

Mini Review

Palliative Care: Its Importance and the Practice in Turkey

Gurhan N*Department of Psychiatric Nursing, Gazi University
Faculty of Health Sciences, Turkey***Corresponding author:** Nermin Gurhan, Department
of Psychiatric Nursing, Gazi University Faculty of Health
Sciences, Turkey**Received:** March 30, 2016; **Accepted:** June 01, 2016;**Published:** June 03, 2016**Abstract**

The concept of "palliative care" has not yet been fully established in our country; it is often considered as "supportive care" or "end stage care" and is usually put on par with pain control. Compared with western countries, the integration process of palliative care into the health care system in our country has been very tardy. Even though no hospices and no regulation for these institutions exist in Turkey, 10 palliative care centres, all in university hospitals, were opened in 2009. In this context, the first palliative care unit was opened in Ege University. And again in the same university, "Palliative Care Practice and Research Centre"; (EÜPBM) was established with the decision no. 23/13 of the Senate of Ege University taken on December 28, 2010 pursuant to the article 7/d-2 of the Law no. 2547 amended by the Law no. 2880 and the approval of the Higher Education Steering Board of YÖK on March 2, 2011. The code of the Centre of EÜPBM came into force after its publication in the Official Gazette no. 27905 of 14.4.2011. In accordance with the statistics provided by the General Directorate of Health Care Services under the Ministry of Health, 148 palliative (support) care centres provide services with a registered bed capacity of 1672 in 29 Healthcare Regions as of January 2016.

Keywords: Palliative; Care; Palliative care**Body Text**

According to the definition of the American Hospice and Palliative Medicine Academy and American Medicine Institute, palliative care is the comprehensive management of physical, social, spiritual and existential needs of patients diagnosed especially with diseases with no treatment options. By definition, palliative care aims to provide the best possible life quality by reducing the pain, controlling the symptoms and improving the functional capacity in a mindful approach in terms of personal, cultural and religious values as well as beliefs and habits of the related individuals. The World Health Organization (WHO); defines the palliative care 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".

Even though palliative care was only applied in the end stage of patients' lives in the beginning, nowadays it is applied with the aim to reduce the suffering and improve the quality of life in individuals facing problems arising from chronic and life-threatening diseases, and it is generally advocated that it should be applied in the earliest possible period [1]. The Worldwide Palliative Care Alliance (WPCA); defines the diseases where palliative care is needed as follows: Cancer, HIV/AIDS, motor neuron diseases, muscular dystrophy, multiple sclerosis and dementia in its end stage. Other authors added other diseases into the list such as brain injuries and cerebral stroke, heart diseases, liver failure, Alzheimer disease, spinal cord injuries etc. [2].

The concept of "palliative care" has not yet been fully established in our country; it is often considered as "supportive care" or "end stage care" and is usually put on par with pain control. Compared with western countries, the integration process of palliative care

into the health care system in our country has been very tardy. This delayed integration of the palliative care in Turkey can be attributed to the extended family structure in our country where the care of patients and elderly people were, until recent times, under the responsibility of the family members. But after the transition from extended family structure to nuclear families, the families can no more get on top of the problems arising from such diseases and the related burdens. At the same time, an urgent need arose for a nursing care service at home with public support integrated in our healthcare system on the grounds of several factors such as a rapid increase in the number of elderly individuals, a high number of people with chronic diseases and disabilities that has reached a ratio of 12%, unwillingness of family members to assume responsibility as care-takers, developments in technologies connected with nursing services at home, early discharges from hospitals that become more and more widespread and insufficient preparation of family members for early discharges etc. "Public health nurses" were delegated with the task of nursing and monitoring the patients with chronic diseases at home in accordance with the directive no. 154 issued pursuant to the Law no. 224 on the Socialization of Healthcare Services that went into effect in 1961. But this service could not be provided at the desired level because of the lack of the required sub-structure for the implementation of the law. Beginning from the 1980s, institutions of "home nursing for elderly people and patients" providing nursing care and support by nurses began to be established in line with the demands of the society.

"The Ordinance on Home Nursing Services" published in the Official Gazette no. 25751 on March 10, 2005 is the first legislative regulation covering home nursing services. Other legal regulations were realized by the Social Services and Child Protection Agency under the Office of the Prime Minister. Within the concept of home nursing, healthcare service is provided to bedridden patients unable

to go to a hospital at home and in family environment. The group of patients of first priority in terms of home nursing was also defined: it included bedridden patients, patients with diseases of respiratory tract, patients having muscular diseases in advanced stage, patients with cancer in terminal stage who need palliative care and newborn babies [3]. However healthcare services at home began to be provided five years too late by force of the directive no. 3895 issued by the Ministry of Health on February 1, 2010 [4]. The projects in association with palliative care are carried out by the Ministry of Health [5]. A workshop on the palliative care organization was held on October 15, 2010 and projects for legislative regulations were designed such as "The Draft of the Directive on the Public-Based Palliative Care Centers" [6]. A working group of palliative care was set up and "Palliative Care Draft Organization Model 2011" was devised in the Ministry [7]. Cancer Fight Office under the TR Ministry of Health carried out a survey across the country to assess the current situation. Then a project was devised under the name Palya-Türk that was then accepted as one the most important building stones of 2010-2015 National Cancer Control Programme. Basically, Palya-Türk is a system based on family practice and built primarily on the nurses providing care service at home with the support of Cancer Early Diagnosis, Screening and Training Centres; (KETEM) and non-governmental organizations [8].

