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Special Report

Engaging Heart Failure Clinicians To Increase Palliative Care Referrals: Overcoming Barriers, Improving Techniques

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Abstract

Background: Heart failure (HF) is the most common cause of hospitalization among adults over the age of 65. Hospital readmission rates, mortality rates, and Medicare costs for patients with this disease are high. Furthermore, patients with HF experience a number of symptoms that worsen as the disease progresses. However, a small minority of patients with HF receives hospice or palliative care. One possible reason for this may be that the HF and palliative care clinicians have differing perspectives on the role of palliative care for these patients.
Aim: The goal of the article is to offer palliative care clinicians a roadmap for collaborating with HF clinicians by reviewing the needs of patients with HF.
Conclusions: This article reviews the needs of patients with HF and their families, the barriers to referral to palliative care for patients with HF, and provides suggestions for improving collaboration between palliative care and HF clinicians.

Introduction

One in nine death certificates in 2009 mentioned heart failure (HF) and the incidence of the disease approaches 10 per 1000 population after 65 years of age.[1] After age 80, remaining lifetime risk for development of new HF remains at 20%, even after adjusting for life expectancy.[1] Acute HF exacerbations can be life-threatening and increase the risk of subsequent hospital admission and intensive treatment.[2] Among patients with HF in one large population study, 83% of patients with HF were hospitalized at least once and 43% hospitalized at least 4 times.[3] Approximately 80% of Medicare beneficiaries with HF were hospitalized in the last 6 months of life.[4] As a result of this high utilization, more Medicare dollars are spent on HF than for any other diagnosis with an estimated total annual cost of HF in the United States exceeding $27 billion.[5]

In terms of the experience for individual patients and their families, previous studies have shown that quality of life in patients with HF is equally or even more greatly affected by their disease than that of patients with cancer. Untreated dyspnea, pain, fatigue, and depression are common symptoms in HF as well.[6] As the disease progresses, symptoms worsen.[7–9] Caregivers of patients with HF also report stress, burden, depressive symptoms, and diminished quality of life.[7,10–12] Research further demonstrates that caregivers who report depressive symptoms and poor health-related quality of life are at increased risk of mortality and morbidity.[13,14]

Despite the serious nature of the disease and the prevalence of uncontrolled suffering in this group of patients, the utilization of palliative care and hospice services by patients with HF is particularly low. While the percentage of patients with HF who receive these services is unknown, the available estimates of utilization show that less than 10% of patients with HF receive palliative care and less than 12% of hospice admissions were for HF patients.[15] In terms of percent of patients with HF who received hospice, the number of Medicare beneficiaries with HF who utilized hospice in last 6 months of life increased from 19% in 2000 to 38% in 2007. Unfortunately, their stays tend to be short; of those with HF who do enroll in hospice, more than one-third enrolled for a week or less.[16] In comparison, in the final 6 months of their life, 55% of patients with cancer enrolled in hospice, and only 15% enroll within 3 days of their death.[17]

We hypothesize that palliative care has the potential to improve clinical outcomes for patients living with HF by improving pain and other symptom control, clarifying goals of care, and guiding treatment decisions to meet those goals.

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Yet, there is a paucity of data regarding the potential benefit of palliative care specifically for patients with HF. Nevertheless, by improving symptom control, clarifying goals of care, and guiding treatment decisions, palliative care has improved clinical outcomes for patients with cancer.[6–8]

The goal of this article is to offer palliative care clinicians guidelines for collaborating with HF clinicians by reviewing the needs of patients with HF. We review the data on the burden of HF, as well as the barriers to referral to palliative care and hospice. Finally, we offer potential ways to improve referral and access to palliative care and hospice. Because there is not yet a substantial body of research in this area, many of these suggestions are drawn from our clinical experience and informal relationships with HF providers across the country. In summary, it is hoped that this work will help palliative care clinicians better understand HF from the perspective of the HF clinicians as a means of improving collaboration to improve the care of HF patients and their families.

