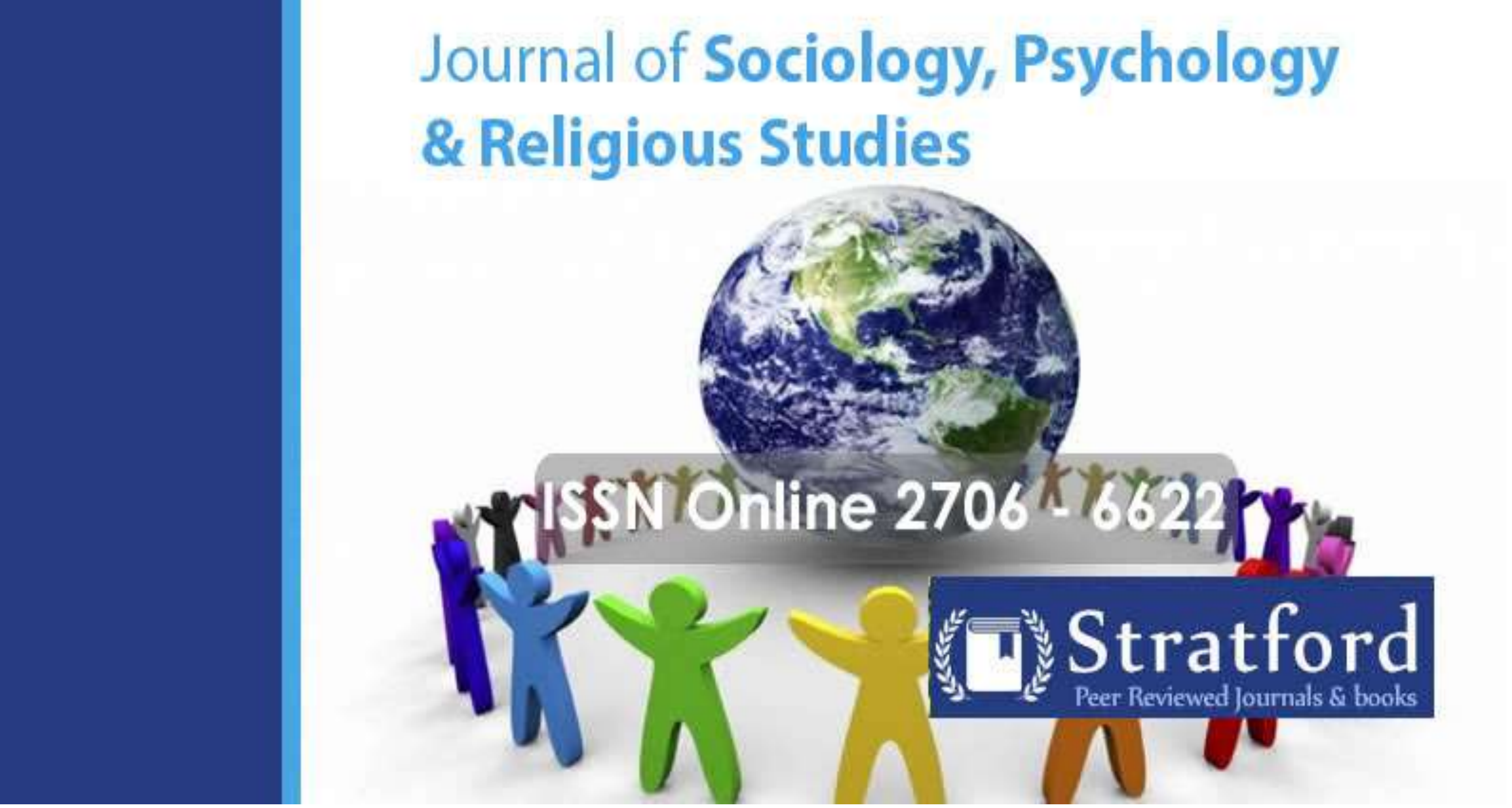

Quality of Life in Adolescents Living with Epilepsy and The Implications for Clinical Psychology

Lydia Wangu Maina, Peterson Mwangi Kimiru, Ph.D., Ruthie Rono, Ph.D. & Osman Hussein Miyanji, Med

ISSN: 2706-6622

Stratford Peer Reviewed Journals and Book Publishing
Journal of Sociology, Psychology and Religious Studies
Volume 7||Issue 2 ||Page 25-41||June |2025|
Email: info@stratfordjournals.org ISSN: 2706-6622

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

[1*]Lydia Wangu Maina, [2]Peterson Mwangi Kimiru, Ph.D., [3] Ruthie Rono, Ph.D. & [4]Osman Hussein Miyanji, Med
[*1] Dean of Students' Department, St. Paul's University, Limuru, University Counselor
[2] School of humanities and social sciences, United States International University-Africa, Assistant professor of Psychology
[3] School of humanities and social sciences, United States International University- Africa, Professor of Psychology

