



The perceived burden of epilepsy: Impact on the quality of life of children and adolescents and their families



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ABSTRACT

Purpose: The assessment of the quality of life (QoL) is relevant for a comprehensive treatment of patients with epilepsy. In children and adolescents, an impact of epilepsy on the QoL of the entire family is expected.

Methods: We asked 293 parents of children and adolescents with epilepsy, included in an observational study on treatment satisfaction, to evaluate the impact of the disease on several aspects of the QoL of the whole family using a specifically organized questionnaire (IEQoL).

Results: The degree of parents' concerns about epilepsy and the severity of the disease correlated with a deterioration of QoL in both the children and the family. This involved all aspects of QoL (conflicts within the family, job, leisure activities, peer relationship, economy) although to a different degree. Parents frequently admitted increased apprehensiveness, even when not justified by the low severity of the disease. There was general agreement between parents and their adolescent children, although in a few cases adolescents overrated their school and daily performance in respect to the parents, suggesting a tendency to overlook their problems.

Conclusion: Epilepsy impairs all aspects of QoL, although at different degree, both in children/adolescents and in their families. Parental apprehensiveness appears to have a role on this, and it may not reflect the severity of the disease.

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1. Introduction

The management of epilepsy encompasses a number of actions that go beyond seizure control without adverse treatment effects. These include psychological and social interventions to help affected individuals to live a normal life and minimize the effects of the disease and its treatment on the various aspects of daily living.

Therefore, assessment of quality of life (QoL) should be part of the clinical evaluation by epileptologists wishing to offer a more comprehensive treatment to their patients.

In the case of epilepsy affecting children and adolescents, a relevant impact of the disease on the QoL of the entire family is to be expected. 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. In this respect, the impact of epilepsy on the family's QoL has been marginally investigated.^{1–6} Moreover, most studies and questionnaires explore specific elements rather than the more general aspects of daily life, leading to a fragmentation of data with less emphasis on the main difficulties caused by the disorder.

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The aim of the present study was to evaluate the impact of the epileptic condition on the QoL of children/adolescents and their families. Using an ad-hoc questionnaire, we asked the parents of children with epilepsy to indicate any change in the QoL, temporally associated with the disorder. We correlated QoL to the main characteristics of the epilepsy, hypothesizing that the social and personal effects of childhood-onset epilepsy differ in relation to the type and severity and possibly the duration of the disorder. In addition, we asked older children and adolescents to respond to a self-report questionnaire in order to compare their views with those of their parents.

2. Materials and methods

2.1. Subjects

Patients were enrolled in the course of a multicenter, observational, open, prospective survey, with three months of follow up, aimed at the evaluation of their satisfaction with the assigned treatment.⁷ Twenty centers located in Northern, Central and Southern Italy were involved, selected on the basis of the geographical distribution to represent the nationwide clinical practice.

All patients were cared by epileptologists operating in each of the 20 centers. Inclusion criteria were age 3 through 17 years and definite diagnosis of epilepsy, i.e. two or more unprovoked seizures⁸ and the need to start or revise drug treatment. Patients with a stable clinical condition were excluded as not fulfilling the aims of the original study. The patients enrolled were divided in two groups: those who needed to start treatment (new diagnosis) and those requiring a treatment change (old diagnosis) due to lack of efficacy and/or adverse events (including poor acceptability). Epilepsy syndromes were stratified in two categories according to severity: low severity (benign focal and childhood absence epilepsy) and high severity (all other epilepsies).

Informed consent, including full understanding of the aims and the conduct of the study in writing, was obtained from the parents or legal representatives. The study protocol was approved by the Ethical Committees of all the participating centers.

2.2. Instruments

Data on the impact of epilepsy on QoL were collected using the self-report questionnaire IEQoL (Impact of the Epilepsy on the Quality of Life) (see [Appendix A](#)). The IEQoL is an instrument that primarily explores various aspects of the patient's and family's life and, secondarily, the degree of understanding of the information imparted by the physician. The form is organized as an interview given to parents which have to give their opinion on the variations of independent aspects of QoL, identifying the main problematic life-related aspects caused by the disorder. Therefore, it does not lead to one or more severity scores deriving from multiple items, each item giving a score only for the QoL aspect specifically examined.

The understanding of each question was firstly tested after submission of the form to 15 parents. Based on the results of the first test, items C2, C3 and E1 were reworded. The revised form was then submitted to 25 unrelated parents and met full understanding by more than 90% of interviewees.

