

Reliability and Validity of the Turkish Version of the Impact of Childhood Neurological Disability Scale in Children with Epilepsy



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Epilepsili Çocuklarda 'Impact of Childhood Neurological Disability Scale' Skalasının Türkçe Versiyonunun Geçerlilik ve Güvenirliliği

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Summary

Objectives: The Impact of Childhood Neurological Disability Scale (ICNDS) was developed by Carol Camfield in 1999. The assessment evaluates the effects of various conditions on overall health, relationships, social life, academic success, the child's self-esteem, hopes for the child and caregiver, and family activities in children with epilepsy. At the end of the assessment, a visual scale is provided to orally score quality of life between 1 (very poor) and 6 (excellent). The aim of this study was to translate and adjust the ICNDS scale for use in Turkey, and to ensure the validity and reliability of the tool.

Methods: The scale was translated into Turkish using the appropriate translation methods. Internal structure consistency and test-retest reliability were measured. Cronbach's alpha coefficient was calculated for all of the subscales, and scale and item-total correlations were determined. Test-retest reliability was assessed statistically using the Pearson correlation test for validity. The demographic data of 80 young patients with epilepsy were recorded. The scale was administered twice.

Results: A total of 28 girls (35%) and 52 boys (65%) were included in the study. The mean age was 6.94±1.45 years, and the mean birth weight was 3049±520 g. A 95% confidence interval for Cronbach's coefficient alpha ranged from 0.973 to 0.989 in the different sections of the tool, and the intraclass correlation coefficient was 0.983 (r=0.966; p=0.000).

Conclusion: The Turkish version of the ICNDS is a valid and reliable measurement to assess the impact of epilepsy in children.

Keywords: Epilepsy; Impact of Childhood Disability Scale; validation.

Özet

Amaç: "Çocukluk Çağı Nörolojik Bozukluk Etki Ölçeği (ÇNBÖ)" 44 maddelik 1999'da Carol Camfield tarafından geliştirilmiştir. Değerlendirmenin skorlanması genel sağlık, ilişkiler, sosyal yaşam, okul-akademik başarı, çocuğun benlik saygısı, çocuğun kendi için umutları ve aile aktiviteleri başlıklarını içerir. Ölçeğin sonunda yaşam kalitesini sözel olarak sorgulayan 1 (çok kötü) – 6 (mükemmel) şeklinde skorlanan bir visüel analog skala yer alır. Bu çalışmada amacımız, ÇNBÖ'nün Türkçe geçerliliğini araştırarak, ülkemizdeki epilepsili çocuklarda güvenilirliğini belirlemektir.

Gereç ve Yöntem: Skalanın uygun validasyon adımlarını takip ederek Türkçe validasyonu yapıldı. Hastaların demografik bilgileri kaydedildi. İç yapı tutarlılığı ve test-tekrar test güvenilirliği hesaplandı. Cronbach alfa katsayıları, her maddenin tüm alt ölçekleri için ayrı ayrı ve ölçek ve madde-toplam korelasyon hesaplandı. Test-tekrar test güvenilirliği için, skala başlangıç ve iki hafta sonra aynı fizyoterapist tarafından tekrar uygulandı. Test-tekrar test güvenilirliği, 'geçerlik geçerliliği' için Pearson korelasyon testi kullanılarak istatistiksel olarak değerlendirildi.

Bulgular: Yirmi sekiz kız (%35), 52 erkek (%65) 80 hasta dahil edildi. Ortalama yaşları 6.94±1.45 yıl, doğum ağırlıkları 3049±520 gr idi. %95 güven aralığı değerlendirmesinde Cronbach alfa 0.973–0.989 arasında; Intraclass Correlation Coefficiancy (ICC) ise 0.983 (r=0.966; p=0.000) bulundu.

Sonuç: ICNDS, Türkiye'de epilepsili çocuklarda fonksiyonların değerlendirilmesi için geçerli ve güvenilir bir ölçümdür.

