

Assessment of Health Related Quality of Life in Children with Epilepsy With Regard to Various Domains of Life

Santosh Shimpiger^{1*}, Sushma Save², Nishigandha Joshi³

¹Department of Pediatrics, H.N Reliance Foundation Hospital, Mumbai 400004, India

²Department of Pediatrics, T.N.M.C and B.Y.L Nair Charitable Hospital, Mumbai 400008, India

³Department of Pediatric Neurology, P D Hinduja Hospital, Mumbai 400016, India

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Corresponding author: Dr. Santosh Shimpiger

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Abstract:

Background: Epilepsy is unpredictable, 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.

Objectives: Emphasis on various factors which can affect the quality of life in children with epilepsy. Certain factors such as seizure frequency and time since last seizure which are not studied extensively in India or abroad are included in this study to establish their effects on different domains of life in children with epilepsy.

Results: Majority of the study participants were in the age group of 8-10 years (42%), followed by 5-7 years (29%) and 11-12 years (29%). Also illustrates the distribution of study participants according to gender. Majority of study participants were males (60%). Also illustrates the distribution of study participants according to maternal education. Majority of the mothers were graduates (41%), followed by 12th standard (30%) and primary education (24%). Only 5% of mothers were illiterate. The mean score was highest for time of more than 365 days. No statistically significant difference was found. In our study we found that children with time since last seizure of more than 1 year (i.e. more than 365 days) had a better quality of life with a mean score of 89.19 compared to those with time since last seizure of less than 7 days with a mean score of 60.77.

Conclusion: The overall quality of life was compromised in children with epilepsy. The quality of life was better in participants of older age group, higher maternal education level, less seizure frequency and more time since last seizure. Sex of the participant did not have a significant impact on the quality of life.

Keywords: Children, Epilepsy, Public health issue, Quality of life, Seizure.

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Introduction

One of the most prevalent long-term neurological disorders in children is epilepsy, which carries a higher risk of poor health-related quality of life. [1] Children with epilepsy struggle in many areas of functioning, such as social competence, academic success, emotional and behavioral issues, and family life. These difficulties persist throughout adulthood. [2] Understanding the possible impacts of epilepsy on many facets of life is essential for managing epilepsy. [3] One of the most important and common neurological conditions throughout childhood is epilepsy. Numerous studies show that having epilepsy as a kid increases the likelihood of negative psychosocial effects, such as anxiety and sadness, low self-esteem, behavioral issues, and trouble in school. [4, 5]

In Indian children with epilepsy, factors influencing quality of life include age, frequency of seizures, parental education, type of epilepsy, and kind of anti-epileptic medication. The most

prevalent effects of epilepsy are on cognition, energy, and focus. [6] Both general and condition-specific metrics can be used to evaluate QOL. Generic QOL measures have the benefit of permitting comparisons with the healthy population and evaluate function, impairment, and distress arising from general ill health. [7] "The degree to which a person enjoys the important possibilities of life" is the focus of quality of life (QOL).

The term health-related quality of life (HRQOL) refers to an individual's assessment of the ways in which their health affects their general well-being and quality of life. One significant and quantifiable result of treatment for illnesses that do not pose a threat to life is quality of life. [8] The objectives of the study were to emphasis on various factors which can affect the quality of life in children with epilepsy. Certain factors such as seizure frequency and time since last seizure which are not studied extensively in India or abroad are included in this

study to establish their effects on different domains of life in children with epilepsy.

Method:

Study design:

An observational, Cross sectional study, a Descriptive study with an analytical wing

Sample size:

100 children diagnosed to have epilepsy attending the Pediatric Outpatient Department, Pediatric Neurology and Epilepsy Clinic or Pediatric inpatient department satisfying the inclusion and exclusion criteria.

The sample size was calculated using the formula [9]

$$\text{Sample size} = \frac{Z(1-a/2)^2 * p(1-p)}{D^2}$$

$Z(1-a/2)$ = standard normal variate at 5% type 1 error ($P < 0.05$) it is 1.96 and at 1% type 1 error ($p < 0.01$) it is 2.58.

p = Expected prevalence in population based on previous studies or pilot studies. It was determined to be 7 [10, 11].

D = Absolute error or precision- has to be decided by researcher. It is taken as 0.05 for this study

Inclusion criteria:

- Children aged between 5 and 12 years of age
- Diagnosed to have epilepsy as defined [12]
- Parents/ guardians willing to give consent for participation in the study.

