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CLINICAL AND SOCIODEMOGRAPHIC FACTORS ASSOCIATED WITH QUALITY OF LIFE IN EPILEPSY PATIENTS AT DR. DORIS SYLVANUS HOSPITAL PALANGKA RAYA

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ABSTRACT

Background: Epilepsy is a chronic neurological disorder that affects patients' physical, psychological, and social aspects, influencing their quality of life (QoL). Identifying clinical and sociodemographic factors related to QoL is essential for comprehensive management.
Objective: To analyze the relationship between clinical and sociodemographic factors and the quality of life of epilepsy patients at the Neurology Polyclinic of RSUD dr. Doris Sylvanus Palangka Raya.
Methods: This analytical observational study with a cross-sectional design involved 53 respondents selected through consecutive sampling. Data were collected using the QOLIE-31 to assess QoL, the MARS-5 to assess medication adherence, the MSPSS to assess social support, and a validated knowledge questionnaire. Relationships between variables were analyzed using the Spearman correlation test with a significance level of $p < 0.05$.
Results: Most respondents were adults aged 19-45 years (83.0%), male (52.8%), and had secondary education. The mean QOLIE-31 score was 52.24 (SD 20.02), indicating moderate QoL. Significant correlations were found between seizure frequency ($r = -0.506$; $p < 0.001$), comorbidity ($r = -0.368$; $p = 0.007$), medication adherence ($r = 0.483$; $p < 0.001$), social support ($r = 0.396$; $p = 0.004$), and knowledge level ($r = 0.587$; $p < 0.001$) with QoL. Age at diagnosis ($p = 0.119$) and epilepsy duration ($p = 0.397$) were not significantly related.
Conclusion: Quality of life in epilepsy patients is significantly associated with seizure frequency, comorbidity, medication adherence, social support, and knowledge level. Improving adherence and psychosocial support can enhance patients' overall well-being.

Keywords: clinical factors, epilepsy, QOLIE-31, quality of life, sociodemographic factors

Introduction

Epilepsy is a chronic neurological disorder derived from the Greek term epilapsia, meaning attack.[1] Epilepsy is characterized by recurrent seizures caused by abnormal electrical activity in the brain's neurons, affecting millions of individuals worldwide.[2] Globally, more than 50 million people live with epilepsy, making it one of the most common neurological disorders. In addition to the risk of seizures, epilepsy increases the likelihood of premature mortality by up to threefold compared with the general population.[3,5] Epilepsy affects not only physical health but also psychological, cognitive, and social functioning, which collectively influence patients' overall quality of life.[6,7]

Developing countries generally report higher rates of epilepsy than developed nations, with a prevalence that tends to be higher among males. In Indonesia, although epidemiological data remain limited, an estimated 1.5 million people are living with epilepsy, with a prevalence of approximately 0.5 0.6% of the total population. According to the World Health Organization (WHO) 2020 data, there were 706 epilepsy-related deaths reported in Indonesia, placing the country at the 183rd position globally.[4,6,8]

As a chronic disease, epilepsy places a substantial burden not only on health but also on patients' quality of life and long-term treatment costs.[9] Quality of life is a multidimensional concept reflecting an individual's perception of various aspects of life, including health, work, education, environment, as well as cultural and spiritual values.[6,10] In the context of modern healthcare, therapeutic success is measured not only by symptom control or survival, but also by the extent to which patients' quality of life can be improved.[7,11]

Based on this background, this study was conducted to examine the quality of life of individuals with epilepsy, as such information is essential to support patient knowledge and improve disease monitoring and management. Moreover, data on the quality of life of epilepsy patients in Central Kalimantan, particularly in Palangka Raya, remain limited.

Methods

This study was an analytical observational study with a cross-sectional design. The independent variables included age at first epilepsy diagnosis, knowledge level, duration of epilepsy, medication adherence, seizure frequency, comorbidity, and level of social support. Data were obtained from outpatient epilepsy patients at the Neurology Polyclinic of dr. Doris Sylvanus General Hospital, Palangka Raya, using a consecutive sampling technique throughout the study period based on predetermined inclusion and exclusion criteria. The total sample consisted of 53 epilepsy patients diagnosed by a neurologist at dr. Doris Sylvanus General Hospital.

Data collection instruments included the Quality of Life in Epilepsy Inventory-31 (QOLIE-31) to assess quality of life, the Medication Adherence Rating Scale-5 (MARS-5) to measure medication adherence, the Multidimensional Scale of Perceived Social Support (MSPSS) to assess perceived social support, and a validated questionnaire on epilepsy knowledge to measure the level of knowledge. All instruments were administered in the Indonesian language and had previously demonstrated validity and reliability. Associations between variables were analyzed using the Spearman correlation test in the bivariate analysis.