Anahtar sözcükler: Epilepsi; Çocukluk Çağı Bozukluk Etki Ölçeği; validasyon.

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Introduction

Epilepsy disorders involve the abrupt, abnormal, and hypersynchronous discharge of neurons in the central nervous system. These disorders have physical and functional effects. While in some cases the effects may be significant and long-term or permanent, in others the effects may be limited.^[1,2] Scales have been developed to measure the impact of epilepsy on children, their family, and their social environment. Such instruments must be accurate, appropriate to the development of the children, include relevant questions for parents, be culturally appropriate, and sensitive to changes in general health. Therefore, these tools must be valid and reliable in the language of the target population.^[3] Disease scales are vital instruments; however, there are very few that are valid and reliable for Turkish children and their parents.^[4,5] As it may be difficult or impossible to obtain information from young children, some instruments include sections for the children and for parents to answer for children who are too young or cannot respond.^[6] The present study produced one of the first validated scales for use with epilepsy patients in our country.

The Impact of Childhood Neurologic Disease Scale (ICNDS) was developed by Carol Camfield in 1999.^[7] The ICNDS contains 44 items that are scored in 4 areas: (1) behavior, which addresses the effects of inattentiveness, impulsivity, and mood; (2) cognition, namely, the ability to think and remember; (3) neurological and physical function; and (4) epilepsy. The effects are measured in the same 11 areas of life for each condition: general health, relationships with family members, social life, academics, the child's self-esteem, hopes for the child and the respondent, and family activities. Each is scored 0 to 3 (0=not at all, 1=a little, 2=some, 3=a lot). The maximum score in each realm is 33 and for the overall scale, the maximum score is 132. A higher score indicates greater impact. The ICND also includes a numeric scale to measure overall quality of life from 1 (poor) to 6 (excellent). Each category score is collected separately to determine a general expression of influences and impact.

Most scales have been developed in English. In order to use them successfully in other cultures, it is not enough simply to translate the language; they must be harmonized culturally and the language should be adapted as necessary.^[8,9] The aim of this study was to create a Turkish adaptation of the ICNDS and examine its validity and reliability in children with epilepsy.

Materials and Methods

Translation and cultural adaptation

Permission and assistance were granted by the IWK Grace Health Centre in Canada for the cultural adaptation of the original ICND.

The ICND scale was first translated from English into Turkish by 2 physiotherapists. The 2 translations were assessed by a committee and condensed into a single version by consensus. The scale was then translated back into English by a native English speaker who was not a healthcare professional. The new English scale was then sent to the original authors for approval of the content. Minor adaptations made to adjust the language for cultural suitability were discussed and approved by committee consensus. The steps of translation was given in Figure 1.

Patients

The study participants were epilepsy patients from the Bezmialem Vakıf University Faculty of Medicine, Department of Pediatrics, Division of Child Neurology who were referred to the Department of Physiotherapy and Rehabilitation. A pre-test study was completed with 5 people to assess the scale for cultural adaptations and the necessary adjustments were made. A total of 80 children were included in the full study: 28 females (35%) and 52 males (65%). The participants were between 5 and 9 years of age, with a mean age of 6.94 ± 1.45 years. The children's demographic information, functionality level, and states affected by the disease were evaluated. The assessment was repeated 2 weeks later with 78 of the 80 children. The demographic characteristics are provided in Table 1.

Written consent indicating voluntary participation in the study was obtained from the families and they were informed



Fig. 1. Steps of translation.

