

Review

Development of Cancer Palliative Care in Turkey

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Abstract

Palliative care is an important component of integrated, person-centered health care. It can be provided alone or in combination with the patient's medical treatment, not only by the palliative care team but also by the healthcare team caring for the patient. The concept of palliative care was developed in 2010 along with the establishment of the National Cancer Control Program in Turkey, and today there are many palliative care units, especially in metropolitan hospitals, that provide comprehensive palliative care. One-third of patients who come to the palliative care unit for treatment of pain, malnutrition, and respiratory problems are cancer patients. The care needs of all patients presenting to the palliative care unit are assessed, and a multidisciplinary team plans comprehensive palliative care for patients. Theoretical and practical patient care training is provided by palliative care nurses for family members or caregivers. Considering the burden of cancer as well as the increasing life expectancy at birth, it can be stated that the actual need for palliative care in Turkey will be much greater in the near future.

Keywords: Cancer, nursing, palliative care, Turkey

Introduction

Palliative care was defined by the World Health Organization (WHO) in 1989 as "care provided with the aim of improving the quality of life of patients facing problems arising from a life-threatening illness and preventing or eliminating all physical, psychosocial and spiritual problems, especially pain, through early recognition and assessment" (Sepulveda et al., 2002). Then in 2014, WHO revised its definition to emphasize the scope of palliative care by including in the definition of palliative care that "palliative care is the conscientious responsibility of all physicians" and that patients' families should also be supported psychologically, socially, spiritually, and physically during the grieving period after the patient's death (World Health Organization, 2022).

Palliative care is an important component of integrated, person-centered health care. Palliative care may be provided alone or in combination with the patient's medical treatment, not only by the palliative care team but also by the healthcare team caring for the patient. It is a global ethical responsibility to relieve the symptoms that cause the patient's suffering, whether physical, psychological, social, or spiritual. It is an important approach to health care that strengthens the individual's ability to function and improves the quality of life by considering cultural and religious values, beliefs, and habits (World Health Organization, 2022).

Turkey is a country with a population of 86,708,278 and an annual growth rate of 1.09%. Life expectancy for both sexes

is 78.5 years (Worldometer, 2020). Based on the Global Cancer Observatory 2020 data, it is estimated that 233,834 people receive a cancer diagnosis and 126,335 people die from cancer annually. The cancer prevalence is 581,636 (5 years) (International Agency for Research on Cancer, 2020).

Considering the burden of cancer as well as the increasing life expectancy at birth, it can be stated that the actual need for palliative care in Turkey will be much greater in the near future. The concept of palliative care was developed in 2010 along with the establishment of the National Cancer Control Program in Turkey (Keskinilic et al., 2016). The Turkish Ministry of Health brought all stakeholders together under the umbrella of a National Cancer Advisory Board and launched the PalliaTurk project, which became a turning point in creating a national policy for palliative care in Turkey (Keskinilic et al., 2016; Kutluk et al., 2021).

Historical Development of Palliative Care in Turkey

Although the legalization of palliative care in Turkey was completed only in 2010, if we look at the attitude of Turkish society toward health and patient care in history, we can see that the development of palliative care dates back many years and includes three periods: the *pre-Islamic period*, the *Islamic period*, and the *post-Islamic period* (Koc, 2021).

In the *pre-Islamic period*, the Turkic tribes, who adopted the Gokturk beliefs and the teachings of shamanism, believed that shamans accompanied the dying on their way to the afterlife and protected their souls from evil spirits. Buyan

buildings, built by Uyghur chiefs out of charity, were used to care for and treat travelers, the elderly, and the sick (Koc, 2021).

In the *Islamic Period*, in Egypt, the first hospital, known as “the ancient Bimaristan,” was built in 872 by Ahmad ibn Tulun, the Abbasid governor of Egypt, for the care of the sick and elderly in the southwestern quarter of present-day Cairo (Savage-Smith, 1994). The Seljuk dynasty established facilities where patients received social support (Koc, 2021).

In the sanatoriums of Haseki (1550) and Atik Valide (1582), which were established during the Ottoman Empire, the requirement for working was that the doctor had to be kind, smiling, compassionate, merciful, and protective like a father in his relations with the patients. In 1895, the Ottoman Sultan Abdulhamid II ordered the establishment of the Darulaceze (Poorhouse), which provided a warm home for the elderly to spend the rest of their days. These buildings are still used today to continue the care and treatment of the elderly and patients (Koc, 2021).

