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ORIGINAL ARTICLE

Development of a quality assessment scale for pediatric palliative care and analysis of its psychometric properties

Desarrollo de una escala de evaluación de la calidad de los cuidados paliativos pediátricos y análisis de sus propiedades psicométricas

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What do we know about the subject matter of this study?

Pediatric palliative care is increasingly used in healthcare. It is aimed at improving the quality of care.

What does this study contribute to what is already known?

It contributes to better quality, effectiveness, and professionalism in pediatric palliative care; it shows the common problems in pediatric palliative care and guides future research.

Abstract

Objectives: to develop a new scale to evaluate pediatric palliative care: the Pediatric Palliative Care Quality Assessment Scale (PPCQAS). **Subjects and Method:** 580 pediatric nurses constituted the sample of the study. They were asked to answer the sociodemographic questionnaire for nurses and a list of questions about the new pediatric palliative care scale, created by the expert opinion of the research team. Exploratory and confirmatory factor analysis was applied to evaluate the construct validity of the Palliative Care Attitude Scale. Pearson correlation coefficients were calculated to understand the relationships between the scale factors as well as the Cronbach and Omega alpha coefficients to observe its reliability based on internal consistency. In addition, test-retest analysis was performed to determine the scale's stability and whether it could measure consistently over time. The PPCQAS and the Neonatal Palliative Care Attitude Scale (NiPCAS) were administered in a single session for criterion validity. **Results:** The scale showed a Cronbach Alpha coefficient of 0.95 and an Omega Alpha coefficient of 0.96. The correlation coefficient used as a test-retest reliability method showed a moderately positive relationship between the two applications (0.54). There were moderate positive correlations between the scores of PPCQAS and NiPCAS for organi-

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zation (r = 0.63; p < 0.01), sources (r = 0.54; p < 0.01), and clinical (r = 0.42; p < 0.01) dimensions. **Conclusion:** These results showed that the pediatric palliative care scale has a unique structure and its validity-reliability is high. It has been determined that the pediatric palliative care scale is an adequate measurement tool.

Introduction

Today, developments in the field of health have extended the life span of individuals suffering from various fatal diseases and cancer and have also positively affected their quality of life[1]. In the age we live in, different types of diseases and cancers are seen, and as a result, it has been observed that death rates are gradually increasing[2]. Although cancer and other deadly diseases are seen in adults, the need for palliative care has increased as a result of their frequent occurrence in children[3]. Palliative care is the identification of life-threatening problems arising from diseases/physiological effects and the problems that threaten the lives of patients and their relatives in general. Life-threatening problems, since what threatens life is the health condition that requires palliative care and therefore these constitute a care strategy that covers the biomedical, social, family, and spiritual areas of a person with no possibility of cure, but who deserves to live until death with quality and die with dignity. It is aimed to bring the quality of life to the best level by making effective evaluations in the palliative care process[4]. Turkey's newly developing palliative care and hospice have not been given due importance for a long time. Even today, no actions are taken to increase the quality of care and life for children in a terminal period[5]. Children should be treated more sensitively than adults and taken with a multidisciplinary approach. If the aforementioned issues are implemented by taking into account the developmental characteristics of children, the destructive effect of cancer and other deadly diseases in the treatment process will be further reduced[6]. In this context, it is to reduce the impact of fatal diseases in health services for children, to relieve the patient during the preparation for death, and to prevent possible psychological trauma and unexpected situations[7]. Today, the gradual increase in different types of severe and fatal diseases in children necessitates pediatric hospices and pediatric palliative care units, which are part of modern health services and care scales that will be used as professionalism in the nursing care process also contribute[8]. Evaluation tools to be used in the pediatric palliative field will reveal the causes of pediatric diseases, the reactions of the patients, and the correct treatment methods to be carried out regarding the disease and will increase the quality of nursing care in the field[9].

This study will be conducted to create a new scale: Pediatric Palliative Care Quality Assessment Scale (PPCQAS). Since there is no pediatric palliative care scale yet, it is important in terms of bringing innovation and affecting the quality of care positively.

Subjects and Method

Study Design

The design included a sequential, exploratory, mixed-method design with qualitative (item generation) and quantitative (methodological study) phases.

