

Health Related Quality of Life in Egyptian Children and Adolescents with Epilepsy

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ABSTRACT

Background: Childhood epilepsy is one of the most significant and prevalent neurological condition in the developing years. The aim of the study was to explore the current status of health related quality of life (HR-QOL) in Egyptian children and adolescents with epilepsy using (WHOQOL-BREF) questionnaire. **Patients and Methods:** This case control study was carried out in Pediatric Neurology Unit and Outpatient Clinic in Department of Pediatrics at Zagazig University Children's Hospital on 110 children, divided into 2 groups, case group included 55 children with epilepsy and control group included 55 apparently healthy children without epilepsy of matched age, sex and social class. All the children were subjected to history taking, clinical examination and assessment of QOL. **Results:** There was a significant decrease in all domains and total score of WHOQOL-Bref questionnaire in the case group. There was a significant –ve correlation between age and psychological domain score, also between number of school failure and both psychological and environmental domain. Disease duration and treatment duration were negatively significantly correlated with all QOL domains. A significant +ve correlation was found between social class score and both general and environmental domain. There was a significant decrease in general and environmental domain score between cases with generalized and partial seizures compared to cases with absent seizures. **Conclusion:** Diminished QOL is common in children with epilepsy than other children. Patients with epilepsy had lower mean scores of all domains of QOL, especially those with frequent fits, those with long duration, and in patients with generalized fits. **Keywords:** Childhood, Epilepsy, Health, Quality of life.

INTRODUCTION

Epilepsy is one of the most common chronic neurologic conditions in children, and it is associated with increased risk for poor health-related quality of life (HR-QOL) ⁽¹⁾. Childhood epilepsy is an elevated hazard for poor psychological outcomes and impacts on quality of life of children but also has a great sway on family functioning. Children being the high-risk group and in crucial development period during which many cognitive and social skills have to be learned. QOL is a significant health outcome to assess children with epilepsy ⁽²⁾. Epilepsy also has a significant emotional impact on parents of affected children, and parental emotional stability has been found to be a major predictor of the quality of life (QOL) of the epileptic child. It has been associated with significant psychosocial maladjustment in both the affected children and their families ⁽³⁾. Children with epilepsy experience difficulty in aspects of functioning, including emotional and behavioral problems, social competence, academic achievement, and family life, with effects extending into adulthood. The management of epilepsy requires recognition of potential effects of epilepsy and all aspects of life ⁽⁴⁾.

Quality of life (QOL) is affected by age, seizure frequency, parent's education, type of epilepsy, and type of anti epileptic in children with epilepsy. Cognition, energy levels and concentration are most commonly affected due to epilepsy ⁽⁵⁾.

The aim of the study was to explore the current status of health related quality of life (HR-QOL) in Egyptian children and adolescents with epilepsy by using (WHOQOL-BREF) questionnaire.

PATIENTS AND METHODS

This case control study was carried out in Pediatric Neurology Unit and Outpatient Clinic in Department of Pediatrics at Zagazig University Children's Hospital on 110 subjects, divided into two groups, case group included 55 children with epilepsy and control group included 55 apparently healthy children without epilepsy of matched age, sex and social class during the period from February 2021 to September 2021, to explore the current status of health related quality of life (HR-QOL) in Egyptian children and adolescents with epilepsy by using (WHOQOL-BREF) questionnaire and the socioeconomic position (SEP) scale ⁽⁶⁾.

Ethical approval:

Written informed consent was obtained from all children' parents or their relatives and the study were approved by the Research Ethical Committee of Faculty of Medicine, Zagazig University. The work has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for studies involving humans.

Inclusion Criteria: Aged between 9 and 16 years, both sexes, ability to answer the questions by himself/herself, and medical diagnosis of epilepsy for more than 2 years.

Exclusion criteria: Children < 9 and > 16 years, previous brain surgery, and use of a concomitant medication with central nervous system effects, or presence of another progressive neurological, psychiatric illness or other chronic disease.



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All patients and controls were subjected to the following:

- History taking obtained for each child included age, sex, child’s hobbies and leisure time activities, sleep disorders, urine incontinence, previous academic failure or success, and last year’s achievements and absenteeism rate.
- Epilepsy was defined as separate occurrence of two or more unprovoked seizures, not diagnosed as neonatal or febrile seizures.
- The diagnosis of epilepsy in the children based on history and the electroencephalographic findings, as all of them underwent electroencephalography.

Clinical examination:

- All the studied children were subjected to full clinical examination to exclude other medical conditions and chronic diseases.

Assessment of HR-QOL of all the studied children and adolescents was held by using WHOQOL-BREF questionnaire (7).