In the *post-Islamic period*, the “Cancer Nursing Home” established by the Turkish Oncology Foundation in 1993 is the first facility to offer palliative care. The “Cancer Nursing Home” was closed in 1997, 4 years after its opening, because it could not raise the financial support necessary for its continuation. In 2006, the Hacettepe Oncology Institute Foundation purchased a historic 12-room house in Ankara and opened the “Hacettepe Hope House” as the second facility providing palliative care to cancer patients (Aslan, 2020).

As a result of the 2-year cooperation agreement between the Regional Office for Europe of the WHO and the Department of Cancer Control of the Ministry of Health of the Republic of Turkey, the “Palliative Care Action Plan” was developed in three workshops between 2008 and 2009 through the joint work of health experts concerned about palliative care, which was then published as part of the National Cancer Control Program 2010–2015 (Figure 1, 2A, and B). This action plan created a model of palliative care appropriate for our country’s conditions and laid out the steps for establishing pilot palliative care centers, creating trained palliative care teams, and also facilitating access to opioids (Keskinilic et al., 2016).

The Pallia-TURK (Palya-Tuerk) project, which is considered one of the most important building blocks of the National Cancer Control Program 2010–2015, has been defined as the most suitable palliative care system for the socio-cultural structure of our country. In this project, which is also supported by non-governmental organizations (NGOs) and focuses on care, the palliative care centers to be established in our country were classified and their functioning was defined (Ozgul et al., 2012).

Level I: Palliative Care Unit

It has been suggested that this level of palliative care, providing mainly outpatient palliative services, should be established in peripheral regions and provided by general practitioners, home care teams, NGOs, and local governors.

Level II: Palliative Care Center

It was suggested that these centers, which have a multidisciplinary team, should be established in health facilities with high labor standards and in the Public Hospital. After patients



Figure 1.
2010–2015 National Cancer Control Program Workshop 2, Ankara.



Figure 2. A, B.

Palliative Care Study Group Efforts to Develop Palliative Care Action Plan. (A) From Left to Right: Bottom—Assoc. Prof. Gulbeyaz Can, Figen Bay, Meral Bakar (Nursing); Top Row: Assoc. Prof. Sibel Eyigor (Physical Therapy, Rehabilitation), Dr. Sheron Eril (Palliative Care Physician), and Dr. Vedat Isikhan (Social Services), 2010–2015 National Cancer Control Program Workshop, Ankara. (B) From Left to Right: Dr. Seref Komurcu (Medical Oncology), Assoc. Prof. Sibel Eyigor (Physiotherapy, Rehabilitation), and Assoc. Prof. Gulbeyaz Can, Meral Bakar (Nursing), 2010–2015 National Cancer Control Program Workshop, Ankara.

admitted to these centers are stabilized as soon as possible, they should be referred to primary care physicians and home care services for further treatment.

Level III: Comprehensive Palliative Care Center

It was suggested that these centers, which include services such as rehabilitation, psychosocial support, nutritional counseling,

occupational therapy, physical therapy, speech therapy, pain management, and palliative care, should be established in the Training and Research Hospitals (Keskinkilic et al., 2016; Ozgul et al., 2012)

Today, these three different palliative care models, comprehensive palliative care center (CPCC), inpatient hospital care (IHC),

and home health care (HHC), are commonly used for the palliative care of cancer patients. The cost-effectiveness of these three models was evaluated in a study by caring for 160 cancer patients. The results of this study show that from a societal perspective, palliative care using the IHC model is more cost-effective than the CPCC model. From the patient's perspective, the HHC model was found to be more cost-effective compared to the other two models (Saygili & Celik, 2019). Depending on the health status of the cancer patient, any of these palliative care models can be used to meet the palliative care needs of the patient.

Following the adoption of the 2010–2015 National Cancer Control Program, numerous palliative care centers were opened in our country between 2012 and 2013 as a result of the 2010 Home Care Services Regulation. The first hospital-based palliative center was opened in 2010 at Okmeydanı Training and Research Hospital with a 2-bed unit and a 10-member team, including an oncologist, a physiotherapist, a psychologist, a nurse, a clergyman, and social volunteers. The first 11-room palliative care center providing comprehensive palliative care services for adult patients was established at the Ankara Ulus State Hospital of the Ministry of Health (Koc, 2021). The first pediatric palliative care center was established in Bursa Dortcelik Maternity and Children's Hospital in 2015 (Aslan, 2020). In 2014, a guideline for palliative care was prepared, and the staffing characteristics of the centers were defined, they were included in the scope of social security, and the number of centers was increased (Koc, 2021).

