(International Print/Online Journal)
SJIF IMPACT FACTOR: 5.565
PUBMED-National Library of Medicine ID-101739732
ISSN (Print): 2209-2870
ISSN (Online): 2209-2862
International Journal of Medical Science and Current Research (IJMSCR)
Available online at: www.ijmscr.com
Volume 6, Issue 5 , Page No: 149-158
September-October 2023
IJMSCR

Questionnaire Based Study On Quality of Life (QOL) in Children with Epilepsy

Chetan Chaudhari*, Minal Wade
Department of Paediatrics, Dr R N Cooper Hospital, Mumbai, Maharashtra, India

***Corresponding Author:**
Dr. Chetan Chaudhari
Department of Paediatrics, Dr R N Cooper Hospital, Mumbai, Maharashtra, India

Type of Publication: Original Research Paper
Conflicts of Interest: Nil

Abstract

Methods: An observational, Cross-sectional and descriptive study.

Epilepsy is characterized by recurrent, episodic, paroxysmal, involuntary clinical events associated with abnormal electrical activity from the neurons of the brain. It is usually chronic and debilitating disorder that impacts not only those bearing with it but also their caregivers. Epilepsy is thought to affect more than 100 million individuals and their families worldwide at some point of their lives, and thus constitutes a major universal public health issue [1].

It is well-known that children with epilepsy have a compromised health-related QOL and may be affected across physical, psychological, social, and educational domains. [2] The cases were studied by observational, cross-sectional study and descriptive analysis was done for each aspect. In this study, we have evaluated the QOL, its risk factors and various demographic determinants in children with epilepsy with or without comorbidities, visiting public tertiary care Hospital. All the basic and necessary informative was collected in form of questionnaires, and source of information was parents or close relatives. The current study found that children with epilepsy presented a higher score in emotional functioning than physical functioning.

Results of study also confirms, Epilepsy affects a child's social functioning at different levels, depending on his/her health status and social abilities.

When considering physical functioning related to physical activities in a child's daily life, this study found that epilepsy affected the child's physical functioning at a moderate to high level.

Overall, this study agrees with other studies that epilepsy impairs many aspects of HRQOL at a different degree.

Keywords: Quality of Life in children with epilepsy, Paediatric epilepsy, Paediatric seizures

Introduction

Epilepsy is characterized by recurrent, episodic, paroxysmal, involuntary clinical events associated with abnormal electrical activity from the neurons of the brain. It is usually chronic and debilitating disorder that impacts not only those bearing with it but also their caregivers. Epilepsy is thought to affect more than 100 million individuals and their families worldwide at some point of their lives, and thus constitutes a major universal public health issue [1].

It is well-known that children with epilepsy have a compromised health-related QOL and may be affected across physical, psychological, social, and educational domains. [2] In this study, we have evaluated the QOL, its risk factors and various demographic determinants in children with epilepsy with or without comorbidities, visiting public tertiary care Hospital. All the cases were studied as per various parameters like age of the patient, socio-economic status, type of epilepsy, association of epilepsy with other morbidities etc. and statistics were made for comparison.

Materials And Methods-

- **Study design:** An observational, Cross-sectional and descriptive study. The study was carried out at a tertiary care Hospital, in a metropolitan city; Mumbai, Maharashtra, India. (Dr R. N. Cooper Hospital, Mumbai)
- **Duration of Research Project:** September 2020 to August 2021 (1 Year)
- **Sample size:**

75 children diagnosed to have epilepsy attending Paediatric Outpatient Department, Paediatric Neurology / Developmental Clinic,

- **Inclusion criteria:**

- Children aged between 5 and 12 years of age
- Diagnosed case of epilepsy with minimum duration of at least 6 months.

- **Exclusion Criteria:**

- Children with severe neuro-developmental conditions (Intellectual disability, developmental delay, cerebral palsy, autism, Attention deficit/hyperactivity disorder (ADHD), behavioural disorders, inherited disorders etc.)
- Children whose primary caregiver was not available to answer the questionnaire were also excluded.

- **Aims and Objectives:**

Primary objective: To assess overall quality of life in children with epilepsy.

Secondary objective:

To determine overall quality of life in children with epilepsy with regard to various domains of life including cognition, behavioral, social, physical.

