Biomedical Research 2019; 30

ISSN 0970-938X
www.biomedres.info

The evaluation of quality of life in children with Epilepsy.

Ali Akbar Momen[1*], Abdolhakim Abareian[1], Reza Azizi Malamiri[2]

[1]Faculty of Medicine, Department of Pediatrics, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran

[2]Department of Pediatric Neurology, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran

Abstract

Introduction: Epilepsy is one of the most common neurological disorders which can occur in any age, strain, and social classes. Seizures can effect on daily life of infants and adolescents and can have a considerable effect on presence in school, society, participating in social activities and performing of especial sports at the school. Therefore, the aim of the present study was to accurate determining and investigating of life quality on function of children with epilepsy.

Method: The present study was performed prospectively and cross sectional on patients with epilepsy referring to Ahvaz Golestan Hospital. All data about the disease will be collected verbally with presence of interviewer and patient's family. The questionnaire of child epilepsy (parent's form) CEQ-P was used in order to evaluate the quality of life (QOL).

Results: The average of seizures during the last month was 6.4 ± 10.8 times, the results showed that the average of cognitive function in patients was significantly higher than mean score of 50 ($p>0.001$). on the other hand, the mean score of emotional function, social function and physical function were 46.03 ± 14.85, 33.50 ± 33.75, and 41.57±24.95, respectively which were significantly higher than the mean score of 50 ($p=0.001$), and finally, the results showed that the total mean score of life quality which was 38.52 ± 18.29 was significantly higher than the mean score of 50 ($p<0.001$).

Conclusion: The results of survey showed that epilepsy has a negative effect on various aspects of life quality of children. We can endeavor with performing appropriate approaches to improve it with recognizing the life quality and trying to improving of life quality and with paying attention to its various aspects.

Keywords: Epilepsy, Quality of life, Children

Accepted on March 20, 2019

Introduction

Epilepsy is one of the most common neurological disorders which can occur in each age, race and social class. This disease, as one of the common brain disorders, is a type of periodic and severe disorder in nerves system which is caused by abnormal discharge of brain cells. It is estimated that there are nearly 50million individuals with epilepsy around the world which around two thirds of these people live in third world countries [1,2]. According to data of Iran epilepsy quality, more than 30000 people are getting into epilepsy yearly in Iran which 10000 persons of them are children and adolescences [3].

Seizure can be effective on daily life of children and adolescences and has an important effect on presence at school, society, participation in social activities and performing especial exercises in the school [4]. Most of children with epilepsy are presented at school and can participate in all activities. Some of them need to consume drug at school, get help in some especial activities or spend more time on some tests [5].

Despite abundant progresses are achieved in medicine science about epilepsy, but the negative semantic load accompanied with the word "epilepsy" still effects the patient more than the disease itself or drug side effects in some societies. Epilepsy can effect specifically on life quality. This subject not only is because of chronicity of the disease or the common drug consumed or its side effects, but also because of bigotries, prejudices, and social problems which still surrounds it [6]. The common purpose of medicine in management of epilepsy is nearly exclusively focused on seizure control with minimum of drug side effects or without side effects whereas the importance of evaluation and gaining life quality is pretermitted in this purpose. Life quality is affected with social shame related to the disease. The studies on children and adults indicate relative and progressive compromising of life quality among epileptic patients [7].

The effects of epilepsy are not limited only to the epileptic child and this disease is effective on all members of family especially mothers which are the main caregiver of the child [8]. Also, anxiety in families having an epileptic child is higher comparing to families with healthy children [9]. The families

with an epileptic child even are more affected comparing to children with other chronic diseases [10].

Most of these concerns lead to excessive protection of parents and also imposed limitation to children activities [11]. On the other hand, the presence of anxiety in parents leads to occurrence of seizure in child which predispose the child to occurrence of epileptic attacks and also effects on growth and evolution of child and leads to failure of his/her activity in the family and society [12].

Growing recognition about the need for evaluation of effect of epilepsy on psychological-social function, has led to increasing of activities about life quality of epileptic patients. The aggressive effects of epilepsy on daily life of children and adolescences, is well searchable using the concept of life quality [13]. The concept of life quality is applicable as a measurable efficiency in treatment of many chronic diseases and epilepsy is also considered as a chronic disease [14].

