

ORIGINAL ARTICLE

Quality of life in children and adolescents with drug-resistant epilepsy: a single-center study in Lima, Peru

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ABSTRACT

Objective: To describe the quality of life and identify its associated clinical and epidemiological factors in children and adolescents with drug-resistant epilepsy treated at a national referral center in Lima, Peru.

Methods: A cross-sectional, single-center study was conducted, including patients younger than 18 years with a diagnosis of drug-resistant epilepsy, treated either on an outpatient basis or hospitalized. Quality of life was measured using the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE), reported by their primary caregivers. Associations between clinical and sociodemographic variables and quality of life were evaluated using linear regression.

Results: A total of 102 patients were included in the study. The mean quality-of-life score was 33.9 points, close to the minimum value of the QOLCE. In both the bivariate and multivariate models, older patient age ($\beta = -0.87$; 95% CI: -1.60 to -0.12; $p = 0.021$), residing outside the capital ($\beta = -9.00$; 95% CI: -13.00 to -4.80; $p < 0.001$), not attending school ($\beta = -14.00$; 95% CI: -18.00 to -9.00; $p < 0.001$), having intellectual disability ($\beta = -16.00$; 95% CI: -23.00 to -8.50; $p < 0.001$), and having total or partial caregiver dependence ($\beta = -12.00$; 95% CI: -20.00 to -5.20; $p < 0.001$) were associated with lower quality of life.

Conclusions: In this group of children and adolescents with drug-resistant epilepsy, a low quality of life was observed. Older patient age, residing outside the capital, not attending school, having intellectual disability, and having total or partial caregiver dependence were associated with lower quality of life.

Keywords: Drug Resistant Epilepsy; Quality of Life; Child; Adolescent (Source: MeSH)

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Calidad de vida en niños y adolescentes con epilepsia farmacorresistente: estudio unicéntrico en Lima, Perú

RESUMEN

Objetivo: Describir la calidad de vida e identificar sus factores clínicos y epidemiológicos asociados en niños y adolescentes con epilepsia farmacorresistente atendidos en un centro de referencia nacional de Lima, Perú.

Métodos: Se realizó un estudio transversal y unicéntrico donde participaron pacientes menores de 18 años con diagnóstico de epilepsia farmacorresistente, atendidos en modalidad ambulatoria u hospitalizados. La calidad de vida fue medida empleando el Cuestionario de Calidad de Vida en niños con Epilepsia (QOLCE), informada por sus cuidadores principales. Las asociaciones entre variables clínicas y sociodemográficas y la calidad de vida se evaluaron mediante regresión lineal.

Resultados: Se incluyeron 102 pacientes en el estudio. El puntaje promedio de calidad de vida fue de 33,9 puntos, cercano al valor mínimo del QOLCE. Tanto en el modelo bivariado como en el multivariado, se observó que la mayor edad del paciente ($\beta = -0,87$; IC 95 %: -1,60 a -0,12; $p = 0,021$), residir en provincia ($\beta = -9,00$; IC 95 %: -13,00 a -4,80; $p < 0,001$), no asistir a la escuela ($\beta = -14,00$; IC 95 %: -18,00 a -9,00; $p < 0,001$), presentar discapacidad intelectual ($\beta = -16,00$; IC 95 %: -23,00 a -8,50; $p < 0,001$) y tener dependencia total o parcial de los cuidadores ($\beta = -12,00$; IC 95 %: -20,00 a -5,20; $p < 0,001$), están asociados con una menor calidad de vida.

Conclusiones: En este grupo de niños y adolescentes con epilepsia farmacorresistente, se observó una baja calidad de vida. Una mayor edad del paciente, residir en provincia, no asistir a la escuela, presentar discapacidad intelectual y tener dependencia total o parcial del cuidador se asociaron con una menor calidad de vida.

Palabras clave: Epilepsia Farmacorresistente; Calidad de Vida; Niños; Adolescentes (Fuente: DeCS)

INTRODUCTION

Epilepsy in childhood represents a public health problem due to its high prevalence (1,2). In high-income countries, the estimated prevalence ranges from 4.9 to 6.68 per thousand inhabitants, whereas in low- and middle-income countries, higher prevalence rates have been reported, ranging from 5.49 to 10.3 per 1,000 inhabitants and reaching 12.7–15.4 per 1,000 in rural populations (3–5). In pediatric populations of low- and middle-income countries, recent studies have estimated epilepsy prevalence rates of up to 17 per 1,000 children and adolescents younger than 18 years (6,7). Despite these international reports, in Peru, there are no epidemiological data for the pediatric and adolescent population, reflecting an important information gap.

