
COMMENTARY

Hospice and Heart Disease: Missed Opportunities

Joni I. Berry

ABSTRACT. A relatively low percentage of eligible heart disease patients receive hospice care in the United States. In 2005, the most recent year with complete reporting, only 18.36% of patients who were dying of heart failure and were hospice eligible actually received hospice care. Reasons for this include the lack of reliable prognostic indicators, the lack of a consensus on when to stop life prolonging therapies, and the relatively high cost of life-prolonging (versus life-enhancing) pharmacotherapy such as dobutamine. In addition, most studies and case reports that address symptom management in hospice care focus on cancer patients, not those with nononcologic diagnoses. This lack of evidence may discourage practitioners who care for cardiac patients from referral to hospice programs, and may keep some hospice practitioners from aggressively targeting this population. Strategies to increase hospice program utilization by heart disease patients are discussed.

KEYWORDS. barriers, heart disease, hospice, utilization, palliative care

In 2005, the latest year for which full statistics were available at the time of this writing, the federal Centers for Disease Control and Prevention (CDC)¹ reported 2,448,017 deaths from all causes in the United States and the American Heart Association (AHA)² an estimated 486,300 deaths from nonacute heart disease. Nonacute heart disease included congestive heart failure, hypertension, and coronary artery disease (excluding sudden deaths). Thus nonacute heart disease accounted for 19.87% of all deaths in the United States that year. In addition, approximately 309,000 people died from acute cardiac causes either in or before they were able to ac-

cess emergency rooms. This equated to 795,300 deaths from all types of heart disease or 32.49% of all deaths in the United States. If cerebral vascular accidents (CVAs) are included, the total is 35.3% of all deaths.

Also in 2005 the National Hospice and Palliative Care Organization (NHPCO)³ reported that an estimated 797,160 patients died in hospice, and of those 89,282 died from heart disease. This number does not include patients with a terminal diagnosis of CVA. Thus, hospice programs served 32.56% of all people who died in that year and only 3.65% of all people dying from heart disease. Of the 486,300 people dying

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from nonacute heart disease in 2005, hospice programs cared for only 89,282 or 18.36% of all the people who were eligible for hospice services.

Although most hospice workers can easily list one or more factors contributing to these low numbers, it is still important to review the factors that have been shown to be barriers to care.⁴⁻⁶ These barriers include

- Historical patterns of care
- Uncertain prognostic indicators
- Increasing number and cost of therapies
- Lack of clinical evidence for care
- Inadequate staff training

Historically most hospices have cared for cancer patients. In fact, the Medicare Hospice Benefit was written with the cancer patient population in mind.⁷ The Medicare requirement that a patient have a prognosis of 6 months or less to live is based on the fairly predictable disease trajectory of the cancer patient population.⁷ There is a general consensus that prognostication is easier in cancer patients, which makes referral to hospice fit more readily into the Medicare guideline of hospice patients having 6 months or less to live. Some members of the public and non-hospice health care professionals have misinterpreted the situation and think that hospice care is only for cancer patients. Although it is true that some hospices admitted only cancer patients in the past, this author does not know of any that still restrict admissions in this way. However, this perception appears to still be prevalent and may be one cause of low referrals.⁴⁻⁶

Heart disease is a disorder that until recently defied attempts to predict prognosis. Of interest is the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment⁸ (SUPPORT), which found that 2 days before death, the average heart failure patient had a predicted prognosis of 6 months or more. This study obviously shows the variance in the actual prognosis and the predicted prognosis made by the patients' physicians. Early in the 1990s NHPCO created prognostic guidelines for many nononcologic diagnosis. Unfortunately these guidelines were adopted by Medicare intermediaries as requirements for hospice admission before they had been tested for validity. Subsequent testing of these guidelines by the SUPPORT Study Group showed that the indicators sug-

gested by NHPCO are not valid as far as predicting prognosis.⁹ Despite this lack of validity, these indicators are still used as screening tools for hospice admissions.

In 2008 Huynh et al.¹⁰ published a simple 4-point item risk score for patients in heart failure. They reviewed all cause mortality at 6 months in 282 patients age 70 and older at Barnes Jewish Hospital in Gainesville, Florida. Patients were followed up to 14 years post initial study hospitalization. Four prognostic indicators were identified:

- Serum urea nitrogen of ≥ 30 mg/dL
- Systolic blood pressure < 120 mm Hg
- Peripheral arterial disease
- Serum sodium < 135 mEq/L

The authors stratified patients by the number of risk factors met by each patient. Six-month mortality increased in a predictable fashion as the number of risk factors increased. The correlation between the number of risk factors and percentages of patients dying within 6 months are illustrated in Table 1.