The questionnaire consisted of 26 items; but one item about appreciation of sexual life was discarded putting into consideration the young age of the studied group. The items assessing four main domains that cover the aspects proposed to judge QOL. The items are assessing four main domains that cover the aspects proposed to judge QOL. The assessed domains had included: physical health, psychological health, social relationships and environmental domain.

Data collection:

Data were collected by using an interview questionnaire that included the following updated

social scale (6): (1) Mother’s education. (2) Father’s education. (3) Working status of the mother. (4) Working status of the father. (4) Use of computer. (5) Per-capita income. (6) Family size. (7) Crowding index. (8) Proper sewage disposal. (9) Proper refuse disposal. The following changes were made to the modified scale of 1983 (8): (1) Working status was separated from education of both the father and the mother. (2) A new educational domain, the use of computer, was added. (3) Home sanitation included only proper sewage and refuse disposal as water supply was found to be available for all the families studied.

Statistical analysis

Data collected throughout history, basic clinical examination, laboratory investigations and outcome measures were coded, entered and analyzed using Microsoft Excel software. Data were then imported into Statistical Package for the Social Sciences (SPSS version 20.0) software for analysis. Qualitative data were represented as number and percentage and quantitative were represented by mean ± standard deviation (SD), range, median, and interquartile range (IQR). Difference and association of qualitative variable were tested by Chi square test (X²). Differences between quantitative data were done by independent t-test. P value < 0.05 was considered significant.

RESULTS

Table (1) showed that there were no statistical significant differences between the studied groups regarding demographic data.

Table (1): Demographic data of the studied groups

Variable		Cases (n=55)		Control (n=55)		t	P
Age (years)	Mean ± SD	12.69±2.68		12.33±2.4		0.75	0.46
	Range	9 – 16		9 - 16			
Variable		No	%	No	%	χ ²	P
Sex	Female	22	40	23	41.8	0.04	0.85
	Male	33	60	32	58.2		
Mother education	Illiterate	11	20	8	14.5	8.7	0.12
	Read and write	5	9.1	3	5.5		
	Primary	2	3.6	11	20		
	Preparatory	9	16.4	7	12.7		
	Secondary	9	16.4	5	9.1		
University	19	34.5	21	38.2			
Father education	Illiterate	5	9.1	1	1.8	6.55	0.26
	Read and write	3	5.5	2	3.6		
	Primary	4	7.3	1	1.8		
	Preparatory	7	12.7	9	16.4		
	Secondary	8	14.5	14	25.5		
University	28	50.9	28	50.9			
Mother work	Not working	35	63.6	31	56.4	0.61	0.44
	Working	20	36.4	24	43.6		
Father work	Not working	5	9.1	3	5.5	0.54	0.46
	Working	50	90.9	52	94.5		
Social class	Low	18	32.7	11	20	3.22	0.20
	Moderate	31	56.4	33	60		
	High	6	10.9	11	20		

SD: Standard deviation, t: Independent t test, χ²: Chi square test, NS: Non significant

Table (2) showed that mean age of onset among the cases group was 6.24 years while mean disease duration was 6.45 years. Most frequent type was generalized tonic clonic (74.5%) and most frequent attacks were convulsions. 87.3% of cases had from 1 to 2 attacks per month and 27.3% had attacks at school. Frequency of headache before attacks was 65.5%, psychological tension was 67.3% and fever was 18.2%. Finally in 9.1% of cases exposure to bright light caused the attack.

Table (2): Epilepsy data among the studied cases group

Variable		Cases (n=55)	
Age of onset (years)	Mean ± SD	6.24±3.45	
	Range	2-13	
	Median (IQR)	5 (3-10)	
Duration (years)	Mean ± SD	6.45±2.93	
Variable		No	%
Type of epilepsy	Absence seizers	4	7.3
	Generalized tonic clonic	41	74.5
	Partial	10	18.2
Description of attacks	Convulsion	50	90.9
	Relaxation with loss of consciousness	5	9.1
Number of attack/month	1-2	47	87.3
	3-4	5	9.1
	5-7	2	3.6
Attacks at school	No	40	72.7
	Yes	15	27.3
Headache before attack	No	19	34.5
	Yes	36	65.5
Psychological tension before attack	No	18	32.7
	Yes	37	67.3
Fever before attack	No	45	81.8
	Yes	10	18.2
Exposure to bright light cause the attack	No	50	90.9
	Yes	5	9.1

SD: Standard deviation, (IQR): Interquartile range

Table (3) showed that mean treatment duration among the cases group was 6.17 years. Almost three quarters of the cases took 1 AED. Also, 70.9% were adherent to drug therapy and 69.1% controlled the attacks for weeks. 73.6% of the cases were admitted to hospital because of epilepsy.

