Neurology Asia 2026; 31(3) : 937 – 946

The Needs of Parents Caring for Children with Epilepsy Questionnaire (NPCEQ-TR): Turkish adaptation, validity, and reliability study

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Abstract

Objectives: This study aimed to translate the Needs of Parents Caring for Children with Epilepsy Questionnaire (NPCEQ) into Turkish (NPCEQ-TR) and evaluate its psychometric properties, including validity and reliability, within a Turkish cultural context. *Methods:* A cross-sectional and methodological design was employed. Data were collected online from 310 parents of children with epilepsy in 2025. The adaptation process followed international guidelines and included translation, back-translation, content validation, and pilot testing. Construct validity was examined through confirmatory factor analysis (CFA). Internal consistency was assessed using Cronbach's alpha and McDonald's omega coefficients. *Results:* The content validity indices were satisfactory (I-CVI = 0.80–1.00; S-CVI = 0.91). The KMO value (0.952) and Bartlett's test ($\chi^2 = 5173.501$, $p < .001$) confirmed that the data were suitable for factor analysis. CFA supported the original five-factor structure, with fit indices indicating an excellent model fit ($\chi^2/df = 1.27$; CFI = 0.976; TLI = 0.974; RMSEA = 0.030). Cronbach's alpha and McDonald's omega coefficients ranged from 0.770 to 0.930 for the subscales, and were 0.958 and 0.950, respectively, for the total scale.
Conclusion: The NPCEQ-TR demonstrated strong construct validity, high internal consistency, and cultural relevance. It is a reliable and practical instrument for assessing the multidimensional needs of parents caring for children with epilepsy, and it can be utilized effectively in family-centered nursing and psychosocial interventions in Turkey.

Keywords: Caregiving; parents; epilepsy; family-centred nursing; psychometric properties; scale adaptation

INTRODUCTION

Epilepsy is one of the most common chronic neurological disorders in childhood, representing a significant health issue that impacts not only the child, but also the biopsychosocial well-being of their family.[1] Caring for a child with epilepsy can place significant emotional, cognitive and physical demands on parents, potentially resulting in a reduced quality of life, social isolation, burnout and mental health issues.[2-4] Research suggests that parents of children with epilepsy often experience high levels of stress, anxiety and depression, which can be exacerbated by accompanying behavioural problems.[5-7] Financial difficulties, social stigma and limited access to information also increase the caregiving burden and restrict parents' coping capacities.[8,9] Therefore, parents require support in various areas beyond medical information about epilepsy, such as behavioural management, crisis coping, emotional support, and access to social services. [10,11]

The assessment of the needs of parents caring for children with epilepsy is guided by two major theoretical frameworks: Lazarus and Folkman's Stress and Coping Model, and

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Date of Submission: 4 March 2026; Date of Acceptance: 23 April 2026

https://doi.org/10.54029/2026yeu

the Family-Centred Care (FCC) approach. The former explains how individuals cognitively appraise stressful situations and develop problem- or emotion-focused coping strategies. For parents of children with chronic illnesses, this process is a key factor in determining psychological resilience and access to support networks.[12-14] The model highlights that parents' perceptions of stress and their coping styles are closely associated with their levels of need. Conversely, the FCC approach views parents as active partners in the care process, emphasizing information sharing, emotional support, and participation in decision-making. Studies have shown that FCC-based interventions can enhance parental self-efficacy, improve family quality of life and increase satisfaction with care.[15-17] Furthermore, empowerment-based family education programmes (e.g. COPE) have been shown to improve coping skills and psychological well-being. Therefore, combining both approaches provides a more comprehensive evaluation.[18,19] This theoretical framework strengthens the psychosocial and family-centred perspective that guided the adaptation of the NPCEQ-TR.

The Needs of Parents Caring for Children with Epilepsy Questionnaire (NPCEQ) was developed by Arash *et al*. (2025).[20] It is a psychometrically robust instrument consisting of 31 items and five subscales that measure parents' needs in areas such as information, support, psychological resilience, social challenges and care management. In the original study, qualitative and quantitative methods were integrated to yield strong psychometric properties, including a content validity index (CVI = 0.877), a five-factor construct validity structure explaining 59.07% of the total variance, and high internal consistency (Cronbach's $\alpha = 0.882$).

