

Original Article

Opinions of Nurses about Palliative Care

Gulcan Bahcecioglu Turan, PhD

Research Assistant, Ataturk University, Faculty of Health Sciences, Department of Internal Medicine Nursing, Erzurum, Turkey

Talip Mankan, PhD

Lect. Asst. Firat University, Faculty of Health Sciences, Department of Nursing, Elazig, Turkey

Hilal Polat, PhD

Lect. Asst. Firat University, Faculty of Health Sciences, Department of Nursing, Elazig, Turkey

Correspondence: Gulcan Bahcecioglu Turan, Res. Asst. Ataturk University, Faculty of Health Sciences, Department of Internal Medicine Nursing, Erzurum, Turkey E-mail: gclcnbah@hotmail.com

Abstract

Objectives: Nurses play an important role in palliative care services. Therefore, further studies are needed in Turkey to investigate nurses' views on the subject. Based on this, it's aimed to determine nurses' level of knowledge about palliative care, increase their sensitivity and awareness, and to perform training activity planning in this regard.

Methods: The study population consisted of nurses working at Firat University Medical Hospital and Elazig Training and Research Hospital located in the Province of Elazig No sampling was performed, and the 500 nurses who agreed to participate in the research was included in the study. The data collection was performed between February and March 2016 in the study. A "Personal Information Form" developed by the researchers and "Expressions of Opinion about Palliative Care Scale" was used for data collection. Evaluation of the data; number and percentage analysis are used.

Results: It was found that, the majority of the nurses surveyed (50.6%) was 30 years of age or older, the majority was female (73.4%) and has a bachelor degree (49.2%), and most of them (35.4%) was working at the profession for 10 years and over. Of the nurses, 80.8% said that definition of the palliative care is "to improve the quality of life of the individual in the terminal period". And, 69.8% of the nurses stated that palliative care aims to "improve the quality of life of the individual"; 88.6% stated that mostly the patients in the terminal stage benefit from the palliative care services, 80.6% stated that palliative care services can be provided in the hospital, and more than half of them stated that should be a nurse, doctor, physiotherapist and psychologist in a palliative care team.

Conclusions: It was found that the majority of the nurses were not knowledgeable about the palliative care, define palliative care as "improving the quality of life of the individual in the terminal period", and expressed that palliative care covers the services offered to cancer patients in the terminal phase.

Keywords: Nurse, Education, Palliative care

Introduction

Palliative care is defined as "an approach for early diagnosis, evaluation and treatment of physical, psychosocial and spiritual problems of patients and families, who face problems accompanied with the life-threatening diseases, for relieving or preventing their pain, with the aim of improving their quality of life". (WHO 2012; Colak and Ozyilkan 2006; Sahan and Terzioglu 2015; Gultekin et al 2010). Elimination of patients' pain and other symptoms,

psychological and social support, nutritional support, and the provision of training needs of the patient is the fundamental objective of palliative care. The underlying goal at this stage is to enhance the quality of life of patients and families. (Beresford and Kerr 2012; Meier 2011; Radbruck et al 2009; Tasar et al 2014). Today, the increase in number of patients with incurable, fatal diseases led palliative care to find a place among other fields of medicine, despite being a new concept. (Aydogan and Uygun 2011; WHO

2014). In Turkey, home health services have been implemented under the health transformation program in 2010 by the Ministry of Health, and legal regulations were enacted for establishing palliative care units in hospitals. (Kabalak et al 2012). Multidisciplinary approach is the fundamental feature of palliative care. Team members consist of doctors, nurses, allied health staff, volunteers, social workers, mourning counselors, chaplains, and others. (Pastrana et al 2008) Nurses play an important role in palliative care services. Therefore, further studies are needed in Turkey to investigate nurses' views on the subject. Based on this, it's aimed to determine nurses' level of knowledge about palliative care, increase their sensitivity and awareness, and to perform training activity planning in this regard.

