

Quality of life of children with epilepsy, a study in Western India

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Abstract

Objectives: To assess the quality of life (QOL) of children with epilepsy and the demographic and clinical factors influencing the QOL in epileptic children.

Method: Seventy six children 2-15 years old with active epilepsy were consecutively enrolled. Baseline demographic data including age, gender, socio-economic status and parental education were obtained from the parents. The type of epilepsy and seizure frequency were assessed. QOL was assessed using the quality of life in childhood epilepsy (QOLCE) questionnaire.

Results: A total of 76 epileptic children aged 2-15 years were evaluated for QOL using the QOLCE questionnaire. Forty (52.6%) children were 5.1-10 years old. There were 45 (59.2%) males and 31 (40.8%) females. Fifty eight (76%) children came from a rural background and 48 (63.2%) belonged to the middle socio-economic class. Thirty nine (51.3%) fathers and 42 (55.3%) mothers were educated till high school. Generalised tonic clonic seizures occurred in 55 (72.4%) children followed by focal seizures and seizures of unknown type. Overall QOL score was 70.7 (12.6). Lowest scores were observed for energy / fatigue subcategory. Subcategories with higher QOL scores were social stigma, social activity anxiety and social interaction. Overall QOL scores were better with educated parents especially mothers. Children belonging to lower and lower middle socio-economic class had poor overall QOL scores of 66.8±12.5.

Conclusions: Overall QOL was compromised in epileptic children and was adversely affected by parental education, especially mother's, and the socio-economic status of the family.

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(Key words: Children, Epilepsy, Quality of life, Socio-economic status)

Introduction

At least two unprovoked seizures occurring more than 24 hours apart or one unprovoked seizure and the probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years are necessary for the diagnosis of epilepsy¹. These children are more prone to the risk of recurrence, impairment of brain function and depression, psycho-pathological problems and behavioural problems²⁻⁴. The quality of life (QOL) of children with epilepsy is significantly affected due to chronicity, effects of medication, prejudice, social convention, social stigma and impairment of brain function⁵. Behavioural problems occur in 43% and psychological disorders in 50-60% of epileptic children^{6,7}. Problems like attention deficit, hyperkinesia, cognitive function impairment, anxiety and low self-esteem have been reported⁸⁻¹². There is a paucity of literature on QOL of children and adults with epilepsy in India¹³⁻¹⁵.

Objectives

The primary objective of the study was to assess the QOL of children with epilepsy. The secondary objectives were to assess the demographic and clinical factors which influence the QOL in children with epilepsy.

Method

Inclusion and exclusion criteria: Children aged 2-15 years with epilepsy for over 6 months were included in the study. Children with co-morbidities, neuro-developmental conditions [mental retardation, developmental delay, cerebral palsy, autism, attention deficit hyperactivity disorder (ADHD) behavioural disorders] and chronic medical conditions [asthma, hypertension, chronic renal failure (CRF), chronic lung disease (CLD), thalassaemia, hypothyroidism) as per records available with parents, were excluded. Children whose primary caregiver was not available to answer the questionnaire were also excluded.

A cross-sectional study was conducted in the paediatric outpatient department of a tertiary care teaching hospital of Western India. The study centre caters to heterogeneous populations representing both urban and rural patients. Parents

of eligible children who consented to participate were assessed for demographic and clinical factors which could influence the QOL. Total number of enrolled children was 76. Following demographic factors were recorded: age, gender, parental educational status, income and place of residence. Socio-economic status was determined as per revised Kuppaswamy classification¹⁶. Clinical factors like seizure type, seizure frequency over preceding 6 months, number of anti-epileptic drugs (AEDs) and duration of seizures were assessed.

Patient's seizures were classified as generalized, focal, and unknown as per revised Classification of the Epilepsies 2017¹⁷. Diagnosis of the syndrome classification of epilepsy was attempted based on seizure semiology, electroencephalographic and neuroimaging findings. Seizure frequency was determined by the mean monthly seizure frequency for at least 6 months prior to enrolment in the study. Seizure frequency was determined as per history recalled by parents or from the records if they were maintaining a seizure diary. It was categorized as less than one seizure per month, one to five seizures per month and more than five seizures per month. Duration of epilepsy was defined as chronological age minus age at diagnosis. Numbers of AEDs in the last 6 months were classified as one AED and more than one AED.

QOL was evaluated using the Quality of Life in Children with Epilepsy (QOLCE) questionnaire¹⁸. The instrument was translated by professional translators in Hindi/ Marathi and was piloted on 10 parents prior to initiation of the study. Pilot study data were analysed for reliability using Cronbach's alpha statistics in SPSS 26 and the value for Cronbach's alpha was found to be 0.905 which can be considered as a highly reliable value. All precautions were exercised to retain the meaning, grammar and simplicity of the original version while being translated. Either father and / or mother was given a self-administered Hindi/Marathi version of the QOLCE questionnaire. Original QOLCE contains 91 items, which fall into five QOL domains with 13 multi-item and three single item subscales: physical function domain (12 items), cognitive function domain (23 items), emotional well-being domain (19 items), social function domain (12 items) and behavioural function domain hub scale (23 items).

