Evaluation of the quality of life related to health in adolescent patients with epilepsy through the application of the scale quality of life impact in epilepsy adolescents

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Abstract

Introduction: Epilepsy is a chronic disease that affects the quality of life (QoL) of adolescent patients. The objective of the study was to determine the QoL related to health in adolescent patients with epilepsy treated at the Federico Gómez Children's Hospital of Mexico using the QoL impact in epilepsy adolescents (QOLIE-AD-48) scale application. **Materials and methods:** An observational, descriptive, and transversal study was carried out. Adolescent patients with a diagnosis of epilepsy and specific characteristics obtained by non-random convenience were evaluated. A questionnaire with socio-demographic data and the QOLIE-AD-48 questionnaire were applied. **Results:** We obtained 35 participants, 51.5% male, with an average age of 14.2 years $\pm$ 1.4 (standard deviation), the average duration of 4.7 years. Regarding schooling, 13% of participants have failed a grade level. About 11.4% do not attend school. Epileptic seizures were classified as focal (71.4%) and generalized (28.6%). The largest number of cases was in monotherapy in 68.6%, and the most common drugs are valproic acid (39.4%) and levetiracetam (27.3%). The QOLIE-AD-48 score was 65.20. The most affected domains, according to gender were: attitude toward epilepsy and physical functioning, for female and male, respectively. Overall, the lowest scores are attitudes toward epilepsy and health perception. **Conclusions:** Despite adequate control of seizures, the QoL related to the health of adolescents with epilepsy is regular. This suggests that not only the crisis and the number of them influence the external environment of adolescents but also that other factors can be included in the overall well-being.

Key words: Quality of life related to health. Epilepsy. Adolescence. Quality of life.

Introduction

Epilepsy is a non-communicable chronic disorder which affects people of all ages. Worldwide, calculations suggest that 1.5-2% of teenagers have epilepsy¹. It is important to mention that epilepsy during adolescence requires special attention, since its diagnosis triggers psychological and social problems, giving rise to significant changes

in the life of the individual and his/her family, resulting in a decrease in quality of life (QoL)^{2,3}.

The World Health Organization defines the concept of QoL as "the perception of an individual of his condition in life, culturally and the value system in which the individual lives, regarding their goals, objectives, expectations, values, and concerns"^{4,5}. In addition, health-related

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QoL (HRQoL) is a multidimensional construct which describes physical, psychological, and social well-being. It focuses on the satisfaction or happiness of an individual, and the way these aspects are affected by illness. HRQoL can be affected by the presence of an illness, especially a chronic one, such as with epilepsy, due to the implications inherent to this disease⁵. While the prognosis can be estimated through the information provided by close relatives, as well as clinical observation, the use of specific scales to measure QoL indicators becomes necessary, hence giving the potential impact of chronic diseases objectivity, specifically epilepsy.

There have been several studies linked to QoL in different countries, using standardized scales and which are generally adapted to a specific disease and other factors, such as the patient's age and local circumstances.

The first QoL scales in epilepsy were mainly oriented toward assessing functional and physical parameters; subsequently, other characteristics were added, such as psychological and social variables. One of the first ones to be implemented was the QoL in Childhood Epilepsy Questionnaire. In the following years, a variety of instruments began to emerge, created with the sole intention of measuring variables at different levels, beyond physical status. Among them, we can mention the impact of pediatric epilepsy scale elaborated in Canada⁶, and the QoL impact in epilepsy adolescents (QOLIE-AD-48)⁵.

The introduction of these instruments is not only limited to the research of therapeutic clinical trials but it also helps in the creation of decision-making models which help us solve problems specific to this population, such as health cost problems and allocation of resources⁴.

In Mexico, there is a limited if not non-existent number of articles regarding QoL in patients with epilepsy. While in prior years, Lopez-Rojas et al.⁷ conducted a study using the QOLIE-31 questionnaire in a third-level hospital for the evaluation of QoL in pediatric patients of a similar age group, it is necessary to stress the fact that said instrument is only recommended for adults (18 and older) with epilepsy⁸. Therefore, there is a need to expand the analysis through an upgrade of the QOLIE-AD-48, designed specifically for adolescents⁵.

