Original Article

Quality of Life in Children with Epilepsy in Wah Cantt, Pakistan: A Cross-sectional Study

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Abstract

Objective: To assess the Quality Of Life (QOL) in children with epilepsy using modified QOLCE-55 questionnaire.

Material and Methods: We consecutively enrolled children aged 4 to 16 years who were under treatment for childhood epilepsy. Basic demographic and clinical details including type of epilepsy, developmental history, family history of epilepsy and any co-morbidity were recorded in a predesigned Performa. QOL was evaluated by using modified QOLCE-55 (39 items) from parents.

Results: A total of 54 children were enrolled in the study, 42 (78%) were males and 12(22%) were female children with epilepsy. Eight children got good QOLCE score, while 24 children had average and 22 children got a poor score. The good score was mostly seen in 4-8 years (40%) of age while the poor score was seen in 12-16 years (70%) age group. Age of the patients (p=<0.001), gender (p=<0.001), associated co-morbidities (p=0.003) and family history of epilepsy (p=0.011) showed a significant effect on the QOLCE score. Type of epilepsy (p= 0.825) and development of a child (p=0.109) did not affect the QOLCE score significantly.

Conclusion: The study showed that Children with co-morbidities, family history of epilepsy and female children of older age group (12-16 years) had poor QOL. Types of seizures and development of the child did not significantly alter the QOLCE score.

Keywords: Children, Epilepsy, Quality of life (QOL), QOL questionnaire.

Introduction

Epilepsy is one of the commonest neurological illness in children and there are different factors which can affect QOL of an epileptic child. Epileptic Children with underlying neurological conditions are the worst sufferers if epilepsy is not well controlled. QOLCE was originally designed as 73 items which were later modified to 76 items instrument in North America.[1]Goodwin SW introduced shortened QOL questionnaire (QOLCE-55) based on 55 questions and assessed aspects included cognition, emotional, social and physical aspects. This QOLCE-55 produced results on risk factors and these results were similar to those of original QOLCE. It also helped to reduce the burden on respondents when assessing health-related QOL in children with epilepsy.[2] Measurement equivalence of QOLCE-55 was examined across age, sex and time and was found to be unbiased questionnaire.[3]QOLCE-55 is considered a reliable and valid measure to assess the psychometric profile of children with epilepsy.[4]

To our knowledge, there is a dearth of literature available regarding the effect of different factors like age, sex, development, type of epilepsy, comorbidities and family history of epilepsy in the Pakistani population. The objective of this study was to assess the parent-reported QOL in epileptic children concerning different clinical and demographic factors. Keeping in mind local socio-demographic factors and to facilitate the parents to complete the questionnaire with ease and minimum time, items were reduced to 39.

Material & Methods

Study Objectives
The primary objective of the study is to assess the parent-reported QOL in children with epilepsy. The secondary objective was to correlate QOLCE score with different clinical and demographic factors.

Study design and settings
The study consecutively enrolled children from the age of 4 to 16 years from neurology clinic who were diagnosed to have epilepsy after a comprehensive evaluation. Children with co-morbid neurological conditions such as neurodegenerative disorders, cerebral palsy, autism, attention deficit hyperactive disorder and other neurological conditions were also included in the study. Children with non-availability of a primary caretaker to answer the questionnaire, children receiving alternative epileptic treatment and those who had associated non-neurological chronic diseases such as congenital heart disease, asthma, chronic renal disease, endocrinal problems were excluded from the study. This study was carried out in the Paediatric Neurology out-patient department of Izzat Ali Shah Hospital in Wah Cantt from January 2017 to December 2017. Informed consent from parents and ethical approval was obtained from the ethical committee before enrolling the patient in the study.

Sample technique: Non-Probability purposive sampling.

