

Health related quality of life and associated factors among adult patients with epilepsy attending Mizan Tepi University Teaching Hospital, Southwest Ethiopia

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A thesis submitted to department of epidemiology, faculty of public health, institute of health, Jimma university; in partial fulfillment of the requirements for masters of public health degree in epidemiology.

June, 2019

Jimma, Ethiopia

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Abstract

Introduction: *In Ethiopia more than 1 million people are estimated to have epilepsy and it remains to be the most prevalent, neglected, and serious neurological disorder. Epilepsy is a devastating disorder that impacts on patients' quality of life. This study assessed health related quality of life and associated factors among patients with epilepsy Mizan Tepi University Teaching Hospital, Southwest Ethiopia, 2019.*

Methods: *This is an institution-based cross-sectional study conducted from February 25 to April 6, 2019. A total of 346 patients with epilepsy who visited the clinic for follow-up for at least 3 months and who were 18 years or older were included in the study. Study subjects were selected using simple random sampling technique. Quality of Life in Epilepsy Inventory 31 was used to assess quality of life. Multivariable linear regression was employed to identify associated factors with health related quality of life among patients with epilepsy.*

Results: *A total of 340 (98.3%) patients with epilepsy participated in the study. The mean score of health related quality of life was 55.6 (SD=20.9). Age ($\beta=-0.35$, 95%CI:-0.46,-0.23), anxiety ($\beta=-6.79$, 95%CI:-9.26,-4.32), depression ($\beta=-7.36$, 95%CI:-10.16,-4.55), low self-esteem ($\beta=-5.29$, 95%CI:-8.07,-2.51), perceived stigma ($\beta=-3.62$,95%CI:-6.30,-0.94), taking medication twice or more times per day ($\beta=-2.4$, 95%CI: -4.58, -0.27), being illiterate ($\beta=-4.1$, 95%CI:-6.87,-1.31) and having more than two seizures for a year ($\beta=-4.18$, 95%CI:-6.97,-1.39) were inversely associated with health related quality of life while income of ≥ 1000 birr per month ($\beta=4.5$, 95%CI:2.00, 6.99), social support ($\beta=0.34$, 95%CI:0.27, 0.40) and being free of seizure for a year ($\beta=6.5$, 95%CI:3.66,9.33) were directly associated with health related quality of life.*

Conclusion: *The mean health related quality of life score of patients with epilepsy in Mizan Tepi University Teaching Hospital is low. Health related quality of life was inversely associated with age, anxiety, depression, low self-esteem, perceived stigma, taking medication twice or more times per day, being illiterate and having more than two seizures for a year. Besides controlling of seizure, public educational campaigns should be conducted in order to raise awareness of the public regarding the need of social support, educational and economic opportunities and eliminate the stigma of epilepsy.*

Key words: Epilepsy: health related quality of life: South west Ethiopia

Acknowledgement

First of all, I would like to thank my beloved wife and my daughter for their unconditional love that kept me going.

Next I would like to extend my gratitude to my advisors Mr. Desta Hiko and Mr. Eshetu Alemayehu for their valuable comments and unlimited support.

Again I would like to thank Mrs. Washaworq, coordinator of psychiatry clinic in Mizan Tepi University Teaching Hospital for her cooperation and providing valuable information.

Last but not least I wish to express my gratitude to Jimma university department Epidemiology and extend my appreciations to Mizan Aman Health Science College, data collectors and my friends for their valuable support.

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List of Acronyms and Abbreviations

AEDs- Anti Epileptic Drugs

HADS Hospital Anxiety and Depression Scale

HRQOL- Health Related Quality of Life

ILAE International League Against Epilepsy

IPAQ International Physical Activity Questionnaire

IQR- Inter Quartile Range

JUSH- Jimma University Specialized Hospital

LMICs- Low and Middle Income Countries

MOH- Ministry of Health

MSPSSS- Multidimensional Scale of Perceived Social Support scale

MTUTU- Mizan Tepi University Teaching Hospital

NICE- National Institute for Health and Care Excellence

PLWE- People Living with Epilepsy

QOL- Quality of Life

QOLIE-31- Quality of Life in Epilepsy Inventory 31

SD- Standard Deviation

WHO- World Health Organization

WHOQOL- World Health Organization Quality of Life

CHAPTER ONE: Introduction

1.1 Background

Epilepsy is a common neurological disorder characterized by recurring seizures which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalized) (1). Epileptic seizures are the clinical manifestations (signs and symptoms) of excessive and/or hyper-synchronous, usually self-limited, abnormal activity of neurons in the brain. Epileptic seizures represent the most common positive signs and symptoms of brain disturbance. All epileptic seizures, however, are not epilepsy, which requires recurrent epileptic seizures in absence of acute pathology. An individual has a one in ten chance of experiencing at least one epileptic seizure in his/her life (2).

Epilepsy is a global health care issue affecting 50 to 70 million people worldwide. It accounts for 0.75% of the global burden of disease and an estimated 2.4 million people are diagnosed with epilepsy each year (1). The annual incidence and prevalence of epilepsy is 67.77 per 100,000 and 7.60 per 1,000 persons respectively(3) and nearly 80% of people with epilepsy live in low- and middle-income countries with limited resources (Southeast Asia, Latin America, sub-Saharan Africa), where the rate of new cases is up to twofold higher than that of high-income countries (1). Active epilepsy is estimated to affect 4.4 million people in Sub-Saharan Africa, while lifetime epilepsy is estimated to affect 5.4 million (4).

Epilepsy remains to be the most prevalent, neglected, and serious neurological disorder as well as one of the major causes of disability in Ethiopia and more than 1 million are estimated to have epilepsy with 500,000 would have active epilepsy (with seizure in the past 1-2 years), of which only 5% seek medical help (5). The annual prevalence and incidence is 5.2/1000 and 64 in 100,000 inhabitants at risk respectively and only 1.6% had been treated with recognized antiepileptic drugs in rural part of the country and as few as 13% were treated with antiepileptic drugs in cities like Addis Ababa (6).

As most of the people with epilepsy live outside of resource rich countries, extensive underdiagnosis, misdiagnosis, and undertreatment are likely (7). Its treatment has traditionally focused on medical therapy, sometimes to the exclusion of psychosocial and quality of life issues. Yet epilepsy can affect many factors that influence patients' quality of life. Coping with

chronic illness, medication issues and side effects, as well as cognitive and behavioral issues related to epilepsy can all have detrimental effects on quality of life (8).

In epilepsy, an often used disease-specific quality of life instrument is the Quality of Life in people living with epilepsy (QOLIE-31) (9). It is characterized by a mix of diverse cognitive and personality measures representing a battery type approach in order to characterize disease and treatment effects and patient status (10).

1.2. Statement of the problem

According to international league against epilepsy (ILAE) epilepsies are classified into four categories as generalized epilepsy, focal epilepsy, combined generalized and focal epilepsy and unknown category (11). Active epilepsy has been defined as epilepsy that has caused two or more unprovoked seizures on different days in the year prior to the assessment date. The condition has serious physical, psychological, social and economic consequences for the concerned persons and their families. Epilepsy is a devastating disorder that impacts on patients' quality of life, irrespective of use of anti-epileptic drugs (AEDs) (2).

Quality of life is a combination of a person's physical, mental and social wellbeing; not just the absence of disease (12). Health related quality of life has come to mean a combination of subjectively assessed measures of health, including physical function, social function, emotional or mental state, burden of symptoms and sense of wellbeing. The development and use of such subjective measures of health status and health related quality of life have been one of the defining aspects of epidemiology. Issues concerning health related quality of life (HRQOL) may well vary with different cultural value systems and different HealthCare Systems(13).

Two-thirds of people with active epilepsy have their epilepsy controlled satisfactorily with anti-epileptic drugs (AEDs). But treatment gap varies from 10 percent in developed countries to 75 per cent in low income countries. Optimal management improves health outcomes and can also help to minimize other, often detrimental, impacts on social, educational and employment activity (12). The annual direct medical and indirect cost of epilepsy in the United States and United Kingdom is estimated \$15.5 and £2 billion respectively (14,15).

Stigma and discrimination related to epilepsy are prevalent worldwide. In many LMICs, lack of medical facilities and social stigma contribute to people with epilepsy being hidden away, unable to contribute to the household's welfare and unable to contribute to the economic burden of epilepsy. Non-adherence has been shown to be linked with increased mortality and morbidity, including more seizures and higher levels of status epilepticus, and negative outcomes such as lower educational attainment, greater cognitive impairment and poorer quality of life (15,16).

Research has shown that many aspects of wellbeing are affected by the experience of epilepsy. Patients face a range of HRQOL problems, whether or not their seizures are well controlled, including limitations of their employment and social opportunities, perceived stigma,

psychological sequelae, including anxiety and depression, memory problems, and other cognitive disturbances, and problems relating to marriage and family life(17).

Issues may also arise as a result of the stigma attached to having epilepsy, which can have led to embarrassment and frustration or bullying, teasing, or avoidance in school and other social settings. For many people with epilepsy, the risk of seizures restricts their independence (some states refuse drivers licenses to people with epilepsy) and recreational activities. Having seizures may make it more difficult to find a job or do certain types of work (18). Even when the best diagnostic and therapeutic facilities are available, about one-third of people with epilepsy fail to achieve seizure freedom and a good quality of life (19).

In one prospective study on HRQOL, mood, and patient satisfaction in epilepsy surgery candidates before and 2 years after epilepsy surgery, HRQOL was improved and anxiety was decreased in patients who were seizure-free after epilepsy surgery. Operated patients found surgery beneficial. But a very important point noticed in that study was that only about half of the seizure-free patients showed HRQOL improvements, in which that seizure freedom does not always improve patients' quality of lives (20).

Although there are numerous studies assessing the HRQOL; In Ethiopia there are limited (only two) studies that addressed quality of life among epileptic patients. One study conducted in Amanuel Specialized Mental Hospital utilized WHOQOL instrument, which is not disease-specific quality of life instrument in patients living with epilepsy. Another study conducted in Jimma university specialized hospital, even though it utilized QOLIE 31 inventory instrument which is an often used epilepsy-specific quality of life instrument; it lacks objective measurements and used subjective items to collect data on self-esteem, physical activity and perceived stigma. Moreover, it didn't assess some important factors like medication adherence and social support which are associated with HRQOL. In addition, the level of, and factors affecting, HRQOL in patients with epilepsy in study area, have not yet been addressed. Therefore, the current study will fill these gaps as it assessed these factors using objective items (validated measurement tools) among PWE in MTUTH.

CHAPTER TWO: Literature Review

2.1. Epilepsy and health related quality of life

Living with epilepsy includes not only dealing with seizures and their impact on health, but also involves developing knowledge and skills to manage the psychological and social challenges and co-existing health conditions associated with the disorder, side effects of medications, and fears of discrimination and prejudice all of which can significantly affect quality of life (21).

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 HRQOL. A systematic review that included 31 countries, of which only 8 were LMICs, revealed that the global mean QOLIE-31 score was 59.8 with a range from 42.1 in the Russian Federation to 82 in Canada. There was a statistically significant difference seen in the QOLIE-31 score by world region and income category, with lower country income level associated with worse QOL (22).

2.2. Socioeconomic factors and HRQOL among epileptic patients

A cross-sectional study carried out on health related quality of life and associated Factors among adult epileptic patients taking Anti-epileptic drugs at Jimma University Specialized Hospital chronic illness clinic, showed that the mean QOL of people living with epilepsy was 58.8 which ranges from 50.8-63.6 across seven domains. Being female and rural residence, were associated with lower quality of life (23). Similarly, various studies revealed that being female (24–28), lower educational attainment level (25,28–31), not being employed (25,28,29,32), younger age (26,30,32), low income (26,29,32) , living in a rural residence (29) and being married (27) were found to be associated with lower mean total QOLIE-31 scores. But, a study in Uganda revealed that being female and married, were significantly associated with better HRQOL (31). Similarly, a study in China reported that married adult epileptic patients have better quality of life than that of unmarried adult patients (33). On the other hand, social support was positively associated with HRQOL(26). Despite of this a study conducted in Serbia, Thailand and Malaysia stated that socio-demographic factors like age, sex, education, employment and marital status were not correlated with QOLIE-31 score (34–36).

Studies conducted in Brazil, JUSH, Malaysia and Warsaw; showed that being female, unemployment and lower educational status were correlated with lower scores in the dimensions of seizure worry (23,24,35,37).

A cross sectional study conducted in Romania on the assessment of quality of life in patients with epilepsy indicated that unemployment and low income; were significantly correlated with lower mean score of social function (32).

A cross sectional study conducted in Warsaw on quality of life in patients with epilepsy showed that marital status and employment were significantly correlated with mean score of cognitive function (37). Likewise, different studies showed that age, unemployment and low income (32), being rural Residence (23) and being female (24) were negatively correlated with cognitive function.

A cross sectional study conducted in Brazil on epilepsy and quality of life: socio-demographic and clinical aspects, and psychiatric co-morbidity indicated that being female was significantly correlated with lower emotional wellbeing mean score (24). Different studies also showed that being female (23), unemployment and low income (32), were significantly correlated with lower emotional wellbeing mean score.

Studies in Brazil and Romania also stated that females (24), unemployment and low income (32) was correlated with lower Energy/Fatigue domain mean score.

A cross sectional study conducted in Russia on factors influencing quality of life in people with epilepsy stated that age was negatively correlated with medication domain mean score (38). On the other hand, low income also was correlated with lower Medication effects domain mean score (32).