Table 1. Demographic characteristics

n=80	Min.-Max.	Mean±SD
Age of the child (years)	5–9	6.94±1.453
Number of seizures	1–20	4.22±4.249
Last seizure age (years)	1–6	3.28±1.518
Gestational age (weeks)	28–42	38.79±2.796
Birth weight (g)	1360–4300	3049.42±520.309
Duration of intensive care unit stay (days)	0–45	2.40±7.835
Number of pregnancies	1–5	2.15±1.115
Number of children	1–5	1.85±0.956
	n	%
Gender of child		
Female	28	35
Male	52	65
Education level of respondent		
Primary	58	72.5
Secondary	5	6.3
High school	11	13.8
University	6	7.5
Antiepileptic drug usage	74	92.5
Problems during pregnancy	4	5
Mother's drug use	9	11.3
Drug addiction	8	10
Hypoxia	5	6.3
Asphyxia	4	5
Methods of delivery		
Normal	38	47.5
Caesarean	42	52.5
Consanguinity	23	28.8
Kernicterus	28	35
Birth trauma	1	1.3
Postpartum infection	1	1.3
Glycemic disorders	3	3.8

Min.: Minimum; Max.; Maximum; SD: Standard deviation.

about the purpose of the study. Criteria for inclusion in the study were: 1) epilepsy diagnosed by a pediatric neurologist, 2) age between 2 and 18 years, and 3) determination made that no other neurological disorders were present.

The children were evaluated with the Gross Motor Function Measurement (GMFM) and the Gross Motor Functional Classification System (GMFCS) by physiotherapists. While GMFCS classifies the child's movement skills, the GMFM evaluates all gross motor function.^[10,11] Eighty children completed both scales initially, and they were repeated 2 weeks later with 78 children. The ICNDS was administered to the parents.

Assessment

Physical, neurological, and clinical status was accepted as unchanged 2 weeks after the initial test. The children didn't receive any treatment during that period to ensure there would be no change in disease status.

Analysis

Cronbach's coefficient alpha was used to measure internal consistency. The Cronbach's alpha statistic is an estimate of the reliability of a scale's measurement calculated from a single administration of the scale. The coefficient was also calculated by eliminating 1 item from each of the 4 realms of interest. All items were examined for correlation with the overall score.^[12]

Intraclass correlation coefficient (ICC) was also used to assess reliability. Several forms of ICC exist. It was calculated with confidence intervals for each section and the total score.^[13] Reproducibility and test-retest reliability were assessed by asking the children's parents to complete the ICNDS again 2 weeks later. The change in mean scores between the test and retest was calculated. Correlation between the results of both tests was determined using the Pearson correlation coefficient to analyze reproducibility.

Validity is an index of how well a test measures what it is supposed to measure. Validity was assessed by calculating the Pearson correlation coefficient between the Turkish version of the ICNDS (ICNDS-TR) and the GMFM and the GMFCS. Pearson correlations were used due to the nonparametric nature of the data. To evaluate the convergent validity of the ICNDS-TR, Pearson correlation coefficients were calculated for the ICNDS-TR overall and 4 section scores, as well as between the GMFM scores and related scores of the GMFCS. Discriminant validity was evaluated by calculating Pearson correlation coefficients between the ICNDS-TR and the GMFM. Higher correlation coefficients are expected for convergent validity, and lower correlation coefficients are expected for discriminant validity.^[12]

The test-retest reliability and correlation of the scale were assessed with ICC and Pearson analysis. ICC values range from 0 to 1. ICC values less than 0.5 indicate poor reliability, between 0.5 and 0.75 suggest moderate reliability, between 0.75 and 0.9 are good, and values greater than 0.90 indicate excellent reliability.^[12–14] The test-retest reliability analysis of the ICNDS-TR responses were evaluated again after 2 weeks with 78 children.

The relationship between the ICNDS and the GMFCS and the GMFM levels was examined using Pearson correlation analysis for concurrent validity with 78 patients. Mean and standard deviation was calculated for the demographic data of the patients. $P < 0.05$ was considered statistically significant.

Ethical approval: The present study was approved on March 21, 2014 (approval number 10840098-54) by the Istanbul Medipol University Clinical Research Ethics Committee and conducted according to Helsinki Declaration principles.

