

Research Article

Factors Affecting the Quality of Life of Epilepsy Patients

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Abstract. People with epilepsy can lead a normal life, but there are many factors that can affect their quality of life. People with epilepsy may feel anxiety and even depression about their life, which can have an impact on productivity. This study aimed to identify factors affecting the quality of life of epilepsy patients. This study used a cross-sectional design with consecutive sampling and 100 respondents. The analysis used the Chi-square test and logistic regression. The results indicated that the majority of people with epilepsy in the study had a low quality of life (62 people, 62%) and the most influential factor affecting the quality of life was seizure type (odds ratio = 9.716, $p = 0.001$). Based on the findings, it can be concluded that education level, seizure frequency, type of seizure, stigma and medication adherence are factors that can affect the quality of life in epilepsy patients. Nurses can provide education on the management of seizures to epilepsy patients and their families, to improve the quality of life of people with epilepsy.

Keywords: determinant factors, quality of life, epilepsy

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1. Introduction

According to the World Health Organization (2018), there are around 50 million people in the world living with epilepsy. It is estimated that between 4 to 10 people out of 1000 people, have epilepsy accompanied by continuous seizures. The prevalence of epilepsy in America is 6 to 7 in 1000 people and it is estimated that about 2.5 million people in America live with epilepsy [1]. The prevalence of people with epilepsy in developed countries is lower than in developing countries, namely, around 4.9 people out of 1000 people, and 12.7 people out of 1000 people in developing countries [2]. Indonesia is one of the developing countries which is estimated to have an incidence of epilepsy around 1.1-1.8 million people out of 237.6 million people in Indonesia [3].

The high prevalence of epilepsy in developing countries will affect the productivity of the population, because patients with epilepsy have an unfavorable impact on their

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lives, namely in the form of psychological, physical and social impacts. [4] [5]. Seizure attacks in patients with epilepsy have an impact on the disruption of social functions, both limitations in activities, work, and social activities. Misconceptions in society can also lead to stigma in patients with epilepsy. This can make the patient's quality of life worse [6] [7].

Several studies have found that gender, education level, and stigma have a significant relationship with the quality of life of patients with epilepsy. However, the type of seizure did not have a significant effect [8]. Gender and age also have a significant influence on the quality of life of patients with epilepsy [9]. The results of a study conducted in the United Arab Emirates [10] found that the frequency of seizures, and adherence to medication can significantly affect the quality of life of epilepsy patients. Meanwhile, age, gender, marital status and education level were not significant.

A research conducted by Hawari [3] revealed that as many as 66 people (45.5%) in patients with epilepsy in Jakarta had a poor quality of life which resulted in a decrease in productivity and community welfare. Therefore, it is necessary to conduct further research on what factors can affect the quality of life of patients with epilepsy.

2. Methods and Equipment

2.1. Methods

The study was cross-sectional study design with bivariate analysis using Chi-square and logistic regression for multivariate analysis. The study was conducted from October 8 to November 16, 2018. The study was conducted on two hospital in Jakarta (Pasar Minggu Regional Public Hospital and Pasar Rebo Regional Public Hospital). The total sample for the study was 100, proportionally allocated for both hospitals and selected by a consecutive sampling technique with inclusion criteria; respondents had been diagnosed with epilepsy, could communicate well, aged 18-60 years and were willing to be involved in the study. The study excluded respondents with respondents who could not read, had a history of stroke, and had a history of psychiatric disorders. Then respondents who have met the criteria fill out the questionnaire that has been provided by filling out the consent form first. When filling out the questionnaire, the researcher accompanied the respondent until the patient finished filling it out. This study has ethical clearance (256/UN2.F12.D/HKP.02.04/2018) by research ethics committee Universitas Indonesia.

2.2. Equipment

The research instrument used in this study were demographic data questionnaire, quality of life questionnaire in patients with epilepsy QOLIE-31[8] [11] [12]. This questionnaire consists of 31 questions, the total score will be categorized into high and low with a scale of 0-100, if the score is high (>67.62) then the quality of life of patients with epilepsy is good and if the result is low (≤ 67.62) it can be This means that the quality of life of patients with epilepsy is poor. This questionnaire has been tested for validity and reliability with a Cronbach alpha value of 0.93 [3].

