

# What Do Turkish Nursing Students Think About Palliative Care?

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## ABSTRACT

**Objective:** The purpose of this study was to identify Turkish nursing students' knowledge, thoughts and attitudes about palliative care.

**Methods:** This is a descriptive survey study that was conducted in Ankara, Turkey on nursing students between 2015 and 2016. In order to obtain the broadest viewpoint, we decided to survey 163 nursing students, including 77 juniors and 86 seniors. The data was collected using an 'Opinion Form on Palliative Care' as well as an Introductory information form.

**Results:** 136 out of a total of 163 junior and senior students were included in this study. Most of the students practiced general medicine, surgery and ICU, and described palliative care as a multidisciplinary health service for terminally ill patients with cancer. Although 89.7% of students had received some degree of palliative care training as part of their education, most of them (66.2%) had felt that it was insufficient. Palliative care topics that students wished were included as part of the curriculum included the basic concepts of palliative care (94.9%), communication (91.9%), legal and ethical issues (89.7%), loss and bereavement (89%), and symptom management (86%). Most students (77.9-76.5%) stated that palliative care training ought to be a mandatory training program.

**Conclusion:** Nursing students who have heard about the concept of palliative care during their education thought that the content of the palliative care education was lacking within their nursing program. Also, most had felt that this specialized content ought to be expanded upon as part of specialization training.

**Keywords:** Palliative care, nursing education, undergraduate, student experience.

## 1. INTRODUCTION

The World Health Organization (WHO) defines palliative care as "an approach that aims to improve the quality of life of patients and their families facing the problem associated with life-threatening illness, by means of early identification and impeccable assessment of pain and other problems; prevention and relief of suffering by meeting physical, psychosocial and spiritual needs" (1). One important premise of palliative care is that it involves an interdisciplinary team approach because there is no specific discipline that is able to meet the holistic needs of patients and their families. Therefore, a palliative care team may consist of a combination of physicians, nurses, pharmacists, social workers, physiotherapists, and spiritual advisors. Each team member plays a unique role that contributes towards achieving successful patient and family outcomes (2).

The nursing role on the palliative care team includes the assessment of the individual's culture, values, beliefs, preferences, direct care, and often care coordination (3).

Specialized training is required in order to properly carry out this role. Thus, the degree of education depends on whether the nurse aims to provide care in primary care or at a specialist level (4). Primary palliative care is a level of care that would be expected of any general nurse who encounters a terminally ill patient, and would include the basic principles of pain and symptom management, communication skills, and awareness of resources such as hospice care. On the other hand, specialty-level care requires advanced education that would allow for the assessment of much more complex symptoms, alongside communication and supportive decisions.

Despite standards both for undergraduate primary palliative nursing education and continuing education programs such as End of Life Nursing Education Nursing Consortium (ELNEC), many nurses throughout Turkey still do not possess a solid foundation or awareness of the broad spectrum meaning of palliative care concept, often confusing it with hospice and

end of life care (5,6). Even though palliative care content has been introduced as part of the basic nursing program, nurses often report that the amount of education that they received as being inadequate (7,8). Hence, it will take time for nursing curricula to accurately reflect current developments in the field, meaning that practicing clinicians will be deprived of gaining the necessary knowledge, skills, and awareness until they reach the point to provide symptom management and palliative care (3,7). Therefore, it is important to integrate palliative care into basic nursing education (9).

Although there is no specific, standard core curriculum for palliative care, progress in terms of incorporating palliative care content is being made in other parts of Europe. For example, palliative care is included as a chapter in the European Oncology Nursing Association (EONS) Cancer Nursing Education Framework (10). Being a special area of expertise, palliative care needs to be a part of basic nursing education, and all nurses need to be completely aware of the fundamentals of palliative care (6).

There are few studies investigating the knowledge and attitudes of nursing students about palliative care (11,12). There is very limited research about palliative care in general, with regards to nursing in Turkey (13,14). Moreover, there are no known studies on palliative care conducted on nursing students in Turkey. Therefore, we decided to conduct a study assessing the knowledge and attitudes of Turkish nursing students regarding palliative care. It is important to depict the status of palliative care education in basic nursing education in order to properly integrate palliative care education into the nursing curriculum and design a continuing education program that reinforcing knowledge and skills of the nurses after graduation. As part of an initial needs assessment for future palliative care training in Turkey, the aim of this study is to determine current knowledge and views of nursing students about palliative care.

