MAKERERE UNIVERSITY

COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICINE

PREVALENCE AND FACTORS ASSOCIATED WITH POOR QUALITY OF LIFE AMONG ADOLESCENTS WITH EPILEPSY ATTENDING THE PAEDIATRIC NEUROLOGY AND PAEDIATRIC PSYCHIATRY CLINICS IN MULAGO NATIONAL REFERRAL HOSPITAL

BY

RUTABINGWA MWIZA WA SE Nice

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SUPERVISORS

1. PROFESSOR MWOROZI EDISON (MBChB,MMED,Dip.CEH,PEHI/IPA)
2. DR. RUJUMBA JOSEPH (BA.SWSA,MA.SSPM,PhD)
3. ASSOCIATE PROFESSOR KAKOOZA ANGELINA. M(MBChB,MMED,PhD,POST DOCTORAL FELLOW)

A DISSERTATION SUBMITTED TO THE DIRECTORATE OF RESEARCH AND GRADUATE TRAINING IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF THE DEGREE OF MASTER OF MEDICINE IN PAEDIATRICS AND CHILD HEALTH OF MAKERERE UNIVERSITY

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DECLARATION

I, Rutabingwa Mwiza Wa Se, affirm that this dissertation titled *"Prevalence and Factors associated with Poor Quality of Life among Adolescents with Epilepsy attending the Paediatric Neurology and Paediatric Psychiatry Clinics in Mulago National Referral Hospital"* is entirely my original work. I declare that this research has not been submitted, either wholly or in part, for academic recognition to any other university or institution of higher learning

Name: Rutabingwa Mwiza Wa Se Nice

Signature: .....

Date: 30/4/2026

APPROVAL

I hereby approve this dissertation and recommend its submission to Makerere University in partial fulfillment of the requirements for the award of the Degree of Master of Medicine in Paediatrics and Child Health.

Supervisor 1

Name: PROFESSOR MWOROZI EDISON ((MBChB,MMED,Dip.CEH,PEHI/IPA)

Signature: .....

Date: 24/06/2025

Supervisor 2

Name: DR. RUJUMBA JOSEPH (BA.SWSA,MA.SSPM,PhD)

Signature: .....

Date: 24/06/2026

Supervisor 3

Name: ASSOCIATE PROFESSOR KAKOOZA ANGELINA M (MBChB,MMED,PhD,POST DOCTORAL FELLOW)

Signature: .....

Date: 24/06/26

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LIST OF ABBREVIATIONS

ASMs	Anti-Seizure Medications
HICs	High-Income Countries
HRQOL	Health-Related Quality of Life
LMICs	Low and Middle-Income Countries
MNRH	Mulago National Referral Hospital
MOH	Ministry of Health
MSPSS	Multidimensional Scale of Perceived Social Support
PHQ-4	Patient Health Questionnaire
PLWE	People Living With Epilepsy
QoL	Quality of Life
QOLIE-AD-48	Quality of Life in Epilepsy Inventory-Adolescents-48
QOLIE-AD-48	Quality of Life in Epilepsy for Adolescents questionnaire
RSES	Rosenberg Self Esteem Scale
UBOS	Uganda Bureau of Statistics
WHO	World Health Organization

OPERATIONAL DEFINITIONS

Anti-epileptic drugs: Medications prescribed to control or reduce the frequency of seizures in people with epilepsy.

Adolescents: As defined by the United Nations, adolescents are individuals between the ages of 10 and 19years

Epilepsy: A chronic neurological disorder characterized by recurrent, unprovoked seizures, diagnosed by a clinician and confirmed through medical records or caregiver reports.

Quality of life: Quality of life refers to how individuals view their position in life, taking into account their cultural values, personal goals, expectations, standards, and concerns (WHO, 1995).

Poor quality of life: Defined as a total score below 60 on the Quality of Life in Epilepsy for Adolescents questionnaire (QOLIE-AD-48), indicating significantly impaired physical, social, and mental well-being among adolescents with epilepsy (Hussain et al., 2020).

Self-esteem: Assessed using the Rosenberg Self-Esteem Scale (RSES), with total scores ranging from 0 to 30. Scores between 15 and 25 were classified as normal self-esteem, scores below 15 as low self-esteem, and scores above 25 as high self-esteem

Seizure: A sudden, brief episode of altered behavior or consciousness, caused by abnormal electrical discharges in the brain (Huff, 2021).

Social support: An exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient (Shumaker & Brownell, 1984). This will refer to the perceived availability of emotional, informational, or practical help from family, peers, or community. Categorized based on the mean item score across the 12 MSPSS items: 1.0–2.9 as low support, 3.0–5.0 as moderate support, and 5.1–7.0 as high support (Zimet et al., 1988)

ABSTRACT

Background: Epilepsy is a major cause of disability among adolescents in low- and middle-income countries, with impacts extending beyond seizure control to physical, psychological, and social well-being. Despite this, evidence on the burden and determinants of poor quality of life (QoL) among adolescents with epilepsy in Uganda remains limited.

Aim: To determine the prevalence of poor quality of life and its associated factors among adolescents with epilepsy attending Mulago National Referral Hospital.

Methods: A hospital-based cross-sectional study was conducted among 383 adolescents aged 10–19 years attending the Paediatric Neurology and Psychiatry Clinics at Mulago National Referral Hospital. QoL was assessed using the QOLIE-AD-48, with poor QoL defined as a score <60. Data on psychological and clinical factors were collected using validated tools. Modified Poisson regression with robust standard errors was used to estimate adjusted prevalence ratios (aPR) and 95% confidence intervals (CI).

Results: The prevalence of poor QoL was 83.3%. Adolescents aged 15–19 years were less likely to have poor QoL compared to those aged 10–14 years (aPR = 0.84, 95% CI: 0.73–0.97). Higher educational attainment was associated with increased prevalence of poor QoL, including primary (aPR = 1.59, 95% CI: 1.14–2.21), secondary (aPR = 1.90, 95% CI: 1.39–2.59), and tertiary education (aPR = 1.95, 95% CI: 1.42–2.67), compared to no formal education. Adolescents uncertain of their family history of epilepsy had lower prevalence of poor QoL (aPR = 0.87, 95% CI: 0.76–0.99), while normal self-esteem was protective (aPR = 0.84, 95% CI: 0.75–0.94). Other clinical and psychological factors were not independently associated with QoL after adjustment.

Conclusion: Poor quality of life among adolescents with epilepsy in this setting is alarmingly high. The pattern of associations suggests that QoL in this population is less driven by traditional clinical markers and more shaped by developmental and psychosocial context, particularly self-perception and lived experience within educational environments. This reframes epilepsy care in adolescents as a multidimensional challenge, requiring integrated models that address not only disease control but also identity, resilience, and social functioning.

Keywords: Epilepsy, adolescents, quality of life, Uganda, prevalence ratio, psychosocial factor

CHAPTER ONE: INTRODUCTION

1.1 Background

Epilepsy is a prevalent neurological disorder and a leading cause of disability in childhood (Biset et al., 2024). It is a heterogeneous condition with multiple seizure types and syndromes, diverse etiologies, and variable prognoses (Puka et al., 2016). Epilepsy incidence usually peaks in the first year of life thus individuals living with this condition face prolonged exposure to seizures and their associated consequences (Mula & Sander, 2016). Recurrent seizures, the clinical hallmark of epilepsy, place a significant burden on patients, caregivers, and society. They can lead to injuries, cognitive decline, and mental health problems such as anxiety and depression, which disrupt learning, mobility, social functioning, work, and daily activities (Aaberg et al., 2017; Christensen et al., 2023). These cumulative effects contribute to a reduced quality of life (QoL) for people living with epilepsy (Ferro et al., 2017; Willems et al., 2018).

Globally, the incidence of epilepsy in children and adolescents ranges from 41 to 187 per 100,000, with higher rates in underdeveloped, particularly rural, regions (Camfield & Camfield, 2015). Developing countries carry a disproportionate burden, with prevalence estimates of 3.6-44 per 1,000 compared to 3.2-8.1 per 1,000 in developed regions (Eslamian et al., 2024). In developing countries, common causes include genetic predisposition, perinatal and neonatal complications, birth asphyxia, and febrile seizures, whereas in developed countries, brain tumors, cerebrovascular disease, and traumatic head injuries are predominant (Farghaly et al., 2018; WHO, 2019).

The World Health Organization defines QoL as “how individuals perceive their place in life within the context of their cultural and value systems, and about their goals, expectations, standards, and concerns” (WHO, 1995). It reflects subjective evaluation of physical health, mental well-being, independence, social connections, personal beliefs, and environmental interaction (Kassie et al., 2021; Pachange et al., 2021). Among PLWE, epilepsy can impair social participation, concentration, school and work performance, emotional well-being, and daily activities, sometimes causing greater perceived burden than the clinical severity alone (Hussain et al., 2020; Ibinga et al., 2015).

In Africa, the cumulative prevalence of epilepsy is estimated at 17.3 per 1,000, with active epilepsy at 6.8 per 1,000 (Eslamian et al., 2024). Epilepsy in Africa is often associated with myths and misconceptions, leading to stigma and discrimination, which reduce QoL (Agbetou

et al., 2023; Biset et al., 2024). The pooled mean QoL score among PLWE in sub-Saharan Africa is 63.79 (Beyene et al., 2025), with good QoL reported in up to 60.5% of cases (Hussain et al., 2020). Poor QoL has been reported at 44.6% in Nigeria, 48.2% in Gabon, and 39.5% in Kenya (Hussain et al., 2020; Ibinga et al., 2015). A range of sociodemographic, clinical, and psychological factors have been associated with QoL among PLWE, and these are reviewed in detail in Chapter Two..

The Uganda Bureau of Statistics estimated the prevalence of epilepsy among adolescents to be 16 per 1,000 in 2017 (UBOS, 2017). Despite being treatable, it remains heavily stigmatized, resulting in significantly impaired QoL compared to the general population and other chronic diseases (Anguzu et al., 2021). A hospital-based study at Mulago and Butabika national referral hospitals reported an average health-related QoL score of 58/100, influenced by frequent seizures, polytherapy, and drug side effects (Nabukenya et al., 2014).

Despite increasing recognition of epilepsy's impact on QoL, adolescents in urban clinical settings remain under-researched in Uganda. The few existing studies either focus primarily on adults or are based in rural populations with different socio-economic and health system dynamics (Anguzu et al., 2021; Kaddumukasa et al., 2019; Nabukenya et al., 2014). This study aims to assess the prevalence and factors associated with poor quality of life among adolescents and children with epilepsy at the Paediatric Neurology Clinic in Mulago National Referral Hospital.

1.2 Statement of the Problem

Children with epilepsy face numerous challenges that significantly impair their quality of life. A hospital-based study conducted at Mulago and Butabika national referral hospitals reported a mean health-related QoL score of 58 out of 100 among people living with epilepsy, suggesting suboptimal physical, emotional, and social well-being (Nabukenya et al., 2014). Poor QoL among this population is often associated with impaired academic performance, social exclusion, and increased vulnerability to mental health issues such as anxiety and depression (Ayanda & Sulyman, 2020; Mofatteh, 2021).

Although Uganda has integrated epilepsy management into broader mental health and non-communicable disease programs (MOH, 2015), most efforts have focused on seizure control and pharmacological treatment, with limited emphasis on improving QoL among adolescents. Children living with epilepsy in Uganda often face additional barriers such as poor health-

seeking behavior, inadequate adolescent-friendly services, and unmet psychosocial needs (Anguzu et al., 2021; M. Kaddumukasa et al., 2019).

Despite growing recognition of the impact of epilepsy on QoL, there has been limited evidence on factors associated with poor QoL among adolescents in urban clinical settings. Most prior studies have focused on adults or rural populations, limiting their applicability. The findings from this study will contribute to the knowledge pool on the factors associated with poor QoL among adolescents with epilepsy. This information can be used by relevant stakeholders, including clinicians, policymakers, caregivers, and school systems, to design targeted interventions aimed at improving the overall wellbeing of adolescents living with epilepsy.

This study therefore aimed to determine the prevalence and factors associated with poor quality of life among adolescents living with epilepsy who were receiving care at the Paediatric Neurology and Paediatric Psychiatry Clinics of Mulago National Referral Hospital.

1.3 Justification

In Uganda, epilepsy is one of the most commonly reported neurological conditions among children, with a national prevalence estimated at 16.9 per 1,000 population (Kakooza MA et al, 2025), and as high as 53 per 1,000 among children with disabilities (UBOS, 2017). Despite this high burden, the impact of epilepsy on their QoL has remained profound due to its association with social stigma, limited access to career opportunities, educational disruption, and psychological distress (Minwuyelet et al., 2022). Previous studies in Uganda either focused primarily on adults or were based in rural populations with different socio-economic and health system dynamics (Anguzu et al., 2021; Kaddumukasa et al., 2019; Nabukenya et al., 2014).

