

NHPCO Practice Report

Hospice Care for Heart Failure Patients

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Introduction

Although approximately 260,000 persons die annually in the United States (USA) with heart failure (HF), HF patients infrequently receive hospice care. Patients with refractory symptoms of HF at rest despite optimal medical therapy (Stage D) have less than a one-year survival^{1,2} and American Heart Association/American College of Cardiology guidelines recommend hospice care as an option for this population. Yet the number referred to hospice is relatively

small.³ Forty-nine percent (49%) of hospice patients have a diagnosis of cancer, whereas only 11% have a primary diagnosis of HF.⁴ No literature characterizes current care for heart failure patients in hospice. No surveys of current practice in hospice have been published to inform physicians and other health care professionals about the services available to HF patients in the hospice setting, and care within hospice agencies appears to be variable.⁵ We conducted a national survey to gain a better understanding of how hospices were caring for persons dying of heart failure.

Methods

In April and May 2003, we solicited a convenience sample of hospice medical directors via e-mail to 156 hospice medical director members of the American Academy of Hospice and Palliative Medicine (AAHPM) and the National Hospice Work Group. Announcements were also placed in bulletins of the AAHPM, the Population-based Palliative Care Research Network (PoPCRN), and the National Hospice and Palliative Care Organization (NHPCO). Participants accessed the survey through the PoPCRN Web site and had the option of completing the survey online or by mail. Only one survey response was accepted per hospice agency. Survey participation was anonymous and responses were not linked to participants' hospices. The invitations to participate were sent by the participating organizations.

Results

Seventy of the 156 medical directors responded, representing hospice agencies from 33 states. Although respondents were similar to medical directors and hospice agencies nationally,⁶ our sample included medical directors of proportionally fewer rural hospices and more not-for-profit agencies (20% vs. 38% and 84% vs. 72%, respectively) than the NHPCO membership, which comprises 75% of the more than 3000 hospices in the USA.

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Reported average daily census (ADC) of the hospices was 128 patients (range 10–1700). On average, 9% of patients (range 2–30%) had a primary diagnosis of HF. The mean length of stay for HF patients was 60 days (range 15–150 days), which was significantly longer than for other diagnoses (mean 39 days, range 7–98 days, $P = 0.002$). Thirty-one percent of hospices provided specific training to their clinical staff regarding care of patients with advanced heart failure; the average length of training was 2 hours (range 1–14 hours). Only 14% of medical directors reported that their hospices had care plans specific to the management of HF patients.

Nearly all medical directors reported that their hospices routinely provided inexpensive, non-invasive heart failure therapies, including oral medications. Intravenous inotropes and other potentially expensive heart failure therapies were not usually provided and often precluded admission (Figure 1). For some respondents, the following therapies precluded admission *only* if the hospice was expected to pay for them: nesiritide or milrinone (19%), dobutamine (24%), intravenous potassium (8%), and continuous positive airway pressure (CPAP) (8%). Ninety-four percent (94%) accepted patients with implantable cardioverter defibrillators (ICDs), but only 13% had policies or procedures to manage the ICDs and 27% had policies or procedures relating to turning off the devices. Forty-five percent of hospice agencies accepted patients with ventricular assist devices (VADs), although few patients with VADs were admitted by any agency.

Provision of intravenous therapies for HF and invasive treatments were not associated with the medical specialty of the medical director or formal training in HF, but there was an inverse relationship between time spent as a hospice medical director and intensity of HF treatment provided at the facility, namely, the more time spent as a hospice medical director, the less likely that the agency provided these interventions. When medical directors agreed that the expected palliative benefit from a therapy determined provision of treatments, they were more likely to provide dobutamine (67% vs. 23%, $P = 0.034$) and accept patients with active ICDs (98% vs. 85%, $P = 0.045$). Hospice agencies that provided intravenous heart failure therapies had a larger ADC than those that did not (Figure 2).

Implications for Practice

Hospice is an important but underutilized option for advanced HF patients and consideration should be given to the examination of barriers to hospice access for HF patients. For hospice care to meet its potential for relieving symptoms and helping patients and family members with end-of-life issues, medical and nursing staff must achieve greater expertise in the care of HF patients. Although no specific standard exists for palliative treatment of advanced HF,⁷ few hospice agencies in the current sample had training, policies or procedures, or standardized care plans for management of HF patients. Hospices also reported financial

