

ADDIS ABABA UNIVERSITY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF NURSING AND MIDWIFERY

**Assessment of Health Related Quality of Life Among Adolescent
With Epilepsy in Government Hospitals, Addis Ababa Ethiopia,
2019.**

INVESTIGATOR: - OLANTU MEKONNEN GUTEMA

A THESIS SUBMITTED TO THE SCHOOL OF GRADUATE
STUDIES OF ADDIS ABABA UNIVERSITY, COLLEGE OF
HEALTH SCIENCES, SCHOOL OF NURSING AND MIDWIFERY
FOR PARTIAL FULFILLMENT OF THE REQUIREMENTS OF
MASTER’S DEGREE IN PEDIATRICS AND CHILD HEALTH
NURSING.

JUNE, 2019

ADDIS ABABA, ETHIOPIA

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APPROVAL BY THE BOARD OF EXAMINATION

This thesis by Olantu Mekonnen Gutema is accepted in its present form by the board of examiners as satisfying thesis requirement for the degree of masters in pediatrics and child health nursing.

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STATEMENT OF DECLARATION

By my signature below, I declare and affirm that this thesis is my own work. I have followed all ethical principles of scholarship in the preparation, data collection, data analysis and completion of this thesis. All scholarly matter that is included in the thesis has been given recognition through citation. I affirm that I have cited and referenced all sources used in this document. Every effort has been made to avoid plagiarism in the preparation of this thesis.

This thesis is submitted in partial fulfillment of the requirement for a graduate degree from the Addis Ababa University at College of Health Sciences, School of Nursing and Midwifery. The thesis is deposited in the Addis Ababa University Digital Library and is made available to local, national and international scientific community. I solemnly declare that this thesis has not been submitted to any other institution anywhere for the award of any academic degree, diploma or certificate.

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ABBREVIATIONS AND ACRONYMS

AARHB - Addis Ababa Regional Health Bureau

AEDs- Antiepileptic drugs

AMSH- Amanuel Mental Specialized Hospital

AWE- Adolescent with epilepsy

CSA - Central Statistical Agency

HRQOL- Health-related quality of life

PedsQL- Pediatrics quality of life inventory

QOL - Quality of Life

TASH- Tikur Anbessa Specialized Hospital

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ABSTRACT

Background: -Epilepsy is a chronic neurologic disorder which affects the individual in different aspect of health domain. Health related quality of life incorporates the increasing awareness of one's psychological, social, and behavioral well-being in addition to physical well-being in chronic disorder. Adolescents with epilepsy has diminished health related quality of life due to the stigma of the disease, the dramatic and often frightening nature of seizures, the lack of control over epileptic activity, and the risk for physical harm.

Objective: - This study aimed to assess health related quality of life and associated factor among adolescent with epilepsy in government hospitals, Addis Ababa, Ethiopia.

Methods: - An institutional based cross sectional study was employed from March 10 to May 10/2019 at Tikur Anbessa and Amanuel Mental specialized hospitals. Random sampling methods and face to face interview data collection method was used. Adolescents were completed PedsQL™ 3.0 Epilepsy Module. Multivariable linear regression was done and significant association was declared at $p < 0.05$.

Result: -A total of 415 adolescents participated in this study with the response rate of 98.3 %. The participants consist of 214 (50.7%) females, 218(51.7) generalized type of seizure and 58.3% on polytherapy. The mean age was 14.19 ± 2.71 years old. Age of first onset of seizure was reported 8.37 ± 4.03 years and duration on follow up were 5.74 ± 3.25 years. The total mean score points for health related quality of life with PedsQL™ 3.0 epilepsy module was 43.28 ± 22.44 . The sub scale had different scores with impact of illness, sleep disorder and family or friend support had greater mean scores than the total mean of health related quality of life scores while cognitive function, executive function and emotional change reported lower mean scores than the total score.

Conclusion and Recommendation: -This study found that type of seizure, marital status, family income, frequency of seizure, age and maternal education level were independent predicting factors for HRQOL among adolescent with epilepsy. This study recommends for health professionals to treat adolescents with epilepsy with all domains of health focusing on psychological aspects.

Key words= Quality of life, Adolescent, HRQOL, Epilepsy and Seizure.

CHAPTER ONE

1. INTRODUCTION

1.1 Background

Epilepsy is globally a chronic neurologic disorder defined as two or more unprovoked seizures with greater than 24 hours apart or one unprovoked seizure and have more than 60% of chance to occur again(1). It is described as brief episodes of involuntary movement that can be some part of body (partial) or the whole part of the body which is generalized. Sometimes there is loss of consciousness(2).

Epilepsy can be idiopathic epilepsy or secondary epilepsy due to head injury, birth trauma, asphyxia, cerebrovascular disease, and intracranial infections and genetic factors(3). The diagnosis of epilepsy is usually clinical based on history of epileptic seizures that is reported by the patient and examinations like electroencephalography demonstrate the type of the seizures(4). By antiepileptic drugs the seizure ceases for some patients while it is life- long for others though they take the medications(5).

Quality of life (QOL) in individuals with epilepsy is resolved principally by the term of the illness and the degree of seizure control (6). Surveying QOL in pediatric epilepsy is particularly imperative in light of the fact that both cognitive and social abilities are created in adolescence. Mental and psychosocial difficulties and co-morbidities are more typical in pediatric epilepsy than in other youth chronic medicinal problems(7).

Health related quality of life (HRQOL) is subjective as the appraisal of the quality of one's own life as it relates to personal expectations, capabilities, and experiences. HRQOL incorporates the increasing awareness of one's psychological, social, and behavioral well-being in addition to physical well-being in chronic disease(8). Adolescents with epilepsy has diminished HRQOL due to the stigma of the disease, the dramatic and often frightening nature of seizures, the lack of control over epileptic activity, and the risk for physical harm(8).

1.2 Statement of the problem

Worldwide about 50 million people have epilepsy which makes it widespread neurological diseases(9, 10). From these 80% of the people with epilepsy are exist in low- and middle-income countries(11). Among the epileptic people children accounts about 40%(9). Globally people with epilepsy and their families go through stigma and discrimination(10).

In Ethiopia an estimate of 1% of people live with epilepsy(12) of which 85% are children and only 3% of them get treatment to control the seizure due to associated stigma with the disease and due to other social and economic factors(13).

Growing up with seizures influences the adolescent's identity and intellectual improvement and interferes with numerous parts of regular day to day existence, including learning at school, relaxation and physical related exercises. Epilepsy has been appeared to highly affect the quality of life (QOL) when adolescents have refractory seizures and extra disability(14).

Epilepsy can profoundly affect wellbeing and QOL. It might upset the advancement of autonomy, social working, peer connections, and confidence, which are all especially vital during adolescence(15). In this formative period, people shape a feeling of character and self-sufficiency, depending intensely on companion connections. Young people start to make instructive, profession, and close relationship choices(16).

At the point when youngsters keep on encountering seizures regardless of hostile to epileptic medication treatment, they are bound to be influenced by other co-morbidities. Basic co-morbidities incorporate, learning debilitation because of brain contortion, depression or social maladjustment because of seizures, intellectual difficulty because of their antiepileptic treatment, behavioral issues, and trouble sleeping(17). Regardless of not having a related incapacity all children and adolescents with epilepsy are in risk of social and learning troubles(18).

Even though in Sub-Saharan Africa greater part of patients with epilepsy found, there are few studies done on these area(19). In study done in Uganda, health-related quality of life (HRQOL) mean score very low 58 out of scale 0- 100 in patients with epilepsy though they are taking the antiepileptic medications(20).

Even if in our country 85% of epileptic patients are pediatrics there is less researches done on this area. Study on health related quality of life among adolescents with epilepsy is not done. But there are studies conducted on the topics behavioral problems in pediatric epilepsy and short term outcome of children with status epileptics. In addition to this, adolescence is the time of puberty (secondary characteristics) and transitional stage to adulthood which they practice to decide by themselves, start intimacy relationships and make choice for their future so, if there is problems like epilepsy make their health condition more difficult. The purpose of this study is to assess the health related quality of life among adolescents with epilepsy and to identify associated factors.

1.3 Significant Of the Study

Assessing health related quality of life provides valuable information about the effect of epilepsy in the adolescent and the co-morbidities related to epilepsy. This study will give a clue, for health profession to consider general health perception of the patients in conjunction of medical management, aiming to them to develop specific management programs respect patient's condition, help them think broadly to identify negative impact of other co-morbidities which are mostly psychological and social than of controlling the seizure.

It helps guideline developer to incorporate health related quality of life assessment in medical practice in the process of guideline development and enhance them to enforce health profession to enact it in practice for patients care.

Finally this study will be basis for other researchers who want to study on related topics.

CHAPTER TWO

2. LITERATURE REVIEW

2.1 Magnitude of Epilepsy

It is evaluated that almost 50 million individuals live with epilepsy around the world; of these individuals, 10 million live on the African mainland(21).

The prevalence of epilepsy vary between developed and developing nations with a predominance rate going from 16 to 51 for each 100,000 population in the developed nations and 35– 111 for each 100,000 population in the developing nations(22).

The estimated of an age-specific global incidence of 3.5 million people developing epilepsy on an annual basis from these 40% are children under 15 years old. Approximate 700 per 100,000 children under the age of 16 years have epilepsy in comparison to 330 per 100,000 in adults(18).

The prevalence of epilepsy studies done in Europe(3), Canada(23), Australia(24) and Saudi Arabia(25) showed that 6.2 per 1000, 5.2 per 1000, b/n 6 - 7.5 per 1000, 6.5 per 1,000 population respectively. A study conducted to assess the prevalence, incidence and etiology of epilepsy was found that high prevalence in adolescents and early age group(3).

