Self-Esteem in Adolescents Living with Epilepsy and the Implications for Clinical Psychology

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ABSTRACT

Background: 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 self-esteem. Self-esteem refers to an individual's self-appraisal of his or her worth as a person and is conceptualized as a feeling that one is good enough. It involves feelings of self-acceptance and self-respect, reflecting a perception rather than a reality. This study explored the impact of epilepsy on self-esteem among adolescents living with epilepsy and the implications for clinical psychology.

Materials and methods: A quantitative research design was utilized, and data was collected from 103 participants aged 13-18 years attending the Kenya Association for the Welfare of People Living with Epilepsy (KAWE) clinics, using a questionnaire and the Rosenberg self-esteem scale (RSES).

Results: The participants' overall self-esteem was within normal parameters, M=17.12 and SD=3.00. The highest score was 25, which falls within the normal range, while the lowest score was 6, indicating a low level of self-esteem. Self-esteem was influenced by education level, living environment, medication regimen, seizure type, and seizure frequency. There was a positive correlation between educational level and self-esteem scores, p=0.004 **(≤ 0.05),** indicating that education improved self-concept and resilience in living with epilepsy. Urban living environments provided better support systems and opportunities that enhanced self-esteem, p= 0.030 **(≤ 0.05),** indicating that environmental factors such as access to social support and economic opportunities played a role in shaping psychological well-being.

Conclusion: There is a need for a multidimensional approach to enhancing self-esteem of adolescents living with epilepsy. Gender and age-specific programs that foster resilience, positive self-concept, and coping skills should be developed to address gaps identified between different age groups and sexes. There is need for policy advocacy to increase access to mental health, particularly in rural and peri-urban areas.

Keywords: Self-esteem, epilepsy, adolescent, Kenya.

INTRODUCTION

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, 2016; Siqueira, Oliveira, & de Souza, 2017). It is associated with a high risk of mortality and seizure-related injury, as well as adverse psychological outcomes and reduced QOL (Chong et al., 2016). 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 level of income, and it is characterized by unpredictable symptom exacerbations (Chan et al., 2010).

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 transitional period from childhood

to adulthood, in which the individual searches for and forms his or her identity, a process that is dynamic and long-lasting, during which the individual tries to find answers to essential questions in his or her life. The adolescent living with epilepsy has 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. The tasks comprise increasing autonomy, differentiating from the nuclear family, self-identity development, and focusing more on peer relationships (Chew et al., 2017; Kroger, 2017; Napolitano et al., 2021; Oleś, 2016; Zouini et al., 2019).

The adolescent, therefore, defines the disorder in practical terms, where apart from seizures, epilepsy becomes about challenges in school, anxiety regarding social situations, limitations in aspects such as employment, driving, and the issue of dependency (Hesdorffer et al., 2013). They feel vulnerable, disempowered, and discriminated against (Chong et al., 2016). The burden of epilepsy also comes in the form of the cost of treatment, mental and emotional disturbance as well as social dysfunction (Grant & Adams, 2009; WHO, 2019). A diagnosis of epilepsy in adolescence negatively impacts the QOL depending on the severity, frequency, and type of seizure, as well as the social and psychological factors (Rozensztrauch & Kołtuniuk, 2022). Balancing a chronic seizure condition with adjusting to the developmental tasks of adolescence leads to stress and subsequently impacts negatively on the QOL (Chew et al., 2017; Guerrini, 2006).

LITERATURE REVIEW

Self-esteem refers to an individual's self-appraisal of his or her worth as a person as opposed to a person's objective talents and abilities or even how one is evaluated by others (Orth & Robins, 2014). It is conceptualized as a feeling that one is good enough. It therefore involves feelings of self-acceptance and self-respect. Self-esteem reflects a perception rather than a reality (Ackerman et al., 2011; Zeigler-Hill, 2013).

A cross-sectional study conducted in Hong Kong aimed at assessing self-esteem in adolescents living with epilepsy and its relationship with psychosocial and disease-related factors compared 140 adolescents with epilepsy to 50 with asthma using the Culture Free Self-esteem Inventory for Children (CFSEI-2). The participants were aged between 10- 18 years and were attending a neurology outpatient clinic in Tuen Mun Hospital. Those with epilepsy reported significantly lower self-esteem scores compared to those with asthma. Independent factors associated with low overall self-esteem were associated with a higher score in depression, a longer duration of epilepsy, and a father's lack of employment. This study concluded that self-esteem was compromised in adolescents with epilepsy when compared to their peers with asthma. The study also established a significant correlation between self-esteem and psychosocial comorbidities (Kwong et al., 2016).

