



# Rethinking the Meaning of Palliation in Heart Failure

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## Abstract

**Purpose of Review** Palliative care follows a philosophy of care that focuses upon the quality of life in patients with chronic or life-threatening illness. It also focuses upon the needs of their families which is a wider scope of care. Cardiovascular disease, and specifically heart failure, affects millions of patients and family members who have a symptom burden that exceeds that of many cancers and other chronic diseases.

**Recently Findings** Historically palliative care has been viewed as an alternative to curative therapies, but over time, it is now recognized that it should be implemented earlier in the course of chronic diseases. Although non-oncologic patients now comprise over half of the patient seen by palliative care, patients with cardiovascular disease are still not being referred to palliative care.

**Summary** Palliative care goes beyond advance directives and end of life planning. There is a need to continue to expand the view of palliative care to encompass interventions that help improve the overall health of these patients, including their psychosocial well-being and quality of life. The collection of papers in this journal provides insight into the breadth of palliative care for patients with heart failure and other cardiovascular diseases.

**Keywords** Palliative care · Shared decision-making · Quality of life · Advance directives · Ethics

## Introduction

Advances in the medical and device management of those with cardiovascular disease have resulted in improved survival, and consequently in an increasing prevalence of patients living with cardiovascular disease, and specifically with heart failure (HF). Over 6 million people are diagnosed with HF in the USA, and this number fails to capture the care givers and family members who are also affected [1]. Heart failure remains a progressive and life-limiting disease, and the focus of care is both to prolong and to enhance the quality of life (QoL) with medical and device therapies, and with transplantation. In the course of HF, there are periods of clinical stability interrupted by exacerbations of symptoms and hospitalizations from which patients may emerge at a lesser functional status. This trajectory is difficult to predict. Physical

symptoms of dyspnea, edema, and fatigue are nearly ubiquitous, yet even during the periods of relative clinical quiescence, there are myriad other symptoms which have been recognized. Depression and anxiety are common, and up to 20% of patients who have received a shock from an implantable cardioverter-defibrillator have symptoms of post-traumatic stress that affects their daily life [2, 3].

Palliative care (PC) follows a philosophy of care that focuses upon the QoL of patients with chronic or life-threatening illnesses, *and* of their families. Historically, PC has been viewed as the alternative to curative or aggressive therapies. Indeed, the World Health Organization's 1990 definition included reference to those whose disease was not responsive to curative treatment. This perspective has changed over time, and it is recognized that the scope of PC should include improvement of QoL with "the early identification and impeccable assessment and treatment of pain and other problems, including the physical, the psychosocial, and the spiritual" [4, 5].

Coincident with this change in framing, there has been increasing recognition of the need for both clinical implementation of PC, and further research into interventions for patients with HF [6]. While there are relatively few trials of PC interventions in HF, these generally show improvement in

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quality of life and symptoms in both inpatient and outpatient settings [7–14]. And despite the fact that the guidelines of the major cardiovascular disease societies recommend the inclusion of PC in the management of HF patients [15–21], uptake has been slow. Recommendations largely focus on the ethical and legal aspects of advance directives and decision-making at the end-of-life, or with the implantation of devices, such as implantable cardio-defibrillators or mechanical circulatory support. PC is now required by the Center for Medicare and Medicaid Services to be integrated into the care of patients being evaluated for left ventricular assist devices (LVADs), although there is little clarity about how best to implement this, and for many centers, the focus has remained on decision-making regarding implantation, similar to clinical guidelines. Without a doubt, decision-making and advance directives are important, but they comprise only a few of the domains within PC. The remainder is centered on the process of care delivery; physical symptoms of patients; the psychosocial realm including cultural, spiritual, and religious practices; care giver needs; and communication. Clinical guidelines fail to address the burden of such devices on the family, or on the quality of life of patients beyond improvements in the physical functional class.

