

# Palyatif Bakımda Nörolojik Hastalıklarda Hemşirelerin Bilgisi Yeterlimi?

## Do Nurses Have Enough Knowledge in Neurological Diseases in Palliative Care?

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### Özet

**Amaç:** Toplumdaki yaşlı sayısının artması ile birlikte nörolojik hastalıkların sayısı artmakta ve bu hastaların palyatif bakım hemşireliği, buna yönelik eğitim programları daha çok önem kazanmaktadır. Bu çalışma hemşirelerin palyatif bakım ve nörolojik hastalıklarla ilgili bilgisini değerlendirmek amacı ile yapılmıştır.

**Gereç ve Yöntemler:** Palyatif bakım merkezinde çalışan en az 6 aylık tecrübesi olan 41 hemşire çalışmaya alındı. Hemşirelerin yaş, cinsiyet, çalışma tecrübesi, palyatif bakım tecrübesi, eğitim durumu, palyatif bakım kursu alıp almadıkları kayıt edildi. Palyatif bakım ve nörolojik hastalıklar ile ilgili 20 soru içeren bir anket uygulandı.

**Bulgular:** Çalışmaya katılan hemşirelerin yaş ortalaması 40.73 idi ve %70.7'si kadındı. Çalışma tecrübeleri ortalaması 18 yıl ve %48.8'inin eğitim durumu lisanslı. Hemşirelerin %46.3'ünün palyatif bakım tecrübesi 5 yıl ve üzeriydi, %51.2'si palyatif bakım kursu almıştı. Hemşirelerin yaşı, cinsiyeti, eğitim düzeyleri ve çalışma tecrübeleri test sonuçlarını etkilemezken, palyatif bakım tecrübesi olanların ve palyatif bakım kursu alanların nörolojik hastalıklar konusunda daha doğru yanıtlar verdiklerini saptadık ( $p<0.05$ ).

**Sonuç:** Palyatif bakım hemşirelerinin bilgi seviyelerini ve mevcut eksiklerini belirlemek, hem uygun eğitim programlarının hazırlanması, hemde hastalara verilen palyatif bakımın kalitesini artırmak açısından önemlidir.

**Anahtar Kelimeler:** Palyatif bakım, Hemşireler, Palyatif bakım bilgisi, Nöroloji

### Abstract

**Objective:** The number of neurological diseases increases with the increasing number of the elderly in the community, and palliative care nursing for these patients and training programs for palliative care nursing gain more importance. This study was carried out to evaluate the knowledge of nurses about palliative care and neurological diseases.

**Material and Methods:** 41 nurses with at least 6 months of experience working in a palliative care center were included in the study. The ages, sexes, work experiences, palliative care experiences, educational statuses and whether they had received palliative care courses were recorded. The questionnaire had 20 questions about palliative care and neurological diseases.

**Results:** The average age of the nurses included in the study was 40.73 and 70.7% were female. The mean work experience was 18 years and the education level of 48.8% was a bachelor's degree. 46.3% of the nurses had 5 years or more palliative care experience, 51.2% of them had taken a palliative care course. While the ages, sexes, education levels and work experiences of the nurses did not affect the study results, we found that those with palliative care experience and those who took palliative care courses gave more accurate answers to the questions on neurological diseases ( $p<0.05$ ).

**Conclusions:** Determining the level of knowledge and current deficiencies of palliative care nurses is important both in terms of preparing appropriate training programs and improving the quality of palliative care provided to patients.

**Keywords:** Palliative care, Nurses, Palliative care knowledge, Neurology

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## INTRODUCTION

Awareness is increasing not only in the palliative care in oncologic diseases but also in the approach to most of the chronic, incurable neurological diseases that disturb autonomy (1). Palliative care has traditionally been considered to be the intensive care of a patient close to death (2). Since there are no treatment options for most common neurological diseases such as dementia, multiple sclerosis, Parkinson's disease, and amyotrophic lateral sclerosis (ALS), it has been reported that the palliative care approach can help create a treatment plan that addresses all aspects of the disease (3).

Nurses are the most valuable palliative care team members that address the physical, functional, social and spiritual dimensions of care (4). The use of information in daily nursing practices is important for improving training preparation and quality in health services (5). Palliative patients are cared for not only in special units but also at home or general care of hospitals and nursing homes. Not only advanced nurses but also new nursing graduates should be able to provide adequate care for palliative patients (6).

