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Psychometric properties of a Turkish version of the quality of life in childhood epilepsy questionnaire

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ABSTRACT

Background: Epilepsy is a neurological disease that requires long-term treatment and monitoring and causes significant restrictions in physical, emotional, intellectual, and social life that negatively affect the quality of life of the individual. This study aimed to test the validity and reliability of the Quality of Life in Childhood Epilepsy Questionnaire in Turkey.

Methods: The study was conducted on 421 parents using a descriptive correlational method. The data of the study were collected using a Descriptive Information Form and the Quality of Life in Childhood Epilepsy Questionnaire. Data analysis and evaluation were performed using factor analysis, Cronbach's alpha, and item–total score correlation.

Findings: The scale consists of 16 items and four sub-dimensions. The four sub-dimensions recorded a variance of 87.83%. Cronbach's alpha coefficient of the Turkish version of the scale was 0.96. The two-month test-retest reliability evaluated with intra-class correlation was 0.85. Confirmatory factor analysis indicated, the model fit index results were recorded as follows: 0.93 as the Goodness-of-Fit Index; comparative fit index, 0.98 and non-normed fit index (NNFI), 0.97.

Conclusions: The study determined that the Turkish version of the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-16) is a valid and reliable measurement tool when used to measure quality of life for Turkish children with epilepsy.

Practice implications: It is recommended that the health-related quality of life should be evaluated to assess the treatment of children with epilepsy and to intervene early in potential risk factors associated with the disease management process. All healthcare professionals can use this scale in interventional studies aiming at evaluating or improving the quality of life of children with epilepsy.

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Introduction

Epilepsy is a chronic disease that is most prevalent among neurological system diseases and affects individuals of all age groups (Leal et al., 2020). It affects nearly 50 million people worldwide, and it is estimated that around two million new cases of epilepsy develop each year (World Health Organization, 2019). At least 50% of the cases begin in childhood or adolescence and affect a total of 65 million people around the world, including 10.5 million under the age of 15 (WHO, 2019).

Epilepsy is a neurological disease that requires long-term treatment and monitoring and causes significant restrictions in physical,

emotional, intellectual, and social life that negatively affect the quality of life of the individual (Conway et al., 2016; Fayed et al., 2015). It is very important to evaluate the well-being and quality of life of children with epilepsy (Bilgiç et al., 2018; Conde-Guzón et al., 2020; Momen et al., 2019). Studies have emphasized that children with epilepsy have lower quality of life compared to their healthy peers due to factors, such as seizure attacks, frequency and severity of seizures, unpredictable time of seizures, side effects associated with antiepileptic drug (AEDs) treatment, and perceived stigma associated with epilepsy (De La Loge et al., 2016; Jovanovic et al., 2015; Love et al., 2016; Momen et al., 2019; Nagabushana et al., 2019). However, it has also been reported that apart from the effects of seizures, emotional and behavioral problems experienced by children with epilepsy further reduce the health-related quality of life (Reilly et al., 2015). Studies conducted so far show that lack of knowledge about epilepsy causes negative attitudes, behavioral problems, and stigma, and thus affects the quality of

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life of children and parents. Especially children face many psychological stressors from the moment of diagnosis, and this causes behavioral problems such as anxiety, fear, depression, and social withdrawal in children (Dunn & Walsh, 2018; LaGrant et al., 2020; Reilly et al., 2015). One of the most important psychosocial problems experienced by children with epilepsy is stigma. Children who are stigmatized due to epilepsy develop stress and depression, their adherence to treatment decreases, and the quality of life of the child declines (Austin et al., 2014; Kanemura & Aihara, 2016; Moon et al., 2016; Mula & Sander, 2016; Radović et al., 2017).

Health-related quality of life (HRQOL) is a multidimensional concept that reflects the individual's well-being in terms of physical, emotional, mental, and social behaviors and is generally defined as the way a patient perceives the effects created by the disease and its treatment. HRQOL refers to an individual's perception of his/her position in life in the context of culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards, and concerns (de Wit & Hajos, 2013). HRQOL measures encompass multiple areas of functioning of subjective wellbeing and are considered crucial to comprehensive management (Nagabushana et al., 2019).

According to the International League against Epilepsy (ILAE) Commission on Epidemiology, HRQOL refers to the “most comprehensive and significant outcome of any chronic health condition.” Evaluating the control of epilepsy only by following the frequency and severity of seizures and screening the side effects of AEDs is not enough to evaluate the general health of children with epilepsy (Nagabushana et al., 2019).

The responses of children aged below 12 may vary during the evaluation of their quality of life depending on their developmental level. Since the child-reported quality of life can vary, parent-reported quality of life should also be measured (Rajmil et al., 2004). Also, it is emphasized that parental reporting is as important as self-reporting of the child in the assessment of health-related quality of life, and it may be difficult for children who lack the necessary cognitive and linguistic skills to explain their difficulties or problems related to their chronic diseases; therefore, the necessity of parental reporting is highlighted in evaluating the quality of life (Conde-Guzón et al., 2020; Pukaa et al., 2020). Parents play a chief role both in the disease management process of the child with epilepsy and in coping with psychosocial problems (Lambert et al., 2014). Parents, as supervisors, are at the center of the management of the disease as much as children, for example, at the time of diagnosis (family observations in determining the age of the onset of seizure and the type of seizure), in follow-ups (decision-making about medical/surgical treatment), and in the management of the seizure that the child can experience at any time (Conde-Guzón et al., 2020). Studies suggest that in the disease management of children with epilepsy, the health-related quality of life of children should be routinely evaluated from a parental perspective, so that the expectations of both the child and the parents will be understood more clearly and therapeutic assistance will be developed (Cianchetti et al., 2015).

