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HEALTH-RELATED QUALITY OF LIFE AND ITS ASSOCIATED FACTORS IN CHILDREN WITH EPILEPSY ON FOLLOW UP IN BAHIR DAR CITY PUBLIC HOSPITALS, AMHARA REGION, ETHIOPIA, 2024

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COLLEGE OF MEDICINE AND HEALTH SCIENCES

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DEPARTMENT OF PEDIATRICS AND CHILD HEALTH NURSING

HEALTH-RELATED QUALITY OF LIFE AND ITS ASSOCIATED FACTORS IN CHILDREN WITH EPILEPSY ON FOLLOW UP IN BAHIR DAR CITY PUBLIC HOSPITALS, AMHARA REGION, ETHIOPIA, 2024.

BY: BEKALU ALEMAYEHU (BSc IN NURSING, MSc STUDENT)

SEPTEMBER, 2024

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A RESEARCH THESIS SUBMITTED TO BAHIR DAR UNIVERSITY COLLEGE OF MEDICINE AND HEALTH SCIENCES SCHOOL OF HEALTH SCIENCES DEPARTMENT OF PEDIATRICS AND CHILD HEALTH NURSING FOR PARTIAL FULFILMENT FOR THE REQUIREMENTS OF MASTER'S DEGREE IN PEDIATRICS AND CHILD HEALTH NURSING

SEPTEMBER, 2024

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Declaration

I am Bekalu Alemayehu and hereby declare that, to the best of my knowledge, this research proposal is my own work; it has not been presented to any institution either partially or in total for any academic award or for publication. The works here are original, where the works of others are quoted and appropriate reference has been given. This research proposal is for partial fulfilment of the degree of Master of Science in Pediatrics and Child Health Nursing of Bahir Dar University.

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EXAMINER'S APPROVAL FORM

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APPROVAL OF THESIS FOR DEFENSE RESULT

We hereby certify that we have examined this thesis entitled "Health related quality of life and its associated factors in children with epilepsy on follow up in Bahir Dar city public hospitals, Amhara region, Ethiopia, 2024." by Bekalu Alemayehu. We recommend that thesis is approved for the degree of "Masters in Pediatrics and Child Health Nursing."

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Lists of acronyms

ADRs:	Adverse Drug Reactions
AEDs:	Anti-Epileptic Drugs
AOR:	Adjusted Odds Ratio
CWE:	Children with Epilepsy
CI:	Confidence Interval
COR:	Crude Odds Ratio
DALYs:	Disability Adjusted Life Years
ILAE:	International League Against Epilepsy
GTC:	Generalized Tonic Clonic Seizure
HRQoL:	Heath Related Quality of Life
OR:	Odds Ratio
PedQoL:	Pediatrics Quality of Life
QoL:	Quality of Life
QoLCE:	Quality of Life of Children with Epilepsy
SPSS:	Statistical Package for Social Sciences
SD:	Standard Deviation
WHO:	World Health Organization

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Abstract

Background: - Epilepsy is a brain disorder causing recurrent seizures from abnormal electrical activity. It can significantly impair a child's quality of life, affecting cognitive, behavioural, emotional, social, and overall health. Despite these impacts, there is limited research on the health-related quality of life and personal experiences of children with epilepsy.

Objective: The aim of this study was to assess health-related quality of life and its associated factors in children with epilepsy in Bahir Dar City public hospitals, Amhara region, Ethiopia, 2024.

Methods: An-institution based cross-sectional study triangulated with phenomenological study design was conducted from May 15 to June 15, 2024. Simple random and purposive sampling were used for quantitative and qualitative studies, respectively, to selecting study participants. The quantitative data were collected by face-to-face interviewing and through chart reviewing. Data were entered into Epi Data version 3.1 and exported to SPSS version 26. Variables with a P value of <0.20 in bivariable analysis were included in multivariable analysis. Model fitness and multicollinearity were checked using Hosmer-Lem show and variance inflation factor tests respectively. Qualitative data was collected through in-depth interviews. Trustworthiness was ensured via audit trails, debriefing, and probing. Analysis was done by Open Code software 4.2.

Results: Out of 247 participants, 236 completed the study (95.5% response rate). The mean age was 10.72 ± 4.17 years. The overall mean HRQoL score was 72.63 ± 21.57, with 41.1% of children showing poor HRQoL. Factors of HRQoL included age 8-12 years (AOR=3.573; 95% CI: 1.110,11.270), age at onset of epilepsy < 1 year (AOR=6.770; 95% CI: 1.382,34.507), age at onset of epilepsy 1-5 years (AOR=4.285; 95% CI: 1.045,17.583), ≤2 seizures/month (AOR=5.5889; 95% CI: 1.026,30.440, ≥3 seizures/month (AO=7.814; 95% CI: 1.403,43.519), status epilepticus (AOR=2.430; 95% CI: 1.054,5.605), hospital admission (AOR=2.866; 95% CI: 1.117,7.352), and family history (AOR=3.596; 95% CI: 1.067,12.121). In qualitative findings, frequent seizures, missing school, stress about disclosing illness, and poor social interaction negatively impact QoL.

Conclusions: Epileptic children have relatively moderate HRQoL. Factors for poor HRQoL include age, age at seizure onset, seizure frequency, family history, status epilepticus, and hospital admissions. Attention should be paid to improve psychosocial problems of epileptic children

Key words: Children, Epilepsy, Quality of life

1. Introduction

1.1. Background

Epilepsy is a neurological disorder characterised by abnormal electrical activity in the brain, leading to recurrent seizures or unusual behaviours, sensations, and sometimes loss of awareness (1). This condition has significant implications for neurological, cognitive, psychological, and social well-being and represents a substantial burden of disease globally (1). The diagnosis of epilepsy is based on criteria that include experiencing at least two unprovoked seizures separated by more than 24 hours, having one unprovoked seizure with a high probability of further seizures (at least 60% risk), or being diagnosed with an epilepsy syndrome (2).

Epilepsy is often misunderstood as a mental illness, a myth that can lead to stigma, social exclusion, and harm to a child's self-esteem and social interactions (3). Children with epilepsy face challenges that can affect their quality of life (QoL), including physical capacity, self-esteem, relationships, and daily activities (4). QoL in people with epilepsy may be impaired by seizures, side effects of medications, and psychosocial problems (5). Children with epilepsy (CWE) are at risk of impaired QoL, and achieving a good QoL is an important treatment goal among CWE (6).

Drug resistance epilepsy occurs in approximately 20–30% of people with epilepsy, and only 50% of children with childhood-onset epilepsy may successfully transit to adulthood, with seizure remission, discontinuation of anti-epileptic medications, and good quality of life (7). Assessing the QoL of pediatric patients with epilepsy is essential for informed decision-making on medications, side effects, and overall well-being (8). For children with epilepsy, it is crucial to address psychosocial needs alongside medical care to support their development and enhance QoL (9).

Quality of life is defined as a person's "perception of their position in life in the context of the culture and value systems in which they live and concerning their goals, expectations, standards, and concerns" (10). It is a broad concept that is intricately impacted by a person's physical health, psychological state, degree of independence, social relationships, and interaction with a prominent environment (11, 12). Health-related quality of life HRQoL is a commonly used health and patient-reported outcome measure that evaluates how well the disease and its treatment have affected functioning (13). QoL gauges how various facets of life affect overall well-being(14).

1.2. Statement of the problem

Epilepsy affects about 10.5 million children worldwide, most of whom live in developing countries (15). It is a global health challenge for children, with a prevalence of 3.2–5.5/1000 in developed countries and 3.6–44/1000 in developing countries (16). The prevalence of epilepsy in children is 0.43% in European countries, with over 63,000 people under the age of 18 affected in Germany (17). In sub-Saharan Africa, the prevalence rate is higher, ranging from 5.09/1000 to 5.98/1000 (18, 19). Its prevalence in Ethiopia is 5.2/1000 (20). Epilepsy affects the QoL of children, and their families, affecting 325,000 children under the age of 15 and 1% of all youth (10).

CWE have severe difficulties in daily life, not only at school but also in hobbies, interaction with other children, and finding an apprenticeship (21). There are 13 million disability adjusted life years (DALYs) due to epilepsy each year, and it is attributed to uncontrolled and untreated epilepsies, which account for more than 0.5% of the total global DALYs (22). Children with epilepsy are affected by the disease and long-term treatment. Epilepsy deteriorates the child's life outcomes, such as having negative impacts on cognitive, behavioural, emotional, social, and overall (HRQoL) (23). Psychological and psychiatric problems are most common in children who have epilepsy (5).

Beyond experiencing seizures, children with epilepsy face numerous challenges, including misconceptions about their intelligence and social abilities. These issues often lead to limited school performance, career opportunities, and marriage prospects. In developing countries, cultural biases further exacerbate these difficulties, with some communities exhibiting less acceptance of individuals with epilepsy, particularly regarding marriage (24). For centuries, epilepsy has been associated with fear, misinformation, prejudice, and social stigma, and the QoL for patients with the illness and their families is impacted by this stigma(25).

Negative attitudes towards individuals with epilepsy can lead to discrimination and social stigma, with some people avoiding contact like shaking hands and even keeping their children away from those with epilepsy (26). Secrecy and social withdrawal are key examples of how epilepsy-related stigma has been demonstrated to infringe on the QoL of people living with epilepsy. The reduction of epilepsy-related stigma is a key focus for WHO, ILAE, and the International Bureau for Epilepsy through the "Bringing Epilepsy Out of the Shadows" campaign. This initiative aims to raise awareness and combat misconceptions, stigmatization, and discrimination globally (27).

Childhood is critical for future health and epilepsy during this time can affect education and later employment (28). Parents' emotional stability is key for children's quality of life and family adjustment in epilepsy (29). Epilepsy alters consciousness, behaviour, motor activity, and autonomy functions, resulting in impaired QoL in children (30). The impact of epilepsy on QoL is influenced by factors like severity of epilepsy, neurological dysfunction, clinical management challenges, antiepileptic drug side effects, family environment, perception of the disorder, sociocultural beliefs, stigma, activity restrictions, coping abilities, and level of healthcare and social support (31).