Today, there are many palliative care units in our country, especially in metropolitan hospitals that provide comprehensive palliative care (Figure 3). At the end of October 2020, the number

of palliative care units in our country was 397 and the number of beds was 5717, and the plan is to increase this number to 5900 by 2021. In terms of population, the number of palliative care beds is higher in large cities such as Istanbul with 18,156, Ankara with 9923, and Izmir with 6638 than in smaller cities, and all patients who meet the criteria for admission to these centers receive care there (Koc, 2021).

Today, oncology (35%), neurology (22%), and chronic pulmonary disease (11%) patients are the most common patient groups admitted to these palliative care centers. The most common reason for patient admission is pain (25%). Other complaints reported by patients include malnutrition, dyspnea, pressure injuries, nausea/vomiting, and fever (Goksel et al., 2020).

The needs of all patients presenting to the palliative care unit are assessed by a multidisciplinary team. If necessary, the patient is admitted as an inpatient, and care and treatment are planned by the unit team. Depending on the patient's condition, other clinicians may also be involved. Patients and their families are supported by psychiatrists, psychologists, morale counselors, physical therapists, and social workers. In addition, patients' family members or caregivers receive theoretical and practical training from palliative care nurses. Part of the nursing services and social care for patients discharged from the ward is provided by the "Ministry of Family and Social Policy" teams. The patient is examined, blood is taken, and if necessary, blood results are monitored and treated by the home care team (Koc, 2021).

Legal Regulations of Palliative Care in Turkey

Within the framework of the legal regulations of palliative care in Turkey, the "Directive on the Implementation Procedures

