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Research Article

Developing the Scale for Quality of Life in Pediatric Oncology Patients Aged 13–18: Adolescent Form and Parent Form

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SUMMARY

Purpose: This study aimed to develop the Scale for Quality of Life in Pediatric Oncology Patients Aged 13–18: Adolescent Form and Parent Form.**Methods:** We used the child and parent information form, Visual Quality of Life Scale, and our own scale, the Scale for Quality of Life in Pediatric Oncology Patients Aged 13–18: Adolescent Form and Parent Form. We finalized the 35-item scale to determine the items, received opinions from 14 specialists on the scale, and pilot-tested the scale in 25 children and their parents. We used Pearson correlation analysis, Cronbach α coefficient, factor analysis and receiver operating characteristics analysis to analyze the data. **Results:** The total Cronbach α of the parent form was .97, the total factor load was .60–.97 and the total variance was 80.4%. The cutoff point of the parent form was 85.50. The total Cronbach α of the adolescent form was .98, the total factor load was .62–.96, and the total variance explained was 83.4%. The cutoff point of the adolescent form was 75.50. As a result of the parent form factor analysis, we determined the Kaiser-Meyer-Olkin coefficient as .83, the Barlett test χ^2 as 12,615.92; the factor coefficients of all items of the parent form ranged from .63 to .98. The factor coefficients of all items of the adolescent form ranged from .34 to .99. As a result of the adolescent form factor analysis, we determined the KMO as .79, and the Barlett test χ^2 as 13,970.62.**Conclusions:** Conclusively, we found that the adolescent form and the parent form were valid and reliable in assessing the children's quality of life.Copyright © 2016, Korean Society of Nursing Science. Published by Elsevier. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Introduction

Cancer is one of the important health problems in both developed and underdeveloped countries. The number of children and adults with cancer is gradually increasing in the world. While childhood cancers constitute approximately the 0.5%–1.0% of total cancers, this rate differs depending on age periods. It has been estimated that the number of new cases will reach 10,380 among children between the ages of 0 and 14 years in America in 2015 [1]. Currently, the 5-year survival rate for childhood cancers exceeds 70.0%–80.0% [2]. When we think of the cancers observed in a human being's lifetime, 1.0%–2.0% of them are diagnosed in the

childhood period. In Turkey, 2,500–3,000 children have been diagnosed with cancer each year [3]. Furthermore, the 5-year survival rate was 64.0% [4]. According to the statistical data from the Turkish Pediatric Oncology Group on tumor, the incidence of cancer in children between the ages of 10 years and 14 years is 22.80 per million ($n = 2,756$) whereas the incidence of cancer in children between the ages of 15 years and 19 years is 7.35 per million ($n = 886$) in Turkey [5].

The quality of life (QOL) of the pediatric oncology patients is multidimensional including social, physical, and emotional executive functions of the child and the family. Measurement of QOL should be performed from the perspective of the child and his or her family as well as be sensitive to developmental changes [6]. QOL of children diagnosed with cancer decreases due to surgical interventions, radiotherapy, chemotherapy, prolonged hospitalization, side effects of treatments, being isolated from the society, being at home or in a closed place, physical and emotional

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problems, changes in the course of disease, child's position and absence of role within the family and society, disruption of school life, lack of support systems and coping methods [7–9].

Cancer treatment is an exhausting process for a child and leads to the physical and spiritual deterioration of the child. Some of the problems can be prevented, reduced or controlled with the help of careful assessment and appropriate interventions [10]. In this regard, the cooperation between parents and nurses becomes important, and family-centered approaches should be used [11]. Nurses should support children with cancer and provide home care service to them. In addition, their families should also be supported in education, counseling, health assessment, medical care assistance, practicing technical skills, and receiving emotional counseling at the hospital as well as during home care [7,8].

Early and effective treatment is essential for a successful cancer treatment and high quality of life [12]. The literature has shown that the life quality of children is adversely affected as a result of the uncontrolled symptoms from cancer treatment and lack of health care [13–16].

Evaluation of QOL in pediatric oncology patients is an important issue. However, the number of studies regarding this issue is limited. Although there are various scales developed for assessing QOL, the validity and reliability studies of these scales have not been sufficiently performed in Turkey [17,18]. Since most of the QOL scales developed in other countries have culture-specific fields and items, they may not be sufficient for assessing the QOL of children in the Turkish population. In our country, there is no such study performed that examines the QOL of pediatric oncology patients. There is also no study with respect to the QOL assessment done by health professionals. In particular, the lack of studies negatively affects nurses who need to determine the QOL of these patients and plan their interventions. There should be more valid and reliable disease-specific tools in order to increase the number of studies related to QOL for children with cancer in Turkey. Accordingly, this study aims to develop a scale for assessing the QOL in pediatric oncology patients aged 13–18 years, the Scale for Quality of Life in Pediatric Oncology Patients Aged 13–18: Adolescent Form and Parent Form.

Methods

Study design

In this descriptive study, the Scale for QOL in Pediatric Oncology Patients Aged 13–18: Adolescent Form and Parent Form was developed.

Settings and sample

The sample calculation was performed using G*Power statistical analysis program by assuming the Type I error as .05 and the Type II error as .20 (80.0% power) with the help of the study performed by Barrera, Pringle, Sumbler and Saunder [19]. Accordingly, the sample size was determined as 91 individuals by using mean scores. There was also another method suggested for calculating the sample size: it included three rules, the 5s, 10s and 100s rule. It emphasized that the researcher should include at least five individuals for each item in order to perform the factor analysis. There should also be 10 individuals for each item unless there is a problem about connecting with people [20]. In the study, we could contact 184 children with cancer who were admitted to the research and training university hospital between April 15th, 2014 and August 15th, 2014. We also established contact with the families of these children.

