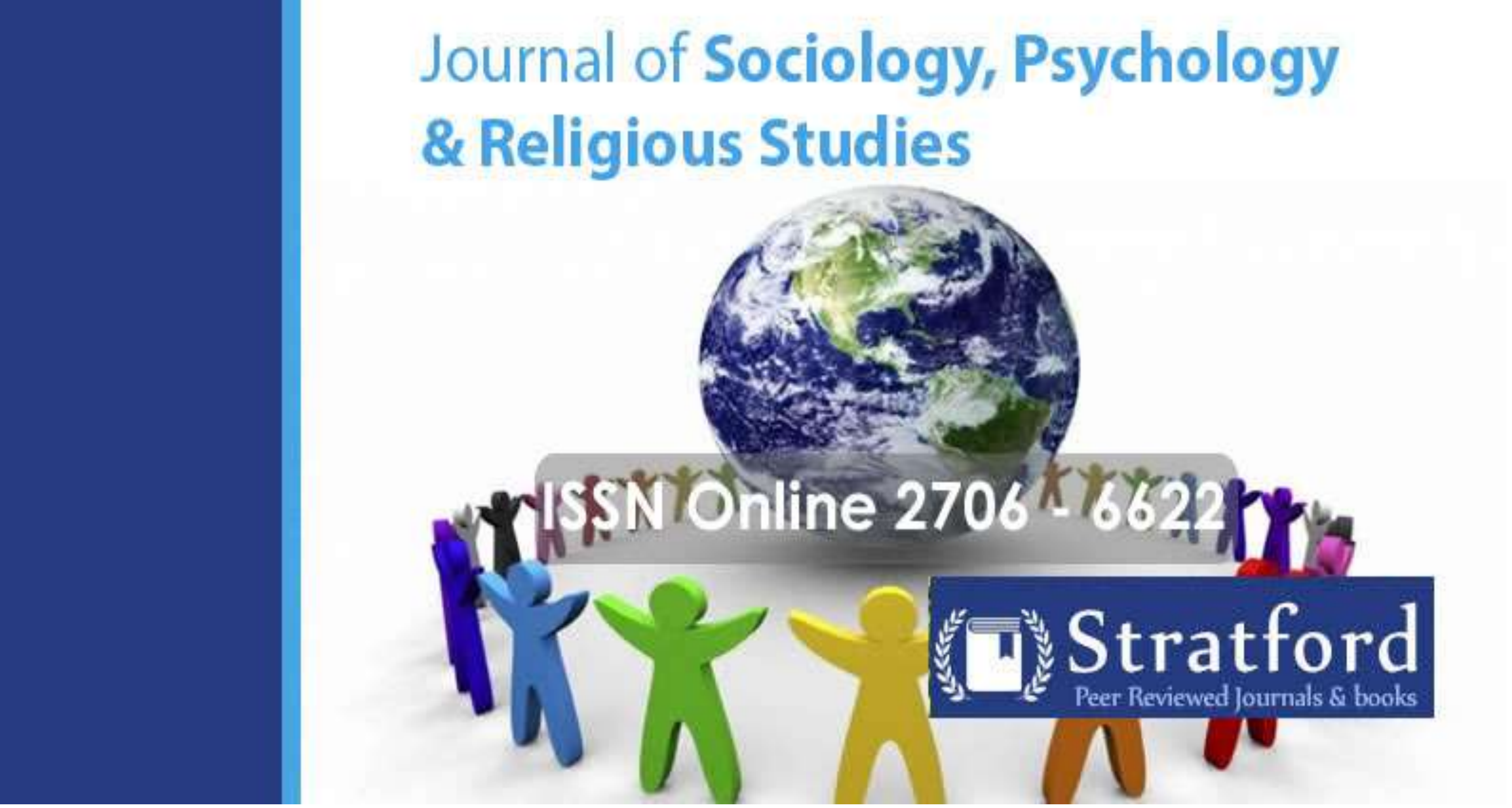

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Extrinsic Determinants of Quality of Life in Adolescents Living with Epilepsy and The Implications for Clinical Psychology

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Abstract

Epilepsy is a global health care concern affecting an estimated 50-70 million people worldwide and accounting for 0.75% of the global burden of disease. Adolescents living with epilepsy have concerns beyond seizures, which impact their psychological well-being and, by extension, their Quality of Life (QOL). This study explored family factors, educational institutions, peer acceptance and socialization, and stigma as extrinsic determinants of QOL among adolescents living with epilepsy and the implications for clinical psychology. A mixed-methods research approach with an explanatory sequential design was employed. Data were collected from 103 participants aged 13-18 years attending the Kenya Association for the Welfare of People Living with Epilepsy (KAWE) clinics, using the Quality of Life in Epilepsy for Adolescents standardized tool (QOLIE-AD-48). Qualitative data was collected through focus group discussions, complementing the quantitative findings by providing context-rich narratives that illuminated how adolescents perceived and navigated their experiences. Social support subscale scored the highest M=72.82, SD=22.68, school behavior M=56.19, SD=22.70, and stigma the lowest M= 43.41, SD=15.06. Social support subscale highlighted the critical role of family and peer support in promoting adolescents' well-being. Cognitive, social, and emotional challenges in educational institutions were often exacerbated by limited institutional support and persistent absenteeism, while peer acceptance and socialization emerged as a vital yet vulnerable domain, with adolescents frequently reporting social isolation, reduced self-esteem, and stigmatization. Internalized and enacted stigma emerged as a cross-cutting issue affecting identity, mental health, and treatment adherence. Family cohesion, teacher understanding, peer inclusion, and societal attitudes were key themes that influenced daily life and self-perception, highlighting the challenges faced by this population. Clinical psychologists should address these challenges through tailored interventions, school-based support, peer relationship enhancement, stigma reduction, cognitive rehabilitation, and culturally sensitive care to improve the psychological well-being and enhance the QOL of adolescents living with epilepsy.

Key words: *Epilepsy, Adolescence, Quality of life, Extrinsic determinants, Kenya*

1.0 Introduction

Adolescents living with epilepsy are faced with the double challenge of dealing with both a chronic condition on the one hand and successfully achieving the age-appropriate developmental tasks of adolescence on the other hand. As a neurological disorder characterized by recurrent and unprovoked seizures, epilepsy in adolescents coincides with the critical developmental period defined by rapid physical changes, evolving identity, and increasing social expectations, creating a unique vulnerability with far-reaching implications for psychological well-being and overall QOL.

In his theory, Erikson underscores the role played by the social and cultural contexts in identity development, where a strong identity in adolescence helps set the individual in the right direction. When childhood has gone well, the adolescent approaches identity formation actively with a sense of autonomy and competence in a relatively secure world but when developmental problems occur in one or more of the first four stages, the adolescent may be hampered by feelings of mistrust, shame, doubt, guilt, and or inferiority. Even under the best circumstances, identity formation is a challenging process. Problems encountered in earlier development may make it more difficult and lessen the likelihood of positive outcomes (Moshman, 2011). For this study, Erikson's theory provides a descriptive language of where the adolescent living with epilepsy stands within a psychosocial development context and where he or she might be "stuck," as well as where he or she is heading in terms of developmental goals (Marcia & Josselson, 2013). The social aspect of development in adolescence is emphasized (Curtis, 2015).

