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# Structuring of Palliative Care in Ankara Ulus State Hospital, Turkey; 2012-2013

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## Abstract

**Purpose:** We aimed to report the first structuring "Comprehensive Palliative Care Center" in the Turkish Ministry of Health, Ankara Ulus State Hospital.

**Methods:** We built up paliative care center in Ankara Ulus State Hospital. Ensuring a peaceful, quiet home environment in general, an ergonomic one for patients and a comfortable one for patients and relatives was created. Doctors, nurses and allied health staff were given both theorically and pratically training course for palliative care. In addition, for informational purposes, symposiums are held for other health care institutions and health care workers.

**Results:** With the passage of the normal course of the disease after treatment, patients are re-taken for follow-up under palliative care and symptom care is continued accompanied by relatives or nurses. These processes increase the confidence towards health professionals and caregivers provide reduction in patients' expectations and accelerate embracing the end of life.

**Conclusion:** In our hospital, we shared our experiences and logic model with colleagues and identified which joint steps to take in the future by organizing a symposium on the subject. We hope that increasing the number of trained personnel and resolution of legal and financial aspects are the key issues in spreading palliative care throughout the country. In this regard, our hospital sets a good example for many State and University hospitals, an awareness of palliative care started to increase, and many centers were opened or started preparations to build new palliative centers.

**Keywords:** Palliative care; Health care workers; Structure; Training

## Introduction

According to World Health Organization (WHO), palliative care is an approach that improves the quality of life of patients and their families facing the problems 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 [1,2]. Although governments in many countries display great efforts to put this issue on the agenda, and for it to be considered as a general human right, the advanced integration of palliative care into the general healthcare system is only available in 20 countries worldwide, which is just 8.5% of the total population. World Palliative Care Association (WPCA) globally targets high quality access to palliative care by everyone for affordable prices by 2015. In order for the dissemination and transportation of palliative care to those in need, a number of required palliative care centers must be achieved [3,4]. In Turkey, need for a national palliative care program was noticed in the 1990s, but did not reach a point beyond the pain treatment offered to cancer patients. Despite the slow progress in advancement of palliative care, pain management has made a rapid progress. The association of pain management, which was established on 1987 by anesthesiologists, later merged with the International Association for the Study of Pain (IASP) in 1993. After this process many national and international publications, congresses and symposiums were organized [5]. A group of oncologists showed concern and took part in training activities on palliative care [6]. "Cancer Welfare Home"; organized by the Turkish Oncology Foundation, which was able to treat cancer patients for a long term by means of palliative care, has served from 1993 to 1997 in Istanbul. Within this period, neglecting the payment to inpatients by social security systems, lack of donor resources and lack of knowledge about the concept "hospice" by patients and their families have led to the closure of this pioneering organization. "Hacettepe House of Hope" established for hospice care was the second attempt to care for cancer patients. It was established under the lead of Hacettepe Institute of Oncology Foundation and was converted into a 12 room hospice bound to Hacettepe Oncology Hospital. However, due to the lack of legal regulations, this establishment was later decided to serve as a treatment center for cancer patients and later provide them with accommodation to stay in as little as a few weeks with the minimal benefit in terms of nursing [7,8].

According to the data taken from European Association for Palliative Care (EAPC) 2005, in Turkey, palliative care services are provided in 10 centers with a total of 241 beds and hospice care service is provided in one center. However, most of these centers are within oncology clinics and in the form of pain control units [9,10]. There was no active policy and work of Ministry of Health on palliative care in 1990s until 2008, when, primarily Cancer Control Department at the Ministry of Health, including Turkish Oncology Group, Palliative Care Organization, Medical Organization and the Association of Pain Oncology initiated a national palliative care program. The first palliative care association was founded in 2006 by algologists, followed by the organization of the first nursing training course by the same association in 2008. Turkish Ministry of Health announced a 5-year national cancer control program including palliative care in 2009 [11]. With the "Palya-Turkish" project of Ministry of Health in 2010, "palliative care" started to be recognized as a medical discipline [12,13].

