

The Implementation and Advancement of Palliative Care Nursing in Turkey

Can G*

Istanbul University Florence Nightingale Nursing Faculty, Abide-i Hurriyet Cad. Sisli, Istanbul, Turkey

*Corresponding author: Can G, RN, PhD, Professor, Istanbul University Florence Nightingale Nursing Faculty, Abide-i Hurriyet Cad. Sisli, Istanbul, Turkey, Tel: 00 90 532 6264969; E-mail: gulbeyaz@istanbul.edu.tr

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Abstract

Over the last two decades the need for palliative care services has risen in the Middle East and surrounding countries, such as Turkey, driven largely by a dramatic increase in patients' needs for late phase cancer care outside the walls of acute care centers. Nurses in Turkey are central to ensuring that the majority of these patients and families receive the highest quality palliative care possible. This manuscript describes the scope of palliative care nursing in Turkey highlighting pertinent legislation and the response of nursing education to provide quality care to patients and families in need. In order to describe in full the issues in providing palliative nursing care, the following areas are explored: (1) historical aspects of palliative care in Turkey, (2) organizational and legislative issues, (3) responses of educational programs, and (4) the research and clinical practice issues that impact palliative nursing care in Turkey. Conclusions are drawn and implications for the advancement of palliative nursing care in Turkey are discussed.

Keywords: Palliative care nursing; Turkey; Health care legislation; Nursing education; Research; Clinical practice

Introduction

Palliative care is a major health care service need in both high income and middle-to-low income countries. The rise in cancer, the second leading cause of death worldwide, and particularly end-stage cancer is a prime reason for the push to improve palliative care. Although more than a third of cancer could be prevented and another estimated third could be cured if diagnosed early, many countries cannot avail themselves the resources nor convince patients to be proactive in seeking health services for suspected problems. In Turkey, cancer patients are more likely to be diagnosed with advanced stage disease, and for this reason the only realistic option is for pain relief and palliative care.

Since the mid-1990s, there has been growing interest in developing a comprehensive approach for palliative care nursing care of patients with cancer in Turkey. Palliative care is an approach that improves the quality of life of patients whose disease is not responsive to curative treatments. Control of pain, management of disease- and treatment-related symptoms, and comprehensive psychological, social, and spiritual care are indispensable approaches in achieving the best quality of life for cancer patients and their families. These approaches can be applied not only in the terminal stage of illness, but also in the earlier period of the disease in conjunction with active treatment [1]. Barriers to the provision of appropriate palliative care have included a wide range of legislative, educational, and clinical practice issues.

Historical Perspectives - Palliative Care in Turkey

The growing interest in developing palliative care services in Turkey began in the mid 1990's. Several meetings were held and various publications appeared in the medical literature supporting the need for

wide spread palliative care services [2,3]. From the mid-1990s up to 2006, pain control and symptom relief for patients with cancer were usually provided by medical oncology units, internal disease units and departments of algology (pain) at major hospitals in the country [2-5].

In 2006, considerable effort was made to open the first three palliative care units that could provide care to cancer patients. These were established in 2006-2007 and were located in the regions of Ankara, Istanbul and Izmir [6]. Following this advancement, the first palliative care program organized by Turkey's Ministry of Health was implemented in 2009 to improve the quality of life of cancer patients and their families. The strategies were developed to establish palliative care centers and improve awareness of palliative care [7].

In many institutions, new palliative care units were established, and the work for further dissemination of this service across the country continues. Although many positive developments related to the provision of palliative care exist, the work related to the specialization of the palliative care nurses has been limited to palliative care education sessions held across the country. In the future, the palliative care concept should be integrated in all nursing school curricula, and legal arrangements must be executed as soon as possible to define palliative care nursing as a specialty in our country.

Palliative Care Legislation

Legislation towards comprehensive Palliative Care services was initiated between 2008-2009 with 3 workshops in Ankara held with the purpose of establishing a National Cancer Control Program (Prevention, Early Diagnosis, Diagnosis and Treatment and Palliative Care) in accordance with recommendations of the World Health Organization. During these workshops, a palliative cancer model was developed by taking into account the conditions and priorities of our country. Decisions were made about the initiatives to be implemented for comprehensive institutionalization of palliative care services including development of palliative care awareness and extension of

the services. The meeting proceedings were published as the Palliative Care Action Plan within the scope of the National Cancer Program 2009-2015 [7].