Various factors significantly impact the QoL of individuals with epilepsy, including being female, younger age, early onset, high seizure frequency, stigma perception, lack of social support, comorbidities, AED nonadherence, and drug side effects (32). People perceive that epilepsy is a curse by God, a sin of witchcraft activity, or demon possession, and it is often regarded as a spiritual issue in some communities, leading people to initially prefer traditional or spiritual treatments over medical care (33).

The main goal of epilepsy treatment is to enhance the patient's health-related quality of life (HRQoL). However, there is a lack of understanding regarding HRQoL and its related factors in children with epilepsy, as well as a scarcity of research on the topic (4, 34). Furthermore, there is limited knowledge about the experiences of children living with epilepsy from their own perspective (35). This study aims to address these gaps by evaluating the HRQoL of children with epilepsy, identifying influencing factors, and exploring their personal experiences with the illness and its impact on their lives.

1.3. Significance of the study

Conducting this study is important for health care professionals and health institutions to formulate a comprehensive treatment program for children with epilepsy, and it can inform healthcare providers about the various challenges faced by children with epilepsy, leading to more holistic and patient-centered care approaches. This study's insights allow healthcare providers to tailor interventions and treatment plans that more effectively address the unique aspects of living with epilepsy, leading to better overall care and improved patient outcomes. It is also imperative for the primary caregiver to look beyond seizure control for improving the wellbeing of children with epilepsy. It is essential in the development of counselling plans to improve the quality of life of epileptic children. It provides evidence for policymakers and advocates to push for better service, support systems, and legal protection of children with epilepsy and their families. It may provide empirical evidence about necessary changes or enhancements. The participants may also benefit from service improvement in the future from the result of the study. This study will also be used as a source for other researchers conducting a similar study.

2. Literature reviews

2.1. Health related quality of life of children

Epilepsy is a common neurologic problem in children, and different studies revealed the overall quality of life of children with epilepsy.

According to a cross-sectional study in Oman, among all domains, school functioning showed the lowest QoL score, and social functioning revealed the highest score from the children and parents perspective. The physical function score showed a highly significant difference between parent and child reported QoL, but the overall QoL scores of the children and parental reports were significantly and positively related (10). A cross-secional study done in Germany revealed that the mean QoL of the patients was 70.7 with a standard deviation ± 12.5, range confidence interval 33–100) (17).

A cross sectional study done in China revealed that children with epilepsy had significantly lower HRQoL scores for overall QoL(53.66 ± 17.65) and all subscales (17). Based on descriptive, correlational, and nonexperimental research in South Korea, the mean children's total HRQoL score was 77.35 out of 100. Social functioning had the highest average score at 82.54, followed by 79.11 for school functioning and 77.06 for physical functioning. The average emotional functioning score was 70.94, the lowest among the four subdomains of HRQoL, and the average psychosocial health summary score was 77.47 (36).

A cross-sectional survey in Poland revealed that overall health related quality of life has reported a low score of 46.42 out of 100 with (SD ± 20.95), with the highest mean scores reported for the social functioning 49.4 with (SD = 27.3) and the physical functioning (49.4 with SD = 28.4).

The lowest mean score was reported for the work/school functioning (42.3 with SD = 27.8) (37). A study done in Oyo, Nigeria, showed that the child's reported total quality of life was 76.12 with a SD of 18.45, physical domain 77.92 with SD + 24.55, emotional domain 82.33 with a SD of 20.6, social domain 77.67 with a SD of 23.18, school domain 65.72 with a SD of 25.34, and psychosocial 75.26 with a SD of 18.49. Twenty-one (70%) children each had good quality of life (total and psychosocial) on both the parent- proxy reported scale and self-reported scale, while 22 (73.3%) and 8 (26.7%) had good quality of life (physical domain) on the parent-proxy reported scale (38).

A cross-sectional study conducted at Ain Shams University in Egypt showed the mean PedQOL total score was 64.4 with SD±6.9 with a minimum score of 56.1 and a maximum of 83.6. The children have got higher scores in the physical and school domains than in the emotional and social domains.

2.2. Factors of health-related quality of life of children with epilepsy

2.2.1. Children and Caregivers sociodemographic factors of quality of life

A study done in the Eastern Province of the Kingdom of Saudi Arabia showed better mean score QoL percentages in males (67) than females (63), adolescents (66) than children (65), and patients with higher family income and socioeconomic status (64) (19). A study in Oman revealed family status, income level, social security coverage, and age of onset are factors affecting quality of life, and children between 5 and 7 years and females, in general, were most affected, and 13-18 year old groups are least affected as reflected by the overall QoL subscale (10).

A study conducted in a tertiary care teaching hospital in Nepal showed QoL was found to be more impaired in older children (QoL was found to be better in younger patients when compared with the older age groups), and those from rural areas have low QoL, but the education of parents did not affect the QoL of children (39). According to a cross-sectional multicenter study from Germany, living in a nursing home or with foster parents and unemployment of the primary caretaker are related to poor quality of life in children and adolescents (17).

According to a study conducted in Madhya Pradesh, India overall QoL was affected more in older children, those living in rural areas, those with lower socioeconomic status, and in mothers with lower literacy levels. Overall QoL was affected more in older children as compared to the younger age group since emotional, social, and behavioural domains were affected more in the older age group (40). A meta-analysis by Mark A. Ferro revealed that child sex, age, and age at onset were not significantly associated with HRQoL (41).

A cross-sectional study conducted at Ain Shams University in Egypt showed the mean PedQoL total score is significantly higher in the children whose parents are first degree relatives (67.6 with SD ±7.9) than those whose parents are second degree relatives (62.4 with SD±5.8) (41). Males with epilepsy had higher score for QoL as compared to females, and patients in basic school had a significantly a higher total QoL score than those in high school, according to a study in Khartoum,

Sudan (12). Parental level of education also had a significant effect on the seizure frequencies. This may have been due to the fact that less educated parents are likely to have less knowledge about the condition and the appropriate care required, as stated in a Nigerian study. In a study conducted in southern Ethiopia, overall QoL was affected more in younger children since epilepsy can significantly impact their cognitive, social, and emotional growth(42).

2.2.2. Clinical factors

A study in private and public tertiary care centers in India revealed that the mean PedQoL score was significantly higher in patients with partial seizures, lower seizure frequency, lower duration of epilepsy, lower number of drugs, absence of comorbidities, and IQ greater than 90 (43). According to a cross-sectional multicenter study from Germany, missing seizure freedom, concomitant diseases, hospitalisation, recent status epilepticus, and relevant degree of disability are predictors of poorer QoL in children and adolescents with epilepsy (17).

Another study in India found children with epilepsy on polytherapy had diminished HRQoL compared with those on monotherapy in domains such as physical, emotional, social functioning, and total HRQoL. However, school functioning was not affected by the number of AEDs. Children with generalized seizures had reduced health related quality of life. Significant predictors of poor HRQoL were adverse drug reactions (ADRs) to AED, polytherapy, longer duration of epilepsy, shorter seizure-free interval, and seizure frequency (44).

A study conducted in China showed that more frequent seizures and longer duration of illness were all associated with lower, and therefore worse, quality of health-related quality of life scores, but types of seizures bring no difference in health related quality of life (45). According to Metha analysis by Mark A. Ferro, duration of epilepsy, seizure type, frequency, and severity, number of antiepileptic drugs, side effects of antiepileptic drugs, presence of a comorbidity, parental anxiety, and family socioeconomic status were significantly associated with HRQoL(41).

A cross-sectional study conducted at Ain Shams University in Egypt showed the mean PedQoL total score is significantly higher in the children whose duration of seizures is less than 3 minutes (67.5 ±6.9) than those whose duration of seizures is 3-4 minutes (61.3 ±5.6), or more than 4 minutes (61.3 ±5.5), and the mean PedQoL total score is significantly higher in the children who are on valproic acid (72.0±8.0) than those on levetiracetam (63.1 ±6.1) and on oxcarbazepine (61.4 ± 4.0).

Other findings from Minia Governorate in Egypt revealed that children who had generalized seizure had a higher score in cognitive domain with mean of 82.8±17, in contrast to the focal seizure with mean of 73.8±26.7. but generalized seizure had lower score in social (mean ±SD, 84.9±18.9), physical (59 with SD±24.8), emotion (71.9 with SD±16.9), and the total score (74 with SD±14.1), in contrast to the focal seizure group. Polytherapy shows to have a lower score of QOLCE (this means that polytherapy led to more impairment in the QoL especially the emotional aspect) (46). In a study conducted in southern Ethiopia, early age of seizure onset, long duration of illness and uncontrolled seizures are negative predictors of health related quality of life (42).

2.3. Conceptual frame works

This conceptual frame work has children and caregivers' socio demographic factors and children's clinical factors that affect the health-related quality of life of children with epilepsy.