Inclusion criteria for the study were accepted as (a) children should be between the ages of 13 and 18 years, and diagnosed with

cancer, and their parents should be primarily responsible for their care, (b) being literate, (c) children and parents must volunteer to participate in the study.

Ethical considerations

This study was approved by the Institutional Review Board of the University (IRB approval no.: 1396-GOA-2014/13-22). Institutional permissions were obtained in order to carry out the study. We also obtained written and verbal consents from children and parents by meeting them and informing them about the aim of the study.

Instruments

Child and parent information form

Child and Parent Information Form was improved by referring to the literature. It consisted of eight questions including the children's sociodemographic features, diagnosis, stage of the cancer, treatments, duration of diagnosis, gender, treatment period and ages of parents [21–23].

Visual Quality of Life Scale

Visual Quality of Life Scale (VQLS) is an assessment instrument that visually assesses the QOL. The scale ranged from 1 to 10, with an increase in the score signifying an increase in the QOL of the child.

Scale for QOL in Pediatric Oncology Patients Aged 13–18: Adolescent Form

According to a literature survey, we found general and child-specific scales regarding QOL and dimensions, which were developed in order to assess QOL [17,18,24]. It consisted of 35 items, and only the 10th item was reversed. Being a Likert-type scale, each item ranged from 1 to 5. The lowest score was 35 whereas the highest score was 175, the higher the score, the greater the QOL of the child.

Scale for QOL in Pediatric Oncology Patients Aged 13–18: Parent Form

In light of the scales on QOL, we formed dimensions to assess QOL [17,18,24]. The form consisted of 35 items and only the 10th item was reversed. Being a Likert-type scale, each item ranged from 1 to 5. The lowest score was 35 whereas the highest score was 175, the higher the score, the greater the QOL of the child.

Stages of study

The development of our scale, and its validity and reliability analyses are explained in the following stages:

Stage for forming item pool

An extensive examination should be performed on the variable which will be measured while designing the scale statements. The statements should comprise all the ideational and affective elements experienced before or when their dimensions should be measured. As a consequence, the scale statements should constitute and represent all aspects of dimensions of the measured and to-be-measured variables [20,25–28]. While forming the item pool of the adolescent form and parent form, we found studies defining the general and child-specific scales on QOL. As a result of our literature review, we formed dimensions to determine the QOL and developed item pools for these dimensions [17,18,24].

Stage for forming specialist opinions

At least 10 specialists recommended using adolescent and parent form in order to determine the content validity of the scales [20,25–28]. Firstly, the 40-item pool was developed. We received the opinions of 14 specialists on the scales (10 academic members from the department of pediatric health and diseases nursing, 3 academic members from the department of oncology nursing and 1 academic member from the department of psychiatric nursing). The scale form was given to specialists and they were asked to grade them between 1 and 4 in order to assess the convenience of the scale items (1 = requires a great change, 4 = very convenient). As a result of the feedback from the specialists, 10 items were excluded from the scale because they had item-level content validity index (I-CVI) at .78, and 2 items were revised according to the feedback from specialists. The “I have nausea and vomit” were revised to “I vomit” and “I have nausea.” In addition, “I’m afraid of the disease and the treatment of the disease” was revised to “I’m afraid of the disease” and “I’m afraid of the treatment of the disease.” Three items were included in the scale according to the specialists’ feedback. Consequently, the scale used in its final form had 35 items. Scores of 14 specialists were assessed with content validity analysis. The I-CVIs ranged from .78 to .99, and they were coherent.

Stage for forming preliminary test

As a result of the opinions of the specialists, the scale was applied to 10–20 individuals who had similar features, but were not included in the sample [20,25–28]. The first version of scales, which was created by taking into account the specialists’ opinions, was applied to 25 children and their parents. Since there was no negative feedback, we decided to apply them to the larger group.

Data collection

Upon obtaining the signed consents, children and their parents filled the Child and Parent Information Form, the VQLS, Scale for QOL in Pediatric Oncology Patients Aged 13–18: Adolescent Form and Parent Form. The data collection process took approximately 10 minutes.

In this study, the researchers collected the data. During data collection, each researcher visited the clinics every day and interviewed the families with children who met our criteria. Written and oral consents of volunteer children and their parents were obtained. Only one family refused to participate in the study because they thought that their child could be negatively affected during the data collection. The participation rate of the study was 99.5% and the scale filling rate was 100.0%.

Data analysis

Validity

Content validity index (CVI), exploratory factor analysis (EFA), confirmatory factor analysis (CFA), contrasted group comparison tests were used for validity analysis. EFA was conducted by using principal component analysis. The I-CVI was used to determine the content validity of the specialists. The I-CVI value should be higher than .78 to have harmony between the specialists. Varimax rotation was applied in order to obtain factors for the approximation of the simple structure. The adequacy of the data for factor analysis was evaluated by using the Kaiser-Meyer-Olkin (KMO) test and Bartlett’s test of sphericity. Eigenvalues greater than 1 was used to determine the factors. The value of .40 or higher on factor loadings was chosen as the significant criteria for assigning items to factor. Validity was examined through concordance validity, construct validity and contrasted group comparison. Concordance validity

was evaluated with the help of CVI-I. Construct validity was examined through EFA and CFA. Contrast group comparison was used for validity analysis. The model verification of the comparative fit index (CFI) was conducted on the basis of the chi-square test, degree of freedom, root mean square error of approximation (RMSEA, normal value < .05; acceptable value < .08), goodness of fit index (GFI, normal value > .95; acceptable values > .90), CFI (normal value > .95; acceptable value > .90), and normal fit index (NFI, normal value > .95; acceptable value > .90) [20,25–28]. The groups were compared amongst each other by Student *t* test.

