

Is palliative care in heart failure patients coming up?

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This article refers to ‘Palliative care in heart failure guidelines: A comparison of the 2021 ESC and the 2022 AHA/ACC/HFSA guidelines on heart failure’ by M. Blum et al., published in this issue on pages xxx.

The aim of the authors of this review¹ is to compare the guidelines of the 2021 European Society of Cardiology (ESC) (2021)² and those of the American Heart Association/American College of Cardiology/Heart Failure Society of America (AHA/ACC/HFSA) (2022)³ on the role of palliative care for patients with heart failure (HF). Four key issues raise from both guidelines: (i) what palliative care is; (ii) how palliative care is done; (iii) who provides palliative care; and (iv) when is the best time to integrate palliative care in HF care.

Palliative care aims to alleviate suffering and improve quality of life (QoL) for persons living with life-threatening illnesses, personalizing the cure and achieving a ‘middle way’ between too much and too little treatment.⁴ This translates into a most person-centred treatment based on prognosis, symptom control, QoL, and personal will.

Historically, palliative care was offered to terminally ill patients at the end of their life. The growing prevalence of people living with advanced chronic conditions has extended the application of palliative care to non-cancer patients, including those suffering from diseases such as HF, with expected poor outcomes and those who suffer from an advanced stage of a life-limiting disease and, thus, the term ‘early palliative care’ was coined.^{1,3,5}

Practically, palliative care consists in a multidisciplinary approach to alleviate physical, psychological, social, financial, and spiritual distress, extended to caregivers and including bereavement support.⁶ This involves, among others, disease specialists, doctors and nurses expert in palliative care, physiotherapists, social workers, psychologists, psychiatrists, dieticians, spiritual counselors, volunteers, occupational therapists.

Indeed, palliative care has a long history of attention to the multi-dimensional suffering of the patient and his family through rigorous

though empathic clinical care, scientific reasoning, dedicated training, and a close attention to the communication with patients and their families and among healthcare professionals.

Palliative care stems from the Hospice Movement^{7,8} which was born in the last decade after 1958 thanks to Cicely Saunders and progressively spread internationally. She involved herself in terminal care in her unique experience as nurse, social worker, and physician.^{7,8}

The intuition/vision of Cicely Saunders (later to become Dame Cicely Saunders) is that pain is not only physical suffering but also emotional, social, and spiritual and for this reason Cicely coined the term ‘Total Pain’ emphasizing the importance of listening to the patient’s story and of understanding the experience of suffering in a multifaceted way.⁴

According to her⁴: ‘This was an approach that saw pain as a key to unlocking other problems and as something requiring multiple interventions for its resolution’. Dame Cicely saw the chance to transform patients passively suffering from life-threatening disease into active subjects, fostering their awareness, dignity and decision-making power through empathy and communication.

In the early 1960s at Montefiore Hospital, New York City, another woman, Elisabeth Kubler-Ross, a psychiatrist, ‘sat down on patients’ beds’,⁷ and as she held their hands, talked with and listened to them for hours as she learned that there was not ‘a single dying human being who did not yearn for love, touch or communication’.⁹

Both those ‘visionary’ women began to develop a method of talking with and listening to patients which was different from the common medical practice of those times and mostly also from the current. While Cicely Saunders coined ‘Total Pain’, a timeless term which is the very essence of medicine and not only of palliative care, Kubler-Ross, through the bedside interview method of patients, developed the theory of the ‘stages of dying’.¹⁰

Thus, what is palliative care nowadays? Palliative care is not only about treating physical symptoms but also and above all a way of

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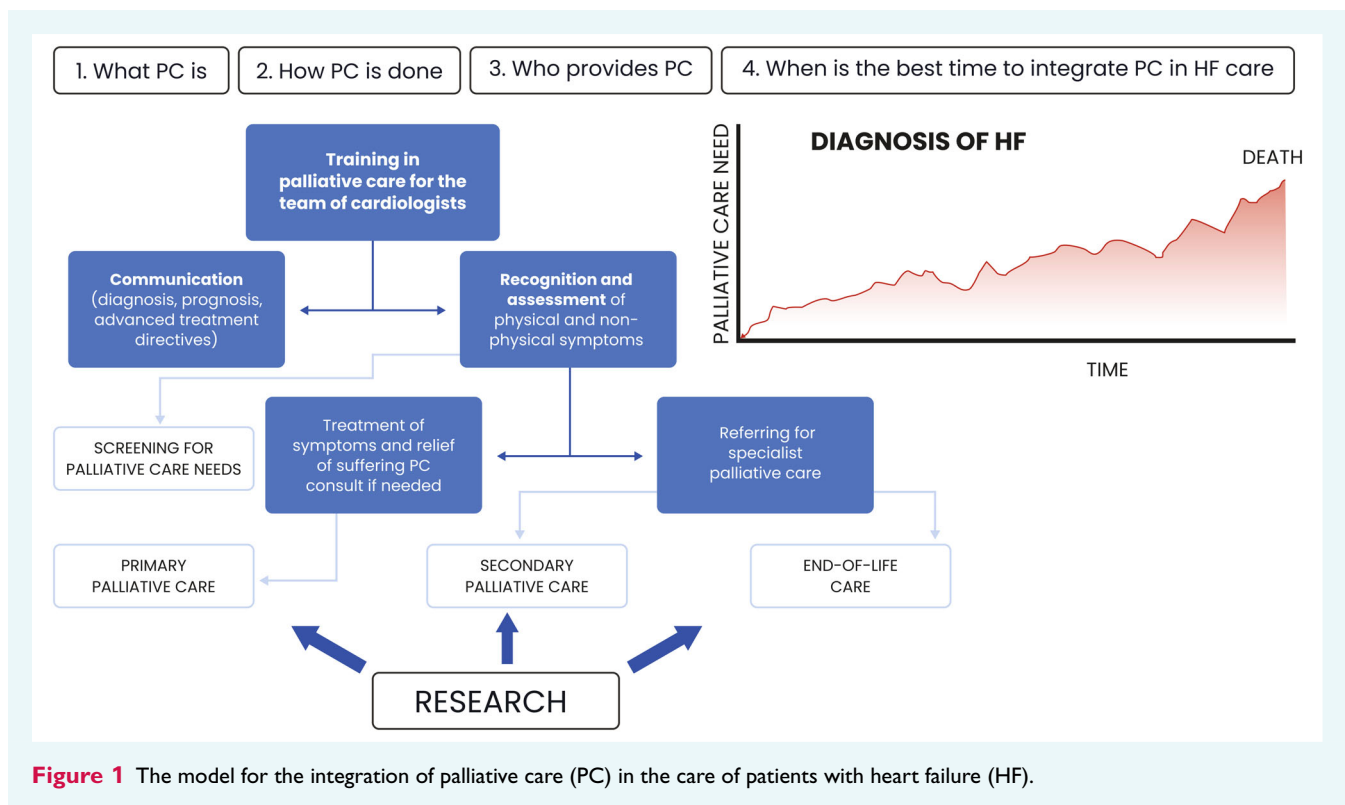