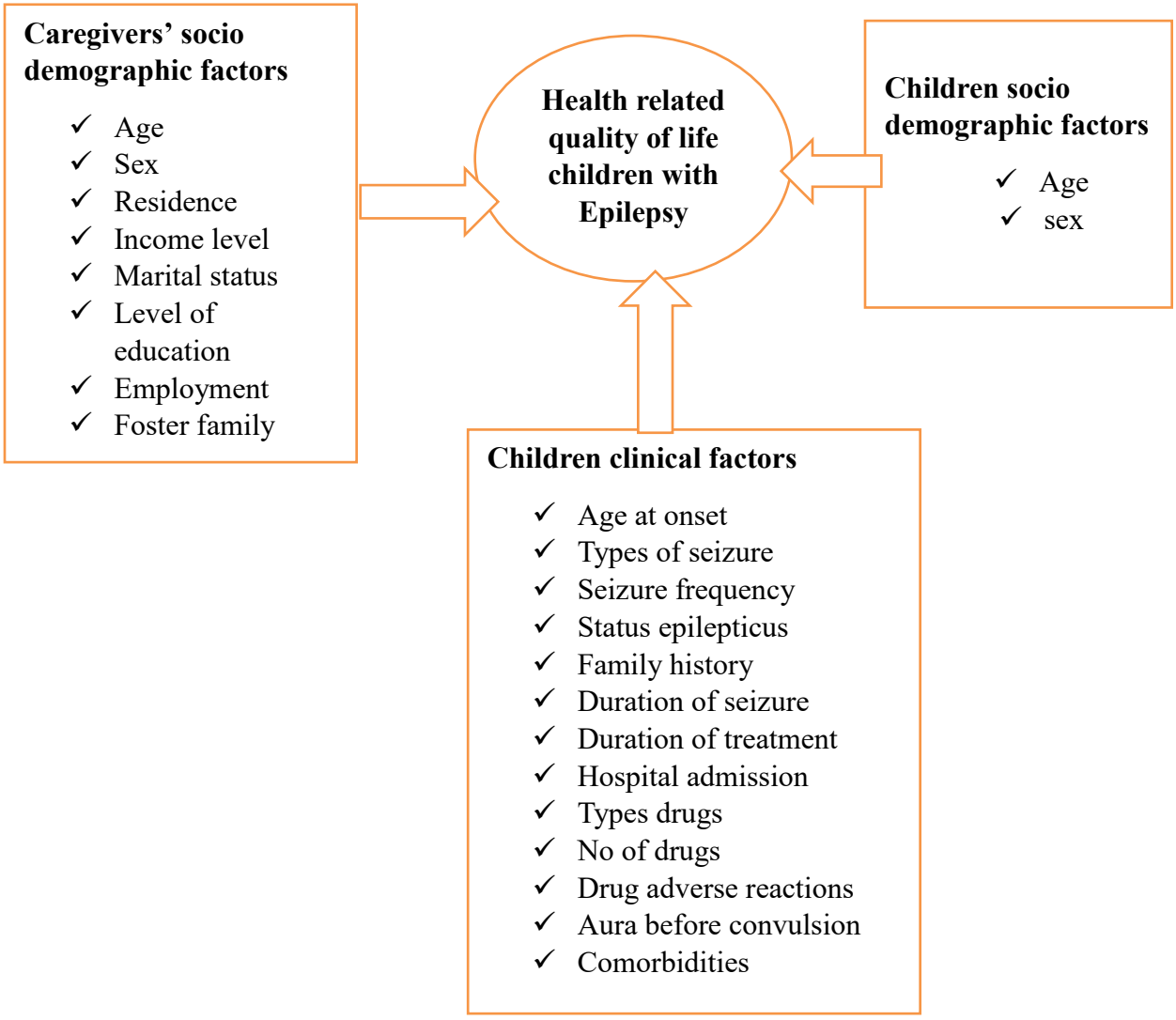


Figure 1: Conceptual framework adapted from different literatures with modifications and showing factors affecting the quality of life of children with epilepsy(10, 12, 17, 46)

3. Objectives

3.1. General objective

Assess health related quality of life and its associated factors in children with epilepsy on follow up in Bahir Dar city public hospitals, Amhara region, Ethiopia, 2024.

3.2. Specific objectives

Determine the level of health-related quality of life of children with epilepsy on follow up in Bahir Dar city public hospitals.

Identify factors of health-related quality of life of children with epilepsy on follow up in Bahir Dar city public hospitals.

Eexplore the lived experience of children with epilepsy on follow up in Bahir Dar city public hospitals

4. Methods and materials

4.1. Study area and periods

The study was conducted in the pediatrics outpatient departments at public hospitals in Bahir Dar city from May 15 to June 15, 2024. Bahir Dar is the capital city of the Amhara National Regional State in the Federal Democratic Republic of Ethiopia, located in the northwestern part of the country on the southern shore of Lake Tana, the largest lake in Ethiopia, and it is 565 km away from the capital Addis Ababa. Its population is estimated to be 455,901 in 2022 by population projection (47). The city has one specialized, one referral, and one primary government hospital (Tibebe Gion, Felege Hiwot, and Adiss Alem, respectively), 11 health centers (including one private health center), 10 health posts, one family guidance association clinic, 4 private general hospitals, and 35 medium private clinics. Felege Hiwot Comprehensive Specialized Hospital is among the three hospitals established in 1963 that have 410 beds and serve more than 5 million people. Tibebe Gion Hospital is a Bahir Dar University teaching hospital established in 2019, which serves more than five million people in the catchment area. Addis Alem Hospital is one of the three hospitals in Bahir Dar City, established in 2016 as a primary hospital, and it has 10 pediatric beds.

4.2. Study design

An institution based sequential mixed-methods design was employed, comprising a cross-sectional quantitative study followed by a phenomenological qualitative study

4.3. Source population and study population

4.3.1. Source population

All children who had anti-epileptic drugs follow up, along with their caregivers, in Bahir Dar city public hospitals for both quantitative and qualitative study.

4.3.2. Study population

For quantitative study: Children aged 5-18 years who have been on anti-epileptic drugs follow up in Bahir Dar city public hospitals, along with their caregivers, and are available during data collection periods.

For qualitative data: Children aged 13-18 years who have been on anti-epileptic drugs follow up in Bahir Dar city public hospitals, and are available during data collection periods.

4.4. Inclusion and Exclusion criteria's

4.4.1. Inclusion criteria

Quantitative: Children aged 5-18 years who have been on treatment for at least 6 months, along with their caregivers, and have parental consent or their own assent.

Qualitative: Children aged 13-18 years who have been on treatment for at least 6 months, along with their caregivers, and have parental consent or their own assent.

4.4.2. Exclusion criteria

For both quantitative and qualitative

Children with neurological disorders, including developmental delays, cerebral palsy, autism, and behavioral issues. Those children who are seriously ill

4.5. Study variables

4.5.1. Dependent variable

Health related quality of life of children with epilepsy

4.5.2. Independent variables

Children sociodemographic variables: age and sex

Caregivers' sociodemographic variables: age, sex, marital status, residence, occupation, income level, Level of educational and foster family

Children's clinical characteristics variables: age at seizure onset, duration of epilepsy, seizure frequency, family history, types of seizure, duration of treatment, AED type, numbers of drugs, adverse drug reactions, hospital admission, status epilepticus, and comorbidities

4.6. Operational definitions

Health related quality of life (HQOL): refers to the physical, school, emotional, psychosocial, and social domains of health that are influenced by a person's experiences, beliefs, expectations, and perceptions (48). It is assessed using a standardized tool such as the Pediatric Quality of Life Inventory (PedQoL), and children who score below the mean on this tool are classified as having poor quality of life, while those scoring at or above the mean are classified as having good quality (49).

4.7. Sample Size Determination and Procedure

4.7.1. Sample Size Determination

Sample size for the quantitative part was determined using a single population proportion formula.

$n = (Z\ \alpha/2)^2\ p(1-p)\ /d2$

where:

n = sample size

Zα/2 = Z-score for the desired confidence level (1.96 for 95% confidence)

p = proportion of the population (0.823), based on a similar previous study(42).

d = margin of error (0.05)

Applying the formula

$n= (1.96)^2\ 0.823(1-0.823)/\ (0.05)^2$

$3.8416\times0.823\times0.177/0.0025$

n≈224, By adding 10% non-response rate, 224×10/100=22.4≈23. Thus, the final sample size was 224+23=247. For the second objective, sample size determination using Epi Info 7.4 by taking statistically significant predictors of previous studies (42) (seizure control and age at onset of seizure) and considering 0.05% level of significance, 80% power of the study, 95% confidence interval, and 1:1 ratio of exposed to the unexposed group.

Factors		AOR	P1	Total with 10% non-response
Seizure control	Exposed <5 years	3.103	0.48	135
	Non exposed >5 years			
Age at seizure onset	Exposed poor control	5.75	0.22	143
	un exposed well control			

resulted in a smaller sample than the single population proportion method. Hence, the study used a final sample size of 247. For qualitative data, 6 subjects were interviewed until data saturation was achieved, meaning no new information emerged.

4.7.2. Sampling procedure and techniques

A simple random sampling technique was employed to select the required number of epileptic children from Bahir Dar city public hospitals. The number of study participants was assigned proportionally based on the number of epileptic children in each of the three hospitals. Lists of monthly participants were prepared in each hospital, and then the sample size from each hospital was calculated. Required numbers were taken randomly by lottery method from each list until reaching enough. In the case of a qualitative study, the multivariant purposive sampling technique was used to maximize variations in participants educational level, age, gender, course of disease, and family structure. Participants were selected purposefully to include children who can explain more about their illness.

