The influence of epilepsy on children's perception of self-concept

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ABSTRACT

The diagnosis of epilepsy can lead to changes in the patient's perception due to factors such as learning and behavioral problems, lack of academic motivation, and low self-esteem. This study aimed to evaluate and compare the knowledge of self-concept in children with epilepsy and those with typical development and verify whether gender and age influence this perception. Eighty children of both sexes, aged between 8 and 14 years, participated in this study. The children were divided into two groups: the epilepsy group, which consisted of 40 children diagnosed with epilepsy, and the control group, which consisted of 40 children with typical development and comparable to group 1 according to sex and age. The Piers-Harris Children's Self-Concept Scale, translated and adapted for the Brazilian population, was used as the evaluation instrument. In total, there were 23 boys and 17 girls in each group, with a mean age of 10.7 years. There were significant differences in the overall score ($p = 0.000$) and the subareas "behavior" ($p = 0.006$), "intellectual and academic status" ($p = 0.001$), and "popularity" ($p = 0.004$). The group of children with epilepsy had a lower average score in self-concept. Children with epilepsy were observed to perceive themselves as clumsy, without many friends, with low academic performance and problems at school, and to experiencing feelings of unhappiness. These findings suggest that, in addition to the treatment of the clinical manifestations of epilepsy, it is extremely important to provide treatment focused on improving the self-concept of school-aged children with this condition.

1. Introduction

According to the International League Against Epilepsy (ILAE), epilepsy is defined as a brain disorder caused by a persistent predisposition of the brain to generate seizures and for causing neurobiological, cognitive, psychosocial, and social consequences, characterized by the occurrence of at least one epileptic seizure [1]. Types of epilepsy and epileptic syndromes are classified according to the types of seizures (focal or generalized), the age of onset, cognitive and developmental history, clinical or associated neurological symptoms, family history, electroencephalographic data, seizure triggers, the percentage of seizures associated with sleep, and prognosis [2].

Epilepsy is one of the most common neurological disorders, without social, ethnic, geographical, age, or gender barriers [3]. Worldwide, the prevalence is approximately 10 to 15 per 1000 people, differing between age groups, with a higher prevalence in children and the elderly [4,5]. In developed countries, there are 50 new cases per 100,000 people per year, while in developing countries, this figure can reach 120 new cases per 100,000 people each year [5]. In Brazil, there are few available prevalence data about the condition in urban areas. In 2002, 18.6 cases per 1000 people were recorded in Rio de Janeiro [4].

Epilepsy is often associated with a variety of physical and neurological symptoms, which limit occupational activities, such as those involved in daily life, as well as practical activities, work activities, education, social activities, and leisure pursuits [6]. Children with epilepsy may experience poor school performance due to comorbidities, such as learning and behavioral problems, as well as overprotective attitudes of parents, lack of academic motivation, school absenteeism, and low self-esteem [7,8,9,10], which is often triggered by stigma, interferes with the quality of life, and results in a negative impact on the psychosocial level [11,12].

Self-concept refers to the beliefs and self-perceptions built along a person's life, involving attitudes, feelings, and knowledge about their abilities, skills, and social acceptance, and directing their conduct, allowing them to assume new responsibilities in life [13]. It is a self-assessment mechanism influenced by cultural aspects and therefore depends on their skills as well as the context where it is employed, allowing the individual to orient himself regarding his future actions [14].

The self-concept, seen in the multimodal model, integrates the self-perception of competence in various fields such as academic, athletic, social, physical appearance, and behavioral characteristics, which should be evaluated separately [15].

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There are few studies on the subject of self-concept in Brazil [16,17], and those focused on children are especially rare [18].

There is also a shortage of studies on the subject of self-efficacy and self-concept in children with epilepsy in Brazil [19]. Specifically regarding the Piers-Harris Children's Self-Concept Scale, we were only able to locate studies that sought to assess this construct in obese children, children with learning difficulties, and maternal depression [14,20,21].

Several studies corroborate the fact that the diagnosis of epilepsy can negatively impact the self-concept, both in children and adults [16,22–24]. De Souza and Salgado [16] found an association between epilepsy and mental health problems, feelings of shame, fear, worry, low self-esteem, and prejudice perception. In their literature review, Ferro et al. [25] did not find differences in self-concept among adolescents with and without epilepsy, but called attention to the scarcity and limitation of the studies found and, therefore, the need for careful interpretation of its outcome, reaffirming the need for more studies that seek to associate self-concept with mental health problems in adolescents with epilepsy. Lee et al. [26] found no significant differences in self-concept when comparing adolescents with epilepsy and normative data. However, their sample contained only 37 adolescents, and the comparison was made with the normative data of the evaluation instrument, not with teenagers of the same age without a diagnosis of epilepsy in the same region where the study was conducted, a factor that would have increased the strength of the results.