Social support variable was assessed using *Multidimensional Scale of Perceived Social Support* (MSPSS) [13]. The instrument has been translated into Indonesian version and has been tested for validity and reliability with a cronbach alpha of 0,847. The MSPSS instrument consists of 12 questions consisting of 3 subscales, namely support from special people as stated in questions number (1, 2, 5, and 10), support from family in questions number (3, 4, 8, and 11) and social support from friends in questions number (6, 7, 9 and 12). All questions are favorable with assessment using a Likert scale 1 = strongly disagree, 2 = disagree, 3 = moderately disagree, 4 = moderately agree, 5 = agree, and 6 = strongly agree. The final score is categorized into two using the median cut off point (4.8), namely low social support if the answer score is <4.8 and moderate to high social support if the answer score is ≥ 4.8 .

Stigma variable was assessed using *Scale of Epilepsy* (SSE) [14] [15]. The SSE has been translated into Indonesian version and has been tested for validity and reliability with a cronbach alpha of 0,911 and modified stigma instrument consists of 36 questions consisting of 5 subscales, namely social isolation, discrimination, inadequacy, incorrect opinions, and fighting stigma. For each question item, the answer choices use a Likert scale. Then the value for each answer is 1 given a value of 25, 2 being given a value of 50, 3 being given a value of 75, and 4 being given a value of 100. The total score is in the range of 25-100, if the total score is <50 = low and ≥ 50 = high.

Medication adherence variable was measured using the Morisky Green Levine Medication Adherence Questioner (MAQ) [16]. This questionnaire has been widely used with a cronbach alpha of 0,704. There are 4 question items using the Guttman scale with the type of answer yes - no. If the answer 'yes' has a score = 1, and if the answer 'no' has a score = 0. The minimum value of the results of this questionnaire is 0 and the maximum value is 4. The measurement results of this questionnaire are said to be high compliance if the total score = 0, and adherence is low if the total score = 1-4.

TABLE 1: The distribution of quality of life of patients with epilepsy by age, sex, marital status, education level, income, seizure frequency, type of seizure, social support, and medication adherence.

Variable	OR (95% CI)	P value
Age 18-40 years 40-60 years	1,171 (0,475-2,889)	0,911
Gender Male Female	0,892 (0,395-2,014)	0,947
Marital Status Single/Unmarried Married	1,033 (0,452-2,361)	1,000
Education level Low High	5,192 (2,051-13,144)	0,001*
Level of income High Low	1,582 (0,639-3,919)	0,447
Seizure frequency ≥12 times in two years <12 times in two years ≥2 years no seizure	Comparison 10,286 (2,244-47,155) 24,000 (3,247-177,405)	0,001**
Type of seizure Focal/partial General	18,951 (2,42-147,91)	0,001*
Social Support Low Moderate – High	1,138 (0,507-2,553)	0,915
Stigma Low High	10,350 (3,857-27,775)	0,001*
Medication Adherence High Low	3,429 (1,435-8,193)	0,009*

** Significant at $\alpha < 0,05$ with Fisher's exact test

3. Results

The Characteristics of respondents in this study were mostly young adults 73 respondents (73%), with the most gender being male 57 respondents (57%). While the most marital status was single or unmarried 61 respondents (61%) with the majority of the respondents' education level being high 56 respondents (56%). Regarding family income, the majority of respondents with low family income were 74 (74%).

The clinical characteristics majority of respondents experienced seizures <12 seizures within two years 65 respondents (65%) with the majority of respondents having focal/partial seizure types 78 respondents (78%). For the social support variable, it was found that more respondents received low social support 52 respondents (52%), for stigma, the majority of respondents received high stigma with 69 respondents (69%). Meanwhile, for medication adherence, it was found that more respondents had low adherence 67 respondents (67%), and most respondents had poor quality of life with a total of 62 respondents (62%).

