



Predictors of positive and negative attitudes toward their condition in Turkish individuals with epilepsy

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ABSTRACT

The purpose of this cross-sectional study was to explore the attitudes of individuals with epilepsy (IWE) toward their condition via self-reported changes in the feelings/thoughts about having epilepsy. We aimed to investigate whether individuals with epilepsy perceive a change in their initial attitudes toward the condition over time. Additionally, if a change was perceived, the variables which predict the current thoughts/feelings toward epilepsy were also examined. Seventy adult IWE participated in the study. Of the 70 participants in the study, 25.7% retained their initial feelings/thoughts without any change. Among the IWE who reported no-change, the most common category was “negative from the beginning”. On the other hand, 74.3% of the participants reported a change. Of the 74.3% of participants reporting change, the most common direction was from negative to positive” (79.2%) seeming to indicate a positive adjustment over the passage of time. In a logistic regression, only three factors were found to predict positive feelings/thoughts toward epilepsy: a clear understanding of the condition, low levels of depression and current employment status. Finally, there is a discussion of the potential applications of the IWE’ self-assessment of their attitudes.

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1. Introduction

Epilepsy is one of the most common chronic neurological illnesses, affecting around 50 million people worldwide and can result in profound psychological consequences.¹ Following diagnosis, many individuals with epilepsy (IWE) are left with only a vague understanding of the word epilepsy and considerable uncertainty about the future.² When IWE experience seizures, especially after long seizure-free periods, they realize the chronicity and unpredictability of epilepsy. As with other chronic illnesses, since people never fully recover, the adjustment process becomes crucial to individual’s functioning and quality of life, and to decreasing their felt stigma.

The term “adjustment” may be defined in a number of ways according to theoretical perspective. However, in general, it is defined as changes in response to the demands from the environment that make an organism more adaptable.³ Adjustment to ill-health can be affected by many variables, including the severity of the illness, the expected prognosis, age of onset, gender,

how rapidly health status deteriorates, and whether the illness involves symptom free periods.⁴

Some researchers have defined mental adjustment to a chronic illness as the cognitive, emotional and behavioral responses of the patient to the diagnosis.^{5,6} In a similar vein, during the adjustment process to a chronic illness, it is known that patients’ illness representations have a significant role in determining coping behavior and adherence to treatment, e.g.^{7,8} Such representations serve as a guide to patient behavior, and therefore to likely adjustment patterns. Although there are many theories explaining the adjustment of the individuals with chronic illnesses, a common notion in all the models is that individuals facing a health crisis develop illness representations which reflect their pre-existing belief structures.³ Whether due to illness severity, individual characteristics, or prior experiences, some participants are unable to develop illness representations which facilitate their adjustment. Additionally, illness representations are not stable over time; individuals may move backwards as well as forwards and there may be deviations during their adjustment process.⁹ Examples of this variation include participants with prior negative illness representations adopting more positive ones because of number of factors such as, high symptom control, a lower than expected illness impact, moderate limitations, and high levels of social support. As emphasized by Stanton et al.,⁴ although chronic

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disease is disruptive and causes significant distress, many individuals with chronic illness report positive adjustment.

The diagnosis of epilepsy is usually a very significant, and emotionally laden event¹⁰ which makes the point of transformation from “normal” to “epileptic”, and this transformation remains as a major life theme for the person affected.¹¹ After this turmoil, it may become extremely difficult for many IWE to deal with the effects of epilepsy, and even in patients with the same type of seizures and seizure frequency, levels of adjustment may show wide variations in response. These variations can be caused by factors, such as employment status, social support levels, family reaction to the diagnosis, felt and enacted stigma, depression, and self-esteem.¹²

Previous research relating to adjustment to epilepsy has mainly investigated coping strategies, e.g.,^{13–17} and has mainly been assessed by using psychometric scales, e.g.^{18,19} In contrast to previous research, this study aimed to assess the adjustment process of IWE by examining their feelings/thoughts toward epilepsy via self-reports. This method was chosen because the analysis patients’ experiences are becoming an important focus in adjustment studies.^{9,20}

In the present study we aimed to examine the participants’ own feelings/thoughts toward epilepsy by comparing their initial, and current emotional and cognitive reactions. We hypothesized that:

- Based on previous research findings concerning reactions to the initial diagnosis,^{10,21} most IWE evaluate their initial reactions as negative.
- Following this, we expected that most IWE would report a change in their feelings/thoughts toward the illness based on their individual contexts (e.g., marital status, employment status, knowledge of and attitude toward epilepsy), and the prognosis of epilepsy (e.g., seizure frequency, level of seizure control, number and amount of AEDs).