## 2. METHODS

### 2.1. Sample and Setting

This study is a descriptive study carried out with junior and senior nursing students studying at a nursing school in Ankara between 2015 and 2016. The nursing school where the study was conducted currently provides a four-year nursing undergraduate education. In the first three years, both clinical practice and theoretical courses are carried out simultaneously; in the final year, students do clinical practice in hospital settings four days a week. Junior and senior students were chosen for the study; given that both have taken courses that consist of subjects about palliative care as well as have had clinical practice in related settings. Currently, there is no specific palliative care course in the nursing curriculum. We decided to conduct the study of 163 nursing students (77 junior and 86 senior), in order to obtain the widest perspective. 136 out of a total of 163 (72 junior and 64 senior) students were included in the study.

### 2.2. Data Collection Tool

The data on demographic features of the students were collected by the introductory information form and data on knowledge and views of the students were collected by the 'Opinion Form on Palliative Care'. The 'Opinion Form on Palliative Care' was developed by Turgay and Kav in order to determine the views of nurses on the philosophy of palliative care and the provision of care services (15). This form consists of sixteen questions and is based on the opinions provided by a group of specialists consisting of health professionals (nurses, physicians, social workers) working in palliative care settings (15). The introductory information form consists of eight questions that define the socio-demographic characteristics of students, such as age, study year (class) and gender.

#### 2.2.1 Data collection

Considering that the nursing school where this study was conducted was also a boarding school, all students were expected to attend study hours during weekday evenings. In one of these study periods, all students were informed about the study, and those who agreed to participate were asked to fill out the questionnaires. Students filled out the data collection forms by themselves using paper and pencil. As students filled out the questionnaires, a researcher (ES) accompanied these students in order to answer possible questions. It took between 15 and 20 minutes to fill out the questionnaires.

### 2.3 Ethical Dimension of the Study

Prior to the study initiation, ethical approval was obtained from the ethical board of the university where the study was conducted. The research protocol was approved by the Gulhane Military Medical Academy research ethics committee before the study (Ethics Committee Approval Number: 03/2015). Students were verbally informed about the aim of study and were told that their personal data would not be disclosed. Students who agreed to participate in this study signed written informed consent forms.

### 2.4 Data Analysis

The data were analysed using SPSS 21.0 software package. The findings were shown in terms of numbers and percentages for categorical variables, and mean  $\pm$  standard deviation (SD) for continuous variables.

## 3. RESULTS

Table 1 shows students' characteristics. The mean  $\pm$  SD age of students was 21 $\pm$ 0.61 years. More than half of the students were juniors (52.9%), and all of them were female. Most students (72.1%) had practiced in general medicine wards as part of their clinical training.

**Table 1.** Nursing Students' Characteristics (n=136)

	n (%)
Study year (class)	
Third year	72 (52.9)
Fourth year	64 (47.1)
Units where the clinical practice performed	
Internal units*	98 (72.1)
Surgical units**	88 (64.7)

\*Internal medicine, gastroenterology, respiratory disease service, cardiology, nephrology, endocrinology, hematology, oncology, neurology, rheumatology.

\*\*Neurosurgery, general surgery, respiratory surgery, cardiovascular surgery, orthopedics, urology.

Table 2 shows 'student' experiences and thoughts about palliative care training'. Most of the students (90%) stated that they had heard about palliative care content during their education. They had never taken any specific palliative care courses. They heard about palliative care in their oncology lectures during their theoretical education as well as during their clinical practice in oncology clinics. 55% of the students who had some degree of palliative care training had thought that that training was not sufficient. The most frequent topics given by students for the question 'what topics should be in the palliative care courses' including 'fundamental principles and concept of palliative care' (94.9%), 'communication' (91.9%), and 'legal and ethical issues in palliative care' (89.7%). Majority of the students thought that nurses (97.1%), physicians (93.4%), psychologists (91.9%), and social workers (85.3%) should be on a palliative care team.

**Table 2.** Nursing Students' Experiences and Thoughts About Palliative Care Training

	n (%)
Have you heard of palliative care in nursing education?	
Is palliative care mentioned in your education?	123 (90.4)
Yes*	
In your opinion, is palliative care training sufficient? **	
Yes	47 (34.5)
No	76 (55.9)
What topics should be included in the palliative care courses? ***	
Fundamental principles and concept of palliative care	129 (94.9)
Communication	122 (89.7)
Legal and ethical issues in palliative care	121 (89.0)
Loss and grief	117 (86.0)
Symptom management	
Who should be in palliative care team? ***	
Nurses	132 (97.1)
Physicians	127 (93.4)
Psychologists	125 (91.9)
Social workers	116 (85.3)
Physical therapists	98 (72.1)
Spiritual advisors	94 (69.1)
Dieticians	89 (65.4)
Volunteers	65 (47.9)
Pharmacists	61 (44.9)

\*In the topics of oncology nursing and end of life.

