

The quality of life of patients with epilepsy in Denpasar: A cross sectional study

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Abstract. Epilepsy is the second most common neurological disorder after headache characterized by recurrent seizures in the cerebral region. The main purpose of the treatment of epilepsy is to control seizures without side effects with an optimal quality of life. Measuring quality of life is still relatively a new method in evaluating epilepsy treatment. This study is a cross sectional descriptive study that aims to determine the quality of life of patients with epilepsy using modified QOLIE 31 questionnaire. Epilepsy patients receiving anti epilepsy drug for at least 1 year were enrolled. Demographic, clinical, and treatment parameters were recorded. Quality of Life (QOL) was measured using the modified Quality of Life in Inventory 31 (QOLIE 31) questionnaire for epilepsy. The results obtained a total score of life quality of epilepsy patients 70.29 with the value of each domains: anxiety 66.27; emotional well being 66.27; energy 55.00; medication effect 66.49; social function 80.53; overall quality of life 86.26; cognitive 63.46. We concluded that the quality of life of patients with epilepsy in this study is quite good.

1. Introduction

Epilepsy is the second most common neurological disorder after headache characterized by recurrent seizure in the cerebral region. The main purpose of epilepsy treatment is to control seizures without side effects with an optimal quality of life. Epilepsy is included in chronic diseases that require long-term therapy. This disease greatly affects various aspects of the life of the sufferer, although the incidence of seizures has been able to be controlled [1-2]. The diagnosis of epilepsy is not only medical but also social because epilepsy patients will encounter so many psychosocial problems, such as anxiety, social stigma, difficulty driving, and even not getting job, which in turn will degrade the quality of life of epilepsy patients [2]. Awareness of the importance of psychosocial aspects in the life of epilepsy patients is what ultimately triggering the importance of evaluating the quality of life in epilepsy patients.

Evaluation of quality of life is still a relatively new method in knowing the effects of therapy or anti-epileptic drugs. Demography characteristic, seizure frequency, and epilepsy duration have been known to have a strong correlation to the quality of life of epileptic patients. However, seizure-free status in epilepsy patients does not always result in epilepsy patients having a maximum quality of life score [1-2]. World Health Organization (WHO) defined QOL as an 'individual's perceptions of his position in life, in the context of the culture and value system in which he lives and in relation to his goals, standards and concerns [3-4]. Quality of life includes welfare in general both individuals and communities. Quality of life includes life satisfaction, including everything from physical health, family, education, work, wealth, religion, finances, and the environment. The quality of life evaluation instruments are broadly



divided into two types: general scale used to assess generally the functional abilities, inadequacies, concerns arising from illness, and specific scales used to measure a particular feature of the disease, certain population or special functions such as emotions. In the assessment of the quality of life in epilepsy patients, several types of instruments can be used, such as Quality of Life in Epilepsy (QOLIE-31), Quality of Life in Epilepsy (QOLIE-10), or Short Form (SF-36) [5-7]. This study is a descriptive study to measure the quality of life of epilepsy patients in the city of Denpasar.

2. Method

After obtaining the institutional ethical committee clearance, we conducted a study in the outpatient department of Neurology at tertiary referral hospital in Denpasar. Sample size was calculated using proportion of epilepsy patient in Indonesia [8-9] and found to be 60. As per the inclusion criteria patients with epilepsy, who were on antiepileptic drugs, subjects aged more than 17 years old, have no communication disturbance, and willing to sign informed consent. Subjects with comorbid conditions like psychotic disorder, mental retardation, dementia in elderly, depression, those with acute symptomatic seizure secondary to strokes, head injuries, neuro infection, brain tumors, metabolic causes such as hepatic failure, renal failure, cardiac failure and subjects who have had recent brain surgery were all excluded from the study.

Demographic data like age, gender, educational status, marital status, and occupation were collected based on medical record. The clinical data like diagnosis, family history of epilepsy, number of pre-treatment seizure, and drug used in therapy were also collected. The seizure free status was considered to be good in case of zero seizures and poor in case of one or more seizures in the six months prior to the interview.

