

THE VIEWS OF ONCOLOGY NURSES ON PALLIATIVE CARE

Onkoloji Hemşirelerinin Palyatif Bakım Hakkındaki Görüşleri

Lecturer Merve HARMAN ÖZDOĞAN

Sinop University, Vocational School of Health Services, Dialysis Program, Sinop/TÜRKİYE

ORCID ID: <https://orcid.org/0000-0003-0408-0573>

Prof. Dr. Özlem OVAYOLU

Gaziantep University, Internal Diseases Nursing, Gaziantep/ TÜRKİYE

ORCID ID: <https://orcid.org/0000-0002-7335-4032>

Prof. Dr. Nimet OVAYOLU

Sanko University, Internal Diseases Nursing, Gaziantep/ TÜRKİYE

ORCID ID: <https://orcid.org/0000-0002-4505-0349>

ABSTRACT

Objective: The study was conducted to evaluate the views of nurses providing care to oncology patients about palliative care.

Methods: The sample of this descriptive study was composed of 92 nurses working in oncology service of a university hospital and a medical faculty hospital. The necessary permissions were obtained before the study. As data collection tool, a "Structured Questionnaire including Descriptive Information and Nurses' Knowledge and Practices about Palliative Care" was used. Descriptive statistics and t-test (Kolmogorov-Smirnov Z test) were used to evaluate data.

Results: It was determined that the age range of the nurses who participated in the study was between 18-53 years, their mean age was 29.09, they were mostly female and had undergraduate degree and their working duration in the profession ranged between 1-5 years. It was found that more than half (54.3%) of the nurses did not receive information about palliative care, those who stated that they received information received this information during high school and university education (72.2%), most of them (80.4%) had no in-service training program on palliative care in their institution, 77.2% thought that "communication and symptom management" should be involved in the subjects in training programs related to palliative care, and 54.3% believed that it would be appropriate to start palliative care when curative treatment is not possible or in advanced stage of disease.

Conclusion: It was seen that majority of nurses did not receive training on palliative care. In accordance with these results, it may be recommended to organise in-service training programs in institutions and to ensure continuity of these trainings.

Keywords: Palliative care, Palliative care nursing, oncology

1. INTRODUCTION

Palliative care, considered among human rights and values, is a care approach aiming to alleviate pain and agony of patients and enhance quality of life. Along with the increase in cancer incidence and improvements in treatment methods, aggressive therapies in the final stage of cancer patients' lives have led the need for palliative care [1,2]. It is stated that more than 20.4 million people around the world need palliative care service. Adults constitutes the majority of this need and 34% of them include the patients diagnosed with cancer. Especially in developed countries, the number of adults requiring palliative care is expected to increase with the growing aging population [2,3].

Cancer is a process involving physical, psychosocial and spiritual problems both for patients and their relatives. During this period, impairments are seen in physical and social functions in cancer patients which reduces their response to treatment and adversely affects the survival time [4,5]. Therefore, palliative care to be given to patients with an interdisciplinary approach is very important [6]. This team includes professionals from various disciplines such as nurses (palliative care nurses, intensive care nurses, clinical nurses), physicians (palliative care specialists, medical oncologists, algologists), physiotherapists, nutrition and dietary experts, occupational therapists, pharmacists, social service specialists, and clergymen [7,8]. In particular, the duties and responsibilities of the nurses in the multidisciplinary team are quite a lot. In this regard, oncology nurses who are involved in palliative care service that emerged with cancer patients in the

1900s should constantly renew their knowledge and skills about palliative care and should be open to improvement [9,10]. Therefore, this study was conducted to evaluate the views of oncology nurses about palliative care.

2. THE VIEWS OF ONCOLOGY NURSES ON PALLIATIVE CARE

2.1. Methods

2.1.1. Type of the Study

The study was designed and applied as descriptive.

2.1.2. Population and Sample of the Study

The population of the study was composed of all nurses working in the oncology department of a university hospital and a medical faculty hospital and the sample of the study consisted of 92 nurses who were working in these services and agreed to participate in the study.

