

Original Paper

Translation and Psychometric Evaluation of the Persian Version of the Pediatric Quality of Life Inventory 4.0 (PedsQL 4.0) for Iranian Children With Cancer



Somaye Pouy¹, Zahra Taheri_Ezbarami², Maryam Rassouli³, Saman Maroufizadeh⁴, Bahram Darbandi⁵, Nazila Javadi-Pashaki^{6*}

1. Assistant Professor, Department of Nursing, School of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran.
2. Associate Professor, Department of Nursing, School of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran.
3. Professor, Cancer Research Center, School of Nursing & Midwifery, Shahid Beheshti University of Medical Sciences, Tehran, Iran.
4. Assistant professor, Department of Biostatistics and Epidemiology, School of Health, Guilan University of Medical Sciences, Rasht, Iran.
5. Associate Professor, Pediatric Diseases Research Center, School of Medicine, Guilan University of Medical Sciences, Rasht, Iran.
6. Professor, Social Determinants of Health Research Center (SDHRC), School of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran.

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ABSTRACT

Introduction: Measuring the health-related quality of life (HRQOL) in children with cancer is very important. The pediatric quality of life inventory™ 4.0 (PedsQL 4.0) is a well-established tool for measuring the HRQOL of children aged 2-18 years with cancer.

Objective: The present study aimed to determine the psychometric properties of the Persian version of the PedsQL 4.0 for Iranian children with cancer.

Materials and Methods: This is a methodological study. The PedsQL™ 4.0 was first translated into Persian and then psychometrically evaluated. The participants included 200 children with cancer and 200 parents referred to a specialized hospital for children in Rasht, Iran, from October 2021 to October 2022, who were selected by a convenience sampling method. The face validity, and construct validity (by confirmatory factor analysis [CFA] were assessed. Internal consistency was assessed by calculating Cronbach's α and the test re-test reliability was measured by calculating the intraclass correlation coefficient (ICC).

Results: The mean age of children and parents was 5.9 ± 4.2 and 37.83 ± 5.86 years, respectively. The CFA results showed that the eight-factor model had a good fit. In the child self-report version, Cronbach's α value for the eight subscales was in the range of 0.72-0.88 and for the overall scale, it was 0.80. In the parent proxy-report version, Cronbach's α value was in the range of 0.82-0.93 and for the overall scale, it was 0.81. In the test re-test reliability, the ICC value in the child self-report version for the age groups 5-7, 8-12 and 13-18 years old was 0.85, 0.78, and 1, respectively. The ICC value in the parent proxy-report version for the age groups 2-4, 7-5, 8-12 and 13-18 years old was 0.97, 0.87, 0.87 and 1, respectively.

Conclusion: The Persian version of the PedsQL 4.0 has good psychometric properties for Iranian children with cancer. Therefore, it can be used as a valid and reliable tool to measure the HRQOL of these children in Iran.

Keywords:

Pediatric quality of life inventory (PedsQL), Children, Health-related quality of life (HRQOL), Cancer, Iran

* Corresponding Author:

Nazila Javadi-Pashaki, Professor.

Address: Social Determinants of Health Research Center (SDHRC), School of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran.

Tel: +98 (911) 3378772

E-mail: n.javadip@gmail.com



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Highlights

- Given the profound impact of cancer on children's health, it is essential to examine their health-related quality of life (HRQOL) after diagnosis.
- The Persian version of pediatric quality of life (PedsQL) 4.0 has acceptable internal consistency and reliability.
- As a valid and reliable tool, the Persian version of PedsQL 4.0 can be used to assess the HRQOL of children with cancer in Iran.

Plain Language Summary

The quality of life of children with cancer are greatly affected by the disease. Examining their HRQOL can be helpful in developing effective interventions for them. Given that there is no valid and reliable questionnaire in Persian to assess the health-related quality of life of children with cancer in Iran, this study translated and psychometrically evaluated the Persian version of the PedsQL 4.0 for children aged 2-18 years with cancer in Iran. The results showed that the Persian PedsQL 4.0 had good psychometric properties and can be used to measure the health-related quality of life of children with cancer in Iran.

