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Evaluation of Palliative Care Patient Outcomes From the Perspectives of Patients, Family Caregivers, and Nurses

Abstract

This descriptive, cross-sectional, and comparative study was conducted to examine differences in Palliative Care Outcomes Scale total scores among hospitalized palliative care patients, their caregivers, and nurses providing care. The study included 53 patients receiving treatment in palliative care units of two public hospitals, 53 caregivers, and 53 nurses. Data were collected using a Personal Information Form and the Palliative Care Outcomes Scale, which assesses patients' physical, emotional, psychological, spiritual, informational, and support needs. Descriptive statistics and one-way analysis of variance were used for data analysis. The mean Palliative Care Outcomes Scale total scores were 14.83 ± 7.01 for patients, 13.55 ± 8.02 for caregivers, and 16.60 ± 7.22 for nurses. No statistically significant difference was found among the three groups ($F=2.260$; $p>0.05$). The findings indicate that total Palliative Care Outcomes Scale scores were comparable across respondent groups. These results suggest consistency in the assessment of palliative care needs among patients, caregivers, and nurses, emphasizing the importance of multidisciplinary alignment in palliative care practice.

Keywords: Caregiver, nurse, palliative care, patient.



Hasta, Hasta Yakını ve Hemşire Gözüyle Palyatif Bakım Hasta Sonuçlarının Değerlendirilmesi

Öz

Bu tanımlayıcı, kesitsel ve karşılaştırmalı çalışma, palyatif bakım ünitesinde yatan hastalar, onların bakım verenleri ve bakım veren hemşireler arasında Palyatif Bakım Sonuç Ölçeği toplam puanları açısından farklılık olup olmadığını incelemek amacıyla yürütülmüştür. Çalışma, iki kamu hastanesinin palyatif bakım ünitelerinde tedavi gören 53 hasta, 53 bakım vereni ve bu hastalara bakım veren 53 hemşire ile gerçekleştirilmiştir. Veriler Kişisel Bilgi Formu ve hastaların fiziksel, duygusal, psikolojik, spiritüel, bilgilendirme ve destek gereksinimlerini değerlendiren Palyatif Bakım Sonuç Ölçeği kullanılarak toplanmıştır. Verilerin analizinde tanımlayıcı istatistikler ve tek yönlü varyans analizi kullanılmıştır. Palyatif Bakım Sonuç Ölçeği toplam puan ortalamaları hastalar için 14.83 ± 7.01 ; bakım verenler için 13.55 ± 8.02 ; hemşireler için 16.60 ± 7.22 olarak bulunmuştur. Üç grup arasında toplam Palyatif Bakım Sonuç Ölçeği puanları açısından istatistiksel olarak anlamlı bir fark saptanmamıştır ($F=2.260$; $p>0.05$). Bulgular, palyatif bakım gereksinimlerinin değerlendirilmesinde gruplar arasında benzer sonuçlar elde edildiğini göstermektedir. Bu sonuçlar, palyatif bakım uygulamalarında disiplinlerarası uyumun ve hasta merkezli yaklaşımın önemini vurgulamaktadır.

Anahtar kelimeler: Hasta yakını, hemşire, palyatif bakım, hasta.



Introduction

Advancements in the field of healthcare have led to an increase in chronic and progressive diseases in parallel with the extension of human lifespan. Life-threatening conditions, including cancer, neurodegenerative, cardiovascular, and respiratory diseases, have created a need for specialized medical care aimed at symptom management and improving quality of life.^{1,2} Palliative care is rapidly evolving as a discipline that has emerged in response to this need, aiming to provide support not only to patients but also to their families.³ The aging population and the increasing prevalence of incurable diseases highlight the growing importance of palliative care, while healthcare services in this field continue to expand through multidisciplinary approaches.⁴

Palliative care is a holistic approach aimed at improving the quality of life of individuals battling life-threatening illnesses and their families, encompassing physical, psychosocial, and spiritual needs.⁵ According to the World Health Organization, palliative care is not only patient-centered but also provides a care model that supports the patient's family members.⁶ At this point, a fundamental challenge for healthcare professionals is monitoring physical symptoms and understanding patient needs that are not visible through standard assessment methods.⁷ In this context, the success of palliative care can be measured not only by clinical outcomes but also by evaluating the perceptions and experiences of patients, their families, and the healthcare professionals providing care.^{8,9}

Among the measurement tools specifically developed in the field of palliative care are the Edmonton Symptom Assessment Scale (ESAS)¹⁰ and Palliative Performance Scale (PPS)¹¹ the Palliative Care Outcome Scale (POS).¹² The use of patient- and family-reported outcome measures in palliative care settings can promote person-centered care, empower patients, enhance effective communication, and contribute to the identification of unrecognized symptoms.¹³

