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Original Research Article

A study on the quality of life of children with epilepsy and the impact of disease on family functioning

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ABSTRACT

Background: Epilepsy is one of the most common chronic neurological disorders in childhood and is associated with significant physical, emotional, social, and educational consequences. Beyond seizure control, children with epilepsy often experience impaired health-related quality of life (HRQoL), while their caregivers face substantial psychosocial burden. So, the study is aimed to assess the QoL of children with epilepsy and to evaluate the impact of the disease on family functioning.
Methods: This hospital-based prospective observational study was conducted in the Department of Paediatrics at Hi-Tech Medical College and Hospital over a period of January 2024 to December 2025. A total of 110 children aged 8-12 years with epilepsy and their primary caregivers were included. Data on demographic and clinical variables were collected using a structured proforma. QoL was assessed using the Pediatric QoL Inventory (PedsQL™ 4.0 Generic core scales) and family functioning was evaluated using the PedsQL™ family impact module. Statistical analysis was performed using SPSS version 26, with $p<0.05$ considered statistically significant.
Results: The mean age of participants was 9.95±1.42 years, with a male predominance (59.1%). The mean QoL score was 66.20±13.45, indicating moderate impairment, with emotional functioning being the most affected domain. The mean family impact score was 60.67±14.42. Children with uncontrolled seizures had significantly lower QoL scores compared to those with controlled seizures ($p<0.001$). Polytherapy and the presence of comorbidities were also associated with poorer QoL and greater family burden.
Conclusions: Childhood epilepsy significantly impairs QoL and adversely affects family functioning. Clinical factors such as seizure control, treatment complexity, and comorbidities are key determinants of these outcomes. These findings highlight the need for a comprehensive, multidisciplinary, and family-centered approach to epilepsy management that extends beyond seizure control.

Keywords: Epilepsy, Quality of life, Family functioning, PedsQL

INTRODUCTION

Epilepsy is one of the most common chronic neurological disorders in childhood and is characterized by recurrent unprovoked seizures resulting from abnormal electrical activity in the brain.[1] It represents a significant cause of neurological morbidity worldwide, with a substantial proportion of affected children residing in low- and middle-income countries where access to comprehensive care may be limited.[2]

Childhood epilepsy is associated not only with the burden of recurrent seizures but also with a wide range of physical, emotional, social, and academic challenges.[3] Children with epilepsy may experience restrictions in daily activities, difficulties in peer interaction, behavioral problems and impaired school performance.[8] Importantly,

these challenges may persist even in children with well-controlled seizures, indicating that seizure control alone does not fully reflect the overall impact of the disease.[7]

In recent years, there has been increasing emphasis on the assessment of HRQoL as a key outcome measure in chronic childhood illnesses, including epilepsy.[5] HRQoL is a multidimensional construct that encompasses physical, emotional, social, and school functioning, providing a more comprehensive understanding of the child's well-being beyond traditional clinical parameters.[5] The PedsQL™ 4.0 Generic Core Scales is a validated tool widely used to assess these domains in children with chronic conditions.[5]

Epilepsy in a child also has a considerable impact on family functioning. Caregivers often experience persistent anxiety related to seizure recurrence, concerns regarding medication adherence and safety, and uncertainty about the child's future.[10] These factors may lead to emotional stress, disruption of daily activities, and impaired family dynamics.[11] The PedsQL™ Family Impact Module has been developed to assess the effects of a child's illness on caregiver functioning and family life.[6]

Several studies have demonstrated that poor seizure control, need for polytherapy, and the presence of comorbidities are associated with reduced QoL in children with epilepsy and increased caregiver burden.[4,9] However, data from Indian paediatric populations remain limited, particularly studies that evaluate both child QoL and family impact simultaneously using standardized instruments.[2]

Therefore, the present study was undertaken to assess the QoL of children with epilepsy using the PedsQL™ 4.0 Generic Core Scales and to evaluate the impact of childhood epilepsy on family functioning using the PedsQL™ Family Impact Module.[5,6] Additionally, the study aims to analyze the association of these outcomes with clinical and sociodemographic factors, thereby providing a more comprehensive understanding of the burden of childhood epilepsy.

Objectives

Primary objectives

Primary objectives were to assess the QoL in children aged 8-12 years with epilepsy and to evaluate the impact of childhood epilepsy on family functioning using the PedsQL™ scales.

