Short Communication

Quality of Life among Children with Epilepsy from a Parent's Point of View

Mustafa Kareem J. Al-Mehnh, Nuhad Mohammad K. Al-Doori[1]

Pediatric of Health Nursing, Ministry of Health, Al-Diwaniyah Health Directorate, [1]Pediatric of Health Nursing, College of Nursing, University of Babylon, Hillah, Iraq

Abstract

Epilepsy is a one of the neurological illnesses defined by disruption of electrical activity in the brain, often causing recurrent seizure activity. Epilepsy can have a significant negative influence on a person's quality of life (QOL), both physically and emotionally as well as social and psychological functions. This study is conducted to assess the QOL for school-age and adolescent children with epilepsy. A (descriptive) cross-sectional study design, conducted on the children with epilepsy in Neuroscience center in Al-Diwaniyah Province. The purposive sample included 106 children (school-age and adolescents) with epilepsy. The tools of study consisted of brief QOL scale modified to assess their QOL, as well as, questions about the demographic characteristics of children. The results found that the highest percentage 48% of children's ages was 11–15 years, and more than half of the samples were male children, and 64% of the sample was educational level in primary schools, and the results of study also revealed 50.9% have moderate level of QOL. The study concluded that the overall assessment of the children QOL with epilepsy was moderate, and there was a significant relationship between some demographic characteristics of the child and with the QOL.

Keywords: children, epilepsy, quality of life

Introduction

Epilepsy is the one of the most serious illnesses, affects 70 million people globally, and is a brain disorder that has an effect on cognition, behavior, knowledge, and other issues that cause human dysfunction. The majority of persons with epilepsy can attain great seizure control.[1]

Epilepsy is considered a collection of brain electrical system abnormalities. Epilepsy transforms a brain that is capable of producing excessive electrical charges into a brain that is susceptible to causing recurring seizures. In most children with epilepsy, it will result in changes in behavior, awareness, and feeling, and may change in movement as well as give convulsions or loss of consciousness that can happen from a few seconds to a few minutes. Seizures can happen to adults as well as young children.[2,3]

Worldwide, epilepsy affects all ages, races, genders, socioeconomic classes, and geographic areas. Geographically, it is stated that the prevalence of epilepsy is highest in rural areas and lowest in developed countries. Additionally, epilepsy has social, neurological, cognitive, and psychological effects.[4,5]

Childhood epilepsy is thought to have long-lasting effects on the development of children. It is an important cause of childhood weakening and disability, and may induce a negative effect on a child's social, physical, and psychological skills.[6]

All these effects have an impact on a child's life chances, life span, and the overall well-being. Children with epilepsy (CWE) are better able to explain how the condition affects them as they get older, because these impacts become more noticeable as cognitive abilities and life experience develop.[7]

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Address for correspondence: Prof. Nuhad Mohammed Kassim Al-Doori, Pediatric of Health Nursing, College of Nursing, University of Babylon, Hillah, Iraq.
E-mail: mustafakaremiq@gmail.com

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Children with epilepsy are among those who are most exposed to a poor quality of life (QOL), because epilepsy is one of the most perilous neurological diseases and has different symptoms from other diseases. It affects children and adolescents especially during childhood.[8]

School-age children and adolescents with epilepsy often report poor socialization, a negative self-image, and diminished hope and ambition. Therefore, it has become necessary to work on improving the QOL in children with epilepsy on a large scale as a very important goal and may be part of the treatment.[9]

Additionally, children and adolescents with epilepsy deal with psychological or psychosocial issues include emotional, behavioral, or environmental issues as well as social stigma. Therefore, rather than just seizure control, QOL should be the main outcome measure in the review and therapy of all children with epilepsy, and with other disability that may be lowering the QOL.[10,11]

School children and adolescents with other diseases and epilepsy suffer from a poor QOL and other psychological disorders. The reason is due to the characteristics of epilepsy and the side effects associated with it.[12,13] The aim of this study was to assess the QOL in children with epilepsy.

Materials and Methods

Research design

A descriptive design, cross-sectional study design was carried out, so as to attain the stated objectives. This study is conducted to assess the QOL among school-age and adolescent children with epilepsy.

