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ATTITUDE-TO-ANXIETY CORRELATION OF EPILEPSY PATIENT CAREGIVERS

Hubungan Sikap dengan Kecemasan Pendamping Pasien Epilepsi

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ABSTRAK

Epilepsi adalah gangguan neurologis yang ditandai dengan kejang tak terduga, yang tidak hanya memengaruhi kualitas hidup pasien tetapi juga keluarga atau pendampingnya akibat dampak fisik, kognitif, dan psikososial yang ditimbulkan. Pendamping pasien sering mengalami masalah psikologis yang mungkin berkorelasi dengan sikap mereka terhadap epilepsi. Penelitian terdahulu menunjukkan sikap yang positif terkait epilepsi akan memberikan respon kecemasan yang lebih rendah. Penelitian ini bertujuan untuk menganalisis hubungan antara sikap dan kecemasan pada pendamping pasien epilepsi di Poliklinik Saraf RSUD Dr. Zainoel Abidin Banda Aceh selama periode Juni hingga Juli 2024. Merupakan studi analitik observasional dengan desain cross-sectional. Subjek penelitian adalah pendamping pasien epilepsi di RSUD Dr. Zainoel Abidin Banda Aceh yang dipilih dengan pendekatan probability sampling menggunakan metode simple random sampling. Sebanyak 43 subjek memenuhi kriteria penelitian. Sikap pendamping dinilai menggunakan Public Attitude Toward Epilepsy (PATE), sementara tingkat kecemasan dinilai menggunakan Hamilton Anxiety Rating Scale (HARS). Uji korelasi Spearman digunakan untuk menguji sikap pendamping pasien epilepsi dengan kecemasan pendamping pasien epilepsi (p value >0,05). Hasil penelitian mendapatkan mayoritas sikap pendamping pasien epilepsi adalah positif, sedangkan mayoritas tingkat kecemasan yang dialami adalah kecemasan sedang. Pendamping dengan sikap positif lebih cenderung memiliki kecemasan sedang (42,9%). Namun, hubungan antara sikap dan kecemasan tidak signifikan secara statistik (p=0,87, r=-0,026). Penting halnya untuk setiap pendamping pasien epilepsi mendapatkan edukasi yang komprehensif mengenai penyakit, penanganan, dan prognosis yang dapat membantu sikap yang lebih positif dan mengurangi stigma yang dapat memengaruhi sikap pendamping pasien epilepsi.

***Kata kunci**: epilepsi, kecemasan, pendamping pasien epilepsi, sikap*

ABSTRACT

Epilepsy is a neurological disorder characterized by unexpected seizures, affecting not only the patient's quality of life but also their families or caregivers due to its physical, cognitive, and psychosocial impacts. Caregivers often face psychological issues, which may correlate with their attitudes towards epilepsy. Previous study found that positive attitude regarding epilepsy will result in a lower anxiety response. This study aimed to analyze the relationship between attitudes and anxiety among caregivers of epilepsy patients at the Neurology Polyclinic of Dr. Zainoel Abidin Regional Public Hospital Banda Aceh in September 2024-January 2025. An analytical observational study with a cross-sectional design. 43 epilepsy patients caregivers at Dr. Zainoel Abidin Regional Public Hospital were selected as research subjects, using a probability sampling approach with the simple random sampling method. Caregivers' attitudes were assessed using the

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Public Attitude Toward Epilepsy (PATE), and anxiety levels were measured using the Hamilton Anxiety Rating Scale (HARS). Spearman correlation test was used to assest the attitude of epilepsy patient caregivers (p value >0.05). The majority of epilepsy patient caregivers' attitudes were positive, while the majority of anxiety levels experienced were moderate. Epilepsy caregivers with positive attitudes were more likely to have moderate anxiety (42.9%). However, the correlation between attitudes and anxiety was not statistically significant (p=0.87, r=-0.026). It is important that caregivers of epilepsy patients receive comprehensive education about the disease, treatment, and prognosis, which can help promote more positive attitudes and reduce the stigma that can affect the attitudes of caregivers of the patients.

