

Quality of Life in Children with Epilepsy

ANJU AGGARWAL, VARSHA DATTA AND *LC THAKUR

From the Departments of Pediatrics and *Neurology, University College of Medical Sciences, Delhi, India.

Correspondence to:

Dr Anju Aggarwal,
Flat No 3C, Block C2B, Janakpuri,
New Delhi 110 058, India.

aanju67@gmail.com

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Quality of life was assessed in 108 epileptic children (6-15 years) using a hindi translation of Quality of Life in Children with Epilepsy (QOLCE) questionnaire. The questionnaire consist of 76 items with 16 subscales covering five domains of life: physical function, social function, cognition, emotional and behavioral well being. Overall score was 62.62 ± 21.32 . Chronbach's- α for all 13 multi-item subscales was above 0.70, indicating good internal consistency and reliability. Pearson correlation revealed good construct validity. Overall quality of life was affected by age, type of epilepsy, seizure frequency and maternal education ($P < 0.05$). Energy levels, language and attention ($P < 0.05$) were better in older children whereas younger children had better self esteem and lower levels of anxiety. Seizure frequency compromised all fields except stigma, attention, and energy levels ($P > 0.05$).

Key words: Children, Epilepsy, Hindi, India, Quality of Life.

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The management of epilepsy requires recognition of potential effects of epilepsy on all aspects of life. It is increasingly being recognized that health-related quality of life measurement adds new and important information to other traditional health outcome measures such as seizure control and cognitive improvement [1,2].

The generic scales used to measure the Quality of Life (QOL) like Child Health Questionnaire are insufficiently sensitive to epilepsy [3]. There is lack of research on QOL among children with epilepsy from the developing countries, with only a few studies from India [4]. We planned the present study to assess the QOL using a Hindi translation of Quality of Life in Children with Epilepsy (QOLCE) questionnaire.

METHODS

A total of 108 children with epilepsy, between the

ages of 6-15 years were recruited from the Departments of Pediatrics and Neurology of University College of Medical Sciences and Guru Tegh Bahadur Hospital, New Delhi. After ethical approval and an informed consent, parents of epileptic children receiving antiepileptics for at least a period of 6 months were interviewed by the investigator. Demographic profile was assessed, which included family type, parents, education status, income, and place of residence. Age, sex, development of child, type of seizure, and therapy was recorded. Diagnosis of the type of epilepsy was made by history, EEG and neuroimaging. Children with mental retardation and those with intractable epilepsy were excluded from the study. Though a formal IQ assessment was not done, we included children studying in age appropriate class in school and those with development comparable to normal siblings.

The QOLCE was translated in Hindi. It was re-translated to English and found to be similar. The

QOLCE was filled and coded by a single investigator, as per the standard instructions available with the questionnaire. QOLCE consists of 16 quality of life subscales (14 multi-item and 2 single item). Each subscales has number of items or questions with responses as excellent, very good, good, fair, and poor. They are changed to 1,2,3,4,5 as per instructions. Then changed on a scale of 100 i.e. 1=0, 2=25, 3=50 and the scores compared. Items corresponding to each subscale are marked and there mean score is score of that subscale.

The data was analyzed using the Statistical Package for the Social Sciences (SPSS) Version 10. An overall QOL score was computed by adding each subscale score for each individual and then dividing by 16. Cronbach's α was used to determine the internal consistency and reliability of the subscales. Pearson correlation was determined for the various subscales to determine the construct validity of the questionnaire. The mean QOLCE scores were compared in children with different seizure types, frequency and family demographic variables using the intragroup Tukey test.

RESULTS

A total of 108 children between the ages of 6 to 15 years were evaluated using the QOLCE. Of the 108 subjects, 87 (33 CT, 54 MRI) had neuroimaging results available (35 neurocysticercosis, 8 tuberculomas, 35 normal). **Table I** shows the demographic data and overall QOL in the various variables. The overall quality of life varied significantly between different age groups, type of epilepsy, time since last seizure and mother's education.

The overall QOL and that for the various subscales is shown in **Table II**. The mean overall QOL score was 62.6±21.32. Cognition was found to be affected most severely with the lowest mean score of 48.4±22.74. Most of the children did not respond to the question related to swimming (Question 3e); hence, the score for physical restriction subscale was calculated excluding this question.

A value >0.7 for Cronbach's α is considered indicative of good internal consistency reliability. All the values obtained for the 13 multi-item subscales were above 0.7, with the highest value of

0.955 obtained for the energy/fatigue subscale. A correlation matrix for the 16 QOLCE subscales was examined to establish its construct validity. High correlations were defined as those falling at or above 0.68 (i.e., more than 45% shared variance). In our study, 102 out of the 128 variables were below 0.68, indicating weak correlation between individual subscales establishing a good construct validity.

The subscales affected by the age were energy/fatigue, attention/concentration, language, anxiety and self esteem. Partial epilepsy was found to impact the levels of physical energy, social interaction and social activity more severely than generalized epilepsy. High seizure frequency or lesser time since last seizure was shown to adversely affect physical activity, memory, language and other cognitive faculties of the child. It was also found to significantly increase the levels of anxiety, decrease self esteem and limit social interactions of the patient. It was noted to significantly alter the behavior, general health and the overall quality of life in such children.