[4] Aga Khan University Medical College of East Africa, The Aga Khan University Hospital, Nairobi, Kenya. Paediatric Neurologist

Email of the Corresponding Author: lymaina@gmail.com

***How to cite this article*: Maina, L. W., Kimiru, P. M., Rono, R., & Miyanji, O. H. (2025). Quality of life in adolescents living with epilepsy and the implications for clinical psychology. *Journal of Sociology, Psychology and Religious Studies*, *7*(2), 25–41. https://doi.org/10.53819/81018102t7055**

Abstract

Epilepsy is one of the most common neurological conditions among children and adolescents. In addition to seizures, adolescents living with epilepsy face significant psychosocial challenges that negatively impact their quality of life (QOL). Research indicates that adolescents with epilepsy generally experience a lower QOL compared to their peers without epilepsy. This part of the study measured the QOL of adolescents living with epilepsy in Nairobi County. The Quality of Life in Epilepsy for Adolescents (QOLIE-AD-48) was used to assess the participants' QOL. An additional tool included a questionnaire to collect demographic and clinical information. The respondents consisted of 103 adolescents aged 13 to 18 years who were diagnosed with epilepsy and attended the Kenya Association for the Welfare of People Living with Epilepsy (KAWE) clinics in Nairobi County. The overall mean for QOL was 59.23, SD=14.69, reflecting a moderate level of QOL among the participants. Challenges such as cognitive difficulties, social stigma, and negative public attitudes significantly impacted school performance and self-esteem, while protective factors included social support, education, urban residency, and monotherapy treatment. The findings indicate the need for comprehensive, individualized care that accounts for demographic and clinical differences. Clinically, the results call for tailored interventions to reduce stigma, strengthen support systems, improve treatment adherence, and enhance cognitive and physical functioning. Targeted psychological support, especially for females and younger adolescents, may help improve coping, resilience, and self-image, ultimately enhancing QOL outcomes.

Key words: *Epilepsy, Adolescents, Quality of life, Clinical psychology, Kenya*

1.0 Introduction

Epilepsy is described as the most common neurological disorder. In children and adolescents, it presents multiple challenges that extend beyond seizure activity and significantly impact psychological well-being. 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).

Erik Erikson's theory applies to this study in that a diagnosis of epilepsy presents the adolescent with a crisis that will either block or facilitate ego growth. The diagnosis is akin to a psychological struggle and hence determines a major aspect of the adolescent's personality, which in this case is identity development. Erik Erikson's theory fell short in terms of explaining and exploring the biological aspects of epilepsy, such as the impact of seizures, medications, and neurological factors. The biopsychosocial (BPS) model was included.

The BPS model is both a concept of clinical care and a practical clinical guide. It is a way of understanding how suffering, disease, and illness are impacted by multiple levels of organization, from societal to molecular. At the practical level, it helps in understanding the patient's subjective experience as an important contributor to accuracy in diagnosis, health outcomes, and also human care (Borrell-Carrió et al., 2004). The theory informed this study in that being healthy is considered a dimension of QOL while health-facilitating behaviors are considered as the 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).

The study objectives were to measure the QOL of adolescents living with epilepsy in Nairobi County, Kenya, as well as to establish the psychological impact of epilepsy on the same population. Evaluating the QOL of adolescents with epilepsy was essential for several reasons. First, it provided empirical data on the effects of epilepsy on daily functioning, social interactions, and mental health. Assessment of QOL also highlighted the gaps and the need for a multidimensional approach to epilepsy management. The findings of this study aimed to inform the development of targeted strategies and policies to enhance support systems and therapeutic interventions for adolescents with epilepsy, thereby improving their overall QOL. This study sought to elucidate the comprehensive implications of epilepsy on adolescent life and advocated for an integrative approach to its management and support.

2.0 Literature review

This section explores the multidimensional concept of quality of life (QOL) in adolescents with epilepsy, examining its contextual, neuropsychological, developmental, and management-related dimensions as informed by global and African research.

https://doi.org/10.53819/81018102t7055

2.1 Contextualizing Quality of Life in Adolescent Epilepsy

The QOL concept is broad in scope. It encompasses health-related quality of life (HRQOL) and pure QOL measures. The HRQOL measures focus on illness and symptoms, while pure QOL measures address various dimensions of human well-being. In children and adolescents, pure QOL measures provide significant insights into daily functioning at home and school, which fall outside the scope of symptom-focused measures. QOL is a measure of well-being, related to the World Health Organization's (WHO) definition of health as a state of complete physical, mental, and social well-being, and not merely the absence of disease. It is defined as an individual’s perception of their position in life, considering the culture and value systems in which they live, along with their goals, expectations, standards, and concerns. Therefore, QOL assessment places the patient at the center of inquiry, granting due weight to their opinion (Orley et al., 1998; Shiraev, 2016a).