Rural and urban settings in Uganda differ in ways likely to shape quality of life among adolescents with epilepsy. Rural communities tend to have more limited access to specialist neurology and mental health services and greater reliance on traditional or spiritual explanations for seizures, often resulting in higher stigma independent of seizure control (Kaddumukasa et al., 2019; Minwuyelet et al., 2022). Urban adolescents have closer access to tertiary care but face a different mix of stressors, including academic competition and socioeconomic pressures, that can equally undermine wellbeing. Since most prior Ugandan studies on epilepsy and QoL were conducted in rural or mixed populations (Anguzu et al., 2021; Kaddumukasa et al., 2019; Nabukenya et al., 2014), their findings may not reflect the experience of adolescents managed within an urban tertiary referral setting. Mulago National Referral Hospital, as the country's largest urban tertiary facility and a major referral point for

paediatric neurology and psychiatry, therefore represents a distinct and previously underexamined population, justifying its selection as the study site for assessing QoL and its associated factors among this group.

By identifying key factors associated with the QoL of adolescents with epilepsy in Uganda, this study generated evidence-based knowledge that can inform healthcare professionals, educators, and community stakeholders in designing interventions to improve QoL in this population. The findings provide an empirical basis for future psychosocial interventions, such as structured medication adherence counselling, psychosocial support programmes addressing depression, anxiety, and self-esteem, and caregiver- or peer-based social support initiatives, that could enhance the overall wellbeing of adolescents with epilepsy. At the policy level, this study contributes the local, context-specific data needed to inform the integration of QoL improvement strategies into national epilepsy care guidelines and adolescent health policies, supporting a shift toward comprehensive epilepsy care that addresses not only seizure control but also mental health, social inclusion, and educational attainment..

1.4 Research questions

1. What proportion of adolescents with epilepsy attending the Paediatric Neurology and Paediatric Psychiatry Clinics in Mulago National Referral Hospital have poor quality of life?
2. What factors are associated with poor quality of life among adolescents with epilepsy attending the Paediatric Neurology and Paediatric Psychiatry Clinics in Mulago National Referral Hospital?

1.5 Study Objectives

1.5.1 General Objective

To assess the prevalence and factors associated with poor quality of life among adolescents with epilepsy attending the Paediatric Neurology and Paediatric Psychiatry Clinics in Mulago National Referral Hospital.

1.5.2 Specific Objective

1. To determine the prevalence of poor quality of life among adolescents with epilepsy attending the Paediatric Neurology and Paediatric Psychiatry Clinics in Mulago National Referral Hospital.

2. To identify the factors associated with poor quality of life among adolescents with epilepsy attending the Paediatric Neurology and Paediatric Psychiatry Clinics in Mulago National Referral Hospital

1.6 Conceptual framework

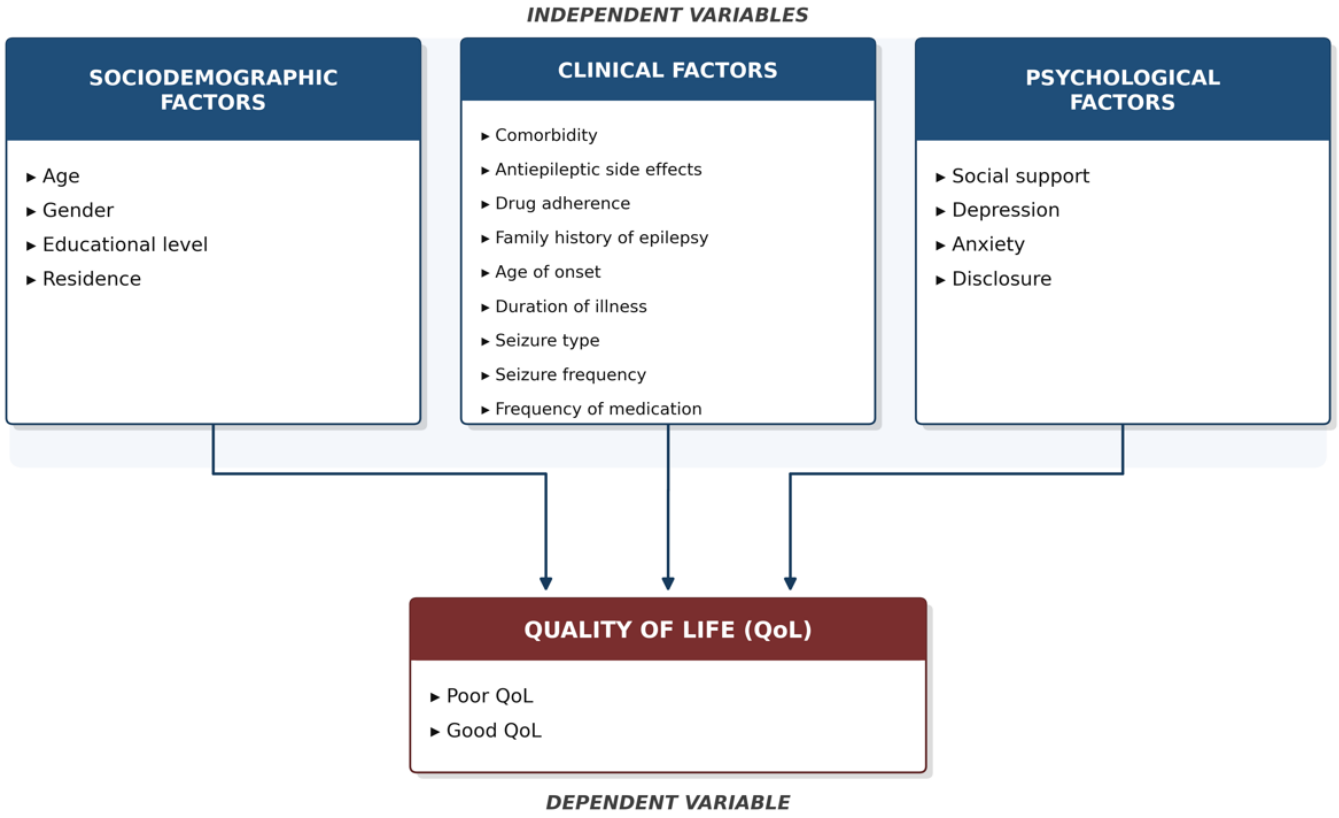

Figure 1: Showing the conceptual framework on factors associated with poor quality of life among adolescents with epilepsy attending the Paediatric Neurology and Paediatric Psychiatry Clinics in Mulago National Referral Hospital.

1.7 Decsription of the conceptual framework

The conceptual framework of this study illustrates the relationship between demographic, clinical, and psychological factors and the quality of life among adolescents living with epilepsy. Sociodemographic factors such as age, gender, educational level, and residence directly and indirectly influence quality of life. Younger children and caretakers that are less educated can influence quality of life by affecting an adolescent's ability to understand and manage their condition effectively. Indirectly, younger children may have less emotional maturity to cope with the challenges of a chronic condition, potentially affecting their mental and social well-being. Rural versus urban residence can determine access to healthcare services and social support systems, all of which contribute to variations in quality of life.

Clinical factors, including age of epilepsy onset, duration of illness, seizure type and frequency, frequency of medication, presence of comorbidities, side effects of antiepileptic drugs,

medication adherence, and family history of epilepsy, have a direct influence on QoL. Adolescents with frequent or severe seizures may face limitations in daily activities, school participation, and independence. Side effects of medication and comorbid physical or neurological conditions can further reduce physical comfort and overall well-being, thereby lowering QoL.

Psychological factors such as social support, depression, anxiety, disclosure, and self-esteem play a crucial role in determining overall life satisfaction and functioning. Adolescents who receive social support from family and peers are more likely to report a higher quality of life. Conversely, children with anxiety and depression can reduce engagement in meaningful activities, leading to a decline in QoL.

CHAPTER TWO: LITERATURE REVIEW

2.0 Poor Quality of life of epileptic individuals

People living with epilepsy generally experience a lower quality of life compared to individuals without the condition or those with other chronic illnesses (Hussain et al., 2020; Yesuf et al., 2024). However, in clinical practice, the focus often remains primarily on controlling symptoms, while the broader aspects of quality of life in PLWE are frequently overlooked (Stotaw et al., 2022). PLWE generally experience a significantly impaired quality of life that extends beyond the fear of seizures and physical injuries to include lifestyle restrictions, cognitive and psychiatric comorbidities, and discrimination that lead to social isolation and reduced opportunities (Lalatović et al., 2022; Minwuyelet et al., 2022).

Globally, epilepsy has been shown to substantially reduce QoL, with many patients experiencing physical, mental, and social challenges. A study conducted in Europe revealed that PLWE had lower QoL, affecting both physical and mental health. The average physical health score among PLWE was 45, compared to 51 in the control group. For mental health, PLWE averaged a score of 41, whereas controls scored 44. Compared to general population norms, PLWE scored below average in most areas, except for vitality and general health. Country-specific results showed that PLWE in Italy had the poorest mental health scores (36.0), significantly lower than those in Germany (42.3), Spain (42.5), and the UK (42.0) (Strzelczyk et al., 2023).

In Asia, studies have also reported low quality of life among individuals with epilepsy. For example, a study conducted in South India reported an average QoL score of 60.29 ± 14.12 (Nagarathnam et al., 2017). A related study carried out among individuals with epilepsy in Saudi Arabia's Qassim Region reported an average QOLIE-31 score of 64.23 ± 17.8, suggesting a moderate quality of life (Altwijri et al., 2021). A study carried out in China revealed that the overall QOLIE-89 score, along with several subscale scores, was reduced, with the most significant declines noted in the seizure worry and medication effects subscales (Zhao et al., 2011).

In Sub-Saharan Africa, studies from various countries have shown differing levels of QoL among PLWE. For example, a cross-sectional study conducted among adult epilepsy patients in Ethiopia reported an overall weighted mean health-related QoL score of 55.6 (SD = 20.9), with only 50.3% of participants scoring above 50 on the QoL scale (Yesuf et al., 2024). A

related study conducted at specialized hospitals in Ethiopia found that 47.8% of participants had a poor QoL (Minwuyelet et al., 2022). Another study conducted in Ethiopia on the quality of life and associated factors among patients with epilepsy reported a mean quality of life score of 61.1 ± 11.6 (Mesafint et al., 2020).

In Uganda, studies have highlighted the significant impact of epilepsy on patients' QoL. A cross-sectional study by Kaddumukasa et al. (2019) reported a mean QOLIE-31 score of 62.4 (SD = 1.6). Another study at Mulago and Butabika national referral hospitals revealed an overall mean HRQOL score of 58 (SD = 13) on a 0-100 scale. Among the different subscales, the lowest mean score was found in the physical domain (41), while the highest was in the psychological domain (65), underscoring the multidimensional burden epilepsy places on affected individuals (Nabukenya et al., 2014).

A study conducted in Kenya using the QOLIE-AD-48 among adolescents with epilepsy reported substantial impairment in multiple domains of quality of life, particularly in social functioning, stigma, and school performance (Maina et al. 2025 QOLIE-AD-48 Kenya adolescents epilepsy). Although the study did not primarily estimate the prevalence of poor QoL, it demonstrated that the QOLIE-AD-48 is sensitive in capturing the multidimensional burden of epilepsy in adolescent populations within African settings. The authors highlighted that psychosocial domains, rather than purely clinical indicators such as seizure frequency, were key drivers of reduced QoL. These findings are directly relevant to the current study, not only because of the comparable population but also due to the use of the same measurement tool, strengthening the methodological validity and comparability of results across similar contexts.

In another African study focusing on adolescents and young people with epilepsy, quality of life was found to be significantly compromised, with notable deficits in emotional well-being, peer relationships, and school participation. The study emphasized that adolescents are particularly vulnerable due to the intersection of chronic illness and critical developmental stages, where identity formation, social integration, and independence are central. Unlike adults, adolescents face unique challenges related to stigma, disclosure, and self-image, which disproportionately affect their perceived quality of life. These findings reinforce the importance of studying adolescent-specific populations, as determinants of QoL in this group may differ substantially from those observed in adult cohorts.

A study conducted in Nigeria among children aged 5–15 years reported reduced health-related quality of life across physical, emotional, and social domains among children living with epilepsy (Adewuya and Ola 2010 Nigerian children epilepsy QoL). Although a different QoL assessment tool was used, the findings consistently showed that epilepsy significantly interferes with school functioning, social interactions, and psychological well-being. The use of a different instrument limits direct comparability with studies using QOLIE-AD-48; however, the overall pattern of impaired quality of life remains consistent. This highlights that while measurement approaches may vary, the burden of epilepsy on quality of life in paediatric populations is well established across different African settings.

A study conducted in Sudan using the QOLIE-AD-48 similarly reported reduced quality of life among adolescents with epilepsy, particularly in domains related to stigma, emotional functioning, and cognitive performance (Ahmed et al. 2020 Sudan QOLIE-AD-48 adolescents). However, the study was limited by a relatively small sample size, which may have affected the precision and generalizability of its findings. Despite this limitation, the study provides important evidence supporting the applicability of the QOLIE-AD-48 in African adolescent populations. Compared to such studies, the current study benefits from a larger sample size, which enhances statistical power and improves the reliability of estimates of both prevalence and associated factors.

