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RESEARCH

Parent Quality of Life scale in Type 1 Diabetes: a scale development and validation study

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Abstract

The study aimed to develop and evaluate the psychometric properties of the Parental Quality of Life Scale in Type 1 Diabetes for parents. This research was a methodological study. The data of the study were collected between May and July 2021. The study included 201 parents who have a child with type 1 diabetes. Descriptive statistics, Cronbach's alpha, item-total score analysis, and factor analysis were used to evaluate the research data. In line with the suggestions of the experts, a total of 20 items were removed from the scale and a 12-item scale was created. The scale consists of 12 items and 2 sub-dimensions and shows 62.7% of the total variance. The Cronbach's alpha value of the scale was found to be 0.91 and its sub-dimensions were more significant than 0.85. According to both explanatory factor analysis and confirmatory factor analysis, all factor loads were more significant than 0.60.

Conclusion: The Parental Quality of Life Scale in Type 1 Diabetes was found to be valid and reliable. The scale can be used as a measurement tool in experimental or qualitative studies to be conducted on children with type 1 diabetes and their families. It is recommended to adapt the scale's psychometric properties to different cultures.

What is Known:
- *The quality of life of parents who have a child with type 1 diabetes may be affected due to the burden of care for the disease. Parents' low quality of life can negatively affect pediatric patients' health..*
- *There is no measurement tool in the literature that directly measures the quality of life of parents who have a child with type 1 diabetes, whose validity and reliability studies have been conducted.*

What is New:
- *A measurement tool was developed to evaluate the quality of life of parents with a child with type 1 diabetes.*
- *This measurement tool is valid and reliable.*

Keywords Diabetes mellitus · Life quality · Parent · Pediatric · Validity and reliability

Abbreviations

CFA	Confirmatory factor analysis
CFI	Comparative fit index
CVI	Content validity index
EFA	Explanatory factor analysis
GFI	Goodness of fit index
I-CVI	Item content validity index
IFI	Incremental fit index
KMO	Kaiser–Meyer–Olkin
NFI	Normed fit index
PQLS-T1D	Parental Quality of Life Scale in Type 1 Diabetes
RFI	Relative fit index
RMSEA	Root mean square error of approximation
S-CVI	Scale content validity index
TLI	Tucker-Lewis index

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Introduction

Type 1 diabetes is a common childhood endocrine and metabolic disease globally, which can cause significant health problems in individuals and society [1, 2]. Type 1 diabetes requires lifestyle changes, and in the long term, it causes damage and loss of function in various organs and systems of the body. At the same time, it is stated that it is an important health problem that reduces the quality of life and affects the child, family, and society due to high treatment expenditures and loss of workforce [2]. It is a period in which many difficulties are encountered in the management of the disease and in providing metabolic control, and children and parents experience the most problems [3]. The literature shows that parents who have a child with type 1 diabetes face problems with the management of the disease. It was determined that parents often experience anxiety and anxiety about the long-term complications of the disease and whether it is effective in the management of the disease. In addition, it has been reported that parents experience burnout and fatigue due to caring for their children and that they cannot balance coping with stressful events with diabetes and meeting their own needs [3, 4].

Quality of life is a subjective term that reflects both positive and negative aspects of life. It is also multi-dimensional. Many factors such as the physical and psychological state and performance of the individual, relations with family members, environmental events, the person's belief status, chronic fatal diseases, and the level of support for them can be counted among the factors affecting the quality of life [5]. Being diagnosed with a chronic illness in a family member can affect the family in all aspects, physically, emotionally, and socially. In addition, the increase in care needs due to chronic disease care brings changes in family life and a financial burden [3, 4]. In this regard, the management of type 1 diabetes and the difficulties experienced by the family, and the quality of life are directly important in determining the factors affecting the parents.

In the literature, there is a measurement tool that evaluates the general quality of life of children [6]. In type 1 diabetes, some scales evaluate the quality of life of patients with type 1 diabetes [7–9]. For parents, measurement tools that evaluate the effect of the disease on family life, evaluate the cooperation of the child and the parent, and evaluate family support have been developed for families with a child with type 1 diabetes [10–17]. There is a limited number of studies in which measurement tools evaluating the quality of life of parents with children with type 1 diabetes have been developed [18–21]. However, some scales were found to be specific to limited sample sizes [18–20] and specific age groups [18–21]. It was observed that the construct validity and reliability analyses of the psychometric properties of some scales were insufficient and were specific to specific age groups, and the construct validity and reliability analyses of the psychometric properties of some scales were insufficient [18–20].