To determine the relationship between-

(a) general Quality of Life (QOL) with factors such as age, gender, parent’s education, seizure type, seizure frequency, and comorbidities.

(b) domain-wise Quality of Life (QOL) with factors such as age, gender, parent’s education, seizure type, seizure frequency, and comorbidities.

The **Case Record Form (CRF)** consists of two parts:

Part 1: Contains items assessing demographic profile and seizure description etc.;

Socio-economic status was determined as per revised Kuppuswamy classification.

Part 2: Contains items specifically assessing health related quality of life of children with epilepsy i.e. **QOLCE-55 questionnaire** [3,4]

The questionnaire contains items specifically assessing health related quality of life of children with epilepsy.i.e.QOLCE-55 questionnaire[4]. The questionnaire has 4 domains and 55 items. It is a shortened version of the original QOLCE-76 questionnaire [5] which had 76 items. This QOLCE-55 questionnaire was formulated. It was validated by the study conducted by Conway et. al.[6] . For our study, it was translated to Hindi and Marathi languages. The QOLCE-55 has four subscales, namely cognitive, social, emotional and physical domains. All items in the four subscales were recoded such that higher scores indicate higher well being. The pre-coded numeric values of items were converted to a 0 to 100 point scale with higher converted scores always reflecting better quality of life.

Taking into consideration the objectives, the outcome measures that were studied are: Age, Gender, Parent's education, Type of Epilepsy, Seizure frequency, Number of seizures in the last six months and Comorbidities, Drug Therapy, Socioeconomic status.

Also, the median of the scores in all the four domains Cognitive, Emotional, Social and Physical were studied and data was analysed as follows:

Statistical Analysis:

After data collection, data entry was done in Microsoft Excel. Data analysis is done with the help of SPSS Software version 23.

Quantitative data like age, no. of seizures in the six months, duration of disease, domain wise QOLCE scores were presented with the help of Median and IQR. Qualitative risk factors like gender, age group, socioeconomic status, seizure frequency pattern/severity were presented with the help of Frequency and Percentage table.

Normality of the data is assessed with Shapiro Wilk Tests and Kolmogorov-Smirnov test. The comparison of total and domain wise QOLCE score and other risk factors like Age group, Gender, Parent education, Seizure type, Seizure frequency in the last six months etc. is done by Mann Whitney U test and Kruskal Wallis H test. 95% confidence interval level taken as significant. ($p<0.05$).

Results:

In this study, median total score (the overall QOL) was **63.8 (range = 30.6)** and all individual domains had low scores which reflects the negative impact of epilepsy on the QOL.

The individual subscale score was highest for cognitive functioning, a median score of 75.0 (range = 43.2), followed by social functioning a median of 71.4 (range = 42.9), emotional functioning a median score of 61.8 (range = 23.2), and physical functioning with a median of 57.3 (range = 30.6). This result was comparable to QOL scores of similar studies conducted in metropolitan city catering to urban population.

Majority of the study participants in our study, were in the age group of 8-10 years (45.3%), followed by 5-7 years (34.7%) and 11-12 years (20%). There was no statistically significant difference found in studying this variable.

In our study, majority of study participants were males (59%). No statistically significant difference was found.

Most of the primary caregivers being mothers/parents in our study, had done formal education up to primary completed (34.7%), followed by those completed highschool education upto 12th standard (32%) and then graduates (21.3%). There were 6.7% completely illiterates amongst all of the participants' parents. The difference was not statistically significant.

Most (86.7%) of the children with epilepsy in present study were able to attend school, of which 55 children were enrolled in a regular school while 10 children attended a special school.

Approximately 60% of 75 children with epilepsy included in our study had no comorbidities. 20 children had mild forms of comorbidity, and 11 cases presented with moderate comorbidities. Only a few children presented with more than one comorbidity. Majority of the study participants had Intellectual Disability (30.7%), followed by CP (8%), ADHD (2.7%), Retts Syndrome (2.7%), TCS (2.7%). Child with severe neurological impairment wasn't included in this study. This study is similar to the previous studies, which reported that children with comorbidities, such as behavioural, cognitive, and neurological problems, have been found to be significantly associated with a decline in HRQOL.