Measuring the QOL helps determine the effects of the disease on the individual. In the case of epilepsy in adolescents, the measure is often obtained from the adolescent's or parent’s perspective. Proxy measurement by a parent, teacher, or health professional is commonly used to assess QOL in children and adolescents due to their limitations in ability, comprehension, language, time perspective, and acquisition bias. In proxy measures, parents often excel at reporting physical problems and behavioral difficulties but are poorer judges of internalized issues such as low self-esteem, embarrassment, and sadness. Their responses may be influenced by their wishes and hopes for the child, their psychosocial circumstances, and their negative affect (Mulhern et al., 1989). For adolescents, QOL can be considered a measure of how they perceive their lives compared to how they reasonably desire or expect it to be. Perception may depend on factors beyond the disease’s severity, including an individual’s age, gender, social status, ethnicity, level of education, anxiety levels, and how one either exaggerates or minimizes symptoms (Riechmann et al., 2019).

The term quality of life represents 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., 1998a; Shiraev, 2016a). In the context of health, QOL is viewed as the way a patient feels and functions. It is subjective and comprises three essential elements, namely, physical health: accounting for aspects such as daily function, 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). QOL 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. It should be inclusive of all areas of life, in addition to taking into consideration the impact of illness as well as that of treatment (Calman, 1984; Orley et al., 1998). 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 to achieve better treatment outcomes (Nabukenya et al., 2014).

2.2 ***Neuropsychological Impact and Global Burden of Epilepsy in Adolescents***

Epilepsy is a neurological disorder defined by the occurrence of at least two unprovoked seizures, spaced at least 24 hours apart. It has significant health implications, including physical, social, and behavioral consequences (Alarcón & Valentín, 2012; Holmes, 2016; Siqueira et al., 2017). The condition is associated with a high risk of mortality, seizure-related injury, adverse psychological outcomes, and reduced QOL. Adolescents are particularly susceptible to epilepsy, making it one of the most common neurological conditions in this age group (Schachter, 2011). The prevalence of epilepsy varies by region and income level. Epilepsy is characterized by unpredictable symptom exacerbations (Chan et al., 2010).

Epilepsy is a global healthcare concern that affects an estimated 50-70 million people worldwide and accounts for 0.75% of the global burden of disease (Granbichler et al., 2017; World Health Organization, 2019). Over 85% of patients worldwide reside in low and middle-income countries (LMICs), primarily concentrated in impoverished regions of Africa, which has the highest population of individuals under the age of 15 years (Paul et al., 2012). In LMICs, the incidence rate ranges from 6 to 10 per 1,000 people, according to WHO's update (Drroopesh, 2017). In Kenya, the incidence of epilepsy is highest among the young and the elderly (Ngugi et al., 2013). A study conducted in Kilifi County, Kenya, recorded the prevalence of epilepsy in children at 21 per 1,000 (Kind et al., 2017). A more recent study estimates the lifetime prevalence of epilepsy in Kenyan children at 21-41 per 1000 (Samia et al., 2019). Epilepsy demonstrates a bimodal distribution based on age, with peaks in the youngest and the elderly (Beghi & Giussani, 2018).

The burden of epilepsy manifests as the cost of treatment, mental and emotional disturbance, as well as social dysfunction (Grant & Adams, 2009). Adolescents living with epilepsy often describe the disorder in practical terms. Apart from seizures, epilepsy is about challenges in school, anxiety regarding social situations, limitations in aspects such as employment, driving, and the issue of dependency (Hesdorffer et al., 2013). Adolescents with epilepsy feel vulnerable, disempowered, and discriminated against. Epilepsy has been associated with undesirable characterizations such as demonic possession, "madness", and even criminal behavior, which leads to stigma (Chong et al., 2016; Hussain et al., 2020a).

Recurrent seizures have the likelihood of disrupting brain functioning, resulting in problems with retention, attention, behavior control, mood changes, and anger reactions. Epilepsy has therefore been closely linked with an individual's neuropsychological functioning, which refers to a set of behavioral tasks controlled by the brain, involving 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, anti-epileptic drug (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).

2.3 ***Developmental and Psychosocial Challenges of Living with Epilepsy in Adolescence***

Adolescence is a unique phase of development characterized by physical and psychological changes, making individuals more vulnerable to somatic and mental health issues. It is also a

https://doi.org/10.53819/81018102t7055

transitional period from childhood to adulthood, in which the individual searches for and forms his or her identity. This process is dynamic and long-lasting, during which the individual tries to find answers to essential questions in his or her life. Adolescents living with epilepsy have concerns beyond seizures. Such an adolescent is faced with the dual challenge of dealing with a chronic condition and successfully achieving age-appropriate developmental tasks such as increasing autonomy, differentiating from the nuclear family, developing self-identity, and focusing more on peer relationships (Chew et al., 2017; Kroger, 2017; Napolitano et al., 2021; Oleś, 2016; Zouini et al., 2019). Balancing a chronic seizure condition with adjusting to the developmental tasks of adolescence, such as increasing autonomy, differentiating from the nuclear family, self-identity development, and focusing more on peer relationships, adds to stress and subsequently impacts negatively on the QOL (Guerrini, 2006).