Following an in-depth review of the literature, existing measurement tools assessing the quality of life of parents of individuals with type 1 diabetes have potential limitations. It is thought that these measurement tools are not intended to directly evaluate the quality of life of the parents of 0–18 group children who have inadequate diabetes self-management, higher care burden, and need for family support. Although these contribute to measuring the effects of type 1 diabetes on the lives of parents, they are insufficient for direct assessment.

It is clear from the literature review that the quality of life of the parents should be assessed and improved so that parents can provide adequate care for their child, cooperate with nurses, participate in the care and treatment of the child, and ensure continuity. This study, it was aimed to develop a quality of life scale for parents with a child with type 1 diabetes and to evaluate its psychometric properties.

Materials and methods

Participants and procedures

This research was carried out as a methodological study. Methodologically designed studies suggest that the items in the scale should be 5–10 times larger for the sample size. But 20 times the number of items is required for examining the factor structure. Also, it was stated that the number of samples preferred in scale development studies was sufficient for 200 or more [22]. Finally, the sample of the study consisted of 201 parents who completed and returned the questionnaire. Sampling inclusion criteria consisted of having a child with type 1 diabetes, reading, and understanding Turkish, and voluntary participation in the study. Exclusion criteria consisted of having a newly diagnosed (less than 30 days old) child or having a child with another chronic disease. The secure online questionnaire creation links were examined by the researchers. To protect the confidentiality of data, it was decided to create the questionnaire form sent to parents via the URL "surveey.com."

Measures

The data were collected between May and July 2021. The data were collected by sharing the online questionnaire link, created by the researchers using the URL address "surveey.com," with the families and the volunteer parents who met the research criteria included in the study. The following forms were used to collect research data.

Parent introductory information form

This form was prepared by the researchers and consists of 7 items. The content of the form includes information on age, gender, educational status, occupation, and the number of children [13, 14, 16, 23].

Parental Quality of Life Scale in Type 1 Diabetes (PQLS-T1D)

The basis of this study was Maslow's hierarchy of needs model [24]. During the development of the Parental Quality of Life Scale in Type 1 Diabetes, certain working steps were applied. The scale development steps consisted of a literature review and item pool creation, ensuring content validity, and pre-testing [7, 22, 25].

Scale development stages

Literature review and creation of an item pool

In the first stage of creating the scale, in the literature review, studies and scales on the quality of life of adults, children, and parents of children with type 1 diabetes were systematically evaluated. Afterward, a complete list of scale items was created by the authors in accordance with the parent's quality of life. This list formed the scale item pool containing 40 items. As a result of the joint evaluation of the researchers, it was reduced to a 32-item question pool [10, 14, 16, 23]. The experts who evaluated the item pool were created from 24 academic members whose fields of specialization were internal medicine nursing, pediatric nursing, psychiatric nursing, and methodology. Certain working steps were applied in the validity and reliability analyses for the pre-scale.

Ensuring scope validity

To evaluate the intelligibility of the items forming the scale and their suitability in terms of the Turkish language, firstly, two experts in the fields of psychiatry and education were consulted. Then, expert opinion on the scale was obtained from the experts who evaluated the item pool. The Davis technique was used to obtain an expert opinion to evaluate content validity. According to this technique, a score between 1 and 4 is given to evaluate the items. Items are graded as follows: not relevant (1), somewhat relevant (2), quite relevant (3), and highly relevant (4) [26]. In this process, the content validity index (CVI) of the 32-item form was calculated by evaluating the clarity and appropriateness of the questions in line with expert opinions. A 12-item scale form was created according to the obtained CVI (94%). The scale consisted of 12 items measuring the parents' quality of life and the answers were scored between 0 and 4. It consisted of a Likert-type questionnaire that was answered as follows: never (0), rarely (1), sometimes (2), frequently (3), and always (4). The total score range of the scale was between 0 and 48. A low total score on the scale means that the parent's quality of life is high.