2.1.3. Data Collection Tools and Data Collection

In the study, "Structured Questionnaire including Descriptive Information and Views and Practices of Nurses about Palliative Care" was used as data collection tool. In this form prepared by the researchers, there are 32 questions including open-ended and sub-titled questions about the nurses' age, gender, educational level, working duration in the profession, the clinic they work in, working duration in that clinic, their opinions about palliative care and their care practices.

2.1.4. Ethical Aspects of the Study

In order to conduct the study, written permission from the Ethics Committee and written permissions were obtained from the General Secretariat of Public Hospitals Association, to which the hospitals where the study was conducted were affiliated, and from the University Hospital Chief Physician. The purpose of the study, duration of the study and what is expected from them were explained to the nurses included in the sample of the study and their informed consents were obtained in accordance with the principle of willingness and voluntariness.

2.1.5. Data Assessment

Descriptive statistics and t-test (Kolmogorov-Smirnov Z test) were used to assess the data. The value of $p < 0.05$ was accepted to be statistically significant.

3. RESULTS

Table 1 shows the data about the descriptive characteristics of the nurses. It was seen that of the nurses included in the study, 90.2% were female, 46.7% had undergraduate degree, 34.8% had a professional experience of 1-5 years, 45.7% were working in stem-cell transplantation unit, 44.6% had a working duration of 0-1 year in the clinic they were working, and 54.3% did not receive any training on palliative care. 45.7% of those who received training about palliative care received their training during school education and 60.5% of them considered the training they received as "partially sufficient".

Table 1. Distribution of Descriptive Characteristics of the Nurses

Descriptive Characteristics	n	%
Gender		
Female	83	90.2
Male	9	9.8
Age	$\bar{X} = 29.0978$	Min = 18.00 Max = 53.00
Educational Level		
Graduate	15	16.3
Undergraduate	43	46.7
Associate	11	12.0
High School	23	25.0
Professional experience		
0-1 years	25	27.2
1-5 years	32	34.8
5-10 years	7	7.6
10 and more	28	30.4

Current Clinic		
Paediatric Onco-Haematology	16	17.4
Stem Cell Transplantation	42	45.7
Oncology	7	7.6
Haematology	7	7.6
Radiation oncology	4	4.3
Gynaecologic Oncology	8	8.7
Ambulatory chemotherapy	8	8.7
Working duration in the current clinic (year)		
0-1 years	41	44.6
1-5 years	29	31.5
5-10 years	4	4.3
10 and more	18	19.6
Have you been trained in palliative care?		
Yes	42	45.7
No	50	54.3
Where did you receive the training?*		
High school or University	26	72.2
In-service trainings	10	27.8
Internet	4	11.1
Books and magazines	4	11.1
Congresses and seminars	12	33.3
Do you think the training you received was sufficient?*		
Yes	11	28.9
No	4	10.5
Partially	23	60.5

Of the nurses participating in the study, 80.4% stated that no in-service training was given about palliative care in their institution, 48.9% of the nurses responded to the question “what palliative care means?” as “a care for extending life expectancy”, 89.1% responded to the question about the purpose of the palliative care as “relieving pain and other symptoms of the patients”, 93.5% of the nurses responded to the question of “who are the patients who can benefit from palliative care” as “oncology patients”, and 84.6% responded to the question of “where the palliative care services are given” as “in hospital environment”. The nurses participating in the study thought that the multidisciplinary team providing palliative care included doctor (96.7%), nurses (93.5%), psychologist (92.4%), physiotherapists (73.9%), dietitian (51.1%) and family members (75.0%) and the number of nurses who believed that clergymen, pharmacists and volunteers were involved in the team was quite low.

It was observed that 77.2% of the nurses expressed that the subjects which should be included in the training program on palliative care should be “communication and symptom management”, 75% thought that home care was the primary service in the services to be provided, and 75% stated that the reason for underdevelopment of the palliative care centres as “not finding adequate funds”. In addition, it was seen that while palliative care service was not given in the institution of 75% of the nurses, palliative care service was given in the institution of 25% of them. In the places providing palliative care service, the team included doctor (100%), nurses (100%), dietitians (50%), physiotherapists (50%), psychologists (33.3%), psychiatrists (33.3%) and auxiliary staff (16.7%). 51.1% of the nurses stated that the palliative care service given “was not provided effectively” and the psychosocial support given to the family “was partially sufficient” (Table 2).