2.3. Clinical and psychological characteristics and health related quality of life

A cross sectional study conducted on quality of life among epilepsy patients in Zhuang populations in Guangxi Guixi area showed that patients with single AED had higher QOLIE-31 scores than those with multiple AEDs (39). Also, various studies revealed that; seizure frequency (24,26,41,27–29,31,32,34,35,40) , polytherapy (24,28,31,41–43), duration of disease (24,27,38), AED side effects (26,31,44), anxiety and depression (23,25,26,34,35,41,44), and less adherence(25), was associated with lower overall HRQOL.

According to a study conducted in Brazil, JUSH, Malaysia and Warsaw; patients using polytherapy with AED, current co-morbidities, and frequency of seizures were significantly correlated with lower scores in the dimensions of seizure worry (23,24,35,37).

Seizure frequency (24,32,35) and using poly-therapy with AED (24), duration of disease (38), taking AEDs several times per day and current co-morbidity (23) were significantly correlated with lower mean score of social function.

The Romanian and Brazilian study showed that seizure frequency was negatively correlated with cognitive function (24,32). Similarly, taking AEDs several times per day, side effect of the treatment and current comorbidity was negatively correlated with cognitive function (23).

Studies in Brazil and Malaysia also stated that seizure frequency was significantly correlated with lower Energy/Fatigue domain mean score (24,35). Also, presence of comorbidity was correlated with lower Energy/Fatigue domain mean score (23).

Studies in Russia and Malaysia indicated that duration of disease (38) and seizure frequency (35) were negatively correlated with Energy/Fatigue domain mean score.

2.4. Personal factors

A cross sectional study conducted on quality of life among epilepsy patients in Bhutan showed that increased self-perceived stigma was found to be associated with lower overall QOLIE-31 scores (30). Similarly, various Studies indicated that increased self-perceived stigma was found to be associated with lower overall QOLIE-31 scores (23,25,44).

Another study done in Brazil on physical activity, stigma, and quality of life in patients with epilepsy revealed that less physical activity is associated with worse quality of life, and higher perception of stigma (45). On the other hand, performing regular exercise (23,46) was positively correlated with QOLIE-31 scores.

2.5. Conceptual Frame Work

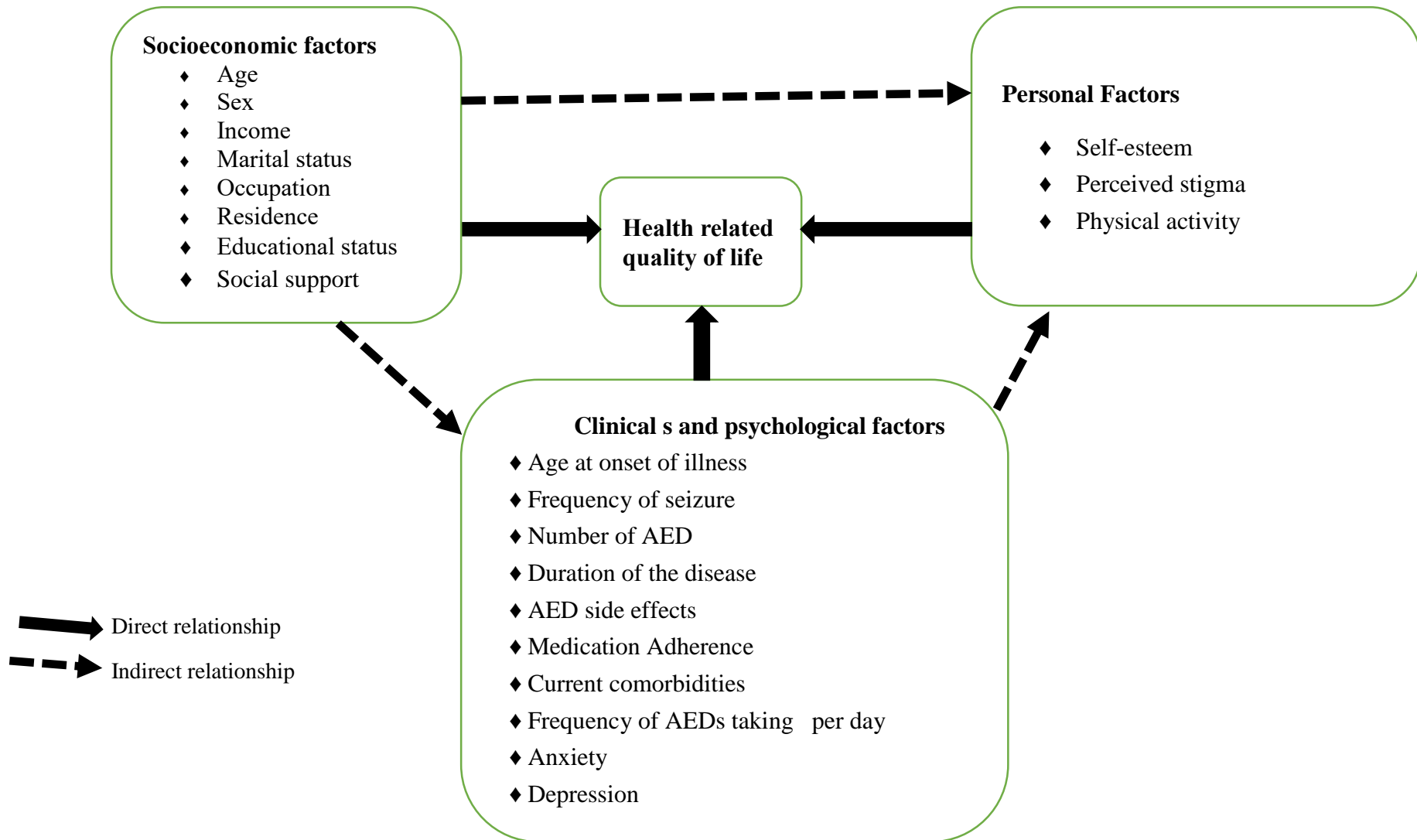


Figure 1 Conceptual framework of the study developed after reviewing literatures

2.6. Significance of the study

Very little study has been done on the socio-demographic, clinical and psychosocial impact of epilepsy on PWE receiving treatment in Ethiopia. This has compounded the neglect on this aspect of the patients' life in the approach to treatment. This study will highlight the impact of living with epilepsy on the quality of life. It will also provide information to health providers to plan time relevant and client specific treatment. The finding from this study will provide information to decision makers and program planners to develop treatment strategies and evaluate existing epilepsy care management. The increased identification of patients' problems with daily functioning and well-being can guide management and lead to improvement in quality of care and patients' HRQOL.

CHAPTER THREE: Objectives

3.1. General Objective

To assess health related quality of life and identify associated factors among patients with epilepsy attending Mizan-Tepi University Teaching Hospital, Southwest Ethiopia, 2019

3.2. Specific Objectives

1. To assess health related quality of life among patients with epilepsy.
2. To identify factors associated with health related quality of life among patients with epilepsy.

CHAPTER FOUR: Methods and materials

4.1. Study area and period

The study was carried out at Mizan Tepi University Teaching Hospital, which is located in Bench Maji zone, Southern Nations, Nationalities, and Peoples' Region (SNNPR), South west Ethiopia. It is 583 kilometers away from Addis Ababa in southwest direction. This hospital was founded in 1987 G.C. It serves more than 1 million people. Now the hospital has 58 medical doctors, 4 specialists, 79 nurses, 75 supportive staff members, and 150 administrative staff members. The hospital has four chronic disease follow-up clinics. Psychiatric clinic is one of those clinics which give service for patients with epilepsy disorder. The clinic currently gives service for about 736 adult epileptic patients. The clinic is staffed with one psychiatry nurse and one health officer. The study was conducted from February 25 to April 6, 2019.

4.2. Study design

A facility based cross sectional study design was employed.

4.3. Population

4.3.1. Source population

All adult (≥ 18 years) patients with epilepsy attending psychiatry clinic of Mizan Tepi University Teaching Hospital for follow up.

4.3.2. Study population

Adult (≥ 18 years) patients with epilepsy attending psychiatry clinic of MTUTH and fulfilled inclusion criteria.

4.3.3. Inclusion criteria

All types of epilepsy (according to ILAE classification) that has been on anti-epileptic drug follow up for at least 3 months with an expectation that patients had a good experience on AEDs were included (23,36)

4.3.4. Exclusion criteria

Two patients who were seriously sick at the time of interview and two patients with severe cognitive impairment were excluded.

4.4. Sample size calculation

4.4.1 Sample size

Among 736 adult patients with epilepsy appointed for the next 1 month from initiation of data collection, 698 were eligible to be included in the study

Sample size formula for first objective
$$n = Z \frac{\alpha}{2}^2 \frac{\sigma^2}{d^2}$$

The sample size for HRQOL was determined using mean for estimation of a single population mean formula using Statulator beta online sample size calculator available at <http://statulator.com/SampleSize/ss1M.html>

(σ)= population standard deviation of overall quality of life score =20 (23). d = The margin of error (level of precision required,) =1.5, α = critical value at 95% confidence interval of certainty (1.96) and the final sample size was = 346.

Sample size formula for second objective
$$n = \frac{z^2 \cdot (\sigma_1^2 + \sigma_2^2)}{d^2}, Z = Z_{\alpha/2} + Z_{\beta}$$

The sample size for factors associated with HRQOL was determined using sample size for comparing two means formula using Openepi online sample size calculator available at <https://www.openepi.com/SampleSize/SSCohort.htm>. d= the difference that we would like to detect between the means), d=mean 1 minus mean 2

Table 1 Sample size determination for factors associated with QOL

Factors	Mean QOL	σ (standard deviation)	d	CL	Power	Ratio of sample size(G2/G1)	Sample size	Reference	
Seizure frequency	≤ 1 per year	64.5	14.6	8	95%	80%	1	61*2=122	(24)
	> 1 per year	56.5	16.8						
Sex	Male	66.0	15.2	5.1	95%	80%	1	167*2=334	(47)
	Female	60.9	17.9						

Therefore, the final sample size for both HRQOL and associated factors was 346.

4.4.2 Sampling technique/ procedure

Patient serial number on follow-up registration logbook was used to get a sampling frame. Then simple random sampling technique was employed using the “select case” procedure on SPSS V.21 to select 346 samples.

4.5. Study variables

4.5.1. Dependent Variable

Health related quality of life

4.5.2. Independent variables

Socioeconomic factors: Age, sex, marital status, income level, educational level, occupational status, religion, ethnicity, residence, social support.

Clinical and psychological factors: Age at onset of illness, duration of illness, duration of AEDs, frequency of AEDs, side effect of AEDs, frequency of seizure, anxiety, depression and current co-morbidities.

Personal factors: Self- esteem, perceived stigma, physical activity.

4.6. Data collection procedures

4.6.1 Data collection instrument and personnel

Data was collected from the participants using multipart structured questionnaire through face to face interview and by reviewing patient chart. The first part of the questionnaire was used to collect data regarding sociodemographic and clinical characteristics of the participants. Seven instruments regarding participants’ medication adherence, psychological status, perception of self-esteem, social support, perception of stigma, level of physical activity and health related quality of life were employed to generate outcome measurements.

Data was collected by three diploma nurses through face to face interview and record review. One health officer was assigned as a supervisor at the time of data collection and the overall data collection process was supervised by the principal investigator.

The data was collected from Monday to Saturday (a day epileptic patients come for follow up) by using a pretested structured questionnaire and by reviewing patient chart. The patients were interviewed after they get the service they needed from the clinic. Also patient’s charts were

reviewed by using structured check list. The items were formulated in a manner that elicits the required data from the chart.

4.6.2. Measurements

4.6.2.1 Quality of life in epilepsy-31(QOLIE-31)

QOLIE-31 Health Survey was used to assess HRQOL. Only the person who has epilepsy was interviewed (not a relative or friend) because no one else knows how they feel. There were 31 questions about the patient ‘s health and daily activities (48). In total, the questionnaire comprises seven different scales: Seizure Worry (five items), Emotional Well-Being (five items), Energy/Fatigue (four items), Social Function (five items), Cognitive Function (six items), Medication Effects (three items), Overall Quality of Life (two items). In addition, there was a single item covering overall health. The scale was scored from 0 to 100. To account for these differences, the scoring system requires conversion from raw, pre-coded numeric values to scores of 0-100 points, with higher converted scores always reflecting better HRQOL. Converted scores for items summed and divided by the number of items in each scale that are answered to determine the Scale Score (range 0-100 points). The total score is not a simple sum or mean of the seven subscales. Overall score was calculated by weighting and summing the product of QOLIE-31 scale scores times its weight and summing over all scales using an empirically derived coefficient to weight and sum scores. To derive QOLIE-31 scale weights QOLIE-89 summary score was regressed on the 7 QOLIE-31 multi item scales. Standardized beta coefficients from this regression analysis were summed, and each beta coefficient was divided by the sum to derive the relative weight for each QOLIE-31 scale. Internal consistency is ranged from 0.77 to 0.93 across all domains (49).