Keywords: anxiety, attitude, epilepsy, epilepsy caregivers

INTRODUCTION

Epilepsy is a neurological disorder characterized by unpredictable seizures that affect the patient's quality of life due to the psychosocial and medical problems they cause. Epilepsy affects approximately 50 million people worldwide, regardless of socio-demographic boundaries[1].Previous studies have shown a prevalence of epilepsy of 4–10 per 1,000 people, making it one of the most common neurological conditions. The incidence rate of epilepsy is estimated at 50–60 per 100,000 people/year. Approximately 8% of people are estimated to have at least one seizure in their lifetime[2], [3].

Epileptic seizures account for 1% of hospitalizations and 3% of emergency department (ED) visits[3]. The impact of chronic and recurrent seizures on physical, cognitive and psychosocial health is not limited to the patient, but can also affect the lives of families or caregivers[4]. Caregivers of patients with epilepsy can also experience psychological problems such as anxiety, depression, guilt, anger, hopelessness, and shame. They also experience sleep disturbances, high stress levels, and a low quality of life. This can impact their work. Research by Zhang et al showed that anxiety and depression are common in caregivers of patients with epilepsy[5].

Research on the relationship between attitudes and anxiety in caregivers of epilepsy patients is still very limited. Research by Yang et al. (2020) showed that attitudes toward epilepsy correlated with anxiety in caregivers of epilepsy patients. This study showed that negative attitudes were associated with increased anxiety scores, as assessed by the Self-Rating Anxiety Scale (SAS)[6].

Based on this background, this study was conducted to examine the relationship between attitudes and anxiety among caregivers of epilepsy patients at the Neurology Polyclinic of Dr. Zainoel Abidin Regional Hospital, Banda Aceh. This study aims to determine the description of attitudes, anxiety, and the relationship between attitudes and anxiety among caregivers of epilepsy patients at the Neurology Polyclinic of Dr. Zainoel Abidin Regional Hospital, Banda Aceh. The results of this study are expected to be useful and provide supporting information for related topics for readers. Comprehensive education about the disease, treatment, and prognosis can help foster more positive attitudes and reduce stigma that can influence the attitudes of caregivers of epilepsy patients. Further research exploring these factors is needed to provide deeper insight into how caregiver attitudes can be influenced by a combination of these factors. In addition, a multidisciplinary approach that considers aspects of knowledge, social support, and emotional well-being is important to dig deeper information so that caregivers can optimally provide care for epilepsy patients. This study was conducted at a referral hospital in Aceh Province, which is a neurology referral center, so it has patients who are predominantly of Acehnese culture. Similar research has never been conducted in this setting.

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METHODS

An observational analytical study using a cross-sectional research design. This design was chosen to capture the relationship between attitudes and anxiety of epilepsy patient companions at a specific point in time, thus minimizing the risk of losing research subjects, and also tending to be efficient and time-saving. It was conducted at the Neurology Polyclinic of Dr. Zainoel Abidin Regional Hospital, Banda Aceh, from September 2024 to January 2025. The subjects in this study were some of the companions of epilepsy patients at Dr. Zainoel Abidin Regional Hospital, Banda Aceh, with a probability sampling approach using the simple random sampling method. The sample size calculation in this study was determined using the Slovin formula. The population of the study subjects was 73 people. The sample size calculation used an error tolerance of 10%, resulting in a total of 43 research subjects. The inclusion criteria included: (1) companions of patients diagnosed with epilepsy in the form of guardians and caregivers of patients for ≥ 6 months; (2) adults ≥ 18 years old; and (3) cooperative and able to communicate well. Exclusion criteria were applied after respondents were known to meet the inclusion criteria but refused to be research respondents and did not complete the research questionnaire. The dependent variable is anxiety, with attitude as the independent variable. Efforts were made to control for external variables in this study by applying inclusion and exclusion criteria.