Table 2. Opinions about palliative care services

Characteristics of the current Institution	n	%
Does your institution have in-service training about palliative care?		
Yes	18	19.6
No	74	80.4
What does palliative care mean? *		
Therapeutic care	39	42.4
Care for extending life expectancy	45	48.9
Preterminal care	20	21.7
Family support care	5	5.4
Care during grieving	44	47.8
None	40	43.5
No idea	8	8.7

What is the purpose of palliative care? *		
Enhancing the quality of life of the individual in the terminal period	66	71.7
Providing a peaceful death to the patient	58	63.0
Relieving pain and other symptoms of the patient	82	89.1
None	3	3.3
No idea	1	1.1
Who are the patient groups who can benefit from palliative care services, in your opinion? *		
Oncology patients	86	93.5
Terminal period patients	76	82.6
All patients having chronic diseases	59	64.1
None	1	1.1
No idea	1	1.1
For you, in which environments can palliative care be provided? *		
Hospital environment	77	84.6
At home	60	65.9
In day care centres	29	31.9
In nursing homes	53	58.2
In palliative care units	71	78.0
None	2	2.2
No idea	3	3.3
Who should be involved in the multidisciplinary team in providing palliative care services? *		
Doctor	89	96.7
Nurse	86	93.5
Psychologist	85	92.4
Religious official	44	47.8
Pharmacist	31	33.7
Social service specialist	37	40.2
Physiotherapist	68	73.9
Dietitian	47	51.1
Family members	69	75.0
Volunteers	40	43.5
None	2	2.2
No idea	2	2.2
In your opinion, which topics should be addressed in the training program about palliative care services?*		
Basic concepts and principles	46	50.0
Communication	71	77.2
Legal and ethical issues	50	54.3
Symptom management	71	77.2
Loss and mourning process	59	64.1
None	1	1.1
No idea	6	6.5
In your opinion, what should be the priority services in comprehensive palliative care services? *		
Home care	69	75.0
Consultation service	27	29.3
Daily-day care	43	46.7
Hospital care	53	57.6
Strengthening support	63	68.5
No idea	5	5.4
In your opinion, what are the reasons why palliative care centres have not developed in Turkey, yet? *		
Lack of awareness of healthcare professionals	46	50.0
Inadequate training of health personnel	45	48.9
Insufficient funds	69	75.0
Cultural reasons	35	38.0
None	4	4.3
No idea	6	6.5
Is Palliative Care Service Provided to Oncology Patients in Your Institution?		
Yes	23	25.0
No	69	75.0

Who is in your palliative care team? *		
Nurse	6	100.0
Doctor	6	100.0
Dietitian	3	50.0
Physiotherapist	3	50.0
Psychologist	2	33.3
Psychiatrist	2	33.3
Auxiliary staff	1	16.7
Do you think the service provided is effective?		
Yes	15	16.3
No	47	51.1
Partially	30	32.6
Do you think that the symptoms seen in patients are adequately evaluated by nurses?		
Yes	32	34.8
No	26	28.3
Partially	34	37.0
Do you think the psychosocial support given to the patient's family is sufficient?		
Yes	14	15.2
No	37	40.2
Partially	41	44.6
Do you cooperate with family members while providing services?		
Yes	67	72.8
No	25	27.2
What is the cooperation with family members?		
Psychological support	10	10.9
Quality care with support treatments	10	10.9
Body care	6	6.5
Physiotherapy	1	1.1
No idea	65	70.7

It was seen that the nurses responded to the question of “what are the most common symptoms of the patients?” as pain (80.4%), depression (45.7%), nausea (30.4%), vomiting (23.9%), fatigue (21.7%), anxiety (19.6%), being full quickly (13%), weight loss (13%), sleep problems (13%), dyspnoea (10.9%), mucositis (8.7%), constipation (8.7%), diarrhoea (8.7%), cough (2.2%), oedema (2.2%) and hair loss (2.2%) (Table 3).