Following a review of the literature, The Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-16) was developed by Goodwin et al. to measure parent-reported of the HRQOL of the children with epilepsy. This scale is a valid and reliable measurement tool that can be used by all healthcare professionals and can be easily filled out by parents due to its low number of items (Goodwin et al., 2018). Currently, there is no measurement tool in Turkey that evaluates the quality of life of children with epilepsy from a parental perspective, is specific to the disease, and has been confirmed for validity and reliability. It is thought that conducting the Turkish validity and reliability study of the QOLE-16 scale will make it possible to obtain standard and objective data on the quality of life of children with epilepsy from a parental perspective, thereby positively influencing the disease management process of the child and the parent. In this context, this study was conducted to examine the Turkish psychometric properties of the QOLCE-16, which evaluates the quality of life of children with epilepsy from a parental perspective.

Purpose

This study aimed to test the validity and reliability of the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-16) in Turkey.

Methods

Study design

A descriptive, cross-sectional, and methodological design was used in the study.

Population and sample of the study

The study was conducted with 421 parents with children who had epilepsy were enrolled in the pediatric neurology outpatient clinic of a university hospital in the western region of Turkey. The inclusion criteria were a) parents who had 4–12-year-old children with epilepsy; b) whose children were diagnosed with epilepsy at least six months ago; and c) who volunteered to participate in the study and submitted written consent were included in the study. The exclusion criteria were a) parents who did not agree to participate in the study and b) whose children had other chronic diseases (diabetes, cerebral palsy, etc.) were not included in the study. The sample size for psychometric studies in the literature is suggested to be as follows: ≥ 1000 , excellent; 500–1000, very good; and 200–500, good (Karagöz, 2018). In this study, the sample consisted of 421 parents who met the inclusion criteria and submitted verbal and written consent.

Ethics committee approval

To conduct the study, first, the permission of the owner of the scale was obtained (Goodwin et al., 2018) via email. Afterward, the approval of the non-clinical research ethics committee and written permission of the institution where the scales would be applied were obtained. After obtaining the necessary permissions, the researchers informed the parents about the purpose of the study. Afterward, the scales were administered to parents who met the inclusion criteria and submitted verbal and written consent.

Data collection tools

The data of the study were collected using a descriptive information form and the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-16). The descriptive information form, which was prepared by the researchers in line with the literature, consists of 13 items soliciting socio-demographic characteristics and information about the child's illness.

The Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-16)

The Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-16) was developed by Goodwin et al. to measure parent-reported of the health-related quality of life of the children with epilepsy aged between 4 and 12. The questionnaire uses a 5-point Likert-type scale and consists of 16 items and four sub-dimensions.

The sub-dimensions, each of which has four items, are cognitive functioning, emotional functioning, social functioning, and physical functioning, respectively. The overall Cronbach's alpha coefficient of the original scale is 0.90. The item-total score correlation of the scale is between 0.58 and 0.79. The model fit indices of the scale are as follows: comparative fit index (CFI) = 0.99; Tucker-Lewis index (TLI) = 0.99; and root mean square error of approximation (RMSEA) = 0.052 (Goodwin et al., 2018).

Translation

The scale was translated into Turkish by three linguists independently. Following this, the translation was reviewed and evaluated by the researchers. Then, the scale was revised by a Turkish language expert. The draft Turkish version of the Quality of Life in Childhood Epilepsy Questionnaire was translated back into English by two independent bilingual, bicultural translators whose native language was English and who had experience in health terminology and linguistic and cultural aspects of the English language, producing two independent back-translated versions of the scale (Sousa & Rojjanasrirat, 2011).

Expert opinion

Content validity assesses the degree to which an instrument has an appropriate sample of items for the construct being measured and it adequately covers the construct domain. It was recommended to use at least three expert opinions to determine content validity of scales (Şencan, 2005). Four nursing faculty members, two pediatric neurologists, and a pediatric psychologist were consulted for an evaluation of the construct and content validity of the scale. The experts were asked to evaluate the items for appropriateness by comparing the original and draft Turkish versions of the questionnaire on a scale with options ranging from 1 (not relevant) to 4 (highly relevant). The item-level content validity index (I-CVI) and the scale-level content validity index (S-CVI) were calculated (Karagöz, 2018; Polit et al., 2007). The CVI value was employed to analyze the consistency of the expert opinions. The CVI for the overall instrument shows the percentage of total items rated by the experts as quite or very relevant based on a four-point scale. A CVI score of greater than 90% indicates excellent agreement (Polit & Beck, 2018).

Preliminary test

It is recommended that after expert opinions are obtained, the scale should be administered to a group of about 20–30 people who have similar characteristics with the subjects of the study but will not be included in the sampling of the study (Şencan, 2005). A pilot study was administered to 30 parents who consented to participate in the study, and this group was excluded from the sampling (Şencan, 2005). Parents did not give any negative feedback about the readability, intelligibility, or response time. No negative feedback was provided about the clarity of the scale after the testing. The comprehensibility of the scale was determined to be sufficient in the pilot and was then applied to the full sample.