Nurses are always considered to be the key element in providing palliative care, therefore they should get good training in palliative care and there should be institutions responsible for providing this training (7). Training of healthcare professionals has a major impact on their knowledge as a basis for better clinical practice (8). Being aware of the level of knowledge of current professionals makes it easier to prepare appropriate training programs to identify their deficiencies and improve the quality of care to be given (9,10). The aim of this study is to evaluate the level of knowledge of the nurses working in palliative care in our hospital on palliative care and neurological diseases and to investigate the effects of their educational status, experiences and the palliative care courses they have taken on the results.

## MATERIAL AND METHODS

The study was approved by the Ankara Numune Training and Research Hospital Ethics Committee (No: E-18-2289, Date: 01.11.2018). All procedures were applied in accordance with the principles of the Declaration of Helsinki. All participants were asked to give their written informed consent before their participation. Approved participants were given a questionnaire containing questions on general palliative care and neurological diseases.

We evaluated the knowledge of the nurses working at Pursaklar State Hospital palliative center on palliative care and neurological diseases. 41 nurses with at least 6 months of experience working in a palliative care center were included in the study. The ages, sexes, work experiences, palliative care experiences, educational statuses and whether they had received palliative care courses were recorded. The questionnaire had 20 items to be answered with 'correct', 'wrong' or 'I do not know'. 7 of the questions were related to palliative care and 13 were related to neurological diseases.

## Statistical Analysis

The study data consists of 41 people. The population aimed to be studied consisted of 41 nurses; who worked in the palliative care unit of Pursaklar Public Hospital and who had at least a 6-month experience in palliative care. The questionnaire was administered to all of the 41 nurses in the study population. Therefore, no calculations were performed to determine the sample size or the study power, or no sampling methods were used. The results represent the evaluation of 41 nurses; who worked in the palliative care unit of Pursaklar Public Hospital and who had at least a 6-month experience in palliative care. Analyzes were conducted on IBM SPSS Statistics 23 package software. While evaluating the study data, frequencies (number, percent) were provided for categorical variables (e.g. sex) and descriptive statistics (mean, standard deviation) for numerical variables (age). Relationships between two independent categorical variables were interpreted by Chi-Square analysis. In cases where the expected value assumption is not provided in the Chi-Square analysis, Fisher Exact test results are used. Statistical significance was interpreted at 0.05 in the analyses.

## RESULTS

The average age of the nurses included in the study was 40.73 and 70.7% were female. The education level of 48.8% of the nurses was a bachelor's degree. The mean working experience was 18 years and the work experience of 51.2% was between 9-19 years. Palliative care experiences were mean 3.46 years, and 46.3% had palliative care experience of 5 years or more. 51.2% of the nurses had taken palliative care courses (**Table 1**).

It was observed that the nurses who participated in the study mostly provided correct answers to the questions on general palliative care, and they answered some of the questions related to neurology wrong or with 'I do not know'. For Q4 and Q20, more than half of the respondents gave wrong answers or 'I do not know'. The rate of wrong/'I do not know' answers for Q2 was 17.1%, 22% for Q3, 17.1% for Q5, and 29.3% for Q13. For Q12 and Q14, all of the participants answered correctly (**Table 2**).

The rate of those who provided the correct answer to Q4 was 18.2% in the nurses with less than 5 years of palliative care experience, while the rate was 47.4% in those with 5 years or more experience. There is a statistically significant relationship between palliative care experience and Q4 success ( $p < 0.05$ ). Accordingly, the rate of those who have a palliative care experience of 5 years or more responding correctly to Q4 is significantly higher than those with a palliative care experience of fewer than 5 years (**Table 3**).