Introduction

Cancer is one of the life-threatening diseases that affects the lives of many children in the world [1-3]. Cancer affects about 50-200 children per million worldwide [4]. In Iran, 19,973 children have been diagnosed with cancer in the recent ten years [5]. Cancer is one of the leading causes of death for children worldwide [6-8]. To reduce the cancer death rate in children, there are many methods such as chemotherapy, bone marrow transplant, and radiotherapy [9-11]. Despite the usefulness of these methods, they have many side effects for children, which affect their health-related quality of life (HRQOL) [12]. HRQOL is an assessment of how a person's well-being is affected over time by a disease, disability or disorder [13]. In children with cancer, due to the impact of the disease on various aspects of their lives, HRQOL assessment is very important [14]. Nowadays, more than 80% of children with cancer survive [15, 16]; therefore, special attention should be paid to their HRQOL [17].

To assess HRQOL in children with cancer, it is necessary to have an appropriate instrument that can assess all physical, psychological and social aspects. This tool should also include child and parent feedback and consider the child's cognitive development [18-20]. There are few tools for assessment such as the Minneapolis-Manchester Quality of Life Instrument and the pediatric quality of life (PedsQL 4.0) [21, 22]. The PedsQL 4.0 is

a suitable instrument for evaluating HRQOL in children, which considers all the mentioned criteria [23]. This tool consists of two parts; one part is the child self-report for ages 5-18 and the other part is the parent proxy-report for ages 2-18 years [23-25]. So far, this tool has been translated into many languages and psychometrically evaluated in different countries, but it has not yet been translated into Persian. Therefore, the present study aimed to determine the psychometric properties of the Persian version of the PedsQL 4.0 for Iranian children with cancer.

Methods

In this methodological study, the population includes the children with cancer and their parents referred to the Pediatric Oncology Department of a specialized hospital for children affiliated to [Guilan University of Medical Sciences](#) in Rasht, Iran, from October 2021 to October 2022. Inclusion criteria for children were age 2-18 years, a definite diagnosis of cancer by the physician for children who were in the active or follow-up treatment phase, and willingness of the child and informed consent of their parents to participate in the study. The children who were not physically or mentally stable (based on the physician's diagnosis) were excluded. Inclusion criteria for parents were the ability to speak Persian, willingness to participate in the study, no mental disorders or a history of hospitalization in psychiatric wards. In general, at least 200 samples are recommended to perform factor analysis according to the literature. This

sample size is able to provide a high test power of 0.80 for a model with 100 degrees of freedom [26]. Keeping this in mind, we included 200 children aged 2-18 years and 200 parents.

The PedsQL 4.0 has 27 items and eight subscales, including pain and hurt (2 items), nausea (5 items), procedural anxiety (3 items), treatment anxiety (3 items), worry (3 items), cognitive problems (5 items), perceived physical appearance (3 items) and communication (3 items). The child self-report is different based on age of the child (age 5-7, 8-12 and 13-18 years old). The parent proxy-report is also different based on the age of the child (age 2-4, 5-7, 8-12 and 13-18 years). The child self-report version uses a 3-point Likert scale (0 = not at all, 2 = sometimes, 4 = a lot) for children aged 5-7 years, while a 5-point Likert scale (0=never, 1=almost never, 2=sometimes, 3=often, 4=almost always) is used for children aged 8-18 years and for the parent proxy-report version.