Search strategy and study selection

The information was collected online from nurses who participated in the research voluntarily and filled out the informed consent form between April 2023 and July 2023 in Turkey. However, approximately 198,465 nurses work in Turkey in general, and since it is impossible to reach almost all nurses, especially pediatric nurses, the sample size was determined in line with the inclusion and exclusion criteria. Pediatric nurses who had access to the Internet were included in the research. A survey was used as a data collection technique in the research, and an online survey form (Google Forms) was spread through social networks and social media. To determine the sample size in the study, the calculation was based on the number of variables used in multivariate data analyses. Determining the number of variables on the basis is also one of the basic criteria for the suitability of research data for analysis[10,11] stated that in the studies conducted, in order to ensure the suitability of the data for analysis, should reach at least 5 or even 10 times the number of variables. In this regard, it was aimed at reaching 650 people since there were 17 statements in the survey. In this context, the sample of the study was selected from nurses in Turkey by convenience sampling method, one of the non-probability sampling methods. Finally, 580 pediatric nurses participated.

Development of the scale

For the new scale development, initial information was collected by the expert opinion of ten faculty members. According to the feedback from the faculty members, necessary arrangements were made by

the research team, and the scale took its final form. After obtaining the approval of the Cyprus Science University Ethics Committee, the PPCQAS was filled with the sociodemographic information form (Google Forms), which was prepared online first among the nurses who worked as pediatric nurses and at the next stage, 50 nurses were given with a 2-week interval (15 days). The pediatric palliative care scale was applied twice in a single session. Finally, PPCQAS and NiPCAS were administered in a single session for criterion validity. The data of 580 pediatric nurses who participated in the study, who completed the sociodemographic data form and the scale questions, were analyzed.

***Defining the purpose of use of the scale tool*:** The pediatric palliative care scale had a single-factor structure and consisted of 17 questions. The purpose of the scale was to develop a new scale to evaluate the quality of children's palliative care.

***Item creation*:** After reviewing the literature, new items were prepared following the structure of the pediatric palliative care concept, considering the previously prepared scale items. Pediatric nurses were asked open-ended questions about pediatric palliative care and expressed their opinions. New items were added to the poll from the opinions received within the scope of the data. In its initial form, the scale consisted of 25 items. The 25-item scale was presented to expert opinion to determine content validity and to remove inappropriate questions from the scale.

***Item reduction*:** After considering the expert opinions and the feedback received, 5 items were removed from the 25-item scale. As a result, the first version of the scale with 20 items was created, to which a sociodemographic data form was added.

***Psychometric testing and further item reduction*:** In the item reduction section, 3 more items were removed from the 20-item scale and included in the form of 17 items, based on the tests performed in the findings section, especially the item loads and the results of the item analysis.

***Final revision of the prototype to turn it into a usable research tool*:** In its final version (Turkish version) the scale consists of a single factor and 17 questions (no new items were added to the final version of the scale). 8 items were removed from the 25 scale items. As a result of the analyses, a single factor was collected. Since the scale consists of 17 questions, the scores obtained from the overall scale were divided by the number of items in order to evaluate the scores obtained from the PPCQAS. The newly developed scale was one-dimensional and the details were included in Appendix1 (*online version* available). Therefore, scores between 1 and 5 were obtained. The following reference ranges were used to interpret these scores: "1.00-1.79" was very low level, "1.80-2.59" was low level, "2.60-3.39" was medium level, "3.40-4.19" was high level and "4.20-5.00" was considered as a very high level.

Data collection

The Sociodemographic data form consisted of 5 questions about the nurses' gender, age, marital status, educational status, and the health institution they work for. The PPCQAS was filled by nurses. The items in the scale were: completely disagree (1), disagree (2), undecided (3), agree (4), and completely agree (5). To evaluate the scores from the PPCQAS, the scores from the overall scale were divided by the number of items. In this way, scores between 1 and 5 were obtained, as mentioned above.

Data analysis

In this study, exploratory factor analaysis (EFA) and confirmatory factor analysis (CFA) were applied to evaluate the construct validity of the PPCQAS. The distinctiveness of the scale was determined by performing item analysis. Cronbach and Omega alpha coefficients were calculated to observe the reliability of the scale based on internal consistency. In addition, test-retest analysis was performed to determine the stability of the scale and to test whether it could measure consistently over time. Analyses were carried out using the SPSS 25.0 statistical package software.

Results

General results

55.2% of the participants were male, 44.8% were female, and 45.2% were between the ages of 31-40 (Table 1). A large proportion of the participants (58.1%) stated that they worked in public hospitals. The lowest score received from the survey was 17, and the highest score was 85. These values showed that the distribution of survey scores was close to the normal distribution. Item-total correlation values were calculated, and correlation coefficients were observed to vary between 0.67 and 0.76.