Data collection process

The researchers informed the parents about the aim of the study in the pediatric neurology training room, obtained their written consent, and then administered the scales used in the study. It took each parent about 10–15 min to complete the questionnaire. During the administration process of the questionnaire, the questions on the scales were found comprehensible by all parents.

Statistical analysis

Data were analyzed using the SPSS Statistics (v.22.0; SPSS, Chicago, Illinois, USA) and AMOS software packages. The descriptive statistics relating to sociodemographic information collected from parents were presented as frequencies, percentages, and mean values.

In this study, content validity and construct validity were used to ensure the validity of the Turkish version of the scale. The Content Validity Index (CVI) was used to assess the fit between the expert judgment (Polit et al., 2007).

Exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) were conducted to examine the validity of the Turkish version of the QOLCE-16. EFA was used to determine the relationship between

item and factor. Before conducting the EFA, the adequacy of the data for factor analysis was evaluated using the Kaiser–Meyer–Olkin (KMO) test and Bartlett's test of sphericity (Şimşek, 2010; Zamanzadeh, Ghahramanian, Rassouli, Abbaszadeh, & Alavi, 2015).

CFA was used to determine whether the items and subscales explained the original scale structure. The model verification of the comparative fit index (CFI) was conducted on the basis of the chi-square test, degree of freedom, root mean square error of approximation (RMSEA), goodness of fit index (GFI) and normal fit index (NFI) (Şencan, 2005).

For the reliability analysis, item-total score analysis, Cronbach's alpha coefficient, split-half analysis (Spearman-Brown and Guttman split-half values) and test-retest analysis were used to determine the internal consistency of the scale and its subscales. Pearson correlation analysis was used for the item–total score analysis. The significance level was accepted to be less than 0.01.

Results

Table 1 presents data regarding the sociodemographic characteristics of the parents included in the study and the sociodemographic and disease information about the children with epilepsy.

Validity analysis

In this study, content validity and construct validity were used to ensure the validity of the Turkish version of the scale.

Content validity

Seven experts were consulted for the draft (Turkish version) form of the scale. The opinions of the seven experts were evaluated with the content validity index. The I-CVI was 0.90 and the S-CVI was 0.94, which were found consistent.

Construct validity

The construct validity of the Turkish version of the QOLCE-16 was evaluated using EFA and CFA analyses. The fit of the sample included in the study for factor analysis was evaluated using KMO and Bartlett X^2 tests (Karagöz, 2018). A Bartlett chi-square test score of <0.05 is required to evaluate factor analysis. A KMO value of close to 1 is considered perfect, and it is found inappropriate when it is <0.50 . The Turkish version is based on EFA, which comprises four subscales, and the total variance of the subscales was 87.834%. Also, the factor load rate of the scale ranged between 0.749 and 0.966 (Table 2).

EFA and CFA

According to the result of CFA, factor load values were found to range between 0.47 and 0.97. The factor loads of the sub-dimensions were between 0.85 and 0.93 for the cognitive functioning sub-dimension, 0.86 and 0.94 for the emotional functioning sub-dimension, 0.87 and 0.97 for the social functioning sub-dimension, and 0.47 and 0.85 for the physical functioning sub-dimension (Fig. 1). As for model fit indexes, model chi-square (χ^2) was 235.54 (df: 92), and the root mean square error of approximation (RMSEA) was 0.062. Another parameter for model fit is calculated by dividing χ^2 value by the degree of freedom. If the result is less than 5, the model fit is evaluated to be satisfactory (Şencan, 2005). The result of this calculation was <5 ($\chi^2/df = 2.56$) (Table 3). Other indices were found as follows: GFI, 0.93; CFI, 0.98; IFI, 0.98; RFI, 0.98; NFI, 0.98; and NNFI, 0.97 (Table 3).

Reliability analysis

Cronbach's alpha coefficient of the Turkish version of the scale was 0.96. The two-month test-retest reliability evaluated with intra-class

Table 1
Demographic characteristics of parents and children with epilepsy (N = 421).

Demographic characteristics of parents having children with epilepsy		
Mean	Standard	Deviation
Age (years)		
Mean age of mothers	33.81	5.43
Mean age of the fathers	37.56	5.39
	N	%
Respondent		
Mother	282	67.0
Father	139	33.0
Total	421	100.0
Education		
Without school leaving certificate	16	3.8
Primary school	86	20.4
Middle school	61	14.5
High school	180	42.8
University	78	18.5
Marital status		
Living with spouse/partner	409	97.1
Single parent	12	32.9
Presence of another person with epilepsy in the family		
Yes	106	25.2
No	315	74.8
<i>Demographic characteristics of children with epilepsy</i>		
	Mean	Standard Deviation
Age (years)		
	9.02	3.9
	N	%
Gender		
Female	193	45.8
Male	228	54.2
Total	421	100.0
School attendance		
Yes	300	71.3
No	121	28.7
When was the last time the child had a seizure?		
0–6 months ago	159	37.8
7–12 months ago	88	20.9
≥13 months ago	174	41.3
How often children had seizures in the past 6 months?		
1–2 times	37	8.8
3–5 times	24	5.7
1–2 times a month	42	10.0
More than once a week	47	11.2
More than once a day	9	2.1
Children taking the medication regularly		
Yes	421	100.0
No	–	–
	N	%
Medication tracking		
Children themselves	35	8.3
Parents	386	91.7
Medication duration of children with epilepsy		
0–11 months	130	30.9
1–3 years	77	18.3
4–6 years	99	23.5
7–9 years	65	15.4
>10 years	50	11.9

correlation was 0.85. According to the split-half analysis, Cronbach's alpha coefficients of the first and second halves were 0.93 and 0.93, the Spearman-Brown coefficient was 0.92, the Guttman's split-half coefficient was 0.88, and the correlation coefficient between the halves was 0.86 (Table 4). The item-total correlations of the scale were found to range between 0.729 and 0.843 and evaluated as statistically significant ($p < .001$).

