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Turkish Reliability and Validity Study of Pediatric Quality of Life Inventory™ 3.0 Diabetes Module by Parental Perspective*

Ebeveyn Perspektifiyle Pediatrik Yaşam Kalitesi Envanteri Diyabet Modülünün Türkçe Geçerlik-Güvenirlik Çalışması

Dijle AYAR ^{a1}, Candan ÖZTÜRK^b

^aLecturer,Faculty of Nursing, Dokuz Eylul University, İzmir, Turkey ^bAssoc. Prof.,Department of Nursing, Faculty of Health Sciences, Sabahattin Zaim University, İstanbul, Turkey

Abstract

Objective: Quality of life is defined as the self-perception of an individual in a cultural and intellectual context. In Turkey, there is no diabetes-specific life quality scale which can assess the life quality of 8-12 year-old children with type 1 diabetes by parental perspective. This study was methodologically performed in order to test the Turkish validity and reliability of the Pediatric Quality of Life InventoryTM 3.0 Diabetes Module-Parental Form which can evaluate the life quality of 8-12 year-old children with type 1 diabetes by parental perspective.

Method: The study group was composed of 111 parents who had 8-12 years-old children with type 1 diabetes registered in İzmir Dokuz Eylül University, Ege University Children's Hospital, Behçet Uz Children's Hospital and Pediatric Endocrinology Clinic of Tepecik Hospital. In order to analyze the data, number/percentage, Chronbach's alpha, and exploratory and confirmatory factor analyses were used.

Results: The Chronbach's alpha value of the scale was 0.86. Kaiser–Meyer–Olkin coefficient was found as 0.80 χ^2 =1527.5 p<0.001. The total item score correlations changed between 0.32 and 0.86 (p<0.001). Model compliance indicators; Comparative Fit Index was 0.87, Goodness-of-fit Index was 0.78 and Root Mean Square Mean Errors was 0.051 p<0.001.

Conclusion: This scale is a reliable and valid scale which can assess the life quality of 8-12 year-old children with type 1 diabetes by parental perspective.

¹E-mail addres: dijleozer87@gmail.com

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Keywords: Inventory, quality of life, type 1 diabetes mellitus, reliability and validity.

Öz

Amaç: Yaşam kalitesi, kültürel ve entellektüel bağlamda kişinin öz-algı durumu olarak tanımlanır. Türkiye'de, 8-12 yaş tip 1 diyabetli çocukların yaşam kalitesini ebeveyn perspektifi ile değerlendiren diyabete özgü yaşam kalitesi ölçeği bulunmamaktadır. Bu çalışma, 8-12 yaş aralığındaki diyabetli çocukların yaşam kalitesini ebeveyn perspektifi ile değerlendiren Pediyatrik Yaşam Kalitesi Envanteri[™] 3.0 Diyabet Modülü-Ebeveyn Formu'nun geçerlik ve güvenirliğini test etmek amacıyla metodolojik olarak yapılmıştır.

Yöntem: Bu çalışmanın örneklemi İzmir Dokuz Eylül Üniversitesi, Ege Üniversitesi Çocuk Hastanesi, Behçet Uz Çocuk Hastanesi ve Tepecik Hastanesi Çocuk Endokronolji Polikliniğine kayıtlı 8-12 yaş aralığında Tip 1 diyabetli çocuğu olan 111 ebeveynden oluşmuştur. Verilerin değerlendirilmesinde sayı/yüzde, Cronbach α analizi, açıklayıcı ve doğrulayıcı faktör analizi kullanılmıştır.

Bulgular: Ölçeğin Cronbach's alpha değeri 0,86'dır. Kaiser–Meyer–Olkin katsayısı 0,80 χ^2 =1527,5 p<0,001 olarak bulunmuştur. Ölçeğin madde toplam puan korelasyonları 0,32 ve 0,86 değerleri arasında değişmektedir (p<0,001). Model uyum göstergeleri; Karşılaştırılmalı Uyum İndeksi=0,87, İyilik Uyum İndeksi=0,78 ve Yaklaşık Hataların Ortalama Karekökü=0,051 olarak p<0,001 bulunmuştur.

Sonuç: Bu ölçek; 8-12 yaş tip 1 diyabetli çocuklarını yaşam kalitelerini ebeveyn perspektifi ile değerlendirebilen geçerli ve güvenilir bir ölçektir.