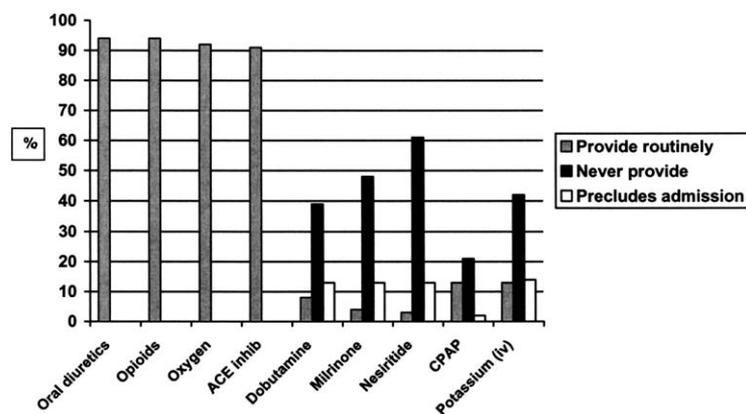


Fig. 1. Percentage of hospices providing inexpensive and more costly treatments for HF patients.

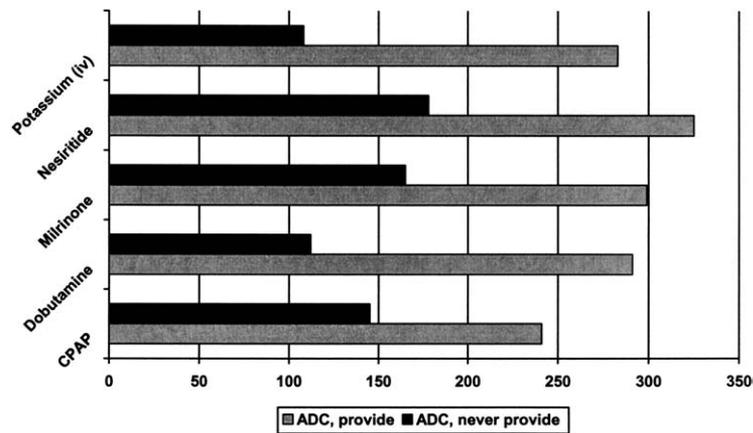


Fig. 2. Relationship of hospice size to provision of costly or invasive HF therapies ($P < 0.05$).

barriers to provision of treatment, another factor that may limit access to hospice care for HF patients.

Lack of staff knowledge and expertise may restrict care provided in hospice for heart failure patients. Heart failure differs significantly from other illnesses, notably cancer, in the course of illness and approaches to treatment.⁵ Meticulous management of fluid status assessed by weight, for example, is critical to managing HF and its symptoms.³ In HF, medications or treatments that are disease-modifying and life-prolonging also influence symptom severity. Lack of understanding about the complexity of the pathophysiology of HF and the effects of available treatments may lead to lack of provision of treatments that improve function and quality of life. An opportunity to improve HF care in hospice may exist through staff education by and in partnership with HF experts.

Another potential barrier specific to hospice care for HF patients is inadequate identification of palliative treatments. Perception that a treatment has palliative benefit was associated with a greater tendency to provide the treatment; hence it is imperative to clarify expected outcomes from treatments provided to persons with advanced HF. The majority of hospice agencies in the survey group did not provide specific intravenous therapies that may effectively palliate refractory volume overload, dyspnea, hypotension, or end-organ dysfunction for some patients and are associated with a prognosis of 3 months on average.⁸ Lack of provision of certain therapies, such as intravenous medications, may exclude patients from hospice care

even though appropriate for admission to hospice given the Medicare-required life expectancy of 6 months. Sleep-disordered breathing occurs in at least half of persons with advanced HF,⁹ and treatment with CPAP improves mechanical function of the left ventricle,¹⁰ and reverses the adverse neurohormonal activation for HF patients with sleep apnea or Cheynes-Stokes respiration.¹¹ CPAP thus may have significant palliative benefit for about half of advanced HF patients, yet it was rarely provided in our survey. Further effort is needed to identify palliative interventions in HF as well as the resources needed to provide such interventions.

Financial barriers to exercising various treatment options were noted by a number of medical directors in the sample. For some HF patients, palliative treatments may be costly.¹² The actual cost of care for HF patients to the hospice should be identified, including staffing and treatment costs in excess of Medicare reimbursement amounts.¹³ The practices of hospices with dedicated programs for advanced HF patients may have addressed some of these financial barriers, but the creation of an outlier payment system should be considered to allow greater hospice access for HF patients to hospices, such as rural programs, that are exceptionally vulnerable to financial risk because of small census and other factors.

Conclusions

This survey is preliminary in that it reports data from a limited sample of hospice medical

directors. Nonetheless, there are no similar data published elsewhere. They suggest important areas for improvement and provide relevant preliminary information on which to base future study. These pilot data also provide support for further work regarding barriers to hospice access for HF patients, better understanding of current practice, and the development of quality indicators for the care of patients dying from HF.

Acknowledgments

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