Legislation for home and hospital-based palliative care services

Following those initial efforts, the first legal regulation for provision of palliative care was provided through the “Directive About the Procedures and Principles of Health Services at Home Offered by the Ministry of Health.” This document was approved by the Ministry of Health on February 1, 2010 which provided for palliative home care services for patients in the terminal phase [8]. As of November 2010; palliative care was established in 68 provinces in a total of 362 Home Health Units within 2nd and 3rd step hospitals. The Home Health Service expenses are paid by the Social Security Institution (SGK) [9,10].

Legislation that ensures provision of palliative care services in hospitals was later approved in 2014 under the publication of the “Directive About the Application Procedures and Principles of Palliative Care” [11]. This directive was eventually repealed and replaced by the publication of the new “Directive About the Application Procedures and Principles of Palliative Care” July 7, 2015

[11]. In the new directive, palliative care services will be carried out by the palliative care centers in inpatient health facilities and by the family physicians and home health service units outside the inpatient health facilities [Article 5 (1)].

It was also expressed that palliative care services to persons living in a nursing home can be provided under a palliative care protocol by the inpatient health facilities in collaboration with the nursing home. This must be approved by the Directorate. Furthermore, in order to ensure the restructuring of palliative care services provided at inpatient health facilities minimum standards were defined for staff and service criteria, physical conditions and medical equipment for the palliative care centers [11].

Currently, in 38 of 81 provinces in Turkey, palliative care is provided in 67 public hospitals affiliated with the Association of Public Hospitals, 2 university hospitals and 1 private hospital, not only to cancer patients but also to all patients who need palliative care (Table 1) [12]. Additionally, 58 hospitals affiliated with the Association of Public Hospitals are waiting for palliative care unit registration, and 148 hospitals are in the planning stages to establish a palliative care unit. With the completion these efforts, every province in Turkey will have available palliative care services for patients in need of palliative care [12].

Region	Total Number of provinces, n	Registered Centers			Centers which are in the application phase			Centers which are in the planning phase		
		Number of provinces, n	Number of hospitals, n	Number of beds, n	Number of provinces, n	Number of hospitals, n	Number of beds, n	Number of provinces, n	Number of hospitals, n	Number of beds, n
Mediterranean Region	8	4	5	49	1	6	33	7	17	230
Eastern Anatolia Region	12	3	3	55	3	4	27	10	18	183
Aegean Region	8	5	15	202	5	10	86	7	22	207
Southeastern Anatolia Region	9	1	1	6	5	11	100	4	12	122
Central Anatolia Region	13	9	16	184	4	4	29	7	30	399
Black Sea Region	17	7	14	141	6	9	96	10	16	178
Marmara Region	11	5	13	145	7	14	181	7	33	396
Total	78	34	67	782	31	58	552	52	148	1715

Table 1: Current status of the palliative care units in public hospitals, Turkey (From the General Directorate of the Health Services. August 17, 2015).

Palliative care costs

Costs for provision of palliative care services at registered inpatient hospitals (according to the Ministry of Health) were included in the scope of reimbursement within the Medical Practice Communiqué of the Social Security Institution published in the Official Gazette dated December 24, 2014. Reimbursement is provided by the Social Security Institution when a patient receives palliative care within the designated palliative care unit of the inpatient institutions which palliative care unit is registered (Article 2.4.4) [13].

Palliative care recognized as a specialty

In 2015, palliative care centers were recognized as a specialty through legislation, and as of September 2015, additional payment to

the non-physician staff who work in these units was mandated [14]. The legal document, “Directive about the Additional Payment to the Staff Who Works in Health Facilities Depending on the Public Hospitals Authority in Turkey” outlines the additional payment guidelines for nurses and other non-medical health professionals who work in the palliative care unit [14]. In regards to palliative care nursing, regulations are lacking that define Palliative Care Nursing as a professional group. In the Nursing Directive published in the Official Gazette on March 8, 2010, palliative care services in nursing are considered as the roles and responsibilities of the oncology nurses who give care in the palliative care process [15].