TABLE I DEMOGRAPHIC PROFILE AND RELATION WITH OVERALL QUALITY OF LIFE (N=108)

Variable	Overall QOL Mean (SD)	P value*
<i>Age</i>		
6-9 y (n=42)	59.3 (17.09)	0.022
9-12 y (n=42)	54.4 (13.76)	
12-15 y (n=24)	60.2 (12.02)	
<i>Type of epilepsy</i>		
Partial (n=86)	52.5 (14.10)	0.049
Generalized (n=18)	59.8 (14.10)	
<i>Time since last seizure</i>		
≤1 wk (n=22)	44.5 (11.44)	0.001
1wk - ≤1 mo (n=10)	51.8 (9.22)	
1mo - ≤6 mo (n=22)	56.8 (17.30)	
6 mo - ≤1 yr (n=24)	63.9 (13.35)	
>1 year (n=30)	64.5 (10.76)	
<i>Mother's education</i>		
Illiterate (n=76)	59.8 (15.4)	0.044
Primary school (n=23)	51.2 (11.60)	
High school (n=9)	55.0 (13.8)	

*P value is significant at the 0.05 level (intragroup comparison by Tukey test).

TABLE II OVERALL QOL SCORE AND CRONBACH'S α OF THE SUBSCALES

Subscales	QOL scores mean (SD)	Cronbach's α
Physical restrictions	59.9 (21.11)	0.799
Energy/fatigue	53.8 (32.22)	0.955
Attention/concentration	58.4 (18.74)	0.793
Memory	59.0 (18.61)	0.873
Language	70.3 (16.62)	0.868
Cognition	48.4 (22.74)	0.707
Depression	70.4 (25.40)	0.923
Anxiety	65.6 (19.51)	0.809
Control/helplessness	62.8 (24.95)	0.819
Self esteem	66.2 (17.88)	0.764
Social interactions	72.1 (22.99)	0.840
Social activities	75.8 (20.28)	0.819
Stigma*	63.8 (25.00)	
Behavior	55.9 (12.24)	0.772
General health*	56.9 (30.73)	
QOL*	62.7 (28.28)	
Overall QOL*	62.6 (21.32)	

* Single item subscales; QOL: Quality of Life by Quality of Life in Children with Epilepsy (QOLCE) questionnaire.

Maternal education status was seen to affect at least 7 of the 16 subscales significantly, namely attention/concentration, memory, cognition, depression, anxiety, self esteem, social interactions, behavior, general health and quality of life. The overall quality of life was also significantly affected by the level of maternal education.

DISCUSSION

Standard measures to assess health related quality of life in children with epilepsy are lacking in India. The questionnaire used in our study consisted of 76 items, 13 of the 16 subscales were multi-item scales, having more than 1 question. Cronbach's α was more than 0.07, the generally accepted criterion of internal consistency reliability. The internal consistency reliabilities calculated in this study and its correlation with seizure severity were similar and of the same magnitude and pattern as that of the QOLCE validated in America epilepsy patients [6]. This is the first study to use an epilepsy specific

instrument to study the effect of the demographic variables on the quality of life of children with epilepsy in India. As in our study, the authors found that mother's education was a major predictor of quality of life, accounting for 39% variance in QOL scores. Nearly 40% of the children were found to have significant psychopathologic maladjustment.

We found a weak correlation between individual subscales. For a questionnaire to have good construct validity, the correlation between subscales measuring different aspects of QOL should not be high (e.g. physical restrictions, and cognition). The strength of the present study is that it demonstrates high levels of internal consistency, reliability and construct validity, as per criteria listed in the ILAE subcommittee report [7].

We observed that lesser the time interval since last seizure, more severe was the compromise in quality of life. Sabaz, *et al.* [5] proved that the QOLCE is sensitive to differences in seizure severity. This result is consistent with previous findings reports [8-10].

Age of the epileptic children was seen to affect the overall QOL and five subscales significantly. The lower self-esteem in older children may be because of the fact that older children may feel ashamed of their condition, and worry about social isolation. Children between 6-9 years of age scored better in the language domain. This is due to easier adaptability and greater learning skills in the younger age group. Devinsky, *et al.* [9] showed that older adolescents reported a poorer overall HRQOL. This finding was not confirmed in our study where older children scored higher in most subscales. QOL in 9-12 year olds is worse than younger children because younger children may be able to carry out more activities normally and not be hampered by epilepsy. Or they may not feel any lack of ability if there is restriction of any activity as much as 9-12 year olds. We feel 9-12 year olds have more adjustment problems than younger children or those 12-15 years olds. 12-15 years ones will have better understanding of the situation and disease, hence less impact on quality of life.

Self esteem and social interaction scores of the

WHAT THIS STUDY ADDS?

- Quality of life is affected by age, seizure frequency, maternal education and type of epilepsy in Indian children with epilepsy.
- Cognition, energy levels and concentration are most commonly affected due to epilepsy.

children with higher educated mothers were lower than the scores of the children with illiterate mothers. This could be explained by the higher expectations from their children by the educated mothers, which led them to perceive the quality of life of their epileptic children more negatively. In a previous Indian study, level of education and better employment status showed a significant positive correlation with the awareness of the public towards epilepsy [11].

Gender was not found to correlate significantly with any subscale. Girls scored marginally better in the language, cognition, social activities and behavior domains. Similarly, in the study by Gambhir, *et al.* [11], 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.* [12] also reported that mean HRQOL total scores were comparable between boys and girls.

Overall quality of life was significantly more compromised in patients of partial epilepsy compared with generalised epilepsy, signifying that partial epilepsy is less well accepted in our community. Though this result may be skewed due to small number of patients with generalised epilepsy compared to partial epilepsy.

The fact that we used a questionnaire in Hindi it will have implications on use of same in our population. Using an epilepsy specific questionnaire we found that, overall quality of life was compromised in epileptic children. Measures to improve the quality of life of epileptic children should be a part of the treatment protocol of epilepsy in children.

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