

## Original Research Article

# A cross-sectional study of quality of life among pediatric patients with epilepsy attending a tertiary care selected hospital at Vijayapur city

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### ABSTRACT

**Background:** Epilepsy is a common chronic neurological disorder in children associated with significant psychosocial morbidity. This study aimed to assess the health-related quality of life (HRQoL) among pediatric patients with epilepsy in a tertiary care setting and evaluate the correlation between child-reported outcomes and parental perceptions.

**Methods:** A descriptive cross-sectional study was conducted at a tertiary care center in South India, involving 106 pediatric patients (aged 6-18 years) with a confirmed diagnosis of epilepsy. HRQoL was assessed using the pediatric quality of life inventory (PedsQL) 4.0 generic core scales. Parental perceptions were evaluated through semi-structured interviews. Data were analyzed using the Chi-square test and Pearson's correlation coefficient ( $p < 0.05$  considered significant).

**Results:** Overall, 66.0% ( $n=70$ ) of participants reported poor HRQoL, 34.0% ( $n=36$ ) reported moderate HRQoL, and none achieved a "good" rating. The lowest mean scores were observed in social functioning ( $6.13 \pm 2.31$ ) and school functioning ( $6.24 \pm 2.34$ ), while physical functioning scores were relatively higher ( $10.0 \pm 3.13$ ). A strong positive correlation was found between child-reported HRQoL and parental perception ( $r=0.98$ ,  $p < 0.001$ ). No statistically significant association was found between HRQoL and clinical variables such as seizure frequency or epilepsy type.

**Conclusions:** Pediatric epilepsy significantly impairs HRQoL, particularly in social and academic domains. The strong correlation between child and parent reports suggests that caregivers are highly attuned to the child's struggles. Management should extend beyond seizure control to include psychosocial support and school-based interventions.

**Keywords:** Child, Epilepsy, Parents, PedsQL, Quality of life

## INTRODUCTION

Epilepsy is the most common long-term problem with the nervous system that affects a lot of children and is the leading health problem for them. Along with the clinical manifestation of relapsing seizures, this sickness significantly affects other aspects of a child's growth and development. In India, the burden of paediatric epilepsy is considerable, with numerous affected children relying on tertiary care centres for diagnosis and long-term management.<sup>1,2</sup> Historically, the main objective of treatment has been the control of relapsing seizures; however, there is growing recognition that effective care

should also consider children's overall health-related quality of life (HRQoL).<sup>3,4</sup>

Epileptic children often deal with multiple physical problems. They may also have problems with their emotions, reduced self-esteem, and feelings of loneliness.<sup>5,6</sup> Research consistently shows that these children have a lower quality of life (QoL) than their peers. Several clinical scenarios, like how repeatedly seizures happen, how long the disease affects, and the bad effects of drug treatment, all play a crucial role in these outputs.<sup>3,7</sup> Along with these, social stigma and ignorance about

epilepsy, especially in developing countries, may make mental health challenging.<sup>4,8</sup>

Epilepsy in children affects the child and the family. Parents and guardians often feel psychologically stressed, anxious regarding their child's future, and the financial burden of long-term therapy.<sup>1,9</sup> These factors can change how they communicate with each other, which can later affect the child's health and happiness. Approved tools, such as the Paediatric Quality of Life Inventory (PedsQL), provide a structured format for assessing multidimensional health aspects and enable a comprehensive assessment of disease.<sup>7,10</sup>

Despite Vijayapur city having a tertiary care centre, there is an information scarcity in the quality of life of children with epilepsy in this district. Local socio-cultural and economic issues may considerably affect the lives of children and their families. Consequently, this study was conducted to assess the HRQoL of epileptic children receiving care at designated tertiary care institutions in Vijayapur. The study also extracted medical and demographic characteristics correlated with HRQoL and assessed the interlink between child-reported results and parental perceptions.