In a descriptive correlational study aimed at assessing the perception of stigma and self-esteem in children and adolescents with epilepsy, 150 children and adolescents aged between 9 and 5 years participated. The participants were attending a pediatric neurology hospital in Turkey associated with epilepsy. Results showed that the participants had a higher perception of stigma and lower self-esteem levels. The findings further underscored the interplay between self-esteem and perception of stigma, with low self-esteem being associated with a higher sense of being stigmatized. Their perceptions of being stigmatized were influenced by several factors such as their educational status, their parents' educational status and income levels, their family type, and self-esteem (Şengül & Kurudirek, 2022).

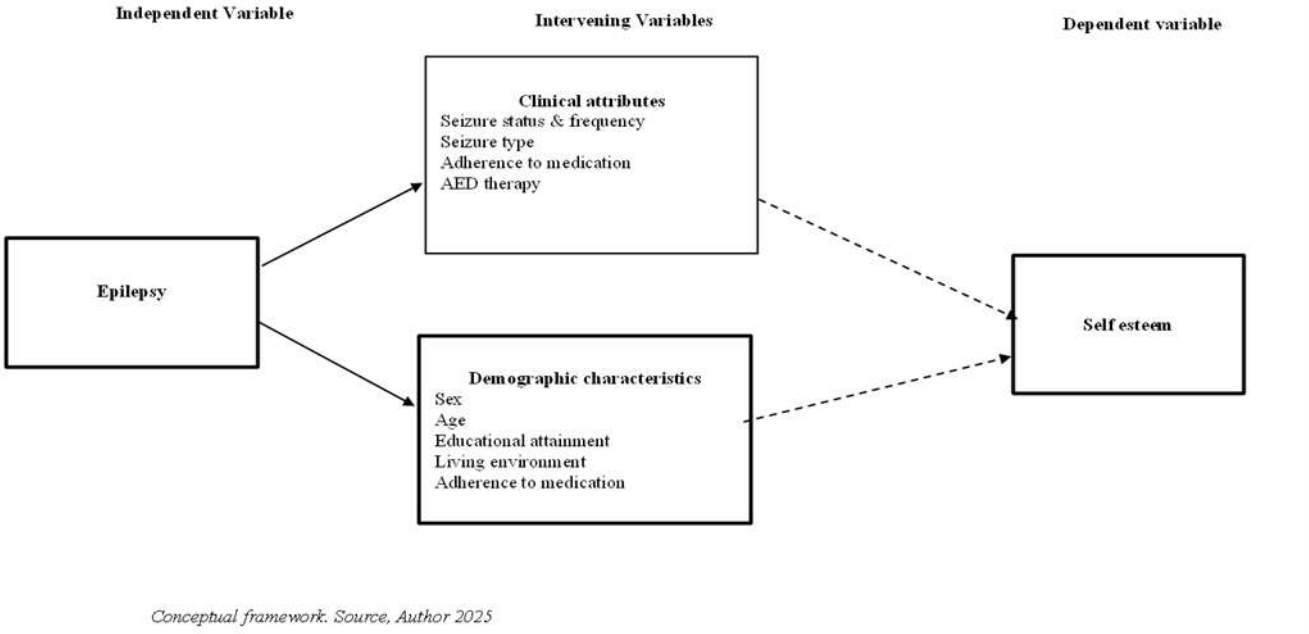
The findings above are supported by a study carried out on 101 Brazilian adolescents of both sexes aged between 10-19 years from both elementary and high school. The study compared the self-esteem of Brazilian adolescents living with epilepsy with those without the condition. It further investigated the correlations between self-esteem and symptoms of depression and anxiety in these adolescents. Adolescents living with epilepsy had lower self-esteem compared to those without epilepsy. There were also significant correlations between self-esteem scores and symptoms of depression and anxiety in both groups, an observation that points to the fact that self-esteem levels were related to the presence of anxiety and depression symptoms regardless of epilepsy diagnosis, an indication that epilepsy can lead to changes in an individual's self-esteem and social interactions and as a result influence their behavior (Siqueira, Oliveira, & De Souza, 2017).