The research instrument used is an instrument that has undergone validity testing, such as the Public Attitude Toward Epilepsy (PATE) questionnaire to assess the Plan Behavior Theory of companions of epilepsy patients.[7], with PATE scores categorized as positive (measurement value: 55–70), neutral (45–54), and negative (<44)[8]; and the Hamilton Anxiety Rating Scale (HARS) questionnaire to assess the anxiety of companions of epilepsy patients[9], with HARS scores categorized as not experiencing anxiety (measurement value: <14), mild anxiety (14–20), moderate anxiety (21–27), severe anxiety (28–41), and very severe anxiety (42–56)[10], [11]. The internal consistency test of these two instruments used the Cronbach's Alpha coefficient value, with test results of 0.836 for PATE and 0.756 for HARS. Univariate analysis was used to explain the frequency distribution and proportion of the variables studied, such as age, gender, education, and occupation. Bivariate analysis was conducted to see the relationship between the theory of planned behavior and the anxiety of epilepsy patient companions. The Spearman correlation test was used to examine the attitudes of epilepsy patient companions and the anxiety of epilepsy patient companions. The Spearman correlation test was used because the data were ordinal. Ethical approval was obtained from the results of the ethics hearing with letter number: 309 / ETIK-RSUDZA / 2024 which was approved by the health research ethics committee of RSUD Dr. Zainoel Abidin.

RESULTS

The characteristics of the research subjects are shown in Table 1 as follows:

Table 1. Characteristics of Research Subjects

Characteristics		n	%
Age	Adults (25–45 years)	23	53.5
	Middle-aged adults (46–54 years)	12	27.9
	Elderly (55–65 years)	8	18.6
	Total	43	100.0
Gender	Female	24	55.8
	Male	19	44.2
	Total	43	100.0
Education	Senior High School	24	55.8
	D1/D2/D3	7	16.3
	Bachelor’s Degree	12	27.9

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Characteristics		n	%
	Total	43	100.0
Region of origin	Banda Aceh	22	51.2
	Aceh Besar	10	23.3
	Pidie	3	7.0
	Bireuen	2	4.7
	North Aceh	2	4.7
	East Aceh	2	4.7
	Other	2	4.7
	Total	43	100.0
Occupation	civil servant	15	34.9
	Housewife	14	32.6
	Entrepreneur	7	16.3
	Honorary	3	7.0
	Farmer	3	7.0
	Military (TNI)	1	2.3
	Total	43	100.0
Marital status	Married	42	97.7
	Unmarried	1	2.3
	Total	43	100.0
Duration of Assisting Epileptic Patients	6 months-1 year	8	18.6
	1-2 years	31	72.1
	> 2 years	4	9.3
	Total	43	100.0
Relationship with Patients	Mother	19	44.2
	Father	17	39.5
	Sibling	7	16.3
	Total	43	100.0

Table 1 shows that most respondents were adults aged 25–45 years (53.5%), followed by middle-aged adults (27.9%) and the elderly (18.6%). More than half were female (55.8%). In terms of education, the majority had completed senior high school (55.8%), while 27.9% had a bachelor’s degree. Most respondents came from Banda Aceh (51.2%), with smaller proportions from Aceh Besar (23.3%) and other districts. Regarding occupation, 34.9% were civil servants and 32.6% were housewives. Almost all respondents were married (97.7%). Most had accompanied epilepsy patients for 1–2 years (72.1%). In terms of relationship with the patient, mothers (44.2%) and fathers (39.5%) dominated, with the rest being siblings (16.3%).

Table 2. Description of the Attitudes of Epilepsy Patient Companions

Characteristics		Frequency (n)	Percentage (%)
Attitude	Negative	5	11.6
	Neutral	10	23.3
	Positive	28	65.1
	Total	43	100.0

Table 2 illustrates the attitudes of caregivers of epilepsy patients. Most caregivers expressed a positive attitude (65.1%), while 23.3% were neutral, and only 11.6% expressed a negative attitude.

Table 3 shows the distribution of patient companion attitudes based on the characteristics of the study subjects. The results indicate that the majority of each characteristic exhibited positive attitudes. Only one subject, with regard to the TNI occupational factor, had a negative attitude.