*2.4 **Challenges in Epilepsy Management and Shifting Research Perspectives***

Studies in the developed world on the QOL of adolescents living with epilepsy indicate that the demands of epilepsy impact various domains of young people's lives. African studies on epilepsy reveal a high burden of the condition, as well as a significant gap in the availability and accessibility of diagnostic tools, epileptic drugs, and specialized therapies, such as physical, occupational, and speech therapy. Cultural beliefs and practices, alongside socioeconomic factors like poverty and lack of access to healthcare, combined with the stigma associated with the condition, pose significant challenges in managing epilepsy, thus highlighting the urgent need for improved management and further research on the condition, along with collaboration among all stakeholders. A study conducted in Kenya targeting children aged between 7-15 years indicated that a good QOL was reported by the majority of children living with epilepsy and their caregivers. Some factors, such as male caregiver gender and lower levels of education, were associated with poor QOL. The study used a quantitative approach employing the CHEQOL-25, a disease-specific QOL measure that documents both the child and caregiver perspectives across the 5 domains. The present study departs from the traditional use of proxy opinions from parents or clinicians in QOL studies, aiming to gain the direct perspective of the adolescent (Mcewan et al., 2004).

3.0 Research Methodology

The study adopted an explanatory sequential design, using a mixed methods research approach, with a QOL perspective. The measure of QOL was, however, purely quantitative, considering that this was an objective from a much wider study. The study population consisted of adolescents living with epilepsy, targeting those attending epilepsy care centers in Nairobi County. The sample consisted of those aged between 13-18 years old and had been diagnosed with epilepsy. The criterion for determining an adolescent diagnosed with epilepsy was based on their enrollment in the care centers, as well as having been referred to the care center by a medical doctor. To further qualify for the survey, they had to be in treatment on anti-epileptic medication for a minimum period of six months, to ensure that the impact of the medication was sufficiently substantial to be reflected in their responses.

From the study population, a sample size of 114 was selected. A total of 103 participated, comprising 60 males and 43 females. 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.

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. There is also a total summary score where high scores indicate a better QOL, and low scores a poor 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).

A pretest study was carried out before the main data collection to evaluate the quality and readability of the research instruments. It was conducted 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. The nature of debriefing after the interview was better established to provide appropriate support to the participants. Feedback from the participants and expert reviewers helped in making the necessary adjustments. The participants gave feedback about the clarity and relevance of the questions, which was put into consideration in editing the questions and interviews to the final script.The QOLIE-AD-48 and questionnaire were administered in English, with support provided for those needing assistance. Data on health, epilepsy effects, and demographics were analyzed using SPSS v2.0 to assess quality of life.

4.0 Results

The response rate was 90.35%, comprising 103 participants out of the initial sample of 114 adolescents living with epilepsy and attending the KAWE clinics in Nairobi County.

*4.1 **Sociodemographic Characteristics***

Table 1 presents the main demographic and clinical features of the participants.

https://doi.org/10.53819/81018102t7055

Table 1: Demographic and Clinical Data of Adolescents Living with Epilepsy

		Number	Percentage
Gender	Male	60	58.3
	Female	43	41.7
Age	13-15	42	40.8
	16-18	61	59.2
Education level	Lower Primary	6	5.8
	Upper Primary	44	42.7
	High school	39	37.9
	College	14	13.6
Living environment	Rural	28	27.2
	Peri-urban	62	60.2
	Urban	14	13.6
Family income in Kenya shillings	Below 10,000	59	57.3
	10,000- 20,999	22	21.4
	21,000-50,999	13	12.6
	51,000-and above	9	8.7
Anti-epileptic medication	Monotherapy	60	58.3
	Di-therapy	43	41.7
Other types of medication	None	97	94.2
	ARV	1	1
	Painkillers	3	2.9
	Sinuses	1	1
	Ulcers	1	1
Seizure type	Generalized onset seizures	99	96.12
	Focal onset seizures	4	3.88
Seizure frequency	Weekly	27	26.21
	Over a week to 6 months	46	44.66
	Over 6 months or seizure-free	30	29.13
Adherence to medication	Adheres	92	89.3
	Does not adhere	11	10.7