Results

Adaptation

In order to harmonize the original scale to the Turkish language and cultural differences, some alterations were made. Clear, simple Turkish terms were substituted where items were found to be difficult to understand or required explanation.

Before administering the new version of the ICNDS, the

scale was explained to the participating families and content validity was discussed. In particular, the fact that the same items are repeated for each realm required explanation, as they sometimes responded, "You asked me that already." It took approximately 15 minutes to answer a total of 44 items.

Reliability and validity

The mean ICNDS-TR scores are provided in Table 2. The scale was determined to be reliable based on test-retest reliability.

Total score of the ICNDS-TR. ICC=0.983 (95% confidence interval [CI], 0.973-0.989) and Pearson's correlation coefficient was statistically significant ($r=0.966$; $p=0.000$).

Part 1. Inattentiveness, impulsivity, or mood: ICC=0.971 (95% CI, 0.954-0.981), and Pearson's correlation coefficient was statistically significant ($r=0.943$; $p=0.000$).

Part 2. Ability to think and remember: ICC=0.965 (95% CI, 0.945-0.978), and Pearson's correlation coefficient was statistically significant ($r=0.933$; $p=0.000$).

Table 2. Results of first and second assessment of Turkish Impact of Childhood Neurologic Disease Scale

	1 st assessment		2 nd assessment		r	p
	n	Mean±SD	n	Mean±SD		
Impact of Childhood Neurological Disability Scale Total	80	29.03±19.887	78	30.85±20.042	0.966	0.000
Impact of Childhood Neurological Disability Scale Part 1	80	6.21±5.910	78	7.09±5.812	0.943	0.000
Impact of Childhood Neurological Disability Scale Part 2	80	6.24±5.870	78	6.55±6.040	0.933	0.000
Impact of Childhood Neurological Disability Scale Part 3	80	7.33±5.919	78	7.98±6.412	0.940	0.000
Impact of Childhood Neurological Disability Scale Part 4	80	9.25±7.409	78	9.24±6.572	0.913	0.000

Impact of Childhood Neurological Disability Scale Part 1: Carelessness, thoughtlessness, or moodiness; Impact of Childhood Neurological Disability Scale Part 2: Ability to think and remember; Impact of Childhood Neurological Disability Scale Part 3: Neurologic or physical limitations; Impact of Childhood Neurological Disability Scale Part 4: Epilepsy. SD: Standard deviation.

Table 3. Results of internal consistency analysis of Turkish Impact of Childhood Neurologic Disease Scale

	1 st assessment	2 nd assessment	Cronbach α	ICC
	Mean±SD	Mean±SD		
Impact of Childhood Neurologic Disease Scale Total	29.03±19.887	30.85±20.042	0.898	0.983
Impact of Childhood Neurologic Disease Scale Part 1	6.21±5.910	7.09±5.812	0.907	0.971
Impact of Childhood Neurologic Disease Scale Part 2	6.24±5.870	6.55±6.040	0.906	0.965
Impact of Childhood Neurologic Disease Scale Part 3	7.33±5.919	7.98±6.412	0.905	0.968
Impact of Childhood Neurologic Disease Scale Part 4	9.25±7.409	9.24±6.572	0.911	0.951

Impact of Childhood Neurologic Disease Scale Part 1: Inattentiveness, impulsivity, or mood; Impact of Childhood Neurologic Disease Scale Part 2: Ability to think and remember; Impact of Childhood Neurologic Disease Scale Part 3: Neurologic or physical limitations; Impact of Childhood Neurologic Disease Scale Part 4: Epilepsy. ICC: Intraclass correlation coefficient; SD: Standard deviation.

