

## Palliative Care to the Cancer Patient: Turkish Nurses' Perspectives

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### Abstract

Palliative care is recognized as an essential component of cancer care in Turkey. The Cancer Control Department of The Turkish Ministry of Health launched the nurse and society-based Pallia-Turk Project in 2010. Nurses play the most important role and bear the most important responsibilities in this project. Because nurses are in contact with patients at all stages of cancer during treatment, they are to be more proactive and innovative to maximize the quality of life of cancer patients and their families. However, challenges in palliative care nursing practices in Turkey can reduce the quality of care given to patients and their families. The most significant barriers to the development of palliative care nursing were identified as the lack of palliative care education and training programs, limited research about palliative care nursing, lack of public awareness, and inadequate legislation about palliative care services. In this article, it is intended to provide information about the current state of palliative care services and palliative care nursing in Turkey.

**Keywords:** Palliative care; Palliative care nursing; Turkey; Pallia-Turk project; Cancer

### Introduction

The concept of palliative care as defined by the World Health Organization is "the approach to improve the quality of life for patients and their families who are facing life-threatening illnesses through the assessment and treatment of pain, and other physical, psychosocial, or spiritual problems" [1]. Palliative care is an all-encompassing approach to cancer care that focuses not only on symptom control, but on other aspects of life important to patients and families in an attempt to prevent and/or alleviate suffering [2]. It can be appropriate at any point in the disease course and can be offered concurrently with life-prolonging or curative therapies [3].

Palliative care has been shown to be associated with benefits including improved patient's quality of life [3-5], mood [4], symptom control [3,6], satisfaction [3] and survival duration [4] and caregivers' depression and stress burden [7] and satisfaction [3]. Palliative care also improve healthcare utilization outcomes such as decreased hospital costs [3,8]. Therefore, palliative care is of vital importance for patients with cancer and their families.

### General information about Turkey

Turkey is a Euro-Asian country that stretches across the Anatolian peninsula in south-western Asia and the Balkan region of south eastern Europe. Turkey is a democratic, secular, unitary, constitutional republic. Turkey's location at the crossroads of Europe and Asia makes it a country of significant geostrategic importance [9].

The majority of the Turkey population is Muslim (95%), but Jewish, Christian, and other groups are also represented [10]. According to

Turkish Statistical Institute data for 2014, Turkey population is 77,695,904. The proportion of the population 65 years and older is 8 percent and the average life expectancy is 76,3 years [79,4 years (female) and 73,7 years (male)] [11].

Along with the increase in the average life expectancy in Turkey, similar to all chronic diseases, the cancer incidence rate has also increased. Cancer is the second cause of death with a rate of 20% after cardiovascular diseases (39.9%); the incidence of cancer is 228.6 per 100,000, which means about 170,819 new cancer patients each year in Turkey [12].

### Current Status Palliative care in Turkey

The need for palliative care has never been greater and is increasing rapidly because the Turkey's aging population and the incidence of cancer is increasing. In parallel with the increasing need for cancer patients in Turkey, the Turkish Ministry of Health has launched a national cancer control program for the next 5 years in 2009 [13,14]. The program includes five main headings: Registry, Prevention, Screening and Early Diagnosis, Treatment and finally Palliative Care [14]. Among these, palliative care was the weakest part of current cancer control activities in Turkey [14-16].

Therefore, the Turkish Ministry of Health, Cancer Control Department launched the nurse and society-based the Pallia-Turk Project in 2010. The Pallia-Turk Project has three level of organization (Table 1) [14-17] and nurses play the most important role and bear the most important responsibilities in this project. Because nurses are in contact with patients at all stage of cancer, during treatment, and care setting and they have more proactive and innovative in the care efforts intent to maximize quality of life of cancer patients and their families [18-20].