Secondary objectives

Secondary objectives were to evaluate the impact of childhood epilepsy on family functioning using the PedsQL™ Family Impact Module, to determine the association between QoL and clinical variables such as seizure type, seizure control, antiepileptic drug therapy, and comorbidities, to assess school-related and behavioral outcomes in children with epilepsy and to examine the relationship between child QoL and family impact scores

METHODS

Study design and setting

This was a hospital-based prospective observational study conducted in the Department of Paediatrics at Hi-Tech Medical College and Hospital over a period of two years from January 2024 to December 2025.

Study population

The study included children aged 8-12 years diagnosed with epilepsy who attended the outpatient or inpatient services of the study center, along with their primary caregivers.

A total of 110 children and their caregivers were enrolled in the study.

Inclusion criteria

Children aged 8-12 years with a diagnosis of epilepsy, children presenting as both outpatient and inpatient cases of epilepsy, caregivers willing to provide informed consent and respondent being the main caregiver, permanently residing with the child were included.

Exclusion criteria

Parents and caregivers not willing to give written informed consent, children with febrile seizures, children with seizure mimickers, children with psychogenic non-epileptic seizures and children with acute symptomatic seizures were excluded from the study.

Sampling technique

A purposive sampling technique was employed. All eligible children presenting, to the study setting during the study period were included until the feasible and sample size was achieved.

Data collection procedure

Data were collected using a predesigned and structured proforma. Information obtained included: Sociodemographic details (age, gender), clinical characteristics (type of seizures, duration of illness, seizure control status), treatment details (type of antiepileptic therapy-monotherapy or polytherapy) and presence of comorbidities, school-related variables (attendance, absenteeism, academic performance, behavioral issues) and caregivers and children were interviewed, and responses were recorded accordingly.

Study instruments

PedsQL™ 4.0 generic core scales

This instrument was used to assess the QoL of children across four domains: Physical functioning, emotional functioning, social functioning and school functioning.

The scores were transformed to a scale of 0-100, with higher scores indicating better QoL.

PedsQL™ family impact module

This module was used to evaluate the impact of the child's illness on family functioning across the following domains: Physical functioning, emotional functioning, social functioning, cognitive functioning, communication, worry, daily activities and family relationships. Higher scores indicated better family functioning and lower impact.

Study variables

The variables analyzed in the study included:

Demographic variables include age and gender.

Clinical variables include seizure type, seizure control and duration of illness.

Treatment variables include monotherapy vs polytherapy.

Comorbidity status includes presence or absence.

Outcome variables include QoL scores and family impact scores.

Outcome measures

Primary outcome

Primary outcomes include total QoL score of children.

Secondary outcomes

Secondary outcomes include domain-wise QoL scores, family impact scores and association of QoL with clinical factors.

Statistical analysis

SPSS v26.0. Independent t test for continuous variables. Chi-square test for categorical variables. Significance $p<0.05$.

RESULTS

A total of 110 children with epilepsy were included in the study. The age of the children ranged from 8 to 12 years, with a mean age of 9.95±1.42 years. The mean age of onset of epilepsy was 6.62±3.45 years, indicating early childhood onset in a substantial proportion of participants.

With respect to clinical characteristics, 83.6% of children had controlled seizures, while 16.4% had uncontrolled seizures. The majority of children (80.9%) were on monotherapy, whereas 19.1% required polytherapy. Comorbid conditions were present in 22.7% of the children.

The mean total QoL score was 66.20±13.45, suggesting a moderately good overall QoL. The mean total family impact score was 60.67±14.42, indicating a considerable psychosocial and functional burden on families caring for children with epilepsy.

Male children constituted 59.1%, while females comprised 40.9% of the study population. Female children had a slightly higher mean QoL score (67.35±12.76) compared to males (65.41±13.96). Similarly, the mean family impact score was marginally higher among females (61.80±13.91) than males (59.89±14.82).

However, independent sample t-tests showed no statistically significant difference between males and females for both QoL ($p=0.460$) and family impact scores ($p=0.498$). Hence, gender did not significantly influence either the child's QoL or the extent of family burden in this study.

Children residing in rural areas constituted 52.7% of the sample, while 47.3% were from urban areas. Rural children demonstrated a higher mean QoL score (67.22±12.42) compared to urban children (65.08±14.56). Family impact scores were also higher in rural families (62.04±13.15) than urban families (59.15±15.71).

These differences, however, were not statistically significant for QoL ($p=0.408$) or family impact ($p=0.295$).

Therefore, Place of residence did not show a significant association with QoL or family functioning, suggesting that epilepsy imposes a comparable burden across urban and rural settings.

