

## Psychometric properties of the revised Turkish version of the cancer patients needs questionnaire for parents of children with cancer

*Kanserli çocukların ebeveynleri için kanserli hasta gereksinimleri soru formunun Türkçe revize versiyonunun psikometrik özellikleri*

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### Abstract

**Purpose:** This study aimed to evaluate the Turkish validity and reliability of the revised version of the Cancer Patients Needs Questionnaire (rCPNQ-T) for parents whose children with cancer.

**Materials and methods:** This methodological study conducted on 142 parents of children with cancer in Turkey's southeast region. Data were collected with sociodemographic form and the rCPNQ-T.

**Results:** The parents' average age was 33.2±6.9 and most of them were a mother. Their children's average age was 6.1±3.6, 72.5% diagnosed with acute lymphocytic leukemia (ALL). According to expert opinions, the content validity index was found to be 0.87, the total Cronbach's  $\alpha$  coefficient of the questionnaire was 0.94, and the Cronbach's  $\alpha$  coefficient of the sub-dimensions was ranged from 0.77 to 0.92.

**Conclusion:** The validity and reliability analyses showed that the rCPNQ-T is a valid and reliable measurement questionnaire, accepted as 4 dimensions (informational, emotional, psychosocial, and practical needs) and 26 items. This scale can be used to determine the parents' needs of children with cancer.

**Key words:** Validity, reliability, cancer, need, parent.

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### Öz

**Amaç:** Bu çalışmanın amacı kanserli çocukların ebeveynleri için kanserli hasta gereksinimleri soru formu revize versiyonunun (rKHGSF-T) Türkçe geçerlik ve güvenilirlik çalışmasını yapmaktır.

**Gereç ve yöntem:** Metodolojik çalışma, Türkiye'nin güneydoğu bölgesinde kanserli çocuğa sahip 142 ebeveyn ile yapıldı. Veriler sosyodemografik form ve rCPNQ-T ile toplandı.

**Bulgular:** Ebeveynlerin yaş ortalamasının 33,2±6,9 ve çoğunun anne olduğu belirlendi. Çocukların yaş ortalamasının 6,1±3,6 ve %72,5'inin akut lenfositik lösemili (ALL) olduğu saptandı. Uzman görüşlerine göre soru formunun kapsam geçerlilik indeksinin 0,87, anketin toplam Cronbach's  $\alpha$  katsayısının 0,94, alt boyutlarının Cronbach's  $\alpha$  katsayısının ise 0,77-0,92 arasında olduğu saptandı.

**Sonuç:** Geçerlilik ve güvenilirlik çalışmasına göre rCPNQ-T'nin, 4 alt boyut (bilgi, duygusal, psikososyal ve uygulama gereksinimi) ve 26 madde olarak geçerli ve güvenilir bir soru formu olduğu belirlenmiştir. Bu ölçme anketi kanserli çocukların ebeveynlerinin gereksinimlerini belirlemek için kullanılabilir.

**Anahtar kelimeler:** Geçerlilik, güvenilirlik, kanser, gereksinim, ebeveyn.

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## Introduction

Having a child with cancer can lead to negative consequences for family structure, mother, father, and siblings. Families who care for cancer patients face many difficulties in the cancer diagnosis and treatment process [1, 2]. Parents experience distress and increase their care burden as they care for sick children and maintain family balance [1]. Parents need information, emotional, practical, physical, and psychosocial support during this crisis. In the studies conducted, it was determined that the parent's information and emotional needs were higher [3]. In a study, the needs of parents were cost difficulties (23%), psychosocial adjustment (18%), psychological distress (14%), and impact in family dynamics (12%) [4]. Parents mostly need information about the child's disease, prognosis, treatment, side effects of treatment, and caregiving problems. Parents need information during the diagnosis and treatment of childhood cancers [5], and also worry about mental and physical problems caused by cancer treatment in their children treated for cancer [6].