The literature indicates that palliative care outcome measures are effective in enhancing patient-centered care in both clinical practice and research.^{13,14} On the other hand, in assessing the symptom burden and care needs of dying or non-communicative palliative care patients, discrepancies may arise between the assumptions of caregiving family members and the evaluations of healthcare professionals. Caregiving family members' subjective experiences regarding the patient's condition are often influenced by their own anxieties and burdens, which can make their assessments less objective.^{15,16} Conversely, healthcare professionals, due to their limited time spent with the patient compared to caregiving family members, may tend to underestimate symptom burden or perceive the patient's quality of life as higher than it actually is.^{17,18} This dilemma aligns with the heterogeneous findings in studies that highlight the low levels of agreement between caregiving family members and healthcare professionals, particularly in the field of psychosocial care.¹⁷

Nurses stand out as healthcare professionals who directly communicate with both patients and their families, playing a key role in guiding the care process.^{13,14} In a systematic review conducted by Bausewein et al., it was found that the use of patient-reported outcome measures by nurses in clinical care contributes to better identification of patient needs and the improvement of care processes.⁸ Nurses play a crucial role in various aspects of patient care, including pain management, symptom relief, and addressing psychological and social needs. In addition to providing high-quality care, the ability of palliative care nurses to effectively evaluate care outcomes is becoming increasingly important.^{12,19} However, it has also been emphasized that technical challenges, time management issues, and other factors faced by nurses in this process may negatively impact the effective integration of palliative care outcome measures into clinical practice.¹³

The measurement of patient care outcomes enables the evaluation of a patient's health status in relation to the healthcare services received and allows for systematic assessment of care processes and results.¹² Additionally, outcome measurement provides a structured approach to identifying patients' physical, psychological, social, and supportive care needs. Therefore, the measurement of patient care outcomes allows us to track these changes and assess the structure, process, and outcomes of care.⁸ In this context, the present study aims to compare Palliative Care Outcomes Scale (POS) total scores among patients receiving palliative care, their caregivers, and nurses providing care. By examining similarities and differences in outcome assessments across these groups, the study seeks to contribute to the development of patient-centered and multidisciplinary palliative care practices.

Materials and Methods

Research Objective

This descriptive, cross-sectional and comparative study aims to examine differences in palliative care patient outcome scores among hospitalized patients, their caregivers, and nurses.

Research Questions:

- How are palliative care patient outcomes reported by patients, caregivers, and nurses?
- Is there a statistically significant difference in the palliative care patient outcomes reported by patients, caregivers, and nurses?

Population and Sample of the Study

The study population consists of patients hospitalized in the palliative care units of two public hospitals located in a provincial center in the Western Black Sea Region of Turkey, their caregivers, and the palliative care nurses responsible for their care. An a priori power analysis was conducted using G*Power (version 3.1.9.7). Based on a medium effect size ($f=0.25$) for one-way ANOVA, a significance level of $\alpha=0.05$, and a statistical power of 0.80 ($1-\beta$), the minimum required total sample size was calculated as 159 participants. The power analysis was conducted to detect differences in total POS scores among the three independent groups using one-way ANOVA. The calculated sample size corresponded to 53 participants per group. Accordingly, the study included conscious, oriented patients receiving palliative care, who had no communication problems and agreed to participate in the study ($n=53$), their family caregivers ($n=53$), and the nurses providing care to these patients ($n=53$) from the selected institutions.

Inclusion criteria for patients were being conscious, oriented, able to communicate, and currently receiving palliative care. Family caregivers were required to be the primary caregiver of the participating patient and aged 18 years or older. Nurses were required to be actively providing care in the palliative care unit at the time of data collection.

Data Collection

The research data were collected between December 15, 2023, and June 15, 2024, using a survey method. In the study, data were collected using a personal information form to assess the descriptive characteristics of patients, caregivers, and nurses, along with the Palliative Care Patient Outcomes Assessment Scale to evaluate their perceptions of palliative care patient outcomes.

The Personal Information Form was developed by the researchers based on the literature and was designed separately for patients, caregivers, and nurses. The patient personal information form consists of seven questions covering personal characteristics and aspects related to their illness process, including gender, age, marital status, education level, occupation, length of hospital stay, and presence of chronic disease. The caregiver personal information form includes six questions related to personal characteristics and caregiving details, covering age, gender, marital status, education level, occupation, and whether they have received training on palliative care. The nurse personal information form consists of six questions addressing personal characteristics and working conditions, including age, gender, marital status, education level, years of professional experience, and weekly working hours.^{12,20}