The Lack of Integration of Palliative Care into the Care of Patients with HF

The clinical course of patients with HF is marked by periods of unpredictable exacerbations characterized by uncontrolled symptoms and a rapid decline in function.[18] With appropriate disease-directed treatments, these patients will have some improvement, but their overall clinical course remains a downward trajectory.[19,20] The serious nature of HF makes palliative care an important model of care that should be offered concurrently with HF-specific therapies. Many clinicians unfortunately continue to think that palliative care is synonymous with end-of-life care, and this may prevent referral early in the course of treatment and thus a missed opportunity at improving their quality of life. [16] Improving collaboration can be a challenge because the research base demonstrating the benefits of palliative care on outcomes and quality of care for patients with HF is still in its early development.[8,21–25]

There are numerous studies currently being conducted to better elucidate the role of proactive palliative care for patients with advanced HF. In an effort to identify the number of National Institutes of Health (NIH)-funded studies relating to improving or integrating palliative care for patients with HF, the authors undertook a search of the NIH Reporter Database.[26] The authors searched the NIH grants database RePorter for grants with key words of ''heart failure'' combined with each of the following key words: ''palliative care,'' ''end-of-life care,'' ''hospice'' and ''end of life.'' Next, two of the authors (L.P.G., N.E.G.) independently hand-reviewed all the identified grants for relevance to palliative medicine, as determined by the National Consensus Project's for Quality Palliative medicine's definition.[27] Currently, there are seven projects in the area of palliative care and HF funded by the NIH.[26] The National Institute of Nursing Research (NINR) is funding four trials to improve symptoms and quality of life for patients with HF and their families. Two trials, funded by the National Heart, Lung and Blood Institute (NHLBI), are exploring way to improve decision making and communication for patients with HF. In addition, a study to assess the effect of palliative care on the utilization and costs of older adults with HF is funded by the National Institute of Aging (NIA).

In spite of the early stage of this field's research base, numerous professional societies have called for the consistent and earlier integration of palliative medicine into the care of patients with advanced heart disease. For example, in their guidelines for the treatment of HF, the American College of Cardiology states: ''Patient and family education about options for formulating and implementing advance directives and the role of palliative and hospice care services with reevaluation for changing clinical status is recommended for patients with HF at the end of life.''[28] Similar guidelines have come out from other leading cardiology societies, including the American Heart Association and the Heart Rhythm Society.[1,14,29,30]

Why Patients with HF are not Referred to Palliative Care

This lack of integration may be due to a few factors. First, the best symptom control for patients with HF is based on disease-directed therapies, which treat the exacerbation. Specifically, interventions including furosemide or vasoactive medications during an acute exacerbation are primary in alleviating the symptom of dyspnea.[8] A patient with advanced HF, whose symptoms are not responding to traditional pharmacologic therapies, has a plethora of advanced therapies available, including comprehensive outpatient HF management programs, biventricular pacemakers, high-risk cardiovascular surgery, inotropes, mechanical circulatory support (MCS, also known as ventricular assist devices [VADs], heart transplant, investigational drugs that include gene therapy, and hospice. Studies have demonstrated that many of these options both improve survival and quality of life.[31–35] Palliative care clinicians may not appreciate the benefits of these treatments, especially since they are often accustomed to the limited number of options for patients with advanced cancer.

Second, the palliative care clinician may apply a different conceptual model when thinking about HF. Palliative care advocates for care that begins at the time of a patient's diagnosis of a serious illness for symptom management, advance care planning and goals of care discussions; and this should continue with an increased emphasis as the disease progresses. HF clinicians may not be aware of the more up-to-date, broader definition of palliative care, which extends beyond end-of-life care for patients who have no disease-specific treatment options and includes caring for patients at all phases of illness.

Early Referral to Palliative Care Patients with HF: But When Exactly?

HF clinicians tend to use a different model when thinking about disease trajectory in HF. The stages of HF, as designated by American Heart Association and American College of Cardiology, was first published as a new classification 2001, which replaced the traditional New York State HF Classification system (Fig. 1). Patients in stage A are those who are high risk but asymptomatic; patients in stage B are those with structural heart disease who have no symptoms; patients in stage C are those with structural heart disease with current or previous symptoms; and patients in stage D are those with refractory symptoms requiring special intervention.

