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Original Article

Validity and reliability of Turkish version of the scales of perceived stigma for children with epilepsy and their parents



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ABSTRACT

Purpose: This study aims to establish a Turkish version of the scales of perceived stigma amongst children with epilepsy and their parents by adopting the scales developed by Austin et al. This study also aims to analyse the scales' validity and reliability in evaluating stigma perceptions amongst the aforementioned population.

Methods: The population of this methodological study consisted of parents and 85 epileptic children between 9 and 16 years old. This population visited the paediatric neurology clinic of a hospital in Erzurum Province, Turkey, between April 2015 and January 2016. The scales of perceived stigma amongst children with epilepsy and their parents, as well as its Turkish version, were used as measuring tools. Experts were also consulted for their opinions. Meanwhile, Bartlett's test, Kaiser–Meyer–Olkin (KMO) index, exploratory factor analysis, principal component analysis, varimax rotation and scree plot test were used to determine the validity of the study. Moreover, the coefficients of Cronbach's α and Pearson's product-moment correlation were used to identify internal consistency, homogeneity and thus reliability

Results: Evaluations and analyses indicated that the Turkish version of the child and parent scales can be used with a single dimension. The mean scores of such scales were 24.02 ± 8.47 and 15.68 ± 4.04 , respectively. All item-total score correlations of the child and parent scales were found to be significant (P < 0.05). The KMO coefficient of the child scale was 0.94, whereas the chi-square value of Bartlett's test of sphericity was significant at 209.311 (P < 0.05). Moreover, the KMO coefficient of the parent scale was found to be 0.80, whereas the chi-square value of Bartlett's test of sphericity was found to be significant at 209.311 (P < 0.05). The Cronbach's α coefficients were 0.95 and 0.87 for the child and parent scales, respectively.

Conclusion: The Turkish version of the child and parent scales of perceived stigma is valid and reliable in measuring the perception of stigma amongst children with epilepsy and their parents.

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1. Introduction

A chronic disease begins with deviating from the normal condition. Such a disease causes permanent deficiencies due to pathological alterations. Moreover, chronic disease rehabilitation requires special education, inspection and observation [1]. The incidence of chronic diseases amongst children has remarkably increased in the last 20 years, affecting 10%—20% of children under

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the age of 13 [2]. One of the most common chronic conditions affecting children and adolescents is epilepsy [3].

Epilepsy is a neurological condition caused by various pathogen processes. This disease has psychological, neurobiological, cognitive and social characteristics which develop with recurrent crises [4,5]. Approximately half the number of epileptic patients start to suffer before the age of 5, whilst 75% of patients observe symptoms before they reach 20 years old [6]. According to the World Health Organization (WHO), the prevalence of epilepsy in developed and developing countries are 6/1000 and 18.5/1,000, respectively [7].

Epileptic children suffer from more psychiatric problems than children with other chronic diseases and society at large [8]. Thus, the psychosocial problems of children and their parents is as

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important as the treatment process itself [1,2]. Parents of epileptic children are generally pessimistic. Epilepsy diagnosis, unlike that of other chronic diseases, places a sociocultural and moral burden on the patients and their parents [8]. They often experience low self-esteem, dependency, discrimination, stigmatisation and parental restrictions. Thus, social, behavioural and psychological problems should be considered in relation to the physical aspects of the disease [9]. Stigmatisation is the primary psychosocial problem the patients and their parents have to cope with.

Stigmatisation is an action performed by society to diminish the prestige of a person who transgresses the limits of social norms. This action causes discrimination and exclusion of certain patient groups from society. It also turns people, groups, or communities with distinctive characteristics into undesired social elements [10]. Society's biases and approaches towards epileptic patients may isolate these patients from other people (such as friends, relatives and neighbours) and even healthcare professionals [7]. Therefore, healthcare staff, particularly nurses, play remarkable roles in ending stigmatisation. Such a responsibility includes organising studies on actions against stigmatisation and discrimination, thereby changing negative perceptions and approaches against epileptic patients. The first step is to determine the perceptions of patients and their parents' perceptions towards the disease.