A community based study in Egypt found that the crude lifetime prevalence rate of epilepsy 12.67 per 1000 people, while the prevalence rate is 9.3/1000 and the incidence rate is 1.5/1000(26). While in Ghana study reveals that the prevalence of epilepsy in the population was 29.2 per 1000 people(27).

Studies covering the weight of epilepsy in African youngsters go between 7.3 per 1,000 in South Africa and 41 for each 1,000 in Kenya(28).

In Ethiopia the crude incidence of epilepsy is 64 per 100,000 while age-adjusted incidence of epilepsy is 43 per 100,000(29).

2.2 Health related quality of life among adolescent with epilepsy

Epilepsy is related to critical psychosocial challenges and shame, which is psychosocial trouble looked by patients with epilepsy that can show influence in their quality of life (QOL)(30, 31). The impression of stigma can impact psychosocial wellbeing and self-esteem, particularly in adolescents with epilepsy, in light of the fact that the improvement of self-character and companion connections is of basic significance in puberty(32).

The results of epilepsy regularly advance in an intricate manner and can be represented by various elements including the impacts of brief chronic dysfunction on the developing brain, the nearness of co-morbid disability, the consequent cognitive issues, and the response of the people and their families to the diagnosis and treatment(6, 33).

Epileptic adolescents are at more risk of cognitive and mental weaknesses; they frequently encounter overwhelming restrictions and social stigma, worry of next seizure, AED reactions, and poor academic accomplishment; along these lines, epilepsy weakens children physical and intellectual wellbeing and psychosocial similarity as prove by emotional, conduct, social, and learning troubles which diminishes the HRQOL as a whole(34).

On study conducted in Montenegro, adolescents with dynamic epilepsy had low QOL and felt the negative effect of the disorder. They additionally had progressively cognitive weaknesses, felt more stigmatized, and had a significantly more distorted impression of their wellbeing than adolescents with latent epilepsy. Not surprisingly, adolescents with the most number of seizures in the previous two years had the low QOL(7).

Study done in Iran on HRQOL among 108 children and adolescents institution based cross-sectional study was assessed by Child Health Questionnaire and QOL in Childhood Epilepsy Questionnaire separately, showed that the HRQOL poorer in the psychosocial aspect and parental emotional have a negative impact on the children and adolescents. It also showed that girls with epilepsy had poorer HRQOL compared to boys with epilepsy(35).

Clarke et al. found that adolescents had poor psychosocial functioning when they experience seizure in the last month, came from lower family functioning, and made greater use of non-

productive (emotion-focused) coping strategies such as wishful thinking, withdrawal, and worry(36).

A cross-sectional study done by Fong Cy. and his colleagues in age group of 8- 18 years children who have epilepsy to assess the QOL in Malaysia, showed that poorer QOL were related with focal seizure and seizure frequency greater than one seizure per month. There was also difference in the report of Malaysian parent and child with epilepsy score agreement poor to moderate(37).

Studies reveal that when adolescents keep on encountering seizures regardless of against epileptic medication treatment, they are bound to be influenced by other co-morbidities. Normal co-morbidities incorporate learning difficulty because of brain contortion, sorrow or social stigma because of seizures, intellectual debilitation because of their antiepileptic treatment, conduct issues, and trouble of sleeping(18).

In fact, cognitive problems have been found to be the strongest risk factor for compromised HRQOL two years after diagnosis, while a combination of emotional and behavioral difficulty and low verbal memory have been shown to produce a 17-fold increase in risk of lower HRQOL(38).

2.3 Factors affecting HRQOL

There are several factors contributing to HRQOL in adolescents with epilepsy. Studies identified epilepsy related factors such as type of seizure, onset of seizure, duration, frequency of seizure and AEDs and adolescent related factors like gender and age as major predictors(7, 35). Other factors related to the HRQOL of AWE are cognitive functioning, impact of illness, sleep disorder/fatigue, executive functioning, behavior/mood change, family education and income(39).

Socio-Demographic factors

There were contrasts in explicit HRQOL scores among male adolescents and female adolescents. In the study done in Iran, HRQOL score was brought down in females contrasted to males(35) while study done in Montenegro adolescents showed females announced

preferable social help from the family and peer which has positive aspect in HRQOL than males(7).

A study conducted in pediatric neurology outpatient clinic in Surabaya on adolescents aged b/n 10- 16 years, found that increasing age was significantly decreased the HRQOL but the sex of the adolescent was not significantly correlated(40).

A comparative study conducted in Greece on 100 children ages grouped between 8- 16 years reported that no association with sex was observed in the HRQOL scores when age in all age groups and for all dimensions, lower HRQOL scores were reported for the group with epilepsy, but the difference was statistically significant only in the age group of 13.5–16 years(41).

Study done to assess quality of life in children with epilepsy in private and public tertiary care centers in India on 601 participants found educational status of parents (guardians), explicitly of the mother, is an essential contributor toward HRQOL as it help to understanding of the conditions of their child. This study showed that higher education and higher income contributed to better score in HRQOL(42).

Epilepsy related factors

A case- control study conducted in China adolescents with epilepsy to determine the QOL and related factors on 47 pairs of active adolescents with epilepsy and matched normal controls, the mean total score of QOLIE-AD-48 of epileptic subjects was 65.6 ± 14.1 and age of onset, seizure worry, and fear of injury were all significantly associated with QOL(43).

In New Delhi India, quality of life was assessed in 108 epileptic children (6-15 years), using a Hindi translation of Quality of Life in Children with Epilepsy questionnaire revealed quality of life was significantly more compromised in patients with partial type of epilepsy compared to generalized epilepsy(44).

The study done by Karnavat et al. in India using the Pediatric Quality of Life Inventory (Peds QL) by proxy report confirms that polytherapy is associated with poor QOL. Specific to adolescents only side effects of AEDs were found as strong predictors for lower QOL(42).

On study conducted in Greece showed that the number of AEDs, the duration of treatment, and the physical disability had a statistically significant effect on HRQOL while the age at onset, the duration of symptoms, side effects of AEDs, seizure control, the time without seizures, and heredity were not statistically significant factors for HRQOL(41).

A study conducted in Egypt to assess HRQOL in children with epilepsy by cross- sectional case- control on 50 epileptic children aged 8- 12 years with control of 50 healthy children found that epilepsy-related risk factors such as age at onset of seizures, types of seizures, duration of the illness, number and duration of antiepileptic drugs were found to be significantly strong predictors of poorer HRQOL life in children with epilepsy(45).

Bravcova D. et al showed in their study that adolescents with epilepsy have significances in lower academic achievement and self-concept. It affects academic self- confidence. Adolescents with epilepsy and learning disability had significantly lower QOL scores(46).

Study done in Turkey to examine sleep problems and association with QOL on 53 children with epilepsy age b/n 7- 18 years and 28 controls children with minor health problem on the same age group showed that sleep problem in children with epilepsy lead to poor QOL(47).

An exploratory study done to assess the relationship between executive functioning and QOL in pediatric intractable epilepsy on fifty-four consecutively referred pediatric epilepsy surgery candidates and their parents were administered IQ measures, the behavior rating inventory of executive function (BRIEF), and the quality of life in childhood epilepsy (QOLCE) showed that poor executive functioning had 9.7 times risk of having poor QOL in adolescents with epilepsy(48).

Geerlings P.J. et al that they conducted to identify risk factors on adolescents and young adults to long term outcome of epilepsy on psychosocial and health related long term problem reveled by their study that unsupportive and unstable family environment had higher risk factor for poor psychosocial and health related outcome(49).

An institution based study conducted in Ethiopia to assess the prevalence of behavioral problems on 384 children and adolescents with epilepsy on follow 36.2% of the CWE have high or abnormal total difficulty score. On adolescents b/n age 11-14 were more likely to have

conduct problem and peer relationship problem which affect the QOL of the adolescents(13).

2.4 Conceptual Framework

The conceptual framework is done from different literatures findings. It shows that the outcome HRQOL has association with those domains listed below and this study will gone show if it happen on this research(7, 13, 35, 39, 40, 42, 44, 46-48).

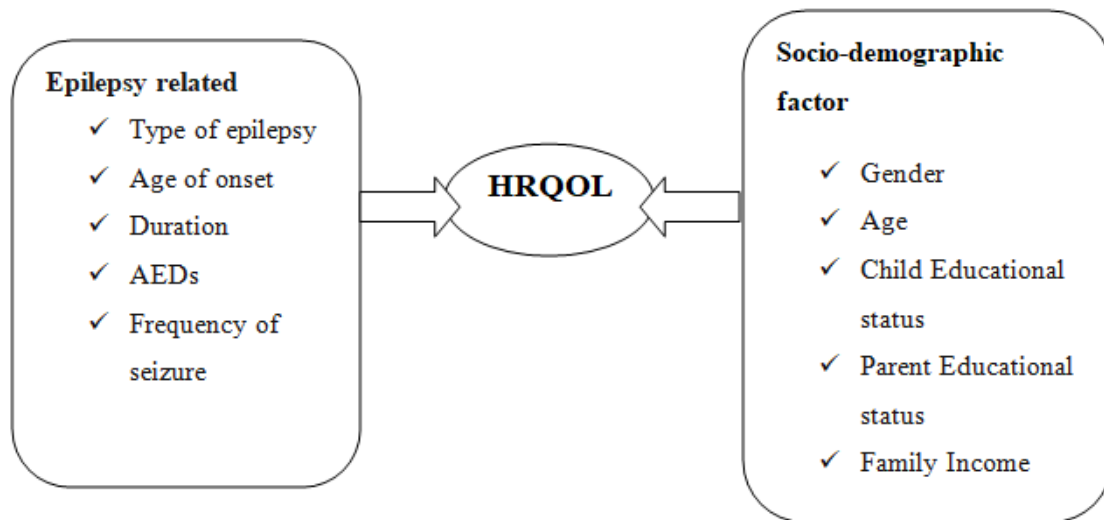


Figure 1:- Conceptual framework on HRQOL among adolescents with epilepsy 2019.