Material and Methods

The present study is a descriptive type research. The study was conducted between November 2015 and June 2016 in the Firat University Faculty of Medicine Hospital and Elazig Training and Research Hospital. The study population consisted of 1084 nurses. No sampling was performed in the study, and the study was completed with 500 nurses who agreed to participate in the research. The Opinions about Palliative Care Form, and Personal Information Form, developed by the researchers, were used for data collection. The personal information form consists of 17 items; the first 5 items are about the nurses' socio-demographic characteristics (age, gender, level of clinical education, etc.), and other items about the knowledge and views of nurses about palliative care. The "Opinions about Palliative Care Scale" was developed by Turgay (2010). The 5-point Likert-type questionnaire is scored in the range of "Strongly disagree" (1 point) and "Strongly agree" (5 points). The form consists of a total of 16 items.

Study data were collected between December 2015 and February 2016. After informing nurses about the research, they were asked to fill the questionnaire distributed to them. The time of answering the questionnaire is approximately 15-20 minutes. Numbers and percentiles were used for the statistical analysis of the data. Approval of the Firat University Non-Interventional Research Department Ethics Board, and the required permissions from the Firat University,

Faculty of Medicine and Elazig Training and Research Hospital were obtained before conducting the study. Volunteer and enthusiastic nurses were included in the research, and they have been informed that they are free to join.

Results

Introductory characteristics of the nurses included in the study were given in Table 1. It was determined that, 73.4% of the surveyed nurses was female, 50.6% was 30 years of age and above, and 49.2% was college graduate. Of the nurses, 35.4% was working in the profession for more than 10 years, 30% was working in internal clinics, and 42.2% was working in the same clinic for 0-2 years (Table 1).

It was determined that, 30.4% of the nurses surveyed has received training about palliative care, and 48% received this training in undergraduate education. It was found that 70.3% of

the nurses who had a training about palliative care has studied ethical issues, and 60.5% deemed the education adequate. Of the nurses, 96.2% indicated that there was in-service training about palliative care in their institution. Of the nurses, 93.2% stated that palliative care training should include "basic concepts and principles in palliative care", and 74% stated that lack of training is the reason behind the inadequate palliative care services (Table 2).

A 84.6% of the nurses surveyed, stated that the terminal-stage patients may benefit from the palliative care, and 80.6% stated that palliative care can be provided in a hospital setting. The majority of nurses stated that there should be nurses, doctors and psychologists in the palliative care team, whereas some of them stated that volunteers, chaplains, dieticians and pharmacist should be included in the team as well. Of the nurses surveyed, 80.8% stated that the meaning of palliative care is "to improve the quality of life of individuals in the terminal stage". According to 69.8% of the nurses, the purpose of palliative care is "to improve the quality of life of the individual" (Table 3)

Table 1. Introductory Characteristics of the Nurses

Introductory Characteristics	N	%
Gender		
Female	367	73.4
Early	133	26.6
Age		
18-23	99	19.8
24-29	148	29.6
30 years and above	253	50.6
Year of Graduation		
Vocational School of Health Associate	78	15.6
Bachelor's degree	134	26.8
Master's Degree	246	49.2
	42	8.4
Seniority in the profession		
0-2	75	15.0
2-5	148	29.6
5-10	100	20.0
10 years and above	177	35.4
Working clinics		
Internal clinics	150	30
Surgical clinics	141	28.2
Oncology, (Hematology, radiation oncology, palliative care unit.)	79	15.8
Intensive care (emergency)	130	26
Working Years in the Present Clinic		
0-2	211	42.2
2-5	173	34.6
5 years and above	116	23.2

Table 2. Opinions of Nurses about Palliative Care Training

Statements	N	%
Ability to Acquire Information about Palliative Care (N=500)		
Yes	152	30.4
No	348	69.6
Sources of Information about Palliative Care (N=152)		
In University Education	73	48
Books and Magazines	22	14.4
Congress and Seminars	8	5.2
Internet	50	32.8
In-Service Training	28	18.4
During Clinical Practice, from the Specialist	11	7.2
Training Content on Palliative Care (N=152)		
Ethical Aspects	107	70.3
Symptom Management	63	41.4
Communicating the Bad News - Communication Skills	45	29.6
Other (Palliative care and general principles)	15	9.8
Consideration about the Adequacy of the Training Provided (N=152)		
Yes	25	16.4
Partially	92	60.5
No	35	23.0
Training Program on Palliative Care in the Institution (N=500)		
Yes	19	3.8
No	481	96.2
Training Content on Palliative Care		
Palliative Care (basic concepts and principles)	466	93.2
Communication	311	62.2