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”. Older children and adolescents (11–17 years included, from now on referred to as “adolescents”), with good intellectual functioning responded to the questionnaire QOLIE-AD-48.⁹ The QOLIE-AD-48 is an instrument specifically developed to assess QoL in adolescents; it contains 48 items in eight subscales: epilepsy impact, memory/concentration, attitudes toward epilepsy, physical functioning, stigma, social support, school behavior, health perceptions, and a total score.

2.3. Data collection

A structured case record form (CRF) 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),¹⁰ seizure frequency, etiology of epilepsy, epilepsy syndrome,¹¹ and adverse events. In the newly diagnosed cases, the IEQoL was administered at the third month of follow-up.

All data recorded in the CRF were transferred into a password-protected computerized database located in the coordinating center (IRCCS-Istituto di Ricerche Farmacologiche “Mario Negri”, Milan).

The study had to be completed after enrollment of at least 300 eligible patients. The numbers were chosen based on empirical considerations (number of eligible cases seen during routine outpatient visits) as a power calculation was not applicable in this context.

2.4. Statistical analysis

Descriptive statistics are reported as counts and percentages. The Pearson's chi-square and the Spearman Rank correlation coefficient were used to compare categorical variables and ordinal variables respectively. Spearman's correlation was applied to the compound scores of domains “B”, “C” and “E”. These compound scores were built according to the sum of the score of each item within the domain. The perception about treatment administration and its effects (domains F1–F4) was not assessed here because it was not pertinent to the purposes of this study. Clinical variables that retained significance in the correlation with IEQoL were then plotted together with the outcome variable (Low/Mid/High QoL) according to the Multiple Correspondence Analysis (MCA). This analysis allows displaying in a Cartesian space the matching structure of the data, to identify clusters.¹² Missing data were handled using the list-wise deletion method. Due to the exploratory nature of the study, we did not adjust for multiple comparisons, but we decided to set significance at the 1% level. Data were analyzed using the Statistical Analysis System (SAS) package for PC (version 9.2).

3. Results

3.1. Population characteristics

Of the 324 patients enrolled (164 girls and 160 boys), 293 completed the 3-month follow-up. The general characteristics of the study population are shown in [Table 1](#). More than half of the patients were between 5 and 10 years and had a disease lasting <12 months. Idiopathic epilepsies (60.4%) prevailed, followed by cryptogenic (22.2%) and symptomatic epilepsies (15.0%). In the 177 patients with idiopathic epilepsy, seizure types were focal in 58, which included the benign epilepsies of childhood (mainly Rolandic epilepsy), and generalized in 113, of which 61 had childhood absence epilepsy, and 52 grand mal seizures and variants. In six patients seizure types were not classified.

Table 1

Demographic and clinical characteristics of the sample (n=293).

	Total n = 293	% 100.0	New diagnosis n = 178	% 60.8	Old diagnosis n = 115	% 39.2	New vs old p-values
Sex							
Females	150	51.2	93	52.3	57	49.6	0.6538
Males	143	48.8	85	47.7	58	50.4	
Age (years)							
3–4	46	15.7	28	15.7	18	15.7	0.9138
5–10	159	54.3	95	53.4	64	55.6	
11–17	88	30.0	55	30.9	33	28.7	
Etiology							
Idiopathic	177	60.4	121	68.0	56	48.7	<0.0001
Symptomatic ^a	44	15.0	15	8.4	29	25.2	
Cryptogenetic	65	22.2	36	20.2	29	25.2	
Unknown	7	2.4	6	3.4	1	0.0	
Seizure type							
Focal	141	48.1	83	46.6	58	50.4	0.6532
Generalized	139	47.4	88	49.4	51	44.3	
Unclassified	13	4.4	7	3.9	6	5.2	
Disease duration (months)							
≤12	159	54.3	134	75.2	25	21.7	<0.0001
13–24	31	10.6	17	9.6	14	12.2	
>24	102	34.9	27	15.3	75	65.2	
Seizure per month							
<1	123	42.0	88	49.4	35	30.4	0.0056
1–10	76	25.9	40	22.5	36	31.3	
10+ (including absences)	94	32.1	50	28.1	44	38.3	
10+ (without absences)	31	10.6	16	9.0	15	13.0	

^a 13 cerebral malformation, 6 neoplasm, 2 CNS infection, 1 cerebrovascular disease, 1 metabolic encephalopathy, 10 abnormal neurological examination (unknown cause), 5 perinatal encephalopathy, 4 tuberous sclerosis, 1 mesial temporal sclerosis, 1 not specified.

The sample included 178 patients with new diagnosis (60.8%), and 115 patients with old diagnosis (39.2%), the latter seen for treatment change due to lack of efficacy and/or adverse events and including a greater number of symptomatic epilepsies and a higher seizure frequency at study entry.