Other legislative issues

According to the Turkish Criminal Code, active and passive euthanasia and assisted suicide are equivalent to killing or murdering, so right of dying patients to issue advanced directives has not yet been established by law in Turkey, and the do-not resuscitate (DNR) order is not yet legal [5]. Additionally lacking are legal arrangements or national policies for the hospice care service in Turkey [5].

Clinical Aspects of Palliative Care

Today in many cities of our country, the establishment of the palliative care units has spread the palliative care services. Nurses who work in these centers continue the palliative care of their patients and give training about the patient care to the family members or caregivers who are responsible for the care of the patient. After the patient is discharged the follow-up and treatment of the patient is continued by the home care team at home [16].

Patient care

Although our country established many positive regulations in the last years to provide patients to reach the palliative care services,

available palliative care services still remain inadequate for the number of cancer patients in need of palliative care. Established new centers provide palliative care not only to cancer patients, but also to all patients who need palliative care. In many institutions where treatment of cancer patients is planned, established special palliative care units for cancer patients are still not available (Table 2). Many cancer patients prefer to receive palliative care services by applying to the institutions where cancer treatment is planned. So many palliative care services continue to be provided by medical oncologists, internists, pain specialists, family physicians, pediatricians, nurses and other health professionals in in-/out-patients units of these hospitals [17]. Many cancer patients and their relatives still think that the “palliative care” is “terminal care” and hold it equivalent to pain control [2,5]. A protective and tolerant attitude toward the disease, a fatalistic mentality, a cohesive effect of the disease on family members, and a shift in the philosophy and targets on the individual are all prevailing characteristics of Turkish society. Therefore, many palliative care needs of cancer patients are still provided by the family and relatives of the patients [18]. Most of the Turkish patients, especially who live in rural areas, still prefer to die at home [5].

Province	Hospital	Constitution of Palliative Care Unit, Year	Number of beds, n
Ankara	Atatürk Lung Disease Education and Research Hospital	2015	13
	Dr. Abdurrahman Yurtaslan Ankara Oncology Education and Research Hospital	2007	13
Batman	Batman Public Hospital	2015	16
Balıkesir	Balıkesir Public Hospital	2015	10
Bursa	Ali Osman Sonmez Oncology Hospital	2015	9
Diyarbakır	Diyarbakır Education and Research Hospital	2013	9
İstanbul	Sureyyapasa Lung Disease Education and Research Hospital	2015	36
	Bagcilar Education and Research Hospital	2015	10
	Bakırköy Dr. Sadi Konuk Education and Research Hospital	2015	9
	Dr. Lütfi Kırdar Kartal Education and Research Hospital	2012	10
	Okmeydanı Education and Research Hospital	2010	2
İzmir	Izmir Aegean University Faculty of the Medicine Hospital, Tülay Aktaş Palliative Care Unit	2006	6
	Izmir Nine September University, Palliative Care Research Center	2012	-
	Izmir Atatürk Education and Research Hospital	2013	12
	Bozyaka Education and Research Hospital	2015	17
	Tepecik Education and Research Hospital	2013	32
Kahramanmaraş	Necip Fazıl City Hospital	2015	11
Kayseri	Kayseri Education and Research Hospital	2015	17
Kocaeli	Anatolian Health Center	2006	18
Kutahya	Dumlupınar University Evliye Çelebi Education and Research Hospital	2015	13
Samsun	Samsun Education and Research Hospital	2015	26

Trabzon	Trabzon Kanuni Education and Research Hospital	2013	15
Yozgat	Yozgat Public Hospital	2015	11

Table 2: Hospitals including both the cancer treatment unit and palliative care unit (as of September 2015).

Fatalism and fear of cancer prevalent

At the same time, some attitudes of patients and families toward illness or death can also prevent provision of proper palliative care to cancer patients in our country [3,4]. Some relatives of patients don't want the patient to be fully informed about her/his disease. So, talking about the disease with the patient can be difficult and is a frequently encountered problem in Turkey. Also, some patients don't want to hear the name of cancer and don't talk about it, because a cancer diagnosis may be regarded as death for them. Therefore, during the meeting with a patient and family, most health professionals act according to the patient or family wishes and cues. At the first meeting they ask the patient/family, "What is your illness/complaint?" or "What do you need to know?" According to the patient's and relative's reply they decided how to talk to the patient [2-4].