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Table 3. Description of Attitudes Based on Characteristics of Epilepsy Patient Companions

Characteristics		Attitude							
		Negative		Neutral		Positive		Total	
		n	%	n	%	n	%	n	%
Age	Adults (25–45 years)	1	4.30	6	26.10	16	69.60	23	100.00
	Middle-aged adults (46–54 years)	1	8.30	3	25.00	8	66.70	12	100.00
	Elderly (55–65 years)	3	37.50	1	12.50	4	50.00	8	100.00
	Total	5	11.60	10	23.30	28	65.10	43	100.00
Gender	Female	2	8.30	9	37.50	13	54.20	24	100.00
	Male	3	15.80	1	5.30	15	78.90	19	100.00
	Total	5	11.60	10	23.30	28	65.10	43	100.00
Education	Senior High School	3	12.50	5	20.80	16	66.70	24	100.00
	D1/D2/D3	1	14.30	0	0.00	6	85.70	7	100.00
	Bachelor’s Degree	1	8.30	5	41.70	6	50.00	12	100.00
	Total	5	11.60	10	23.30	28	65.10	43	100.00
Occupation	civil servant	0	0.00	5	33.30	10	66.70	15	100.00
	Housewife	2	14.30	4	28.60	8	57.10	14	100.00
	Entrepreneur	1	14.30	1	14.30	5	71.40	7	100.00
	Honorary	1	33.30	0	0.00	2	66.70	3	100.00
	Farmer	0	0.00	0	0.00	3	100.00	3	100.00
	Military (TNI)	1	100.00	0	0.00	0	0.00	1	100.00
	Total	5	11.60	10	23.30	28	65.10	43	100.00
Duration of Assisting Epileptic Patients	6 months-1 year	1	12.50	1	12.50	6	75.00	8	100.00
	1-2 years	4	12.90	8	25.80	19	61.30	31	100.00
	> 2 years	0	0.00	1	25.00	3	75.00	4	100.00
	Total	5	11.60	10	23.30	28	65.10	43	100.00
Relationship with Patients	Mother	2	10.50	6	31.60	11	57.90	19	100.00
	Father	3	17.60	2	11.80	12	70.60	17	100.00
	Sibling	0	0.00	2	28.60	5	71.40	7	100.00
	Total	5	11.60	10	23.30	28	65.10	43	100.00

Table 4. Description of Anxiety in Companions of Epilepsy Patients

Characteristics		Frequency (n)	Percentage (%)
Anxiety	Mild	8	18.6
	Moderate	20	46.5
	Severe	15	34.9
	Total	43	100.0

Table 4 shows the anxiety levels of caregivers of epilepsy patients. Most caregivers experienced moderate anxiety (46.5%), followed by severe anxiety (34.9%), and mild anxiety (18.6%).

Table 5 shows the distribution of anxiety levels based on subject characteristics. The majority of age groups experienced moderate anxiety, except for middle-aged adults, who experienced more severe anxiety. Both women and men generally exhibited moderate anxiety. Subjects with high school and D1/D2/D3 education mostly experienced moderate anxiety, while subjects with S1 education experienced more severe anxiety. Patient companions with varying durations of epilepsy support also mostly experienced moderate anxiety. Similarly, the majority of companions, including mothers, fathers, and siblings, tended to experience moderate anxiety.

Table 5. Description of Anxiety Based on Characteristics of Epilepsy Patient Companions

Characteristics		Anxiety							
		Light		Currently		Heavy		Total	
		n	%	n	%	n	%	n	%
Age	Adults (25–45 years)	5	21.70	11	47.80	7	30.40	23	100.00
	Middle-aged adults (46–54 years)	1	8.30	5	41.70	6	50.00	12	100.00
	Elderly (55–65 years)	2	25.00	4	50.00	2	25.00	8	100.00
	Total	8	18.60	20	46.50	15	34.90	43	100.00
Gender	Female	5	20.80	11	45.80	8	33.30	24	100.00
	Male	3	15.80	9	47.40	7	36.80	19	100.00
	Total	8	18.60	20	46.50	15	34.90	43	100.00
Education	Senior High School	3	12.50	12	50.00	9	37.50	24	100.00
	D1/D2/D3	2	28.60	4	57.10	1	14.30	7	100.00
	Bachelor's Degree	3	25.00	4	33.30	5	41.70	12	100.00
	Total	8	18.60	20	46.50	15	34.90	43	100.00
Occupation	CIVIL SERVANT	5	33.30	7	46.70	3	20.00	15	100.00
	Housewife	3	21.40	7	50.00	4	28.60	14	100.00
	Entrepreneur	0	0.00	2	28.60	5	71.40	7	100.00
	Honorary	0	0.00	2	66.70	1	33.30	3	100.00
	Farmer	0	0.00	1	33.30	2	66.70	3	100.00
	Military (TNI)	0	0.00	1	100.00	0	0.00	1	100.00
	Total	8	18.60	20	46.50	15	34.90	43	100.00
Duration of Assisting Epileptic Patients	6 months-1 year	3	37.50	3	37.50	2	25.00	8	100.00
	1-2 years	5	16.10	15	48.40	11	35.50	31	100.00
	> 2 years	0	0.00	2	50.00	2	50.00	4	100.00
	Total	8	18.60	20	46.50	15	34.90	43	100.00
Relationship with Patients	Mother	5	26.30	8	42.10	6	31.60	19	100.00
	Father	2	11.80	8	47.10	7	41.20	17	100.00
	Sibling	1	14.30	4	57.10	2	28.60	7	100.00
	Total	8	18.60	20	46.50	15	34.90	43	100.00