In collectivist cultures such as those in Turkey, family roles, access to healthcare, shared caregiving responsibilities and dynamics of stigma differ markedly from those in Western societies. The literature emphasizes that using measurement tools without cultural adaptation may lead to incomplete or biased representations of parental needs. Thus, instruments should be adapted not only linguistically, but also semantically and experientially.[21,22] Measurement invariance studies also suggest that cultural variations in parent–child relationships may impact measurement results.[23] Studies that have adapted scales in Turkish samples have reported that culture-sensitive modifications lead to greater validity and reliability, particularly in areas such as parental involvement, anxiety, and caregiving burden.[24,25] In this context, translating the NPCEQ into Turkish will fill a significant gap in clinical and academic fields by identifying the informational, emotional support, empowerment and caregiving management needs of parents of children with epilepsy in their cultural context.

The aim of this study was therefore to translate the NPCEQ into Turkish, examine its validity and reliability, and demonstrate its usability as a culturally appropriate, psychometrically sound assessment tool for evaluating the needs of parents caring for children with epilepsy.

METHODS

Study design and participants

This study employed a quantitative methodological research design. Data were collected via an online questionnaire distributed through social media platforms. The snowball sampling method was used to recruit participants. Data collection continued until the planned sample size was reached, completing the study in 2025.

The study population consisted of parents of children diagnosed with epilepsy. In scale development and adaptation studies, it is recommended that the sample size be at least five to ten times the number of items.[26] Since the NPCEQ-TR consists of 31 items, the minimum required sample size was 155 participants, and the ideal sample size was 310. Accordingly, the study sample consisted of 310 parents who were recruited via social media using the snowball sampling method and who participated in the study on a voluntary basis.

In this study, the inclusion criteria were being aged 18 years or older, being a parent of at least one child with epilepsy, being able to read and understand Turkish, and providing informed consent through the online form. The exclusion criteria were having a child with an additional congenital or acquired disability and incomplete or erroneous completion of the questionnaire form.

Data collection tools

Data were collected using two instruments: the 'Introductory Information Form', which was developed by the researchers to determine the sociodemographic characteristics of parents, and the 'Needs of Parents Caring for Children with

Epilepsy Questionnaire (NPCEQ-TR)'.

The NPCEQ-TR is a questionnaire designed to determine the care needs of parents of children with epilepsy. This questionnaire is the Turkish adaptation of the original NPCEQ, which was developed by Arash *et al*. (2025). The scale consists of five subdimensions: 'Enhancing caregiving and support capacity', 'Psychological-emotional needs', 'Empowerment of parents in child care and management', 'Parents' social challenges', and 'Enhancing parental awareness'. It includes 31 items rated on a 5-point Likert scale (1 = None; 5 = Very much). Items Q21, Q22, Q28, Q30 and Q31 are reverse-scored. The total score ranges from 31 to 155, with higher scores indicating a greater need for support and information. In the original study, Cronbach's alpha was reported as 0.882.[20]

Data collection

Data were collected via an online questionnaire created using Google Forms. To reach eligible participants, the survey link was shared in open and closed social media groups, as well as in forums and support communities for parents of children with chronic illnesses. Participation was voluntary, and the introductory section of the form explained the purpose and scope of the study, along with a statement on voluntary participation.

To ensure confidentiality, the survey was conducted anonymously. IP tracking and unique session codes were used to prevent duplicate entries. The data were securely stored by the researchers and analysed solely for scientific purposes.

Ethical considerations

Ethical approval was obtained from the Erzurum Technical University Scientific Research and Publication Ethics Committee (Approval No: 10/02, Date: 10.07.2025).

Statistical analysis

The data were analysed using SPSS 30.0 and AMOS 24.0 software, with a significance level of $p < 0.05$. Descriptive statistics were calculated alongside factor analyses, Cronbach's alpha coefficients, item–total correlations and fit indices, in order to assess the validity and reliability of the scale.