Legal and Ethical Aspects	219	43.8
Symptom Management	241	48.2
Loss and Grief Period	211	42.2
Reasons for Inadequate Palliative Care Services		
Ignorance	324	64.8
Inadequate Education	370	74.0
Economic Inability	197	39.4
Lack of State Budget	184	36.8
Unqualified Staff,	286	57.2
Cultural Reasons	161	32.2

It is multiple responses and Percentages are calculated from the number of (N)

Table 3. Opinions of Nurses about the concept, meaning and purpose of Palliative Care

Statements	N	%
Opinions about Patient Groups that can Benefit from Palliative Care Services		
Oncological Patients		
Patients in the Terminal Stage	373	74.6
Patients with Chronic Disease	423	84.6
Geriatric Patients	231	46.2
Alzheimer's Disease	256	51.2
	173	34.6
What are the Appropriate Settings for Providing Palliative Care Services?		
Hospital	403	80.6
Home	237	47.4
Nursing Homes/Dispensary	247	49.4
Palliative Care Unit	402	80.4
Hospice	61	12.2
Health Care Center	31	6.2
Opinions on the Palliative Care Team Members		
Nurse	480	96.0
Doctor	459	91.8
Psychologist	392	78.4
Physiotherapist	259	51.8
Dietitian	173	34.6
Social Service Expert	255	51.0
Volunteers	185	37.0
Clerics	193	38.6
Pharmacist	91	18.2
Opinions on the Meaning of Palliative Care		
"Improve the quality of life of patients in the terminal stage"	404	80.8
"End-stage care"	301	60.2
"Treatment and care for symptoms"	190	38.0
"Medical care"	107	21.4
"Pain management"	206	41.2
"Supportive Therapy"	180	36.0
"Physical and psychological support"	250	50.0
"Comfortable/peaceful death"	189	37.9
"Preventive care"	128	25.6
Opinions on the Purpose of Palliative Care		
"Improving the quality of life of the individual"	349	69.8
"Relieving the individual"	293	58.6
"Meeting the needs of dependent patients"	218	43.6

It is multiple responses and Percentages are calculated from the number of (N)

Table 4. Opinions of Nurses about Palliative Care (n=500)*

Statements	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. Palliative care covers the services offered to cancer patients in the terminal stage.	26.0	51.0	9.4	9.2	4.4
2. Palliative care is suitable when curative treatment is not possible or the patient is in the end-stage.	16.8	50.2	20.6	10.6	1.8
3. Palliative care should be provided by a multidisciplinary team.	38.4	42.6	15.6	2.0	1.4
4. In palliative care, patient and family is a member of the decision-making team.	32.2	51.4	11.2	4.8	0.4
5. A doctor shall preside at the palliative care team	26.6	38.4	18.6	11.0	5.4
6. Patients and caregivers should be able to reach palliative care professionals, 24 hours a day, 7 days a week.	38.8	47.6	8.4	3.0	2.2
7. Burnout is inevitable for the individuals working in the field of palliative care.	34.0	47.0	11.8	6.0	1.2
8. Palliative care requires working individuals to control their emotions.	34.8	50.2	9.6	3.8	16.0
9. Emotionally empowering programs should only cover the patients and their relatives.	8.2	27.8	17.6	34.0	12.4
10. Palliative care treats the symptom without investigating the cause of symptoms.	8.2	29.6	25.0	25.6	11.6
11. Palliative care deals with pain management only.	5.0	16.6	18.4	42.0	18.0
12. Palliative care centers should be hospital-based.	24.2	39.8	16.4	15.0	4.6
13. Patients should have a right to not to undergo a cardiopulmonary resuscitation (DNR), and legal regulations should be enacted in this regard.	23.6	42.0	23.4	7.0	4.0
14. Palliative care should be a separate field of expertise.	35.4	50.2	9.8	3.8	0.8
15. Palliative care should be included as a compulsory course in college education for health professionals.	29.4	42.6	22.2	4.4	1.4
16. When there is a need in palliative care, this should be the responsibility of the state to guarantee the provision of this care for everyone.	39.2	46.6	9.8	3.2	1.2

Given as percentages (%).

