



Examination of health literacy and personal impact of epilepsy in patients with epilepsy

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ABSTRACT

Aim: We conducted this study to examine the impact of health literacy on the personal impact of epilepsy in patients with epilepsy.

Method: We conducted this cross-sectional and correlational study with 125 individuals who were admitted to the neurology outpatient clinic of a university hospital in eastern Turkey, who met the research criteria, and who accepted to participate in the study. We collected the data by using the "Descriptive Information Form (DIF)", "The Personal Impact of Epilepsy Scale (PIES)", and "Health Literacy Scale (HLS)".

Results: We found that the mean HLS total score of the participants was 104.84 ± 22.88 . We also found the mean PIES total score to be 27.08 ± 18.56 . Regression results using PIES as a dependent variable reported that the model created was statistically significant ($F(21,83) = 11.398, p < 0.05$). Among the variables included in the model, income status and HLS were negative ($\beta = -0.209$; $\beta = -0.194$; $\beta = -0.364$, respectively) predictors of the PIES total score. However, seizure status in the last year, number of drugs used, and seizure type were positive predictors of the PIES total score. We found that the variables included in the analysis explained 74% of the total PIES score.

Conclusion: In conclusion, the health literacy level (HLL) of the participants was sufficient or very good, and the effect of the disease on individuals with epilepsy was low. The effect of the disease on individuals with epilepsy decreased as the level of health literacy increased.

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1. Introduction

Health literacy is associated with self-care and the management of chronic diseases [1]. Patients with a low health literacy level (HLL) have difficulty in understanding health-related information and are known to have difficulties in managing chronic diseases. These patients are at greater risk in terms of poor health outcomes [2]. Epilepsy has many negative effects on people. Health literacy is the ability to understand the health information necessary to make appropriate health decisions and is associated with the health outcomes of patients with epilepsy [3]. Zhang et al. reported that low education levels led to less knowledge about anti-epileptic drugs [4]. Paschal et al. found that the frequency of seizures and the rate of dose skipping were low in children with epilepsy whose parents had high levels of health literacy [5]. Revealing the factors that

increase or decrease the negative impact on seizures, side effects of drugs, and work and social activities will guide the development of strategies. The age of patients, the frequency of seizures, and the existence of other illnesses all have an impact on how epilepsy affects an individual [6]. Since the success of managing each disease is also affected by health literacy, examining the effects of these two on each other will make a significant contribution to the literature. We conducted the present study to examine the impact of health literacy on the personal impact of epilepsy in patients with epilepsy.

2. Materials and methods

2.1. Design

The present study is a cross-sectional and correlational research.

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2.2. Study universe and sample

We conducted the present study between April 2022 and January 2023 at the Neurology Outpatient Clinic of the Atatürk University Health Research and Application Center in Erzurum Province, located in the east of Turkey. Erzurum is located at 39°55' north latitude and 41°16' east longitude in the Eastern Anatolia region. The province is surrounded by Ardahan-Artvin-Rize from the north, Gümüşhane-Erzincan-Bayburt from the west, Bingöl-Muş from the south, and Ağrı-Kars and Iğdır from the east. The institution in which the research was conducted provides health services to epilepsy cases from all these neighboring cities. All participants were included in the study after they were evaluated in the neurology outpatient clinic and their definitive diagnosis was made at least six months ago. Prior power analysis in the G-Power 3.1.9.4 program was used to determine the sample size of the study. In the prior power analysis, we determined the effect size by taking into account the comparison of the marital status variable in the study of Esen and Kolcu (2022) for the t-test in independent groups and the average of health literacy scores (HLS)[7]. As a result of this analysis, we found an effect size of 0.77 with a significance level of 0.05 and a power of 0.95. Accordingly, we found the minimum number of patients to be included in the study to be 88. Between these dates, 105 patients who accepted to participate in the study and met the research criteria were included in the study. Since 1978, the Atatürk University Research Hospital has been providing high-quality healthcare to large populations by combining cutting-edge technology with qualified personnel. In addition to 14 provinces and its region, it expands its service network worldwide and provides services in all disciplines, mainly surgical medicine, internal medicine, diagnostics, and imaging, with its modern equipment and experienced staff. The hospital is a state university hospital and treats patients free of charge.

2.3. Data collection tools

We collected data by using the “Descriptive Information Form (DIF)”, “The Personal Impact of Epilepsy Scale (PIES)”, and “Health Literacy Index (HLI)” through the self-report method.

2.3.1. Descriptive information form

This form created by the researchers includes the information about participants' age, gender, marital status, educational status, occupation, income status, number of medications used for other comorbidities, seizure frequency, and diagnosis duration.