It is further complemented by the Biopsychosocial (BPS) model which provides a more comprehensive framework for understanding the lived experiences of the adolescents living with epilepsy. The BPS model achieves this by placing the adolescent within a broader context that demonstrates the interplay of biological vulnerabilities such as medication side effects, seizure frequency, as well as psychological processes, for example self-esteem, anxiety and depression and specifically for this study extrinsic social factors like family dynamics, cultural beliefs peer relations and school environments and indicate how they either support or undermine the adolescents ability to cope, thrive and achieve a positive quality of life. The theory considers heath as a dimension of QOL while health-facilitating behaviors and factors as predictors of QOL (Irtelli et al., 2020). The BPS model considers epilepsy as a multidimensional condition influenced by biological, psychological, and social factors. It emphasizes the interplay between these domains in shaping an individual's QOL. From a biological perspective, the model considers factors such as seizure frequency, type, and severity. Psychological factors include cognitive functioning, mental health, and self-perception, while social factors involve social support, stigma, and the impact of epilepsy on relationships and daily activities. This model acknowledges the complex nature of epilepsy and highlights the need for a holistic understanding of its effects on adolescents' QOL (Elliott & Richardson, 2014).

This study explored the extrinsic determinants influencing QOL of adolescents living with epilepsy through an in-depth examination of how adolescents interpret and respond to living with epilepsy within the family, education institutions, peer relationships, and community settings, and the implications for clinical psychology.

2.0 Literature Review

This section explores existing research on epilepsy, particularly its impact on adolescents' quality of life. It focuses on the prevalence of epilepsy, challenges of adolescence, and the role of extrinsic factors such as family, school, peers, and stigma. The review highlights global and local perspectives, revealing key gaps in culturally relevant adolescent-focused studies.

2.1 **The Scope and Prevalence of Epilepsy**

Epilepsy is a neurological disorder defined by the occurrence of at least two unprovoked seizures at least 24 hours apart and has significant health implications, including physical, social, and behavioral consequences (Alarcón & Valentín, 2012; Holmes, 2012, 2016; Siqueira et al., 2017). It is one of the most common neurological conditions in adolescents (Schachter, 2011).

A global healthcare concern, it affects 50-70 million people worldwide. It is estimated to account for 0.75% of the global burden of disease (Granbichler et al., 2017; World Health Organization, 2019). Over 85% of epilepsy patients are found in Low and Middle Income Countries (LMICs), most of which occur in impoverished regions of Africa, which is home to the highest number of the world's population under the age of 15 years (Paul et al., 2012). In developing countries, an incidence rate ranging from 6 to 10 per 1,000 people is indicated (Drroopesh, 2017). The annual incidence of epilepsy in developed countries is estimated at 50 per 100,000 of the population and 82 per 100,000 in developing countries, nearly double the incidence in developed countries (MOH, 2016).

Among children and adolescents, the prevalence of epilepsy is reported at 3.4 to 3.9 per 1000 in developed countries and is much higher in developing countries (Larsson & Eeg-Olofsson, 2006). A range of 3.2 to 5.5 per 1000 is reported in developed countries, and 3.6 to 44 per 1,000 in developing countries (Camfield & Camfield, 2015). The wide range arises from different case definitions, sampling methods, etiologies, age, and sex distribution in the various existing studies (Chin, 2012). The prevalence of epilepsy in Africa is 12.7 per 1000 (Samia et al., 2022). In Kenya, the incidence of epilepsy is highest early and late in life (Ngugi et al., 2013). In children, it is recorded at 21 per 1,000 (Kind et al., 2017). A more recent estimate gives the prevalence of lifetime epilepsy in Kenyan children at 21-41 per 1000 (Samia et al., 2019). Based on age, epilepsy has a bimodal distribution with peaks in the youngest individuals and the elderly (Beghi & Giussani, 2018).

Recurrent seizures have the likelihood of disrupting brain functioning resulting in problems with retention, attention, behavior control, changes in mood, and anger reactions. Epilepsy has therefore been closely linked with an individual's neuropsychological functioning, which refers to a set of behavior tasks controlled by the brain and that involve spheres such as language, visual perception skills, memory, attention, and executive skills. When compared to their healthy counterparts, epileptic patients differ in their neuropsychological functioning (Bögli et al., 2022; Masood & Rafique, 2012). In epilepsy, neurologic symptoms are produced on an intermittent basis which is only during the seizure. However, far from the seizures, the major factors that the patient perceives as interfering with his or her daily living include psychosocial problems, AED therapy, and its side effects (St Louis et al., 2015). These have a significant impact on the patient's QOL (Fayed et al., 2015).

2.2 **Adolescence in the Context of Epilepsy**

Adolescence is a distinctive phase of development characterized by multiple physical and psychological changes and an increased vulnerability to both somatic and mental health problems. These challenges and vulnerability factors are part of an intricate biopsychosocial matrix, which comprises numerous factors such as inherited biological traits and psychological, societal, and cultural influences. All these have an impact on the adolescent's overall wellbeing (Zouini et al., 2019). Adolescence is considered a transitional period from childhood to adulthood and a period of life where the individual searches for and forms his or her identity. The process of identity formation is a dynamic and long-lasting one, during which the young person tries to find answers to essential questions in his or her life. "Who am I?" "What do I want to accomplish?" "Which ideals are important to me?" "Who do I want to become in the future?" "What is my place in the community?" "How do I go about building relationships with others?" and "What choices do I make?" are some of the questions that the adolescent grapples with (Oleś, 2016).

To the adolescent dealing with epilepsy, the concern is beyond seizures. He or she is faced with the double challenge of dealing with both a chronic condition on the one hand and successfully achieving the age-appropriate developmental tasks of adolescence on the other hand. The tasks comprise increasing autonomy, differentiating from the nuclear family, self-identity development, and focusing more on peer relationships (Chew et al., 2019). Such adolescents find themselves faced with the dual challenge of dealing with a critical stage of development as well as a chronic condition (Chew et al., 2017; Guerrini, 2006). This extra demand on top of living with epilepsy leads to stress and subsequently impacts negatively on an adolescent's QOL.

2.3 Quality of life

The term QOL was introduced in the medical literature in the 1960s, and its popularity in research has grown (Marcel W. M, 2014). QOL is defined as an individual's perception of his or her position in life, as well as in the cultural and value system context in which they live, and how this relates to their individual goals, expectations, standards, and concerns (Orley et al., 1998). In the context of health, it is viewed as the way a patient feels and functions. It is subjective, not always easy to measure, and comprises three essential elements namely, physical health: accounting for aspects such as daily functioning, general health, pain, resilience, seizure frequency, and severity, as well as medication-related side effects. The second element is psychological health and includes aspects such as emotional health, issues of self-esteem, and cognition. Social health is the third element and comprises relationship aspects with friends and family, occupational standing, and independence-related issues (Fayers & Machin, 2016).

Quality of life is an internal experience that is influenced by what is happening externally but is colored by an individual's earlier experiences, mental state, personality, and expectations. It places the patient at the center of inquiry giving their opinion due weight and as a result, it is considered a better indicator of assessment. This ensures that the patient's concerns rather than those of the service provider are heard and can thus be addressed (Orley et al., 1997). It should be inclusive of all areas of life, in addition to putting into consideration the impact of illness as well as that of treatment (Calman, 1984). In the Kenyan setting, seizure control is traditionally the main focus in the management of epilepsy (Kinyanjui et al., 2013). Adoption of a holistic approach has been suggested in previous research, with the objective of achieving better treatment outcomes (Nabukenya et al., 2014).