Table 2 Formula for calculating QOLIE-31 overall score

QOLIE-31 scale	Final score	Weight	Subtotal (Final score*weight)
Seizure worry	_____	0.08	
Overall quality of life	_____	0.14	
Emotional well-being	_____	0.15	
Energy/fatigue	_____	0.12	

Cognitive functioning	_____	0.27	
Medication effects	_____	0.03	
Social functioning	_____	0.21	
Total/overall score(sum of all domains)			_____

4.6.2.2. *The Hospital Anxiety and Depression Scale (HADS)*

Current psychological distress was measured by the 14-item Hospital Anxiety and Depression Scale (HADS) which classifies cases or borderline cases of anxiety and depression with cut-offs at 0–7 for normal, 8–10 for borderline, ≥ 11 for case estimates (50). The Amharic version of HADS had been validated to be used in Ethiopia with Cronbach’s alpha for anxiety and depression subscales and the full scale ranging from 0.78 -0.81, 0.76 and 0.87 respectively (51).

4.6.2.3. *The Rosenberg self-esteem scale*

The Rosenberg self-esteem scale was used to assess respondent’s self-esteem. It consists 10 questions. Each question has 4 choices. Positive question ranged from 3 to 0(strongly agree to strongly disagree). Negative questions' which are reversed scores. The score range from 0-30. Score of 15 to 25 are within normal range; scores below 15 suggest low self-esteem. The internal consistency is also acceptable with Cronbach’s alpha coefficient level of 0.97 (52,53).

4.6.2.4. *The Medication Management subscale*

Medication adherence was recorded using the ten-item Medication Management subscale from the Epilepsy Self-Management Scale. Scores range from 10 to 50, with greater scores indicating better adherence to medication plans (54).

4.6.2.5. *The stigma of epilepsy scale.*

To measure the social impact of epilepsy, perceived stigma was assessed with the stigma of epilepsy scale. It includes three items. It is scored on a Likert type four-point scale: “not at all”, “yes, maybe”, “yes, probably” and “yes, definitely”, which is scored from 0 to 9 and categorized as not stigmatized (score of 0), mild-moderate (score of 1–6) and highly stigmatized (score of 7–9). The internal consistency is also acceptable with Cronbach’s alpha coefficient level of 0.78 (55).

4.6.2.6. *International Physical Activity Questionnaire short form (IPAQ)*

Physical activity was assessed using the seven-item International Physical Activity Questionnaire short form (IPAQ). This measure assesses the types of intensity of physical activity and sitting time that people do as part of their daily lives are considered to estimate total physical activity in MET-min/week and time spent sitting. MET minutes represent the amount of energy expended carrying out physical activity. A MET is a multiple of their estimated resting energy expenditure. One MET is what respondent expend when he/she is at rest. Therefore 2 METS is twice what he/she expend at rest.

The development of an international measure for physical activity commenced in Geneva in 1998 and was followed by extensive reliability and validity testing undertaken across 12 countries (14 sites) during 2000. The final results suggest that these measures have acceptable measurement properties for use in many settings and in different languages, and are suitable for national population-based prevalence studies of participation in physical activity (56,57).

4.6.2.7. *Multidimensional Scale of Perceived Social Support(MSPSS)*

Perceived social support was assessed using the 12-item Multidimensional Scale of Perceived Social Support(MSPSS). The items directly address social support tended to divide into factor groups relating to the source of the support (i.e., Family, Friends, or Significant Other). Each of these groups consisted of four items. A 7-point rating scale ranging from very strongly disagree (1) to very strongly agree (7) was implemented. The total score ranges from 12 to 84. Higher scores indicate strong social support. The reliability of the total scale is 0.88 (58).

4.6.3. Data Processing and Analysis

Data were coded, recoded, cleaned and explored to identify outliers, missing values and inconsistencies. The coded data were checked for completeness and entered into EpiData manager 4.4 and analyzed by SPSS V.21. In the descriptive analysis, the mean with SD, frequency and percentages were calculated. For the purpose of this analysis, dummy variables (for k categories, k-1 dummy variables) were created for categorical variables such as educational status, marital status, occupational status, level of anxiety, level of depression, level of physical activity, level of perceived stigma, level of self-esteem and frequency of seizure.

Skewness that ranged in between ± 1 was taken as normally distributed; except for the duration of disease, all variables satisfied normality assumptions. Duration of disease did not satisfy normality assumption, so to normalize we used logarithmic transformation. Linearity assumptions and homogeneity of variances were checked by scatter plots, and there was no clear pattern on scatter plot (no heteroscedasticity). Durbin-Watson of 1.5–2.5 was taken as independent observations and there was no autocorrelation threat.

Multicollinearity was checked and the maximum variable inflation factor reported was 1.92, which indicates that there was no multicollinearity threat. Interaction terms were created for seizure frequency with depression, seizure frequency with stigma, seizure frequency with anxiety, seizure frequency with self-esteem, anxiety with depression and depression with self-esteem and they were all not significant.

Simple and multivariable linear regression were fitted for overall HRQOL to identify associated variables. For the goodness of model fit, all linear regression assumptions (i.e. adjusted R-squared, overall F-test, residual plots and outliers) were considered. According to these parameters the fitted model was good of fit to explain outcome variables (adjusted $R^2=0.794$, $F(11,328)=119.6$, $p<0.001$). Variables with a p value less than 0.25 during the simple linear regression were selected for multivariable linear regression. Stepwise variable selection method was used to identify independently associated variables. A p value less than 0.05 was considered as independently associated factor for multivariable linear regressions.

4.6.4. Data quality management

A standardized and validated questionnaire was prepared in English and translated to Amharic and retranslated back to English for consistency. The questionnaire was pretested on 5% (18) of the population a week before actual data collection period in Mizan Health Center. The response rate during the pretest was 100%, and some modifications such as correction of typing errors, and arrangement of the questionnaire (some items were reverse-coded) were done. During the pretest, internal consistency of the questionnaire was assessed and Cronbach's alpha was computed; QOLIE-31 (0.71-0.91 across all domains), self-esteem (0.98), medication adherence (0.74), stigma (0.79), and social support (0.97), which was acceptable for this population.

To collect expected quality, data collectors and supervisor were trained for two days until they become familiar with the instrument. The training included the contents of the tool, ethical

considerations, and way of data mining from the chart. At time of data collection filled questionnaires were checked for completeness and consistency of information by the supervisor on daily basis and typing errors were edited manually. After data collection, each filled checklist were given a unique code by the principal investigator.

4.6.5. Operational definitions

Health related quality of life: was based on total score calculated on the Quality of Life in Epilepsy Inventory- 31 scale (QOLIE- 31). Total score ranges from 0-100 points, with higher score reflect better HRQOL.

Seizures frequency- the number of seizures occurred in the last 1 year prior to the interview.

Co-morbidity – those patients with “a medical or psychiatric or neurologic condition which causes, is caused by, is related to or simply coexists with epilepsy” and that was verified by a physician were considered having comorbidities.

Anxiety: those patients with HADs scored for anxiety 8 and above were considered having the problem.

Depression: those patients with HADs scored for depression 8 and above were considered having the problem.

Low self-esteem: those patients with Rosenberg self-esteem scale scored below 15 were considered having the problem.

Medication adherence: self-report medication adherence was based on total score calculated on the Medication Management subscale from the Epilepsy Self-Management Scale. Scores ranged from 10 to 50, with greater scores indicated better adherence to medication plans.

Perceived stigma: those patients with stigma of epilepsy scale scored one and above were considered having the problem.

Physical activity: was based on total score calculated on the international physical activity questionnaire score.

Those who scored HIGH on the IPAQ engaged in

- Vigorous intensity activity on at least 3 days achieving a minimum total physical activity of at least 1500 MET minutes a week OR
- 7 or more days of any combination of walking, moderate intensity or vigorous intensity activities achieving a minimum total physical activity of at least 3000 MET minutes a week.

Those who scored MODERATE on the IPAQ engaged in

- 3 or more days of vigorous intensity activity and/or walking of at least 30 minutes per day OR
- 5 or more days of moderate intensity activity and/or walking of at least 30 minutes per day OR
- 5 or more days of any combination of walking, moderate intensity or vigorous intensity activities achieving a minimum total physical activity of at least 600 MET minutes a week.

Those who did not meet any of the criteria for either MODERATE or HIGH levels of physical activity scored a LOW level of physical activity on the IPAQ.

Social support: was based on total score calculated on the Multidimensional Scale of Perceived Social Support scale. The total score ranged from 12 to 84. Higher scores indicated strong social support.

4.6.6. Ethical consideration

Before the study begins ethical clearance was obtained from the ethical review committee of Jimma University. Official permission was secured from the Mizan Tepi University Teaching Hospital. The study subjects were informed about the objective and purpose of the study and verbal consent was obtained from participants. Information provided were kept in separate room.

4.6.7. Dissemination plan

The findings of this study was presented to JU, Institute of Health, Epidemiology Dept. It Will be presented to concerned bodies and in the study area. The findings will be presented in different seminars, meetings and workshops. The result will also be disseminated through publication on reputable journal.

5. Result

5.1 Socioeconomic Characteristics of the Respondents

A total of 340 patients with epilepsy participated in the study making the response rate 98.3%. The mean age of the participants was 31.26 (SD= 10.12) years. Of 340 subjects, 183 (54%) were males, 189(55.6%) were married, 183 (53.1 %) were rural dwellers, 212 (62.4 %) were protestant, 89 (26.2%) can read and write, 232(68.2 %) had job and 128 (37.6 %) were Bench by ethnicity (Table 3). The mean score for the perceived social support was 56.86 (SD=20.48).

Table 3. Socio-demographic characteristics of adult patients with epilepsy attending Mizan Tepi University Teaching Hospital (N=340), 2019

Variable		Frequency	Percent
Sex	Male	183	53.8
	Female	157	46.2
Ethnicity	Bench	128	37.6
	Menit	53	15.6
	Kafa	61	17.9
	Sheko	50	14.7
	Amhara	41	12.1
	Others	7	2.1
Marital Status	Married	189	55.6
	Single	125	36.8
	Divorced	23	6.8
	Others (widowed and separated)	3	0.9
Educational level	Illiterate	78	23
	Can read and write	89	26
	Primary level (1-8)	73	21
	Secondary level (9-12)	70	21
	Tertiary level (college and above)	30	9
Occupational status	Have occupation	232	68.2
	No occupation	65	19.1
	Student	43	12.6

5.2. Clinical and psychological Characteristics of the Respondents

The mean age at onset of epilepsy was 23.97(SD=8.1) years. The median duration of epilepsy since its onset was 3.1 years (IQR=4 years). Two hundred seventy-five (80.9 %) of the respondents had one or more seizure attacks for a year, 232(68.2%) were taking one type of drug, 37(10.9%) were with comorbidities and 220(64.7%) reported no side effects of antiepileptic drugs (64.7 %). The Medication Adherence Scale average score was 41.2 out of 50.

Regarding psychological characteristics of respondents, 142(41.8%) had some level of anxiety and 171(50.3 %) had some level of depression.

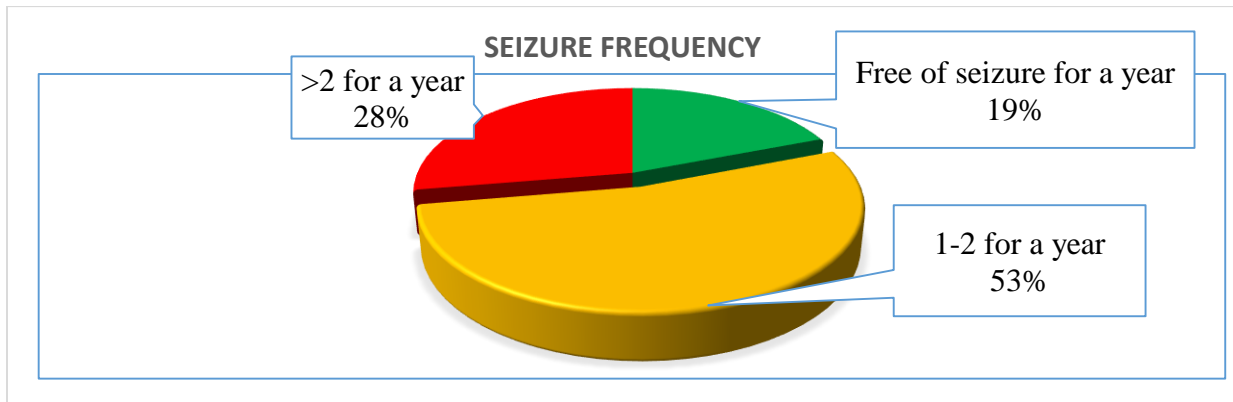


Figure 2 frequency of seizure among adult patients with epilepsy attending Mizan Tepi University Teaching Hospital (N=340),2019

5.3. Personal characteristics of the Respondents

Almost half of respondents, 169(49.7%) were categorized under low physical activity (figure 3) and 150 (44.1%) perceived low self-esteem. Majority of respondents, 263 (77.4%) felt some level of epilepsy-related stigma.

