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Psychometric properties of the Turkish version of the pediatric quality of life: The family impact module in parents of children with type 1 diabetes

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ABSTRACT

The aim of this study was to examine the validity and reliability of the Turkish version of the Pediatric Quality of Life (PedsQL™): The Family Impact Module. The sample of this methodological study included 201 parents whose children were diagnosed with diabetes in the endocrinology policlinics of two hospitals. The data were statistically analyzed based on frequency counts, percentages, and reliability/validity analyses. The internal consistency reliability coefficient of the scale was 0.926. The alpha coefficients of the sub-scales varied from 0.518 to 0.954. According to confirmatory factor analysis, the model fit indices of the scale were determined as follows: a goodness-of-fit index of 0.97 and a comparative fit index of 0.96. The findings indicate that the scale can be used as a valid and reliable tool to identify the difficulties that families of children with diabetes face.

Chronic disease is constantly increasing in Turkey and worldwide, and is emerging as a significant health problem. It is estimated that the prevalence of children under the age 18 with a chronic disease is between 5% and 30%, with 10–15% requiring special care (Erdem et al., 2013; Riana et al., 2004; Roberts, Behl, & Akers, 2004).

Owing to advances in medicine and technology, the survival rate of children with chronic diseases has increased (Katz, 2002). However, the time spent at hospitals, the complexity of medicine administration, and intensive medical treatments all heavily influence family members emotionally, physically, and financially. This further impacts the child's adjustment to the disease (Çakan & Sezer, 2010; Iovchuk, 2003; Katz, 2002).

Family attitudes during the diagnosis and treatment process directly influence the child's quality of life (Scarpelli et al., 2008). For this reason, the impact of parents' psychological status in relation to the treatment process in

pediatric chronic diseases needs to be evaluated and monitored. Affected families should be provided with the necessary family training, in addition to psychological and social support (Xu, Yang, Gong, Zhai, & Peng, 2006).

There are currently a variety of different scales that identify how children with chronic diseases affect their families. Among these, the Pediatric Quality of Life (PedsQL™): Family Impact Module (FIM) is the preferred scale (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). It examines aspects of the family process (Ab Rahman et al., 2011; Bullinger, Schmidt, Petersen, & Ravens-Sieberer, 2006; Chen, Hao, Feng, Zhang, & Huang, 2011; Eiser & Morse, 2001; Mano, Khan, Ladwig, & Weisman, 2009; Peterson et al., 2005). The PedsQL™: FIM assesses family functioning and is intended to measure the impact of a chronic health condition on parents and families. It has been validated through its reliability in smaller studies. The PedsQL™: FIM consists of 36 items that make up 8 scales: physical functioning, emotional functioning, social functioning, cognitive functioning, communication, anxiety, daily activities, and family relationships.

Through international publication, the PedsQL™: FIM has been translated into different languages (Al-Gamal & Long, 2016; Chen et al., 2011; Medrano et al., 2013; Scarpelli et al., 2008). The study by Medrano et al. (2013), which focused on the families of children aged 2–17 years with any chronic disease, found a Cronbach's alpha value of 0.91. In another study by Scarpelli et al. (2008), which concentrated on children treated in a hematologic oncology clinic in Brazil, a Cronbach's alpha value of 0.89 was found, with sub-dimensions varying from 0.60 to 0.81. Research carried out in Malaysia with families of 44 physically disabled children revealed a Cronbach's alpha coefficient above 0.70 (Rahman et al., 2011).

In China, a study of families of children with asthma or heart disease was carried out by Chen et al. (2011). It was found that the CFI and Cronbach's alpha of the scale to be 0.97 for families of children with heart disease and 0.96 for families of children with asthma. The cross-cultural adaptation was performed following the PedsQL™ Measurement Model Translation Methodology and consisted of 4 steps: forward translation, backward translation, preliminary test, and field test. Thus, it was concluded that the scale was valid, reliable, and compatible with Chinese culture. It was then suggested that further studies be conducted in families of children who have different chronic diseases.

The aim of this study was to assess the psychometric properties of the Turkish PedsQL™: FIM, which has been developed to examine the impact of childhood type 1 diabetes mellitus (T1DM) on families. T1DM is defined as a “family disease” due to the parents' role in disease management and the relationship between family function and children's adaptation to the disease (Williams, Laffel, & Hood, 2009). Therefore, it is argued that identifying the

effects of type 1 diabetes on families will influence family care and lessen the burden of chronic diseases on families.

