

## Special Article – Palliative Care

# International Palliative Care: Update on Turkey's Experience on Developing Community Palliative Care Programs

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## Short Communication

Palliative care (PC) is the comprehensive integrated care of patients and their families who face problems associated with life-threatening illness. It prevents and relieves suffering of any kind – whether physical, psychological, social or spiritual – experienced by adults and children living with serious chronic or life-limiting health problems [1,2]. The need for PC is increasing along with the ageing of world population and the rise in the incidences of cancer and other non-communicable chronic diseases. It is estimated that PC is needed in 40–60% of dying patients [3]. In 2014, the World Health Assembly Resolution on Palliative Care called for all countries to incorporate PC provision into their healthcare systems. Unfortunately the desired outcomes have not yet been obtained, and a huge unmet need for PC still exists for chronic life-limiting health problems in most parts of the world.

Turkey is among the countries which have recognized the necessity for PC services and initiated a community-based PC program. PC awareness, which started there in the 1990's, gained acceleration with the 'Transformation Program in Health. At the center of this program is the protection of the individual's health in a community setting. 'Good quality and sustainable health service accessible to everybody' is the program's main theme [4]. In 2009, the Turkish Ministry of Health launched a national cancer control program for the next five years under the main headings: Registry, Prevention, Screening and Early Diagnosis, Treatment and Palliative Care. Of these, PC was the weakest sector of cancer control activities [5].

The Pallia-Turk project in 2010 focused on two main topics: opioid availability and implementation of a community-based PC model. With Pallia-Turk, Turkey worked to educate health professionals and regulators to overcome the perceptual, cultural and financial obstacles that many clinicians face in their effort to promote basic issues of cancer, PC awareness and pain control [6]. Close collaboration with some national and international cancer PC organizations increased the progress of PC activities. The Cancer Control Department pioneered the first domestically produced morphine tablets through the efforts of a national drug company and Hacettepe University. Several workshops, symposiums and conferences were organized

to improve PC recognition and develop skills for quality care. In 2014, the Turkish Ministry of Health published guidelines entitled 'Directives for Palliative Care Services Implementation Procedures and Principles' to regulate the standards of PC units established in hospitals and revised them one year later. The directives highlighted the importance of teamwork, psychological, social and spiritual support, while integrating PC provision for patient and family. The role and necessity of close relations with family physicians and home care teams were also emphasized.

After the directives, the small number of PC units increased rapidly to a total of 4,752 registered hospital beds in 358 healthcare settings in 81 cities by 2018. Unfortunately, there are only two PC units for children in the country. Although Turkey has reached about 50% of PC beds for 1,000,000 inhabitants as recommended by the European Association for Palliative Care [7], nearly all are hospital beds. Lacking are hospices, community hospice teams, home PC teams or 'hospital at home' organizations. Though the existing home care teams are not specialized for PC, they are expected to provide it. A certification program of PC nursing was approved by the health ministry and initiated across the country aiming to cover all nurses working in PC units. A workshop on 'Pain Management in Palliative Care' was organized with participation of many experts (pain specialist's, medical oncologists, geriatricians, family practitioner, anesthesiologists, pediatricians, emergency experts, and so on) and national guidelines were published in 2016.

Although the physical conditions of the units are well established, gaps and barriers in PC provision must be addressed. In Turkey, there is no formal comprehensive PC curriculum or PC specialty. Training is usually obtained from symposiums, workshops and literature, whereas it should be included in the curricula for medical faculties, nursing and related professionals' education. Opiophobia is still common not only among healthcare team members but also among patients and families. Many types of opioids are lacking in the market. Despite some improvement, the country has a complicated and restrictive regulatory system for prescribing opioids. Many professionals are reluctant to prescribe opioids due to confusion about side effects and burdensome procedures.

