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Quality of Life Assessment among Adult Epileptic Patients Taking Follow Up Care at Jimma University Medical Center, Jimma, South West Ethiopia: Using Quality of Life in Epilepsy Inventory-31instrument

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Methods: Institution based cross sectional study was used. A total of 314 epilepsy patients already receiving antiepileptic drugs for at least 3 months were randomly selected and interviewed. Quality of life in epilepsy inventory-31instrument was used to measure health quality of life. T-test, one way Anova and Pearson correlation were used to compare means and association between dependent and outcome variables. Multiple Linear regression analysis was performed to assess the association between health related quality of life and explanatory variables. P value < 0.05 was considered statistically significant in this study.

Keywords: *epilepsy, quality of life, qolie-31instrument, jumc.*

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Quality of Life Assessment among Adult Epileptic Patients Taking Follow Up Care at Jimma University Medical Center, Jimma, South West Ethiopia: Using Quality of Life in Epilepsy Inventory-31instrument

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Result: From the total study participants, 304 (96.8 %) were interviewed. The average total Quality of life score of domains/subscales was; Seizure worry (50.8±19.9); Overall Quality of life (59.8±20.0); Emotional wellbeing (59.1 ±14.8), Energy/fatigue (59.9 ±13.6), Cognitive function (56.0 ±15.5), Medication effects (61.5±19.4), Social functioning (63.6 ± 17.7) and total (Overall) quality of life (58.8±10.6). Sex, Residence of the client, occupational status, performing regular exercise, Doing daily activities independently, Sleep pattern, Frequency of Anti Epileptic drugs (AEDs) taken/day, Side effect of the treatment, age of the patient when Anti Epileptic drugs started, current co-morbidities and Level of anxiety and depression was significantly associated with at least one of the seven domains of Quality of life score.

Conclusion and Recommendation: Being female, Rural residence, Taking AEDs several times per day, becoming older age, side effect of treatment, current comorbidity with anxiety and depression and other disease, and also those with perceived stigma were associated with lower quality of life. On the other hand performing regular exercise, performing daily activities and enough and regular pattern of sleep were related to better QOL. In addition to controlling seizure, interventions to address the physical, mental, psychological, social and emotional aspects for health wellbeing is likely to achieve better health outcomes for epileptic patients.

Keywords: *epilepsy, quality of life, qolie-31instrument, jumc.*

I. Introduction

Epilepsy is a neurologic disorder characterized by recurrent episode of seizure. The cause of epileptic seizure is often unknown but in some people the condition is inherited also it is caused by brain damage due to different causes [1].

Epilepsy is public health problem in the world. It has been estimated that at least 70 million people suffer from epilepsy and epilepsy is responsible for 1% contribution to the global burden of diseases while this contribution is 80% in the developing countries [2,3]. The incidence rate of epilepsy is generally higher in developing countries compared to developed countries which are figured in median as 43.4/100 000 people per year and 68.7/100, 00 people per year in developing countries [4]. In Ethiopia, crude incidence of epilepsy is 64 per 100,000 [5].

Epilepsy can be associated with profound physical, psychological and social consequences [6]. It may interfere with social functioning by limiting educational opportunities, employability, and interpersonal relationships and also increase the risk of death [7].

Quality of Life (QOL) has been defined by the World Health Organization (WHO) as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment [8].

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Improving the diagnosis, treatment, prevention, and social acceptability are important factors in achieving the objective of the management of epilepsy. Quality of life is recognized as an important outcome in epilepsy treatment [9].

The investigator has come across a limited study done in Ethiopia addressing quality of life among epileptic patients. Thus main aim of this study was to determine cognitive, emotional, social, physical and psychological aspect of QOL by using Quality Of Life in Epilepsy Inventory-31(QOLIE-31) instrument among adult epileptic patients taking follow up care at Jimma University Medical Center (JUMC).