Ethical issues: Ethical approval was obtained from the Institutional Ethics Committee of Smt. Kashibai Navale Medical College and Hospital, Pune, India (IEC No. SKNMC/Ethics/app/2018/413). Written informed consent was obtained from the parents prior to enrolment in the study.

Statistical analysis: Data were entered into Microsoft Excel and analysed using Statistical Package for Social Sciences (SPSS) version 20. Categorical variables were expressed in terms of frequency and percentage and continuous were expressed in terms of mean and SD. Sub categorical variables and overall QOL scores were compared with demographics, seizure control, duration of treatment etc. using unpaired t-test for two group comparison and Analysis of Variances (ANOVA) for 3 or more group comparisons with $p < 0.05$ as significance value.

Results

A total of 76 epileptic children aged 2-15 years were evaluated for QOL using the QOLCE questionnaire. Table 1 shows the demographic profile of children with epilepsy. Forty children were 5.1 to 10 years old. Forty five (59.2%) were male; 51.3% fathers and 55.3% mothers were educated till high school. Fifty eight (76%) children came from a rural background. Forty eight (62.2%) belonged to the middle socio-economic class and 22 (28.9%) to the lower socio-economic class.

Table 1: Demographic profile (n=76)

Characteristic	Frequency (%)
<i>Age group (years)</i>	
1-5	17 (22.3)
5.1-10	40 (52.6)
10.1-15	19 (25.0)
<i>Gender</i>	
Female	31 (40.8)
Male	45 (59.2)
<i>Mother's education</i>	
<12 th grade	19 (25.0)
>12 th grade	11 (14.5)
Till 12 th grade	39 (51.3)
Illiterate	07 (09.2)
<i>Father's education</i>	
<12 th grade	11 (15.0)
>12 th grade	16 (21.0)
Till 12 th grade	42 (55.0)
Illiterate	07 (09.2)
<i>Socioeconomic class</i>	
High	01 (01.3)
Middle	48 (62.2)
Lower	22 (28.9)
Lower middle	05 (06.6)

Table 2 shows the clinical profile of children with epilepsy. Generalised tonic clonic seizures was the commonest type occurring in 55 (72.4%) children followed by focal seizures in 10 (22%) children. Out of total enrolled children 56 (73.7%) had good control of seizures; 63 (82.9%) children were on monotherapy.

Table 2: Clinical profile of children with epilepsy

Characteristic	Frequency (%)
<i>Seizure type</i>	
Generalised tonic-clonic	55 (72.4)
Focal	10 (13.2)
Unknown	11 (14.5)
<i>Type of seizure control</i>	
Poor	06 (07.9)
Moderate	14 (18.4)
Well	56 (73.7)
<i>Drug therapy</i>	
Monotherapy	63 (82.9)
Polytherapy	13 (17.1)
<i>Schooling status</i>	
Delay drop	06 (07.9)
Delayed	04 (05.3)
Dropout	10 (13.2)
Normal	56 (73.7)
<i>Other</i>	
Family history of epilepsy	03 (03.9)
Microcephaly	08 (10.5)

Overall QOL score was 70.7 (SD 12.6). Table 3 outlines the QOL scores in each subcategory. Lowest mean QOL score was observed for energy /fatigue subcategory and the highest QOL score for stigma subcategory.

Table 3: Mean QOL score in each subcategory

Subcategory	Mean (SD)
Physical restrictions	64.8 (19.2)
Energy/fatigue	62.5 (18.0)
Attention/concentration	64.5 (16.5)
Memory	70.1 (15.3)
Language	75.0 (15.8)
Cognition	66.5 (17.1)
Depression	63.5 (17.0)
Anxiety	66.1 (16.7)
Control /helplessness	73.0 (16.2)
Self esteem	66.8 (19.7)
Social interaction	77.6 (13.9)
Social activity	78.3 (13.1)
Stigma	82.9 (16.9)
Behaviour	74.5 (17.5)
General health	72.4 (14.5)
QOL	72.7 (14.2)
Overall QOL	70.7 (12.6)

Table 4 outlines the demographic factors affecting overall QOL. Overall QOL scores were better with educated parents especially mothers. Children belonging to lower and lower-middle socio-economic class had poor overall QOL scores. Parental education and socio-economic status had a significant impact on QOL scores.