The findings above are corroborated by those of a qualitative study conducted in the government hospitals of

Bahir Dar City in Ethiopia aimed at exploring the lived experiences of young people with epilepsy. A total of 11 participants aged between 12-24 years were taken through semi-structured interviews. The findings indicated that participants went through painful experiences related to psychosocial, physical, economic, and health care. However, they stated that coping strategies for epilepsy included support from family, the community, as well as religious institutions (Ayele et al., 2023).

The reviewed studies indicate lower self-esteem among adolescents with epilepsy linked to stigma, depression, and anxiety. While cross-cultural data offer valuable insights, the research remains largely cross-sectional, limiting causal inferences. Few studies disaggregate the influence of family dynamics, socioeconomic status, and cultural perceptions on self-esteem. Additionally, minimal attention has been paid to resilience factors or protective mechanisms that could buffer self-esteem decline. Longitudinal and intervention-based research assessing how psychosocial support, inclusive education, and mental health services can enhance self-esteem and overall psychosocial well-being in adolescents living with epilepsy, especially within Low and middle-income countries (LMICs), is lacking.

Figure 1: Conceptual Framework



Conceptual framework. Source, Author 2025

MATERIALS AND METHODS

Study Design: The study adopted a quantitative research design.

Study location: Data was therefore gathered from individuals attending the KAWE epilepsy clinics of Nairobi County, namely: Huruma Lions, Riruta, and Karen, and who had met the eligibility criteria were included in this study.

Sample size: 103

Sample size calculation: To determine the sample size, Slovin's formula was used where n was the sample size, N was the population, and e was the sampling error or error of precision (Kothari, 2004). This formula allowed for the sampling of the population with a degree of accuracy by considering confidence levels and the degree of error.

Subjects and selection method: The study population consisted of adolescents living with epilepsy, specifically 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. This research employed the convenience sampling method, a technique that is most applicable in clinical research and is also widely used in the field (Elfil &

Negida, 2017). The subjects were therefore enrolled based on their availability and accessibility. The method was quick, inexpensive, and convenient. The rationale behind this was that in the case of epilepsy, only a limited number of people can serve as primary data sources since the population is relatively small and specific. The criterion of determining an adolescent diagnosed with epilepsy was based on their enrollment to the care centers, as well as having been referred to the care center by a medical doctor. Attending the epilepsy care center was proof enough that they had been diagnosed with epilepsy.

Inclusion criteria: To further qualify for the survey, they had to be in treatment on anti-epileptic medication for a minimum period of six months. Being on medication for such a period ensured that AED effects and side effects could be detected in case the patient was experiencing any.

Data collection tools and procedure: The data collection tools comprised a questionnaire to collect demographic and clinical data, and the Rosenberg self-esteem scale (RSES). These were researcher-administered, and every participant was interviewed individually. The RSES is the most widely used scale to assess self-esteem worldwide. Rosenberg's self-esteem scale (RSES) is scored as a Likert scale and is widely used to assess overall feelings of self-worth and self-acceptance. Participants respond to 10 questions using a 4-point Likert scale format ranging from strongly agree to strongly disagree. Items 3,5,6,8 and 9 are reverse scored. Higher scores indicate high self-esteem. The psychometric properties of a translated RSES in Eritrea demonstrate a high internal consistency and reliability (Amahazion, 2021). It is a reliable and valid scale for use with adolescents aged 13 years and above.

Where the respondent was not able to complete them on his or her own, the researcher read out the questions and then filled in the answers. Quantitative data was analyzed using SPSS version 20, and it was presented in descriptive statistics.

Ethical considerations: This research was conducted ethically. Before data collection, participants were provided with sufficient, appropriate, and accurate information regarding the research. This allowed them to make an informed decision on whether or not to participate in the data collection. Participants' informed consent was obtained from their parents and/or guardians in written form. Verbal assent was obtained from the participants under the age of 18 years as well as permission to use the recording. The rationale for using the recording was explained to the participants.

Potential risks to the participants in this research were in the form of psychological harm. Some participants' fear of getting embarrassed or feeling judged by the researcher was managed by normalizing living with epilepsy through information giving, a nonjudgmental attitude from the researcher, and creating a safe space for all the participants during the data collection process. Debriefing was also conducted with every participant after the interviews.