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Also in 2010, Turkish Ministry of Health took the first step forward in "palliative care area" by a circular order and initiated "Home Health Care Service". Regarding to this issue, Middle East Cancer Consortium (MECC), in collaboration with San Diego Hospice Center organized courses for family physicians and nurses. Training was continued in 2012 with the organization of a more comprehensive course [14]. First step in the "hospital palliative care" was taken by the initiation of legal regulations about the structuring and functioning of these organizations, followed by a pilot study oriented towards adult patients resulting in the opening of first "Comprehensive Palliative Care Center" in the Turkish Ministry of Health, Ankara Ulus State Hospital in December 2012. For years, palliative care units were only available in oncology clinics and were only allowed to serve cancer patients until the creation of the center in our hospital which is planned to serve all palliative care patients in need.

## Model of Palliative Care in a Hospital

This center contains 11 private rooms, with the availability of a fridge, tea/coffee, etc. system, disability type bath and a toilet in each room. Wireless central monitoring system hidden in bedside panel, aspiration system, emergency response system and continue positive airway pressure (CPAP) support kit is also available. Ensuring a peaceful, quiet home environment in general, an ergonomic one for patients and a comfortable one for patients and relatives was created. TV, music and the Internet service are available. Also, patient greeting and admission area in the entrance, arena-style relaxation with an artificial waterfall and central patient follow-up desk are available. Doctors' room, recreation room, kitchen and bathroom with special transport system are located within this area. There is an associated bed-service area with support devoted to ambulatory patients. A part of this area contains pain, physical therapy and psychiatry clinics. Non-severe interfering room for "outpatient" pain patients, physiotherapy room and outpatient hospital room with bed are also available in the same location. The other area contains training room where patients and their families rest and receive training, an activity room, a winter and a summer garden, a place of worship and a kitchen that belongs to the patient's relatives.

Anesthesiologists work in our palliative care constantly in a 7/24 system. In addition, internal medicine specialists, cardiologists, general surgeons, pulmonary disease specialists and infectious disease specialists serve as consultants here. Physiotherapists implement bedside treatment to patients and they provide training to their family/caregiver. Bedside ultrasound, echocardiography, X-ray, hemofiltration and plasmapheresis are available. Support units like MR, CT, biochemistry, microbiology and blood center are open and available 24 hours.

Ten single-bed rooms belonging to the algological unit are available for the patients that undergone intervention with the possibility of a long-term follow-up in necessary conditions. As well as analgesics, invasive pain treatment is applied on the patients, and also the port catheter, neurolytic blocks are performed. Wound care team consisting of nurses, a palliative care physician, a plastic and reconstructive surgeon takes in passive/active wound care, surgery, corrective actions, which are implemented when necessary. Psychiatrists, physiotherapists, alternative medicine experts and "other area specialist" doctors are available for support and consultation services.

Psychologists working at the palliative care center make interviews with the patients and their relatives, and lead the team in managing the clinical process. For the spiritual care, two days a week, a preacher (male/female), discusses with all the patients and their relatives (individually or collectively) and provides information about the philosophy of Islam on life, death and life after death, religious tasks and tries to find solutions for their spiritual problems. He/She (preacher) also provides information for the palliative care team, takes place in relieving their spiritual and psychological feelings of burnout. On the other hand, home care team visits discharged patients on a regular basis to record the overall vital signs, provides training in terms of wound care, nutrition, the use of home mechanical ventilation and making checks, blood tests, and provides materials for the laboratory. Currently, construction of 16 palliative care rooms is still underway and planned to be completed within 3 months. In addition, a project of web-based tele-medicine services has been initiated to follow-up patients in the process of home care.

Doctors, nurses and allied health staff are given training in palliative care periodically in our hospital. In addition, for informational purposes, symposiums are held for other health care institutions and health care workers. In order to raise public awareness about palliative care, information about "Home Care", "Palliative Care", "Global Patient Care" is given, available both for health professionals and patients and their relatives through visual and written media channels, our official hospital web site, information brochures, books and they are updated regularly. Because of the ambiguity of policies and legal regulations of Ministry of Health in Turkey regarding palliative care, "Long Term Intensive Care Units" (LT-ICU) have been opened in our hospital. These units are used for solving the secondary or alternate problems of patients and for the implementation of alternate patient care. Support is provided in intensive care, in situations such as stress-induced ulcer bleeding, acute respiratory failure due to aspiration pneumonia, gross bleeding in catheter or ostomy destinations, acute abdominal pain, etc. or secondary complications due to disease/treatment, radiation pneumonitis, acute renal failure pleurisy, pericarditis, immune deficiency due to sepsis. In addition, interventional procedures, percutaneous endoscopic gastrostomy, and permanent vascular access device and ventilator in LT-ICU patients are followed in the process of adaptation.