In Turkish culture, great importance is attached to the nutrition of children. Families think that the more the child eats, the healthier and better nourished she will be. Therefore, families may perceive the recommended diet as prevention of the growth and development of their children, and this causes families to be caught in a dilemma. This situation increases the anxiety levels of families and may cause tension in family processes (Aslan & Şahin, 2017; Balaban, Özdoğan, & Uçar, 2018; Erdem, Özel, Çınar, & Işıksan, 2017; Erdim, Ergün, & Kuşuoğlu, 2017). Family processes related to management of a disease with complex care requirements such as diabetes play a key role for the success of the disease management (Chen et al., 2011; Scarpelli et al., 2008). When the literature was reviewed, no reliable and valid instrument for Turkish families of children with diabetes was found. PedsQL™: FIM is a measurement tool that assesses all the aspects of family process in chronic diseases. Therefore, the aim of this study was to evaluate the validity and reliability of the Turkish version of The PedsQL™: FIM.

Methods

Study design

The present study was designed to evaluate the psychometric characteristics of the Turkish version of the PedsQL™: FIM. Participants consisted of 201 parents of children with type 1 diabetes registered in the pediatric endocrinology outpatient clinics of two hospitals in Western Turkey.

Participants

A sample size of 100–200 subjects for the whole scale or 5–10 subjects for each item is recommended to ensure that the factor analysis is valid when adapting the scale (Brown, 2015). In the present study, the target sample size was 5 subjects per item, a total of 180 subjects. The study was carried out in pediatric endocrinology polyclinics of a public hospital and a university hospital in İzmir. While the socio-economic levels of individuals who were admitted to the public hospital were lower, the socio-economic levels of the individuals who were admitted to the university hospital were higher.

The sample can be considered a fair representation of the Turkish-speaking public in general. Parents of children aged 11–17 years old and diagnosed with T1DM at least one year ago were included. T1DM diagnosis is made by a pediatric endocrinologist according to ISPAD and ADA criteria. Criteria for participation in the present study was the absence of disabilities hampering comprehension, having the ability to speak Turkish, and

voluntary participation. Those who had children with thyroiditis, celiac disease, type 2 diabetes, or any disability that hampered comprehension were excluded. No sampling method was applied, and the study included all the families whose children were diagnosed with T1DM and who met the inclusion criteria and agreed to participate. "Children who participated in the pilot study were excluded from the remainder of the study" özellikle bu kısmı). Of the participants 95% were women, 92.5% were married, and 95.5% lived in a nuclear family. Among the participants, 42.3% of mothers were primary school graduates, and approximately half of them lived in a city center. In addition, 50.0% of the participants had middle income, and 92.5% of the parents had health insurance and attended hospitals for regular check-ups. The average age of the mothers was 39.36 ± 5.78 years old and that of the fathers was 42.54 ± 6.01 years old. The average number of the family members was 4.27 ± 1.22 (Table 1).

Procedure and measurements

Prior to beginning this research, written consent from James W. Varni (Varni et al., 2004), the owner of the scale, was received via e-mail, and official permission was granted by the University Ethics Committee (protocol number: 2288-GOA; decision number: 2015/21–17). Moreover, during the data collection

Table 1. Demographic characteristics of participants.

		<i>n</i>	%			
Gender	Female	191	95.0			
	Male	10	5.0			
Marital Status	Married	186	92.5			
	Previously married	15	7.5			
Family Type	Nuclear family	192	95.5			
	Extended family	9	4.5			
Mother's Education Level	Not literate	6	3.0			
	Literate	5	2.5			
	Primary School	85	42.3			
	Middle School	19	9.5			
	High School	53	26.4			
Place of Residence	University	33	16.4			
	City Centre	110	54.7			
	Town	72	35.8			
Health Insurance Status	Village	19	9.5			
	Yes	186	92.5			
Regular Check-Ups.	No	15	7.5			
	Yes	189	94.0			
Total	No	12	6.0			
		201	100			
		<i>n</i>	Min.	Max.	Mean	Sd
Mother's Age		201	27	54	38.36	5.64
Father's Age		201	27	59	42.65	6.01
Number of Family Members		201	1	9	4.21	1.15
Diabetes Age		201	1	13	4.71	2.99

process, written consent was obtained from all participants, who had been informed that they could withdraw from the study at any time. The PedsQL™: FIM and introductory information form were presented to all participants, who then completed the scale and the form in approximately five minutes.

Introductory information form

The form consists of 16 questions on participants' age, gender, level of education, family type, place of residence, health insurance status, number of family members, diabetes duration, and regular check-ups.

