Integrating Palliative Care Into Heart Failure Care

Paul J. Hauptman, MD; Edward P. Havranek, MD

Heart failure is a condition for which both palliative care and hospice care can be appropriate. The disease’s increasing prevalence and predilection for elderly patients with significant comorbidity underscore the need to integrate these modes of care with the acute care approach that has dominated heart failure treatment. We propose integration of a palliative care approach early in the course of heart failure treatment and a tiered process for selecting patients for hospice care. A transition of the focus to palliative care rather than mortality reduction should occur over time, when clinical status deteriorates and advanced therapeutic options become inappropriate or ineffective. Failure to respond to the need for palliative care puts at risk the mandate to treat the patient with heart failure during the entire course of illness.

Heart failure (HF) is an increasingly prevalent, often progressive condition associated with high morbidity and mortality and marked functional impairment that disproportionately affects the elderly. Data from the National Hospital Discharge Survey show that annual hospitalizations for HF increased by 294,000 from 1985 to 1995. Heart failure is the leading cause of hospitalization among Medicare beneficiaries. For 2003, estimates from the American Heart Association heart disease and stroke statistics suggest that the annual number of discharges approached 1 million; the actual numbers may be even higher because coding from the International Classification of Diseases, 9th Revision, may underestimate the number of patients admitted with HF by one third. Patients with HF report physical function scores nearly 2 SDs from the mean for patients with normal health, and significant comorbidities are common. Readmission rates are high: up to 44% at 6 months in elderly patients. For newly diagnosed HF in the community setting, mortality is estimated at 24%, 37%, and more than 75% at 1, 2, and 6 years, respectively. For advanced cases, a combined end point of mortality or rehospitalization has been reported to occur in up to 81% at 1 year.

PALLIATIVE CARE

We recognize that there is controversy regarding the boundaries of the concepts of palliative care. We have adopted a definition of palliative care and a distinction between palliative care and hospice care contained in a recent publication of the National Consensus Project for Quality Palliative Care. Palliative care is an interdisciplinary team approach to optimizing symptom management and quality of life that does not necessarily exclude any medical therapy and takes into account physical, psychosocial, and spiritual needs and

If organic lesions . . . have made evident progress, if all functions which are connected to the circulation suffer already from its alteration, then the prognosis is altogether desperate; the physician has no longer to estimate the danger of the disease; whenever he ascertains its existence, he recognizes a mortal affection; and his experience can enlighten him only in estimating the time that the patient will be able to lead a lingering life, and in the choice of the means capable of rendering it the most supportable.

Jean Nicolas Corvisart

Author Affiliations: Division of Cardiology, Saint Louis University School of Medicine, St Louis, Mo (Dr Hauptman), and the Denver Health Medical Center, Denver, Colo (Dr Havranek). Financial Disclosure: None.
patient/family preferences. As such, palliative care can be integrated with conventional HF care that emphasizes life-prolonging treatment. This duality of care should be considered a normal approach to patients with HF. Under this conceptualization, hospice care is a specialized form of palliative care in which the patient has decided to forgo all life-prolonging treatment.

Palliative care includes communication to the patient and family of the prognosis and treatment options for the illness in question, identification of patient and family goals and needs, and use of an interdisciplinary approach to meet the symptomatic, psychological, and spiritual needs identified. For patients with HF, each of these tasks is associated with unique challenges. Because HF is an illness with a highly variable trajectory, prognostication is difficult. Consideration of several clinical factors, however, can yield estimates that are useful to patients; we discuss these variables in more detail herein. The array of treatment options is particularly broad in HF and includes a number of technologically invasive therapies. Because there is frequently “one more thing to try,” shifting the focus of care from life extension to symptom relief can be particularly difficult. Finally, an interdisciplinary approach has been relatively slow to reach the care of advanced HF, because there has been little tradition and experience with this approach among cardiologists.

An increased focus on palliative care is appropriate after hospitalization for HF, particularly in the elderly. Up to one third of elderly patients experience a deterioration of physical functioning with hospitalization. In general, the palliative care approach has improved patient outcomes as judged by symptom control, quality of life, and satisfaction with care. The evidence for effectiveness of the palliative care approach, however, comes from a heterogeneous array of studies in which patients with cancer predominate. Further study establishing effectiveness specific to HF is needed, as is evidence-based delineation of the key elements in a palliative care program for HF.

DETERMINING SHORT-TERM PROGNOSIS IN ADVANCED HF

Predicting prognosis in HF is difficult because its clinical course is highly variable. Nonetheless, a great deal of data on the prognostic value of a variety of clinical variables can be brought to bear on the issue if the provider and patient are prepared to accept a greater degree of uncertainty when predicting outcome compared with other terminal illnesses such as malignancy.