Table (3): Treatment data among the studied cases group

Variable		Cases (n=55)	
Duration of treatment (years)	Mean ± SD	6.17±3.05	
Variable		No	%
Number of AED	1	41	74.5
	2	11	20
	3	2	3.6
	4	1	1.8
Drugs adherence	No	16	29.1
	Yes	39	70.9
Control interval	Days	15	27.3
	Weeks	38	69.1
	Months	2	3.6
Hospital admission	No	9	16.4
	1-2	35	53.6
	3-5	11	20

SD: Standard deviation, AED: Antiepileptic drug.

Table (4) showed that there was a statistical significant decreases in all domains and total score of WHOQOL-Bref questionnaire among cases group compared to control group.

Table (4): WHOQOL-Bref questionnaire results among the studied groups

Domain		Cases (n=55)	Control (n=55)	t	P
General health	Mean ± SD	44.77±12.66	75.45±9.31	14.48	<0.001**
Physical health	Mean ± SD	42.92±14.49	84.48±7.78	18.74	<0.001**
Psychological health	Mean ± SD	44.77±11.31	69.32±7.41	13.46	<0.001**
Social life	Mean ± SD	48.18±12.13	60.68±8.13	6.35	<0.001**
Environmental	Mean ± SD	45.28±10.04	64.43±8.01	11.05	<0.001**
Total	Mean ± SD	35.75±7.97	57.44±4.62	17.46	<0.001**

SD: Standard deviation t: Independent t test **: highly significant

Table (5) showed that there was a statistical significant –ve correlation between age and psychological domain score, also between number of school failure and both psychological and environmental domain. Disease duration and treatment duration were negatively significantly correlated with all QOL domains. A statistical significant +ve correlation was found between social class score and both general and environmental domain.

Table (5): Correlation between WHO-QOL questionnaire domain and some parameters among the studied cases group

Variable	General (n=55)		Physical (n=55)		Psychological (n=55)		Social (n=55)		Environment (n=55)	
	r	P	r	P	R	P	r	P	R	P
Age (years)	-0.03	0.84 NS	-0.02	0.92 NS	-0.25	0.03*	0.02	0.90 NS	-0.10	0.48 NS
Social class score	0.31	0.02*	0.09	0.52 NS	0.03	0.84 NS	-0.05	0.73 NS	0.37	0.009*
N school failure	-0.14	0.14 NS	0.12	0.40 NS	-0.26	0.03*	0.04	0.77 NS	-0.33	0.01*
Age of onset(y)	0.19	0.17 NS	0.09	0.52 NS	-0.05	0.71 NS	0.20	0.06 NS	0.18	0.12 NS
Duration(y)	-0.26	0.03*	-0.25	0.04*	-0.27	0.02*	-0.25	0.04*	-0.34	0.01*
Attack/m	0.02	0.90 NS	-0.26	0.03*	-0.34	0.01*	-0.27	0.03*	0.05	0.75 NS
Duration of ttt(y)	-0.27	0.03*	-0.28	0.03*	-0.26	0.03*	-0.26	0.03*	-0.32	0.01*
N. of drugs	0.07	0.61 NS	-0.04	0.78 NS	-0.11	0.42 NS	-0.16	0.24 NS	-.008	0.56 NS
N. hospitalization	-0.03	0.87 NS	0.01	0.92 NS	0.07	0.63 NS	0.08	0.58 NS	0.02	0.88 NS

r: Pearson’s correlation coefficient, NS: Non significant, *: Significant

Table (6) showed that there was a statistical significant decrease in general and environmental domain score among cases that had generalized and partial seizures compared to cases that had absent seizures.

Table (6): Relation between WHO-QOL questionnaire domain and type of epilepsy among the studied cases group

Domain	Type	N	Mean	SD	F	P
General	Absence seizures	4	59.38	27.72	3.18	0.03*
	Generalized tonic	41	43.29	10.86		
	Partial	10	45.00	8.74		
Physical	Absence seizures	4	52.68	27.87	1.07	0.35 NS
	Generalized tonic	41	41.72	13.93		
	Partial	10	43.93	9.38		
Psychological	Absence seizures	4	52.08	23.69	0.91	0.41 NS
	Generalized tonic	41	44.31	10.53		
	Partial	10	43.75	7.92		
Social	Absence seizures	4	59.38	27.72	1.9	0.16 NS
	Generalized tonic	41	47.26	10.27		
	Partial	10	47.50	9.86		
Environmental	Absence seizures	4	56.25	25.13	3.01	0.04*
	Generalized tonic	41	44.89	8.02		
	Partial	10	42.50	6.78		