Drug-resistant epilepsy is defined as the failure of two adequate trials of antiseizure medications, used either in monotherapy or in combination, appropriately selected and tolerated, to achieve sustained seizure freedom (8). Recent meta-analyses have shown wide variability in the prevalence of drug-resistant epilepsy, with pooled estimates close to 30% (9). In pediatric populations specifically, epidemiological studies have estimated that approximately 8% to 15% of patients with epilepsy develop drug-resistant epilepsy (10,11). This condition may emerge during the therapeutic course and represents a substantial additional disease burden (12). Furthermore, several studies indicate that patients with drug-resistant epilepsy have a higher risk of mortality due to sudden death and greater morbidity compared with those who respond to treatment (13,14).

Clinically, persistent seizures in the context of drug-resistant epilepsy have been associated with greater neuropsychological impact, including cognitive difficulties and emotional disturbances, attributable both to epileptic activity and to treatment effects (8,13). At the psychosocial level, greater seizure severity has been associated with limitations in social functioning, manifested as avoidance behaviors and social isolation, as well as increased anxiety and concern related to seizures, negatively affecting quality of life (13,15). The impact of drug-resistant epilepsy is particularly relevant in pediatric patients, as it is associated with a high frequency of cognitive and developmental alterations during critical stages of neurodevelopment (16).

Drug-resistant epilepsy requires comprehensive and multidisciplinary management that considers the physical, social, and emotional aspects of the patient (17). In this context, therapeutic goals are not limited to reducing seizures and controlling medication-related adverse effects but also include promoting an adequate quality of life (18). Therefore, it is necessary to independently evaluate treatment goals related to seizure reduction and quality of life in pediatric populations, as several studies have shown no significant relationship between these two variables (14–16).

Studies conducted in high-income countries indicate that children with drug-resistant epilepsy have moderately impaired quality of life compared with the general population (19–22). However, these results may not represent the quality of life of patients living in Latin America and the Caribbean (LAC), including Peru. To our knowledge, no studies have yet examined the quality of life in pediatric patients with drug-resistant epilepsy in LAC countries. This is particularly relevant because low- and middle-income countries, such as most LAC countries, bear the greatest global burden of epilepsy-related disease (4). It is recognized that many LAC countries face challenges within their health systems, including centralized specialized services, limited resources leading to delays in access to surgical or pharmacological treatments, problems within referral networks across levels of care, limited caregiver training for children with chronic diseases, and greater stigmatization due to sociocultural attitudes toward epilepsy (23).

Despite the magnitude of the problem, quality of life in children and adolescents with drug-resistant epilepsy has been scarcely studied in LAC countries, generating a regional knowledge gap. As an initial exploration to address this issue, this study presents the experience of a national level III referral hospital in Lima (Peru), specialized in pediatric epilepsy care. The aim was to describe the quality of life of these patients and identify associated clinical and epidemiological factors.

METHODS

Study design and population

A descriptive cross-sectional single-center study was conducted. Recruitment was carried out from December 2022 to March 2023, consecutively including all children and adolescents diagnosed with drug-resistant epilepsy who were treated at a national level III referral hospital for complex pediatric conditions located in Lima (Peru).

In this study, drug-resistant epilepsy was defined as therapeutic failure after two appropriately selected and tolerated antiseizure medication regimens (either as monotherapy or in combination), according to the diagnostic criteria proposed by the International League Against Epilepsy (ILAE) (24). By protocol, patients who had undergone epilepsy surgery and those with neurometabolic or neurodegenerative disorders were excluded.

Variables, instruments, and procedures

Quality of life was measured using the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE) (25). This scale is designed to evaluate the quality of life in children and adolescents with epilepsy aged 4 to 18 years, reported by their primary caregiver. The four main domains of the QOLCE include cognitive, emotional, social, and physical functioning. The version of the QOLCE used in this study was the Spanish abbreviated 16-item version (QOLCE-16) (26). The QOLCE-16 yields scores ranging from 0 to 100, where higher scores indicate better quality of life. This version has been validated in Spanish, demonstrating very

good psychometric properties. Factor loadings for the four domains were greater than 0.35 and statistically significant ($\alpha = 0.05$). The four-factor model showed adequate fit [χ^2 ($p = 0.054$), comparative fit index = 0.985, Tucker–Lewis index = 0.982, root mean square error of approximation = 0.056 (0.000–0.0987), weighted root mean square residual = 0.707]. In addition, it demonstrated adequate convergent validity with the PedsQL™ 4.0 ($r = 0.791$) and discriminant validity with the PSQ ($r = -0.280$). There are no psychometric data for the QOLCE in Peru.