3.2. Variation in quality of life of families (parents and their children/adolescents with epilepsy) (Table 2)

a) *Parental reactions to the diagnosis* (Table 2B). Parental concerns were frequently reported though at different degree. Only a small minority of parents reported no concerns. Sorrow after the diagnosis, perception of the severity of the disease and worries

about the children's future were reported in moderate to high degree by about three-fourths of parents. Sorrow and worries ranked higher than the perception of severity. Further correlations to determine whether such concerns and perceptions were clinically justified indicate that sorrow about the diagnosis and worries about the offspring's future were not related to the severity of the disease ($p = 0.1859$ and $p = 0.1458$). At no surprise, the perception of epilepsy severity was greater with an old compared to a new diagnosis ($p = 0.0017$). Finally, the degree of parents' concern about epilepsy (domain B) was highly correlated ($p < 0.0001$) with worse QoL both in the family and in children (data not shown).

Table 2

Responses by parents to IEQoL questionnaire (n=293).

Domain	Question	High or a lot n(%)	Moderate n(%)	Mild n(%)	None n(%)
B	Attitude toward epilepsy				
	B1. Sorrow caused to you by the diagnosis	148 (50.7)	80 (27.4)	43 (14.7)	21 (7.2)
	B2. How severe you consider the disorder	42 (14.4)	180 (61.6)	48 (16.4)	22 (7.5)
	B3. Worries about son's future	122 (41.6)	99 (33.8)	61 (20.8)	11 (3.8)
C	Family: Change in QoL after onset of epilepsy				
	C1. Degree of change of family life	56 (19.1)	101 (34.5)	83 (28.3)	53 (18.1)
	C2. Increase of tension/conflicts in family	25 (8.5)	75 (25.6)	81 (27.7)	112 (38.2)
	C3. More parent's apprehensiveness	125 (42.7)	89 (30.4)	59 (20.1)	20 (6.8)
	C4. Worsening in parent's work	16 (5.5)	54 (18.4)	85 (29.0)	138 (47.1)
	C5. Worsening in parent's non-working activities	21 (7.2)	51 (17.4)	90 (30.7)	131 (44.7)
	C6. Worsening in parent's extra-family relationships	15 (5.1)	36 (12.3)	69 (23.6)	173 (59.0)
	C7. Economic problems caused by child's epilepsy	8 (2.7)	31 (10.6)	60 (20.5)	194 (66.2)
D	Family: general wellness				
	D2-D1. Deterioration of wellness	49 (16.8)	60 (20.5)	103 (35.3)	80 (27.4)
	D3. Degree of present wellness	59 (20.2)	85 (29.1)	106 (36.3)	42 (14.4)
	D3-D1. Deterioration of wellness (present)	11 (3.8)	35 (12.0)	112 (38.4)	134 (45.9)
E	Children QoL				
	E1. Child/adolescent suffers due to epilepsy	23 (7.9)	72 (24.6)	90 (30.7)	108 (36.9)
	E2. Epilepsy influenced school performance	40 (13.7)	53 (18.1)	72 (24.6)	128 (43.7)
	E3. Epilepsy reduced peer relationships	17 (5.8)	39 (13.3)	56 (19.1)	181 (61.8)
	E4. Epilepsy reduced extra-curricular activities	21 (7.2)	41 (14.0)	62 (21.2)	169 (57.7)

b) *Family's QoL after the onset of epilepsy* (Table 2C). No changes in family's life (C1) after onset of epilepsy was reported by only 53 parents (18.1%). In most of these cases (41, 77.4%) children were affected by idiopathic epilepsy. Mild changes were reported by 83 cases (28.3%), among which 52 (62.6%) had idiopathic epilepsy, while moderate to high changes by 157 cases (53.6%), among which 84 (53.5%) had idiopathic epilepsy. Compared to symptomatic/cryptogenic epilepsies, idiopathic epilepsies were associated with less deterioration of QoL ($p < 0.01$).

The majority of parents reported increased apprehensiveness (C3); about one-third reported moderate to high increase of intra-familial tension/conflicts (C2). In smaller proportions of cases, job (C4), leisure activities (C5) and extra-family relationships (C6) were considered significantly deteriorated. The disorder was also thought to cause significant economic problems (C7), although the least frequently (13.3% of cases).

c) *Wellness changes after epilepsy* (Table 2D). At the moment of the inquiry (D3), family wellness was perceived as impaired by about 50% of parents. However, when other factors affecting wellness in the period following diagnosis were excluded (see questions D4 and D5, data non shown), the deterioration attributable to epilepsy appeared only slightly reduced (40.8% of families).