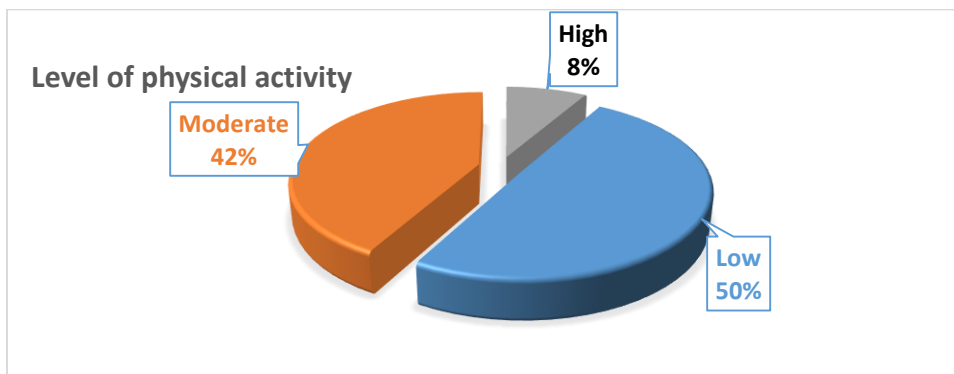


Figure 3 Level of physical activity among adult patients attending Mizan Tepi University Teaching Hospital (N=340),2019

5.4. Health related quality of life among people with epilepsy.

Figure 4 shows the mean and SD scores of QOLIE-31 subscales. The mean total score of QOLIE-31 was 55.6 (SD=20.9). The highest mean (SD) score was the medication effects, 59.05(23.16) and the lowest was seizure worry subscale, 44.73 (24.98). One hundred sixty-nine, 169 (49.7%) of the respondents scored below the mean in overall HRQOL. Cronbach's alpha for overall sample ranged from 0.81 to 0.92 across all domains.

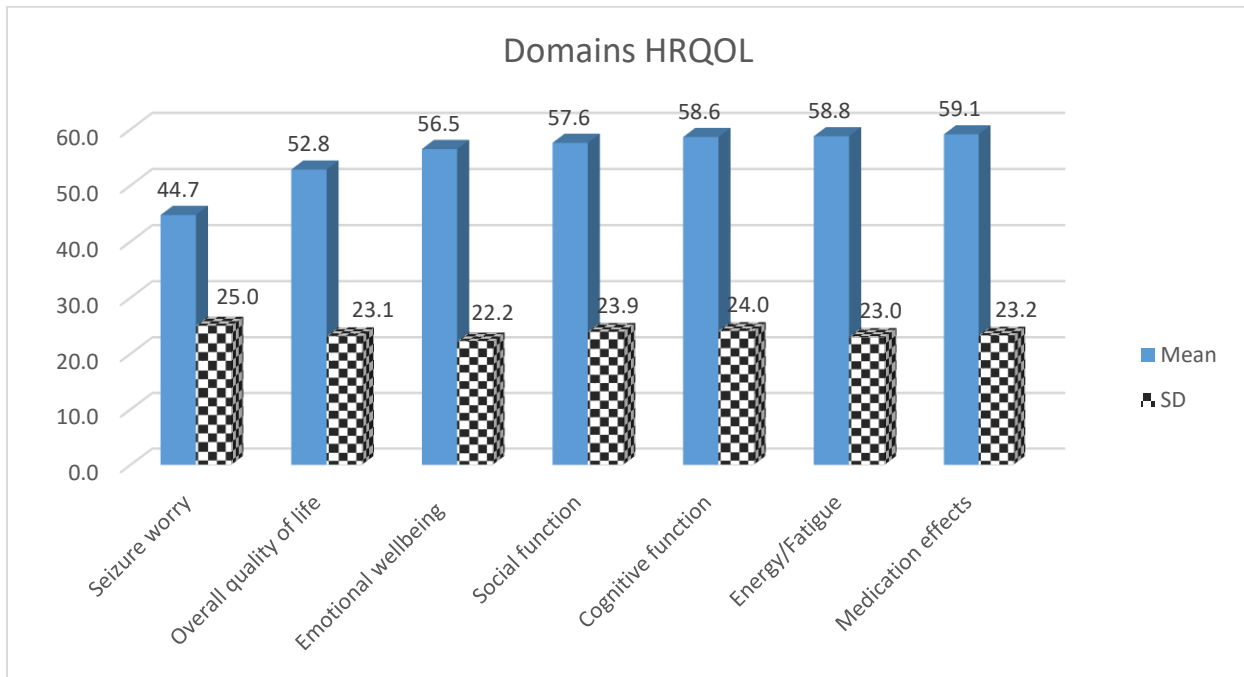


Figure 4 Domains of HRQOL of adult patients attending Mizan Tepi University Teaching Hospital (N=340),2019

Table 4 Simple linear regression for factors associated with HRQOL of patients with epilepsy at MTUTH (N=340),2019

Variables		Unstandardized Coefficients	p-value	(95% CI for B)
		B		
Age		-0.6	<0.001*	(-0.82, -0.40)
Sex	Female	-2.5	0.271	(-6.98, 1.97)
Marital status	Single	8.5	<0.001*	(4.0, 13.1)
	Divorced	-27.1	<0.001*	(-35.5, -18.7)
Educational level	Illiterate	-23.6	<0.001*	(-28.2, -18.9)
	Can read and write	-6.4	0.013*	(-11.4, -1.35)
	Secondary	22.0	<0.001*	(17.0, 27.0)
	Tertiary	13.1	0.001*	(5.3, 20.8)

Occupational status	Student	14.2	<0.001*	(7.6, 20.8)
	No occupation	-20.2	<0.001*	(-25.5, -15.0)
Monthly income	Monthly income \geq 1000 birr	17.0	<0.001*	(12.8, 21.3)
Residence	Urban	11.5	<0.001*	(7.1, 15.8)
Clinical and psychological characteristics	Age of onset	-0.1	0.44	(-0.39, 0.17)
	Duration of epilepsy (log)	-1.5	0.58	(-6.8, 3.8)
	Seizure free for a year	23.5	<0.001*	(18.4, 28.6)
	More than two seizures for a year	-25.5	<0.001*	(-29.7, -21.3)
	Polytherapy	-15.0	<0.001*	(-19.5, -10.5)
	Frequency of medication (twice or more per day)	-10.6	<0.001*	(-14.9, -6.2)
	Medication side effects	-11.7	<0.001*	(-16.2, -7.2)
	Medication adherence	1.4	<0.001*	(1.1, 1.6)
	Comorbidity	-0.5	0.9	(-9.6, 8.5)
	Anxiety	-22.5	<0.001*	(-26.3, -18.6)
	Depression	-27.8	<0.001*	(-31.1, -24.5)
Personal and social characteristics	Perceived social support	0.7	<0.001*	(0.67, 0.82)
	Low self-esteem	-27.1	<0.001*	(-30.5, -23.7)
	Perceived stigma	-20.8	<0.001*	(-25.7, -15.9)
	Moderate physical activity	16.7	<0.001*	(12.6, 20.9)
	High physical activity	-3.9	0.34	(-12.0, 4.2)
*Candidate for multivariable linear regression, $p < 0.25$				

5.5. Factors independently associated with HRQOL among adult patients with epilepsy

Age, anxiety, depression, low self-esteem, perceived stigma, taking medication twice or more times per day, being illiterate and having more than two seizures for a year were inversely associated with health related quality of life while monthly income of \geq 1000 birr per month, social support and being free of seizure for a year were directly associated with health related quality of life.

As social support score increases by 1 unit, HRQOL score is expected to increase by 0.34 unit on average ($\beta=0.34$). Those PWE who are free of seizures for a year are expected to have 6.5 higher HRQOL score compared with respondents who had 1-2 seizures for a year ($\beta=6.5$). Respondents who earn \geq 1000-birr monthly income are expected to have 4.5 higher HRQOL score compared with respondents who earn <1000-birr monthly income ($\beta=4.5$).

As age increase by one year, HRQOL score is expected to decrease by 0.35 on average ($\beta = -0.35$). Those PWE who are depressed were expected to have 7.36 lower HRQOL score compared with respondents who are not depressed ($\beta = -7.36$). The rate of average change in HRQOL among PWE who are with anxiety is 6.79 lower compared to patients without anxiety ($\beta = -6.79$). The rate of average change in HRQOL among PWE who are self-esteemed is 5.29 lower compared to patients with good self-esteem ($\beta = -5.29$). Those PWE who are illiterate are expected to have 4.1 lower HRQOL score compared with respondents who are primary school level ($\beta = -4.1$). Those who had more than two seizures for a year are expected to have 4.18 lower HRQOL score compared with respondents who had 1-2 seizures for a year ($\beta = -4.18$). Adult patients with epilepsy who perceive some level of stigma are expected to have 3.62 lower HRQOL score compared with respondents who do not perceive stigma ($\beta = -3.62$). Those PWE who are taking medication twice or more times per day are expected to have 2.43 lower HRQOL score compared with respondents who are taking their medication once a day by controlling other variables in the model ($\beta = -2.43$). (table 5)

Table 5 Multivariable linear regression model showing independently associated factors with overall (total) HRQOL among adult patients with epilepsy attending Mizan Tepi University Teaching Hospital, 2019

	Unstandardized Coefficients	(95%CI) for B
	B	
(Constant)	59.32	(52.86, 65.78)*
Perceived social support	0.34	(0.27, 0.40)*
Depression	-7.36	(-10.16, -4.55)*
Low self-esteem	-5.29	(-8.07, -2.51)*
Age	-0.35	(-0.46, -0.23)*
Seizure free for a year	6.50	(3.66, 9.33)*
Anxiety	-6.79	(-9.26, -4.32)*
Monthly income ≥ 1000 birr	4.50	(2.00, 6.99)*
Illiterate	-4.09	(-6.87, -1.31)**
More than 2 seizures for a year	-4.18	(-6.97, -1.39)**
Stigma	-3.62	(-6.30, -0.94)**
Taking medications twice or more times per day	-2.43	(-4.58, -0.27)**

Strength of statistical significance: * ($p < 0.001$), ** ($p < 0.05$)

6. Discussion

The overall mean of HRQOL among study participants was low and half of the respondents scored below the mean. The highest mean score was the medication effects and the lowest was seizure worry domain. Monthly income of ≥ 1000 birr per month, social support and being free of seizure for a year were directly associated with health related quality of life. However, age, anxiety, depression, low self-esteem, perceived stigma, taking medication twice or more times per day, being illiterate and having more than two seizures for a year were inversely associated with health related quality of life

According to this finding, the overall mean HRQOL among study participants was low (55.6) when compared with other findings. Studies conducted in Warsaw, Uganda, Jimma and China have also reported comparable level of HRQOL among patients with epilepsy, at 55.18(14.75), 58(13), 58.8(20) and 53.9(8) respectively (23,31,37,39) . However, studies conducted in Moscow 42.13 (4.14) and Bhutan 48.9(17.7) reported lower level of HRQOL among patients with epilepsy (30,38). This difference could be most of the patients who were recruited for those studies in both countries were previously untreated (newly diagnosed) for epilepsy (38) and with more than one seizure per year (30) . The second reason for higher score for overall HRQOL might be a result of the seizure frequency of our study population. In the current study, 27.6% of participants had more than two seizures per year and 19.1% of participants had been completely seizure-free in the previous 12-month period, whereas in Russian study seizures occurred several times per week in 57.9% patients, and only 4.5% of participants had been completely seizure-free in the previous 12-month period (38). It is well-established that seizure frequency affects the overall HRQOL, and for our population, a reduction in seizure frequency may have benefited overall HRQOL.

On the other hand, a study conducted in United Kingdom and Malaysia reported a higher mean total score of HRQOL at 66(14) and 68(15.9) respectively (25,35). This inconsistency may be due to methodological difference. Patients who were recruited for both studies in those countries were minimum education level of junior high school (25,35) and epilepsy had been stable for the 6 months preceding their participation (35). The second justification for a higher mean total score might be due to the availability of neurologists and standard medical care in both countries (25,35).

Age was inversely associated with overall HRQOL. This finding is also supported by one study (38). This consistency could be their lower physical reserve and energy retention in older adults

compared to the younger generation (59). These reflects that younger people were more likely to enjoy better health than the elders. Ageing may decline in most physiological and psychological systems that limited different abilities. However, our finding is inconsistent with other studies (26,30,32). This inconsistency may be due to methodological difference and differences in sociodemographic factors.

In this study being illiterate was inversely associated with overall HRQOL. Educational difficulties were attributed mainly to lack of financial support, seizures, embarrassment and personality problems (28). Illiteracy may result in poorer understanding of seizure management and medication adherence, increased self-perceived stigma, and poor access to employment opportunities and income. Other studies also support this finding (25,28–31).

This result showed that average monthly household income (≥ 1000 birr) was directly associated with HRQOL. Patients with high-income levels have high access to medical facilities and are, therefore, likely to have regular drug intake and frequent checkups. Other studies also support this finding (29,41)

In the present study, there was a strong trend towards poor HRQOL with increased number of seizures. It was found that patients with more than 2 seizures had low HRQOL scores. On the other hand, being free of seizures for a year was directly associated. This finding is also supported by several studies (24,26,41,27–29,31,32,34,35,40). This consistency could be patients who have higher seizure had low social contact and feelings of stigmatization (38) and will always be in the uncomfortable position as they can't predict when will the next seizure occur and may take precautions and impose restrictions to avoid of having seizures at inappropriate times, public places or social events. They can be restricted from driving (using transportation) and may be denied job and career opportunities which can translate into a lower HRQOL (18).

In this study, half and 4 in ten of the respondents had some levels of depression and anxiety respectively. Anxiety and depression were inversely associated with overall HRQOL. Depression and anxiety are common psychological distresses in patients with epilepsy, exerting a profound negative effect on their health-related quality of life. This was consistent with the result of most studies which assessed level of anxiety and depression (23,25,26,34,35,41,44).

Majority of PWE in this study felt some level of epilepsy-related stigma. Stigma associated inversely with overall HRQOL. This finding is consistent with other studies (23,25,30,44,60). This

consistency could be explained by their frequent seizure attack, as patients with frequent seizures reported low social contact and feelings of stigmatization (38) and patients with felt stigma are also prone to have poorer self-esteem, higher levels of anxiety, and depression. They are also more likely to be underemployed or unemployed with lower rates of marriage and greater social isolation (61).