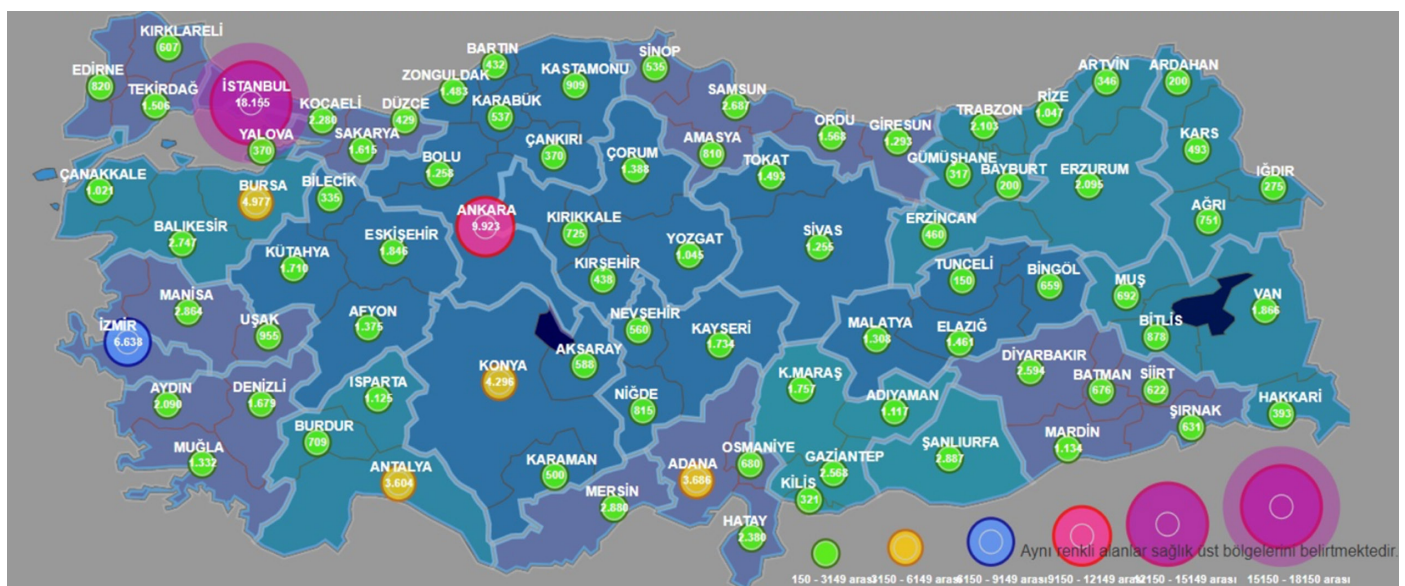


Figure 3. Number of Beds in Palliative Care Centers in Different Provinces and Hospitals on June 19, 2018.
Reference: (Ministry of Health General Directorate of Public Hospitals, Turkey <https://khgm.saglik.gov.tr/TR-40027/palyatif-bakim-merkezlerimiz-in-il-ve-hastanelerimizdeki-yatak-sayilari-ile-ilgili-bilgiler.html>)

and Principles of Palliative Care" dated 07.07.2015 with the number 840 of the Ministry of Health, General Directorate of Health Services, came into force (Republic of Turkey Ministry of Health, 2015).

This directive defines the establishment of the centers, the minimum standards that should be present in the centers, the professional members and tasks that should be included in the palliative care team, the working principles of the palliative care units, and the scope of palliative care services.

Nursing in Palliative Care

In 2015, the "Directive on Implementation Procedures and Principles for Palliative Care Services" came into effect. The policy defined the structure of palliative care units; established the physical requirements for the establishment of palliative care units; the duties, powers, and responsibilities of nurses who will work in palliative care units; the scope of services, training, and supervision in palliative care units; and the collaboration of palliative care units with other institutions and organizations. This policy

- enabled early recognition and treatment of pain and other symptoms in palliative care patients;
- defined the role of palliative care units in improving the quality of life of palliative patients;
- defined the work procedures, physical conditions, minimum standard of instruments, equipment, and personnel for the palliative care unit;
- demonstrated how suffering can be alleviated or prevented through medical, psychological, social, and moral support for palliative patients and their family members (Republic of Turkey Ministry of Health, 2015).

Article 8 of the Directive explains the duties, powers, and responsibilities of palliative care staff. This article states that palliative care is under the supervision and responsibility of the attending physician and that nurses, medical secretarial staff, administrative and technical staff, cleaners, and other healthcare providers must perform their duties as directed by the physician. It was also emphasized that psychologists, social workers, dieticians, and physical therapists do not have to work full time at the center and will support the unit from inside or outside the hospital as needed (Republic of Turkey Ministry of Health, 2015).

The regulation amending the Nursing Regulation, published in the Official Gazette on April 19, 2011, as number 27910, clarifies the duties, powers, and responsibilities of the palliative care nurse within the scope of the oncology nurse specialization. The duties and responsibilities of the nurse practitioner working with palliative care patients are as follows:

- a. Provide ongoing emotional support to the person and their family.
- b. Assess and treat the patient's pain and other symptoms and guide the patient and family in symptom control at home.
- c. Provide the person and his or her family with the information necessary to reach the hospital and emergency services.

- d. Improve quality of life by helping the patient maintain independence and control and make decisions in daily care.
- e. Identify social supports for the patient and family and help them obtain assistance.
- f. Inform the patient and family about the economic aspects of the disease and the economic support they can receive (Republic of Turkey Ministry of Health, 2011).

Nurses are the important member of the palliative care team. Their roles and responsibilities should not be under the responsibility of the palliative care physician. Article 8 is one of the items that need to be revised in future amendments to the palliative care regulation because of the position of nurses in palliative care (Republic of Turkey Ministry of Health, 2015).

In 2017, a consensus conference for oncology nurses titled "Evidence-Based Palliative Care in Cancer" was held in Turkey. Many nurses and other healthcare professionals from the palliative care team from countries affiliated with the Middle East Cancer Consortium attended the meeting. During the meeting, the integration of non-pharmacological interventions in the management of palliative symptoms in cancer such as pain, dyspnea, nausea and vomiting, diarrhea and constipation, anorexia and cachexia, fatigue, insomnia, distress, delirium, and approaches that can be effective in empowering family members and healthcare professionals were discussed and strategies for palliative care of cancer patients were identified (Can, 2019).

Oncology nurses recommended the use of massage, reflexology, and music along with pain therapies to relieve cancer-related pain; the use of positioning, facial cooling, breathing and relaxation exercises, or O₂ therapy along with pharmacologic therapies to treat dyspnea; the maintenance of a food diary to treat anorexia and the use of abdominal massage for constipation; the use of psychosocial interventions, rest, and activity balance to treat fatigue; the use of sleep hygiene and psychosocial support to treat insomnia; and the use of psycho-oncologic interventions to treat distress (Can, 2019).

