

The state of Home Palliative Care in Portugal



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Abbreviations: HPCST: Hospital PC Support Teams; PC: Palliative Care

Mini Review

According to World Health Organization over than 40 million people per year worldwide, require palliative care (PC) [1]. With the increase of life expectancy, as consequence of better living conditions and better health care, diseases with no prospect of curative treatment have increased, and the need for PC arise [2].

In Portugal, PC emerged in the early 1990s. The first important marks of PC in Portugal were the foundation of the Portuguese Association for Palliative Care (“Associação Nacional de Cuidados Paliativos”) in 1995 and the *Home Palliative and Long-Term Care Team in Odivelas Healthcare Center* (“Equipa de Cuidados Continuados e Paliativos do Centro de Saúde de Odivelas”) in 1997. In 2006, the Portuguese government approved the creation of the *National Network for Integrated Continuous Care units* (“Rede Nacional de Cuidados Continuados Integrados - RNCCI”), responsible for ensuring *national coverage of needs of people in dependency on continuing care integrated and palliative care* [3]. In 2012, the approval of a new law (law nº52/2012) made palliative care accessible for all Portuguese citizens, improving the equity of the national health care system regarding PC [3].

All primary, prehospital, hospital and Integrated Continuous Care services should be able to identify patients with palliative needs, provide an adequate PC and, in the case of greater clinical complexity, ask for support to specific teams, which may intervene as consultants or in the direct provision of care in a collaborative and integrated PC model [4]. Whenever possible, the patient should be accompanied at the place of their preference, knowing that most end-of-life patients prefer their home [5].

Home Palliative Care Teams give care to patients at their homes and provide support to their formal or informal caregivers and families, as well as they offer advice to family doctors and

nurses to provide care at home [4]. With Home Palliative Care, patients feel more comfortable, safe and loved; they spend more time with their families; the daily routines have a greater flexibility; families are more involved in the process of patient care and aggressive treatments that consume resources are prevented [6]. Understandably, more than 50% of patients want to be treated and die at home, despite this, in Portugal, 33% of them do not see their desire respected [7].

According to the methodology defined by *Murtagh and Higginson* and accepting that death registers and causes of death are a credible way of assessing needs in developed countries, and that 69% to 82% of those who die need PC, in Portugal, 71.500 to 85.000 patients needed PC [8]. For Home Palliative Care the recommendations suggests, at least, one team of Home PC (HPCT) per 100.000 or 150.000 habitants. Considering this numbers, there should exist between 66 e 101 HPCT [4]. However, in Portugal there are only 20 HPCT and only 12 of those are linked to RNCCI. Hospital PC support teams (HPCST) that support the entire hospital structure should exist at 1:1 per hospital or hospital centre. In 2016, 37 HSCPs were identified, what means that only five, of the 42 hospitals/hospital centres and Local Health Units in Continental Portugal, do not currently have HSCPs. Nevertheless, efforts should be made to assess the working conditions of the existing teams [4].

Internationally, there is growing interest in monitoring palliative care (PC) development. However, health care in the later stages of life is, in general, poorly developed in the European countries, when compared with United States, Canada or Australia, for example. Addressing this matter, a ranking classification to compare scores for PC development in the countries of the European Union (2007-2013), was created. In that study the U.K. achieved the highest level of development,

followed by Belgium, Holland and Sweden. In comparison to 2007, Holland, Malta, and Portugal showed the biggest improvements, whereas the positions of Spain, France, and Greece deteriorated [9].

According to *Portuguese Strategic Plan for the Development of Palliative Care 2017-2018* there is an intention to construct the National Network of Palliative Care ("Rede Nacional de Cuidados Paliativos-RNCP"). The national network of PC should be balanced with regard to proximity to services and rational management of limited resources; redundancy and complementarity of services offered; comprehensive response and response to the needs of patients with palliative needs and their families. Eight general strategic lines were defined to achieve these objectives, they are:

- i. Organization and Coordination;
- ii. Improvement and generalization of PC basic level;
- iii. Adequacy of specialized assistance resources in PC;
- iv. Training and qualification of health professionals;
- v. Accreditation and monitoring of specialized PC teams;
- vi. Improvement of information systems;
- vii. Information and awareness of the population;
- viii. Research in PC [4].

Now that the year 2018 is over, it is important to carefully examine the strategic plan applied and analyse its

implementation. Above all goals, doctors and other health professionals should respect the autonomy of the patient, and struggle to ensure that, whenever possible, death may occur at their preferred location, and in the company of who the patient chooses.

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