Cancer can negatively affect the quality of life of family members who care for cancer patients in many ways, especially psychologically. Parents of children with cancer experience more anxiety and depression [7]. Stress and side effects of treatment caused by cancer in children cause emotional and social problems in children and family members. In general, parents adapt to their child's cancer, but some families experience posttraumatic stress disorder [8]. If the stress levels of individuals who care for cancer patients are not controlled, they may be at risk for physical and mental health problems [9]. Family needs should be assessed to help the emotional difficulties of family members who care for cancer patients [10]. These requirements should be evaluated regularly throughout the process [5]. Assessment of parent's supportive care needs is very important in planning interventions that best meet these needs. Caregivers who care for cancer patients have an important role at every stage of the disease. They should be included in treatment and the assessment of the needs of patients with cancer [9]. This study aimed to evaluate the Turkish validity and reliability of the revised version of the Cancer Patients Needs

Questionnaire (rCPNQ-T) for parents whose children with cancer.

## Materials and methods

### Study design and participants

This methodological study conducted between January 2019 and January 2020 on parents of children with cancer at a large, tertiary care center in Turkey's southeast region. There are two clinics in this hospital, adult and pediatric oncology units. These clinics have 72 beds. Parents who wanted to participate in the study and had children with cancer were included in the study. One hundred and forty-two parents of children with cancer who met the study criteria constituted the sample. At least 5 or 10 individuals are recommended per measurement tool item in the measurement tool development studies [11]. For this reason, the sample size of the study was determined as five times each item in the questionnaire. Study participants recruited using convenience sampling; the researchers gave information about the study and reviewed the written informed consent from parents. If the parent agreed to participate, he/she filled the rCPNQ-T. The rCPNQ-T administered to 10 parents for the face validity, these parents excluded from the sampling.

### Data collection tools

**The sociodemographic form:** It consisted of questions about the parent and his/her children with cancer such as age, education, gender, children's diagnosis, and hospital stay time.

**Revised Version of the Cancer Patients Needs Questionnaire (rCPNQ):** Ji et al. [3] conducted the reliability of the rCPNQ at Chinese parents of children with cancer. It resulted in a 6-dimension, 8-factor, 29-items. They excluded some items and dimensions. As a result, the tool had four dimensions; emotional needs (EN), practical needs (PrN), informational needs (IN) and psychosocial needs (PyN), and 26 items. There are five items in the IN dimension, ten items in the EN dimension, three items in the PrN dimension, and eight items in the PyN dimension. The measurement was the questionnaire for each item ranging from 1 to 5

(1=no need/not applicable or already satisfied; 5=extremely high need for help). Cronbach's  $\alpha$  was  $\geq 0.74$  for each factors; IN ( $\alpha=0.88$ ,  $\lambda=3.48$ ), EN ( $\lambda=7.31$ ) factor 1 ( $\alpha=0.93$ ), factor 1 ( $\alpha=0.85$ ), PrN ( $\alpha=0.90$ ,  $\lambda=2.48$ ), PyN ( $\lambda=5.22$ ) factor 2 ( $\alpha=0.88$ ) and factor 2 ( $\alpha=0.74$ ) [3].

The rCPNQ obtained from Ji who permitted Turkish validity and reliability. Two language experts translated the revised version of the rCPNQ into Turkish. The researchers reviewed the two translations and obtained a single Turkish version. Other language expert back translated the rCPNQ-T into English. The researchers reviewed and compared it with the English version to verify the content of the items.

The Turkish and English versions of the rCPNQ were sent to the ten experts including a pediatric oncologist (n=2), pediatric hematologist (n=2), pediatric oncology nurse specialist (n=3), PhD in Pediatric Nursing (n=3). They reviewed items as follows; 1=needs many changes/inappropriate, 2=needs a few changes, 3=appropriate, 4=highly appropriate). Their opinions measured with the content validity index (CVI) for each item and the overall scale. After giving the scale the final state, the rCPNQ-T administered to 10 parents for the face validity. All items were understandable by parents.