The Pediatric Quality of Life Inventory Family Impact Module

This scale was developed by James Varni in 2004 to measure the effects of having a child with disease on families. It consists of 36 statements with a total of 8 sub-factors. The rating of the scale with all positive items is a 5-point Likert-type scale (never [0]; seldom [1]; sometimes [2]; frequently [3]; always [4]). Reverse scoring is carried out when the items are transformed into scores (0 = 100; 1 = 75; 2 = 50; 3 = 25; 4 = 0). Higher scores indicate good family function with low levels of negative impact. The total Cronbach's alpha coefficient is 0.97 and the alpha confidence coefficient of the sub-factors is 0.82–0.97 (physical functionality, 0.91; emotional functionality, 0.90; social functionality, 0.88; cognitive functionality, 0.93; communication, 0.88; anxiety, 0.82; daily activities, 0.91; family relations, 0.97) (Varni et al., 2004).

Adaptation of the Pediatric Quality of Life Inventory Family Impact Module

This scale was translated from English to Turkish and back-translated to English by 3 linguists who were native Turkish speakers. The translated scale was evaluated in terms of cultural compatibility and scope validity by 7 teaching fellows in the field of nursing. The scale was finally revised in light of the feedback provided by these scholars.

Once the process of translation was complete, the scale was presented to 10 academics and nurses; 5 nursing faculty members, 2 diabetes specialist nurses, 2 pediatricians, and 1 faculty member from the Pediatric Diabetes Association. These experts, whose comments were received via e-mail, evaluated the items in terms of their comprehensibility and cultural compatibility. The Davis technique was used to investigate the scope validity on the basis of expert views (Davis, 1992). As a result of this evaluation, the sum of the first two ratings were divided by the number of experts to elucidate the scope validity index (SVI). If the SVI was larger than 0.80, the scope validity of the item was considered valid (Gözüm & Aksayan, 2002). The scale was administered to 10 people in a pilot study, and their opinions and the comprehensibility of the items were recorded.

Data analysis

Data were analyzed using the SPSS (Statistical Package for the Social Sciences) v22.0 and LISREL (Linear Structural Relations) 8.8 programs. Demographic characteristics of the participants were analyzed using descriptive statistics. The mean \pm standard deviation was utilized for continuous data. Principal component analysis was performed to achieve greater accuracy. The Kaiser–Meyer–Olkin (KMO) and Barlett’s tests were administered prior to factor analysis to identify sample adequacy and its compatibility with factor analysis. Cronbach’s alpha and the total item score correlations were used to establish reliability.

Results

In the present study, we included parents of children with T1DM who were in the clinic on the days of data collection. A total of 201 parents met the inclusion criteria. The experts were shown the original and translated versions of the PedsQL™: FIM and asked for their evaluation. Using the Davis technique, the scope validity index was calculated as 0.88.

Factor analysis identified the structural validity of the PedsQL™: FIM. Prior to the factor analysis, the KMO test was used to determine whether the sample size was sufficient. The KMO value of the PedsQL: FIM was 0.782, and the Bartlett’s test value was $\chi^2 = 4392.174$; $p < 0.001$. The total descriptive variance rate of the scale was 67.01%.

Results of the confirmatory factor analysis show respective factor-loading ranges of: Factor 1 (physical condition), 0.66–0.79; Factor 2 (emotional condition), 0.68–0.79; Factor 3 (social condition), 0.69–0.84; Factor 4 (cognitive condition), 0.66–0.88; Factor 5 (communication), 0.52–0.77; Factor 6 (anxiety), 0.69–0.79; Factor 7 (daily activities), 0.85–0.93; and Factor 8 (family relations), 0.89–0.94 (Table 2).