A small percentage of the participants (10.7%) did not depend on medication to control their seizures. Although most of them (69.3%) have been on monotherapy, but few others took multiple drugs or more than two antiepileptic drugs (AEDs); 16% taking 2 drugs, 2.7% taking 3 drugs and 1.3% taking 5 drugs. (Polytherapy). Similar to previous studies, we found that children receiving polytherapy, had poor cognitive functioning and overall QOL compared with those on monotherapy.

Out of 75 participants in our study, 48 (64%) children were diagnosed with generalized seizures (GTCS) and 17 (22.7%) children were diagnosed with focal seizures. Similar to few of previous studies, we found that overall quality of life was significantly more compromised in patients of generalized epilepsy compared with partial epilepsy.

The median scores of Cognitive and Social domains decreased with increase in the seizure frequency as it was statistically significant also. In our study we found that the median scores of quality of life were highest in all the 4 domains, ie cognitive, social, emotional and physical were highest in children who had no seizure episodes in the last six months.

It was also found that, children with onset of seizures in early infancy had comparatively lower QOL (52.4, 44.2) than children who were affected during the age 1-5 years (60.0, 30.9) or the age 6-10 years (74.8, 24.5); suggesting more impact is seen if attained epilepsy earlier in life.

Table 1 : Descriptive Statistics of all the scores as amongst all the study participants

Table 1 : Descriptive Statistics of all the scores as amongst all the study participants

SCORE	Mean	SD	Median	Range	Minimum	Maximum	Range
I (cognitive)	69.9	28.1	75.0	43.2	5.7	100.0	94.3
II (emotional)	62.6	16.1	61.8	23.2	34.4	88.6	54.3
III (social)	69.0	26.1	71.4	42.9	10.7	100.0	89.3
IV (physical)	55.6	21.2	57.3	30.6	12.5	100.0	87.5
Total	63.9	20.2	**63.8**	**30.6**	21.3	96.0	74.7

*SD – Standard Deviation.

Table 2: Distribution of Seizure type amongst study participants

Distribution of Seizure type amongst study participants

Seizure type	Frequency	Percent
GTCS	48	64.0%
Focal	17	22.7%
Atonic	5	6.7%
Myoclonic	3	4.0%
Absence	2	2.7%
Total	75	100.0%

Table 3: Median total scores age groups, Kruskal Wallis H test

Median total scores age groups, Kruskal Wallis H test

Age Groups	Median, IQR	IQR	Z	p value
5-7 Years	61.4	25.9	1.076	0.584 (Non-Significant)
8-10 years	65.2	33.0		
11-12 Years	64.3	40.4		

Table 4: Median total scores gender wise with Mann Whitney U test

Median total scores gender wise with Mann Whitney U test				
Gender	Median, IQR	IQR	Z	p value
Male	62.6	31	-0.775	0.439 (Non-Significant)
Female	66.8	34		

Table 5: Median total scores parent education (Kruskal Wallis H test)

Median total scores parent education (Kruskal Wallis H test)				
Parent's Education	Median, IQR	IQR	Kruskal-Wallis H	p value
Illiterate	60.2	28.2	7.148	0.128 (Non-Significant)
Literate	66.7	18.7		
Primary	68.8	29.8		
High School	56.9	21.8		
Graduate	81.4	36.6		

Table 6: Median total scores age of onset of Epilepsy (Kruskal Wallis H test)

Median total scores age of onset of Epilepsy (Kruskal Wallis H test)				
Age of Onset	Median, IQR	IQR	Kruskal Wallis H test	p value
0	52.4	44.2	8.714	0.0333 (Significant)
1-5 Years	60.0	30.9		
6-10 Years	74.8	24.5		
11-12 Years	65.4			

Table 7: Domain wise median scores according to gender (Mann Whitney U test)

Domain wise median scores according to gender (Mann Whitney U test)

Gender	Cognitive Domain	Emotional Domain	Social Domain	Physical Domain
	Median, IQR	Median, IQR	Median, IQR	Median, IQR
Male	73.4 , 54	61 , 23.8	71.4 , 42.9	56.3 , 31.3
Female	75 , 35.2	63.6 , 29.7	71.4 , 46.4	66.7 , 31.3
Z	-0.368	-0.958	-0.482	-1.491
P value	0.713 (Non-Significant)	0.338 (Non-Significant)	0.630 (Non-Significant)	0.136 (Non-Significant)

