Burden of epilepsy on adolescents and their families in Zagazig University hospital. "A cross sectional study"

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Background
Epilepsy is a chronic neurological disorder, which has potentially adverse cognitive and psychosocial consequences.
Objectives
To assess the quality of life (QOL) of adolescents with epilepsy (AWE) and their families and also factors affecting it, related to both the disease burden and the antiepileptic drug.
Patients and methods
A cross-sectional study was done on 217 AWE and one parent each. Sociodemographic and disease-related data were collected. Patients completed the QOL in epilepsy questionnaire (AD-48) and pediatric epilepsy side effects questionnaire. The parents completed impact of epilepsy on QOL questionnaire.
Results
Mean patients' age was 14.33 years old, having disease since a mean duration of 6.62 years. Overall, 59.5% of them received polytherapy, with 37.3% having received new line of drugs. Approximately one-third of them had partial seizures. Half of them had one or two attacks per month. The mean total QOL score was 55.91±5.55. The largest percentage of parents reported that epilepsy had worse effects on their attitude, family change, general well-being, and adolescents' QOL. There are significant relationships between QOL and mother education, age group, disease duration, seizures frequency, and type and line of antiepileptic drugs. There are significant negative correlations between all pediatric epilepsy side effects questionnaire domains and QOL.
Conclusions
Epilepsy had adverse effect on AWE and their families. Illiterate mothers, older, increasing duration, seizure frequency, generalized type, and being on old or combined drug regimens are the predictors of poor QOL.

Keywords:
adolescents, epilepsy, predictor, quality of life

Introduction

The management of epilepsy involves a number of actions that goes beyond just seizure control without adverse treatment effects. These actions include psychological and social interventions. Hence, management strategy of adolescents with epilepsy (AWE) should be comprehensive, including measuring quality of life (QOL) [1–3].

Adolescence is a time of rapid physical, psychological, and social development. For young people with epilepsy, the normal needs and concerns linked to being an adolescent are overlapped with the health problem that can hence add additional limits on lifestyle and independence. It is essential for healthcare professionals to recognize the effect of epilepsy on patients' lives and to understand their specific needs [4].

It is expected that there is a significant effect of epilepsy on adolescents' and their families' QOL. For this reason, along with an inquiry on the child's clinical condition, information should be obtained on the social and personal effect of epilepsy on various family members [5–7].

Identifying modifiable and nonmodifiable predictors of QOL status over the course of epilepsy treatment can aid clinicians to better comprehend which patients are at danger of having reduced QOL and need well-timed interventions. Yet, there is a lack of research on QOL among AWE from the developing countries, including Egypt [8,9].

Aim

The aim was to assess the QOL of AWE and their families and also factors affecting it, related to both the disease burden and the antiepileptic drugs (AEDs).

Patients and methods

This cross-sectional study was conducted in the Pediatric and Neurology Outpatient Clinics of Zagazig University hospitals. The center is a governmental tertiary center that caters to heterogeneous population, representing both urban and rural patients.

The sample size was calculated by EpIOpen software (Open Source Epidemiologic Statistics for Public Health, Version, www.OpenEpi.com) with power of study 80% and confidence limit 95%. Assuming that 520 AW attending outpatient clinics of Zagazig University hospital within 6 months and prevalence of bad QOL among children and AWE being 60% [9], so 217 patients with epilepsy were included and one parent each.

Inclusion criteria

The following were the inclusion criteria:

(1) Patients with primary epilepsy of both sexes aged from 11 to 18 years old.
(2) All selected patients should have good medication adherence.

Exclusion criteria

(1) Patients with presence of associated comorbidities or developmental conditions were excluded.