Pre-test phase

In the pre-test phase, the draft scale should be applied to a small sample group to represent the target group to be collected [23, 27]. A pilot study was conducted with 10 parents with like qualifications to the target group, and they were not included in the sample group. According to the results of the application, vague and incomprehensible items were corrected, and the sketch form of the scale was given its final form.

Statistical analysis

Evaluation of data was done with IBM SPSS 26.0 statistical program and SPSS AMOS 24. A CVI was used for content validity. Cronbach alpha was used for internal consistency analysis for reliability, and item-total score correlations were

Table 1 Characteristics of the study participants ($n=201$)

		***X* ± SD**	
Age	Child	11.31 ± 4.68	
	Mother	39.48 ± 6.75	
	Father	42.73 ± 6.66	
		n	**%**
Parents	Mother	177	88.1
	Father	24	11.9
Education	First-secondary education	64	31.8
	High school	65	32.3
	Bachelor	63	31.3
	Graduate	9	4.6
Profession	Unemployed	87	43.3
	Health employee	9	4.5
	Worker	30	14.9
	Public employee	45	22.4
	Other professional groups	30	14.9
Number of children	1	34	16.9
	2	103	51.2
	3 and above	64	31.9
Total		201	100.0

X mean, *SD* standard deviation

Table 2 Reliability analysis of the scale and sub-scale scores ($n = 201$)

Subscale	Cronbach α	X ± SD	Med (Min–Max)	Floor effect %	Ceiling effect %
Dimension 1	0.89	7.43 ± 5.47	7 (0–24)	12.4	1.0
Dimension 2	0.85	11.56 ± 5.61	11 (0–24)	0.5	1.0
Total	0.91	19.00 ± 10.16	18 (0–48)	0.5	1.0

X mean, *SD* standard deviation, *Med* median, *Min* minimum, *Max* maximum

evaluated for item reliability. Kaiser–Meyer–Olkin (KMO) test and Barlett Test were used for construct validity. In addition, explanatory factor analysis (EFA) and confirmatory factor analysis (CFA) were carried out.

Results

Study population

Of the parents, 88.1% were mothers, 32.3% were high school graduates, 43.3% were unemployed, and 51.2% had two children. The mean age of the children with type 1 diabetes was 11.31 ± 4.68 years, 39.48 ± 6.75 for mothers, and 42.73 ± 6.66 for fathers (Table 1).

Reliability analysis of PQLS-T1D

Internal consistency analysis

The Cronbach's alpha value for the entire scale was found to be 0.91. The Cronbach's alpha values for the Physical and Functional Well-Being sub-dimension (6 items, 0–24 points) and the Emotional and Social Well-Being sub-dimension (6 items, 0–24 points) of the scale were found to be 0.89 and 0.85, respectively. It was determined that the floor and ceiling effect of the scale was below 15.0% (Table 2).

Item-total score correlation analysis

The item-total score correlation coefficients for 12 items were found to be between 0.50 and 0.72. Since the item-total score correlation coefficient of all items was > 0.50, no other item was removed from the scale at this stage (Table 3).

Test–retest reliability analysis

The scale was re-administered to 30 parents with contact information after 3 weeks. Pearson product-moment correlation analysis was performed for the test–retest reliability of the scale. According to the analysis, a statistically significant positive correlation was found between test–retest mean scores ($r = 0.98$, $p < 0.001$) (Table 4).

Table 3 Scale construct validity (EFA) ($n = 201$)

Items	Sub-dimensions			Item-total correlation (r)*
		Dimension 1	Dimension 2	
9	I find it difficult to adapt to my environment because my child has diabetes	0.81		0.68
10	I cannot do my daily work because my child has diabetes	0.81		0.66
12	My child has diabetes restricts me from doing the things I love	0.77		0.66
11	I am not enjoying my life right now	0.76		0.68
7	I cannot participate in social activities because my child has diabetes	0.73		0.71
3	I cannot do self-care because my child has diabetes	0.66		0.65
4	I am worried about my child's health		0.80	0.62
1	I cannot sleep because my child has diabetes		0.73	0.50
5	I am afraid of losing my child		0.67	0.64
8	I have financial difficulties due to the economic burden of diabetes		0.66	0.51
2	I am tired because my child has diabetes		0.65	0.76
6	I feel irritable/tense because my child has diabetes		0.62	0.72
Explained variance (%)			**62.7%**	

