



Investigation of illness perception and pregnancy avoidance in sexually active women with epilepsy



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ABSTRACT

Aim: The aim of the study was to examine the perception of illness and avoidance of pregnancy in sexually active women with epilepsy.

Methods: This study was completed with 82 women with epilepsy who were sexually active and who were admitted to the neurology clinic and outpatient clinic between June and September 2022. The descriptive information form, Brief Illness Perception Questionnaire (IPQ-B), and Pregnancy Avoidance Scale (PAS) were used to collect the data.

Results: The mean age of the patients in the study was 32.96 ± 5.92 years and the mean disease duration was 11.19 ± 7.46 years. Among the patients, 75.6% had previous pregnancies, 70.7% did not have miscarriage or abortion, 69.5% previously gave birth, 61% used a contraceptive method (condom, intrauterine device (IUD), pills, etc.) in their last sexual intercourse, 52.4% had good communication with their spouses, 20% had two children, 51.2% had three or more seizures, and 86.6% used antiseizure medications (ASMs). The mean PAS score of the patients was 2.31 ± 1.14 and the mean IPQ-B score was 35.10 ± 13.16 . The regression analysis found that the perception of illness was a significant positive predictor of avoidance of pregnancy and explained 17% of it.

Conclusion: Women with epilepsy avoided pregnancy and had negative illness perceptions. Moreover, negative illness perception increased pregnancy avoidance in women with epilepsy.

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1. Introduction

Epilepsy is a long-term paroxysmal disease commonly encountered in neurology, and it requires adaptation to the disease and its side effects. The thought of having a long-term disease, the difficulties experienced during treatment, and the physical and psychosocial problems impair individuals' emotional states [1]. Illness perception consists of patients' cognitions and beliefs about their illnesses [2]. Negative beliefs about a disease are of great interest, as they are associated with a poor quality of life in patients with epilepsy [3,4]. According to Leventhal's self-regulation theory, epilepsy exhibits features such as a long-term disease course, frequent relapses, and social stigma, similar to the important features of disease perceptions. This puts patients under a great deal of pressure

and makes them susceptible to a highly negative perception of illness. Patients with a negative perception of illness are more likely to perceive the illness as long-term and lose confidence in treatment, thus making them more hesitant to seek support or change their lifestyle [4,5]. A different approach is required for the follow-up and treatment of epilepsy in female patients due to menstruation, pregnancy, and menopause.

Specifically, pregnancy has special importance in terms of maternal and infant health. Maternal and infant mortality rates and pregnancy and birth complications are more common in epilepsy patients than in the normal population. A mother's seizures or the antiseizure medication used during pregnancy may adversely affect the development of the baby. It has been reported that the rate of congenital major or minor malformations in the children of women with epilepsy is 2–5 times higher than that of the general population [6]. Getting pregnant is an important decision for women with epilepsy. Due to complications that may occur during pregnancy (e.g., increased seizure frequency and the effects of antiseizure medication on possible metabolic changes),

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pregnancy is considered risky for women with epilepsy [7]. Although women with epilepsy were once advised to avoid pregnancy, epilepsy is no longer considered a contraindication for pregnancy [8]. However, due to myths about epilepsy and pregnancy in society (e.g., it is difficult to get pregnant if you have epilepsy; if I have a seizure while pregnant, I will miscarry; my baby will also have epilepsy; if you have epilepsy, it is not safe to become pregnant; and you cannot breastfeed because of the drugs used for epilepsy) [10], about one-third of women with epilepsy who are of childbearing age consider not having children or having fewer children [9]. The issue of women viewing their condition as a possible barrier to reproduction should be addressed [9,10]. In addition, although there is evidence that perceptions of illness can affect individuals' experience of a long-term illness, the effectiveness of treatment, and recovery from illness they also play an important role in coping styles and quality of life [5,11]. It has been observed that these two issues are not addressed in the world or in Turkey. Providing counseling and education to patients is an important aspect of quality care and should be evaluated by identifying patients' knowledge of their condition [10]. Therefore, the present study aims to examine the perception of illness and avoidance of pregnancy in sexually active women with epilepsy. This study is needed to improve policies and practices and to provide information for women living with this condition. It also contributes to insufficient qualitative data on women's reproductive health and diseases [9].

2. Materials and methods

2.1. Type of study

This study has a descriptive, cross-sectional, and correlational design.