Study tools

All studied AWE were interviewed using the following questionnaire:

(1) Sociodemographic information was obtained by using the questionnaire of El-Gilany *et al.* [10] to assess socioeconomic status of the study participants.
(2) Quality of life in epilepsy (QOLIE AD-48) for children and adolescents: it is a disease-specific instrument for the assessment of health-related quality of life (HRQOL) in AWE [11].
It contains 48 (and three optional) items on eight subscales: epilepsy effect (12 items), memory/concentration (10 items), attitudes toward epilepsy (four items), physical functioning (five items), stigma (six items), social support (four items), school behavior (four items), and health

perceptions (three items). The subscale scores, as well as an overall score, range from 0 to 100; the higher the score, the better the QOL. It is a sensitive, validated, and test–retested ($r=0.83$) instrument, which is easy to administer and to score. The average time for completion is 15–20 min. The QOLIE AD-48 could provide information about a variety of issues pertinent to AWE, foremost HRQOL [12].
(3) Pediatric epilepsy adverse effects questionnaire:
It is a 19-item measure of AED adverse effects collected 1 month after diagnosis. Scores range from 0 to 100, with higher scores representing more adverse effects. The pediatric epilepsy side effects questionnaire (PESQ) has strong internal consistency and test–retest reliability. Cronbach's alphas for the current sample were as follows: total (a¼.96), cognitive (six items; a¼.94), motor (four items; a¼.94), behavioral (three items; a¼.92), general neurological (four items; a¼.75), and weight (two items; a¼.88) [13].
(4) A structured case record form:
A structured case record form was used for the collection of a number of variables. Data recorded included, among others, demographics, clinical findings, date of seizure onset, seizure type(s), seizure frequency, etiology of epilepsy, epilepsy syndrome, and adverse effects.

For parents

(1) Impact of epilepsy on quality of life (IEQOL) [14]:

The IEQOL includes a brief section on the satisfaction about the information imparted to the family by the treating physician (items A1–A2). Five domains follow (B through F) with questions concerning the reactions of the parents when faced with epilepsy (B1–B3), the changes in the family's QOL after the onset of the disease (C1–C7), the family's wellness and its changes (D1–D5), the status of the child's/adolescent's QOL (E1–E4), and the perception about treatment administration and its effects (F1–F4). For each domain, the answer should document a change after the onset of epilepsy, which is categorized, using a Likert scale, as 'high,' 'moderate,' 'mild,' or 'none.'

All questionnaires were translated into Arabic by an expert panel and retranslated again to English. Arabic translations of QOLIE AD-48, PESQ, and IEQOL were reliable (Cronbach's alpha was 0.84, 0.83, and 0.79, respectively).

Operational design

Pilot study

This was done on 10% of sample (22 patients and their parents) to calculate necessary time for questionnaire and check feasibility, and ease of understanding of questionnaires. No modifications were done.

Field work

All patients completed history taking and thorough clinical examination. Then they were asked to complete the study questionnaires. One parent for each parent filled in IEQOL. This took 45 min for each patient and his/her parent.

Administrative design and ethical consideration

The study was approved by ethical committee in Faculty of Medicine, Zagazig University. The necessary permissions were taken from pediatric and neurology outpatient clinics.

An informed verbal consent was taken from all study participants after explaining objectives of the study. Confidentiality of data was assured.

Statistical analysis

Data were analyzed using the statistical package for the social sciences, version 20 computer program (IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp). The results were presented as tables. Data were presented as means±SDs, number, and percentage (frequency distributions). The χ^2 test was used for the comparison between the categorical data. The independent Student *t* test (two sided) and nonparametric tests were used for comparing the numerical data. A *P* value of less than 0.05 was considered statistically significant throughout all statistical tests within this study.

Results

More than half of them were from 11 to less than 15 years old. The largest percentage of them was female from urban areas. Approximately two-thirds of them were from low and middle social class. Approximately one-fifth of their mothers had high education.