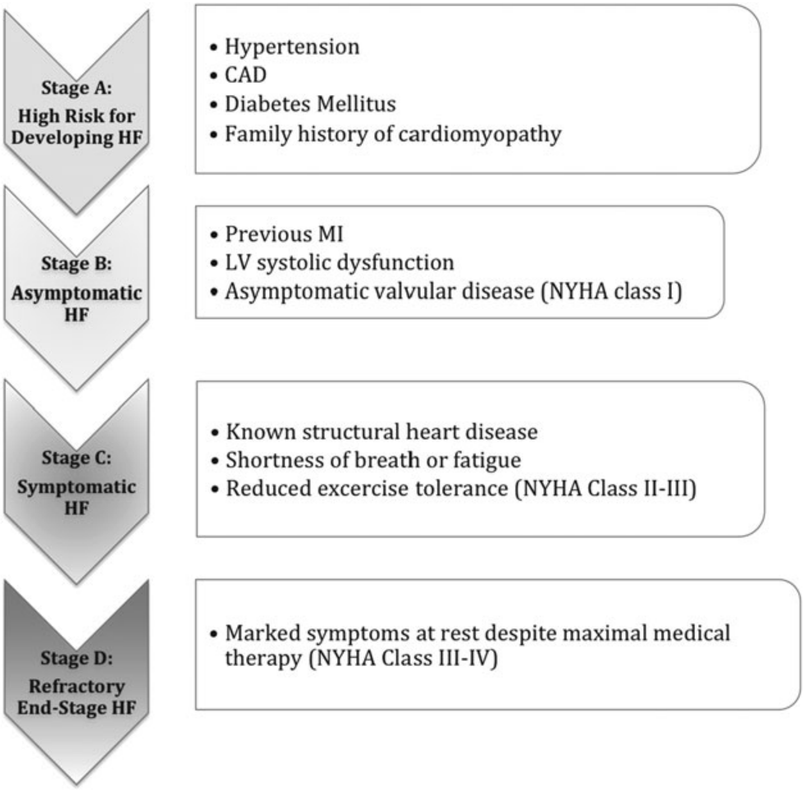

FIG. 1. Stages of heart failure (HF). Adapted from Hunt SA, Baker DW, Chin MH, Cinquegrani MP, Feldman AM, Francis GS, Ganiats TG, Goldstein S, Gregoratos G, Jessup ML, Noble RJ, Packer M, Silver MA, Stevenson LW, Gibbons RJ, Antman EM, Alpert JS, Faxon DP, Fuster V, Gregoratos G, Jacobs AK, Hiratzka LF, Russell RO, Smith SC Jr; American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Committee to Revise the 1995 Guidelines for the Evaluation and Management of Heart Failure); International Society for Heart and Lung Transplantation; Heart Failure Society of America: ACC/AHA Guidelines for the evaluation and management of chronic heart failure in the adult. Circulation 2001;104:2996–3007.

The rule of thumb in palliative care is that palliative care should be introduced at the time of diagnosis, but this traditional way of thinking may seem outdated and out of touch when discussed with a HF clinician. Indeed, it would be impossible and probably unwarranted for a palliative care team to see every patient with stage A HF (i.e., those who are at high risk of developing HF). Stage B patients may also be ‘‘too early’’ based on their current place in the disease trajectory and the substantial number of patients with stage B HF. Indeed, this concept of ‘‘too early’’ is one that palliative care often fights against because typically referrals come ‘‘too late’’; this may be a rare case where there is indeed a group of patients with HF who are truly ‘‘too early’’ to benefit from a traditional specialty-level palliative care intervention. Given the broad range of clinical presentations from stage A to stage D, ideally, the HF clinician would offer primary palliative care, with the support of palliative care specialists as needed, until the patient reaches stage C and possibly D. At that time, the patient could be referred to specialist-level palliative care to assist when symptoms and decision making become more complex.