CHAPTER THREE

3. OBJECTIVES

3.1 General objective

- To assess health related quality of life and associated factors among adolescents with epilepsy in government hospitals, Addis Ababa Ethiopia, 2019.

3.2 Specific objectives

- To determine health related quality of life among adolescents with epilepsy.
- To identify associated factors with HRQOL among adolescents with epilepsy.

CHAPTER FOUR

4. MATERIALS AND METHODS

4.1 Study area and period

This study was conducted in Addis Ababa from March 10- May 10/2019. Addis Ababa is the capital city of Ethiopia and the largest city geographically located at center of Ethiopia.

According to the Central Statistical Agency of Ethiopia (CSA), by population projection in 2015 the total population of Addis Ababa is 3,273,000 persons(50). Based on Addis Ababa Regional Health Bureau (AARHB) 2006 report, under its administration there are six hospitals, one Public health laboratory and two health Science colleges and 5 by federal government (51). The study was conducted from March 10- May 10/2019 in government hospitals in Addis Ababa namely Tikur Anbessa and Amanuel Mental specialized hospitals.

4.2 Study design

- An institutional based cross sectional study was conducted.

4.3 Population

4.3.1 Source population

- All adolescents with epilepsy attending seizure/ neurology clinic in government hospitals in Addis Ababa.

4.3.2. Study population

- The selected adolescents with attending seizure/ neurology clinic in selected government hospitals in Addis Ababa.

4.4 Eligibility Criteria

Inclusion criteria

- Adolescents aged 10-18 years with epilepsy who had been on follow up for at least 3 months.

Exclusion Criteria

- Adolescents who have severed defects cannot respond like autism, cerebral palsy.
- Adolescents who are not willing to participate in the study.
- Adolescents who are on repeated follow up.

4.5 Sample size determination

Sample size is calculated using single population proportion formula. By considering the following assumption, about 50% of the population proportions have good health related quality of life, 95% confidence interval, 5 % margin of error the sample size calculated as follows.

$$n = \frac{(Z_{\alpha/2})^2 \times p(1-p)}{d^2}$$

Where

n- Initial Sample size

z- Standard normal value at 95% CI which is 1.96

P-50% Estimated the population proportion have good health related quality of life

d- Possible margin of error tolerated which is 5%.

$$n = \frac{(1.96)^2 \times 0.5(1-0.5)}{(0.05)^2}$$

$$n = 384$$

By adding 10% of non-respondents rate final sample size will be 422.

4.6 Sampling technique and procedure

The study subjects were selected from the selected government hospitals in Addis Ababa which were Tikur Anbessa Specialized Hospital (TASH) and Amanuel Mental Specialized Hospital (AMSH) selected by lottery method from St. Peter, Zewditu, Abet, TASH, St. Paul and AMSH hospitals. There were total of 530 adolescents identified who had been on epilepsy follow up for the last three month from September to November 2018 in the selected hospitals. The need sample size was proportionally allocated for each hospitals.(see figure 2) Study participants were selected from each hospitals using manually random sampling method from the frame eligible patients visiting the neurology/ seizure clinic during the data collection period were interviewed. Study participants who had been on repeated follow up during data collection time was excluded by using code number given on their medical chart and the next study subject was selected.

Proportional allocation for each selected hospital

$$\text{TASH} = \frac{\text{AWE on follow up at TASH} \times \text{Total sample size}}{\text{AWE on follow up in selected hospitals}}$$

$$\text{TASH} = \frac{247 \times 422}{530} = 197$$

$$\text{AMSH} = \frac{\text{AWE on follow up at AMSH} \times \text{Total sample size}}{\text{AWE on follow up in selected hospitals}}$$

$$\text{AMSH} = \frac{283 \times 422}{530} = 225$$

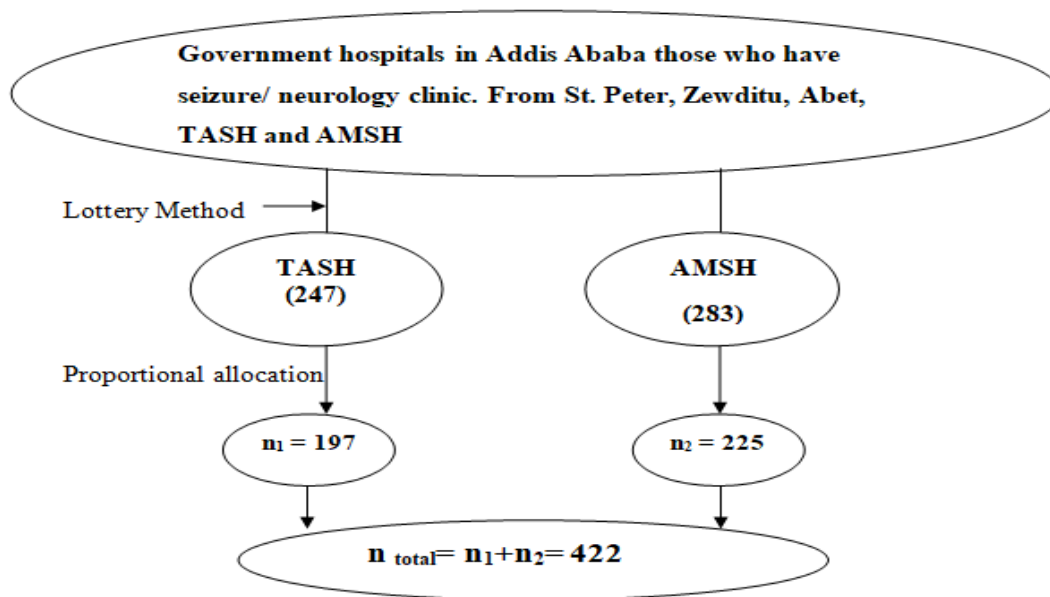


Figure 2: Schematic presentation of sampling technique and sample size proportional allocation 2019.

4.7 Operational definition

Health-Related Quality of Life (HRQOL):- represents the functional effects of an illness and its resulting therapy on a patient, as perceived by the individual patient. It is measured by PedsQL™ 3.0 Epilepsy Module with 36 total items with 6 sub scales impact of illness, cognitive functioning, sleep disorder, executive functioning, emotional change and family or friends support. The mean scores of each sub scales is taken to measure HRQOL as a total scores from 0 – 100 points.

Epilepsy: - is a chronic neurological condition with abrupt disturbances in the electrochemical firing of neurons in the brain cause seizures. It's causing change in an individual's sensation, awareness, and/or behavior and has various origins, symptoms, courses, and prognoses.

Seizure: -A seizure is an individual episode in which an abrupt discharge of electrical activity in the brain may cause changes in sensation, behavior or consciousness.

Monotherapy: - refers to the use of one antiepileptic drug.

Polytherapy: - refers to the use of more than one type of antiepileptic drugs.

PedsQL™ 3.0 Epilepsy Module: - for adolescent report composed of 36 items comprising 6 dimensions. Which are impact (12 items), cognitive functioning (6 items), sleep/rest (3 items), executive functioning (6 items), emotional/mood problems (5 items) and support from family/friend (4 items). The rating is in Likert scale from 0 (Never) to 4 (Almost always). Scores are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25 and 4=0. If greater than 50% of the items in the scale are missing, the scale scores should not be computed. Mean score is Sum of the items over the number of items answered.

Adolescents: - According WHO they are age group from 10 to 18 years when early adolescents are between 10- 14 years and late adolescents between 15- 18 years.

4.8 Variables

4.8.1. Dependent variable

Health related quality of life

4.8.2. Independent variables

Socio- Demographic factor

- ✓ Gender
- ✓ Age
- ✓ Child Educational status
- ✓ Parent Educational status
- ✓ Income

Epilepsy related

- ✓ Type of seizure
- ✓ Age of onset of seizure
- ✓ Duration on follow up
- ✓ Number of AEDs
- ✓ Frequency of seizure

4.9 Data collection tool and procedure

Data collection instrument had two parts these were part-I Socio- demographic and medical condition and part -II PedsQL™ 3.0 Epilepsy Module for adolescent report. It is adopted from Mapi Research Trust online questioner provider(52). The instrument adopted in English and was translated to Amharic. It was translated back to English by independent translator to check for consistency. Data collection was started by obtaining permission from TASH and AMSH. Adolescents those meet the inclusion criteria and their parents was explained to the purpose of the study and reassured the confidentiality. Both adolescents and their parents those willing for participation in study was interviewed. The data collectors and supervisors were four and two BSC trained health professionals respectively. The principal investigator trained the health professionals on the instrument and way of collecting the information to have common understanding on the tool. The principal investigator also checked the collected data every day for its completeness. Data was collected through face to face interview from March 10- May 10/2019. The internal consistency reliability coefficient of Cronbach's α for adolescents self-report was 0.97.

4.10 Data quality control

Data quality was ensured during collection, coding, entry and analysis. To increase the quality of data during data collection three teams namely data collectors, supervisors and investigators were assigned and properly designed, structured and pretested questioner were used. Pretest was conducted before data collection on about 10% of sample in Abet Hospital. Supervision of data collectors was done by supervisors and includes observation of how the data collectors were collecting data. The filled questioner was checked by data collectors, supervisors and principal investigator for completeness and clarity on a daily basis.