The objective of this study was to determine the QoL linked to health in adolescent patients with epilepsy who were treated at the "Federico Gómez" Children's Hospital of Mexico through the application of the QOLIE-AD-48; additionally, and if possible, to determine the socio-demographic characteristics of this population and their influence over this disease.

Materials and methods

Design of the study and sample

An observational, prospective, longitudinal study was conducted from January 1, 2016, to May 31, 2016. The use of a population by convenience was determined, including patients who attended the Neurology Outpatient Clinic of the "Federico Gómez" Children's Hospital of Mexico, which is a third-level government hospital unit located in Mexico City. Hence, it has a high volume of patients coming from all over the country. For practicality, epileptic crises are classified based on the International League against Epilepsy (ILAE) from 1981 as focal and generalized.

The study included both male and female patients, between the ages of 12 and 17 years and 11 months, integrated into society, capable of reading Spanish, and with a documented diagnosis of active epilepsy (at least one seizure in the past 6 months), from any etiology. Moreover, for this study, patients with intellectual impairment were excluded, as well as patients with psychotic pictures, as well as those who had undergone brain surgery in the last year and other chronic concomitant diseases which directly affected QoL (i.e., alcoholism, drug abuse, chronic renal failure)

Data recollection technique

Socio-demographic data were obtained, such as gender, age, time of diagnosis, evolution time of the disease and its etiological cause, type of epilepsy, and therapy employed. Data collection was performed manually, daily, with a subsequent review of the proper filling out of each of the instruments, and finally, electronically captured in a spreadsheet using Microsoft Office 2016™.

After initial assessment and data recollection, the QOLIE-AD-48 questionnaire was conducted. It is worth noting that the Spanish version of this questionnaire is an individual, self-applicable instrument previously validated by Benavente-Aguilar et al.^{9,10} In addition, just as in the original version, it has proven to have trustworthy psychometric properties and validity.

The questionnaire has 48 individual questions in eight domains distributed into different sections, which are evaluated as follows:

1. Impact of the epilepsy – 12 items (questions 25-27, 29-34, 36, 47, and 48)
2. Memory and concentration – 10 items (questions 8, 12-20)
3. Attitude toward epilepsy – 4 items (questions 43-46)

4. Physical functioning – 5 items (questions 3-7)
5. Stigma – 6 items (questions 37-42)
6. Social support – 4 items (questions 21-24)
7. Behavior at school – 4 items (questions 9-11 and 27)
8. Perception of health – 3 items (questions 1, 2, and 35).

The score obtained in the questionnaire is converted to a scale from 0 to 100 points, with the help of tables and mathematical operations previously designed for this questionnaire. The sum of the scores in each area provides the global score, which indirectly reflects the patient's QoL. High scores always indicate a better QoL. The values for these points are divided as follows:

- 91-100: excellent QoL.
- 81-90: very good QoL.
- 71-80: good QoL.
- 61-70: a regular QoL.
- Less or equal to 60: bad QoL.

Statistical analysis

The data obtained were analyzed using Microsoft's Excel™, from Microsoft Office 2016™, using descriptive statistics for the exposition of demographic data. The results obtained are shown in means and standard deviation (SD) when the variables are quantitative, and in percentages when qualitative.

Results

A total of 35 patients with a documented diagnosis of epilepsy were obtained. The average age was 14.2 ± 1.4 (SD) years, with a fairly equal gender distribution, yet with a slight male predominance (51.5%). The average age for the onset of epilepsy was 8.9 ± 4.6 (SD) years old, with an average evolution of the disease of 4.7 ($\pm$ SD) years. Additional socio-demographic data are listed in Table 1.

Factors linked to alterations of QoL

When evaluating the level of education, 88.6% of the participants had some formal education, and only 4 participants were found to be without any educational background. Moreover, from the 31 patients who attended school, 13% had failed or missed a school year, all of them male. Out of this group of patients with failed school years, 50% presented at least one seizure a day, 75% were found to be in management with polypharmacy, mainly with valproic acid and topiramate. The rest of the data is shown in table 2.

Focal epileptic seizures occurred in 71.4% of the participants. There was a predominance of focal seizures secondarily generalized (44%). On the other hand, 40% of the cases corresponded to a focal crisis with alteration in alertness, and only 16% were considered simple focal seizures. In general seizures, half of the cases were tonic-clonic.