Anahtar Sözcükler: Envanter, yaşam kalitesi, tip 1 diabetes mellitus, geçerlik ve güvenirlik.

Introduction

Type 1 diabetes mellitus (T1DM) is characterized by the chronic immune mediated destruction of pancreatic β -cells, which leads to partial or, in most cases, absolute insulin deficiency.¹More than 79,000 children are diagnosed with T1DM everyday throughout the world.²In Turkey, it is estimated that there are about 15,000 children with diabetes, mostly of school age, and about 1,500–1,700 children are diagnosed with TIDM every year.³

Increasing numbers of youth with diabetes require intensive treatment programs to reduce the development of complications. Intensive management increases the burdens placed on routines and relationships of children and their families. Intensive treatment of type 1 diabetes often disrupts a child's usual activities, requires disease-focused behaviors from the child and family, and potentially impacts overall quality of life, holistic nursing care is important and quality of life is individual, it varies from person to person⁴Diabetic care requires many injections of insulin per day, multiple daily glycemic controls and a specific diet in order to obtain a satisfactory metabolic control with an impact on the daily physical, emotional, and social well-being of patients and their parents.⁵ It is agreed that enhancing quality of life (QOL) and wellbeing is as important as metabolic control and prevention of secondary morbidity.⁶Quality of life is defined as the self-perception of the individual's status within the context of cultural and intellectual conditions.7Quality of life is assessed by various standardized Quality of Life instruments, which make data comparisons possible. When assessing QOL in children with diabetes, either a generic or a disease-specific approach may be employed. A generic approach allows for comparisons between children with diabetes and healthy children or children with other conditions. However, a disease-specific approach allows for the assessment of dimensions that are uniquely relevant to the lives of children with diabetes and therefore may be more sensitive to change or between group differences.8

Children are often seen as unreliable respondents because they lack the reading, linguistic, and cognitive skills to respond to quality of life measures. Alternatively, parents are viewed as appropriate proxy respondents to provide information concerning the child's illness and quality of life. For children living with a chronic illness, parents are often the primary health care provider. Parents become responsible for the monitoring of symptoms, adjusting of medications, and organizing of health care interventions and are, therefore, viewed as suitable proxy reporters.⁹Ronen et al.

(2003)¹⁰describe the parent proxy report as being important in exploring the parent's perceptions of the child's illness and the effect that it has on the child, and family.

In literature, various measurement tools are present related to the quality of life levels of individuals with diabetes. Majority of these tools are specific for the adolescents with Type 1 diabetes¹¹ and other diseases¹². There are no diabetes related scales measuring the effect of diabetes on the quality of life of children (8-12 ages) through parent questionnaires in Turkey. The aim of this study was to test the reliability and validity of a Turkish version of The Pediatric Quality Of Life InventoryTM 3.0 Diabetes Module-Parent Report (PedsQLTM 3.0 Diabetes Module-Parent Report).¹³

Materials and Methods

Design and participants

The study sample consisted of 111 parents who had children 8–12 years of age who were diagnosed with T1DMfor a minimum of six months prior to the study. In general, studies that have adapted scales have followed the rule that the sample size should be more than 100 to conduct the factor analysis, or that the sample size should be calculated by selecting 5–10 individuals per item in the scale.¹⁴ In our study, the initial target was to reach 140 parents by selecting 5 individuals per item. However, only 111 parents meeting the inclusion criteria were reached.

To be included in the study:(a) parents had to have a child 8–12 years of age who had diabetes; (b) the child had to be diagnosed with TIDM at least 6 months before the study; and (c) the parents had to be able to read and understand the questions included in the scale in Turkish. Parents were excluded from the study: (a) if their child had diabetes-driven thyroiditis and celiac disease, which are frequently seen with diabetes; or (b) the child had neurological problems.

The researchers provided parents with instructions about how to complete the scale and its intended purpose. All the parents who were present in the polyclinic on the days of the data collection and met the inclusion criteria were included in the study. Randomization was not used. Children with diabetes came to their appointments in the polyclinic with one of their parents. The parent (mother/father) accompanying the child to the appointment in the polyclinic was included in the research. All parents who were present in the polyclinic on the days of the data collection agreed to take part in the study; no parent refused to take part in the study. The parents who participated in the study had a mean age of 37.94±5.27 (min 27 – max 55). Less than half (44.6%) of the parents had elementary school degrees, and 57.7% had a household income equal to their expenditures. Over three-quarters of the participants (77.5%) were mothers.

