QoL-Role functioning	62.57	25.16	0.52**	0.41**	–						
4. Knowledge parcel 1	3.68	1.24	0.09	–0.02	0.05	–					
5. Knowledge parcel 2	3.47	1.12	0.16*	0.09	0.14*	0.52**	–				
6. Knowledge parcel 3	3.88	1.46	0.01	0.03	–0.03	0.48**	0.53**	–			
7. Anxiety	7.36	3.91	–0.29**	–0.50**	0.35**	–0.16*	–0.10	–0.03	–		
8. Depression	5.39	3.53	–0.24**	–0.60**	–0.33**	–0.15*	–0.22**	–0.13	0.59**	–	
9. Attitude	59.31	7.88	0.17*	0.23**	0.16*	0.24**	–0.24**	0.35**	–0.19**	–0.42**	–
10. Stigma	7.08	2.55	0.23**	0.33**	0.36**	0.07	0.16*	0.08	–0.27**	–0.27**	0.14*

Notes: *N* = 205.

* *p* = .05.

** *p* < .01.

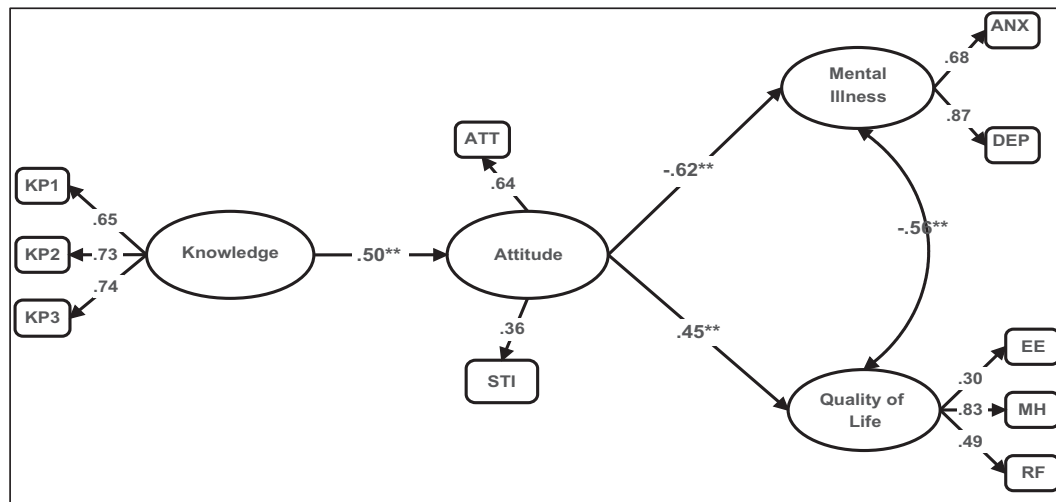


Fig. 2. Standardized parameter estimates for the proposed model. Notes: $N = 205$; KP1–KP3 = parcels created for knowledge-latent variable; ATT = attitude, STI = stigma; DEP = depression, ANX = anxiety, EE = epilepsy effect, MH = mental health, RF = role functioning.

social anxiety level increases and depression becomes inevitable [21]. Psychiatric problems accompanying stigma is an expected condition as patients experience many social problems in school life, finding work, and marriage [3,15,46]. This condition affects the treatment compliance and a vicious cycle develops. Patients subject to social or psychological isolation due to prejudices give up seeking health; self-management is negatively affected and coping with the disease becomes difficult. The perceived stigma level increases to a higher extent in patients who cannot manage the disease. Many studies have reported that anxiety and depression are associated with stigma and psychiatric problems should not be overlooked [15,18,24–27,47,48]. From a different point of view, personality studies have reported that introvert [49], pessimistic, and avoidant [50] personality traits are in the foreground in PwE, and these patients experience more anxiety and depression [49–51]. The perceived stigma level may be higher in that type of patients as they are more pessimistic towards the disease, and naturally, anxiety and depression may be common psychiatric problems in patients with epilepsy. Considering our proposed model demonstrating that knowledge, attitude, and perceived stigma account for 39% of the variance in anxiety and depression, all these variables should be evaluated in PwE for promotion of mental health.

Apart from the disease burden, psychosocial problems impair the quality of life in PwE. The present study, which addresses the psychosocial aspect of the disease, has revealed that perceived stigma significantly affects the quality of life. A recent meta-analysis reported contributory factors to the quality of life in PwE as stigma, knowledge, attitude, and anxiety and depression [18]. The findings of this meta-analysis study support the findings of our proposed model. Our model accounted for 20% of the variance in the quality of life. The fact that our model explained a low variance in the quality of life suggests that other factors such as self-management, social support, and locus of control may also be effective. Therefore, the factors that may affect the quality of life of PwE should be considered in a wide range and the dynamic relations between all these factors should be revealed by further analysis.

5. Conclusion

In conclusion, knowledge, attitudes, and perceived stigma seem to be important for mental health and the quality of life in PwE. Therefore, positive attitudes may be developed through educating patients with epilepsy, and the quality of life and mental health may be improved when the perceived stigma levels decrease.

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Conflict of interest

None.

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