	Primary Level Organization	Secondary Level Organization	Tertiary Level Organization
What is service?	Simple acute measures (pain relief, constipation and parenteral drug administration)	The patient who could not be managed by family physicians will be admitted to a hospital to get necessary consultations.	It takes care of complex patients who can not be managed at the primary or secondary levels.
Who are providers?	Family physicians Home care teams One general practitioner Three nurses	Physician (the head of the team educated and experienced in palliative care) Co-physicians Nurses Physiotherapist Dietician Psychologists Social workers	Physicians (internal medicine physicians, medical oncologist, cardiologists, anesthesiologist/algologist, general practitioners), Experienced oncology nurses (one for two patients) Social Workers Physiotherapists Dietician Psychologists Religious People
Where is the palliative care?	Home Family Physicians' office.	Hospitals	Hospitals

**Table 1:** The Pallia-Turk Project Organization's Level.

## Palliative Care Nursing in Turkey

### Education

The nurses in Turkey are either graduated from nursing high schools or nursing departments of universities. Clinical nursing education is carried out by faculty members of nursing schools after completion of or in conjunction with theoretical courses [18,21]. Most oncology nurses gain experience while working in oncology clinics, from more experienced nurses, and the oncologist, and some of them are certified by attending postgraduate courses for oncology nurses [18,21,22].

Lack of palliative care education and training opportunities is the most frequently reported barrier to the development of palliative care in Turkey [10,14,15,17,18,22-24]. Palliative care in general has not been yet integrated into the curriculum of nursing at both undergraduate and postgraduate level [18,21,22]. There is little palliative care education for undergraduate and postgraduate nursing students in some nursing schools [15,22,25]. Nurses acquire his/her palliative care knowledge and skills after graduation, from programs with different formats: workshops, seminars, and courses [22].

With the start of The Pallia-Turk, Turkey has worked to educate medical and auxiliary professionals (oncology nurses, oncologists, pain experts, anaesthesiologists, internal medicine specialists, pediatricians, pathologists, social workers, psychologists, art therapists, and spiritual counsellors) [17,18] and regulators to overcome the perceptual, cultural, and financial obstacles that many clinicians (mainly family physicians, general practitioners, and nurses in the community) face in their effort to promote basic issues of cancer awareness, palliative care, and pain control [17]. The Cancer Control Department is in close collaboration with some professional national (Turkish Society of Palliative Care, Turkish Society of Medical Oncology and Oncology Nursing Association of Turkey) and international societies [Middle East Cancer Consortium (MECC), World Health Organization Institut Català d'Oncologia (WHO ICO) Center, San Diego Hospice, American Society of Clinical Oncology (ASCO), Union for International Cancer Control (UICC)] to implement nationwide training modules to nurses, physicians and other professionals [14]. Turkey has been a member of the MECC since 2004. MECC has organized 34 symposiums in the

2004-2014 to raise the awareness of health policy makers, health care professionals, and the public. In these symposiums, the majority of the participants were nurses and oncologists. Of the 434 participants, 27.1% were nurses, 26.9% oncologists, 16.8% epidemiologists, 12.6% internal medicine specialists and family physicians, 8% were the Turkish Ministry of Health officials, and 8.6% were anaesthesiologists and psychologists. MECC has been involved in training physicians and nurses in basic principles of palliative care, including the usage of opioids for pain management [17].

Several seminars and workshops have been organized in cooperation with ONS, jointly with MECC. Hacettepe University Oncology Hospital has been contributing to this cooperation, and it has been leading efforts in providing many nurses with these seminars and workshops in Turkey. Nursing Services Coordination Office, which is part of the organization structure of Hacettepe University Hospitals, has been leading the efforts in Turkey to increase the oncology nurses' knowledge and skills ([http://www.hastane.hacettepe.edu.tr/129\\_en.html](http://www.hastane.hacettepe.edu.tr/129_en.html)). International cooperation efforts allow nurses to learn about different nursing practices of different cultures and also to share their experiences [26]. In 2014, ONS and MECC organized a foundational course in palliative care for nurses from various countries in the Middle East, including Iraq, Iran and Turkey in Hacettepe University in Ankara/Turkey. This course program included a wide range of topics, including symptom management, the psychosocial and spiritual components of palliative care, palliative care structures, setting up palliative care service and caring for the caregiver. After each session, each member of the team led smaller groups in break-out discussions. It was in the small groups that more intimate conversation and in-depth understanding of translating knowledge into their own practice occurred.