Reliability

Pearson correlation analysis was used for the total-item score analysis of the scales and subdimensions. Cronbach α was used for the internal consistency of scales and subdimensions. Floor and ceiling effects were used for reliability analysis [20,25–28]. We used the receiver operating characteristics (ROC) analysis to determine the cutoff point of the scale. In all types of analyses, 5.0% significance level was used.

Results

Sample characteristics

The mean age of children was 14.6 years (\pm 1.4 years); 52.2% of them were male and 47.8% of them were female; 60.3% of them were in the remission stage; 57.6% of them were diagnosed with leukemia; 59.8% of them received only chemotherapy. The mean age of the parents was 40.4 years (\pm 3.1 years), and 73.4% of them were mothers (Table 1).

Validity analyses

Content validity

As a result of the specialists’ feedback, 10 items were excluded from the scale. This was because the I-CVI value was the lowest at .78. These items included the following: I am afraid of the recurrence of the disease. I am scared about what will happen to me. I do not participate in social activities. If my father and my brothers visited more often, I would be happy. Being stared at by others bothers me. I do not feel like doing the things that I used to do.

Table 1 Sociodemographic Characteristics of Children and Their Parents.

| Sociodemographic Characteristics | n | % |
|---|-----|------|
| Gender | | |
| Male | 96 | 52.2 |
| Female | 88 | 47.8 |
| Stage of disease | | |
| New diagnosis | 53 | 28.8 |
| Remission | 111 | 60.3 |
| Relapse | 20 | 10.9 |
| Diagnosis | | |
| Leukemia | 106 | 57.6 |
| Lymphoma | 18 | 9.8 |
| CNS tumor | 19 | 10.3 |
| Other solid tumors | 41 | 22.3 |
| Duration of treatment (mo) | | |
| 1–4 | 67 | 36.4 |
| 5–9 | 60 | 32.6 |
| \geq 10 | 57 | 31.0 |
| Treatments | | |
| Chemotherapy | 110 | 59.8 |
| Chemotherapy-radiotherapy-surgery | 74 | 40.2 |
| Parent type | | |
| Mother | 135 | 73.4 |
| Father | 47 | 25.5 |
| Other (e.g., grandmother, grandfather, aunt, uncle) | 2 | 1.1 |

Financial difficulties resulted from my disease makes me sad. I am having difficulties in gathering my attention. I am having difficulties in remembering. I cannot go to school. Additionally, three items were included in the scale according to specialists' feedback. These include the following: include the following: I feel unwilling to do anything. I feel sad about missing school continuously. I feel sad that I cannot do what I like to do. Two items were revised to the following: I have nausea/I vomit, and I am afraid of the disease/I am afraid of the treatment of the disease. Consequently, the scale used

in its final form had 35 items. The scores of the 14 specialists were assessed by content validity analysis; the I-CVIs ranged from .78 to .99, which were coherent.

Construct validity

Construct validity of the parent form was tested through a number of different approaches. One of these approaches was the factor analysis. As a result of the factor analysis, the KMO coefficient was determined as .83 and the Barlett test χ^2 was 12615.92

Table 2 Exploratory Factor Analysis of Parent Form and Adolescent Form.

| Parent form | | | Adolescent form | | |
|---|----------------|------------------------|--|----------------|------------------------|
| Scale items | Factor loading | Variance explained (%) | Scale items | Factor loading | Variance explained (%) |
| 1. My child is afraid of the disease. | .60 | 80.4 | 1. I am afraid of the disease. | .80 | 83.4 |
| 2. My child is afraid of the treatment. | .84 | | 2. I am afraid of the treatment | .78 | |
| 3. My child is afraid of going to the hospital. | .79 | | 3. I am afraid of going to the hospital. | .88 | |
| 4. My child feels angry with his/her parents after the diagnosis. | .74 | | 4. I feel angry with my parents after the diagnosis. | .89 | |
| 5. My child feels angry with everyone after the diagnosis. | .75 | | 5. I feel angry with everyone after the diagnosis. | .84 | |
| 6. My child is bored when in treatment for a long time. | .65 | | 6. I am bored when in treatment for a long time. | .81 | |
| 7. My child is afraid of procedures such as intravenous-port opening or operations taking blood. | .66 | | 7. I am afraid of procedures such as intravenous-port opening or operations taking blood. | .69 | |
| 8. My child is afraid of receiving procedures in the lumbar region (e.g., taking samples from the bone marrow). | .79 | | 8. I am afraid of receiving the procedures in the lumbar region (e.g., taking samples from the bone marrow). | .84 | |
| 9. My child often feels sad. | .79 | | 9. I often feel sad. | .76 | |
| 10. My child generally feels good. | .74 | | 10. I generally feel good. | .76 | |
| 11. My child is worried about what happens to him/her. | .64 | | 11. I am worried about what happens to me. | .84 | |
| 12. My child cannot make things that his/her friends make. | .87 | | 12. I cannot make things that my friends make. | .89 | |
| 13. My child gets tired very quickly. | .87 | | 13. I get tired very quickly. | .87 | |
| 14. My child feels powerless to do anything. | .73 | | 14. I feel powerless to do anything. | .94 | |
| 15. My child feels unwilling to do anything. | .86 | | 15. I feel unwilling to do anything. | .86 | |
| 16. My child does not talk to friends as much as before. | .66 | | 16. I do not talk to my friends as much as before. | .87 | |
| 17. My child feels pain. | .82 | | 17. I feel pain. | .91 | |
| 18. My child cannot sleep. | .84 | | 18. I cannot sleep. | .82 | |
| 19. My child needs more help with daily activities (e.g., eating, getting dressed). | .79 | | 19. I need more help with daily work (e.g., eating, getting dressed) | .77 | |
| 20. My child lies down continuously throughout the day. | .81 | | 20. I lie down continuously throughout the day. | .89 | |
| 21. My child has nausea. | .64 | | 21. I have nausea. | .83 | |
| 22. My child vomits. | .78 | | 22. I vomit. | .62 | |
| 23. My child cannot get the taste of food. | .81 | | 23. I cannot get the taste of food. | .80 | |
| 24. My child has nausea when thinking of medication. | .84 | | 24. I have nausea when thinking of medication. | .90 | |
| 25. My child feels sad for he/she cannot eat what he/she likes. | .92 | | 25. I feel sad for I cannot eat what I like. | .91 | |
| 26. My children's appetite decreased. | .94 | | 26. My appetite decreased. | .81 | |
| 27. My child dislikes some treatment at night. | .92 | | 27. I dislike some treatments at night. | .92 | |
| 28. My child dislikes to go to hospitals for some procedures. (e.g., MRI, PET, and etc.) | .92 | | 28. I dislike to go to hospitals for some procedures (MRI, PET etc.). | .85 | |
| 29. My child is bored when waiting for the hospital to process things (e.g., outpatient and diagnostic procedures). | .94 | | 29. I am bored when waiting for the hospital to process things (e.g., outpatient and diagnostic procedures). | .83 | |
| 30. My child feels sad for constantly being in the hospital. | .87 | | 30. I feel sad for constantly being in the hospital. | .78 | |
| 31. My child is tired of wearing masks continuously in the hospital. | .97 | | 31. I am tired of wearing masks continuously in the hospital. | .86 | |
| 32. My child is tired of wearing masks continuously in the hospital. | .80 | | 32. I am tired of wearing masks continuously in the hospital. | .96 | |
| 33. My child dislikes depending on fluid/serum machine constantly. | .92 | | 33. I dislike depending on fluid/serum machine constantly. | .89 | |
| 34. My child feels sad about missing school continuously. | .81 | | 34. I feel sad about missing school continuously. | .74 | |
| 35. My child feels sad when he/she does what he/she likes to do. (e.g., to play) | .87 | | 35. I feel sad when I do what I like to do (e.g., to play). | .76 | |