Social support can be received from family members, friends, colleagues, as well as medical personnel. Perceived social support was positively correlated with HRQOL. It was also noted that this association showed significant linearity ($r=0.73$) i.e. as perceived support increased their mean QOL improved. Greater social support has been linked to better quality of life in patients with chronic diseases. Better social support can improve the feeling of being ‘connected’ for people with epilepsy, which in turn can have an influence on their perceived quality of life. Also psychosocial support can reduce emotional stress and improve social interactions, which can improve the availability of social support and improve HRQOL. Other studies also support this finding (60,62,63).

Low self-esteem was inversely associated with total HRQOL. This finding is consistent with other studies (64,65). Patients who lack the social support that friendships offer are likely to feel isolated; subsequently, these feelings of isolation may have a negative impact on self-esteem which can translate into a lower HRQOL. Low self-esteem can result in general dissatisfaction and can adversely affect specific aspects of life (64).

Taking medication twice or more times per day was inversely associated with overall HRQOL. Quality of life was lower among patients who were taking AEDs twice or more times per day than taking once a day. This is consistent with a study conducted in Jimma (23).

Strength of this study: We used internationally valid tools to assess HRQOL, anxiety, depression, self-esteem, perceived stigma, physical activity, medication adherence and perceived social support. Also we employed better statistical analysis (linear regression) which doesn’t let loss of information for continuous outcomes variables and we used relatively larger sample size.

Despite above strength, this study has two potential limitations that should be considered while utilizing the findings of this study: First: duration of disease was determined from the time epilepsy was diagnosed by health professional. We did not take the time patients self-reported the symptoms of the diseases. This may underestimate strength of association between duration of disease and

HRQOL due to big discrepancy between these two reports. The second: this study relies on self-reports for some factors like physical activity, seizure frequency and medication adherence which are prone to recall and social desirability biases. This could overestimate or underestimate the strength of association between these variables and HRQOL.

7. Conclusion and recommendation

7.1. Conclusion

The mean health related quality of life score of patients with epilepsy in Mizan Tepi University Teaching Hospital is low. Health related quality of life was inversely associated with age, anxiety, depression, low self-esteem, perceived stigma, taking medication twice or more times per day, being illiterate and having more than two seizures for a year. On the other hand, monthly average household income of >1000 birr, social support and being free of seizure for a year were directly associated. It is obvious that current management of epilepsy that focuses on only seizure control does not improve HRQOL of the patients receiving AEDs. These results revealed that epilepsy-specific, psycho-social, and economic dimensions were important factors for the health related quality of life of patients with epilepsy.

7.2. Recommendation

Based on our findings the following recommendations are forwarded for the concerned bodies.

Health care professionals/ MTUTH: should do more roles on both preventing seizures and reintegrating PWE into community life. Also screening and intervention of depressive and anxiety problems should be incorporated in the regular epilepsy care management.

Mass media: should play a role to raise awareness of the public regarding the need of social support, educational and economic opportunities and eliminate the stigma of epilepsy.

For researchers: More research is needed on different aspects of epilepsy in order to understand it and improve its management which will ultimately improve HRQOL of PWE.

ASSURANCE OF PRINCIPAL INVESTIGATOR

The undersigned agrees to accept responsibility for the scientific ethical and technical conduct of the research project and for provision of required progress reports as per terms and conditions of the Faculty of Public Health in effect at the time of grant is forwarded as the result of this application.

Name of the student: _____

Date. _____ Signature _____

APPROVAL OF THE FIRST ADVISOR

Name of the first advisor: _____

Date. _____ Signature _____

APPROVAL OF THE SECOND ADVISOR

Name of the second advisor: _____

Date. _____ Signature _____

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Annexes

Annex I: Document review checklist

Respondent 's identification number _____

Please review patient chart and record the data as follows. For those options listed please circle the options and if it is not listed put the information on the space provided.

I1. Number of anti-epileptic drugs prescribed _____.

I2. Type of medication the patient is currently using?

1.	Phenobarbital
2.	Phenytoin
3.	Carbamazepine
4.	Clonazepam
5.	Ethosuximide
6.	Sodium valproate
7.	Other (specify) _____.

I3. Duration of epilepsy _____

I4. Evidence of comorbidities noted (verified by a physician)

1. None
2. Heart problem
3. Hypertension
4. Diabetic mellitus
5. Neurologic disorders
6. Psychiatric disorders
7. Sleep disorder
8. Other (specify) _____.

Annex II: Questionnaire and Measurements

Jimma University

College of Public Health

Department of Epidemiology

Questionnaires for Health related quality of life and associated factors among adult epileptic patients taking anti-epileptic drugs at MTUTH.

Consent form:

Hello: My name is ----- and I am from Jimma University. We are conducting a study on Assessment of health related quality of life and associated factors among adult epileptic patients taking anti-epileptic drugs at MTUTH. As part of this you are kindly requested to be included in the study which has great importance to improve the medical care which patients receive for epilepsy and ultimately their quality of life. The interview will take a maximum of 30 minutes. It will not cause you any physiological, financial or psychological harm nor affect the health care service you are getting. Your participation will be based on your willingness and you have the right not to participate fully or partially. If you agree to be included in the study, I will start my question by asking general identification questions.

May I continue? 1. Yes

2. No

Name of the interviewer ----- Date ----- Signature -----

Name of the supervisor ----- Date ----- Signature -----

Part I SOCIODEMOGRAPHIC AND CLINICAL DATA

A: - SOCIO - DEMOGRAPHIC DATA

Please ask respondents and record the responses for the following questions. Please circle the responses of the respondents and put the responses for open ended and for semi-closed questions (if the response is not listed) on the space provided.

A1	Your age, please?.	-----Years
A2	Sex	1. Male 2. Female
A3	What is your Ethnic group?	1. Bench 2. Me'enit 3. kafa 4. Sheko 5. Amhara 6. Others (specify) _____
A4	What is your Religion?	1. Muslim 2. Orthodox 3. Protestant 4. Catholic 5. Other(specify)_____
A5	What is your marital status?	1. Married 2. Single 3. Divorced 4. Widowed 5. Separated
A6	Educational level?	1. Illiterate 2. Read and write 3. Primary school 4. High school 5. Higher education
A7	What is your Occupation?	1. Government employee 2. Merchant 3. Farmer 4. House wife 5. Daily laborer 6. No occupation 7. Student 8. other
A8.	Average income (cash and kind) in Birr per month ?	_____ Birr
A9	Where is your Residence?	1. Rural 2. Urban

B. MEDICAL CHARACTERISTICS

	Question	Answer	Remark
B1.	How old are you when you get epilepsy?	_____ Years old.	
B2.	How long is the duration of the disease since its onset?	_____ Years.	
B3.	How frequent is the seizure?	____per year	
B4.	When did you first start your anti-epileptic drug treatment?	_____ Years	
B5.	How many types of anti-epileptic drugs are you taking for your epilepsy daily?	_____.	

B6.	How often do you take your medications?	_____times/day			
B7.	Did you encounter any side effects of treatment?	1. Yes	2. No		
B8.	If ‘Yes’ in the question no.B7, what are the side effects of the treatment	_____			
B9.	Did you encounter any epilepsy related complication in the past?	1. Yes	2. No		
B10.	What health complaints other than seizure do you have currently?	_____			

PART II: Personal and psychosocial characteristics

A. Medication Adherence

Please circle one number for each statement to show how often you do the following. As you answer the questions, please think about your activities in the past year.

	Question	Answer					
		Never	Rarely	Some times	Most of the Time	Always	
C1	When my seizure medication is running out, I spread out the time between doses.	5	4	3	2	1	
C2	When my seizure medication is running out, I take less medication at each time.	5	4	3	2	1	
C3	I take my seizure medication the way my doctor orders it.	1	2	3	4	5	
C4	I take my seizure medication at the same time each day.	1	2	3	4	5	
C5	I have to put off having my seizure medication refilled because it costs too much money.	5	4	3	2	1	
C6	I miss doctor or clinic appointments.	5	4	3	2	1	
C7	If I had side effects from the seizure	5	4	3	2	1	

	medications, I would skip a dose without asking my doctor.						
C8	I plan ahead and have my seizure medication refilled before I run out	1	2	3	4	5	
C9	I miss doses of my seizure medication because I do not remember to take it	5	4	3	2	1	
C10	I skip doses of seizure medication	5	4	3	2	1	

B. Hospital Anxiety and Depression (HAD) scale

Instruction- This is a self-screening questionnaire for depression and anxiety. Patients are asked to choose one response from the four given for each interview. The patient should be instructed not to take too long over their replies: their immediate reaction to each item will probably be more accurate than a long thought-out response. The questions relating to anxiety are marked "A", and to depression "D". The score for each answer is given in the right column. Instruct the patient to answer how it currently describes their feelings.

A. I feel tense or 'wound up':	Most of the time	3
	A lot of the time	2
	From time to time, occasionally	1
	Not at all	0
D. I still enjoy the things I used to enjoy	Definitely as much	0
	Not quite so much	1
	Only a little	2
	Hardly at all	3
A. I get a sort of frightened feeling as if something awful is about to happen:	Very definitely and quite badly	3
	Yes, but not too badly	2
	A little, but it doesn't worry me	1
	Not at all	0
D. I can laugh and see the funny side of things:	As much as I always could	0
	Not quite so much now	1
	Definitely not so much now	2
	Not at all	3
A. Worrying thoughts go through my	A great deal of the time	3

mind:	A lot of the time	2
	From time to time, but not too often	1
	Only occasionally	0
D. I feel cheerful:	Not at all	3
	Not often	2
	Sometimes	1
	Most of the time	0
A. I can sit at ease and feel relaxed:	Definitely	0
	Usually	1
	Not Often	2
	Not at all	3
D. I feel as if I am slowed down:	Nearly all the time	3
	Very often	2
	Sometimes	1
	Not at all	0
A. I get a sort of frightened feeling like 'butterflies' in the stomach:	Not at all	0
	Occasionally	1
	Quite Often	2
	Very Often	3
D. I have lost interest in my appearance:	Definitely	3
	I don't take as much care as I should	2
	I may not take quite as much care	1
	I take just as much care as ever	0
A. I feel restless as I have to be on the move:	Very much indeed	3
	Quite a lot	2
	Not very much	1
	Not at all	0
D. I look forward with enjoyment to things:	As much as I ever did	0
	Rather less than I used to	1
	Definitely less than I used to	2
	Hardly at all	3
A. I get sudden feelings of panic:	Very often indeed	3
	Quite often	2

	Not very often	1
	Not at all	0
D. I can enjoy a good book or radio or TV program:	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3
Scoring (add the As = Anxiety. Add the Ds = Depression). The norms below will give you an idea of the level of Anxiety and Depression. 0-7 = Normal 8-10 = Borderline abnormal 11-21 = Abnormal		

C. Self-esteem

Please read each statement and record a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past two weeks. There are no right or wrong answers. Do not spend too much time on any one statement.

	Strongly disagree	Disagree	Agree	Strongly agree
I feel that I am a person of worth, at least on an equal plane with others	0	1	2	3
I feel that I have a number of good qualities	0	1	2	3
All in all, I am inclined to feel that I am a failure (R)	3	2	1	0
I am able to do things as well as most people	0	1	2	3
I feel I do not have much to be proud of (R)	3	2	1	0
I take a positive attitude toward myself	0	1	2	3
On the whole, I am satisfied with myself	0	1	2	3
I wish I could have more respect for myself (R)	3	2	1	0
I certainly feel useless at times (R)	3	2	1	0
At times I think that I am no good at all (R)	3	2	1	0
Total score =				
Typical scores on the Rosenberg scale are around 22, with most people scoring between 15 and 25. A score of less than 15 suggests low self-esteem may be an issue.				

D. Epilepsy stigma scale

Please tell me how much you agree or disagree with each of the following 3 statements.

Because of epilepsy:	not at all	yes, maybe	yes, probably	yes, definitely
Other people are uncomfortable with me	0	1	2	3
Treat me as inferior	0	1	2	3
Prefer to avoid me	0	1	2	3
category Not stigmatized (score of 0), mild-moderate (score of 1–6) and highly stigmatized (score of 7–9)				

E. Physical activity

The questions will ask you about the time you spent being physically active in the last 7 days. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Question	Answer	Remark
During the last 7 days, on how many days did you do vigorous physical activities like heavy lifting, digging, aerobics, or fast bicycling?	_____ days per week	No vigorous physical activities Skip to question 3
How much time did you usually spend doing vigorous physical activities on one of those days?	_____ hours per day _____ minutes per day	Don't know/Not sure
During the last 7 days, on how many days did you do moderate physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.	_____ days per week	No moderate physical activities Skip to question 5
How much time did you usually spend doing moderate physical activities on one of those days?	_____ hours per day _____ minutes per day	Don't know/Not sure
During the last 7 days, on how many days did you walk for at least 10 minutes at a time?	_____ days per week	No walking Skip to question 7
How much time did you usually spend walking on one of those days?	_____ hours per day _____ minutes per day	Don't know/Not sure

During the last 7 days, how much time did you spend sitting on a week day? Include time spent at work, at home, while doing course work and during leisure time.	_____	Don't know/Not sure
	hours per day _____ minutes per day	

F. Perceived social support

Please tell me how much you agree or disagree with each of the following 3 statements.