Discussion

The evaluation of the quality of life of the child with epilepsy and his/her family will make it possible to establish a more realistic and holistic relationship with the patient, as well as obtaining standard and objective data. Thus, it is emphasized that the healthcare service provided

Table 2
Factor analysis and corrected item–total correlation of Turkish version of the quality of life in childhood epilepsy questionnaire.

Item No	Item Description	Factor Loading	Corrected Item Total Correlations
Child's Cognitive Functioning			
1	Had trouble understanding directions?	0.896	0.879
2	Had difficulty following complex instructions?	0.907	0.890
3	Had difficulty following simple instructions?	0.888	0.865
4	Had trouble remembering things people told him/her?	0.931	0.920
Child's Emotional Functioning			
5	Felt nobody understood him/her?	0.926	0.917
6	Felt down or depressed?	0.928	0.917
7	Felt frustrated?	0.892	0.870
8	Felt confident?	0.937	0.924
Child's Social Functioning			
9	How limited are your child's social activities compared with others his/her age because of his/her epilepsy or epilepsy-related problems?	0.915	0.901
10	Affected his/her social interactions at school or work?	0.923	0.910
11	Isolated him/her from others?	0.906	0.885
12	Made it difficult for him/her to keep friends?	0.966	0.960
Child's Physical Functioning			
13	Played freely outside the house like other children his/her age?	0.845	0.820
14	Been able to do the physical activities other children his/her age do?	0.749	0.705
15	Played freely in the house like other children his/her age?	0.836	0.452
16	Needed more supervision than other children his/her age?	0.750	0.724
Explained Variance (%) 87.834%			

to the child and his/her family can reach a much better and qualified level. Studies have shown that children with epilepsy have a low quality of life compared to their healthy peers and that health professionals do not attach enough importance to the quality of life in the management of epilepsy (Nagabushana et al., 2019). However, it is emphasized in the literature that quality of life in children with epilepsy is increasingly gaining importance in the management of epilepsy due to the medical, social, and psychological complications of seizures and antiepileptic drugs (Crudgington et al., 2020).

Health professionals should be aware of the factors that affect the quality of life of children, especially with the recommendation of individualized antiepileptic drugs specific to children with epilepsy (Riechmann et al., 2019). Using epilepsy-specific quality of life scales will help find out about the level of quality of life of children, recognize the effects of quality of life on epilepsy management, provide child-specific individualized care and treatment (Cianchetti et al., 2015; Pachange et al., 2021). The validity and reliability results of the scale whose validity and reliability study was conducted in this study in the Turkish sample are given below.

Validity analysis

Content validity analysis

The results of the content validity analysis indicated a high level of fit among expert opinions and also a satisfactory item representation of the intended areas. It was determined that item and scale-level content validity indices were greater than 0.80, there was a high level of agreement among experts, and the items adequately represented the intended domain. Accordingly, we concluded that the statements of the scale were found to correlate with Turkish culture, representing and providing the area to be measured for content validity (Ruddock

