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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].

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