Seizure control emerged as one of the most important determinants. Children with controlled seizures had a markedly higher mean QoL score (71.55±6.29) compared to those with uncontrolled seizures (38.89±1.99). Similarly, families of children with controlled seizures reported substantially higher family impact scores (66.57±5.85) than those with uncontrolled seizures (30.54±1.19).

These differences were highly statistically significant for both QoL and family impact ($p<0.001$).

Hence it is seen that Poor seizure control is associated with severely compromised QoL in children and profound disruption of family functioning, highlighting seizure control as a critical therapeutic goal.

Children on monotherapy had significantly better outcomes than those on polytherapy. The mean QoL score among children on monotherapy was 68.57±11.60, compared to 56.16±16.22 among those on polytherapy. Similarly, family impact scores were higher in the monotherapy group (63.32±12.21) than in the polytherapy group (49.44±17.73).

These differences were statistically significant for both QoL ($p<0.001$) and family impact ($p<0.001$). Requirement of polytherapy, often a marker of severe or refractory epilepsy, is associated with poorer QoL and greater family burden.

Table 1: Descriptive statistics showing mean values of all parameters and scores.

Variables	N	Minimum	Maximum	Mean	SD
Total family impact score	110	28	73	60.67	14.423
Residence	110	1	2	1.53	0.502
Sex	110	1	2	1.41	0.494
Type of seizure	110	1	5	3.31	1.210
Age of onset	110	2	12	6.62	3.448
Seizure control	110	0	1	0.84	0.372
Anti-epileptic drug therapy	110	1	2	1.19	0.395
Age (in years)	110	8	12	9.95	1.420
Comorbidity	110	0	1	0.23	0.421
Total QoL sore	110	35	82	66.20	13.453

Table 2: Relationship of QoL and family impact score with gender.

Variables	Gender	N	Mean	SD	P value
Total QoL	Male	65	65.41	13.956	0.461
	Female	45	67.35	12.760	
Total family impact score	Male	65	59.89	14.824	0.468
	Female	45	61.80	13.911	

Table 3: Relationship of QoL and family impact score with residence.

Variables	Residence	N	Mean	SD	P value
Total QoL score	Urban	52	65.08	14.562	0.408
	Rural	58	67.22	12.418	
Total family impact score	Urban	52	59.15	15.711	0.295
	Rural	58	62.04	13.150	

Table 4: Relationship of QoL and family impact score with seizure control.

Variables	Seizure control	N	Mean	SD	P value
Total QoL score	Yes	92	71.55	6.288	0.000
	No	18	38.89	1.986	
Total family impact score	Yes	92	66.57	5.847	0.022
	No	18	30.54	1.186	

Table 5: Relationship of QoL and family impact score with type of drug therapy.

Variables	Anti-seizure medication	N	Mean	SD	P value
Total QoL score	Monotherapy	89	68.57	11.604	0.001
	Polytherapy	21	56.16	16.218	
Total family impact score	Monotherapy	89	63.32	12.208	0.000
	Polytherapy	21	49.44	17.725	

Table 6: Relationship of QoL and family impact score with comorbidity.

Variables	Comorbidity	N	Mean	SD	P value
Total QoL score	Yes	25	45.41	9.862	0.000
	No	85	72.32	6.371	
Total family impact score	Yes	25	36.39	8.800	0.000
	No	85	67.82	4.541	

Children with comorbid conditions exhibited significantly poorer outcomes. The mean QoL score among children with comorbidities was 45.41±9.86, compared to 72.32±6.37 in children without comorbidities. Similarly, family impact scores were markedly

lower in families of children with comorbidities (36.39±8.80) compared to those without (67.82±4.54).

These differences were highly statistically significant ($p<0.001$). This shows that the presence of comorbidities substantially worsens both the child's QoL and the family's psychosocial functioning, underscoring the need for comprehensive and multidisciplinary management.

The findings demonstrate that clinical factors-particularly seizure control, treatment complexity, and comorbidities-are far stronger determinants of QoL and family functioning than sociodemographic variables such as gender or residence.