4.11 Data Processing and Analysis

All returned questioners were checked for completeness and clarity, cleaned manually, coded and entered and analyzed in SPSS version 21 statistical package by the principal investigator. Frequencies and Percentage were used to summarize descriptive statistics, mean and standard deviation tables and charts were used for data presentation. Multivariable linear regression analysis was conducted to identify factors associated with health related quality of life.

Statistical significance was declared at $p < 0.05$. To select variables to Multivariable linear regression, variables were calculated by independent t- test and ANOVA tests, then variables which had significant difference at $p < 0.05$ on the bivariate analysis were taken to the multivariable analysis to calculate the predicting factors to HRQOL among adolescents with epilepsy.

4.12 Ethical consideration

Ethical clearance was obtained from institutional review board (DRPC) of Addis Ababa University, college of health sciences, school of nursing and midwifery. After ethical clearance received, permission to conduct the research was obtained from Tikur Anbessa Specialized Hospital and Amanuel Mental Specialized Hospital. Information sheet was prepared and read to all eligible participants of the study. All participants were informed the purpose of the study and their participation is on voluntary basis. Verbal informed consent form parents/ caregivers and assent form adolescents was received from all participants. In order to keep the confidentiality, codes were used in place of name and medical registration number of the participants.

4.13 Dissemination of the result

The result of this study will be presented to Addis Ababa University College of health sciences, school of nursing and midwifery as partial fulfillment of the requirement of master degree in pediatrics and child health nursing. Furthermore the result will be shared with neurology/ seizure unit of Tikur Anbessa Specialized Hospital and Amanuel Mental Specialized Hospital. The document of the research will be prepared and submitted to appropriate journals for possible publication.

CHAPTER FIVE

5. RESULT

5.1 Socio-demographic Characteristics

A total of 415 participants included in the study with the response rate of 98.3 %, from this about 201 (48.4%) of them were males and about 214 (51.6%) of them were females. The mean age of adolescents was 14.19 ± 2.71 . About 64.8% of them were married parenting. Regarding educational status of parents, about 60 (14.7%) of adolescents mother and about 23 (6.3%) adolescents father were unable to read and write while 26.2% of mothers and 36.7% of fathers were above grade 12. The mean income of the respondents family per month were 2934.84 ± 2802.16 .

Table 1:- Socio-demographic characteristics of adolescent with epilepsy in government hospitals, Addis Ababa, Ethiopia 2019.

Variables		Frequency (n=415)	Percent (%)
Sex	Male	201	48.4
	Female	214	51.6
Age	Early Adolescent	213	51.3
	Late Adolescent	202	48.7
Grade	Under grade 5	137	33.0
	Grade 6- 8	117	28.2
	Grade 9- 12	161	38.8
Family Marital status	Single	7	1.7
	Married	269	64.8
	Divorced	97	23.4
	Widowed(partner died)	42	10.1
Mother Education Level(n=409)	Unable to read and write	60	14.7
	Read and write	90	22.0
	Grade1-8	75	18.3
	Grade 9-12	77	18.8
	Above 12	107	26.2
Father Education Level(n=368)	Unable to read and write	23	6.3
	Read and write	59	16.0
	Grade 1-8	61	16.6
	Grade 9-12	90	24.5
	Above 12	135	36.7

Continued Table 1.....			
Occupation of Mother(n=403)	Unemployed	144	35.7
	Government/ private employee	135	33.5
	Self employed	64	15.9
	Other	60	14.9
Occupation of Father(n=350)	Unemployed	4	1.1
	Government/ private employee	109	31.1
	Self employed	172	49.1
	Other	65	18.6
Family Income per Month	Low	138	33.3
	Medium	257	61.9
	High	20	4.8

5.2 Clinical Characteristics

The mean age of seizure onset for participants were 8.37 ± 4.03 years (mean $\pm$ SD) and the mean duration on follow up for the respondents were 5.75 ± 3.25 years (mean $\pm$ SD). 218(52.5) of adolescents had generalized type of seizure and 246(59.3%) of participants were taking more than one AEDs. About 51.6% of adolescents with epilepsy had occasional seizure and 42.9% of participants responded their condition that they had not at all severed from their last visits. 17.3% of participants reported that they had family history of seizure. A 208(50.1%) of the respondents had injuries during seizure and 223(53.7%) had side effects from the AEDs.

Table 2:- Clinical characteristics of adolescent with epilepsy in government hospitals, Addis Ababa, Ethiopia 2019.

Variables		Frequency(n=415)	Percent
Age of onset	Less than or equal 7 years	169	40.7
	Greater than 7 years	246	59.3
Duration on follow up	Less than or equal 5 years	203	48.9
	Greater than 5 years	212	51.1
Type of seizure	Partial	197	47.5
	Generalized	218	52.5
Number of AEDs	Monotherapy	169	40.7
	Polytherapy	246	59.3
Frequency of seizure	None	96	23.1
	Once/ few times per week	42	10.1
	Few times per month	63	15.2
	Occasionally	214	51.6
Severity from last visit	Extremely sever	18	4.3
	Very sever	46	11.1
	Moderately sever	100	24.1
	Somewhat sever	73	17.6
	Not at all sever	178	42.9
Family History with epilepsy	Yes	72	17.3
	No	343	82.7
Injury during seizure	Yes	208	50.1
	No	207	49.9
Side effect of AEDs	Yes	223	53.7
	No	192	46.3
Interference with Daily activities	Yes	169	40.7
	No	246	59.3

5.3 Adolescents self-report of HRQOL

Total mean scores of adolescents self-report for total PedsQL™ 3.0 Epilepsy Module scoring was 43.28±22.44 points. The minimum total score PedsQL™ 3.0 EM was 0, and the maximum was 100. Among the subscale scores, family or friend support had the highest mean of 62.36 points, and the lowest mean was observed for item in emotional changes 26.60 points. On the sub scales cognitive functioning, executive functioning and emotional changes were below the mean of the total HRQOL scores, while the sub scales impact of illness, sleep disorder and family or friend support were above the mean of total HRQOL scores.

Table 3: -Adolescents Self-report on PedQL™ 3.0 Epilepsy Module of adolescents (mean ± Standard deviation), in government hospitals, Addis Ababa, 2019.

PedsQL EM sub Scales	Mean	Std. Deviation	Minimum	Maximum
Impact Of Illness	44.46	31.87	.00	100.00
Cognitive Functioning	40.08	30.03	.00	100.00
Sleep Disorder	45.86	31.17	.00	100.00
Executive Functioning	40.35	28.47	.00	100.00
Emotional Changes	26.60	25.60	.00	100.00
Family/ Friend Support	62.36	29.57	.00	100.00
Total HRQOL Score	43.28	22.44	.00	100.00

EM = Epilepsy Module Higher score indicate better quality of life.

5.4. Bivariate analysis of HRQOL

The bivariate analysis of PedsQL™ 3.0 Epilepsy module Core Scales of adolescents in t-test according to their different socio-demographic and clinical characteristics, revealed that total mean HRQOL score of adolescents were associated with age group ($t=4.730$, $p=0.000$), family marital status ($t=5.362$, $p=0.000$), duration on follow up ($t=3.617$, $p=0.000$) and type of seizure ($t = 9.052$, $p=0.000$), number of AEDs taken ($t=8.189$, $p=0.000$).

Table 4:- PedsQL™ 3.0 epilepsy module Scales items in t-test according to socio-demographic and clinical characteristics of adolescent with epilepsy in government hospitals, Addis Ababa, 2019.

Variables		N%	t-test	p-value
Age	Early	51.3	4.730	0.000
	Late	48.7		
Sex	Male	48.4	1.471	0.142
	Female	51.6		
Marital status	Married	64.8	5.362	0.000
	Single/ others	35.2		
Age of onset	≤7 years	40.7	0.639	0.523
	>7 years	59.3		
Duration of follow up	≤5 years	48.9	3.617	0.000
	>5 years	51.1		
Type of seizure	Partial	47.5	9.052	0.000
	Generalized	52.5		
No of AEDs	Monotherapy	40.7	8.189	0.000
	Polytherapy	59.3		

The mean difference is significant at the $p < 0.05$ level.

The bivariate analysis of PedsQL™ 3.0 Epilepsy module Core Scales of adolescents in ANOVA according to their different socio-demographic and clinical characteristics, revealed that total mean HRQOL score of adolescents were associated with grade of the adolescent ($F(2,414)=5.261$, $p=0.006$), maternal educational level ($F(4,408)=3.530$, $p=0.008$), family income per month ($F=12.311$, $p=0.000$) and frequency of seizure ($F(3,414)= 10.126$, $p=0.000$) adolescents.

Table 5:- PedsQL™ 3.0 epilepsy module Scales items in ANOVA according to socio-demographic and clinical characteristics of adolescent with epilepsy in government hospitals, Addis Ababa, 2019.

	Variables	N %	F – test	P – value
Family income per month	Low	33.3	12.311	0.000
	Medium	61.9		
	High	4.8		
Grade	Under 5	33.0	5.261	0.006
	Grade 6-8	28.2		
	Grade 9-12	38.8		
Mother Education	Unable to read and write	14.7	3.530	0.008
	Read and write	22.0		
	Grade 1-8	18.3		
	Grade 9-12	18.8		
	Above 12	26.2		
Father Education	Unable to read and write	6.3	1.976	0.098
	Read and write	16.0		
	Grade 1-8	16.6		
	Grade 9-12	24.5		
	Above 12	36.7		
Frequency of seizure	None	23.1	10.126	0.000
	Few times a week	10.1		
	Few times a month	15.2		
	Occasionally	51.6		

The mean difference is significant at the $p < 0.05$ level.