Clinical and epidemiological characteristics of the patient were evaluated using a data collection form. The variables included patient age in years, patient sex, place of residence, patient educational level, caregiver educational level, age at first seizure in years, age at diagnosis in years, age at initiation of antiseizure medication in years, number of antiseizure medication regimens received, duration of antiseizure treatment in years, adverse effects of antiseizure medications, seizure frequency per day, comorbidities, diagnosis of intellectual disability, abnormal psychomotor development, and level of dependence.

Chronic diseases generate total or partial dependence. The former is characterized by a total loss of autonomy and consequently requires a caregiver to assist with daily activities (3–6). In partial dependence, the individual can perform self-care but requires a caregiver to provide support and accompaniment during the disease process and when accessing health services.

Statistical analysis

Social, physical, emotional, and cognitive functioning, as well as overall quality of life, were identified through evaluation of the distribution of continuous variables. Variables with normal distribution were reported as means \pm standard deviations (SD), whereas those with non-normal distribution were described using medians and interquartile ranges (IQR).

Exploratory analyses were conducted to identify clinical and sociodemographic variables associated with higher or lower quality of life using simple linear regression. In this study, candidate variables for the multivariable model were selected based on clinical relevance. To ensure model validity, assumptions of residual normality, linearity, homoscedasticity, and absence of multicollinearity were verified, the latter evaluated using the variance inflation factor ($VIF < 10$).

For both bivariate and adjusted analyses, $p < 0.05$ was considered statistically significant. All statistical analyses were performed using R Studio statistical software (RStudio, PBC, Boston, MA, USA).

Ethical considerations

The study was approved by the Institutional Ethics Committee of the health facility where the study was conducted (Code: PI-453-2020). All primary caregivers participating in the study received written information about the study and provided consent to participate. To ensure confidentiality, patient names and identifying information were not digitized or included in the database; only alphanumeric codes were used for analysis.

RESULTS

The study population consisted of 110 pediatric patients diagnosed with drug-resistant epilepsy who were treated during the study period. Of these, 6 patients with a history of epilepsy surgery and 2 who could not be contacted were excluded. The final sample consisted of 102 patients.

Some epidemiological characteristics of the study participants are presented in Table 1. Most patients included in the study were male (58.8%), had a mean age of 8.6 years (SD = 3.8 years), and approximately half came from outside Lima (49.0%). In addition, more than 50% of the participating patients had not accessed formal schooling (52.9%). The mother was the primary caregiver in almost all cases (88.2%), and nearly half of the primary caregivers had not accessed higher education (51.0%).

Clinical characteristics are also shown in Table 1. The mean age at the first epileptic seizure was 2.4 years (SD = 3.1), and the mean age at epilepsy diagnosis was 2.7 years (SD = 3.1). At the time of data collection, the average number of antiseizure medications received by the children was 5.4 (SD = 1.9), including valproic acid, topiramate, clobazam, levetiracetam, lamotrigine, cannabidiol, and clonazepam. These antiseizure medications had been administered for an average duration of 5.8 years (SD = 3.1). Notably, 42.2% of patients experienced adverse effects related to antiseizure medications, including irritability, vomiting, hypertransaminasemia, and rash. Regarding comorbidities, nearly all patients presented abnormal psychomotor development (93.1%), intellectual disability (79.4%), and partial or total dependence on their primary caregivers (83.3%).

Table 2 presents the results of the quality-of-life assessment of study participants measured using the QOLCE. The mean total quality-of-life score was 33.9 points (SD = 22.4). Regarding its dimensions, the mean cognitive functioning score was 25.1 points (SD = 31.4), emotional functioning was 55.7 points (SD = 22.6), physical functioning was 25.3 points (SD = 29.1), and social functioning was 28.8 points (SD = 28.5).