Palliative Care Patient Outcomes Assessment Scale (POS) was developed by Hearn and Higginson in 1999 using data derived from a review of outcome measures recommended for evaluating palliative care in patients with advanced cancer.²⁰ The Turkish validity and reliability study of the POS was conducted by Kocatepe et al.¹² The adaptation study validated three parallel versions of the scale separately for patients, caregivers, and healthcare professionals. The content validity ratios were above 0.80 for all three versions. The Cronbach's alpha coefficients were reported as 0.64 for the patient version, 0.73 for the caregiver version, and 0.68 for the staff version.¹² The POS consists of three parallel forms designed for patients, caregivers, and nurses, each including the same 10 core items evaluating the patient's physical, emotional, psychological, spiritual, informational, and support needs. Each item is rated on a five-point Likert scale ranging from 0 ("not at all") to 4 ("very severe"). Two additional questions assess the patient's performance status, one of which is open-ended. The total score is calculated by summing the 10 core items, yielding a range of 0–40. Higher scores indicate greater palliative care needs. In the present study, each group completed its respective validated version of the POS, and group comparisons were conducted using total scale scores. No subscale analyses were performed. In this study, the Cronbach's alpha coefficients were 0.71 for the patient version, 0.81 for the caregiver version, and 0.84 for the nurse version.

Data Analysis and Evaluation

Data analysis was conducted using IBM SPSS Statistics for Windows, Version 25.0 (IBM Corp., Armonk, NY, USA). For the analysis of descriptive characteristics of patients, caregivers, and nurses, frequency (n) and percentage (%) values were used. To determine the perceptions of patients, caregivers,

and nurses regarding palliative care patient outcomes, mean and standard deviation values were calculated. The statistical significance level was set at $\alpha = 0.05$. To assess the homogeneity of variances, Levene's test was performed. The test result was not statistically significant ($p = 0.483$), indicating that the assumption of homogeneity of variances was met. The normality assumption was assessed using skewness and kurtosis coefficients. According to Hair et al., skewness and kurtosis values between -1.5 and $+1.5$ are considered acceptable for normal distribution in social sciences.²¹ In the present study, all skewness and kurtosis values fell within this range. Based on these measurements, a one-way analysis of variance (One-way ANOVA), one of the parametric methods, was used to determine whether there were differences in palliative care patient outcome perceptions among the three groups.

For the implementation of the study, ethical approval was obtained (protocol no: 2023/420), along with official written permission from the institutions where the research was conducted. Additionally, informed consent was obtained from the participants, and written permission was secured from the author for the use of the scale. This study was conducted in accordance with the principles of the Helsinki Declaration.

Results

The descriptive characteristics of the patients, caregivers, and nurses included in the study are presented in Table 1. Accordingly, the mean age of the patients was 75.15 ± 13.95 (min: 19, max: 95), with 56.6% being female, 50.9% married, 52.8% having primary education, 90.6% unemployed, and 81.1% having a chronic disease. The mean age of the caregivers was 56.60 ± 13.80 (min: 22, max: 84), with 66.0% being female, 81.1% married, 49.1% having primary education, 56.6% employed, and 62.2% being the patient's child. For nurses, the mean age was 30.66 ± 6.12 (min: 23, max: 50), with 90.6% being female, 69.8% married, and 96.2% holding a university degree. The mean professional experience was 7.61 ± 7.09 years (min: 0.1, max: 32), the mean duration of working in a palliative unit was 2.86 ± 3.86 years (min: 0.1, max: 24), and the mean weekly working hours were 49.79 ± 12.46 hours (min: 35, max: 72) (Table 1).

Table 1. Descriptive characteristics of patients, caregivers, and nurses

Characteristics	Patients		Caregivers		Nurses	
	n	%	n	%	n	%
Gender						
Female	30	56.6	35	66.0	48	90.6
Male	23	43.4	18	34.0	5	9.4
Marital Status						
Married	27	50.9	43	81.1	37	69.8
Single	26	49.1	10	18.9	16	30.2
Education Level						
Illiterate	8	15.1	-	-	-	-
Literate	5	9.4	-	-	-	-
Primary Education	28	52.8	26	49.1	-	-
Secondary Education	6	11.3	14	26.4	-	-
University	6	11.3	10	18.9	51	96.2
Postgraduate	-	-	3	5.7	2	3.8
Employed						
Yes	5	9.4	30	56.6	-	-
No	48	90.6	23	43.4	-	-
Chronic Disease						
Present	43	81.1	-	-	-	-
Absent	10	18.9	-	-	-	-
Degree of Relationship						
Spouse	-	-	9	17.0	-	-
Child	-	-	33	62.3	-	-
Sibling	-	-	11	20.7	-	-

Age (Mean ± SD)	75.15±13.95	56.60±13.80	30.66±6.12
Professional Experience (Mean ± SD)	-	-	7.61±7.09
Years in Palliative Unit (Mean ± SD)	-	-	2.86±3.86
Weekly Working Hours (Mean ± SD)	-	-	49.79±12.46

Note. SD = standard deviation.