More specifically, palliative care clinicians should be involved once patients with HF develop symptoms, including shortness of breath, fatigue and decreased exercise tolerance (stage C). By initiating a relationship with stage C patients, the bond is already established before patients reach stage D—the patients for whom palliative care could have the greatest impact. The palliative care clinician and the HF specialist together would engage in goals of care discussions and an understanding of realistic outcomes, and depending on the outcomes of those ongoing discussions, consider advanced therapies, such as inotropes, VADs or heart transplant, or alternatively, hospice care, for those choosing to forgo or are not eligible for these life-prolonging therapies.

Furthermore, caregivers of stage C and certainly stage D HF patients should be routinely assessed for caregiver burden and depressive symptoms. The palliative care clinicians can work with the HF clinician to help caregivers to access available support services to prevent and ameliorate burden. Caregivers of patients with high levels of HF symptoms and cognitive dysfunction may need more intensive interventions to reduce caregiving burden and improve health-related quality of life.

Why the Current Model of Hospice Does not Fit with HF

The goal of hospice is to provide comprehensive, interdisciplinary, team-based palliative care for patients with an easily identifiable short prognosis. A patient can be enrolled in hospice when, in the opinion of two physicians, the patient has a prognosis of 6 months or less, if the disease follows its natural course.[36] In order to become eligible for hospice, patients must agree to relinquish insurance coverage for curative or life-prolonging therapies. The optimal time for

Table 1. A Selection of Seminal Articles on Palliative Care for Patients with Heart Failure

Title	*Authors*	*Citation*	*Focus of article*
Palliative care for patients with HF.	Pantilat SZ, Steimle AE.	*JAMA* 2004;291: 2476–2482.	Reviews palliative care for HF, in terms of prognosis, advanced directives, symptoms and comorbidities
Defining the role of palliative care in older adults with heart failure.	Bekelman DB, Hutt E, Maoudi FA, et al.	*Int J Cardiol* 2008; 125:183–190.	Presents the potential for concurrent palliative care with HF care for older adults with HF.
2009 Focused update incorporated into the ACC/AHA 2005 Guidelines for the Diagnosis and Management of HF in Adults.	Hunt SA, Abraham WT, Chin MH, et al.	*J Am Coll Cardiol* 2009; 53:e1–e90.	Presents a broad overview of HF from diagnosis to treatment, includes a section on end-of-life concerns
Palliative care in congestive HF.	Goodlin SJ.	*J Am Coll Cardiol* 2009; 54:386–396.	Proposes medical treatments for disease-specific HF symptoms
Hospitalization as an opportunity to integrate palliative care in HF management.	Widera E, Pantilat SZ.	*Curr Opin Support Palliat Care.* 2009 Dec; 3(4):247–51.	Examines the role of hospitalization for HF as an opportunity to assess comprehensive patient needs
Palliative care in the treatment of advanced HF.	Adler ED, Goldfinger JZ, Kalman J, et. Al.	*Circulation* 2009;120: 2597–2606.	Presents a broad overview of palliative care needs of patients with HF
HRS Expert Consensus Statement on the Management of Cardiovascular Implantable Electronic Devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy.	Lampert R, Hayes DL, Annas GJ, et al.	*Heart Rhythm* 2010;7: 1008–1026.	Offers a decision-making algorithm for withdrawing CIED therapies
Palliative Care and mechanical circulatory support: a new frontier for synergy between cardiology and palliative medicine.	Goldstein N, May C, Meier D.	*Circ Heart Fail* 2011; 4:519–527.	Outlines role of palliative care specifically for patients undergoing placement of a ventricular assist device (VAD)
Palliative care and end-of-life issues in patients treated with left ventricular assist devices as destination therapy.	Swetz KM, Ottenberg, AL, Freeman MR, et al.	*Curr Heart Fail Rep* 2011; 8:212–218.	Reviews key areas associated with caring for patients with destination therapy
Decision making in advanced heart failure: A scientific statement from the American Heart Association.	Allen LA, Stevenson LW, Grady KL, et al.	*Circulation* 2012; 125:1928–1952.	Reviews advanced decision making for patients with advanced HF and their families
Preparedness planning before mechanical circulatory support: A ‘‘how-to’’ guide for palliative medicine clinicians.	Swetz KM, Kamal AH, Matlock DD, et al.	*J Pain Symptom Manage* 2014; 47:926–935.	Presents several key strategies for engaging patients who are receiving mechanical circulatory support in preparedness planning