We used the QOLIE-31 questionnaire in Indonesia version. The questionnaire has 31 questions and seven domains which are anxiety of seizure, overall quality of life, emotional wellbeing, energy, cognitive, medication effect, and social function. The questionnaire was self-administered to the subject. Prior to the analysis, first, we checked the completeness of data. The collected data will be coded, tabulated and analyzed descriptively. Categorical data will be expressed in the form of frequency, distribution, and proportion, while continuous data such as quality of life will be displayed in the form of mean and standard deviation or median if data distribution is not normal.

3. Result

Table 1. Respondent Characteristic

Characteristic		n (%) (n=60)
1	Age	
	- < 50 y.o	54 (90.0%)
	- 50 y.o	6 (10.0%)
2	Gender	
	- Male	32 (53.3%)
	- Female	28 (46.6%)
3	Education	
	- Low	20 (33.3%)
	- High	40 (66.7%)
4	Working	
	- No	31 (51.6%)
	- Yes	29 (48.4%)
5	Marriage Status	
	- No	31 (51.6%)
	- Yes	29 (48.4%)

Table 1. Cont.

6	Treatment duration	
	- <10 years	38 (63.3)
	- 10 years	22 (36.7)
7	Number of AED used	
	- Mono therapy	27 (45.0)
	- Poly therapy	33 (55.0)
8	Adverse event	
	- No	20 (33.3)
	- Yes	40 (66.7)
9	Adherence (Medication Posses Ratio/MPR)	
	- Low	0 (0.0)
	- High	60 (100.0)
10	Seizure Remission	
	- No	29 (48.4)
	- Yes	31 (51.6)

We had 60 epilepsy patients as respondents of our study. Most of respondents below 50 years old, male, high education background, not working, and not married. More than 50% have undergone therapy less than 10 years, used more than one type of antiepileptic drug, had complaints of adverse event, and have no seizure in last 6 months. All of respondent have high adherence to treatment [Table 1]. The quality of life measured by QOLIE-31 displays quality of life that divided into 7 domains, including seizure worries, emotional well-being, energy / fatigue, medication effects, social functioning, overall quality of life, and cognitive. Higher score means better quality of life. Total score of quality of life was 70.29 ± 12.98 . The domain with the highest quality of life scores is overall quality of life 86.26 ± 11.28 and the energy domain got the lowest score of 55.00 ± 17.66 [Table 2].

Table 2. Quality of Life Measurement Result

Domain QOLIE-31	Mean \pm SD (n=60)	Minimum-Maximum Score
Anxiety of seizure	$66,27 \pm 21,22$	30,66-96,00
Emotional Wellbeing	$68,48 \pm 15,38$	32,00-100,00
Energy	$55,00 \pm 17,66$	20,00-85,00
Medication Effect	$66,49 \pm 22,53$	13,33-100,00
Social Function	$80,53 \pm 16,01$	21,00-100,00
Overall Quality of Life	$86,26 \pm 11,28$	45,00-95,00
Cognitive	$63,46 \pm 21,74$	10,00-96,67
Total Score	$70,29 \pm 12,98$	23,73-92,45

4. Discussion

Epilepsy is a chronic disease that greatly affects the patients. Seizures that appear episodically often alter the live of epilepsy patient, so the assessment of quality of life becomes very important. Based on the guidelines for the management of epilepsy in Indonesia in line with the International League against Epilepsy (ILAE), the goal of epilepsy management is to get people with epilepsy to live a normal life and achieve optimal quality of life [10]. To achieve these objectives requires good observation or assessment of the frequency, type of seizures, and selection of antiepileptic drugs with minimal side effects. Currently, quality of life evaluation is considered an important parameter to be assessed in clinical examination, which is if possible, provides a better understanding of the problems faced by epilepsy patients, especially epilepsy patients with uncontrolled seizures [6].