Table 2 presents the comparison of the scores obtained by patients, caregivers, and nurses from the Palliative Care Patient Outcomes Assessment Scale. Accordingly, the mean score for patients was 14.83±7.01, for caregivers 13.55±8.02, and for nurses 16.60±7.22. No significant difference was found in the evaluations of palliative care patient outcomes among patients, caregivers, and nurses ($F=2.260$; $p>0.05$) (Table 2).

Table 2. Comparison of mean scores on the palliative care patient outcomes assessment scale (POS) among patients, caregivers, and nurses

Scale	Patients (n:53)		Caregivers (n:53)		Nurses (n:53)	
	Min-Max	Mean ± SD	Min-Max	Mean ± SD	Min-Max	Mean ± SD
Total POS	0-31	14.83±7.01	4-33	13.55±8.02	3-29	16.60±7.22
Statistic*			$F= 2.260$	$p= 0.108$		

$p<0.050$, *One-Way ANOVA Test

Discussion

Palliative care is a holistic approach aimed at improving the quality of life of individuals with life-threatening illnesses, addressing not only the management of physical symptoms but also encompassing psychological, social, and spiritual needs.⁵ In the palliative care process, patients, caregivers, and healthcare professionals are all involved in the evaluation of care needs and outcomes. While caregivers experience emotional and physical burdens during the care process, nurses, as direct care providers, systematically assess patients' symptom burden and overall comfort levels.⁹ In this context, comparing palliative care patient outcome assessments across patients, caregivers, and nurses is important for understanding the consistency of outcome evaluation and supporting patient-centered and multidisciplinary care practices.

In this study, no statistically significant difference was observed in total POS scores across patients, family caregivers, and nurses. However, previous research has demonstrated discrepancies between patients and caregivers in outcome assessments within palliative care settings.^{15,16} In their study comparing POS scores among patients, caregivers, and nurses, Kocatepe et al. reported that patients (11.70±5.97) and caregivers (12.87±7.18) had similar total scores, whereas nurses (9.83±5.22) reported significantly lower scores.¹² These findings suggest potential differences in outcome assessment among respondent groups. The literature further indicates that healthcare professionals may evaluate care needs primarily based on clinical and medical criteria, which could contribute to variations in outcome scoring compared with patients and caregivers.⁹ When compared with the findings of the present study, the differences in results may be attributed to the fact that caregivers, due to their individual concerns and caregiving burden, may evaluate patients' symptoms less objectively. Conversely, healthcare professionals, who spend a more limited amount of time with patients compared to caregivers, may have a tendency to underestimate symptoms or perceive the patients' quality of life as higher than it actually is when compared to patient and caregiver reports.⁹

Based on the findings of this study, the absence of significant differences in total POS scores suggests consistency in outcome assessment between professional and non-professional caregivers regarding physical, psychological, emotional, and spiritual needs, as well as informational and practical support. Such alignment in assessment may facilitate patient-centered care and support effective communication and collaboration among stakeholders in palliative care settings.

This study has several limitations. First, the research was conducted in the palliative care units of two public hospitals in a single province, which may limit the generalizability of the findings. Second, the cross-sectional design prevents the evaluation of changes in patient outcomes over time and does not allow causal interpretations. Third, the use of self-reported measures may introduce response bias.

Conclusion

This study demonstrated that hospitalized patients in palliative care units, their caregivers, and nurses reported comparable total POS scores. Given the increasing importance of outcome measurements in healthcare services and their necessity in improving service quality and promoting accountability,^{22,23} it

is recommended that palliative care patient outcomes be assessed collaboratively with both service providers and recipients. Considering the growing emphasis on outcome measurement in healthcare and its role in quality monitoring and accountability, the routine and collaborative assessment of palliative care outcomes involving both care providers and recipients may contribute to a more comprehensive evaluation of patient needs. Future studies employing longitudinal or multi-center designs may provide deeper insight into variations in outcome assessment within palliative care settings.



Reviewer: External, Independent.

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Declarations:

1. Originality Statement: This study is original and has not been published previously. This study was not derived from any thesis.

2. Author Contributions: Conceptualization: SCP, BC; Idea: SCP, BC; Literature Review: SCP, BC; Data Collection: SCP; Data Processing: SCP; Analysis: BC; Writing – Original Draft: SCP, BC; Writing – Review and Editing: SCP, BC

3. Ethics Committee Approval: Ethics committee approval for this study was obtained from the Bolu Abant İzzet Baysal University Clinical Research Ethics Committee with the decision dated 05/12/2023 and numbered 2023/420.

4. Funding/Support: This study did not receive any financial support.

5. Conflict of Interest: The authors declare that there is no conflict of interest in this study.

6. Generative Artificial Intelligence Statement: No generative artificial intelligence tools were used at any stage of this study.

7. Sustainable Development Goals: This work is related to the following United Nations Sustainable Development Goals.



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