Study sample and setting

A total of sample study was 106 parents of children with epilepsy were selected through a "non-probability" (purposive) sample from total parents of children with epilepsy that fallow up to the center of Neuroscience in Al-Diwaniyah Province were selected for the present study. To answer a questionnaire regarding the quality of life of their children with epilepsy.

Instrument of the study

The Quality of Life in Childhood Epilepsy (QOLCE) is the modified version of the QOL derived from the original QOL of 55-item by Goodwin *et al.*[14] It has been modified and developed by the researchers and presented to experts for validity, and then was tested for the reliability of the questionnaire for the research. The QOL from a parent's point of view, which they reported during the questionnaire for children with epilepsy, that provides overall assessment of whose ages ranged between 6 and 18 years through the four domains of QOL assessment: cognitive function (17 items), emotional function (13 items), function social (7 items), and physical function (6 items). A three-point Likert scale is used to rate items as follows: always = 3, sometimes = 2; never = 1. The instrument that was used in our study consisted of two parts. The first part contains items for assessing the demographic characteristics of children. The second part contains a questionnaire to assess the QOL of children with epilepsy.

Data collection

All the children with their parents were chosen individually through their follow-up consultation in the neurology consultation at the specialized neurological center. The researcher was present while filling out the questionnaire to clarify the inquiries from the parents and to ensure that the questionnaire elements were understood correctly. The interview time for each person ranged from 15 to 20 min. The data collection was done from July 26, 2022 to December 13, 2022.

Ethical considerations

The study was conducted in accordance with the ethical principles that have their origin in the Declaration of Helsinki. The study protocol and the subject information and consent form were reviewed and approved by a local ethics committee according to the document No. 2407 in July 17, 2022 to obtain this approval.

Results

Table 1 shows the statistical distribution of children by their demographic data. It explains that the highest percentage of the children subgroup are: those age ranging 11–15 year (48.1%), more than half are a male children (52.8%), with most of them in primary school as a level of education (64.2%). The order of a children with epilepsy among these siblings is ranked first (38.7%).

As per Table 2 which shows the assessment of each part of the QOL being displayed by calculating the mean. It is clear from the results that the highest mean was (2.38), which is for social functions, and means that the social functions of the child are good and have a high QOL in this domain. As for the lowest mean, it was 2.26 for the emotional functions, and this means that the QOL is moderate emotionally, as shown by the general assessment of the QOL of children with epilepsy was moderate at an overall rate.

Table 3 shows the relationship between the QOL and demographic date of children with epilepsy and also reveals there is a significant relationship between child's age with epilepsy and QOL whereas the significance was with *P* value of 0.04, whereas there is significance at *P*-value (0.05) with gender. There is no significant relationship between the educational level of the child and the QOL, and there is also no significant relationship between the child's sequence in the family and the QOL.

Table 1: Child characteristic (n = 106)

Childe characteristic	Rating and interval	Frequency	Percentage
Age (years) Mean ± SD 11.27 ± 2.65	6–10	47	44.3
	11–15	51	48.1
	16+	8	7.5
Gender	Male	56	52.8
	Female	50	47.2
Levels of education	Doesn't read and write	14	13.2
	Primary school	68	64.2
	Secondary school	24	22.6
Sequence of the child in the family	1st	41	38.7
	2nd	26	24.5
	3rd	21	19.8
	4th	12	11.3
	5th	4	3.8
	6th	2	1.9

Table 2: Descriptive statistics of overall domains

Main domain		Responses			Statistical Measurement	Asses.
		Low	Moderate	High	MS	
Cognitive domain	Freq.	3	43	60	2.31	Moderate
	%	2.8	40.6	56.6		
Emotional domain	Freq.	0	64	42	2.26	Moderate
	%	0	60.4	39.6		
Social domain	Freq.	0	39	67	2.38	High
	%	0	36.8	63.2		
Physical domain	Freq.	3	42	61	2.28	Moderate
	%	2.8	39.6	57.5		
Overall quality of life	Freq.	0	54	52	2.30	Moderate
	%	0	50.9	49.1		

Table 3: Relationship between the QOL and demographic date of children with epilepsy

Factors associated	Statistical measurement	QOL
Child's age	Chi-square	9.745
	Df	4
	Sig.	0.04
Gender	Chi-square	6.001
	Df	2
	Sig.	0.05
Level of education	Chi-square	0.296
	Df	4
	Sig.	0.99
Sequence of the child in the family	Chi-square	9.631
	Df	10
	Sig.	0.47