2.2. Population and sample

The population of the study consisted of 110 female patients with epilepsy who applied to the Neurology Clinic and Outpatient Clinic of Firat University Hospital in Elazig, east of Turkey, between June and September 2022. The study was completed with a total of 82 patients between the dates specified because 10 of the female patients with epilepsy did not approve to participate in the study and 18 did not meet the research criteria (being a sexually active woman diagnosed with epilepsy for at least 6 months, being over the age of 18, not having a psychiatric problem, and being able to communicate adequately). In the post hoc power analysis performed using the G-Power 3.1.9.4 program to determine whether the sample size was sufficient, the effect size of the study was 0.3 at 96% power and 0.05 significance level.

2.3. Data collection instrument

Research data were collected within 10–15 min through face-to-face interviews with the patients using the descriptive information form, Brief Illness Perception Questionnaire (IPQ-B), and PAS.

2.3.1. Descriptive information form

The form prepared by the researchers included 17 questions on age, marital status, family structure, educational status, working status, income status, pregnancy, miscarriage or abortion, giving birth, having sexual intercourse in the last three months, communication with the spouse, using a contraceptive method (condom, IUD, pill, etc.) in the last sexual intercourse, number of children, seizures, use of drugs for epilepsy, number of drugs for epilepsy, and duration of illness.

2.3.2. IPQ-B

The questionnaire developed by Broadbent et al. [12] contains questions on the components related to illness perception. The questionnaire has eight sub-dimensions, with each item scored between zero and ten. An increase in scores in sub-dimensions 3, 4, and 7 (personal control, treatment control, and compliance, respectively) indicates a positive response, while an increase in sub-dimensions 1, 2, 5, 6, and 8 (results, duration, illness intelligibility, anxiety, and emotional representation, respectively) indicates a negative reaction. Sub-dimensions 1, 2, 5, 6, and 8 are reversely scored. The minimum possible score from the questionnaire was 8, while the maximum possible score was 80. As the illness perception score increases, the level of being affected by the illness according to different parameters and the level of perceiving the illness as worrisome increases [13].

2.3.3. PAS

This scale was developed by Rocca et al. in 2019 [14]. The Turkish validity and reliability study of the scale was conducted by Okyay et al. [15]. The scale was created to prospectively measure the range of women's preferences for a possible future pregnancy and to determine women's desire to avoid pregnancy. The scale has 14 items rated on a five-item Likert-type scale. Each item was scored as 0 ("strongly agree"), 1 ("agree"), 2 ("undecided"), 3 ("disagree"), and 4 ("strongly disagree"). The minimum possible score on the scale was 0, while the maximum possible score was 4. A high item-total score indicates a high desire to avoid pregnancy [14]. The reversely scored items of the scale are items 3, 7, 9, 11, 12, 13, and 14. The Cronbach's alpha value of the Turkish validity and reliability study was 0.94 [15]. The Cronbach's alpha value of the present study was 0.95.

2.4. Data assessment

The statistical program SPSS version 22.00 was used in the data assessment. The percentage, mean, and standard deviation were used as descriptive statistics. The kurtosis and skewness coefficients were used to analyze the normality distribution of the data. Simple and multiple linear regression analyses were used in the data analysis. The t-test was used to compare paired independent variable groups, and the ANOVA test was used to compare three or more independent variables. In the ANOVA Test, Benjamini-Hochberg correction was used to determine the differences. The level of significance was set to $p < 0.05$.

2.5. Ethical considerations

Prior to the study, approval from the Firat University Non-interventional Research Ethics Committee (dated May 26, 2022, no. 2022/07-10) and permission from the institution in which the study would be conducted were obtained. The patients included in the study were informed about the aim and application method of the study, and their verbal consent was obtained. The study was conducted after the ethical standards of the Helsinki Declaration. Volunteering participants were included in the study, and their personal identity information was kept confidential.

3. Results

The mean age of the participants was 32.96 ± 5.92 years and the mean disease duration was 11.19 ± 7.46 years. All of the patients were married, 86.6% had a nuclear family, 52.4% had an educational status of high school and above, 70.7% had an income equal to expenses, 74.4% were not working, 75.6% had previous pregnancies, 70.7% did not have miscarriage or abortion, 69.5% gave birth

previously, 79.3% had sexual intercourse in the last three months, 61% used a contraceptive method (condom, IUD, pill, etc.) in their last sexual intercourse, 52.4% had good communication with their spouses, 20% had two children, 51.2% had three or more seizures, 86.6% used ASMs, and 47.6% of those who used ASM used more than two drugs (Table 1).