Language validity

During the language validity process, the scale was independently translated into English by two individuals: one who was familiar with the content, and one who was a linguistic expert. The researchers compared and combined the translations, then had two bilingual experts back-translate the combined version into English. The back-translated version was then compared with the original to ensure semantic equivalence. After obtaining ethical approval, a pilot study was conducted with ten parents to assess clarity, and necessary revisions were made based on their feedback. The pilot data were not included in the main analysis.

Content validity

To determine content validity, the Turkish and English versions of the scale were sent via email to ten academic experts in the field. Each expert rated the relevance of each item on a 4-point scale, where 1 = not relevant and 4 = highly relevant. The expert evaluations were analysed using Davis's method and the Content Validity Index (CVI) was calculated for each item. Items with a CVI below 0.80 were reviewed and revised based on the experts' recommendations.

Construct validity

Exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) were performed to determine the construct validity of the scale. The Kaiser–Meyer–Olkin (KMO) coefficient and Bartlett's test of sphericity were applied to assess the adequacy of the sample for factor analysis. The obtained factor structure was then compared with that of the original scale.

Internal consistency

Internal consistency was evaluated using Cronbach's alpha coefficients and item–total correlations. A Cronbach's alpha value of ≥ 0.70 and an item–total correlation of ≥ 0.30 were accepted as criteria for reliability.[27] The results showed that the Turkish version of the scale had a high level of internal consistency.

RESULTS

Table 1 lists the characteristics of the parents of children with epilepsy.

Table 1: Sociodemographic characteristics of the parents (n = 310)

Variables	Categories	n	%
Gender	Female	189	61.0
	Male	121	39.0
Age (years)	18–29	37	11.9
	30–39	119	38.4
	40–49	101	32.6
	50 and above	53	17.1
Marital status	Married	278	89.7
	Single/divorced/widowed	32	10.3
Educational level	Primary school and below	61	19.7
	High school	97	31.3
	University and above	152	49.0
Employment status	Employed	127	41.0
	Unemployed	183	59.0
Number of children	1	83	26.8
	2	106	34.2
	3 or more	121	39.0
Child's age (years)	0–6	102	32.9
	7–12	126	40.6
	13 and above	82	26.5
Duration of epilepsy (years)	<1	43	13.9
	1–3	91	29.4
	4–6	108	34.8
	>6	68	21.9
Type of epilepsy	Generalized	187	60.3
	Focal	123	39.7
Parent's relationship to the child	Mother	198	63.9
	Father	112	36.1

Validity findings

Content validity

According to expert evaluations, the Item-Level Content Validity Index (I-CVI) values ranged from 0.80 to 1.00, while the Scale-Level Content Validity Index (S-CVI) was calculated as 0.91. These results indicate that the items adequately represent the content domain and possess satisfactory content validity.

Construct validity

Prior to factor analysis, sample adequacy and data suitability were confirmed using the Kaiser–Meyer–Olkin (KMO) measure and Bartlett's Test of Sphericity. The KMO value was 0.952, indicating excellent sampling adequacy, and Bartlett's Test of Sphericity was statistically significant ($\chi^2 = 5173.501$, $p < .001$). These results demonstrated that the dataset was appropriate for factor analysis.

As shown in Table 2, factor loadings obtained from the Confirmatory Factor Analysis (CFA) ranged from 0.554 to 0.832. The item scores ranged from 2.68 to 2.77, indicating moderate levels of perceived need among participants. Corrected item–total correlations ranged from .487 to .730, suggesting good item discrimination. These findings confirmed the multidimensional, five-factor structure of the NPCEQ-TR and

Table 2: Mean scores, corrected item–total correlations, and CFA factor loadings of the NPCEQ-TR