## METHODS

A cross-sectional descriptive design was used to assess health-related quality of life (HRQoL) in a cohort of children with epilepsy. The research was conducted in the Department of Paediatrics at BLDEA's Shri B. M. Patil Medical College and Research Institute in Vijayapur, Karnataka, from February to April 2026.

Data were collected from 106 follow-up cases of epileptic children between the ages of 6 and 18 who were visiting the OPD. A purposive sampling technique was used to collect the data. Sample size was calculated using the single-population proportion formula with a 95% confidence interval (CI) and an estimated prevalence. The final study group comprised 106 individuals, after accounting for a possible 10% attrition rate.

The study participants, like epileptic children (pre-diagnosed) between the ages of 6 and 18, and in a stable condition to respond to questionnaires, and parents or their guardians are willing to give their written consent, are included. Exclusion criteria involved children with considerable cognitive or intellectual problems that affect their ability to respond to the questionnaire, and children with serious neurological factors that were not related to epilepsy, such as cerebral palsy or other long-term medical issues, were also not considered.

Data were collected using three instruments:

Demographic and clinical data collection form: this tool collected data on the participant's age, gender, socio-

economic status, type of epilepsy, frequency of seizures, and current treatment modalities.

The 4.0 generic core scales of the pediatric quality of life inventory (PedsQL) were the primary tool for measuring HRQoL across four domains: physical, social, emotional, and school performance. The tool uses a five-point Likert scale, and the final scores are converted to a 0-100 range, with higher scores indicating a better quality of life.<sup>7,11,12</sup>

Schedule for parent interviews: we conducted semi-structured interviews with carers to assess their perceptions of the child's quality of life and how the illness affected the family.

## Ethical considerations

The subjects' confidentiality and anonymity were maintained, and the information was used solely for research purposes. The Institutional Ethics Committee (IEC) of BLDE Association's Shri B. M. Patil Institute of Nursing Sciences, Vijayapur, gave ethical clearance (Ref: BLDEINS/IEC/56/2026). Before the children could join the study, their parents or legal guardians had to give their written permission.

## Statistical analysis

We used descriptive and inferential statistics for the analyses. We utilised frequencies and percentages to summarise categorical variables, and mean and standard deviation to summarise continuous variables. The chi-square test was utilised to analyse the association between quality-of-life categories and categorical factors, including epilepsy type and seizure frequency. We utilised Pearson's correlation coefficient ( $r$ ) to examine the relationship between the child's reported quality of life and the parent's perception of it. A  $p$  value less than 0.05 was deemed statistically significant.

## RESULTS

### Demographic and clinical profile

There were three age groups of participants, and the biggest group was teenagers aged 16 to 18 years ( $n=53$ , 50.0%). There were slightly more males ( $n=58$ , 54.7%) than females ( $n=48$ , 45.3%) in the gender breakdown. Half of the patients lived in rural areas (50.0%,  $n=53$ ) and the other half in urban areas (50.0%,  $n=53$ ). Most of the participants ( $n=61$ , 57.5%) were from nuclear families. Generalised epilepsy was the most common diagnosis ( $n=47$ , 44.3%), followed by unknown or other forms ( $n=34$ , 32.1%) and focal epilepsy ( $n=25$ , 23.6%). Seizure control differed among the children: 33.0% ( $n=35$ ) were seizure-free at the time of assessment, while 21.7% ( $n=23$ ) suffered more than three seizures per month. Medical management mostly consisted of monotherapy ( $n=68$ , 64.2%), and the majority of the sample ( $n=73$ , 68.9%) indicated consistent treatment adherence. Only 24.5%

(n=26) of the patients reported no comorbidities. The rest had learning difficulties (n=27, 25.5%), behavioural

problems (n=27, 25.5%), or other comorbid conditions (n=26, 24.5%) (Table 1).