### Data analysis

Statistical Package for the Social Sciences (SPSS) 24.0 software used to evaluate the data. The CVI used to analyze the experts' opinions and determined by Lawshe Method. The descriptive statistics (percentage and mean) also used. The normality of the questionnaire scores tested with the Shapiro-Wilk normality test. Whether data and sample size are suitable for factor analysis evaluated by Kaiser-Meyer Olkin's coefficient (KMO) and the Bartlett test. Confirmatory factor analysis (CFA) used for if the items and dimensions explain the structure of the questionnaire. The fit of the model was evaluated with fit indices, Pearson's chi-square ( $X^2$ ), root-mean-square error of approximation (RMSEA), degree of freedom (df), goodness of fit index (GFI), normal fit index (NFI), Incremental Fit Index (IFI), Relative Fit Index (RFI), comparative fit index (CFI), and Tucker-Lewis Index (TLI) were investigated as the fit

indices. The reliability coefficients calculated to determine the reliability of the questionnaire and dimensions. Cronbach  $\alpha$  was accepted as  $\geq 0.70$ . Both halves of Cronbach's alpha values with the split-half method, the Guttman's split-half and the Spearman-Brown coefficients and the correlation between two halves evaluated. The item-total score correlation coefficient was evaluated; bivariate correlation analysis was conducted between factors. The significance level accepted as  $p < 0.05$  for this study.

Approval was obtained from Gaziantep University Clinical Research Ethics Committee and Gaziantep University where this study was conducted before the study commenced. Consent was obtained from the children who participated in the study and their parents.

## Results

### Sample characteristics

The parents' average age was  $33.2 \pm 6.9$ , 81% (n=115) were mother, 82.4% (n=117) had a high school degree or lower, 67.6% (n=96) had lower income, and 90.8% (n=129) had another child. The children's average age was  $6.1 \pm 3.6$ , 72.5% (n=103) diagnosed with Acute lymphocytic leukemia (ALL), 69% (n=98) stayed hospital for 1-2 weeks, and all of them received chemotherapy treatment (Table 1).

### Content validity

Ten experts provided their opinions about the questionnaire items. They rated each item ranging from 1 to 4. Based on the expert opinions, the CVI was 0.87 (ranged from 0.70 to 1.00 for items).

### Construct validity

#### CFA

To perform factor analysis, the KMO test performed if the sample size should be sufficient and distributed normally. In this study, KMO's coefficient was 0.881, the Bartlett test  $X^2$  value was 2313.242, these results were found to be significantly at an advanced level ( $p=0.001$ ), showed that the sample size was good and the data was normally distributed.

According to the CFA results, the fit indices were  $X^2=531.067$ ,  $df=287$ ,  $X^2/df=1.850$ ,

**Table 1.** Sample characteristics

<b>Descriptive characteristics</b>	<b>X±SD (min-max)</b>	
<b>Parents' age</b>	33.2±6.9 (18-54)	
<b>Child's age (year)</b>	6.1±3.6 (0.4-15)	
<b>Parents' gender</b>	<b>n</b>	<b>%</b>
Mother	115	81
Father	27	19
<b>Parents' education</b>		
≤ high school degree	117	82.4
> high school degree	25	17.6
<b>Income status</b>		
Lower	96	67.6
Moderate-High	46	32.4
<b>Have another child</b>		
Yes	129	90.8
No	13	9.2
<b>Child's gender</b>		
Girl	58	40.8
Boy	84	59.2
<b>Child's diagnosis</b>		
Acute lymphocytic leukemia (ALL)	103	72.5
Acute myelocytic leukemia (AML)	11	7.7
Solid tumor	28	19.7
<b>Elapsed time after diagnosis</b>		
1-6 week	30	21.1
7-12 week	20	14.1
>13 week	92	64.8
<b>Hospital stay time</b>		
1-2 week	98	69
3-4 week	14	9.9
>5 week	30	21.1
<b>Chemotherapy treatment time</b>		
1-4 week	30	21.1
5-8 week	14	9.9
9-12 week	10	7
>13 week	88	62
<b>Relapsed</b>		
Yes	5	3.5
No	137	96.5

RMSEA=0.078, GFI=0.79, NFI=0.78, RFI=0.75, IFI=0.88, TLI= 0.87, CFI=0.88. The RMSEA below 0.08, the division of the chi-square value by the df should be smaller than 5, and the other fit indices must be close or greater than 0.90 [12]. The factor loadings of the dimension of the informational needs ranged from 0.65

to 0.77, the dimension of the emotional needs ranged from 0.63 to 0.83, the dimension of the psychosocial needs ranged from 0.53 to 0.78, and the factor loadings of the dimension of the practical needs ranged from 0.66 to 0.84 (Figure 1).