($p < .001$). Only one factor was extracted. The factor loadings were .60–.97. The total variance was 80.4% (Table 2).

For the adolescent form, as a result of the factor analysis, KMO was determined as .79 and the Barlett test χ^2 was 13,970.63 ($p < .001$). Only one factor was extracted. The exploratory factor loadings were .62–.96. The total variance was 83.4% (Table 2).

CFA

As illustrated in Figure 1, the factor coefficients of all items of the parent form ranged from .63 to .98. The model concordance indicators were the following: RMSEA = .078, GFI = .90, CFI = .92, NFI = .89, NNFI (Non-normed Fit Index) = .90, and IFI (Incremental Fit Index) = .91 (Figure 1, Table 3).

Table 3 Confirmatory Factor Analysis of the Parent Form and Adolescent Form.

| Scales | χ^2 | df | χ^2/df | GFI | CFI | NFI | NNFI (TLI) | IFI | RMSEA |
|-----------------|----------|-----|-------------|-----|-----|-----|------------|-----|-------|
| Parent form | 2,689.11 | 560 | 4.80 | .90 | .92 | .89 | .90 | .91 | .078 |
| Adolescent form | 1,882.14 | 418 | 4.50 | .90 | .91 | .90 | .90 | .91 | .079 |

Note. CFI = comparative fit index; GFI = goodness of fit index; IFI = Incremental Fit Index; NFI = normal fit index; NNFI = Non-normed Fit Index; RMSEA = root-mean-square error of approximation; TLI = Tucker-Lewis Index.

As shown in Figure 2, the factor coefficients of all items of the Adolescent Form were ranged from .34 to .99. The model concordance indicators were the following: RMSEA = .079, GFI = .90, CFI = .91, NFI = .90, NNFI = .90 and IFI = .91 (Figure 2, Table 3).