Therefore, we aimed to examine whether IWE perceive a change in their initial feelings and thoughts about having epilepsy with the passage of time, and to identify variables which predict the direction of this perceived change (either to positive or to negative).

- Lastly, based on the findings of previous studies, e.g.,^{18,22–30} we hypothesized that the current feelings and thoughts (either positive or negative) of IWE toward epilepsy would be largely explained by depression, epilepsy knowledge, attitude toward epilepsy, impact of epilepsy, seizure frequency and current employment status. We expected that participants with lower levels of depression, lower impact of epilepsy and also those with more positive attitudes, higher knowledge about epilepsy and, those currently in employment would be more likely to evaluate their current feelings and thoughts toward epilepsy as positive. In addition, participants with lower seizure frequencies were expected to report positive feelings/thoughts toward epilepsy, because of unfulfilled negative expectations, e.g., fewer than anticipated seizures. High seizure frequency also has been shown to be related to low quality of life (QOL) and high level of depression,^{23,26,31–35} which in turn could negatively affect the current feelings/thoughts.

2. Methods

2.1. Participants

The criteria for the inclusion of the 70 participants in the study were as follows: the experience of seizures for a minimum of four years, and either experiencing of at least one seizure within the last two years or continuing treatment with anti-epileptic drugs (AEDs). All participants underwent detailed neurological and

Table 1

Demographic and clinical characteristics of the participants.

	Participants (n = 70)
Sex (%)	
Female	68.6
Age (SD)	32.3 (10.5)
Years of education (SD)	9.2 (3.9)
Marital status (%)	
Single	48.6
Married	42.9
Divorced/widow	8.6
Occupational status (%)	
Employed	47.1
Unemployed	14.3
Housewife	22.9
Student	14.3
Retired	1.4
Age at seizure onset (SD) (year)	15.9 (6.8)
Duration of the illness (SD) (year)	16.6 (10.6)
Number of AEDs (SD)	1.6 (0.8)
Seizure type (%)	
Generalized tonic-clonic	45.7
Simple partial	18.8
Complex partial	21.4
Absence	2.9
Myoclony	11.4
Seizure frequency (%) (per month)	
None	12.9
<10	72.9
>10	13.3
Intractable seizures (%)	
Yes	58.6

neuropsychological evaluations, and those with below average IQ (less than 90), those with serious additional impairments (e.g., hearing, seeing, etc.) and other neurological and psychiatric disorders were excluded.

All the participants were recruited from the epilepsy outpatient clinic at Istanbul University, Cerrahpaşa Faculty of Medicine, Department of Neurology. Demographic and clinical characteristics of the participants are shown in Table 1.

2.2. Measures

Four different scales were administered to assess participants’ level of depression, level of knowledge about epilepsy, attitudes toward epilepsy, and impact of epilepsy. A separate form for clinical and demographic information was also provided.

2.2.1. Depression

Beck Depression Inventory (BDI),³⁶ a 21-item depression scale, was administered to assess depression levels. Scores range between 0 and 63, with higher scores indicating increased severity. In the present study, score of 17 and over were considered as indicating severe depression. The validity and reliability of the BDI for Turkish population was tested by Hisli³⁷ ($\alpha = 0.74$).

2.2.2. Epilepsy Knowledge Scale

Epilepsy Knowledge Scale³⁸ has 16 items and it was developed for the Turkish population. Possible responses to items on the knowledge scale were “True”, “False” and “Don’t know”. Responses are given the values of one for true answers and zero for false items and “don’t know”, giving a total between a maximum of 16 and a minimum of zero, where higher scores represent a greater knowledge of epilepsy. The Knowledge Scale yielded a Kuder–Richardson-20 internal consistency coefficient of 0.72.³⁸

2.2.3. Epilepsy Attitude Scale

This scale consists of 14 items developed in order assess the Turkish public’s attitudes toward epilepsy.³⁸ Scores on this scale

Table 2

The percentages of the perceived initial and current feelings and thoughts toward epilepsy.