	Very strongly disagree	strongly disagree	Mildly disagree	neutral	Mildly agree	strongly agree	Very strongly agree
There is a special person who is around when I am in need.	1	2	3	4	5	6	7
There is a special person with whom I can share my joys and sorrows	1	2	3	4	5	6	7
I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
There are special persons in my life who cares about my feelings.	1	2	3	4	5	6	7
My family really tries to help me.	1	2	3	4	5	6	7
I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
I can talk about my problems with my family.	1	2	3	4	5	6	7
My family is willing to help me make decisions.	1	2	3	4	5	6	7
My friends really try to help	1	2	3	4	5	6	7

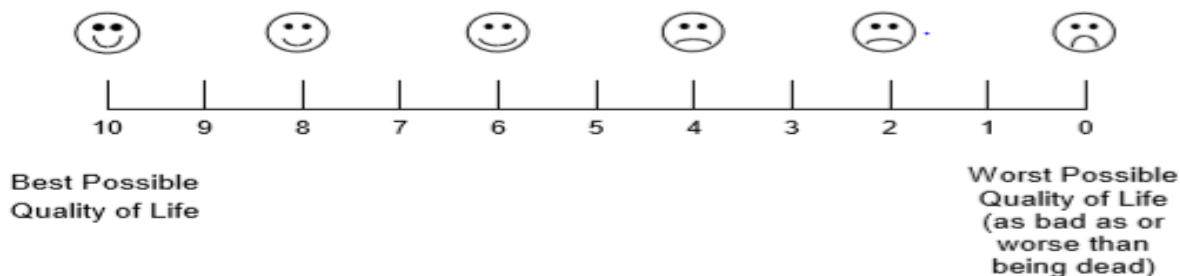
me.							
I can count on my friends when things go wrong.	1	2	3	4	5	6	7
I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
I can talk about my problems with my friends.	1	2	3	4	5	6	7
Total							

G: QOLIE-31 questionnaire items

This questionnaire asks about your health and daily activities. **Answer every questions by encircling the appropriate number** (1, 2, 3,). If you are unsure about how to answer the questions, please give the best answer you can and write a comment or explanation in the margin.

Please feel free to ask someone to assist you if you need help reading or marking the form.

I1. Overall, how would you rate your quality of life? (Circle one number on the scale below)



The following questions are about how you **FEEL** and how things have been for you during the **past 4 weeks**. For each question, please indicate the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks...?

(Circle one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I2. Did you feel full of pep?	1	2	3	4	5	6
I3. Have you been a very nervous person?	1	2	3	4	5	6
I4. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
I5. Have you felt calm and peaceful?	1	2	3	4	5	6
I6. Did you have a lot of energy?	1	2	3	4	5	6
I7. Have you felt downhearted and blue?	1	2	3	4	5	6
I8. Did you feel worn out?	1	2	3	4	5	6
I9. Have you been a happy person?	1	2	3	4	5	6
I10. Did you feel tired?	1	2	3	4	5	6
I11. Have you worried about having another seizure?	1	2	3	4	5	6
I12. Did you have difficulty reasoning and solving problems (such as making plans,	1	2	3	4	5	6

making decisions, learning new things)?						
I13. Has your health limited your social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6

(Circle one number)

	Very well : could hardly be better	Pretty good	Good and bad parts about equal	Pretty bad	Very bad: could hardly be worse
I14. How has the QUALITY OF YOUR LIFE been during the past 4 weeks (that is, how have things been going for you)?	1	2	3	4	5

The following question is about **MEMORY**.

(Circle one number)

	Yes, A great deal	Yes, Somewhat	Only a little	No. not at all
I15. In the past 4 weeks, have you had any trouble with your memory?	1	2	3	4

Circle one number for how often in the *past 4 weeks* you have **had trouble remembering or how often this memory problem** has interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I16. Trouble remembering things people tell you	1	2	3	4	5	6

The following questions are about **CONCENTRATION** problems you may have. Circle one number for **how often** in the **past 4 weeks** you had trouble concentrating or **how often** these problems interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I17. Trouble concentrating on reading	1	2	3	4	5	6

I18. Trouble concentrating on doing one thing at a time	1	2	3	4	5	6
--	---	---	---	---	---	---

The following questions are about problems you may have with certain **ACTIVITIES**.

Circle one number for **how much** during the **past 4 weeks** your **epilepsy or antiepileptic medication** has caused trouble with...

	A great deal	A lot	Somewhat	Only a little	Not at all
I19. Leisure time (such as hobbies, going out)	1	2	3	4	5
I20. Driving (or transportation)	1	2	3	4	5

The following questions relate to the way you **FEEL** about your **seizures**.

(Circle one number on each line)

	Very fearful	Somewhat fearful	Not very fearful	Not fearful at all
I21. How fearful are you of having a seizure during the next month?	1	2	3	4

	Worry a lot	Occasionally worry	Don't worry at all
I22. Do you worry about hurting yourself during a seizure?	1	2	3

	Very worried	Somewhat worried	Not very worried	Not worried at all
I23. How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	1	2	3	4
I24. How worried are you those medications you are taking will be bad for you if taken for a long time?	1	2	3	4

For each of these **PROBLEMS**, circle one number for **how much they bother you** on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = extremely bothersome.

	Not at all bother some	Extremely bothersome
--	------------------------	----------------------

I25. Seizures	1	2	3	4	5
I26. Memory difficulties	1	2	3	4	5
I27. Work limitations	1	2	3	4	5
I28. Social limitations	1	2	3	4	5
I29. Physical effects of antiepileptic medication	1	2	3	4	5
I30. Mental effects of antiepileptic medication	1	2	3	4	5

I31. How good or bad do you think your **HEALTH** is? On the thermometer scale below, the best imaginable state of health is 100 and the worst imaginable state is 0. Please indicate how you feel about your health by circling one number on the scale. **Please consider your epilepsy as part of your health when you answer this question**

Worst Imaginable Health State (as bad as or worse than being dead)										Best Imaginable Health Stat
	0	10	20	30	40	50	60	70	80	

Thank you very much for your valuable time.

በጅማ ዩኒቨርሲቲ የጤና ኢንስቲትዩት

የኢፒዲሞሎጅ ትምህርት ክፍል

በሚዛን ቴፒ ዩኒቨርሲቲ ቲችንግ ሆስፒታል በሚጥል በሽታ ህክምና የሚወስዱ እና ክትትል እያደረጉ ያሉ ህሙማንን ስለ ጤና ነክ የኑሮ ደረጃ ያላቸውን ግንዛቤ መጠየቂያ ቅጽ፤

ህሙማን በጥናቱ ለመሳተፍ ፈቃደኛ ሥለመሆናቸው የሚገልጹበት ፎርም

ጤና ይስጥልኝ ? የእኔ ስም----- ይባላል። በሚዛን ቴፒ ዩኒቨርሲቲ ቲችንግ ሆስፒታል በሚጥል በሽታ ህክምና የሚወስዱ እና ክትትል እያደረጉ ያሉ ህሙማንን ስለ ጤና ነክ የኑሮ ደረጃ ስላላቸው ግንዛቤ ጥናት በማድረግ ላይ የምንገኝ ሲሆን እርስዎም በዚህ ጥናት እንዲሳተፉ ስንጠይቅ በታላቅ አክብሮት ነው።

ይሄ ጥናት ለ ሚጥል በሽታ ህሙማን የሚሰጠውን ህክምና እና በይበልጥ የጤና ነክ የኑሮ ደረጃ ለማሻሻል ከፍተኛ እገዛ የሚያደርግ ይሆናል። በተጨማሪም ህሙማኑ ህክምናውን በተሟላ እና በበቂ ሁኔታ ተከታትለው እንዲጨርሱና ህመማቸውን እንዲቆጣጠሩ ለማስቻል ያግዛል። ለቃለ መጠይቁ እንዲሳተፉ ስንጠይቅ፤ ቃለመጠይቁ የሚፈጀው ቢበዛ 30 ደቂቃ ሲሆን፤ የእርስዎ ስምም ሆነ አድራሻ በመጠይቁ ውስጥ አይካተትም። እንዲሁም የዕርስዎ ማንነትም ሆነ የሠጡት ምላሽ የዕርስዎ ሥለመሆኑ በምንም ሁኔታ አይገለጽም። በዚህ ጥናት ለመሳተፍ እኛ የእርስዎን ሙሉ ፍቃደኝነት ስንጠይቅ ያለምንም አስገዳጅነት ሲሆን ፈቃደኛ ካልሆኑ ከመጀመሪያውም ሆነ ቃለ መጠይቁን ከጀመሩ በኋላ በመሐል ማቋረጥ ይችላሉ።

በጥናቱ ለመሳተፍ ፈቃደኛ ነዎት?

አዎ፤ ቃለ መጠይቁን ይጀምሩ

አይደለሁም፤ አመስግነው ያቁሙ።

የ ጠያቂው ስም-----ቀን-----ፊርማ -----

የ ተቆጣጣሪው ስም -----ቀን-----ፊርማ-----

Identification number_____

ክፍል አንድ ማህበራዊ፣ኢኮኖሚያዊ እና ክሊኒካል/ጤናነክ መጠይቆች

A: - ማህበራዊ እና ኢኮኖሚያዊ መጠይቅ

እባክዎ ምላሽ ሰጪዎችን ይጠይቁ እና ለሚከተሉት ጥያቄዎች ምላሾችን ያክቡ ወይም መልሱ ያልተዘረዘረ ከሆነ በተሰጠው ክፍት ቦታ ላይ ይመዝግቡ።

A1	እድሜ	----- ዓመት
A2	ፆታ	1. ወንድ 2. ሴት
A3	ብሔር	1. ቤንች 2. መኸኒት 3. ካፋ 4. ሸኮ 5. አማራ 6. ሌሎች (ይግለጹ) _____
A4	ሃይማኖት	1. ሙስሊም 2. ኦርቶዶክስ 3. ፕሮቴስታንት 4. ካቶሊክ 5. ሌላ (ይግለጹ) _____
A5	የጋብቻ ሁኔታ	1. ያገባ/ች 2. ያላገባ/ች 3. የፈታ/ች 4. የሞተበት/ባት 5. የተለያየ/ች
A6	የትምህርት ደረጃ	1. ማንበብ ሆነ መጻፍ የማይችል 2. ማንበብ እና መጻፍ 3. የመጀመሪያ ደረጃ ትምህርት 4. ሁለተኛ ደረጃ ትምህርት 5. ከፍተኛ ትምህርት
A7	የስራ ሁኔታ	1. የመንግስት ሰራተኛ 2. ነጋዴ 3. አርሶአደር 4. የቤት እመቤት 5. የቀን ሰራተኛ 6. ስራ አጥ 7. ሌላ ካለ ይጥቀሱ _____
A8.	አማካኝ የወር ገቢ (በጥሬ ገንዘብ ወይም በዕቃ)	1. _____ ብር 2. ገቢ የለኝም
A9	የሚኖሩት የት ነው?	1. ገጠር 2. ከተማ

B. ክሊኒካል/ጤናነክ መጠይቆች

	ጥያቄ	መልስ
B1.	የሚጥል በሽታ ያጋጠመዎ (በሽታው እንዳለበዎት ያወቁት) በስንት ዓመትም ነበር?	_____ ዓመት.
B2.	የሚጥል በሽታው ከጀመረዎ ምን ያህል ጊዜ ይሆናል? (ከበሽታው ጋር ለምን ያህል ጊዜ ቆየ) ?	_____ ዓመት
B3.	ይህ በሽታ በዓመት ምን ያህል ጊዜ ይጥልዎታል?	_____ ጊዜ
B4.	የሚጥል በሽታ መድሃኒትዎን ለመጀመሪያ ጊዜ የጀመሩት መቼ ነበር? (እስካሁን ለምን ያህል ጊዜ መድሃኒት ወስደዋል)	_____ ዓመት _____ ወራት
B5.	ለሚጥል በሽታዎ በየቀኑ ስንት አይነት መድሃኒት እየወሰዱ ነው?	_____
B6.	በየቀኑ ምን ያህል ጊዜ መድሃኒትዎን ይወስዳሉ?	_____ ጊዜ
B7.	ከሕክምናው/ ከመድሃኒቱ ጋር የተያያዘ የጎንዮሽ ጉዳት ተከስቶ ነበር?	1. አዎ 2. የለም
B8.	በ <ጥያቄ> ቁጥር 7 ላይ ከሆነ 'የታመመ' ከሆነ, የሕክምናው/የመድሃኒቱ የጎንዮሽ ጉዳቶች ምንድን ናቸው?	_____
B9.	ከሚጥል በሽታ ጋር የተያያዘ (የተወሳሰበ) ችግር አጋጥሞዎታል ያውቃል?	1. አዎ 2. አያውቅም
B10.	በአሁኑ ጊዜ ከመጣል/ ከማንዘፍዘፍ ሌላ ምን ዓይነት የጤና ችግሮች አሉ?	_____

ክፍል ሁለት : ግላዊ ስነልቦናዊ እንዲሁም ማህበረሰባዊ ጉዳዮችን የሚዳስስ መጠይቅ

A. መድሃኒት ክትትል

ለእያንዳንዱ መግለጫ አንድ ቁጥር ያክብቡ. ለጥያቄዎቹ መልስ በምትሰጥበት ጊዜ, ባለፈው አመት ያደረጓቸውን ተግባሮች አስብ.