HF, heart failure.

enrollment in hospice is when curative treatments become more harmful than beneficial or when patients are in the last weeks or months of life.[37–39]

However, even in advanced stages of illness, many HF patients who may seem to be at the end of life to the palliative care clinician may at the same time be seen by the HF clinician as late stage C/stage D and thus remain candidates for life-sustaining interventions such as VAD or transplant. This makes the hospice benefit inappropriate for many of these patients. Given that these truly are advanced therapies, it is possible that a small number of patients may be deemed no longer candidates and thus, eligible for hospice only a few days before death. Late referrals to hospice for this group should not be considered a ‘‘failure’’ but instead, reframed in the mind of the palliative care clinician as part of the inherent complexity in treating a disease with such complex options and unpredictable trajectory.

At the same time, it may be helpful to educate HF clinicians about the limited evidence that hospice for patients with HF prolongs survival. Connor et al.[40] examined the 5% file of the entire Medicare beneficiary population from 1998–2002 to compare survival of 83 hospice patients with HF and 457 nonhospice patients with HF and found that those enrolled in hospice had a survival of 402 days compared to 321 days for those not enrolled in hospice. This increased survival may be due to hospices' intensive symptom management and regular nursing visits, which allow for regular titration of medications for symptom management.

The Ideal Model of Palliative Care for Patients with HF

One way to better integrate palliative care into the model of HF is for clinicians to focus on the ''hope for the best and plan for the worst'' model. In this role, the palliative care team helps to treat symptoms and provides emotional support as the HF team tries to reverse the exacerbation or moves the patient towards advanced therapies, while at the same time proceeding with discussions about goals of care and end-of-life care planning. This helps the patient and family see the palliative care team as being integrated with the HF clinicians—all working together to obtain their goal of moving towards advanced therapies (as applicable) while at the same time continuing to engage in ''what if'' conversations to determining what the ''fate worse than death'' might be. This type of goal setting assures planning while also working toward the goal of sustaining life.

Integrating palliative care into the model of HF care means a rethinking for both palliative care clinicians and HF practitioners alike. This type of culture change can be a slow process. The key to establishing a collaborative relationship is to identify a palliative care champion within the cardiology group at one's own institution. Because of the culture of most hospitals, this individual most often will need to be a physician to ensure buy-in from HF clinicians. This collaboration can serve to help ''translate'' the palliative care paradigm to HF clinicians and vice versa. When communicating with cardiology and HF colleagues, it may be helpful to refer to the HF literature that calls for earlier palliative care involvement in the treatment of patients with advanced HF. Numerous excellent reviews have been published on the potential benefits of palliative care for patients with HF. Table 1 presents a selection of the seminal articles about palliative care for patients with HF; this table is not a comprehensive review.

Quality Performance Improvement: Growing Opportunities for Collaboration between HF and Palliative Care Clinicians

Recently, a number of accreditation bodies have mandated the involvement of palliative care clinicians or the incorporation of palliative care domains into the care of patients with HF. For example, in 2013, the Centers for Medicare and Medicaid (CMS) mandated that facilities currently credentialed by the Joint Commission for placement of VADs as destination therapy (the use of mechanical circulatory support when there is no option of heart transplant) must include a palliative care specialist as a member of the multidisciplinary team caring for the patient.[41]

In addition, effective January 1, 2014, two of the Joint Commission's six new mandatory performance measures for all patients with HF, both inpatient and ambulatory for the Advanced Certification in Heart Failure are central to palliative care.[42] The first measure is documentation of a ''discussion of advanced directives and advanced care planning'' and necessitates that medical record includes mention of a discussion of advance directives/advance care planning with a healthcare provider. The second measure is ''advance directive executed'' and it assures there is documentation in the chart for patients who have created such a document.