Table 3. Distribution of the symptoms of patients according to the nurses

Symptoms	n	%
Pain*	37	80.4
Fatigue	10	21.7
Mucositis*	4	8.7
Constipation*	4	8.7
Being full quickly *	6	13.0
Dyspnoea*	5	10.9
Weight loss*	6	13.0
Sleep problem*	6	13.0
Depression*	21	45.7
Cough*	1	2.2
Nausea*	14	30.4
Oedema*	1	2.2
Anxiety*	9	19.6
Vomiting*	11	23.9
Diarrhoea*	4	8.7
Hair loss*	1	2.2

* Percentages were taken over multiplied n because people gave more than one answer.

It was seen that 54.3% of the nurses responded as “it is appropriate to start palliative care when curative treatment is not possible or in advanced stage of the disease”, 90.2% responded as “palliative care should be given by multidisciplinary team”, 77.2% responded as “patient and his/her family are members of decision-making team in palliative care”, 85.9% responded as “patient and the caregivers can reach to palliative care professionals 24/7”, 87% responded as “emotionally strengthening programs should cover healthcare professionals, patients and their relatives”, 78.3% responded as “legal arrangements should be made for cardiopulmonary resuscitation to be applied to patients”, 82.6% responded as “palliative care should be a separate expertise field”, 68.5% responded as “palliative care nursing should be a compulsory course in university education programs” and 41.3% responded as “I agree” to the expression that “palliative care centres should be hospital-based” (Table 4).



Table 4. Distribution of the nurses' opinions on palliative care

	I agree n (%)	I disagree n (%)	Undecided n (%)	X	SD	Kolmogoro v-Smirnov Z	p
It is appropriate to start palliative care when curative treatment is not possible or in advanced stage of disease.	50 (54.3)	23 (25.0)	19 (20.7)	1.6630	0.80216	0.339	.000
Palliative care should be provided by a multidisciplinary team.	83 (90.2)	-	9 (9.8)	1.1957	0.59741	0.531	.000
In palliative care, the patients and their families are members of a decision-making team.	71 (77.2)	2 (2.2)	19 (20.7)	1.4348	0.81611	0.475	.000
Patients and caregivers should reach to palliative care professionals 24/7.	79 (85.9)	-	13 (14.1)	1.2826	0.70049	0.515	.000
Emotionally strengthening programs should cover healthcare professionals, patients and their relatives.	80 (87.0)	2 (2.2)	10 (10.9)	1.2391	0.63539	0.516	.000
Palliative care only includes pain control.	3 (3.3)	80 (87.0)	9 (9.8)	2.0652	0.35717	0.475	.000
Palliative care centres should be hospital based.	38 (41.3)	33 (35.9)	21 (22.8)	1.8152	0.78347	0.264	.000
Legal arrangements should be made for cardiopulmonary resuscitation to be applied to patients.	72 (78.3)	1 (1.1)	19 (20.7)	1.4239	0.81515	0.481	.000
Palliative care should be a separate expertise field	76 (82.6)	4 (4.3)	12 (13.0)	1.3043	0.69122	0.496	.000
Palliative care nursing should be a compulsory course in university education programs	63 (68.5)	7 (7.6)	22 (23.9)	1.5543	0.85632	0.426	.000

In the responses to the purpose of palliative care, it was determined that those working in oncology and haematology services marked "relieving pain and other symptoms of the patient" option, those working in radiation oncology service chose "providing comfortable and peaceful death to patients", all of those working in ambulatory chemotherapy service selected "enhancing the quality of life of individuals in the terminal period" and "relieving pain and other symptoms of the patient" options (Table 5).

Table 5. Distribution of the responses given for the purpose of palliative care

Clinic the nurses were working in	Purpose of palliative care				
	Enhancing the quality of life of the individual in terminal period	Providing comfortable and peaceful death to patient	Relieving pain and other symptoms of the patient	None	No idea
Paediatric oncology	11 (68.8)	6 (37.5)	13 (81.3)	2 (12.5)	0 (0)
Stem Cell Transplantation	28 (66.7)	26 (61.9)	36 (85.7)	0 (0)	1 (2.4)
Oncology	5 (71.4)	5 (71.4)	7 (100)	0 (0)	0 (0)
Haematology	5 (71.4)	5 (71.4)	7 (100)	1 (14.3)	0 (0)
Radiation oncology	2 (50)	4 (100)	4 (100)	0 (0)	0 (0)
Gynaecologic oncology	7 (87.5)	5 (62.5)	7 (87.5)	0 (0)	0 (0)
Ambulatory chemotherapy	8 (100)	7 (87.5)	8 (100)	0 (0)	0 (0)
Total (n)	66	58	82	3	1

* Percentages were taken over multiplied n because people gave more than one answer.