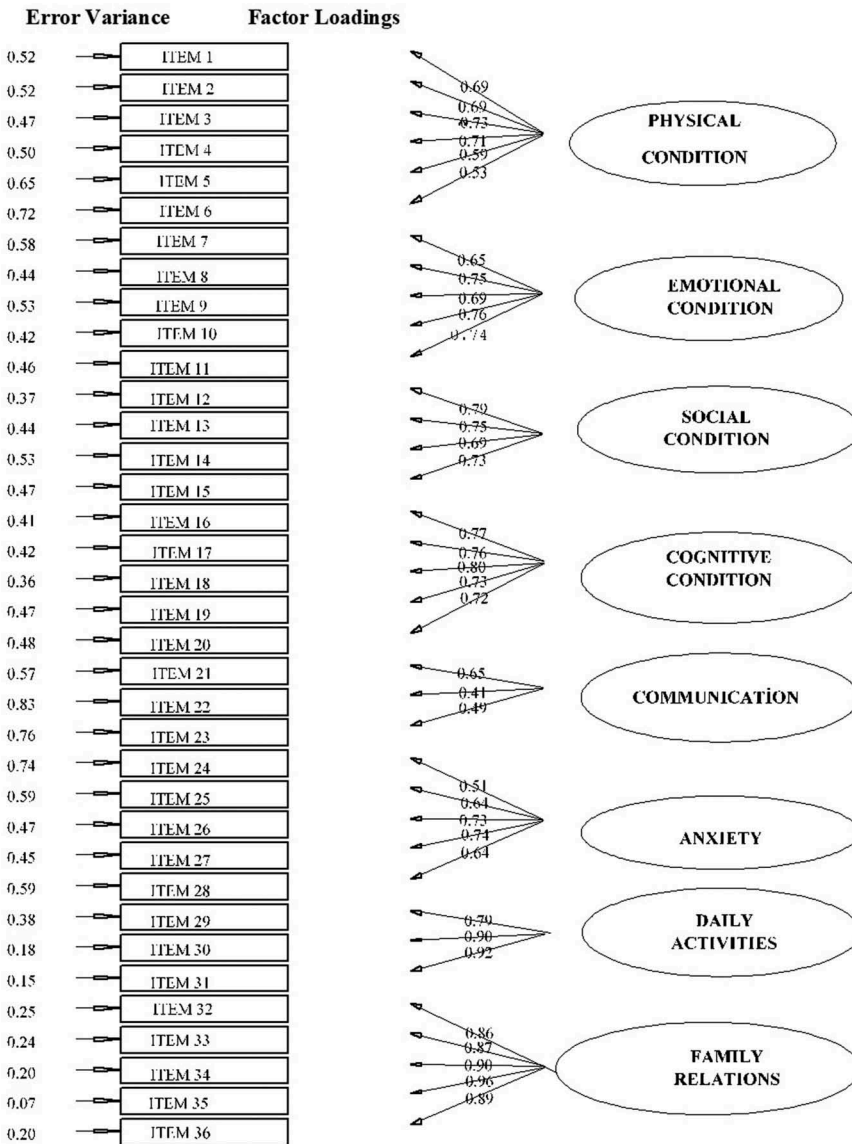
Various compatibility indices were utilized to examine the applicability of the PedsQL: FIM. Among these, the following values were identified: comparative fit index (CFI) = 0.96; goodness-of-fit index (GFI) = 0.97; adjusted goodness-of-fit index (AGFI) = 0.97; and non-normed fit index (NNFI) = 0.91, with $\chi^2 = 963.31$, for $df = 566$, $p < 0.001$, and a root mean square error of approximation (RMSEA) of 0.059. The results of the confirmatory factor analysis highlighted that the factor loads of all items in the PedsQL: FIM varied between 0.28 and 0.99. The t-values of the items were higher than 1.96 (Figure 1). This calculation was less than five ($\chi^2/SD = 1.70$) (Table 3) in the current analysis.

The findings of the present study show that Cronbach’s alpha was 0.926 for the Turkish PedsQL: FIM. The alpha coefficients of the sub-scales varied between 0.518 and 0.954, whereas the total item correlations varied between 0.25 and 0.61 ($p < 0.001$) (Table 2).

Table 2. Factor analysis and corrected item–total correlation of the PedsQL: Family Impact Module.

Item	Physical Condition	Emotional Condition	Social Condition	Cognitive Condition	Communication	Anxiety	Daily Activities	Family Relations	Corrected Item–Total Correlation	Cronbach's α
I feel tired during the day.	0.700								0.531	0.815
I feel tired when I wake up in the mornings.	0.789								0.505	
I feel so tired that I cannot do the things I like.	0.692								0.552	
I have headaches.	0.697								0.546	
I feel physically weak.	0.738								0.450	
I feel nauseous.	0.659								0.384	
I feel anxious.		0.759							0.493	
I feel sad.		0.761							0.570	
I feel angry.		0.682							0.514	
I feel frustrated.		0.786							0.556	
I feel helpless and hopeless.		0.788							0.538	
I feel isolated from others.			0.719						0.584	
I feel problems in receiving support from others.			0.688						0.551	
I find it difficult to spare time for social activities.			0.835						0.476	
I do not have enough energy for social activities.			0.828						0.519	
I have difficulty in concentrating.				0.658					0.544	
I have difficulty in remembering what other people said.				0.801					0.530	
I have difficulty in remembering something I have just heard.				0.881					0.534	
I have difficulty in thinking quickly.				0.813					0.488	
I have difficulty in remembering something I have just thought of.				0.846					0.469	
I think that others do not understand my family situation.					0.521				0.424	
It is hard to talk about my child's health situation with others.					0.766				0.252	
I have difficulty to convey my feelings to doctors and nurses.					0.721				0.320	