The amounts of systematic and classified studies on social function and the effect of this disease on life of children have been very limited Therefore, the present study is designed aiming for determination and accurate evaluation of life quality on function of children with epilepsy.

Method

Study design

The present study was an epidemiologic-descriptive-analytical study based on Hospital data as a futuristic and cross sectional one on patients referring to neurology unit and clinics of children in Ahvaz Golestam Hospital during 2017. All data related to the history of disease was collected on person with the presence of an interviewer.

Inclusion criteria: Epilepsy as unfolding of seizures without a distinct agent as two or more cases. All children under 15 years old with at least a history of 6 months of epilepsy will insert the study.

Exclusion criteria: All children with neurodevelopmental defects (evolution delay, mental retardation, cerebral paralysis, autism, ADHD, behavioral disorders) and chronic background diseases (diabetes, asthma, hypertension, chronic kidney failure, chronic lung diseases, thalassemia, hypothyroidism) will not insert the study.

Also children whom their first grade caregivers do not cooperate to answer the questions of the questionnaire will omitted from the study and other children are substitute them.

Data collecting tools: CEQ-P children epilepsy questionnaire (parents form) in order to evaluate the quality of life (QOL), was used. The first part includes the items evaluating the demographic data, description of seizure and treatment of child seizure profile (CSP). The second part includes items that specifically evaluate health related quality of life (HRQOL) in epileptic children?

Questionnaire scoring: The total score of questionnaire is 100 and higher scores indicate better life quality. In the present study, the scores are used in order to finding correlation with various factors effective in life quality of the patients.

Data analysis

Descriptive statistical methods including average and standard deviation for quantitative variables and frequency and percentage for qualitative variables are used in order to data analysis and chi-square statistical tests were used in order to making correlation between qualitative variables.

T-test was used in order to compare the quality of life in various groups (age groups, gender and education) and variance test (for more than two groups) and Post HOC test were used. If data distribution was not normal, we will use the parametric equivalents of the mentioned test. Data analysis will perform using SPSS software V22.

Results

Demographic data

In the present study, 104 children with minimum epilepsy period of 6 months were inserted to study, among them 48 cases (53.85%) were girls and 56 individuals (53.85%) were boys. The average age of evaluated patients was 6.6 ± 3.6 years old. Among the evaluated patients, 38.5% were in age group of "younger than 5 years", 48.1% in age group of "5 to 10 years" and 13.4% in age group of "older than 10 years".

Type and numbers of seizures

From the 104 evaluated patients, 57 cases (54.8%) had generalized seizure, 37 patients (35.6%) showed focal seizure, on the other hand, 60 individuals (58%) were consuming one type of drug, whereas 44 patients (42%) were consuming more than one type of drug (Table 1). Also, the mean of total numbers of seizures were 11.6 ± 21.3 times and the mean seizures occurred in the recent month was 6.4 ± 10.8 times.

Table 1. *Patients distribution based on seizure type and consumed drug.*

Parameters	Subgroups	Frequency	Frequency percentage
Seizure type	Generalized	57	54.8%
	Focal	37	35.6%
	Without response	10	9.6%
Consumed drug	One drug	60	58%
	More than one drug	44	42%

Analytical results

The results showed that the mean cognitive function in patients had been significantly higher than the average score (50) ($p>0.001$). on the other hand, the mean sensory performance

score 46.03 ± 14.85, mean score of social function 33.50±33.75 and mean score of physical function 41.57 ± 24.95 had been significantly lower than average score (50) (p=0.001) and finally the results showed that total score of life quality 38.52 ± 18.29 had been significantly lower than average core (50) (p<0.001) (Table 2).

Table 2: Mean, standard deviation, minimum, maximum score of each function areas.

Sub index	Number	Mean score	Standard deviation	Minimum	Maximum
Cognitive function score	104	55.64	11.40	2917	81.94
Emotional function score	104	46.03	14.80	5.00	100
Social function score	104	33.50	33.75	0.00	100
Physical function score	102	41.47	24.95	0.00	90.63
Total score of life quality	102	38.52	18.29	0.00	100

The below table shows results of mono-sample t-analysis or mono-group t. in this table, the function score related to each function area has compared with the mean score of 50 (Table 3).