Participants included 103 adolescents, comprising 41.7% females and 58.3% males, aged between 13 and 18 years. Their mean age was 15.9 years, with a standard deviation of 1.96. Each had been diagnosed with epilepsy for at least six months and had been receiving treatment with AEDs for a minimum of the same duration. Regarding educational attainment, 5.8% of the participants were enrolled in lower primary school, 42.7% attended upper primary school, and 37.9% were enrolled in high school. Another 13.6% were either enrolled in college or had completed high school and were pursuing skills-based programs at tertiary institutions. The vast majority of participants, or 60.2%, resided in the peri-urban region of Nairobi County. In contrast, 27.2% and 13.6% were from rural and urban areas, respectively. Most participants (57.3%) reported monthly incomes of less than Ksh. 10,000 per family, while 21.4% had incomes between Ksh. 10,000 and Ksh. 20,999. Approximately 12.6% reported incomes between Ksh. 21,000 and Ksh. 50,999, with a smaller percentage (8.7%) earning Ksh. 51,000 or more.

The clinical profile of the participants revealed a mean age of epilepsy onset at 7.8 years (SD = 5.12), with diagnosis occurring at a mean age of 9.05 years (SD = 5.19). The average duration of living with epilepsy was 7.8 years (SD = 4.89), and treatment had been ongoing for a mean of 6.7 years (SD = 4.9). A majority (58.3%) were on monotherapy, while 41.7% received di-therapy or polytherapy. Most participants (94.2%) were not using any other medications, although a small percentage (5.8%) reported use of ARVs, painkillers, or drugs for ulcers. Regarding seizure types, 94.12% experienced generalized onset seizures and 3.88% had complex focal onset seizures. Seizure frequency varied, with 12.21% experiencing weekly seizures, 44.66% having seizures between one week and six months, and 29.12% being seizure-free or having seizures beyond six months. Notably, 89.3% adhered to their medication regimens, while 10.7% did not.

The second questionnaire utilized was the QOLIE-AD-48, a widely accepted and standardized measure of Quality of Life that is tailored specifically to the needs of patients with epilepsy. This instrument was employed to gather information on the overall QOL, which is represented by the total summary score, as well as the eight distinct subscales. These subscales encompass epilepsy impact, memory and concentration, attitudes toward epilepsy, physical functioning, stigma, social support, school behavior, and health perceptions. The results are presented in Table 2

The table below displays the values of participants' QOL on the QOLIE-AD- 48 and its subscales

Table 2: 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

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

The mean QOLIE-AD total score was M 59.23, SD = 14.69. This score ranged from 16.26 to 94.27, with higher values indicating 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.

On the subscales, the average score of 69.56 on the epilepsy impact subscale suggests that participants generally experienced a moderate impact from their condition. However, the standard deviation of 17.52 indicated that individual experiences are varied. The cognitive function subscale, which assessed memory and concentration, had a mean score of 58.17, indicating moderate difficulties in this area. The substantial standard deviation of 24.18 suggests that various participants encounter diverse levels of cognitive challenges.

The physical functioning subscale evaluated the influence of epilepsy on physical activities. The mean score of 68.20 indicated a satisfactory level of physical functioning, although some individuals reported substantial impairments, with a minimum score of 0.00 and a high standard deviation of 22.76. The stigma subscale assessed the extent to which adolescents experience stigmatization due to epilepsy. With a mean score 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 wide range of 22.68 and substantial standard deviation 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 purpose of the attitudes towards epilepsy scale is to evaluate personal perceptions and attitudes towards epilepsy. The average score of 42.18 indicated predominantly unfavorable attitudes or perceptions, which could be influenced by societal stigma or personal experiences. The standard deviation of 21.23 signified that attitudes towards epilepsy varied among individuals. A mean score of 52.10 indicated a moderate level of health perception, and the large standard deviation of 28.26 implied a wide range of diverse health perceptions, varying from poor to good.

The QOLIE-AD-48 instrument offered valuable insights into the QOL experienced by adolescents with epilepsy, as well as the specific areas in which they faced challenges. Overall, the scores indicated a moderate level of QOL, with noticeable variations among the participants. The subscales that stood out as areas of concern were stigma, memory and concentration, and school behavior. These domains exhibited lower mean scores and wider ranges, suggesting that many of the participants encountered significant difficulties in these areas.

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.

Table 3 presents the results of the QOL scores among various demographic and clinical characteristics of the participants.

