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.

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 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

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.

2.3.2. 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 January 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.

3. Results

3.1. Validity findings of Turkish version of child and parent scales of perceived stigma

The validity of language, content and construct of the stigmatisation scales for epileptic children and their parents was assessed. The mean scores of such scales were 24.02±8.47 and 15.68±4.04, respectively.

3.1.1. Language validity

The scales were translated into Turkish by two English language experts with the help of a lecturer and researcher in paediatrics. The translated version was revised and converted into a single form by the researcher. This form was back translated into English by an expert in both languages and cultures. The original and translated scales were compared and checked for errors, such as inappropriate phrases. The final forms of the scales were presented before 10 experts (assistant, associate and full professors) in different fields (paediatric, psychiatric and internal medicine nursing). Such a consultation enabled the selection of the most appropriate translations for each item, as well as the generation of the Turkish version of the scales.

3.1.2. Content validity

The content validity index (CVI) was used to evaluate the experts' opinions. The experts were asked to select one of the following options: 1 = not appropriate, 2 = appropriate but needs minor revisions, 3 = quite appropriate and 4 = completely appropriate. The mean values, medians, standard deviations and lowest and highest scores were used to analyse the scores provided by the experts. Necessary revisions were performed in accordance with the opinions of these experts. Moreover, the child and parent scales were merged into one form. The CVI calculation indicates that an item is excluded from a scale or index if its acceptable mean score is below 2 [17]. The content validity criteria (CVC) and CVI of the child and parent scales were found to be (0.62 and 1.00) and (0.62 and 0.96), respectively. The content validity of both scales was statistically significant because their CVI was greater than their CVC. No item was excluded.

3.1.3. Construct validity

The KMO sampling adequacy measurement was performed to evaluate the applicability of factor analysis for the sampling group. Such an evaluation was conducted before determining the factor structure of the child and parent scales. In addition, the Bartlett's test of sphericity was employed to identify if the factor analysis of the sampling group was appropriate and more than zero.

The KMO coefficients of the child and the parent scales are 0.94 and 0.80, respectively. Moreover, their chi-square value for the Bartlett's test of sphericity are both significant at 625.456 ($P < 0.05$) and 209.311 ($P < 0.05$), respectively.

The findings indicate that the sample size is appropriate for factor analysis. A structure with a single factor which has a total eigenvalue higher than 1.00 emerged following the factor analysis of the child scale. A single factor has an eigenvalue and total variance of 6.07 and 76%, respectively. Meanwhile, a structure with a single factor which has a total eigenvalue higher than 1.00 emerged following the factor analysis of the parent scale. The eigenvalue and total variance of a single factor in the parent scale were found to be 3.3 and 66%, respectively (Table 1).

Table 2 indicates that the factor loads of all items are above 0.30, which makes them acceptable in factor analysis [18]. The factor loads of the Turkish child scale varied between 0.833 and 0.896. Thus, none of its items was excluded (Table 2). Furthermore, Table 3 indicates that the factor loads of all items in the parent scale are above 0.30. The factor loads of the Turkish parent scale varied between 0.757 and 0.896. Thus, none of its items was excluded (Table 3).

3.2. Reliability findings on Turkish version of child and parent scales of perceived stigma

Findings on the reliability of the child and parent scales were derived through item and internal consistency analyses.

3.2.1. Item analysis

Item analysis was conducted to evaluate the relationship between individual item and total item scores [18,19]. This analysis also helped to identify if each item was weighted equally.

As Table 4 shows, the item-total score correlations of the items on the child scale are significant at $P < 0.05$. The item-total score correlations were between 0.836 and 0.900, which are above the acceptable threshold for item analysis.

As shown in Table 5, the item-total score correlations are between 0.767 and 0.884, which are above the acceptable threshold for item analysis. Therefore, the total correlation value of the Turkish parent scale possesses the appropriate reliability level (Table 5).

3.2.2. Internal consistency

Cronbach's α coefficient analysis is used to determine the internal consistency and homogeneity of items in Likert-type scales [16,20]. The Cronbach's α coefficients of the child and parent scales were high at 0.95 and 0.87, respectively.

4. Discussion

Patients coping with a chronic condition such as epilepsy face numerous challenges beyond their physical impairment. Therefore, the capability to measure these challenges precisely is imperative. The psychosocial consequences of epilepsy, such as depression, anxiety, cognition and social factors, may affect a person's long and short-term quality of life depending on the severity of the condition [21].

The KMO coefficient of the child scale was found to be 0.94, which is expected to be equivalent to or higher than 0.70 [22–24]. This finding indicates that sample size is not appropriate for factor analysis. According to Tavşancıl [25], the factor structure of the scale is powerful if the variance rates obtained from factor analysis are substantial.

Table 1 shows that the chi-square value for the Bartlett's test of sphericity is significant at 625.456. Therefore, the data are appropriate for factor analysis. The calculated chi-square value of the Bartlett's test of sphericity has to be statistically significant for the data to be suitable for factor analysis [19,20].

Findings demonstrate that the KMO coefficient of the parent scale is 0.80, which is expected to be equivalent to or higher than 0.70 [22–26]. This result indicates that the sample size is not appropriate for factor analysis. Table 1 demonstrates that the chi-square value of the Bartlett's test of sphericity is significant at 209.311. Thus, the data are appropriate for factor analysis.

Factor analysis converts many variables into a few categories or factors. Informative factor analysis is conducted to determine construct validity. The most significant step in the model estimation of factor analysis is determining the number of factors [26,27]. Principal component analysis and varimax rotation method were used for exploratory factor analysis. Varimax analysis was conducted to bring the factors together with the items that have a high correlation [28]. A structure with single factor which has a total

Table 1
The KMO and Bartlett's test of the child and parent scales.