The results of the analysis in table 1 show that there is a significant effect between the quality of life of patients with epilepsy on the level of education ($p = 0.001$; < 0.05) and respondents with higher education have a 5.191 times greater chance of having a good quality of life in patients with epilepsy compared to respondents with low education (OR=5,192; CI=2,051-13,144). The results of statistical tests also showed that there was a significant effect between the frequency of seizures on the quality of life of patients with

TABLE 2: Results of Multivariate Final Modeling Analysis of Variables Affecting Quality of Life for Patients with Epilepsy (n=100).

Variable	B	Wald	P	Exp (B)	95%CI	
					Min	Max
Type of seizure	2,274	4,175	0,041	9,719	1,097	86,041
Stigma	1,675	6,983	0,008	5,337	1,541	18,482
Medication adherence	1,540	6,217	0,013	4,666	1,390	15,661
Constant	-5,192	15,389	0,000	0,006		

epilepsy ($p = 0.001$; <0.05). Further analysis showed that respondents who had seizures <12 seizures within two years were 10.286 times more likely to have a good quality of life compared to respondents who had seizures 12 seizures in the last two years, and respondents who were free of seizures during the last two years. 2 years had a 24,000 times greater chance of having a good quality of life compared to respondents who had seizures 12 seizures within two years (OR=10,286; CI= 2,244 - 47,155 and OR= 24,000; CI= 3,247-177,405).

The results of statistical tests showed that there was a significant effect between the type of seizure attack on the quality of life of patients with epilepsy ($p = 0.001$; < 0.05) and the results of further analysis showed that respondents with focal or partial attacks had 18.951 times greater chance of having quality of life. good in epilepsy patients compared to respondents who experienced generalized attacks (OR=18,951; CI= 2,42-147,91). The results of statistical tests on stigma showed that there was a significant effect between stigma on the quality of life of patients with epilepsy ($p = 0.001$; < 0.05), where low stigma had a 10.350 times greater chance of having a good quality of life in patients with epilepsy compared to respondents who has a high stigma with (OR=10.350; CI=3.857-27.775). While on medication adherence, it is known that there is a significant effect between medication adherence and the quality of life of patients with epilepsy ($p= 0.009$; < 0.05).

Based on the OR values in table 2, it can be explained that the type of seizure variable has the greatest influence on the quality of life in patients with epilepsy with OR = 9.719 (95% CI = 1.097; 86.041). Then the stigma variable with OR = 5,337 (95% CI = 1,542; 18,482), and the last is adherence to treatment with OR = 4,666 (95% CI = 1,390: 15,661).

4. Discussion

4.1. Demographic Characteristics

There was no significant relationship between age and quality of life in patients with epilepsy. The results of the Epilepsy Council of The UK in 2011 social problems including a sense of isolation by the environment as well as problems in adapting to daily activities in epilepsy patients will increase with age and can affect the quality of life of epilepsy patients. Meanwhile, according to research conducted in the USA, [17] the older the age of people diagnosed with epilepsy, the worse the quality of life in patients with epilepsy, because the younger the age when diagnosed with epilepsy, the better in controlling the emotions caused by the social problems they experience.

However, in this study, the majority of younger respondents had poor quality of life as well as middle-adult respondents, this could be due to various factors, including the majority of respondents having low medication adherence, seizure frequency <12 seizures over a period of time. two years, and has a high stigma. This can increase social problems, such as feeling isolated from the environment and at work. In the surrounding environment, respondents find it difficult to find a life partner, make friends, and get the wrong assumption from the community such as epilepsy can be contagious, difficult to have children, epilepsy can be passed on to their children, and even considered to be possessed. Meanwhile, in the work of the majority of respondents, it is difficult to find work because the seizures of the respondent can come back suddenly and can interfere with their work, so that the quality of life of patients with epilepsy will be poor. The results of this study are not much different from a study conducted in Bhutan [8] which stated that there was no significant relationship between age and quality of life in epilepsy patients ($p= 0.06$). About 124 people (72%) in epilepsy patients had a low quality of life between the ages of 19-35 years.

The same thing with gender, it was no significant relationship between gender and quality of life in patients with epilepsy. The results of this study are not much different from a study conducted in Serbia, [18] which stated that there was no significant relationship between gender and quality of life in patients with epilepsy ($p=0.734$). In general, men and women have different aspects of living their daily lives with epilepsy. Women are more likely to pay attention to biological and psychosocial aspects, while men are more concerned with socio-economic aspects [19]. This may be caused by other factors that play a role in determining the quality of life of patients with epilepsy.