Table 4: Demographic factors affecting overall quality of life (QOL)

Demographic factor	Overall QOL Mean ±SD	p-value
<i>Education of mothers</i>		
Illiterate (7)	66.8±9.1	0.033
<12th (19)	65.9±12.8	
12 (39)	71.3±11.4	
>12th (11)	79.3±14.8	
<i>Education of fathers</i>		
Illiterate (7)	65.5±8.4	0.08
<12th (11)	63.2±14.7	
12 (42)	72.4±12.3	
>12th (16)	73.5±11.6	
<i>Socio-economic class</i>		
Lower & Lower Middle (27)	66.8±12.5	0.046
Higher and Middle (49)	72.8±12.3	

On analysis we observed that with increasing age, behaviour issue subcategory score was increasing. Mean score for age group 2-9 years (n=45) was 69.6±15.4 and 87.5±16.9 for 12-14years. Mean score showed statistically significant difference for different age groups (p<0.05).

Overall QOL scores in males were: physical restriction (65±19.5), energy (62.2±18.2), attention/concentration (63.9±15.6), memory (69.4±15.9), cognition (65±17.2), depression (62.8±16.5) and anxiety (65.5±14.4). Overall QOL scores in females were: physical restriction (64.5±19.1), energy (62.9±18.1), attention/

concentration (63.3±17.9), memory (70.9±14.5), cognition (68.5±17.1), depression (64.5±17.9) and anxiety (66.9±19.8). It was found that there was no significant difference gender-wise in overall QOL scores in each subcategory.

Table 5 is a comparison of clinical scores with different seizure types. Children with GTC seizures had lower QOL scores (between 60-65) in subcategories like physical restriction, energy, attention concentration, cognition, depression, anxiety, self-esteem and better scores (between 71-80) in language, social interaction, social activity, behaviour, stigma.

Table 5: Comparison of clinical scores with different seizure types

Subcategory	Type of seizure		p-Value
	GTC (n=55)	Other (n=21)	
Physical restrictions Mean ± SD	62.3±19.2	71.4±18.2	0.063
Energy/fatigue Mean ± SD	60±17.7	69.1±17.5	0.05
Attention/concentration Mean ± SD	61.8±15.1	71.4±18.1	0.022
Memory Mean ± SD	68.2±13.9	75±17.7	0.082
Language Mean ± SD	64.5±16.5	71.4±18.2	0.117
Cognition Mean ± SD	60.5±16.4	71.4±16.3	0.011
Depression Mean ± SD	64.5±16.4	70.2±16.9	0.185
Anxiety Mean ± SD	71.8±15.2	83.3±14.4	0.004
Control /helplessness Mean ± SD s	71.4±17.6	77.4±10.9	0.149
Self-esteem Mean ± SD	64.1±20.3	73.8±16.7	0.054
Social interaction Mean ± SD	76.8±14.3	79.8±12.8	0.412
Social activity Mean ± SD	76.8±13.5	82.1±11.6	0.114
Stigma Mean ± SD	80.5±17.1	89.3±14.9	0.041
Behaviour Mean ± SD	71.5±17.2	82.1±16.1	0.017
General health Mean ± SD	70.5±14.5	77.4±13.5	0.062
QOL Mean ± SD	70.9±15.1	77.4±10.9	0.076

GTC: Generalised tonic clonic

As shown in Table 6, children whose seizures were well controlled had better overall QOL scores (77.2±9.8) than those with poor control (45.8±10.2). This we found in almost all the subcategories (p=0.001, p<0.01). On analysis it was

found that with increase in the duration of treatment overall QOL had been affected (67.4±14.6) (p = 0.001, p<0.01). QOL score had been affected in almost all the subcategories.

Table 6: Comparison of clinical scores with seizure control

Subcategory	Seizure control			p-value
	Well (n=56)	Moderate (n=14)	Poor (n=6)	
Physical restrictions Mean ± SD	70.5±17.9	50±9.8	45.8±18.8	0.001
Energy/fatigue Mean ± SD	67.8±17	48.2±6.7	45.8±18.8	0.001
Attention/concentration Mean ± SD	55.4±14.4	50±15.8	64.5±16.5	0.002
Memory Mean ± SD	73.2±14.1	64.3±16.1	54.2±10.2	0.003
Language Mean ± SD	69.2±15.8	64.3±16.2	45.8±18.8	0.004
Cognition Mean ± SD	68.7±16	50±9.8	45.8±10.2	0.001
Depression Mean ± SD	70.1±16.1	58.9±12.4	45.8±10.2	0.001
Anxiety Mean ± SD	78.1±12.6	73.2±18.3	50±15.8	0.001
Control /helplessness Mean ± SD s	77.7±12.3	66.1±15.8	45.8±18.8	0.001
Self-esteem Mean ± SD	70.1±19.9	58.9±15.8	54.2±18.8	0.042
Social interaction Mean ± SD	81.3±11.9	71.4±9.1	58.3±20.4	0.001
Social activity Mean ± SD	81.25±10.9	75±9.8	58.3±20.4	0.001
Stigma Mean ± SD	87.9±13.4	71.4±19.2	62.5±13.7	0.001
Behaviour Mean ± SD	79.2±15.1	64.3±18.9	54.2±10.2	0.001
General health Mean ± SD	76.3±11.1	66.1±15.8	50±15.8	0.001
QOL Mean ± SD	77.2±9.8	66.1±15.8	45.8±10.2	0.001