II. Methods and Materials

a) Study design and population

A cross-sectional study was conducted in chronic illness clinics of JUMC between March 1/2015 – May1/ 2015. The study population was all people aged 18 years and above who had been on anti- epileptic drugs for at least 3 months with an expectation that patients would have a good experience on AEDs and possibly would knowledgeably describe seizure control features [10, 25]. By using Single population formula a total of 314 samples were selected based on a study report which shows the proportion (P) of epileptic patients who are in lower Health Related Quality of Life (HRQOL) were 45.8% [17]. The estimated 5% margin error of the true HRQOL (on 0–100 scale) with 95% Confidence interval was used with 10% non-response rate. The hospital gives follow up care for epileptic patients every Thursday, thus using systematic sampling, a sampling interval of 3 patients were enrolled and interviewed on a weekly basis for a period of 8 weeks.

b) Data collection instrument

The questionnaire had 5 parts, HRQOL instruments (QOLIE-31), Hospital Anxiety and Depression Scale (HADS), Sociodemographic, medical and personal factors.

In this study HRQOL was measured based on total score of Quality Of Life in Epilepsy (QOLIE)-31questionner. A QOLIE- 31questionner- containing 31 items categorized under seven domains covering the following concepts of health: overall quality of life, cognitive functioning, emotional well-being, social functioning, energy/fatigue, seizure worry and medication effects.

Energy/fatigue scale Assess feelings of tiredness, loss of energy and the overall impact of this issue on life Emotional well being (mood) scale assess the mood of the client such as feeling of nervousness, being calm and peaceful, happiness Social functioning domain assess how the Health limited social activities (such as visiting with friends or close relatives) Cognitive functioning scale used to assess mental activity such as thinking, reading, concentrating and memory problems Medication effects scale assess the physical and mental effect of AED, as well as worries about the medication taken Seizure worry scale assess impact of seizures such as bothering and worries about having another seizure, hurting from seizure, embracement or social problems resulting from having seizure next time. Overall quality of life scale considers the above all domains or scales.

The score corresponding to each scale as well as QOLIE-31 total score was calculated for each patient. Each item is scored on a scale of 0 to 100, with a score of zero equivalent to maximum disability or worst quality of life and a score of 100 equivalent to no disability or a high quality of life. However, possible categories or response sets for scoring vary across questions. Examples of response sets used include (i) 0, 25, 50, 75, 100; (ii) 0, 20, 40, 60, 80, 100; (iii) 0, 33,67, 100. Hospital Anxiety and Depression (HAD) Scale was used to measure patient's current comorbidity with anxiety and depression which may affect patient's quality of life [24].

Questions on patient socio-demographics, personal factors such as (perceived stigma and sleeping pattern) and some clinical characteristics (such as partial or generalized epilepsy type) were also included in the integrated questionnaire. Medical records were reviewed to extract additional information pertaining to the date of initiation of AEDs, and type of therapy (poly-therapy or mono-therapy).

The questionnaire was administered by trained nurses hired from other hospitals and technical support was given by the Principal Investigator.

At time of data collection filled questionnaires was checked for completeness and consistency of information by the supervisor on daily basis and typing errors was manually edited.

Questionnaire was prepared in English and translated to local language. Questionnaire was pre-tested on 5% of sample size a week before actual data collection period in other public (Shenen Gibe) hospital and after pre-test necessary modification was done.

c) Variables

Dependent variables: The Seven domains of QOLIE-31 (Social function, Medication effect, Cognitive Function; Overall quality of life; Seizure worry; Emotional wellbeing and Energy/Fatigue)

Independent variables: Sociodemographic, Clinical and Personal factors.

III. Data Analysis Procedure

The coded data was checked, cleaned and entered into Epi data version 3.1 and then analysed by SPSS window version 20.0.

Frequencies and percentages were used to summarize the Sociodemographic, personal factors and medical characteristics of the patients.

Independent t test and one way Anova was done to compare means, and also Pearson correlation was done between the dependent and continuous independent variables. Then those variable with P<0.2 was selected for regression.