We conducted a research to assess the quality of life in epilepsy patient in one of public hospital at Denpasar. This hospital is included to tertiary referral hospital. We used 60 patients diagnosed with epilepsy as respondent and we found most of patients were male and below 50 years old. The incidence

of epilepsy in developed countries follows the bimodal distribution with the first peak at the age of five and the second peak at age 65, unfortunately in developing countries bimodal distribution is not visible. The prevalence of epilepsy in developing countries is higher in the second decade of the second decade than in the elderly. Possible causes are low incidence and average life expectancy in developed countries is higher. The prevalence of epilepsy by sex in Asian countries reports men are slightly higher than women [11]. Our study defines epilepsy patients with a minimum education level of high school as high education background. Although most of our respondents have high education background, many of them are known not to get a job. It is different when compared with developed countries when education plays an important role in a job, but not in Indonesia, many people with higher education do not get a job, allegedly closely related to macroeconomic changes [12]. Most of respondents (51.6%) are not married. Discrimination and social inclusion experienced by epilepsy patients makes it difficult for them to be married and have children [13]. Duration of therapy is one of the predictors of poor prognosis in epilepsy patients. The longer duration of therapy, complications and side effects will appear more [14]. There were 36.7% of respondents had undergone therapy for more than 10 years. Most of the respondents have experienced adverse effect. The adverse effects of drugs are closely related to the type of antiepileptic drugs used in patients. More than fifty percent of respondents have achieved seizure remission in past six month. Seizure remission is the most important parameter in the management of epilepsy. Epilepsy patients who are able to achieve seizure -free within 6 months are usually highly likely to achieve complete remission in epilepsy [15]. Based on MPR score, all respondents have high adherence with treatment.

The examination of the quality of life of epilepsy patients in our study using QOLIE-31 questionnaire resulted in mean of total score of 70.29 ± 12.98 , which was higher than that performed in Egypt (69.4), India (64.61), United States (63.0), Spain (61.8), and France (61.9). A study in India in 2015 involving 60 study subjects earned mean of total quality of life score of 64.61 ± 8.97 , with the highest domain was emotional wellbeing 70.53 ± 11.12 , and the lowest domain of seizure anxiety of 57.55 ± 16.06 [14]. The results of this study are also better than in Malaysia with the mean of total score is 68.9 ± 15.9 , with the highest domain in the medication effect 79.4 ± 28.5 , and the lowest domain on seizure concerns 47.5 ± 25.0 [16]. This difference in outcomes can be attributed to state differences that result in differences in outlook, culture and socioeconomic factors that influence the measurement of quality of life, so different results in different countries can't be a reference.

Although Indonesia does not have a standard of quality of life for epilepsy patients, our study concludes that our respondents have a good quality of life with mean of total score 70.29 ± 12.98 , and mean score of each domain does not have a value below 50. We estimate high adherence to treatment resulting in our respondents having a good quality of life. In a study conducted at the United States in 2008, epilepsy patients who did not adhere to treatment had a lower quality of life score [17]. The highest domain in this study is the overall quality of life that reached score of 86.26 ± 11.28 . Almost no respondent who experienced complaints seizures in the last month (item number 14 questions on the questionnaire). In contrast to previous research, the lowest domain is energy 55.00 ± 17.66 , this may be caused or influenced by antiepileptic drugs that trigger sedation or fatigue. Some anti-epilepsy drugs are known to have inhibitory effects, with sedation as a side effect. Anti epileptic drug from benzodiazepine class such as Clonazepam and Clobazam often cause sedation [18]. Phenytoin triggers the inhibition of enzymes that convert folate, increase folate catabolism, and inhibit the appetite center so that the incoming food is reduced and make epileptic patients received phenytoin as antiepileptic drug lack of energy [19].

5. Conclusion

Epilepsy being a chronic syndrome affects quality of life of the subjects. Thus efforts should be undertaken to control seizures and improve the overall Quality of Life of the subjects in order to achieve the goal of epilepsy treatment.

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