The first institution that provided long-standing palliative care to patients were "Cancer Care Centres" established by the Turkish Oncology Foundation in Yeşilköy İstanbul. These centres provided service between 1993-1997. But as, in that period, the patients who received palliative care were not reimbursed within the social security system, the donations fell short and the concept of hospice was not sufficiently understood by the patients and their families, these institutions could not stand up to the conditions and were closed. Another, and second, attempt to establish a "hospice" for palliative care was the one initiated by the Foundation of Hacettepe Oncology Institute in 2006. In this context, a historical residence near Hacettepe Oncology Hospital was turned into a hospice with 12 rooms. However because of the lack of legislative regulations, it was projected that the house named "Hacettepe Hope House" would provide a minimal nursing and accommodation service to patients with cancer for a few weeks during their treatment and the following period [9]. In the following period, some other centres were opened for this purpose: a Palliative Care Unit of Anadolu Healthcare Centre [10] was established within the Oncology Department in 2006, and again in 2006, Tülay Aktaş Palliative Care Unit was opened within Ege University followed in July 2007 by the establishment of the Pain and Palliative Care Clinic within Dr. Abdurrahman Yurtaslan Oncology Education and Research Hospital [11].

In addition to these, a Working Group for Supportive Treatments was created within the structure of Turkish Oncology Group (TOG) in 1999 with about 40 members from 18 different centres. This group has made contributions in terms of training and improving the standards in the field of palliative care through meetings and other events. The issue of palliative care was discussed in a more intense manner in the congresses held after 2000, but no significant development could yet be noted in terms of practical relevance and currency of this service across the general population [9].

In 2006, the association of Palliative Care was established with the aim to provide multidisciplinary care to cancer patients in the terminal stage. This organization has also been accredited by the Palliative Care Group of the European Medical Oncology Union.

Generally, palliative care is not included in the study programmes in the faculties of medicine and nursing including the residency education and it is not accepted as a field of specialty [9]. The education for home nursing is provided as a subject within the programme of Public Health Nursing. It is a practice with varying working hours. The subject of palliative care was first initiated as an optional subject within the Nursing Programme of the Faculty of Health Sciences of Başkent University in 2006 and it is still lectured in this form. In recent years, it has begun to be given as a subject within psychiatry nursing in a few nursing programmes. Furthermore, home care certificate programmes are provided in some nursing faculties and nursing departments in the faculties of health sciences with the support of home nursing associations.

In recent years, Turkey ensured the support of the European Union (EU); the Middle East Cancer Consortium (MECC); and World Health Organization (WHO); in the field of palliative Care/Treatment where a rapid development has been recorded. Four workshops of large scale were held in 2008 within the framework of the Biennial Cooperation Agreement (BCA); 2008-2009 signed between the TR Ministry of Health and Regional Office for Europe of the World Health Organization (WHO); and action plans were designed during these events to improve "The National Cancer Control Programme" in 2008 [12]. Generalization of palliative care services was strongly underlined as an important constituent in the list of priority measures to be taken against the increasing cancer incidence within "The National Cancer Control Programme".

Even though no hospices and no regulation for these institutions exist in Turkey, 10 palliative care centres, all in university hospitals, were opened in 2009. In this context, the first palliative care unit was opened in Ege University. And again in the same university, "Palliative Care Practice and Research Centre"; (EÜPBM) was established with the decision no. 23/13 of the Senate Ege University taken of on December 28, 2010 pursuant to the article 7/d-2 of the Law no. 2547 amended by the Law no. 2880 and the approval of the Higher Education Steering Board of YÖK on March 2, 2011 [13,14]. The code of the Centre of EÜPBM came into force after its publication in the Official Gazette no. 27905 of 14.4.2011. In accordance with the statistics provided by the General Directorate of Health Care Services under the Ministry of Health, 148 palliative (support) care centres provide services with a registered bed capacity of 1672 in 29 Healthcare Regions as of January 2016.

Whilst "The Code of Practice for Palliative Care Services" regulating the minimal standards to be applied for the services given in the palliative care centres on an inpatient basis came into force pursuant to the related official approval no. 253 from 7.7.2015, an amendment was made in Article 12 of the Directive issued for the amendments to be made in the Directive of Healthcare Practices of the Social Security Institution through publication in the [15] Official Gazette no. 29597 from 18 January 2016, and the statement "the formalities about foreign nationals who have general health insurance or the ones who have a dependant status through someone with

general health insurance” was added following the statement “the formalities about palliative care” included in the subparagraph (b) of the second paragraph of the Article 5.2.1 of this directive.

In spite of these developments and the great deal of distance covered, our country is still beset by some problems in the field of home nursing services some of which are as follows:

- Insufficiency, differences and confusions in terms of field definitions,
- Lack of consciousness, misperceptions,
- Lack of multi-disciplinary approach (simultaneous involvement of several scientific branches),
- Lack of, and confusion in, regulations,
- Lack of sufficient personnel,
- Lack of service norms,
- Lack of education/training norms,
- Lack of training,
- Lack of supervision,
- Lack of coordination and collaboration between governmental agencies,
- Unrecorded, unapproved services, wide-spread illicit work and the related problems,
- Insufficiencies in the public and private financing system in terms of home nursing,
- Isolation of family members who take part in the care process, insufficient educational status of these family members and the lack of support for them.

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