Epilepsy has been found to have a severe impact on adolescents' QOL where early age at onset, severity of seizures, and a longer duration of epilepsy are related to a poor QOL (Liu & Han, 2015). Early age at onset or childhood epilepsy is a factor associated with the frequency of seizures and in due course impairs the QOL (Nadkarni et al., 2011). Uncontrolled seizures have damaging effects on cognition and behavior of adolescents since that is when the brain is developing (Berg et al., 2012). Adolescents living with epilepsy are at a greater risk of emotional, behavioral, and academic interruption compared with both healthy controls and those with other chronic medical conditions. The rates of non-adherence to antiepileptic medications have also been found to be quite high, resulting in less than optimal seizure control and hence a negative impact on quality of life (Weyand et al., 2016).

2.4 Extrinsic Determinants

Extrinsic factors are external influences, circumstances, or environmental conditions that can affect adolescents living with epilepsy (Majee et al., 2020). For purposes of this research, extrinsic factors refer to external aspects that impact the adolescent's QOL, which are family factors, educational institution factors, peer acceptance and socialization, and stigma.

2.5 Family Factors

Family comprises a group of people related by either blood or law who live together or associate with one another for a shared purpose. The purpose is usually to provide food, shelter, and raising children (Wilson, 1985). For this study, family factors were considered as the conditions or features of a family environment that influence the QOL of adolescents living with epilepsy.

Literature highlights the crucial influence of family factors on the well-being of adolescents living with epilepsy, with studies linking family stress, cohesion, and parental mental health to adolescents QOL(Adewuya, 2006; Goodwin et al., 2017; Mendes et al., 2017; Riechmann et al., 2019). While research from the Western context supports these associations, there is a gap in culturally diverse perspectives, especially from LMICs. Additionally, few studies explored targeted interventions for improving parental well-being as a strategy for enhancing child outcomes.

2.6 Educational Institutions Factors

Education is closely related to lifelong opportunities. Those alienated from education face a higher risk of marginalized life pathways that are costly for them and their communities (McLean & Syed, 2014). Educational institution factors are those associated with the school environment, which in turn impact the adolescent’s QOL. In the general population, children and adolescents record a high incidence of epilepsy. Their education is often adversely affected, as is their psychosocial development, and subsequently their QOL at a critical period of development (Kendall-Taylor et al., 2008). Adolescents living with epilepsy feel vulnerable, disempowered, and discriminated against (Chong et al., 2016). In most instances, they also suffer comorbidities and have higher incidences of mental disorders, learning disorders, and challenges in their psychosocial development. Adolescents living with epilepsy stand a greater risk of emotional, behavioral, and

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academic interruption when compared to their healthy controls (Weyand et al., 2016). These risks can be mitigated, potentially minimizing their continuation into adulthood.

Reviewed literature highlights the impact of school environments on the QOL of adolescents living with epilepsy. Studies reveal that cognitive impairment, stigma, absenteeism, and inadequate institutional support hinder educational attainment (Anguzu et al., 2021; Johnson et al., 2022; Roberts & Whiting, 2011). Notably, data from Kenya and many LMICs remain scarce, underscoring the need for context-specific studies.

2.7 Peer Acceptance and Socialization

Adolescents living with epilepsy have been found to exhibit lower social competencies in comparison to those without epilepsy (Russ et al., 2012). Those with childhood-onset epilepsy have been reported to have a high rate of social problems despite being within the normal range intellectually. This adversely impacts the QOL, and low scores have been reported. Social bonds are pertinent to daily living. They are therefore an essential determinant of QOL. In epilepsy patients, numerous factors can impede cognitive and affective functions and hence negatively impact smooth social interactions (Steiger & Jokeit, 2017).

Reviewed literature consistently indicates that adolescents with epilepsy experience diminished social competence, peer exclusion, and internalized stigma, which negatively impacted QOL (Drewel et al., 2009; Gebauer-Bukurov et al., 2015; Hilberink et al., 2018). Social withdrawal was often linked to anxiety, parental overprotection, and cognitive impairments (Chong et al., 2016; Jakovljević & Martinović, 2006). However, most of the studies relied on parent-reported data, neglecting adolescents' direct voices and contextual influences such as cultural norms. The absence of research from Africa limits cross-cultural applicability.

2.8 Stigma

The history of epilepsy can be summed up as four thousand years of ignorance, superstition, and stigma, followed by another one hundred years of knowledge, superstition, and stigma. This observation is reinforced by the fact that despite the study of epilepsy going back hundreds of years, superstition and stigma have remained a constant, regardless of the increased knowledge of epilepsy (Kale, 1997).

Stigma refers to the negative perception and corresponding actions associated with a person or group of people based exclusively on specific social characteristics they possess or are associated with (Shiraev, 2016). The social consequences of living with epilepsy can be enormous. Stigma is a feature of many chronic health problems and contributes to the hidden burden of disease. People living with epilepsy in both the developing and developed world have been reported to experience stigma and exclusion, which are common features of epilepsy. Epilepsy stigma serves as a major contributor to the disease burden. It is the concepts of epilepsy held by the general public that constitute a significant part of the problems encountered daily by people living with epilepsy, as opposed to the severity of the problem (de Boer, 2010). The stigma of epilepsy, therefore, affects how people living with the disease are viewed.

Literature highlights stigma as a pervasive psychosocial burden among individuals with epilepsy, significantly affecting education, employment, and social integration (Aydemir et al., 2016;

Kirabira et al., 2018; Nyakwana et al., 2014). While studies capture both felt and enacted stigma, a research gap exists in understanding how cultural beliefs interact with systemic health literacy to sustain stigma. Additionally, few studies have incorporated adolescent voices or examined protective factors such as peer education or community-based stigma reduction.

3.0 Research Methodology

The study adopted a mixed methods approach using an explanatory sequential design, where quantitative data collection and analysis informed the subsequent qualitative phase focusing on adolescents aged 13–18 with epilepsy attending KAWE care centers in Nairobi County. Eligibility required a confirmed epilepsy diagnosis, a doctor referral, and at least six months of anti-epileptic treatment. Purposive sampling was used in the qualitative phase to select participants who could provide deeper insights into the quantitative findings.

Participants were provided with sufficient, appropriate, and accurate information regarding the study before data collection. Informed consent was obtained directly from those aged 18 years and above and from parents or guardians for the minors in written form. Permission to record was sought by the researchers from the participants, and the rationale for recording was explained. Debriefing was conducted with every participant after the interviews. Ethical approval was obtained from the University Ethical Review Board (IRB), the National Commission for Science, Technology and Innovation (NACOSTI), KAWE, the County government of Nairobi at City hall, and relevant Sub-county offices.

A pretest study was carried out before the main data collection to evaluate the quality and readability of the research instruments at the Nanyuki Cottage Hospital’s epilepsy clinic using a sample of 20 adolescents living with epilepsy selected through purposive sampling. The process helped identify ambiguities in the tools. Important items, such as adherence to medication, were incorporated to give a better understanding of the respondents' experiences. The time required to complete the questionnaires was increased to ensure that the respondents had adequate time to respond to the questionnaires.