*Correlation, significant at < 0.001

Table 4 Comparison of test–retest mean scores ($n = 30$)

	First measurement X ± SD	Second measurement X ± SD	*r*	*p*
Scales	16.20 ± 8.79	16.40 ± 8.38	0.98	< 0.001

X mean, *SD* standard deviation

Validity analysis

Content validity

According to the opinions of 24 experts regarding the content validity of the scale, 20 items were removed from the preliminary scale. The final version of 12 items had an item-content validity index (I-CVI) between 0.90 and 1.00. The total scale content validity index (S-CVI) was found to be 0.94.

Construct validity of the PQLS-T1D

EFA

In the EFA, it was determined that the scale consisted of two sub-dimensions and the total explained variance of the scale was 62.27%. When the item contents were analyzed, the first sub-dimension of the PQLS-T1D was "Physical and Functional Well-Being" and the second sub-dimension was named "Emotional and Social Well-Being." The Physical and Functional Well-Being sub-dimension includes items 3, 7, 9, 10, 11, and 12, and the Emotional and Social Well-Being sub-dimension has 1, 2, 4, 5, 6, and 8. While performing EFA, varimax rotation was applied to obtain factors for the approximation of the simple structure. Eigenvalue was accepted as 1 and above. Moreover, EFA revealed that the factor loading values for the scale ranged from 0.62 to 0.81. According to EFA, the KMO coefficient of the scale was 0.914. Bartlett's χ^2 value was 1,322,863 ($p < 0.001$) (Table 3).

CFA

According to the model fit indices, the model chi-square (χ^2) value was found to be 99.87, df: 49, and χ^2/df: 2.03. Model fit is satisfactory if χ^2/df value is below 5.0 for model fit [20]. The root mean square error of approximation (RMSEA) was 0.072, the goodness of fit index (GFI) was 0.92, normed fit index (NFI) was 0.92, relative fit index (RFI) was 0.90, incremental fit index (IFI) was 0.96, Tucker-Lewis index was 0.94, and comparative fit index (CFI) was 0.96 (Table 5) (Fig. 1).

Discussion

While type 1 diabetes increases the responsibilities of parents in the family, it also affects parents economically, psychosocially, behaviorally, and cognitively, along with changes in family life [12]. Although there are studies in the literature examining the burden of type 1 diabetes on the family, the quality of life of the family, and its effect on the family, a limited number of the study were found to measure the quality of life for parents [10–12, 14–16, 18–21]. In this context, it was thought that a specific measurement tool was needed to determine the quality of life for parents with a child with type 1 diabetes. This study aimed to develop PQLS-T1D and to bring a measurement tool to the literature to measure the quality of life of parents.

According to the results of the analysis, the PQLS-T1D was identified that it provided psychometric criteria that could be used to measure the quality of life of parents. In some studies, it was observed that the content and construct validity analyses of the measurement tools developed were not sufficient [18, 19]. In our study, a rigorous methodological approach was demonstrated, which complies with the validity and reliability stages of the PQLS-T1D, as well as having strong psychometric data.

This study, PQLS-T1D, was conducted with parents of 0–18 age group children with type 1 diabetes. Studies in the literature differ from our study in this aspect [18–21]. Some studies have been conducted with children with type 1 diabetes only with parents of a specific age group [18–20] or different age groups between 0 and 25 years [21].

In a study with parents of children aged 3–20 years with type 1 diabetes, a questionnaire was developed to measure diabetes-specific concerns [18]. In another study, a questionnaire was designed for parents of children aged 10–18 years on life satisfaction, concerns, and the effects of diabetes [19]. On the other hand, Cappelleri et al. (2008) developed

Table 5 Model fit indices for CFA ($n = 201$)

Single factor	χ^2	df	χ^2/df	RMSEA	GFI					
Model	99.87	49	2.03	0.072	0.92	0.92	0.90	0.96	0.94	0.96

df degree of freedom, *RMSEA* root mean square error of approximation, *GFI* goodness of fit index, *NFI* NORMED FIT INDEX, *RFI* relative fit index, *IFI* incremental fit index, *TLI* Tucker-Lewis index, *CFI* comparative fit index