		Child Scale	Parents Scale
Kaiser-Meyer-Olkin Test (KMO)		0.936	0.799
Bartlett's Test of Sphericity	χ^2	625.456	209.311
	SD	28	10
	P	<0.001	<0.001

Note: SD: Standard Deviation.

Table 2
Factor loads matrix of the child scale.

Item	Component
8. How often do you avoid from talking with other people about your attacks?	0.896
3. How often do you feel that other children get disturbed by your attacks?	0.888
4. How often do you feel that people may avoid from being friends with you when they learn you have attacks?	0.888
7. How often do you hide the fact that you have attacks from other children?	0.875
6. How often do you feel that you are embarrassed due to your attacks?	0.873
1. How often do you feel that you are different than other children due to your attacks?	0.863
2. How often do you feel that people may dislike you when they learn you have attacks?	0.851
5. How often do you feel that people may not wish to go out with you or invite you to parties when they learn you have attacks?	0.833

Table 3
Factor loads matrix of the parent scale.

Item	Component
5. _____ is stigmatized by many people due to the attacks.	0.888
2. What I tell people about _____ 's attacks does not matter. People generally go their own way.	0.825
3. _____ always feels like he/she has to prove himself/herself due to epileptic attacks.	0.811
1. Those who know _____ has attacks treat him/her differently.	0.778
4. _____ will have problems finding a partner due to epileptic attacks.	0.757

Table 4
Item-total score correlations of the child scale.

	r	P
Item 1	0.854	<0.001
Item 2	0.851	<0.001
Item 3	0.888	<0.001
Item 4	0.887	<0.001
Item 5	0.836	<0.001
Item 6	0.874	<0.001
Item 7	0.877	<0.001
Item 8	0.900	<0.001

Table 5
Item-total score correlations of the parent scale.

	r	P
Item 1	0.767	<0.001
Item 2	0.819	<0.001
Item 3	0.809	<0.001
Item 4	0.779	<0.001
Item 5	0.884	<0.001

eigenvalue higher than 1.00 emerged from the factor analysis of the child scale. The eigenvalue and total variance of a single factor were found to be 6.07 and 76%, respectively. Thus, the original scale suits the single factor structure. Meanwhile, a structure with a single factor which has a total eigenvalue higher than 1.00 emerged from the factor analysis of the parent scale. The eigenvalue and total variance of a single factor were found to be 3.3 and 66%, respectively. Thus, the original scale suits the single factor structure.

Table 2 indicates that the factor loads of all items are above 0.30 which makes them acceptable in factor analysis [18]. According to Kline, such a value is acceptable because it is over 40% [29,30]. The factor loads of the Turkish child scale varied between 0.833 and 0.896. Thus, none of its items was excluded (Table 2). Meanwhile, Table 3 indicates that the factor loads of all items in the parent scale are above 0.30. The factor loads of the Turkish parent scale varied between 0.757 and 0.896. Thus, none of its items was excluded (Table 3).

As Table 4 shows, the item-total score correlations of the items in the child scale are significant at $P < 0.05$. Item-total score correlation is an indicator if an item evaluates a characteristic that should be measured completely. The lowest value that may be an indicator of an item's consistency was 0.20 [31,32]. The item-total score correlations are between 0.836 and 0.900, which are above the acceptable threshold for item analysis. Therefore, the total correlation value of the Turkish child scale is at the appropriate reliability level.

Cronbach's α coefficient analysis is used to determine the internal consistency and homogeneity of items in Likert-type scales [16,33]. High α coefficients indicate that the items are consistent, and the scale consists of items measuring the same characteristics. Reliability coefficients should be close to 1 for Likert-type scales [33]. In previous literature, the correlation coefficient for detecting time-induced changes in a scale is positive and high. Moreover, the value for scales is at least 0.70 [20,25]. The Cronbach's α coefficients of the child and parent scales were high at 0.95 and 0.87, respectively. Thus, both the child and parent scales do not have any problematic item, and their internal consistency is high.

Limitations of Research: The study was conducted amongst children with epilepsy and their parents who visit the neurology clinic of a certain hospital. Therefore, the results of the study can be generalised only to the population of children with epilepsy and their parents.

5. Conclusion and recommendations

The following conclusions can be drawn from the study:

- All the experts agreed for the scale items to be translated to Turkish using the reliability criteria for harmonisation between the content validity and independent observers. Moreover, the scale is appropriate for the Turkish culture.
- The total item correlation of the scale items indicate that no item was excluded. Such finding was due to a statistically significant relationship between the items and scale. Thus, each item is reliable enough for use.
- The scale had a high internal consistency coefficient for the sample group. Thus, each item represented the scale.
- The child and parent scales should be used as a single-dimension scale.
- Consequently, the scale can be used to determine the level of stigmatisation amongst parents and epileptic children aged between 9 and 16 years old.

Author contributions

Study conception/design; Semra Köse, Ayda Çelebioğlu.
Data collection/analysis; Semra Köse.
Drafting of manuscript; Semra Köse, Ayda Çelebioğlu.
Critical revisions for important intellectual content; supervision; Semra Köse, Ayda Çelebioğlu.
Statistical expertise; Ayda Çelebioğlu, Semra Köse.
Administrative/technical/material support; Semra Köse, Ayda Çelebioğlu.

Appendices. Supplementary data

Appendices include the Turkish version of the scales of perceived stigma for children with epilepsy and their parents, and a Chinese abstract of this article. Supplementary data related to this article can be found at https://doi.org/10.1016/j.ijnss.2018.07.004.

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