Exclusion Criteria:

Children diagnosed with neuro-developmental conditions on the basis of history and clinical examination or by review of previous records or OPD/ IPD document of the participant, like

- Mental retardation[13]
- Developmental delay[14]
- Cerebral palsy[15]
- Autism[16]
- Attention-deficit Hyperactivity Disorder (ADHD)[17]
- Learning disability[18]

Statistical Analysis: The gathered information was put into a Microsoft Excel spread sheet, which was then exported to the data editor of SPSS Version 20.0. (SPSS Inc., Chicago, Illinois, USA).

Kruskal Wallis Test, Mann Whitney U test were used for frequencies and percentages to summarize the variables. A P value < 0.05 was considered as significant.

Results:

Table 1: Distribution of study participants according to age, gender, maternal education

Age group	Number	Percent
5-7 years	29	29.0
8-10 years	42	42.0
11-12 years	29	29.0
Total		100.0
Gender	Number	Percent
Males	60	60.0
Females	40	40.0
Total	100	100.0
Maternal education	Number	Percent
Illiterate	5	5.0
Primary education	24	24.0
12 th Standard	30	30.0
Graduation	41	41.0
Total	100	100.0

Table 1 illustrates the distribution of study participants according to age. Majority of the study participants were in the age group of 8-10 years (42%), followed by 5-7 years (29%) and 11-12 years (29%). Also illustrates the distribution of study participants according to gender. Majority of

study participants were males (60%). Also illustrates the distribution of study participants according to maternal education. Majority of the mothers were graduates (41%), followed by 12th standard (30%) and primary education (24%). Only 5% of mothers were illiterate.

Table 2: Mean total scores based on the types of epilepsy

Types of epilepsy	Mean± Std. Deviation	P
Absence	52.41	0.18 Not Significant
Atonic	72.86±10.78	
GTCS	76.11±15.38	
Mixed	87.82	
Partial	68.23±15.41	
Kruskal Wallis Test, *Statistically significant, p<0.05		

The distribution of study participants according to the types of epilepsy. Majority of the study participants had GTCS (63%), followed by partial epilepsy (33%) and atonic epilepsy (2%). Only 1% of the study participants had absence epilepsy and mixed epilepsy. **Table 2** illustrates the mean total scores based on the types of epilepsy. The mean score in study participants with atonic epilepsy was 72.86±10.78, GTCS was 76.11±15.38 and partial epilepsy was 68.23±15.41. No statistically significant difference was found.

Table 3: Mean total scores based on seizure frequency, time since last seizure

Seizure frequency	Mean± Std. Deviation	P
0	85.02±8.66	0.23 Not Significant
1 to 5	64.81±13.07	
6 to 50	53.95±5.99	
More than 50	54.17±8.01	
Time since last seizure	Mean± Std. Deviation	P
Up to 7 days	60.77±12.46	0.54 Not Significant
8- 30 days	68.81±11.82	
30-365 days	82.29±10.05	
More than 365 days	89.19±2.86	
Kruskal Wallis Test, *Statistically significant, p<0.05		

Table 3 illustrates the mean total scores based on the seizure frequency. The mean score was lowest for seizure frequency of 6-50. No statistically significant difference was found.

In the study we observed that children with seizure frequency of more than 50 in the last 3 months with a mean of 54.17 had decreased quality of life than those with no seizures with a mean of 85.02.

The quality of life decreased with a decrease in seizure frequency. Thus the difference in their quality of life is clinically significant but statistically insignificant.

Table 3 illustrates the mean total scores based on time since last seizure. The mean score was highest for time of more than 365 days. No statistically significant difference was found. In our study we found that children with time since last seizure of more than 1 year (i.e. more than 365 days) had a better quality of life with a mean score of 89.19 compared to those with time since last seizure of less than 7 days with a mean score of 60.77. The quality of life increased with greater time since last seizure. The difference in their quality of life is clinically significant, but not statistically significant.