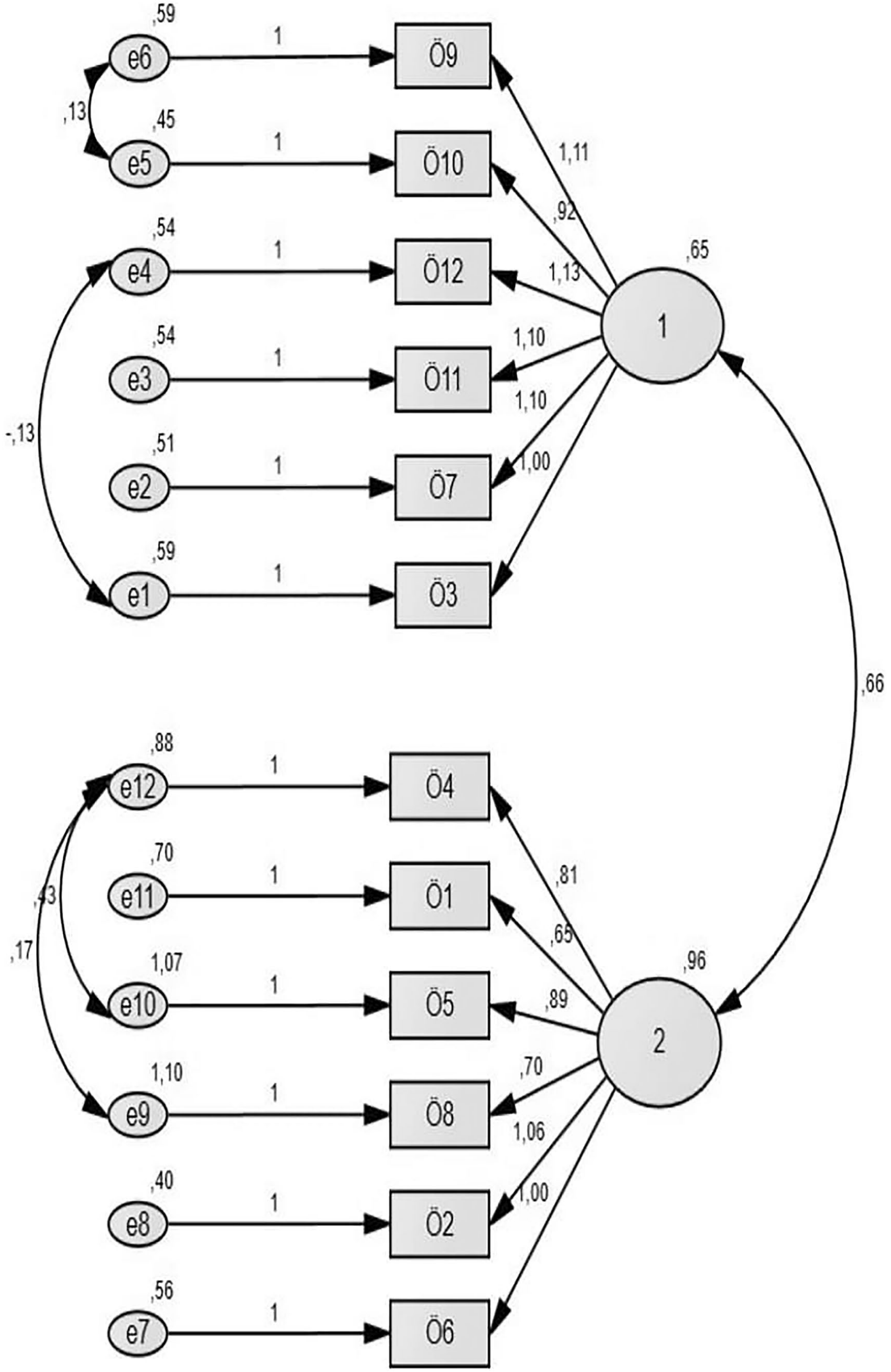

Fig. 1 Path diagram of CFA for scale. df 49, $p < .001$, RMSEA (root mean square error of approximation) 0.072, χ^2 99.87