Clinical nursing care

Palliative care is provided to patients with cancer by nurses who have completed their undergraduate or graduate education; however, palliative care nursing is not recognized as a nursing specialty in Turkey [2]. Still there is no curriculum, graduate/postgraduate programs, or national certification programs for nurses on palliative care in Turkey [2,4]. Many nurses gain experience with palliative care from the courses they take during their nursing education and the palliative care education organized by the Ministry of Health and professional cancer congress [15].

Nurses providing palliative care, especially for those caring for dying patients, face many physical, psychological, social, and spiritual problems themselves. This type of care can be one of the most difficult experiences for nurses [19]. Talking about death with patients and relatives can be uncomfortable for them [19,20], even though they have received education on end of life [19]. Caring for these patients may cause the feelings of grief, helplessness, anxiety, and fear [19]. Nurses who work on these units are considered as personnel who works in a field that require specialty, and as noted, nurses who work on these units receive an additional payment for their work on the palliative care unit [14].

Palliative Care Nursing Education

In our country, nursing education started in the year 1925 by the establishment of the first nursing school, is given at the university level

University	Course Name	Semester	E/C	T	P	ECTS
Undergraduate program						
Bülent Ecevit University Zonguldak Health College Nursing Department	HEL210 Palliative Care	III or IV	E	2	2	4
Çankırı Karatekin Üniversitesi Health College Nursing Department	HEM405 Palliative Care Nursing	VIII	E	2	0	3
Hitit University Health College Nursing Department	4610421 Palliative Care	VII	E	2	0	2

today. In some nursing schools, the education program as the Master of Science (MSc) since 1968 and the Doctor of Philosophy (PhD) since 1972 is also carried out in nursing [21].

Palliative care education

Many compulsory and elective courses about the nursing care in the curriculum program of the undergraduate as well as graduate nursing education exist, but palliative care nursing education is provided by faculty members who usually work in the department of the Internal Medicine Nursing or carry out studies in the field of oncology within the scope of undergraduate and/or graduate education programs.

This is only optional and occurs only at some universities; therefore the scope of the palliative care nursing education varies from university to university. In undergraduate and graduate programs, the Internal Medicine Nursing course offers only one palliative care course (2-4 hours within the scope of a 14-week program) and in others is a separate course as an elective course (2-4 hours per week for 14 weeks) (Table 3). Within the scope of the Palliative Care Nursing course issues about the palliative care services in the world and in our country; crisis, death, loss, mourning process concepts; ensuring of the comfort of the patient whose death is approaching; support of the individual and family in the terminal phase and continuation of the quality of life; hospice services; the roles and responsibilities of the palliative care team are discussed [6].

Although many positive developments related to the provision of services in some hospitals exist, works related to the education and specialization of palliative care nurses are limited to palliative care education sessions held across the country. The objective to integrate palliative care education into undergraduate and graduate programs and to create professional palliative care teams has not been reached [7]. Currently, no Palliative Care Education Program exists in the nursing curriculum that is approved by the Higher Education Council (YOK). Palliative care courses are provided as a 2 hour course within the curriculum of some undergraduate and graduate nursing schools.

Kafkas University Kars Health College Nursing Department	BSD-412 Palliative Care	VIII	E	2	0	3
Nineteen May University Samsun Health College Nursing Department	HEM217 Palliative Care	III	E	2	0	2
Başkent University Faculty of Health Sciences Department of Nursing and Health Services	HSH417 Palliative Care	-	E	2	0	5
İstanbul Science University Florence Nightingale Nursing College	Palliative Care	V	E	2	0	2
Toros University Faculty of Health Sciences Department of Nursing and Health Services	HEM 211 Palliative Care	III	E	2	0	3
Master Program						
Ege University Faculty of Nursing Oncology Nursing Master Program	Palliative Care and End of Life Care	III	C	3	0	6
Nine September University Faculty of Nursing	Palliative Care Nursing			2		4
Afyon Kocatepe University Afyon Health College Nursing Department	Palliative Care and End of Life Care			2		4
Yıldırım Beyazıt University Faculty of Health Sciences Nursing Department	Palliative and End of Life Care			3		7
Doctoral Program						
Ege University Faculty of Nursing	Palliative Care in Chronic Diseases		E	2	0	4
Adnan Menderes Aydın Health College Nursing Department	Oncology Nursing and Palliative Care					
E: Elective, C: Compulsory, T: Theoretical, P: Practice, ECTS: European Credit Accumulation and Transfer System (The ECTS credit is a number which describes the quantity of homework, study and responsibility given to the student for completing the course)						

Table 3: Palliative care education in nursing school curricula.