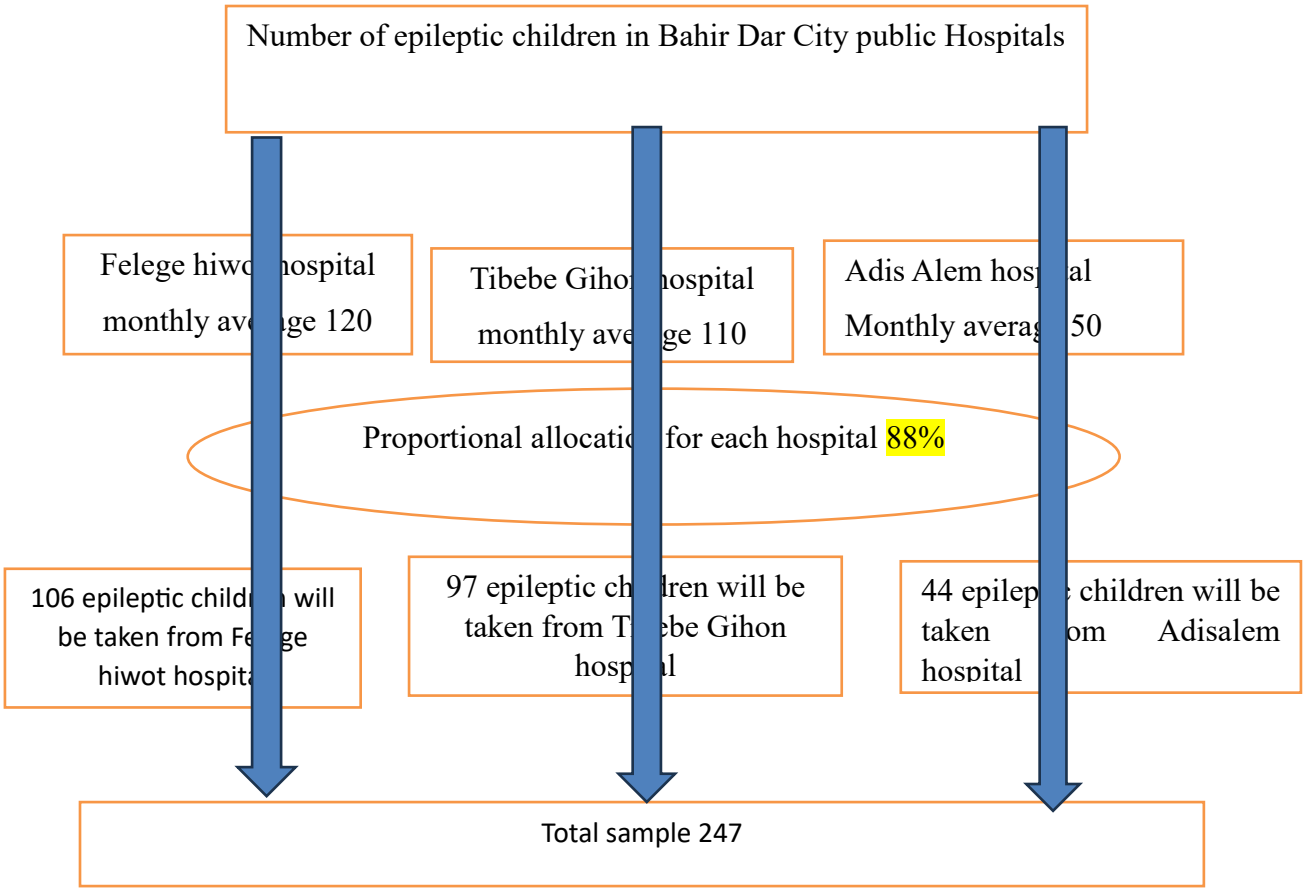


Figure 2: Sampling procedures in selecting study participants from the three public hospitals in Bahir Dar city to conduct a study on health-related quality of life and its associated factors in children with epilepsy.

4.8. Data collection tools and procedures

Data collection tools were adapted from similar previous studies and modified (35, 38, 50, 51, 52). Quantitative data were collected by using a well-structured questionnaire through face-to-face interviews and through chart review for clinical data during the study period. The data were collected by 1 MSC pediatrics nurse and 2 BSC nurses. The data collection tool had 3 parts: sociodemographic, clinical characteristics, and quality of life that were assessed using pediatrics quality of life inventory version 4.0. It was a 23-item measurement tool designed to measure health-related quality of life for pediatric patients; via a self-report and a parent proxy report.

The Pediatric QoL inventory contains 23 items with 4 domains: physical (eight items), emotional (five items), social (five items), and school (five items) functioning domains. A 5-point response scale is used across the child self-report and parent proxy-report with in the last one month (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). Items are reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). This instrument yields a total score, a physical health summary score, and a psychosocial health summary score (emotional, social, and school functioning).

Qualitative data were collected by principal investigators using a semi structured interview guide through an in-depth interview, and children were encouraged to express more statements and their feelings to enrich the raw data. The aims, methods, and content of the interview were clarified to the interviewees, and they promised to observe the principles of confidentiality and anonymity. The interview was conducted until conceptual saturation reached the point where no further new information was obtained. Six participants were interviewed and it lasted for 10-15 minutes. Not was taken during the interview regarding body language, facial expressions, and nonverbal cues.

4.9. Data quality assurance

The data collection tool was first developed in English and then translated to Amharic language and translated back to English to maintain consistency and for analysis. A pretest was conducted on 5% of the total sample size (13) out of the study population in Woreta general hospital one week before actual data collection and necessary adjustments were made on the tool. The questionnaire was checked for clarity, simplicity, and understandability, and the data was cleaned up and cross-checked before analysis. Two days of training were given for data collectors about

data collection and techniques of interviewing. Strict supervision was conducted during data collection.

In the case of qualitative data, the English version questionnaires were translated to the local Amharic language, and after that, an in-depth interview was conducted in a separate and silent room, then the responses were recorded by phone and a note was taken. The rigor of the findings was ensured by different approaches like why and how. Trustworthiness of the data was assured through peer debriefing, checking, and rechecking throughout data collection and analysis to ensure findings would likely be repeatable by others, by documenting a clear coding schema that identifies the codes and patterns identified in analyses (audit trail) or the rigorous techniques used to gather the data.

4.10. Data analysis

Data were checked for completeness and consistency, and then it was cleaned by reviewing, analyzing, detecting, modifying, or removing dirty data, coded and entered using Epi Data version 3.1, and it was exported to SPSS software version 26 for analysis. Descriptive statistics, means (SD), and frequencies (percentages) were calculated for continuous and categorical variables, respectively. Binary logistic regression was used for analysis. Factors of quality of life of each independent variable were first analyzed by using the bivariable logistic regression method, and significant variables with a p value <0.20 were entered to multivariable logistic regression, and p values <0.05 into multivariable logistic regression were declared as significantly associated variables. The model fitness was tested by the Hosmer–Leme show goodness-of-fit tests (p value = 0.801), and multicollinearity was tested by the variance inflation factor.

In the case of qualitative data first, the children's narratives were read thoroughly to gain an understanding of their experiences. Second, meaningful statements and phrases were extracted from each transcript. Third, these statements and phrases were thematised to form categories and subthemes. Collected data from the in-depth interview were transcribed and then translated into English. Accuracy and consistency of transcription and translation were cross-checked, and then thematic analysis was done by using an open code software version 4.2. The ideas were organised into concepts and presented in narratives using a transcribed form of the study in each thematic area. Finally, the narrative qualitative information was triangulated with quantitative findings.

4.11. Ethical considerations

Ethical clearance was obtained from Bahir Dar University College of Medicine and Health Sciences institutional review board (CMHS/IRB 01-008 protocol number 919/2024). Support letters were also written from Amhara Public Health Institute to the selected public hospitals and concerned others to obtain permission and cooperation during the data collection process. Informed written consent was obtained from caregivers and assents from the children before the data collection process after explaining to the children and their caregiver, the required information, the purpose of the study, the right not to participate, the need for their participation in this research, and confidentiality. The required information was explained for children in simple language and an understandable manner. Confidentiality of the information was preserved, and the privacy of the respondents was maintained by making the questionnaires anonymous and putting them in secured places after the data collection.

4.12. Dissemination of the study

The result of this study will be submitted to Bahir Dar University College of Medicine and Health Science School of Health Sciences Department of Pediatrics and Child Health Nursing. The result will be available in libraries, and online publishing will also be considered. It will be disseminated to different hospitals through conference presentations.

5. Results

5.1. Sociodemographic characteristics of children

A total of 236 children participated in the study with a response rate of 95.5%. Out of 236 participants, 128 (54.2%) were males, and 74 (31.4%) of the participants were in the age group of 5-7 years with a mean age of 10.72±4.169 years with a minimum age of 5 years and maximum age of 17 years. Of the participants, 82 (34.7%) had not started school yet, and 16 (6.8%) were in grades 9–12. Among 236 study participants, 202 (85.6%) were living with their families. In the qualitative study, a total of 6 children had participated in an in-depth interview. Out of the 6 participants, 3 were males and the remaining 3 were females. Ages of the participants range from 15 to 17. Regarding educational status, the minimum class was 3 and the maximum class was 11. Their interview records were coded as p1…p6.

Table 1: Sociodemographic characteristics of epileptic children at Bahir Dar city public hospitals, Bahir Dar, Ethiopia, 2024 (n = 236).

	Category	Frequency	Percent
Age	5-7	74	31.4
	8-12	72	30.5
	13-18	90	38.1
Sex	Male	128	54,2
	Female	108	45.8
Educational status	Not started	82	34.7
	Dropped	21	8.9
	Kindergarten	29	12.3
	1-4	53	22.5
	4-8	35	14.8
	9-12	16	6.8
Child’s primary care giver	Two parent	202	85.6
	One parent	26	11
	Biological relatives	4	1.7
	Others	4	1.7

5.2. Sociodemographic characteristics of Caregivers

Among the caregivers of the child, 147 (62.3%) were 30-45 years old, and 121 (51.3%) were males. Concerning marital status, 208 (88.1%) were married and 19 (8.1%) were separated. Regarding level of education, 57 (22.5%) were unable to read and write, and 62 (26.3%) were in college and above. Out of 236 caregivers, 82 (33.1%) were farmers and 9 (3.8%) were daily laborers. Out of the total caregivers, 129 (54.7%), had a monthly income of <3500 Ethiopian birr. *Table 2*: sociodemographic status of epileptic children's Caregivers in Bahir Dar city public hospitals, 2024.

Variables	Category	Frequency	Percent
Caregiver available	Father	103	43.6
	Mother	114	48.3
	Others	19	8.1
Age of family	< 30	58	24.6
	30-45	147	62.3
	>45	31	13.1
Sex	Male	121	51.3
	Female	115	48.7
Marital status	Married	208	88.1
	Separated	19	8.1
	Widowed	7	3.0
	Others	2	0.8
Educational status	Unable to read and write	53	22.5
	Able to read and write	37	15.7
	Primary	44	18.6
	Secondary	40	16.9
	College and above	62	26.3
Employments	Government employee	72	30.5
	Merchants	62	26.3
	Daily laborer	9	3.8
	Farmer	78	33.1
	House wife	15	6.4
Residency	Urban	135	57.2
	Rural	101	42.8
Level of income	< 3500 ETB	129	54.7
	>=3500 ETB	107	45.3

5.3. Clinical characteristics of the child

Among the participants, 211 (89.4%) had generalized tonic Clonic seizures, and 27 (11.4%) had a family history of epilepsy. Regarding duration of illness, 107 (45.3%) stayed with the disease from 1–5 years, and 18 (7.6%) lived with the disease for < a year. Concerning the frequency of seizures, 39 (16.5%) of the participants had 3 or more seizures per month, and 55 (23.3%) had 1-2 seizures per month. Out of 236 participants, 60 (25.4%) were admitted to the hospital due to epilepsy, 27 (11.4%) had other comorbidities besides epilepsy, and 78 (33.1%) had status epilepticus in the last year. Out of the total participants, 131 (55.5%) had poor control of seizures. Regarding duration of treatment 107(45.7%) stayed 1-5 years in treatment, 29 (12.3%) stayed in treatment less than 1 year, 70 (30.9%) stayed in treatment 5-10 years, and 16 (6.8%) stayed above 10 years.