5.5. Multivariable linear regressions analysis of factor associated with HRQOL

Multivariable linear regression analysis was adjusted for significant confounder of PedsQL™3.0 epilepsy module scales of adolescents such as age, family marital status, family income per month, grade of the adolescent, maternal educational level, durations on follow up, type of seizure, number of antiepileptic drugs taken and frequency of seizure, those were some of characteristics of adolescents which had make difference in HRQOL scoring of adolescents with epilepsy indicted in bivariate analysis. The multivariable result reveled that late adolescent, married parents, medium income, unable to read and write, partial type of seizure, monotherapy of AEDs and seizure free (none for frequency of seizure) were an independent influencing factors for HRQOL scoring of adolescents with epilepsy which

explain 32.3% of the variability of total HRQOL score of adolescents ($R^2=0.323$, Adjusted $R^2=0.312$, $F_{(7,414)} = 27.769$, $p<0.001$).

Type of seizure, parent's marital status, parent's monthly income, frequency of seizure and number of antiepileptic drugs had significance to higher the HRQOL while age of the adolescents and maternal education level had significance to lower the HRQOL.

Adolescents who had a partial type of seizure had a higher HRQOL ($\beta = 9.044$, $p=0.000$) than adolescents with generalized type of seizure. Followed by married parents ($\beta = 9.265$, $p=0.000$) and medium income parents ($\beta = 8.121$, $p=0.000$).

Similarly adolescents who had seizure free (none) frequency of seizure had variability ($\beta = 8.474$, $p=0.000$). Adolescents who had taken monotherapy of antiepileptic drugs were significantly had higher HRQOL ($\beta = 6.732$, $p=0.005$).

On the other hand, adolescents who were in late adolescence had lower HRQOL ($\beta = -7.572$, $p=0.000$). Also maternal education level, those mothers' of adolescents who were unable to read and write, had lower HRQOL ($\beta = -7.365$, $p=0.007$).

Table 6:- Multivariable linear regression analysis predictors for HRQOL of adolescents with epilepsy in governmental hospitals, Addis Ababa, 2019.

Variable	Unstandardized Coefficients		Standardized Coefficients Beta	T	Sig.	95.0% Confidence Interval for B		Collinearity Statistics	
	B	Std. Error				Lower Bound	Upper Bound	Tolerance	VIF
(Constant)	28.009	2.333		12.008	.000**	23.424	32.594		
Type of Seizure	9.044	2.341	.201	3.863	.000**	4.442	13.645	.612	1.635
Family Marital Status	9.265	1.964	.197	4.718	.000**	5.405	13.126	.950	1.052
Family Income	8.121	1.957	.176	4.150	.000**	4.274	11.968	.926	1.080
Age	-7.572	1.879	-.169	-4.031	.000**	-11.265	-3.879	.948	1.055
Frequency of Seizure	8.474	2.289	.159	3.702	.000**	3.975	12.974	.897	1.115
No of AEDs	6.732	2.380	.148	2.829	.005*	2.054	11.410	.611	1.636
Maternal Education	-7.365	2.699	-.116	-2.729	.007*	-12.671	-2.060	.928	1.078

Dependent Variable: HRQOL

Predictors: (Constant), Partial type, Married, Medium, Late, None (seizure free), Monotherapy, Unable to read and write

**p<0.001, *p<0.01

CHAPTER SIX

6. DISCUSSION

This study demonstrated the health related quality of life among adolescent with epilepsy in government hospitals, Addis Ababa Ethiopia. The study revealed that , adolescents scores in emotional change, cognitive functioning and executive functioning sub scale of HRQOL were the lower than the total mean score reported of HRQOL of adolescents which was similarly reported with study conducted in Nigeria which was $46.24 \pm 1.73(53)$. This might be due to their presence in similar geographical location, Sub Saharan region, and low-medium income countries. The lower emotional sub scale might be due to cultural misconception about epilepsy seen as evil sprite or cures.

In this study age was negatively associated with HRQOL of adolescents and sex of the adolescent was not associated with HRQOL which was similar with the study conducted in Surabaya(40) and Greece(41) while the study done in Iran(35) reported that sex of the adolescent had significant difference which being a girl had a negative association to HRQOL compared to boys. This might be explained as adolescents are disturbed with anything they faced because of it is sensitive stage of development that they try to do and decided everything by their own. Older adolescents felt embarrassed and fear of stigma they face. The sex difference might be due to their culture and religion effects on girls had too many restrictions.

This study also showed that maternal education level which was unable to read and write had independent predictor factor with negative association to HRQOL, while study done in India(42) showed that increased in education level increased the HRQOL. This might be the reason that when they know and understand the condition more, they may worry and be anxious more about their child's condition. On the same study reported that higher income had positive association with HRQOL. On this study medium income had positive association and predicting factor for HRQOL. This might be due to the difference of income classification from country to country from job to job.

In addition this study revealed that marital status of the family was significant to HRQOL being married had a positive association and predicting factor for HRQOL of adolescents with

epilepsy. This finding has similarity with Study done to assess risk factors for AWE on long term effect on health by Geerlings P.J. et al.,2015 showed unstable family setting were risk for poor health related outcome.(49). This might be due to the disease need for the support of family and had great effect on the adolescent condition with family functioning.

In contrast to study conducted in China(43), this study revealed that the age of onset of first seizure had no significance and association with HRQOL when their study showed that onset had significance with QOL. This might be due to the difference in the study design that they used case-control study design.

This study reported that monotherapy had a strong positive association and predicting factor which higher HRQOL. But Karnavat et al (42) had reported polytherapy had association and study conducted in Italy(54) showed no significance difference the number of antiepileptic drugs. This might be due to the treatment guideline difference among the areas of the study. It might also be due to there is treatment gap and shortage of treatment in low and medium income countries like ours with a single drug had a great effect of perception response on adolescents and since HRQOL is subjective response it had difference.

Study done in Malaysia(37) revealed partial seizure and frequency of more than once per month had negative association on QOL while this study showed partial seizure and frequency of seizure being none had a strong positive association and independent predicting factor. This might be the reason of they used parent proxy report and had a difference with that of self-report. It also might be due to the seizure causes injury, stigma and embarrassment that adolescents faced at the time.

CHAPTER SEVEN

7. STRENGTH AND LIMITATION

7.1 Strength

The strength of this study was, the sample size was taken maximum number of participants and was obtained from two different hospitals of Addis Ababa which increased the representativeness of data. And the study used a tool which was developed and validated for the purpose of research use and clinical use.

7.2 Limitation

The main limitation of this study was it had no comparative group to compare with the study group. Furthermore other determinant factors for HRQOL are not explored in this study such as family functioning and comorbidities.

CHAPTER EIGHT

8. CONCLUSION AND RECOMMENDATION

8.1. Conclusion

In conclusion, this study found that health related quality of life mean score of 43.28 ± 22.44 points. On this score the sub scales had different scores. Impact of the illness, sleep disorder and family or friend support had better mean score than the total mean score of HRQOL and the rest sub scales cognitive functioning, executive functioning and emotional change had lower mean score than the total HRQOL scores.

This study also concluded that type of seizure, marital status of parent, family income per month, frequency of seizure and number of AEDs were predicting factors that higher (increases) HRQOL score among adolescents with epilepsy.

On this study age of adolescents and maternal educational level predictor of lower (decreases) HRQOL score among adolescents with epilepsy.

8.2. Recommendations

Based on this study finding, the following recommendations could be forwarded for the respective bodies:-

Health profession: Health professionals must work on all aspect of health to overcome cognitive functioning, executive functioning and especially emotional change since it was the lowest of the others to improve health related quality of life of adolescents with epilepsy.

Government and non-Government (NGO) organizations: - organizations working on epilepsy should focus on adolescents those who are in late adolescence and mother's education level those who are unable to read and write since these were predicting factors to lower the health related quality of life among adolescents with epilepsy.

Researchers: There might be other factor which determine health related quality of life beyond what were examined, this study recommend researcher to explore other factors.

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10. APPENDIX

Annex A: Information sheet

Hello. My name is _____ and I am data collector of the study conducted by Olantu Mekonnen student at Addis Ababa university college of health sciences , conducting this research for partial fulfillment of master's of science degree in pediatrics and child health nursing. We would very much appreciate your participation in this study. The information you provide will help us to know health related quality of life and to improve quality of life of adolescents with epilepsy. The interview takes between 10-20 minutes to complete. I shall also interview your child.

Name of advisor: - Mr. Zeleke Argaw (MSN, Asst. professor) and Mr. Tewodros Tesfaye (MSC)

Name of the organization: Addis Ababa University, College of Health Sciences, School of Nursing and Midwifery.

Name of the Sponsor: Addis Ababa University

Title of the Research Project:- Assessment of health related quality of life among adolescents with epilepsy in government hospitals Addis Ababa, Ethiopia, 2019

Introduction: Information sheet , consent and assent form will be prepared for parents and adolescents respectively. Who attending service in neurology/seizuer clinic who will be volunteer to participate in research project.

Purpose: The purpose of this study is to find out health related quality of life of adolescents with epilepsy. The information that you provide are very essential, not only for the successful accomplishment of the study but also for producing relevant information which will help in improving the provision of the service to adolescents with epilepsy. I will provide research results to concerned body for intervention.

Procedure:: In order to achieve the above objective, information which is necessary for the study will be taken from adolescents with epilepsy. Your responses will not be linked to you or your child and are completely anonymous and confidential. There is no right or wrong answers in this study.

Risk/ Discomfort:- By participating in this research project, you may feel that it has some discomfort especially on spending your time. You can stop but I am Sure there is no risk in participating in this research project.

Benefits:- There may not be direct benefit to you but your participation is likely to help us in assessing health related quality of life and associated factor in adolescent with epilepsy. So that it help to improve health related quality of life and healthcare service delivery for patients with epilepsy. You will not be provided any incentive or payment to take part in this project.

Alternative Procedures:- You may choose your child not to participate in this study and it will not affect the health care that will be given to your child.