Palliative care nursing as a specialty

In our country, there are many identified specialist areas like oncology nursing, diabetes nursing, and home care nursing in the scope of the nursing law; however, palliative care nursing is not recognized as a nursing specialty in Turkey. Unfortunately, the roles

and responsibilities of palliative care nursing under the current directive are not defined.

Currently, palliative care nursing is reported as the roles and responsibilities of oncology nurses who give care during the palliative care process (Table 4) [15].

The nurse provides to the individual and its family a continuous emotional support.
She/he evaluates the patient's pain and other symptoms and provides their management, informs the individual and its family about making the symptom control at home.
She/he gives the required information to the individual and its family for reaching the hospital and emergency services.
She/he improves the quality of life of the individual by helping to maintain its independence and control during the daily care and to make its elections.
She/he determines the social supports for the individual and its family and helps them to receive support.
She/he informs the individual and its family about the financial significance of the disease and economic support that they can receive.

Table 4: Roles and responsibilities of nurses who give a palliative care service in Turkey.

In order to offer qualitative palliative care services in our country, necessary legislation must be incorporated as soon as possible, so the palliative care nurses can specialize and palliative care nursing can be defined as a specialty.

In our country, the interest in the palliative care nursing education has increased in the last years, especially after the year 2010. At that time, there was a significant increase in the number of education programs about palliative care, but moving forward, it is important to make palliative care nursing educations legal to provide specialization in the palliative care nursing [2,17].

Nursing testimonials

Lack of awareness of palliative care is one of the most frequently reported barriers to the development of palliative care in our country [2,22]. More than half of the healthcare professionals had not received any education in palliative care [22]. Again, no certificate programs are approved by the Ministry of Health for Palliative Care Nursing [2]. However, nurses would like to be informed about palliative care principles and practice [17].

In our country, development of the palliative care nursing is important to reorganize the undergraduate and graduate curriculum programs in the future in such a way to cover the palliative care nursing education and create and execute after education certificate programs approved by the ministry [2,17]. Some nurses improve their knowledge and skills about palliative care by participating in congresses, symposiums, meetings, courses and workshops organized in our country and international meetings. These postgraduate learning programs rely mostly on reading material without clinical training [2].

But some of them gain experience about the palliative care services by going to the palliative care centers in other countries by taking advantage of different scholarships and contribute to the development of the palliative care services in our country. One of these nurses is Ayfer Elçigil who in 2006 received education about palliative care during a 6-month fellowship at New York Calvary Hospital. The Assoc. Prof. Ayfer Elçigil who works as faculty member at the Nursing College

of the Koç University, now organizes meetings and develops courses to provide the widespread of the palliative care nursing in our country today.

Nursing organizations

The Oncology Nurses Association takes an active role in the widespread education about palliative care nursing. It works in cooperation with the Ministry of Health, University Institutions and other Oncology Associations countrywide and continues the Palliative Care Nursing Educations and gives support by participating as an educator in meetings organized by other institutions.

Oncology nurses also participate in the Palliative Care Education courses organized by different international organizations such as the Public Hospitals Union, Oncology Nurses Association, Medical Associations and MECC, ESMO to improve their knowledge and experiences about the palliative care (Table 5) [4,5].