Convergent validity analysis

It was observed that the internal reliability criteria CR > 0.70 and AVE > 0.50 conditions were met; the concordance validity condition (CR > AVE) was met, thus indicating that convergent validity was achieved[12].

Item analysis results

It was observed that the averages of the item scores of the participants in the lower and upper groups were in favor of the participants in the upper group.

Exploratory factor analysis (EFA)

Exploratory factor analysis is an important research method to understand the scale structure and evaluate the validity of the measurement tool[13]. The Kaiser-Meyer-Olkin (KMO) value calculated for the PPCQAS is 0.90. This test was used to evaluate the validity of the data set on which factor analysis was performed and to increase the accuracy of the analysis14,15. According to the test results, the chi-square value was statistically significant [Bartlett's Sphericity (χ^2 136) = 7667.26; $p < 0.001$]. According to the factor analysis results, the factor loadings of the items in the PPCQAS took values between 0.51 and 0.63. The single-factor structure of the scale explained 57.89% of the total variance. Common variance values calculated for the scale items varied between 0.51 and 0.63 (Table 2).

Confirmatory factor analysis (CFA)

To improve model fit values, modification index values were examined and the relationships between the error values of some items were released (Figure 1).

Reliability analysis results

Cronbach and Omega Alpha coefficients were calculated to determine the reliability of the PPCQAS. Values between 0.60 and 0.80 indicate that the measurement tool was highly reliable and values between 0.81 and 1.00 indicated that the measurement tool was highly reliable[16]. The obtained values are shown in Table 3. Cronbach Alpha coefficient calculated to determine the reliability of the PPCQAS was 0.95. The Omega Alpha coefficient calculated for the scale was 0.96.

Test-Retest analysis results

The test-retest reliability method was used to evaluate the ability of the measurement tool to consistently produce similar results[17]. It was observed that the mean and standard deviation values calculated as a result of the two applications were quite close to each other, despite the 15-day time difference. In addition, the correlation coefficient between the two applications was calculated as 0.54. This value showed that there was a moderately positive relationship between the two applications. These results indicated that the PPCQAS had a stable structure, made consistent measurements and was reliable (Table 4).

Table 1. Distribution of participants by sociodemographic characteristics

		N°	%
Gender	Male	320	55.2
	Female	260	44.8
Age	20-25	51	8.8
	26-30	152	26.2
	31-40	262	45.2
	40 age and over	115	19.8
Marital status	Married	477	82.2
	Single	92	15.9
	Other	11	1.9
Education status	Health Vocational High School	36	6.2
	Associate degree	103	17.8
	License	400	69.0
	Master's degree and above	41	7.1
Health institution	Family medicine	34	5.9
	Public hospital	337	58.1
	Private hospital	192	33.1
	Other	17	2.9
Total		580	

Table 2. Factor loads of PPCQAS items

Item no	Factor load 1	Common variance	MTK	Self-worth	Explained variance (%)
m8	0.80	0.63	0.76	9.84	57.89
m12	0.79	0.62	0.75		
m15	0.78	0.61	0.74		
m14	0.78	0.60	0.74		
m13	0.78	0.60	0.74		
m16	0.77	0.60	0.74		
m9	0.77	0.60	0.74		
m10	0.77	0.59	0.73		
m2	0.77	0.59	0.74		
m11	0.76	0.58	0.72		
m17	0.76	0.57	0.72		
m7	0.76	0.57	0.72		
m6	0.75	0.57	0.72		
m1	0.75	0.56	0.71		
m3	0.73	0.53	0.70		
m4	0.72	0.52	0.68		
m5	0.72	0.51	0.67		

IRC= Item-rotal correlation. PPCQAS: Pediatric Palliative Care Quality Assessment Scale.