The confidentiality and anonymity of the participants were observed. Maintaining complete confidentiality of the information obtained during focus group discussions can prove problematic since the researcher cannot ensure that the participants will not disclose information shared by others. This was managed by continually reinforcing the issue of confidentiality throughout the process and encouraging the participants not to disclose what was discussed outside the group. For the qualitative phase of data collection, any identifiable information was removed from the transcripts in the quotations used by the researcher in the transcripts. Information collected from the participants was stored securely to maintain confidentiality. Ethical approval was obtained from the University Ethical Review Board (IRB) as well as the National Commission for Science, Technology, and Innovation (NACOSTI), KAWE, the County government of Nairobi at City Hall, Dagoretti sub-county, Lang'ata Sub- County, and Starehe Sub- County offices.

RESULTS

The participants' overall self-esteem was found to be within normal parameters, with a mean score of 17.12 and a standard deviation of 3.00. The highest score obtained was 25, which falls within the normal range, while the lowest score recorded was 6, indicating a low level of self-esteem.

Table 1presents the results of the self-esteem scores among various demographic and clinical characteristics of the participants.

Table no 1: Shows the self-esteem of adolescents living with epilepsy across different demographics and seizure characteristics

		MIN	MAX	Mean	Sd.
Gender	Male	13.00	25.00	17.53	2.59
	Female	6.00	22.00	16.56	3.45
Age	13-15	6.00	25.00	16.43	3.13
	16-18	7.00	24.00	17.61	2.84
Education level	Lower Primary	14.00	21.00	15.67	2.66
	Upper Primary	6.00	25.00	16.25	3.26
	High school	13.00	24.00	18.00	2.54
	College	14.00	23.00	18.07	2.64
Living environment	Rural	13.00	20.00	16.68	1.91
	Peri-urban	6.00	24.00	16.90	3.25
	Urban	15.00	25.00	19.15	3.08
Family income in Ksh.	Below 10,000	6.00	24.00	17.17	3.25
	10,000- 20,999	7.00	21.00	16.91	2.97
	21,000-50,999	13.00	20.00	16.92	2.06
	51,000 and above	14.00	22.00	17.67	3.04
Anti-epileptic medication	Monotherapy	13.00	25.00	17.38	2.60
	Di-therapy	6.00	24.00	16.77	3.49
Seizure type	Generalized onset seizures	7.00	25.00	17.22	2.84
	Focal onset seizures	6.00	18.00	14.75	5.85
Seizure frequency	weekly	7.00	23.00	17.33	3.26
	Over a week to 6 months	6.00	21.00	16.65	2.73
	Over 6 months or clear of seizures	13.00	25.00	17.67	3.13
	Once a year or no	13.00	24.00	17.22	2.90
	Seizure free	14.00	22.00	17.63	3.07
Adherence to medication	Adheres	6.00	25.00	17.08	2.84
	Does not adhere	7.00	22.00	17.55	4.30

N/A= Not applicable, MIN= minimum, MAX= maximum, SD= standard deviation.

The average self-esteem score for males was M=17.53, SD=2.59, while the average for females was M=16.5, SD=3.45. There was greater variability in the self-esteem scores among females. The mean self-esteem score for males was higher than for females. Despite this difference, there was no statistically significant difference in gender at the 0.05 significance level. Adolescents aged 13-15 years had a mean score of M=16.43, SD=3.13, while those aged 16-18 had a mean score of 17.6, SD=2.84. This suggested a modest increase in self-esteem with age in this particular population. The difference in self-esteem between the two age groups was not

statistically significant at the 0.05 level, but it was very close to significance.

Higher education levels were associated with higher self-esteem scores with college-educated participants having the highest mean score of 18.07, high schoolers at 18.00, upper primary at 16.25, and lower primary at the lowest 15.67. The trend indicated a potential positive impact of education on self-esteem. The p-value 0.018 **(≤ 0.05)** further supports this conclusion by indicating that there are statistically meaningful disparities in self-esteem scores among the various educational levels **(see Table 2).** The results of the ANOVA test suggest that the average self-esteem scores tend to increase with each ascending level of education. In particular, adolescents in high school and college students exhibit higher average self-esteem scores compared to their counterparts in lower and upper primary school.