From the study population, a sample size of 114 was arrived at using Slovin’s formula. A total of 103 adolescents participated, comprising 60 males and 43 females. Quantitative data was collected using a questionnaire and the QOLIE-AD-48 tool, both administered by a researcher. Every participant was interviewed individually. The QOLIE-AD-48 is an epilepsy-specific QOL measure designed specifically for the adolescent population and is comprised of 48 items in 8 subscales as follows: epilepsy impact 12 items, memory and concentration 10 items, attitudes towards epilepsy 4 items, physical functioning 5 items, stigma 6, school behavior 4, and health perceptions 4 items. There is also a total summary score where high scores indicate a better QOL (Cramer et al., 1999). This tool has been used in developing countries, during which cross-cultural transferability, test-retest reliability, as well as internal consistency, have all been well demonstrated (Siqueira et al., 2014), for example, in Nigeria (Adewuya, 2006).

The variables of interest were family factors, educational institutions’ factors, peer acceptance and socialization, and stigma. All these variables were quantitatively assessed using the QOLIE-AD-48 as well as qualitatively through the focus group discussions. Family factors, educational institution factors, and stigma were quantitatively measured through the social support subscale, school behavior subscale, and stigma subscale, respectively. The peer support and socialization variable was also assessed through the social support subscale

The second phase of data collection used a qualitative approach. The participants were selected based on the extreme or outlier cases that emerged from the quantitative results. Four groups were interviewed, and the information was obtained using a recorder. The interviews were then transcribed, and field notes were typed. The main themes were identified, and data grouped into the relevant sections through coding. Core themes and categories of issues were identified and conceptualized, and a framework for structuring the results was arrived at. This process helped in data reduction by distinguishing the most relevant and significant study results, which responded directly to the study objective. The focus group results were presented in narrative form and illustrated with quotations.

4.0 Results

The variables of interest in this objective were family factors, educational institutions' factors, peer acceptance and socialization, and stigma. All these variables were quantitatively assessed using the QOLIE-AD-48 as well as qualitatively through the focus group discussions. Family factors, educational institution factors, and stigma were quantitatively measured through the social support subscale, school behavior subscale, and stigma subscale, respectively. The peer support and socialization variable was also assessed through the social support subscale. All the variables were also qualitatively measured and analyzed using thematic approach

Table 1 displays the values of participants' QOL on the QOLIE-AD- 48 and its subscales

Table1: Values of QOLIE-AD-48 and its Subscales

N=103	**MIN**	**MAX**	**X**	**SD**
QOLIE-AD-48	16.24	94.27	59.23	14.69
Epilepsy impact	16.67	100.00	69.56	17.52
Memory/Concentration	0.00	100.00	58.17	24.18
Physical functioning	0.00	100.00	68.20	22.76
Stigma	0.00	75.00	43.41	15.06
Social support	12.50	100.00	72.82	22.68
School behavior	0.00	100.00	56.19	22.70
Attitudes towards epilepsy	0.00	100.00	42.18	21.23
Health perceptions	0.00	100.00	52.1	28.26

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N: Number of subjects; SD; standard deviation; MIN; minimum; MAX; maximum; X; mean

The QOLIE-AD total score was M 59.23, SD = 14.69. This score ranged from 16.26 to 94.27, where higher values indicated better QOL. The variability between the highest and lowest scores emphasized the diverse range of experiences among the participants. The measure of skewness at 0.053 suggested that the distribution of QOL scores was roughly symmetric and close to normal.

The stigma subscale assessed the extent to which adolescents experienced stigmatization due to epilepsy. With a mean of 43.41, participants generally reported high levels of stigma. The range of scores suggests that some adolescents experienced significant stigma, which negatively impacted their social experiences and self-perception. The social support subscale evaluated the perception of support from family and friends. A mean score of 72.82 suggested that most participants felt well-supported, but the substantial standard deviation 22.68, indicated that support levels were variable, with some adolescents feeling less supported. The school behavior scores reflected the impact of epilepsy on academic and behavioral performance at school. The mean score of 56.19 suggested moderate difficulties in school settings, with significant variation among participants, SD = 22.70, ranging from no reported issues to severe challenges.

The results demonstrated a diverse range of experiences among adolescents with epilepsy, as evidenced by the varying scores across all subscales. While some individuals were able to manage their condition effectively, others encountered significant challenges. These findings suggest the importance of developing targeted interventions that address specific areas of need, such as enhancing social support networks, reducing the impact of stigma, and providing resources to improve cognitive and physical functioning.

4.1 Family Factors

The social support subscale has the highest mean, 72.82 **(See Table 1**). It evaluated the perception of support from family and friends. A mean score of 72.82 suggested that most participants felt well-supported, but the wide range (22.68) and substantial standard deviation indicated that support levels were variable, with some adolescents feeling less supported. The focus group discussions shed more light on this area.

For some participants, the support took the form of counseling, encouragement, and being accompanied to the hospital and other places by parents, siblings, or other relatives. One participant reported receiving counseling from her mother, a strong support system. There were restrictions, such as not being allowed to walk unaccompanied, as well as not being allowed to cook or cover up when asleep. Another respondent felt that these restrictions made her perceive herself as less than her younger brother, who could for instance be allowed to cook while the participant was not. For this particular participant, the restrictions were been reduced with improvement. She felt like she was viewed as a patient before but was then in a place where the family viewed her differently.

> *"When I was younger, I could not walk alone on the road just in case I got a seizure. My mom was also afraid….she was afraid of leaving me alone in the house. She didn't want me to cook using gas ….and I would not be allowed to be near an open fire. She was also afraid when I covered my head with bedding at night. This was very common in the*

> *past but with time she has changed. When it used to happen I would feel lesser than other people for example my younger brother could do more than me so this used to make me feel as if I was less than other people, I would feel very bad because I was being treated like a child"* FGD2-1

Others felt that although there was support, the reactions to seizures impeded at times.

> *"My mother is supportive, but sometimes she worries too much and is overprotective. She does not give me as much freedom as I would want. I am not able to do some things such as walking alone to a friend's house on my own because she is afraid that I might fall"* FGD1-11

> *When I fall, my mother panics, then she prays and prays and prays a lot. Sometimes this makes me uncomfortable". FGD1-2*

> *"I appreciate that at home, my parents help me take my medicine and also help with my homework. This makes living with epilepsy very easy for me. My sister is also very helpful. I tell her everything that bothers me and she understands".* FGD1-4

4.2 Educational Institutions' Factors

The QOLIE-AD-48's school behavior subscale's mean average score of 56.19 for the participants indicates that they experience moderate difficulties in academic performance and school-related behavior **(See Table 1)**. The relatively high standard deviation of 22.70 suggests significant variability among the participants, indicating that some face considerable challenges while others perform relatively well.

The quantitative aspect of this study identified participants who were managing their schoolwork effectively despite their epilepsy, as well as those who were struggling with it. Among the former group, the majority had their seizures under control, along with other factors that contributed to their success. One participant noted that the fact that she no longer fell contributed to her not drawing the attention of her peers.

> *"I am more comfortable at school because I am now in a different environment, and I have met new people who did not know me at my primary school. I make sure that I take my medication so that I do not fall" FGD2-13*

A participant in the lower primary who was still experiencing seizures reported a challenging experience at school. Although the class teacher was aware and understanding of the student's condition, other students were insensitive in their interactions with him.