In the marital status, there was no significant effect of marital status on quality of life in patients with epilepsy. This result is not much different from the results of a study conducted in the United Arab Emirates [10] which stated that there was no significant effect between marital status and quality of life in patients with epilepsy ($P= 0.74$). The purpose of a marriage relationship in addition to the religious and biological aspects is the socio-psychological aspect so that they support each other [20]. When the support from the partner is good, the quality of life will also be good and vice versa. However, in this study there was no significant effect of marital status on quality of life in patients with epilepsy. This may be caused by other factors that play a role in determining the quality of life of patients with epilepsy, such as medication adherence. A total of 67 people (67%) respondents in this study the majority had low medication adherence. With low adherence to medication, seizures cannot be controlled. Seizures that occur frequently will have a negative impact on the quality of life of patients with epilepsy [2].

However, in the education level was a significant effect between the education level on the quality of life in patients with epilepsy. The opinion is the same as the research conducted in Bhutan [8] which found that the education level had a significant relationship with the quality of life of epilepsy patients with (p value = 0.001). With higher education, it will provide a better understanding of seizure management, medication adherence, influence coping strategies and reduce stigma in patients with epilepsy [8]. So that the quality of life of epilepsy patients becomes good.

The last of demographic characteristics is family income, it was no effect between family income on quality of life in patients with epilepsy. The same opinion is from the results of a study conducted in the USA [21] which found that there was no significant relationship between family income and quality of life in patients with epilepsy. The medical and transportation costs incurred by respondents to go to health services and the costs of daily living put psychological pressure on patients with epilepsy, because the majority of them have low incomes. This psychological pressure makes patients with epilepsy trigger seizures. This can have an impact on the quality of life in patients with epilepsy to be worse [22]. However, the government has paid for routine medical expenses with the existence of a health treatment card from the government or a Kartu Indonesia Sehat (KIS) for underprivileged families, thus minimizing the trigger for psychological changes in patients due to the availability of these facilities. So that family income does not affect the quality of life of patients with epilepsy.

4.2. Clinical Condition

In this study, there was a significant relationship between seizure frequency and quality of life in patients with epilepsy. These results are in line with research conducted in Taiwan [23], where H. Chen, Tsai, Hsi, & Chen, (2016) stated that seizure frequency has a significant relationship with the quality of life of patients with epilepsy ($p=0.01$). The more frequent the occurrence of seizures, the more psychosocial disturbance in patients with epilepsy, due to disruption of social activities and work limitations. When a seizure occurs, the brain will experience a balance disorder and the serotonin hormone will be disrupted, resulting in potential depression. The more frequent the seizures, the more neurons proceed to death. Psychosocial disorders, serotonin disorders and necrotic neurons have an impact on the quality of life to be worse [22]. Therefore, there is a significant relationship between seizure frequency and quality of life in patients with epilepsy.

The results of this study also showed that there was a significant effect between the type of seizure attack on the quality of life of patients with epilepsy. The same opinion was expressed by a study conducted in China [24] which found that there was a significant relationship between the type of seizure attack and the quality of life of patients with epilepsy ($p < 0.05$).

Patients with generalized seizures have a tendency to be accompanied by decreased consciousness, tonic-clonic seizures, myoclonic seizures which have a negative impact on quality of life. Whereas in the type of focal seizure, there is a tendency to experience focal seizures with awareness or focal seizures that spread and become tonic-clonic seizures [25]. The impact of generalized seizure type is worse than focal type, because after experiencing an attack the patient tends to experience fatigue, confusion accompanied by dizziness and sometimes can't communicate well. However, in focal attacks, the patient tends to be conscious so that after the attack the patient can continue communication or activities as usual. This is what makes patients with epilepsy with generalized attack type have worse social functions which have an impact on poor quality of life [23]. Thus, there is a significant relationship between the type of seizures and the quality of life of patients with epilepsy.