Functional capacity remains the most important predictor of mortality in HF. Determination of functional capacity by measurement of maximum oxygen consumption with cardiopulmonary exercise testing has been the gold standard for assessing functional capacity in HF, because it is believed to be the most discriminatory measure. Other measurements derived from cardiopulmonary exercise testing results may provide a slight advantage compared with maximum exercise testing. However, cardiopulmonary exercise testing is not widely available and may not be appropriate for elderly patients with other comorbidities that limit their ability to exercise. A variety of standardized instruments, each with its advantages and disadvantages, are available for gauging functional capacity. These include the New York Heart Association classification and disease-specific health status questionnaires such as the Minnesota Living With Heart Failure Questionnaire and the Kansas City Cardiomyopathy Questionnaire. Deterioration in functional capacity may be particularly indicative of high risk of mortality during the next 6 months.

Renal dysfunction (as evidenced by elevated serum urea nitrogen and serum creatinine levels), hyponatremia, or intolerance to angiotensin-converting enzyme inhibitors because of hypotension are predictive of poor outcome. Hypoperfusion can also result in severe dysfunction of the liver and, in advanced cases, the cerebrum. Uremia, liver failure, or delirium complicating HF portends poor short-term outcomes when HF treatment is maximal and no other reversible causes can be found. Multivariable models predicting outcome in advanced HF are available. In a comprehensive study of survival in patients referred for transplantation, Aaronson et al found maximal oxygen consumption, left ventricular ejection fraction, and hyponatremia to be significant predictors of outcome, in addition to heart rate, blood pressure, ischemic etiology, and QRS widening on electrocardiogram. In a recent randomized trial of left ventricular assist devices as destination therapy, patients undergoing medical management who had a left ventricular ejection fraction of less than 25%, New York Heart Association functional class IV symptoms present for longer than 90 days, and maximal oxygen consumption of 12 mL/kg per minute or less or dependence on inotropic support had a 6-month mortality of approximately 50%. A recent observational study of patients in a university setting, rigorously selected for dependence on continuous inotropic support, demonstrated a 6-month mortality of approximately 75% in patients characterized by an average of 1.9 hospitalizations in the preceding 6 months, a mean left ventricular ejection fraction less than 20%, and a mean serum sodium level of 132 mEq/L.

THE SPECTRUM OF THERAPEUTIC OPTIONS

Standard medical therapy consists of diuretics, angiotensin-converting enzyme inhibitors, β-adrenergic antagonists, aldosterone antagonists, and possibly digoxin. Two of the agents, diuretics and digoxin, may improve functional capacity without affecting survival. In addition, recent advances have widened the array of options to include long-term inotropic therapy, cardiac resynchronization pacing, high-risk mitral valve repair or replacement or revascularization cardiac surgery, ventricular assist devices as destination therapy, external counterpulsation, and cardiac transplantation. In general, the evidence supporting use of these therapies is still emerging. The goal of these therapies, however, is stabilization rather than cure, and the number of eligible patients who are candidates for or have access to these therapies is limited. For example,
heart transplantation, although effecting a prolongation of life, is limited by small numbers of donor hearts and by restrictive selection criteria. An important emerging option is formal multidisciplinary management. Published data on HF disease management demonstrate that these programs result in decreased hospitalizations, decreased readmissions, increased appropriate medication use, decreased medication errors, and improved health-related quality of life.30 The major limiting factors for the widespread adoption of formal multidisciplinary programs are perceived cost issues and access to care. Participation in research trials may also be an alternative for a limited number of patients.

TRANSITION TO HOSPICE CARE

The National Hospice Organization (NHO) has published a guideline for determining prognosis in noncancer diseases40 that Medicare fiscal intermediaries have used to help determine eligibility for hospice payment. These guidelines are intended to supplement the general Medicare guideline that the patient’s attending physician and the hospice director believe the patient’s life expectancy is 6 months or less if the terminal illness runs its normal course. The NHO guidelines contain disease-specific and non–disease-specific components.

The latter components specify that the patient has a life-limiting condition, has elected palliation, and has documented clinical progression of disease or impaired nutritional status related to the terminal process. Documented clinical progression is defined by serial physician assessment (or nursing assessment for homebound patients), multiple emergency department visits or hospitalizations within 6 months, a Karnofsky performance status of less than 50%, or dependence in at least 3 of 6 basic activities of daily living (ie, bathing, dressing, transfers, feeding, continence, and independent ambulation to the bathroom). Impaired nutritional status is defined by loss of greater than 10% of body weight, with a serum albumin level of less than 2.5 g/dL as supporting evidence. The disease-specific component for HF is limited in scope, as it requires that the patient is optimally treated with diuretics and vasodilators and has symptoms compatible with New York Heart Association functional class IV. Documentation of an ejection fraction of 20% or less is suggested but not required.