The majority of nurses surveyed stated that they agree/completely agree with the "Patients and caregivers should be able to reach palliative care professionals, 24 hours a day, 7 days a week", "Healthcare workers need to control their emotions for palliative care", "Palliative care should be a separate field of expertise", and the "When there is a need in palliative care, this should be the responsibility of the state to guarantee the

provision of this care for everyone" statements; whereas they stated that they disagree with the "Emotionally empowering programs should only cover the patients and their relatives" statement (Table 4).

Discussion

The findings of the study, which has been conducted to reveal the opinions of the clinic nurses on the palliative care, have been

discussed on the light of literature.

It was determined that the majority of the surveyed nurses was female (73.4%), 30 years of age and over, college graduate (49.2%), was working in the profession for 10 years and over. This indicates that our study group consists of middle age women mostly (Table 1).

Considering the training and knowledge of nurses on the palliative care, more than half of the nurses (69.6%) were found to have no training on the palliative care, and 92.2% had no in-service training for palliative care in their institution. It was determined that the knowledgeable nurses had acquired this knowledge during their college education, and more than half (60.5%) of the nurses were found to deem this education somewhat adequate, and, it was also found that the training program provided was addressing ethical issues mostly (70.3%) (Table 2). In the literature, it has been stated that palliative care was not a priority subject in nursing curriculum and work program. (Bush and Shahwan-Akl (2012); Barclay et al 2003) The provision of limited, if any, training on the palliative in curriculum is the major obstacle in the implementation of palliative care. (Bingley and Clark 2008) This negatively affects the quality of life of the patient and family in the course of terminal illness as well as affecting the family after the death of their patient. (Sen et al 2016; Elcigil 2012; Kahveci and Gokcinar 2014)

It was reported in Turgay's (2010) study that the majority of health care workers had no training on the palliative care, and it was also reported that the knowledgeable ones had acquired this during their college education; this is because, the majority of the health personnel who participated in the research had been graduated from the same university, and the subject of palliative care had been provided as an elective course. In the United States, Ferrell et al. (2010) had analyzed the data on palliative care education in nursing between 2000 and 2010, and determined that patients with cancer and their families had severe physical, mental and psychosocial

symptoms in the course of the disease, and concluded that oncology nurses should be trained on the palliative care in order to be able to provide the necessary care to the patients and families. It has been reported in a study by Uslu (2013) conducted with midwives and nurses that midwives and nurses do not have adequate knowledge about palliative care. Our study findings was similar to the literature, and it has been determined that midwives and nurses do not have adequate knowledge about palliative care. It's believed that this is caused by the lack of palliative care training in nurses' formal and in-service training. On the other hand, this may be due to unwillingness of health care professionals (nurses and other health care professionals) to participate in the training program related to palliative care after graduation. (Ozcelik et al 2010) Our study supports the project of provision of palliative care services in 81 provinces of Turkey through the Palliative Care Nursing certification program conducted by the Ministry of Health (2015a)

Considering the knowledge of nurses about the meaning and purpose of palliative care; it was determined that nurses define the meaning of the palliative care as "Improving the quality of life of individuals in the terminal stage" (80.8%), "Terminal stage care" (60.2%), and "Treatment and care for symptoms" (38%) mostly. It was also determined that the purpose of palliative care according to the nurses is "Improving the quality of life of the individual" (69.8%), "Relieving the individual" (58.6%), and "Meeting the needs of dependent patients" (43.6%) mostly (Table 3). In the literature, the palliative care is defined with terminal stage concepts such as "appropriate death", "good death", "peaceful death", "tolerable death", and emerged as the "care dying individual" care", later it has been transformed to "terminal care", "supportive care", and "terminal stage care" concepts, and deemed equivalent to pain management. (Bingley and Clark 2008)

A study by Mahone and McAuley (2010),

conducted for revealing the personal opinions of oncology nurses on the palliative care, reported that perceptions of nurses had only been focused on the symptom management. Again in this study, it was determined that the majority of the nurses surveyed was unable to distinguish between palliative care and hospice care, believing that terminal-stage patients should receive palliative care. And in a focus group study conducted by Pahlsh and Ceronsky (2007) in order to reveal perceptions of oncology nurses on the palliative care, it was reported that nurses use 14 definitions about the nature of the palliative care, with similar phrases such as "it's family-centric", "it's a process", "it's symptom management", "it's an attempt to relieve", "it's trying to improve the quality of life", "it focuses on the preferences of the patient and family". Although the definitions of the nurses included in this study on the palliative care have similarities with the above-mentioned studies, the definitions such as "improving the quality of life of individuals in the terminal stage", and "terminal stage care" come to the fore particularly.

