Integrating Palliative Care Into Heart Failure Care

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

eart 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. *Arch Intern Med.* 2005;165:374-378

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 Corvisart¹

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.²⁻⁵ Data from the National Hospital Discharge Survey⁶ show that annual hospitalizations for HF increased by 294000 from 1985 to 1995. Heart failure is the leading cause of hospitalization among Medicare beneficiaries.⁷ For 2003, estimates from the American Heart Association heart disease and stroke statistics8 suggest that the annual number of discharges approached 1 million; the actual numbers may be even higher because coding from the International Classification of Dis-

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. *eases, 9th Revsion*, may underestimate the number of patients admitted with HF by one third.⁹ Patients with HF report physical function scores nearly 2 SDs from the mean for patients with normal health,¹⁰ and significant comorbidities are common.¹¹ Readmission rates are high: up to 44% at 6 months in elderly patients.¹² 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.^{5,13} For advanced cases, a combined end point of mortality or rehospitalization has been reported to occur in up to 81% at 1 year.¹⁴

PALLIATIVE CARE

We recognize that there is controversy regarding the boundaries of the concepts of palliative care.¹⁵⁻¹⁹ 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.²⁰ 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

(REPRINTED) ARCH INTERN MED/VOL 165, FEB 28, 2005 WW

374

WWW.ARCHINTERNMED.COM

patient/family preferences. As such, palliative care can be integrated with conventional HF care that emphasizes life-prolonging treatment. This duality of care²¹ 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 lifeprolonging 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.^{20,22} For patients with HF, each of these tasks is associated with unique challenges. Because HF is an illness with a highly variable trajectory,23 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 functioning²⁴ with hospitalization. In general, the palliative care approach has improved patient outcomes as judged by symptom control, quality of life, and satisfaction with care.²⁵ 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 testing²⁶ 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.27 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 Questionnaire²⁸ and the Kansas City Cardiomyopathy Questionnaire.²⁹ Deterioration in functional capacity may be particularly indicative of high risk of mortality during the next 6 months.23

Renal dysfunction³⁰ (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 avail-

able. In a comprehensive study of survival in patients referred for transplantation, Aaronson et al³¹ 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,³² 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%³³ 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,34 cardiac resynchronization pacing,35 high-risk mitral valve repair or replacement or revascularization cardiac surgery,³⁶ ventricular assist devices as destination therapy,32 external counterpulsation,³⁷ and cardiac transplantation.³⁸ 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,

(REPRINTED) ARCH INTERN MED/VOL 165, FEB 28, 2005 WWW.ARCHINTERNMED.COM

37

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.³⁹ 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). Im*paired 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 reclarification 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-

376





cieties as well as research groups, such as the Palliative Care–Heart Failure Education and Research Trials collaborative group (available at http://www.pc-heart.org). Failure to acknowledge the importance of this mode of care puts at risk the mandate to treat the patient during the entire course of illness, even when therapeutic options have been exhausted.

Accepted for Publication: September 30, 2004.

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

REFERENCES

- Corvisart JN. An essay on the organic diseases and lesions of the heart and great vessels (1812). In: Willius FA, Keys TE, eds. *Classics of Cardiology*. New York, NY: Dover Publications Inc; 1941: 1:289.
- Schocken DD, Arrieta MI, Leaverton PE. Prevalence and mortality rate of congestive heart failure in the United States. *J Am Coll Cardiol.* 1992; 20:301-306.
- Ho KK, Pinsky JL, Kannel WB, Levy D. The epidemiology of heart failure: the Framingham Study. *J Am Coll Cardiol.* 1993;22(suppl A):6A-13A.
- Senni M, Tribouilloy CM, Rodeheffer RJ, et al. Congestive heart failure in the community: a study of all incident cases in Olmsted County, Minnesota, in 1991. *Circulation*. 1998;98:2282-2289.
- Senni M, Tribouilloy CM, Rodeheffer RJ, et al. Congestive heart failure in the community: trends in incidence and survival in a 10-year period. Arch Intern Med. 1999;159:29-34.
- 6. Haldeman GA, Croft JB, Giles WH, Rashidee A.