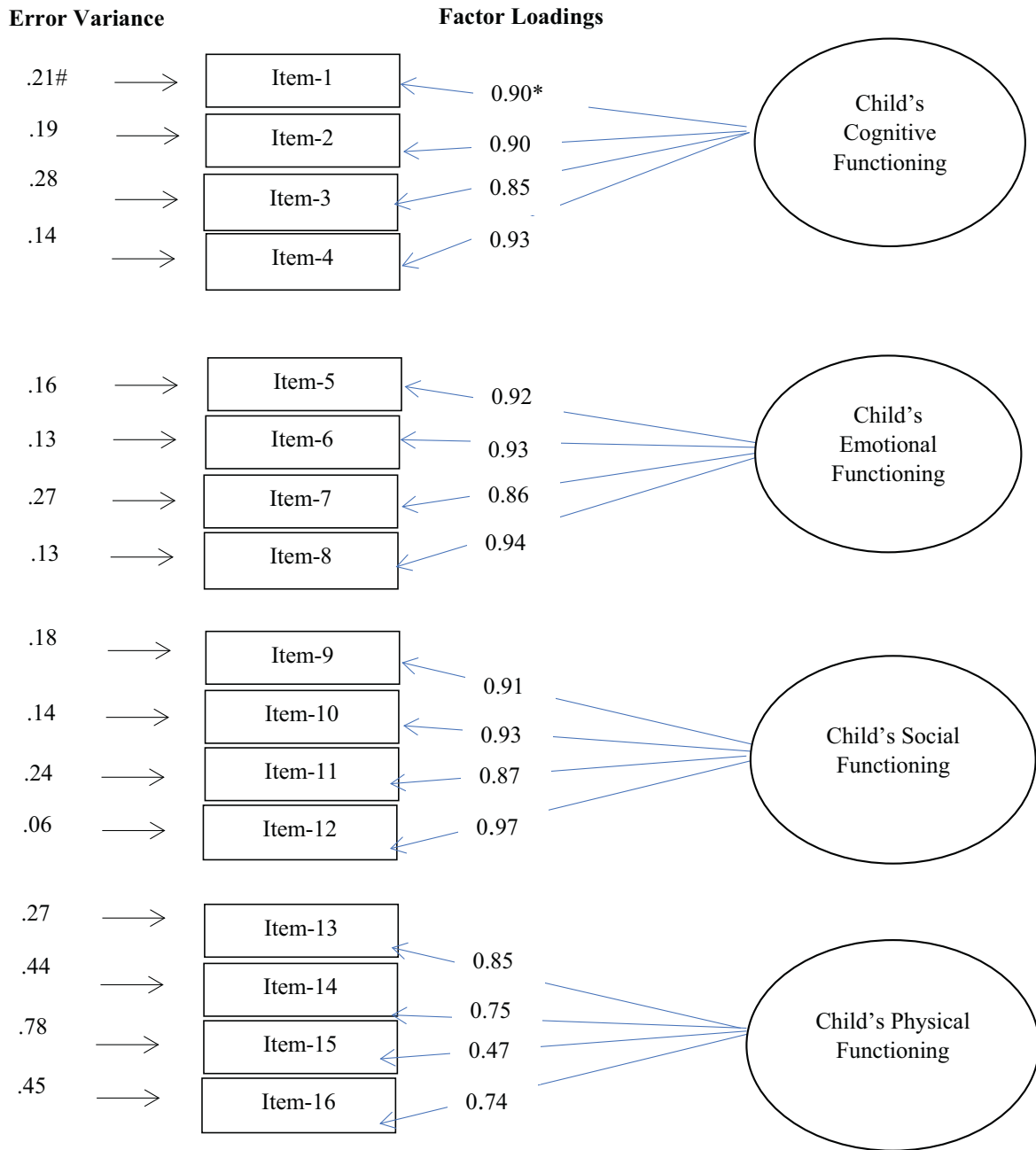


Fig. 1. Confirmatory factor analysis of Turkish version of The Quality of Life in Childhood Epilepsy Questionnaire (QOLE-16). *Factor loadings; #Error variance: The part of the total variance caused by anything irrelevant that was not experimentally controlled.

et al., 2017). The results of this study showed that the scale could evaluate the quality of life of children with epilepsy from a parental perspective in a Turkish sample.

Table 3
Model goodness of fit indices of the Quality of Life in Childhood Epilepsy Questionnaire.

Four Factor Model	χ^2	df ^a	χ^2/df	RMSEA ^b	GFI ^c	CFI ^d	IFI ^e	RFI ^f	NFI ^g	NNFI ^h
Model	235.54	92	2.56	0.062	0.93	0.98	0.98	0.98	0.98	0.97

^aDegree of Freedom, ^b(Root Mean Square Error of Approximation), ^cGoodness of Fit Index, ^dComparative Fit Index, ^eIncremental Fit Index, ^fRelative Fit Index, ^gNormed Fit Index, ^hNNFI: non-normed fit index.

Construct validity of the scale

The fit of the sample included in the study for factor analysis was evaluated with KMO and Bartlett χ^2 test. The Bartlett test was significant and the KMO value was greater than 0.60, which indicated that the data were appropriate for factor analysis and that the sample size was adequate (DeVellis, 2016; Jonhson & Christensen, 2014). Generally, the explained variance in multidimensional scales should be greater than 40%, and the higher the total variance, the stronger the construct validity (Çam & Baysan-Arabaci, 2010; Şencan, 2005). These findings supported the construct validity of the scale (Şencan, 2005).

EFA and CFA

In the literature, it is emphasized that the factor load should be at least 0.30 for an item to be included on a scale (DeVellis, 2016;

Table 4
Results of the reliability analysis of the scale and sub-dimension (n = 421).

	Cronbach α	First half Cronbach α	Second half Cronbach α	Spearman Brown	Guttman split-half	Correlation between two halves	M \pm SD (Min-Max)
Scale Total	0.96	0.93	0.93	0.92	0.88	0.86	38.26 \pm 13.46 (20–57)
1st sub-dimension	0.94						
2nd sub-dimension	0.75						
3rd sub-dimension	0.95						
4th sub-dimension	0.77						

Jonhson & Christensen, 2014). The EFA result revealed that the Turkish version of the scale maintained the initial established scales in terms of factor load because of the resemblance factor load that yielded validity and well-fortified characteristics for the Turkish sample. In this study, it was observed that the Turkish version preserved the original structure and had a strong factor structure for the Turkish sample since the factor loads of all items on the scale were greater than 0.30 and similar to the factor loads in the original scale (Goodwin et al., 2018). According to the results of this study, the scale consists of items that can accurately measure the quality of life of children from a parental perspective and that it can measure the quality of life at an adequate level (Jonhson & Christensen, 2014). The results of this study showed that the scale had valid and strong construct validity for the Turkish sample.