2.2 Factors Associated with Poor QoL

2.2.1 Sociodemographic factors

Gender

Gender has been shown to significantly impact QoL among PLWE. According to a study by Laskar et al. (2023), women with epilepsy tend to experience more anxiety, lower employment rates, and higher divorce rates compared to men, which negatively impact psychosocial aspects of QoL. An institutional cross-sectional study conducted in Northeast Ethiopia on factors associated with QoL among epileptic patients found that health-related quality of life score among individuals with epilepsy was significantly higher in males (Kassie et al., 2021). A mixed study conducted in South Ethiopia found that male participants were 4.47 times more likely to have poor QoL than their counterparts (Alemu et al., 2023).

Educational level

An institutional cross-sectional study conducted in Northeast Ethiopia on factors associated with QoL among epileptic patients found that health-related quality of life score among individuals with epilepsy was significantly higher in those with higher levels of education (Kassie et al., 2021). A study by Minwuyelet et al. (2022) conducted in Northwest Ethiopia revealed that participants with lower educational levels were 3.11 times more likely to have poor QoL than their counterparts. A related study carried out in Ethiopia among adults with epilepsy found that illiteracy was significantly linked to lower quality of life scores (Yesuf et al., 2024).

Age

In Northwest Ethiopia, a study showed that individuals aged 25-34 years were 64% less likely to experience poor quality of life compared to those aged 18-24 or above 35 years (Minwuyelet et al., 2022). Similarly, research conducted in India among middle and secondary school students with epilepsy indicated a significant relationship between the child's current age and their quality of life (Pachange et al., 2021). Another cross-sectional study in Ethiopia identified a negative association between age and HRQoL (Yesuf et al., 2024). In line with these findings, a different Ethiopian study reported that older adults were 59.10% less likely to report good health-related quality of life compared to younger individuals (Stotaw et al., 2022).

Residence

Residence is associated with socioeconomic factors such as household poverty and education level, which strongly influence QoL (Anguzu et al., 2021). For example, children with epilepsy living in poorer households or with lower education levels have significantly lower QoL scores, regardless of residence. A cross-sectional study conducted in Ethiopia found that patients who lived in urban areas were 7.07 times more likely to have a good HRQoL than patients who lived in rural areas (Stotaw et al., 2022). A study carried out in Southwest Ethiopia among adult epilepsy patients attending follow-up care revealed that the participants' place of residence, whether urban or rural, had a significant association with at least one of the seven domains of quality of life (Shiferaw & Hailu, 2018).

2.2.2 Clinical factors

Age of onset of epilepsy

A multicentre study conducted in Italy investigating the effects of age, age at onset, and duration of epilepsy found that age at onset was a significant positive predictor of the overall

Epi-QoL score (Edefonti et al., 2011). A related study conducted in Northeast Ethiopia on factors associated with QoL among epileptic patients found that health-related quality of life score among individuals with epilepsy was significantly higher in those with a later age at onset of epilepsy (Kassie et al., 2021). In a study by Stevanovic et al. (2011), age at epilepsy onset was a significant predictor of QoL.

Seizure frequency

A study in Ethiopia examining the health-related quality of life (HRQoL) of adult epilepsy patients found that seizure frequency significantly impacts well-being. Patients experiencing more than two seizures per year reported notably lower HRQoL scores. Conversely, those who remained seizure-free for at least one year showed marked improvements in quality of life (Yesuf et al., 2024).

Further supporting this, another Ethiopian study on epilepsy and quality of life identified seizure frequency as a key determinant of patient outcomes. Individuals with frequent seizures were significantly more likely to report poorer HRQoL compared to those with fewer episodes (Mesafint et al., 2020). Another cross-sectional study conducted in Northeast Ethiopia on factors associated with QoL among epileptic patients found that health-related quality of life score among individuals with epilepsy was significantly higher in those with experienced more than five seizures before treatment initiation (Kassie et al., 2021).

Duration of epilepsy

A cross-sectional institution-based study conducted in Nigeria revealed that those with a longer duration of epilepsy were less likely to have a poor score on the health satisfaction QoL compared to those with shorter duration (Ayanda & Sulyman, 2020). Research in India examining quality of life (QoL) among middle and secondary school students with epilepsy revealed that the age at first seizure onset played a significant role in their well-being (Pachange et al., 2021). Additionally, a study by Srikanth et al. (2021) focused on women with epilepsy during their reproductive years, highlighting that longer illness duration (over 10 years) was strongly linked to poorer QoL. The study also explored the impact of stigma, further exacerbating challenges in this patient group.

Family history of epilepsy

Research indicates that familial epilepsy history may significantly influence QoL for individuals with epilepsy, though findings vary across populations. An Iranian study examining

pediatric epilepsy patients demonstrated that those with a family history of epilepsy tended to experience poorer health-related quality of life (Momeni et al., 2015). Conversely, a cross-sectional study in Northeast Ethiopia reported contradictory findings, showing better QoL scores among epileptic patients with affected family members (Kassie et al., 2021). This discrepancy may be partially explained by differences in cultural perceptions and stigma surrounding epilepsy across these regions.

The potential role of stigma as a mediating factor warrants particular attention. Familial epilepsy history might amplify perceived stigma in some cultural contexts, thereby worsening quality of life outcomes. Alternatively, in communities where epilepsy is more normalized within families, the presence of affected relatives could provide crucial social support that mitigates stigma's negative effects.

Frequency of anti-seizure medication

Medication regimens significantly impact quality of life (QoL) in epilepsy patients across multiple dimensions. Research by Wassenaar et al. (2016) established that frequent medication changes, particularly treatment intensification, progressively reduce QoL scores. This aligns with Ethiopian studies showing poorer QoL outcomes for patients requiring twice-daily dosing (Yesuf et al., 2024) and demonstrates that even maintenance regimens affect QoL, with daily dosing frequency influencing at least one life domain in all patients (Shiferaw & Hailu, 2018). The cumulative evidence suggests that treatment complexity itself may compromise patient well-being. While regimen changes introduce acute QoL reductions, chronic medication burdens. These findings highlight the need for balanced therapeutic strategies that consider both seizure control and quality-of-life preservation in epilepsy management.

Anti-seizure medication side effects

Anti-seizure medication side effects (ASMs) are strongly associated with reduced quality of life in people with epilepsy. Common side effects include tiredness, dizziness, cognitive problems (such as memory and concentration difficulties), mood changes, and social challenges like isolation and stigma, all of which negatively impact QoL (Mutanana et al., 2020; Nabukenya et al., 2014). In children, these side effects notably affect psychosocial functioning, including emotional, social, and school domains (Jovanovic et al., 2015).

Research from Ethiopia presents intriguing findings regarding ASMs side effects and QoL outcomes. One study surprisingly found patients experiencing medication side effects reported

better QoL than those without (Mesafint et al., 2020) while another Southwest Ethiopia study demonstrated that side effects significantly impacted at least one QoL domain in all patients (Shiferaw & Hailu, 2018). These seemingly contradictory results may reflect different methodological approaches or patient population characteristics.

Seizure type

Generalized tonic-clonic seizures tend to have the most negative impact due to their severity, unpredictability, physical risks, and associated social stigma, leading to restrictions in daily activities such as driving and employment (Mayor et al., 2022). A study conducted in India found that experiencing generalized tonic-clonic seizures was a significant contributor to lower QoL (Srikanth et al., 2021). This could be explained by the fact that people with generalized epilepsy are likely to have more stigma than other types. A study in Indonesia found that individuals with generalized tonic-clonic seizures had lower stigma scores (59.5) compared to those with absence-type seizures (71.0) (Fitri et al., 2025).

Drug adherence

Studies across Ethiopian regions demonstrate a strong association between medication adherence and quality of life in epilepsy patients, though with some notable variations. The most consistent finding comes from Northwest Ethiopia, where poor adherence was associated with an 8.36-fold increased likelihood of reduced QoL (Minwuyelet et al., 2022). This aligns with another study showing better QoL among adherent patients (Mesafint et al., 2020). However, a Northeast Ethiopia study presented contrasting results, reporting higher QoL scores in poorly adherent patients (Kassie et al., 2021), suggesting potential regional differences in treatment patterns or measurement approaches.

Comorbidity

An institutional cross-sectional study conducted in Northeast Ethiopia on factors associated with QoL among epileptic patients found that health-related quality of life score among individuals with epilepsy was significantly higher in those with other co-morbid conditions (Kassie et al., 2021). Another study conducted in Ethiopia found that patients without a comorbid disease were 3.57 times more likely to have a good HRQoL than patients with a comorbid disease (Stotaw et al., 2022). A study by Shiferaw and Hailu (2018) found that the presence of current comorbidities was associated with at quality of life domains.

2.2.3 Psychological factors

Depression and anxiety

Depression and anxiety are both strongly associated with significantly lower quality of life (QoL) across multiple domains, including physical, emotional, social, and role functioning. Depression and anxiety are highly prevalent in people with epilepsy and are strongly associated with poorer quality of life (Çamcı et al., 2025). Both conditions independently predict lower QoL scores, affecting emotional, social, and overall functioning beyond the impact of seizure frequency or severity (Song et al., 2024). Anxiety may be even more common than depression in epilepsy.

The detrimental impact of psychiatric comorbidities on quality of life (QoL) in epilepsy patients is well-documented across Ethiopian studies. Research from Northwest Ethiopia demonstrated that both anxiety and depression nearly quadrupled the likelihood of poor QoL (Minwuyelet et al., 2022). Complementary findings from Southwest Ethiopia revealed that elevated anxiety and depression levels significantly impaired at least one QoL domain in all assessed patients (Shiferaw & Hailu, 2018), suggesting these mental health conditions have multidimensional effects on wellbeing.

Social support

Multiple Ethiopian studies consistently demonstrate that social support significantly influences quality of life in epilepsy patients. A South Ethiopia study found patients with poor social support had 3.74 times higher odds of reduced QoL (Alemu et al., 2023), while another study showed good social support positively correlated with better health-related QoL (Yesuf et al., 2024). The dose-dependent relationship was particularly evident in research revealing progressively worse QoL outcomes with diminishing social support, poor support and moderate support both showed significant negative associations compared to good support (Mesafint et al., 2020).

Disclosure status

The decision to disclose an epilepsy diagnosis plays a crucial role in shaping an individual's QoL. Studies have shown that disclosure is influenced by personal factors such as seizure frequency, social support, and perceived stigma, all of which directly or indirectly impact QoL (Ogawa et al., 2024). In a cross-sectional study from Turkey, Yeni et al. (2016) found that individuals who openly disclosed their epilepsy experienced significantly lower levels of

perceived stigma than those who concealed their condition. Reduced stigma, in turn, is strongly associated with better QoL outcomes. Supporting this, Nagarathnam et al. (2017) demonstrated that higher stigma levels were significantly linked to lower scores across both total and subscale QoL measures, indicating that individuals who faced greater stigma, often due to nondisclosure, tended to report poorer well-being. These findings suggest that encouraging safe and supported disclosure of epilepsy may be a key strategy to improve QoL among people living with the condition.

Self-esteem

The interplay between epilepsy-related psychosocial factors and self-esteem significantly influences QoL outcomes. Frequent seizures, social exclusion, and stigma collectively undermine self-worth (Çamcı et al., 2025; Kaddumukasa et al., 2019), creating a cascade of negative effects on emotional and social well-being. This relationship is quantitatively demonstrated in an Ethiopian study where low self-esteem showed a strong negative association with health-related QoL (Yesuf et al., 2024). The protective role of self-esteem is further corroborated by Turkish research, where patients with higher self-esteem consistently reported better overall QoL (Bahçebaşi & Özer, 2024).

2.4 Summary of the literature review

Epilepsy significantly diminishes quality of life across physical, mental, and social domains, with studies globally reporting lower QoL scores compared to the general population. In Europe, PWE exhibit poorer physical (45 vs. 51) and mental health (41 vs. 44) scores, while Asian and African studies highlight challenges in social functioning and medication effects. Factors such as frequent seizures, generalized tonic-clonic episodes, and medication side effects further worsen QoL. Sociodemographic disparities, including gender, lower education, rural residence, and older age, also contribute to reduced well-being. Psychological and social factors, such as depression, anxiety, and low self-esteem, are strongly linked to poorer QoL, while strong social support and disclosure of epilepsy status improve outcomes. However, much of the existing evidence comes from studies in Europe, Asia, and other African countries, with limited context-specific data in Uganda. By generating localized evidence, this research will contribute to tailored interventions that improve the well-being of young epilepsy patients in Uganda.

CHAPTER THREE: METHODOLOGY

3.1 Study design

This was a hospital-based cross-sectional descriptive study employing quantitative methods of data collection conducted at Mulago National Referral Hospital. A hospital-based design was chosen over a community-based approach for several reasons. First, epilepsy is a relatively uncommon condition in the general population, with national prevalence estimated at 16 to 17 per 1,000 (UBOS, 2017), meaning a community-based survey would require screening a very large number of households to identify a sufficient number of adolescent cases.

