Review

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Palliative Care: The Italian State of the Art and a Worldwide Overview

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Abstract: The right to live with dignity during the final stages of existence, enshrined in national and supranational Charters of Rights, represents a significant step towards humanizing medicine and is integral to the right to health. Palliative Care, rooted in health, dignity, and therapeutic self-determination, has emerged as a fundamental human right and a moral imperative within health systems. It seeks to alleviate suffering, emphasizing the holistic well-being of patients with life-limiting illnesses. This paper provides a comprehensive global perspective on Palliative Care, with special attention to its implementation in Italy. Palliative Care is a crucial dimension of care, designed to enhance the quality of life for patients suffering from progressive and incurable diseases. Despite its growing need due to an aging population and increased prevalence of chronic illnesses, still remains a significant disparity in access to these essential services worldwide. Insufficient resources, legislative constraints, and limited training for healthcare providers pose challenges to the widespread adoption of Palliative Care. In Italy, although laws have been enacted to ensure the provision of Palliative Care, its availability remains inconsistent across different regions. Financial constraints and insufficient support hinder the comprehensive dissemination of these services. Recognizing the significance of Palliative Care, the Catholic Church also endorses its implementation as a response to human suffering and an approach to end-of-life care. Efforts to strengthen Palliative Care are critical to meeting the rising demand and ensuring access to compassionate and dignified care for all individuals in need. Through legislative advancements and adequate resources, Italy can make significant strides in advancing the provision of Palliative Care.

Keywords: Palliative Care; Bioethics; end of life; Law no. 38/2010

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1. Introduction

The right to live with dignity the final stages of existence (contained in the Charters of Rights of national and supranational rank) constitutes an impetus towards the humanization of medicine and is part of the right to health (to be considered no longer the mere absence of disease or the average and statistical qualification of a general standard, but the global status of psycho-physical well-being of the person in his identity, expression of the personalistic principle) responding to the need to bring a benefit to the moral and psycho-physical integrity also of the terminal patient [1]. To date, the physician's mission is to ensure respect for the dignity and therapeutic self-determination of the patient according to the principle of equity in access to care and the quality of care. The aim of this paper is to give a worldwide overview about Palliative Care with a focus on the Italian state of the art.

2. What is Palliative Care

Health, dignity, and therapeutic self-determination are the pillars of modern Palliative Care, which have become a fundamental human right and a moral imperative of all health systems that consider relief from suffering an essential dimension of care [2]. As explained by the recent definition of the International Association for Hospice & Palliative Care these treatments aim to improve the quality of the remaining life of the patient suffering from a worsening disease, with poor prognosis and unresponsive to any type of treatment, with a holistic and personalized care model that frees him from the "total pain" (that is, from pain not only in its physical dimension but also emotional, social and spiritual)[3]. This happens through the management of the needs of the entire patient/family nucleus by the multidisciplinary team, without anticipating or postponing death and excluding both abandonment and therapeutic obstinacy in the perspective of the revolutionary vision of "to care" which, through the pioneering contribution of Dr. Cicely Saunders (and the establishment of the Hospice Movement -1967- a new method of clinical treatment for achieving relief of the incurable patient in "A Space for Dying") aims at an accompaniment towards the inevitable end overcoming that, until the first half of the twentieth century, was traditional medicine (inspired by the vision "to cure" that considered the dying bearer of medical disvalue and pain an instrument of expiation) [4].

3. A worldwide overview of Palliative Care need

With the recognition of the protection of the dignity of the person as a cardinal principle of the right not to suffer, the fundamental nucleus on which Palliative Care is based, this prototype for the protection of the "process of dying" (thanks to Professor Vittorio Ventafridda, protagonist of this development both at supranational and Italian level) has been taken up both in Europe (first recognition, in 1988, by the European Association for Palliative Care) and by international organizations (first definition, in 1990, by the WHO) used to promote the use of these treatments turned out to be one of the most efficient models for the changes of recent decades[5,6].