Discussion

Epilepsy is regarded as one of the most prevalent neurological diseases in children in this age group, which has high comorbidities and associated with mental and health behavioral issues, which clearly impact on the QOL and also has bad psychological effects on the life of the child and a greater impact on the family's performance.[15]

From the statistical distribution of children by their demographic data of children, it explains that the highest percentage of the children subgroup are: those age ranging 11–15 year (48.1%). Regarding the gender of participants, male children were the dominant gender among children with epilepsy, The male children had the highest percentage more than half in the study sample (52.8%), whereas this result agrees with the results shown by the study,[16] which showed that the percentage of male children in this study is 66.30%, with most of them in primary school as a level education (64.2%). The sequence of the child in the family that the first is (38.7%).

Enhancing QOL is one of the top priorities for healthcare professionals, and its assessment is a crucial part of clinical illness management for any condition. On QOL evaluations and the factors influencing QOL its outcomes in CWE, various research works have been conducted. These studies' findings consistently demonstrate that

epileptic children are more likely than non-epilepsy children to have lower QOL.[17,18]

The results of our study to assess the QOL of children with epilepsy, when discussing each part separately from the other, show that with regard to the cognitive functions part, it was found that the assessment of cognitive functions is moderate level for children with epilepsy, and this result agreed with the result of the research,[19] which showed that the cognitive functions of children with epilepsy are moderate level and also the result of our study agrees with a study in Iran.[20] The majority of cognitive function in children with epilepsy are affected by a variety of interrelated factors, including early onset of epilepsy, frequency, severity, and duration of seizures, along with antiepileptic drug treatment.

As for the emotional functions part, it was found that the assessment of emotional functions was moderate for children with epilepsy; also our results agree with the result of the research,[21] which showed that the emotional functions of children with epilepsy are of a moderate level. It is possible that the reason is due to the anxiety, the psychological state, and low self-confidence that the child feel through as a result of epilepsy, as well as the accompanying negative feelings that are generated as a result of the seizure, as well as the result of the societal view of the epileptic children.

As for the part of social functions, it was found that the assessment of social functions was more than moderate level for children with epilepsy. And our results agree with the result of the research,[22] which showed that social functions were rated more than moderate for people with epilepsy. There are many factors that lead to a low level of the quality of life for children with epilepsy, including: fear of seizures that occur in front of people, unwillingness to mix for fear of discrimination, fear of danger to the epileptic patient, fear of discrimination, and people's lack of acceptance of the patient.

As for the part of the physical functions, it was found that the assessment of the physical functions was moderate level for children with epilepsy. Our results are agree with the result of the study,[23] which showed that physical functions were at moderate level for children with epilepsy. The fear of a seizure is one of the most important things that accompanies a person's thinking of an injured person. Therefore, parents should always be supervised when performing activities and events to prevent the occurrence of any risk associated with a seizure. As a result, children's physical functions decrease to reduce the chances of a seizure occurring.

As for the overall QOL assessment, it was found that the QOL assessment was moderate level for children with epilepsy. And our results agree with the result of the study.[24] Also, the results of our study agree with the results shown by the study,[19] which showed that the QOL of children with epilepsy parents' prospective, which showed that children with epilepsy will have a moderate or less QOL. The reason for this is the lack of control of seizures, in addition to the side complications associated with the disease, as well as the stigma and disability associated with it. In addition to many of the factors mentioned above, it leads to a low level in the QOL for children with epilepsy.

Conclusion

The study concluded that the overall assessment of the QOL for children with epilepsy was moderate, and there was a significant relationship between some demographic characteristics of the child with the QOL.

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Conflict of interests

The authors have no conflict of interests.