Linear regression was performed to assess the association between HRQOL and different explanatory variables. P value < 0.05 was considered statistically significant in this study.

Finally the result was presented using statement, tables and figures.

Ethical Approval

Before the data collection, ethical clearance letter was obtained from ethical review committee of Jimma University College of public health and medical sciences. The letter was submitted to the JUMC management and permission was obtained to interview as well as access patients and their medical records. The respondents were informed about the purpose of the study, and their oral consent was obtained. The respondents' right to refuse or withdraw from participating in the interview was fully maintained and the information provided by each respondent was kept strictly confidential by making each questionnaire coded and not sharing personal information of any patient to the third party.

IV. Result

Socio-demographic, Clinical and Personal Characteristics of the respondents

From the total 314 study participants enrolled, 304 were interviewed. Of the total respondents, 177 (58.2%) were male; the average age was 28 years and only 133 (43.8%) were currently married. Majority of the participants, 198(65.1%), at least able to read and right and 124 (40.8%) of them were Farmers; 207(68.1%) of them were Rural dwellers. Cost of treatment for epilepsy among 260 (85.5%) participants was free.

Regarding the seizure type, 271 (89.1%) subjects had generalized onset seizure and 33 (10.9%) has focal onset (partial) seizure. 260 (85.5%) respondents has at least one seizure per year and 44 (14.5%) of them were seizure free at least for a year. The average age of the respondents when they get epilepsy and age of the pt when AEDs started was 18 and 21 years respectively. Concerning the type of AEDs, 191 (62.8%) and 90 (29.9%) respondents take one and two AEDs respectively. Also 165 (54.3%) and 136 (44.7%) respondents take AEDs once and twice per day respectively. Out of the total respondents, 119 (39.1%) reported side effect of the AED treatment; 104 (34.9%) of them reported complications related to epilepsy. 63 (20.7%) and 56 (18.4%) clients has current comorbidities (other than depression and anxiety) and previous history of hospital admission respectively (Table 1).

From the total respondents, 100 (32.9%) of the respondents have expressed perceived stigma due to the disease (epilepsy); 266 (87.5%) of the respondents were reported they are compliant to self care and 259 (85.2 %) perform daily activities (work) independently. Also 227 (74.7 %) of clients have reported family support in their day to day life. Concerning substance abuse 66 (21.7%) of the client ever used substance and 47 (15.5 %) were using substances currently. Regular physical exercise and enjoying recreational activities are practiced among 52 (17.1%) and 132 (43.4 %) of the respondents. 237 (78%) of clients get enough and regular sleep daily (Table 2).

According to Hospital Anxiety and depression scale (HAD scale, 106 (35%) and 88 (29 %) of patients has abnormal score of anxiety and depression respectively (Table 3).

Table 1: Clinical characteristics of the respondents at

Variable	Categories	Frequency	Percentage %
Seizure type	Generalized onset seizure Focal onset seizure	271 33	89.1 10.9
Seizure frequency	≥1 seizure per year Seizure free for a year	260 44	85.5 14.5
Number of AEDs	One Two Three Four	191 91 20 2	62.8 29.9 6.6 0.7
Frequency of AEDs taken per day	One Two Three	165 136 3	54.3 44.7 1
History of current comorbidity	Yes No	63 241	20.7 79.3

Table 2: Personal Characteristics of Respondants at JUMC, Jimma, Ethiopia, 2015 (n= 304)

Variable	Categories	Frequency	Percentage %
Perceived self esteem	Yes No	234 70	77 23
Perceived Stigma	Yes No	100 204	32.9 67.1
Compliance to Self-care	Yes No	266 38	87.5 12.5
Family support	Yes No	227 77	74.7 25.3
Regular Exercise	Yes No	52 252	17.1 82.9
Recreational activities	Yes No	132 172	43.4 56.6
Enough and regular sleep	Yes No	237 67	78.0 22.0