The ongoing rise of Palliative Care is not only due to a growing need caused by the progressive aging of countries with high economic development and the increase in the incidence of chronic and evolutionary diseases for which there is no possibility of cure (a research conducted by the World Health Organization -Worldwide Palliative Care Alliance estimates in Europe an annual need of 560 adult patients per 100,000 inhabitants: of these, 60% are affected by non-oncological diseases, overturning the idea that palliative care was born in oncology to accompany the terminally ill in their last days – to date only 40%) [7–12]. Also, the integration of active oncological treatment with the delivery of Palliative Care is one of the most effective responses for the psycho-physical well-being of a patient with advanced cancer. Research shows that with the same oncological treatment, patients who had consented to early palliative treatment, according to the paradigm of simultaneous care, in line with the results of an early and shared planning of care - a decisive tool for aligning contemporary medicine with patient/family choices - enjoy better quality and increased life expectancy by presenting lower rates of depressive symptoms assessed through multidimensional assessment of needs [13].

Unfortunately, however, on the occasion of World Palliative Care Day (9 October 2021) the new Report (standard indicators to be used to assess and monitor the provision of Palliative Care in countries around the world) and the Technical Report (practical approaches and resources to support policy, strategy and practice in the field of Palliative Care) released by the WHO stated that despite the fact that there are over 56.8 million people in need of this care (of which 25.7 million in the last year of life) worldwide, only 1 in 10 people are receiving them, estimating a doubling of this need globally by 2060 [14].

Recently, a WHO report 107 - Left behind in pain - highlighted that, globally, there are significant disparities in access to opioid drugs for cancer care. In particular, 90% of the distribution of opioid drugs equivalent to morphine is the prerogative of the richest 10% of countries and developed to the world. The reasons for this disparity are to be found in the availability of resources (technological and economic) together with legislative and political choices that are most often restrictive in the countries developing.

Urgent action and political support are needed to increase access to these essential services that have become indispensable also due to the recent COVID-19 pandemic with the need for adequate training for all healthcare workers (because the demand for palliative services exceeds that provided by specialist teams alone) [15,16].

Where are we at in Italy?

Even in Italy we are still far from a widespread diffusion of Palliative Care despite the right to the best possible treatment of suffering (in hospital care, at home, in Hospice) is now guaranteed to everyone by a specific Law (Law no. 38/2010, one of the first rules adopted in Europe establishing qualified assistance in the palliative field through adequate health and social assistance support for the patient and his family) which has met with the consent of professionals and non-profit organizations - SICP (1987), FCP (1999), Cittadinanzattiva (2005) allocated on the national territory since the initial consent only at home level (1979) [17]. This Law is the point of arrival of a revolutionary process that began with Law no. 39/1999 launching the national program for home palliative care and the implementation of Hospices and continued with a series of Agreements in the State-Regions Conference that have made the field of Palliative Care one of the most defined and shared among all those of territorial assistance at national level [18,19]. Law no. 219/2017 takes up the concept that, through informed consent, the Palliative Cares are an institution to be promoted in care relationships as well as to be ensured even in the event of refusal or revocation of health treatment both in advanced treatment directives (DAT) and in shared care planning (PCC) and for which continuous and adequate training of healthcare personnel is necessary [20].

Although the undoubted legislative goals achieved (in 1999 n. 5 Hospice for 55 beds; in 2005 n. 165 Hospice for 1888 beds; in 2010 n. 229 Hospice for 2592 beds; in 2014 n. 230 Hospice for 2600; in 2020 n. 277 Hospice for 2963; in 2022 n. 307 Hospice for 3326, with a more significant concentration in Northern Italy than in the Southern Regions) as well as a recent update of the “essential levels of assistance” (which should involve the absence of budget limits or disparities in places of care and that, in the perspective of early palliative care, has expanded the provision to the early stages of the incurable disease including, in the drafting of the "Individual Care Plan" -PAI- the "multidimensional assessment of needs" -VMD) and a jurisprudence deployed on attributing responsibility to physicians for the unjust pain suffered by the terminally ill for the failure to administer the necessary palliative cares (constituting a specification of the right to health), the diffusion of the structures, the ramification of the "National networks of palliative care for continuity of care" (which provides three networks for management, namely palliative care for adults, pain therapy and palliative care and pain therapy for the pediatric population) and the "Information campaign for citizens" photograph a discrepancy in legislative application at regional level[17,21–26]. That is due to the lack of resources following cuts in health funds (Decree of the Ministry of Health no. 70/2015) to deal with the international financial crisis of 2007 and the sovereign debt crisis of 2011 [27]. Current data show that, thirteen years later, seven out of ten citizens still do not know Law 38/2010 (of these: 38% have pathology that causes pain, 80% with chronic pain) and only one person out of four among those who would be entitled to it receives palliative cares (regional coverage rate: Lombardy: 33%; Emilia-Romagna: 26%; Lazio and Valle-d'Aosta: 25%; Basilicata, Sardinia, Friuli-Venezia Giulia: 24%; Veneto: 23%; Autonomous provinces of Bolzano and Trento: 29% and 27%) compared to 543,500 adults in need/per year (regional need: Lombardy 83,176; Lazio 50,221; Campania 47,082 potential patients) and a total offer of only 124,063 units (79,648 patients assisted at home; 42,572 in hospice; 1,843 in day hospital) [28,29]. To these must be added 35,000 needy minors of which only 5% can access it (Regions with greater shortages: Campania, Marche and Liguria) [30].