Table 4: Mean scores of individual domains according to age group, gender

Variables		Cognitive domain	Emotional domain	Social domain	Physical domain
Age group	5-7 years	81.79±19.19	70.37±9.84	70.2±23.15	56.45±19.65
	8-10 years	83.09±14.64	72.4±11.03	71.41±23.02	58.29±17.65
	11-12 years	87.85±17.05	75.85±11.75	81.91±24.23	70.1±19.68
P		0.31	0.16	0.06	0.07
Variables		Cognitive domain	Emotional domain	Social domain	Physical domain
Gender	Males	85.14±16.15	71.92±9.71	71.13±24.07	60.22±19.12
	Females	82.52±17.76	74.14±12.74	78.56±22.74	62.62±20.28
P		0.46	0.22	0.12	0.63

Table 4 illustrates the mean scores of individual domains according to age groups. The mean score was highest in 11-12 yrs old followed by 8-10 years and 5-7 years for Cognitive domain. Similar pattern was seen for Emotional domain, Social domain and Physical domain. No statistically

significant difference seen. **Table 4** illustrates the mean scores of individual domains according to gender. The mean score was higher for males as compared to females for Cognitive domain. However, mean scores of Emotional domain, Social domain and Physical domain was higher for

females as compared to males. No statistically significant difference seen.

Table 5: Mean scores of individual domains according to types of epilepsy

Variables		Cognitive domain	Emotional domain	Social domain	Physical domain
Types of epilepsy	Absence	53.12	65.9	50.00	40.62
	Atonic	96.88±4.42	77.27±16.07	67.85±10.11	49.47±12.54
	GTCS	86.09±16.77	74.05±11.14	77.83±22.94	64.71±20.15
	Mixed	100	72.72	100	78.57
	Partial	79.96±15.84	70.38±10.71	67.31±24.50	55.26±17.20
P		0.13	0.49	0.23	0.89

Table 5 illustrates the mean scores of individual domains according to types of epilepsy. The mean score of Cognitive and emotional domain was highest was study participants with atonic epilepsy followed by GTCS and partial epilepsy. The mean score of Social domain was highest for study participants with GTCS. The mean score of Physical domain was highest was study participants with GTCS followed by partial and Atonic epilepsy. No statistically significant difference seen.

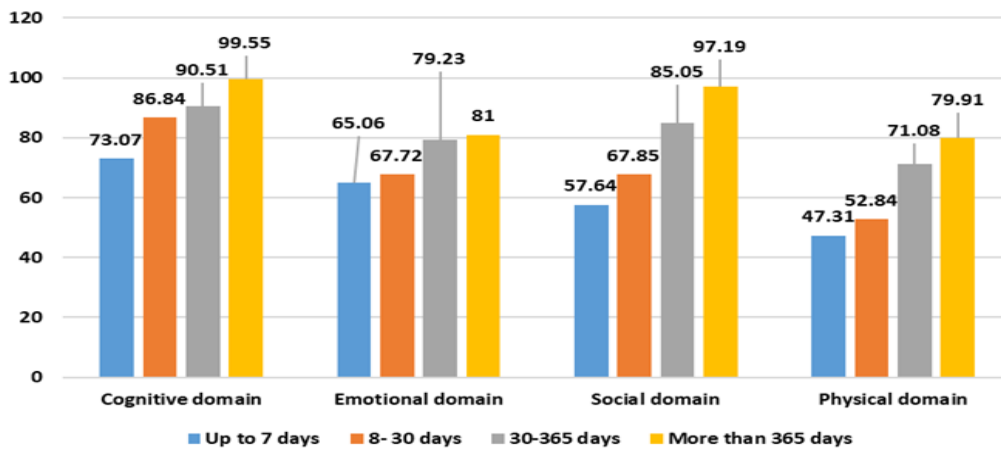


Figure 1: Mean scores of individual domains according to time since last seizure

Figure 1 illustrates the mean scores of individual domains according to time since last seizure. A similar pattern was noticed in all the domains. The mean scores increased with increase in the time since last seizure. And this was statistically significant.

Table 6: Mean scores of individual domains according to seizure frequency

		Cognitive domain	Emotional domain	Social domain	Physical domain
Seizure frequency	0	93.07±11.79	80.43±7.32	89.58±17.67	74.42±12.83
	1 to 5	79.22±16.43	67.34±8.74	62.37±20.19	50.64±16.51
	6 to 50	66.02±8.75	57.38±7.56	49.10±5.32	43.3±17.02
	More than 50	55.20±3.61	66.66±1.32	53.57±23.42	41.12±12.8
P		0.00*	0.00*	0.00*	0.00*

Table 6 illustrates the mean scores of individual domains according to seizure frequency. The mean score of Cognitive and Physical domain decreased with increase in the seizure frequency. The mean score of Emotional domain and social domain was highest for seizure frequency of 0. This was statistically significant.