## Results, Barriers and Discussion

Demographic data of palliative care patients followed from December 2012 is shown in tables 1 and 2. With the passage of the normal course of the disease after treatment, patients are re-taken for follow-up under palliative care and symptom care is continued accompanied by relatives or nurses. These processes increase the confidence towards health professionals (caregivers), provide reduction in patients' expectations and accelerate embracing the end of life. Unlike western countries, in Turkey, patient relatives often pray to "Allah" as a religious requirement of Islam, for their ill relatives to die quickly without suffering too much. This in Islam is an approach "Only Allah is capable of ending the life that he granted, Allah gives trouble in this world to his loved servants, but his/her sins will be forgiven and peace will be regained in afterlife". Models of palliative care and ways of approach towards euthanasia were examined in other Muslim countries [15,16]. During these ongoing pilot studies, overview of the Turkish and Muslim people towards death, acceptance and grief processes were closely experienced and according to this information, our dialogue protocols, maintenance methods, physical and spiritual approaches were reorganized, resulting in the development of a special algorithm exclusively for Turkey. Twenty percent of the raw materials used in the medical opioids in the world are produced in our country. Policies regarding oral morphine are not fully established and derivatives of sublingual fast/slow-release morphine are not available in Turkey. Doctors also do not have enough experience in the use and

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| Age (year) | 67.77 ± 15.70 |
| Gender (Male/Female) | 108/71 (60/40 %) |
| Duration of stay (day) | 10.16 ± 10.29 |
| Transfer from home | 97 (54 %) |
| Transfer from intensive care | 35 (20 %) |
| Transfer from other centers | 47 (26 %) |
| Discharged from hospital | 111 (62 %) |
| Transfered to intensive care | 40 (22 %) |
| Transfered to other centers or nursing home | 5 (3 %) |
| In-hospital deaths | 23 (13 %) |

Values are expressed as the mean ± standard deviation or number (%).
**Table 1:** Demographic Characteristics of Palliative care unit patients

| | N= 179(%) |
|---|---|
| Cancer | 54 (30%) |
| Complicating systemic disease (cardiac failure, hypertension, diabetes, respiratory failure) | 41 (23%) |
| Respiratory failure (Chronic obstructive pulmonary disease, pneumonia) | 15 (8%) |
| Complicating chronic renal failure | 5 (3%) |
| Geriatric patients (Dementia, Alzheimer's, Parkinson's disease) | 23 (13%) |
| Cerebral hypoxia, sequelae of head trauma | 8 (5%) |
| Cerebrovascular disease | 31 (17%) |
| Multiple organ failure | 2 (1%) |

**Table 2:** Primary Diagnoses

side effects of morphine [15]. Belief of morphine being a "sin", fear of addiction and the thought of "pain and suffering can cleanse sins", we also resulted in limited use of morphine like other Muslim countries [16-19]. In order to overcome these problems and for "spiritual care" to take place in palliative care, National Religion Psychology and Spiritual Care Workshop event was organized in May 2012. In this regard, those who had doctorate in psychology of religion were given the chance to attend to specialization and graduate education in the field of psychology of religion. In addition, decisions were taken on building their legal infrastructure [20].

## Conclusion

In our hospital, we shared our experiences and logic model with colleagues and identified which joint steps to take in the future by organizing a symposium on the subject in June 2013. We are aware that there is still a long way to go, and a lot of work to be done for the functioning of a comprehensive palliative care. We believe that increasing the number of trained personnel and resolution of legal and financial aspects are the key issues in spreading palliative care throughout the country. In this regard, our hospital sets a good example for many State and University hospitals, an awareness of palliative care started to increase, and many centers were opened or started preparations to build new palliative centers. In order to increase public awareness and to spread it throughout the country, civil society organizations, municipalities and the media also play a key role and appropriate steps in this regard were taken. In addition, telemedicine project was initiated for home care, which is a subgroup of palliative care. By the year 2014 many of these applications is expected to be available in the center.

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