Participant characteristic (N=70)	Neutral (%)	Positive (%)	Negative (%)
Participants who perceive no-change over time (n=18, 25.7%)	29.4	5.9	64.7
Participants who perceive change over time (n=52, 74.3%)	–	79.2	20.8

were averaged to create a composite attitude scale, resulting in a range of scores from 5 (completely agree) to 1 (completely disagree). Total scores on the attitude scale can vary between 14 and 70. Higher scores indicate more positive attitudes toward IWE and epilepsy in general. The Cronbach's alpha was found to be 0.84 for this scale.³⁸

2.2.4. Impact of epilepsy

The Perceived Impact of Epilepsy Scale³⁹ was administered to determine the impact of epilepsy on daily life. The scale contains both generic and epilepsy-specific items, covering the most important areas of everyday life, including relationships with spouse/partner, relationships with other close family members, relationships with friends, social life/social activities, work, health, feelings about self, and plans and ambitions for the future. In this scale the higher the score, the greater the impact of epilepsy. The Cronbach's alpha of the scale was found to be 0.82.³⁹

2.2.5. Information form

This form was created to collect information about participants' clinical and demographic characteristics, containing questions on age of onset, seizure frequency, number of AEDs and the existence of other chronic conditions. In terms of demographics, information was sought on age, gender, level of education, occupational and marital status. The following questions were used to assess the initial and current feelings and thoughts of the participants: (1) "I want you to evaluate your initial feelings and thoughts about having epilepsy after your diagnosis. Could you describe them?"; (2) "Have you experienced any change in these feelings and thoughts with the passage of time?"; (3) "If your answer is yes, could you evaluate your current feelings and thoughts about having epilepsy?". The answers were recorded in writing verbatim by the first author (N.A.).

2.3. Procedure

After completing the information form, the BDI, Impact of Epilepsy Inventory, Epilepsy Knowledge and Epilepsy Attitude Scales were administered in a randomized order to counter any possible ordering effects. All administrations were conducted in the form of face to face interviews with the first author (N.A.). The present study was approved by the Ethics Committee of the Cerrahpaşa Faculty of Medicine, Istanbul University. Additionally, all participants gave written informed consent for their participation in the study.

2.4. Statistical analysis

All answers to open-ended questions were transferred verbatim to Excel files for examination and content analysis. This analysis was carried out by two qualified coders, both with post graduate degrees in the field of psychology who were blind to the aims of the study. The aim of the qualitative analysis was to determine whether there was any change in feelings and thoughts toward epilepsy, and if so, its direction (to negative, positive, or neutral). Where no change was found, they determined whether the feelings/thoughts were negative, positive, ambivalent or neutral. Coders first decided what kind of expressions was evaluated as positive, negative, ambivalent or neutral. Then the coders worked

independently, before comparing their coding. They were in agreement in all but three instances of coding, which they resolved themselves.

For multivariate analysis SPSS for Windows, version 17 was used. A direct logistic regression analysis was performed to explain the variance in the current feelings and thoughts. In this analysis, a "negative attitudes toward epilepsy" group was composed of two sub-groups: first, those had negative evaluations of their illness since diagnosis, and second, those with a current negative illness evaluations. Similarly, a "positive attitudes toward epilepsy" group was composed of those with a positive evaluations from the beginning, and those with a current positive perception. Therefore, in the analysis, current feelings/thoughts toward epilepsy consisted of two categories: positive (coded as 2) and negative (coded as 1). The predictor variables were: depression, epilepsy knowledge, attitude toward epilepsy, impact of epilepsy, occupational status (1 = currently working; 2 = not working) and seizure frequency (1 = none; 2 = less than ten per month; 3 = more than ten per month). Before the analysis, the data were examined and no signs of multicollinearity or singularity were found.

3. Results

3.1. Change and the direction of the change

The results showed that 25.7% (N = 18) of the participants were classified as reporting no change in terms of their feelings/thoughts toward epilepsy over time (see Table 2). Of these, 29.4% showed neutral feelings and thoughts toward their epilepsy:

"I have never felt different or inferior because of my epilepsy. Neither before nor now" [F, 23]^d
5.9% expressed positive feelings and thoughts:

"I accepted my illness from the beginning and I am fine with it. I thought it was Allah's will" [F, 29];
and 64.7% revealed negative feelings and thoughts:

"I have always have problems with being an epileptic and feel so sorry about it. I have always thought about when I will get rid of it. And I still feel in the same way" [M, 34].