\*\*If they said they had palliative care training.

\*\*\*More than one answer.

Table 3 shows students' views of palliative care. Most of the students are of the opinion that 'palliative care should be provided by a multidisciplinary team (91.2%)', 'working in palliative care requires being able to control one's own feelings (81.6%)', 'patient and family caregivers should collectively make decisions (78.7%)', 'the government should assure individuals' reaching out to palliative care when needed (78.7%)', 'palliative care should be a specific field specialty exclusive of oncology and other fields (77.9%)', and 'palliative care courses should be a mandatory component of health science programs (76.5%)'. The least agreed upon thoughts by students included that 'palliative care should consist of only pain management (12.5%)', 'physicians should lead palliative care teams (15.4%)', 'emotionally empowering programs should cover only patients and their families (19.1%)', 'palliative care should be hospital based (25.7%)', and 'palliative care should focus on symptom management without focusing on reason behind the symptoms (36.8%)'.

**Table 3.** Nursing Students' Views About Palliative Care

	Agree n (%)	Neutral n (%)	Disagree n (%)
Palliative care should be served by a multidisciplinary team	124 (91.2)	10 (7.4)	2 (1.5)
Working in palliative care requires one to be able to control their emotions	111 (81.6)	23 (16.9)	2 (1.5)
Patient and family caregivers are collective decision makers	107 (78.7)	23 (16.9)	6 (4.4)
Being able to reach palliative care when needed should be a government guarantee	107 (78.7)	26 (19.1)	3 (2.2)
Palliative care should be a specific specialty exclusive oncology and other branches	106 (77.9)	26 (19.1)	4 (2.9)
Palliative care courses should be mandatory in all health science programs	104 (76.5)	28 (20.6)	4 (2.9)
Patients and caregivers should be able to reach palliative care teams 24/7	94 (69.1)	39 (28.7)	3 (2.2)
Palliative care comprises of health services for terminal cancer patients	85 (62.5)	30 (22.1)	21 (15.4)
Palliative care should start when curative treatment is not possible or at the terminal stage of disease	82 (60.3)	44 (32.4)	10 (7.4)
Exhaustion is inevitable for those who work in palliative care since they continuously face loss	72 (52.9)	51 (37.5)	13 (9.6)
Patients should have right to not be resuscitated (DNR). Legislative regulations about DNR should be made	66 (48.5)	61 (44.9)	9 (6.6)
Palliative care focuses on symptom management without focusing on the reason of symptoms	53 (39.0)	48 (35.3)	35 (25.7)
Palliative care needs to be hospital based	35 (25.7)	50 (36.8)	51 (37.5)
Emotionally empowering programs should only serve patients and their families	26 (19.1)	56 (41.2)	54 (39.7)
Physicians should lead palliative care teams	21 (15.4)	60 (44.1)	55 (40.4)
Palliative care consists only of pain management	17 (12.5)	37 (27.2)	82 (60.3)

#### 4. DISCUSSION

This is the first study to be carried out in Turkey that assesses nursing students' views about palliative care. In this study, most of the students had received palliative care education, but more than half of the students who received that education had reported that they found their education inadequate. Similarly, a literature review also shows that nursing students have inadequate training on palliative care (16-18). In addition, Karkada et al. reported that only 43.4% of nursing students were aware of palliative care, and that they gained such awareness during their training on cancer management (16). In a study conducted by Glover et al., 85% of nursing students reported that they did not receive adequate palliative care training (17). Khraisat et al. reported that 70% of nursing students did not receive any training on palliative care during their nursing education (18). Recent studies on palliative care have recommended that undergraduate nursing programs should include a significant amount of theoretical and clinical practice on palliative care (19-21). Many other studies also report that attitudes towards palliative care can be improved through palliative care courses (22-24). Moreover, the World Health Organization (WHO) recommends compulsory palliative care courses for a basic professional qualification (1). In this study, although most of the students thought that they have inadequate palliative care education, their views on palliative care education for health professionals were positive.

In this study, most of the students stated with regard to palliative care that the following topics should be included in the curriculum: 'fundamental principles and concept of palliative care', 'communication', 'legal and ethical issues in palliative care', 'loss and grief', and 'symptom management'. This shows the tendency towards the basic concepts of palliative care with regards to the concept and scope of palliative care education among students. WHO emphasizes the importance of symptom management in the content of palliative care; it also highlights that symptom management is not the only component of palliative care in the curriculum (1). The fact is that students think that topics such as communication and legal regulations hold a very important place in both palliative care philosophy and symptom management, as well as think that they ought to be included in palliative care education. Considering the legal regulations on practice are extremely important in palliative care, it is important to address legal regulations and ethical issues related to the subject in palliative care education.

