



Parenting stress evaluation and behavioral syndromes in a group of pediatric patients with epilepsy



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ABSTRACT

The aim of the present work was to measure the amount of stress in parents of children with epilepsy and to determine whether and how parenting stress is linked to behavioral symptoms of the children. Parenting stress was measured with the Parenting Stress Index (PSI) and behavioral symptoms with the Child Behavior Checklist (CBCL). Data obtained from 26 parents of children with epilepsy were compared with those obtained from 31 parents of healthy children. Children with epilepsy obtained higher scores in all the subscales of PSI and in almost all the subscales of CBCL compared with healthy children. Epilepsy caused a high level of parenting stress and of problematic behaviors since the behavioral symptoms predicting the degree of parenting stress significantly differed between healthy children and children with epilepsy. Therefore, parents of children with epilepsy should be offered psychological support to cope with parenting stress and to improve the relationship with their children.

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1. Introduction

Children's chronic diseases and disabilities may cause critical effects on the entire family [1]. These effects depend on a number of characteristics of the child, the parents, and their environment [2]. Being aware of the effects produced by children's disease on their parents is important because it allows one to encourage coping strategies and to offer the support needed to reduce the emotional burden related to the situation. It also helps to promote an improvement in the relationship between parents and children, including those children without medical problems, resulting in a greater ability to combine medical care with work and relationships with friends and with the partner [1,3]. On the other hand, stress, in general, decreases the ability to withstand adversity and predisposes people to develop mood disorders [4].

Research has already shown a sensible measure of parenting stress [5] in connection with the effects of externalizing and internalizing behavioral problems of healthy children [6]. While behavioral problems occurring in children with epilepsy have been established in the literature [7,8], parenting stress has been investigated only recently [9,10].

Moreover, an increased level of stress is detected in parents of autistic children in proportion to the severity of the condition [11], of children with diabetes [12], or of children with asthma [13]. Given that having children with diseases such as those mentioned above can generate parenting stress, we may assume that also having children with epilepsy, characterized by unpredictable crisis onset, can cause stress related to treatment concerns in their parents. Parenting stress is an

important theoretical concept since in the literature it has shown its relevance for explaining disorders and resilience of families in influencing the behaviors adapted by parents [5,9]. Abidin introduces his PSI stating that an early identification of "child–parent" stressing systems and interventions focused at reducing this stress might reduce the frequency and intensity of emotional and behavioral disorders in the children. For this purpose, the PSI measures the stress perceived in the parent–child interaction. Parenting stress is a specific form of stress uniquely perceived by parents that results from the demands of being a parent. It is a multidimensional concept composed of the factors that can produce dysfunctional parental behaviors, which are divided in two major domains: child characteristics and parent characteristics [5]. The short form of the PSI, used in this study, is described in detail in the Measures section.

To our knowledge, only one study has examined parenting stress and behavior of children with drug-resistant epilepsy [10]. Children with epileptic syndromes can have a high incidence of behavioral disorders [14]. Epilepsy is a condition that predisposes children to develop behavioral problems, which increase with seizure recurrence [15] and which create in turn stress in the parents. In addition, clinical variables (time of onset, type of seizure, seizure rates) and personal expectations (feelings and emotions about the current health status and future of the child) also explain the increase of parenting fears while lowering children's quality of life [16,17]. In adults, instead, the quality of life is influenced more by mood disorders and antiepileptic drug (AED) side effects than by sociodemographic and clinical variables [18,19].

The main goal of our work was to identify the possible presence of a greater stress in parents of children with epilepsy, determining whether and how parenting stress is linked to behavioral disorders of children

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with epilepsy. We analyzed the relationships between parenting stress and behavioral disturbances in the sample of children with epilepsy and in the Control Group to verify whether it is possible to find the same relationships or different ones and, in the latter case, in which way they differ.

A secondary aim was to verify if the age of children with epilepsy could favor a reduction in the level of parenting stress, considering that parents of toddlers may be more willing to fulfill their caregiving role [20], for example by being present all the time, by reducing social activities, by taking care of their children's health, and by preventing harmful accidents. On the other hand, parents of children at school age may have an overload of worries concerning challenges that their children have to face, like learning, socializing, gaining autonomy, and developing psychological well-being [21,22].

2. Methods

This study was conducted in a pediatric clinic specialized in the treatment of epilepsy. The patients were under the care of a pediatric neurologist. Informed consent was obtained from the parents of all subjects, and the study was approved by the Ethical Committee of the University of Chieti. The parents completed questionnaires before, during, or after the control visit of their children. Two questionnaires were administered, the *Parenting Stress Index – Short Form* (PSI-SF) [23] and the Italian version of *Child Behavior Checklist/4–18* (CBCL/4–18) [24,25]. Data collection took approximately half an hour in each case. The questionnaires of three participants were excluded because of poor reliability of responses.

In order to study the eventual presence of behavioral syndromes, we administered CBCL to the parents of pediatric patients, but, unfortunately, because of the very few responses given by parents of patients < 4 years of age, we have performed this evaluation only on parents of children with epilepsy aged 4 years or more.