Sample size calculation:
The sample size was calculated using the sample size calculator as follow:
Confidence level = 95% (1.96)
Power of test = 80%
Significance level = 5%
Margin of Error= 0.05
The expected proportion in population: not more than 3%
Sample size n = 45

Study Methodology
The study questionnaire was developed and different demographic factors were recorded including age, gender and residential address. Clinical factors were recorded in terms of the type of epilepsy, family history of epilepsy, developmental history and co-morbid conditions. Type of epilepsy was classified as generalised, focal and mixed based on seizure semiology, electroencephalographic and neuroimaging findings. All the patients were taking anti-epileptic medications during the study.

Modified QOLCE-55 questionnaire was used to assess the quality of life, however, to facilitate the parents to complete the questionnaire easily with little time, items were reduced to 39 (Table 1). QOLCE was translated to Urdu by professional translator and precautions were taken so that the original meaning of the questionnaire was retained.

Statistical Analysis
All data was entered in SPSS version 19. Demographic and clinical variables were entered as numerical and proportion. QOLCE score was entered as numerical. For analysis purpose, more than 80% of the total score (39 items) was taken as a good score. QOLCE score between 60 to 80% was taken as average and less than 60% of total QOLCE score was taken as a poor score which represents poor quality of life. These three categories of QOLCE score were compared with demographic and clinical factors.

Table 1: Modified QOLCE with 39 items

	Child's cognitive functioning
1	Had difficulty attending to an activity?
2	Had difficulty reasoning or solving problems?
3	Had trouble concentrating on a task?
4	Had difficulty concentrating on reading?
5	Reacted slowly to things being said and done?
6	Found it hard remembering things?
7	Had trouble remembering names of people?
8	Had trouble remembering where s/he put things?
9	Planned to do something then forgot?
10	Had trouble finding the correct words?
11	Had difficulty following simple instructions?
12	Had difficulty following complex instructions?
13	Had trouble understanding what s/he read?
14	Had trouble writing?
15	Had trouble talking?
	Child's emotional functioning
16	Felt down or depressed?
17	Felt happy?
18	Wished s/he was dead
19	Felt frustrated?
20	Worried a lot?
21	Felt confident?
22	Felt excited or interested in something?
23	Felt pleased about achieving something?
24	Felt valued?
25	Felt no one cared?
26	Angered easily?
27	Hit or attacked people
28	Swore in public?
29	Was obedient?
30	Demanded lot of attention?
	Child's social functioning
31	Limited his/her social activities (visiting friends, close relatives, or neighbours)?
32	Affected his/her social interactions at school or work?
33	Limited his/her leisure activities (hobbies or interests)?
34	Made it difficult for him/her to keep friends?
	Child's physical functioning
35	Needed more supervision than other children his/her age?
36	Played freely in the house like other children

	his/her age?
37	Participated in sports activities (other than swimming)?
38	Played with friends away from you or your home?
39	Been able to do the physical activities, other children his/her age do?

Results

A total of 54 children from age 4 to 16 years were enrolled in the study, 42 (78%) were male and 12(22%) female. Table 2 outlines the details of demographic and clinical factors affecting childhood epilepsy. For analysis purpose, age was divided into three categories. There were 10 children in 4 to 8 years age group, 22 children in 8 to 12 years age group and 20 children were in between 12 to 16 years of age. Older age groups had poor to average QOL score whereas the younger age group had relatively better score (p=<0.001). Although, the vast majority of males (57%) had average QOL score, however, 66.7% of female patients had poor QOL whereas, 33% of male children had poor score (p=<0.001).

In all types of epilepsy, the majority of the children showed average or poor QOLCE, however, the difference between generalised and focal was not statistically significant (p=0.825).

Six children with associated co-morbidities showed poor QOL and the group of children without having a co-morbid condition, QOL varied from poor in 16 (33%) children to average score in 24 (50%) children. The difference between the two groups was significant (p=0.003).