Measures

The PedsQL[™] 3.0 Diabetes Module–Parent Form was developed by Varni, Burwinkle, Jacobs, Gottschalk, et al. (2003).¹³The scale measures the quality of life of children 8–12 years old with T1DM,based on the perception of their parents. The scale consists of 28 items with five sub-scales that measure: diabetes symptoms (11 items), treatment barriers (4 items), treatment adherence (7items), worry (3 items), and communication (3 items). A five-point Likert scale was used in which 0=never a problem, and 4=almost always a problem. Items were linearly transformed to a 0–100 score. The score was 100 if the items were rated 'never a problem' and 0 if the items were rated 'almost always a problem'. Thus, higher scores indicate higher health-related quality of life.¹⁵Reliability coefficients of the original sub-scale were 0.81 for diabetes symptoms, 0.68 for treatment barriers, 0.73 for treatment adherence, 0.81 for worry and 0.84for communication.¹³A family information questionnaire was also used to collect socio demographic information on the parents for the study, including the parents' age, education, relation to the child and income.

Adaptation of the PedsQLTM 3.0

The Turkish adaptation and use of the PedsQL[™] 3.0 Diabetes Module–Parent Form was undertaken with the written permission of the original authors. The scale was independently translated into Turkish by three linguists. The Turkish version was then translated back into English by a different linguist. Expert opinions were sought from five nursing faculty members, two diabetes

nurses, one pediatric oncologist and one faculty member from the Pediatric Diabetes Association. The experts were shown the original and translated versions of the PedsQLTM 3.0 Diabetes Module–Parent Formand asked to evaluate the items for compatibility on a scale of 1–4 (1=very compatible, 2=compatible, 3=requires minor modification, 4=requires major modification). Following minor wording changes to a few items in response to the compatibility analysis and expert evaluations, the instrument was deemed suitable for testing.

Pilot Study

After the scale was revised, it was tested on 10 parents. The findings of the parents who completed the scale in the pilot study were not included in the findings of the study sample. Because no negative feedback was received from the parents, it was decided that the scale could be used with an adequately large sample to tests its reliability and validity.

Data Collection

The study sample consisted of parents who had an 8–12-year-old child with Type 1 Diabetes Mellitus and were registered in the Pediatric Endocrinology Polyclinic of Dokuz Eylül University Hospital, Ege University Pediatric Hospital and Behçet Uz Children Hospital and Tepecik Education and Research Hospital located in İzmir. The study was conducted between March 2011 and May 2012. Data were collected through face-to-face interviews with parents in the training room of the diabetes nurses.

Statistical Analyses

Statistical Package for the Social Sciences version 15.0 (SPSS Inc, Chicago, IL, USA) was used for statistical evaluation of the data. The initial coherence analysis of the experts was performed using content analysis. Pearson's correlation coefficient was used to measure the correlations among the sub-scales and the correlations between each sub-scale and the total score. Two types of factor analysis were conducted: exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) to examine the scale's structure and how the individuals items fit with the sub-scales.

Reliability

The reliability analysis employed Cronbach's alpha coefficient, the split-half method and item total correlation analysis. Cronbach's alpha is the most widely used method for evaluating internal consistency. A Cronbach's alpha of 0.70 is acceptable for new measures, indicating that this level represents a modest degree of homogeneity.¹⁶

The split-half correlation between the halves of the test was the first measure of internal consistency. The scale was divided into two equal parts, and the scores of the two halves were calculated. The correlation between the scores on the two halves provided the split-half reliability.¹⁷ Use of the Spearman–Brown prophecy formula permits extrapolation from the obtained reliability coefficient to the original length of the test, typically raising the reliability of the test.¹⁸

Item-total analysis is used to explain the relationship between the item scores and the total score of the instrument. The capacity of the test items to measure the desired quality is important for the reliability of the instrument. High correlation coefficients indicate a strong association of the item with the theoretical construct being measured, and that the item is able to measure the intended construct effectively¹⁹