The distribution according to the etiology of epilepsy within the group was as follows: About 48.6% symptomatic (17 cases), followed by idiopathic causes with 34.3%, and cryptogenic causes, which only represented 17.1%. Complete results of the symptomatic causes are close to the MRI reports, where findings showed that 13 of the participants in this study (37.1%) had alterations.

Most patients (63%) reported one or zero seizures a year. For the rest of the participants, patterns went from 1 seizure per month (17.1%) to 1 seizure per day (11.4%) and 1 seizure per week (8.6%). Reports show that females had better control over their seizures (70.6% with ≤ 1 seizure/year), while in males the pattern was ≤ 1 seizure/year in 55.5%.

Regarding received antiepileptic pharmacotherapy, findings show that the majority of patients were being treated through a regime based on monotherapy (68.6%). Among the 33 participants, the most prominent pharmaceutical was valproic acid with 39.4% followed by levetiracetam with 27.3%. It is important to note that these numbers were only determined by the frequency with which the pharmaceutical was registered in the current treatment of the patient according to the recollection sheet; however, medication combinations are not described in this paper, nor is their effectiveness.

Subscales linked to the QoL of the adolescent patient with epilepsy

Once we applied the QOLIE-AD-48 scale, we were able to obtain an average of the subscales/domains of 63.38. The affection is more significant in females, with a score of 60.91, versus that reported in males, which were 65.76.

The predominant domains for each gender significantly differ from one another. The areas with the best score for females were the impact of epilepsy and behavior at school. On the other hand, in males, the areas of social stigma and social support stand out (Fig. 1).

Discussion

In this study, demographic factors linked to the QoL in adolescent patients with an epilepsy diagnosis were

Table 1. Demographic characteristics of the population. Value of significance 0.5

No.	Sexo	Age *	Diagnostic age *	ILAE 1981 classification	Etiology	Frequency	Therapy/drug	Schooling level	Failed a year	Therapy	Sleep disorder	EEG	RMN
1	F	12	10	CPS	Symptomatic	1/7	OXC	P	N	N	Y	Normal	Anormal
2	F	14	11	TC	Cryptogenic	1/30	OXC	S	N	N	N	Normal	Normal
3	F	13	1	GSPC	Symptomatic	< 1/365	TPM	S	N	N	N	Act. Epileptic	Anormal
4	F	16	10	GSPC	Idiopathic	1/365	LVT	B	N	N	N	Act. Epileptic	Normal
5	F	15	13	CPS	Symptomatic	1/30	LVT	S	N	N	N	Act. Epileptic	Normal
6	F	15	3	Tonic	Symptomatic	< 1/365	LVT	P	N	N	N	Normal	Normal
7	M	15	12	CPSG	Idiopathic	< 1/365	AVP	P	N	N	N	Normal	Normal
8	F	15	14	TC	Symptomatic	< 1/365	LVT	S	N	N	N	Act. Epileptic	Normal
9	M	16	14	GSPC	Cryptogenic	1/365	CBZ	B	N	N	N	Act. Epileptic	Normal
10	M	12	1	Absences	Idiopathic	1/30	VPA	P	Y	Y	N	Normal	Normal
11	M	15	13	TC	Provocada	< 1/365	VPA	B	N	N	N	Act. Epileptic	Normal
12	M	16	11	TC	Symptomatic	< 1/365	None	B	N	N	N	Normal	Normal
13	M	17	10	CPC	Cryptogenic	1/1	MVP + VPA + OXC	S	Y	N	N	Act. Epileptic	Anormal
14	M	12	0.1	CPC	Symptomatic	1/30	VPA	S	N	N	Y	Normal	Normal
15	F	16	4	GSPC	Symptomatic	< 1/365	VPA + LMT	B	N	N	N	Act. Epileptic	Anormal
16	M	14	12	GSPC	Symptomatic	< 1/365	VPA	S	N	N	N	Act. Epileptic	Anormal
17	F	13	12	CPC	Idiopathic	1/30	LVT + OXC	S	N	N	N	Act. Epileptic	Normal
18	F	16	3	CPC	Symptomatic	1/7	MVP + VPA	S	N	N	N	Act. Epileptic	Anormal
19	F	14	12	CPC	Idiopathic	< 1/365	LVT	S	N	Y	N	Normal	Normal
20	M	15	12	CPC	Symptomatic	1/365	VPA	S	N	N	N	Act. Epileptic	Anormal
21	M	15	6	CPC	Idiopathic	1/1	VPA + MVP	P	N	N	N	Normal	Normal
22	M	14	12	CPS	Idiopathic	1/1	LVT + CNZ	S	N	N	N	Normal	Normal