Regarding disease-specific characteristics, ~60% of them received polytherapy. The largest percentage is on AEDs. Approximately 31% of patients had last attack since 1 week to less than 1 month. Approximately one-third of them had partial seizures. The mean disease duration among them was 6.62 years old. On asking about frequency of attacks in the past month before our study, one-half

Table 1 Sociodemographic and clinical data of studied cases

	n (%) (*N*=217)
Age (years)	
11 to <15	101 (46.5)
15–18	116 (53.5)
Sex	
Male	143 (65.9)
Female	74 (34.1)
Time since last seizure	
≤1 week	43 (19.8)
1 week to ≤1 month	67 (30.9)
1 to ≤6 months	44 (20.3)
6 months to ≤1 year	31 (14.3)
>1 year	32 (14.7)
Type of therapy	
Monotherapy	87 (40.1)
Polytherapy	130 (59.9)
Type of AEDs	
Traditional	69 (31.8)
New	81 (37.3)
Combined	67 (30.9)
Duration	
Mean±SD	6.62±2.23
Median (range)	7 (3–10)
Type of seizures	
Partial	71 (32.7)
Generalized	145 (67.3)
Frequency of attack	
Once/week (4/months)	39 (18)
Once/2 weeks (2/months)	55 (25.3)
Once/3 weeks	42 (19.4)
Once/month	53 (24.4)
Zero/month	28 (12.9)

AED, antiepileptic drug.

of them had one or two attacks per month. Approximately 37% of them were on new AEDs (Table 1).

On assessing self-reported HRQOL, mean effect of epilepsy was 64.88 (±7.95), mean memory and concentration domain was 60.18 (±7.77), mean attitude 60.6 (±11.59), mean physical 67.37 (±7.95), mean stigma 56.77 (±7.77), mean social support 49.22 (±9.61), mean school performance 47.75 (±7.98), mean health perception 40.09 (±10.19), and mean total score was 55.91 (±5.55). Health perception, school performance, and social support had the worst score.

On assessing relation between some demographic criteria and total QOL score, there were statistically nonsignificant relations between sex, residence, and QOL. However, there were statistically significant differences between age group, mother education, and QOL. Youngest age group and higher maternal education had the highest QOL score (Table 2).

Table 2 Relation between demographic factors and self-reported quality of life

Demographic factors	QOL Mean±SD	P
Sex		
Male	56.15±5.55	0.316
Female	55.35±5.54	
Age groups (years)		
11 to <15	57.06±5.303	0.003**
15–18	54.84±5.79	
Social class		
Very low	53.67±5.85	0.006*
Low	57.25±5.08	
Middle	56.25±5.37	
High	54.88±5.55	
Residence		
Rural	55.95±5.48	0.886
Urban	55.82±5.62	
Mother education		
Illiterate	53.41±5.6	<0.001**
Read and write	52.75±5.54	
Basic education	56.44±4.48	
Secondary education	56.82±5.07	
High education	59.88±5.55	

QOL, quality of life. *P<0.05 is statistically significant. **P value less than or equal to 0.001 indicates statistically highly significant difference.

Table 3 Relation between disease-specific characteristics and quality of life

Disease-specific characteristics	QOL Mean±SD	P
Duration groups		
3 to <6	56.89±5.42	<0.001**
6–10	54.08±5.35	
Type of seizures		
Partial	58.32±3.7	<0.001**
Generalized	54.68±5.91	
Frequency of attack		
Once/week (4/months)	47.76±3.56	<0.001**
Once/2 weeks (2/months)	54.85±4.46	
Once/3 weeks	57.74±2.83	
Once/month	58.78±3.89	
Controlled(0/month)	60.63±2.54	
Therapy		
Monotherapy	59±3.97	0.212
Polytherapy	53.77±5.48	
Type of AEDs		
New	57.32±4.82	0.028*
Traditional	55.39±5.37	
combined	54.97±6.02	
Time since last seizure		
≤1 week	56.35 ± 5.86	0.916
1 week to ≤1 month	55.87 ±4.46	
1 month to ≤6 months	56.05±5.52	
6 months to ≤1 year	55.79 ± 5.34	

AED, antiepileptic drug; QOL, quality of life. *P value less than 0.05 indicates statistically significant difference. **P value less than or equal to 0.001 indicates statistically highly significant difference.