Confidentiality: The information collected from this research project will be kept confidential and all records and other information obtained will be kept strictly confidential and your child's protected health information will not be used without permission. All data collection tools will be identified by number or otherwise coded to protect any information that could be used to identify your child or you.

Number of Participants: 422 adolescents with epilepsy.

Voluntary Participation: It is up to you to decide whether your child takes part in this study or not. Refusal to participate research has no penalty or loss of benefits to which your child is otherwise entitled. This will not affect your relationship with the investigators. If you are voluntary to give information for the study, you can show your willingness by saying "yes".

1. If yes, proceed to the next page 2. If no, thank you, and skip to the next participant

Name of data collector _____ Signature of interviewer: -----Date: -----/-----/-----

If you have questions, complaints or concerns about this study, you can contact the principal investigator Olantu Mekonnen

Cell Phone; [+251921063002](tel:+251921063002)

Email address: olaniigutema@gmail.com.

Annex B: Consent and assent form

1. Consent form

I understand all conditions stated above. I have understood that Participation in this study is entirely voluntarily. I will tell that the answers to the questions will not be given to anyone else. If respondent does not agree to be interviewed, lets them thanks and go to the next respondent. You can stop at any time. If respondent say “YES” continues.

1. Name of interviewer_____ Signature_____ date____/____/____

(Signature of interviewer certifying that respondent has given informed consent verbally)

2. Assent form (10-18 years)

Your parent has agreed that you take part in our study where we are looking at the health related quality of life among adolescents with epilepsy. Your participation in the study is fully voluntarily. Any information you provide not be given to anyone else. You can stop at any time. If respondent does not agree to be interviewed, lets them thanks and go to the next respondent. If respondent say “YES” continues.

1. Name of interviewer_____ Signature_____ date____/____/____

(Signature of interviewer certifying that respondent has given informed consent verbally)

Annex C: English version of questionnaire

Part I. Socio-Demographic and medical questioners

Title: Assessment of Health related quality of life among adolescents with epilepsy in government hospitals, Addis Ababa Ethiopia 2019.

Code # _____ Date of data collection _____

Name health facility _____

Direction: The following socio-demographic and medial related questioners are developed from different Literature. For each question parents will be participated if question is difficult for adolescents to answer it.

A. Socio-Demographic questioners			
No	Question	Coding Categories	
100	What is the age of the child (Enter in the space)	_____ year	
101	The child sex?	1. Male 2. Female	
102	Family Setting: Who do you live with?	1. Lives with both parents 2. Lives with mother 3. Live with father 4. Others, specify _____	
103	Number of children in family (enter space)	_____ number	
104	What is the child mother educational level?	1. Unable to read & write 2. Read and Write 3. Grade 1-8 4. Grade 9-12 5. Above 12	
105	What is the child father educational level?	1. Unable to read & write 2. Read and Write 3. Grade 1-8	

		4. Grade 9-12 5. Above 12	
106	What is the child parents/guardian marital status	1. Single 2. Married 3. Divorced 4. Widowed/partner died	
107	Occupation of the child mother/guardian	1. Unemployed 2. Government/private employee 3. Self employed 4. Other specify_____	
108	Occupation of the child father/guardian	1. Unemployed 2. Government/private employee 3. Self employed 4. Other specify_____	
109	What is the average family income per months?	_____ birr	

B) Medical related questioners			
110	Age of first seizure (excluding febrile seizure)?	_____year or/month	
111	How long has he/she been on medication/follow up?	_____year or month	
112	What is the type of seizure does he/ she have?	1. Partial 2. Generalized	
113	How many Antiepileptic drugs do he/ she takes totally?	1. Monotherapy 2. Polytherapy	
114	What grade is your child?	_____grade	
115	Does he/ she have any family with epilepsy?	1. Yes 2. No	
116	How would you rate its severity from his/her last visit? Please check one answer.	1. Extremely severe 2. Very severe 3. Moderately severe 4. Somewhat severe 5. Not at all severe	
117	How many times is the frequency of seizures?	1. None 2. Once/few times per week 3. Few times per month 4. Occasionally	
118	Is there any injury during seizures?	1. No 2. Yes specify_____	
119	Is there any side effect of antiepileptic drugs?	1.No 2. Yes specify_____	
120	Is there interference of epilepsy or drugs with daily activities?	1. No 2. Yes specify_____	

Part II: - PedsQL™ Epilepsy Module Version 3.0 TEEN REPORT

Direction: - On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past **ONE** month ,**0** if it is never a problem, **1** if it is almost never a problem ,**2** if it is sometimes a problem,**3** if it is often a problem,**4** if it is almost always a problem.

In the past **ONE MONTH**, how much of a problem has this been for you?

		Never	Almost Never	Some- times	Often	Almost always
	Impact of Epilepsy/Treatment					
201	It is hard for me to do the same physical activities or sports as other teens	0	1	2	3	4
202	It is hard for me to be as independent as other teens my age (e.g., driving, riding bikes)	0	1	2	3	4
203	I am not allowed to do activities because of my epilepsy	0	1	2	3	4
204	It is hard for me to take epilepsy medicine and/or other treatments (e.g., a special diet)	0	1	2	3	4
205	I do not like being left alone in case I have a seizure	0	1	2	3	4
206	I miss school or social activities because of epilepsy, and/or its treatments	0	1	2	3	4
207	I feel different from other teens or family members	0	1	2	3	4
208	I feel embarrassed when a seizure happens	0	1	2	3	4
209	It is hard for me to avoid seizure triggers (e.g., flashing lights, being tired)	0	1	2	3	4
210	I use epilepsy or medication side effects as an excuse to avoid doing something I didn't really want to do?	0	1	2	3	4
211	I feel that epilepsy or medications limited my social activities (such as hanging out with friends) compared to others my age?	0	1	2	3	4
212	I feel alone and isolated from	0	1	2	3	4

	others because of my epilepsy/ seizures					
Cognitive Functioning						
213	It is hard for me to think quickly	0	1	2	3	4
214	It is hard for me to remember things	0	1	2	3	4
215	It is hard for me to learn new things	0	1	2	3	4
216	I need extra help at school (e.g., tutor, extra time on tests)	0	1	2	3	4
217	It is hard for me to keep up with schoolwork	0	1	2	3	4
218	It is hard for me to understand what I read	0	1	2	3	4
Sleep/Fatigue						
219	I feel tired during the day	0	1	2	3	4
220	It is hard for me to sleep (e.g., falling and staying asleep)	0	1	2	3	4
221	I need more sleep than other teens	0	1	2	3	4
Executive Functioning						
222	It is hard for me to stay organized	0	1	2	3	4
223	It is hard for me to do what I am told	0	1	2	3	4
224	It is hard for me to pay attention	0	1	2	3	4
225	It is hard for me to finish things I started	0	1	2	3	4
226	I act without thinking	0	1	2	3	4
227	It is hard for me to sit still	0	1	2	3	4
Emotional problems						
228	I feel grouchy	0	1	2	3	4
229	I feel angry	0	1	2	3	4
230	I feel sad or blue	0	1	2	3	4
231	I feel tense or anxious	0	1	2	3	4
232	I feel easily frustrated	0	1	2	3	4
Support from family/friends						
233	I have someone available to help me if I needed and wanted help	0	1	2	3	4
234	I have someone I could confide in or talk to about things that were	0	1	2	3	4

	troubling me					
235	I have someone I could talk to when I am confused and needed to sort things out	0	1	2	3	4
236	I have someone who accepted me as I am both my good points and bad points	0	1	2	3	4

Annex D Amharic version

የመረጃ ወረቀት

ጤና ይስጥልኝ የእኔ ስም _____ ይባላል። እኔ የጥናቱ መረጃ ሰብሳቢ ነኝ።

እኔ በአዲስ አበባ ዩኒቨርሲቲ የጤና ሳይንስ ኮሌጅ የነርቪንግ እና የሚድዋይፈሪ ትምህርት ክፍል ውስጥ ተማሪ የሆኑት አላንቱ መኮንን በሚያካሂዱት ጥናት እና ምርምር ላይ መረጃ ሰብሳቢ ነኝ። በዚህ ጥናት እና ምርምር ላይ እንዲሳተፉ በጣም እናበረታታለን። እርስዎም ሆኑ ልጆ የሚሰጡት መረጃ የሚጥል በሽታ ያለባቸውን ታዳጊ ልጆች ከጤና ጋር የተዛመደውን የኑሮ ጥራት ለማወቅ እና ለማሻሻል ይረዳናል። ቃለ-መጠይቁን ለመጨረስ ከ10-20 ደቂቃዎች ይወስዳል። ልጅዎን ቃለ መጠይቁ ላይ እዲሳትፍ የእርሶን ፍቃድ ይፈልጋል።

የአማካሪዎች ስም:- አቶ ዘለቀ አርጋው እና አቶ ቴዎድሮስ ተስፋዬ

የድርጅቱ ስም:- አዲስ አበባ ዩኒቨርሲቲ ጤና ሳይንስ ኮሌጅ የነርቪንግ እና የሚድዋይፈሪ ትምህርት ክፍል

የስፖንሰር ስም:- አዲስ አበባ ዩኒቨርሲቲ

የጥናትና ምርምር ፕሮጀክት ርዕስ:- የሚጥል በሽታ ያለባቸውን ታዳጊ ልጆች ጤናን የሚመለከቱ የህይወት ደረጃ ምንነት የዳሰሳ ጥራት በአዲስ አበባ የመንግስት ሆስፒታሎች ውስጥ 2011።