> *"….the other students make fun of me and say mean things about me when I fall. This makes me very angry, and I fight them back……sometimes I will find myself throwing*

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> *an object at such a person. It is not a good thing to have epilepsy and I am not in control. They should know that I don't like having epilepsy. Nobody does." FGD1-15*

Other participants preferred to stay away from school as often as possible, which led them to skip classes frequently. In focus group discussions, it was revealed that the academic performance of such was quite poor. A participant said that he experienced difficulty with independent completion of assignments and reading from the blackboard. He frequently experienced headaches at school and had difficulty remembering content. The poor academic performance and the perception that some of these adolescents do not belong may have been a contributing factor to the participants' dislike of school.

> *"My performance at school is poor, and my grades keep dropping. I get stressed and experience headaches during exams and this has caused me to fall a lot of times during exams. I wish all our teachers understood what I am going through"* FGD1-7

> *"It would help if there was a room set aside where one can go to when they fall instead of just sitting in class …and then everyone is staring at you. I feel tired after a seizure and I just want to go home and sleep instead of waiting for school to end"* FGD1-2

To address these challenges, it is essential to provide tailored educational support and interventions to help students with epilepsy succeed in school environments.

4.3 Peer Acceptance and Socialization

The social support subscale has the highest mean, 72.82, an indication that most participants felt supported **(See Table 1**). In focus group discussions, some adolescents felt understood and supported by their peers, though a number did not.

> *"My friends understand when I am not feeling well. They do not insist that I join them when I am not feeling up to it"* FGD2-1

Other participants were well-integrated with their peers and well-socialized. A 17-year-old could swim, go to the gym, and even drive. His friends were aware of what to do during a seizure. He therefore felt safe in their company. On the risk of having a seizure when driving or carrying out strenuous physical activities, he was confident that he could predict the seizures from the aura and so keep away from such activities. However, it was not always like this for this particular participant. His parents gradually removed restrictions as his seizure frequency reduced. Others found safe spaces in church youth activities and hobbies they had engaged in. A 15-year-old who had been seizure-free for one year was in the drama club of his school and was also a member of a theater group that presented set book plays to other schools. He came across as very confident and very well-integrated with his peer group. A 17-year-old spoke of her socialization activities revolving around the church and being affirmed by the prophet (church leader) about her condition, which normalized epilepsy for her. She felt accepted by the church community and her peer group.

Some felt isolated and not quite as belonging. For example, a 15-year-old reported that when walking to school, other children would avoid walking with her because if she had a seizure, she would delay them. She wished that her peers were more understanding of her situation. Others didn't like the unpredictable and declarative nature of epilepsy. One participant found it very disorienting.

> *"It is not a good thing, and it can cause you to fall at any time. It is like a spirit….. it just makes you fall……. it can cause you to fall, you start shaking and have a severe headache, it is a bad experience and then it is very dark".* FGD1-14

4.4 Stigma

The stigma subscale on QOLIE-AD-48 had a mean score of 43.41, indicating moderate feelings of stigma among participants (See Table 1). It is also the scale with the lowest upper score of 75 compared to all the other subscales that have 100 % scores. The mean score suggests that stigma is high in this population. Some participants had disclosed their condition, but others had not. One participant reported of his friends paying him a visit and getting his medication on the table. When they asked what it was for, he said it was for a headache. He reported feeling lonely and not having someone else apart from his grandmother, to whom he would confide regarding his condition. For others, the stigma was reinforced by their loved ones. A 17-year-old participant reported that her mother did not want her to disclose her condition to her friends and would be very unhappy. Some spoke of their peers speaking ill of them in school and imitating them on how they get seizures and laughing at them. This would make them very angry.

Others did not experience the stigma, even after disclosing their condition. Their families were also open about their condition and spoke freely about it. Such participants appeared to have better accepted their condition compared to those who were not free to disclose. One of them has educated his friends on what needs to be done following a seizure. This participant's disclosure has ensured that the patient is not lonely. On dating, some have been limited by epilepsy, but others have friends of the opposite sex.

5.0 Discussion

5.1 Family Factors

Family support emerged as a crucial determinant of the participants' QOL, highlighting the protective role of family in chronic illness management. The relatively high mean score, M=72.82, on the social support scale indicates that most participants experienced significant emotional support. Provision of counseling by parents and family members and being accompanied to the clinic, and general emotional availability were frequently cited as positive experiences. Variability in responses, however, reflects notable differences in familial approaches. Overprotective behaviors, such as restricting independent activities, were associated with negative self-perceptions. Adolescents who perceived themselves as overly restricted often reported diminished self-worth and feelings of inferiority, particularly when compared to their siblings. Notably the findings also demonstrated that improvements in seizure control often prompted a reassessment of restrictions, leading to greater autonomy and enhanced self-esteem supporting the view that family attitudes significantly influence adolescents' psychological adjustment and overall QOL. These findings are supported by studies conducted in the United Kingdom and Portugal, where family cohesion was positively related to QOL outcomes for both children and parents, and negatively affected their children's outcomes through adverse associations with perceived stigma (Mcewan et al., 2004b; Mendes et al., 2017).

5.2 Educational Institution's Factors

Experiences within educational settings were mixed, as reflected by an overall mean score of 56.19 on the school behavior subscale. While some participants reported effective management of their epilepsy and supportive peer networks at school, others encountered significant barriers. Reports of bullying, academic underperformance, memory impairments, and challenges such as difficulty reading from the blackboard underscored the multifaceted impact of epilepsy on educational attainment. These findings corroborate earlier studies indicating that cognitive deficits contribute to school difficulties and avoidance behaviors (Austin et al., 2004; Enkhtuya et al., 2024).

Moreover, the limited availability of accommodations and the lack of teacher awareness regarding epilepsy were significant stressors, reinforcing the need for targeted interventions within school systems to support adolescents with epilepsy. Participants' desire for dedicated rest spaces and informed educators parallels recommendations from prior research advocating for inclusive educational environments to mitigate academic disruptions and social isolation (Johnson et al., 2021).

5.3 Peer Acceptance and Socialization

Peer relationships played a pivotal role in adolescents' well-being, with the highest mean score, M=72.82, on the social support subscale, reaffirming the value of supportive friendships. Consistent with findings of a study conducted on young adults living with epilepsy in the United Kingdom (Batchelor & Taylor, 2023), participants with informed and empathetic peers reported greater participation in social activities and were more confident. However, the unpredictability of seizures sometimes disrupted their relationships, leading to experiences of avoidance and social withdrawal. The social consequences of epilepsy, especially the fear of having seizures in public, have been well documented and are known to negatively impact integration with peers (Chew et al., 2019). Adolescents with limited peer acceptance experienced heightened feelings of alienation, emphasizing the importance of social education and peer support initiatives.

5.4 Stigma

Stigma remained a significant psychosocial burden, with participants reporting moderate levels of perceived stigma, M=43.41. Experiences of bullying, concealment encouraged by family members, and fear of disclosure were common. These findings correspond with findings that stigma in epilepsy can lead to secrecy, low self-esteem, and poor psychosocial adjustment (Jacoby et al., 2005). Notably, adolescents who disclosed their condition and actively educated their peers experienced lower levels of stigma, suggesting that disclosure, when managed appropriately, can be empowering.