3.2 Study period

The study was conducted over 3 months, specifically between December 2025 and February 2026.

3.3 Study setting

This research was conducted at Mulago National Referral Hospital (MNRH), Uganda's premier tertiary care facility and principal teaching hospital. Located 4.5 km northeast of Kampala's central business district at Upper Mulago Hill Road in Kawempe Division, the hospital occupied a strategic position serving both urban and referred national cases. As the country's highest-level referral center, MNRH handled complex epilepsy cases from across Uganda, making it an ideal site for examining quality of life determinants in this patient population. The hospital's academic affiliations significantly enhanced its research capacity, particularly through its partnership with Makerere University College of Health Sciences and other universities. It is a super specialized institution that provides an array of medical services such as Adolescent health, Physiotherapy, Occupational therapy, Ear, Nose and Throat (ENT), Paediatric neurology, and Paediatric Psychiatry. This study was conducted in both the Paediatric Neurology Clinic and the Paediatric Psychiatry Clinic.

The Paediatric Neurology Clinic operated as a specialized outpatient unit offering assessment, diagnosis, and long-term follow-up services for children with neurological disorders, including epilepsy. At the time of the study, the clinic had 360 patients with epilepsy, of which 23% were adolescents. The clinic attracted patients from various parts of Uganda with an estimated monthly attendance of 273 patients, 18% being adolescents, providing a rich, socio-economically and culturally diverse context for exploring the quality of life of adolescents living with epilepsy. It operated twice a week and was run by two paediatric neurologists,

residents in the master's program of Paediatrics and child health, and registered nurse practitioners. The Paediatric Neurology Clinic also had its own pharmacy which eased the acquisition of drug refills. On Mondays, the clinic operated alongside the Paediatric Psychiatry Clinic, which also attended to children and adolescents with epilepsy, whether or not they had behavioral issues. At the time of the study, 153 children and adolescents with epilepsy were enrolled in the clinic. It was staffed by pediatric psychiatrists, psychiatry master's residents, and registered nurse practitioners. While both clinics manage adolescents with epilepsy, they differ in clinical focus and patient pathway. The Paediatric Neurology Clinic served as the primary point of diagnosis and ongoing seizure management, including antiseizure medication initiation, dose adjustment, and long-term neurological follow-up. The Paediatric Psychiatry Clinic, which operated alongside it on Mondays, primarily managed adolescents with epilepsy who had co-occurring psychiatric or behavioural symptoms, such as depression, anxiety, conduct difficulties, or intellectual disability, requiring specialist psychiatric input beyond seizure control alone.

3.4 Study population

3.4.1 Target population

Adolescents with epilepsy in Uganda.

3.4.2 Accessible population

All adolescents with epilepsy attending the Paediatric Neurology and the Paediatric Psychiatry Clinics in Mulago National Referral Hospital.

3.4.3 Eligible population

All adolescents with epilepsy attending the Paediatric Neurology and the Paediatric Psychiatry Clinics in Mulago National Referral Hospital during the study period.

3.5 Eligibility

3.5.1 Inclusion criteria

- Adolescents with a confirmed diagnosis of epilepsy as documented in their medical records.
- Adolescents attending the Paediatric Neurology Clinic or the Paediatric Psychiatry Clinic at Mulago National Referral Hospital during the study period.

- Adolescents younger than 18 who could provide assent and whose parent/guardian provided informed consent to participate in the study. Those aged 18 and above were able to provide informed consent
- Provision of consent by adolescents aged 18 and 19 years

3.5.2 Exclusion criteria

- Adolescents who are unable to understand and respond meaningfully to the study questions, either verbally or in writing, even with assistance, were excluded.
- Adolescents with a medical or psychiatric conditions requiring urgent care or hospitalization at the time of recruitment, however those who improve and stabilize during the study period were included.

3.6 Sample size determination

Sample size for objective 1

The sample size was determined using the formula by Kish Leslie for cross-sectional studies, using results from research conducted at specialized hospitals in Northwest Ethiopia found that 47.8% of participants had a poor quality of life (Minwuyelet et al., 2022).

$$n = \frac{Z^2 pq}{e^2}$$ Where,

n = required sample size

Z = the normal curve constant that represents the level of confidence (1.96)

e = the desired level of precision estimated at 95%.

p = the estimated proportion of participants with epilepsy with poor QoL (47.8%)

q = 1-p

$$n = \frac{(1.96)^2 \times 0.478 \times (1-0.478)}{(0.05)^2}$$

N=383

Final sample Size = 383

Sample size for objective 2

For objective two, the Fleiss formula was used for comparing proportions to determine the minimum sample size required to detect a difference. Using results from the same study above by Minwuyelet et al. (2022).

$$\text{N Fleiss} = \frac{\left[z\alpha_{/2}\sqrt{(r+1)p(1-p)} + z_{\beta}\sqrt{rp_0(1-p_0) + p_1(1-p_1)}\right]^2}{r(p_0-p_1)^2}$$

$$\text{P} = \frac{p_0 + rp_1}{r+1}$$

Where;

α = 0.05, the probability of a type I error (significance level) is the probability of rejecting the true null hypothesis

β = 0.2, the probability of type II error (1 - power of the test) is the probability of failing to reject the false null hypothesis.

P_0 = 70.3% (exposed), the proportion of depressed epileptic individuals with poor QoL (0.703).

P_1 = 23.3% (unexposed), the proportion of non-depressed epileptic individuals with poor QoL (0.233).

r = 0.33, the ratio of unexposed to exposed in the study

N1Fleiss-cc = 42 required sample size for the exposed population using the Fleiss formula with continuity correction.

N2 = r x N1Fleiss-cc = 0.33×42=14 required sample size for the unexposed population

The final sample size is 56

The sample size calculated for objective one (383) was used.

Depression was selected as the basis for the objective two sample size calculation because it has consistently emerged in the literature as one of the strongest and most clinically significant psychological correlates of poor QoL among people with epilepsy, including in the same Northwest Ethiopian population used for the objective one calculation (Minwuyelet et al., 2022), making it methodologically convenient to derive both estimates from a single comparable source. The substantial gap between the proportion of poor QoL among depressed

(70.3%) and non-depressed (23.3%) individuals in that study reflects a large effect size, which is why the resulting Fleiss-derived sample size (56) was markedly smaller than the sample size required for objective one (383). Rather than using the smaller depression-based estimate, the larger of the two calculated sample sizes was retained as the final study sample, a standard and conservative approach that ensures the study remains adequately powered not only to detect the strong depression-QoL association reported elsewhere, but also to detect more modest associations involving other clinical, sociodemographic, and psychological factors that this study aimed to examine.

3.7 Sampling procedure

Consecutive sampling was used and a proportionate sampling strategy was employed to ensure that participants are recruited from each clinic in line with the distribution of eligible children. The Paediatric Neurology Clinic has 360 enrolled patients and the Paediatric Psychiatry Clinic had 153 enrolled patients. Based on a final sample size of 383, proportionate allocation was applied to determine the number of participants to be recruited from each clinic. 70% of participants were recruited from the Neurology Clinic and 30% from the Psychiatry Clinic yielding 268 and 115 participants respectively.

3.8 Dependent and Independent Variables

3.8.1 Dependent variable

The primary outcome of this study was poor quality of life. To assess QoL among adolescents with epilepsy, the study utilized the Quality of Life in Epilepsy for Adolescents questionnaire (QOLIE-AD-48), a validated self-administered tool comprising 48 items. The QOLIE-AD-48, originally developed in 1999 by a panel of seven field experts, was chosen due to its extensive use in studies across countries (Ferro et al., 2011; Siqueira et al., 2014). The questionnaire contains 48 items across eight subscales: epilepsy impact (12 items), memory and concentration (10 items), attitudes toward epilepsy (4 items), physical functioning (5 items), stigma (6 items), social support (4 items), school behavior (4 items), and health perceptions (3 items), along with a total summary score.

3.8.2 Independent variables

Sociodemographic factors: Age, gender, educational level, and residence.

Clinical factors: Age of epilepsy onset, duration of illness, seizure type and frequency, frequency of medication, presence of comorbidities, side effects of antiepileptic drugs, medication adherence, and family history of epilepsy.

Psychological factors: Social support, depression, anxiety, disclosure, and self-esteem. Social support was assessed using the Multidimensional Scale of Perceived Social Support (MSPSS), a 12-item scale developed by Zimet et al. (1988) to measure perceived support from three sources: significant others, family, and friends. It is a 12 item tool with each item rated on a 7-point Likert scale ranging from 1 (very strongly disagree) to 7 (very strongly agree). The scale comprises three subscales: Significant Other (items 1, 2, 5, 10), Family (items 3, 4, 8, 11), and Friends (items 6, 7, 9, 12).

Anxiety and depression were assessed using the four-item Patient Health Questionnaire (PHQ-4) (Kroenke et al., 2009). The total score was obtained by summing the scores of all four items. A total score of ≥3 on the first two items indicated possible anxiety, while a total score of ≥3 on the last two items indicated possible depression. Self-esteem was assessed using the Rosenberg Self-Esteem Scale, a 10-item scale developed by Morris Rosenberg (Rosenberg, 1965). Scoring was done as follows: for items 1, 2, 4, 6, and 7, responses were scored as strongly agree = 3, agree = 2, disagree = 1, and strongly disagree = 0. For items 3, 5, 8, 9, and 10, which are negatively worded, the scoring was reversed: strongly agree = 0, agree = 1, disagree = 2, and strongly disagree = 3. The total score was ranging from 0 to 30. Scores between 15 and 25 were interpreted as within the normal range, while scores below 15 indicated low self-esteem, and >25 as high self-esteem.

3.9 Data collection tools

Structured questionnaires were used for data collection and consisted of MSPSS for social support, PHQ-4 for anxiety and depression, RSES for self-esteem and QOLIE-AD-48 for the quality of life

The MSPSS was selected because it is a widely validated 12-item tool that consistently demonstrates strong reliability and validity in measuring perceived social support from family, friends, and significant others. Its original development study reported high internal consistency and stable factorial structure, confirming its robustness across populations (Zimet et al., 1990). Evidence from Uganda further supports its applicability in African settings with, Nakigudde et al. (2009) reporting Cronbach's $\alpha \approx 0.83$, indicating that the scale performs well among adolescents in similar contexts.

The PHQ-4 was chosen due to its efficiency and strong psychometric performance as an ultra-brief screener for anxiety and depression. A systematic review across 19 countries demonstrated good internal consistency (α = 0.72-0.88) and a stable two-factor structure, confirming its reliability for both clinical and non-clinical populations (Caro-Fuentes & Sanabria-Mazo, 2024). Its suitability for use in SSA settings is also supported by evidence from Tanzania, where Materu et al. (2020) reported Cronbach's α = 0.81 and confirmed construct validity through factor analysis (Materu et al., 2020).

The RSES was included because it is the most extensively validated global self-esteem measure, with evidence supporting its strong psychometric properties in adolescent populations. Dittmann et al. (2009) found high internal consistency (α = 0.82 to >0.90) and strong test-retest reliability (r = 0.87), demonstrating its stability over time (Dittmann et al., 2009). More recent adolescent validations continue to show robust internal consistency and a meaningful factor structure that captures both positive and negative self-evaluations (Moksnes et al., 2024).

The QOLIE-AD-48 was selected as the primary quality-of-life assessment tool because it is specifically designed for adolescents with epilepsy, ensuring relevant and sensitive measurement of disease-related QoL domains. Regarding its psychometric properties, its development study reported high internal consistency (α = 0.74-0.94) and strong test-retest reliability (r = 0.83) (Cramer et al., 1999). Further translations/adaptations also report very high internal consistency (α = 0.95) and good test-retest reliability (Brabcova et al., 2021).

3.10 Data collection procedure

Recruitment of research assistants.

The study engaged four research assistants, all enrolled medical officers recruited from outside the Paediatric Neurology Clinic at Mulago National Referral Hospital, to minimize potential response bias. Before data collection, the research assistants participated in a two-day training session covering the study protocol, data collection instruments and procedures, as well as research ethics and the code of conduct. Their primary responsibilities included administering structured questionnaires and standardized assessment tools: PHQ-4, Rosenberg Self-Esteem Scale (RSES), and QOLIE-AD-48. The principal investigator (PI) was involved and oversaw the entire data collection process, providing supervision and ensuring data quality control throughout the study.

Enrolment of Study Participants

Research assistants, together with the PI, were stationed in the Paediatric Neurology Clinic and Paediatric Psychiatric Clinic at MNRH to receive and conduct sampling of participants. These were then introduced to the study and then requested to provide informed consent for those ≥18 years and both assent and informed consent from parents from those below 18 years. During this initial phase, the study team provided information about the study (refer to Appendix I).