Taking into account the limitations mentioned in the above studies, as well as the implications that the diagnosis of epilepsy can bring, the shortage of case-control and cross-sectional studies relating self-concept and epilepsy in school-aged children in Brazil makes this study necessary in order to demonstrate the correlation between self-concept and epilepsy, as stated in international literature, in the Brazilian cultural context and addressing only school-aged children. Thus, the objective was to evaluate the perception of the self-concept of children with epilepsy and those with typical development, to compare and verify whether there were differences between the two groups, and to determine whether gender and age influence the perception.

2. Material and methods

2.1. Participants

Participants in this study included 80 children of both sexes, aged between 8 and 14 years, who were divided into two groups. The epilepsy group consisted of 40 children diagnosed with epilepsy and followed at Children's Epilepsy Clinic (AEPI) of the Clinical Hospital of Ribeirão Preto Medical School, University of São Paulo, Brazil.

The control group consisted of 40 children with typical development with the same characteristics of the epilepsy group (age, sex, and socioeconomic status), enrolled between the 3rd and 9th grades of elementary school in a public school in Ribeirão Preto, São Paulo, Brazil. The municipality of Ribeirao Preto has about 650,000 inhabitants and a high human development index, being located in the state of São Paulo, one of the economic centers of the country.

For inclusion in both groups, the children could not have cognitive or behavioral deficits that could interfere in their cooperation and/or understanding of the proposal, which was confirmed through review of data in medical or school records of the participants.

The consent of all participants involved in the study was obtained in accordance with the standards established by the Ethics in Human Research Committee of Ribeirão Preto Medical School Clinical Hospital, which also approved the present study.

2.2. Instruments

2.2.1. Children's and their families characterization form

The instrument was developed by the researchers in order to identify and characterize the study participants' families through personal and demographic data and information about the health history of the child, the latter specifically for the children of the epilepsy group.

2.2.2. Piers-Harris Children's Self-Concept Scale

Originally proposed by Piers and Harris [27], the Children's Self-Concept Scale consists of 80 items, presented in the form of sentences, which assess the total child self-concept and self-concept in six subareas: intellectual and academic status (17 items), behavior (16 items), anxiety (14 items), appearance (13 items), popularity (12 items), and satisfaction (10 items). The items require simple "yes" or "no" answers. Each answer receives a score equal to 1, which corresponds to a positive evaluation of itself, not necessarily related to yes or no. The answers are then summed with a positive value, which can be grouped according to the subscales or presented by the total score. The higher the total score, the more positive is the reflected self-concept [18]. The Piers-Harris Children's Self-Concept Scale has a high internal consistency index, presenting an *alpha* of 0.91 [15].

The version of the Children's Self-Concept Scale translated and adapted for Brazilian Portuguese [28] was used to quantitatively measure the self-concept of the participants of the study in order to compare its results according to the epilepsy and control group division.

2.3. Data collection procedures

To collect the epilepsy group data, children and their families were approached in the waiting room at the Children's Epilepsy Clinic (AEPI) of the Clinical Hospital of Ribeirão Preto Medical School while awaiting the consultation. They were informed of the purpose of the study and the procedures for the application of the questionnaire. After their acceptance, the participants were asked to sign the consent form, and the self-concept assessment tool was administered with the child as well as the characterization form for those responsible for the child's care.

To collect the control group data, the public school students were pre-selected with the help of the director and pedagogical school coordinators to comply with the criterion of similarity regarding sex and age with the participants of the epilepsy group. Invitation letters stating the purpose of the study and the procedures for the administration of the questionnaire were sent to those responsible for the children, and then they were asked about the possibility of participation. The consent form and the characterization form were included in the same envelope as the invitation letter, and those who agreed with the child's participation were invited to complete and sign them. The questionnaire was administered in the school library with those participants whose parents returned the envelopes with the completed and signed documents.

The assessment tool was administered individually, with an average duration of 15 min. The sentences were read aloud by a single appraiser who wrote down the child's response on the printed questionnaire, in order to minimize biased questionnaire understanding on the part of the study participants.

2.4. Data analysis procedure

Demographic data were compiled in Microsoft Excel® and analyzed descriptively. The self-concept scale of each child was completed following the specific recommendations of the instrument. We used the SPSS Statistic 21 program for statistical data analysis, and the Student's *t*-test was used to compare the results between the two groups and between genders. A level of $p = 0.05$ was considered statistically significant. Descriptive statistics were also used as percentages and averages to describe the results of each group, both for the overall and subareas scores. To investigate the influence of age in groups, the Pearson's correlation test and one-way analysis of variance (ANOVA) were used.