Translation and cross-cultural adaptation were first done based on Beaton et al.'s four-step approach. For this purpose, after correspondence with the developer of the main version (Dr. James W. Varni) [25] and obtaining permission from him, the forward and backward translation was carried out. First, an Iranian translator

and a nurse familiar with English translated the questionnaire from English to Persian. Then, an initial Persian draft was obtained after checking the quality of translations and making modifications. A nurse familiar with English back-translated it into English. To compare the translated English draft with the original version of the questionnaire, it was emailed to Dr. Varni. Finally, the final Persian draft was approved after revising and editing. The flowchart of the study process is presented in Figure 1.

Parents were asked to complete both parent proxy-report (for ages 2-18) and child self-report (for ages 2-4) versions. The versions for 5-18 years old were completed by children. The information for parents (including age, relationship with the child, education and economic status) and children (including age, sex, type of cancer, and disease status) were also recorded. During the completion of the questionnaires, the researcher was available and answered their questions. The average time to complete the questionnaires was 20 minutes.

For content validity assessment, 10 experts in the fields of oncology, pediatric nursing, and psychometrics were asked to give their opinions about the grammar, wording, item allocation, and compatibility of the final

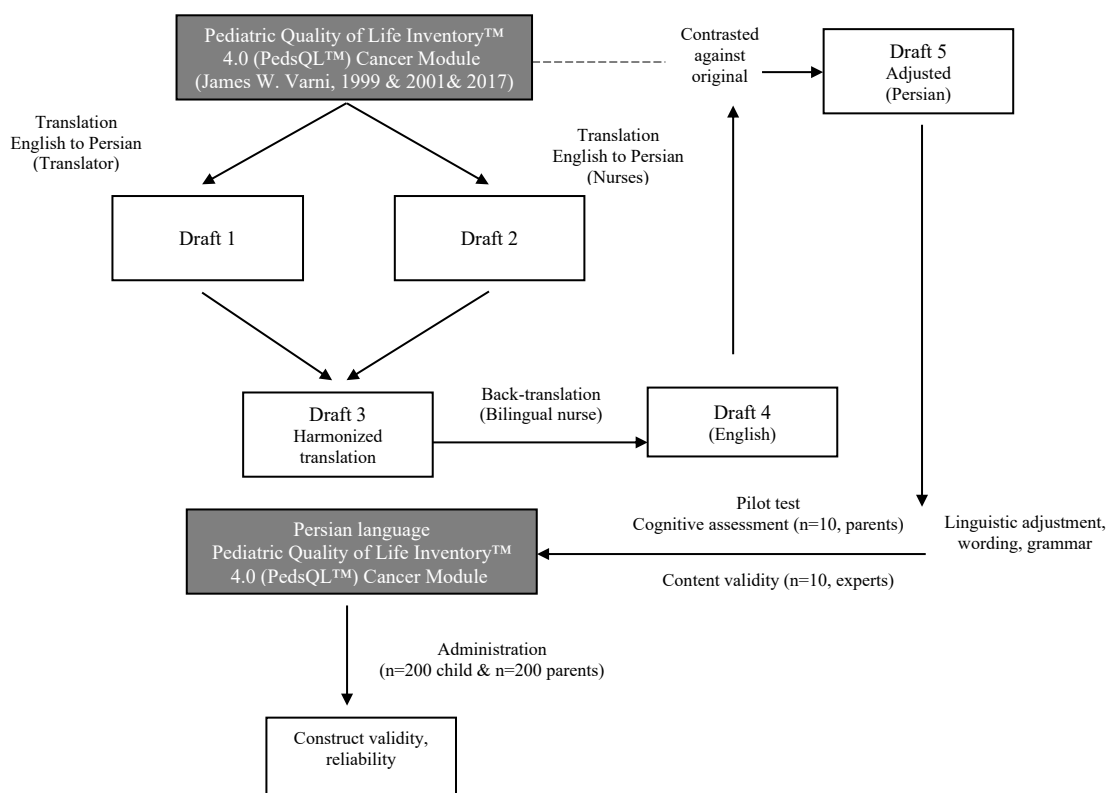


Figure 1. Flowchart of the study process

draft with Iranian culture. The feasibility and comprehensibility of the items were assessed by 10 parents of children with cancer.