Adolescents living in urban environments had the highest mean, M=19.15, SD=3.08, followed by those in peri-urban areas, M=16.90, SD=3.25, and rural areas, M=16.68, SD=1.91. Adolescents from the highest-income families had slightly higher mean self-esteem compared to those from lower-income families. On the drug regimen, those on monotherapy had a higher self-esteem, M=17.38, SD= 2.60 compared to those on di or polytherapy, M=16.77, SD=3.49. This indicated that a less complex medication regimen contributed to higher self-esteem. Participants with generalized onset seizures had a higher mean score of M=17.22, SD= 2.84 on self-esteem compared to those with focal onset seizures of M=14.75, SD = 5.85. The small sample for the latter limited the robustness of these findings. Participants who were seizure-free for six months and more exhibited the highest mean, M=17.67, SD=3.13, highlighting the positive impact of extended periods without seizures on self-esteem.

Table 2: Shows the Self-Esteem Chi Squares of Adolescents Living with Epilepsy in Relation to Different Demographics and Clinical Characteristics

Clinical and demographic characteristics	X2	df	p
Gender	15.49	15	0.104
Age	82.83	75	0.063
Educational level	38.81	45	**0.004**
Living environment	33.67	30	**0.038**
Family income	36.90	45	0.880
Anti-epileptic medication	16.48	15	0.305
Seizure type	70.90	60	0.180
Seizure frequency	103.41	90	0.775
Adherence to medication	26.37	15	0.624

X^2 = Chi square, df=Degrees of freedom, Sig =statistical Significance

Urban living environments in this population generally provided better support systems and opportunities that enhanced self-esteem. The p-value is 0.030 **(≤ 0.05),** indicating statistically significant differences in self-esteem scores among the various location groups. This indicated that environmental factors such as access to social support and economic opportunities played a role in shaping psychological well-being. There was a positive correlation between educational level and self-esteem scores, p=0.004 **(≤ 0.05).** Education among the participants enhanced their self-concept and resilience as far as living with epilepsy was concerned.

DISCUSSION OF THE RESULTS

The majority of the participants recorded self-esteem levels that were within the normal range with gender differences being minimal. Older adolescents had higher self-esteem compared to their younger counterparts.

Higher education attainment and urban residency correlated with higher self-esteem due to greater access to resources and social opportunities compared to rural areas. Continued seizure freedom and a simpler medication regimen were associated with higher self-esteem, an indication that seizure management had psychological benefits. These findings are supported by those of an earlier study, which depicted children with epilepsy as having a high perception of stigma and that their perceptions of being stigmatized were influenced by their educational status, family income level as well as their self-esteem (Şengül & Kurudirek, 2022).

Implications for clinical psychology

The observed differences in self-esteem across gender, age, education level, and living conditions indicate the importance of addressing psychosocial factors in epilepsy management. Clinicians should focus particularly on females and older adolescents who show lower self-esteem. The positive link between higher education attainment and self-esteem suggests that acquiring education could improve psychological well-being. Regarding medication, monotherapy was linked to higher scores, indicating that simplifying treatment plans might enhance psychological outcomes. The notable differences based on seizure type and frequency further highlight the need for tailored interventions to boost self-esteem, especially for those with focal seizures and more frequent episodes. Prioritizing seizure control is crucial, as longer seizure-free periods appeared to enhance self-esteem. Incorporating these psychosocial insights into epilepsy management can improve self-esteem in adolescents living with epilepsy, supporting the need for holistic patient-centered approaches in clinical settings.

CONCLUSIONS AND RECOMMENDATIONS

Findings highlight that self-esteem among adolescents with epilepsy is influenced by various factors including education level, living environment, medication regimen, seizure type, and seizure frequency. This underscores the need for a multidimensional approach to understanding and enhancing self-esteem for this population of adolescents living with epilepsy. Female adolescents who demonstrated slightly lower and more variable self-esteem scores may benefit from gender-specific programs that foster resilience and positive self-concept. Similarly, age-specific interventions, particularly for younger adolescents, could help build coping skills and enhance self-esteem by addressing the modest gap identified between different age groups. There is a need to advocate for policies that increase access to mental health services for adolescents with epilepsy, particularly in rural and peri-urban areas. Ensuring that mental health support is included in the broader framework of epilepsy care can help address the diverse needs of this population. Future research in LMICs should also focus on evaluating the effectiveness of different psychosocial interventions such as CBT, family therapy, and peer support programs in improving the QOL and mental health of adolescents with epilepsy through intervention studies.

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