The available data suggest that we need to improve on the performance of the NHO guidelines. Fox and colleagues41 investigated compatibility of the NHO guidelines with the Medicare hospice benefit requirement of life expectancy of less than 6 months. Among the 1312 patients with HF enrolled in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), 58% of patients meeting the criteria in the NHO guidelines were alive at 6 months. Expert consensus guidelines for the management of HF do not offer advice for timing the transition to hospice care. For example, the American College of Cardiology/American Heart Association guidelines provide a limited number of formal recommendations for the patient group classified with advanced (stage D) HF.42 Perhaps as a consequence of this paucity of guidance, palliative and hospice care are probably underused in HF care. Only 5% of hospitalized patients with severe failure have a do-not-resuscitate order.43 Hospice care is rarely provided at the time of hospital discharge.44 Estimates of patient preference for resuscitation are frequently inaccurate.45

APPROACHING THE PATIENT WITH ADVANCED HF

We present a treatment algorithm that incorporates palliative care into HF care early in the course of the disease and establishes the conditions that should be met for referral of the patient with advanced HF to hospice care (Figure). The first step is clinical assessment that emphasizes the need to document evidence for severe left ventricular dysfunction and lack of active correctable ischemia, a diligent search for reversible factors, and the use of maximal medical therapy. Discussion of advance directives should be initiated. In the setting of continued clinical worsening, whether or not the deterioration is punctuated by a hospitalization, reassessment of reversible causes is again performed and advanced therapeutic options are considered. When eligibility for advanced therapeutic modalities is unclear, this step may require that the generalist consult with a cardiologist and/or an HF specialist in a referral center. When the attending physician has determined that the prognosis is poor and that life-prolonging therapies are likely to be ineffective, a formal consultation, if possible with a palliative care team, should be considered. The focus on symptom relief and attention to psychosocial and spiritual needs of the patient and family become paramount. We encourage a clarification of treatment preferences and a discussion about living wills and advanced directives that encompass a variety of likely contingencies throughout the course of HF care, with reclassification as the patient’s clinical status changes.

If further aggressive treatment options have been considered and rejected, it is then appropriate to solicit the preferences of the patient and family with regard to hospice care, rather than pursue further intermittent acute care characterized by advanced diagnostic and therapeutic interventions.

LIMITATIONS AND FUTURE DIRECTIONS

We have intentionally excluded patients with HF and preserved left ventricular systolic function because of generally acknowledged uncertainty about prognostication in this group.46 We have defined an algorithm for patients with advanced HF that incorporates palliative care early in the course of care and provides guidance for appropriate transition to hospice care. This algorithm should be subjected to debate and further research; without this attention, underuse of the palliative care option will undoubtedly continue, to the detriment of patients and their families.47 Mechanisms to develop research priorities include the involvement of professional so-
Assess Clinical Status
(especially during or shortly after recovery from acute exacerbation)
- Assess LVEF; document severe LV systolic dysfunction
- Assess and treat exacerbating factors
- Administer maximum tolerated medical therapy
- Discuss prognosis and goals with patient and family
- Address all symptoms
- Coordinate care with interdisciplinary team

Progression of Illness
- Severe functional limitation or end-organ hypoperfusion
- Evidence for significant disease progression in the prior 6 months
- Multiple hospital admissions or emergency department visits
- Loss of ability to perform activities of daily living

- Reassess and treat exacerbating factors
- Reassess goals of care in light of diminished life expectancy
- Consider advanced therapeutic options
- Readiness for symptom control
- Consider expanded interdisciplinary team and expanded role for interdisciplinary team
- Ineligible for or declines advanced therapeutic options
- Ineligible for or declines destination therapy or heart transplant
- Patient and family aware of prognosis and desire symptom relief but not further acute episodic care

Hospice Care
- Generally will include medical therapy, possibly including inotropic support, and will focus on symptom relief, directed by hospice/palliative care specialist
- Will not include an active ICD or acute care hospitalization for exacerbation

ICD indicates implantable cardioverter-defibrillator; LV, left ventricular; LVF, LV function.

Figure. Algorithm for integrating palliative care into the care of patients with advanced heart failure. ICD indicates implantable cardioverter-defibrillator; LV, left ventricular; LVF, LV function.

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Correspondence: Paul J. Hauptman, MD, Division of Cardiology, Saint Louis University Hospital FDT-15, 3635 Vista Ave, St Louis, MO 63110 (hauptmp@slu.edu).

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