Validity

The validity analysis employed the coherence analysis of the expert opinions (Content Validity Index), and explanatory and confirmatory factor analysis, using structural equation modeling. 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. There are various approaches to assessing content validity using an expert panel, but nurse researchers have been in the forefront of developing an approach that involves the calculation of a Content Validity Index (CVI). The items that have a CVI over 0.80 are considered acceptable.²⁰

Factor analysis is a method for identifying clusters of related variables that is, dimensions underlying a central construct.¹⁴The first type of factor analysis that was used is known as exploratory factor analysis (EFA), which essentially assumes no a priori hypotheses about the dimensionality of a

set of items. Another analysis was also conducted: confirmatory factor analysis (CFA), which is a subset of sophisticated statistical techniques referred to as structural equation modeling.¹⁶

Ethical Considerations

The study had the permission of the licensor, and the approval of institution where the study conducted and the Ethics committee (02.25.2011; 2011/05-12), Verbal assent was obtained from the children and written consent was obtained from the parents before the study was conducted.

Results

Reliability

The Cronbach's α for the Turkish version of the PedsQLTM 3.0 Diabetes Module–Parent Report was 0.86. Internal consistency (reliability) for the sub-scales of the Parent Report was: 0.68 for diabetes symptoms, 0.47 for treatment barriers, 0.79 for treatment adherence, 0.76 for worry and 0.67 for communication. The split-half reliability was 0.61 for the first half of the Parent Report and 0.86 for the second half. The correlation coefficient between the first and second halves was 0.70 (p<0.001). Itemtotal correlations varied between 0.32 and 0.86 and were statistically significant (p<0.001) (Table 1).

Table 1. Item-Total C	orrelation Coefficients	of the Pediatric Oua	litu of Li	fe Inventoru™ 3.0
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Diabetes Module-Parent Form (n=111)

Subscale		Items	Item-Total Correlation	
			r	
1 2 3 4 5 5 6 7 7 8 9 10	1	Feeling hungry	.53	
	2	Feeling thirsty	.55	
	3	Having go to the bath room too often	.63	
	4	Having stomach aches	.64	
	5	Having head aches	.45	
	6	Going "low"	.44	
	7	Feeling tired or fatigued	.68	
	8	Getting shaky	.57	
	9	Getting sweaty	.54	
	10	Having trouble sleeping	.32	
11 12 13 13 14	11	Getting irritable	.35	
	Needle sticks (i.einjections/bloodtests) causing him/her pain	.48		
	13	Getting embarrassed about having diabetes	.59	
	14	Arguing with me or my spouse about diabetes care	.66	
Ê	15	It is hard for me tosticktomy diabetescare plan	.73	
16 17 18 19	16	It is hard formy child to take blood glucose tests	.73	
	17	It is hard formy child to take insülin shots	.74	
	18	It is hard formy child to exercise	.51	
	19	It is hard formy child to track carbonhydrates or exchanges	.51	
Adł	20	It is hard formy child to wear my idbracelet	.45	
21	21	It is hard formy child to carry a fast-acting	.49	
22 23 24 24 25	22	It is hard formy child to eat snacks	.51	
	23	Worrying about "going low"	.78	
	24	Worrying about whether or not medical treatments are working	.82	
	25	Worrying about long -term complications from diabetes	.86	
Communication	26	Telling the docters and nurses how she/he feels	.77	
	27	Asking the doctors and nurses questions	.81	
	28	Explaining my illness too there people	.75	

Validity

Inter-rater agreement was tested with the Index of Content Validity, which yielded 90% agreement between the experts. The Keiser–Meyer–Olkin (KMO) constant of the scale was 0.80 and the result of the Bartlett test was χ^2 = 1527.5 p<0.001.KMO measure of sampling adequacy estimates the degree of distinct and reliable factors in factor analysis, where values of 0.70–0.80 are considered to be good.²¹The total amount of explained variance was 68% for the explanatory factor analysis.