To determine the construct validity, confirmatory factor analysis (CFA) was used. Maximum likelihood estimation was used to estimate the factor matrix. Several fit indices are used in CFA, including χ^2/df , χ^2 , df , goodness of fit index (GFI), adjusted goodness of fit (AGFI), comparative fit index (CFI), root mean square residuals (RMSR), root mean square error of approximation (RMSEA), and normed fit index (NFI). The acceptable values were considered as $\chi^2/\text{df} < 5$, CFI > 0.9 , GFI > 0.9 , AGFI > 0.9 , and RMSEA < 0.08 [26, 27]. Considering the studies assessed the different versions of the PedsQL 4.0, a sample size of 200 children and 200 parents was determined to perform the CFA. To determine the internal consistency of the Persian version, the questionnaire was given to 200 participants, and Cronbach's α coefficient was calculated. To determine the test re-test reliability, the questionnaire was completed by 50 children

aged 2-18 and their parents ($n=50$), and the Intraclass correlation coefficient (ICC) was calculated. Statistical analyses were done in SPSS software, version 21. Descriptive statistics (frequency, percentage, Mean $\pm$ SD) were used to describe the data, to perform CFA, LISREL software, version 8.8 was used.

Results

The age of children and their parents was 5.9 ± 4.2 and 37.83 ± 5.86 years, respectively. Other demographic and clinical characteristics are presented in Table 1. In the child self-report version, Cronbach's α value for the eight subscales was in the range of 0.72-0.88 and for the overall scale, it was 0.80 (Table 2). In the parent proxy-report version, Cronbach's α value was in the range of 0.82-0.93 and for the overall scale, it was 0.81 (Table 3). In determining the construct validity, all fit indices had acceptable value and confirmed the fitness of the final model (Table 4). Since the values were above 0.7 in both

Table 1. Demographic characteristics of participants (200 children and 200 parents)

Variables		No. (%)
Children	Child age (y)	2-4 28(14)
		5-7 88(44)
		8-12 50(25)
		13-18 34(17)
	Gender	Male 117(58.5)
		Female 83(41.5)
	Status of disease	Newly diagnosed 183(91.5)
		Recurrent disease 17(8.5)
	Type of tumor	Leukemia 130(65)
		Lymphoma 47(23.5)
		Neuroblastoma 10(5)
		Nephroblastoma 9(4.2)
		Rhabdosarcoma 4(2)
Parents	Blood relationship with child	Mother 180(90)
		Father 11(5.5)
		Other 9(4.5)
	Age of parents (y)	20-30 13(6.5)
		31-40 87(43.5)
		41-50 166(83)
		51-60 34(17)
	Educational level	Illiterate 8(4)
		Lower than high school 28(14)
		High school 35(17.5)
		Bachelor's degree 103(51.5)
		Master's degree 26(13)
	Economic status	Very high 9(4.5)
		High 8(4)
		Low 73(36.5)
		Very low 110(55)