Figure no:1 Distribution of comorbidity among all patients

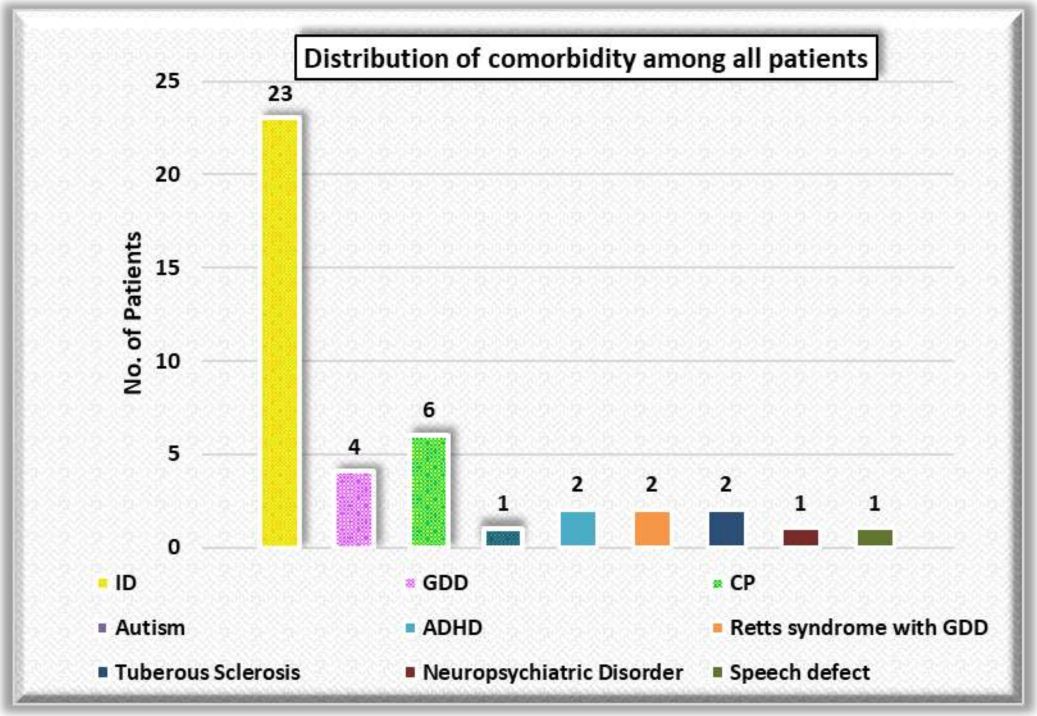
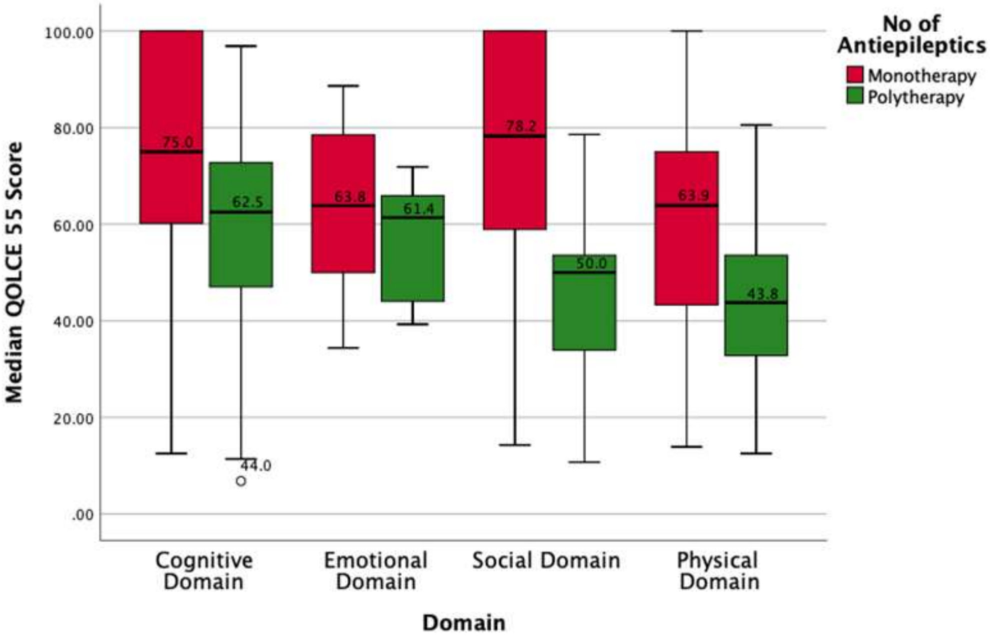