Date	Symposium/Course	Organization/Place	City
May 4-6, 2015	Palliative Care Nursing Course	Koç University Nursing, College Semahat Arsel Nursing Education and Research Center (Sanerc)	Istanbul
April 10, 2015	Palliative Care Nursing Course	In cooperation with the Respiratory Research Association of Turkey, Atatürk Chest Diseases and Chest Surgery Education and Research Hospital, and Oncology Nursing Society	Ankara
June 11-13, 2014	ELNEC (End of Life Nursing Education Consortium) Palliative and End of Life Care Course	In cooperation with the Oncology Nursing Society and Başkent University	Ankara
April 3-4, 2014	Palliative Care Symposium	In cooperation with the Yeditepe University, Faculty of Health Sciences Nursing Department and T.R. Ministry of Health, Association of Northern and the Southern Public Hospitals	Istanbul
February 27-28, 2014	III. Palliative Care Nursing Course	In cooperation with the Dr. Abdurrahman Yurtaslan Ankara Oncology Education and Research Hospital and Oncology Nursing Society	Ankara
November 16, 2013	TAKD Palliative care workshop in lung cancers	9 September University	İzmir
September 27-29, 2013	NCCN Palliative Care Course	Ankara University	Ankara
September 19-20, 2013	Palliative Care and Hospice Symposium	Bezmialem Foundation University	Istanbul
May 23, 2013	Palliative Care Symposium	Aegean University Faculty of Medicine	İzmir
February 23-26, 2012	Palliative Care and Supportive Treatment Course in Patients with Lung Cancer	5. National Lung Cancer Congress	Istanbul
February 10-11, 2012	I. Palliative Care Nursing Course	Oncology Nursing Society	Ankara
January 29, 2010	Palliative Care Meeting	Okmeydani Hospital	Istanbul
March 21-22, 2008	Basic Principles Nurses Education Course in Palliative Care	Tülay Aktaş Oncology Hospital	İzmir
March 21-22, 2008	Palliative Care Symposium in Oncology Patients	Tülay Aktaş Oncology Hospital	İzmir
April 7-8, 2006	Palliative Approach Symposium in Cancer & Home Care Course	XI. Aegean Oncology Days	İzmir
November 17 to 18, 2006	ESMO course on Palliative Care in Cancer	Medical Oncology Association	Ankara
April 7 and 8, 2006	The Palliative Approach Symposium	With partnership of the Aegean University Cancer Research and Practice Center and the Department of Internal Diseases Nursing of the Aegean University School of Nursing	İzmir

October 7 to 9, 2004	International interim meeting on home care and hospice	Medical Oncology Association (Joint meeting with MASCC)	Istanbul
May 16 to 17, 2003	First postgraduate education: palliative care in cancer	Medical Oncology Association	Ankara

ESMO: European Society for Medical Oncology; MASCC: Multinational Association of Supportive Care in Cancer, TAKD: Turkish Lung Cancer Association

Table 5: Examples of palliative care meetings organized in Turkey.

Nursing Research in Palliative Care

Although some palliative care units were established in our country since 2006, the number of nursing studies published on palliative care in national and international literature is very limited, and it is still impossible to obtain results of the palliative care services provided in our country (number of patients who receive a palliative care, number of nurses who work in these units, costs, etc.).

Some studies are available. One evaluated the opinions of nurses about the establishment and widening of the palliative care services [17,22], and the emotional impact level of nurses who give care to dying patients was questioned [19,20]. Additionally, the effect of the case management approach on the palliative care services was evaluated [23].

The results of these studies revealed that nurses working with cancer patients have higher awareness about palliative care [17], caring for dying patients is one of the most difficult aspects of the nursing profession [19,20] and most of the nurses had difficulty in talking to oncology patients about end-of-life issues [20]. However, these studies stated that palliative care should be provided in comprehensive professional palliative care centers by the staff trained according to contemporary standards and guidelines [17] and that palliative care based on the case management program can be used in the management of the palliative cancer patients [23].

Lack of awareness of palliative care and the lack of educational resources in this field continue to be the most frequently reported barriers in development of the palliative care in Turkey. Palliative care education should be included in nursing/midwifery curriculum and in-service education programs should be established [22,24].

Conclusions

Consequently, in our country, most legal regulations about the provision of the palliative care services are almost completed. In many institutions, new palliative care units were established which provide a palliative care service, and works for the prospective dissemination of this service across the country continue.

To provide a more effective provision of the palliative care service in our country, in the future, the palliative care concept should be integrated in the curriculum of all nursing schools; and public awareness of palliative care should be increased by educational materials and media programs; partnership with community-based organizations that work with the palliative care patients should be established.

To assess the effectiveness of the palliative care services courses, clinical trials and congress on the palliative care should be planned, and in the planning of the care palliative care guidelines should be established based on the cultural structure of our country.

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