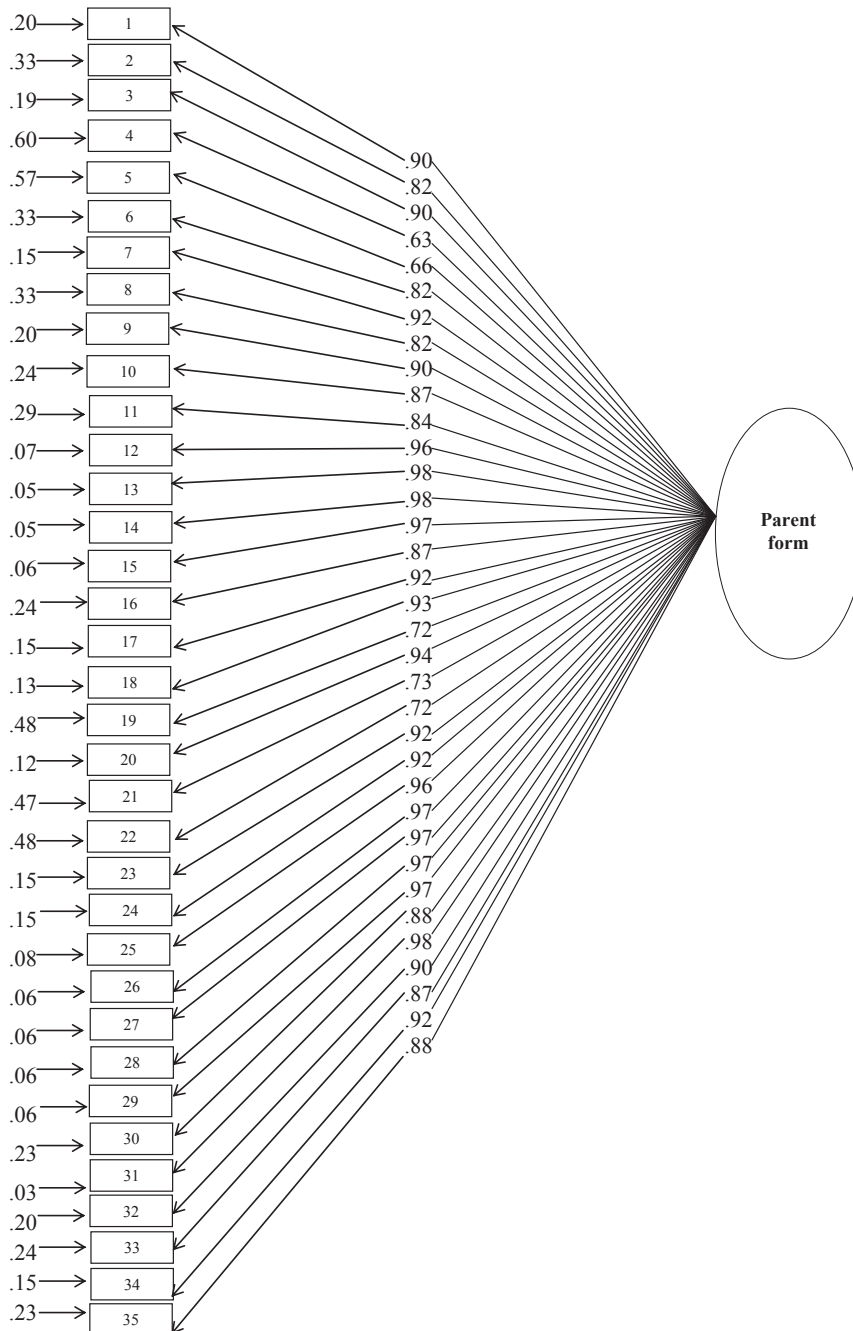


Figure 1. Confirmatory factor analysis of the parent form. Note. $df = 560$, $p < .001$, RMSEA = .078, root mean square error of approximation, $\chi^2 = 2,689.11$.

Cutoff point

In order to determine the optimum cutoff point, one of the most effective methods is the Diagnostic Index (DI), which is calculated through values obtained from the ROC analysis and the Youden index (YI) [29]. The value of YI varies between -1.00 and +1.00; the closer it is to +1.00, the greater the power of distinction becomes [20]. When these two indices obtain the highest value, the scale score determines the optimum cutoff point for the scale [29].

Table 4 shows the values of the DI and YI that were calculated as a result of the ROC analysis, performed to determine the cutoff point. Particularly, YI is defined as the point that is closest to + 1.00, where the best distinction could be made. The cutoff point is determined through the comparison with the point where DI obtains the highest value [20,29]. We determined 75.50 points as the

cutoff point, where the adolescent form had the highest DI and YI values. We measured the sensitivity of the scale as .90 and the specificity of the scale as .95 at this point. Children with a score of 75.40 or less were regarded as having low QOL (Table 4). We determined 85.50 points as the cutoff point, where the parent form had the highest DI and YI values. We measured the sensitivity of the scale as .81, and specificity of the scale as .98 at this point. Children with a score of 85.40 or less were regarded as having low QOL (Table 4).

Known group comparison

One of the methods used for determining the construct validity of scales is the group comparison method [26,30]. In this analysis, a significant difference is expected between the mean values of the