Wellness was reported to be deteriorated by 46 (39.7%) cases with epilepsy of low severity (i.e. Rolandic or childhood absence), compared with 112 (63.6%) cases with epilepsy of high severity ($p < 0.0001$). Wellness deterioration appeared more evident at the beginning of the disease than at the time of interview, suggesting an adaptation to the situation initially caused by the disorder.

d) *Perceived effects of epilepsy on children's QoL* (Table 2E). Mild to severe suffering from the disorder was reported by 185 parents (63.1%) (E1). Among the 108 individuals reporting no suffering, 71 (65.7%) were affected by idiopathic epilepsies. Only 18.8% of parents reporting deterioration of the family's QoL judged epilepsy not to cause adverse effects on the life of their children (not in the table). A moderate to severe negative influence on school performance was reported in 93 cases (31.8% of the total population), of which 47 with symptomatic/cryptogenic epilepsies 40.5% of 116 patients compared to 46 (26.0%) of 177 patients with idiopathic epilepsies ($p < 0.01$). Both social relationships and leisure activities were judged as mildly to severely deteriorated in near half of cases.

3.3. Disease-related variables and family's QoL (Table 3)

Symptomatic/cryptogenic epilepsies, high seizure frequency and old diagnosis appeared relevant in most aspect of family's QoL deterioration, while age, seizure type (focal or generalized) and comorbidities did not. Adverse events appeared significant only with respect to social relationships. In relation to the aspects of family's QoL, more marked differences concerned the presence of intra-familial tension and/or conflicts and apprehensiveness ().

3.4. Disease-related variables and children's QoL (Table 4)

As with the family's QoL, factors negatively influencing children's QoL were symptomatic/cryptogenic epilepsies, high seizure frequency and old diagnosis. This occurred in relation to all aspects of children's QoL.

Table 3
Family QoL items (C1–C7) by patients' demographic and clinical data.

	n	C1. General Mod/high n(%)	C2. Conflicts Mod/high n(%)	C3. Apprehensiveness Mod/high n(%)	C4. Job Mod/high n(%)	C5. Leisure Mod/high n(%)	C6. Extra-fam. relationsh. Mod/high n(%)	C7. Economy Mod/high n(%)
Age (years)								
<10	185	94 (50.8)	63 (34.1)	136 (73.5)	40 (21.6)	43 (23.2)	28 (15.1)	22 (11.9)
10+	108	63 (58.3)	37 (34.3)	78 (72.2)	30 (27.8)	29 (26.9)	23 (21.3)	17 (15.7)
Sex								
Females	150	74 (49.3)	44 (29.3)	105 (70.0)	36 (24.0)	27 (18.0)	19 (12.7)	19 (12.7)
Males	143	83 (58.0)	56 (39.2)	109 (76.2)	34 (23.8)	45 (31.4)*	32 (22.4)	20 (14.0)
Etiology								
Cryptogen/symptomatic	116	73 (62.9)	52 (44.8)	96 (82.8)	36 (31.0)	40 (34.5)	28 (24.1)	20 (17.2)
Idiopathic	177	84 (47.5)*	48 (27.1)*	118 (66.7)*	34 (19.2)	32 (18.1)*	23 (13.0)	19 (10.7)
Epilepsy severity								
High	176	108 (61.4)	68 (38.6)	140 (79.5)	48 (27.3)	53 (30.1)	35 (19.9)	28 (15.9)
Low (rolandic, petit mal epilepsy)	117	49 (41.9)*	32 (27.4)	74 (63.2)*	22 (18.8)	19 (16.2)	16 (13.7)	11 (9.4)
Seizures per month (petit mal excluded)								
<1	155	75 (48.4)	47 (30.3)	112 (72.3)	33 (21.3)	34 (21.9)	20 (12.9)	17 (11.0)
1+	74	55 (74.3)**	36 (48.6)*	63 (85.1)	25 (33.8)	26 (35.1)	20 (27.0)*	16 (21.6)
Diagnosis								
New	178	79 (44.4)	45 (25.3)	115 (64.6)	32 (18.0)	36 (20.2)	24 (13.5)	16 (9.0)
Old	115	78 (67.8)***	55 (47.8)***	99 (86.1)***	38 (33.0)*	36 (31.3)	27 (23.5)	23 (20.0)*
Seizure's type								
Focal	141	77 (52.5)	54 (38.3)	108 (76.6)	36 (25.5)	36 (25.5)	24 (17.0)	19 (13.5)
Generalized	139	78 (56.1)	42 (30.2)	99 (71.2)	34 (24.5)	35 (25.2)	27 (19.4)	20 (14.4)
Comorbidities								
No	218	115 (52.8)	69 (31.7)	156 (71.6)	48 (22.2)	54 (24.8)	38 (17.4)	24 (11.0)
Yes	75	42 (56.0)	31 (41.3)	58 (77.3)	22 (29.3)	18 (24.0)	13 (17.3)	15 (20.0)
Adverse events								
No	253	133 (52.6)	88 (34.8)	183 (72.3)	56 (22.1)	57 (22.5)	35 (13.8)	30 (11.9)
Yes	40	24 (60.0)	12 (30.0)	31 (77.5)	14 (35.0)	15 (37.5)	16 (40.0)***	9 (22.5)