Table 3: Clinical characteristics of epileptic children at Bahir Dar city public hospitals, Bahir Dar, Ethiopia, 2024 (n = 236).

Variables	Category	Frequency	Percent
Age at onset of seizure	< 1 year	55	23.3
	1-5 years	89	37.7
	5-10 years	57	24.2
	10 years	35	14.8
Duration of illness	< 1 year	18	7.6
	1-5 years	107	45.3
	5-10 Years	78	33.1
	>10 years	33	14
Frequency of seizure	Not for the last 1 month	65	27.5
	1-2 times/month	55	23.3
	>=3/month	39	16.5
	No for the last 1 year	45	19.1
	No for the last 2 years	32	13.6
Number of anti-epileptic drugs	One	150	63.3
	Two	84	35.6
	Three	2	0.8
Hospital admission due to epilepsy	Yes	60	25.4
	No	176	74.6
Other comorbidities	Yes	27	11.4
	No	209	88.6
Status epilepticus	Yes	78	33.1
	No	158	66.9
Types of seizure	Generalized	211	89.4
	Focal	25	10.6

Adverse drug reaction	Yes	29	12.3
	No	207	87.7
Aura before seizure	Yes	119	50.4
	No	117	49.6
Anti-epileptic drugs	Phenytoin	95	40.3
	Phenobarbital	37	15.7
	Sodium valproate	19	8
	Phenytoin & phenobarbital	39	16.5
	Phenytoin & valproic acid	23	9.75
	Phenobarbital & valproic acid	12	5.08
	Others	11	4.7

5.4. Health related quality of life of children with epilepsy

The overall mean health related quality of life of children in this study was 72.63 (SD±21.57) with a confidence interval (69.86, 75.39). The psychosocial summary score was 70.10 (SD±22.11). The physical domain score was the highest with a mean of 80.21 (SD±26.77), followed by the social domain with a mean of 78.83 (SD±26.21). The emotional domain score was the lowest, with a mean of 61.72 (SD ±26.66), followed by school domain 69.75 (SD ±24.14). Physical and social domains were above the total mean health related quality of life score, while emotional and school domains were below the total mean health related quality of life score.

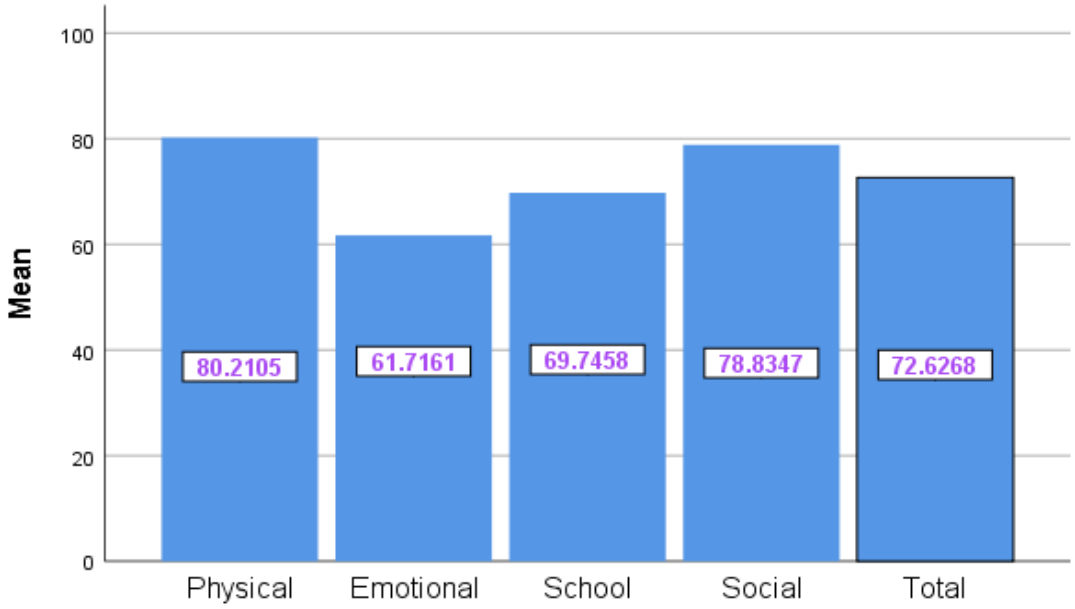


Figure 3: Graphs showing mean scores in domains of pediatrics quality of life inventory in assessing health related quality in children with epilepsy in Bahir Dar city public hospitals, 2024

The overall child reported quality of life was 75.04 with SD±18.05, while the parent proxy reported was 72.94 with SD±22.10, which showed similar patterning. Child reported quality of life in the physical domain was 84.70, which was the highest, and the emotional domain was the lowest, which was 62.53. Similarly, the parent proxy report showed the highest physical domain, which was 80.14, and emotional domain was the lowest, which was 61.31. Emotional and school domains were below the total mean health related quality of life score in both child reported and parent proxy reported.

Table 4: Parent proxy reported and child self-reported health related quality of life in epileptic children in Bahir Dar city public hospitals, Ethiopia, 2024.

Scale	**Child reported**	**Parent proxy reported**
	Mean with standard deviation	**Mean with standard deviation**
Physical	84.70±20.87	80.14±27.63
Emotional	62.53±25.79	61.31±27.43
School	69.23±23.82	71.55±24.33
Social	83.70±22.73	78.76±26.85
Psychosocial	71.82±19.70	70.54±22.47
Total	75.04±18.05	72.94±22.09

5.4.1. Physical experience

Seizures can have an impact on the physical health and quality of life of children. In a quantitative study using the Pediatric Quality of Life Inventory (PedQOL) version 4, the mean score for the physical domain quality of life was found to be 80.21 with a standard deviation of ±26.77. This indicates a significant variation in how children experience physical health issues related to seizures. In a qualitative study, individuals with epilepsy highlight the significant physical experiences they endure, including the frequency and intensity of seizures, the physical exhaustion, and the precautions taken by their families to ensure their safety. In a qualitative study, participants shared their personal experiences with seizures, highlighting the physical challenges they face:

Participant 2 (age 17) described the frequent and exhausting nature of her seizures.

"It dropped me at least 10 times a day, and at night, I find myself lying in another place because it makes me roll; after that, I feel tired." ***She added that***

"While I was sleeping, if my family didn't hold me, it would hit me on the ground and my leg would hurt, and my tongue would be cut and hurt. My family did not want me to fetch water from a stream because I am a rural girl and don't let me approach firework because it would drop me there."

Participant 5 (age 17) described the physical manifestations of her seizures:

"First, I feel it, and then it would drop me. It has a shaking feature, and it covers my face; my face becomes flushed."

5.4.2. Emotional experience

Living with epilepsy can significantly impact the emotional well-being of children. The total mean score for the emotional domain among epileptic children is 61.72 with a standard deviation of ±26.66, indicating a lower quality of life in this area. This quantitative finding is supported by qualitative interviews, where children express their feelings of anger and desperation.

Participant 6 (age 15) shared feelings of distress and desperation.

"I get distressed, and I still get distressed. I say I'd rather die when it drops me. Sometimes I get overwhelmed, and I was going to kill myself with poison. My epilepsy has been bothering me since I was a child."

Another child said, *"I don't think I'm going to cope with my epilepsy until God says it's over, but I think it will take time for me to get better. The God gave my luck to me.*" (**participant 5, age 17)**

5.4.3. Social experience

Epileptic children often face unique social challenges that significantly impact their social well-being. The total mean score of social domains among these children is 78.83 with SD±26.21, indicating a considerable emotional burden. In the qualitative study, individuals with epilepsy highlight the significant impact of their condition on their social experiences, including participation in social events, family relationships, and interactions with neighbors and peers. Their accounts reveal the challenges they face in maintaining social connections and the emotional strain of dealing with societal perceptions and discrimination. Children with epilepsy describe their social lives with a mix of caution and adaptation.

One participant shared how their condition affects their participation in social events*:*

"Neighbors know everything; now I don't go to a wedding like this event; that's one thing. I don't go in a place where there is a song, a lot of noise, and gunshots because my seizure may start in this situation, and if I go to a wedding, I sit far from the situation, and half of my friends come to me and chat with me." (participant 4, age 17)

Another participant discussed the impact of epilepsy on family relationships:

"My relationship with the family is cool. They tell me about my epilepsy: don't play a lot, don't watch TV a lot, don't watch mobile. Since I watch TV concentrating, they told me it makes your seizure start and you will have headache." **(Participant 3, age 16).**

Another participant expressed concerns about discrimination:

*"I don't want my friends to hear about my epilepsy. I don't want to talk to them because I'm afraid they're going to discriminate me." (***Participant 1, age 16)**

5.4.4. School experience

The school experience of children with epilepsy is often marked by significant emotional and social challenges. In this study examining the quality of life among these children, the total mean score for the school domain was found to be 69.75 (SD ±24.14). This score reflects the various difficulties they face in an educational setting, impacting their academic performance and social interactions at school. This is supported by a qualitative study, and the following quotes from children with epilepsy highlight their struggles in academic impact, school dropout, secrecy and fear, emotional strain and stigma, and reaction of peers and teachers.

Participant 4 (age 17) highlighted the academic impact of epilepsy.