Table 2. Mean scores and Cronbach's α values for the child self-report version

	Subscale	Mean+SD	α	Skewness
	Total	77.14+15.44	0.80	-0.771
	Pain and hurt	85.02+19.77	0.72	-1.182
	Nausea	82.1+24.29	0.88	-1.62
	Procedural anxiety	72.29+31.82	0.88	-1.0224
	Treatment anxiety	92.2+17.09	0.83	-2.923
	Worry	76.44+25.12	0.81	-1.121
	Cognitive problems	71.95+22.13	0.73	-0.537
	Perceived physical appearance	70.2+28.09	0.75	-0.781
	Communication	66.94+27.66	0.73	-0.589
2-4 years	Pain and hurt		NA	
	Nausea			
	Procedural anxiety			
	Treatment anxiety			
	Worry			
	Cognitive problems			
	Perceived physical appearance			
	Communication			
5-7 years	Total	72.06+14.78	0.77	0.041
	Pain and hurt	84.13+18.78	0.73	-0.781
	Nausea	76.21+22.87	0.83	-1.37
	Procedural anxiety	54.30+37.21	0.89	-0.172
	Treatment anxiety	86.22+21.78	0.79	-2.371
	Worry	73.55+27.98	0.72	-0.978
	Cognitive problems	73.11+23.18	0.77	-0.612
	Perceived physical appearance	70.22+29.12	0.77	-0.812
	Communication	58.78+27.12	0.71	-0.431
8-12 years	Total	78.72+24.4	0.82	-0.913
	Pain and hurt	86.22+21.78	0.79	-1.923
	Nausea	82.78+25.66	0.93	-1.833
	Procedural anxiety	78.28+27.68	0.90	-1.331
	Treatment anxiety	93.28+15.12	0.83	-3.721
	Worry	77.97+26.87	0.82	-1.120
	Cognitive problems	71.42+21.12	0.73	-0.612
	Perceived physical appearance	71.98+28.89	0.81	-0.912
	Communication	67.87+28.1	0.77	-0.601
13-18 years	Total	80.64+14.78	0.83	-0.891
	Pain and hurt	84.72+19.12	0.75	-0.793
	Nausea	87.32+20.78	0.91	-1.783
	Procedural anxiety	84.29+19.78	0.77	-1.165
	Treatment anxiety	97.12+14.87	0.94	-5.777
	Worry	77.8+25.12	0.84	-1.340
	Cognitive problems	71.32+24.72	0.82	-0.298
	Perceived physical appearance	68.4+27.82	0.80	-0.745
	Communication	74.18+25.12	0.83	-0.820

NA: Not applicable.

versions, it can be said that the Persian version had acceptable internal consistency.

For the test re-test reliability, the ICC values for each age group of children are presented in Table 5. Except for the treatment anxiety subscale in the 5-7 years age

group and the worry subscale in the 13-18 years age group, the ICC values were good to excellent. The ICC values for the parent proxy-report version also were good to excellent.