Turks have a traditional family structure. Families are extensive, and when a family member experiences a life-limiting illness, all members gather around them to take part in their care. Although patients with advanced illness nearing end of life report a wish to be cared for and to die at home, most of them still present to emergency departments in the last weeks or days of life as in several other countries [8,9]. The place of death is most often the hospital, mainly because of inadequate support in the community. For advanced illness, continuity of care throughout the disease trajectory and across

different settings in the healthcare system is mandatory. Therefore, expanded community and home-based PC with input from specialist physicians enabling management of complex pain and other symptoms can be beneficial [10]. Patient and caregiver education, coordination of referrals, regular home visits, or available telephone counseling and psychosocial support may offer alternatives to prevent PC patients' admission to emergency departments with unmet needs. Care organizations must diversify by including institutions offering social services besides healthcare. There is also great difficulty in informing patients of a diagnosis of cancer. Because family members do not want patients to be fully informed of cancer diagnosis and the incurable nature of the disease, the bad news and poor prognosis are frequently withheld. In addition, the right of dying patients to issue advance directives and do-not-resuscitate (DNR) orders is not yet legal in Turkey.

PC must be available for all patients regardless of age and stage of the disease. Although cancer patients receive the greater part of care in many countries, patients with cardiovascular diseases, chronic respiratory diseases, neurologic diseases, dementia, and so on also experience many symptoms that must be treated [11]. It was estimated that at least 20% of cancer patients and 5% of non-cancer patients require specialist PC in the last year of life [12]. There is a need to improve care strategies for geriatric patients with advanced dementia, stroke or other neurologic diseases. In some European countries, these populations are mainly supported in neurology clinics. In 2016, a consensus was made for the collaboration of neurology and PC clinics in the care of chronic progressive neurologic diseases [13]. In our country, because the number of centers for stroke and posttraumatic brain damage is inadequate, these patients are given care at PC clinics. Patients with neurologic diseases are generally bed-bound and have longer duration of functional impairment requiring prolonged basic care. The inadequacy of home-based palliative care and other out of hospital organizations produces difficulties in the continuity of care at discharge which may lead to longer hospitalization periods. Patients with cardiovascular diseases also have limited access to PC units. The uncertainty in determining prognosis and length of survival in patients with diseases other than cancer may influence the decision of PC referrals.

Although there are many headings to be investigated and improved, the identification of people in need of palliative care, optimal organization methods of PC networks that are based in the community and home, adequate pain and symptom control, PC for children, education and training of healthcare professionals and caregivers, opioid accessibility, end of life and advanced directives, communication skills, coordination for the continuity of care, care for non-cancer patients, and solution of financial and staffing problems constitute the prerequisites. Optimal PC organization and research for consensual definition of goals and quality standards, and uniform national criteria for admission and discharge at all levels of care must be carried out. Continuity of care throughout the disease trajectory and across different settings in the healthcare system is mandatory. Admission of patients to PC services usually occurs at a late stage. There is still some misunderstanding about the purpose and nature of PC. It is regarded as end-of-life care or a place to facilitate the discharge of intensive care unit patients. There may be patient and family reluctance, as PC is generally associated with dying. The

potential benefits of early integrated PC have yet to be fully realized by patients, families and health-care professionals. A sustainable, quality and accessible PC system should be integrated into primary healthcare, community and home-based care, as well as supporting care providers such as family and community volunteers [14]. Last year, the Turkish Ministry of Health started work on a plan to set up mobile home-based PC teams integrated with the existing home care teams.

The development of global hospice-PC activities of countries was categorized into four groups by National Hospice and Palliative Care, Worldwide Palliative Care and International Observatory on End of Life Care (IOELC). In 2006, Turkey was assessed as a Group 2 country with capacity building activity, but no established hospice and PC services. Its category rose to Group 3b in 2011, characterized by the development of PC activism in several locations, with growth of local support in those areas, the availability of morphine, several hospice-PC services from a community of providers who were independent of the healthcare system, and the provision of some training and education initiatives by hospice organizations [15]. Although many goals remain, Turkey's aim is to be a 4b country where advanced integration into mainstream service provision is obtained.

PC is a basic human right and an essential component of comprehensive and integrated care. It should be considered an ethical duty for health professionals and be provided in any healthcare setting, including patients' homes [2]. Many models of PC programs have been implemented in different countries, and results show that they can improve both patient and caregiver outcomes [16]. However, PC is not yet equally available to all patients, even in highly organized systems. National health systems are responsible for including PC in the continuum of care for patients with chronic life-limiting health problems and developing national policies and plans in accordance with principles of universal health coverage [14]. Future studies are needed to improve PC programs compatible with the culture, determine the appropriate measures for assessing unmet needs of patients with life-limiting disease and their families, and produce guidelines for effective treatments.

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