5.5 Implications for clinical psychology

The results of this study highlight several critical areas of concern for adolescents living with epilepsy. The substantial variability in QOL scores underscores the need for tailored interventions targeting specific challenges faced by these populations. Key areas requiring attention include reducing the impact of stigma, enhancing social support networks and providing resources to improve cognitive and physical functioning. Overall, these findings suggest the importance of comprehensive care strategies that account for the unique demographic and clinical characteristics of each patient.

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The role of family dynamics, especially over protectiveness, underscores the importance of family therapy as part of the treatment plan. Clinical psychologists should work with both adolescents and their families to foster supportive environments that encourage autonomy and self-management without reinforcing feelings of helplessness and dependency. The study also emphasizes the critical role of psychosocial support including peer groups and community engagement in mitigating the stigma associated with epilepsy. Clinicians should advocate for group therapy or support groups where adolescents can share experiences and develop coping strategies reducing the sense of isolation and helping them form a positive social identity. These interventions combined with teacher management techniques can improve overall QOL and psychological well-being for adolescents living with epilepsy.

The findings from this study highlight the complex and multifactorial nature of the challenges faced by adolescents living with epilepsy. Clinical psychology has a critical role to play in addressing this challenge through centered interventions, school-based support, peer relationship enhancement, stigma reduction, cognitive rehabilitation, and culturally sensitive care. By focusing on these areas clinical psychologists can significantly improve the emotional and psychological well-being of adolescents living with epilepsy, ultimately enhancing their overall QOL

6.0 Recommendations

The study recommends addressing misconceptions about epilepsy in culturally appropriate ways through the implementation of relevant psychoeducation programs. These programs have the potential to improve adolescents' self-perception and reduce feelings of isolation. The study further suggests that such psychoeducation initiatives be delivered by clinicians, mental health workers, and government administrators, among others. Additionally, it recommends the adoption of family-based interventions and community programs that promote social inclusion and reduce stigma, thereby creating a supportive environment and fostering a stronger sense of belonging among adolescents living with epilepsy.

7.0 Conclusion

The extrinsic factors significantly influenced the QOL of adolescents living with epilepsy. Family support, while generally positive, can sometimes result in overprotection, which negatively impacts the adolescent’s sense of independence. In educational settings, while some adolescents managed their epilepsy well and succeeded academically, others faced significant challenges including bullying, poor academic performance, and lack of suitable accommodations. Peer relationships were equally varied with some adolescents enjoying strong support networks while others faced isolation and rejection. Stigma remained a pervasive issue with many adolescents experiencing feelings of shame and secrecy, although openness about the condition appeared to mitigate some of these effects.

References

Adewuya, A. O. (2006). Parental psychopathology and self-rated quality of life in adolescents with epilepsy in Nigeria. *Developmental Medicine & Child Neurology*, *48*(7), 600–603. https://doi.org/10.1111/j.1469-8749.2006.tb01322.x

Alarcón, G., & Valentín, A. (2012). *Introduction to Epilepsy*. Cambridge University Press. http://ebookcentral.proquest.com/lib/stpaulslimuru-ebooks/detail.action?docID=866845

Anguzu, R., Akun, P., Katairo, T., Abbo, C., Ningwa, A., Ogwang, R., Mwaka, A. D., Marsh, K., Newton, C. R., & Idro, R. (2021). Household poverty, schooling, stigma and quality of life in adolescents with epilepsy in rural Uganda. *Epilepsy & Behavior: E&B*, *114*(Pt A), 107584. https://doi.org/10.1016/j.yebeh.2020.107584

Austin, J. K., Dunn, D. W., Johnson, C. S., & Perkins, S. M. (2004). Behavioral issues involving children and adolescents with epilepsy and the impact of their families: Recent research data. *Epilepsy & Behavior*, *5*, 33–41. https://doi.org/10.1016/j.yebeh.2004.06.014

Aydemir, N., Kaya, B., Yıldız, G., Öztura, İ., & Baklan, B. (2016). Determinants of felt stigma in epilepsy. *Epilepsy & Behavior*, *58*, 76–80. https://doi.org/10.1016/j.yebeh.2016.03.008

Batchelor, R., & Taylor, M. D. (2023). Experiences and perspectives of peer support among young adults with epilepsy. *Epilepsy & Behavior Reports*, *21*, 100590. https://doi.org/10.1016/j.ebr.2023.100590

Beghi, E., & Giussani, G. (2018). Aging and the Epidemiology of Epilepsy. *Neuroepidemiology*, *51*(3–4), 216–223. https://doi.org/10.1159/000493484

Berg, A. T., Zelko, F. A., Levy, S. R., & Testa, F. M. (2012). Age at onset of epilepsy, pharmacoresistance, and cognitive outcomes. *Neurology*, *79*(13), 1384–1391. https://doi.org/10.1212/WNL.0b013e31826c1b55

Bögli, S. Y., Wang, S., Romaguera, N., Schütz, V., Rafi, O., Gilone, M., Keller, E., Imbach, L. L., & Brandi, G. (2022). Impact of Seizures and Status Epilepticus on Outcome in Patients with Aneurysmal Subarachnoid Hemorrhage. *Neurocritical Care*, *36*(3), 751–759. https://doi.org/10.1007/s12028-022-01489-0

Calman, K. C. (1984). Quality of life in cancer patients—An hypothesis. *Journal of Medical Ethics*, *10*(3), 124–127.

Camfield, P., & Camfield, C. (2015). Incidence, prevalence and aetiology of seizures and epilepsy in children. *Epileptic Disorders: International Epilepsy Journal with Videotape*, *17*(2), 117–123. https://doi.org/10.1684/epd.2015.0736

Chew, J., Carpenter, J., & Haase, A. M. (2017). Young People's Experiences of Epilepsy: A Scoping Review of Qualitative Studies. *Health & Social Work*, *42*(3), 167–176. https://doi.org/10.1093/hsw/hlx020

Chew, J., Carpenter, J., & Haase, A. M. (2019). Living with epilepsy in adolescence—A qualitative study of young people's experiences in Singapore: Peer socialization, autonomy, and self-esteem. *Child: Care, Health and Development*, *45*(2), 241–250. https://doi.org/10.1111/cch.12648

Chin, J. (2012). Epilepsy treatment in sub-Saharan Africa: Closing the gap. *African Health Sciences*, *12*(2), 186–192. https://doi.org/10.4314/ahs.v12i2.17

Chong, L., Jamieson, N. J., Gill, D., Singh-Grewal, D., Craig, J. C., Ju, A., Hanson, C. S., & Tong, A. (2016). Children's Experiences of Epilepsy: A Systematic Review of Qualitative Studies. *Pediatrics*, *138*(3). https://doi.org/10.1542/peds.2016-0658

Cramer, J. A., Westbrook, L. E., Devinsky, O., Perrine, K., Glassman, M. B., & Camfield, C. (1999). Development of the Quality of Life in Epilepsy Inventory for Adolescents: The QOLIE-AD-48. *Epilepsia*, *40*(8), 1114–1121. https://doi.org/10.1111/j.1528-1157.1999.tb00828.x

Curtis, A. C. (2015). *Defining adolescence*. *7*, 40.

de Boer, H. M. (2010). Epilepsy stigma: Moving from a global problem to global solutions. *Seizure*, *19*(10), 630–636. https://doi.org/10.1016/j.seizure.2010.10.017

