

Place of Palliative Care in Heart Failure

Lugar dos Cuidados Paliativos na Insuficiência Cardíaca

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Introduction

Palliative care (PC) improves the quality of life (QoL) of patients and of their families who are facing challenges - physical, psychological, social or spiritual - associated with life-threatening illnesses. Additionally, it is described that early delivery of PC reduces unnecessary hospital admissions and the use of health services, as Emergency department. Unfortunately, it is estimated that worldwide only about 14% of people who need PC receive it.¹

Actually, most of the policies regarding PC across the European countries are dedicated to oncology patients. However, in developed countries other diseases represent the leading causes of death and morbidity, as cardiovascular diseases. In Portugal, heart failure disease (HF) is the second cause of death and a prospective study performed indicates that these numbers are going to have an exponential increase in the next decades.²

HF syndrome is characterized by a range of signs and symptoms that vary along the disease's trajectory.

Advanced HF is a life-shortening condition and planning for adverse events and the end of life should be integrated during early phases of the illness. Evidence-based management has improved long-term survival in patients with HF.

The prognostication of the disease progression for individual patients with HF is difficult, as there is no 'typical' dying

trajectory. A regular revisiting during the process of the disease is necessary to allow adjustment to changing circumstances.³

Symptoms management

An unintended consequence of increased longevity is that patients with HF are exposed to a greater symptom burden over time. In addition to classic symptoms such as dyspnea and edema, patients with HF frequently suffer additional symptoms such as pain, depression, gastrointestinal distress, and fatigue. In addition to obvious effects on quality of life, untreated symptoms increase clinical events including emergency department visits, hospitalizations, and long-term mortality.

During the HF evolution, patients typically experience debilitating physical and emotional symptoms, loss of independence, and disruptions to social roles, all of which severely degrade QoL. Physical symptoms in advanced HF, such as pain and breathlessness, are highly distressing for patients and caregivers, yet remain under-recognized and undertreated. Patients and their caregivers often face decisions about high-risk and complex treatments (e.g., cardiac devices, transplantation) without adequate prognosis communication, decision support, or advance care planning. In addition, HF management poses enormous financial and resource stress on families, healthcare systems, and society.⁴

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Along HF course patients and their families experience stress and suffering from a variety of sources. The management of such symptoms demands a global approach based on patients and family needs, education, communication, empowerment, and regular medication doses adjustments. Loss of functional capacity/autonomy may occur gradually or abruptly, and sudden death is a frequent event. Spiritual distress, including meaninglessness and hopelessness, is common in advanced disease. Spiritual care is a core component of PC in these patients, yet often neglected by health care professionals.

PC is an interdisciplinary methodology and an overall approach to care that improves quality of life and alleviates suffering for those living with serious illness, regardless of prognosis.⁴ Symptom management in one of the basic pillars on PC. Symptom management in patients with HF consists of two key components: comprehensive symptom assessment and sufficient knowledge of available approaches to alleviate the HF symptoms. Successful treatment addresses not just the physical but also the emotional, social, and spiritual aspects of suffering. Despite a lack of formal experience during cardiovascular training, symptom management in HF can be learned and implemented effectively by cardiology providers. Co-management with palliative medicine specialists can add significant value across the spectrum and throughout the course of HF.

Barriers to implementation of PC in HF

The majority of adults in need of PC have chronic diseases such as cardiovascular diseases (38.5%).¹ In fact, PC approach is not widely integrated in advanced HF failure. One of the reasons pointed out for professionals is that it is a difficult to identify patients with PC needs.^{6,7} Indeed, it is important to use and to disseminate tools that may facilitated this process in HF.

Adequate educational and training programs on PC among health professionals on HF are urgently needed in order to improve access and patient's outcomes. Indeed, new health policies should be design and effectively implemented to reduce the impact of such condition in people's quality of life and to reduce the social burden associated to it.

PC involves a range of services delivered by multiple professionals that all have equally important roles to play – physicians, nurses, social workers, pharmacists, physiotherapists, and spiritual guiders — in support of the patient and their family. It should be provided through person-centered and integrated health services that pay special attention to the specific needs and values and preferences of individuals.¹

However there still are several identified barriers in the implementation of PC approaches in this group of patients:

- lack of awareness among policymakers, health professionals and the public about what PC is, and the benefits it can offer to patients and health systems.
- misconceptions about PC and cultural and social barriers, such as beliefs about death and dying.
- Fear of losing the contact with the cardiologist and with cardiovascular care, and thus losing associated technological and pharmacological innovation.
- The scarcity of human resources.

Overcoming barriers: “Unidade Mais Sentido”

Around the world, there has been a growing focus on the importance of this topic. PC to HF patients have been recommended in the Joint Task force of the European Society of Cardiology (ESC) and the European association of Palliative care (EAPC).⁸ Here, we propose a closer look at a Portuguese Unit (the “Mais Sentido” Unit) an Unit with a PC approach dedicated to supporting patients with advanced HF integrated in a Cardiology Service at Centro Hospitalar Lisboa Norte. It consists of a day-care hospital which includes ambulatory sessions, home-visiting, phone-support and hospitalization.

The improvement of the quality of life, with a focus based on the assessment and intervention on the multiple domains of the HF patient's life – physical, psychological, autonomy, social/relational, spiritual, and caregiver – is the main goal of the team. It is formed by a multidisciplinary team, and their elements have different levels of PC education and training. Being part of a Cardiology Department, with a Cardiologist, nurses and other professionals with advance proficiency caring for people/family with HF it is an added valued that should be considered.

We believe that a palliative approach to these patients and family's needs must include a cardiologist and a HF nursing expert, as to manage HF symptoms is required a continuous updating of the best care practices regarding to treatment optimization.

Despite the evidence-based for PC in HF it is not widely disseminated, this area still in continuous growth through the interest of international cardiology scientific community. Given the growing prevalence of HF, the integration of PC within HF management represents an opportunity to affect the public health issue of poor QoL in patients and caregivers, while also optimizing care delivery. Furthermore, research and clinical implementation of structured PC approaches in HF can serve

as a model for explore the role of PC in other chronic, non-malignant illnesses.

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