Discussion

In our study, majority of the study participants were in the age group of 8-10 years (42%), followed by 5-7 years (29%) and 11-12 years (29%). The mean score was highest in 11-12 years (80.00±15.23) followed by 8-10 years

(71.23±14.74) and 5-7 years (69.7±15.94). There was a statistically significant difference found, i.e. the overall quality of life improved with increase in age.

The study by Arya et al [19] observed that 12-15 year olds had more compromised scores on behavioral 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 behavior.

Similar study by Nadkarni et al [20] concluded that overall quality was affected more in older children

as compared to younger age group, this may be due to the fact that older children are more likely to perceive a greater negative impact on life and general health and have more negative attitude toward epilepsy. A similar conclusion was reported by study conducted by Devinsky et al [21].

In our study, majority of study participants were males (60%). 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. The study conducted by Aggarwal et al [22] concluded that gender was not found to correlate significantly with any subscale. Similarly, in the study by Gambhir, et al. [23] negative attitude was significantly correlated with lower level of education and occupation, but no significant difference was noticed with regard to sex. Stevanovic, et al. [24] also reported that mean Health related quality of life total scores were comparable between boys and girls. Similarly, the study conducted by Arya et al [19] also had concluded that gender did not affect the overall quality of life and any of the subscales significantly.

In the study by Nadkarni et al [20], better quality of life was observed in children of literate mothers. This can be attributed to the fact that mothers with higher education are supposed to have a more scientific and logical approach to the problems faced by children with epilepsy. But a study by Aggarwal et al [22] concluded that self-esteem and social interaction scores in children with higher educated mothers were lower than the scores of the children with illiterate mothers.

In our study we found that quality of life did not vary significantly with type of epilepsy. Though the mean score for quality of life in children suffering from GTCS seizure disorder was highest, i.e. 76.11, compared to children other types of epilepsy, but the difference was not statistically significant. Similar study by Arya et al [19] had concluded that type of seizure did not significantly affect the quality of life in children with epilepsy. However the study by Nagesh et al [25] concluded that patients with GTCS and Myoclonic had poor quality of life in family relationships, social life and ability to work.

In our study we found that the mean scores of quality of life were highest in all the 4 domains, i.e. cognitive, social, emotional and physical were highest in children who had no seizure episodes in the last three months. The mean scores in all the four domains decreased with increasing seizure frequency. Thus we found that the quality of life varied significantly with seizure frequency. The study by Aggarwal et al [22] also had concluded that higher seizure frequency adversely affected the

quality of life. A similar study by Sabaz et al [26] also proved that quality of life in children with epilepsy is sensitive to differences in seizure severity. The study by Nadkarni et al [20] also had concluded that poorer quality of life was seen in children with higher seizure frequency.

The affection of quality of life in children with epilepsy has not been studied widely and research is insufficient. However the study by Nagesh et al [25] also had concluded that lesser the time interval since last seizure, more severe was the compromise in quality of life which supports our study.

Conclusion:

In our study, we found that the overall quality of life was compromised in children with epilepsy. The quality of life was better in participants of older age group, higher maternal education level, less seizure frequency and more time since last seizure. Sex of the participant did not have a significant impact on the quality of life. The management of epilepsy should not be limited to only control of seizures. Other factors which affect the quality of life should be considered and treatment should be tailored accordingly with a holistic approach to make a difference in the lives of children with epilepsy and their caregivers.

Limitations:

The sample size of the study was 100 which is relatively a very small sample size when the prevalence of epilepsy is considered. As our study was conducted in a tertiary care centre of a metropolitan city, majority of the participants of our study hailed from the urban localities and very few from the rural areas. The factors related to drug therapy such as the number of antiepileptics the participant was receiving and compliance to antiepileptics, which might impact the quality of life were not included in our study.

Ethical approval: The study was approved by the Institutional Ethics Committee, Academic Research Projects (ECARP)

References:

1. De Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. *Epilepsy Behav* 2008; 12:540-6.
2. Davies S, Heyman I, Goodman R. A population survey of mental health problems in children with epilepsy. *Dev Med Child Neurol* 2003; 45:292-5.
3. Baker GA. The psychosocial burden of epilepsy. *Epilepsia* 2002; 43:26-30.
4. Austin JK, Risinger MW, Beckett LA. Correlates of behavior problems in children with epilepsy. *Epilepsia* 1992; 33:1115-22.