Table 3: Respondants current level of anxiety and depression measured by HAD scale. (n=304)

Variable	Categories	Frequency	Percentage (%)
Level of anxiety	Normal Borderline abnormal Abnormal	74 124 106	24.3 40.8 34.9
Level of depression	Normal Borderline abnormal Abnormal	92 124 88	30.3 40.8 28.9

Mean scores of QOL domains of QOLIE-31among epileptic patients at JUMC, Jimma, Ethiopia, 2015. (n= 304)

The average total QOL score of domains/subscales was as follows: Seizure worry (50.8±19.9); Overall QOL (59.8±20.0); Emotional wellbeing (59.1 ±14.8), Energy/fatigue (59.9 ±13.6), Cognitive function (56.0 ±15.5), Medication effects (61.5±19.4), Social functioning (63.6 ± 17.7) and total (Overall) quality of life (58.8±10.6). 153 (50.3%) have Overall HRQOL score of Greater than the mean and 151(49.7%) have Overall HRQOL score of less than the mean.

Factors associated with socio-demographic, personal characteristic and clinical factors with the seven domains of QOL

On bivariate analysis the factors found to fulfill the minimum requirement (p-value<0.2 in this study) were entered in to linear regression for further analysis in order to control confounding effects.

The results of linear regression analysis showed Sex, Residence of the client (urban or rural), occupational status, performing regular exercise, Doing daily activities independently, Sleep pattern, Frequency of AEDs taking/day, Side effect of the treatment, age of the patient when AEDs started, current co-morbidities and Level of anxiety and depression was significantly

associated with at least one of the seven domains of QOL score (table 4-8).

Overall quality of life domain: was significantly associated with level of depression (P= 0.006) (Table 6).

Seizure worry domain: of quality of life was significantly associated with occupational status, performing regular exercise, Perceived stigma because of the illness, current co-morbidities, Level of anxiety and level of depression(P<0.05) (Table 4).

Emotional wellbeing domain: was significantly associated with Sex, Perceived stigma because of the illness, Level of anxiety and depression (P<0.05) (Table 6).

Energy/Fatigue domain: was significantly associated with Level of anxiety and depression (P<0.05) (Table 6).

Cognitive Function domain: was significantly associated with Residence of the client (urban or rural), frequency of AEDs taking per day, Side effect of the treatment, current comorbidity, Having enough and regular sleep, and Level of anxiety and depression(P<0.05) (Table 7).

Medication effect domain: was significantly associated with level of anxiety and depression, Doing daily activities independently, Perceived stigma because of the illness and age of the patient when AEDs started (P<0.05) (Table 8).

Social functioning domain: was significantly associated with level of anxiety and depression, frequency of AEDs taking per day and current co-morbidity (P<0.05) (Table 5).

Table 4: Multivariable analysis result of variables predicting the seizure worry of QOLIE-31 instrument among epileptic patients at JUMC, Jimma, Ethiopia. 2015 (n= 304)

QOLIE-31 domains	Variables	Unstandardized B	P	95% CI for B	
				Lower Bound	Upper Bound
Seizure worry	Constant	48.568	.000	32.502	64.635
	Current co-morbidities Yes No	-9.889	.001*	-15.548	-4.229
	Performing regular physical exercise Yes No	6.409	.040*	.305	12.513
	Housewife Non housewife (ref)	-18.154	.001*	-29.010	-7.298
	Student Non student (ref)	-8.753	.028*	-16.536	-.970
	Anxiety No anxiety(ref)	-7.653	.012*	-13.606	-1.700
	Depression No depression(ref)	-8.598	.005*	-14.591	-2.605

Dependent variable: Seizure worry domain
Non housewifes: Those without occupation, Merchants, Farmers, Daily laborers, Governmental employees and Students
Non students: Those without occupation, Merchants, Farmers, Daily laborers, Governmental employees and Housewifes
*Note: *represents variables having statistically significant association. ref: Represents "reference"*