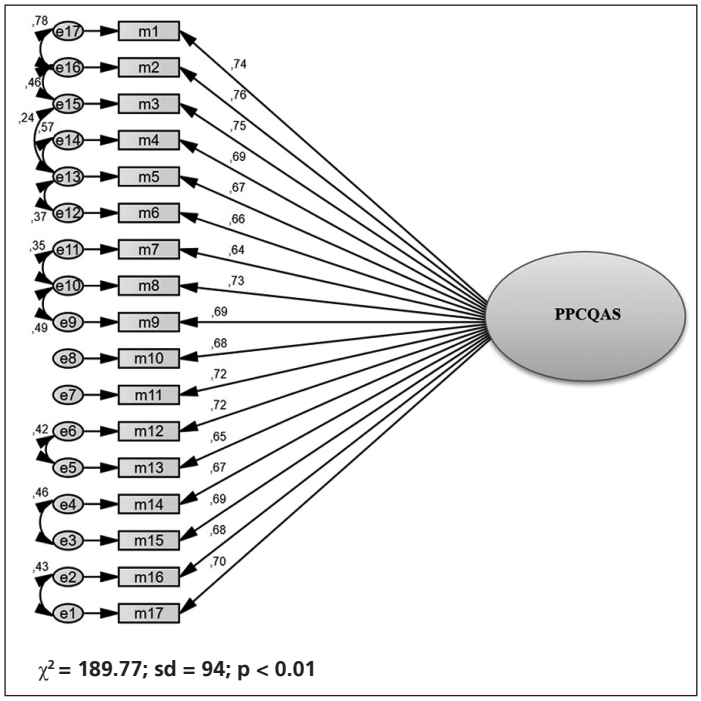

Figure 1. Confirmatory factor analysis model of the PPCQAS.

Table 3. Reliability coefficients of PPCQAS

Scale	Item number	Cronbach Alfa	Omega Alfa
PPCQAS	17	0.95	0.96

PPCQAS: Pediatric Palliative Care Quality Assessment Scale.

Table 4. Descriptive information on test-retest reliability of PPCQAS and Pearson correlation coefficients

Factor	Application	Ave	Ss	r
Overall scale	First application	72.12	7.46	0.54**
	Last application	69.78	10.62	

**p < 0.01; N = 50. PPCQAS: Pediatric Palliative Care Quality Assessment Scale.

Table 5. Pearson correlation coefficients of PPCQAS and NiPCAS scores

Variables		NiPCAS		
		Organization	Resources	Clinic
PPCQAS	r	0.63	0.54	0.42
	p	< 0.01	< 0.01	< 0.01
	N	50	50	50

PPCQAS: Pediatric Palliative Care Quality Assessment Scale.
NiPCAS: Neonatal Palliative Care Attitude Scale.

Scale validity results

In this study, NiPCAS (a scale consisting of three sub-dimensions: organization, resources and clinical) whose validity and reliability have been tested by Akay and Aytekin Özdemir (2021)[18] was chosen as a comparative criterion. NiPCAS scores for organization ($r = 0.63$; $p < 0.01$), resources ($r = 0.54$; $p < 0.01$), and clinical ($r = 0.42$; $p < 0.01$) dimensions, showed positive correlations between the scores (< 0.01). The results indicated that the PPCQAS and the NiPCAS are consistently related to each other and measure the same features (Table 5).

Discussion

This study was conducted to develop a new scale within the scope of evaluating the palliative care quality of children. According to the exploratory factor analysis, the results of the descriptive analysis we applied in our study (the lowest score from the questionnaire is 17, and the highest score is 85) were close to the normal distribution; there was a strong relationship between the variables, and it is suitable for factor analysis (Barlett Sphericity ($\chi^2(136)$) = 7667.26; $p < 0.001$). These findings were similar to those in the qualitative and quantitative study of Cam et al. (2010)[19] in preparing the attitude scale. In the study of Siegert et al. (2010)[20] the Psychological Well-being and Quality of Care: factor-analytical analysis of palliative care outcome scale, it was concluded that the descriptive analysis results were normal and there was a positive relationship between the variables. Neonatal Palliative Care Attitude Scale: a tool developed to measure the barriers and facilitators of palliative care in neonatal nursing, where Kain et al. (2009)[21] successfully achieved its quality. The results of a factor analysis also support our findings.

According to the CFA results of our research, it was concluded that the goodness of fit values was compatible with the data, and the calculated factor loads were found to be statistically significant. In the Benito et al. (2014)[22] study of the development and approval of a new tool for the evaluation and spiritual care of palliative care patients, it was determined that the items that emerged were compatible with each other. The results of Mason (2004)[23] study of the evaluation of postgraduate palliative care education, the validity and reliability of two scales examining perceived effectiveness and outcome expectations in palliative care, are similar to our findings, which revealed that the item factor loads were compatible.