5. Sturniolo MG, Galletti F. Idiopathic epilepsy and school achievement. *Arch Dis Child* 1994; 70:424-8.
6. Agarwal A, Datta V, Thankur LC. Quality of life in children with epilepsy. *Indian pediatr* 2011; 48:893-6.
7. Landgraf JM, Abetz L, Ware JE. Child health questionnaire (CHO). The Health Institute, New England Medical Center 1996; 1st edn.
8. Sudhanshu S, Pankaj A, Sorabh J, Nidhi S, Garima C, Nirali D. Assessment and comparison of clinical dental status and its impact on oral health-related quality of life among rural and urban adults of Udaipur, India: A cross-sectional study. *J Basic Clin Pharm* 2015; 6:5-58.
9. McColl L, Marley S, Brooks S, Harrison SC. Select statistical services, Sample size calculator, Available at: <https://select-statistics.co.uk/calculators/sample-size-calculator-population-proportion>. [Last accessed on Nov 21 2019]
10. Amalakanti S. Recent advances in epilepsy. Available at: <https://www.econicon.com/ecne/pdf/ECNE-05-00117.pdf> [Last accessed on Nov 21, 2019]
11. Amudhan S, Gururaj G, Parthasarathy S. *Annals of Indian Academy of Neurology-Epilepsy in india-epidemiology and public health*. Available at: <http://www.annalsofian.org/article.asp?issn=09722327;year=2015;volume=18;issue=3;spage=263;epage=277;aulast=Amudhan> [Last accessed on Nov 5, 2019]
12. Swaiman KF, Ashwal S, Ferriero DM, Schor NF, Finkel RS, Gropman AL, et al Overview of Seizures and Epilepsy in children, Swaiman's Paediatric Neurology, 6th edition, Elsevier, 2018, P.498-500
13. Wimbley K, Paras NK. Diagnostic criteria for Mental Retardation. Available at: <https://behavenet.com/node/21026>. Last accessed on nov 19, 2019
14. Kalra. V, Chapter no-7, Developmental assessment and mental retardation, In: *Practical Paediatric Neurology*, 2nd edition, Sirmour (H.P), Arya publications, 2016, p.143-163.
15. Stanton BF, St Geme WJ, Schor FN, Cerebral Palsy, In: *Nelson Textbook of Pediatrics*, 20th edition, Canada, Elsevier, 2016, P2896-99.
16. Swaiman. KF, Ashwal S, Ferriero DM, Schor NF, Finkel RS, Gropman AL, et al *Autistic Spectrum Disorders*, (eds.) Swaiman's Paediatric Neurology, 6th edition, China, Elsevier, 2018, P.459-71
17. Mandelbaum DE, Attention Deficit Hyperactivity Disorder, In: Swaiman. KF, Ashwal. S, Ferriero. DM, Schor. NF, Finkel. RS, Gropman AL, et al, (eds) Swaiman's Paediatric Neurology, 6th edition, Published in China, Elsevier, 2018, P.447-58
18. Robert M, McKenzie K, Ilangko S, Barns L The LDAO Definition of Learning Disabilities and DSM 5, 2015, Available at <http://www.ldao.ca/wpcontent/uploads/LDAO-Definiton-and-DSM-5.pdf>. [Last accessed on nov 19, 2019]
19. 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.
20. Nadkarni J, Jain A, Dwivedi R. Quality of life in children with epilepsy. *Ann Indian Acad Neurol* 2011; 14:279-282
21. Devinsky O, Westbrook L, Cramer J, Glassman M, Perrine K, Camfield C. Risk factors for poor health-related quality of life in adolescents with epilepsy. *Epilepsia*. 1999;40:1715-20
22. Aggarwal A, Datta V, Thakur L. Quality of life in children with epilepsy. *Indian pediatr* 2011; 48:893-6.
23. Gambhir SK, Kumar V, Singhi PD, Goel RC. Public awareness, understanding and attitudes towards epilepsy. *Indian J Med Res*.1995;102:34-8
24. Stevanovic D. Health-related quality of life in adolescents with well-controlled epilepsy. *Epilepsy Behav*. 2007;10:571-5
25. Nagesh A, Gade A, Puchchakayala G, Bhava S, Kagitapu S, Madanu S. Assessment of health related quality of life in children with epilepsy using quality of life in childhood epilepsy questionnaire (Qolce-55) in tertiary care hospital. *JB, Clin Pharm* 2017; 8:135-6]
26. 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.