Table 4. Results of analysis of Turkish Impact of Childhood Neurologic Disease Scale

	ICNDS 1 st assessment Total score	ICNDS 1 st assessment Part 1	ICNDS 1 st assessment Part 2	ICNDS 1 st assessment Part 3	ICNDS 1 st assessment Part 4	ICNDS 2 nd assessment Total score	ICNDS 2 nd assessment Part 1	ICNDS 2 nd assessment Part 2	ICNDS 2 nd assessment Part 3	ICNDS 2 nd assessment Part 4
ICNDS 1 st assessment Total score	1									
ICNDS 1 st assessment Part 1	.801	1								
ICNDS 1 st assessment Part 2	.827	.806	1							
ICNDS 1 st assessment Part 3	.860	.570	.616	1						
ICNDS 1 st assessment Part 4	.704	.258	.292	.566	1					
ICNDS 2 nd assessment Total score	.966	.815	.828	.855	.605	1				
ICNDS 2 nd assessment Part 1	.725	.943	.741	.530	.183	.782	1			
ICNDS 2 nd assessment Part 2	.807	.850	.933	.600	.270	.850	.804	1		
ICNDS 2 nd assessment Part 3	.837	.564	.645	.940	.535	.875	.520	.618	1	
ICNDS 2 nd assessment Part 4	.748	.321	.384	.669	.913	.723	.256	.360	.664	1

ICNDS Part 1: Inattentiveness, impulsivity, or mood; ICNDS Part 2: Ability to think and remember; ICNDS Part 3: Neurologic or physical limitations; ICNDS Part 4: Epilepsy. ICNDS: Impact of Childhood Neurologic Disease Scale.

Part 3. Neurological or physical limitations: ICC=0.968 (95% CI, 0.949-0.979), and Pearson's correlation coefficient was statistically significant (r=0.940; p=0.000).

Part 4. Epilepsy: ICC=0.951 (95% CI, 0.923-0.968), and Pearson's correlation coefficient was statistically significant (r=0.913; p=0.000).

Quality of life visual scale: ICC=0.722 (95% CI, 0.567-0.822), and Pearson's correlation coefficient was statistically significant (r=0.577; p<0.01).

Concurrent validity was measured using the Pearson's correlation coefficient of the ICNDS and GMFM levels. A statistically significant correlation was found (r=0.396; p <0.01).

Cronbach's alpha coefficient examining the internal consistency of the scale ranged from 0.973 to 0.989. The internal consistency analysis of the scale was given in Table 3. The test-retest results of the scale were consistent (Table 4).

Discussion

Scales are valuable to assess such things as cognitive status, functional level, and family stress in children with epilepsy. Disease-specific scales have been developed and used in many studies to assess functional status and symptoms as well as outcome measures in children with epilepsy disorders.^[15-18]

Most scales in the literature were created in the English language. To achieve equivalence between the original source and a new version of the scale for individual assessment of health status in another country, cultural adaptation of a scale is necessary to ensure that the use of language is appropriate and properly recognizes the target culture.^[19]

This study created a Turkish version of the ICNDS using the accepted standards, and confirmed that it is valid and reliable. Test-retest results for the ICNDS-scale adaptation demonstrated construct validity, and reliability levels were excellent. This is consistent with other studies.^[20,21]

There was a correlation between the ICNDS and the GMFM and the GMFCS in the compliance validity analysis. These results indicate that there is a relationship between functional level and disease impact in children with epilepsy.

The results obtained in this study indicated that the ICNDS-TR is a valid and reliable scale that is easily understandable and suitable for use in studies of the functional and social status of Turkish children with epilepsy and other neurological disorders and their families.

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Ethics Committee Approval

This study was approved by the Medipol University Clinical Research Ethics Committee (approval number 10840098-54; March 21, 2014).

Peer-review

Externally peer-reviewed.

Conflict of interest

The authors declare that they have no conflict of interest.

Authorship Contributions

Concept: F.K.M.; Design: F.K.M.; Supervision: F.K.M.; Materials: M.T.; Data collection &/or processing: M.T.; Analysis and/or interpretation: F.K.M., M.T.; Literature search: M.T.; Writing: F.K.M., M.T.; Critical review: F.K.M.

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