In the responses given for the meaning of palliative care, it was determined that those with graduate (66.7%) and associate degree (63.6%) were in agreement in "preterminal care", those with undergraduate degree (51.2%) agreed with "care for extending life expectancy" and "preterminal care" options and those with high school degree (56.5%) agreed with "therapeutic care" option (Table 6).

Table 6. Distribution of responses to the meaning of palliative care

Educational level	The meaning of palliative care						
	Therapeutic care	Care for extending life expectancy	Preterminal care	Family support care	Care during grieving	None	No idea
Graduate	6 (40)	6 (40)	10 (66.7)	5 (33.3)	5 (33.3)	2 (13.3)	0 (0)
Undergraduate	16 (37.2)	22 (51.2)	22 (51.2)	19 (44.2)	10 (23.3)	4 (9.3)	2 (4.7)
Associate	4 (36.4)	6 (54.5)	7 (63.6)	5 (45.5)	3 (27.3)	2 (18.2)	0 (0)
High school	13 (56.5)	10 (43.5)	6 (26.1)	11 (47.8)	2 (8.7)	0 (0)	3 (13)
Total	39	44	45	40	20	8	5

* Percentages were taken over multiplied n because people gave more than one answer.

4. DISCUSSION

Cancer patients experience different physical, psychological, social and economic problems starting from the diagnosis stage and throughout the treatment process. Therefore, palliative care service is needed to eliminate the problems experienced by the patients and their families and to enhance the quality of their lives [11]. The nurses in the team that will provide this service play a major role in the provision of the service. In this respect, the views of the nurses working in oncology clinics about palliative care were examined in this study. In the present study, it was determined that the mean age of the nurses was quite low, the majority of them were female (90.2%), had undergraduate degree (46.7%) and had a working duration of 1-5 years in the profession. In the study by Gülay Turgay, it was determined that the majority of the healthcare professional were female and the mean age was young population [12].

Palliative care is not included among the priority subjects of the training and work program of healthcare professionals traditionally and accordingly, there are barriers to the implementation of palliative care [11,13,14]. Palliative care has a limited place in both in-service and general training programs and nurses do not receive adequate training in palliative care. This forces the nurses to provide services and care without sufficient scientific competency. It was found in the present study that 54.3% of the nurses did not receive training about palliative care and those who received the training found their training “partially sufficient”. In the study by Ahmet Seven, the knowledge level of the nurses about palliative care was determined to be insufficient [15]. It is also emphasised in the literature that healthcare professionals have lack of knowledge especially in terms of symptom management and palliative care [16].

Palliative care is known to be a service served to reduce and eliminate the symptoms of the disease and its treatment and focusing on relieving the patient’s agony and enhancing the quality of life [11]. Furthermore, palliative care is defined with end-of-life care concepts such as “appropriate death”, “good death”, “peaceful death”, and “tolerable death”, introduced as “death care” and then changed to “terminal care” [17]. In the present study, it was determined that 48.9% of the nurses responded to the question of “what is palliative care?” as care for extending life expectancy, 47.8% responded as the care given during grieving, and 42.4% responded as therapeutic care. In another study, definitions of healthcare professionals on palliative care were similar to ours and most of them were seen to define it as “enhancing the quality of life” of an individual in terminal period and “preterminal care” [12].

Palliative care aims to enhance quality of life, integrate the physical, spiritual, social and psychological dimensions of care and ensure the patient to experience a comfortable death in the last days of the life [18,19]. In the present study, it was determined that majority of nurses responded as relieving the pain and other symptoms of the patient, enhancing the quality of life of the individual in terminal period, and providing a peaceful and comfortable death to the patient. In a study, a focus group was established to examine the concept of palliative care, the participants suggested to expand the end-of-life care to include the entire stage of the disease of the individuals living with a disease limiting his/her life, the experts forming the focus group stated that the main objectives of palliative care should include “establishing relationship, goal, ensuring symptom relief, advocacy, communication, acceptance, being flexible and seeing the individual as unique” [20].