There was a statistically significant relationship between taking palliative care courses and the success of Q2, Q3, Q4, Q5, Q13 and Q20 in the nurses participating in the study ( $p < 0.05$ ). Accordingly, the rate of those who provide correct answers to Q2, Q3, Q4, Q5, Q13 and Q20 in those who have taken palliative care courses is significantly higher than those

who have not taken palliative care courses. While all of those who have taken palliative care courses provided the correct answer to Q2, this rate is 65% in those who did not take the course. While 95.2% of those who have taken palliative care courses provided correct answer to Q3, this rate is 60% in those who did not take the course. While 47.6% of those who have taken palliative care courses provided correct answer to Q4, this rate is 15% in those who did not take the course. While all of those who have taken palliative care courses provided correct answer to Q5, this rate is 65% in those who did not take the course. While 90.5% of those who have taken palliative care courses provided the correct answer to Q13, this rate is 50% in those who did not take the course. While 76.2% of those who have taken palliative care courses provided the correct answer to Q20, this rate is 15% in those who did not take the course (**Table 4**)

**Table 1. Demographic data**

	Mean± SD	n(%)
<b>Age</b>	40.73 ± 3.033	
40 Years and Younger		19(46.3)
40 Years and Older		22(53.7)
<b>Gender</b>		
Female		29(70.7)
Male		12(29.3)
<b>Educational Status</b>		
High School		4(9.8)
Associate's Degree		15(36.6)
Bachelor's Degree		20(48.8)
Master's Degree		2(4.9)
<b>Work Experience</b>	18 ± 4.511	
9-19 Years		21(51.2)
20-23 Years		20(48.8)
<b>Palliative Care Experience</b>	3.46 ± 1.823	
Less than 1 year		10(24.4)
1-5 Years		12(29.3)
5 Years and Above		19(46.3)
<b>Taking Palliative Care Courses</b>		
Yes		21(51.2)
No		20(48.8)

SD: Standard Deviation

## DISCUSSION

This study is the first study conducted in our country to evaluate the level of knowledge of palliative care nurses on palliative care and neurological diseases. The increasing need for palliative care also increases the need for healthcare professionals trained in symptom management, nutrition, wound care, complementary therapies, and communication. Nurses are the most important first contact points of

patients. Assessing nursing knowledge is important because knowledge plays a causal role in attitude or behavioral consistency (11). Palliative care center first started in our hospital in 2012 in our country and spread to the whole country in time. 53.7% of the nurses working in our palliative care unit are over 40 years of age and 70.7% are female. The education level of 48.8% of the nurses is a bachelor's degree and their mean working experience is 18 years. Their palliative care experiences are 3.46 years and 51.2% have taken palliative care courses.

In this study, the nurses were asked 7 questions on general palliative care and 13 questions on neurological diseases. It was observed that while the nurses provided mostly correct answers to the questions on general palliative care, more than half of the answers to the 4th and 20th questions on neurology were answered wrong or with "I do not know". In the 4th question, 68.3% of the nurses answered the question of starting palliative care in case of neurological diseases from the time of diagnosis wrong or with 'I do not know'. The quality of life of patients living with chronic neurological diseases decreases before reaching the terminal stage (12,13). It is thought that palliative care provided in the early stage of neurological diseases will improve the quality of life and symptom management. In chronic neurological diseases, there are uncertainties about the prognosis of the diseases. In line with our study, the study carried out by Gofton et al. showed that many physicians and resident participants had difficulty in defining the prognosis for a particular patient, which showed that there were uncertainties about when to start including palliative care services (14). In question 20, 53.7% of the nurses answered wrong or with 'I do not know' to the question on whether the worsening of Parkinson's symptoms may be caused by the administration of certain anti-emetic or neuroleptic agents. Similarly, in previous studies, the deficiencies in the knowledge of the nurses on Parkinson's disease and in disease management have been shown (15,16). Jarman et al. showed that nurses who have been trained in the care of patients with Parkinson's disease help to maintain patients' well-being (17).

While there was no relationship between the age, sex, education levels, and work experiences and the results of the questionnaire, the rate of those who provided correct answer to Q4 in those with a palliative care experience of 5 years or more was significantly higher than those with a palliative experience of fewer than 5 years. It was observed that nurses with palliative care experience gave more correct answers to starting palliative care early in neurological diseases. Amir Hosein et al. carried out a palliative care test on nurses and showed that nurses with high educational level and working in intensive care units were better in palliative care practices (18).