Table 3: Quality of Life of Adolescents Living With Epilepsy Across Different Demographics and Seizure Characteristics

		MIN	MAX	Mean	Sd.	p-value
Gender	Male	16.15	94.27	59.21	15.57	0.988
	Female	33.85	86.46	59.25	13.54	0.988
Age	13-15	33.85	86.46	60.08	13.95	0.627
	16-18	16.15	94.42	58.64	15.26	0.621
Education level	Lower Primary	16.15	63.02	42.36	15.67	**0.009**
	Upper Primary	33.85	86.46	59.85	12.67	
	High school	34.38	86.46	58.61	15.12	
	College	50.00	94.27	66.22	14.58	
Living environment	Rural	16.15	84.38	57.33	14.73	0.652
	Peri-urban	33.85	86.46	60.31	14.14	
	Urban	34.38	94.27	58.17	17.71	
Family income in Ksh.	Below 10,000	16.15	85.42	57.21	15.20	0.46
	10,000- 20,999	39.58	86.46	61.81	13.88	
	21,000-50,999	40.10	94.27	61.78	15.07	
	50,000-and above	52.08	86.46	62.44	12.61	
Anti-epileptic medication	Monotherapy	35.42	94.27	62.90	14.22	**0.02**
	Di-therapy	16.15	85.42	54.11	13.93	
Seizure type	Generalized onset seizures	16.15	94.27	59.16	14.86	0.08
	Focal onset seizures	46.88	72.92	60.94	14.22	
Seizure frequency	Weekly	16.15	81.77	49.38	11.84	**0.002**
	Over 1 week to 6 months	34.90	84.38	59.70	12.07	
	Over 6 months or seizure-free	34.38	94.27	67.36	15.74	
Adherence to medication	Adheres	16.15	94.27	59.38	15.22	0.897
	Does not adhere	47.92	80.21	58.00	9.53	

MIN= Minimum, MAX= Maximum, Sd= Standard Deviation

According to the data, demographic and epilepsy-related factors play a role in determining the QOL of the participants in this population. The average QOL scores for male participants (M=59.21, SD= 15.57) and female participants (M=59.25, SD= 13.54) were almost identical, suggesting no significant difference in QOL between the two genders. However, the higher standard deviation for male participants than female participants indicated that male QOL scores were more spread out around the mean, suggesting greater variability.

The QOL scores of younger individuals aged 13-15 were slightly higher than those of their older counterparts, suggesting a potential age-related difference in the perceived QOL. Likewise, individuals with higher education levels displayed higher QOL scores, indicating a positive effect of education on QOL. Peri-urban residents had the highest mean QOL scores, suggesting that their living environment contributed to their better QOL. Additionally, higher family income was found to be correlated with higher QOL scores, indicating a significant impact of economic status on QOL.

The analysis revealed a significant difference in QOL scores between adolescents receiving monotherapy and those receiving di/polytherapy. Those receiving monotherapy reported higher QOL scores compared to those receiving multiple AEDs. The p-value of 0.002 **(≤0.05)** indicates that the difference in mean QOL scores between the monotherapy and di-therapy groups is statistically significant. The results indicate that simpler medication regimens were associated with better QOL among the participants in this population.

The impact of seizure type, whether generalized or focal onset, on QOL scores was minimal, although participants with the latter had slightly higher scores. Fewer seizures were linked to higher QOL scores, indicating that frequent seizures negatively impacted QOL. Medication adherence had a slight positive effect on QOL scores, which underscores the importance of adherence in managing epilepsy and enhancing QOL.

5.0 **Discussions**

The findings of this study highlighted the challenges as well as protective aspects that influenced the QOL of the participants under study in Nairobi County. The results show considerable differences in QOL scores, which indicates that adolescents with epilepsy experienced a wide range of challenges on the one hand as well as protective factors that significantly influenced the participants' overall QOL on the other hand.

The overall mean score was 59.23, SD=14.69, reflecting a moderate level of QOL among the participants, with the standard deviation signifying a considerable variation of the QOL measure among this population. This is further underscored by the wide range of scores from 16.26 to 94.27, and an indication that the experiences of the participants were diverse, with some being severely impacted while others were living relatively well-managed lives. These findings are supported by a study carried out in Brazil on children and adolescents attending an outpatient clinic and aged between 10 and 19 years, where their QOL was found to be negatively impacted by epilepsy, with a score of M=68.73, SD= 15.09 (Siqueira et al., 2014).

The mean score of 69.56, SD = 17.52, on the epilepsy impact subscale suggested a strong impact of epilepsy on this population and significant individual differences in how the condition affected their daily lives. Cognitive functioning difficulties were highlighted as common, with a mean score of 58.17, SD=24.18, as reflected on the memory and concentration subscale, with a varying degree of impairment among the participants. Physical functioning measures showed generally satisfactory physical health, although the significant range in scores from 0.00-100.00 indicated that some of the participants faced severe physical limitations. These results are concurrent with the findings of previous research conducted in Zurich, where epilepsy has been found to negatively impact a set of behavioral tasks controlled by the brain, such as language, visual perception skills, memory, attention, and executive skills. Epilepsy patients were also found to differ in their neuropsychological functioning (Bögli et al., 2022; Masood & Rafique, 2012).