QOL ranged from poor to average in most of the children either developmentally normal or developmentally delayed. The difference between the two groups is not statistically significant (p=0.109). Family history of epilepsy also affected QOL adversely. It was poor in 64 % of children with a positive family history of epilepsy and 25 % in children with no family history of epilepsy.

Table 2: Demographic and Clinical factors affecting childhood epilepsy

		QOLCE Score categories			
	n	Poor(<25) n(%)	Average(25 to 32) n(%)	Good(>32) n(%)	P-Value
Age					
8-12	24	8(33.3%)	14(58.3%)	2(8.3%)	<0.001
12-16	20	14(70.0%)	4(20.0%)	2(10.0%)	
Gender					
Male	42	14(33.3%)	24(57.1%)	4(9.5%)	<0.001
Female	12	8(66.7%)	0(0.0%)	4(33.3%)	
Type of epilepsy					
Generalized	40	16(40.0%)	18(45.0%)	6(15.0%)	0.825
Focal	10	4(40.0%)	4(40.0%)	2(20.0%)	
Mixed	4	2(50.0%)	2(50.0%)	0(0.0%)	
Related co-morbidities					
Yes	6	6(100.0%)	0(0.0%)	0(0.0%)	0.003
No	48	16(33.0%)	24(50.0%)	8(16.7%)	
Development of the child					
Normal	42	16(38.1%)	18(42.9%)	8(19.0%)	0.109
Delayed	12	6(50.0%)	6(50.0%)	0(0.0%)	
Family history of epilepsy					
Yes	22	14(63.6%)	5(22.7%)	3(13.6%)	0.011
No	32	8(25.0%)	19(59.4%)	5(15.6%)	

Discussion

Quality of life questionnaire is an important tool which is carried out in many chronic diseases. It highlights the cognitive, emotional, social and physical aspects of epileptic children which often get ignored in the management of these children. It also gives an idea of a parent's perception of the disease.

This study showed that the majority of children had low QOL, varying from poor to average. Worst affected groups were with co-morbidities and those who had delayed development. It was poor in 100% of epileptic children with co-morbidities whereas in developmentally delayed QOL ranged from poor to average.

QOL was recorded poor in older (70%) while the average in younger age group (60%). Nadkarni J et al in their study on epileptic children found that QOL was affected mostly in older children,[5] whereas in another study children who had onset at a younger age were found to have low QOL.[6]

In the current study effect of generalised and focal epilepsy on QOL was comparable though not statistically significant; however, it was unfavourable in 80-85% of epileptic children. Arya V et al showed similar results and concluded that QOL was compromised in epileptic children but the type of epilepsy did not matter much. [8]In another study it was found that the overall QOL was lower in patients with generalized epilepsy as compared to partial epilepsy.[7] Monir Z et al found impaired QOL in epileptic children with generalised and frequent fits and those on polytherapy.[6]

We also tried to evaluate the effect of associated co-morbid conditions on QOL in children with epilepsy. All the children with the co-morbid condition were found to have poor QOLCE score while it was less observed in children without the co-morbid condition. Further study is required to see the relation of individual co-morbid condition with QOL.

Development of child although was not statistically significant but children with delayed development had an average or low score. Further studies may be useful to see this relationship as well. Family history of epilepsy was significant in this study. Most of the children had poor QOLCE score who had a positive family history of epilepsy.

Nadkerni J et al concluded that QOL was mostly affected in those living in rural areas, lower socioeconomic status and in mothers with lower

literacy level. Our study did not include socioeconomic factors but in future, this may be considered. Also, QOL was low in children with higher seizure frequency, those receiving multiple drug therapy, having a partial seizure and on prolonged treatment.[8] Seizure control is an important factor which affects the QOL and further study is required in Pakistan where this factor should be considered. QOLCE in children underwent epilepsy surgery has shown better outcome with seizure reduction.[9]Purusothaman V et al introduced Paediatric Refractory Epilepsy Questionnaire (PREQ) in children undergoing epilepsy surgery to assess the severity of epilepsy along with mood, neuro-development and quality of life. A larger study using modified PREQ is underway which will further develop PREQ.[10]