In cultural adaptation studies, it is recommended that both an explanatory factor analysis and a confirmatory factor analysis should be conducted (Jonhson & Christensen, 2014). In this study, the suitability of the factor structure determined by the explanatory factor analysis was evaluated with the confirmatory factor analysis. As a result of CFA, it was determined that the value obtained by dividing the degree of freedom by the chi-square value was less than five, the RMSEA was less than 0.08, the fit indices were greater than 0.90, and that the factor loads of all items were greater than 0.30. Goodwin et al. (2018) also found fit indices of greater than 0.80 and an RMSEA value of less than 0.08. On the other hand, EFA results indicated that the scale confirmed the four-factor structure and results indicate that the original form of the scale and that the items in each sub-dimension defined their factor and measured the concept to be measured adequately. Accordingly, the results of this study are similar to the results of confirmatory factor analysis in the original scale. As a result of CFA, it was found that the items on the scale were related to their sub-dimensions, they were appropriate for assessing the quality of life of children with epilepsy, and that the scale was suitable for evaluating the quality of life of children with epilepsy from a parental perspective in the Turkish sample (Jonhson & Christensen, 2014).

Reliability analysis of the scale

Internal consistency analysis of the scale and its sub-dimensions

The calculation of the Cronbach's alpha coefficient is the frequently used method in the literature for determining the reliability levels (Şencan, 2005). A Cronbach's alpha coefficient of less than 0.60 indicates that the scale has low reliability. A value between 0.60 and 0.80 shows the scale is quite reliable. A value between 0.80 and 1.00 indicates that the scale is highly reliable (Şencan, 2005). In this study, Cronbach's alpha coefficients of the overall scale and sub-dimensions were greater than 0.80, which indicated that the scale had a high level of reliability (Karagöz, 2018). The Cronbach's alpha values in this study were found above 0.80, which showed that the Turkish version of the scale was similar to the original scale and had a strong internal consistency (Goodwin et al., 2018). Cronbach's alpha results in this study revealed that the items on the scale were consistent with each other, they were created to measure the quality of life in children with epilepsy and that they formed a whole. This result indicated that it was a reliable scale in measuring the quality of life from a parental perspective.

One of the methods recommended in the literature for the analysis of reliability is the split-half method. In the split-half method used in this study, Cronbach's alpha values of both halves were greater than 0.70, there was a strong and significant relationship between the two halves, the Spearman-Brown and Guttman Split-Half coefficients were greater than 0.70, and the scale had a high level of reliability (Şencan, 2005). These results indicated that each item was highly correlated with the scale, they adequately represented the domain to be measured, the scale measured the subject to be measured sufficiently, and that the item reliability of the scale was high. While these results demonstrated that the internal validity of the scale was high, the results could not be compared with the findings reported by Goodwin et al. (2018), as a two-halves analysis was not conducted in that study. In addition, the test-retest analysis was performed to test the reliability of the scale. The test-retest analysis is the correlation between the scores. It is obtained by applying a scale to the same group of individuals at certain intervals. High test re-test correlation coefficients show high reliability, and a correlation coefficient between 0.80 and 0.90 indicates good reliability. In this study, the test-retest correlation coefficient was 0.848, and this value indicated that the Turkish scale had a high correlation coefficient. These results showed that each item was highly correlated with the scale, they determine that the topic is measured adequately. These results showed that the items on the scale were consistent with each other, were suitable for measuring the quality of life, and were related to each other.

Item-total score analysis of the scale and its sub-dimensions

Item-total score analysis shows the relationship between the scores obtained from the scale items and the total score of the scale (Şencan, 2005). This value must be positive and greater than 0.30 (Şencan, 2005). In this study, it was found that both item-total score and item-sub-dimension total score correlation coefficients were positive and greater than 0.30. It was also determined that all items of the scale had a high level of correlation with the total score, they measured the desired quality at an adequate level, and that the items of the scale had a high level of reliability. The result of this study indicated that the items are related to the whole scale and that the items can measure the quality of life.

The use of the scale in clinical practice

It is recommended that the health-related quality of life should be evaluated to assess the treatment of children with epilepsy and to intervene early in potential risk factors associated with the disease management process (Phillips et al., 2020). With the introduction of this scale to the Turkish language, the evaluation of the quality of life of children with epilepsy can be done with a measurement tool whose validity and reliability have been established. With the use of this scale, it will determine the quality of life of children and families followed in outpatient clinics and allow early intervention. In addition, it is thought that the introduction of this scale to the literature will help examine the quality of life of children with epilepsy from different cultures and factors affecting it and contribute to the field by providing an intercultural comparison. All healthcare professionals can use this scale aiming at evaluating or improving the quality of life of children with epilepsy. These studies evaluate children's quality of life from a parental

perspective cross-sectionally. Longitudinal and experimental studies are recommended to evaluate the long-term effectiveness of the scale. In addition, the scale can be used to evaluate the quality of life of children with epilepsy in clinics.

Limitation

This study has some limitations. The study sample consisted of parents of children with epilepsy who came to the pediatric neurology outpatient clinic of a university hospital, and it is thought that this may increase the risk of selection bias, reduce representativeness, and limit the generalizability of the results. In addition, cross-cultural comparisons could not be made due to the lack of studies that conducted the validity and reliability study of the scale in different languages.