2.1. Participants

Twenty-six parents of children, with previously diagnosed epilepsy according to the guidelines of the International League Against Epilepsy, were included in the study; they were enrolled from January 2011 to December 2012. To be eligible for the study, each patient had the following:

- 1) age at the first seizure between 1 month and 12 years;
- 2) idiopathic epilepsy, defined as 2 or more unprovoked seizures.

Patients with seizures caused by infections of the CNS or by metabolic disturbances or those patients with abnormal neurological examination and delayed psychomotor development were excluded from the study. Moreover, patients with other chronic diseases (e.g., chronic asthma), genetic syndromes, major congenital malformations, or other neurological diseases were excluded from the study. Finally, we have excluded the patients suffering from symptomatic forms of epilepsy. Thirteen out of 26 children suffered from generalized epilepsy, 13 patients suffered from partial epilepsy, and 1 patient was unclassified. The mean \pm SD age at onset of epileptic seizures was 5.1 ± 4.9 years. All patients were receiving monotherapy, 20 valproic acid, 6 carbamazepine, and 1 phenobarbital: the mean duration of antiepileptic drug therapy was 2.7 ± 1.9 years; all patients showed AED plasma levels in the therapeutic range. Magnetic resonance imaging (MRI) studies were available in all the 26 cases: in all children, MRI was normal.

The Control Group was composed of 31 parents of children aged from 6 to 11 years (mean age = 8.39; SD = 1.647) attending a local elementary school, with no overt behavioral or cognitive disorders. Control subjects were recruited in a primary school of the same area of the patients with epilepsy: they were screened to see if they had

behavioral or cognitive disorders with a neuropsychological evaluation carried out by a child neuropsychiatrist. The parents of the healthy control children were recruited by means of written invitations, and a briefing was held with a physician. Informed consent was obtained from the parents of all subjects.

2.2. Measures

The PSI-SF [23] is a 36-item questionnaire designed to measure the level of parenting stress. It consists of three subscales that measure the following: the distress of the parent's role (parenting distress subscale – PD), the degree of emotional satisfaction received by the interactions with the child (parent–child difficult interaction subscale – P-CDI), and the perception of having a child particularly difficult to manage and control because of his temperament (difficult child subscale – DC). The sum of the items of the subscales provides the level of total stress (Tot. PSI). Scores indicating a level of moderate to high stress are those located between the 55th and the 80th percentile. A score over the 80th percentile is a clear indication of strong parenting stress. The Italian version of the PSI-SF has been validated on 1352 subjects (1251 mothers, 137 fathers), with Cronbach's alpha values between .78 and .93 and internal validity with values close to 1 for the three factors with the total stress scores [23].

The CBCL/4–18 [24] is a tool for the assessment of behavioral and emotional problems of children and adolescents aged 4 to 18 years. The CBCL consists of a multiaxial questionnaire of 113 questions to be answered on a scale from 0 (definitely false) to 2 (often or definitely true) composed by nine syndrome scales that focus on different aspects of behavior: Withdrawn/Depressed (W/D), Somatic complaints (Som), Anxious/Depressed (A/D), Thought problems (Tho), Social problems (Soc), Attention problems (Att), Rule-breaking behavior (Rbb), Aggressive behavior (Agg), and other kinds of behavioral problems (Other). In addition to the syndrome scales, the questionnaire also provides two broad groupings of syndromes: Internalizing that encompasses problems that are mainly within the self and Externalizing that comprises problems that mainly involve conflicts with other people. The Internalizing score is computed by summing the scores for the three subscales: W/D, Som, and A/D, while the Externalizing score is computed by summing the scores for the two subscales Rbb and Agg. The Total Problems score of CBCL is the sum of the Internalizing, of the Externalizing, and of the Other subscale scores. Child Behavior Checklist/4–18 norms were based on the 95th and 98th percentile (T score = 67 and T score = 70) for syndrome scales and on the 82th and 90th percentile (T score = 60 and T score = 63) for Internalizing, Externalizing, and Total Problems scales. Norms were calculated on a database collected by submitting 2025 CBCLs (response rate: 71.7%) to a sample composed by children and adolescents aged between 4 and 18 years [25]. Internal consistency for each subscale and Total Problems is good (Cronbach's $\alpha > .65$) [25].

2.3. Statistical analyses

We tested our hypothesis in the following way:

1. Verify, through an analysis of the correlations of the subscales of the PSI and CBCL both in the group of children with epilepsy and in the Control Group, composed by children without specific brain injuries or psychiatric problems, if there is a convergence between the scores of the two tests, which is a dependency between the subscales of the two tests. In order to study the eventual presence of behavioral syndromes, we administered CBCL to parents of pediatric patients, but, unfortunately, because of the few responses given by parents of patients < 4 years of age, we have performed this evaluation only for parents of children with epilepsy aged 4 years or more. Therefore, children with epilepsy were split into two groups: Group I with 16 children aged from 4 to 12 years (mean age = 8.31;

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