During enrollment, socio-demographic information such as age, gender, educational level, and residence (rural vs urban) were obtained through interviews with participants. Clinical factors such as age of epilepsy onset, duration of illness, seizure type (generalized vs focal), and their frequency, frequency of medication, presence of comorbidities, side effects of antiepileptic drugs, medication adherence, and family history of epilepsy. Psychological factors such as depression, anxiety, self-esteem, social support, and disclosure status were also collected. Social support was assessed using questions adopted from the MSPSS. Depression and anxiety were assessed using questions adopted from the PHQ-4; self-esteem was evaluated using questions from the Rosenberg Self-Esteem Scale.

Quality of Life (QoL) – assessed using the QOLIE-AD-48, which includes 48 items grouped into eight subscales: epilepsy impact, memory/concentration, attitudes toward epilepsy, physical functioning, stigma, social support, school behavior, and health perceptions. Overall, the interview took approximately 30 to 45 minutes.

Participants found to have low QoL, depression, anxiety, and other states such as low self-esteem were linked to the paediatric psychiatric clinic. All data collection procedures adhered to ethical standards, maintaining privacy and confidentiality throughout the process.

3.12 Quality control

A structured questionnaire was designed based on a thorough review of existing literature. To ensure content validity, the questionnaire was subjected to face validity assessment by a trained quantitative expert and an expert in psychology and epilepsy. This process ensured that the items were relevant, clear, and appropriately measured the intended constructs.

The principal investigator (PI) developed standard operating procedures (SOPs) to guide the entire data collection process, ensuring consistency and adherence to study protocols.

Research assistants underwent a two-day training on the use of the data collection tools and SOPs, emphasizing standardized administration of interviews and ethical conduct.

Trained research assistants conducted face-to-face interviews, while the PI regularly reviewed completed questionnaires for accuracy and completeness before the participant concludes the interview. Standardized tools were used for key study variables, including quality of life, depression, anxiety, and self-esteem, to ensure reliability, validity, and comparability of the data.

The data collection tools including the structured questionnaires, standardized tools, and consent and assent forms followed a rigorous translation process to ensure accuracy and cultural appropriateness. All instruments were first translated from English into the common local language (Luganda) by a professional translator familiar with health research terminology. A second independent translator then back-translated the materials into English to verify consistency and identify discrepancies. Any differences identified were reviewed by a bilingual research team and resolved through consensus to maintain semantic, conceptual, and technical equivalence. The translated tools were also pilot-tested with a small group of participants from the study population to assess clarity, comprehension, and cultural relevance. Necessary adjustments were made before full data collection began. This process ensured that all participants, including adolescents and caregivers, fully understood the study procedures, risks, and their rights.

3.13 Data management

Data were entered into the Kobo Collect tool. The final data were exported to Stata 16.0 for cleaning and analysis. The collected data and other study records were retained by the PI in a secure location for at least 3 years after completion of the study. These were stored on a password-protected computer. Missing data were minimized at the point of collection through real-time completeness checks, in which the principal investigator reviewed each questionnaire for completeness before the participant concluded the interview, allowing any missing responses to be addressed immediately

3.14 Data analysis

Descriptive statistics were applied to summarize the study population. For continuous variables, data were presented as means and standard deviations if normally distributed, and as medians with interquartile ranges (IQR) if the data were skewed. Categorical variables were summarized using frequencies and percentages, and results were presented in tables and graphs.

Poor Quality of Life among Children with Epilepsy

Quality of life was assessed using the QOLIE-AD-48. Consistent with previous studies (Altwijri et al., 2021; Mesafint et al., 2020; Yesuf et al., 2024; Zhao et al., 2011), overall QoL was categorized as poor or good based on the distribution of total scores. If the data were normally distributed, adolescents scoring below the mean were classified as having poor QoL, while those scoring at or above the mean were classified as having good QoL. If the data were skewed, the median was used instead of the mean. Poor QoL was the primary outcome and it was coded as 1 while good QoL was coded as 0.

The prevalence of poor QoL was calculated as the proportion of adolescents whose QoL scores <60. All findings were summarized in tables and reported with corresponding 95% confidence intervals.

Factors associated with Poor QoL

Prior to fitting the multivariable model, multicollinearity among candidate predictors was assessed using the variance inflation factor (VIF), with a VIF exceeding 5 considered indicative of moderate collinearity. Model goodness-of-fit was evaluated using the deviance, Pearson chi-square statistic, and the dispersion ratio (Pearson chi2/residual df), the latter used to confirm that the modified Poisson approach was appropriate for this binary outcome. The linearity assumption for continuous predictors on the log scale was assessed using a likelihood ratio test comparing models with and without quadratic terms, and model fit for individual observations was assessed using Pearson residuals.

To determine the factors associated with poor quality of life, both bivariate and multivariable modified Poisson regression analyses were conducted to report crude and adjusted prevalence ratios, respectively. Variables achieving a p-value below 0.2 in the bivariate analysis were considered for inclusion in the multivariable model, alongside age group, which was retained a priori given its established clinical relevance regardless of its bivariate significance. Confounding was assessed using the change-in-estimate criterion, whereby a variable was considered a confounder if its inclusion in the model altered the prevalence ratio of the variable of interest by more than 10%, and confounders identified by this method were retained in the final model regardless of statistical significance. Interaction between key variables, including age group and self-esteem, and between sex and educational level, was assessed by introducing two-way interaction terms into the multivariable model and testing their statistical significance using the Wald test, with a significant interaction term ($p<0.05$) indicating effect modification.

No statistically significant interactions were identified, and the final model was therefore reported without interaction terms. A p-value of less than 0.05 was considered statistically significant for all other associations..

3.15 Ethical considerations

Ethical approval for this study was obtained from the School of Medicine Research and Ethics Committee (SOMREC-2025-620) through the Department of Paediatrics and Child Health. A dual consent process was implemented: written informed consent was collected from participants aged ≥18 years, while for minors, both parental/caregiver consent and adolescent assent were secured. This process occurred during routine visits to the Paediatric Neurology and Psychiatry Clinics at Mulago National Referral Hospital. To ensure confidentiality, personal identifiers such as participant names were replaced with unique study codes, and all interviews were conducted in private settings. Data collected were treated with strict confidentiality and were only accessible to authorized members of the research team. All electronic data were securely stored on password-protected devices. If the study results were published, no personal identifying information was disclosed. Participants found to have low QoL, depression, anxiety, and other states such as low self-esteem were linked to the paediatric psychiatric clinic.

3.16 Dissemination of findings

A report detailing the study findings was prepared and submitted as part of the requirements for the Master of Pediatrics and Child Health degree. Copies of the final dissertation were submitted to the Department of Pediatrics and Child Health, as well as the Directorate of Research and Graduate Training at Makerere University. Additionally, a copy of the report was provided to the Pediatric Neurology Clinic at Mulago National Referral Hospital, where the study was conducted. A resulting manuscript will be submitted to an appropriate journal.

CHAPTER FOUR: RESULTS

4.0 Study flow chart

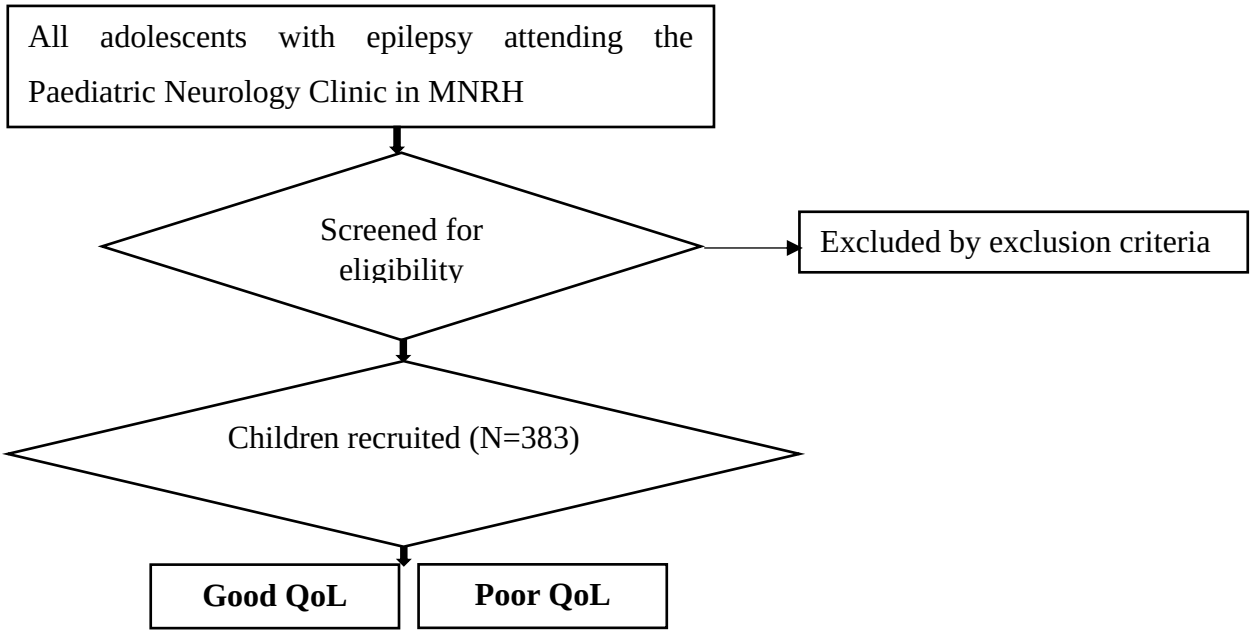

Figure 2: Study flow chart

4.1Socio-demographic, clinical and psychological characteristics of the study population

Table 1 presents the sample characteristics of the respondents. A total of 383 adolescents with epilepsy were enrolled in the study, and all were included in the analysis. The mean age of participants was 15.7 (SD ±2.83) years; Majority (69.5%) were aged 15–19 years and 50.9% were male. Most participants had attained primary education (42.0%) and resided in urban areas (81.7%).

Clinically, the mean age at onset of epilepsy was 8.16 (SD ±4.86) years, with more than half of the participants (51.9%) experiencing onset between 9–19 years. The majority had lived with epilepsy for at least a year (94.8%) and experienced generalized seizures (87.9%). In the past month, 40.2% of participants reported experiencing at least one seizure. Most participants were taking medication twice daily (78.9%), while 28.7% reported experiencing side effects from antiepileptic drugs. A minority (5.2%) had comorbidities, 32.6% were adherent to their medication, and 36.6% reported a family history of epilepsy.

Regarding psychological characteristics, most participants reported high social support (94.5%) and had disclosed their condition (68.4%). Possible anxiety and depression were reported among 3.9% and 6.5% of the participants, respectively. Additionally, 36.6% of participants had low self-esteem.

Table 1a: Demographic characteristics of 383 adolescents included in the study on poor quality of life among adolescents with epilepsy at MNRH

Characteristic (N=383)	Frequency (N)	Percent (%)
Socio-demographics		
Age of adolescent (years), mean (SD)	15.7 (±2.83)	
Age group		
10-14	117	30.6
15-19	266	69.5
Gender		
Male	195	50.9
Female	188	49.1
Educational level		
No formal education	32	8.4
Primary	161	42.0
Secondary	133	34.7
Tertiary	39	10.2
Other	18	4.7
Place of residence		
Urban	313	81.7
Rural	70	18.3
Age of epilepsy onset (years), mean (SD)	8.16 (±4.86)	
Age of epilepsy onset (years)		
0-8	184	48.0
9-19	199	51.9
Duration of the illness		
<1 year	18	4.7%
1 – 5 years	134	35.0%
>5 years	231	60.3%
Type of seizure experienced		
Generalized	337	87.9
Focal	46	12.0
Frequency of seizures in the past month, mean (SD)	1.09 (±2.42)	
Frequency of seizures in the past month		
None	229	59.8
At least once	154	40.2
Frequency of medication		
Once daily	78	20.4
Twice daily	302	78.9
More than twice daily	3	0.8
Side effects of antiepileptic drugs		
Yes	110	28.7
No	273	71.3
Presence of comorbidities		
Yes	20	5.2
No	363	94.8

Table 1b: Demographic characteristics of 383 adolescents included in the study on poor quality of life among adolescents with epilepsy at MNRH

Characteristic (N=383)	Frequency (N)	Percent (%)
Frequency of medication		
Once daily	78	20.4
Twice daily	302	78.9
More than twice daily	3	0.8
Side effects of antiepileptic drugs		
Yes	110	28.7
No	273	71.3
Presence of comorbidities		
Yes	20	5.2
No	363	94.8
Adherence to medication		
Yes	125	32.6
No	258	67.4
Family history of epilepsy		
Yes	140	36.5
No	160	41.8
Not sure	83	21.7
Psychological		
Social support		
Low	1	0.3
Moderate	20	5.2
High	362	94.5
Disclosure		
Yes	262	68.4
No	121	31.6
Possible anxiety		
Yes	15	3.9
No	368	96.1
Possible depression		