Scale Items	Mean±SD	Corrected Item-total Correlations	Factor Load Value				
			F1	F2	F3	F4	F5
Item 1	2.71±1.48	.636	.709				
Item 2	2.71±1.51	.642	.731				
Item 3	2.75±1.51	.614	.643				
Item 4	2.74±1.51	.604	.710				
Item 5	2.72±1.49	.702	.665				
Item 6	2.73±1.50	.730	.793				
Item 7	2.71±1.54	.613	.709				
Item 8	2.69±1.50	.597	.832				
Item 9	2.75±1.53	.647	.684				
Item 10	2.74±1.50	.634	.799				
Item 11	2.71±1.52	.640	.649				
Item 12	2.71± 1.51	.563		.611			
Item 13	2.71± 1.50	.500		.642			
Item 14	2.72± 1.49	.555		.674			
Item 15	2.70± 1.53	.537		.695			
Item 16	2.72± 1.51	.534		.687			
Item 17	2.77± 1.49	.487		.711			
Item 18	2.68± 1.52	.613			.678		
Item 19	2.71± 1.52	.548			.729		
Item 20	2.75± 1.51	.602			.554		
Item 21	2.74± 1.52	.624			.694		
Item 22	2.72± 1.49	.589			.819		
Item 23	2.74± 1.52	.594			.714		
Item 24	2.69± 1.49	.519			.680		
Item 25	2.72± 1.53	.573				.665	
Item 26	2.68± 1.53	.612				.672	
Item 27	2.71± 1.52	.649				.682	
Item 28	2.74± 1.49	.624				.789	
Item 29	2.69± 1.50	.520					.710
Item 30	2.72± 1.52	.555					.690
Item 31	2.69± 1.54	.535					.695

Note.
F1 = Enhancing caregiving and support capacity;
F2 = Psychological–emotional needs;
F3 = Empowerment in child care and management;
F4 = Social challenges;
F5 = Increasing parental awareness.

provided strong evidence of construct validity in the Turkish sample.

Confirmatory Factor Analysis (CFA)

When the fit indices obtained from the confirmatory factor analysis were examined, the model demonstrated an excellent fit to the data: $\chi^2 = 540.08$, df = 424 ($p < 0.05$). The fit index results are presented in Table 3.

These findings confirm that the five-factor structure of the scale is valid in the Turkish sample and that the model shows a good level of fit. The path diagram obtained from the CFA is illustrated in Figure 1.

Reliability findings

The internal consistency of the scale was evaluated using Cronbach's alpha and McDonald's omega

Table 3: Model fit indices of the confirmatory factor analysis for the NPCEQ-TR

Fit Criteria	Found	Appropriate	Acceptable	Result
χ^2/df (CMIN/DF)	1.27	< 2	< 5	Perfect fit
RMSEA	0.030	< 0.05	< 0.08	Very good fit
CFI	0.976	> 0.95	> 0.90	Perfect fit
RMR	0.089	< 0.05	< 0.08	Acceptable fit
SRMR	0.039	< 0.05	< 0.08	Perfect fit
TLI	0.974	> 0.95	> 0.90	Very good fit

Note.
CFI = Comparative Fit Index; RMSEA = Root Mean Square Error of Approximation;
RMR = Root Mean Square Residual; SRMR = Standardized Root Mean Square Residual;
TLI = Tucker–Lewis Index.

(Ω) coefficients. The Cronbach's alpha values ranged from 0.847 to 0.930 for the subdimensions and was 0.958 for the total scale. The omega reliability coefficients ranged from 0.770 to 0.977 across subdimensions, with an overall omega of 0.950 for the total scale (see Table 4). These results indicate that the NPCEQ-TR is a highly reliable instrument with excellent internal consistency.

Additionally, the correlations between subdimensions were positive and statistically significant (r = 0.485–0.612, p < 0.01), suggesting that while the subdimensions are interrelated, they remain conceptually distinct constructs. The corrected item–total correlation coefficients ranged between 0.487 and 0.730, all exceeding the 0.30 threshold, further supporting the internal consistency and coherence of the scale items.