Another factor that significantly affected the results was observed to be taking palliative care courses. Nurses who received palliative care courses were found to have significantly higher rates of providing correct answers to Q2, Q3, Q4, Q5,

**Table 2. Palliative care questions and distribution of answers**

		Correct n(%)	Wrong/I do not know n(%)
<b>General Palliative Care</b>			
Q1	Palliative Care is only for cancer patients	41(100)	0(0)
Q6	Assessment and care should be provided by a multidisciplinary team approach consisting of physicians, nurses, psychologists, nutritionists, physiotherapists, social workers and spiritual care specialists.	41(100)	0(0)
Q7	Communication with patients and families should be clear, including goals and therapy options. Patients and their relatives should be included in the treatment protocol.	41(100)	0(0)
Q8	Patients' symptoms, pharmacological and non-pharmacological management should be regularly reviewed.	41(100)	0(0)
Q9	Carers' needs should be evaluated regularly.	39(95.1)	2(4.9)
Q10	Those working in palliative care should receive training and psychosocial support to reduce the risks of emotional exhaustion and burnout.	41(100)	0(0)
Q11	It is necessary to inform the relatives of the patients about the process of death and explain that they will die in peace with proper care	39(95.1)	2(4.9)
<b>Neurological Diseases</b>			
Q2	Neurological patients need less palliative care compared to cancer patients.	34(82.9)	7(17.1)
Q3	Palliative care in neurological diseases is only provided for the patients who are at the last stage of their life	32(78.0)	9(22)
Q4	Palliative care in neurological diseases should start from diagnosis.	13(31.7)	28(68.3)
Q5	As part of a broader palliative care assessment, the principles of symptom management should be applied in neurological care	34(82.9)	7(17.1)
Q12	Neurological diseases may have symptoms of motor, psychiatric, nutritional problems and urinary dysfunction.	41(100)	0(0)
Q13	Interactions of neurological drugs with antibiotics, analgesics, anti-inflammatory drugs and anticoagulants can worsen neurological symptoms and/or cause serious or fatal complications.	29(70.7)	12(29.3)
Q14	Patients with dementia may have symptoms of motor, psychiatric, and urinary dysfunction.	41(100)	0(0)
Q15	When advanced dementia patients can no longer swallow food or fluids, it may be necessary to insert a nasogastric or percutaneous endoscopic feeding tube.	40(97.6)	1(2.4)
Q16	Patients diagnosed with dementia, Parkinson's disease, stroke, etc. can no longer make the medical decisions for themselves with the progression of their symptoms.	40(97.6)	1(2.4)
Q17	In neurological diseases, the ability to verbally express challenging symptoms such as pain, anxiety, restlessness, nausea, shortness of breath, constipation, hallucinations, or delusions gradually disappear.	40(97.6)	1(2.4)
Q18	Neurological patients may experience severe respiratory failure and may need a mechanical ventilator.	38(92.7)	3(7.3)
Q19	Muscle weakness and respiratory failure may develop in patients with multiple sclerosis, myasthenia gravis and ALS.	40(97.6)	1(2.4)
Q20	Worsening of Parkinson's symptoms may be caused by the administration of certain anti-emetic or neuroleptic agents.	19(46.3)	22(53.7)

Q: Question

**Table 3. Examining the Relationship Between Palliative Care Experience and Questions**

	Less than 5 year(n=22)		5 Years and Above(n=19)		p
	Correct n(%)	Wrong/I do not know n(%)	Correct n(%)	Wrong/I do not know n(%)	
<b>General Palliative Care</b>					
Q9	20(90.9)	2 (9.1)	19(100.0)	0(0.0)	0.385 <sup>a</sup> 0.490
Q11	21(95.5)	1(4.5)	18(94.7)	1(5.3)	0.000 <sup>a</sup> 1.000
<b>Neurological Diseases</b>					
Q2	17(77.3)	5(22.7)	17(89.5)	2(10.5)	0.383 <sup>a</sup> 0.419
Q3	16(72.7)	6(27.3)	16(84.2)	3(15.8)	0.258 <sup>a</sup> 0.466
Q4	4(18.2)	18(81.8)	9(47.4)	10(52.6)	4.011 <sup>b</sup> 0.045*
Q5	18(81.8)	4(18.2)	16(84.2)	3(15.8)	0.000 <sup>a</sup> 1.000*
Q13	13(59.1)	9(40.9)	16(84.2)	3(15.8)	3.107 <sup>b</sup> 0.078*
Q15	21(95.5)	1(4.5)	19(100)	0(0.0)	0.000 <sup>a</sup> 1.000*
Q16	22(100)	0(0.0)	18(94.7)	1(5.3)	1.187 <sup>a</sup> 0.463*
Q17	21(95.5)	1(4.5)	19(100)	0(0.0)	0.000 <sup>a</sup> 1.000*
Q18	19(86.4)	3(13.6)	19(100)	0(0.0)	1.146 <sup>a</sup> 0.235*
Q19	22(100)	0(0.0)	18(94.7)	1(5.3)	1.187 <sup>a</sup> 0.463*
Q20	8(36.4)	14(63.6)	11(57.9)	8(42.1)	1.901 <sup>b</sup> 0.168*