Regarding epilepsy-specific criteria, there were statistically significant differences between disease duration, seizure type, frequency of attack, type of AEDs, and total QOL score, with those with shorter disease duration, on new line of AEDs, and had no attacks in the previous months had the better QOL. Patients with generalized seizures had significantly the worst QOL. No difference was found between mono or polytherapy and time since last seizures and QOL (Table 3).

On measuring parents' burden on QOL, the largest percentage of parents reported that epilepsy had highly adverse effects on their attitude, family change, general well-being, and adolescents' QOL (Fig. 1).

There was statistically significant relationship between parents-reported QOL and their child self-reported QOL. Both parents and their offsprings had approximately the same evaluation of QOL (Table 4).

By using PESQ, different domains of adverse effects were assessed; the least reported adverse effect was cognitive domain (28±10.6) whereas the worst affected one was behavioral (43.35±11.87) followed by weight gain (38.11±18.47) and motor domains (38.04 ±9.78) followed by general neurological domain (31.31 ±7.15). The mean total PESQ score was 34.3 (±4.76).

On studying correlation between PESQ score and total QOL score, there are significant negative correlations between cognitive, general neurological behavioral, weight gain, and motor domains and QOL. Decreasing adverse effect scores was linked to improvement in QOL (Table 5).

On studying the potential risk factors for poor self-reported QOL, having an illiterate mother increased the risk for poor QOL by 2.428 folds, having generalized seizures increased the risk by 12.44 folds, whereas being older adolescent and/or having epilepsy for longer period increased the risk for poor QOL by 3.398 and 0.12 fold, respectively. Being on old or combined drug regimen increased the risk by 4.183 folds. More frequent attacks of epilepsy increased the risk by 0.43 folds (Table 6).

Discussion

Epilepsy can significantly impair QOL, not merely owing to its chronic course, need for regular medications use, and adverse effects but also owing to being a stigma with social constraints [15].

Figure 1
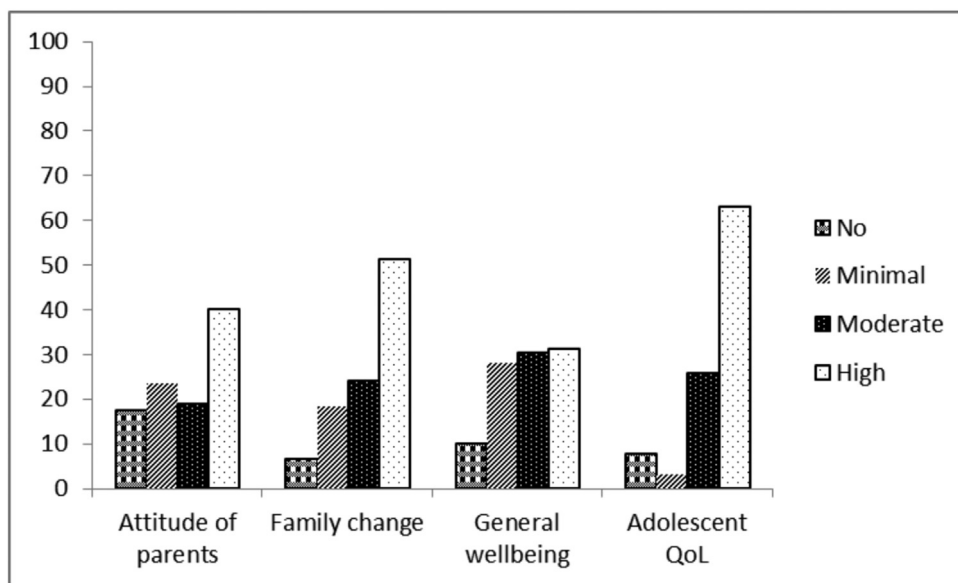
Combined bar chart showing scores of patients' burden on quality of life.

Table 4 Relation between parent-reported patient quality of life and patient self-reported quality of life

	QOL Mean±SD	F	P
No effect	59.99±4.84	12.000	<0.001**
Minimal effect	57.98±5.57		
Moderate effect	56.21±4.19		
High effect	53.66±5.33		

QOL, quality of life. **P value less than or equal to 0.001 indicates statistically highly significant difference.