Table 6. Results of the Correlation Test between the Attitude of the Companion and the Anxiety Level of the Companion of Epilepsy Patients

Attitude	Anxiety								p	r
	Light		Currently		Heavy		Total			
	n	%	n	%	n	%	n	%		
Negative	0	0.00	4	80.00	1	20.00	5	100.00	0.870	-0.026
Neutral	2	20.00	4	40.00	4	40.00	10	100.00		
Positive	6	21.40	12	42.90	10	35.70	28	100.00		
Total	8	18.60	20	46.50	15	34.90	43	100.00		

*Spearman Correlation Test

Table 6 shows the relationship between caregiver attitudes and anxiety levels. Most caregivers with positive attitudes tended to have moderate anxiety (42.9%). However, no significant relationship was found between attitude and anxiety (p=0.870; r=-0.026), indicating that attitude does not play a role in determining caregiver anxiety levels.

DISCUSSION

The results of the study (p=0.870, r=-0.026) indicated that the relationship between attitude and anxiety levels among caregivers of epilepsy patients at the neurology clinic at Dr. Zainoel Abidin Regional Hospital in Banda Aceh was neither statistically nor practically significant (practically irrelevant correlation). However, the trend pattern showed that caregivers with positive attitudes had lower anxiety scores than those with negative attitudes. This can be explained by the relationship between positive attitudes and confidence in facing challenges, which can reduce anxiety. Previous research by

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Satria, Evy, and Dew at Dr. Soebandi Regional Hospital in Jember, effective education can increase knowledge, transform negative attitudes into positive ones, and ultimately significantly reduce anxiety[12]. Caregivers who understand that epilepsy is a medical condition that can be managed with appropriate treatment will be more confident in their roles, thereby reducing anxiety levels[13]. Educational factors can influence caregivers' understanding of epilepsy and how to support patients. Higher education is often associated with more positive attitudes toward epilepsy patients and can improve patients' quality of life due to a better understanding of the condition[12], [14]. However, limited education is not always an obstacle if there is an effective educational program for companions[15]. Social support from family and community also influences caregivers' attitudes and anxiety. Caregivers who receive emotional support from their environment tend to have more positive attitudes and lower levels of anxiety[16]. Conversely, social isolation or stigma against epilepsy can exacerbate negative attitudes and increase anxiety[17].

Based on the distribution of anxiety levels, the majority of caregivers of epilepsy patients (46.5%) experienced moderate anxiety. Moderate and severe anxiety in caregivers can be caused by uncertainty regarding the patient's condition, concerns about sudden seizure episodes, or a lack of knowledge about epilepsy management[18]. High levels of anxiety can also be associated with the psychological and emotional burden experienced by the companion[19]. This suggests that this anxiety can negatively impact the caregiver's relationship with the patient, even the quality of care provided. Emotional support from extended family or the surrounding community can also play a role in reducing caregiver anxiety.

According to Sitorus, anxiety is not only influenced by demographic characteristics, but also by internal factors such as anxiety management, understanding of epilepsy, and the individual's emotional state[20]. Caregivers with a good understanding of the patient's condition tend to be more confident and have lower levels of anxiety[19]. In addition, factors such as previous experience as a caregiver or the presence of social support can also influence anxiety levels[18]. At Sanglah General Hospital in Denpasar, it was found that caregivers with more experience usually had lower levels of anxiety because they were more familiar with the patient's condition.

