



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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¹ See Appendix B.

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.

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