Table 3. Mean scores and Cronbach's α values for the parent proxy-report version

Subscale		Mean+SD	α	Floor Effect	Ceiling Effect	Skewness
Total		72.33+15.3	0.81	59.48	91.17	-0.671
Pain and hurt		83.15+23	0.88	61.80	105.87	-1.238
Nausea		81.4+25.71	0.93	53.87	106.18	-1.481
Procedural anxiety		59.61+32.12	0.92	32.31	95.29	-0.501
Treatment anxiety		86.22+18.97	0.91	66.72	103.81	-1.381
Worry		81.86+21.87	0.88	58.21	103.12	-1.321
Cognitive problems		69.01+21.82	0.85	48.18	91.38	-0.481
Perceived physical appearance		73.55+24.78	0.87	49.89	99.12	-0.901
Communication		61.15+25.62	0.82	37.80	88.26	-0.417
2-4 years	Total	72.69+16.87	0.85	58.91	92.67	-0.481
	Pain and hurt	84.12+18.97	0.86	67.61	105.28	-1.481
	Nausea	77.92+24.77	0.92	48.12	97.91	-0.151
	Procedural anxiety	46.87+35.02	0.89	22.18	93.18	-0.215
	Treatment anxiety	83.22+25.53	0.95	49.13	103.12	-0.850
	Worry	84.97+23.87	0.93	66.12	111.12	-2.120
	Cognitive problems	70.11+21.01	0.89	59.13	97.87	-0.660
	Perceived physical appearance	76.21+23.77	0.90	60.71	107.18	-1.871
	Communication	58.15+29.12	0.78	37.36	94.35	-0.815
5-7 years	Total	73.78+12.87	0.85	60.77	86.87	-0.112
	Pain and hurt	85.71+18.78	0.79	65.22	103.22	-0.871
	Nausea	79.21+28.72	0.94	52.71	104.77	-1.581
	Procedural anxiety	46.78+34.15	0.93	14.44	81.79	-0.113
	Treatment anxiety	84.32+18.98	0.86	66.80	101.12	-1.118
	Worry	85.97+18.99	0.80	68.18	103.71	-1.012
	Cognitive problems	71.81+19.87	0.87	50.12	91.77	-0.421
	Perceived physical appearance	77.38+21.13	0.83	56.71	98.81	-1.118
	Communication	59.12+25.97	0.85	33.18	85.12	-0.271
8-12 years	Total	65.97+17.21	0.81	58.71	91.75	-0.841
	Pain and hurt	81+25.21	0.95	54.21	105.77	-1.381
	Nausea	83.21+26.38	0.96	55.71	108.28	-1.721
	Procedural anxiety	69.71+28.71	0.95	38.79	96.89	-0.821
	Treatment anxiety	88.18+16.79	0.85	71.21	104.21	-1.421
	Worry	79.12+25.18	0.87	55.81	103.87	-1.321
	Cognitive problems	65.21+21.87	0.82	43.18	87.21	-0.180
	Perceived physical appearance	69.18+25.9	0.81	44.21	94.87	-0.751
	Communication	61.18+25.38	0.80	37.12	85.66	-0.451
13-18 years	Total	76.9+15.91	0.85	61.58	92.78	-0.381
	Pain and hurt	81.77+22.81	0.91	57.81	102.88	-0.921
	Nausea	85.28+22.87	0.93	62.31	106.87	-1.621
	Procedural anxiety	75.11+26.18	0.88	48.78	100.81	-0.721
	Treatment anxiety	89.18+15.12	0.92	76.81	103.12	-1.021
	Worry	77.38+22.18	0.87	58.91	97.81	-1.028
	Cognitive problems	68.91+23.71	0.89	43.21	91.68	-0.421
	Perceived physical appearance	71.46+26.18	0.87	47.81	96.21	-0.742
	Communication	66.18+24.77	0.88	42.78	88.31	-0.282

Table 4. Values of fit indices for parent-proxy report and child self-report versions

Version	χ^2	df	χ^2/df	RMSR	RMSEA	CFI	GFI	AGFI
Parent-proxy report	687.22*	212	3.25	0.057	0.066	0.95	0.91	0.88
Child self-report	612.34*	214	2.66	0.051	0.067	0.93	0.92	0.89

Abbreviations: RMSR: Root mean square residual; RMSEA: Root mean square error of approximation; CFI: Comparative fit index; GFI: Goodness of fit index; AGFI: Adjusted goodness of fit index.

*P=0.001

Discussion

The present study investigated the psychometric properties of the Persian version of the PedsQL 4.0 for Iranian children with cancer. The results showed the appropriate reliability and validity of the Persian PedsQL 4.0. Construct validity in this research was done using the CFA. The main version of the PedsQL 4.0 cancer has eight factors [23]. Our results showed that the Persian version (for both child self-report and parent proxy-report) had a good fit to the data and the eight-factor model was confirmed.

According to the Cronbach's α values, all subscales of the Persian PedsQL 4.0 in the child self-report and parent proxy-report versions for all age groups had good or acceptable internal consistency. In line with the present study, the results of a psychometric study on the Chinese version of the PedsQL™ 4.0 showed that the Cronbach's α values for the whole scale and the subscales in the child self-report and parent proxy-report were at an acceptable level and had a good internal consistency [28]. For the Brazilian version, a study showed that the Cronbach's α values for the child and parent versions were at an acceptable level, but in contrast to our study, most of the subscales were not at a good level [29]. For the original version, Cronbach's α values for