Q: Question, a.Fisher's Exact Test b: Chi-Square Test \*: p <0.05 (Statistically significant)

**Table 4. Examining the Relationship Between Taking Palliative Care Course and Questions**

	Those who have taken the course(n=21)		Those who have not take the course(n=20)		p
	Correct n(%)	Wrong/I do not known(%)	Correct n(%)	Wrong/I do not known(%)	
<b>General Palliative Care</b>					
Q9	21(100)	0(0.0)	18(90.0)	2(10.0)	2.208 <sup>a</sup> 0.137*
Q11	20(95.2)	1(4.8)	19(95.0)	1(5.0)	0.000 <sup>a</sup> 1.000*
<b>Neurological Diseases</b>					
Q2	21(100)	0(0.0)	13(65.0)	7(35.0)	6.564 <sup>a</sup> 0.003*
Q3	20(95.2)	1(4.8)	12(60.0)	8(40.0)	5.510 <sup>a</sup> 0.009*
Q4	10(47.6)	11(52.4)	3(15.0)	17(85.0)	5.034 <sup>b</sup> 0.025*
Q5	21(100)	0(0.0)	13(65.0)	7(35.0)	6.564 <sup>a</sup> 0.003*
Q13	19(90.5)	2(9.5)	10(50.0)	10(50.0)	8.107 <sup>b</sup> 0.004*
Q15	21(100)	0(0.0)	19(95.0)	1(5.0)	1.462 <sup>a</sup> 0.488*
Q16	20(95.2)	1(4.8)	20(100)	0(0.0)	0.000 <sup>a</sup> 1.000*
Q17	21(100)	0(0.0)	19(95.0)	1(5.0)	1.462 <sup>a</sup> 0.488*
Q18	21(100)	0(0.0)	17(85.0)	3(15.0)	1.547 <sup>a</sup> 0.107*
Q19	21(100)	0(0.0)	19(95.0)	1(5.0)	1.462 <sup>a</sup> 0.488*
Q20	16(76.2)	5(23.8)	3(15.0)	17(85.0)	15.425* 0.000*

Q13, and Q20 than those who did not take a palliative course. All of the questions that the nurses who took palliative care courses answered correctly compared to those who did not take courses were related to neurological diseases. In previous studies, similarly, it was shown that nurses who completed palliative care training programs were more successful in knowledge tests and that these training programs played an active role in improving palliative care (19,20). Proctor et al.

carried out a palliative care exam for nurses and showed that work experience and palliative care experience contributed to the knowledge base and that non-specialist nurses were insufficient on some aspects such as complex symptom control, dyspnea management, and electrolyte imbalance (21). In another study where palliative care knowledge test was applied to nurses, there was a poor correlation between test scores and age and current work experience (22).

As a conclusion; in the questionnaire we applied to palliative care nurses in our hospital, we found that the nurses provided mostly correct answers to the questions on palliative care, while they were inadequate in questions on neurological diseases. While the ages, sexes, education levels and work experiences of the nurses did not affect the results of the questionnaire, we found that those with palliative care experience and those who took palliative care courses gave more accurate answers to the questions on neurological diseases. We think that it is important for nurses to be trained on this subject in order to care for these patients due to the slow progression of neurological diseases and the uncertainty in their prognosis. The number of neurological diseases increases with the increasing number of the elderly in the community, and palliative care nursing for these patients and training programs for palliative care nursing gain more importance.

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