Table 3. Results of t test for comparison of mean score of each function area with the mean score.

Score	Mean score	Standard deviation	Statistics t	Freedom degree	Difference from the mean score	P-value
Cognitive function score	55.64	11.40	5.047	103	5.64	<0.001*
Emotional function score	46.03	14.80	-2.74	103	-3.96	0.008*
Social function score	33.50	33.75	-4.987	103	-16.5	<0.001*
Physical function score	41.47	24.95	-3.453	101	-8.5	0.001*
Total score of life quality	38.52	18.29	-6.342	101	-11.48	<0.001*

Discussion

Epilepsy in one of the most important diseases of nervous system, which arises because of sudden, frequent and excessive electrical discharge of brain neurons [15]. Epilepsy can come with destructive consequences in economic, social and cultural aspect for epileptic patients [16,17]. The life of an epileptic patient is not only adaptation with psychological-social consequences caused by attacks and long-term medical treatment, but also the epileptic patients must face negative attitudes and wrong beliefs present in most of societies about epilepsy which are more unpleasant than the attacks [18].

Epilepsy phenomenon often causes psychological-social problems because of being lengthy and from various aspects effects on life quality of these people [19]. Social exchanges, familial relationships and social activities are listed as key agents effective on life quality of epileptic patients [20]. Also many evidences show that factors related with demographic characteristics, drugs, factors related to seizure and physiological variables are among factors participant in low quality of epileptic patients [21,22]. This disease leads to problem such as lack of self-respect, depression, anxiety, social isolation and fear of death during the attack [21].

The quality of life in patients with epilepsy is lower than general population and is equal to the life quality of other chronic diseases such as asthma and diabetes, even worse [23,24]. The continuity of seizures, failure of cognitive function are the most important reasons of life quality dropping out. However, patients without seizure, have an appropriate satisfaction of life [25], and patients having better life quality have higher psychological health [26]. Therefore, the present study aimed for evaluating of life quality in epileptic children of Ahvaz City.

The results of the present study showed that the average of total score of life quality is 38.52 that was lower significantly than the average score which was 50. These results were opposite to the survey of Nagesh et al. They evaluated in their survey the health related life quality in epileptic children using a questionnaire of life quality of epileptic children (QOLCE-55) at tertiary Hospital. The results of their study showed that the mean total score of life quality in epileptic children is 45.78 which was higher than the life quality of epileptic children in the present study [27]. The reason for this difference can be different distribution of age range in both studies and difference in type of epilepsy in children of both studies. Also, these results were opposite to results of Arya et al. study. They evaluated in their survey the life quality of epileptic children in northern India. The results of their study showed that the mean life quality score in children was 66.7 which is higher than life quality of children in the present study [28]. The reason of the difference of life quality in this two studies can be resulted from difference in type of epilepsy and numbers of seizures times in children of both studies. These results were opposite to the results of Aggrowal et al. study

which showed that the mean life quality score is 62.6 in epileptic children of Delhi. They showed that the total life quality is affected by age, type of epilepsy, seizure frequency and maternal education [24]. The difference in type of epilepsy and times of seizures can be effective in difference of life quality in the two studies. Also, all mentioned studies are executed in the Indian sample. The reason for difference of life quality in this survey with our study can be the different economical-social status of samples. Haji and Mahmoudfakhe showed in a survey that the total life quality score is 47.04 in epileptic people (53), which was higher than the quality life score of the present study. Also, Shahhamzeh et al. showed in their study that the life quality score of epileptic patients is 48.79 [29] which was higher than our results. Among the reasons of different results of these studies, the different age range between the samples of studies can be mentioned. In Haji and Haji survey and Shah Hamzeh et al. study adult people were evaluated [25,29]. Raty et al. believe that life quality in epilepsy is along with psychological-social, health, hygiene, individual relationships, personal growth, economical-social status, social activities and being recognized by the society variables [30].