Drewel, E. H., Bell, D. J., & Austin, J. K. (2009). Peer Difficulties in Children with Epilepsy: Association with Seizure, Neuropsychological, Academic, and Behavioral Variables. *Child Neuropsychology*, *15*(4), 305–320. https://doi.org/10.1080/09297040802537646

Drroopesh. (2017, February 11). WHO updates fact sheet on Epilepsy (10 February 2017). *Communitymedicine4asses*. https://communitymedicine4asses.com/2017/02/11/who-updates-fact-sheet-on-epilepsy-10-february-2017/

Elliott, J. O., & Richardson, V. E. (2014). The biopsychosocial model and quality of life in persons with active epilepsy. *Epilepsy & Behavior*, *41*, 55–65. https://doi.org/10.1016/j.yebeh.2014.09.035

Enkhtuya, B., Bayarsaikhan, A., Lkhagvasuren, B., Sainbat, U., Bayanmunkh, B., Avirmed, T., & Tsend, B. (2024). Emotional intelligence in children with epilepsy. *IBRO Neuroscience Reports*, *16*, 260–266. https://doi.org/10.1016/j.ibneur.2024.01.013

Fayed, N., Davis, A. M., Streiner, D. L., Rosenbaum, P. L., Cunningham, C. E., Lach, L. M., Boyle, M. H., & Ronen, G. M. (2015). Children's perspective of quality of life in epilepsy. *Neurology*, *84*(18), 1830–1837. https://doi.org/10.1212/WNL.0000000000001536

Fayers, P. M., & Machin, D. (2016). *Quality of Life: The Assessment, Analysis and Reporting of Patient-Reported Outcomes*. John Wiley & Sons, Incorporated. http://ebookcentral.proquest.com/lib/stpaulslimuru-ebooks/detail.action?docID=4107720

Gebauer-Bukurov, K., Markovic, J., Sekulic, S., & Bozic, K. (2015). Social competence among well-functioning adolescents with epilepsy. *Epilepsy & Behavior*, *42*, 54–60. https://doi.org/10.1016/j.yebeh.2014.11.004

Goodwin, S. W., Wilk, P., Campbell, M. K., & Speechley, K. N. (2017). Emotional well-being in children with epilepsy: Family factors as mediators and moderators. *Epilepsia*, *58*(11), 1912–1919. https://doi.org/10.1111/epi.13900

Granbichler, C. A., Zimmermann, G., Oberaigner, W., Kuchukhidze, G., Ndayisaba, J.-P., Taylor, A., Luef, G., Bathke, A. C., & Trinka, E. (2017). Potential years lost and life expectancy in adults with newly diagnosed epilepsy. *Epilepsia*, *58*(11), 1939–1945. https://doi.org/10.1111/epi.13902

Guerrini, R. (2006). Epilepsy in children. *The Lancet*, *367*(9509), 499–524. https://doi.org/10.1016/S0140-6736(06)68182-8

Hilberink, S. R., van Ool, M., van der Stege, H. A., van Vliet, M. C., van Heijningen – Tousain, H. J. M., de Louw, A. J. A., & van Staa, A. (2018). Skills for Growing Up-Epilepsy: An exploratory mixed methods study into a communication tool to promote autonomy and empowerment of youth with epilepsy. *Epilepsy & Behavior*, *86*, 116–123. https://doi.org/10.1016/j.yebeh.2018.05.040

Holmes, G. L. (2012). Consequences of Epilepsy Through the Ages: When Is the Die Cast? *Epilepsy Currents*, *12*(Suppl 3), 4–6. https://doi.org/10.5698/1535-7511-12.4s.4

Holmes, G. L. (2016). Effect of Seizures on the Developing Brain and Cognition. *Seminars in Pediatric Neurology*, *23*(2), 120–126. https://doi.org/10.1016/j.spen.2016.05.001

Irtelli, F., Durbano, F., Irtelli, F., & Durbano, F. (2020). Quality of Life and Biopsychosocial Paradigm: A Narrative Review of the Concept and Specific Insights. In *Quality of Life—Biopsychosocial Perspectives*. IntechOpen. https://doi.org/10.5772/intechopen.91877

Jacoby, A., Snape, D., & Baker, G. A. (2005). Epilepsy and social identity: The stigma of a chronic neurological disorder. *The Lancet. Neurology*, *4*(3), 171–178. https://doi.org/10.1016/S1474-4422(05)01014-8

Jakovljević, V., & Martinović, Ž. (2006). Social competence of children and adolescents with epilepsy. *Seizure*, *15*(7), 528–532. https://doi.org/10.1016/j.seizure.2006.06.005

Johnson, E., Atkinson, P., Muggeridge, A., Cross, J. H., & Reilly, C. (2021). Inclusion and participation of children with epilepsy in schools: Views of young people, school staff and parents. *Seizure*, *93*, 34–43. https://doi.org/10.1016/j.seizure.2021.10.007

Johnson, E., Atkinson, P., Muggeridge, A., Cross, J. H., & Reilly, C. (2022). Impact of epilepsy on learning and behaviour and needed supports: Views of children, parents and school staff. *European Journal of Paediatric Neurology*, *40*, 61–68. https://doi.org/10.1016/j.ejpn.2022.08.001

Kale, R. (1997). Bringing epilepsy out of the shadows: Wide treatment gap needs to be reduced. *BMJ*, *315*(7099), 2–3. https://doi.org/10.1136/bmj.315.7099.2

Kendall-Taylor, N., Kathomi, C., Rimba, K., & Newton, C. R. (2008). Traditional Healers and Epilepsy Treatment on the Kenyan Coast. *Epilepsia*, *49*(9), 1638–1639. https://doi.org/10.1111/j.1528-1167.2008.01580_1.x

Kind, C. J., Newton, C. R. J. C., & Kariuki, S. M. (2017). Prevalence, risk factors, and neurobehavioral comorbidities of epilepsy in Kenyan children. *Epilepsia Open*, *2*(4), 388–399. https://doi.org/10.1002/epi4.12069

Kinyanjui, D. W. C., Kathuku, D. M., & Mburu, J. M. (2013). Quality of life among patients living with epilepsy attending the neurology clinic at Kenyatta National Hospital, Nairobi, Kenya: A comparative study. *Health and Quality of Life Outcomes*, *11*, 98. https://doi.org/10.1186/1477-7525-11-98

Kirabira, J., Nakawuki, M., Fallen, R., & Zari Rukundo, G. (2018). Perceived stigma and associated factors among children and adolescents with epilepsy in south western Uganda: A cross sectional study. *Seizure*, *57*, 50–55. https://doi.org/10.1016/j.seizure.2018.03.008

Larsson, K., & Eeg-Olofsson, O. (2006). A population based study of epilepsy in children from a Swedish county. *European Journal of Paediatric Neurology: EJPN: Official Journal of the*

European Paediatric Neurology Society, *10*(3), 107–113. https://doi.org/10.1016/j.ejpn.2006.02.005

Liu, X., & Han, Q. (2015). Risk Factors on Health-Related Quality of Life in Children With Epilepsy: *Clinical Pediatrics*. https://doi.org/10.1177/0009922815580405

Majee, W., Schopp, L., Johnson, L., Anakwe, A., Rhoda, A., & Frantz, J. (2020). Emerging from the Shadows: Intrinsic and Extrinsic Factors Facing Community Health Workers in Western Cape, South Africa. *International Journal of Environmental Research and Public Health*, *17*(9), 3199. https://doi.org/10.3390/ijerph17093199

Marcel W. M. (2014). Definitions of Quality of Life: What Has Happened and How to Move On. *Topics in Spinal Cord Injury Rehabilitation*, *20*(3), 167–180. https://doi.org/10.1310/sci2003-167

Marcia, J., & Josselson, R. (2013). Eriksonian Personality Research and Its Implications for Psychotherapy. *Journal of Personality*, *81*(6), 617–629. https://doi.org/10.1111/jopy.12014

Masood, S., & Rafique, R. (2012). Neuropsychological functions in epilepsy patients. *Journal of Ayub Medical College Abbottabad*, *24*(2), 10–13.