However, this kind of postgraduate learning programs mostly on reading material without clinical training. Palliative care education programs should be, including theoretical and clinical aspects. To this end, the Hacettepe University Hospitals Nursing Services Coordination Office applied to the Turkish Ministry of Health to obtain permission to create a program involving theoretical instruction as well as clinical training entitled "Palliative Care Nursing Certificate Program", with an aim to embellish the palliative care nurses with the knowledge, skills, and attitudes required by their profession, and the

Ministry approved this application. Via this certification program, all palliative care nurses in 81 provinces of Turkey are aimed to be covered.

## Research

There is very limited research about palliative care in general and about nursing in Turkey. The most important reasons of this situation are lack of awareness about palliative care amongst nurses [27] and absence of trained nurses [15,16,27]. A study examining the oncology healthcare professional's (235 nurse, 84 doctors, 18 physiotherapist, 16 dietician, 7 health officer, 5 social workers, 4 psychologists) views on palliative care found that 53.7% of healthcare professional never received any education or training in palliative care, neither at school nor thereafter [15]. In another study investigating palliative care practices of the oncology nurses, it was reported that 52.2% of the nurses had not received any palliative care education, and 67.7% of the nurses who had stated that they received palliative care education did not find this education sufficient [25].

A frequently reported barrier to the development of palliative care nursing is the limited knowledge about opioid analgesics. Yıldırım et al. (2008) studied oncology nurses' knowledge and attitudes regarding pain management, and found that they lack sufficient knowledge and attitude regarding the management of cancer pain [28]. Also lack of professional knowledge about the strong opioids among physicians is reported to be a problem in Turkey. Lack of knowledge about opioids often results in reluctance and fear on the part of doctors and nurses to use necessary doses of opioids to patients [18] and this may result in low usage and potentially increased suffering at the end of life [24]. A lack of palliative care nursing education and training programs may also result in limited knowledge about opioid analgesics among nurses.

There are some country information about the number of patients who receive palliative care; how and where they die; practices; and clinical, organizational, and economic issues related to the caring process. The Department of Cancer Control at the Ministry of Health in Ankara made a decision in 2008 to promote advocacy for palliative care in the community with the involvement of primary care physicians and nurses. Before implementing these services, the Ministry of Health assessed the need and costs and planned the logistics. These need and cost assessments were carried out using data that were provided by the Turkish National Social Security Data Bank. The Ministry of Health collaborated with three leading universities and asked them to analyse data provided by the country's cancer registry network to help them in planning the new national program. The data included [17]:

The percentage of cancer patients dying at home or in hospitals.

How many times cancer patients were admitted to emergency departments during the last 12 months prior to death?

The median duration of hospitalization (at the terminal stage) prior to death.

The overall cost of medical services prior to death (including total and per day costs).

These data obtained from the Turkish National Social Security Data Bank were analysed for all cancer patients dying annually in Turkey.

In a new publication, published by Hacikamiloglu et al. contains primary level palliative care services. According to this publication, in 2010 primary level palliative care began with the activation of 407

home care teams that treated 16.651 patients. The number of patients served climbed steadily thereafter, reaching 834 home care teams treating 416.175 patients by 2014 [17].

## Clinical aspects

Palliative Care Units have been established in university hospitals, hospitals administered by Public Hospitals Authority of Turkey, and private hospitals [26]. Based on the 2015 data provided by the Turkish Ministry of Health, there exist 87 palliative care units endorsed by the Turkish Ministry of Health [29]. Palliative care units contain private rooms with the availability of a fridge, disability type bath and toilet. Ensuring a peaceful, quiet home environment in general, an ergonomic one for patients and a comfortable one for patients and their families is intended to be created. Team room, examination room, interview room, recreation room for cancer patients and their families, kitchen and bathroom are located within this unit. The palliative care team consists doctors, nurses, physiotherapist, dietician, social worker and psychologist [30]. Primarily nurses, doctors, and other healthcare professionals who received palliative care education are assigned to these units. However, because they possess insufficient palliative care knowledge, they get consultations from related disciplines [18].