Yes	25	6.5
No	358	93.5
Self esteem		
Low	140	36.6
Normal	243	63.5

Table 1c: Table: Scoring of the QOLIE-AD-48, MSPSS, and PHQ-4 Instruments

Instrument	Items / Scoring method	Score range	Category / Cutoff	Result in this study, n (%)
Quality of Life in Epilepsy for Adolescents (QOLIE-AD-48)				
QOLIE-AD-48	48 items across 8 subscales, transformed to a 0-100 scale; higher scores indicate better QoL. Mean = 45.9, SD = 13.3 (this study).	0-100 (observed: 10.7-79.7)	Poor QoL: <60 Good QoL: ≥60	Poor QoL: 319 (83.3%) Good QoL: 64 (16.7%)
Multidimensional Scale of Perceived Social Support (MSPSS)				
MSPSS	12 items, 7-point scale (1-7); score = mean of all items. Mean = 6.21, SD = 0.69 (this study).	1-7 (observed: 2.25-7.00)	Low support: 1.0-2.9 Moderate support: 3.0-5.0 High support: 5.1-7.0	Low: 1 (0.3%) Moderate: 20 (5.2%) High: 362 (94.5%)
MSPSS (binary, used in regression)	*Low and Moderate support categories combined into a single category for analysis, given the very small Low support cell.*	--	Low/Moderate vs High	Low/Moderate: 21 (5.5%) High: 362 (94.5%)
Patient Health Questionnaire-4 (PHQ-4)				
PHQ-4 total	4 items, each scored 0-3; total = sum of all 4 items.	0-12 (observed: 0-12)	Categorized by severity: None, Mild, Moderate, Severe	None: 287 (74.9%) Mild: 79 (20.6%) Moderate: 11 (2.9%) Severe: 6 (1.6%)

PHQ-4 anxiety subscale	Items 1-2 (nervous/anxious; worrying); subscale score = sum of these 2 items.	0-6	Possible anxiety: score ≥3	Possible anxiety: 15 (3.9%) No possible anxiety: 368 (96.1%)
PHQ-4 depression subscale	Items 3-4 (feeling down/hopeless; little interest); subscale score = sum of these 2 items.	0-6	Possible depression: score ≥3	Possible depression: 25 (6.5%) No possible depression: 358 (93.5%)

4.2 Prevalence of Poor Quality of Life

The prevalence of poor quality of life among adolescents with epilepsy was 319/383 (83.3%) (n as shown in figure 3.

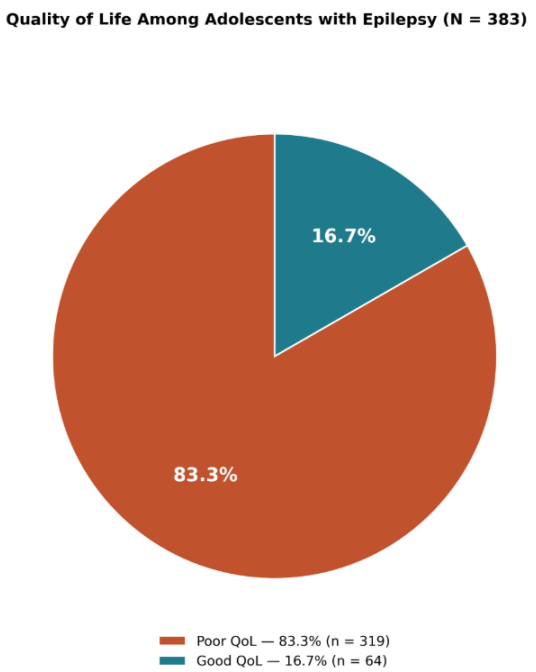

Figure 3: Prevalence of quality of life among 383 adolescents included in the study on poor quality of life among adolescents with epilepsy at MNRH

4.3 Factors Associated with Poor Quality of Life

Table 2 presents the results of the bivariable and multivariable modified Poisson regression analyses of factors associated with poor quality of life among adolescents with epilepsy.

To estimate the independent effect of each variable on poor quality of life, factors that were significantly associated at the bivariable level ($p < 0.20$) were considered for inclusion in the multivariable analysis. These included educational level, age of epilepsy onset, duration of illness, frequency of medication, presence of comorbidities, adherence to medication, family history of epilepsy, disclosure status, possible depression, and self-esteem. Although age group was not statistically significant at the bivariable level, it was included in the multivariable model based on a priori considerations.

In the multivariable modified Poisson regression analysis, age group, educational level, family history of epilepsy, and self-esteem were significantly associated with poor quality of life among adolescents with epilepsy ($p < 0.05$). Adolescents aged 15–19 years had a lower prevalence of poor quality of life compared to those aged 10–14 years (aPR = 0.84, 95% CI: 0.73–0.97, p = 0.021).

Educational level was significantly associated with poor quality of life. Adolescents with primary (aPR = 1.59, 95% CI: 1.14–2.21, p = 0.005), secondary (aPR = 1.90, 95% CI: 1.39–2.59, $p < 0.001$), and tertiary education (aPR = 1.95, 95% CI: 1.42–2.67, $p < 0.001$) had a higher prevalence of poor quality of life compared to those with no formal education.

Adolescents who were not sure about their family history of epilepsy had a lower prevalence of poor quality of life compared to those with a positive family history (aPR = 0.87, 95% CI: 0.76–0.99, p = 0.036). Additionally, adolescents with normal self-esteem had a lower prevalence of poor quality of life compared to those with low self-esteem (aPR = 0.84, 95% CI: 0.75–0.94, p = 0.004).

Table 2a: Factors associated with poor quality of life among 383 adolescents with epilepsy attending the Paediatric Neurology and Paediatric Psychiatry Clinics at Mulago National Referral Hospital, Uganda.

Factor	uPR (95%CI)	P-value	aPR (95%CI)	P-value
Age group				
10-14	Ref		Ref	
15-19	0.94 (0.86-1.04)	0.267	0.84 (0.73-0.97)	**0.021**
Gender				
Male	Ref			
Female	1.01 (0.93-1.11)	0.698		
Educational level				
No formal education	Ref		Ref	
Primary	1.89 (1.36-2.62)	<0.001	1.59 (1.14-2.21)	**0.005**
Secondary	2.14 (1.55-2.97)	<0.001	1.90 (1.39-2.59)	**<0.001**
Tertiary	2.22 (1.60-3.08)	<0.001	1.95 (1.42-2.67)	**<0.001**
Place of residence				
Urban	Ref			
Rural	0.93 (0.81-1.06)	0.291		
Age of epilepsy onset (years)				
0-8	Ref		Ref	
9-19	1.22 (1.11-1.35)	<0.001	1.06 (0.98-1.16)	0.118
Duration of the illness				
Years	Ref		Ref	
Months	1.21 (1.15-1.27)	<0.001	1.04 (0.92-1.17)	0.549
Type of seizure experienced				
Generalized	Ref			
Focal	0.99 (0.86-1.14)	0.897		
Frequency of seizures in the past month				
None	Ref			
At least once	0.94 (0.86-1.03)	0.247		
Frequency of medication				
Once daily	Ref		Ref	
Twice daily	0.94 (0.85-1.04)	0.242	1.01 (0.92-1.11)	0.781
More than twice daily	1.14 (1.05-1.24)	0.002	1.11 (0.82-1.50)	0.490

uPR unadjusted prevalence ratio, aPR adjusted prevalence-ratio, 95% CI 95% confidence interval

Table 2b:Continuation of factors associated with poor quality of life among 383 adolescents with epilepsy attending the Paediatric Neurology and Paediatric Psychiatry Clinics at Mulago National Referral Hospital, Uganda.

Factor	uPR (95%CI)	P-value	aPR (95%CI)	P-value
Side effects of antiepileptic drugs				
Yes	Ref			
No	1.09 (0.97-1.21)	0.120		
Presence of comorbidities				
Yes	Ref		Ref	
No	1.29 (0.93-1.79)	0.117	1.08 (0.83-1.41)	0.528
Adherence to medication				
Yes	Ref		Ref	
No	1.14 (1.02-1.27)	0.017	1.09 (0.98-1.20)	0.080
Family history of epilepsy				
Yes	Ref		Ref	
No	1.04 (0.95-1.14)	0.341	1.02 (0.94-1.12)	0.507
Not sure	0.82 (0.70-0.96)	0.015	0.87 (0.76-0.99)	**0.036**
Social support				
Low/Moderate	Ref			
High	1.09 (0.86-1.40)	0.450		
Disclosure				
Yes	Ref		Ref	
No	1.20 (1.11-1.30)	<0.001	1.01 (0.94-1.10)	0.640
Possible anxiety				
Yes	Ref			
No	0.87 (0.64-1.19)	0.402		
Possible depression				
Yes	Ref		Ref	
No	0.70 (0.51-0.97)	0.035	0.86 (0.65-1.13)	0.275
Self esteem				
Low	Ref		Ref	
Normal	0.73 (0.65-0.82)	<0.001	0.84 (0.75-0.94)	**0.004**

Model Diagnostics:

Variance inflation factors for all predictors in the multivariable model ranged from 1.07 to 5.98, with age at onset of epilepsy (VIF = 5.98) and duration of illness (VIF = 5.39) showing

the highest values, reflecting their expected mathematical relationship with current age. No VIF exceeded 6, and multicollinearity was not considered to materially distort the model estimates. The model showed a dispersion ratio of 0.17 (Pearson chi2 = 61.87, residual df = 367), substantially below 1; this underdispersion is an expected feature of fitting a Poisson model to a binary outcome rather than evidence of model misspecification, and is precisely why robust (sandwich) standard errors, rather than model-based standard errors, were used throughout. A likelihood ratio test for non-linearity in the two continuous predictors, age at onset and duration of illness, was non-significant (LR = 0.33, p = 0.846), supporting the assumption of linearity on the log scale. Examination of Pearson residuals found no observations exceeding the conventional threshold of 2, indicating no individual cases with poor fit or disproportionate influence on the model.

CHAPTER FIVE: DISCUSSION

5.1 Prevalence of poor quality of life

This study found a markedly high prevalence of poor quality of life (QoL) among adolescents with epilepsy attending Mulago National Referral Hospital, with more than four in five participants affected. This finding highlights that epilepsy in this population extends beyond a neurological disorder to a complex biopsychosocial condition that significantly affects emotional wellbeing, social functioning, and daily life. It reinforces global evidence that epilepsy is associated with substantial disability and reduced quality of life, particularly in low- and middle-income settings where treatment gaps and stigma remain pervasive (World Health Organization [WHO], 2024; Newton & Garcia, 2012).

The magnitude of poor quality of life observed in this study (83.3%) is higher than that reported in previous Ugandan and regional studies. The high prevalence observed in this study should also be interpreted in the context of the measurement tool used. The QOLIE-AD-48 is a well-validated instrument specifically designed for adolescents with epilepsy and has demonstrated strong psychometric properties, including high internal consistency (Cronbach's α ranging from 0.74 to 0.94) and good test-retest reliability (Cramer et al., 1999; Brabcova et al., 2021). Importantly, its applicability has been demonstrated in African settings, including studies conducted among adolescents in Kenya and Sudan, where it effectively captured multidimensional impairments in quality of life, particularly in psychosocial domains such as stigma, social functioning, and school participation (Wanjiru et al., 2023; Ahmed et al., 2020). This suggests that the high prevalence reported in the current study is unlikely to be an artefact of poor measurement, but rather reflects a true and substantial burden of impaired quality of life in this population. In Uganda, Nabukenya et al. (2014) reported a mean overall health-related quality of life score of 58.2 (±15.4) among patients attending national referral hospitals,

while Anguzu et al. (2021) reported a higher mean QoL score of approximately 63.5 (±14.8) among adolescents with epilepsy in rural Uganda. Although these studies assessed quality of life using continuous scores rather than prevalence estimates, their findings suggest a comparatively moderate level of impairment relative to the markedly high burden of poor QoL observed in the present study. A recent systematic review and meta-analysis conducted in Ethiopia reported a pooled prevalence of poor quality of life of 45.1% (95% CI: 39.7%–50.4%), with individual studies ranging from 24.4% to 51% (Andualem et al., 2024). The higher burden identified in this study is likely attributable to the tertiary-care setting, where adolescents often present with more severe, chronic, or treatment-resistant forms of epilepsy.

5.2 Factors associated with poor quality of life

Age was independently associated with QoL, with older adolescents (15–19 years) having a lower prevalence of poor QoL compared to younger adolescents (10–14 years). This suggests that younger adolescents may be particularly vulnerable to the impact of epilepsy. Early adolescence is a developmental stage characterized by limited coping mechanisms, higher emotional dependence, and challenges in understanding chronic illness. In contrast, older adolescents may develop better coping strategies, improved illness awareness, and greater autonomy in self-management. However, this finding contrasts with earlier work by Devinsky et al. (1999), which reported poorer QoL among older adolescents, suggesting that contextual and sociocultural factors may influence how age interacts with illness experience.