World Palliative Care Board and the World Health Organisation state that patients suffering from cancer, AIDS, motor neuron diseases and progressive neurological diseases, advanced organ failure, diabetes, multiple sclerosis, Parkinson’s disease, rheumatoid arthritis and cardiovascular diseases have the right to receive palliative care [21,22,23]. In the present study, most of the nurses stated that “cancer patients, terminal period patients and patients with chronic diseases” should benefit from palliative care.

All team members in palliative care that requires multidisciplinary teamwork must be trained about palliative care principles, supportive communication types and symptom control to provide communication and coordination. Members of this team include medical oncologist, specialist clinical nurse, algologist, dietitian, physical therapist, social service expert, pharmacist, religious official, psychologist, volunteers and non-governmental organisations [23,24,25]. In a study, it was reported that palliative care team members mostly consisted of nurses, doctors, psychologists, physiotherapists, dieticians, social workers, volunteers, religious officials and pharmacists, only 26 participants emphasised that family members were included in this group [12]. In the present study, it was stated that doctors, nurses, psychologists, physiotherapists, dieticians and family members should be included in the multidisciplinary palliative care

team, some of the participants stated that religious officials, pharmacists, social service experts and volunteers should also be included in this team along with them.

Palliative care training has started to attract attention in Turkey in the 1990s and continues to attract attention, today. In this field, the number of medical oncologists, algology doctors, academic and clinical nurses who want to work by receiving palliative care training in this field is quite high. The palliative care nurse who has a primary caregiver relationship directly with the patient should provide clear information to the patient and his/her family using effective communication techniques, listen carefully to the patient, help him/her to cope with his/her anxieties, have the ability to notice the changes in the patient's general condition and constantly renew his/her knowledge [2,26]. In a study, it was stated that the palliative care training to be given should include the subjects of "basic concepts, principles and communication" [12]. In the present study, it was stated that nurse should include basic concepts, principles and communication and mention symptom management, legal and ethical issues and what needs to be done in the loss and grief process.

When we look through the history of Turkey, it is seen that hospitals, physicians and auxiliary personnel provided general health service to the people for free in Seljuk and Ottoman era. Today, there are no modern palliative care centres in Turkey [15, 28]. In addition, in the teams providing hospital-based palliative care service, there are limited number of professionals receiving training and education at expert level in palliative care. Besides, there are no graduate education programs in palliative care nursing in nursing departments and quite limited information is given in nursing trainings [26,28]. In the present study, the reasons for not developing palliative care in Turkey were stated to be insufficient resources, lack of awareness of healthcare professionals and inadequate training.

In cancer patients who need palliative care, multiple symptoms can be seen at the same time. Some of these symptoms impair the quality of life of the patient and cause anxiety in family members. Pain is one of the most common symptoms. In a study, it was determined that 90% of the patients admitted to the palliative care clinic experienced pain and both incidence and severity of pain symptoms decreased on the third and seventh day [6]. In another study conducted with terminal period cancer patients, it was found that 45% of the patients had pain [29]. In a study conducted by Breivik et al., on 5084 cancer patients, it was determined that 56% of the patients experienced moderate to severe pain in the last month and daily living activities of 69% of them were affected [30]. In the present study, it was observed that the nurses thought to face mostly with pain symptom.

5. CONCLUSION AND RECOMMENDATIONS

It was observed that most of the nurses who participated in the present study did not receive training about palliative care, those who received the training found their training as "partially sufficient", there was no in-service training about palliative care in the institution of most nurses and they did not know exactly what palliative care meant. It was seen that the majority of nurses responded to the purpose of palliative care as "relieving the pain and other symptoms of patients" and the symptoms other than pain were less taken into account. It was also determined that the purpose of palliative care was perceived differently according to the current clinics. It was seen that although doctors, nurses and psychologists were included in the team providing palliative care, there was no clear information about the other people who should also be included in this team. In the light of these data obtained from the present study, it can be recommended to establish in-service training programs related to palliative care and to ensure the continuity of these training, to direct the nurses working in oncology units to palliative care nursing certification programs and to receive training and for the institution and hospital managers to support nurses in this regard.

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