Also, the results of the present study showed that the averages of cognitive function, social function, emotional function, and physical function are 55.64, 33.50, 46.03 and 41.57 respectively. These results showed that the epileptic children of the present study have the most problems area of social function and the least problem in cognitive aspect. The results of the present study were parallel to survey of Shahhamzeh et al. [29]. They also showed that the epileptic patients have the least problems in cognitive aspect. Also, the results of the present study were parallel with results of Darabi et al. survey. They also showed that the least problem is seen in cognitive aspect among the epileptic patients. Aggarwal et al. showed that the most problems of epileptic children is in cognitive function aspect and the average was 48.2 [24]. The reason for difference in these surveys can be attributed to difference in type of epilepsy and therefore the difference in consumed drugs. Also, the results of the present survey were opposite to results of Nagesh et al. study. They showed that the most problems of epileptic children are in cognitive aspects and the least problems were in physical aspects [27]. The reason of difference in results of surveys can be attributed to cultural, economical-social, type of epilepsy, number of seizure times and gender differences between the studied people. Nedkarni et al. showed that age, location of inhabitancy, economical-social status, training of mothers, type of seizure and frequency and number of anti-epileptic drugs are among effective agents on life quality of epileptic children [31]. Therefore, difference in each of these variables can be the reason of difference in results of various studies. Haji and Mahmoud Fakhe showed that the most problems of life quality among epileptic patients were in effects of drug aspect and the least problems are in concern from seizure which is different from our results [25]. The reason can be attributed to application of different measurement tools of life quality in the two surveys. Consuming of anti-epileptic drugs often leads to decelerate the brain function, creation of confusion, drowsiness, fatigue, felling lethargic, anxiety, decreasing of focusing and behavioral disorders in individuals. These complications can effect on all dimensions of the epileptic patient.

Conclusion

The present survey creates an insight about life quality of epileptic children in Ahvaz city. Overall, the life quality of epileptic patients is affected by the disease and their life quality is appropriate. The most important problems of Ahvaz epileptic children are in social function aspect which this issue can be affected by social marking and low self-confidence of these children. Therefore, necessary measurements for improvement of QOL are also essential in addition to regular drug treatment. It seems that cognitive and behavioral functioning is severely affected and this show that QOL should be an important index in management of epileptic children.

References

1. Neligan A, Sander J. The incidence and prevalence of epilepsy. London: UCL Institute of Neurology 2009.
2. Aguiar BV, Guerreiro MM, McBrian D, Montenegro MA. Seizure impact on the school attendance in children with epilepsy. Seizure 2007; 16:698-702.
3. Baker GA, Hargis E, Hsih MM-S, Mounfield H, Arzimanoglou A, Glauser T, Pellock J, Lund S, International Bureau for Epilepsy. Perceived impact of epilepsy in teenagers and young adults: an international survey. Epilepsy Behav 2008; 12:395-401.
4. Hirfanoglu T, Serdaroglu A, Cansu A, Soysal AS, Derle E, Gucuyener K. Do knowledge of, perception of, and attitudes toward epilepsy affect the quality of life of Turkish children with epilepsy and their parents? Epilepsy Behav 2009; 14:71-77.
5. Fenichel GM. Clinical pediatric neurology: a signs and symptoms approach: Elsevier Health Sciences; 2009.
6. Datta SS, Premkumar TS, Fielding S, Chandy S, Kumar S, Eagles J, Cherian A. Impact of pediatric epilepsy on Indian families: influence of psychopathology and seizure related variables. Epilepsy & Behaviour 2006; 9:145-151.
7. Thomas SV, Koshy S, Nair CS, Sarma SP. Frequent seizures and polytherapy can impair quality of life in persons with epilepsy. Neurol India 2005; 53:46-50.
8. Akay AP, Kurul SH, Ozek H, Cengizhan S, Emiroglu N, Ellidokuz H. Maternal reactions to a child with epilepsy: depression, anxiety, parental attitudes and family functions. Epilepsy Res 2011; 95:213-220.
9. Ferro MA, Speechley KN. Depressive symptoms among mothers of children with epilepsy: a review of prevalence, associated factors, and impact on children. Epilepsia 2009; 50:2344-2354.
10. Chiou HH, Hsieh LP. Parenting stress in parents of children with epilepsy and asthma. Journal of child neurology 2008; 23:301-306.