2.3.2. The personal impact of epilepsy scale

Fisher et al. developed PIES in 2015. The scale consists of 25 items and 3 sub-scales to evaluate the effect of epilepsy on individuals [8]. Özer et al. conducted a validity and reliability study of the scale in Turkish in 2021 [9]. The scale has a 5-point Likert type, and it is scored between 0 and 4. Its subscales are the effects of seizures (9 questions), side effects of medications (7 questions), and comorbidities (9 questions). The highest total score that can be obtained from the PIES scale is 100. Scores on this scale are evaluated out of one hundred. In general, 0–25 can be interpreted as very low, 25–49 low, 50–69 medium, 70–89 high, and 90–100 very high. The increase in the score on the scale reflects a more negative situation. Cronbach's alpha values of the total scale and sub-scales are between 0.72 and 0.95 [9]. In this study, we found Cronbach's alpha values of the scale to be between 0.83 and 0.94.

2.3.3. Health literacy scale

Sørensen et al. developed HLS as the 47-item European Health Literacy Survey (HLS-EU) in 2013 [10]. Toçi et al. later revised it as the HLS [11]. Aras and Temel conducted the Turkish validity

and reliability study in 2017 [12]. The scale consists of 25 items and four sub-scales. Access to information includes five items (items 1–5), and understanding information includes seven items (items 6–12). The appraisal or evaluation subscale includes eight items (items 13–20). The application or using subscale also includes five items (items 21–25). The minimum possible total score is 25, and the maximum possible total score is 125. All items on the scale have a positive structure; there is no reverse item. Low scores indicate insufficient, problematic, and poor health literacy, whereas high scores indicate adequate health literacy. A higher score indicates a higher level of health literacy in an individual. Cronbach's alpha reliability coefficients of the total scale and sub-scales were found to be between 0.74 and 0.91 [12]. In this study, we found the Cronbach's alpha reliability coefficient of the scale to be between 0.93 and 0.97.

2.4. Ethical considerations

The Ethics Committee of Istanbul Sabahattin Zaim University approved the study on March 25, 2022, with a 2022/3 numbered approval. The hospital in which the study was conducted gave May 18, 2022, dated, and E-16710634-04-500.03.06-2200161910 numbered permission to conduct the study. The study was carried out in accordance with the principles of the Helsinki Declaration of Human Rights. The researchers explained the study to the participants and obtained their verbal consent for participation.

2.5. Statistical methods

We used SPSS 25 software to evaluate the data by using the numbers, percentages, arithmetic mean, standard deviation, t-test, one-way analysis of variance (ANOVA), correlation, and regression analysis in independent groups. The statistical significance level for these analyses was determined as $p < 0.05$.

3. Results

We found that the mean age of the participants was 31.82 ± 10.53 years and the time that passed after diagnosis was 10.30 ± 9.18 years. We also found that 51.4% of the participants were women, 58.1% of the participants were married, 39% of the participants were high school graduates, 55.2% of the participants were not working, 80% of the participants had an income equal to their expenses (at a moderate level), 80% of the participants had a nuclear family structure, 28.6% of the participants did not have a seizure in the last year, 81% of the participants had an unknown type of initial seizure, 82.9% of the participants did not have any other chronic disease, 84.8% of the participants used antiepileptic drugs, and 57.1% of these drug users used a single drug (Table 1).

We found the total mean HLS score of the participants as 104.84 ± 22.88. In terms of HLS sub-scale mean scores, access to information sub-scale mean score was 21.41 ± 4.95, understanding information sub-scale mean score was 28.68 ± 6.96, evaluation sub-scale mean score was 33.25 ± 7.76, and application sub-scale mean score was 21.48 ± 5.00. We found the mean PIES total score as 27.08 ± 18.56. In terms of PIES sub-scales, the mean scores from the effect of seizure, drug side effects, and comorbidity sub-scales were 9.15 ± 8.57, 6.59 ± 5.06, and 11.34 ± 6.94, respectively (Table 2).

We conducted multiple regression analysis to estimate the relation of the variables of HLS, age, gender, marital status, education status, income status, employment status, family structure, number of seizures in the last year, seizure type, presence of other chronic diseases, antiepileptic drug use, number of antiepileptic drugs used, and diagnosis year with PIES total mean score. When

Table 1
Descriptive characteristics of the patients.