Fig No.2: comparison of domain wise median scores according to antiepileptics drugs



Discussion:

Paediatric epilepsy is associated with various comorbidities. It is well-known that children with epilepsy have a compromised health-related QOL and may be affected across physical, psychological, social, and educational domains. [7] Several studies indicate that childhood epilepsy is a high risk factor for poor psychosocial outcomes including depression and anxiety, low self-esteem, behavioural problems and academic problems. In literature, there are various factors that affect the quality of life in children with epilepsy. Age at epilepsy onset, number of AEDs, and parental depression are important HRQOL predictors, but specific to adolescents only, seizure worry/concerns and side effects of AEDs were found as strong predictors. [7] Type of epilepsy, seizure frequency in the last 1 year and the number of antiepileptic medications were found in another study as the major predictors significantly affecting QOL in paediatric patients with epilepsy [8]

In Our study, median total score (the overall QOL) was **63.8 (range = 30.6)** and all individual domains had low scores which reflects the negative impact of epilepsy on the QOL.

The individual subscale score was highest for cognitive functioning, a median score of 75.0 (range = 43.2), followed by social functioning a median of 71.4 (range = 42.9), emotional functioning a median score of 61.8 (range = 23.2), and physical functioning with a median of 57.3 (range = 30.6). This result was comparable to QOL scores of similar studies conducted in metropolitan city catering to urban population.

Majority of the study participants in our study, were in the age group of 8-10 years (45.3%), followed by 5-7 years (34.7%) and 11-12 years (20%). Median total QOLCE score amongst 5-7 years age group was (61.4, 25.9) and 8-10 years age group was (65.2, 33) and 11-12 years age group was (64.3, 40.4). This was not statistically significant. There was no statistically significant difference found, even when the domain wise scores were considered. However, the study by Arya et. al. [86] observed that 12-15 years olds had more compromised scores on behavioural subscales as compared to their younger (9-12 years) counterparts. It was explained in their study that older children may feel ashamed of their condition and thus may show more aggression and dissatisfaction in their behaviour.

In our study, majority of study participants were males (59%). No statistically significant difference was found in overall quality of life between males and females and in the individual domains i.e. cognitive, social, emotional and physical.

Most of the primary caregivers being mothers/parents in our study, had done formal education up to primary completed (34.7%), followed by those completed high school education upto 12th standard (32%) and then graduates (21.3%). Only 5.3% of mothers were literate without any formal education. There were 6.7% completely illiterates amongst all of the participants' parents. In our study, the overall quality of life was found to be highest in children whose mothers/parents were graduates, with a median total score of 81.4 (IQR 36.6), compared to children with lower parental education levels. The difference was not statistically significant. When the domain wise quality of life was assessed, the median score was highest in graduates in cognitive and social domain, but statistically significant result was not seen.

In terms of socioeconomic status, majority 34(45.3%) subjects were from Upper Lower class; followed by 19(25.3%) subjects were from Lower Middle class, 6(8%) subjects were from Lower class, 12(16%) subjects were from Upper Middle class, 4(5.3%) subjects were from Upper class. Overall QOL was not affected by socioeconomic status of the family except for statistically significant difference was seen in emotional domain scores, highest in Upper and Upper Middle class.

Childhood epilepsy has a severe impact on parental QOL and psychological health as well.

Most (86.7%) of the children with epilepsy in present study were able to attend school, of which 55 children were enrolled in a regular school while 10 children attended a special school. On comparing median total QOLCE scores, patients who attended regular school higher was (73.4, 27) than amongst patients who attended special school was (51.8, 34.1).