The above factors also influence the attitudes of epilepsy companions[20]. Research by Sugandi[19]. Research shows that while higher education can help caregivers develop a more positive attitude, factors such as social support and direct experience with patients are more influential. It is understandable that a positive attitude of epilepsy caregivers is crucial because it directly impacts patient adherence to treatment and social acceptance within the family. A strong emotional bond between the patient and caregiver, especially the mother, can be a crucial factor in the success of patient care. Previous research by Satria, Evy, and Dewi at Dr. Soebandi Regional Hospital in Jember, this relationship can help improve patients' quality of life by providing more consistent emotional and physical support[12].

This study found no significant relationship between attitudes and anxiety among caregivers of epilepsy patients. This contradicts previous research, such as that found by Yang et al, who found a link between attitudes and anxiety[6]. The difference between the results of Yang et al.'s study and the results of the study at Dr. Zainoel Abidin Regional Hospital may be caused by several factors, one of which is the suspected presence of certain confounding variables, thus causing bias in the study results. Furthermore, the respondent selection process is suspected to have influenced the validity of the study results. Another possible contributing factor is the less conducive conditions of the research location for interviews, which affected data collection.

Although this study found a statistically insignificant relationship, this does not mean that conceptually there is no relationship between attitudes and anxiety levels. Other,

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more dominant factors may be confounding factors. This study did not examine variables such as cultural characteristics, social support, perceived stigma, and so on. Overall, the relationship between attitudes and anxiety in caregivers of epilepsy patients is complex and influenced by various factors, including knowledge, social support, emotional well-being, and depression. When these factors are present, attitudes or self-efficacy may have a weak or even insignificant independent effect[21]. It is important that patient companions and patients with epilepsy receive attention and evaluation so that the burden on companions of patients with epilepsy can be reduced[4].

The opportunity for the knowledge of companions of epilepsy patients to develop is very high and educational programs related to the psychosocial burden for companions have proven effective[15]. Caregivers carry a significant burden. Despite adapting various methods to address this issue, the emotional burden remains serious. Therefore, to improve the comfort and ability of caregivers of epilepsy patients to manage this issue, the community and healthcare professionals need to provide them with informational support, psychological support, and a supportive environment. Healthcare professionals can take roles and actions that can reduce the burden on caregivers and improve their mental health. Furthermore, effective programs need to be created to increase knowledge and develop the skills and awareness of caregivers in caring for patients. The community must also take a stance to improve the stigma-free environment for epilepsy[22].

In Aceh, this study is the first to examine the relationship between attitudes and anxiety levels of caregivers of epilepsy patients. A limitation of this study at Dr. Zainoel Abidin Regional Hospital is that it only examined one independent variable, namely attitude, which does not represent other factors influencing the anxiety levels of caregivers of epilepsy patients. Further research examining other factors is needed to broaden and deepen knowledge about how caregiver attitudes can be influenced by a combination of these factors. The relatively small sample size (n=43), especially in some subcategories, may limit the power of statistical analysis and the generalizability of the findings, potentially affecting the validity of the generalizability of the results. The cross-sectional approach in this study also cannot explain causal relationships. Furthermore, during the data collection process for this study, the polyclinic conditions were crowded and less conducive at times, potentially reducing the subjects' concentration when completing the questionnaires. This could affect the comfort of caregivers completing the questionnaires. Optimizing the comfort of research subjects is important to ensure a more conducive data collection process. Therefore, further research can be conducted by considering the limitations of this study and using them as a reference. In this way, new research can explore more complex and comprehensive scientific spaces.

CONCLUSION

The results of statistical tests showed no significant relationship between the attitude of the companion and the anxiety level of the companion of epilepsy patients, however, in percentage terms, the majority of the attitudes of the companions of epilepsy patients at the Neurology Polyclinic of Dr. Zainoel Abidin Banda Aceh Hospital showed a positive attitude, while the majority of the anxiety levels experienced by the companions of epilepsy patients were moderate. It is important for every companion of epilepsy patients to receive comprehensive education about the disease, treatment, and prognosis that can help a more positive attitude and reduce stigma that can affect the attitudes of companions of epilepsy patients.

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