**Table 1: Sociodemographic and clinical characteristics of pediatric epilepsy patients (n=106).**

Variables	N	Percentage	
<b>Gender</b>	Male	58	54.7
	Female	48	45.3
<b>Age group (years)</b>	Children (6-15)	53	50
	Adolescents (16-18)	53	50
<b>Residential area</b>	Rural	53	50
	Urban	53	50
<b>Family type</b>	Nuclear	61	57.5
	Joint	45	42.5
<b>Type of Epilepsy</b>	Generalised	47	44.3
	Focal	25	23.6
	Unknown	34	32.1
<b>Seizure frequency</b>	Seizure-free	35	33
	Less than once per month	24	22.6
	1-3 episodes per month	24	22.6
	More than 3 episodes per month	23	21.7
<b>Treatment Type</b>	Monotherapy	68	64.2
	Polytherapy	38	35.8
<b>Treatment adherence</b>	Regular	73	68.9
	Irregular	33	31.1
<b>Comorbidities</b>	Learning difficulties	27	25.5
	Behavioral problems	27	25.5
	Others	26	24.5
	None	26	24.5

**Table 2: Mean and standard deviation of quality of life scores.**

Domain	No. of items	Mean score	Standard deviation
<b>Physical functioning</b>	8	10.0	3.13
<b>Emotional functioning</b>	5	6.60	2.18
<b>Social functioning</b>	5	6.13	2.31
<b>School functioning</b>	5	6.24	2.34

### Assessment of QoL

The QoL of an epileptic child was assessed across four primary domains using validated measurement tools. The distribution of scores and clinical severity is detailed below (Table 2).

An examination of the individual domains (Table 3) indicated that the highest mean score was found in physical functioning (10.0±3.13). Conversely, ratings were significantly lower and largely stable in emotional (6.60±2.18), school (6.24±2.34), and social functioning (6.13±2.31). These data indicate that, although physical impairments exist, the psychological and academic aspects of a child's life are more significantly affected by the burden of epilepsy.

**Table 3: Distribution of patients by quality of life (QoL) levels.**

Level of QoL	Score range	Frequency	Percentage
<b>Poor</b>	≤33	70	66.0
<b>Moderate</b>	34-66	36	34.0
<b>Good</b>	≥67	0	0.0
<b>Total</b>		106	100

### Factors influencing QoL

The relationship between clinical variables, such as seizure frequency, epilepsy type, and comorbidities, with QoL levels was examined to ascertain the determinants of well-being in paediatric epilepsy.

### Clinical variables and QoL association

As shown in Table 4, several clinical factors were evaluated using chi-square analysis. Interestingly, no single clinical variable demonstrated a statistically significant association with QoL in this study population.

Even though the differences weren't statistically significant, we did see some descriptive tendencies. For example, 13 children with learning disabilities were in the "poor QoL" group, whereas only 7 children with no comorbidities were in the "good QoL" group. The total p-values for seizure frequency ( $p=0.18$ ), epilepsy type

( $p=0.23$ ), and comorbidities ( $p=0.21$ ) indicate that the impact on QoL in this group may be influenced by factors beyond these particular clinical parameters (Table 4).

### Parental perception and correlation with child QoL

The research additionally assessed parental perceptions of their child's quality of life. Fifty-nine (55.7%) of the parents thought their child's QoL was "moderate", while forty-seven (44.3%) thought it was "poor" (Table 5). Interestingly, just as the kids' self-reports, no parents thought their child's QoL was "good".

**Table 4: Association of clinical factors with quality of life levels (n=106).**

Variables	Poor (n=36)	Moderate (n=70)	Chi-square ( $\chi^2$ )	P value
<b>Seizure Frequency</b>			4.87	0.18 (NS)
Seizure-free	10	25		
< 1/month	12	12		
1-3/month	9	15		
> 3/month	5	18		
<b>Type of epilepsy</b>			2.87	0.23 (NS)
Generalized	17	30		
Focal	11	14		
Unknown	8	26		
<b>Comorbidities</b>			4.48	0.21 (NS)
None	7	19		
Learning difficulty	13	14		
Behavioral problems	10	17		
Others	6	20		

NS: non-significant ( $p>0.05$ ).