DISCUSSION

This study confirmed the five-factor structure

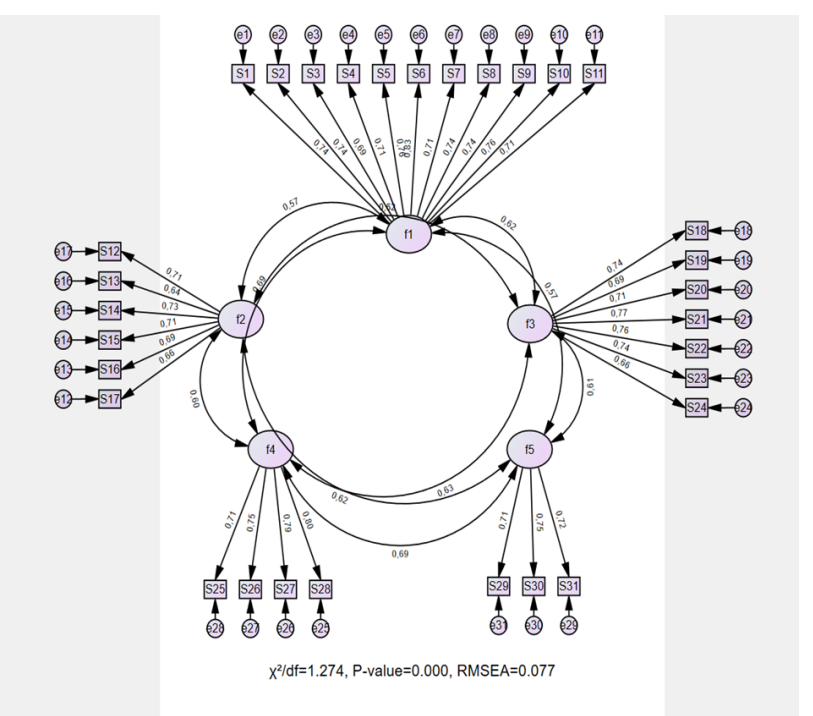

Figure 1. Path diagram of the five-factor model of the NPCEQ-TR.
Note. Standardized estimates are shown. All factor loadings were significant at p < .001.

Table 4: Correlation values, mean scores, and reliability results of the NPCEQ-TR and its subdimensions

Scale and Subdimensions	F1	F2	F3	F4	F5	Number of Items	Min–Max	Mean ± SD	α	Ω
F1	1	–	–	–	–	11	11–55	29.95 ± 12.76	.930	.930
F2	.504**	1	–	–	–	6	6–30	16.26 ± 6.86	.847	.846
F3	.563**	.533**	1	–	–	7	7–35	19.17 ± 8.13	.884	.885
F4	.612**	.518**	.547**	1	–	4	4–20	10.80 ± 5.04	.847	.847
F5	.485**	.503**	.507**	.558**	1	3	3–15	8.13 ± 3.78	.770	.771
Total	.875**	.753**	.804**	.781**	.692**	31	33–153	84.31 ± 29.40	.948	.950

Note.
F1 = Enhancing caregiving and support capacity;
F2 = Psychological–emotional needs;
F3 = Empowerment in child care and management;
F4 = Social challenges;
F5 = Increasing parental awareness.
α = Cronbach's alpha coefficient;
Ω = McDonald's omega coefficient.
p < .001 for all correlations (**).

of the scale in the Turkish sample, with high internal consistency (α = 0.958; ω = 0.950) and strong corrected item–total correlations (0.487–0.730). These results suggest that the NPCEQ-TR effectively measures the various needs of parents caring for children with epilepsy within a Turkish cultural setting.

The original study by Arash *et al.* (2025) found that the NPCEQ had a five-factor structure, with fit indices of CFI = 0.96 and RMSEA = 0.05, and a total Cronbach's alpha of 0.882.[20] The Turkish adaptation yielded similar or even stronger psychometric values (CFI = 0.976, RMSEA = 0.030, α = 0.958), indicating that the scale's structural validity was preserved across cultural contexts. These results suggest that the NPCEQ-TR meets international psychometric standards while retaining epilepsy-specific content relevance for Turkish parents, establishing it as a valid assessment tool for this population.

The results are consistent with those of other instruments used to assess stress, anxiety and coping strategies among parents of children with epilepsy. For example, Lu *et al*. (2022) found that the Parenting Stress Index (PSI) identified three main areas: child characteristics, parental psychology, and family dynamics.[28] Similarly, Banihani *et al*. (2025) confirmed the PSI's factor structure in families of children with complex health needs, demonstrating that family support and service burden were the strongest predictors of parental stress.[29] The NPCEQ-TR's "psychological–emotional needs" and "care management" dimensions incorporate these concepts into the Family-Centered Care (FCC) theoretical framework.