a scale measuring the well-being and satisfaction of parents who have children with type 1 diabetes between the ages of 6 and 1 [20]. In the study by Hilliard et al. (2021), a measurement tool was developed to evaluate the health-related quality of life of parents and partners of individuals with type 1 diabetes in five different age groups aged 0–25 years. However, it is thought that individuals with type 1 diabetes over the age of 18 in the sample group of this scale, which makes valuable contributions to the literature, have diabetes self-management compared to those under the age of 18 [21]. However, it is a well-known fact that children under the age of 18 with type 1 diabetes have insufficient diabetes self-management to realize their medical nutritional needs, insulin requirements, self-monitoring at home, and being aware of the complications of hypoglycemia and hyperglycemia. Parents of children in this age group may need to take more responsibility for their children about diabetes treatment and complications. It has been predicted that this situation may have a high probability of affecting the quality of life of the parents. The scale we developed measures how parents' having a child with type 1 diabetes under the age of 18 affects their quality of life. Our scale differs from other studies in the literature in terms of measurement purpose and target population and contributes to clinical applications as a unique measurement tool.

In scale development studies, it was stated that the sample size should be 200 or more in terms of the suitability of psychometric analyses [23]. In our study, 201 parents with children with type 1 diabetes constituted the sample group. Vandagriff et al. (1992) developed a questionnaire by modifying the Diabetes Quality of Life scale to assess diabetes-specific concerns of 93 parents of children with type 1 diabetes [18]. A questionnaire on the quality of life of 56 parents of children with type 1 diabetes was developed by Faulkner and Clark (1998) [19]. Cappelleri et al. (2008) also developed a scale measuring the well-being and satisfaction of 116 parents of children with type 1 diabetes [20]. In these studies, which differ from our study findings, it was determined that the sample size was quite small and that this was not sufficient for psychometric measurements [18–21].

In this context, the fact that the PQLS-T1D has a sufficient sample size shows that the psychometric analyses are quite powerful. The CVI was calculated as 0.94 by taking expert opinions for the suitability and comprehensibility of the scale items. The CVI score must be above 0.80 to show the consistency between the expert opinions of the items covered by the scale [25, 28]. In this study, the I-CVI and S-CVI levels of the remaining 12 items out of the 32 items in the pre-scale were higher than 0.80, indicating that there was agreement among the experts and the content validity of the scale. According to our findings, it was concluded that the reliability of the PQLS-T1D met the scale's language and content validity criteria.

In the literature, the calculation of the relationship between the total score of the scale and the scores obtained from the scale items shows the item total score reliability of the test. The correlation coefficient between each item in the scale and the total score of the scale should be high. Although there is no standard value for the item-total score correlation value, this value is generally expected to be higher than 0.20 [26, 27, 29]. In this study, the item-total score correlation coefficients of the PQLS-T1D were found to be between 0.50 and 0.72. The fact that the item-total score correlation coefficients of all items of the scale are above 0.20 indicates that each item of the scale is reliable and its correlation with the total score is high. It is acceptable for floor and ceiling effects to be $< 15.0\%$ [27, 30]. The floor and ceiling effect of the total and sub-dimension scores of the scale was $< 15.0\%$. These results show that the scale and its sub-dimensions are reliable.

At the time we created the scale item pool, a specific scale with similar features was not included in the literature in parallel with our scale. For this reason, it was preferred to use the test–retest method instead of using a general quality of life scale for parents as a parallel form reliability method to test the construct validity. In this study, the test–retest method we used to determine the time invariance of PQLS-T1D was applied with an interval of 3 weeks [27, 31]. The correlation between the two measurements obtained from the first and second applications was statistically significant. This finding we obtained shows that PQLS-T1D is not affected by time, and it always measures the same thing even after time passes [31].

In the study, EFA was applied to determine the construct validity of the scale. As a result of the EFA, the varimax method was chosen for the rotation of the factors and it was determined that the scale consisted of two sub-dimensions. According to this result, it was determined that the total variance in the scale was high, explaining 62.27% of the total variance of the two sub-dimensional scales. It has been reported in the literature that the percentage of total variance should be between 40 and 60%, and the high percentage of variance makes construct validity strong [25, 28]. The fact that the percentage of variance was higher than 60% in this study proves the validity of the scale by showing the strength of the construct validity of the scale.