Characteristics	Number (n = 105)	%
Gender		
Female	54	51.4
Male	51	48.6
Marital status		
Married	61	58.1
Single	44	41.9
Educational status		
Primary education	34	32.4
High school	41	39.0
Undergraduate and higher	30	28.6
Working status		
Yes	47	44.8
No	58	55.2
Income status		
Income < expense	11	10.5
Income = expense	84	80.0
Income > expense	10	9.5
Family structure		
Nuclear	84	80.0
Extended	21	20.0
Number of seizure in the past year		
1	22	21.0
2	14	13.3
3	10	9.5
4	29	27.6
None	30	28.6
Seizure type		
Focal start	12	11.4
Unknown start	85	81.0
Generalized start	8	7.6
Presence of another chronic disease		
Yes	18	17.1
No	87	82.9
Anti-seizure medication use		
Yes	89	84.8
No	16	15.2
Number of anti-seizure medication used (n = 89)		
1	60	57.1
More than 1	29	27.6
	Mean ± SD	Min–Max
Age (yr)	31.82 ± 10.53	18–62
Diagnosis year (yr)	10.30 ± 9.18	1–45

we examined the analysis result for the total PIES mean score, we found that the model created was statistically significant ($F(21,83) = 11.398, p < 0.05$). Among the variables included in the model, income status (moderate, good) and HLS were negative ($\beta = -0.209; \beta = -0.194; \beta = -0.364$, respectively) predictors of PIES total score, whereas seizure status in the last year, number of drugs used, and seizure type were positive predictors of PIES total score. We found that the variables included in the analysis explained 74% of the total PIES score (Table 3).

Table 2
HLS and PIES mean scores of the patients (n = 105).

Scales	Number of items	Minimum score	Maximum score	Mean ± SD	
HLS Sub-scales	HLS total	25	43	125	104.84 ± 22.88
	Access to information	5	8	25	21.41 ± 4.95
	Understanding information	7	9	35	28.68 ± 6.96
	Evaluation	8	8	40	33.25 ± 7.76
	Application	5	7	25	21.48 ± 5.00
	PIES total	25	0	69	27.08 ± 18.56
PIES Sub-scales	Effect of seizures	9	0	27	9.15 ± 8.57
	side effect of drugs	7	0	18	6.59 ± 5.06
	Comorbidity	9	0	26	11.34 ± 6.94

PIES: The Personal Impact of Epilepsy Scale; HLS: Health Literacy Scale; SD: Standard deviation.

We performed multiple regression analysis to estimate the relation of the variables of age, gender, marital status, education status, income status, employment status, family structure, number of seizures in the last year, seizure type, presence of other chronic diseases, antiepileptic drug use, number of antiepileptic drugs used, and diagnosis year with the HLS total mean score. When we examined the analysis result for the total HLS mean score, we found that the model created was statistically significant ($F(19,85) = 2.196, p < 0.05$). Among the variables included in the model, only having a seizure was a negative ($\beta = -0.429$) predictor of the HLS total score (Table 4).

4. Discussion

The significance of health literacy has been made clear by the increase in the rate of long-term illnesses and related health issues today [13]. Health literacy is accepted as a key element in the management of chronic diseases. Patients with low health literacy have poor self-care, inadequate knowledge of their illnesses, limited access to healthcare, and poor health outcomes [14]. Individual assessment is required to understand the effects of epilepsy on patients, to evaluate the impact of treatment and self-management interventions, and to develop optimal treatment [15]. We conducted the present study to understand the relationship between the overall effect of epilepsy and the health literacy of patients with epilepsy. In the literature review, we found that ours is the first study to link the general effect of epilepsy with health literacy in patients with epilepsy.

The highest possible score on the HLS scale is 125. We found a mean score of 104 in the study. We found the HLL of individuals with epilepsy to be high because it is close to the total score that can be obtained. We found in this study that patients with epilepsy had a sufficient understanding of and capacity to use HLLs, health knowledge, and tools. Scrivner et al. [16] found that the level of health literacy was insufficient in patients with treatment-resistant epilepsy. A nation's level of health knowledge is crucial. Health facilities will be used effectively in a nation with a high degree of health knowledge. As the level of health literacy of the patients rises, they will decide which level of health institution they should apply to in order to solve the problem, and the patient density of the hospitals will be balanced. Another advantage of having a high level of health literacy is that it enables patient-doctor communication to be more understandable, cooperative, and harmonious. When the patient applies to the health institution, he or she will be able to more accurately express his or her symptom [16]. In this study, we found that the frequency of seizures negatively affected the level of health literacy. In a study evaluating the health literacy of parents of pediatric patients with epilepsy, Paschal et al. [5] found a significant association between higher health literacy and fewer missed drug doses and seizures. Health literacy, which determines the ability to access and use

Table 3
Regression results using PIES as dependent variables.