Sajobi TT et al conducted Health-related quality of life (HDQOL) survey in children with new-onset epilepsy for 1 year and highlights the parent's perception of the disease.[11] Epileptic children can be quite difficult to manage and it may be difficult some times to understand a child's perception of the disease. Fong CY compared the QOL score of parent and child self-report by using CHEQOL-25. In general, mean parental reported QOL score was higher than that of child self-report.[12]It is important to keep parental anxiety in our mind that can affect QOL scores. Williams et al reported that over-anxious parents are more likely to perceive higher risk for their children and may misinterpret information about their child's condition [13].

In developing countries, managing a child with epilepsy can be quite costly and has social implications. Family social background and education has been highlighted in different studies which may affect QOL. Anxiety, depression and low esteem are known to be associated with epileptic children.[14,15,16] Low socioeconomic status also contributes towards low esteem in these children. Gutierrez-Angel AM et al used WHOQOL and WHOQOL-BREF to assess the quality of life and level of burden in children with epilepsy. They found that aggressive behaviour and a longer duration of epilepsy was associated with lower QOL. Care-giver higher education also has a positive impact on QOL.[17]The impact of the disease in older children's psychology may lead to aggressive behaviour.[18] This study has not assessed the psychological factors individually but it was included in the overall QOLCE questionnaire. The academic underachievement is commonly observed in epileptic children due to multiple factors which include the effect of recurrent seizures on developing brain,

psychological impact of the disease and side effects of the anti-epileptic drugs. [19,20]This study encompasses some of the questions related to academics but more studies are required to analyse this in detail.

This study also concluded that female children had poor QOL than male children but the sample size of female children was small. The reason may be that male children are given more access to health facilities in our socioeconomic background.

Conclusion

QOL is an important tool in the management of epilepsy. This study concludes that older (age 12-16 years) and female children seem to have a relatively poor quality of life. Children with other co-morbid conditions and those with a positive family history of epilepsy have poor QOL. Type of epilepsy and development of child does not mainly affect the QOL. Further studies are required to see the relation of other demographic and clinical factors with QOL in epileptic children in Pakistan.

References

1. Sabaz M, Lawson JA, Cairns DR, Duchowny MS, Resnick TJ, Dean PM, Bye AM. Validation of the quality of life in childhood epilepsy questionnaire in American epilepsy patients. Epilepsy & Behavior. 2003 Dec 1;4(6):680-91. https://doi.org/10.1016/j.yebeh.2003.08.012
2. Goodwin SW, Lambrinos AI, Ferro MA, Sabaz M, Speechley KN. Development and assessment of a shortened Q uality of L ife in C hildhood E pilepsy Q uestionnaire (QOLCE□55). Epilepsia. 2015 Jun;56(6):864-72. https://doi.org/10.1111/epi.13000
3. Ferro MA, Goodwin SW, Sabaz M, Speechley KN. Measurement equivalence of the newly developed Quality of Life in Childhood Epilepsy Questionnaire (QOLCE□55). Epilepsia. 2016 Mar;57(3):427-35. https://doi.org/10.1111/epi.13296
4. Conway L, Widjaja E, Smith ML, Speechley KN, Ferro MA. Validating the shortened Quality of Life in Childhood Epilepsy Questionnaire (QOLCE□55) in a sample of children with drug□resistant epilepsy. Epilepsia. 2017 Apr;58(4):646-56. https://doi.org/10.1111/epi.13697
5. Nadkarni J, Jain A, Dwivedi R. Quality of life in children with epilepsy. Annals of Indian Academy of Neurology. 2011 Oct;14(4):279. doi: 10.4103/0972-2327.91948
6. Monir ZM, EL-Alameey IR, Eltahlawy E. Health related quality of life of children with epilepsy in Egypt. Journal of The Arab Society for Medical Research. 2013 Jul 1;8(2):53. DOI: 10.4103/1687-4293.123787
7. Stevanovic D. Health-related quality of life in adolescents with well-controlled epilepsy. Epilepsy & behavior. 2007 Jun 1;10(4):571-5. https://doi.org/10.1016/j.yebeh.2007.02.015
8. 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. Journal of pediatric neurosciences. 2014 Jan;9(1):17. doi: 10.4103/1817-1745.131473