Conclusions

As a result of the analysis, it was determined that the Turkish version of the QOLCE-16 consisted of four sub-dimensions similar to the original scale. In addition, similar to the original scale, it was found that Cronbach's alpha coefficients of both the overall scale and sub-dimensions were high and that the Turkish version of the scale achieved cultural equivalence. The study determined that the Turkish version of the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-16) is a valid and reliable measurement tool when used to measure quality of life for Turkish children with epilepsy.

Declaration of Competing Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the article.

References

- Austin, J. K., Perkins, S. M., & Dunn, D. W. (2014). A model for internalized stigma in children and adolescents with epilepsy. *Epilepsy & Behavior*, 36, 74–79. <https://doi.org/10.1016/j.yebeh.2014.04.020>.
- Bilgiç, A., Işık, Ü., Çolak Sivri, R., Derin, H., & Çaksen, H. (2018). Psychiatric symptoms and health-related quality of life in children with epilepsy and their mothers. *Epilepsy & Behavior*, 80, 114–121. <https://doi.org/10.1016/j.yebeh.2017.12.031>.
- Çam, M. O., & Baysan-Arabacı, L. (2010). Qualitative and quantitative steps on attitude scale construction. *Hemşirelikte Araştırma Geliştirme Dergisi [Journal of Research and Development in Nursing]*, 12(2), 59–71.
- Cianchetti, C., Messina, P., Pupillo, E., Crichiutti, G., Baglietto, M. G., Veggiotti, P., et al. (2015). The perceived burden of epilepsy: Impact on the quality of life of children and adolescents and their families. *Seizure*, 24(C), 93–101. <https://doi.org/10.1016/j.seizure.2014.09.003>.
- Conde-Guzón, P. -A., Soria-Martín, C., Cancho-Candela, R., Quirós-Expósito, P., Conde-Bartolomé, P., & Bulteu, C. (2020). Parental report of quality of life in children with epilepsy: A Spanish/French comparison. *Epilepsy & Behavior*, 105, 106968. <https://doi.org/10.1016/j.yebeh.2020.106968>.
- Conway, L., Smith, M. L., Ferro, M. A., et al. (2016). Correlates of health-related quality of life in children with drug resistant epilepsy. *Epilepsia*, 57, 1256–1264. <https://doi.org/10.1111/epi.13441>.
- Crudgington, H., Rogers, M., Morris, H., et al. (2020). Epilepsy-specific patient-reported outcome measures of children's health-related quality of life: A systematic review of measurement properties. *Epilepsia*, 61, 230–248.
- De La Loge, C., Dimova, S., Mueller, K., Phillips, G., Durgin, T. L., Wicks, P., & Borghs, S. (2016). PatientsLikeMe® online epilepsy community: Patient characteristics and predictors of poor health-related quality of life. *Epilepsy & Behavior*, 63, 20–28. <https://doi.org/10.1016/j.yebeh.2016.07.035>.
- DeVellis, R. F. (2016). *Scale development, theory and applications* (4th ed.). India: SAGE Publication Inc.
- Dunn, D., & Walsh, K. (2018). Anxiety in children and adolescents with epilepsy. *Journal of Pediatric Epilepsy*, 7(3), 097–102. <https://doi.org/10.1055/s-0038-1676537>.
- Fayed, N., Davis, A. M., Streiner, D. L., Rosenbaum, P. L., Cunningham, C. E., Lach, L. M., Boyle, M. H., & Ronen, G. M. (2015). Children's perspective of quality of life in epilepsy. *Neurology*, 84(18), 1830–1837. <https://doi.org/10.1212/WNL.0000000000001536>.
- Goodwin, S. W., Ferro, M. A., & Speechley, K. N. (2018). Development and assessment of the quality of life in childhood epilepsy questionnaire (QOLCE-16). *Epilepsia*, 59, 668–678. <https://doi.org/10.1111/epi.14008>.
- Jonhson, B., & Christensen, L. (2014). *Educational research: Quantitative, qualitative, and mixed approaches*. SAGE publication.
- Jovanovic, M., Jocić-Jakubi, B., & Stevanovic, D. (2015). Adverse effects of antiepileptic drugs and quality of life in pediatric epilepsy. *Neurology India*, 63(3), 359. <https://doi.org/10.4103/0028-3886.158203>.
- Kanemura, H., & Aihara, M. (2016). Perceived stigma in children with epilepsy. *Pediatr Ther*, 6(2), 1–4. <https://doi.org/10.4172/2161-0665.1000286>.
- Karagöz, Y. (2018). *SPSS ve AMOS 23 applied statistical analysis* (1st ed.). Nobel Publication.
- LaGrant, B., Marquis, B. O., Berg, A. T., & Grinspan, Z. M. (2020). Depression and anxiety in children with epilepsy and other chronic health conditions: National estimates of prevalence and risk factors. *Epilepsy & Behavior*, 103, 106828. <https://doi.org/10.1016/j.yebeh.2019.106828>.
- Lambert, V., Gallagher, P., O'Toole, S., & Benson, A. (2014). Stigmatising feelings and disclosure apprehension among children with epilepsy. *Nursing Children and Young People*, 26(6), 22–26. <https://doi.org/10.7748/ncyp.26.6.22.e440>.