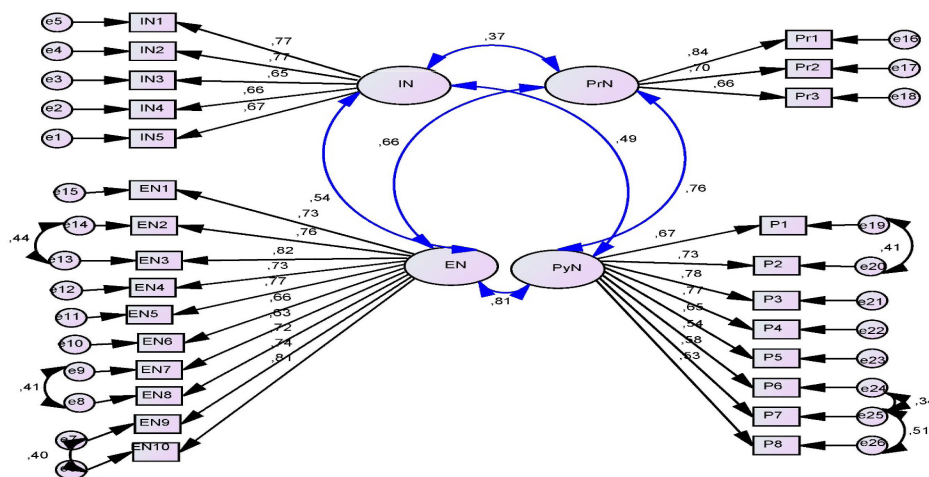


Figure 1. Factor loadings

### Reliability analyses

Reliability coefficients calculated to determine the reliability of the resulting factors. Cronbach's  $\alpha$  of the total questionnaire was 0.94, dimensions of the questionnaire ranged from 0.77 to 0.92. Both halves of Cronbach's  $\alpha$  values with the split-half method, the Guttman's split-half, and the Spearman-Brown coefficients, and the correlation between two halves were above 0.70 (Table 2). The item total score correlation coefficient ranged from 0.41 to 0.75.

### Correlations between the questionnaire and dimensions scores

Correlations between the questionnaire and dimensions were determined between from 0.315 to 0.923 ( $p < 0.01$ ) (Table 3).

### Discussion

Evaluation of the methods and techniques used in research with a measurement tool that thought to be precise and accurate called validity. There are many methods to measure the validity of a measuring tool. The content and construct validity used in this study. The CVI must be greater than 0.62 according to Lawshe table [13]. Based on the expert opinions, the content validity of the rCPNQ-T is statistically significant.

In the construct validity of the questionnaire CFA analysis performed. The KMO coefficient was perfect and acceptable (perfect=0.90, very good=0.80, moderate=0.60-0.70 and bad=0.50). The Bartlett test used for data normality, higher result indicated significant [14]. The CFA is a

method that tests the relationships between variables through a model [15]. The CFA results in this study determined that 26 items of the questionnaire represented at a significance level of  $p < 0.001$  in four dimensions. The items and four dimensions constituted the original structure of the questionnaire, the CFA loads were determined to be above 0.50. According to the fit indices, the 4-factor model was well fit, although the goodness-of-fit indexes was a slightly lower.

Reliability is the consistency between independent measurements of a quality that desired to measure. There are different methods of determining reliability. Cronbach's alpha coefficient determines the internal consistency and homogeneity of the items. If the Cronbach alpha coefficient is  $> 0.90$ , the scale is perfectly reliable. The reliability coefficients calculated in this study. Cronbach's  $\alpha$  of the total questionnaire was 0.94, dimensions of the questionnaire ranged from 0.77 to 0.92. Both halves of Cronbach's alpha values with the split-half method, the Guttman's split-half, and the Spearman-Brown coefficients, and the correlation between two halves were above 0.70 that showed a strong and significant relationship. According to these results, the questionnaire was determined to have high reliability.

