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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

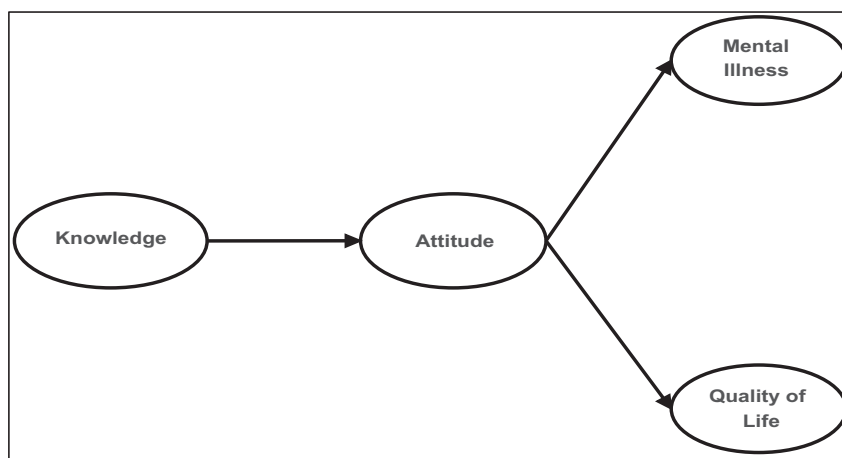


Fig. 1. Conceptual diagram for the proposed model concerning structural relations of the study variables.

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