References

1. Samanta D, Elumalai V, Hoyt ML, Modi AC, Sajatovic M. A qualitative study of epilepsy self-management barriers and facilitators in Black children and caregivers in Arkansas. Epilepsy Behav 2022;126:108491.
2. Nazarov AI. Consequences of seizures and epilepsy in children. Web Scientist: Int Scientific Res J 2022;3:483-9.
3. Nagesh A, Gade A, Puchchakayala G, Bhava S, Kagitapu S, Madanu S, *et al*. 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. J Basic Clin Pharmacy 2017;8:74-7.
4. Chemnitz E. An 8-year longitudinal assessment of health-related quality of life in children with epilepsy. Thesis. The University of Western Ontario. 2020. Available from https://ir.lib.uwo.ca/etd/7318.
5. Shibeeb NF, Altufaily YAS. Parental knowledge and practice regarding febrile seizure in their children. Med J Babylon 2019;16:58-64.
6. Lagunju IA, Bella-Awusah TT, Takon I, Omigbodun OO. Mental health problems in Nigerian children with epilepsy: Associations and risk factors. Epilepsy Behav 2012;25:214-8.
7. Hussain SRA, Orwa J, Sokhi DS, Kathomi CM, Dossajee H, Miyanji O, *et al*. Determining the quality of life of children living with epilepsy in Kenya—A cross-sectional study using the CHEQOL-25 tool. Seizure 2020;76:100-4.
8. Cappelletti S, Tondo I, Pietrafusa N, Renzetti T, Pannacci I, Gentile S, *et al*. Improvement of quality of life in adolescents with epilepsy after an empowerment and sailing experience. Epilepsy Behav 2020;106:106957.
9. Mohammed WK, Jafaar SA. Quality of life for patients with epilepsy in Baghdad city. Kufa J Nurs Sci 2014;4:85-96.
10. Choi HY, Kim SE, Lee HW, Kim EJ. Social behavioral problems and the health-related quality of life in children and adolescents with epilepsy. Psychiatry Invest 2016;13:488-95.
11. Tareq AA. Health-related quality of life of chronic obstructive pulmonary disease patients. Med J Babylon 2020;17:69.
12. Aryal S, Jha A. Quality of life in epilepsy patients: A cross sectional study. J Psychiatrists' Assoc Nepal 2020;9:59-63.
13. Naser WE. Assessment of the quality of life of Iraqi children with juvenile idiopathic arthritis: A single-center study. Med J Babylon 2019;16:65.

14. Goodwin S, Ferro MAW, Sabaz M, Speechley KN. Measurement equivalence of the newly developed Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). Epilepsia 2016;57:427-35.
15. Guilfoyle SM, Wagner JL, Modi AC, Junger KF, Barrett LE, Riisen AC, *et al*. Pediatric epilepsy and behavioral health: The state of the literature and directions for evidence-based interprofessional care, training, and research. Clin Practice Pediatric Psychol 2017;5:79.
16. El azizi MM. Quality of life in children with epilepsy. Thesis N 170. universite cadi ayyad faculte de medecine et de pharmacie Marrakech. 2020.
17. Bompori E, Niakas D, Nakou I, Siamopoulou-Mavridou A, Tzoufi MS. Comparative study of the health-related quality of life of children with epilepsy and their parents. Epilepsy Behav 2014;41:11.
18. Moreira H, Carona C, Silva N, Frontini R, Bullinger M, Canavarro MC. Psychological and quality of life outcomes in pediatric populations: A parent child perspective. J Pediatr 2013;163:1471-8.
19. EL Nabawy Ahmed G, Abdelgawad Said D. Quality of life of children with epilepsy: Parent prospective. Int Egypt J Nurs Sci Res 2022;3:318-36.
20. Honari B, Homam SM, Nabipour M, Mostafavian Z, Farajpour, A, Sahbaie N. Epilepsy and quality of life in Iranian epileptic patients. J Patient-Reported Outcomes 2021;5:1-7.
21. Maha A, Nahid SA, Mohammed AHS, Doaa A. Quality of life in childhood epilepsy. Med J Cairo Univ 2020;88:1477-85.
22. Tegegne MT, Muluneh NY, Wochamo TT, Awoke AA, Mossie TB, Yesigat MA. Assessment of quality of life and associated factors among people with epilepsy attending at Amanuel mental specialized hospital, Addis Ababa, Ethiopia. Sci J Public Health 2014;2:378-83.
23. Pachange PN, Dixit JV, Arjun MC, Goel AD. Quality of life among middle and secondary school children with epilepsy. J Neurosci Rural Practice 2021;12:490-4.
24. Nikolić1 D, Rogač Z. Quality of life in children with epilepsy. Scr Med 2019;50:134-7.