Hospitalization of patients with heart failure: National Hospital Discharge Survey, 1985 to 1995. *Am Heart J.* 1999;137:352-360.

- Dicker RC, Ordin FL, Han LF, Campbell MK. Introducing the Medicare Quality of Care Surveillance System. Baltimore, Md: Health Care Financing Administration; 1997:1-35. Publication 1. Quality resume.
- American Heart Association. *Heart Disease and* Stroke Statistics: 2003 Update. Dallas, Tex: American Heart Association; 2004.
- Goff DC Jr, Pandey DK, Chan FA, Ortiz C, Nichaman MZ. Congestive heart failure in the United States: is there more than meets the I(CD Code)? the Corpus Christi Heart Project. Arch Intern Med. 2000;160:197-202.
- Ware JE, Kosinski M, Keller SD. SF-36 Physical and Mental Health Summary Scales: A User's Manual. Boston, Mass: Health Institute, New England Center; 1994:B2.
- Havranek EP, Masoudi F, Westfall K, Wolf P, Ordin DL, Krumholz HM. The spectrum of heart failure in older patients: results from the National Heart Failure project. *Am Heart J.* 2002;143: 412-417.
- Krumholz HM, Parent EM, Tu N, et al. Readmission after hospitalization for congestive heart failure among Medicare beneficiaries. *Arch Intern Med.* 1997;157:99-104.
- Ho KK, Anderson KM, Kannel WB, Grossman W, Levy D. Survival after the onset of congestive heart failure in Framingham Heart Study subjects. *Circulation*. 1993;88:107-115.
- Croft JB, Giles WH, Pollard RA, Keenan NL, Casper ML, Anda RF. Heart failure survival among older adults in the United States. *Arch Intern Med.* 1999; 159:505-510.
- Byock I. Hospice and palliative care: a parting of the ways or a path to the future? J Palliat Med. 1998;1:165-176.
- WHO definition of palliative care. Available at: http: //www.who.int/cancer/palliative/definition/en/. Accessed January 7, 2004.
- American Geriatrics Society. Position statement: the care of dying patients. Available at: http://www .americangeriatrics.org/products/positionpapers /careofd.shtml. Accessed December 30, 2003.
- American Academy of Hospice and Palliative Medicine. Position statement: definitions of palliative care and palliative medicine. Available at: http: //www.aahpm.org/positions/definition.html. Accessed December 30, 2003.
- Doyle D, Hanks GWC, MacDonald N, eds. Oxford Textbook of Palliative Medicine. 2nd ed. New York, NY: Oxford University Press Inc; 1998:3.
- National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. Available at: http://www.nationalconsensusproject.org/guidelines.html. Accessed August 10, 2004.
- 21. Pantilat SZ, Steimle AE. Palliative care for patients with heart failure. *JAMA*. 2004;291:2476-2482.
- 22. Morrison RS, Meier DE. Clinical practice: palliative care. N Engl J Med. 2004;350:2582-2590.
- Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. JAMA. 2003;289:2387-2392.
- Sager MA, Franke T, Inouye SK, et al. Functional outcomes of acute medical illness and hospitalization in older persons. *Arch Intern Med.* 1996; 156:645-652.
- Finlay IG, Higginson IJ, Goodwin DM, et al. Palliative care in hospital, hospice, at home: results from a systematic review. *Ann Oncol.* 2002; 13(suppl 4):257-264.