* $p < 0.01$.

** $p < 0.001$.

*** $p < 0.0001$.

Table 4

Children/adolescents QoL items (E1–E4) by patients' demographic and clinical data.

	<i>n</i>	E1. Suffering Mod/high <i>n</i> (%)	E2. School ^(a) Mod/high <i>n</i> (%)	E3. Peer relationships Mod/high <i>n</i> (%)	E4. Leisure Mod/high <i>n</i> (%)
Age (years)					
<10	185	53 (28.7)	35(31.5)	32 (17.3)	35 (18.9)
10+	108	42 (38.9)	45 (41.7) [*]	24 (23.2)	27 (25.0)
Sex					
Females	150	42 (28.0)	49 (32.7)	26 (17.3)	27 (18.0)
Males	143	53 (37.1)	44 (30.8)	30 (21.0)	35 (24.5)
Etiology					
Symptomatic	116	48 (41.4)	47 (40.5)	37 (31.9)	37 (31.9)
Idiopathic	177	47 (26.6) [*]	46 (26.0) [*]	19 (10.7) ^{***}	25 (14.1) ^{**}
Epilepsy severity					
High	176	68 (38.6)	66 (37.5)	44 (25.0)	47 (26.7)
Low (rolandic epil., petit mal)	117	27 (23.1) [*]	27 (23.1) [*]	12 (10.3) [*]	15 (12.8) [*]
Seizure per month (petit mal excluded)					
<1	155	39 (25.2)	37 (23.9)	20 (12.9)	21 (13.5)
1+	74	43 (58.1) ^{***}	41 (55.4) ^{***}	27 (36.5) ^{***}	32 (43.2) ^{***}
Diagnosis					
New	178	38 (21.4)	34 (19.1)	20 (11.2)	18 (10.1)
Old	115	57 (49.6) ^{***}	59 (51.3) ^{***}	36 (31.3) ^{***}	44 (38.3) ^{***}
Seizure's type					
Focal	141	50 (35.5)	44 (31.2)	28 (19.9)	34 (24.1)
Generalized	139	43 (30.9)	48 (34.5)	27 (19.4)	27 (19.4)
Comorbidities					
No	218	67 (30.7)	65 (29.8)	36 (16.4)	43 (19.7)
Yes	75	28 (37.3)	28 (37.3)	20 (26.7)	19 (25.3)
Adverse events					
No	253	80 (31.6)	74 (29.3)	44 (17.4)	50 (19.8)
Yes	40	15 (37.5)	19 (47.5)	12 (30.0)	12 (30.0)

^a Patients not attending school have been excluded.^{*} $p < 0.01$.^{**} $p < 0.001$.^{***} $p < 0.0001$.

The multiple correspondence analysis (MCA, Fig. 1) gives a visual representation of the data in the tables, showing higher family's and children's QoL and low concern closer to idiopathic epilepsy, low disease severity, low number of seizures, and newly diagnosed epilepsy. Conversely, low and mid QoL and high and mid concern are represented close to symptomatic/cryptogenetic epilepsies, higher disease severity, high number of seizures and old epilepsy.

3.5. Parents' vs. adolescents' perception of QoL

Self-evaluation of adolescents' QoL (using the QOLIE-48 inventory) was compared to their parents' assessment with the IEQoL. Parents' perception of adolescents' suffering due to epilepsy (E1, IEQoL) was significantly correlated to the adolescents' attitudes toward epilepsy (questions 43–46, QoLIE-48) ($p = .0001$). However, in 11 adolescents (47.8%) of the 23 whose parents reported no suffering from epilepsy, the QoLIE's item "Attitudes toward epilepsy" scored lower than 50 (unfavorable). School performance (E2) also resulted highly correlated with performance in schoolwork, concentration, thinking, remembering, understanding, etc.) (questions 8 and 12–20, QOLIE) ($p < 0.0001$). However, in contrast to 33 parents declaring that epilepsy affected "moderately" or "a lot" their adolescents' school progress, 26 (78.8%) of their adolescents/children declared that epilepsy did not severely impact their memory and concentration (scoring ≥ 60 in the QOLIE's "Memory/concentration" domain). Peer relationship (E3) was highly correlated with social life (questions 25–33, QOLIE) ($p < 0.0001$). A perfect concordance was observed among the 51 parents who reported that epilepsy did