Most of the students stated that palliative care should be given by a multidisciplinary team. They also stated that the palliative care team should include nurses, physicians, psychologists, and social workers. In order to provide effective palliative care, the members of a multidisciplinary team need to have understanding of their role and contributions in order to achieve their desired goals (2). In this study, the necessity of multidisciplinary team was correctly identified by nursing students. Consistent with the results of current study, a study conducted by Sujatha et al. had also revealed

that nursing students had identified the occupational groups that are included in palliative care (2). In addition, students believe that 'patient and family caregivers are important decision makers, and communication is important for palliative care'. Palliative care aims to improve the quality of life of the patient and their family by involvement of patient, family members, and all healthcare professionals. Seeing patient and family as the members of a team is a key factor in terms of setting goals and thus achieving those goals. Communication is crucial for successful care. Improving communication means more patient and family participation both in decision-making and in advanced care planning. A recent integrative review had reported that communication is a key component of palliative care, and moreover that it is important to evaluate educational outcomes related to self-efficacy, comfort level, and knowledge related to therapeutic communication with the patient, with caregivers, and among the multidisciplinary team (7).

More than half of the students in the present study also stated that palliative care should start when medical treatment is no longer possible or at the terminal stage of disease, as well as indicated that palliative care practices are necessary for cancer patients in terminal period. Given the general principles of palliative care, it was observed that some of the students' opinions were not compatible with the understanding that palliative care practices should start at the stage of diagnosis. It is thought that this result is related to the provision of available palliative care services in our country, whereby there are mostly hospital-based services and inpatient units, and whereby terminally ill patients are generally treated in these units. This result also may be related to the fact that students learn palliative care only in intensive care and oncology courses.

In this study, most students, think that all palliative care patients should be able to reach palliative care services and the team that provides those services 24/7. These results were also supported by the results of the study conducted by Sujatha et al. (2). Many studies indicate that hospital-based palliative care teams can be helpful in order to relieve cancer patients' physical discomfort and to provide both psychological and social support (25,26). The hospital-based palliative care teams are to provide active care to patients whose disease is not responsive to medical treatment, to offer consultation service to acute care clinicians, and to embed the principles of hospice and palliative care within acute hospital settings (27). In our country, palliative care services are provided by the state in public hospitals; however, the concept of palliative care is commonly understood as 'end-of-life care' and is presented in a hospital-based structure (14). In this study, a small number of students believe that palliative care services should be provided as a community-based service in hospitals. Although there are home health services that function in cooperation with palliative care in our country, it is known that these services are not enough for all patients needing to palliative care in their living areas.

Although the opinions of students about working in this field with palliative care are positive, most of the participants mentioned the importance of controlling emotions while working in this care field. Slightly more than half of the students stated that exhaustion is inevitable for people who work in palliative care due to frequently facing loss. This result shows that almost half of the nursing students provide palliative care for terminally ill patients who are emotionally stressed. This reality, which teaches to provide care only for survival rather than death, can create distress and difficulty in health professionals (28). Attitudes towards death and dying may be related to healthcare professionals' personal spiritual and/or scientific beliefs (29), and may also be related to the belief systems of the population within which nurses are giving healthcare to. When the healthcare professions are not well prepared to deal with all this reality, facing death and giving care to dying people can be distressing and exhausting (28). These findings show the importance of equipping nurses and nursing students with improved self-efficacy in order to deal with death, as well as in order to care for patients with life-threatening diseases.

### Limitations of the Study

There are some limitations identified in this study. The study was conducted in only one nursing school with a small sample size. This prevents us from generalising the study results; there is a need for future research with a larger sample size. Despite these limitations, the results of this study provide valuable insight about Turkish nursing students' viewpoints towards palliative care.

## 5. CONCLUSION

Our results show that although most nursing students receive palliative care training, this training remains inadequate and unspecific. It is highly recommended that topics such as fundamental principles and concepts of palliative care, communication, legal and ethical subjects in palliative care, loss and grief, and symptom management be included as part of the curriculum. No other health care professionals spend more time with seriously ill patients than the nurses do. Therefore, prior to entering professional career, nursing students should be taught about basic palliative care practice and its importance during the course of diagnosis and treatment of any serious illness, as well as be taught about the nurses' responsibilities within the scope of delivering basic palliative care. Education is the key for improving palliative and end of life care. Nursing faculties also play an important role in terms of improving quality of life of patients and their families through providing students with palliative care training.

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