መግቢያ:- በሚጥል በሽታ ወደ መንግስት ሆስፒታሎች በኒውሮሎጂ ክሊኒክ ውስጥ ለአገልግሎት ወይም ለክትትል የሚመጡ እና ጥናቱ ላይ ለመሳተፍ ፈቃደኛ የሆኑ ወላጆች እና ለታዳጊ ልጆች የመረጃ ዝርዝር የፍቃድ እና የመስማማት ፎርም ተዘጋጅቶል።

ዓላማ:- የዚህ ጥናት ዓላማ የሚጥል በሽታ ያለባቸው ታዳጊ ልጆች ከጤናነት ጋር የተዛመዱ እና የህይወት ደረጃቸው ምን ላይ እንዳለ ለማወቅ ረዳል። እርስዎ ሆኑ ልጆዎ የሚሰጡት መረጃ ለጥናቱ ስኬታማነት ብቻ ሳይሆን አገልግሎቱን ለማሻሻል እና የሚጥል በሽታ ያለባቸው ታዳጊ ልጆች የሚረዳ ጠቃሚ መረጃን ለማቅረብ ከፍተኛ ድርሻ ይኖረዋል። የጥናቱ ውጤት ጉዳዩ ለሚመለከታቸው አካል ይሰጣል።

የአሠራር ሂደት:- ከላይ የተጠቀሱትን ዓላማዎች ለማሳካት የሚያስፈልገውን መረጃ የሚጥል በሽታ ካለባቸው ታዳጊ ልጆች እና ከወላጆቻቸው ይወሰዳሉ። ይህም መረጃ ሙሉ በሙሉ የማይታወቅ ሚስጢራዊ ኮድ ተደረጎ እና ታሽጎ ለማንም ሳይሰጥ ይቀመጣል። ይህ ምላሾች ከእርስዎ ወይም ለልጅዎ ከሚሰጥ አገልግሎት ጋር አይያያዙም። በዚህ ጥናት ውስጥ ትክክለኛ ወይም የተሳሳቱ መልሶች የሉም።

አደጋ / ስጋት : - በዚህ ጥናት ላይ በመሳተፍ ጊዜዎን እንደምንሻማዎት ሊሰሞዎት ይችላል። ሆኖም ግን የጥናቱ ውጤት ለሚያመጣው ለውጥ ብለው እንደሚሰተፉ እናምናለን። እንዲሁም በጥናቱ በመሳተፍ ምንም አይነት ጉዳት አያደርስበትም።

ጥቅማ ጥቅሞች: - ለእርስዎ በቀጥታ ጥቅም ላይኖረዎት ይችላል። ነገር ግን የእርስዎም ሆነ የልጅ ተሳትፎ በሚጥል በሽታ ለተያዙ ታዳጊ ልጆች ጤናን ለማጎልበት የሚሰጥ የጥራት ደረጃና የተያያዙ ጉዳይ ጋር በመገጣጠም ሊረዳን ይችላል። የሚጥል በሽታ ላለባቸው ታካሚዎች የኑሮ ጥራት እና የጤና እንክብካቤ አገልግሎት ሰጪዎችን ለማሻሻል ይረዳል። በዚህ ፕሮጀክት ለመሳተፍ ምንም ዓይነት ማበረታቻ ወይም ክፍያ አይሰጥዎትም።

ተለዋጭ አካሄዶች: - በዚህ ጥናት ውስጥ ተሳታፊ እንዳይሆን መምረጥ ይችላሉ። እና ለእርስዎ የሚሰጥዎትን የጤና እንክብካቤ ሆነ አገልግሎት አይነካም።

የአሳታፊዎቹ ቁጥር:- 422 በሚጥል በሽታ ለተያዙ ታዳጊ ልጆች ሪፖርት ይወሰዳል።

ምስጢራዊነት:- በዚህ ጥናት የተሰበሰበ መረጃ በሙሉ ምስጢራዊነት ይጠበቃል። ሁሉም መዝገቦች እና ሌሎች መረጃዎች ምስጢር የተጠበቁ ናቸው። የልጅዎ የተጠበቀ የጤና መረጃ ያለፍቃድ ጥቅም ላይ አይውልም። ሁሉም የመረጃ አሰባሰብ መሳሪያዎች በቁጥር ወይም በሌላ መንገድ ልጅዎን ለመለየት ሊያገለግሉ የሚችሉ ኮዶች ይደረጋል።

በጥናቱ ያለመሳተፍ መብት:- እርስዎ ሆኑ ልጆዎ በዚህ ጥናት መሳተፍ ወይም አለመሳተፍዎን የመወሰን መብት እርስዎ ውሳኔ ነው። በጥናቱ ውስጥ ላሉ ጥያቄዎች መልስ አለመስጠት ይችላሉ። በማንኛውም ሰአት ጥናቱ ማቆም ይችላሉ። ለጥናቱ መረጃ ለመስጠት ፈቃደኛ ከሆኑ ፈቃደኝነትዎን "አዎን" ብለው በመናገር ማሳየት ይችላሉ።

1. አዎ ቃለመጠይቁን ይቀጥሉ

2. አይደለሁም ቃለመጠይቁን ከሆነ, አመሰግናለሁ, እና ወደሚቀጥለው ተሳታፊ ይዝለሉ

የቃለ መጠይቁ ጠያቂ ስም -----ፊርማ -----ቀን: ----- / ----- / ---

በዚህ ጥናት ውስጥ ጥያቄዎች, አቤቱታዎች ወይም ስጋቶች ካሉዎት በሚከተለው ስልክ መደወል ይችላሉ።

አላንቱ መኮንን የስልክ ቁጥር + 251921063002

የኢሜል አድራሻ: olaniigutema@gmail.com

የፈቃድ እና የስምምነትመግለጫ ቅፅ

1. የወላጅ ፈቃድ

ከላይ የተዘረዘሩትን ሁሉንም ሁኔታዎች ተረድቻለሁ። በዚህ ጥናት ውስጥ የምሳተፈው ሙሉ በሙሉ በፍቃደኝነት ነው። እንደተነገረኝ ለጥያቄዎቹ የምሰጠው መልሶች ለሌላ ማንኛውም ሰው አይሰጥም። እንዲሁም ስለማንነት ለማንም አይገለጥም። ስለሆነም በጥናቱ ላይ ለመሳተፍ ፍቃደኛ ነኝ። ተሳታፊው ፍቃደኛ ካልሆኑ አመስግነው ወደ ሚቀጥለው ተሳታፊ ይለፉ። ተሳታፊው ፍቃደኛ ከሆነ ግን ይቀጥሉ።

የጠያቂው ስም _____ ፊርማ _____ ቀን ____ / ____ / ____

(የቃለ-መጠይቁ ጠያቂ ፊርማ ተሳታፊው ሙሉ በሙሉ ፍቃደኛ መሆኑን ያረጋግጣል)

2. የልጆች የስምምነት ቅፅ (ከ10-18 ዓመት)

የሚጥል በሽታ ያለባቸው ታዳጊ ልጆች በሚኖሩበት ጊዜ ከጤና ጋር የተዛመደውን የኑሮ ጥራት ደረጃ የተመለከተው ጥናታችን ላይ እዲካፈሉ ወላጅዎ ተስማምተዋል። በጥናቱ ውስጥ የሚያደረጉት ተሳትፎ ሙሉ በሙሉ በፈቃደኝነት ነው። የሚሰጡት ማንኛውም መረጃ ለሌላሰው ለማንም አይሰጥም። በማንኛውም ጊዜ ማቆም ይችላሉ። ቃለ-መጠይቅ ለመጠየቅ ካልተስማሙ ግን እናመሰግናለን እና ወደ ሚቀጥለው ተሳታፊ ይቀጥሉ።

የጠያቂው ስም _____ ፊርማ _____ ቀን ____ / ____ / ____

(የቃለ-መጠይቁ ጠያቂ ፊርማ ተሳታፊው ሙሉ በሙሉ ፍቃደኛ መሆኑን ያረጋግጣል)

የአማርኛ መጠይቅ ቅፅ

ቁጥር _____

መረጃው የተሰበሰበበት ቀን _____

መረጃ የተወሰደበት ተቐም _____

ርእስ:- የሚጥል በሽታ ያለባቸውን ታዳጊ ልጆች ጤናን የሚመለከቱ የህይወት ደረጃ ምንነት የዳሰሳ ጥራት በአዲስ አበባ በተመረጡ የመንግስት ሆስፒታሎች ውስጥ 2011።

ክፍል 1:- ማህበራዊ፣ ግላዊ እና ሕክምና ነክ ጥያቄዎች

መመሪያ:- የሚከተሉት ማህበራዊ እና የሕክምና ጥያቄዎች ከተለያዩ ጥናት ላይ የተገኙ ናቸው።

ለእያንዳንዱ ጥያቄ ላይ መልስ መስጠት ታዳጊው/ዋ ከባድ ከሆነባቸው ወላጆች መሳተፍ ይችላሉ።

ሀ. ማህበራዊ እና ግላዊ ጥያቄዎች

ተ/ቁ	ማህበራዊ እና ግላዊ ጥያቄዎች	
100	የልጅ ዕድሜ ስንት ነው (በቦታው ውስጥ ይሙሉ)	_____ ዓመት
101	የልጅ ጾታ?	1. ወንድ 2. ሴት
102	የቤተሰብ ቅንጅት: ከማን ጋር እንደሚኖሩ?	1. ከሁለቱም ወላጆቻቸው ጋር 2. ከእናት ጋር 3. ከአባት ጋር 4. ሌሎች _____
103	የልጆች ብዛት በቤተሰብ ውስጥ?	_____ ቁጥር
104	የእናት የትምህርት ደረጃ	1. ማንበብ እና መጻፍ አይችሉም 2. ማንበብ እና መጻፍ ይችላሉ 3. 1ኛ-8ኛ ክፍል 4. ከ 9 ኛ - 12 ኛ ክፍል 5. ከ 12ኛ እና ከዚያ በላይ
105	የአባት የትምህርት ደረጃ	1. ማንበብ እና መጻፍ አይችሉም 2. ማንበብ እና መጻፍ ይችላሉ 3. 1ኛ-8ኛ ክፍል 4. ከ 9 ኛ - 12 ኛ ክፍል 5. ከ 12ኛ እና ከዚያ በላይ
106	የልጁ ወላጆች / አሳዳጊ የጋብቻ ሁኔታ	1. ያለግባች 2. ያገባች 3. የተፋታች 4. ባሏ የሞተባች
107	የልጁ እናት ስራ	1. ስራ የላትም 2. የመንግስት / የግል ሰራተኛ