(REPRINTED) ARCH INTERN MED/VOL 165, FEB 28, 2005

WWW.ARCHINTERNMED.COM

- Myers J, Gullestad L, Vagelos R, et al. Clinical, hemodynamic, and cardiopulmonary exercise test determinants of survival in patients referred for evaluation of heart failure. *Ann Intern Med.* 1998; 129:286-293.
- Milani RV, Lavie CJ, Mehra MR. Cardiopulmonary exercise testing: how do we differentiate the cause of dyspnea? *Circulation*. 2004;110:e27-e31.
- Rector T, Cohn JN; Pimobendan Multicenter Research Group. Assessment of patient outcome with the Minnesota Living with Heart Failure questionnaire: reliability and validity during a randomized, double-blind, placebo-controlled trial of pimobendan. Am Heart J. 1992;124:1017-1025.
- Green C, Porter C, Bresnahan D, Spertus J. Development and evaluation of the Kansas City Cardiomyopathy Questionnaire: a new health status measure for heart failure. J Am Coll Cardiol. 2000; 35:1245-1255.
- Dries DL, Exner DV, Domanski MJ, Greenberg B, Stevenson LW. The prognostic implications of renal insufficiency in asymptomatic and symptomatic patients with left ventricular systolic dysfunction. *J Am Coll Cardiol.* 2000;35:681-689.
- Aaronson KD, Schwartz JS, Chen TM, Wong KL, Goin JE, Mancini DM. Development and prospective validation of a clinical index to predict survival in ambulatory patients referred for cardiac transplant evaluation. *Circulation*. 1997;95:2660-2667.
- Rose E, Gelijns A, Moskowitz A, et al. Long-term mechanical left ventricular assistance for endstage heart failure. N Engl J Med. 2001;345: 1435-1443.
- Hershberger R, Nauman D, Walker T, Dutton D, Burgess D. Care processes and clinical out-

comes of continuous outpatient support with inotropes (COSI) in patients with refractory endstage heart failure. *J Card Fail*. 2003;9:180-187.

- Mikolajczak P, George A, Oliver D, Hoover R, Hedrich O, Hauptman PJ. Preliminary economic analysis of chronic continuous home inotropic therapy in end-stage heart failure: insights from a multistate Medicare database [abstract]. *J Card Fail.* 2004;10(suppl):S109.
- Abraham WT, Fisher WG, Smith AL, et al. Cardiac resynchronization in chronic heart failure. *N Engl J Med.* 2002;346:1845-1853.
- Badhwar V, Bolling SF. Mitral valve surgery in the patient with left ventricular dysfunction. *Semin Thorac Cardiovasc Surg.* 2002;14:133-136.
- Soran O, Fleishman B, DeMarco T, et al. Enhanced external counterpulsation in patients with heart failure: a multicenter feasibility study. *Congest Heart Fail.* 2002;8:204-208.
- Miniati DN, Robbins RC. Heart transplantation: a thirty-year perspective. *Annu Rev Med.* 2002; 53:189-205.
- Phillips C, Wright S, Kern D, Singa R, Shepperd S, Rubin H. Comprehensive discharge planning with postdischarge support for older patients with congestive heart failure: a meta-analysis. *JAMA*. 2004;291:1358-1367.
- Standards and Accreditation Committee and Medical Guidelines Task Force. *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases*. 2nd ed. Arlington, Va: National Hospice Organization; 1996.
- Fox E, Landrum-McNiff K, Zhong Z, Dawson NV, Wu AW, Lynn J; SUPPORT Investigators. Evaluation of prognostic criteria for determining hospice eligibility in patients with advanced lung,

heart, or liver disease. JAMA. 1999;282:1638-1645.

- 42. Hunt SA, Baker DW, Chin MH, et al. ACC/AHA guidelines for the evaluation and management of chronic heart failure in the adult: a report of the 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), 2001. Available at: http://www.acc.org/clinical /statements.htm. Accessed December 30, 2003.
- Wachter RM, Luce JM, Hearst N, Lo B. Decisions about resuscitation: inequities among patients with different disease but similar prognoses. *Ann Intern Med.* 1989;111:525-532.
- 44. Jaagosild P, Dawson NV, Thomas C, et al; SUPPORT Investigators. Outcomes of acute exacerbation of severe congestive heart failure: quality of life, resource use, and survival: the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments. Arch Intern Med. 1998;158:1081-1089.
- 45. Krumholz HM, Phillips RS, Hamel MB, et al. Resuscitation preferences among patients with severe congestive heart failure: results from the SUPPORT project: Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Circulation*. 1998;98:648-655.
- Zile MR, Brutsaert DL. New concepts in diastolic dysfunction and diastolic heart failure, I: diagnosis, prognosis and measurements of diastolic function. *Circulation*. 2002;105:1387-1393.
- Goodlin SJ, Hauptman PJ, Arnold R, et al. Consensus statement: palliative and supportive care in advanced heart failure. *J Card Fail*. 2004;10: 200-209.