affect "in no way" their child's peer relationship, and the respective adolescents' self-reports, none of which were compatible with unsatisfactory social life (score $< 50\%$). A significant correlation ($p = 0.0001$) was also found between leisure activities (E4) and daily activities (questions 3–7, QOLIE). However, 18 (85.7%) adolescents reported they were not burdened by epilepsy in their physical and daily activities (score $\geq 60\%$), in contrast to their parents declaring that epilepsy reduced "moderately" or "a lot" their extracurricular activities.

3.6. Evaluation of medical information (domain A of the questionnaire)

With reference to the information imparted by doctors on the nature and future of the disorder, 240 parents (81.9%) answered it was sufficiently clear, 46 (15.7%) declared uncertainty and 7 (2.4%) said it was unclear; six of the latter had children with idiopathic epilepsies.

4. Discussion

Our study focused on the self-reported changes in the QoL of children and adolescents with newly diagnosed or chronic epilepsy requiring treatment changes. Differently from the other studies on QoL of epileptic patients, changes of the main aspects of the QoL, rather than absolute values, were measured to reflect the impact of the onset and diagnosis of epilepsy and the start of treatment or the consequences of a relevant therapeutic problem.

The data collected concerned the main aspects of family and children's life, and were evaluated in relation to several features of

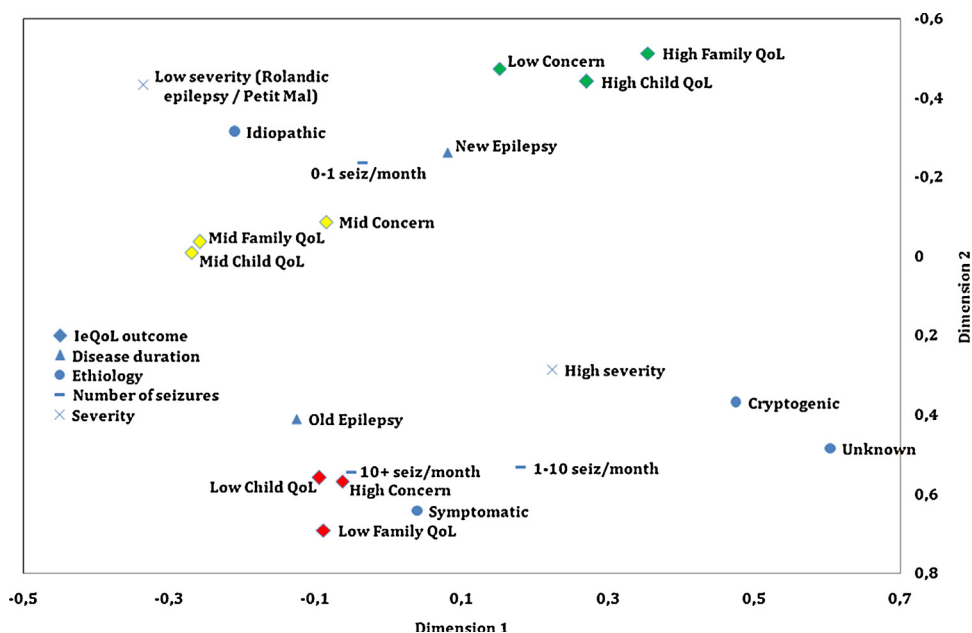


Fig. 1. Multiple correspondence analysis (MCA) of clinical and outcome variables. MCA plotting of the levels of the outcome variables (Low/Mid/High concern, child QoL and family QoL) and levels of disease duration, etiology, number of seizures and severity. The interpretation of the MCA plot is based upon proximities between points (i.e., variables levels) in a two-dimensional space. The proximity between levels of different variables (i.e., “High concern”, “Low child QoL”, “Low family QoL”, “Symptomatic”, “10+ seiz/month”, “Old epilepsy” etc.), suggests that those levels tend to appear together in the dataset as a cluster. Conversely, “new epilepsy”, “0–1 seiz/month”, “Idiopathic” and “Low severity epilepsies” were closer to Medium and High QoL.

the epileptic disorder. Although parents’ judgment was the main aim of the study, self-reported data from adolescents were also collected to consent a comparison of patients and parents’ views.