Finally, the Affordable Care Act established the Hospital Readmissions Reduction Program, which requires CMS to reduce payments to inpatient prospective payment systems hospitals with excess readmissions for HF, effective for discharges beginning on October 1, 2012.[43] One study demonstrated a reduction in 30-day readmission rates for patients with HF by using various strategies to better integrate hospital care and primary care through improved communication between the hospital and outpatient setting.[44] Palliative care leaders[45] have argued that palliative care offers this improved coordination of care between settings of care by ensuring treatment is aligned with patients' goals of care.

While many of these efforts are in their early stages, the developing performance measures and quality improvement initiatives bolster the opportunities for collaboration between HF clinicians and palliative care clinicians. We have included only a few examples of these quality improvement measures, but it is likely that future opportunities to utilize the strengths of each field will continue to develop.

Customizing a Palliative Care Program to Outreach to Patients with HF

Given the large number of patients with HF, the palliative care team should be deliberate in setting their goals before

Table 2. A Guide to Building Bridges with Heart Failure Colleagues

Develop a better understanding of the pathophysiology of HF, the underlying etiologies of HF, as well as the clinical management including evaluation and treatment options.
Establish a palliative care champion within the cardiology department who can spearhead collaboration.
Carefully consider specific, measurable goals or benchmarks when establishing a collaboration between palliative care and HF teams
Ensure that the palliative care team has the resources (staffing and financial support) to meet the established goals or benchmarks
When working with HF clinicians as well as patients with HF and their families: Acknowledge the uncertainty associated with the complex and unpredictable trajectory of HF. Use the ''hope for the best, plan for the worst'' paradigm to acknowledge the potential life-prolonging treatment options but also the progressive nature of the illness Work to help clarify and review the goals of the patient and family. Ensure symptom control at all times
Harness the growing opportunities for quality performance improvement as a way to integrate palliative care into the care of inpatient and ambulatory patients with HF

HF, heart failure.

establishing a HF program. What is the goal of the program? Is it: To increase the number of referrals from the HF clinicians? To decompress the volume of patients in the cardiac care unit? To reduce rehospitalizations? To improve patient-centered outcomes? Each of these goals may require a different approach and business model; therefore, a planned approach is required. (For more information on how to create a business plan for palliative care, go to www.capc.org.) Without such a strategy, the volume of work may overwhelm the team.

Before starting, be sure that there are appropriate resources to meet the desired goals and outcomes. The numbers of patients hospitalized with HF can be quite large, so be cautious when calculating the number of referrals. Offering to see every patient in the hospital with HF, for example, may be an unobtainable goal that will simultaneously pull the precious resources of personnel and time away from patients with other chronic diseases who also need the services of the palliative care team.

Finally, remember that this is a complex patient population with individuals for whom ''cure'' (cardiac transplant) or ''stabilization'' (VAD) may be right around the corner. The ultimate goal of palliative care clinicians is to help patients and families understand the complex disease trajectory, clarify goals and assist in having goals of care conversations over time. The goal is not to force acceptance that the patient is at the end of life on the patient, family nor on the referring clinicians. As always, a key part of the work of the palliative care team is to ensure symptom control at all times. Table 2 summarizes these techniques to improve collaboration with HF clinicians.

Conclusions

The role of palliative care is complex for patients with advanced HF and their families. Better models to integrate palliative care earlier in the disease trajectory and a stronger evidence base for the role of palliative care for these patients are desperately needed. Because the course of HF is complex and unpredictable, the focus of palliative care offered must fit this different paradigm. By acknowledging this uncertainty and working to help clarify and review the goals of the patient and family, the palliative care team can both increase referrals from HF clinicians while simultaneously improving care for this chronically ill population.

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Author Disclosure Statement

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