(Continued)



Chi-Square=963.31, df=566, P-value<0.00000,

Figure 1. Confirmatory factor Analysis of Pediatric Quality of Life: The Family Impact Module in Parents of Children with Type 1 Diabetes.

Table 3. Results of the confirmatory factor analysis for the Pediatric Quality of Life Inventory Family Impact Module.

χ^2/SD	χ^2	df	p	RMSEA	CFI	GFI	AGFI	NNFI
1.70	963.31	566	< 0.001	0.059	0.96	0.97	0.97	0.91

Table 4. Participants' score distribution in the Pediatric Quality of Life Inventory Family Impact Module.

	<i>n</i>	Mean	SD	Minimum	Maximum
Physical Score	201	39.78	19.5	0.00	75.00
Emotional Score	201	37.93	20.9	0.00	75.00
Social Score	201	49.92	21.7	6.25	75.00
Cognitive Score	201	43.36	23.8	0.00	75.00
Communication Score	201	50.97	19.1	0.00	75.00
Anxiety Score	201	42.97	18.7	1.25	75.00
Daily Effects Score	201	43.57	26.5	0.00	75.00
Family Effects Score	201	44.20	26.4	0.00	75.00
Total Score	201	43.22	15.1	3.89	75.00

Participants received an average score of 43.22 ± 15.1 in the PedsQL: FIM, with scores varying between 1.25 and 75.00. The highest score was received in the sub-dimension of communication (50.97 ± 19.1), with the lowest score being in the emotional sub-dimension (37.93 ± 20.9) (Table 4).

Discussion

This is the first study to investigate the impact of childhood T1DM on families in Turkey. Our results support the reliability and validity of the PedsQL: FIM. The scope validity index (SVI) value was identified as 0.88, suggesting that linguistic and cultural compatibility is sufficient for use of the index in Turkish (Polit & Beck, 2008).

Factor analysis was used to identify the structural validity of the PedsQL: FIM. The Barlett's test value, which examines the applicability of the dataset for factor analysis, was seen to be suitable and the data were inter-related and compatible with factor analysis ($\chi^2 = 4392.174$; $p < 0.001$).

The factor structure of the scale was evaluated through both exploratory factor analysis (EFA) and confirmatory factor analysis (CFA). The PedsQL: FIM, which has an eight-dimension structure in its original language, retained its structure with 8 sub-dimensions in Turkish. Additionally, fit index values obtained via CFA show that the PedsQL: FIM, with its 36 items and 8 sub-dimensions, did not require any changes when presented in Turkish.

Furthermore, the Cronbach's alpha value obtained in the present study was close to the value of the original scale, thus indicating it as highly reliable. The following values were found for the reliability coefficients of the sub-dimensions of the scale: physical condition, 0.784; emotional condition, 0.832; social condition, 0.795; cognitive condition, 0.864; communication, 0.653; daily activities, 0.818; and family relationships, 0.944 (Table 4). Although the Cronbach's alpha value of the scale was lower than that of the original scale, it did retain a high level of reliability.

Conclusion

The translated Turkish version of the PedsQL: FIM was found to be a valid and reliable scale for the evaluation of the effects of children with T1DM on families. It would be useful to re-analyze the internal validity of the scale using different pediatric patient groups.

Study limitations

There are certain limitations of the present study. Firstly, test-retest was not applied in the study group. Secondly, concurrent/convergent and divergent validity were not examined. Third, translation was not assisted by psychological personnel, although several items are concerned with mental health (i.e., anxiety, and emotional and cognitive condition). Last, because childcare is considered a female responsibility in Turkish culture, it was primarily women who participated in the present study.

Implications for practice

In pediatric endocrinology, there should be valid and reliable instruments for identifying the effects of T1DM on families across different languages. Given the importance of the parent's role in effective disease management and the child's adaptation to the disease, families of children with diabetes should be routinely evaluated. The PedsQL: FIM presents as a quick, easy, cost-effective tool for use by care teams. Diabetes teams can use this scale to determine family problems and improve family-centered care.

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