(Continues)

Table 1. Demographic characteristics of the population (*Continued*)

No.	Sexo	Age *	Diagnostic age *	ILAE 1981 classification	Etiology	Frequency	Therapy/drug	Schooling level	Failed a year	Therapy	Sleep disorder	EEG	RMN
23	F	13	3	CPC	Symptomatic	< 1/365	VPA	S	N	Y	N	Act. Epileptic	Anormal
24	F	14	13	GSPC	Symptomatic	< 1/365	VPA + LVT	S	N	Y	N	Normal	Anormal
25	M	14	3	Atonic	Cryptogenic	1/1	LVT + MVP + PRM	P	Y	Y	Y	Act. Epileptic	Normal
26	F	15	10	CPC	Symptomatic	1/365	VPM	B	N	N	N	Act. Epileptic	Anormal
27	M	15	14	TC	Symptomatic	< 1/365	LVT	S	N	N	N	Act. Epileptic	Anormal
28	F	17	16	Tonic	Symptomatic	< 1/365	None	B	N	N	N	Normal	Normal
29	M	12	0.4	GSPC	Cryptogenic	1/7	TPM + OXC	P	Y	N	Y	Act. Epileptic	Normal
30	M	13	11	GSPC	Symptomatic	< 1/365	VPM	S	N	Y	N	Act. Epileptic	Anormal
31	M	15	11	CPC	Idiopathic	1/30	CBZ	S	N	N	N	Normal	Normal
32	F	12	5	GSPC	Cryptogenic	< 1/365	CBZ	P	N	N	N	Normal	Normal
33	M	12	11	Tonic	Idiopathic	1/365	CBZ	S	N	N	N	Normal	Normal
34	M	12	11	CPS	Idiopathic	< 1/365	OXC	P	N	N	Y	Act. Epileptic	Normal
35	F	14	10	CPC	Idiopathic	< 1/365	MVP	S	N	N	N	Normal	Normal

SPC: simple partial crisis; TC: tonic-clonic; GSPC: generalized simple partial crisis; CPC: complex partial crisis; OXC: oxcarbazepine; TPM: topiramate; LVT: levetiracetam; VPA: valproic acid; CBZ: carbamazepine; LMT: lamotrigine; CNZ: clonazepam; PRM: primidone; MVP: magnesium valproate; P: primary; S: secondary; B: bachelor's, Y: yes; N: no; ILAE: International League against Epilepsy.