The majority of the nurses participated in the study stated that oncological patients and patients in the terminal stage can benefit from palliative care services, and palliative care services can be provided in the hospital setting (80.6%); and the majority stated that lack of training is the reason behind the inadequate palliative care services. The fact that nurses think mostly the patients in the terminal stage can benefit from palliative care services, and their inability to distinguish between palliative care and hospice care suggests that there is a lack of awareness and training in this regard. According to the nurses participated in the study, a palliative care team should include nurses, doctors, psychologists, physiotherapists, social workers, chaplains, dieticians, volunteers, and pharmacists. In addition, the majority agreed to the "In palliative care, patient and family is a member of the decision-making team" statement. It's believed that this is due to

lacking "family members" option in the questionnaire for team members. Similarly, the fact that the majority of nurses didn't count chaplains, pharmacists, dieticians, and social workers as team members suggests that the palliative care practices are not adopted by nurses well, and they were uncertain about the team members.

The majority of nurses stated that "basic concepts, principles and communication" subjects should be addressed in a course on palliative care (Table 2). This focus on the main theme/basic concepts, instead of sub-themes, suggests that the individuals lack knowledge about the concept and scope of palliative care.

When examining the views of nurses towards the expressions about palliative care, it was observed that the majority of nurses responded the "Palliative care covers the services offered to cancer patients in the terminal stage" statement with the "agree" and "strongly agree" options. It was determined that the majority of the nurses participated in the study responded to the "Palliative care should be provided by a multidisciplinary team" statement with the "Agree/Strongly agree" response. Almost half of the nurses (50.2%) stated that they agree with the "Palliative care requires working individuals to control their emotions" statement, whereas 34% of the nurses has disagreed with the "Emotionally empowering programs should only cover the patients and their relatives" statement. This finding suggests that nurses consider palliative care services as an emotionally distressing care provided to patients in the terminal stage. One quarter of the nurses responded the "Palliative care treats the symptom without investigating the cause of symptoms" statement with the "neither agree nor disagree" response, whereas almost half of them (42%) has disagreed with the "Palliative care deals with pain management only" statement. The majority of nurses (50.2%) agreed to the "Palliative care should be a separate field of expertise" statement; whereas, about half (42.6%) of the

participants agreed to the "Palliative care should be included as a compulsory course in college education for health professionals" statement (Table 4).

Recommendations

In our study, it was determined that the majority of nurses hadn't received training about palliative care, and those who received that training were found to have received this training at the college. In addition, the majority of knowledgeable nurses about palliative care was found to have inadequate knowledge, and had no comprehensive in-service training on the palliative care. It was determined that the majority of nurses was college graduate; however only the minority had received a course on the palliative care in their college education. It was determined that nurses do not have adequate knowledge about palliative care, and unable to distinguish between palliative care and hospice. Based on these results;

- In-service training programs can be improved in order to raise awareness and teach basic principles to the nurses and other health care workers working in the palliative care services.

- The subject of palliative care can be integrated into the undergraduate curriculum in nursing departments. It can be suggested to develop a certified training program after graduation.

References

Abu-Saad Huijer H, Dimassi H, Abboud S.(2009) Perspectives On Palliative Care In Lebanon: Knowledge, Attitudes, And Practices Of Medical and Nursing Specialties. *Palliative Supportive Care* 7(3), 339-47.

Aydogan F, Uygun K. (2011) Palliative Treatment in Patients with Cancer. *Clinical Development* 24(3), 4-9.

Barclay S, Wyatt P, Shore S, Finlay I, Grande G, Todd, C. (2003)Caring For The Dying: How Well Prepared Are General Practitioners? A Questionnaire Study In Wales. *Palliative Medicine* 17(1),27-39.

Bartlett N, Koczwara B. (2002) Control Of Nausea And Vomiting After Chemotherapy :What Is The Evidence? *Internal Medicine Journal* 32(8), 401-408.