In general, a negative attitude toward the epileptic condition was manifested by about three-quarters of parents of the study. Although parents of children with epilepsies of low severity showed less negative attitudes than parents of children with more severe disease, more than one-third of them showed concerns that did not seem justified in view of the favorable prognosis of the disease. This could be explained by inadequate information received by the caring physician but, for the most part, by insufficient understanding of the nature of the disorder, resulting in excessive emotional reactions. In fact, this negative attitude was correlated to an increased apprehensiveness, appearing significant also in low-severity varieties of epilepsy and followed by a change of family’s life. An increase of “parent’s apprehensiveness” was reported in about three-fourths of cases and was a source of tensions and conflicts in one-third. This shows how emotional factors play a role in worsening QoL, in accordance with reports who found a significant correlation between parental anxiety¹³ and stress, fear and concern¹⁴ and child’s QoL. It should be also noted that, in the parents’ view, work and leisure activities were affected in about one-fourth of cases, an aspect of QoL not frequently evaluated. Moreover, deterioration of extra-familial relationships and economic problems were claimed by parents, although in a low percentage.

As expected, higher concerns were associated with the more severe epilepsy varieties, more frequent seizures, and adverse effects of treatment. This confirms the findings reported in several other studies.^{15–19}

Compared to parents of children with newly diagnosed epilepsy, parents of children with chronic epilepsy (“old diagnosis”) reported greater impairment in different aspects of QoL. This seems to contradict the results reported by Speechley et al.²⁰ who found that QoL tends to improve six months after the onset of the disease, and of Wu et al.,¹⁴ who found family stress higher in the first compared to the second year after onset, suggesting the

manifestation of adjustment mechanisms. This apparent contradiction is due to the fact that our “chronic” population consisted of subjects undergoing treatment changes due to lack of efficacy or adverse effects regardless of the duration of the disease. Anyway, our data confirm that adaptation occurs, inasmuch “deterioration of wellness” by self-report was greater at the beginning of the disease than at the time of the interview. Thus, greater impairment of QoL in our “old diagnosis” population reflects the presence of a more severe disease rather than lack of adaptation (since these patients were investigated when a change in treatment was needed, not during the routine management of their chronic disease).

Our study focused on the parental reaction upon learning that the child, unexpectedly, is going to be affected for years to come by a disease loaded with “stigma” or that the child needs a change in treatment because ineffective or poorly tolerated. These news, inevitably, must be viewed by the parent as set-backs that send negative signals about unfavorable prognosis. Either event, new diagnosis of epilepsy or a set-back in treatment, increase parental anxiety with the consequences described above and eventually lead to deterioration of family’s QoL. As our data indicate, in some cases the concerns raised by the disease are more detrimental than the disease itself. The pervasive belief that epilepsy is a “bad” disease that inevitably will lead to social discrimination is deeply rooted and difficult to correct even in view of good prognosis. Parents are the first in line to deal with the “stigma” and may not be free of prejudice themselves. The team of caregivers should be aware that parents may overreact to “bad news” and provide all necessary support during this period of adjustment. More research on parental reactions and their ways of adapting to a new reality will be necessary to facilitate this process and ease the pressure on family life.

A significant correlation was found between the responses of older children and adolescents and the parents’ opinions about QoL. This agrees with Haneef et al.,²¹ but not with others^{22–24} who, however, used the same questionnaire in parents and their children. Nonetheless, it should be noted that a number of our

adolescents disagreed with their parents' judgment, particularly concerning the items "suffering of the adolescent due to epilepsy" and "reduction of leisure activities". A more optimistic view of some parents concerning the "suffering due to epilepsy" suggests a tendency to overlook the problems of their children. On the other hand, the more optimistic adolescent's view concerning "leisure activities" and, "memory/concentration capabilities" suggests their own desire to alleviate the negative effects of the disorder. These interpretations, mainly speculative, will need to be verified by comparing subjective opinions with school reports and teachers' assessments.

4.1. Strengths and limitations of the study

A major strength is the large sample size, associated with high response and retention rates. Additional strengths are the comparison between newly diagnosed and chronic epilepsy and the assessment of changes in QoL as a consequence of the disease. Moreover, the study includes comparison of adolescents' QoL with that of their close family members. The ease of use of IEQOL (completed in less than 5 min by the majority of interviewees) must be also emphasized.