9. Sabaz M, Lawson JA, Cairns DR, Duchowny MS, Resnick TJ, Dean PM, Bleasel AF, Bye AM. The impact of epilepsy surgery on quality of life in children. Neurology. 2006 Feb 28;66(4):557-61. DOI: https://doi.org/10.1212/01.wnl.0000197788.38783.09

10. Purusothaman V, Ryther RC, Bertrand M, Harker LA, Jeffe DB, Wallendorf M, Smyth MD, Limbrick DD. Developing the pediatric refractory epilepsy questionnaire: a pilot study. Epilepsy & Behavior. 2014 Aug 1;37:26-31. https://doi.org/10.1016/j.yebeh.2014.04.025

11. Sajobi TT, Speechley KN, Liang Z, Goodwin SW, Ferro MA, Wiebe S. Response shift in parents' assessment of health-related quality of life of children with new-onset epilepsy. Epilepsy & Behavior. 2017 Oct 1;75:97-101. https://doi.org/10.1016/j.yebeh.2017.07.015

12. DIN NC. Neuropsychology of Epilepsy in Malaysia: A Narrative Review. Jurnal Sains Kesihatan Malaysia (Malaysian Journal of Health Sciences). 2019 Jun 27;17(2). DOI : http://dx.doi.org./10.17576/JSKM-2019-1702-11

13. Williams J, Steel C, Sharp GB, et al. Parental anxiety and quality of life in children with epilepsy. Epilepsy Behav 2003; 4:483-486

14. Matthews WS, Barabas G, Ferrari M. Emotional concomitants of childhood epilepsy. Epilepsia. 1982 Dec;23(6):671-81. https://doi.org/10.1111/j.1528-1157.1982.tb05083.x

15. Ettinger AB, Weisbrot DM, Nolan EE, Gadow KD, Vitale SA, Andriola MR, Lenn NJ, Novak GP, Hermann BP. Symptoms of depression and anxiety in pediatric epilepsy patients. Epilepsia. 1998 Jun;39(6):595-9. https://doi.org/10.1111/j.1528-1157.1998.tb01427.x

16. Hoare P, Mann H. Self-esteem and behavioural adjustment in children with epilepsy and children with diabetes. Journal of Psychosomatic Research. 1994 Nov 1;38(8):859-69. https://doi.org/10.1016/0022-3999(94)90073-6

17. Gutierrez-Angel AM, Martinez-Juarez IE, Hernandez-Vanegas LE, Crail-Melendez D. Quality of life and level of burden in primary caregivers of patients with epilepsy: effect of neuropsychiatric comorbidity. Epilepsy & Behavior. 2018 Apr 1;81:12-7. https://doi.org/10.1016/j.yebeh.2018.01.034

18. Pratt HD. Interpersonal violence, aggression, and antisocial behaviours in the adolescents. The Indian Journal of Pediatrics. 1999 Jul 1;66(4):589-602.

19. Fastenau PS, Shen J, Dunn DW, Austin JK. Academic underachievement among children with epilepsy: proportion exceeding psychometric criteria for learning disability and associated risk factors. Journal of learning disabilities. 2008 May;41(3):195-207. https://doi.org/10.1177/0022219408317548

20. Ibekwe RC, Ojinnaka NC, Iloeje SO. Factors influencing the academic performance of school children with epilepsy. Journal of tropical pediatrics. 2007 Oct 1;53(5):338-43. https://doi.org/10.1093/tropej/fmm034