Dependent variables	Model	Independent variables	B	S. Error	β	T	p	95% Confidence interval	
								Lower	Upper
PIES	1	Constant	53.567	14.226		3.765	0.000	25.271	81.862
		Income (Moderate)	-9.636	3.940	-0.209	-2.446	0.017	-17.472	-1.800
		Income (Good)	-12.232	5.764	-0.194	-2.122	0.037	-23.693	-0.772
		Number of seizures in the last year (2 times)	11.863	4.679	0.218	2.535	0.013	2.558	21.167
		Number of seizures in the last year (3 times)	19.715	4.976	0.313	3.962	0.000	9.821	29.609
		Number of seizures in the last year (4 times)	30.995	3.503	0.750	8.848	0.000	24.030	37.960
		Number of drugs used (More than 1)	14.581	6.561	0.353	2.22	0.029	0.532	27.630
		Seizure type (Generalized start)	10.422	4.432	0.150	2.351	0.021	2.763	22.846
		HLS	-0.295	0.056	-0.364	-5.308	0.000	-0.406	-0.185
		R = 0.862 F (21,83) = 11.398	R ² = 0.743 p = 0.000*						

*p < 0.05; PIES: The Personal Impact of Epilepsy Scale; HLS: Health Literacy Scale.

Table 4
Regression results using HLS as dependent Variables.

Dependent variables	Model	Variables	B	S. Error	β	t	p	95%confidence interval	
								Lower	Upper
HLS	2	Constant	107.423	23.784		4.517	0.000	60.134	154.712
		Number of seizures in the last year (4 times)	-21.875	6.013	-0.429	-3.638	0.000	-33.830	-9.920
		R = 0.574, F (19,85) = 2.196	R ² = 0.329 p = 0.008						

*p < 0.001; HLS: Health Literacy Scale; SD: Standard deviation.

information to protect and maintain health, improves the effective treatment of chronic diseases and prevention of complications, improves drug compliance, and increases disease control [17]. It has been observed that after drug usage instructions are a serious problem for patients with low levels of health literacy; patients do not take their drugs at the right time and use the wrong amount. This situation causes negative health consequences, risky health behaviors, and an increase in costs [18,19].

This study found that epilepsy illness had a minimal effect on individuals. Cognitive, social, and psychiatric comorbidities (such as depression, anxiety, social limitations, driving restrictions, work, school, and relationship problems) had little impact on patients' lives. In addition, we found that the effect of epilepsy on individuals increased as the clinical situation worsened (seizure status in the last year, the number of drugs used, and the seizure type). According to Reyes-Miranda et al. [6], epilepsy had a modest effect on participants; the severity of the epilepsy effect was greater and was correlated with the number of seizures. According to Martz et al. [21], a clinically meaningful improvement was defined as a decrease of 8% or more in the PIES score for both the overall score and each subscale.

Another result we found was that the effect of epilepsy on individuals decreased as the level of health literacy increased. People with limited ability to understand and use health information and resources may find it challenging to manage their health conditions [20]. Poor medical compliance, more hospitalizations, less prophylactic healthcare, a worsened health status, and greater mortality are all consequences of a low level of health literacy [16,18,19]. Lower health literacy has been associated with higher rates of diabetic foot and amputation [1]. It is reported that low health literacy is a global barrier for patients with epilepsy to live in appropriate conditions, just like other long-term health conditions [3,14]. In a study of 140 adult patients with epilepsy, adequate health literacy was associated with a good quality of life [21]. Scrivner et al. (2019) found that a 1% increase in health liter-

acy was associated with a 6.61-point increase in quality of life in patients with treatment-resistant epilepsy [22]. Patients with epilepsy who had poor health literacy also reported higher levels of stigma related to the disease [21]. If individuals with epilepsy do not have access to adequate information about the disease, this can have a negative impact on the disease. On the contrary, having good access to relevant and clear information can increase empowerment over the disease [14,21].

4.1. Limitations of the study

This study has some limitations. Firstly, the sample size was small because the sample group was special, the study was conducted in a single center, and there was only one neurology outpatient clinic. The findings cannot be generalized to all epilepsy patients due to the limited sample size and the unique cultural, educational, and social characteristics of each participant. Secondly, due to the cross-sectional type of the study, a temporal relationship and, accordingly, a potential cause-effect relationship could not be established between the variables. Thirdly, we used a questionnaire form with closed-ended questions and collecting the study data. Although this enabled us to reach more epilepsy patients, it was not possible for the participants to express their opinions other than the questions in the form. For this reason, we recommend different types of studies on the health literacy of epilepsy patients and the personal impact of epilepsy disease.

5. Conclusion

As a conclusion, we found that the HLL of the participants was sufficient and the effect of the disease on individuals with epilepsy was low. We also found that the effect of the disease on individuals with epilepsy decreased as the level of health literacy increased. The frequency of seizures negatively affected the level of health lit-

eracy. In addition, we observed that the effect of the disease on individuals with epilepsy increased as the clinical situation worsened (seizure status in the last year, the number of drugs used, and the seizure type). We recommend that health literacy and the effect of the disease on individuals with epilepsy should be regularly evaluated, and the research should be conducted with different sample groups.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have seemed to influence the work reported in this paper.

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