The first limitation is the representativeness of the study population. This was not a population-based study and our patients with chronic epilepsy were those needing medical intervention for inefficacy and/or poor tolerability of the assigned treatment. Different results may be expected in other, more representative populations. The second limitation is the short follow-up period, which prevents any inference on the long-term outcome of our firstly diagnosed individuals. The third limitation is the difficulty in comparing our findings to those of the other studies that used different instruments to assess QoL in children, adolescents and their parents. The last limitation is the exclusion of

patients not requiring treatment initiation or changes, therefore the results might be different in children and adolescents with stable epilepsy.

5. Conclusions

Our results suggest that QoL of children and adolescents with epilepsy and their families is frequently unsatisfactory even in the presence of benign epilepsies of childhood. Excessive parental apprehensiveness appears frequently associated with QoL deterioration. Such inadequate perception of the burden of epilepsy reported by parents of children with low disease severity prompts a more in-depth information and assistance by the caring epileptologist. The routine use of a simple and comprehensive inventory like the one we used is recommended. Completed by the parents soon before the visit, it gives an immediate glance to the epileptologist on the issues to be explored with a clinical interview. This information facilitates the understanding of the family's and child's condition and needs, and helps improving therapeutic assistance.

Conflict of interest statement

None of the authors and of the TASCA Study Group has conflict of interest concerning the present study.

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Appendix A

The text of the IEQoL questionnaire for parents is provided here. Those who want to get the electronic file, ready to printing for the administration (.xls format), they can get it for free writing to the author's address cianchet@unica.it.

I.E.Q.o.L. Impact of Epilepsy on the Quality of Life By Carlo Cianchetti, University of Cagliari, Italy

QUESTIONNAIRE FOR PARENTS Filled out by Father ☐ Mother ☐

Dear Parent, please answer the following questions accurately. This will aid us in assisting and treating your child more effectively. Place an "X" in the box corresponding to your answer.

Your son/daughter has a disorder that causes critical episodes and which is defined as epilepsy.

A1) Does what your doctors have told you about the nature and future of this disorder seem sufficiently clear?

yes ☐ uncertain ☐ no ☐

A2) If not sufficiently clear, is this due to:

poor explanations or limited clarity on the part of the doctors ☐ or
to the fact that the doctors themselves have reported limited current knowledge of the disorder? ☐

B1) Has the knowledge that your child is suffering from this disorder caused you

great ☐ average ☐ moderate ☐ slight ☐ sorrow?

B2) Does the disorder your child is suffering from seem to you something

very serious ☐ moderately serious ☐ not too serious ☐ not serious ☐ ?

B3) Does the disorder of your child make you worry about his future?

a lot ☐ average ☐ a little ☐ not at all ☐

Now report what happened after your child's disorder became evident and was diagnosed as epilepsy:

C1) Has your family life changed? yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

C2) Is there more tension and/or conflict among family members?

yes, a lot ☐ moderately ☐ a little ☐ none ☐

C3) Are you more apprehensive (that is, do you worry more) about what is happening?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

C4) Have your child's problems caused changes for the worse in your work?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

C5) Have your child's problems worsened your non-working activities (pastimes, hobbies, vacations, etc.)?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

C6) Have your child's problems worsened extrafamily relationships (friends, social groups, etc.)?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

C7) Has your child's disorder caused economic problems?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

Answer the following questions by putting an "X" at the point on the scale from 0 to 100 which seems closest to your evaluation.

D1) What was the level of your family's well-being before your child's disorder became evident? (minimum well-being = 0, maximum well-being = 100)

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

D2) What was the level of your family's well-being in the months immediately after your child's disorder became evident?

(minimum well-being = 0, maximum well-being = 100)

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

D3) What is the current level of your family's well-being (minimum well-being = 0, maximum well-being = 100)?

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

D4) After the diagnosis of epilepsy, were there other facts which negatively influenced your family's well-being? yes ☐ no ☐

D5) If so, what degree of influence do you believe they have had in reducing your family's well-being?

(minimum influence = 10; maximum influence = 100)

.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Now try to indicate how you evaluate your child's condition:

E1) Does he appear to suffer a great deal due to his disorder?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

E2) Has the disorder influenced his progress at school?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

E3) Has the disorder reduced his relationships with his peers?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

E4) Has the disorder reduced his extracurricular activities (sports, playing, etc.)?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

Now try to indicate how you view the therapy your child is currently receiving:

F1) Do you think the present therapy is effective?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

F2) Does your child accept his current therapy?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

F3) Or: does your child undergo his present therapy unwillingly or does he tend to refuse it?

yes, a lot ☐ moderately ☐ a little ☐ no, he undergoes it without problems ☐

F4) Does your child generally undergo any type of therapy unwillingly?

yes, a lot ☐ moderately ☐ a little ☐ not at all ☐

Appendix B. the TASCA Study Group:

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