Therefore, to date, it is necessary to strengthen the CP, adopting a framework of implementing measures consistent with the principles and regulatory provisions by mapping the organizational models in order to fill the inhomogeneities and make the nodes of the welfare network dialogue in an optimal way, also because the current gaps are one of the reasons that can induce the terminally ill to choose the most extreme route of medically assisted suicide to end his suffering [31–33].

As far as Italy is concerned, we must refer to those leading cases that, in recent years, have cracked the idea that Palliative Care or continuous deep palliative sedation can always be considered modalities conforming to one's personal dignity of a dying person who (only in cases where he is: capable, with irreversible pathology source of intolerable psychic and / or physical suffering and dependent on a life-sustaining therapeutic intervention) could prefer his right to obtain death thanks to a lethal drug (despite the most recent obstructionism and illicit delays in the procedure for ascertaining the requirements) [34,35]. In these cases the Palliative Cares play a fundamental role as both the mechanism of the "Double Pronunciation" of the Constitutional Court (triggered by the Cappato/Antoniani case following the inertia of the Legislator) and the bill on the "Provisions on voluntary medically assisted death" (approved by the Chamber of Deputies on 10 March 2022 but not by the Senate due to the change of Legislature) considered them the pre-requisite of the subsequent choice to resort to pharmacological death (to refuse or interrupt, to proceed with this request) in order to avoid that health facilities prematurely renounce to guarantee therapies aimed at eliminating the suffering of the patient becoming a sort of balance to that basic incompatibility with the practice of euthanasia (in fact, the countries that legalize it discourage the use of CP - only 10% - as are usually considered alternative practices, axiologically incompatible)[36–39].

Given the delays for this kind of care, the choice adopted by Italy could make feasible a path that, if not imposed compulsorily, may not find concrete application, urging, again, to strengthen the offer: in fact, in this line of thought are resumed the principles contained in Law 38/2010.

It is hoped that a specific rule on the end of life will be approved as soon as possible and outline a clear legislative procedure, in line with the dictates of jurisprudence, which always respects the (essential) condition of personal dignity (to date, unfortunately, still too often disregarded).

Palliative Care, the Vatican’s view

Since the protection of life is one of the prerequisites of Palliative Care, the Catholic Church also favors their provision considering them the only tool that can be used in the perspective of the end of life: even the Pontifical Academy Pro Vita highlights how Law 38/2010 is still little known and applied today, while "it would be a concrete response to the suffering of many people, for true help and accompaniment" [40–42].

Conclusion

Therefore, it can be concluded that, to date, in a vision shared both worldwide and nationally (both by the Vatican State and by the Italian one) Palliative Care are the indispensable approach in order to heal, at least, the “wounds of the soul of captive bodies” [43]. Therefore, to increase them is necessary to guarantee, to all applicants, the administration. One step in that direction is the recent news of the Italian legal system: since 23 September 2021, the SICP has been accredited in the List of Scientific Societies and Technical-Scientific Associations of Health Professions, at the Ministry of Health - Directorate General of Health Professions and Human Resources of the National Health Service. In addition, in the autumn of 2022 the first "Specialization Schools in Medicine and Palliative Care" started for graduates in Medicine and Surgery, defining the need of a specific training on the subject, which defines its value, allowing the National Health System to better respond to the needs of patients and their families [44–46]. Until now, despite the progress within the University (establishing the need for specific credits) the graduate could become a palliative physician only through specializations identified as equivalent (Anesthesia and Resuscitation, Hematology, Geriatrics, Infectious Diseases, Internal Medicine, Neurology, Oncology, Pediatrics, Radiotherapy) together with the frequency of specific training and updating courses.

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