Approximately 60% of 75 children with epilepsy included in our study had no comorbidities. 20 children had mild forms of comorbidity, and 11 cases presented with moderate comorbidities. Only a few children presented with more than one comorbidity. Majority of the study participants had Intellectual Disability (30.7%), followed by CP (8%), ADHD (2.7%), Retts Syndrome (2.7%), TCS (2.7%). Child with severe neurological impairment wasn't included in this study. This study is similar to the previous studies, which reported that children with comorbidities, such as behavioral, cognitive, and neurological problems, have been found to be significantly associated with a decline in HRQOL. This might be explained by the fact that children with epilepsy who exhibit comorbidities suffer from poor cognitive functioning, delayed development, behavioral problems, and poor social skills and social interaction. The higher number of comorbidities deteriorated HRQOL in children with epilepsy.

A small percentage of the participants (10.7%) did not depend on medication to control their seizures. Although most of them (69.3%) have been on monotherapy, but few others took multiple drugs or more than two antiepileptic drugs (AEDs); 16% taking 2 drugs, 2.7% taking 3 drugs and 1.3% taking 5 drugs. (Polytherapy).

Out of 75 participants in our study, 48 (64%) children were diagnosed with generalized seizures (GTCS) and 17 (22.7%) children were diagnosed with focal seizures. In the study conducted by Nagesh A. et. al.[10], out of 104 children, 64 children were boys (61.54%) and 40 children were girls (38.46%), with the most frequent seizure types was generalized tonic clonic seizures (GTCS) were seen in 71 (68.26%) children.

In our study, the median total score in study participants with Atonic epilepsy was highest (73.6, 19.5), followed by Focal seizures was (67.1, 28.3) as compared to GTCS which was (63.5, 34.5), and further low scores seen with Myoclonic (21.4,) and with Absence seizures (57.8). The difference was statistically significant. The median score of Cognitive and Social domain was higher in children with Focal epilepsy. These patients also had poor perception of overall health and had no clear ambitions or plans for the future. It is noticed that they felt that their standard of living is low with poor relationship with friends and had poor self-esteem.

In the current study we observed that, the median scores based on the seizure frequency was lowest for seizure frequency of 11-50. This was statistically significant. Children with seizure frequency of more than 50 in the last 6 months with a median score of 51.8 had decreased quality of life than those with no seizures with a median of 74.9. The median scores of Cognitive and Social domains decreased with increase in the seizure frequency as it was statistically significant also. In our study we found that the median scores of quality of life were highest in all the 4 domains, ie cognitive, social, emotional and physical were highest in children who had no seizure episodes in the last six months. Also, the median QOL score was highest (75.0, 32.9) for yearly seizures. This was statistically significant. Children with daily and weekly seizures had decreased quality of life. The overall quality of life (total median score) and individual domain subscale scores decreased with increasing seizure frequency.

Regarding age of onset of epilepsy, it was found that, children with onset of seizures in early infancy had comparatively lower QOL (52.4, 44.2) than children who were affected during the age 1-5 years (60.0, 30.9) or the age 6-10 years (74.8, 24.5); suggesting more impact is seen if attained epilepsy earlier in life. The difference was statistically significant. It was also found that most of these children with earlier age of onset of seizures were having profound impairment in cognitive and social function, as compared to others.

The current study found that children with epilepsy presented a higher score in emotional functioning than physical functioning.

Results of our study also confirms, Epilepsy affects a child's social functioning at different levels, depending on his/her health status and social abilities.

When considering physical functioning related to physical activities in a child's daily life, this study found that epilepsy affected the child's physical functioning at a moderate to high level, which is similar to the results from a previous study.

Overall, this study agrees with other studies that epilepsy impairs many aspects of HRQOL at a different degree.

Conclusion-

This cross-sectional survey of child- and caregiver-reported preferences enriches understanding of the priorities of children with epilepsy for improving HR-QOL. This results show that epilepsy is associated with lower HR-QOL outcomes. Among many of the factors investigated in our study, only type of seizure, seizure frequency, age at onset of epilepsy, presence of comorbidities, number of anti-epileptic drugs and socioeconomic status, have shown an impact on the QOLCE total score. Age of onset of epilepsy and comorbidity were negatively correlated to HRQOL.

Age of Onset, comorbidity and Seizure frequency could co-predict overall quality of life in children with epilepsy. The strongest factor influencing quality of life in childhood epilepsy was Seizure frequency as in children having seizures daily or weekly suffer poor QOL.