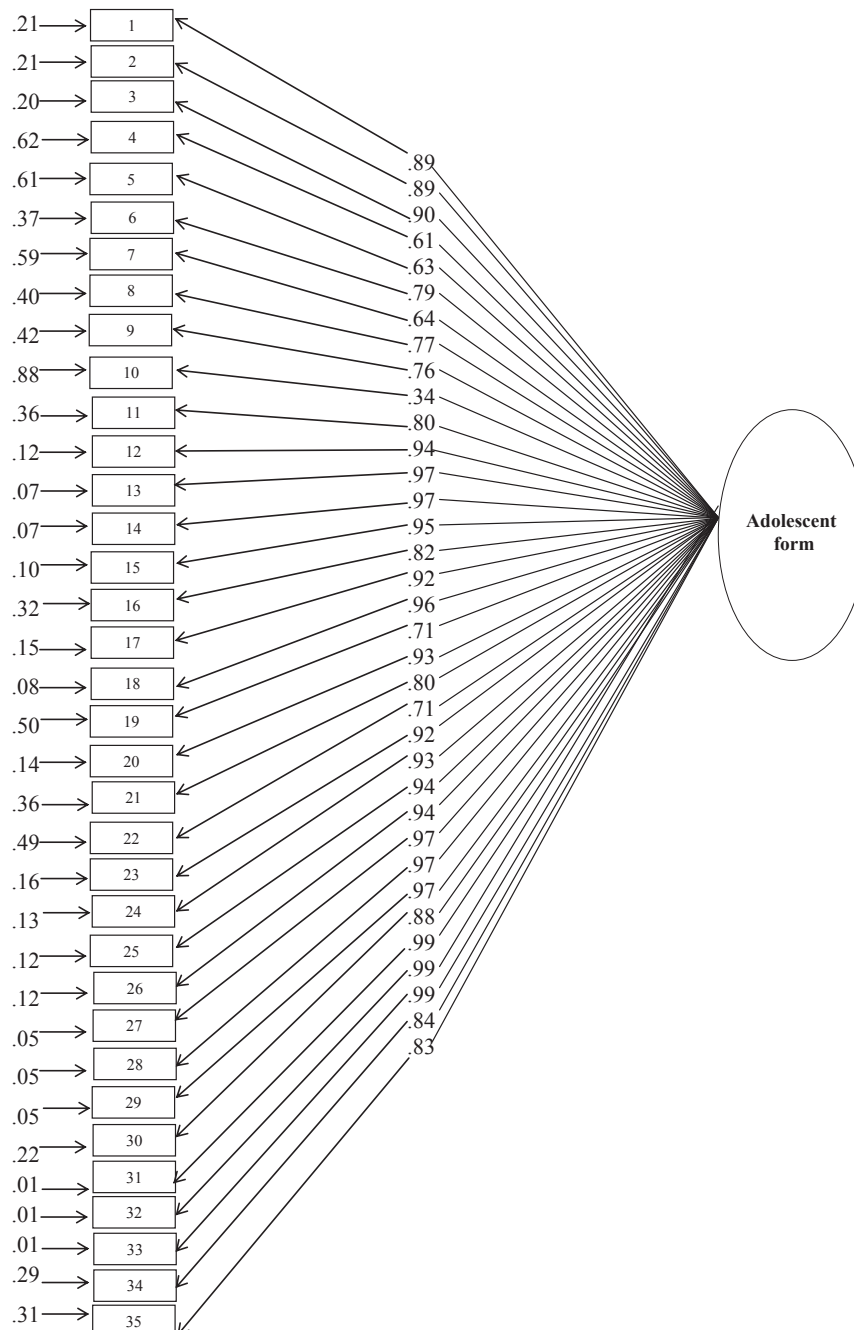


Figure 2. Confirmatory factor analysis of adolescent form. Note. $df = 418$, $p < .001$, RMSEA = .079, root mean square error of approximation, $\chi^2 = 1,882.14$.

Table 4 Cutoff Point, Prediction Values and Values of AUC in Predicting State of Quality of Life in ROC Analysis of Adolescent Form and Parent Form.

| Scales | Cut point | Sensitivity | Specificity | <i>p</i> | AUC (95% CI) | Youden Index | Diagnostic Index |
|-----------------|-----------|-------------|-------------|----------|-------------------|--------------|------------------|
| Parent form | 75.50 | .90 | .95 | < .001 | .964 (0.94, 0.99) | .851 | 1.851 |
| Adolescent form | 85.50 | .81 | .98 | < .001 | .922 (0.88, 0.97) | .800 | 1.800 |

Note. AUC = area under the curve; CI = confidence interval; ROC = receiver operating characteristics.

QOL score of children low/high QOL according to the cutoff points. According to the parent form, we determined the score average of children with QOL 51.91 (\pm 13.52) and the score average of children without QOL 84.63 (\pm 5.34). According to the state of QOL, we found a statistically significant difference between the score averages of the parent form ($t = 23.23, p < .001$; Table 5).

According to the adolescent form, we determined the score average of parents with QOL as 55.62 (\pm 15.73) and the score average of parents without QOL as 92.44 (\pm 1.82). According to the state of QOL, we found a statistically significant difference between the score averages of the parent form ($t = 26.61, p < .001$; Table 5).

Reliability analyses

Reliability Analysis of the Parents and Adolescent Form

The reliability coefficient, Cronbach alpha of the parent form was .97, while that of the adolescent form was .98 in total for the scale (Table 6).

Mean score of the parent form was 64.82 (\pm 19.44); floor and ceiling effects were 6.5% and 0.0%, respectively; skewness was $-.194$, and Cronbach α was .97 in total for the scale (Table 6).

Mean score of the adolescent form was 65.52 (\pm 21.23); floor and ceiling effects were 6.5% and 0.0%, respectively; skewness was $-.058$ and Cronbach α was .98 in total for the scale (Table 6).

Total item score correlations of parent form and test-retest correlations of items

By examining the item-total score correlations of the scale consisting of 35 items for the reliability study, we determined that the correlation coefficients of only two items were on margin (that of item 7 was .081; that of item 8 was .097), while the correlation coefficients of the other items were between .32 and .99 ($p < .001$).

Additionally, after examining the correlation between the first and the second application scores of each item, we found the test-retest reliability coefficient of the scale to be between .31 and .99, which was statistically significant ($p < .001$).

Total item score correlations of adolescent form and test-retest correlations of items

We determined that the correlation coefficients of only one item were on margin (item 7 was .193). The correlation coefficients of the other items were between .40 and .99 ($p < .001$).

Additionally, while examining the correlation between the first and the second application scores of each item, we determined that the test-retest reliability coefficient of the scale was between .32 and .99, which was statistically significant ($p < .001$).

Table 5 Comparison of Average Score With and Without Quality of Life of Parent and Child Based on Parent Form and Adolescent Form.

| Quality of life | Parent form | | | | Adolescent form | | | |
|-----------------|-------------|---------------|----------|----------|-----------------|---------------|----------|----------|
| | <i>n</i> | Mean (SD) | <i>t</i> | <i>p</i> | <i>n</i> | Mean (SD) | <i>t</i> | <i>p</i> |
| Yes | 111 | 51.91 (13.52) | 23.23 | < .001 | 134 | 55.62 (15.73) | 26.61 | < .001 |
| No | 73 | 84.63 (5.34) | | | 50 | 92.44 (1.82) | | |

Table 6 Cronbach α Coefficient and Reliability Analysis of Quality of Life Scale for Parent Form and Adolescent Form.

| Scales | Cronbach α | Mean (SD) | Floor effect % | Ceiling effect % | Skewness |
|-----------------|-------------------|---------------|----------------|------------------|----------|
| Parent form | .97 | 64.82 (19.44) | 6.5 | 0.0 | $-.194$ |
| Adolescent form | .98 | 65.52 (21.23) | 6.5 | 0.0 | .058 |

Test-retest reliability of adolescent form and parent form (stability)

After we applied the parent form twice every 3 weeks, we assessed the stability, in other words the test-retest reliability coefficient of the scale with Pearson product-moment correlation coefficient. A positive and statistically significant relationship was determined between the test-retest score averages of the scale ($r = .97, p < .001$; Table 7).