	ጥያቄ	ምላሽ				
		በጭራሽ	አልፎ አልፎ	አንዳንድ ጊዜ	አብዛኛውን ጊዜ	ሁል ጊዜ
C1	የሚጥል በሽታ መድኃኒት እየተሟጠጠ ሲሄድ, የሚወስዱበትን የጊዜ ልዩነት ያሰፋሉ. (ለምሳሌ በየቀኑ የሚወስዱትን በየሁለት ቀን መውሰድ)	5	4	3	2	1
C2	የሚጥል በሽታ መድኃኒት እያለቀ ሲሄድ, በእያንዳንዱ ጊዜ ትንሽ መድሃኒት ይወስዳሉ?	5	4	3	2	1
C3	የሚጥል በሽታ መድኃኒትን ሐኪም ባዘዘልዎ መንገድ ይወስዳሉ?	1	2	3	4	5
C4	መድኃኒትን በየቀኑ በተመሳሳይ ጊዜ ይወስዳሉ?	1	2	3	4	5
C5	ብዙ ገንዘብ ስለሚያስከፍል ወርሃዊ የሚጥል በሽታ መድኃኒት የሚወስዱበትን ጊዜ (የቀጠሮ ጊዜ) ገንዘብ እስኪሟላ ያራዝማለሉ/ያሳልፋሉ?	5	4	3	2	1
C6	የሐኪም ወይም የክሊኒክ ቀጠሮ ያሳልፋሉ?	5	4	3	2	1
C7	ከሚጥል በሽታ መድሃኒቶች የጎንዮሽ ጉዳት ካጋጠመዎ ይክተሩን ሳይጠይቁ የሚወስዱትን የመድኃኒት መጠን ያሳልፉ ነበር?	5	4	3	2	1
C8	መድኃኒት ከማለቁ በፊት አስቀድመው መድኃኒቱን ለማምጣት/ለማሟላት ያቅዳሉ?	1	2	3	4	5
C9	መድኃኒቱን መወሰድ ስለሚረሱ መድኃኒት የማይወስዱበት ጊዜ ነበር?	5	4	3	2	1
C10	የሚጥል በሽታ መድሃኒቶችን መጠን ያሳልፉ ነበር?	5	4	3	2	1

B. የሆስፒታል የጭንቀት እና የድብርት መለኪያ

መመርያ:- ለእያንዳንዱ ጥያቄዎች ከቀረቡት አራት አማራጭ መልሶች አንድ መልስ ብቻ ይምረጡ :: ታካሚዎች እያንዳንዱን ጥያቄዎች ለመመለስ ረጅም ጊዜ መወሰድ የለባቸውም::

A	የመጨነቅ የወጥረት ስሜት ምን ያህል ይሰማዎታል?	በጣም ብዙ ጊዜ	3
		ብዙ ጊዜ	2
		አልፎ አልፎ	1
		ምንም አይሰማኝም	0
D1	ቀደም ሲል ያስደስቱዎት የነበሩ ነገሮች አሁን ምን ያህል ያስደስቱዎታል?	አሁንም እንደድሮው ያስደስቱኛል	0
		ከድሮው ትንሽ ቀንሷል	1
		በጥቂቱ ያስደስቱኛል	2
		በጭራሽ እያስደስቱኝም	3
A2	አንድ መጥፎ ነገር ሊያጋጥምዎ የተቃረበ የሚመስል የፍርሃት ስሜት ይሰማዎታል?	እጅግ በጣም ይሰማኛል	3
		በጣም ይሰማኛል	2
		በጥቂቱ ይሰማኛል	1
		ምንም አይሰማኝም	0
D2	መሳቅና የነገሮችን አስደሳች ጎን ማየት ይችላሉ?	አብዛኛውን ጊዜ እችላለሁ	0
		እንደድሮው ባይሆንም እችላለሁ	1
		በጥቂቱ እችላለሁ	2

		ምንም አልችልም	3
A3	ጭንቀትን የሚያጭሩ አስፈሪ ሀሳቦች በአይምሮዎ ምን ያህል ጊዜ ይመላለሳሉ?	በጣም ብዙ ጊዜ	3
		ብዙ ጊዜ	2
		አልፎ አልፎ	1
		አንዳንዴ ብቻ	0
D3	ደስተኛ ነዎት?	ምንም ደስተኛ አይደለሁም	3
		ብዙ ጊዜ ደስተኛ አይደለሁም	2
		ብዙም ባይሆን ደስተኛ ነኝ	1
		አብዛኛውን ጊዜ ደስተኛ ነኝ	0
A4	ተረጋግተው መቀመጥ እና ዘና ማለት ይችላሉ?	ሁሌም እችላለሁ	0
		አብዛኛውን ጊዜ እችላለሁ	1
		ብዙውን ጊዜ አልችልም	2
		ምንም አልችልም	3
D4	ስራዎን ሲያከናውኑ ወዘተ ፍጥነትዎ ምን ያህል የቀነሰ ይመስልዎታል?	እጅግ በጣም ብዙ ጊዜ	3
		በጣም ብዙ ጊዜ	2
		አልፎ አልፎ	1
		ምንም አልቀነሰም	0
A5	ሆድ አካባቢ የሚሰማ የመደንገጥ ወይም የመሸበር ስሜት ይሰማዎታል?	ምንም አይሰማኝም	0
		አልፎ አልፎ	1
		ብዙ ጊዜ	2
		በጣም ብዙ ጊዜ	3
D5	ለአለባበስዎ ትኩረትን መስጥት አቁመዎልዎ?	አዎን ምንም ትኩረት እየሰጠሁ አይደለም	3
		የምረልገውን ያህል ትኩረት እየሰጠሁ አይደለም	2
		ድሮ ከምሰጠው ትኩረት በጥቂቱ ያነሰ ትኩረትን እሰጣለሁ	1
		ሁሌም የምሰጠውን ትኩረት እሰጣለሁ	0
A6	አንድ ቦታ መሄድ ያለብዎ ይመስል ተረጋግቶ መቀመጥ ይቸግርዎታል?	በጣም ብዙ ጊዜ ይቸግረኛል	3
		ብዙ ጊዜ ይቸግረኛል	2
		ብዙም አይቸግረኝም	1
		ምንም አይቸግረኝም	0
D6	መጪ ነገሮችን በደስታ ይጠብቃሉ?	አዎ ሁሌም በተለመደው መጠን እጠብቃለሁ	0
		ከተለመደው በጥቂቱ ባነሰ መጠን እጠብቃለሁ	1
		ከተለመደው ባነሰ መጠን እጠብቃለሁ	2
		ምንም በደስታ አልጠብቅም	3
A7	ድንገተኛ የሆነ የድንጋጤ ወይም የመሸበር ስሜት ይሰማዎታል?	በጣም ብዙ ጊዜ ይሰማኛል	3
		ብዙ ጊዜ ይሰማኛል	2
		አልፎ አልፎ ይሰማኛል	1
		ምንም አይሰማኝም	0
D7	በመጸህፍት ወይም በሬድዮ ወይም በቴሌቪዥን ዝግጅቶች ራስዎን ያዘናናሉ (ያስደስታሉ) ?	አዎን ብዙ ጊዜ	0
		ብዙም ባይሆን አዎ	1
		አልፎ አልፎ	2
		በጣም አልፎ አልፎ	3

C. Self-esteem/ በራስ መተማመን

መመሪያ:- ለእያንዳንዱ ጥያቄዎች ከቀረቡት አራት አማራጭ መልሶች አንድ መልስ ብቻ ይምረጡ :: ታካሚዎች እያንዳንዱን ጥያቄዎች ለመመለስ ረጅም ጊዜ መውሰድ የለባቸውም።

ጥያቄ	ምላሽ			
	በጣም እስማማለሁ	እስማማለሁ	አልስማማም	በጣም አልስማማም
1. እርባና/ዋጋ ያለኝና ቢያንስ ከሌሎች ጋር በእኩል ሁኔታ እንዳለሁ ይሰማኛል	3	2	1	0
2. ብዙ ጥሩ/መልካም የሆኑ ነገሮች እንዳሉኝ ይሰማኛል	3	2	1	0
3. በአጠቃላይ ሲታይ በነገሮቼ የውድቀት ስሜት ባጋደለ መልኩ ይሰማኛል	0	1	2	3
4. አብዛኛውን ሰዎች የሚሰሩትን ስራ መስራት አችላለሁ	3	2	1	0
5. ብዙ የምኩራራባቸው ነገሮች ያሉኝ ያህል አይሰማኝም	0	1	2	3
6. ለራሴ በጎ/አዎንታዊ የሆነ አመለካከት አለኝ	3	2	1	0
7. በአጠቃላይ በራሴ ደስተኛ ነኝ	3	2	1	0
8. ከዚህ የበለጠ ለራሴ ክብር ብሰጥ ኖሮ ደስ ይለኝ ነበር/እፈልግ ነበር	0	1	2	3
9. አንዳንድ ጊዜ ምንም ጥቅም/እርባና የሌለኝ ያህል ይሰማኛል	0	1	2	3
10. አንዳንድ ጊዜ በፍጹም ጥሩ ሰው እንዳልሆንኩ አስባለሁ	0	1	2	3

D. Epilepsy stigma scale / በሚጥል በሽታ ምክንያት ስለሚኖር መገለል

በሚከተሉት ሀሳቦች ውስጥ ምን ያህል እንደሚስማሙ ወይም እንደማይስማሙ ይንገሩን.

በሚጥል በሽታ ምክንያት:	እረ በጭራሽ	ሊሆን ይችላል	ምናልባት	አዎ በእርግጠኝነት
ሌሎች ሰዎች ከእርስዎ ጋር መሆን ምችት አይሰጣቸውም/አይሰማቸውም	0	1	2	3
ሌሎች ሰዎች እርስዎን እንደ የበታች ይቆጥሩዎታል	0	1	2	3
ሌሎች ሰዎች እርስዎን ማስወገድ/ማግለል ይመርጣሉ	0	1	2	3

E. Physical activity/ የአካል ብቃት እንቅስቃሴ

ጥያቄዎቹ ባለፉት 7 ቀናት ውስጥ በአካል ንቁ መሆንዎን ይጠይቁዎታል. ንቁ ተሳታፊ መሆንዎን ባያሟሉም እንኳን እባክዎ ለእያንዳንዱ ጥያቄ ይመልሱ. በቤትዎ ውስጥ እና በስራ ቦታዎ ውስጥ ስለሚሰሩዎቸው እንቅስቃሴዎች ከቦታ ወደ ቦታ ለመሄድ, እና በመዝናኛ ጊዜ ውስጥ ለመዝናኛ, ለአካል እንቅስቃሴ ወይም ለስፖርት ያደረጓቸውን እንቅስቃሴዎች ያስቡ.

ጥያቄ	ምላሽ	ማስታዎሻ
1. ባለፉት 7 ቀናት ውስጥ ቢያንስ ለ10 ደቂቃ ብርቱ ጉልበት የሚጠይቁ አካላዊ እንቅስቃሴዎችን ያደረጉት ለስንት ቀናት ነው? እንደ ከባድ ክብደት ማንሳት, መቆፈር, ኤሮቢክስ ወይም ፈጣን ብስክሌት የመሳሰሉትን	_____ ቀን/ናት	ምንም ጠንካራ የአካል እንቅስቃሴ ካላደረጉ ወደ ጥያቄ 3 ይለፉ
2. በአብዛኛው በእነዚያ ቀናት ውስጥ ብርቱ ጉልበት የሚጠይቁ አካላዊ እንቅስቃሴዎችን በማድረግ ምን ያህል ጊዜ ያሳልፋሉ?	በቀን ___ ሰዓት [ከ0-16] በቀን ___ ደቂቃ [ከ0-960]	አላውቅም / እርግጠኛ አይደለሁም

3. ባለፉት 7 ቀናት ውስጥ መጠነኛ ጉልበት የሚጠይቁ አካላዊ እንቅስቃሴዎችን ያደረጉት ለስንት ቀናት ነው? (ብስክሌቶችን በመደበኛነት ፣ ውሃ ዋና፣ ልብስ ማጠብ) የእግር ጉዞ /መራመድን አይጨምሩ.	_____ ቀን/ናት	መካከለኛ አካላዊ እንቅስቃሴ ካላደረጉ ወደ ጥያቄ 5 ይዘለሉ
4. በእነዚያ ቀናቶች ወቅት መጠነኛ አካላዊ እንቅስቃሴዎችን በማድረግ ምን ያህል ጊዜ ያሳልፋሉ?	_____ ሰዓት [h0-16] _____ ደቂቃ [h0-960]	አላውቅም / እርግጠኛ አይደለሁም
5. ባለፉት 7 ቀናት ውስጥ በአንድ ጊዜ ቢያንስ ለ 10 ደቂቃዎች ያደረግከው/የተጓዘከው ስንት ቀን ነው?	_____ ቀን/ናት	የለም ከሆነ ወደ ጥያቄ 7 ይዘለሉ
6. በአብዛኛው በእነዚያ ቀናት ውስጥ የእግር ጉዞ በማድረግ ምን ያህል ጊዜ ያሳልፋሉ?	_____ ሰዓት [h0-16] _____ ደቂቃ [h0-960]	አላውቅም / እርግጠኛ አይደለሁም
7. ባለፉት 7 ቀናት ውስጥ ምን ያህል ጊዜ ቁጭ በማለት/ተቀምጠው አሳለፉ? በቤት ውስጥ፣ በስራ ቦታ እና በመዝናኛ ጊዜ ውስጥ ያሉትን ጊዜያት ይጨምሩ.	_____ ሰዓት [h0-16] _____ ደቂቃ [h0-960]	አላውቅም / እርግጠኛ አይደለሁም