The mean PAS score (minimum: 00.00 and maximum: 4.00) of the patients was 2.31 ± 1.14 , and the mean IPQ-B score (minimum: 10.00 and maximum: 66.00) was 35.10 ± 13.16 .

Nuclear family group, pregnancy status, communication status with spouse, and number of seizures in the last one year find statistically significant differences in PAS value ($p < 0.05$) (Table 2).

Table 1
Descriptive characteristics of the patients.

Characteristics	Number (n = 82)	%
Marital status		
Married	82	100
Family structure		
Nuclear	71	86.6
Extended	11	13.4
Educational status		
Literate	21	25.6
Primary education	18	22
High school and over	43	52.4
Income status		
Income < expense	22	26.8
Income = expense	58	70.7
Income > expense	2	2.4
Working status		
Working	21	25.6
Not working	61	74.4
Previous pregnancy		
Yes	62	75.6
No	20	24.4
Miscarriage and/or abortion		
Yes	24	29.3
No	58	70.7
The state of having given birth		
Yes	62	69.5
No	20	30.5
Having sexual intercourse in the last 3 months		
Yes	65	79.3
No	17	20.7
Using a contraceptive method (condom, IUD, pill, etc.) in the last sexual intercourse		
Yes	32	39
No	50	61
Communication with the spouse		
Good	43	52.4
Moderate	30	36.6
Poor	9	11
Number of children		
1	25	30.5
2	28	34.1
3	7	8.5
≥4	2	2.4
None	20	24.4
Seizures (in the past year)		
1	13	15.9
2	3	3.7
≥3	42	51.2
None	24	29.3
Using drugs for epilepsy		
Yes	71	86.6
No	11	13.4
Number of drugs for epilepsy		
Single drug	32	39
More than one drug	39	47.6
None	11	13.4
	Mean ± SD	
Age	32.96 ± 5.92	
Disease duration	11.19 ± 7.46	

Table 2
Comparison of PAS scale averages by descriptive characteristics.

Characteristics		X ± SD	p
Family structure	Nuclear	2.42 ± 1.12	0.034
	Extended	1.63 ± 1.06	
Previous pregnancy	Yes	2.47 ± 1.13	0.020
	No	1.82 ± 1.06	
Communication with the spouse	Good	1.94 ± 1.09	0.001
	Moderate	2.58 ± 1.16	
	Poor	3.2 ± 0.42	
Seizures (in the past year)	1	1.74 ± 1.06	0.010
	2	2.1 ± 1.04	
	≥ 3	2.62 ± 1.21	
	None	2.68 ± 1.1	

$p < 0.05$; PAS: Pregnancy Avoidance Scale.

Multiple regression analysis was conducted to estimate the total mean scores of PAS and IPQ-B with the following variables: age, marital status, family structure, educational status, working status, income status, pregnancy, miscarriage or abortion, giving birth, having sexual intercourse in the last three months, communication with the spouse, using a contraceptive method (condom, IUD, pill, etc.) in the last sexual intercourse, number of children, seizures, use of drugs for epilepsy, number of drugs for epilepsy, and duration of illness. In the analysis of the results, the model created was statistically significant in terms of the PAS mean score (F (25,56): 2.187, $p = 0.008$). The variables of previous pregnancy (yes), communication with the spouse (moderate), and number of seizures in the last year (three or more) were positive significant predictors of pregnancy avoidance, whereas family-type (nuclear) was a negative significant predictor of pregnancy avoidance. In the analysis of the results, the model created was statistically significant in terms of the IPQ-B total mean score (F(25,56): 1.652, $p = 0.036$). The variable of disease duration was a statistically significant and positive predictor of illness perception (Table 3).

The model created as a result of the regression analysis was statistically significant (F(1.80) = 16.626, $p < 0.001$). The independent variable IPQ-B total score was a positive significant predictor of the dependent variable PAS score ($\beta = 0.415$, $p = 0.000$), explaining 17% of it (Table 4).