The next part is an analysis of the answers of participants who indicated a change in their initial feelings/thoughts (N = 52, 74.3%). Two main categories emerged from this analysis; "negative to positive" and "neutral to negative" (see Table 2).

(1) negative to positive (79.2%):

"Now I am happy because I can go wherever I want and can do whatever I want to do. But it used to limit my life a lot, even I had to go to the toilet with someone" [M, 47];

"Now I do not feel self-pity. I follow my treatment and take my medicines. I used to be really pessimistic about my condition,

^d In this and subsequent quotations, informant type is denoted by the codes in the parentheses; F, female; M, male; number, age.

Table 3
Logistic regression results for predicting the current feelings/thoughts toward epilepsy with the passage of time.

Variables	B	Wald χ^2 test	Odds ratio	95% Confidence interval for odds ratio	
				Lower	Upper
Depression**	-0.12	6.36	0.89	0.81	0.97
Impact of epilepsy	-0.04	0.17	0.96	0.80	1.15
Epilepsy knowledge**	0.77	5.83	2.16	1.16	4.04
Attitude toward epilepsy	-0.05	0.47	0.95	0.82	1.10
Seizure frequency		3.88			
Seizure frequency (1)	0.89	0.43	2.43	0.17	34.46
Seizure frequency (2)	2.25	3.57	9.48	0.92	97.55
Employment status (1)*	1.75	4.18	5.73	1.08	30.50
Constant	-7.13	2.09			

* $p < 0.05$.

** $p < 0.001$.

but now I am not. My epilepsy is now like a friend to me. After my diagnosis, I was even able to have a child" [F, 35].

(2) neutral to negative (20.8%):

"I used not to mind about it, but now it really upsets me, because it does not go, whatever I do" [F, 18].

3.2. Explaining the current feeling and thoughts toward epilepsy

Data from 59 IWE were incorporated into the analysis, 18 with negative and 41 with positive feelings/thoughts toward epilepsy. Cases with missing and/or extreme values and those with neutral feelings/thoughts toward epilepsy were excluded. A test of full model with all predictors was statistically significant χ^2 (7, $N = 59$) = 24.30, $p < 0.001$, Nagelkerke $R^2 = 0.48$ indicating that the predictors reliably distinguish between those with positive and those with negative feelings and thoughts. The model correctly classifies 61% of those with negative, and 85.4% of those with positive feelings/thoughts toward epilepsy, with a 78% overall success rate. The results presented in Table 3 showed that depression, epilepsy knowledge and current working status predicted positive feelings/thoughts toward epilepsy. Participants with lower levels of depression, greater understanding of the illness, and who were in employment at the time were more likely have positive feelings/thoughts toward epilepsy.

4. Discussion

The main aim of the present study was to examine the patients' own evaluations of their initial and current feelings and thoughts toward epilepsy. A secondary aim was to determine the variables which explain current negative or positive attitudes. This aim was grounded in both previous research and personal communication with IWE, which revealed a wide range of attitudes to both epilepsy and in coping strategies. Some IWE experience a minor negative impact, while others experience severe depression, high levels of anxiety and felt stigma, giving the impression of almost total incapacitation, e.g.^{12,40} Because of this significant variation, it was seen as important to examine whether initial feelings/thoughts toward epilepsy persist or change over time. The investigations into patients' self-evaluations of the initial and current feelings/thoughts toward epilepsy showed that among those who show no change, a persisting negative attitude was the most common. This result indicates that those with initial negative reactions may be more resistant to change. This result is also in accordance with Baker's⁴¹ finding, which showed that almost half of 6000 individuals with epilepsy across ten different European countries have difficulties in accepting their condition.

In contrast, those who reported a change between their initial and current attitudes most commonly declare a shift from "negative to positive", which could be an indication of adjustment. As we expected, the majority of individuals evaluate their illness representation as negative on diagnosis; however, most adopt a more positive attitude over time. These findings are in accordance with Kralik,⁹ who pointed to an "extraordinary" phase of turmoil and distress when chronic illness is first diagnosed, after which most patients subsequently pass to an "ordinary" phase, characterized by the adaptation of their lives to allow for a chronic illness.