Table 5: Multivariable analysis result of variables predicting social functioning domain of QOLIE-31 instrument among epileptic patients at JUMC, Jimma, Ethiopia, 2015. (n= 304)

QOLIE-31 domains	Variables	Unstandardized B	P	95% CI for B	
				Lower Bound	Upper Bound
Social functioning Domain	Constant	78.122	.000	71.392	84.851
	Frequency of AED taking /day Once/day ≥2 times/day	5.581	.004*	1.769	9.393
	Current comorbidities Yes No	-6.060	.011*	-10.731	-1.389
	Anxiety No Anxiety(ref)	-8.365	.002*	-13.602	-3.128
	Depression No depression(ref)	-6.485	.017*	-11.809	-1.160

Dependent variable: social functioning domain
*Note: *represents variables having statistically significant association.*
ref: Represents "reference"

Table 6: Multivariable analysis result of variables predicting the Emotional wellbeing, Energy/Fatigue and Overall QOL domains of QOLIE-31 instrument among epileptic patients at JUMC, Jimma, Ethiopia, 2015. (n= 304)

QOLIE-31 domains	Variables	Unstandardized B	P	95% CI for B	
				Lower Bound	Upper Bound
Emotional wellbeing domain	Constant	60.594	.000	50.876	70.312
	Sex Male Female(ref)	4.368	.007*	1.228	7.507
	Perceived stigma Yes No	-6.406	.000*	-9.733	-3.079
	Anxiety No anxiety(ref)	-8.528	.000*	-12.705	-4.351
	Depression No depression(ref)	-9.481	.000*	-13.739	-5.224
Energy/ Fatigue domain	Constant	67.487	.000	64.024	70.951
	Anxiety No Anxiety(ref)	-5.136	.014*	-9.212	-1.060
	Depression No depression(ref)	-8.112	.000*	-12.356	-3.867
Overall QOL domain	Constant	48.954	.000	37.354	60.554
	Depression No depression(ref)	-6.899	.006*	-11.807	-1.991

Dependent variable: Emotional wellbeing domain, Energy/Fatigue domain, Overall QOL domain
*Note: *represents variables having statistically significant association.*
ref: Represents "reference"

Table 7: Multivariable analysis result of variables predicting the Cognitive function domain of QOLIE-31 instrument among epileptic patients at JMC, Jimma/Ethiopia, 2015 (n= 304)

QOLIE-31 domains	Variables	Unstandardized B	P	95% CI for B	
				Lower Bound	Upper Bound
Cognitive function domain	Constant	85.745	.000	72.511	98.979
	Residence Rural Urban (ref)	-5.255	.003*	-8.722	-1.788
	Frequency of AEDs taking/day Once/day ≥2 times /day (ref)	4.122	.011*	.941	7.302
	Side effects of AEDs Yes No	-3.568	.029*	-6.766	-.370
	Current comorbidities Yes No	-4.997	.014*	-8.987	-1.008
	Enough and regular sleep Yes No	3.866	.046*	.062	7.669
	Anxiety No anxiety (ref)	-6.792	.002*	-11.126	-2.457
	Depression No depression (ref)	-11.902	.000*	-16.278	-7.526

Dependent variable: Cognitive function domain
*Note: *represents variables having statistically significant association.*
ref: Represents "reference"

Table 8: Multivariable analysis result of variables predicting the Medication effect domain of QOLIE-31 instrument among epileptic patients at JMC, Jimma/Ethiopia, 2015 (n= 304)

QOLIE-31 domains	Variables	Unstandardized B	P	95% CI for B	
				Lower Bound	Upper Bound
Medication effect domain	Constant	77.888	.000	69.932	85.844
	Doing daily activities Independently Yes No	7.496	.012*	1.678	13.314
	Perceived stigma Yes No	-5.372	.019*	-9.838	-.906
	Age of the patient when AEDs started	-.723	.020*	-1.329	-.116
	Anxiety No Anxiety(ref)	-11.375	.000*	-17.249	-5.501
	Depression No depression (ref)	-7.926	.006*	-13.567	-2.286

Dependent variable: Medication effect domain
*Note: *represents variables having statistically significant association*
ref: Represents "reference"

V. Discussion

Epilepsy has a great influence on the three levels of quality of life (physical, mental and social health), where the social functioning has a significant role in obtaining a good QOL.