Table 3 shows the results of the bivariate regression analyses between clinical and epidemiological variables and quality of life. Older age ($\beta = -1.90$; 95% CI: -3.00 to -0.79; $p < 0.001$) and a higher number of antiseizure medications received ($\beta = -2.90$; 95% CI: -5.10 to -0.66; $p = 0.012$) were significantly associated with lower quality of life. Additionally, living in a province outside the capital city ($\beta = -26.00$; 95% CI: -33.00 to -19.00; $p < 0.001$), not attending school ($\beta = -31.00$; 95% CI: -37.00 to -24.00; $p < 0.001$), having been diagnosed with intellectual disability ($\beta = -22.00$; 95% CI: -30.00 to -9.00; $p < 0.001$), having abnormal psychomotor development ($\beta = -13.00$; 95% CI: -26.00 to -10.00; $p < 0.001$), and having total or partial dependence on caregivers ($\beta = -40.00$; 95% CI: -49.00 to -32.00; $p < 0.001$) were also associated with lower quality of life.

The same table (Table 3) presents the results of the multivariable analysis. In this model, older patient age was

Table 1. Sociodemographic and clinical characteristics of pediatric patients with drug-resistant epilepsy

Characteristics	n (%)
Primary caregiver	
Mother	90 (88.2)
Others (father, sibling, grandparent, etc.)	12 (11.8)
Caregiver educational level	
Primary and/or secondary education	52 (51.0)
Higher education (complete or incomplete)	50 (49.0)
Patient age in years (mean ± SD)	8.6 ± 3.8
Patient sex	
Female	42 (41.2)
Male	60 (58.8)
Patient residence	
Lima	52 (51.0)
Province	50 (49.0)
Patient educational level	
Preschool or primary education	48 (47.1)
None	54 (52.9)
Age at first seizure in years (mean ± SD)	2.4 ± 3.1
Age at diagnosis in years (mean ± SD)	2.7 ± 3.1
Age at initiation of antiseizure medication in years (mean ± SD)	2.8 ± 3.2
Number of antiseizure medications received (mean ± SD)	5.4 ± 1.9
Duration of antiseizure treatment in years (mean ± SD)	5.8 ± 3.1
Adverse effects of antiseizure medications	
No	59 (57.8)
Yes	43 (42.2)
Seizure frequency per day (mean ± SD)	3.6 ± 9.9
Intellectual disability	
No	21 (20.6)
Yes	81 (79.4)
Psychomotor development	
Abnormal	95 (93.1)
Normal	7 (6.9)
Level of dependence	
Total or partial	85 (83.3)
None	17 (16.7)

SD: standard deviation.

Table 2. Quality of life of patients with drug-resistant epilepsy

Quality of life	Mean	SD
Cognitive functioning	25.1	31.4
Emotional functioning	55.7	22.6
Physical functioning	25.3	29.1
Social functioning	28.8	28.5
Total quality of life	33.9	22.4

SD: standard deviation.

associated with an average decrease of 0.87 points in quality of life for each additional year of age ($\beta_a = -0.87$; 95% CI: -1.60 to -0.12; $p = 0.021$). Living outside the Peruvian capital was associated with a reduction of 9 points in the quality-of-life score compared with Lima residents ($\beta_a = -9.00$; 95% CI: -13.00 to -4.80; $p < 0.001$). Not attending school showed an even greater decrease, with an average reduction of 14 points ($\beta_a = -14.00$; 95% CI: -18.00 to -9.00; $p < 0.001$), representing a considerable impact on social and emotional development. Similarly, having intellectual disability reduced the quality-of-life score by an average of 16 points ($\beta_a = -16.00$; 95% CI: -23.00 to -8.50; $p < 0.001$), and having total or partial dependence on caregivers was associated with a decrease of 12 points ($\beta_a = -12.00$; 95% CI: -20.00 to -5.20; $p < 0.001$). No statistically significant associations were found between quality of life and type of primary caregiver, caregiver educational level, patient sex, number of antiseizure medications received, duration of antiseizure treatment, seizure frequency, medication-related adverse effects, or psychomotor development.

DISCUSSION

The treatment goals of drug-resistant epilepsy in pediatric patients extend beyond the control of seizure frequency. One of the most crucial therapeutic goals for these patients is achieving an adequate quality of life. The present study was designed to describe the quality of life and identify associated factors among pediatric patients with drug-resistant epilepsy treated at a national referral center in Lima, Peru.

The quality of life of children with drug-resistant epilepsy may be affected by the physical, emotional, and social limitations associated with the disease. The main findings of this study revealed that the mean quality-of-life score among the included patients was 33.9 points (SD = 22.4), which is close to the lower limit of the QOLCE (0 points).