Palliative Care Education in Turkey

Palliative care units have been established everywhere in our country, awareness of palliative care has grown in society, and many healthcare providers have started to work in these units. This increases the need for trained and experienced teams that can provide comprehensive palliative care.

In the letter of the Council for Higher Education dated 11.12.2013 numbered 65470 on "Palliative Care Education," it was stated that it would be appropriate to offer palliative care education during medical education for physicians and in-service education for nurses (Koc, 2021). Today, palliative care education is taught theoretically and practically in the curricula of some nursing schools, as there are differences in nursing school curricula (Can, 2015). One study showed that palliative care education significantly increased students' knowledge of palliative care, but the number of students who wanted to work in palliative care significantly decreased after the education (Birge & Beduk, 2022).

Another training program that nurses working in palliative care complete after graduation is the Palliative Care Nursing Certified Training Program. This Department of Health-approved certificate program is offered by many palliative care units that meet the criteria and includes 35 hours of theory and 80 hours of practice. The certificate program includes educational topics on the purpose, philosophy, and principles of palliative care, the current situation and planning of palliative care services in the world and in our country, the role and responsibilities of palliative care, teamwork in palliative care centers, patient and staff safety, infection control, patient assessment, symptom management, the patient, and important palliative care issues related to end-of-life care for the family (Ministry of Health General Directorate of Health Services, 2015).

However, there are also oncology nurses who state that they have not received training in palliative care or that the training they have received has been inadequate (Uslu Sahan & Terzioğlu, 2014). These nurses can increase their knowledge of palliative care through continuing education such as courses, symposia, workshops, and congresses (Can, 2019).

Palliative Care Research in Turkey

Most cancer patients come to the palliative care unit in the last days of their lives to treat pain and nutritional problems. Indeed, it is important to plan palliative care early when a life-threatening cancer is diagnosed.

As advocated by nurses, early integration of palliative care into cancer care improves symptoms, enhances patients' quality of life, and alleviates suffering for family members. It also reduces unnecessary medical interventions and costs associated with symptom management (Aksu & Sentürk Erenel, 2021; Temiz et al., 2022).

There are many nursing interventions that can be used in palliative cancer care, and the effectiveness of these interventions has been confirmed in many studies in our country. Yıldırım et al. (2020) showed that abdominal massage decreased the severity of opioid-induced constipation and symptoms associated with opioid-induced constipation (Yıldırım et al., 2019). In another study, the use of lavender in palliative care improved patients' sleep quality (Yıldırım et al., 2020). The use of a hand-held fan decreased patients' shortness of breath, increased oxygen saturation, and improved the quality of life in lung cancer patients with dyspnea (Kocatepe et al., 2021). The use of foot baths with warm salt water improved the quality of life related to fatigue in cancer patients (Akyuz Özdemir & Can, 2021) and cold/warm salt water reduced the severity of peripheral neuropathy and increased the quality of life of patients (Kayıkçı & Can, 2022). The use of reflexology improved the sensory functions of patients damaged by peripheral neuropathy due to chemotherapy (Kurt & Can, 2018).

Conclusion and Recommendations

In our country, the treatment of cancer patients is provided by various healthcare institutions such as university hospitals, government hospitals, and private hospitals. Since palliative

care units are only established in public hospitals, it may be a problem for cancer patients if they need to receive palliative care services in a unit other than the one where they are being treated. Especially for patients who trust their treating oncologist and fear that the attending physician will abandon them if their disease does not respond to treatment, referral to another unit with which they are unfamiliar may cause additional anxiety. Therefore, before referring the patient and family to the palliative care unit, it is important to know if the patient and family are ready to receive this service and what their expectations are. In addition, it is important for many in the community to respect the wishes of the deceased, to provide assistance and support at home during the dying process, to be clear and honest in the medical staff's communication with the patient and family, to have palliative care available when needed, to respect the patient's privacy during care, and to care for the patient and not forget the family after death. Consequently, palliative care that meets the expectations of the patient and family and takes into account the cultural characteristics of the society will increase the satisfaction of the patient and family (Dunn, 2006).

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