In the current study, sex is associated with emotional well-being function. It was found that among the Male patients emotional well-being domain of QOL score were higher than female a counterpart which is similar with the Indian studies [11, 12]. These women came from both urban and rural areas in economic transition. This may indicate that biological and psychological factors (family issues, personal life, and motherhood) may play a more important role. Therefore,

future studies need to find the reason for this lower quality of life in women with epilepsy.

In this study, residence of patient was associated with cognitive aspect quality of life. Those clients living in rural area has lower quality of life. This may be related to information difference about the disease and treatment, higher cost and distance to reach health institution among the rural residents and also may be higher social isolation in the rural area. This result is similar with previous studies done in Kenya and India [13, 14].

Seizure worry domain of quality of life is associated with occupation of the patient. According to study quality of life is decreased among housewife and students. The groups are dependent to other family members for economic dependence. This study is similar with previous studies [13, 15, 16, 25].

Regarding clinical factors, frequency of AEDs taking per day was a factor associated with cognitive function and social function domains. Quality of life is higher among patients who were taking AEDs once a day (QD) than two or greater times per day. Similarly different literatures [10, 15-18] suggested that polytherapy receiving patients had lower mean QOL score as compared to their counterpart.

In this study cognitive aspect of quality of life was associated with Side effect of the treatment. Those patients who reports side effect of current AEDs has lower quality of life. This finding is concurrent with previous study done including Uganda and South Korea with the same instrument [3, 10, 19].

In current study medication effect and social function domain of quality of life has association with patient's age when AEDs started. Quality of life decreased as among clients who started AEDs at older age which is similar with study finding from South Korea [15]

According to this study, overall HRQOL score and all domains of quality of life score is decreased among patients experiencing current comorbidity. Having current anxiety and depression decreased overall HRQOL score than those without anxiety and depression. This was consistent with the result of most studies which assessed comorbidities as well as level of anxiety and depression [17, 19-23].

Concerning personal factors of the patients, current experience of having enough and regular sleep associated with higher cognitive function domain of QOL. Also Emotional wellbeing, medication effect and social function domain of quality of life score was lower among patients who experienced perceived stigma because of the illness which is in line with previous studies [10, 15, 17]. Another finding of this study was performing regular exercise was associated with better score of seizure worry domain of quality of life scale. Also Medication effect domain was associated with doing daily activities independently.

VI. Conclusions And Recommendations

Being female, Rural residence, Taking AEDs several times per day, becoming older age, side effect of treatment, current comorbidity with anxiety and depression and other disease, and also those with perceived stigma were associated with lower quality of life. On the other hand performing regular exercise, performing daily activities and enough and regular pattern of sleep were related to better QOL.

It is evident that current management of epilepsy that focuses on only seizure control does not improve HRQOL of the patients receiving AEDs. In addition to controlling seizure and antiepileptic drugs side effects, the treatment of epilepsy should include clinical counseling and other interventions to address the physical, mental, psychological, social and emotional aspects for health wellbeing is likely to achieve better health outcomes for epileptic patients. Also recognition of co morbid psychiatric illness like depression and anxiety in people with epilepsy should be of great concern for health care providers.

a) Consent for publication

All authors are agreed to disseminate and publish the current research result

b) Availability of data and materials

All the data sets used and/or analyzed during this study are included in the article.

c) Author's contribution

This work was carried out in collaboration between all authors. Author DS designed the study, performed the statistical analysis, wrote the protocol, and wrote the first draft of the manuscript. Author EH managed the analyses of the study. Author DS managed the literature searches. Both authors read and approved the final manuscript.

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