In the Chinese version of the questionnaire resulted in a 6-dimension, 8-factor, 29-item survey. Each factors of the scale had Cronbach's  $\alpha \geq 0.74$ ; informational needs ( $\alpha = 0.88$ ,  $\lambda = 3.48$ ), emotional needs ( $\lambda = 7.31$ ) factor 1 ( $\alpha = 0.93$ ), factor 2 ( $\alpha = 0.85$ ), practical

**Table 2.** Results of the reliability analyses of the questionnaire and dimensions

Total scale and dimensions	Cronbach $\alpha$	First half of cronbach $\alpha$	Second half of cronbach $\alpha$	Spearman brown	Guttman split-half	Correlation between two halves	M $\pm$ SD (min-max)
Total scale	0.94	0.89	0.90	0.87	0.87	0.78	84.5 $\pm$ 23.6 (26-130)
Informational needs	0.83						18.6 $\pm$ 24.1 (5-25)
Emotional needs	0.92						30.9 $\pm$ 11.2 (10-50)
Practical needs	0.77						9.5 $\pm$ 3.4 (3-15)
Psychological needs	0.87						25.4 $\pm$ 8.4 (8-40)

**Table 3.** Correlation matrix between factors

Factors	1	2	3	4	5
1. Total questionnaire	-				.883**
2. Dimension of the informational needs		.642**		.747**	.437**
3. Dimension of the emotional needs			.923**	.483**	.706**
4. Dimension of the practical needs				.630**	.656**
5. Dimension of the psychological needs					-

\*\*p<0.001

needs ( $\alpha=0.90$ ,  $\lambda=2.48$ ), psychosocial needs ( $\lambda=5.22$ ) factor 1 ( $\alpha=0.88$ ) and factor 2 ( $\alpha=0.74$ ). They excluded some items. As a result, the tool had four dimensions; EN, PrN, IN and PyN and 26 items. There are 5 items in the IN dimension, 10 items in the EN dimension, 3 items in the PrN dimension, and 8 items in the PN dimension (3). In this study, it observed that the Cronbach alpha coefficient is higher than the Chinese version. As the result of the analyzes, the rCPNQ-T was accepted as 4 dimensions and 26 items (the IN dimension=5 items, the EN dimension=10 items, the PrN dimension=3 items, and the PN dimension=8 items).

The item-total score correlation coefficients ranged from 0.41 to 0.75 in this study, should be at least 0.30 and positive, showed that items in the scale are correlated with the scale and items effectively, and measures the fact to be measured adequately [16]. Correlations between the questionnaire and dimensions were determined between from 0.315 to 0.923 ( $p<0.01$ ). It indicated that the factors were able to discriminate the dimensions.

The parents of children with cancer expressed the strongest needs for emotional and psychological in Turkey. In China, they expressed the strongest needs for informational and emotional [3]. Parents need informational, emotional, practice, physical, and psychosocial support [17, 18]. Meeting these needs through this rCPNQ-T can help these families in better control and treatment of their children's condition. Assessment of parent's needs is very important in planning interventions that best meet these needs. Therefore, nurses should be sensitive to the unmet needs of caregivers and provide the support they need.

Consequently the rCPNQ-T was accepted as four dimensions and 26 items (the IN dimension=5 items, the EN dimension=10 items, the PrN dimension=3 items, and the PyN dimension=8 items). It was determined that the rCPNQ-T was valid and reliable to measure emotional, practical, informational, and psychosocial needs for help.

There are some difficulties and limitations in this study. These are that parents who have problems with cancer diagnosis and treatment do not want to participate in the

research, the questionnaire has no cut-off point, and the questionnaire is in a different culture and language. In addition, as in the Chinese version, the test-retest could not be done in this study because the children were discharged immediately. The comparison could not be made due to the lack of adaptation of rCPNQ-T by different cultures. For this reason, the discussion section was insufficient.

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### Author contributions

Concept, Design, Supervision, Resources and Materials-E.B.K.; Data Collection and/or Processing-E.B.K. and G.Ö.G.; Analysis and/or Interpretation-M.B.; Literature Search--E.B.K. and G.Ö.G.; Writing Manuscript--E.B.K. and G.Ö.G.; Critical Review-E.B.K. and G.Ö.G.

**Ethics committee approval:** Institutional review board approval was granted and the study was reviewed and approved by the Gaziantep University Clinical Research Ethics Committee at the study center (date:04.07.2018 and decision no:2018/164).