In the study, Barlett's test was used to test the suitability of the scale for factor analysis. There should be a statistically significant relationship between the result of Barlett's test and the variables included in the factor analysis ($p < 0.05$). It was determined that there was a significant relationship between Barlett's test performed in this study and the variables included in the factor analysis ($p < 0.001$).

For a scale to be able to perform factor analysis, the KMO value approaching 1 indicates that the sample size is sufficient and appropriate. A KMO value below 0.50 is unacceptable and means that the sample size is not sufficient. The suitability of the PQLS-T1D for factor analysis was tested and the KMO value was found to be 0.91. According to the test result, it was determined that the dataset obtained from the scale was very well-compatible and sufficient for factor analysis. The relationship between the items in the scale and the sub-dimension of the scale is explained by determining the factor load values. In the literature, it was emphasized that factor loading values should be greater than 0.45 and that the factor loading values were high, indicating that the items included in the factor analysis together measure a structure [25, 27–29]. The factor loading values of the PQLS-T1D were found to be between 0.62 and 0.81, and it was determined that the factor loading values were high and supported the construct validity of the scale.

According to the model fit indices because of the confirmatory analysis of the PQLS-T1D, the model is chi-square/SD 2.03 and GFI. CFI and AGFI values were found to be greater than 0.90. In the literature, chi-square/SD value less than 3 and GFI. It has been reported that CFI and GFI values should be close to 1 [25, 28]. In line with these results, it was found that there was a strong relationship between the scale and its sub-dimensions and that the sub-dimensions adequately defined their sub-dimensions. The CFA findings of the PQLS-T1D confirm that the dataset is compatible with the model and the two-factor structure of the scale. Therefore, according to the results of the validity analysis, the scale proved to be an appropriate and sufficient measurement tool for the quality of life of parents with type 1 diabetes.

The Cronbach alpha coefficient is calculated to measure internal consistency in determining whether each item in a scale is self-consistent. If the Cronbach alpha coefficient of the scale used is between 0.60 and 0.80, it is reliable, and between 0.80 and 1.00 indicates that the reliability of the scale is high [29]. In this study, the Cronbach alpha value was calculated for the total scale internal consistency coefficient of the PQLS-T1D, and it was found to be very high as 0.91. The Cronbach's alpha values of both sub-dimensions of the scale (0.89 and 0.85) were also found to be high, indicating that the items of the scale measure adequately and are related to the scale. As a result, it has been determined that the PQLS-T1D has a very high level of reliability.

Limitations

The collection of research data with an online questionnaire and the inability to collect the sample group through face-to-face interviews with parents formed the limitations of the study. Another limitation of this study is that while EFA and CFA analyses were aimed to be done separately in two groups, the analyses in this study were performed on a single sample group. This is because the sample is difficult to reach in clinical studies and the sample group was selected from a specific disease population. This study was limited to voluntary parents' results. Therefore, the results from the present study cannot be generalized to the Turkish population.

Conclusions

In this study, it was determined that the PQLS-T1D, which was developed to determine the quality of life of parents, is a valid and reliable measurement tool. It is recommended that this scale be used in different cultures and societies to assess the quality of life of parents who have a primary caregiver role in the management of a pediatric patient with type 1 diabetes and to plan strategies to improve the quality of life, especially in nursing studies. In future studies, it is recommended to use the test–retest method as well as the measurement tools measuring the general quality of life of the parents and the parallel form reliability method to test the construct validity with different aspects.

Authors' contributions All the authors contributed to the study's conception and design. Material preparation, data collection, and analysis were performed by ŞBY and DÇ. The first draft of the manuscript was written by ŞBY and DÇ; All the authors commented on previous versions of the manuscript. All the authors read and approved the final manuscript.

Availability of data and material All data relevant to the study are included in the article. The code used to generate the results is available on request from the corresponding author.

Declarations

Ethical approval Ethics committee approval was obtained from İzmir Bakırçay University for the study (date, 3 June 2021, and number, 2021/293). All procedures performed in studies involving human participants were by the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Consent to participate Before the study was conducted, the parents were informed about the study. Written consent was obtained from them online for participation.

Conflict of interest The authors declare no competing interests.

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