SD: Standard deviation, NS: Non significant, *: Significant

DISCUSSION

Epilepsy is a common chronic neurological condition in developing years that can negatively impact one's physical, social and emotional function. In Austria, behavioral and emotional problems were reported in 22% of epileptic children, and studies have described feelings of shame, rejection, fear, worry, low self esteem, and perception of stigma to be common in children with epilepsy⁽⁹⁾. Increasing attention is being focused on problems experienced by children with epilepsy as a result of stigma, which is associated with poor psychosocial health outcomes and impaired QOL. Epilepsy may interfere with social functioning by limiting educational opportunities, employability, and interpersonal relationships and also increase the risk of death⁽¹⁰⁾.

Our study showed that there were no statistical significant differences between the studied groups regarding demographic data. **Monir et al.**⁽¹¹⁾ found the same while **Sherman et al.**⁽¹²⁾ found that sociodemographic factors were weak predictors of a poorer total QOL score in children with epilepsy.

Our study cleared that mean age of onset among the cases group was 6.24 years while mean disease duration was 6.45 years. Most frequent type was generalized tonic clonic (74.5%) and most frequent attacks were convulsions. 87.3% of cases had from 1 to 2 attacks per month and 27.3% had attacks at school. Frequency of headache before attacks was 65.5%, psychological tension was 67.3% and fever was 18.2%. Finally in 9.1% of cases exposure to bright light caused the attack. **Monir et al.**⁽¹¹⁾ showed a comparison of the types of seizures and epilepsy-related variables in the studied patient groups. Highly significant differences ($P < 0.001$) were found between patient subgroups regarding the age at onset of seizures, the duration of therapy, the number of antiepileptic drugs, and seizure frequency per month.

Our study reported that mean treatment duration among the cases group was 6.17 years. Almost three quarters of the cases took 1 AED. Also, 70.9% were adherent to drug therapy and 69.1% controlled the attacks for weeks. 73.6% of the cases were admitted to hospital because of epilepsy.

Our study illustrated that there was a statistical significant decreases in all domains and total score of WHOQOL-Bref questionnaire among cases group compared to control group. In agreement with our results, **Monir et al.**⁽¹¹⁾ and **Crossley et al.**⁽¹³⁾. **Karnavat**⁽⁴⁾ found that pediatric epilepsy is associated with various comorbidities. It is well-known that children with epilepsy have a compromised health-related QOL and may be affected across physical, psychological, social, and educational domains.

Our study revealed that there was a statistical significant -ve correlation between age and psychological domain score and also between number of school failure and both psychological and environmental domain. Disease duration and treatment

duration were negatively significantly correlated with all QOL domains. A statistical significant +ve correlation was founded between social class score and both general and environmental domain. **Monir et al.**⁽¹¹⁾ showed that epilepsy-related risk factors such as the age at onset of seizures, types of seizures, the duration of illness, number and duration of antiepileptic drugs, as well as children's learning problems were found to be significantly strong predictors of an impaired all domains of QOL. **Abbas et al.**⁽¹⁴⁾ found a significantly poor QOL in children with epilepsy and longer seizure and treatment durations. **Guekht et al.**⁽¹⁵⁾ reported that patients with frequent seizures had a lower QOL score, which is in agreement with our results. **Benavente et al.**⁽¹⁶⁾ also found that Duration of the illness, severity of epilepsy and seizure frequency were related to diminished QOL in children with epilepsy. **Miller et al.**⁽¹⁷⁾ found that the epileptic patients who were taking one antiepileptic drug had a slightly higher HRQOL score than those on multiple drugs.

Our study revealed that there was no statistical significant differences between presence or absence of nocturnal enuresis and QOL domain among studied cases group. Our study revealed that there was a statistical significance decrease in general and environmental domain score among cases that had generalized and partial seizers compared to cases that had absent seizers. Physical, psychological and social domain also were decreased in cases that had generalized and partial seizers compared to cases that had absent seizers but without statistical significance. **Monir et al.**⁽¹¹⁾ showed that seizures control were found to be significantly strong predictors of an impaired general and environmental domain score. **Stevanovic**⁽¹⁸⁾ found that the overall QOL was significantly lower in patients with generalized epilepsy compared with those with partial epilepsy.

CONCLUSION

Diminished QOL is common in children with epilepsy. Patients with epilepsy had lower mean scores of all domains of QOL, especially those with frequent fits, those with long duration, and in patients with generalized fits.

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