Table 2. Clinical characterization of adolescents diagnosed with epilepsy

Variable	Total (n = 35)	Men (n = 18)	Women (n = 17)
Age (average $\pm$ SD)	14.2 $\pm$ 1.4 (years)	14.11 $\pm$ 1.60 (years)	14.35 $\pm$ 1.32 (years)
Diagnostic age (average $\pm$ SD)	8.98 $\pm$ 4.63 (years)	9.14 $\pm$ 4.76 (years)	8.82 $\pm$ 4.63 (years)
Time of evolution	5.24 $\pm$ 4.27 (years)	4.97 $\pm$ 4.09 (years)	5.53 $\pm$ 4.55 (years)
Scholastics			
Primary	7 (20%)	5 (71.43%)	2 (28.57%)
Secondary	17 (48.57%)	7 (41.18%)	10 (58.82%)
Middle-high school	7 (20%)	3 (42.86%)	4 (57.14%)
No formal education	4 (11.43%)	3 (75%)	1 (25%)
Etiology			
Symptomatic	16 (45.72%)	7 (43.75%)	9 (56.25%)
Cryptogenic	6 (17.14%)	4 (66.67%)	2 (33.33%)
Idiopathic	12 (34.28%)	6 (50%)	6 (50%)
Provoked	1 (2.86%)	1 (100%)	0 (0%)
Crisis type			
Focal epileptic seizures	25 (71.43%)	10 (40%)	15 (60%)
Simple partials	4 (11.43%)	2 (50%)	2 (50%)
Partially generalized partial	11 (31.43%)	4 (36.36%)	7 (63.64%)
Complex partials	10 (28.57%)	4 (40%)	6 (60%)
Generalized seizures	10 (28.57%)	8 (80%)	2 (20%)
Tonic-clonic	5 (14.28%)	4 (80%)	1 (20%)
Tonic	3 (8.57%)	2 (66.67%)	1 (33.33%)
Atonic	1 (2.86%)	1 (100%)	0
Absence	1 (2.86%)	1 (100%)	0
Seizure frequency			
< Once a month	22 (62.86%)	10 (45.45%)	12 (54.55%)
$\geq$ Once a month	13 (37.14%)	8 (61.54%)	5 (38.46%)
Number of antiepileptic drugs			
Monotherapy	24	12 (50%)	12 (50%)
Polytherapy	9	5 (55.56%)	4 (45.44%)
No treatment	2	1 (50%)	1 (50%)
Drugs used			
Oxcarbazepine	6 (17.14%)	3 (50%)	3 (50%)
Levetiracetam	10 (28.57%)	3 (30%)	7 (70%)
Topiramate	6 (17.14%)	4 (66.66%)	2 (33.34%)
Valproic acid	10 (28.57%)	6 (60%)	4 (40%)
Magnesium valproate	3 (8.57%)	1 (33.34%)	2 (66.66%)
Carbamazepine	4 (11.43%)	3 (75%)	1 (25%)
Primidone	1 (2.85%)	1 (100%)	0
Clonazepam	1 (2.85%)	1 (100%)	0
Lamotrigine	1 (2.85%)	0	1 (100%)

analyzed, obtaining similar results to previous studies through the QoLIE-48 questionnaire (Table 3)¹¹⁻²⁰.

A male predominance was found¹¹⁻²⁰. However, females were reported as more susceptible to the psychosocial strains caused by the disease. Thus, females suffered greater auto-anxiety, lower self-happiness, and more negative attitudes toward their condition compared to males²¹. This concurs with the data documented through the “Latin American Epilepsy Report,” where the need to give women with epilepsy proper holistic medical attention were reported, one that goes beyond simple control of seizures^{22,23}.

In a study conducted by Devinsky et al.²¹ into factors of an incorrect prognosis of HRQL in adolescents with epilepsy, the areas which were significantly affected were the attitude toward epilepsy and perception of health, creating a worse HRQL. Similarly, Austin et al.²⁴ found more problems in the QoL among females compared to adolescent males. These problems included anxiety, unhappiness, attitude, poor relationships with their classmates, and social problems.

Our results concur with the description above since when we make a distinction between genders for each of the domains, the lower observed scores for this

Figure 1. Comparative graph between both sexes for the results obtained from the application of the quality of life impact in epilepsy – 48 Spanish version questionnaires.

group are specifically those domains previously mentioned. Moreover, 50% of the participants had both areas affected during evaluation²⁵.

Although age did not have a significant correlation with QoL in epilepsy, it is important to remember that adolescence is characterized by being a stage of transition involving different conducts which may interfere in the proper management of the disease²⁶. Previous epidemiologic data have proven that the age of onset of epilepsy can have a significant association with the QoL of the patients, because early onset epilepsy can lead to a significant delay in development as a consequence of the presence of frequent seizures during the formative years, or as a result of the adverse effects of medication during times of social and cognitive development²⁷.

Within this study, 13% of the analyzed population had to miss some portion of the school year; this could be linked to the presence of learning disorders. It is worth noting that according to Jackson et al.²⁸, academic problems are evident in up to 50% of epilepsy cases.

Different types of learning problems in children with epilepsy are described in the literature, not only as a consequence of failure in the cognitive sphere but also secondary to lack of attention, memory or language disorders, to name a few²⁹. Battistini et al.³⁰ found a greater incidence of disorders specific to learning in 87% of the cases of patients with epilepsy.

Regarding the “frequency of seizures” factor, there is evidence of a decrease in cognitive capacity parallel to

an increase in the frequency of the events. Moreover, it has an accumulative adverse effect³¹. Similarly, the effects of pharmaceuticals, already noted by Lennox³², on cognitive functions, have been the object of numerous studies in the past 30 years. These effects depend on the medication, the dosage, and associations with other medications (polytherapy). In addition, not only can it generate learning disorders but also school absence and emotional disorders, among other things^{33,34}.