In terms of predicting current feelings/thoughts toward epilepsy, our hypothesis was partially supported. Epilepsy knowledge, depression levels and current status in employment all predicted a significant variance in the current feelings/thoughts toward epilepsy, especially where these were positive. Similarly, some previous studies^{18,42} found that participants with high degree of epilepsy knowledge also scored high in adjustment. This result indicates that the dissemination of accurate knowledge about epilepsy has the potential to create a significant difference in the long-term adjustment process. Also, as stated by number of studies, e.g.,^{15,22,43,44} clinical factors such as seizure frequency play modest roles in determining the QOL of IWE, whereas depression strongly accounts for most of the variance in QOL values. The role of depression as an important predictor in long-term adjustment is also supported by this study. Furthermore, the present study indicates the importance of employment status on adjustment, highlighting the importance of encouraging the efforts of IWE to find work, and the necessary legislation to prevent discrimination and enacted stigma in the job seeking process and in the work place. On the other hand, it was found that neither impact of epilepsy, attitude toward epilepsy nor seizure frequency predicted current feelings and thoughts.

The present study highlights the potential for gaining insight into adjustment to epilepsy through the comparisons of patients' self-evaluation of past and current attitudes. Such insight could be of significant practical value in view of the limited time and resources available for dealing with such issues throughout the world.

4.1. Limitations of the study

Because we relied on participants' retrospective self-reports, there was a danger that evaluation of initial feelings/thoughts toward epilepsy may be influenced by current feelings and thoughts. Therefore, the findings of this study should not be taken as definitive. In order to assess changes in the attitudes toward epilepsy, future studies which longitudinally examine the attitudes should be carried out.

Another limitation of the present study was selecting participants only from the hospital population, since patients being treated by a specialized neurologist in a hospital setting may differ from those without this opportunity, in terms of seizure control, and hence in the adjustment process. Therefore, it is not possible to claim that the participants in this study represent the general epilepsy population in Turkey. Also, the relatively small number of participants is neither sufficient for generalizing the findings, nor for a high statistical power.

Finally, although we asked participants to report both their thoughts and their feelings, it is unlikely that they would be able to distinguish between these. In future studies, more elaborative interviews could explore both of these aspects in a more balanced way.

4.2. Future directions

Future research already planned will have the aim of examining changes in feelings/thoughts toward epilepsy using a longitudinal design, including the application of scales and a semi-structured interview. A time period of five years from diagnosis will be covered, and evaluations will be conducted at regular intervals.

5. Conclusion

Only one fourth of the IWE in this study were found to experience no change in their feelings/thoughts toward epilepsy over time. Among these, the most common category was “negative from the beginning”, which indicates the importance of preventing the initial negative reactions. In Turkey, an important step in this respect is to replace the original word for the illness, the Arabic term “sara”, also used in Turkish, with the word “epilepsy”, in order to medicalize the condition. This is essential because, for Turkish people, “sara” has strong negative connotations, such as falling to the ground, and having tonic-clonic convulsions accompanied by foaming at the mouth. This change, together with dissemination of accurate and unbiased information about the condition to those affected and their families immediately on diagnosis could have a very significant impact. Furthermore, culturally appropriate ways for minimizing initial negative reactions should be considered for each context.

On the other hand, where change was perceived by IWE, it was mainly observed from negative to positive, which seems to indicate a positive adjustment to the condition. Only higher knowledge about epilepsy, lower levels of depression and employment predict the current positive attitude toward epilepsy. These results also emphasize the importance of providing accurate information to IWE, and taking into account the role of psychological well-being of the IWE in the adjustment process. Encouraging IWE to seek employment via decreasing overprotective attitudes, providing the necessary legislations, and deploying national campaigns in order to increase awareness of epilepsy also seem to be crucially important to the long-term adjustment of IWE.

Finally, in situations where time, resources and expertise are limited, the self-evaluation of initial and current feelings/thoughts about epilepsy by IWE can make a valuable contribution to understanding the adjustment process, and levels of adjustment. Such insight is potentially valuable in further evaluative work, especially in terms of assessing emotional well-being.

Conflict of interest

The authors declare no conflict of interest. The present study was approved by the Istanbul University, Cerrahpaşa School of Medicine, Faculty of Ethics Committee [31.01.2006, no: 2378]. We also confirm that we have read the Journal's position on issues

involved in ethical publication and affirm that this report is consistent with those guidelines.

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