According to the results of the segregation and merger validity analysis, it was pointed out that it met the internal security criteria and provided convergence

validity. According to the item analysis results, each item in the scale was found to be significantly significant (factor loads 0.64 to 0.76). These findings were found to be consistent with the Palliative Care Self-Reported Practices Scale and the Palliative Care Difficulties Scale by Nakazawa et al. (2010)[24]. In the validity and reliability study of the two scales, which evaluated the self-reported practices of health professionals and the difficulties they experienced in palliative care, it was determined that the items in the scale were significant and compatible with each other. In Ringdal et al.'s (2003)[25] measurement of the quality of palliative care, psychometric properties of the FAMCARE Scale, and Belar's (2021)[26] study of wanting to die in palliative care and accelerating death, a cross-sectional study factor analysis revealed that the scale items were compatible and the results of the internal security criteria were determined to be positively affected.

According to the results of the reliability analysis of the scale, it was determined that the scale was highly reliable (0.96). This result shows that the scale is a reliable scale that can be used. As a result of the validity and reliability study of the Memorial Delirium Assessment Scale-Thai version (MDAS-T) for the evaluation of delirium in palliative care patients in Klankluang et al. (2020)27, the reliability analysis result was 0.98, indicating that it is a reliable scale. The reliability analysis of Zhuand et al.'s (2019)[28] study of the validity, reliability, and diagnostic accuracy of the Respiratory Distress Observation Scale for the evaluation of dyspnea in adult palliative care patients shows parallelism with our findings. Likewise, in the study of dos Santos et al. (2021)29, the Quality Care Questionnaire-Palliative Care short-form study with acceptable measurement characteristics in Brazilian cancer patients was found to be 0.82, and it shows closeness.

As a result of the test-re-analysis of the scale, despite the 15-day time difference, it was observed that the mean and standard deviation values calculated as a result of the two applications were quite close to each other. In addition, the correlation value (0.54) between the two applications indicated that there was a moderate positive relationship between the two applications, that the scale had a stable structure, that it made consistent measurements, and that it was reliable. Evaluation of the trio of palliative and end-of-life care education-practice-proficiency in the units of nursing care: In the study of content validity, applicability, and reliability of a new tool, it was concluded that the results of the newly developed scale are usable and valid scale. In Kain et al.'s (2009)[30] study of neonatal palliative care attitude scale: developing a tool to measure the barriers and facilitators of palliative care in neonatal nursing, it was found that the scale's mean and standard deviation values were close, and it was a usable, valid and reliable scale. The development and validity study of the Palliative Care Knowledge Scale by Kozlov et al. (2017)[31] and the development of the Pediatric Palliative Screening Scale (PaPaS) by Bergstraesse et al. (2013)[32], a tool to identify children in need of palliative care, resulted in a qualitative approach study. According to the correlation results, it was stated that there was a positive relationship, and it was a reliable and usable scale.

According to the criterion validity results of the scale, the organization ($r = 0.63$; $p < 0.01$), resources ($r = 0.54$; $p < 0.01$), and clinical ($r = 0.42$; $p < 0.01$) dimensions of the newly developed PPCQAS and the NiPCAS that we used in our previously developed research are consistently related to each other and measure the same feature. The criterion validity results also showed that the developed pediatric palliative care scale was valid and served its purpose. Developing and validating a baseline outcome measure for palliative care by Hearn and Higginson (1999)[33], the Palliative Care Outcome Scale, concluded that the palliative care core control project provided criterion validity in the advisory group study. In Ostgathe et al.'s (2019)[34] study of determining the need for specialized palliative care in adult cancer patients developing and validating a screening procedure based on proxy evaluation by physicians and filter questions, it was stated that the criterion results of the newly developed scale were valid, and the item contents were consistent. In the study of Nagoya et al. (2020)[35] to develop a representative quality-of-life rating scale for the end-of-life care of pediatric cancer patients evaluated from a nurse's point of view, the relevant scale was found to be a usable scale according to the criterion validity results; similarly, in the results by Donnelly et al.[36] of the new scale study of developing and evaluating a measure of parent and child need in care are also similar to our criterion validity findings.

There are limitations in this study. Since it is almost impossible to reach all nurses working in every field, pediatric nurses who participated voluntarily and in the research were included.

In conclusion, the PPCQAS is a valid and reliable scale that can be used by pediatric nurses. Since the items on the scale are not too long, it can be easily used by pediatric nurses in the care of children in need of palliative care.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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