In line with the findings of Hosny *et al*. (2023) that psychoeducational programmes significantly improved coping strategies, particularly emotional coping and parental empowerment[30], the NPCEQ-TR's subdimensions of 'psychological–emotional needs' and 'social challenges' demonstrated strong theoretical validity.

Similarly, validation studies of the Impact on Family Scale (IFS) have demonstrated an acceptable model fit (CFI = 0.91; RMSEA = 0.06) and emphasized that parental burden is a multifaceted concept that impacts the entire family.[31] The high fit indices observed in the NPCEQ-TR (CFI = 0.976, TLI = 0.974, RMSEA = 0.030) suggest that the scale accurately reflects this family-system-based approach. Furthermore, when compared with other epilepsy-specific tools, such as the Epileptic Seizure Parental Burden Scale (ESPBS) (α = .93; CFI = .97; RMSEA = .055)[32], and the Quality of Life in Childhood Epilepsy Questionnaire–Chinese version (QOLCE-16-C) (α = .938; CFI = .974; RMSEA = .058)[33], the NPCEQ-TR achieved 'excellent fit' criteria for both the CFI and RMSEA values.

The relationships reported in studies examining psychosocial determinants among parents of children with epilepsy also align with the NPCEQ-TR subdimensions. For example,

Jakobsen and Elklit (2021) found that coping and self-control mediated parental stress (β = 0.37)[6], while Smith *et al*. (2023) reported the protective effect of family resources on well-being (β = −0.49).[34] Furthermore, Wei *et al*. (2024) demonstrated that family resilience was strongly associated with social support (r = 0.75).[35] Together, these findings further support the theoretical validity of the NPCEQ-TR's 'psychological–emotional needs', 'social challenges', and 'care management' subdimensions.

From a cultural standpoint, parental roles, stigma experiences, and healthcare accessibility are critical factors influencing caregiving needs in collectivist societies such as Turkey. Schilling *et al.* (2021)[21] and Susanty *et al.* (2020)[22] emphasized the need for psychosocial scales to undergo both linguistic and semantic adaptation. Similarly, Escalante-Barrios *et al*. (2020) demonstrated in a U.S.–Turkey measurement invariance comparison that parent–child relationships must be evaluated in a culturally sensitive manner.[23] Recent Turkish studies[24,25] have reported high psychometric indicators in parent-related scales, which indirectly supports the local contextual validity of the NPCEQ-TR. Furthermore, maintaining the validity indices reported in the original version by Arash *et al.* (2025) within the Turkish sample provides important evidence of cross-cultural validity.[20]

This study has several limitations. The use of snowball sampling and online data collection may have introduced selection bias, thereby limiting the sample's representativeness. Test–retest reliability and measurement invariance analyses were not conducted, meaning that temporal stability and cross-group equivalence could not be evaluated. Furthermore, the findings are based solely on self-reported data, which may be subject to social desirability bias.

In conclusion, the NPCEQ-TR has been evaluated as a theoretically grounded instrument, based on Lazarus and Folkman's coping model and the Family-Centered Care approach. This study provides the first validated adaptation of a tool designed to assess the needs of parents caring for children with epilepsy within a Turkish cultural context, thereby making a unique contribution to the field.

The NPCEQ-TR can be used by nurses, psychologists, and other healthcare professionals to identify and prioritize the multidimensional needs of parents caring for children with epilepsy. Further research is needed to evaluate the NPCEQ-TR through test–retest reliability, measurement invariance across subgroups, and longitudinal designs.

DISCLOSURE

Ethic: Ethical approval was obtained from the Erzurum Technical University Scientific Research and Publication Ethics Committee (Approval No: 10/02, Date: 10.07.2025). At the beginning of the online survey, participants were informed about the purpose, voluntary nature, and confidentiality of the study, and electronic informed consent was obtained by selecting the consent checkbox. All procedures adhered to the principles of the Declaration of Helsinki. Informed consent was obtained from all study participants and parents of child participants in accordance with applicable laws and ethical standards.

Conflict of interests: None

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