Results

Respondent Characteristics

In this study, the characteristics of the respondents were grouped into two main categories: clinical factors and sociodemographic factors, with a total of 53 participants.

Table 1. Clinical and sociodemographic characteristics of respondents

Category	n (%)
1. Age	
Adult (19–45 years)	44 (83)
Middle-aged (45–59 years)	5 (9.4)
Older (≥ 60 years)	4 (7.5)
2. Sex	
Male	28 (52.8)
Female	25 (47.2)
3. Education Level	
Primary school	4 (7.5)
Junior high school	8 (15.1)
Senior high school	27 (50.9)
Diploma (D1/D2/D3)	1 (1.9)
Bachelor's/Master's degree	13 (24.6)
4. Occupation	
Unemployed	15 (28.3)
Housewife	10 (18.9)
Student	6 (11.3)
Government/public sector/civil sector	6 (11.3)
Private sector/Self-employed	14 (26.4)
Others	2 (3.8)
5. Age at epilepsy diagnosis	
<10 years	12 (22.6)
10–20 years	20 (37.7)
>20 years	21 (39.6)
6. Duration of epilepsy	
<5 years	9 (17.0)
5–10 years	17 (32.1)
>10 years	27 (50.9)
7. Seizure frequency (past month)	
None	30 (56.6)
1–3x	22 (41.5)
≥3x	1 (1.9)
8. Comorbidities	
None	26 (49.1)
1–2 conditions	25 (47.2)
≥2 conditions	2 (3.8)
9. Follow-up adherence	
Regular	53 (100)
Irregular	0 (0)

Based on Table 1, most respondents were adults (83.0%), with a relatively balanced sex distribution, 52.8% male and 47.2% female. The majority had completed senior high school education (50.9%). In terms of occupation, the largest proportion of respondents was unemployed (28.3%).

For clinical characteristics, most participants were diagnosed with epilepsy at >20 years of age (39.6%) and

had been living with the condition for more than 10 years (50.9%). More than half had not experienced any seizures in the past month (56.6%). Nearly half of the respondents reported having no comorbidities (49.1%), and all participants were recorded as attending regular follow-up visits.

Distribution of Quality of Life, Medication Adherence, Social Support, and Knowledge Levels

Table 2. Category distribution of quality of life, medication adherence, social support, and knowledge level scores

Variable	n (%)
Quality of Life (QOLIE-31)	
Poor	23 (43.4)
Moderate	21 (39.6)
Good	9 (17.0)
Medication Adherence (MARS-5)	
High	8 (15.1)
Moderate	45 (84.9)
Social Support (MSPSS)	
High	26 (49.1)
Moderate	25 (47.2)
Low	2 (2,0)
Knowledge level	
Good	6 (11.3)
Moderate	15 (28.3)
Poor	32 (60.4)

The mean total quality of life score based on the QOLIE-31 was 54.41 ± 20.61, which falls within the moderate category. As shown in Table 2, the distribution of QOLIE-31 scores indicates that most respondents were categorized as low (43.4%), followed by moderate (39.6%), and high (17.0%).

For medication adherence measured using the MARS-5, the majority of respondents were classified as moderate (84.9%), followed by high adherence (15.1%), with no respondents categorized as low. Regarding social support based on the MSPSS, most respondents reported high levels of support (49.1%) and moderate levels (47.2%), whereas low support was reported in only 2.0% of respondents.

Meanwhile, knowledge level was predominantly low (60.4%), followed by moderate (28.3%), with only a small proportion demonstrating high knowledge (11.3%).

Bivariate Analysis

Table 3. Spearman correlation analysis

Variable	*r*	*p*
Age at diagnosis	0.217	0.119
Duration of epilepsy	-0.119	0.397
Seizure frequency	-0.506	<0.001
Comorbidities	-0.368	0.007
Medication adherence	0.483	<0.001
Social support	0.396	0.004
Knowledge level	0.587	<0.001

Based on the Spearman correlation analysis shown in Table 3, seizure frequency ($r = 0.506$; $p < 0.001$) and comorbidities ($r = 0.368$; $p = 0.007$) demonstrated significant negative correlations with quality of life. In contrast, medication adherence ($r = 0.483$; $p < 0.001$), social support ($r = 0.396$; $p = 0.004$), and knowledge level ($r = 0.587$; $p < 0.001$) showed significant positive correlations. Meanwhile, age at diagnosis ($p = 0.119$) and duration of epilepsy ($p = 0.397$) were not significantly associated with quality of life.