Table 5 Correlation between type of adverse effect and total quality of life scale

	r	P
Cognitive	−0.560	<0.001**
Motor	−0.398	<0.001**
Behavioral	−0.442	<0.001**
General neurological	−0.523	<0.001**
Weight gain	−0.474	<0.001**

**P value less than or equal to 0.001 indicates statistically highly significant difference.

Table 6 Multivariate analysis for predictors of poor self-reported quality of life

Variables	Odds ratio	Confidence interval	P
Mother education (illiterate)	2.428	0.406–14.527	0.331
Frequency (increasing)	0.43	0.278–0.665	<0.001**
Drug type (old and combined)	4.183	1.395–12.542	0.011*
Age group (older)	3.398	1.181–9.779	0.023*
Duration (longer)	0.12	0.034–0428	0.001**
Seizure type (generalized)	12.44	3.206–48.272	<0.001**

*P value less than 0.05 indicates statistically significant difference.
**P value less than or equal to 0.001 indicates statistically highly significant difference.

QOL was studied previously in Egypt among AWE [7]. A more recent Egyptian study used the Arabic translation of the 23-item Pediatric QOL Generic Core Scales for patients, which is a parent scale, and included children aged 8–12 years [8]. The current study is unique in appraising both self-reported QOL and parents-evaluated patient QOL to compare their views with those of their parents. Moreover, the occurrence of adverse effects of antiepileptic medications in our patients and its effect on their QOL were assessed using the 19-item PESQ.

In this study, QOL was correlated to the main characteristics of the epilepsy, hypothesizing that the social and personal features of childhood-onset epilepsy vary concerning the type, severity, and possibly the duration of the disorder. Age inversely affected the overall QOL as the youngest age group had the highest QOL score. The lower QOL score in older adolescents can be attributed to perceived stigma and that they feel more embarrassed of their condition, and worry about social isolation. Similarly, Nadkarni et al.

[16] exhibited that older adolescents had a poorer HRQOL. Nonsignificant difference was observed with respect to sex. Stevanovic [17] also stated that total HRQOL scores were equivalent between boys and girls. Adolescents with higher maternal education had the highest QOL score thanks to better care, understanding of the disease pattern, and keeping on

regular therapy, and generally the level of education and better employment status are usually associated with increased awareness of the public toward epilepsy. This finding is parallel to that reported by different studies [8,18,19]. On the contrary, a previous study reported lower self-esteem scores and lower QOL in adolescents with higher educated mothers than those of the children with illiterate mothers, and they postulated that this occurs owing to the higher expectations of the educated mothers from their adolescents, which led them to perceive the QOL of their AWE more negatively [20].

Overall QOL was significantly compromised in patients of generalized epilepsy. They had poor QOL in social relationships and ability to work, as a result, generalized epilepsy is less well accepted in our community. This finding is in harmony with that conveyed by Adla *et al.* [21] and Monir *et al.* [9]. This contradicts that reported by Aggarwal *et al.* [20] who stated poorer overall QOL in patients with partial seizures. They speculated that this result may be skewed owing to small number of patients with generalized epilepsy compared with partial epilepsy in their sample.

QOL is also related to seizure frequency. The current study denoted that the lesser the seizure frequency, the better the self-reported QOL, especially those related to physical, social, and psychological variables. Similar results were conveyed by Siqueira *et al.* [22] in Brazilian AWE. Their patients reported good QOL scores when they themselves perceived the disease as under control. Similarly, the higher the seizure frequency, the lower the QOL scores. Viteva [23] proved that the QOL is sensitive to differences in seizure frequency. These results are also consistent with previous reports [24–26].

AWE perceive stigma as a result of epilepsy, and this has significant effect on their QOL and social relations. Many adolescents experience bullying, being talked about, and laughed at. They were conscious of being treated differently from other siblings and peers by both parents and teachers. AWE also experienced overprotectiveness that leads to restriction of their daily activities. AWE may perceive this act as prejudice [27,28].