In case of the adolescent form, which was also applied twice every 3 weeks, the stability was evaluated. A positive and statistically significant relationship was also determined between the test-retest score averages of the scale ($r = .96, p < .001$; Table 7).

Additionally, we conducted the Student *t* test for dependent groups. We tested whether there was a difference between the mean scores of the scale as a result of the two measurements being applied every 3 weeks. However, we did not detect any statistically significant difference between the score averages ($p > .050$; Table 7).

Relationship between study variables of adolescent form and parent form

We evaluated the relationship between the variables with Pearson correlation analysis and found a statistically significant relationship between the parent form and adolescent form at a level of *r* at .98, between the parent form and parent Visual analog scale (VAS) score at a level of *r* at $-.65$ and the adolescent VAS score at a level of *r* at $-.70$ ($p < .010$).

Discussion

It is possible to use a form that enables the specialists to evaluate the coherence of items by giving points. Common consensus may be provided as an indicator of the content validity by the majority of the specialists [20,26]. In this study, we received opinions from 14 specialists to assess the coherence of the items of the adolescent form and parent form with regard to their language and content. We also assessed the suggestions of specialists on the expression and content of the items; we excluded some of the items from the scale and changed the statements from one item. Furthermore, the

Table 7 Test-Retest Score Averages Obtained from Adolescent Form, Parent Form and Their Comparison (*N* = 30).

| Scales | Quality of life scale | | <i>r</i> | <i>p</i> | <i>t</i> | <i>p</i> |
|-----------------|--------------------------------|---------------------------------|----------|----------|----------|----------|
| | First implementation Mean (SD) | Second implementation Mean (SD) | | | | |
| Parent form | 69.73 (16.81) | 70.31 (16.61) | .97 | < .001 | 0.80 | .428 |
| Adolescent form | 69.92 (18.12) | 71.43 (17.04) | .96 | < .001 | 1.69 | .100 |

specialists suggested the removal of some items because they contained similar parts to other items, and one item reminded the reader of the recurrence of cancer. Minimum values related to the number of specialists signified the statistical significance of the item according to content validity analysis. If the consensus of experts were more than .80, this was then interpreted as indicative of a high content validity [20–26]. In this study, I-CVI and Scale-Content validity index values were more than .78. According to the analysis, the expert scores were coherent. The adolescent form and parent form items are appropriate for the Turkish culture.

As a result of the factor analysis, KMO of the parent form was above .83, and Bartlett test was significant ($p < .001$). These values showed that the number of samples was convenient for factor analysis [20–31]. According to EFA, only one factor was extracted, and the factor load was above the set point of .60 for all items [27]. According to our findings, the parent form had adequate construct validity for the Turkish population. As a result of factor analysis, KMO of the adolescent form was above .79, and Bartlett test was significant ($p < .001$). These values showed that the number of samples was convenient for factor analysis [20–31]. According to EFA, only one factor was extracted, and the factor load was above the set point of .62 for all items [27]. According to our findings, the adolescent form had adequate construct validity for the Turkish population.

The factor structure of the scale becomes stronger as the rate of the variance is higher. In studies when the variance rates are between 40.0% and 60.0%, total variance is accepted as sufficient [20,31]. However, in our study, we obtained a high and sufficient total variance that could be explained at a rate of 80.0% in both scales. The results of our analyses suggested that the adolescent form and parent form had coherent construct validity.

The relationship of items with factors is explained by the factor loading value. We expected that the factor loadings were higher than .40 [31]. According to CFA, we found that the scales were one factor in Turkish samples, and the factor loading was above the set point of .40 for all items of adolescent and parent form. According to our findings, the scales had adequate construct validity.

The literature has specified that model compliance indicators should be as GFI, NFI, NNFI and CFI $> .90$ and RMSEA $< .08$ [13,28]. This study detected that RMSEA was less than .080 and all other compliance indices were more than .90. Accordingly, the findings are compatible with the model. They confirm the one-factor structure; the items are in association with the scale; items define the factors sufficiently.

The factor loadings of the scale were between .34 and .99. According to CFA, the scale was one factor in Turkish samples. In this study, RMSEA (which is one of the indices of the adolescent form) was less than .080, and all other compliance indices were more than .90. These findings are compatible with the model, confirm the one-factor structure, in association with the scale and define the factors sufficiently.

EFA and CFA of the child form supports its structural validity; it shows that the child form is a valid tool to be used with Turkish samples.

As a result of the ROC analysis, performed to determine the cutoff point, we determined 85.50 points as where the sensitivity was the highest and the specificity was the lowest in the parent form. We detected the sensitivity of the scale as .81 and the specificity as .98 at this point. Children, who had the score of 85.40 or less compared to that of the parent form, were evaluated as having a low QOL. As a result of the ROC analysis performed to determine the cutoff point, we determined 75.50 points as which explained the highest sensitivity and the lowest specificity in the adolescent form. In addition, we also detected the sensitivity of the scale as .90 and the specificity as .95. Children who had 75.40 points or less

were evaluated as having low QOL. The ROC curve gave a coherent cutoff point for the assessment of the instrument and the decisions that were made according to this cutoff enabled us to obtain the sensitivity and specificity rates. Sensitivity is defined as “the condition where those who are sick in reality are also sick according to the cutoff point which is taken during the test”. Specificity is defined as “the condition where those who are healthy in reality are also found healthy as a result of the test”. The curve moves upward (high sensitivity area) and to the left (low false positive rate area) as the test becomes better. If the area under the ROC curve (AUC) is .50, there is no distinction. If the AUC is between .50 and .70, the power of distinguishing the test is statistically insignificant. If the AUC is between .70 and .80, it is acceptable. If AUC is between .80 and .90, it is very good. If AUC is above .90, it is excellent [32]. Accordingly, it has been observed that the AUC of the parent form was between .93 and .99, which showed an excellent level of distinction. It also had the ability to significantly distinguish the children with and without low QOL. On the other hand, the AUC of the adolescent form was between .93 and .99 and had an excellent capacity of distinction. It also gave the possibility to significantly distinguish the children from each other in terms of having low or high QOL.

