Symptoms of anxiety and depression and family's quality of life in children and adolescents with epilepsy

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ABSTRACT

Introduction: We studied children and adolescents with epilepsy (CAWE) and their families to evaluate symptoms of anxiety and depression, quality of life (QoL), and their correlations with epilepsy characteristics.

Material and methods: The study included 326 (52.5% females) 8 to 18 years old CAWE. Anxiety and depression were assessed with the "Self-administered psychiatric scales for children and adolescents" (SAFA), and family's QoL with the parents' report "Impact of Epilepsy on QoL" (IEQoL).

Results: The CAWE exhibiting abnormal (T ≥ 70) scores were 8.0% in the anxiety scale, 9.2% in the depression scale, and 4.6% in both scales. Social anxiety was the predominant anxiety symptom, while irritable mood and desperation were the most frequent symptoms of depression. Depressive symptoms were associated with parents' complaint of higher worries about the child's condition and future and lower well-being of the family.

Severity and duration of the epilepsy and polypharmacy were independent from abnormal scores of anxiety and depression, but were associated with parents' worries about the child's condition and family's well-being.

Conclusions: Anxiety and depression in CAWE are independent from the characteristics of the disease but are correlated to the lower well-being of the family. A search of these emotional problems is recommended for better care of the patients and their families.

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1. Introduction

Anxiety and depression in persons with epilepsy are more frequent than in the general population at all ages. Several studies have been done on anxiety and depression in children and adolescents with epilepsy (CAWE), and have been the object of reviews [1–3]. Some focused on the prevalence of these affective problems [4–13] while others evaluated their relationship with epilepsy characteristics [14–21] or with health-related quality of life (HRQoL) of the patients and/or their families [22–24].

An investigation of all these aspects and their correlations in the same population of CAWE has been accomplished in relatively small samples [25] and only very recently in a large cohort of CAWE [26]. In those studies, the evaluation of anxiety and depression has been done using self-rating [25] and parent-rating [26] tools.

On this background, we aimed to investigate these multiple relationships in a very large population of CAWE, using a self-rating tool for the detection of anxiety, depression and somatic complaints. Our research hypothesis was that anxiety, depression and somatic complaints are highly prevalent among children and adolescents with epilepsy and that these symptoms are associated with greater disease severity and with poor quality of life of patients and of their parents/caregivers. The purpose of the study was thus to evaluate the prevalence of anxious and depressive symptoms and verify if anxiety and depression are associated with some characteristics of the epilepsy phenotype and to HRQoL both in patients and in their family members.

2. Material and methods

2.1. Subjects

The data were obtained from CAWE and their parents/caregivers in the course of a multicenter, observational, prospective open study. Nine epilepsy centers in Northern, Central, and Southern Italy were involved, representing a balanced nationwide sample. The eligibility criteria were as follows: a) epilepsy of any type; b) age 8 through 18 years; c) level of intelligence (assessed by clinical judgment, including school proficiency) adequate for the understanding of a self-completed questionnaire; d) being followed by the local center for at least three months (to confirm the diagnosis and have an insight of the severity of the disease); e) absence of chronic disorders unrelated to epilepsy and affecting HRQoL. The study was originally nested in a cohort study designed to assess satisfaction of CAWE with assigned treatments [27]; patient recruitment was then continued with the intent to collect a convenience sample of at least 300 eligible patients.

The CAWE were selected randomly from hospitalized and ambulatory patients. Written informed consent, including full understanding of the aims and conduct of the study, was obtained from the parents or legal representatives. No assent was requested from the child. The study protocol was approved by the Ethics Committees of all the participating centers.