The effect of epilepsy on cognitive functioning was reported by adolescents in the present study as well as other ones [28,29]. This comprised compromised attention/concentration, slower thinking rapidity with intellectual slow down, muddled speech, and word finding difficulty.

For adolescents, the cognitive effects of having epilepsy and its effect on school and examination attendance could affect educational performance, with poor academic achievement. Our results are in harmony with those of Wo *et al.* [27]. For AWE, there may be little motivation to accomplish educational qualifications, as they might think that no-one would employ them [30].

Self-evaluation of adolescents' QOL was compared with their parents' opinions about QOL. Parents' perception of adolescents' suffering owing to epilepsy was significantly correlated to the adolescents' attitudes toward epilepsy. This agrees with Haneef *et al.* [31] but not with others [32–34].

This study also concentrated on the parental reaction towards that their child has epilepsy, they may feel stigmatizing towards that. It is going to be affected for years by a disease loaded with 'stigma'. Moreover, the cost of disease (e.g. the need for relatively expensive long-term AEDs and possibly symptomatic therapy for potential adverse effects, the need for special diet, and frequent specialist visits) increases economic burden on the family. This increases parental anxiety and eventually leads to deterioration of family's QOL.

The present study appraised the association between the occurrence of the adverse effects of AEDs and the QOL among AWE. Presence of adverse effects of AEDs is associated with lower QOL scores.

The present data go hand in hand with other studies [32–37] that demonstrated that AED-related adverse effects substantially influence the overall functioning and well-being in children and adolescents and significantly disturb the general aspects of the HRQOL in the physical, cognitive, and psychosocial domains. Patients of this study have reported certain physical effects of AEDs that were experienced independently of seizures, for example, fatigue, increased need for sleep, headache, dizziness, imbalance, and weight gain. Similar physical symptoms were reported in previous studies [29,38,39].

This is an important concern for clinical practice in deciding suitable actions to lessen the adverse effects of AEDs, such as reducing the dosage, altering the dosage schedule, or even changing its type. Thus, it may be possible to develop precise interventions for decreasing the burden of these adverse events while targeting specific areas like the social and school functioning [40]. According to our results, patients with older age, longer disease duration, generalized seizures, high

seizure frequency, and using old or combined AEDs regimen are the main risk factors for impaired HRQOL. Additional risk factors were reported by Nagarathnam *et al.* [41] who reported that education and polytherapy were significant predictors of poor QOL. Generally speaking, treatment with AEDs may improves aspects of the patients' lives associated with the concept of physical effects with better seizure control, which may lead to a long-term benefit in terms of educational qualifications as the patient become more regular at school attendance with lower days of absence. However, there are some aspects of the patients' lives that are unlikely to be improved with current AED treatments, for example, self-esteem and stigma. These usually need an alternative interventional approach involving both the whole society as well as epileptic individuals. Raising public awareness toward epilepsy as long as application psychotherapy and psychoeducation to epileptic patientscan improve their outcome [42]. In recent years, the goal of epilepsy treatment has been not only control of seizures but also improvement of QOL. However, special attention should be given for adolescence age group as adolescence is a transitional stage of physical and mental development and may have a great influence in the life stages of life.

Conclusions

Diminished QOL is a common feature of epilepsy. Epileptic patients had lower mean scores of all domains of QOL, especially those with older age, higher disease duration, generalized fits, high seizure frequency, and using old or combined antiepileptic regimen. The scope of management of epilepsy should include optimal seizure control and improvement of the HRQOL of the affected children.

Strengths and limitations of the study

This study has major strengths that include considering both adolescents and parents as raters, including different seizures types, and studying various variables influencing the QOL issues including AEDs adverse effects. The study had some limitations. The number of patients was small, as it is applied in a single center. We did not compare QOL of epileptic adolescents with those of healthy age-matched controls, as we have used disease-specific questionnaire that could not be applied to healthy individuals.

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