Beresford L, Kerr K. (2012) Next Generation Of Palliative Care: Community Models Offer Services Outside The Hospital.2012 http://www.chcf.org/publications/2012/11/n_ext-generation-palliative-care (Access:2 June 2016).

Bingley A, Clark, D. (2008).Palliative Care in the Region Represented By The Middle East Cancer Consortium. <http://mecc.cancer.gov/PCMONOGRAPH.pdf> (Access: 2016 January 3).

Bush T, Shahwan-Akl L. (2012) Palliative Care Education: Does It Influence Future Practice?. *Contemporary Nurse* 2(4), 2-5

Colak D, Ozyilkan O. Palliative Care in Patients With Cancer. *Journal of Internal Medical Sciences* 2(10), 1-9.10.

Elcigil A.(2012) Palliative care nursing (Compilation). *Gulhane Medical Journal* 54, 329-334

Ferrel, B, Virani R, Mallay P, Kelly K. (2010) The Preparation Of Oncology Nurses in Palliative Care. *Seminars In Oncology Nurse* 26(4),259-265.

Gultekin M, Ozgul N, Olcayto E, Tuncer M. (2010) Current Status of Palliative Care Services in Turkey. *Turkish Journal of Gynecologic Oncology* Page 1-6.

Kabalak A, Ozturk H, Erdem AT, Akin S. (2012) A Comprehensive Palliative Care Center Implementation In SB Ulus State Hospital. *Journal of Contemporary Medicine* 2,122-6.

Kahveci K, Gokcinar D.(Eds) (2010). *Palliative Care*. Nobel bookstores, Istanbul

Mahon M.M, Mcauley W.J. (2010) Oncology Nurses' Personal Understandings About Palliative Care. *Oncology Nursing Forum* 37(3),141-50.

Meier D E. (2011) Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value In Healthcare. *Milbank Quarterly* 89(3), 343-380.

Ministry of Health (2015a) Palliative Care Nursing Standards Certified Training ProgramAnnouncementhttp://www.saglik.gov.tr/T_R/belge/1-44143/palyatif-bakim-hemsireligi-sertifikaliegitim-programi-.html (Access:5 January 2016)

Ozcelik H, Fadiloglu C, Karabulut B et al. (2010) Palliative Care Activity in The Field of Oncology In Turkey, *Journal Of Palliative Care* 26(4),305-310.

Pastrana T, Junger S, Ostgathe O, Elsner F, Radbruch L. (2008)A Matter of Definition Key Elements Identified in a Discourse Analysis of Definitions of Palliative Care. *Palliative medicine* 22(3),222-232

Pavlish C, Ceronsky L.(2007) Oncology Nurses' Perceptions About Palliative Care. *Oncol Nurs Forum* 34(4),793-800.

Radbruch L, Payne S, Bercovitch M, et al. (2009) *White Paper On Standards and Norms for Hospice*

- And Palliative Care In Europe Part I. Recommendations From The European Association For Palliative Care. *European Journal Of Palliative Care* 16(6),278-289.
- Sahan Uslu F, Terzioglu F. (2015) Palliative Care Education and Organization in the World and Turkey. *Cumhuriyet Nursing Journal* 4(2),81-90.
- Sen S, Aygin D, Sert H.(2016) Palliative Oncological Treatments and Care. *Online Turkish Journal of Medical Sciences* 1(1),21-35
- Tasar Tosun P, Sahin S, Akcicek F. (2014) Palliative Care in Geriatrics. *Akad Geriatric* 6, 73-78.
- Turgay G. (2010) Opinions of Health Personnel about Palliative Care. Department of Nursing, Master.Thesis, Baskent University, Institute of Health Sciences, Ankara
- Uslu F.(2013) Determination of the Palliative Care Practices of the Midwives and Nurses in the Gynecological Oncology Units in the Centrum of Ankara, Obstetrics and Gynecology Nursing Program, Master's Thesis. Hacettepe University, Institute of Health Sciences, Ankara
- WHO (World Health Organization) 2012 Definition of Palliative Care [http:// www. Who.int /cancer/palliative/definition/ en/](http://www.who.int/cancer/palliative/definition/en/) (Access:2016 June 3)
- Worldwide Palliative Care Alliance. Global Atlas Of Palliative Care at the End of Life. 2014.http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf (Access: 4 June 2016)