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Palliative Care Unit in an Oncology Hospital in Turkey

*Gonca Tuncel Oğuz[1], Gülçin Özalp Şenel[1] and Michael Silbermann[2]**

[1]AY Ankara Oncology Education and Research Hospital, Pain and Palliative Care Unit, Turkey

[2]Department of Palliative Care, Middle East Cancer Consortium, Israel

Editorial

Palliative care is defined by the World Health Organization as 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual' [1]. For cancer patients, combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden [2].

The A.Y. Ankara Oncology Education and Research Hospital was founded in 1956 throughout the efforts of Turkish Cancer Research Society. Today, it serves as atertiary training hospital with many modern facilities in cancer treatment such as robotic-assisted chemotherapies, new radiation technologies, surgical procedures and bone morrow transplantation. Experienced health care personnel from all disciplines care for oncological patients who come from all parts ofthe country.

The initiative or palliative care approach began in the hospital's pain unit which was established in 1991 as a division of anesthesiology department. It was organizedprimarily for pain management of patients with a diagnosis of cancer. Medicaltreatment for pain was administered with/without necessary invasive procedures such as nerve blocks, neurolytic blocks or neuraxial drug infusions when needed. Although some interventions were applied to provide symptom relief other than pain control, there was no established palliative service designed to routinely meet the needs of these patients. They were frequently given care in medical oncology unit, radiation oncology unit or surgical wards. Majority of the clinicians in these departments were unfamiliar with appropriatealgorithms for pain management and had little experience with the use of morphine and manage its side effects. Opioids were regarded as 'heavy' drugs to be saved for the very end-stage. With the establishment of pain unit, the approach to pain management and opioid use began to change and the number of patients referred to our unit for pain control gradually increased by year. During that period, opioid formulations were very limited in the country.

By 2006, the growing cancer population along with growing suffering due to pain and other symptoms, and the unmet needs of patients prompted the decision to establish a new inpatient unit. The hospital chief physician and the pain unitteam worked together on a report regarding the necessity and design of a palliative care unit. The Palliative Care Unit was finally implemented in July 2007 with 18 inpatient beds. The standards of the clinic were not optimal and the health-care personnel were not completely trained in palliative care. The training mostly relied on the experience of the team about pain management and reading materials.

The concept of palliative care has improved and disseminated slowly in Turkey. There was no legislation regarding palliative care.The Turkish Ministry of Health launched a 5-year national cancer control program in 2009 and the Pallia-Turk project, a unique population - based program focusing on the primary-care level followed in 2011 [3]. Close collaborationwith several national organizations and involvement in the workshops and education programs of international societies [MECC-Middle East Cancer Consortium] improved knowledge and awareness about palliative care. The palliative care team in the hospital has participated as trainers in nationwideeducationsymposiumsfor nurses, physicians and other professionals.The Palliative Care Unit also served as an advisory model for oncologic palliative care and was awardedseveral appreciative commemorative admiration plaques by the Cancer Control Department. In 2014, a directive entitled 'Directives for Palliative Care Services Implementation Procedures and Principles' was published by The Turkish Ministry of Health to regularize the standards of palliative care units established in hospitals. The directive highlighted the importance of teamwork, psychological, social, and spiritual support, integration of palliative care for both the patient and the family and close contact with family physicians and home care teams. However, the doctor responsible for the unit was defined as 'preferably an

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Correspondence:
Michael Silbermann, Department of Palliative Care, Middle East Cancer Consortium, Haifa, Israel, E-mail: cancer@mecc-research.com

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anesthesiologist' whichledto heated discussions over the role of the anesthesiologist and concern about his/her relation with intensive care.Palliative care units weredisregardedas a kind ofintensive care units by several clinicians and decision makers in health care. Certain ethical and reimbursement issues also arose. Although the distinctive philosophy of palliative care is well emphasized in the educational programs, residual misunderstanding of the underlying concepts and terms of palliative care remain.General palliative care can be provided by primary care professionals and specialists treating patients with life-threatening diseases with good basic palliative care skills and knowledge [4]. We hope that the ministry will amend the regulations and provide the involvement of physicians from various specialties with necessary education, willingness and permanency. A palliative care specialty is needed and should be made available in the country inthe future.

Our palliative care unit is the first registered service with 13 inpatient beds in 2015, following the announcement of the official regulations by the Turkish Ministry of Health.We aim to improve quality of life of patients and their families by controlling pain and other symptoms, while also addressing psychological, social, and spiritual problems. The unit mainly serves cancer patients at all stages of the illness. The palliative care team consists of 4 physicians (3 pain specialist, 1 anesthesiologist), 12 nurses, 1 medical secretary and 2 cleaning staff. Patients are accepted in the palliative care service from pain unit, other services in the hospital, emergency department and other hospitals (university, government or private). Palliative care is also provided in pain unit for outpatients and in other services by consultationto manage pain and other symptoms.The number of cancer patients given palliative care in the last 5 years (2011-2015) are presented in Table 1.

The palliative care unit is supported by the anesthesiology clinic after working hours during the day. A psychiatrist and psychologist accompany daily visits to patients once a week and also work in liason. Social workers, physiotherapists and spiritual-care specialists give support to the unit on the appointed days.Regular family meetings are organized on Thursdays with input bynurses / doctors and psychologist. The families meet each other, share their feelings and experiences and sometimes cry together.All patients and caregivers are informed about the concept of palliative care upon admission to the clinic and their expectations are addressed. Written informed consent is obtained. During their stay, necessary reports for medications and devices are prepared for the continuation of palliative care at home.Insufficient organization of palliative care settings other than hospitals (hospice, nursing home) prolongs the length of stay in the units. A detailed epicrisis is prepared at discharge to serve a reference for family physicians and home-care teams. Contact telephone numbers of the unit are also given.

