

Team-based Palliative and End-of-life Care for Heart Failure



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KEYWORDS

- Palliative care • Hospice care • Heart failure • Interdisciplinary communication • Patient care team
- Comprehensive health care

KEY POINTS

- Palliative care is one component of holistic, supportive care of patients throughout the course of disease, intensified at end of life and extending into the bereavement phase for their caregivers.
- Team-based palliative care for heart failure implies a multidisciplinary approach, including primary care, cardiology, and palliative care, each represented by various providers (eg, physicians, advanced practitioners, nurses, case managers, and pharmacists).
- Patients require a heart failure medical home, where various specialties may take a more central role in coordination of patient care at different times in the disease span, sometimes with consultation by palliative care and sometimes transitioning focus to palliative care at the end of life.

INTRODUCTION

Among an estimated 5.1 million Americans with heart failure, the prevalence of advanced disease is 5% to 10%.¹ As such, nearly half a million Americans struggle with significant symptom burden, psychosocial stressors, and difficult decisions imposed by their end-stage heart failure. Disease prevalence is expected to grow 25% by 2030, primarily because of improved survival, whereas costs are projected to increase from \$32 billion in 2013 to \$70 billion in 2030.¹ With increased emphasis on patient-centered care,^{2,3} and in response to unsustainable health care expenditures, there has been increasing attention placed on palliative and end-of-life care for patients with advanced heart failure.⁴

The 2013 American College of Cardiology Foundation (ACCF)/American Heart Association (AHA) guidelines support the use of palliative care in patients with end-stage heart failure as level 1B.⁴ Medicare's 2014 update to National Coverage Determination for mechanical circulatory support (MCS) even mandates a multidisciplinary team that includes a palliative care specialist.⁵ However, there is limited evidence to guide the content, implementation of, and integration of palliative care interventions into existing heart failure disease management. Therefore, this article explores evidence supporting a team-based approach to palliative and end-of-life care for patients with heart failure, comments on the current state of multidisciplinary care for such patients, identifies

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knowledge gaps, and discusses opportunities for future study.

Team-based Care Implies a Multidisciplinary Approach

Ample evidence shows that team-based care for patients with heart failure decreases rehospitalizations and improves survival through education, structured follow-up, patient self-care, and care-plan adherence.^{6,7} However, few pilot studies have assessed the efficacy of multidisciplinary palliative care in improving outcomes germane to end-stage heart failure (ie, quality of life, symptom control, decreased health care use, lower financial and caregiver burdens), in part because of heterogeneity in defining what palliative care is and how it should be delivered. **Table 1** details selected clinical trials and intervention studies that support a multidisciplinary palliative approach by incorporating specialties tailored to patient needs to facilitate the inevitable transitions in chronic heart failure care.

What's in a Name? Palliative Care is Supportive Care

Historically, the term palliative care was conflated with hospice care: a focused approach to dying patients for whom disease-targeted treatment or cure is no longer viable. However, this narrow restriction has given way to a more holistic view of disease management in which supportive care is afforded to all patients with chronic or life-threatening illness (**Fig. 1**). Optimal palliative care ideally begins early in the course of the disease and continues in parallel with heart failure-targeted therapy in an integrative, multidisciplinary manner.²⁰⁻²² All health care providers should strive to treat the whole patient collaboratively with a team of colleagues. Likewise, heart failure clinicians should maintain concurrent foci on treating disease, extending survival, and optimizing quality of life for patients with chronic heart failure at all disease stages.

Building on Experience or Diverging Pathways? Palliative Care in Cancer and in Heart Failure

Evidence and education have helped to normalize early, integrated palliative care approaches and improve outcomes for patients with advanced cancer.^{23,24} Because of a dearth of evidence in the cardiology literature, heart failure guidelines and consensus statements have partially relied on cancer care studies to recommend best practices for treating patients at end of life.^{4,22} However, despite similar or worse symptom

burden, depression, and spiritual well-being for patients with advanced heart failure compared with those with advanced cancer,²⁵ heart failure has been associated with less access to palliative care and use of hospice, and higher rates of resource use and aggressive treatment.^{26,27} This disparity highlights a need to better inform providers and patients of options for progressive and end-of-life heart failure.

Some clinicians have noted that translating the model of palliative cancer care to heart failure may not be feasible or appropriate, given a less predictable course of disease progression and less well-defined transition stages by which to time interventions.²² Even so, evidence-based cancer care provides a foundation from which integrated palliative heart failure care can expand. For example, the ENABLE: CHF-PC (Educate, Nurture, Advise, Before Life Ends: Comprehensive Heart Care for Patients and Caregivers) trial (see **Table 1**) evolved from a series of successful palliative cancer care trials, and its recently published feasibility pilot results were promising.¹¹

THE LOGISTICS OF TEAM-BASED PALLIATIVE CARE IN HEART FAILURE

Who Makes up the Clinical Palliative Care Team?

Various health care providers from multiple fields comprise the clinical component of a multidisciplinary palliative care team, along with patients and caregivers (**Fig. 2**). The 3 main specialties are primary care, cardiology, and palliative care, each represented by various physicians, advanced practitioners, and nurses. A collaborative interface between these specialties leads to improved communication and understanding of patients' goals, more streamlined referrals to specialists, and better end-of-life experiences.²⁸ Interdisciplinary care increases prescriptions for symptom control medication and decreases hospitalizations, length of stay, and cost of care.⁷ These 3 specialties should constitute the core of the patient's heart failure medical home. Each specialty may take a more central role in coordination of patient care at different times in the disease span (**Fig. 3**).

This partnership can be challenging because of prognostic uncertainty, difficulty with optimal timing of consultation, the desire to save patients, and the fear of failing them. Such barriers stem from an inaccurate perception of palliative care as synonymous with hospice.^{29,30} Palliative care should not be seen as giving up or accepting death, but as 1 component of a collaborative, supportive approach to patient care (**Box 1**).

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