Figure 1 The model for the integration of palliative care (PC) in the care of patients with heart failure (HF).

doing medicine that considers all the needs of the sick person. Palliative care does not aim to cure but to take care, and therefore the time devoted to listening is paramount to understand the needs of patients. Communication and relationship are the basis of the care process and palliative care is about communication and curing relationship. ‘The pain seemed to go by just talking’, Cecily Saunders reported a patient had told her.^{11,12}

Who and how assess, treat, and monitor symptoms and suffering related to life-limiting conditions? Who has the duty to communicate with patients and families? Indeed, symptoms and suffering must be assessed with validated tools that allow to monitor them over time and they must be treated adequately according to international guidelines.

Are those tools to be used only by specialists or experts in palliative care? Should we think to have a palliative care expert in every specialistic clinic/department, for example, cardiology? Should we think to have them available from the beginning of the disease across all the stages of HF or to ask for a consultation when the patient is at the end of life?

What the guidelines are telling us is that a basic palliative care training is necessary for all medical students and health-care providers during their programmes, to be refreshed in the years of residency programmes and during their clinical practice, consistently with the individual field of interest. This may promote a model of primary palliative care for physicians treating patients with organ-specific life-limiting conditions (Figure 1).

In a model of primary palliative care for HF, the cardiologist assesses the symptoms, talks to the patient and his family, discloses

the prognosis, shares the decisions on treatment in accordance with the patient values and starts a discussion about life-sustaining therapies and advanced care planning. Following his/her assessment, the cardiologist may always seek for the consult of a palliative care expert/specialist.

Over time, with the progression of the disease, the involvement of a palliative care specialist will increase progressively, and the model of secondary palliative care will take place. The communication started earlier will continue, the support to caregivers will be strengthened, the advanced care planning will be re-assessed and updated to the changing clinical picture and the worsening physical and non-physical suffering will be assessed and treated. Approaching the end-of-life phase, the availability, and the role of hospice care, about which the patient would have been informed earlier,¹³ will be further discussed, including short-term prognosis and goals or values. Planning for bereavement support becomes necessary at this phase. Indeed, the awareness of the severity of the disease, of the poor prognosis, the chance of withdrawal/withholding of active or invasive therapies that are no longer expected to provide benefits, will change over time and, respecting the indications and values that the patient shares with us, the cardiologist/palliative care specialist team will have to discuss these issues often during the course of the disease, even with family members.

Finding the right amount of time for communication with patients and their families during the whole trajectory from the beginning of the disease until death, may seem an impossible task. The need for specialist staff to dedicate to each patient and to

support the family, and the training needed to do so are paramount and one can be discouraged in doing so.

But, minding our responsibility as healthcare providers for a patient who has no chance of cure, we should organize our wards and clinical activities in a way that allows us to take the time necessary for each patient and promote a primary/secondary palliative care model in which the progressive involvement of the palliative care specialist will have a different intensity depending on the phase of the disease and personal training.

Further research on these issues is needed to support evidence-based practice of palliative care in cardiology.

The method of integration of HF therapy with a palliative care approach needs to be explored, and the effects on patients' QoL must be assessed. Unexplored issues, among others, include the right time of the integration of palliative care into HF care; which are the best tools to screen if a patient needs a secondary, specialist palliative care approach (pathophysiologic variables? patient-reported outcome measures?); the role of home wearable tools, patient-reported outcomes¹⁴ and telemedicine to monitor disease-related symptoms and their impact on QoL and cost-effectiveness. Outcome measures may include assessing the need for hospitalization or readmission after discharge, particularly for people living in rural or remote areas.

In conclusion, beyond the local differences in clinical practice, the importance of having officially endorsed guidelines on palliative care for specialist patients, lies in the fact that these guidelines promote a model of training and practicing palliative care for disease-specific specialists, to allow them to recognize and treat the main symptoms and sufferings limiting the intervention of the palliative care expert to counselling. At the same time, the adoption of the guidelines allows to screen for those patients whose suffering needs the intervention of a secondary involvement of specialized palliative care team.

Only the adoption of this modulated model of integration of disease-specific/palliative care will make it possible to address the challenge of soothing the suffering of thousands of patients with

chronic organ diseases in a way that is compatible with the available resources of the worldwide healthcare systems.

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