Factor loadings of the PedsQLTM 3.0 Diabetes Module-Parents Report were 0.21–0.68 for diabetes, 0.31–0.82 for treatment barriers, 0,14–0,79 for treatment adherence, 0.66–0.76 for worry and 0.51–0.72 for the communication sub-scales. Model fit indicators were: Non-Normed Fit Index (NNFI)= 0.85, Comparative Fit Index (CFI)=0.87, Incremental Fit Index (IFI)= 0.87,Goodness of Fit Index (GFI)= 0.78, χ^2 = 432.34,df 337, and Root Mean Square Error of Approximation (RMSEA)= 0.051, p<0.001(Figure 1).

Discussion

Reliability

The total Cronbach's alpha was 0.77 for the original version of the scale, and the Cronbach's alpha of the present scale was above 0.80. The Cronbach's alpha of the sub-scales of the original scale varied between 0.68 and 0.84. The Cronbach's alphas of the sub-scales for versions translated into Persian, Swedish and Greek have been found to vary more, ranging between 0.68 and 0.73, 0.54 and 0.91, and 0.65 and 0.78. In our Turkish sample, the Cronbach's alphas of the subscales tended to fall within these values (i.e., 0.67 to 0.79), with the exception of treatment barriers, which was 0.47. The split-half reliability was 0.86 and 0.61 in the first and second halves of the instrument respectively, and the correlation between the halves was 0.70. These values meet the generally accepted criteria, and are equal to or greater than the split-half reliabilities reported for the original version of the scale.

Validity

Expert opinions were sought from nine specialists to evaluate the cultural and linguistic properties of the Turkish translation of the scale, and their views on the context and expression of the items were also taken into in revising some of the items. In light of these findings, it was concluded that the scale was compatible with the Turkish culture that it represented the concept it was intended to measure. Thus, its content validity was verified.

The results of analyses of the parent scale using the KMO coefficient and the Bartlett test indicated that the sample size and the data structure were suitable for factor analysis. The total explained variance was 68%. The larger the percentage of explained variability, the stronger the factor structure is. In social science studies, explained variance ratios of 60% are commonly considered fairly high.²⁰Hence, the total explained variance in the current study was considered satisfactory.

Factor loadings are expected to be between 0.30 and 0.40. Confirmatory factor analysis of the "PedsQLTM 3.0 Diabetes Module–Parent Report" showed that factor distributions of the items were compatible with the original version of the scale. Model fit parameters were acceptable according to the NNFI, the CFI 0.87, the IFI, the GFI and the RMSEA. The results of confirmatory factor analysis showed GFI, NFI, NNFI and CFI >0.90 and a RMSEA <0.80.

Another parameter for model fit is calculated by dividingits χ^2 value by its degree of freedom. If the outcome is under the value of five, the model fit is satisfactory.¹⁹ This calculation was less than five (1.28) in the current analysis, indicating that the data were compatible with the scale, the items and sub-scales were related, and items in each sub-scale could define the corresponding factor sufficiently.



Figure 1. Confirmatory Factor Analysis of The Pediatric Quality of Life InventoryTM 3.0

*Factor loadings.;#Error variance: The part of the total variance caused by anything irrelevant that was not experimentally controlled

These results support the construct validity of the parent questionnaire and indicate that the instrument is a valid tool that can be used in Turkish populations.

The reliability and validity studies of the PedsQL[™] 3.0 Diabetes Module in different cultures, such as Hungarian parents²¹, Swedish parents²², Greek parents²³ and Iranian parents with diabetic children²⁴ also showed that the instrument was reliable. The current work showing the reliability of the Turkish version of the instrument will make further international comparisons possible.

Limitations

The study has several limitations. Another limitation is the study's relatively small size sample. This was because that it was difficult to reach parents who had children with diabetes mellitus within the 8–12 age groups, and met the inclusion criteria. While the sample size was adequate to conduct the analyses, a larger sample would increase confidence in the findings. Some of the factors loadings for the items on the sub-scales were also low. Retesting the scale with a large sample should eliminate the concerns associated with these preliminary findings.

Conclusions

This scale is a reliable and valid instrument to measure the health-related quality of life in Turkish children with Type 1 Diabetes Mellitus in the 8–12 age groups from perspective of their parents. We hope that the use of this scale will help professionals to assess how parents perceive the quality of life of their children with diabetes.

Competing interests

The authors declare that they have no competing interests.

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Contribution of Authors

Design of Study: C Ö, D A Data Collection or/and Analysis: D A, C Ö Preperation of Manuscript: D A, C Ö

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