Cancer treatment is a long journey for the patient and the family. Palliative care is essential throughout this journey and can be started at any time in the disease trajectory in conjunction with active treatment. Unfortunately, we still face barriers to the effective integration of palliative care in cancer care. It is usually considered as an end stage, or terminal care, and referral to a palliative care organization often occurs late in the course of disease. InTurkey,thereis great difficulty in informing a diagnosis of cancer to the patients.Often, family members do not want the patient to be fully informed about the cancer diagnosis or incurable nature of the disease. Therefore, bad news and poor prognosis are frequently withheld from the patient and the truth is shared only with the family.Sometimes, this may lead to self despair in patients waiting for curative therapies, and increase their depressive mood. Notably, the right of dying patients to issue advance directive and do-not-resuscitate [DNR] order is not legal in Turkey.

Despite these unfavorable circumstances, we try to alleviate patients' suffering by providing symptom control and psychosocial and spiritual support. Pain is one of the important symptoms in palliative care and has a major impact on quality of life of cancer patients [5,6]. Difficult access to opioids and the lack of well-established palliative care facilities results in under-treatment of pain.Turkey is one of the countries with statistical evidence of inadequate morphine consumption per capita. In 2010, the adequacy of opioid analgesic consumption was only 7% - based on a per capita consumption of 14.31 mg morphine equivalents [7]. Many cancer patients are treated by health-care professionals lacking the essential skills for pain management. Opiophobia is still common not only on the part of health-care practitioners, but also in families and patients. Modern principles of cancer pain treatment, opioid doses and side effects are not fully recognized by physicians and nurses. Misguided concerns about dependency, tolerance and side effects limit the optimal use of opioids in medical practice.

Many types of opioids are lacking in the market in Turkey. We have only tramadol, transdermal fentanyl, hidromorphone, oxycodone and morphine in the country. Immediate release oral morphine is very new, therefore we have used parenteral forms for many years. Oxycodone came into the markets a few years ago. All forms and doses of opioids are not also available. Moreover, Turkey has a complicated, restrictive, and burdensome regulatory system for prescribing opioids. A color coded prescription system is used - namely, red prescription sheets for strong opioids and green sheets for sedatives and weak opioids.The total doses that can be prescribed in one prescription are also limited.

In a recent study, we examined the patterns of opioid use among cancer patients in our palliative care unit [8] and found that the daily oral morphine equivalent dosage per patient is 172±58 mg (40-328). Indications for opioid use were pain (61%), dyspnea (19%), and both dyspnea and pain (20%). The results show the importance of opioid use to alleviate pain and dyspnea in palliative care settings. Despite the limited variety of opioids in our country, a more adequate and effective level of pain management can be obtained byimproving the education of health practitioners. The confident and safe use of opioids in palliative care is essential.

The Cancer Control Department, together with other organizations, is working hard to disseminate the modern philosophy of palliative care and opioid use throughout the country. Several meetings have been held for health-care professionals who wish work in a palliative care team. In our hospital, we have organized 'Palliative Care Nursing Symposium' in 2014 and 'Spring Symposium in Oncologic Palliative Care'in 2016 with the contribution of speakers from several disciplines.

In Turkey, there is no formal comprehensive palliativecare curriculum and palliative care specialty. Training is usually obtained from symposiums, workshops, literature, whereas it should be included in the curricula for medical faculties, nursing and related professional's education. Some certification programs for nurses are being planned by the ministry.Yet, not all health care team are aware

of the palliative care strategies, and a significant proportion of the population does not have access to palliative care at all. It isessential that an improved palliative care program should be integrated in the national health care systems to control suffering.Manyterminally ill patients are admitted to emergency departments because of inadequate support in the community, difficulty in controlling symptoms at home or inability to further care for the dying patient.Although the concept of palliative care is more pronounced in our hospital, still, a large number of those patients are referred to intensive care unit for further care. An absence of legislative regulations, coordinated referral systems, and an insufficient number of palliative care services result in futile hospitalization in intensive care units.Palliative care needs to be integrated and balanced with other care services to address the needs of patients and their families [9]. A comprehensive system of services, including inpatient units working in close collaboration with home-care teams and family physicians, should be available to cover all care needs and treatment options.Although the number of palliative care services has increased in the past few years in Turkey, integration with family physicians and home-care teams has not been sufficiently established to cover the increasing palliative care demand. Similarly, organizations that provide visits to patient's homes are insufficient, andbereavement services and follow-up support for the family after the death of the patient also need to be improved. In our unit, we give bereavement support by telephone calls and the families usually visit the service and the staff afterwards to express their gratitude.

The Turkish Ministry of Health is working to improve the national health strategies and deliver palliative care educationin a culturally sensitive manner accessible to all segments of the population. Legislative regulations about end of life care, advance directives and DNR orders are still under discussion. Awareness in public and health professionals and coordination of palliative care services with home-care teams areneeded to be improved.

Palliative care is a fundamental human right. All patients should have accesses to such care at any stage of the illness. Our aim must be to provide the best possible quality of life for patients keeping in mind the words of Dame Cicely Saunders, the founder of modern hospice and palliative care, ‘we will do all we can, not only to help you die peacefully, but also live until you die’.

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