The quality of life described in this study was considerably lower than that reported in other studies including pediatric patients with drug-resistant epilepsy who had not undergone surgery and were treated in healthcare facilities located in high-income countries. After an exhaustive literature review, several studies were identified reporting higher quality-of-life scores among pediatric patients with drug-resistant epilepsy

treated in specialized healthcare facilities in the United States (mean = 57.3, SD = 14.4) (19), Canada (mean = 49.2, SD = 27.5 (21); mean = 60.18, SD = 16.69 (27); mean = 57.41, 95% CI: 53.80–61.03 (28)), Australia (children without intellectual disability: mean = 59.3, SD = 16.0; children with intellectual disability: mean = 46.0, SD = 16.2) (20), and Saudi Arabia (mean = 52.8, SD = 12.9) (17), compared with the score reported in the present study. It is noteworthy that all these studies also used the QOLCE to measure quality of life, enabling a general comparison of scores while accounting for methodological and population differences between studies.

Table 3. Factors associated with quality of life in pediatric patients with drug-resistant epilepsy

Characteristic	Crude models			Adjusted model		
	β	95% CI	p	β_a	95% CI	p
Primary caregiver						
Mother	Ref.			Ref.		
Others	3.50	-10.00 to 17.00	0.603	1.40	-4.30 to 7.20	0.602
Caregiver educational level						
University studies	Ref.			Ref.		
Primary and/or secondary education	-4.30	-13.00 to 4.30	0.301	1.60	-2.10 to 5.30	0.403
Patient age	-1.90	-3.00 to -0.79	<0.001	-0.87	-1.60 to -0.12	0.021
Patient sex						
Female	Ref.			Ref.		
Male	-2.40	-11.00 to 6.40	0.601	-5.70	-7.00 to 4.40	0.704
Patient residence						
Lima	Ref.			Ref.		
Province	-26.00	-33.00 to -19.00	<0.001	-9.00	-13.00 to -4.80	<0.001
Educational level						
Preschool or primary	Ref.			Ref.		
None	-31.00	-37.00 to -24.00	<0.001	-14.00	-18.00 to -9.00	<0.001
Number of antiseizure medications	-2.90	-5.10 to -0.66	0.012	0.20	-0.91 to 1.30	0.702
Duration of treatment (years)	-0.63	-2.10 to 0.86	0.413	-0.74	-1.60 to 0.16	0.113
Seizure frequency per day	-0.02	-0.05 to 0.04	0.075	0.02	-0.03 to 0.05	0.504
Adverse effects of antiseizure medications						
No	Ref.			Ref.		
Yes	5.70	-3.00 to 14.00	0.204	-1.20	-5.60 to 3.20	0.602
Intellectual disability						
No	Ref.			Ref.		
Yes	-22.00	-30.00 to -9.00	<0.001	-16.00	-23.00 to -8.50	<0.001
Psychomotor development						
Normal	Ref.			Ref.		
Abnormal	-13.00	-26.00 to -10.00	<0.001	-11.00	-23.00 to 1.10	0.072
Level of dependence						
None	Ref.			Ref.		
Total or partial	-40.00	-49.00 to -32.00	<0.001	-12.00	-20.00 to -5.20	<0.001

CI: confidence interval; Ref.: reference category.

Previous studies have reported that the presence of intellectual disability and younger age at seizure onset in pediatric patients with drug-resistant epilepsy are associated with lower quality of life (20). In contrast, the patient’s chronological age (19,21,22,27,28) and caregiver sex (21,28,29) have not shown a consistent association with this variable. On the other hand, the relationship between seizure frequency and quality of life has been described heterogeneously in the literature. Some studies report that higher seizure frequency is associated with worse quality of life (20,27), while others have found no significant relationship (21,28). Although these findings largely align with ours, this study identified additional factors associated with patient quality of life, such as residing outside the capital, not attending school, and having total or partial dependence on caregivers.

This study suggests that inequities in access to quality public services faced by pediatric patients with drug-resistant epilepsy treated at a national referral hospital in Lima may constitute a barrier to achieving a better quality of life. In the Peruvian health system, specialized services are often centralized in capital cities or large urban areas, limiting access to pediatric neurology and high-complexity treatments such as epilepsy surgery or vagus nerve stimulation (4,30,31). In this context, it was expected that patients living far from Lima would experience a lower quality of life.