The stigma subscale had the lowest score, with a mean of 43.41, indicating high levels of stigmatization experienced by the participants. This is a particularly concerning finding as stigma not only impacts social interactions but also causes psychological distress, leading to a diminished QOL. These findings are concurrent with an Ireland study that employed a mixed methods study approach where children and adolescents living with epilepsy, as well as their families, experienced stigma by being socially excluded and restricted in activities. They were also teased, bullied, and subjected to internalized negative feelings of epilepsy (Benson et al., 2016). Stigma was also found to constitute a significant part of the problems experienced by people living with epilepsy (de Boer, 2010).Addressing misconceptions about epilepsy can be achieved through the implementation of culturally relevant psychoeducation programs that can potentially improve adolescents' self-perception and reduce feelings of isolation

Social support, as measured by a mean score of 72.82, appeared to be a strong protective factor for many adolescents; however, the high standard deviation of 22.68 indicated that support was not available to all participants. The findings related to school behavior, with a mean score of 56.19, reflected moderate challenges that may have been exacerbated by cognitive difficulties and stigma. Attitudes toward epilepsy were evident in a low mean score of 42.18, indicating that negative perceptions were prevalent among the participants. These attitudes were influenced by the stigma experienced and the personal experiences of the participants. This study also established that these unfavorable attitudes further undermined their self-esteem, as revealed through the focus group discussions. These findings were corroborated by a study conducted in Uganda, which investigated the impact of epilepsy on learning and behavior, as well as the necessary support systems for children with epilepsy. Epilepsy was associated with stigma and restrictions in the school environment. A majority of the children, 53%, living with epilepsy reported that their condition negatively impacted their learning, memory, attention, concentration, and consequently their academic performance.

The demographic and clinical characteristics of the participants played a significant role in determining QOL. The absence of significant gender differences in overall QOL scores indicated that both male and female adolescents faced equal challenges in this population. Age-related differences in QOL scores, with higher scores in younger adolescents, reflected the developmental demands that come with age. The positive association between higher education levels and corresponding QOL highlights the importance of educational attainment in improving life outcomes for individuals with epilepsy. Similarly, the higher QOL scores among urban and peri-urban residents, as well as those from higher-income families, emphasize the influence of socioeconomic factors on well-being, indicating that access to resources and healthcare plays a crucial role in the effective management of epilepsy. Schools and community organizations should collaborate to create inclusive learning environments and provide reasonable accommodations.

The significant difference in QOL scores between adolescents on monotherapy and those on polytherapy, with the former reporting better QOL, suggests that simpler medication regimens may reduce treatment burden and improve adherence, ultimately enhancing QOL. There was a clear association between lower seizure frequency and medication resulting in higher QOL. These findings align with those of a study conducted in Kenya using proxy reports from parents, where a low level of education, a higher seizure burden, and a low annual income were significantly associated with a low QOL. A study conducted in Khartoum, Sudan, also found that QOL was statistically significantly lower in patients on polytherapy and those who did not adhere to medication (Mohamed & E.Mohamed, 2020).

6.0 Implications for Clinical Psychol

The research findings highlight several implications for clinical psychology concerning adolescents with epilepsy in Nairobi County. The considerable variation in QOL scores emphasizes the need for tailored interventions that address specific challenges faced by this population. Major areas requiring attention to improve QOL include reducing the impact of stigma, strengthening social support systems, and offering resources to enhance cognitive and physical functioning. Moreover, strategies aimed at improving adherence could substantially boost QOL outcomes. These findings underscore the importance of comprehensive care approaches that consider each patient's unique demographic and clinical characteristics.

7.0 Conclusions

This study highlights several critical areas of concern for adolescents living with epilepsy in Nairobi County. The significant variability in QOL scores underscores the need for tailored interventions to address the specific challenges faced by this population. Key areas requiring attention include reducing the impact of stigma, enhancing social support networks, and providing resources to improve cognitive and physical functioning. Additionally, interventions aimed at simplifying medication regimens and promoting adherence could significantly enhance QOL outcomes. These findings suggest the importance of comprehensive individualized care strategies that consider each patient's unique demographic and clinical characteristics.

8.0 Recommendations

The study's findings suggest that clinical psychologists and counselors should develop targeted psychological interventions due to the notable variability in quality of life (QOL) scores across gender and age demographics. Female adolescents, who exhibited somewhat lower and more inconsistent self-esteem scores, may gain from gender-focused programs that promote resilience and positive self-image. Likewise, interventions tailored to specific age groups, especially for younger adolescents, could strengthen coping skills and boost self-esteem, thereby addressing the modest disparity identified between various age groups.