The present study aims to establish a Turkish version of the scales of perceived stigma for children with epilepsy and their parents on the basis of the scale developed by Austin et al. [11]. This study also aims to analyse the scales' validity and reliability in evaluating stigma perceptions amongst young epilepsy patients and their parents.

2. Methods

2.1. Pattern, place and date of study

This study was conducted at a paediatric neurology clinic and polyclinic of a hospital between April 2015 and January 2016.

2.2. Population and sampling

The study's population consisted of parents (n = 85) and children (n = 85) whose ages ranged between 9 and 16 years old. They visited the hospital's paediatric neurology clinic and polyclinic for regular check-up during the predetermined dates. The number of participants could not be specified because the data for the monitoring of people diagnosed with epilepsy could not be obtained from the hospital. No special sampling method was employed. However, the sample size was at least three times and at most five or ten times as many as the number of items on the scale [12]. Thus, the child scale with more items (8) than the parent scale was considered in this study. The objective was to contact at least 80 children and their parents for the sampling. Thus, a total of 85 children qualified on the basis of the following criteria: diagnosed with epilepsy, displayed symptoms for at least three months, age range between 9 and 16, literate, no mental or communicational issue, no co-morbid chronic disease (such as diabetes, cerebral palsy and MMR), and volunteered to participate in the study.

2.3. Data collection tools

2.3.1. Introductory form

The researchers created an introductory form after reviewing the literature [11–15]. This form includes a total of 34 questions on the socio-demographic characteristics of participants, disease characteristics and medicines taken by the patients, and the personal characteristics of their parents.

232 Child scale

The child scale was developed by Austin et al., in 2004 to determine attack-related fears, embarrassment, and feelings of children aged between 9 and 14. The child scale also aims to determine how these factors affect the perceptions of children. It consists of eight items that are answerable through a five-point Likert scale (1 - never, 2 - seldom, 3 - occasionally, 4 - frequently and 5 - quite frequently). The mean score was derived by dividing the total scores of each item by the total number of items (n = 8). High mean scores indicate high stigmatisation perception, and the scale has a Cronbach's α value of 0.81, according to Austin et al. [11].

2.3.3. Parent scale

The parent scale was developed by Austin et al., in 2004 to determine how the parents of epileptic patients compare their children with others. This scale consists of five items that are answerable through a five-point Likert scale (1 - I strongly disagree, 2 - I disagree, 3 - I cannot decide, 4 - I agree and 5 - I strongly agree). The mean score was derived by dividing the total scores of each item by the total number of items (n = 5). High mean scores indicate high stigmatisation perception, and the scale has a Cronbach's α coefficient of 0.79, according to Austin et al. [11].

2.4. Data collection

Data were collected via face-to-face interviews between April 2015 and Ianuary 2016. An appointment system was adopted to follow and monitor epileptic children in the polyclinic. The interviews with the participants were conducted after their routine health check-ups in the secretarial and registration offices next to the polyclinic. The participants were asked questions based on the introductory form, which took approximately 5 min. Moreover, the researcher introduced the child and parent scales to the epileptic children and their parents, respectively. The respondents were asked to complete the scale in approximately 10 min. The test-retest method was used to enhance the reliability of the data. A total of 10 children and their parents retook the scales after two weeks. As determined by the researcher, such a period is long enough to prevent the participants from remembering the items and short enough to prevent any substantial measurable change [16].

2.5. Data analysis

The data were analysed using SPSS 22.0. Meanwhile, the data from the introductory form were evaluated as numbers and percentage values. Experts were also consulted for their opinions. Meanwhile, Bartlett's test, Kaiser—Meyer—Olkin (KMO) index, exploratory factor analysis, principal component analysis, varimax rotation and scree plot test were used to validate the data. Moreover, the coefficients of Cronbach's α and Pearson's product-moment correlation were used to identify internal consistency, homogeneity and thus reliability.

2.6. Study ethics

Permission to adapt the child and parent scales into Turkish and to study them was obtained from the developer herself, Joan K. Austin. Ethics approval numbered 10.03.2015/03 was obtained from the Ethics Committee of the Faculty of Health Sciences at Atatürk University. Moreover, formal written consent was obtained from the hospital where the study was conducted. Ultimately, the study was discussed amongst the participants, and their verbal consent was secured before data collection.

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