The clinical presentation of epilepsy is another important factor. About 75% of the participants of this study presented seizures with focal characteristics; these being results similar to those obtained in studies of the QoL of adolescents in different countries^{35,36}.

Even though the ILAE-1981 criteria were used, epidemiological data inherent to epileptic seizures is discordant concerning previous publications. There are evident differences concerning the etiology of our study. Almost half of the participants began with seizures of a symptomatic etiology without presenting differences according to gender. Available studies show the influence of the etiology in the prognosis of epilepsy³⁷; this association is evident concerning seizures symptomatic to neurological alterations or birth defects, not so much when other causes of symptomatic seizures are taken into consideration.

Complete control of seizures has been considered as one of the main determinants in QoL; however, the absence of seizures, or a reduction, must not be sought for at all costs, especially when the adverse effects of

Table 3. Comparison of the results obtained for the quality of life of adolescents with epilepsy in different countries among the population using the QOLIE-AD-48 questionnaire

Variable study	López-Sánchez et al. Mexico, 2018 (n = 35)	Siqueira et al. ¹⁴ Brazil, 2014 (n = 50)	Zamani et al. ¹⁵ Iran, 2014 (n = 197)	Wu et al. ¹² China, 2010 (n = 47)	Wang et al. ²⁰ China, 2009 (n = 99)	Barbosa et al. ¹⁹ Brazil, 2008 (n = 93)	Stenovanovic et al. ¹⁷ Serbia, 2005 (n = 67)	Benavente et al. ⁹ Spain, 2004 (n = 66)	Benavente et al. ¹⁰ Spain, 2002 (n = 54)	Cramer et al. ²⁵ United Kingdom, 1999 (n = 97)
Impact of epilepsy	70.25	75.29	68.9	70.1	70.9	74.4	83.2	92.3	91.2	70.6
Memory/ concentration	64.2	66.60	65.1	66.1	74.4	69.6	78	76	75.2	67.6
Attitude towards epilepsy	53.3	35.00	22.56	69.2	24.1	39.3	75.4	35.6	34.1	39.8
Physical functioning	53.7	85.20	70.37	67.1	81	76.1	90	94.8	94.0	63.6
Stigma	70.3	64.69	52.55	62.9	62.1	74.7	82.2	86	87.3	71.3
Social support	69.8	86.12	56.11	33.2	69.8	81.5	75.7	81	81.4	72.4
School behavior	70.3	84.37	83.85	86.3	90.7	83.3	91.3	92	91.5	90.3
Perception of health	55.2	67.16	61.67	52.8	58.9	69.2	79.6	66.9	62.5	65.8
Total	63.38	70.55	60.14	65.6	66.49	69.9	81.9	78.075	79	67.67

QOLIE-AD-48: quality of life impact in epilepsy adolescents.

the utilized medications are more present in comparison to those of the subjacent illness^{38,39}.

In our study, reports show that approximately a third of the participants are found to be under a polytherapy regime; nevertheless, only 22.2% presented an adequate control of convulsive events. On the contrary, participants with monotherapy had proper control of their seizures in 75% of cases. This may come as a result of the fact that monotherapy facilitates adherence to treatment⁴⁰.

Memory and learning

Most children and adolescents (70%) report problems with memory and/or other learning aspects. Young people do not feel physically or mentally capable of learning. Therefore, continuous learning is essential. Seizures and postictal periods often produce transitory memory problems. Some patients comment that a short seizure, in the context of a school day, would erase their memory for the day⁴¹.

Attitude toward epilepsy

This domain appears in all studies as the area with the lowest score; similar data were obtained in the studied sample. Despite this, the result is above the studies by Benavente-Aguilar (35.6 and 34.7, respectively)^{9,10}, Cramer et al. (39.8)²⁵, Barbosa et al. (39.8)¹⁹, Zamani et al. (22.5)¹⁶, and Wang et al. (24.1)²⁰. The low scores of this domain may reflect the poor understanding of seizures and/or epilepsy, which could significantly affect HRQoL perception and daily functioning⁹. Therefore, the most positive attitudes can be generated by a better understanding of the disease.