## Specialty vs Primary Palliative Care

Specialty PC (sPC) developed initially with a focus on oncology, but now, the case mix for both palliative and hospice care comprises over 60% with non-cancer diagnoses. Of these, 23% patient have HF [22]. Conversely, fewer than 10% of HF patients are referred to specialty PC compared with almost 50% of those with cancer [23–25]. Feder et al. showed that only 47% of veterans with cardiopulmonary disease had palliative care at the end of life compared with 74% of cancer patients [26]. Multiple comparisons have demonstrated similarities between HF patients and those with cancers and other chronic diseases; the symptom burden of pain, anxiety, and fatigue are often worse than that of even metastatic lung and pancreatic cancer [27]. Yet most HF patients are not referred for care to address these needs. But PC can also be delivered by primary clinicians, those without specialty training in PC; these primary PC (pPC) providers can be cardiologists, internists, pulmonologist, and nephrologist, in short anyone who cares for patients with significant physical and psychological symptom burdens. One could argue that anyone prescribing a loop diuretic for dyspnea is indeed practicing pPC because the goal is to reduce symptom burden. A destination LVAD is a form of palliative care, albeit very aggressive. Nonetheless, the label of PC is off-putting to many clinicians as PC continues to be viewed through the lens of failure (the double meaning of the word is intended), instead of being recognized as a complementary approach to curative treatment.

There has been movement to include basics of pPC in the training of cardiovascular and specifically HF clinicians. Once again, the focus has been on advance care planning, and decision-making with the development tools available to help with many of these conversations. Decision aids for implantable devices are available [28–30]; web-based tools developed by Vital Talk [31], the Conversation project [32], or Five Wishes [33] can help structure difficult conversations. Even those clinicians who are more attuned to the PC needs of patients focus on the physical symptoms of fatigue and dyspnea, often referring to sleep specialists rather than mental health providers to address the depression-related fatigue that can be present in 20% of patients [34]. These referrals may not be meeting the needs of the patients. Patients report need for improved communication, and concerns about dependency upon others that accompanies their decline in physical functioning [24, 35, 36]. It is also important to acknowledge the spiritual need that might arise from the reality that waiting for a heart transplant necessarily means that someone else will have to die. The spiritual aspect of care can be addressed with chaplaincy and with PC services. In the articles that follow, a surrogate decision-maker is used interchangeably with medical agent, or agent for medical power of attorney. While there are distinct legal differences between these positions, the focus should be to spotlight the complex nature of these discussions and the different needs of the participants.

## Uncertain Trajectory of Heart Failure

One persistent concern within HF, which is not unique to the incorporation of PC, is the uncertain trajectory of the disease itself. As some of the goals of pPC are to help with communication about prognosis and the disease course, the discussion of goals of care are difficult when prognostication itself is challenging. Despite risk models and severity scores, the most useful tool in this regard may be the “surprise” question—“would you be surprised if this patient were to die in the next year?” A negative response has a negative predictive value of 0.88 in patients hospitalized for cardiac disease who did not require inotropes, intubation, or intensive care [37]. The clinical uncertainty of HF may create a reluctance to introduce formal PC into the care of patients. There is a concern that a discussion of prognosis will decrease hope, and increase patient anxiety; qualitative data suggest that this is not the case [38]. However, reframing the construct of PC, recognizing that it provides complimentary care at all stages of HF renders the early implementation of PC as important as traditional guideline directed therapies intended to improve survival and reduce morbidity.

Improving QoL and health status is also associated with a survival benefit. Three predictors of health status, namely depression, symptom burden and spiritual well-being are core

foci of PC, suggesting that with a more intentional focus on the less physical aspects of HF, we might be able to improve survival for patients, reinforcing the need for improved access to PC [39–41].