Educational level was significantly associated with QoL, with poor QoL prevalence rising from 43.8% among adolescents with no formal education (n=48) to 82.8% among those with primary education (n=163), 94.0% among those with secondary education (n=133), and 97.4% among those with tertiary education (n=39). While stigma and academic pressure within school environments offer one plausible explanation (Kirabira et al., 2020), this fully monotonic

gradient, with the entire comparison anchored to a single small reference group, warrants closer methodological scrutiny before being interpreted as a genuine protective effect of having no formal education.

First, the no-formal-education group, at n=48, is both the smallest educational category and the reference category against which all three other prevalence ratios were estimated. Any imprecision in this single group's QoL estimate propagates into every comparison in the gradient; a handful of differently-classified cases within this group could meaningfully shift the magnitude, and potentially the significance, of all three adjusted prevalence ratios.

Second, and more importantly, this group is unlikely to represent adolescents who are otherwise comparable to their schooled peers but simply happen not to be enrolled. In a setting where primary education is nominally free and widely accessed, the absence of any formal education among adolescents aged 10 to 19 is itself a marker of an underlying selection process, plausibly reflecting more severe or earlier-onset epilepsy that prevented school enrollment altogether, coexisting intellectual or developmental disability, profound household poverty, or simply younger age within the 10-14 band, where some children may not yet have started school for reasons unrelated to epilepsy. If any of these factors independently shapes how adolescents experience or report their quality of life, the apparent protective effect of no formal education may be substantially confounded by the very reasons these adolescents are unschooled in the first place, rather than reflecting a true causal effect of education itself.

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Contrary to the rural disadvantage emphasized in the justification for this study, place of residence was not independently associated with QoL in this sample, and the unadjusted data in fact trended in the opposite direction to much of the published literature: urban-residing adolescents had a marginally higher, though statistically non-significant, prevalence of poor

QoL (84.3%) than their rural counterparts (78.6%) (crude PR = 0.93, 95% CI 0.82-1.06, p = 0.290)

Family history of epilepsy was associated with poorer QoL, suggesting that family context plays an important role in shaping adolescents' perceptions of illness. Adolescents with affected family members may internalize fears related to chronic illness, disability, or stigma, especially if they have witnessed negative outcomes in relatives. This aligns with broader literature indicating that familial and social factors significantly influence QoL in epilepsy (Baker et al., 1997). However, the finding that those unsure of their family history had better QoL should be interpreted cautiously, as it may reflect reporting bias or limited awareness.

Self-esteem emerged as a strong independent predictor of QoL, with normal self-esteem significantly reducing the likelihood of poor QoL. This highlights the central role of psychological wellbeing in the lived experience of epilepsy. Low self-esteem may arise from stigma, social exclusion, academic challenges, and perceived differences from peers, and may further worsen emotional distress and social withdrawal. Previous studies have demonstrated that self-esteem is strongly associated with QoL and mental health outcomes among adolescents with epilepsy (Kwong et al., 2016). This finding underscores the importance of integrating psychosocial care into routine epilepsy management. Self-esteem was measured using the Rosenberg Self-Esteem Scale (RSES), and it is worth noting that this protective association held after adjustment for education and other covariates, despite a markedly different pattern at the simple, unadjusted level. In stratified comparisons, adolescents with low self-esteem actually had a lower crude prevalence of poor QoL (67.9%) than those with normal self-esteem (92.2%), the reverse of the adjusted finding. This divergence is most plausibly explained by confounding by educational level, since the subgroup with no formal education, who had the lowest prevalence of poor QoL overall, may also differ systematically in how self-esteem is reported or experienced developmentally. This illustrates why the adjusted estimate,

rather than the crude bivariate pattern, should be treated as the more reliable basis for interpreting the direction of the self-esteem-QoL relationship in this population.

Several clinical variables traditionally associated with QoL, including seizure frequency, medication burden, and comorbidity, were not significant in the multivariable model. While these factors are well-established determinants of QoL in another study (Nabukenya et al., 2014), their lack of significance in this study suggests that psychosocial factors may play a more dominant role in this context. It is also possible that the measurement of clinical variables did not fully capture long-term disease burden or that limited variability reduced statistical power.

From a clinical and public health perspective, these findings emphasize the need for a shift from a purely biomedical model of epilepsy care to a more holistic, adolescent-centered approach. Such care should include routine assessment of quality of life, psychological support, family counseling, and school-based interventions aimed at reducing stigma and supporting academic participation. This aligns with global recommendations advocating for person-centered epilepsy care that addresses both medical and psychosocial needs (WHO, 2024).

The loss of significance for seizure frequency, medication burden, and comorbidity warrants closer examination, since these are among the most consistently reported clinical predictors of QoL elsewhere in the epilepsy literature Several features of how these variables were measured and distributed in this sample plausibly explain the discrepancy. Comorbidity was reported by only 20 of 383 participants (5.2%), and frequency of medication dosing was heavily concentrated in a single category, with 302 of 383 participants (78.9%) taking medication twice daily and only 3 taking it more than twice daily; both distributions left little statistical variability for these variables to demonstrate an independent association, regardless of whether

a true relationship exists. Seizure frequency was assessed as a single self-reported measure of frequency in the past month, a narrow window that may not adequately capture the cumulative, long-term seizure burden that has been linked to QoL in studies using longer recall periods or clinician-verified seizure diaries; a single recent month may include an atypically good or bad period that does not reflect the adolescent's usual disease trajectory.

5.3 Strengths of the Study

This study has several strengths. First, it focuses on adolescents, a population that is often underrepresented in epilepsy research despite being particularly vulnerable to psychosocial challenges. Second, the study was conducted in a national referral hospital, providing access to a clinically relevant population and enhancing the applicability of findings to tertiary care settings. Third, the use of standardized tools to assess quality of life and psychosocial factors improves the reliability and comparability of the findings. Additionally, the study employed multivariable analysis, allowing for adjustment of potential confounders and identification of independent predictors of poor quality of life.

5.4 Limitations of the Study

Despite its strengths, several limitations should be considered when interpreting these findings. The cross-sectional design inherently limits causal inference, as exposure and outcome were assessed simultaneously. While this restricts conclusions on temporality, the use of multivariable modified Poisson regression allowed adjustment for key confounders, strengthening the validity of the observed associations.

A key methodological limitation relates to the age range covered by the QOLIE-AD-48, which was originally designed for adolescents aged 11–17 years, whereas the present study included participants aged 10–19 years. This introduces a potential limitation in terms of strict age applicability. However, the tool was selected because it remains the only epilepsy-specific

quality of life instrument tailored to adolescents and has been widely used in similar studies, including those conducted in African contexts (Wanjiru et al., 2023; Ahmed et al., 2020). Furthermore, alternative tools such as the QOLIE-31 are primarily validated in adult populations and do not adequately capture adolescent-specific domains such as school functioning and developmental psychosocial experiences. In this study, the QOLIE-AD-48 was considered the most appropriate tool as it better reflects the lived experiences of adolescents with epilepsy, despite minor deviations in age range. Nevertheless, this limitation should be considered when interpreting the findings.

The hospital-based nature of the study may limit generalizability, as adolescents attending a national referral hospital are more likely to present with more severe, chronic, or treatment-resistant epilepsy. However, recruitment from both the Paediatric Neurology and Paediatric Psychiatry clinics, which draw patients from diverse geographical and socio-economic backgrounds across Uganda, enhanced the heterogeneity of the sample and improved the relevance of findings within tertiary care settings.

Psychological variables were assessed using screening tools rather than diagnostic instruments, which introduces the possibility of misclassification bias. This was mitigated through the use of well-validated tools with established reliability and cross-cultural applicability, including the PHQ-4, MSPSS, and Rosenberg Self-Esteem Scale, thereby ensuring consistent and standardized measurement of key constructs. Information bias arising from the use of self-reported measures is another important consideration. Several key variables, including quality of life, depression, anxiety, self-esteem, disclosure status, and medication adherence, were based on adolescents' own accounts rather than objective or independently verified measures.

In addition, some sub-groups, particularly participants without formal education and those with comorbid conditions, had relatively small sample sizes, potentially limiting statistical precision

and stability of estimates. This was addressed by presenting confidence intervals to reflect uncertainty and by interpreting such findings with caution, avoiding overgeneralization.

The use of consecutive sampling, while practical for a clinic-based study, introduces a potential source of selection bias, as participants were enrolled only on days and times when the principal investigator and research assistants were present at the clinics, meaning adolescents attending outside these periods, or those who declined participation, could differ systematically from those enrolled, for instance in attendance patterns, illness severity, or family support.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This study found that poor quality of life is highly prevalent among adolescents with epilepsy attending Mulago National Referral Hospital, affecting 83.3% of participants, a substantially higher burden than reported in most prior Ugandan and regional studies, and a finding that constitutes this study's principal contribution to the literature: documenting an exceptionally high burden of poor QoL among adolescents specifically within a Ugandan tertiary care setting, a population and context that had not previously been characterized in this way. Quality of life was found to be influenced by clinical factors as well as by sociodemographic and psychological factors, including age, educational level, history of epilepsy in the family, and self-esteem, all of which were significant predictors in the adjusted model, while several commonly reported clinical factors, including seizure frequency, medication burden, and comorbidity, were not significant predictors in this sample. These findings highlight the need for adolescent-centered epilepsy care that extends beyond seizure control to also address the psychosocial dimensions of this population's wellbeing.

6.2 Recommendations

Health workers managing adolescents with epilepsy at Mulago National Referral Hospital and similar tertiary facilities should incorporate routine, structured quality of life screening, using a validated tool such as the QOLIE-AD-48, into standard outpatient epilepsy visits, rather than relying on clinical impression alone, given that 83.3% of adolescents in this study had impaired QoL that would not necessarily be apparent from seizure control status.

Given that self-esteem was an independent predictor of QoL, brief, structured psychosocial support, including individual or group counselling focused on building self-esteem, should be

made available to adolescents attending epilepsy clinics, with referral pathways into existing psychiatric services where these are already co-located, as they are at Mulago.

The Ministry of Health, through the Child and Adolescent Mental Health Policy Guidelines, should support the integration of mental health services into routine epilepsy clinics at regional and national referral facilities, building on the existing model already in place at Mulago, where paediatric neurology and paediatric psychiatry clinics operate alongside one another, rather than treating this co-location as exceptional.

Given that younger adolescents (10-14 years) had a higher prevalence of poor QoL, and that this study's age-group finding points to a specific, identifiable vulnerable subgroup, the establishment of structured, age-appropriate adolescent support groups within or affiliated with epilepsy clinics should be piloted, providing a peer-based setting in which younger adolescents in particular can build coping skills and reduce isolation.

Schools should be engaged in stigma-reduction efforts targeting teachers and peers, given the strong association between educational attainment and poor QoL observed in this study and existing Ugandan evidence linking school-based stigma to psychosocial wellbeing among adolescents with epilepsy (Kirabira et al., 2020); this recommendation requires coordination with the education sector and is therefore more resource- and time-intensive to implement than the clinic-based recommendations above.

Family-centred approaches to epilepsy care may also be of value, given that family history of epilepsy was independently associated with poorer QoL in this study. This recommendation should be understood as indirectly rather than directly supported by the present findings, since family functioning, caregiver burden, and the quality of family relationships were not directly assessed in this study; family history of epilepsy was captured only as a single yes/no/unsure

item. Future work directly measuring family dynamics would be needed before this recommendation could be considered strongly evidence-based.

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APPENDIX I: QUESTIONNAIRE

Study ID …….

Date of Data Collection ……

Instructions: For each of the following statements, please indicate how often you have experienced or felt this way. Choose one response for each item.

SECTION A: Demographic Information

1. Age: _____ years

2. Gender:

   A. Male
   B. Female

3. Educational level:

   A. No formal education
   B. Primary education
   C. Secondary education
   D. Tertiary education
   E. Other (specify): _____

4. Place of residence:

   A. Urban
   B. Rural

SECTION B: Clinical Information

5. Age at onset of epilepsy: _____ years

6. Duration of illness: _____ years/months

7. Type of seizures experienced

   A. Generalized

B. Focal
C. Unknown

8. Frequency of seizures in the past month: _____

9. How often do you take your medication?

A. Once daily
B. Twice daily
C. More than twice daily

10. Do you experience any side effects from antiepileptic drugs?

A. Yes, If yes, specify: _____
B. No

11. Do you have any other health conditions (comorbidities)?

A. Yes, If yes, specify: _____
B. No

12. Do you sometimes skip or forget to take your epilepsy medication?

A. Yes
B. No

13. Is there a history of epilepsy in your family?

A. Yes
B. No
C. Not sure

SECTION C: Psychological factors

14. Social support (Multidimensional Scale of Perceived Social Support (MSPSS)

Instruction: To complete it, tick one number per statement that best reflects how you personally feel. Here's a quick recap of the scale for reference: **1** = Very Strongly Disagree, **2** = Strongly Disagree, **3** = Mildly Disagree, **4** = Neutral, **5** = Mildly Agree, **6** = Strongly Agree, and **7** = Very Strongly Agree

SN	Statement	1	2	3	4	5	6	7
1	There is a special person who is around when I am in need.							
2	There is a special person with whom I can share joys and sorrows.							
3	My family really tries to help me.							
4	I get the emotional help & support I need from my family.							
5	I have a special person who is a real source of comfort to me.							
6	My friends really try to help me.							
7	I can count on my friends when things go wrong.							
8	I can talk about my problems with my family.							
9	I have friends with whom I can share my joys and sorrows.							
10	There is a special person in my life who cares about my feelings.							
11	My family is willing to help me make decisions.							
12	I can talk about my problems with my friends.							