Physical functioning

In this study, the physical functioning domain, defined by activities such as playing, exercise and domestic chores, was scored within parameters in 76.3% of participants, with a score of 67.57, data only compared to those results obtained by Cramer et al.²⁵ (63.6); the rest of the reports have better scores. It is worth noting that in this domain, females were the most affected.

Stigma

The stigma linked to epilepsy is common, though it varies between cultures. At present, studies worldwide show improvement in public attitudes toward epilepsy,

yet “old ideas” remain an influence in popular concepts of epilepsy, which results in continuous errors of perception and negative attitudes⁴¹. These negative attitudes may generate low self-esteem, alterations in independence, bad relationships, anxiety, depression, and difficulty in education and business, as well as social discrimination in people with epilepsy who experience the stigma due to their base diagnosis^{21,42}.

The studied population showed that only 23% of participants had a low score for this domain, yet, in comparison to the rest of the domains, it remained above average. In the literature, most analyzed studies show adequate scores for this subscale, the lowest scores being from China and Iran^{12,15,16,20}. Previous data indicated that there was a considerable cultural variation between our country and the rest of the world.

Stigma and discrimination are linked to a loss of identity and the threat imposed by the inability to perform normally in social roles³⁹. Ethnographic studies of local communities in China also found that people with epilepsy are considered of low social value, and thus face significant rejection¹².

Social support

Social support refers to the exchanges of emotional and instrumental resources between an individual and his/her social environment, destined to improve the individual's health. It can also be conceived as a resource which contributes to improving a patient's QoL⁴².

The average score for this subscale in our study was 69.8, a score below most countries, yet higher than those of China and Iran^{12,15,16}. This variation in results is caused mainly due to cultural traits; an example of these is Asian countries, where patients with epilepsy are described as the target of prejudicial behavior⁶. In China, as in most developing countries, predominant cultural attitudes stigmatize people with epilepsy^{12,40}. In a study conducted by Elliott et al.⁴¹ in Toronto, children, and adolescents with refractory epilepsy discuss aspects related to the quality and quantity of their social interactions with their relatives and friends.

Behavior at school

This subscale presented an average of 70.35, which within the domains remain in an intermediate position; however, it is one of the domains with the highest percentage of affected participants (53%). When comparing this score with other countries, our population falls under the rest. The highest scores were obtained in a

study conducted by Stevanovic^{17,18} in Serbia (93.57 and 91.3, respectively).

Perception of health

This area is characterized by being one of the lowest scores compared to the rest of the subscales; moreover, when compared to results from other countries, where the scores were between 61.67 and 81.42; we can observe that it remains an adjacent score. Females predominate this area with partial control of seizures.

Conclusions

Based on the application of the QOLIE-AD-48 questionnaire, it was concluded that, despite adequate control of crises, HRQoL in patients between 12 and 17 years of age is regular. This suggests that it is not only the seizures and the number of them that affect the external environment of adolescents but also that there are other factors which may modify the patient's integral well-being.

We were able to observe that, within the female group, the specific areas of "perception of health" and "impact of epilepsy" are usually the most affected. On the contrary, in males, we were able to observe that the domains "physical functioning" and "perception of health" are those which contribute most to the alterations in their QoL and, subsequently, in their "behavior at school."

This makes us continue with the constant effort against stigmatization of patients with epilepsy, which as we can see in both areas "social support" and "social behavior" are directly influenced, and this determinately affects the evolution of our patients in the alterations in their social and gathering circles, which in many occasions forces them to perform different activities to those of a child without epilepsy, or in some cases they are treated differently during the same school activities. Great communication is necessary not only with the patient but with the most influenceable people in their surroundings so that he/she can reinforce trust, lower anxiety levels and develop a life with normal characteristics.

Ethical disclosures

Protection of human and animal subjects. The authors declare that the procedures followed were in accordance with the regulations of the relevant clinical

research ethics committee and with those of the Code of Ethics of the World Medical Association (Declaration of Helsinki).

Confidentiality of data. The authors declare that they have followed the protocols of their work center on the publication of patient data.

Right to privacy and informed consent. The authors have obtained the written informed consent of the patients or subjects mentioned in the article. The corresponding author is in possession of this document.

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