"It has reduced my grades; off course, my reading ability has decreased; how many schools have I represented?" Another participant described the immediate reactions of peers and teachers.

"When my seizure starts in school, students and teachers take me out of the class and splash me with water." **Participant 5 (age 17**)

Participant 3 (age 16) discussed the secrecy and fear surrounding their condition:

"My schoolmate doesn't know about my epilepsy because I didn't tell them and I don't want to tell them."

Participant 6 (age 15) shared their experience of school dropout due to their condition:

"I quit my school when I got sick, and I'm going to a place of holy water and treatment."

5.4. Factors of health-related quality of life

The assumption of binary logistic regression was satisfied with the dependent variable being dichotomous, observations were independent, there was no multicollinearity among independent variables, and there was no significant outlier. In bivariable analysis, age of the child, sex of the child, family history of epilepsy, parents' educational status, employments, age at onset of seizure, total duration of treatment, duration of illness, duration of seizure in minutes, frequency of seizure, hospital admission due to epilepsy, status epilepticus, and other comorbidities were associated with quality of life since they were p values <0.20.

In the multivariable analysis model, about 50.3 % of the total variation in health-related quality of life among epileptic children was explained by variables in the model, and the model was a good fit with the data since Hosmer and Lem show a test value of 0.801 > 0.05. Age, age at onset of seizure, frequency of seizure, status epilepticus, family history of seizure, and hospital admission due to epilepsy were independent factors of quality of life.

Epileptic children aged 8-12 years were 3.58 times (AOR = 3.573; 95% CI: 1.110, 11.270) more likely to have poor health related quality of life than those who were 13-18 years. Early seizure onset was negatively related to health related quality of life. Those who had seizure onset < 1 year were nearly 7 times (AOR = 6.770; 95% CI: 1.382, 34.507) more likely to have poor health related quality of life than those whose seizure onset > 10 years, and seizure onset 1-5 years were nearly 4 times (AOR = 4.285; 95% CI: 1.045, 17.583) more likely to have poor health related quality of life than those whose seizure onset > 10 years.

Children with 1-2 seizures/month were 5.5 times (AOR = 5.5889; 95% CI: 1.026, 30.440) more likely to have poor health- related quality of life than those who had no seizure for the last 2 years, and those with 3 or more seizures/month were around 8 times (AOR = 7.814; 95% CI: 1.403, 43.519) more likely to have poor health-related quality of life than those who had no seizure for the last 2 years. Children who had family history of epilepsy were 3.6 times (AOR = 3.596; 95% CI: 1.067, 12.121) more likely to have poor health-related quality of life than those who had no family history, and those who admitted hospital due to epilepsy had nearly 3 times (AOR = 2.866; 95% CI: 1.117, 7.352) poorer health-related quality of life than those who did not admitted to hospital. Children who had status epilepticus in the last year had 2.4 times (AOR = 2.430; 95% CI: 1.054, 5.605) poor health-related quality of life than those who had not.

Table 5: Bivariable and multivariable logistic regression analysis of variables associated with overall HRQOL among patient epileptic children on anti-epileptic drugs follow up Bahir Dar city public hospitals, Bahir Dar, Ethiopia, 2024 (n = 236).

Variables	Categories	Quality of life		COR (95%CI)	P value	AOR (95% CI)
		Poor	Good			
Age	5-7	39	35	3.064(1.595,5.888)	0.135	2.822 (0.724,10.995)
	8-12	34	38	2.461(1.275,4.749)	0.033	3.573 (1.110,11.270) *
	13-18	24	66	1		1
Age at onset of seizure	< 1 year	36	19	7.579(2.795,20.549)	0.021	6.770 (1.382,34.507) *
	1-5 years	44	45	3.911(1.548,9.879)	0.043	4.285 (1.045,17.583) *
	5-10 years	10	47	0.851(0.291,2.489)	0.981	0.982 (0.225,4.282)
	>10 years	7	28	1		1
Frequency of seizure	No for the last month	25	40	2.708(0.978,7.501)	0.56	4.165 (0.963,18.015)
	1-2 times /month	27	28	4.179(1.487,11.742)	0.047	5.5889 (1.026,30.440) *
	3 or more times /month	22	17	5.608(1.885,16.683)	0.019	7.814 (1.403,43.519) *
	No for the last years	17	28	2.631(0.900,7.693)	0.246	2.331 (0.558,9.729)
	No for the last 2 years	6	26	1		1
Family history of seizure	Yes	16	11	2.299(1.016,5.201)	0.039	3.596 (1.067,12.121) *
	No	81	128	1		1
Hospital admission. Due to epilepsy	Yes	41	19	4.624(2.464,8,679)	0.029	2.866 (1.117,7.352) *
	No	56	120	1		1
Status epilepticus in the last 1 year	Yes	48	30	3.559(2.018,6.276)	0.037	2.430 (1.054,5.605) *
	No	49	109	1		1

6. Discussion

The overall mean health-related quality of life of children in this study was 72.63 (SD±21.57) with a confidence interval of (69.86, 75.39), with 41.1% having poor health related quality of life. This indicates that epileptic children in this study had relatively moderate health related quality of life. In this study, it was observed that reports of both parents and children on HRQOL items had similar patterns in emotional, social, and school functioning. This might be due to parents who are closely involved in their child's care and daily life having a good understanding of the child's experiences, leading to similar reports. In addition, caregivers are reliable proxies for their children and have positive relationships. However, in terms of physical domain and social domain, scores of the parents were lower than those of their epileptic children, comparable with a study in southern Iran (4). This is due to caregivers, Stress and anxiety about their child's condition might lead parents to report a poorer quality of life than the child themselves. Furthermore, caregivers might feel pressure to present a more negative picture of their child's condition if they believe it will garner more support or understanding.

According to this study, children with epilepsy had an overall health-related quality of life of 72.63 with SD ±21.57. This result is in line with research from Germany, where the mean QoL of epileptic children was 70.7 with SD ± 12.5, and Iran, where the overall HRQoL of children with epilepsy was 71.95 with SD ± 11.16 (17, 53), These similar HRQoL outcomes may be due to the use of the same study design, validated measurement tools, and similar study populations. In addition, medication side effects, seizure control, and the need for regular medical appointments influence health related quality of life similarly. The overall health related quality of life of epileptic children in this study was lower than a study conducted in India with a mean HRQoL of 81 with SD±8 (44). The discrepancy in HRQoL scores between the studies may be attributed to several factors, including the impact of enhanced epilepsy education and treatment options, which could improve quality of life. Additionally, differing cultural attitudes towards epilepsy, variations in socioeconomic status, and demographic differences in the study populations.

A higher HRQoL was seen in another South Korean investigation, where the mean QoL of epileptic children was 77.35 with SD ± 11.16 (36). This may be attributed to differences in advanced medical technology, access to specialized care, and overall standards of living. Enhanced social support systems and well-developed services for individuals with chronic conditions could

also play a significant role in influencing quality of life outcomes. In contrast, the HRQoL in this study was greater than the QoL in a study conducted in Egypt, which was 64.4 with SD+6.9(49). A later study's lower sample size and sociocultural difference may be the possible reason.

Regarding the two health summary scores, the psychosocial summary score is more affected than the physical summary score in this study. This finding is consistent with a cross-sectional study conducted in India (43), and it may be because stress, anxiety, and depression have an impact on psychosocial functioning. Furthermore, cultural attitudes and social support systems can influence psychosocial aspects. Among the four domains of the PedQOL inventory, children in this study exhibit higher scores in the physical domain compared to the other domains, which aligns with a study conducted in Egypt (49). The physical symptoms of epilepsy, such as seizures and their side effects, might be well managed, and children might perceive their physical health as less affected compared to others.

Children with epilepsy had the lowest average emotional functioning scores among the four domains, a result that is consistent with findings in South Korea (36). This may be attributed to Children with chronic conditions like epilepsy may experience significant emotional stress, anxiety, or depression due to their condition, including fear of seizures or feelings of being different from peers, leading to lower scores in the emotional domain. Besides, children may struggle with effective coping strategies to manage the emotional burdens associated with their condition. This struggle can lead to feelings of frustration, sadness, or emotional instability.

Additionally, our research findings revealed that the quality of life for children with epilepsy was highest in the social and physical domains, while the preschool/school/work functioning domain scored the lowest, paralleling research findings in Poland (37). This may be due to the support received from family and friends, along with effective medication management that helps maintain physical health. Emotional and school functioning were among the most compromised domains in this study, which corresponds with a study in Oman that showed emotional and social functioning are significantly affected (10). The unpredictability of seizures can cause anxiety and fear, impacting children's emotional well-being and causing them to worry about seizures at school or in social settings. This anxiety may lead to school absences, stigma, or bullying, reducing their willingness to attend. Additionally, parents might keep their child at home due to concerns about seizures in school, which, along with decreased self-esteem, can affect academic performance.

Regarding factors affecting the quality of life of epileptic children, age at seizure onset and frequency of seizure have a significant negative impact on health-related quality of life in epileptic children in this study. Frequent seizures worsen physical impairments and safety issues and reduce daily activities. It can lead to physical health issues such as injuries from falls or accidents during a seizure, as well as fatigue and reduced physical stamina. Children with high seizure frequency may also experience more side effects from medications used to manage their condition, while early onset seizures disrupt development, education, and social interactions, leading to daily life challenges and delays or impairments in cognitive and motor skills. This is supported by research from Oman (10). In this study, hospitalization and recent status epilepticus are independent factors affecting the quality of life for children with epilepsy. Because this can lead to increased medical complications, greater emotional distress, and disrupted daily routines, negatively impacting the overall quality of life. Extended hospital stays can also interfere with schooling, potentially leading to academic delays or difficulties in keeping up with peers. Research in Germany supports this findings(17).