F. Perceived social support/ ማህበራዊ ድጋፍ

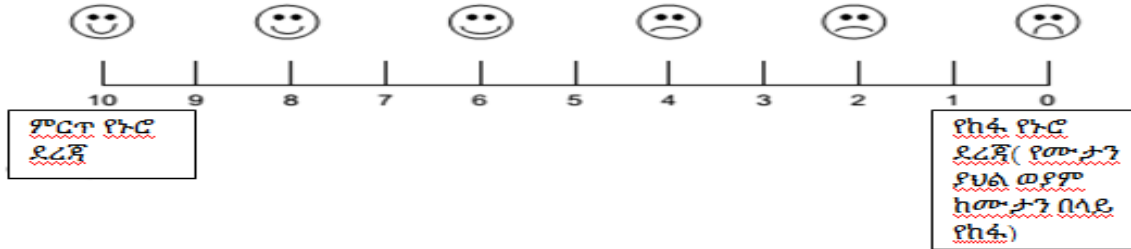
ለሚከተሉት ጥያቄዎች ምን ያህል እንደሚስማሙ ና እንደማይስማሙ ይግለጹ :

ጥያቄ	እጅግ በጣም አልስማማም	በጣም አልስማማም	በትንሹ አልስማማም	ገለልተኛ ነኝ	በትንሹ እስማማለሁ	በጣም እስማማለሁ	እጅግ በጣም እስማማለሁ
1. በአቅራቢያዬ/በዙሪያዬ በምረልገው/በሚያስፈልገኝ ጊዜ የሚገኝ ልዩ ሰው አለ.	1	2	3	4	5	6	7
2. ደስታዬን እና ሃዘኔን ልገልጽለት የምችለው አንድ ልዩ ሰው አለ	1	2	3	4	5	6	7
3. ለእኔ ልዩ የማጽናኛ/የምቶት ምንጭ የሆነልኝ ልዩ ሰው አለኝ.	1	2	3	4	5	6	7
4. በሀይወቴ ውስጥ ስለ ስሜቴ የሚጨነቁ ልዩ ሰዎች አሉ.	1	2	3	4	5	6	7
5. ቤተሰቦቼ እኔን ለመርዳት ይጥራሉ.	1	2	3	4	5	6	7
6. ከቤተሰቤ የምረልገውን ስሜታዊ እርዳታ እና ድጋፍ አገኛለሁ.	1	2	3	4	5	6	7
7. ከቤተሰቦቼ ጋር ስለ ችግራዬ መነጋገር እችላለሁ.	1	2	3	4	5	6	7
8. ቤተሰቦቼ ውሳኔዎችን እንድወስን ያግዙኛል.	1	2	3	4	5	6	7
9. ጓደኞቼ እኔን ለመርዳት ይጥራሉ.	1	2	3	4	5	6	7
10. ነገሮች ሳይሳኩ ሲቀሩ በጓደኞቼ ላይ መተማመን እችላለሁ. (የምተማመንባቸው ጓደኞች አሉኝ)	1	2	3	4	5	6	7
11. ደስታዬን እና ሃዘኔን የማካፍላቸው ጓደኞች አሉኝ.	1	2	3	4	5	6	7
12. ከጓደኞቼ ጋር ስለ ችግራዬ መነጋገር እችላለሁ.	1	2	3	4	5	6	7

G: የሚጥል በሽታ ታካሚዎች የኑሮ ደረጃ- 31(QOLIE-31) መጠይቅ

ይህ መጠይቅ ስለርስዎ ጤና እና የየቀኑ እንቅስቃሴዎች ይጠይቃል። እያንዳንዱን ጥያቄ አግባብ ባለው ቁጥር (1, 2, 3,) በመጠቀም ይመልስ። ጥያቄዎች ባለፉት 4 ሳምንታት ውስጥ ስለ ስሜተዎ ምን ዓይነት ነገሮች እንደነበሩ ይሆናል።

G1. በአጠቃላይ, የኑሮዎ ጥራት/የኑሮ ደረጃዎ እንዴት ይገመታል? ከታች ባለው መለኪያ ላይ አንድ ቁጥር ይምረጡ።



የሚቀጥሉት ጥያቄዎች ምን እንደሚሰማዎት እና ባለፉት አራት ሳምንታት ውስጥ ነገሮች እንዴት እንደነበሩ ነው.

ለእያንዳንዱ ጥያቄ, በተሰማዎት ስሜት በጣም የቀረበውን አንድ መልስ ያመልክቱ። ባለፉት 4 ሳምንታት ውስጥ ምን ያህል ጊዜ ነው ...?

	ሁልጊዜ	በጣም ብዙ ጊዜ	ብዙ ጊዜ	አንዳንድ ጊዜ	በጣም ትንሽ ጊዜ	መቼም/ምንም ጊዜ
G2. የሙሉ-ነት ስሜት ተሰምቶዎት ያወቃል?	1	2	3	4	5	6
G3. በጣም ብስጤ ሰው ነዎት/ነበሩ?	1	2	3	4	5	6
G4. የበታችኛነት ስሜት ምን ያህል ለማስወገድ የሚከብድ ስሜት ተሰምቶዎት ያወቃል?	1	2	3	4	5	6
G5. የተረጋጋና ሰላማዊ ስሜት ተሰምቶዎት ያወቃል?	1	2	3	4	5	6
G6. በቂ ኃይል አለዎት/ነበረዎት?	1	2	3	4	5	6
G7. የመከፋት ምን ያህል የድብርት ስሜት ተሰምቶዎት ያወቃል?	1	2	3	4	5	6
G8. ጥቅም የለሽ የመሆን ስሜት ይሰማዎታል?	1	2	3	4	5	6
G9. ደስተኛ ሰው ነዎት/ነበርክ/ሽ?	1	2	3	4	5	6
G10. የድካም ስሜት ይሰማዎታል?	1	2	3	4	5	6
G11. ሌላ የማንዘፍዘፍ ወይም የመጣል ችግር ይገጥመኛል ብለው ፈርተው ነበር?	1	2	3	4	5	6
G12. የማስተዋል እና ችግሮችን የመፍታት ድክመት ነበረበዎት? ለምሳሌ የማቀድ፣ ወሳኔ የመስጠት፣ አዲስ ነገር የማወቅ)	1	2	3	4	5	6
G 13. የጤናዎ ሁኔታ ከማህበራዊ እንቅስቃሴዎች ገደቦች ነበር (ለምሳሌ ጓደኞችዎን ወይም የቅርብ ዘመድን መጎብኘት)	1	2	3	4	5	6

(አንድ ቁጥር ብቻ ያክብቡ)

	በጣም ጥሩ፣ በተሻለ ሁኔታ	ጥሩ	ጥሩ እና የሆኑ እኩል ናቸው	መጥፎ	በጣም መጥፎ፣ ከዚያም በላይ የከፋ
G14 ባለፉት 4 ሳምንታት የህይወት ጥራት/የኑሮ ደረጃዎ በምን አይነት ሁኔታ ውስጥ ይገኛል? (ማለትም፣ ነገሮች እንዴት እየሄዱልዎት ነበር)?	1	2	3	4	5

ከዚህ በታች ያሉት ጥያቄዎች ስለ ማስታወስ ችሎታ ይሆናል። (አንድ ቁጥር ብቻ ያክብቡ)

	አዎ, በጣም ብዙ ነው	አዎ, በተወሰነ መጠን	ጥቂት ብቻ	አይ, በጭራሽ የለም
G15. ባለፉት 4 ሳምንታት ውስጥ የማስታወስ ችግር አጋጥሞዎት ነበር?	1	2	3	4

ባለፉት 4 ሳምንታት ውስጥ ምን ያህል ጊዜ የማስታወስ ችግር ነበረዎት ወይም ይህ የማስታወስ ችግር በተለመደው ህይወትዎ ወይም ሥራዎ ምን ያክል ጣልቃ ገብቷል።

	ሁልጊዜ	በጣም ብዙ ጊዜ	ብዙ ጊዜ	በተወሰነ ጊዜ	በጣም ትንሽ ጊዜ	መቼም/ምንም የለም
G16. ሰዎች የሚነግሩዎትን ነገር ለማስታወስ ችግር አጋጥሞዎት ነበር።	1	2	3	4	5	6

የሚከተሉት ጥያቄዎች እርስዎ ሊኖሩዎት ስለሚችሉ የ ትኩረት ችግሮች ናቸው። ባለፉት 4 ሳምንታት ውስጥ ምን ያህል በተደጋጋሚ ችግር ላይ እንደወደቁ ወይም እነዚህ ችግሮች በተለመደው ሥራዎ ወይም በሚኖሩበት ጊዜ ውስጥ ምን ያህል ጊዜ ውስጥ ጣልቃ ገብተዋል።

	ሁልጊዜ	በጣም ብዙ ጊዜ	ብዙ ጊዜ	በተወሰነ ጊዜ	በጣም ትንሽ ጊዜ	መቼም/ምንም የለም
G17. በንባብ/በስራ ላይ ትኩረት የማድረግ ችግር	1	2	3	4	5	6
G18. በአንድ ጊዜ አንድ ነገር ወይም ስራ ላይ የማተኮር ችግር	1	2	3	4	5	6

የሚከተሉት ጥያቄዎች አንዳንድ እንቅስቃሴዎች ላይ ሊኖሩዎት ስለሚችሉ ችግሮች ይሆናል። ባለፉት አራት ሳምንታት ውስጥ በሚጥል በሽታ እና መድሃኒቱ ምክንያት ምን ያህል ጊዜ ለችግር ተዳርገዋል ...

	በጣም ብዙ	ብዙ	በተወሰነ ደረጃ	ጥቂት ብቻ	እረ በጭራሽ
G19. በመዝናኛ ጊዜ (እንደ የትርፍ ጊዜ ማሳለፊያዎች፣ ክቤት ወጣ ብሎ ለመዝናናት)	1	2	3	4	5
G20. መኪና መንዳት፣ ትራንስፖርት መጠቀም ወይም በጉዞ ላይ	1	2	3	4	5

የሚከተሉት ጥያቄዎች ስለበሽታው (የሚጥልዎት ወይም የሚያዝፈዝፎት ችግር) ከሚሰማዎት ስሜት ጋር ይሆናል።

	በጣም እፈራለሁ	በተወሰነ መጠን እፈራለሁ	በጣም አልፈራም	በጭራሽ አልፈራም
G21. በሚቀጥለው ወር ውስጥ የሚጥልዎት ወይም የሚያዝፈዝፎት ችግር ይከሰታል ብለው ምን ያህል ይፈራሉ?	1	2	3	4

	ብዙ እጨነቃለሁ	አልፎ አልፎ እጨነቃለሁ	በፍጹም አልጨነቅም
G22 በሚጥለኝ ሠዓት ራሴን እንዳለሁ ብለው ይጨነቃሉ?	1	2	3

ጥያቄዎች	በጣም እጨነቃለሁ	በተወሰነ ደረጃ እጨነቃለሁ	በጣም አልጨነቅም	በፍጹም አልጨነቅም
G 23. በሚቀጥለው ወር ውስጥ የሚጥልዎት ወይም የሚያንዘፈዝፎት ችግር ምክንያት አሸማቂቃለሁ ወይም ሌሎች ማህበራዊ ችግሮችን ያስከትልብኛል ብለው ምን ያህል ይጨነቃሉ?	1	2	3	4
G24. የሚወስዷቸው መድሃኒቶች ለረጅም ጊዜ ከተወሰዱ መጥፎ ስሜት ያሳድሩብኛል ብለው ምን ያህል ይጨነቃሉ?	1	2	3	4

ከዚህ በታች ለተዘረዘሩት ችግሮች ፣ ምን ያህል እንዳስቸገረዎት ከ 1 እስከ 5 ካሉት ምርጫዎች አንዱን ያክብቡ. 1= በፍጹም አላስቸገረኝም፣ እና 5= እጅግ በጣም አስቸግሮኛል ማለት ናቸው.

	በፍጹም አላስቸገረኝም	በጣም አላስቸገረኝም	ገለልተኛ ነኝ	በጣም አስቸግሮኛል	እጅግ በጣም አስቸግሮኛል
G 25. የሚጥል በሽታ (ማንዘፍዘፍ ወይም መጣል)	1	2	3	4	5
G26. የማስታወስ ችግሮች	1	2	3	4	5
G27. የሥራ ገደቦች (ስራ ማስተጋገል)	1	2	3	4	5
G28. ማህበራዊ ውሳኔዎች (ማህበራዊ ጉዳይ ማስተጋገል)	1	2	3	4	5
G29. የሚጥል በሽታ መድሃኒት አካላዊ ተጽእኖዎች	1	2	3	4	5
G30. የሚጥል በሽታ መድሃኒት አእምሮአዊ ተጽእኖዎች	1	2	3	4	5

G31. ጤናዎ ምን ያህል ጥሩ ነው ወይስ መጥፎ? አጠቃላይ ጤንነትዎ ምን ያህል ጥሩ ወይም መጥፎ ነው ብለው ያስባሉ? መልሱን ሲሰጡ ያለበዎትን የሚጥል በሽታ ከግምት ውስጥ ያስገቡ።

በመጥፎ ሊገመት የሚችል የጤና ሁኔታ (ከጥንቅቅ ወይም ከላይ በላይ የከፋ ነው)											ጥሩ ሊገመት የሚችል ድንቅ የጤና ሁኔታ
	0	10	20	30	40	50	60	70	80	90	100

ለሰጡኝ ውድ ጊዜ በጣም አመሰግናለሁ።