		3. የግል ስራ 4. ሌላ ይግለጹ(_____)
108	የልጁ አባት ስራ	1. ስራ የለውም 2. የመንግስት / የግል ሰራተኛ 3. የግል ስራ 4. ሌሎች የተገለጹ _____
109	በወር ውስጥ አማካይ የቤተሰብ ገቢ ስንት ነው?	_____ ብር

ለ) ከሕክምና ጋር የተገናኙ ጥያቄዎች

ተ/ቁ	ከሕክምና ጋር የተገናኙ ጥያቄዎች	
110	መጀመሪያ የመጣል (መናድ) ችግር በስንት አመት አጋጠው?(ከትኩሳት ጋር የተያያዘ አያካትትም)	በ _____ ዓመት ወይም / ወር
111	እሱ / እሷ በመድኃኒት / ክትባቱ / ምን ያህል ቆይተዋል?	_____ ዓመት ወይም ወር
112	እሱ / እሷ ምን ዓይነት የመጣል (መናድ) ችግር ነው?	1. በከፊል 2. አጠቃላይ (ሙሉ በሙሉ)
113	በአጠቃላይ ምን ያህል መድሃኒቶች ይወስዳል(ትወስዳለች)?	1. አንድ 2. ሁለት እና ከዚያ በላይ
114	የትምህርት ደረጃው / ዋ	_____ ክፍል
115	የሚጥል በሽታ ያለበት ቤተሰብ ውስጥ አለ?	1. አዎ 2. አይ
116	ከመጨረሻውን ቀጠሮ ችግሩን ምን ያህል ክብደት ይሰጡታል?	1. እጅግ በጣም ከባድ 2. በጣም ከባድ 3. በመጠኑ አደገኛ 4. በተወሰነ ደረጃ የከፋ 5. በከፋ ጉዳት አይደለም
117	የመጣል (መናድ) ችግር ስንት ጊዜ ነው?	1.የለም 2.በሳምንት አንዴ ወይም የተወሰነ ጊዜ 3.በወር አንዴ ወይም የተወሰነ ጊዜ 4.አልፎ አልፎ
118	በሚጥለው ጊዜ ጉዳት ደርሶበ/በት ያውቃል?	1. አይ 2.አዎ ይግለጹ _____

119	የ መድሃኒቶች የጎንዮሽ ጉዳት ደርሶበ/ባት ያውቃል?	1. አይ 2.አዎ ይግለጹ _____
120	የሚጥል በሽታ ወይም መድሃኒቶች ዕለታዊ እንቅስቃሴን በተመለከተ ጣልቃ መግባት አለ?	1. አይ 2.አዎ ይግለጹ _____

ክፍል ሁለት:- PedsQL ™ የሚጥል በሽታ ሞጁል ስሪት 3.0 የልጆች ዘገባ

አቅጣጫ:- በሚቀጥለው ገጽ ላይ ለእርስዎ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ናቸው። እባክዎ ባለፈው አንድ ወር ውስጥ ምን ያህል ችግር ያላለዎት እንደሆነ ይንገሩን። **0** ከእርሱ ፈጽሞ ችግር ካልሆነ፤ **1** አሁን ችግር ካልሆነ፤ **2** አንዳንድ ጊዜ ችግር ከሆነ፤ **3** ብዛኛውን ጊዜ ችግር ከሆነ እና **4** ሁልጊዜም ችግር ከሆነ።

ባለፈው **አንድ ወር** ውስጥ ይህ ለእርስዎ ምን ያህል ችግር አጋጥሞዎታል?

ተ/ቁ		0	1	2	3	4
ተጽዕኖ						
201	እንደ ሌሎች ልጆች አንድ አይነት የአካል እንቅስቃሴዎችን ወይም ስፖርቶችን ማድረግ ከባድ ነው	0	1	2	3	4
202	እንደ የእድሜዬ ያሉ ሌሎች ልጆች (እንደ ቢስክሌት መንዳት) ከሌሎች ጋር ነጻ ሆኖ መገኘት ያስቸግረኛል	0	1	2	3	4
203	በሚጥል በሽታዬ ምክንያት እንቅስቃሴዎችን እንዲያደርግ አልፈቀድኩም።	0	1	2	3	4
204	የሚጥል በሽታ መድኃኒት እና / ወይም ሌሎች ህክምናዎችን መውሰድ አስቸጋሪ ነው	0	1	2	3	4
205	ብቻ መቆየት አልፈልግም አጋጣሚ ከጣለኝ	0	1	2	3	4
206	የሚጥል በሽታ ወይም ህክምናዎቼ ምክንያት ትምህርት እና ማህበራዊ እንቅስቃሴዎች ያመልጠኛል	0	1	2	3	4
207	ከሌሎች ልጆች ወይም ከቤተሰብ አባላት የተለየ ስሜት ይሰማኛል	0	1	2	3	4
208	የመናድ ችግር በሚፈጠርበት ጊዜ እፍረት ይሰማኛል	0	1	2	3	4
209	ለእኔ የመናድ ችግር መቀስቀሻዎችን ለማስወገድ (ለምሳሌ ብልጭ ድርግም የሚሉ መብራቶች) ከባድ ነው	0	1	2	3	4
210	የሚጥል በሽታ ወይም የመድሃኒት ሰበብ በማድረግ እኔ ማድረግ የማልፈልገውን ነገር ላለማድረግ እጠቀማለሁ	0	1	2	3	4

211	የሚጥል በሽታ ወይም መድኃኒቶች የእኔን ማህበራዊ እንቅስቃሴዎች (ከጓደኞቼ ጋር አብሮ መሄድ) እንደ እኔ ዕድሜዬ ከሌሎች ጋር ሲነጻጸር ውስን እንደሆነ ይሰማኛል	0	1	2	3	4
212	በሚጥል በሽታ / በሚሰጠኝ መድኃኒቶች እክል ምክንያት ከሌሎች የተለየው እና የተገለልኩ ስሜት ይሰማኛል	0	1	2	3	4
የአስተሳሰብ ተግባር						
213	በፍጥነት ማሰብ ይከብደኛል	0	1	2	3	4
214	ነገሮችን ማስታወስ ይከብደኛል	0	1	2	3	4
215	አዲስ ትምህርቶችን መማር ይከብደኛል	0	1	2	3	4
216	በትምህርት ቤት ተጨማሪ እርዳታ እፈልጋለሁ (ለምሳሌ:-አስጠኝ ፣ በፈተናዎች ላይ ተጨማሪ ጊዜ)	0	1	2	3	4
217	ከትምህርት ቤት ስራዎች ጋር መጓዝ አስቸጋሪ ሆኖብኛል	0	1	2	3	4
218	አንብቤ ለመረዳት አስቸጋሪ ሆኖብኛል	0	1	2	3	4
እንቅልፍ / ድካም						
219	በቀኑ ውስጥ ድካም ይሰማኛል	0	1	2	3	4
220	እንቅልፍ መተኛት ይከብደኛል (ለምሳሌ:-እንቅልፍ መውሰድ ና ተኝቶ መቆየት)	0	1	2	3	4
221	ከሌሎች ወጣቶች ይልቅ ብዙ እንቅልፍ እፈልጋለሁ	0	1	2	3	4
አስፈጻሚ ተግባራት						
222	በተደራጀ ሁኔታ መቆየቱ ለኔ አስቸጋሪ ነው	0	1	2	3	4
223	ለእኔ የተነገረኝን ማድረግ ከባድ ነው	0	1	2	3	4
224	ትኩረት መስጠጥ በጣም ከባድ ነው	0	1	2	3	4
225	የጀመርኩትን ነገሮች ማጠናቀቅ ይከብደኛል	0	1	2	3	4
226	ሳላስበው የማደርገውን ነገሮች አሉ	0	1	2	3	4
227	ቁጭ ብዬ ለመቀመጥ ይከብደኛል	0	1	2	3	4
ስሜ / ባህሪ						
228	ቁጣ ቁጣ ይለኛል	0	1	2	3	4
229	እናደዳለሁ	0	1	2	3	4
230	አዝናለሁ	0	1	2	3	4
231	እጨነቃለሁ	0	1	2	3	4
232	በቀላሉ የፍርሀት ስሜት ይሰማኛል	0	1	2	3	4
እርዳታ ከቤተሰብ/ከጓደኞቼ						
233	እርዳታ የሚያስፈልገኝ ከሆነና ከፈለግኩ ለማግኘት የሚያግዝኝ ሰው አለኝ	0	1	2	3	4
234	የሚያስጨንቁኝን ነገሮች በተመለከተ ምስጢር	0	1	2	3	4

	የምናገርበት ሰው አለኝ					
235	ግራ እንደተጋባሁና ነገሮችን ለማስተካከል ብያስፈልገኝ ሰው አለኝ	0	1	2	3	4
236	እኔ እንደሆንኩኝ ጥሩ ሆነ መጥፎ ነገሮች እንዳለሁ የሚቀበለኝ ሰው አለኝ	0	1	2	3	4