Discussion

QOL in children with epilepsy is significantly affected. There are many other factors which also affect the QOL. The poor access to health care, low socio-economic status and illiteracy continue to handicap management of most chronic childhood illnesses in developing countries like India. It is not surprising to know that parental illiteracy and poverty compromise QOL among children with chronic illnesses like leukaemia and cerebral palsy^{19,20}. Even epileptic children belonging to

lower socio-economic status have been reported to have overall poor health related QOL²¹. Similar observations have been reported earlier from the Indian subcontinent by Malhi P, *et al*¹³ and Aggarwal A, *et al*²². The overall QOL score in the present study was 70.7 (SD 12.6) which was comparable to QOL scores of 62.62 (SD 21.32) in a study by Aggarwal A, *et al*²² conducted in a metropolitan city catering to an urban population.

We found that the overall QOL in children with epilepsy was more affected in terms of physical restrictions and decreased energy levels, depression, attention /concentration whereas most cognitive functions and social interactions and activities were less affected. In our study QOL scores were low for anxiety [66.12 (SD 16.7)], depression [63.49 (SD 17)] and self-esteem [66.78 (SD 19.7)]. This also has been reported in previous studies by Hoare P, *et al*¹⁰, Matthews WS, *et al*²³ and Ettinger AB, *et al*²⁴. We observed low QOL scores in assessment of self-esteem [66.78 (SD 19.7)]. Similar observations have been seen in a study conducted by Dalgas-Pelish P²⁵ among 98 school going children from lower socio-economic status. However, the overall internal consistency of self-esteem subcategory in QOLCE is close to 0.76 in an Indian study by Aggarwal A, *et al*²². We believe that the answers to these questions among Indian children could be influenced by other factors such as gender, age and socio-economic status rather than epilepsy alone.

In our study, QOL scores for cognitive functions were 66.45 (SD 17.1) for cognition, 64.47 (SD 16.5) for attention/concentration, 70.07 (SD 15.3) for memory and for emotional functions scores were 63.49 (SD 17) for depression, 66.12 (SD 16.7) for anxiety and 74.45 (SD 17.5) for the behaviour subcategory. The QOL scores in a previous Indian study by Aggarwal A, *et al*²² had compromised cognitive scores but performed better on emotional subscales. Similarly, in a study by Malhi P, *et al*¹³ conducted on 42 Indian epileptic children, 30% of parents perceived change in their child's behaviour, and decreased ability to concentrate on their studies. In our study, children did not have significant behavioural issues and cognitive impairment was not perceived to impair the QOL. This could probably be due to the difference in ethnicity and the predominantly rural background of the enrolled children in the present study.

In our present study we found that 12-14 year old children had better scores on behavioural subcategory (87.5±16.9) compared to their 2-9 year old counterparts (69.6±15.4). Poor performance on behavioural subscales among teenagers is anticipated when they move to high school from primary school. It is quite possible that older children may feel ashamed of their condition and thus may show more aggression and dissatisfaction in their behaviour²⁶. Present study is not consistent with this finding, as other factors, like upbringing of children and surrounding environment also play a major role in the behavioural issues in children.

In our study QOL scores in subcategories like physical, cognitive, emotional were in range of 62-70 in both males and females. There was no

significant difference in QOL scores in most subcategories. Similar observations were found in a study by Aggarwal A, *et al*²². In our study QOL scores for girls in various subcategories were 62.9±18.1 for energy, 65.3±17.9 for attention / concentration and 66.9±19.8 for anxiety. In earlier studies by Malhi P, *et al*¹³ and Aggarwal A, *et al*²², girls experienced higher energy levels, better attention-concentration with low anxiety levels and low social stigma. However, we did not find any significant difference in our study.

The limitation of our study was a smaller data size. Similar studies with larger data size will be able to have better insight. Empowering a mother's education is of utmost importance for better QOL of children with epilepsy. Hence, measures to improve their QOL should be stressed in addition to the regular drug treatment.

Conclusions

In this study, severity of epilepsy was directly proportional to the compromise in QOL. Longer duration of treatment and poor seizure control significantly affected the QOL of the children with epilepsy. Overall, QOL was found to be compromised in children with epilepsy and was adversely affected by demographic factors like parental education, especially mother's and socio-economic status of the family.

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