In this analysis, we expected a significant difference between the mean QOL of children with and without low QOL. This study determined the QOL of children according to the parent form cutoff point. A significant difference was also determined between the scale score averages by the child's QOL level ($p < .001$). The presence of the difference not only indicated that the parent form could significantly determine the low QOL of children, but also revealed the construct validity of the scale [26,30]. This study determined the QOL of children according to the adolescent form cutoff point. A significant difference was also determined between the scale score averages by the child's QOL level ($p < .001$). The difference indicates that the adolescent form could significantly determine children with low QOL. Also, it reveals the construct validity of the scale [26,30].

The reliability coefficient in an assessment instrument should be close to 1 as much as possible [20,26,30]. The reliability coefficient α of the parent form was .97. The reliability coefficient α of the adolescent form was .98. The internal consistency of the scale had a high level of reliability. Both the scale and its subdimensions had a Cronbach α of above .90, which shows that the scale had very good reliability [26].

The value used in item selection is suggested to be .20 or more. High correlation coefficient is accepted as an indicator of the coherence of the item [20,26,30]. While examining the item-total score correlations of the parent scale with 35 items for the reliability study, we determined that the correlation coefficients of only two items were on the margin, while the correlation coefficients of all items were greater than .32 ($p < .001$). While examining the item-total score correlations of the adolescent form, the correlation coefficient of only one item was on margin and the correlation coefficients of all items were greater than .40 ($p < .001$). We observed that the items in the scale were compatible with its theoretical structure and provide a sufficient correlation. Item-total score analysis is accepted as an indicator of not only the reliability, but also the validity (internal consistency) and it reflects the construct validity of the scale [30].

Because the two items of the parent form and one item of the adolescent form had high correlation with their own subscale total score, the tool's reliability was not affected when these items were removed from the scale. Thus, we decided not to remove them from the tool.

Other instruments suggest that the correlation coefficient between the test-retest scores be at least .70 [20,26]. In our study, we

determined the stability coefficient of two applications of the parent form, which was repeated every 3 weeks, as .97 ($p < .001$). On the other hand, the stability coefficient of two applications of the adolescent form, which was also repeated every 3 weeks, was .96 ($p < .001$). It was observed that the parent and adolescent form had a high reliability and the results were similar to both the initial as well as repeated measurements.

Even if the test-retest correlation coefficient is sufficient, studies [20,26] recommended examining the score averages and standard deviations of two measurements, and having similar results. According to our results, there was no statistically significant difference between the score averages ($p > .050$). We observed that the adolescent form and the parent form were highly reliable because individuals had similar and consistent responses and the instrument was proven stable [20,26,30].

Even though there was a significant difference between the total scores of individuals, they may give different answers to each item. Thus, other studies [20,26,30] also required consideration be given to the consistency among the items in both applications. Examining the correlation between the first and the second application scores of each item, we found that items of the test-retest reliability coefficients of parents form items were higher than $r = .31$ ($p < .001$). On the other hand, items of the test-retest reliability coefficients of the adolescent form were higher than .32 ($p < .001$). Items in the adolescent and parent forms give similar results in both measurements, which signify that the items are comprehensible and measure consistently.

The relationship between the variables was assessed with Pearson correlation analysis. There was a highly significant association between the scores of the parent form and the adolescent form ($r = .98$), between scores of the parent form and parent VQLS ($r = -.65$), and between the scores of the adolescent form and child VQLS ($r = -.69$, $p < .010$). A high level of relationship was observed between the scores of the adolescent form and the parent form as well as between the scale scores and VQLS scores. A high level of relationship signifies that the scales measure similarly and accurately. This result reveals that the scales are both valid and reliable.

There is no sufficient number of scales measuring QOL, which can be used in children aged 13–18 years and with verified validity and reliability. In our country, there is also few scales that measure the QOL of children with cancer. Thus, the adolescent form and parent form developed in our study are convenient and comprehensive for hospitals as they not only identify the QOL of children aged 13–18 years, but are also customized for use in the Turkish culture. Additionally, the majority of the children and parents participating in our study were from almost every region of Turkey, which supported the generalization of the scale.

Limitations

Even though this study has various strengths, it also has some limitations. Firstly, excluding the children whose diagnosis duration was less than 1 month and having almost two third of diagnoses as hematological cancers were a limitation of this study. The second limitation was that CFA was performed on the same sample. When the samples were divided into two, there were less than 100 individuals in each group, thus breaking the rule which stated that there should be at least 100 individuals in each group. As such, analyses were done separately.

Conclusion

Since there is no sufficient number of valid and reliable identification instruments for pediatric patients in Turkey, we recommend this scale be used in pediatric oncology clinics.

Assess the long term outcomes of the scale in the future.

There should be valid and reliable instruments that can determine the QOL of pediatric oncology patients, and be applicable for nursing interventions. This study suggests that the Scale for the Quality of Life in Pediatric Oncology Patients Aged 13–18: Adolescent Form and Parent Form is valid and reliable for measuring QOL in children. This instrument is also convenient for professionals for managing QOL. Professionals can develop interventions for children and parents using the results obtained from this scale.

Conflicts of Interest

None of the authors have any conflicts of interest to declare.

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