Limitation Of The Study

Study recruited children from a wide age range and the quality of life might be expressed differently between the young children and adolescents.

Interpretation of results is constrained by the small sample size of this study and it should therefore be noted that views discussed might not be generalizable to other children with epilepsy. Further studies using larger numbers should therefore be attempted, taking account of the need for samples from different cultures and regions.

IQ testing record was not available with many of the participants and hence decision in this regard was based on the history and clinical judgement.

The evaluation of quality of life by a caregiver or parent proxy might be limited to the individual perceptions of health status and functioning among adolescents.

Unfortunately, reliability and the psychiatric condition of the caregivers were not assessed. Another limitation is the response bias due to the survey-based nature of the study

References

1. Alla Guekht, et. al. The road to a World Health Organization global action plan on epilepsy and other neurological disorders. Epilepsia. 2021;62:1057–1063.
2. Gambhir SK, Kumar V, Singhi PD, Goel RC. Public awareness, understanding & attitudes toward epilepsy. Indian J Med Res 1995;102:34–38
3. Indian Council of Medical Research, National ethical guidelines for biomedical and health research involving human participants. Available at:https://main.icmr.nic.in/sites/default/files/guidelines/ICMR_Ethical_Guidelines_2017.pdf [Last accessed on September 21, 2021]

4. Saleem SM. Modified Kuppuswamy socioeconomic scale updated for the year 2020. Indian Journal of Forensic and Community Medicine. 2020 Mar 15;7(1):1-3.
5. Goodwin SW, Lambrinos AI, Ferro MA, et. al. Development and assessment of a shortened Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). Epilepsia 2015; 56: 864–872.
6. Sabaz M, Cairns DR, Lawson JA, Nheu M, Bleasel AF, Bye AM. Validation of a new quality of life measures for children with epilepsy. Epilepsia. 2000;41:765-74.
7. Capovilla G, Kaufman KR, Perucca E, Moshe SL, Arida RM. Epilepsy, seizures, physical exercise, and sports: A report from the ILAE Task Force on Sports and Epilepsy. Epilepsia. 2016;57(1):6–12.
8. Kadam P, Bhalerao S. Sample size calculation. Int J Ayurveda Res. 2010;1(1):55. Available from: /pmc/articles/PMC2876926/
9. WMA declaration of Helsinki- Ethical principles for medical research involving human subjects. Available at: https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/ [Last accessed on September 21, 2021]
10. Indian Council of Medical Research, National ethical guidelines for biomedical and health research involving human participants. Available at:https://main.icmr.nic.in/sites/default/files/guidelines/ICMR_Ethical_Guidelines_2017.pdf [Last accessed on September 21, 2021]
11. Saleem SM. Modified Kuppuswamy socioeconomic scale updated for the year 2020. Indian Journal of Forensic and Community Medicine. 2020 Mar 15;7(1):1-3.
12. Goodwin SW, Lambrinos AI, Ferro MA, et. al. Development and assessment of a shortened Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). Epilepsia 2015; 56: 864–872.
13. Sabaz M, Cairns DR, Lawson JA, Nheu M, Bleasel AF, Bye AM. Validation of a new quality of life measures for children with epilepsy. Epilepsia. 2000;41:765-74.
14. Conway L, Widjaja E, Smith ML, et. al. Validating the shortened Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55) in a sample of children with drug-resistant epilepsy.Epilepsia 2017; 58: 646– 656.
15. Karnavat P.K., Hegde A.U. and Kulkarni S.: Quality of Life in Children with Epilepsy in Private and Public Tertiary Care Centers in India. International Journal of Epilepsy, 5 (01): 028-37, 2018.
16. Altwaijri, et al.: Quality of life in paediatrics with intractable epilepsy in a large paediatric university hospital in Riyadh, Saudi Arabia. Journal of Family Medicine and Primary Care, Volume 9 : Issue 11 : November 2020, pg. 5523-5536.
17. Arya V, Gehlawat VK, Kaushik JS, Gathwala G. Assessment of parent reported quality of life in children with epilepsy from Northern India: A cross-sectional study. J Paediatr Neurosci 2014; 9:17.