Discussion

This study involved 53 patients with epilepsy, the majority of whom were adults, with a relatively balanced sex distribution. Age plays an important role in therapeutic response and psychosocial adaptation, and quality of life tends to be lower among older individuals due to comorbidities and cognitive decline.[4,12] Most respondents had completed senior high school education or its equivalent, had been living with epilepsy for more than 10 years, experienced seizure frequencies of ≤1 episode per month, and demonstrated good medication adherence. The mean QOLIE-31 score fell within the moderate category; however, a substantial proportion of respondents still exhibited low quality of life. This indicates that the quality of life among epilepsy patients requires further attention and improvement efforts. In addition, cultural factors, social stigma, and limited access to healthcare services remain ongoing challenges in the management of epilepsy in Indonesia.[8,13]

No significant association was found between age at diagnosis and quality of life among patients with epilepsy. This finding is consistent with previous studies reporting that the age of seizure onset is not related to quality of life.[14] The quality of life of individuals with epilepsy is more strongly influenced by clinical factors, such as seizure frequency and the presence of comorbidities, rather than the age at which the disease first appears.[15] In addition, the homogeneity of respondents, most of whom were within the adult age group, may have contributed to the lack of a significant association in this study. Adults generally possess better adaptive capacity in managing their condition. Long-term adaptation mechanisms have been shown to play an important role in shaping quality of life perceptions among individuals with chronic illnesses, including epilepsy.[16,17]

A strong and significant positive association was found between patients' knowledge about epilepsy and their quality of life. The greater the level of understanding, the better the quality of life reported. This finding is consistent with previous studies showing that patients with higher knowledge levels tend to have better quality of life scores.[18] Adequate knowledge contributes to improved medication adherence, helps patients avoid seizure triggers, and enables them to better cope with social stigma.[19] Although most respondents had a

secondary-level education, their knowledge levels were predominantly low, indicating suboptimal health literacy.

The duration of epilepsy was not significantly associated with quality of life. This finding is consistent with previous studies reporting no meaningful relationship between disease duration and quality of life among individuals with epilepsy.[15,18] Most respondents in this study had been living with epilepsy for more than five years, indicating that the majority were in the chronic phase of the condition. Patients with long-standing epilepsy generally develop long-term adaptation mechanisms that help stabilize their quality of life.[17] Furthermore, individuals who adopt adaptive coping strategies such as accepting their condition, maintaining medication adherence, and adjusting their daily activities tend to experience a better quality of life.[16]

A moderate and significant positive association was found between medication adherence and quality of life among patients with epilepsy. Higher levels of medication adherence are associated with improved seizure control and better perceived quality of life among individuals with epilepsy.[2] This finding aligns with previous studies demonstrating that medication adherence is closely linked to improved quality of life in individuals with epilepsy.[20] Osman et al. further emphasized that non-adherence and inappropriate medication use significantly reduce the quality of life of epilepsy patients.[21] Moreover, adherence is associated with a reduced risk of seizure episodes, which in turn contributes to a better quality of life.[22]

Seizure frequency showed a strong and significant negative correlation with quality of life, as more frequent seizures are associated with poorer psychosocial functioning and reduced well-being.[23] The more frequently seizures occurred, the lower the quality of life experienced by patients. In this study, individuals with higher seizure frequency tended to have lower quality of life scores. This finding is consistent with previous research, which emphasizes that poor seizure control, characterized by frequent seizure episodes, is significantly associated with reduced quality of life.[15] The more often seizures occur, the greater their impact on the quality-of-life decline, making seizure frequency one of the most significant clinical determinants.[21]

Comorbidities showed a moderate and significant negative association with quality of life. The greater the number of comorbid conditions, the lower the quality-of-life scores reported by patients. Respondents with comorbidities tended to have lower quality of life scores compared to those without comorbid conditions. This finding is consistent with previous studies indicating that psychiatric disorders such as depression and anxiety, as well as chronic physical illnesses, can reduce quality of life by increasing psychological, physical, and social burden.[6,24]

Social support demonstrated a moderate and significant positive association with quality of life among patients with epilepsy. Higher levels of social support were associated with better perceived quality of life. This finding is consistent with the study by Unalan et al., which showed that perceived social support, whether emotional, informational, or tangible, has a direct effect on improving quality of life.[25] Family and environmental support has also been shown to reduce depressive symptoms, enhance emotional stability, and improve the overall quality of life of individuals with epilepsy.[6,26]

This study has several limitations. First, the number of respondents was relatively limited, which may have introduced representation bias. Future studies are encouraged to include a larger and more diverse population. Second, the use of self-report questionnaires carries the risk of social desirability bias and recall bias. Therefore, employing more specific and objective instruments in future research would help improve data accuracy. Third, the cross-sectional design of this study does not allow for the determination of causal relationships between variables.

Conclusion

Age at diagnosis and duration of epilepsy were not associated with patients' quality of life. In contrast, knowledge level and medication adherence showed significant positive associations with quality of life. Seizure frequency and comorbidities demonstrated significant negative associations, whereas social support was significantly and positively associated with the quality of life of patients with epilepsy. However, this study has limitations, particularly the relatively small sample size and the use of participants from a single hospital, which may limit the generalizability of the findings to the wider population.

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