Patients with 3 or more risk factors clearly were candidates for a palliative care discussion and possibly referral. The authors stated that patients with two risk factors and a 6-month mortality rate approaching 50% were likely to benefit from a palliative care intervention. Age by itself was not predictive of mortality; neither were race; New York Heart Association class; presence of comorbidities such as dementia, stroke or transient ischemic attack (TIA), atrial fibrillation, or flutter; body mass index; serum hemoglobin; or presence of diastolic heart failure (heart failure with low normal ejection fraction).

In a 2007 study Hauptman and colleagues¹¹ reviewed data from 182,898 heart failure

TABLE 1. Correlation Between the Number of Risk Factors and Percentage of Patients Dying Within Six Months

No. of risk factors	% risk of dying in 6 months
0	3.7
1	16.3
2	41.0
3 or more	61.7

“episodes” and found the same indicators of risk. This study looked at heart failure patients referred to hospice for a variety of reasons. Risk factors for 6-month mortality included lower serum sodium, lower systolic blood pressure, and higher serum urea nitrogen. In addition, the study implicated older age and absence of lipid-lowering drugs as risk factors. The last item may have been more a factor of functional inability than causation. Silveira and colleagues¹² analyzed survival in patients maintained on lipid-lowering drugs (statins) and patients whose statins were discontinued. In this analysis there was no difference in time to death in each patient cohort.

Another review by Hauptman and Havarnek¹³ listed several other prognostic indicators gathered from other observational studies. These were

- Functional capacity as a measure of maximum oxygen consumption
- Renal dysfunction
- More than 1.9 hospitalizations in the prior 6 months (75% mortality)
- Mean left ventricular ejection fraction (LVEF) <70% present for longer than 90 days coupled with maximal oxygen consumption of 12 mL/kg/min (50% 6-month mortality)

Note that patients with diastolic heart failure do not show this type of precipitous declines in LVEF during their course of illness. These last indicators have not been studied as rigorously as the ones listed by Huynh and colleagues.¹⁰ This author suggested a greater emphasis be given to the four items listed in their study, with the criteria listed by Hauptman and Havarnek¹³ given secondary consideration.

Many authors discuss the paradox of improved therapies for heart failure, which has resulted in an increasing numbers of patients living with debilitating disease.^{14–17} In an eloquent paper entitled “Ethical Issues in Heart Failure,” Kirkpatrick and Kim¹⁴ emphasized this issue and point out the failure of modern health care to provide adequate palliative care to this vulnerable population.

Although few heart failure patients have any discussion with their physicians about advanced care directives, end-of-life care, goals of therapy, treatment limitations, or decision-making capac-

ity, many when asked do desire such conversations. Kirkpatrick and Kim¹⁴ quote one study of cardiac rehabilitation patients in which 96% of patients wanted to discuss advance directives but only 15% reported ever having this type of conversation with their physician. They report that in a separate study 23% of patients wanted do-not-resuscitate (DNR) orders but only 25% had a conversation with their doctor on this topic. In addition, physicians showed only 75% accuracy in guessing their patients’ preferences. This obviously means they could guess correctly much more often than they chose to have the conversation. The authors admit that end-of-life discussions with cardiac patients are often more difficult than with other types of patients, particularly cancer patients. The major reason for this discrepancy is the more uncertain prognosis and the variable disease trajectory found in cardiac patients. Perhaps if hospice programs worked more closely with cardiologists, they could communicate about these issues more effectively. Often nonpalliative care practitioners simply have not yet learned the type of language or the approaches found effective for patients at end-of-life.

The cost of invasive therapies for heart failure is another difficult stumbling block to care.¹⁸ A study of hospice medical directors by the U.S. Cancer Pain Relief Committee⁴ reports that cost of therapies directly influences admission to hospice programs. Those hospice programs that did offer therapies such as intermittent dobutamine infusions tended to be larger programs with an average daily census of over 225 patients. This appears to reflect the need to spread the cost of these therapies over more patients.

A review of the available literature reveals a growing body of knowledge regarding palliative care in cardiac patients; however, they give little direct information, as evidenced by specific studies in this population.^{4,5,15,19} Many authors review symptom management issues but are unable to give evidence of their efficacy when applied to cardiac care.

Lastly, lack of staff training and familiarity with heart failure–specific assessment criteria are mentioned as causative factors in the failure of hospice programs to accept more heart failure patients.⁴ This author’s experience discussing hospice with cardiologists suggests that some do not trust hospice care and do not have

faith that the hospice nurses have the tools to adequately care for these patients.

Although somewhat disheartening, the data on hospice care for heart failure patients also reflect great opportunity. There is a wealth of information available on treatment of end-stage cardiac disease.^{19–22} Interventions such as focused training for nurses, specialized assessment tools for cardiac disease, and outreach to cardiologists may lead to improved access for this large group of patients who could benefit greatly from the excellent palliative care provided by hospices.

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