Heart failure is a field that is ripe for PC, with many of the prerequisite organizational structures in place including collaboration with multidisciplinary teams. There are models of the shared care of patients that can be expanded to PC. Early in clinical trajectory, primary care might coordinate care, with both cardiology and sPC as consultants; this would progress with clinical changes so that cardiology would assume stewardship for care, leading to oversight by a HF cardiologist. As clinical therapeutic or curative options decrease and symptom burden increases, sPC might then become the coordinating specialty for a given patient. Development of care pathways such as this could have multiple benefits, not the least of which is that patient symptoms are being addressed at all stages of care, and there is open communication about clinical status.

In their review of options for home therapies, Graffagnino et al. [42], present the physiology of benefits and risk associated not only with inotropes but also with diuretics which are the cornerstone of PC for HF. Understanding the physiology can help guide adjustments in either oral diuretic choice, including when to consider combination therapy, or conversion to alternative medications. As they discuss, the option of home intravenous or subcutaneous use of loop diuretics can be very useful in the control of congestive symptoms in heart failure. These options are some that pPC could incorporate into their practice along with other home-based programs, such as weight monitoring, and the newer hemodynamic monitoring. The use of inotropes as well, as they discuss, is one that is well-suited to cardiology practice but also highlights the need for collaboration with sPC. Discussions about end of life and goals of care, specifically addressing defibrillation can be led by pPC, but are often addressed by sPC who are able to integrate other supportive care measures.

Pak, Jones, and Mather present a discussion about the liminal position of mechanical circulatory support (MCS) [43]. The threshold MCS straddles is that of being a form of life-sustaining treatment, with similarities to dialysis and ventilatory support, and being a “biofixture,” something that is implanted within a patient. While this characteristic of MCS is one that people struggle with, Pak and colleagues correctly distinguish deactivation from either physician-aid-in-dying, or euthanasia, focusing on the importance of the discussion of patient autonomy, and determination of benefits and burdens of continued MSC therapy. They suggest that patients are now living long enough to experience their disabilities associated with non-cardiovascular comorbidities, in addition to those related to HF and the MCS itself, and that one role for palliative care might be to help elucidate patient preferences and to anticipate deactivation. While they emphasize the importance of the discussion and staging of MCS deactivation,

they stay short of stating what we must consider with all MCS: all MCS must be eventually turned off; for those who are bridge to transplant, it is deactivated at explant, but for the remainder, the time and conditions of deactivation will need to be orchestrated carefully.

Cardiac rehabilitation (CR) is not often thought of as a form of palliative care, and as Epstein and colleagues note, it is increasingly recognized as an important intervention to improve patients’ symptoms and quality of life. Explaining the molecular pathways and the pathophysiology behind these exercise and dietary interventions, one signal shines through their article, “CR gives meaning to survival” [44]. Specifically, with HF, CR can help with the physical manifestations of frailty and sarcopenia, while also improving cognition which is known to decline in HF.

## Conclusion

The question of what should trigger referral for sPC becomes less important because of their early involvement. What milestones might signal foreseeable events requiring clinical decisions or anticipation of worsening symptoms are important to recognize: events such as recurrent hospitalizations for HF, the decrease of guideline directed therapies or the escalation of diuretics, considerations for renal replacement therapy, major life events such as the loss of a spouse or partner, or the diagnosis of another life-limiting disease, such as a cancer. All of these events signal a change in the trajectory of illness at which point sPC might be able to further assist in patient care, and may be a point in which shared management of patients is even more crucial.

Palliative care should ideally reflect, and address patient needs and not their prognosis. The collection of articles in this journal speak to the needs of patients with HF. Advancements in both medications and technologies mean that patients are now able to survive with HF to experience their disabilities and comorbidities. If we consider the totality of a person, we can refocus what and how we think about providing care, to incorporate measures to reduce hospitalizations, and morbidity, to improve or maintain independence, decrease frailty, and improve the quality of life of patients and their families.

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## Compliance with Ethical Standards

**Conflict of Interest** The authors declare that they have no conflicts of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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