McLean, K. C., & Syed, M. (2014). *The Oxford Handbook of Identity Development*. Oxford University Press, Incorporated. cheung://ebookcentral.proquest.com/lib/stpaulslimuru-ebooks/detail.action?docID=1814987

Mendes, T. P., Crespo, C. A., & Austin, J. K. (2017). Family Cohesion, Stigma, and Quality of Life in Dyads of Children With Epilepsy and Their Parents. *Journal of Pediatric Psychology*, *42*(6), 689–699. https://doi.org/10.1093/jpepsy/jsw105

Moshman, D. (2011). *Adolescent Rationality and Development: Cognition, Morality, and Identity, Third Edition*. Taylor & Francis Group. http://ebookcentral.proquest.com/lib/stpaulslimuru-ebooks/detail.action?docID=668764

Nabukenya, A. M., Matovu, J. K., Wabwire-Mangen, F., Wanyenze, R. K., & Makumbi, F. (2014). Health-related quality of life in epilepsy patients receiving anti-epileptic drugs at National Referral Hospitals in Uganda: A cross-sectional study. *Health and Quality of Life Outcomes*, *12*(1), 49. https://doi.org/10.1186/1477-7525-12-49

Nadkarni, J., Jain, A., & Dwivedi, R. (2011). Quality of life in children with epilepsy. *Annals of Indian Academy of Neurology*, *14*(4), 279–282. https://doi.org/10.4103/0972-2327.91948

Nyakwana, T. D. O., Simbauni, J. A., & Jowi, J. O. (2014). *Factors Underlying Stigmatization of Epilepsy: A Comparative Case Study of Suba and Meru Central Districts, Kenya*. *9*(1), 18.

Oleś, M. (2016). Dimensions of Identity and Subjective Quality of Life in Adolescents. *Social Indicators Research*, *126*(3), 1401–1419. https://doi.org/10.1007/s11205-015-0942-5

Orley, J., Saxena, S., & Herrman, H. (1998). Quality of life and mental illness: Reflections from the perspective of the WHOQOL. *The British Journal of Psychiatry*, *172*(4), 291–293. https://doi.org/10.1192/bjp.172.4.291

Orley John, Saxena Shekhar, & Herman Helen. (1997). *Quality of life and mental illness; Reflections from the perspective of the WHOQOL. The British Journal of psychiatry. 1996172:2SIL.93*. https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/quality-of-life-and-mental-illness/0EA416AA253BB400160E338CD3E20FEE

Paul, A., Adeloye, D., George-Carey, R., Kolčić, I., Grant, L., & Chan, K. Y. (2012). An estimate of the prevalence of epilepsy in Sub–Saharan Africa: A systematic analysis. *Journal of Global Health*, *2*(2), 020405. https://doi.org/10.7189/jogh.02.020405

Riechmann, J., Willems, L. M., Boor, R., Kieslich, M., Knake, S., Langner, C., Neubauer, B. A., Oberman, B., Philippi, H., Reese, J. P., Rochel, M., Schubert-Bast, S., Seeger, J., Seipelt, P., Stephani, U., Rosenow, F., Hamer, H. M., & Strzelczyk, A. (2019). Quality of life and correlating factors in children, adolescents with epilepsy, and their caregivers: A cross-sectional multicenter study from Germany. *Seizure*, *69*, 92–98. https://doi.org/10.1016/j.seizure.2019.03.016

Roberts, J., & Whiting, C. (2011). Caregivers of school children with epilepsy: Findings of a phenomenological study. *British Journal of Special Education*, *38*. https://doi.org/10.1111/j.1467-8578.2011.00519.x

Russ, S. A., Larson, K., & Halfon, N. (2012). A National Profile of Childhood Epilepsy and Seizure Disorder. *PEDIATRICS*, *129*(2), 256–264. https://doi.org/10.1542/peds.2010-1371

Samia, P., Hassell, J., Hudson, J., Ahmed, A., Shah, J., Hammond, C., Kija, E., Auvin, S., & Wilmshurst, J. (2022). Epilepsy research in Africa: A scoping review by the ILAE Pediatric Commission Research Advocacy Task Force. *Epilepsia*, *63*(9), 2225–2241. https://doi.org/10.1111/epi.17321

Samia, P., Hassell, J., Hudson, J.-A., Kanana, M., Kariuki, S. M., Newton, C. R., & Wilmshurst, J. M. (2019). Epilepsy diagnosis and management of children in Kenya: Review of current literature. *Research and Reports in Tropical Medicine*, *Volume 10*, 91–102. https://doi.org/10.2147/RRTM.S201159

Schachter, S. C. (2011). *Evidence-based Management of Epilepsy*. TFM Publishing Ltd. http://ebookcentral.proquest.com/lib/stpaulslimuru-ebooks/detail.action?docID=3410365

Shiraev, E. (2016). *Personality Theories: A Global View*. SAGE Publications. wod

Siqueira, N. F., Oliveira, F. L. B. B., & De Souza, E. A. P. (2017). Impaired responsibility dimension of self-esteem of Brazilian adolescents with epilepsy. *Epilepsy & Behavior*, *73*, 1–5. https://doi.org/10.1016/j.yebeh.2017.05.009

St Louis, E. K., Ficker, D. M., & O'Brien, T. J. (2015). *Epilepsy and the Interictal State: Co-Morbidities and Quality of Life*. John Wiley & Sons, Incorporated. http://ebookcentral.proquest.com/lib/stpaulslimuru-ebooks/detail.action?docID=1982915

Steiger, B. K., & Jokeit, H. (2017). Why epilepsy challenges social life. *Seizure*, *44*, 194–198. https://doi.org/10.1016/j.seizure.2016.09.008

Weyand, C., Wagner, J., & Brooks, B. (2016). Pediatric psychology and epilepsy: A state of the field and call to action. *Clinical Practice in Pediatric Psychology*, *4*(1), 90–97. https://doi.org/10.1037/cpp0000129

Wilson, A. (1985). *Family*. Taylor & Francis Group. http://ebookcentral.proquest.com/lib/stpaulslimuru-ebooks/detail.action?docID=166044

World Health Organization. (2019). *Epilepsy: A public health imperative*. World Health Organization. https://apps.who.int/iris/handle/10665/325293

Zouini, B., Sfendla, A., Senhaji, M., Råstam, M., & Kerekes, N. (2019). Somatic health and its association with negative psychosocial factors in a sample of Moroccan adolescents. *SAGE Open Medicine*, *7*, 2050312119852527. https://doi.org/10.1177/2050312119852527