Table 5. Test re-test reliability (ICC values) of the Persian PedsQL 4.0

Subscale	Age Group (y)			
	2-4	5-7	8-12	13-18
Child self-report	NA	Pain and hurt		
		Nausea	0.43, 0.53	0.37, 0.95**
		Procedural anxiety	0.49, 0.81**	0.95, 0.95**
		Treatment anxiety	0.71, 0.98**	0.92, 0.98**
		Worry	0.85, 0.47	0.65, 0.66
		Cognitive problems	-0.07, -0.13	0.92, 0.22
		Perceived physical appearance	0.89, 0.84**	0.94, 0.21
		Communication	0.67, 0.79**	0.75, 0.93**
		Total	0.78, 0.89**	0.85, 0.94**
			0.74, 0.44	0.92, 0.97**
Parent proxy-report		Pain and hurt	0.84, 0.78**	0.82, 0.84*
		Nausea	0.78, 0.85**	0.92, 0.79*
		Procedural anxiety	0.67, 0.78*	0.86, 1.00**
		Treatment anxiety	0.92, 0.85**	
		Worry	0.84, 0.71**	0.95, 0.98**
		Cognitive problems	0.95, 0.84**	0.98, 1.00**
		Perceived physical appearance	0.98, 0.97**	0.88, 1.00**
		Communication	0.98, 0.97**	0.97, 0.88*
		Total	0.41, 0.35	0.84, 0.74
			0.96, 0.87*	0.95, 0.88**

NA: Not applicable; ICC: Intra class correlation.

*P≤0.05, **P=0.01.

the subscales of “perceived physical appearance” and “communication” in the children self-report were not at acceptable level [23].

The results of test re-test reliability assessment showed that except for the “treatment anxiety” subscale for 5-7 year age group and the “worry” subscale for the 13-18 year age group, the ICC values for all subscales of child and parent versions and different age groups were good to excellent. For the Japanese version, the ICC values of the subscale “treatment anxiety” in children aged 5-7 and 13-18 years old and the subscale “worry” for children aged 8-12 years were in the low range [30]. For the Chinese version, the ICC values for all subscales of child and parent versions were in the good to excellent range [28]. In the Brazilian version, the ICC was not calculated separately for different age groups, but they were in the appropriate range for the whole scale [29]. The low ICC of the “treatment anxiety” subscale for 5-7 year age group in our study can be due to the difficulty of explaining treatment anxiety by the items in this subscale for young children. The low ICC of the “worry” subscale for children aged 13-18 years may be due to the difference in treatments during two weeks, according to the items in this subscale. In this study, data collection was done in one hospital in northern Iran, which can affect the generalizability of the results to other centers.

In conclusion, the Persian version of the PedsQL™ 4.0 has acceptable psychometric properties and can be used as a valid and reliable tool to assess the HRQOL of Iranian children with cancer. It can help researchers and physicians in Iran to better understand the experiences of children with cancer and create more effective interventions to improve their quality of life. It is recommended that future studies focus on the sensitivity and responsiveness of this tool and provide the results to compare data for healthy children.

Ethical Considerations

Compliance with ethical guidelines

This study was approved by the Ethics Committee of [Guilan University of Medical Sciences](#), Rasht, Iran (Code: IR.GUMS.REC.1400.267). The participants were free to leave the study at any time and their information was kept confidential. Written informed consent was obtained from parents and verbal consent from children to participate in the study.

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Authors' contributions

Conceptualization, design, and resources: Somaye Pouy, Zahra Taheri Ezbarami, Maryam Rassouli and Nazila Javadi-Pashaki; Data collection: Somaye Pouy, and Saman Maroufizadeh; Data analysis: Nazila Javadi-Pashaki, Somaye Pouy and Saman Maroufizadeh; Investigation, and writing the original draft: Somaye Pouy, Zahra Taheri Ezbarami, Maryam Rassouli and Nazila Javadi-Pashaki; Review and editing: All authors.

Conflict of interest

The authors declared no conflict of interest.

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