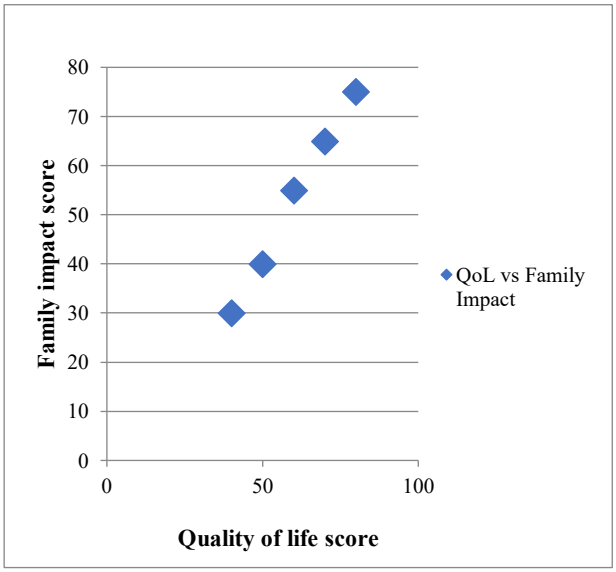

Figure 1: Relationship between QoL and family impact.

This scatter diagram demonstrates that poor QoL is related with more negative impact on family's psychosocial and physical functioning implicating that uncontrolled refractory type of seizure with comorbidities make the children dependent on family even for daily activities.

DISCUSSION

The present study evaluated the QoL in children with epilepsy and its impact on family functioning using standardized instruments. The findings demonstrate that childhood epilepsy is associated with a moderate reduction in QoL, with a mean QoL score of 66.20±13.45, and imposes a considerable burden on family functioning, as reflected by a mean family impact score of 60.67±14.42.[3,10]

One of the key findings of this study is that the emotional domain was the most affected component of QoL. This highlights the significant psychological burden experienced by children with epilepsy, including fear of seizures, social stigma, and anxiety related to their condition.[14] These findings emphasize that the impact of epilepsy extends beyond physical health and affects emotional well-being to a greater extent.[14]

Another important observation is the strong association between seizure control and QoL. Children with uncontrolled seizures had significantly lower QoL scores compared to those with controlled seizures.[9] This underscores the importance of effective seizure management in improving overall well-being. However, despite good seizure control in the majority of children, QoL impairment persisted, suggesting that seizure control alone may not be sufficient to ensure optimal outcomes.[7]

The study also demonstrated that polytherapy and the presence of comorbidities were associated with poorer QoL. Children receiving multiple antiepileptic drugs may experience more side effects, increased treatment burden, and greater disruption of daily activities[3]. Similarly, comorbid conditions such as cognitive or behavioral issues further contribute to reduced functioning across multiple domains.[4]

In addition to child-related outcomes, the study highlights the substantial impact of epilepsy on family functioning. Caregivers reported significant impairment, particularly in domains related to worry and daily activities.[10] The unpredictable nature of seizures, concerns regarding the child's safety, and long-term prognosis contribute to increased caregiver stress and reduced QoL.[11]

Importantly, a significant relationship was observed between child QoL and family impact, indicating that poorer QoL in children is associated with greater caregiver burden.[10] This finding supports the concept that

childhood epilepsy is not an isolated condition but rather a family-centered disorder, affecting both the child and the caregiver.[10]

School-related difficulties were also notable, with a considerable proportion of children experiencing absenteeism and academic challenges. These findings reflect the broader social and educational impact of epilepsy and highlight the need for supportive interventions in school settings.[8]

Overall, the findings of this study reinforce the need for a holistic and multidisciplinary approach in the management of childhood epilepsy.[7] In addition to achieving seizure control, interventions should address psychological well-being, educational support, and caregiver counselling.[7]

Limitations

Cross-sectional design limits causal inference, single-center study reduces generalizability and questionnaire-based assessment may introduce reporting bias

CONCLUSION

Childhood epilepsy is associated with a significant reduction in HRQoL and exerts a substantial impact on family functioning. In the present study, children demonstrated moderate impairment in overall QoL, with emotional functioning being the most affected domain. In parallel, caregivers experienced considerable burden, particularly in terms of worry and disruption of daily activities. Clinical factors such as poor seizure control, use of polytherapy, and the presence of comorbidities were identified as important determinants of both reduced QoL and increased family burden. Furthermore, the observed association between child QoL and family impact underscores the interdependent nature of these outcomes, highlighting that epilepsy affects not only the child but the entire family unit.

Recommendations

Findings of this study emphasize that optimal management of childhood epilepsy should extend beyond seizure control and incorporate a comprehensive, multidisciplinary approach. Interventions should include psychological support for children, counseling and education for caregivers, and strategies to address school-related challenges and social integration. Early identification of at-risk children and families, along with targeted supportive measures, may help improve long-term outcomes. Future research should focus on longitudinal assessment and the development of intervention-based models to enhance QoL and reduce caregiver burden.

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