**Table 5: Distribution of parental perception of child's QoL (n=106).**

Level of perception	Frequency	Percentage
<b>Poor</b>	47	44.3
<b>Moderate</b>	59	55.7
<b>Good</b>	0	0.0

**Table 6: Correlation between child QoL and parental perception.**

Variables	Mean score	SD	Pearson 'r'	P value
<b>Child QoL score</b>	28.99	8.13	0.98	<0.001*
<b>Parent perception score</b>	45.5	7.61	—	—

SD: standard deviation; r: Pearson correlation coefficient; QoL: quality of life. \*Statistically significant ( $p<0.05$ ).

To assess the accuracy of parental reporting, a Pearson correlation analysis was performed between child-reported QoL scores and parent-perceived QoL scores (Table 6).

The child's actual QoL scores and the parents' impressions were extremely strongly related ( $r=0.98$ ,  $p<0.001$ ). This almost perfect correlation shows that parents are very aware of their child's problems and health, which makes parental reports a good way to measure QoL in the management of paediatric epilepsy.

## DISCUSSION

Our data show that a large number of children with epilepsy have a lower quality of life. In particular, 66.0% of participants were in the "poor" QoL group, while the rest received "moderate" scores. No children got a "good" rating. These findings show that epilepsy not just extends beyond the seizures, but it also affects the overall health of the child.

Previous QoL studies on epilepsy show similar findings, revealing that children with epilepsy have markedly diminished QoL in comparison to their healthy peer group, especially in psychosocial aspects.<sup>13,14</sup> When assessing specific areas, the psychological factors of life, including emotional well-being and academic performance, are more significant than physical performance. This shows that non-medical stressors, including epileptic social stigma and the consequent anxiety, are considerable contributors to decreased overall well-being. These results align with earlier studies that highlight the complicated characteristics of paediatric QoL and the substantial impact of chronic illnesses on psychosocial well-being.<sup>15,16</sup>

In this study, no statistically significant correlation was found between seizure-related variables, such as seizure frequency and epilepsy classification, and QOL. This finding concurs with prior findings in that the severity of a condition may not fully explain differences in QoL.<sup>17</sup> On the other hand, related studies have reported contrasting results, suggesting that the greater the number of seizures, the lower the QoL.<sup>12</sup> The possible reason for these contradictions may be differences in samples, measurement tools, and sociocultural environments. Under conditions where knowledge about the disease is poor and stigma persists, the diagnosis of epilepsy can exert a considerable psychological impact.

The statistical analysis revealed that no significant correlation existed between sociodemographic factors, including age, gender, and socioeconomic status, and the results regarding quality of life. These declining trends of QoL found in various categories point to the numerous issues surrounding epilepsy among the studied population. Studies similar to this one have been conducted before.<sup>18</sup> Such consistently lower scores of QoL in various categories suggest that there is extensive social stigma surrounding epilepsy in the studied environment.

A significant finding in this study was the robust positive association between the child's quality of life and parental impression. This emphasises the interconnectedness of child and family well-being in the context of chronic illnesses. Carers may experience worry and engage in overprotective behaviours, which may unintentionally restrict the child's social interactions and autonomy. These results underscore the importance of using family-centred strategies in the management of paediatric epilepsy. Overall, the results of this study reinforce the assumption that epilepsy in children is associated with significant problems in many parts of life, especially when it comes to how they interact with other people. It is crucial to address these problems to enhance overall health outcomes.

## CONCLUSION

This study finds that children with epilepsy in Vijayapur have a significant drop in their health-related quality of life, especially when it comes to their social life and

schoolwork. There isn't a strong correlation between the intensity of clinical seizures and QoL scores, suggesting the importance of psychosocial factors. A strong positive link was found between what children said about their well-being and what their parents saw ( $r=0.98$ ). This alignment implies that carers are quite aware of the problems their kids are having, which supports the need for family-centred diagnostic examinations. The results emphasise the necessity for a holistic strategy in the treatment of infantile epilepsy. Along with medicine, alternative therapies should include psychological support, family counselling, and school-based measures to address the condition's broader psychosocial impacts and improve quality of life outcomes.

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