11. Williams J, Steel C, Sharp GB, DelosReyes E, Phillips T, Bates S, Lange B, Griebel ML. Parental anxiety and quality of life in children with epilepsy. Epilepsy Behav 2003; 4:483-486.
12. Aydin K, Yildiz H. Teachers' perceptions in central Turkey concerning epilepsy and asthma and the short-term effect of a brief education on the perception of epilepsy. Epilepsy Behav 2007; 10:286-290.
13. Rajmil L, Herdman M, de Sanmamed MJF, Detmar S, Bruil J, Sieberer UR, Bullinger M, Simeoni MC, Auquier P; Kidscreen Group. Generic health-related quality of life instruments in children and adolescents: a qualitative analysis of content. Journal of adolescent Health 2004; 34:37-45.
14. Chehrehgosha M, Seyyedolshohadayee M, Hosseini AF. Quality of life and its related factors in adolescents with epilepsy. IJN 2011; 24:47-54.
15. Cavazos J, Spitz M. Epilepsy, juvenile myoclonic 2007.
16. de Boer HM. Epilepsy stigma: moving from a global problem to global solutions. Seizure 2010; 19:630-636.
17. Tanywe A, Matchawe C, Fernandez R. The experiences of people living with epilepsy in developing countries: a systematic review of qualitative evidence. JBI database System Rev Implement Rep 2016; 14:136-192.
18. Babikar HE, Abbas IM. Knowledge, practice and attitude toward epilepsy among primary and secondary school teachers in South Gezira locality, Gezira State, Sudan. J family Community Med 2011; 18:17-21.
19. Zigheymat F, Naderi Z, Ebadi A, Kachuei H, Mehdizade S, Ameli J, Niknam Z. Effect of education based on «precede-proceed» model on knowledge, attitude and behavior of epilepsy patients. Journal of Behavioral Sciences 2009; 3:223-229.
20. Hills MD. The psychological and social impact of epilepsy. Neurology Asia 2007; 12:10-12.
21. Jacoby A, Baker GA. Quality-of-life trajectories in epilepsy: a review of the literature. Epilepsy Behav 2008; 12:557-571.
22. Schachter SC. Quality of life for patients with epilepsy is determined by more than seizure control: the role of psychosocial factors. Expert review of neurotherapeutics 2006; 6:111-118.
23. Beattie PE, Jones MSL. A comparative study of impairment of quality of life in children with skin disease and children with other chronic childhood diseases. Br J Dermatol 2006; 155:145-151.
24. Aggarwal A, Datta V, Thakur L. Quality of life in children with epilepsy. Indian pediatrics 2011; 48:893-896.
25. Haji A, Mahmoud Fakhe H. Relationship of social support and self-management with quality of life in patients with epilepsy. JHC 2015; 17:240-247.
26. Rowan AJ, Ramsay R, Collins J, Pryor F, Boardman K, Uthman B, Spitz M, Frederick T, Towne A, Carter GS, Marks W, Felicetta J, Tomyanovich ML, VA Cooperative Study 428 Group. New onset geriatric epilepsy: a randomized study of gabapentin, lamotrigine, and carbamazepine. Neurology 2005; 64:1868-1873.
27. Nagesh A, Gade A, Puchchakayala G, Bhava S, Kagitapu S, Madanu S, Nune A. 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.
28. 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.
29. Shahhamzeh M, Fasihi HT, Kabir K, Montazeri A, Asadi SM, Saei V. The relationship between self-management and quality of life in epileptic patients who referred to Iranian epilepsy association. JHC 2017; 19:189-198.
30. Räty LK, Larsson BMW. Quality of life in young adults with uncomplicated epilepsy. Epilepsy Behav 2007; 10:142-147.
31. Nadkarni J, Jain A, Dwivedi R. Quality of life in children with epilepsy. Ann Indian Acad Neurol 2011; 14:279-282.

Correspondence to:

Ali Akbar Momen

Department of Pediatrics

Faculty of Medicine

Ahvaz Jundishapur University of Medical Sciences

Ahvaz

Iran