There are some ethical issues nurses can encounter in clinic about palliative care. Nurses and physicians believe that each person diagnosed with cancer, should be informed of his or her diagnosis [18], but in Turkey, there is a difficulty of informing cancer diagnosis to the patients [10,18,23] cancer diagnosis may be regarded as death for them [23]. Family members often want to withhold the diagnosis and/or "bad news" from the patient [10] and thus prevent to terminal period patients the opportunity to make choices related to palliative care [18]. Also the right of dying patients to issue advance directive has not yet been established by law in Turkey, and the do-not-resuscitate (DNR) order is not yet legal [10,18]. In addition to these, patients and their families do not know what palliative care means. For many people palliative care means that there is nothing to do for the patients and the relatives of the patients [22].

The most important subject of palliative care is pain management, and nurses and doctors lack sufficient pain management training [17,26]. Nurses and physicians learn only about opiate side effect, not their potential benefits and modern principles of pain relief [17]. Concerns such as dependency, tolerance development, and respiration depression limit the use of opioids in medical practice [10,14,18,23,24]. There is still opiophobia in many nurses and physicians.

Opiophobia is common not only in health care team members but also in patients and families [14,10,31]. Many patients have a resistance to taking opioids. Because they are not sufficiently informed about them [10,31]. Some patients and their family have belief of morphine being a "sin" and fear of addiction and the thought of "pain and suffering can cleanse sins." All of these reason, there are limited use of opioids and inadequate pain control [14,31].

## Legislation

There is no legislation in Turkey regarding palliative care services. However, in 2015, a directive entitled "Directive for Palliative Care Services Implementation Procedures and Principles" was published to govern the minimal service standards of palliative care units established in hospitals. This directive highlights the importance of the fact that nurses and the other healthcare professionals should consider the integrated provision of the palliative care to the patients and their

families, and also the importance of teamwork in palliative care is underlined in this directive [30].

In "Regulation Amending the Nursing Regulation" enacted in 2011, duties, authorities, and responsibilities of oncology nurses providing palliative care services are listed as follows [32]:

Oncology nurses providing palliative care services:

Provide an on-going emotional support to patients and their families.

Evaluate and manages the patients' pain and other symptoms, and inform the patients and their families to allow them to control symptoms at home.

Inform patients and their families regarding their access to hospital and urgent care services.

Help patients to attain and maintain daily self-care and control, and help them in making their choices, and thereby increase their quality of life.

Identify social support mechanisms available for patients and their families, and help them benefit from these support mechanisms.

Inform patients and their families about the economic aspects of the disease, as well as the financial supports available for them.

### National nursing organization about palliative care

National associations are important to promote national standards in palliative care education and practice, and to protect the interests of their members. There is a national association which called "Turkish Palliative Care Association" about palliative care in Turkey. It was established with the goal of providing multidisciplinary care to terminally ill cancer patients in 2006 [33].

There is no Turkish hospice palliative care nursing association yet, but it is set up as a subgroup for working palliative care nurses, as a branch of the Oncology Nursing Association of Turkey. In 1989, it was established with the goal of improve the understanding and knowledge of oncology nursing and disseminate this knowledge and understanding. The Turkish Oncology Nursing Association Oncology Nursing Society is a member of the European Oncology Nursing Society (EONS) and International Society of Nurses in Cancer Care (ISNCC). This group are organizing symposiums for palliative care nursing [34].

### Conclusion

Palliative care is a fundamental human right, and all patients are to be provided with this service. Palliative care nurses have a unique and primary responsibility for advocating for the right of patients to maintain their quality of life for as long as possible and to experience a dignified and peaceful death.

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