4. Discussion

In this study, that examined the effect of illness perception on pregnancy avoidance in sexually active women with epilepsy, women were found to have high rates of pregnancy avoidance and high levels of being affected by the disease or perceiving their illness as worrisome. Although no studies were found on pregnancy avoidance in sexually active women with epilepsy, a descriptive study identifying the pregnancy concerns of patients with epilepsy and a qualitative study investigating the perceptions of women with epilepsy about pregnancy concerns were found [16,17]. Mann et al. [16] reported that women younger than 45 years were highly undecided (61.7%) about the decision to have children due to their epilepsy. In this study, 477 men and women who had different sociodemographic characteristics and who were sexually active or inactive were included, and a different measurement instrument was used [16]. In their qualitative study, Atarodi-Kashani et al. [17] found that nulliparous women were concerned that epilepsy could prevent a safe pregnancy. Addressing the effects of healthy women or different factors on pregnancy avoidance may be useful to evaluate the results of this study. In a study evaluating pregnancy avoidance in healthy married women with PAS, the level of pregnancy avoidance was found to be low (2.133 ± 1.100) in women who had 1–5 years of marriage (2.095 ± 1.103) and those who had between 18–29 years of mar-

Table 3
Regression analysis results of the patients in terms of their descriptive characteristics.

Dependent variables	Model	Independent variables	B	S.E	Standard (Beta)	t	p	95% Confidence interval	
								Lower	Upper
PAS	1	Constant	0.873	2.545		0.343	0.733	-4.254	6.000
		Family type (nuclear)	-0.991	0.462	-0.295	-2.144	0.038	-1.923	-0.060
		Previous pregnancy (Yes)	1.715	0.647	0.374	2.652	0.011	0.413	3.018
		Communication with the spouse (Moderate)	0.617	0.217	0.391	2.843	0.007	0.180	1.054
		Number of seizures in the last year (3 and more)	0.264	0.115	0.314	2.292	0.027	0.032	0.496
		R = 0.730, F _(25,56) = 2.187 p = 0.008							
IPQ-B	2	Constant	68.671	34.048		2.017	0.049	0.052	137.290
		Disease duration	0.580	0.230	0.335	2.518	0.016	0.116	1.044
		R = 0.675, F _(25,56) = 1.652 p = 0.036							

p < 0.05; PAS: Pregnancy Avoidance Scale; IPQ-B: Brief Illness Perception Questionnaire.

Table 4
Regression analysis results.

Dependent variables	Model	Variables	B	S. Error	β	t	p	95% Confidence interval	
								Lower	Upper
PAS	1	Constant	23.659	1.774		13.338	0.000*	20.129	27.189
		IPQ-B	0.172	0.042	0.415	4.078	0.000*	0.088	0.255
		R = 0.415, F _(1,80) = 16.626 p = 0.000*							

*p < 0.001, PAS: Pregnancy Avoidance Scale; IPQ-B: Brief Illness Perception Questionnaire; DurbinWatson: 1.800.

riage [18]. When the study results were examined, women with epilepsy tended to avoid pregnancy in general. This result finds that risk factors affecting health may affect pregnancy avoidance.

Studies have compared different parameters of illness perception in different groups using different scales [5,19]. Ji et al. [5] and Whitehead et al. [19] reported that patients thought their illness would last long and that the consequences of epilepsy would be great. Moreover, the patients had a weak belief about disease control and believed that epilepsy caused great emotional effects. Although these studies were conducted with different scales and groups, our study results are similar, and female patients with epilepsy consider their disease to be a serious condition.

Various factors increase the primiparous rate and the number of self-abortions in women with epilepsy. Nulliparous women with epilepsy are known to have a high fear of becoming pregnant. Having a high number of epileptic seizures, having a previous pregnancy, and fears such as not complying with drug therapy during pregnancy may cause women to avoid pregnancy [16,17,20,21]. The number of drugs used for epilepsy, seizure frequency, and education level have been associated with childbearing concerns [16]. One study reported uncertainty about the potential adverse effects of epilepsy and ASMs on fertility, teratogenicity risks, and epilepsy heritability [22]. The regression analysis results of the present study found a significant positive correlation between pregnancy avoidance scores and having previous pregnancies, moderate communication with the spouse, and three or more seizures in the last year, whereas a significant negative correlation was found between pregnancy avoidance scores and having a nuclear family. According to Turkey Demographic and Health Survey 2018 data, the total fertility rate is 2.3. In rural areas, this rate increased to 2.8. In the study, when we look at the number of children of women with epilepsy, we see that the number of women with epilepsy who gave birth more than two times is quite low and remains below the fertility rate. This situation supports our study results [23]. Although studies have found that women with epilepsy have similar thoughts about pregnancy, the relationship between parameters

such as “communication with the spouse”, and pregnancy avoidance was evaluated for the first time in the present study. The significance of these parameters may be because happy families with epilepsy have a positive view of getting pregnant, or that, on the contrary, unhappy families may want to become pregnant to save their marriage. In addition, the thought that problems in the family environment may affect the child may have created anxiety in this group.