- Leal, S. T. F., Santos, M. V., Thomé, U., Machado, H. R., Escorsi-Rosset, S., Dos Santos, A. C., et al. (2020). Impact of epilepsy surgery on quality of life and burden of caregivers in children and adolescents. *Epilepsy & Behavior*, 106, 106961. <https://doi.org/10.1016/j.yebeh.2020.106961>.
- Love, C. E., Webbe, F., Kim, G., Lee, K. H., Westerveld, M., & Salinas, C. M. (2016). The role of executive functioning in quality of life in pediatric intractable epilepsy. *Epilepsy & Behavior*, 64, 37–43. <https://doi.org/10.1016/j.yebeh.2016.08.018>.
- Momen, A. A., Abareian, A., & Malamiri, R. A. (2019). The evaluation of quality of life in children with epilepsy. *Biomedical Research*, 30, 1–5.
- Moon, H. -J., Seo, J. G., & Park, S. P. (2016). Perceived stress and its predictors in people with epilepsy. *Epilepsy & Behavior*, 62, 47–52. <https://doi.org/10.1016/j.yebeh.2016.06.038>.
- Mula, M., & Sander, J. W. (2016). Psychosocial aspects of epilepsy: A wider approach. *BJPsych Open*, 2(4), 270–274. <https://doi.org/10.1192/bjpo.bp.115.002345>.
- Nagabushana, D., Praveen-Kumar, S., & Agadi, J. B. (2019). Impact of epilepsy and antiepileptic drugs on health and quality of life in Indian children. *Epilepsy and Behavior*, 93, 43–48. <https://doi.org/10.1016/j.yebeh.2019.01.021>.
- Pachange, P. N., Dixit, J. V., Arjun, M. C., & Goel, A. D. (2021). Quality of life among middle and secondary school children with epilepsy. *J Neurosci Rural Pract*, 12(3), 490–494. <https://doi.org/10.1055/s-0041-1725242>.
- Phillips, N. L., Widjaja, E., & Smith, M. L. (2020). Family resources moderate the relationship between seizure control and health-related quality of life in children with drug-resistant epilepsy. *Epilepsia*, 61, 1638–1648. <https://doi.org/10.1111/epi.16602>.
- Polit, D. F., & Beck, C. T. (2018). *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. Lippincott Williams & Wilkins.
- Polit, D. F., Beck, C. T., & Owen, S. V. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Research in Nursing & Health*, 30(4), 459–467. <https://doi.org/10.1002/nur.20199>.
- Pukaa, P., Speechley, K. N., & Ferro, M. A. (2020). Convulsive status epilepticus in children recently diagnosed with epilepsy and long-term health-related quality of life. *Seizure*, 80, 49–52. <https://doi.org/10.1016/j.seizure.2020.05.025>.
- Radović, N. I., Božić, K., Đurić, A. P., Vodopić, S., Radulović, L., & Vujić, S. (2017). Health-related quality of life in adolescents with epilepsy in Montenegro. *Epilepsy & Behavior*, 76, 105–109. <https://doi.org/10.1016/j.yebeh.2017.07.009>.
- Rajmil, L., Herdman, M., Sanmamed, M. J. F., et al. (2004). Generic health-related quality of life instruments in children and adolescents: A qualitative analysis of content. *Journal of Adolescent Health*, 34(1), 37–45.
- Reilly, C., Taft, C., Nelander, M., Malmgren, K., & Olsson, I. (2015). Health-related quality of life and emotional well-being in parents of children with epilepsy referred for presurgical evaluation in Sweden. *Epilepsy & Behavior*, 53, 10–14. <https://doi.org/10.1016/j.yebeh.2015.09.025>.
- Riechmann, J., Willems, L. M., Boor, R., et al. (2019). Quality of life and correlating factors in children, adolescents with epilepsy, and their caregivers: A cross-sectional multicenter study from Germany. *Seizure*, 69, 92–98. <https://doi.org/10.1016/j.seizure.2019.03.016>.
- Ruddock, H. K., Christiansen, P., Halford, J. C. G., & Hardman, C. A. (2017). The development and validation of the addiction-like eating behaviour scale. *International Journal of Obesity*, 1(11), 1710–1717.
- Şencan, H. (2005). *Sosyal ve davranışsal ölçümlerde güvenilirlik ve geçerlilik [Reliability and validity in social and behavioral measures]*. (Seçkin Yayıncılık).
- Şimşek, Ö. (2010). Yapısal eşitlik modellemesine giriş temel ilkeler ve LISREL uygulamaları Ekinoks. *İstanbul*, 2010.
- Sousa, V. D., & Rojjanasrirat, W. (2011). Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: a clear and user-friendly guideline. *Journal of Evaluation in Clinical Practice*, 17(2), 268–274. <https://doi.org/10.1111/j.1365-2753.2010.01434.x>. PMID:20874835.
- de Wit, M., & Hajos, T. (2013). Health-related quality of life. In M. D. Gellman, & J. R. Turner (Eds.), *Encyclopedia of behavioral medicine*. New York: NY Springer.
- World Health Organization (2019). Epilepsy. <https://www.who.int/news-room/factsheets/detail/epilepsy>.
- Zamanzadeh, V., Ghahramanian, A., Rassouli, M., et al. (2015). Design and implementation content validity study: development of an instrument for measuring patient-centered communication. *Journal of Caring Sciences*, 4(5), 165–175. <https://doi.org/10.15171/jcs.2015.017>.