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

Benson, A., O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2016). The stigma experiences and perceptions of families living with epilepsy: Implications for epilepsy-related communication within and external to the family unit. *Patient Education and Counseling*, *99*(9), 1473–1481. https://doi.org/10.1016/j.pec.2016.06.009

Berman, A. H., Liu, B., Ullman, S., Jadbäck, I., & Engström, K. (2016). Children's Quality of Life Based on the KIDSCREEN-27: Child Self-Report, Parent Ratings and Child-Parent Agreement in a Swedish Random Population Sample. *PLoS ONE*, *11*(3), e0150545. https://doi.org/10.1371/journal.pone.0150545

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.

Chan, D., Phuah, H.-K., Ng, Y.-L., Choong, C.-T., Lim, K.-W., & Goh, W. H. S. (2010). Pediatric epilepsy and first afebrile seizure in Singapore: Epidemiology and investigation yield at presentation. *Journal of Child Neurology*, *25*(10), 1216–1222. https://doi.org/10.1177/0883073809358924

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

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 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

Elfil, M., & Negida, A. (2017). Sampling methods in Clinical Research; an Educational Review. *Emergency*, *5*(1), e52.

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

Grant, I., & Adams, K. M. (2009). *Neuropsychological Assessment of Neuropsychiatric Disorders*. Oxford University Press USA - OSO. http://ebookcentral.proquest.com/lib/stpaulslimuru-ebooks/detail.action?docID=415581

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

Hesdorffer, D. C., Beck, V., Begley, C. E., Bishop, M. L., Cushner-Weinstein, S., Holmes, G. L., Shafer, P. O., Sirven, J. I., & Austin, J. K. (2013). Research implications of the Institute of Medicine Report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*: *Epilepsy Across the Spectrum: Promoting Health and Understanding*. *Epilepsia*, *54*(2), 207–216. https://doi.org/10.1111/epi.12056

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

Hussain, S. R., Orwa, J., Sokhi, D. S., Kathomi, C. M., Dossajee, H., Miyanji, O., Ngugi, A., & Samia, P. (2020b). Determining the quality of life of children living with epilepsy in Kenya—A cross-sectional study using the CHEQOL-25 tool. *Seizure*, *76*, 100–104. https://doi.org/10.1016/j.seizure.2020.01.007

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

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

Kroger, J. (2017). Identity Development in Adolescence and Adulthood. In *Oxford Research Encyclopedia of Psychology*. https://doi.org/10.1093/acrefore/9780190236557.013.54

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

Mcewan, M. J., Espie, C. A., Metcalfe, J., Brodie, M. J., & Wilson, M. T. (2004). Quality of life and psychosocial development in adolescents with epilepsy: A qualitative investigation using focus group methods. *Seizure*, *13*(1), 15–31. https://doi.org/10.1016/S1059-1311(03)00080-3

Mohamed, I., & E.Mohamed, S. (2020). Quality of life among adolescents with epilepsy: An outpatient based study, Khartoum, Sudan. *Khartoum Medical Journal*. https://www.semanticscholar.org/paper/Quality-of-life-among-adolescents-with-epilepsy%3A-An-Mohamed-E.Mohamed/7ddb5a3c385f48d0aa19d2acb029a93d102f4d6c

Mulhern, R. K., Horowitz, M. E., Ochs, J., Friedman, A. G., Armstrong, F. D., Copeland, D., & Kun, L. E. (1989). Assessment of quality of life among pediatric patients with cancer. *Psychological Assessment: A Journal of Consulting and Clinical Psychology*, *1*(2), 130–138. https://doi.org/10.1037/1040-3590.1.2.130

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

Napolitano, C. M., Sewell, M. N., Yoon, H. J., Soto, C. J., & Roberts, Brent. W. (2021). Social, Emotional, and Behavioral Skills: An Integrative Model of the Skills Associated With Success During Adolescence and Across the Life Span. *Frontiers in Education*, *6*. https://www.frontiersin.org/articles/10.3389/feduc.2021.679561

Nicholas, A. (2023). Unlocking the hidden burden of epilepsy in Africa: Understanding the challenges and harnessing opportunities for improved care. *Health Science Reports*, *6*(4), e1220. https://doi.org/10.1002/hsr2.1220

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: The Journal of Mental Science*, *172*, 291–293. https://doi.org/10.1192/bjp.172.4.291

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

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

Schramme, T. (2023). Health as Complete Well-Being: The WHO Definition and Beyond. *Public Health Ethics*, *16*(3), 210–218. https://doi.org/10.1093/phe/phad017

Shiraev, E. (2016b). *Personality Theories: A Global View*. SAGE Publications, Incorporated. https://ebookcentral.proquest.com/lib/stpaulslimuru-ebooks/detail.action?docID=6403174

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

Siqueira, N. F., Oliveira, F. L. B. B., Siqueira, J. A., & Souza, E. A. P. de. (2014). Quality of Life in Epilepsy: A Study of Brazilian Adolescents. *PLOS ONE*, *9*(9), e106879. https://doi.org/neuropsychological

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

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