Our study findings revealed that overall QoL was affected more in younger children, and this is in line with a study conducted in southern Ethiopia (42). This may be due to the fact that overall QoL was affected more in younger children, since epilepsy can significantly impact their cognitive, social, and emotional growth. Family history of epilepsy affects health-related quality of life negatively, and this finding is consistent with research in Iran (53). It may be the result of stress within the family as well as negative attitudes toward those who have the condition, which can lead to social stigma and discrimination. Some people avoid making physical contact with those who have the condition, such as shaking hands, and even keep their children away from those who have it. If there is epilepsy in the family, this can also lead to a lack of support for the affected family (25).

In qualitative findings, frequent health issues, such as recurrent seizures, can lead to physical injuries and significant exhaustion, impacting daily functioning. These health challenges may also result in frequent school absences, further compounding difficulties in maintaining educational progress. Emotional stress related to managing and disclosing one’s illness can exacerbate feelings of hopelessness, while poor social interactions due to these circumstances can diminish overall quality of life.

7. Strengths and limitations of the study

7.4. Strength of the study

The study used both child reported and parent proxy reported Questionnarie to gain more comprehensive information about the subjects and medical records to gain all the clinical condition of the epileptic child. This study used a mixed study design, and it can offer a holistic understanding of the quality of life of children with epilepsy, capturing both statistical trends and personal experiences

7.5. Limitation of the study

Children may have difficulty accurately recalling past events or experiences, leading to recall bias in the data collected. Other factors affecting HRQOL, like medication adherence, stigma, anxiety, and depression, were not examined in this study.

8. Conclusion

In this study, children with epilepsy had a moderate level of health-related quality of life, which may indicate that while the children were functioning relatively well, they might still experience significant challenges or impacts related to their epilepsy. Among the 4 domains, emotional and school functioning were the most affected. Age, age at onset, frequency of seizure, family history, status epilepticus, and hospitalization were factors affecting the quality of life of epileptic children.

9. Recommendation

Based on this study finding, the following recommendations were made:

Amhara Health Bureau: Should launch an awareness campaign to reduce stigma and increase understanding of epilepsy in the community and advocate for inclusive education policies that support children with epilepsy in mainstream schools**.**

For health professionals: They should not only concentrate on diagnosing and treating epilepsy but also focus on providing holistic care to enhance the overall quality of life for patients living with epilepsy. Pay attention to reduce the frequency of seizures and improve their psychosocial well-being. Collaborate with psychologists, social workers, and educators to address the comprehensive needs of children with epilepsy. Ensure optimal medication management to minimize side effects and improve seizure control, which can significantly enhance quality of life. Health professionals undergo specialized training in epilepsy management to enhance their skills and knowledge, thereby improving the quality of life for children with epilepsy.

For further researchers: Conduct studies with a larger sample size, including a diverse population, to better understand the impact of epilepsy and its treatment on the children's quality of life

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11. Annexes

11.1. Information sheet

Title: - Health-related quality of life and its associated factors in children with epilepsy on follow up in Bahir Dar city public hospitals, Amhara region, Ethiopia,2024.

Name of investigator: Bekalu Alemayehu (BSC in Nursing, MSC student)

Name of organization: Bahir Dar university college of medicine and health sciences school of health sciences department of pediatrics and child health nursing

Purpose of the study: To assess health-related quality of life and its associated factors in children with epilepsy on follow up in Bahir Dar city public hospitals, Amhara region, Ethiopia,2024

Confidentiality: Your name will not be written in this form and will never be used and the information you give for me will be kept confidential.

Risks: This study will not inflict any harm on the study participants since the participation is questioning and answering only no experimental trial

Benefits: It will not have direct benefits for you However, you may be benefited from the results of the study as it may be utilized for service improvement in the future.

Personal contact: For further information you can contact

Principal investigator: Bekalu Alemayehu (BSC in Nursing, MSC student)

Adress: 0936109963

Advisors:

1. Getasew Tesfa (assistant professor, PhD fellow)
   Adress: 0913714361
2. Awoke Kebede (MSc, assistant professor in pediatrics and child health nursing)
   Adress: 0918292547

11.2. Consent Form

Hello,

My name is Bekalu Alemayehu, and I am a student in Pediatrics and Child Health Nursing at Bahir Dar University, College of Medicine and Health Sciences. I am currently conducting research on the health-related quality of life and its associated factors in children with epilepsy who are receiving follow-up care at public hospitals in Bahir Dar City. I would like to ask you a few questions about your child's experiences with epilepsy, specifically concerning physical, emotional, school/work, and social conditions. Your responses are very important for obtaining reliable data for this study, and your cooperation is greatly appreciated.

Please be assured that your name will not be recorded in this form, and all information you provide will be kept confidential. Your data will be handled with the utmost respect for your privacy, and you have full autonomy over your information. This is not an experimental study, so there is no risk of harm to you or your child. While there are no direct benefits to you or your child, the results of this study may help improve services for children with epilepsy in the future.

Participation is entirely voluntary, and you can withdraw at any time without any consequences. It will not take much time to complete.

May I have your permission to proceed with the questions?

Please sign here----------

Thank you for your time and cooperation.

Oral assent

Hi my name is Bekalu Alemayehu. I doing a study to learn more about health-related quality of life and its associated factors in children with epilepsy, who had follow-up in the Bahir Dar city public hospitals. I would like you to help me in answering questions regarding your epileptic illness. I will ask you questions related to your physical, social, emotional and school issue. It will not take long, and it will not hurt. Your answers will be kept private, and no one will know what you said. If you don't want to do it, that's okay. Do you want to help me?"

11.3. English version questionnaires

Part one: Socio demographic data of the child

100	Age (years)					
101	Sex					
102	Education status	No	Kindergarten	1-4	5-8	9-12

Part one: Socio demographic data of caregivers

103	Age					
104	Sex	Male	Female			
105	Children's parent available	Mothers	Father	Other specify		
106	Residence	Urban	Rural			
107	Marital status	Married	Divorced	Widowed	Other specify	
108	Level of monthly income					
109	Educational status	Unable to read & write	Able to read &write	Primary	Secondary	College and above
110	History of Epilepsy	Yes	No			

Part two: Clinical characteristics of the child

200	Age at onset of seizure	<1 year	1 to 5	5 to 10	>10	
201	Duration of illness	<1 year	1 to 5	5 to 10	>10	
202	Duration before Rx					
203	Type of seizure	Generalized seizure	Focal seizure			
204	Family history of seizure	Yes	No			
205	Frequency of seizure	Nil in last month	2 times month	3 times/month	Non for the last 1 year	Non for the last 2 years
206	Total duration of treatment					
207	Seizure control	Well controlled	Poor control			
208	Number of anti-epileptic drugs	One	Two	Three		
209	Type of anti-epileptic drug	Valproic acid	Phenytoin	Phenobarbital	Other…. Specify	
210	Getting anti-epileptic drugs	For free	Buying			
211	Adverse drug reaction	Yes	No			
212	Aura before seizure	Yes	No			

Part three: Quality of life assessment tool Pediatrics quality of life inventory version 4 questionaries

In the past one month how much of a problem has this been in children

Code	Physical domain items	Never	Almost never	Sometimes	Often	Almost always
300	Difficulty of walking					
301	Hard to ran					
302	Hard to do sport or exercise					
303	Hard to lift something heavy					
304	Hard to take bath					
305	Hard to do chores around house					
306	Hurt or ache					
307	Low energy					

In the past one month how much of a problem has this been in children

Code	Emotional domain items	Never	Almost never	Sometimes	Often	Almost always
308	Feel afraid or scared					
309	Feel sad or blue					
310	Feel angry					
311	Trouble sleeping					
312	Worry about what will happen					

In the past one month how much of a problem has this been in children

Code	School/work functioning items	Never	Almost never	Sometimes	Often	Almost always
313	Hard to concentrate					
314	Forget things					
315	Trouble keeping up with school work					
316	Missing school because of not feeling well					
317	Missing school to go to the doctor or hospital					

In the past one month how much of a problem has this been in children

Code	Social functioning items	Never	Almost never	Sometimes	Often	Almost always
318	Trouble getting along with peers					
319	Other children not want to be friends					
320	Other kids tease me					
321	Can not do things other children in my age can do					
322	Hard to keep up when I play with others					

Open ended interview guide for qualitative study adopted from different literatures

1. What do you know about your epilepsy?
2. How do you feel when you have a seizure? What do you do at that time?
3. Please talk about how you get along with your parents and siblings
4. Please describe how your illness influences your life and your schoolwork's
5. Tell me about how your friends or others feel about you having seizures.
6. How well do you think you've coped with having epilepsy? Things makes you feel better when you're worried?
7. What do you think about the medication or treatments you receive? feel about going to the doctor or hospital for your epilepsy?