At the educational level, 52.9% of participants were not attending school. This figure is consistent with a population-based study in Peru that found that only 52% of individuals aged 3 to 18 years with disabilities access the educational system (32). Furthermore, a large proportion of patients (83.3%) showed partial or total dependence on their primary caregivers, which could increase the burden on families. In the absence of public training programs in positive parenting, this situation may worsen, further limiting support for families.

The findings suggest that difficulties within health and education systems may affect the overall development of pediatric patients with drug-resistant epilepsy, thereby affecting their quality of life. However, these results should be interpreted with caution, as they come from a national referral hospital and may not be generalizable to the entire pediatric population of Peru. This selection bias limits the extrapolation of findings but simultaneously provides an initial approximation of the reality faced by patients with drug-resistant epilepsy who access highly specialized care.

An encouraging finding of the study was that the emotional functioning score (mean = 55.7 points) fell within the range reported in previous studies (22,28). This result may be influenced by the active role of primary caregivers in supporting patients' emotional well-being. Scores were not expected to approach the maximum possible values because antiseizure medication treatment is associated with behavioral side effects such as depression, anxiety, irritability, concentration problems, mood changes, or psychosis (33). Nevertheless, the quality of the mother-child relationship and secure attachment may contribute to better emotional functioning, preventing scores from approaching the lowest possible values (34).

Another relevant finding was the absence of an association between seizure frequency and quality of life in the adjusted model. This result is consistent with some previous studies demonstrating that seizure reduction does not always translate into improved perceived quality of life (21,28).

These findings suggest that although seizure control remains a central treatment goal, it is not the only determinant of quality of life in this population. Cognitive, functional, and psychosocial factors may play an equal or even more important role than seizure frequency. Therefore, evaluation of treatment quality in pediatric patients with drug-resistant epilepsy should adopt a comprehensive approach that considers not only traditional clinical outcomes such as seizure frequency but also the multiple factors that influence patient and family quality of life.

This study has several limitations. Since the QOLCE is an instrument that measures quality of life as reported by caregivers, there is a risk that caregivers may underestimate or overestimate certain aspects of their child's quality of life, influenced by their own emotions and concerns, as reported in another study (21). Furthermore, although the QOLCE instrument has been validated in Spanish, it has not been thoroughly validated in Peru; therefore, quality-of-life scores may not have been determined with complete precision during the study. Finally, because the study was conducted at a national referral hospital for complex pediatric conditions, the included patients may represent more severe cases than those treated at other levels of care. This introduces a potential selection bias and limits the generalization of the results to the entire pediatric population of the country. In addition, the unequal distribution of human and economic resources in the health sector means that patients referred from remote regions to Lima face an even greater gap in access to diagnosis and treatment, which could worsen their quality of life (31).

Despite these limitations, this study has several strengths. To our knowledge, this is the first study to provide a general overview of quality of life among pediatric patients with drug-resistant epilepsy treated in a lower-middle-income country such as Peru. In addition, it is the first study to evaluate the association between variables such as patient schooling and place of residence with quality of life in this population.

In this context, further research on this topic is needed, including validation studies of the QOLCE instrument, multicenter studies, and longitudinal studies evaluating quality of life in the medium and long term in patients from low- and middle-income countries. This would contribute to developing interventions aimed at overcoming barriers and inequalities in the educational and healthcare systems, ultimately enabling the treatment goal of improving quality of life in pediatric patients with drug-resistant epilepsy to be satisfactorily achieved.

CONCLUSION

In this cross-sectional study, low quality of life was observed among pediatric patients with drug-resistant epilepsy.

Regression analysis showed that older patient age, living outside the capital, not attending school, having intellectual disability, and having dependence on primary caregivers were associated with lower quality of life.

The mean score obtained was lower than that reported in studies from other countries. Although the evaluated populations are not directly comparable, this finding suggests possible contextual differences that may influence quality of life and provides preliminary evidence on this issue in a relatively underexplored Latin American setting.

Author contributions

CMD: Conceptualization, Data curation, Formal analysis, Methodology, Investigation, Writing – original draft, Writing – review and editing.

CSSS: Conceptualization, Investigation, Writing – original draft, Writing – review and editing.

RAGA: Formal analysis, Writing – review and editing.

Conflicts of interest

The authors declare no relevant financial or non-financial conflicts of interest.

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Data availability

The data supporting the findings of this study are available upon request from the corresponding author.

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