4.3. Social Support

Social support in this study showed no effect between social support on quality of life in patients with epilepsy. Different results were obtained in a study conducted in China

[26] which found that there was a significant relationship between social support and quality of life in patients with epilepsy ($p < 0.001$). With good social support it will affect self-management for patients with epilepsy and reduce the sense of discrimination and anxiety experienced by patients with epilepsy, thus the quality of life increases [12]. However, in this study there was no significant relationship between social support and the quality of life of patients with epilepsy, because the majority of respondents had a high stigma against their epilepsy and low medication adherence.

4.4. Stigma

On stigma, the results of this study showed that there was a significant effect of stigma on the quality of life in patients with epilepsy. The results of this study are not much different from the research conducted by Maria [12] who found that there was a significant negative relationship between stigma and quality of life in patients with epilepsy ($p = 0.001$). The stigma possessed by respondents can interfere with their social activities, so that respondents will feel discriminated against both in looking for work, looking for a life partner, and in the community. This has a negative impact on the quality of life of patients with epilepsy, because stigma is a social process characterized by exclusion, rejection and blame [2]. Thus, stigma has a significant negative relationship to the quality of life of patients with epilepsy.

4.5. Medication Adherence

The results of statistical tests that this study showed a significant effect between medication adherence and quality of life in patients with epilepsy. The results of this study are in line with research conducted in Hong Kong [27] which found that medication adherence had a significant positive relationship to the quality of life of patients with epilepsy ($p \geq 0.001$).

Seizures in epilepsy can be controlled by drugs, because about 75% of patients with epilepsy have seizures controlled with regular drug use or medication adherence (Espinosa-jovel et al, 2018). Seizures that occur frequently will stigmatize patients with epilepsy. stigma in epilepsy is usually limited social activities characterized by limited opportunities for education, employment, marriage. Stigma has a negative impact on the quality of life of patients with epilepsy [2]. This means that if adherence to medication is good, the frequency of seizures will be controlled. So that social function is good and

quality of life is increasing. On the other hand, if adherence to medication is low, the quality of life will be poor.

4.6. The Most Influential Factors on the Quality of Life of Patients with Epilepsy

The results of this study revealed that the most dominant factor affecting the quality of life of patients with epilepsy was the type of seizure attack (OR= 9.716; CI= 1.097 – 86.041). The multivariate outcome showed that seizure type prevented 9,716 times of low quality of life in patients with epilepsy. The results of further statistical tests showed that the three variables, namely the type of seizure, stigma and medication adherence, could contribute to improving the quality of life in patients with epilepsy by 57.37%.

The types of seizures can be classified into generalized and focal. In the generalized seizure type, abnormal electrical activity in the brain involves the cerebral hemispheres, whereas in focal or partial seizures it only occurs in certain areas of the brain and then spreads. [25]. Patients with generalized seizures tend to be accompanied by decreased consciousness, tonic-clonic seizures, myoclonic seizures which have a negative impact on quality of life. Whereas in the type of focal seizure, there is a tendency to experience focal seizures with awareness or focal seizures that spread and become tonic-clonic seizures [25]. The impact of generalized seizure type is worse than focal type, because after experiencing an attack the patient tends to experience fatigue, confusion accompanied by dizziness and sometimes can't communicate well. However, in focal attacks, the patient tends to be conscious so that after the attack the patient can continue communication or activities as usual. This is what makes patients with epilepsy with generalized attack type have worse social functions which have an impact on poor quality of life [23].

5. Conclusion

There is a significant effect between education level, type of seizure, seizure frequency, stigma and medication adherence on the quality of life of patients with epilepsy. Meanwhile, there is no significant effect between age, gender, marital status, social support, and family income on the quality of life of patients with epilepsy. The most dominant factor in influencing the quality of life of patients with epilepsy in this study was the type of seizure.

The results of this study can be used as a reference in developing nursing assessments for patients with epilepsy, because as we know that the majority of patients with epilepsy have poor quality of life. So that an accurate assessment is needed to immediately provide appropriate treatment for people with epilepsy and the right way to avoid the triggers of seizures.

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Conflict of Interest

There is no conflict of interest in this study.

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