የስምምነት ቅጽ

ሰላም እንዴት ናችሁ እኔ በቃሉ አለማየሁ እባላለሁ። በባህር ዳር ዩኒቨርሲቲ በሕክምናና ጤና ሳይንስ ኮሌጅ በጤና ሳይንስ ትምህርት ቤት በማስተርስ ፕሮግራም የህፃናት ጤና ነርስ ትምህርት ክፍል ተማሪ ስሆን በህፃናት ነርሲንግ የማስተርስ ሳይንስን በከፊል ለማሟላት የምርምር ስራዬን እየሰራሁ ነው። የሚጥል በሽታ ባለባቸዉ ልጆች ላይ ያለዉን የኑሮ ሁኔታ እና በኑሯቸዉ ላይ ተጽኖ የሚያሳድሩ ምክንያቶችን እያጠናሁ ነዉ። የጥናቱ አላማም የሚጥል በሽታ ባለባቸዉ ልጆች ላይ ያለዉ የኑሮ ሁኔታ ምን እንደሚመስል ማወቅና የኑሮ ሁኔታቸዉን ተጽኖ ዉስጥ የሚያሳድሩ ምክንያቶችን ማወቅ ነዉ። ስለ ልጁ ሶሽወ ስነ ህዝብ፣ ስለሚጥል በሽታ ህመሙ፣ ስለ አካላዊ፣ስነልቦናዊ፣ማህበራዊና ስለትምህርት ሁኔታዉ የተወሰኑ ጥያቄወችን ለእርስዎና ለልጅዎ መጠየቅ እፈልጋለሁ። ጥያቄዎቹ ብዙ ጊዜ አይወስዱም ከ 10 ደቂቃ በላይ አትቆዩም የእናንተ መልስ ለኔ ጥናት በጣም አስፈላጊ ነዉ። ምክንያቱም ታማኝ መረጃ የማገኘዉ ከናንተ ስለሆነ ትብብራችሁ ያስፈልገኛል። ስማችሁና ማንነታችሁ ስለማይጻፍ የምትሰጡት ማንኛዉም መረጃም ሚስጥራዊነቱ የተጠበቀ ነዉ ። በናንተ ላይ የሚደርስ ምንም አይነት ጉዳት የለዉም ። ቀጥተኛ የሆነ ጥቅም የለዉም ነገር ግን ጥናቱ ከተጠናቀቀ በኋላ በሚገኘዉ ለዉጥ ተጠቃሚ ልትሆኑ ትችላላችሁ። ለጥያቄዎች ፍቃደኛ ካለሆናችሁ በማንኛዉም ጊዜ ማቋረጥ ትችላላችሁ፡ ፡ፍቃደኛ ከሆናችሁ ጥያቄዉን ልቀጥል. ማንኛዉም አይነት ጥያቄ ወይም ቅሬታ ካለ ጥናታዊ ምርምር ሰሪዉንና አማካሪዎችን ማገኘት ይችላሉ። ዋና ጥናታዊ ምርምር ሰሪ በቃሉ አለማየሁ ስልክ 0936109963. አማካሪወች አቶ ጌታሰዉ ተስፋ (ፒኤችዲ ፊሎዉ) ስልክ 0913714361 እና አቶ አወቀ ከበደ (በህጻናት ነርሲንግ ረዳት ፕሮፌሰር) ስልክ 0918292547.

እኔ ከላይ ያለዉን መረጃ አንብቤ ስለ ጥናቱ አላማና ስለሂደቱ ተረድቻለሁ ስለሆነም እኔና ልጄ መሳተፍ እንደምንችል በፊርማየ አረጋግጣለሁ----------

ቃል ማረጋገጫ

ሰላም ስሜ በቃሉ አለማየሁ ይባላል። በባህር ዳር ከተማ የህዝብ ሆስፒታሎች የሚጥል በሽታ ትክክል ያላቸውን ህጻናት ከጤና ጋር የተያያዙ የህይወት ጥራት እና ተያያዥ ምክንያቶች የበለጠ ለማወቅ ጥናት አያደረኩ ነዉ። የሚጥል በሽታን በተመለከተ ለሚነሱ ጥያቄዎች መልስ በመስጠት እንድትተባበሩኝ እፈልጋለሁ። ከአናንተ አካላዊ፣ ማህበራዊ፣ ስሜታዊ እና የትምህርት ቤት ጉዳይ ጋር የተያያዙ ጥያቄዎችን እጠይቅሃለሁ። ብዙ ጊዜ አይፈጅም, እናም በመሳተፍህ የሚደርስ ጉዳት የለውም. መልሶቻችሁ በሚስጥር ይቀመጣሉ፣ እና የተናገራችሁትን ማንም አያውቅም። ማድረግ ካልፈለግክ ምንም ችግር የለውም።

እባክህ ልትረዳኝ ትችላለህ?

11.4. አማርኛ መርህ መጠይቅ

ክፍል 1: የልጁ የሶሽወ ስነ ህዝብ መረጃ

100	ዕድሜ(በአመት)					
101	ጸታ					
102	የትምህርት ደረጃ	ያልጀመረ	ኬጅ	1-5	5-10	11-12

የልጁ ቤተሰብ የሶሽወ ስነ ህዝብ መረጃ

105	ዕድሜ					
106	ጸታ	ወንድ	ሴት			
107	የተገኘ የቤተሰብ አባል	አባል	እናት	ሌላ ካለ ይገለጽ		
109	የሚኖሩበት ቦታ	ከተማ	ገጠር			
110	የጋብቻ ሁኔታ	ያገባ	የተፋታ	የሞተበት	ሌላ ይገለጽ	
1111	የገቢ ሁኔታ	በቂ ነዉ	በቂ አይደለም			
112	የትምህርት ደረጃ	ማንበብና መጻፍ የማይችል	ማንበብና መጻፍ የሚችል	የመጀመሪያ ደረጃ	ሁለተኛ ደረጃ	ኮሌጅና በላይ
113	የሚጥል በሽታ	ያለበት	የሌለበት			

ክፍል 2፡ ከልጁ የህመም ሁኔታ ጋር የተገናኘ መጠይቅ

200	የሚጥል በሽታው የጀመረበት ዕድሜ	ከ 1 አመት ያነሰ	ከ1-5 አመት	ከ 5-10 አመት	ከ10 አመት በላይ	
201	ህመሙ የቆየበት ጊዜ	ከ 1 አመት ያነሰ	ከ1-5 አመት	ከ 5-10 አመት	ከ10 አመት በላይ	
202	ህመሙ ሳይታከም የቆየበት ጊዜ					
203	የሚጥለው አይነት	ሙሉ አካል	ከፊል			
205	የቤተሰብ የሚጥል በሽታ ታሪክ	አለ	የለም			
206	የማንዘፍዘፍ ድግግሞሽ	ባለፈው ወር አልጣለኝም	በወር 2 ጊዜ	በወር 3 ጊዜ	በ 1 አመት ዉስጥ አልጣለኝም	በ 2 አመት ዉስጥ አልጣለኝም
207	የህክምናው ቆይታ					
208	የሚጥለዉን መቆጣጠር ተችሎአል	በደንብ	በጥቂቱ			
209	የሚወሰደዉ የመዳኒት ብዛት	1	2	3		
210	የሚወሰደዉ የመዳኒት አይነት	ቫልቮሪክ አሲድ	ፌኒቶይን	ፌኖ ባርቢቶል	ሌላ ይገለጽ	
211	መድሃኒቱ እንዴት ይገኛል	በነጻ	በግዥ			
212	የመድሃኒቱ የጎንዮሽጉዳት	አለ	የለም			
213	ማንዘፍዘፉ ከመጀመሩ በፊት የሚታይ ምልክት	አለ	የለም			

ክፍል 3 የህይወት ጥራት ግምገማ የሚጥል በሽታ መጠይቅ

ባለፈዉ 1 ወር ዉስጥ ከእነዚህ ምን ያህሎች ተከስተዋል በልጁ ላይ

ኮድ	ከአካላዊ እንቅስቃሴ ጋር በተገናኘ	በፍጹም	አልፎ አልፎ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ
300	ለመንቀሳቀስ መቸገር					
301	ለመሮጥ መቸገር					
302	ስፖርት /እንቅስቃሴ ለማድረግ መቸገር					
303	ከባድ ነገሮችን ማንሳት መቸገር					
304	ሻወር ለመዉሰድ መቸገር					
305	ቤት ዉስጥ የሚሰሩ ስራዎችን ለመስራት መቸገር					
306	ህመም/ጉዳት					
307	አቅም አለመኖር					

ባለፈዉ 1 ወር ዉስጥ ከእነዚህ ምን ያህሎች ተከስተዋል በልጁ ላይ

ኮድ	ከስሜት ጋር በተገናኘ	በፍጹም	በጣም አልፎ አልፎ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ
308	የፍርሃት ስሜት መሰማት					
309	የመከፋት ስሜት					
310	የመናደድ ስሜት					
311	እንቅልፍ ማጣት					
312	ለወደፊቱ መጨነቅ					

ባለፈዉ 1 ወር ዉስጥ ከእነዚህ ምን ያህሎች ተከስተዋል በልጁ ላይ

ኮድ	ከትምህርት ና ከስራ ጋር የተገናኘ	በፍጹም	በጣም አልፎ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ
313	ትኩረት ለማድረግ መቸገር					
314	መርሳት					
315	ትምህርትን ለመከታተል መቸገር					
316	በህመም ምክንያት ከትምህርት መቅረት					
317	ለሃኪም ቀጠሮ ከትምህርት መቅረት					

ባለፈዉ 1 ወር ዉስጥ ከእነዚህ ምን ያህሎች ተከስተዋል በልጁ ላይ

ኮድ	ከማህበራዊ ህይወት ጋር የተገናኘ	በፍጹም	በጣም አልፎ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ
318	ከአቻዎች ጋር መግባባት አለመቻል					
319	ሌሎች ከእኔ ጋር ጓደኛ መሆን አይፈልጉም					
320	ሌሎች ያፌዙብኛል					
321	ጓደኞች የሚያደርጉትን ማድረግ መቸገር					
322	ከሌሎች ጋር እየተጫወትኩገኝ መቀጠል አለመቻል					

ለጥራት ጥናት የተዘጋጀ መጠይቅ

1. ስለ የሚጥል በሽታ ምን ታውቃለህ/ ታዉቂያለሽ?
2. የሚጥል በሽታ ሲያጋጥምህ/ሽ ምን ይሰማሀል/ ይሰማሻል? በዚያን ጊዜ ምን ታደርጋለህ/ ታደርጊያለሽ?
3. ስለ ትምህርት ቤት ህይወት ንገረኝ/ ንገሪኝ; ከአስተማሪዎችዎ፣ከትምህርት ጓደኞቻችሁ እና ከትምህርቶቻችሁ ጋር እንዴት ትሄዳላችሁ?
4. እባክህ ከወላጆች ከወንድሞና እህት ጋር እንዴት እንደምትስማማ ተናገር/ ተናገሪ
5. ህመሙ በህይወታችሁ እና በትምህርት ቤት ስራችሁ ላይ እንዴት ነዉ ተጽኖ የሚያሳድረዉ
6. የሚጥል በሽታን ምን ያህል እንደተቋቋሙት ያስባሉ? ስትጨነቅ/ስትጨነቂ የሚያረጋጉህ/የሚያረጋጉሽ ነገሮች
7. ስለምትቀበለዉ/ስለምትቀበይዉ መድሃኒት ወይም ህክምና ምን ታስባለህ/ታስቢያለሽ