In studies evaluating the perception of illness in different diseases, the perception of illness has been reported to be associated with the duration of the illness [24,25]. In the present study, the regression results found a significant and positive relationship between disease duration and illness perception scores. Normally, as the duration of the disease increases in long-term diseases, adaptation to the disease also increases [26]. However, a lack of information about the current disease and the symptoms experienced by the individual may have caused this result.

In the present study, a positive correlation was found between the levels of being affected by the disease or the increased anxiety levels of women with epilepsy and their pregnancy avoidance. No studies have been found in the literature examining the relationship between the perception of illness and pregnancy avoidance. In a study examining illness perception in patients with cancer, patients who received recent treatment had a negative perception of their illness and saw their illness as long-term, and patients who had a negative illness perception did not use effective ways of coping with their disease [25]. In case of an illness, an individual attributes cognitive or emotional meaning to this illness, and this creates the individual's illness perception. Individuals' illness perceptions affect their ways of coping with situations [27,28]. In terms of epilepsy and pregnancy, women with epilepsy try to manage their disease well in addition to being a good mother [29,30]. However, normally seen pregnancy and motherhood conditions may disrupt the disease and cause new concerns in women with epilepsy, as they are afraid that epilepsy will be transmitted to their babies. Although it is possible that pregnant women with

epilepsy will encounter more maternal and fetal risks than normal pregnant women, these risks are much more exaggerated [31]. Due to this reason and similar reasons, they can use coping mechanisms that are not problem-oriented, such as giving up on managing the disease [25]. In our study, the positive relationship between the perception of illness and the avoidance of pregnancy can be interpreted in two ways. Firstly, it may be considered due to women's concerns about pregnancy, motherhood, or the baby due to their epilepsy. Secondly, it can be said that most of the pregnant women with epilepsy got pregnant once, but they may have avoided having more children because of their illness or the difficulties experienced by women with postpartum epilepsy.

5. Limitations of the study

This study has some limitations. First, 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 women with epilepsy due to the limited sample size and the unique cultural, educational, and social characteristics of each participant. However, working in a group with heterogeneous characteristics provided the opportunity to evaluate the effect of disease characteristics on illness perceptions and pregnancy avoidance. Future researchers who will work on a similar subject should conduct different studies with larger samples, including the spouse or other family members, and evaluate other epilepsy-related features (epilepsy-related stigma, stress, marital problems, and low self-esteem). Second, due to the cross-sectional design of the study, a temporal relationship and, accordingly, a potential cause-effect relationship could not be established between the variables. Third, a questionnaire with closed-ended questions was used to collect the study data. Although this enabled us to reach more women with epilepsy, the participants could not express their opinions other than through the questionnaire. For this reason, we suggest conducting different types of studies on illness perception and pregnancy avoidance in women with epilepsy. In addition, the fact that the coronavirus disease 2019 (COVID-19) outbreak was ongoing at the time of the study could have caused increased anxiety in women with epilepsy, as illness perception and approach to pregnancy also changed during this period. Therefore, we recommend repeating the study at a later time.

6. Conclusion and recommendations

The results found that women with epilepsy avoided pregnancy and had negative illness perceptions. It was found that having a previous pregnancy, having a moderate level of communication with the spouse, and having three or more seizures a year were positive predictors of pregnancy avoidance, while having a nuclear-type family was a negative predictor of pregnancy avoidance. It was found that illness perception was a positive predictor of pregnancy avoidance. In addition, it was concluded that negative illness perception increased pregnancy avoidance in women with epilepsy.

According to the results of the study, perceptions about epilepsy affect views on pregnancy. For this reason, the awareness about getting pregnant of women with epilepsy who are of reproductive age can be increased by evaluating their illness perceptions, as raising awareness contributes to changing the perception of illness. Women with epilepsy who have a negative perception of the disease cannot cope with the disease and tend to give up on everything. For this reason, health personnel should improve their understanding of care for women with epilepsy. A clear explanation should be given about the risks related to pregnancy and

fetuses and the precautions to be taken, and negative illness perceptions should be changed using different intervention methods. A negative illness perception not only affects thoughts about pregnancy but also negatively affects the quality of life. Future studies should focus on how to improve the attitudes of women with epilepsy toward their disease and on interventions to address their pregnancy, delivery, and postpartum concerns.

Declaration of Competing Interest

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

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