2.2. Instruments

Scale di Autosomministrazione per Fanciulli e Adolescenti/Self-administered psychiatric scales for children and adolescents (SAFA) [28] is a tool for the detection of symptoms that were included in the Diagnostic & Statistical Manual of Mental Disorders (DSM) [29] (see Appendix A). This is an Italian battery of self-administered psychiatric scales for children and adolescents (8–18 years old). For this study, we used the following first three scales of the battery: SAFA-A for Anxiety symptoms, SAFA-D for Depressive symptoms, and SAFA-S for Somatic complaints. Although somatic complaints are frequent manifestations of anxiety and depression [30], in the SAFA battery they are arranged in a separate domain.

The answers were evaluated by transforming the raw scores into standardized T scores. $T \geq 70$ scores correspond to values of 2 or more standard deviations (SD) beyond the mean (representing less than 2.5% of the population); these values were interpreted as abnormal and used to state if the disorder of interest was present. In some occasions, we also evaluated the cases scoring $T \geq 65$ (1.5 SD or higher beyond the mean, up to 2 SD) which represent the subjects with a borderline condition. This was done in order to give further validation of the results obtained using the cut-off $T \geq 70$, even considering that in psychiatry the cut-off $T \geq 65$ is frequently used.

Impact of Epilepsy on the Quality of Life (IEQoL) [31] (see Appendix A is a questionnaire to be completed by parents or caregivers to explore various aspects of HRQoL of patients and families after the onset of the epilepsy. For the purposes of this study, all items, except D1–D5, were assigned a score from 1 (no changes after diagnosis) to 4 (the most worsening after diagnosis). Items D1–D5 have a score ranging from 0 (the lowest level of well-being) to 100 (the highest level). Only selected IEQoL items and combinations of items were evaluated, as follows: B2 to measure the perceived severity of epilepsy (range 1–4), B3 to measure worries about the child's future (range 1–4), the sum of all items from C2 to C7 to measure the general worsening of family's HRQoL after epilepsy diagnosis (range 6–24), D3 to measure the family's current well-being (range 0–100), the difference between D1 and D3 to measure the worsening of the family's well-being after epilepsy diagnosis (range from −100 to 100), the sum of all items from E1 to E4 to measure the worsening of the child's condition, and HRQoL after diagnosis (range 4–16).

2.3. Data collection

Patients' demographics, date of seizure onset, seizure type(s), seizure frequency in the last month, etiology of epilepsy, epilepsy syndrome, disease severity, current treatments, and adverse events were recorded from medical charts. Epilepsy severity was defined by two of us (CC and EBe) upon clinical judgment considering seizure type(s), epilepsy syndrome, and presence of seizures in the last month. The following categories were so identified: a) benign forms (rolandic epilepsy, occipital epilepsy, Panayiotopoulos and Gastaut type); b) mild (absences uncomplicated and with good seizure control); c) moderate (focal and generalized motor seizures good seizure control; absences with poor seizure control and myoclonic absences); d) severe (focal and generalized motor seizures with poor seizure control and/or relevant neurologic comorbidities). Poor seizure control was defined as persistent seizures with presence of seizures in the last month. Good seizure control was defined as seizure freedom or rare seizures during the course of the disease and absence of seizures in the last month. The demographic and clinical data were included by the local investigators in an ad-hoc case record form (CRF). All data recorded in the CRF were anonymized and transferred into a password-protected computerized database located in the coordinating center (IRCCS - Istituto di Ricerche Farmacologiche "Mario Negri", Milan).

2.4. Statistical analysis

The numbers and percentages of CAWE with anxious, depressive, and somatic symptoms were calculated from the results of the SAFA-A, SAFA-D, and SAFA-S scales. A separate analysis was done for patients with a borderline condition. Frequencies and percentages were compared within subgroups of CAWE according to sex, education (primary [age 8–11 years], lower secondary [age 12–14 years], upper secondary [age 15–18 years]), epilepsy severity (benign, mild, moderate, severe), disease duration (less than 1 year, and 1 year or longer), and antiepileptic treatment (number and type of drugs), using the chi-square or Fisher's exact test.

Normal and abnormal SAFA-A and SAFA-D scores were correlated to the IEQoL, using the Wilcoxon–Mann–Whitney test. The same IEQoL