15. Have you always disclosed your epilepsy condition to anyone?

A. Yes
B. No

16. Depression and anxiety (PHQ-4)

Instruction: Tick the most appropriate

Over the last two weeks, how often have you been bothered by the following problems?	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
Feeling nervous, anxious or on edge				
Not being able to stop or control worrying				
Feeling down, depressed or hopeless				
Little interest or pleasure in doing things				
Total				

17. Self-esteem (Rosenberg Self-Esteem Scale)

Instruction: Please record the appropriate answer for each item, depending on whether you strongly agree, agree, disagree, or strongly disagree with it. 1 = strongly agree, 2 = agree, 3 = disagree, and 4 = strongly disagree

No.	**Statement**	**1**	**2**	**3**	**4**
1	On the whole, I am satisfied with myself.				
2	At times I think I am no good at all.				
3	I feel that I have a number of good qualities.				
4	I am able to do things as well as most other people.				
5	I feel I do not have much to be proud of.				
6	I certainly feel useless at times.				
7	I feel that I'm a person of worth.				
8	I wish I could have more respect for myself.				
9	All in all, I am inclined to think that I am a failure.				
10	I take a positive attitude toward myself.				

SECTION D: Quality of Life in Epilepsy (QOLIE-AD-48)

Please answer every question by circling the appropriate number (1, 2, 3, 4, 5). If you are not sure about how to answer a question, please give the best answer you can. You may write notes

in the margin to explain your feelings. Even if some questions look similar, answer every question. If you are unsure about how to answer a question, please give the best answer you can and write a comment or explanation on the side of the page.

PART 1: GENERAL HEALTH

1. In general, would you say your health is: *(Circle one number)*

Excellent	Very Good	Good	Fair	Poor
5	4	3	2	1

2. **Compared to 1 year ago,** how would you rate your health in general **now?**

Much better now	Somewhat better now	About the same now	Somewhat worse now	Much worse now
5	4	3	2	1

The following questions are about activities you might do during a TYPICAL DAY. We want you to answer how much **your health** limits you in these activities. *(Circle one number on each line)*

In the past 4 weeks, how often has your health limited:	Very often	Often	Some-times	Not often	Never
3. Heavy activities, such as running, participating in very active sports (such as gymnastics, roller-blading, skiing)?	1	2	3	4	5

	Very often	Often	Some-times	Not often	Never
4. Moderate activities (such as walking to school, bicycle riding)?	1	2	3	4	5

	Very often	Often	Some-times	Not often	Never
5. Light activities (such as carrying packages or a school bag full of books)?	1	2	3	4	5

6. Other daily activities (such as taking a bath/shower alone, going to and from school alone)?	1	2	3	4	5

The following questions are about your regular daily activities, such as chores at home, baby-sitting, attending school being with friends and family, doing homework, or taking part in after-school activities and lessons. We want to know i you had any of the following difficulties with your regular activities as a result of any **physical problems (such as illness) or emotional problems (such as feeling sad or nervous)?**

In the past 4 weeks, how often have physical or emotional problems caused you to:	Very often	Often	Some-times	Not often	Never
7. Do fewer things than you would have liked to do?	1	2	3	4	5
8. Limit the ***kind*** of schoolwork, chores, sports, or other activities you did?	1	2	3	4	5
9. Have ***difficulty*** performing the schoolwork, chores, sports, or other activities you did (for example, it took extra effort) ?	1	2	3	4	5

In the past 4 weeks, how often:	Very often	Often	Some-times	Not often	Never
10. Did you skip school for no reason?	1	2	3	4	5
11. Were you in trouble in school (with teachers or other staff)?	1	2	3	4	5
12. Were you in trouble out of school (with police, security guards, bus driver, etc)?	1	2	3	4	5

These questions are about how you FEEL and how things have been for you during **the past 4 weeks.** For each question, please indicate the one answer that comes closest to the way you have been feeling.
(Circle one number on each line)

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
In the past 4 weeks, how often have you:					
13. Had trouble concentrating on an activity?	1	2	3	4	5
14. Had trouble concentrating on reading?	1	2	3	4	5

The following questions are about mental activities and language problems that may interfere with your normal schoolwork or living activities. *(Circle one number on each line)*

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
In the past 4 weeks, how often have you:					
15. Had difficulty thinking?	**1**	2	3	4	5
16. Had difficulty figuring out and solving problems (such as making plans, making decisions, learning new things)?	**1**	2	3	4	5
17. Had a problem with complicated projects that require organization or planning like computer games or difficult homework)?	**1**	2	3	4	5
18. Had trouble remembering things you read hours or days before?	**1**	2	3	4	5
19. Had trouble finding the correct word?	**1**	2	3	4	5
20. Had trouble understanding your teachers?	**1**	2	3	4	5
21. Had trouble understanding what you read?	**1**	2	3	4	5

The following questions ask about the support you get from others (including family and friends). (Circle one number on each line)

	Very Often	Often	Some-times	Not often	Never
In the past 4 weeks, how often did you:					
22. Have someone available to help you if you needed and wanted help?	5	4	3	2	1

	Very Often	Often	Some-times	Not often	Never
23. Have someone you could confide in or talk to about things that were troubling you?	5	4	3	2	1
24. Have someone you could talk to when you were confused and needed to sort things out?	5	4	3	2	1
25. Have someone who accepted you as you were, both your good points and bad points?	5	4	3	2	1

PART 2: EFFECTS OF EPILEPSY AND ANTIEPILEPSY MEDICATIONS

The following questions ask about how your epilepsy or medications (antiepileptic drugs) have affected your life in the past 4 weeks. *(Circle one number on each line)*

In the past 4 weeks, how often did you:	Very Often	Often	Some-times	Not often	Never
26. Feel that **epilepsy or medications** limited your social activities (such as hanging out with friends, doing extra-curricular activities)compared with social activities of others your age?	1	2	3	4	5
27. Feel alone and isolated from others because of your epilepsy/seizures ?	1	2	3	4	5
28. Miss classes because of seizures or medications?	1	2	3	4	5
29. Use epilepsy or medication side effects as an excuse to avoid doing something you didn't really want to do?	1	2	3	4	5
30. Feel embarrassed or "different" because you had to take medications?	1	2	3	4	5

In the past 4 weeks, how often did you:	Very Often	Often	Some-times	Not often	Never
31. Feel that epilepsy or medications limited your school performance?	1	2	3	4	5
32. Feel you had limitations because of your seizures?	1	2	3	4	5
33. Feel that epilepsy or medications limited your independence?	1	2	3	4	5

	Very Often	Often	Some-times	Not often	Never
I34. Feel that epilepsy or medications limited your social life or dating?	1	2	3	4	5
35. Feel that epilepsy or medications limited your participation in sports or physical activities?	1	2	3	4	5

The following question asks about possible side effects from antiepileptic drugs.
In the past 4 weeks, how did you feel:

	Very Bad	Bad	OK	Good	Very good
36. About how you looked (side effects such as weight gain, acne/pimples, hair change, etc.)?	1	2	3	4	5

In the past 4 weeks, how much were you bothered by:

	A Lot	Some	Not much	A little	Not at all
37. Limits set by parents/family because of your epilepsy or medications?	1	2	3	4	5

Next are some statements people with epilepsy sometimes make about themselves.
For each statement, circle the answer that comes closest to the way **you** have felt about **yourself** in the **past 4 weeks.**

	Strongly agree	Agree	Disagree	Strongly disagree
38. I consider myself to be less than perfect because I have epilepsy.	1	2	3	4
39. If I applied for a job, and someone else also applied who didn't have epilepsy, the employer should hire the other person.	1	2	3	4
40. I can understand why someone wouldn't want to date me because I have epilepsy.	1	2	3	4
41. I don't blame people for being afraid of me because I have epilepsy.	1	2	3	4
42. I don't blame people for taking my opinions less seriously than they would if I didn't have epilepsy.	1	2	3	4
43. I feel that my epilepsy makes me mentally unstable.	1	2	3	4

The following questions ask about your attitudes toward epilepsy. Circle one number for how often in the **past 4 weeks** you have had these attitudes.

	Very bad	A little bad	Not sure	A little good	Very good	
44. How good or bad has it been that you have epilepsy?	1	2		3	4	5

	Very Unfair	A little unfair	Not sure	A little fair	Very fair
45. How fair has it been that you have epilepsy?	1	2		3	4	5

	Very sad	A little sad	Not sure	A little happy	Very happy
46. How happy or sad has it been for you to have epilepsy?	1	2	3	4	5

	Very bad	A little bad	Not sure	A little good	Very good
47. How bad or good have you felt it is to have epilepsy?	1	2	3	4	5

	Very often	Often	Some-times	Not often	Never
48. How often do you feel that your epilepsy kept you from starting new things?	1	2	3	4	5

Optional Items:

In the past 4 weeks, how often did you:	Very often	Often	Some-times	Not often	Never
Worry about having another seizure?	1	2	3	4	5
Fear dying because of seizures?	1	2	3	4	5
Worry about hurting yourself during a seizure?	1	2	3	4	5

Thank you for participating

Supplementary material

Stratified Analysis: Characteristics of Adolescents with Good Quality of Life (n=64) Compared with Those with Poor Quality of Life (n=319)

Note: poor_qol = 0 corresponds to Good QoL (n=64, 16.7%) and poor_qol = 1 corresponds to Poor QoL (n=319, 83.3%), consistent with the dataset coding.

Characteristic	Good QoL n=64, n (%)	Poor QoL n=319, n (%)	Prevalence of poor QoL within group	Direction
Sociodemographic characteristics				
Male sex	34 (53.1%)	161 (50.5%)	82.6%	**Similar**
Female sex	30 (46.9%)	158 (49.5%)	84.0%	**Similar**
Age 10-14 years	16 (25.0%)	101 (31.7%)	86.3%	**Similar**
Age 15-19 years	48 (75.0%)	218 (68.3%)	82.0%	**Similar**
No formal education	27 (42.2%)	21 (6.6%)	43.8%	**Strongly favours Good QoL**
Primary education	28 (43.8%)	135 (42.3%)	82.8%	**Mixed**
Secondary education	8 (12.5%)	125 (39.2%)	94.0%	**Favours Poor QoL**
Tertiary education	1 (1.6%)	38 (11.9%)	97.4%	**Strongly favours Poor QoL**
Urban residence	49 (76.6%)	264 (82.8%)	84.3%	**Similar**
Rural residence	15 (23.4%)	55 (17.2%)	78.6%	**Similar**
Clinical characteristics				
Skips/forgets medication	30 (46.9%)	95 (29.8%)	76.0%	**Favours Good QoL**
Does not skip medication	34 (53.1%)	224 (70.2%)	86.8%	**Favours Poor QoL**
Family history: Yes	21 (32.8%)	119 (37.3%)	85.0%	**Similar**
Family history: No	18 (28.1%)	142 (44.5%)	88.8%	**Favours Poor QoL**
Family history: Not sure	25 (39.1%)	58 (18.2%)	69.9%	**Favours Good QoL**
Psychological characteristics				
Disclosed epilepsy status	57 (89.1%)	205 (64.3%)	78.2%	**Favours Good QoL**
Did not disclose	7 (10.9%)	114 (35.7%)	94.2%	**Strongly favours Poor QoL**

Low/Moderate social support	5 (7.8%)	16 (5.0%)	76.2%	**Similar**
High social support	59 (92.2%)	303 (95.0%)	83.7%	**Similar**
Normal self-esteem	19 (29.7%)	224 (70.2%)	92.2%	**Strongly favours Poor QoL***
Low self-esteem	45 (70.3%)	95 (29.8%)	67.9%	**Strongly favours Good QoL***
No possible depression	54 (84.4%)	304 (95.3%)	84.9%	**Favours Poor QoL***
Possible depression	10 (15.6%)	15 (4.7%)	60.0%	**Favours Good QoL***
No possible anxiety	60 (93.8%)	308 (96.6%)	83.7%	**Similar**
Possible anxiety	4 (6.2%)	11 (3.4%)	73.3%	**Mild, small n**

*Prevalence of poor QoL within group refers to the proportion with poor QoL among all adolescents sharing that characteristic (row-wise), distinct from the n (%) columns, which show the composition of each QoL group (column-wise). *Indicates a direction that runs counter to clinical expectation and to the adjusted multivariable findings reported elsewhere in this thesis; see narrative below.*