Consensus Statement

End-of-Life Care in Patients With Heart Failure

DAVID J. WHELLAN, MD, MHS,[1] SARAH J. GOODLIN, MD,[2] MICHAEL G. DICKINSON, MD,[3] PAUL A. HEIDENREICH, MD, MS,[4] CONNIE JAENICKE, NP, RN-C MSN,[5] WENDY GATTIS STOUGH, PharmD,[6] AND MICHAEL W. RICH, MD,[7] ON BEHALF OF THE QUALITY OF CARE COMMITTEE, HEART FAILURE SOCIETY OF AMERICA

Philadelphia, Pennsylvania; Portland, Oregon; Grand Rapids, Michigan; Palo Alto, California; Minneapolis, Minnesota; Buies Creek, North Carolina; and St. Louis, Missouri

ABSTRACT

Stage D heart failure (HF) is associated with poor prognosis, yet little consensus exists on the care of patients with HF approaching the end of life. Treatment options for end-stage HF range from continuation of guideline-directed medical therapy to device interventions and cardiac transplantation. However, patients approaching the end of life may elect to forego therapies or procedures perceived as burdensome, or to deactivate devices that were implanted earlier in the disease course. Although discussing end-of-life issues such as advance directives, palliative care, or hospice can be difficult, such conversations are critical to understanding patient and family expectations and to developing mutually agreed-on goals of care. Because patients with HF are at risk for rapid clinical deterioration or sudden cardiac death, end-of-life issues should be discussed early in the course of management. As patients progress to advanced HF, the need for such discussions increases, especially among patients who have declined, failed, or been deemed to be ineligible for advanced HF therapies. Communication to define goals of care for the individual patient and then to design therapy concordant with these goals is fundamental to patient-centered care. The objectives of this white paper are to highlight key end-of-life considerations in patients with HF, to provide direction for clinicians on strategies for addressing end-of-life issues and providing optimal patient care, and to draw attention to the need for more research focusing on end-of-life care for the HF population. (*J Cardiac Fail 2014;20:121−134*)

Key Words: Advanced heart failure, end-of-life care, hospice, palliative care.

Heart failure (HF) with either reduced ejection fraction (HFrEF) or preserved ejection fraction (HFpEF) is characterized by a broad range of symptoms. Patients with HF tend to follow a variable course after the initial insult (eg, coronary artery disease, myocardial infarction, genetic conditions, or environmental factors such as alcohol), but many progress owing to maladaptive remodeling and recurrent damage to the myocardium leading to the development of worsening symptoms. The American College of Cardiology Foundation/American Heart Association (AHA) guideline for the management of HF characterizes HF progression into 4 stages, in which stage A includes individuals with risk factors for HF but without structural heart disease, stage B includes persons with structural heart disease without HF symptoms, stage C represents symptomatic HF, and stage D reflects refractory symptoms despite guideline-directed medical therapy (GDMT).[1]

Although a large body of evidence has accumulated to guide the management of patients with chronic HF, there is little consensus on the care of these patients near or at the end of life. Many factors warrant consideration in this population, including prognosis, patient treatment goals, and available treatment options. Discussing end-of-life issues,

From the [1]Department of Medicine, Jefferson Medical College, Philadelphia, Pennsylvania; [2]Division of General Internal Medicine and Geriatrics, Portland Veterans Affairs Medical Center and Oregon Health and Science University, Portland, Oregon; [3]Frederik Meijer Heart & Vascular Institute, Spectrum Health, Grand Rapids, Michigan; [4]Center for Health Policy, Center for Primary Care and Outcomes Research, Veterans Affairs Palo Alto Medical Center, Palo Alto, California; [5]Veterans Affairs Medical Center, Minneapolis, Minnesota; [6]Campbell University College of Pharmacy and Health Sciences, Buies Creek, North Carolina and [7]Washington University School of Medicine, St. Louis, Missouri.

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Reprint requests: David J. Whellan, MD, MHS, Professor of Medicine, Jefferson University, 925 Chestnut Street, Mezzanine, Philadelphia, PA 19107. Tel: 215-955-2007; Fax: 215-503-7420. E-mail: djw150@jefferson.edu

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such as advance directives, palliative care or hospice, and device deactivation, is critical to guiding patient and family expectations and helping them to cope with terminal illness and death. Appropriate strategies can be used to improve HF symptoms and quality of life throughout HF care, including the end-of-life period. Recognizing that most HF patients die before stage D, it is important to address dying early in the course of HF because of the risk of sudden death and potential need for resuscitative measures. Patients' preferences regarding end-of-life care should be revisited periodically as the condition and prognosis evolve.

Despite the difficulty and complexities of end-of-life issues in HF patients, there is minimal evidence-based guidance to inform the care of this population. The objectives of this white paper are to highlight key end-of-life considerations in patients with HF, to provide direction for clinicians on strategies for addressing end-of-life issues and for providing optimal patient care, and to draw attention to the need for more research focusing on end-of-life care for the HF population.

Defining the Stage D HF Population

Epidemiology

The prevalence of stage D HF has not been well documented. Approximately 5.7 million Americans ≥20 years of age have HF.[2] The proportion of these patients with stage D is uncertain, although it has been estimated to be 5%−10%.[3] These figures suggest that there are 300,000−600,000 patients in the USA with stage D HF.

Patient Characteristics

The Acute Decompensated Heart Failure National Registry Longitudinal Module (ADHERE LM) enrolled 1,433 patients with stage D HF. Patients with stage D HF were younger, more often male, and more likely to have a history of dyslipidemia, coronary artery disease, and chronic renal insufficiency than other patients hospitalized for acute decompensated HF. Stage D patients were also more likely to have a permanent pacemaker or implantable cardioverter-defibrillator (ICD),[4] a finding that has important implications for palliative care or hospice discussions. The estimated 1-year survival in this population was 71.9%, and the estimated 1-year freedom from survival or hospitalization was 32.9%. This survival rate is higher than the 6-month survival of 67% in the Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheterization (PAC) Effectiveness (ESCAPE) PAC Registry, which included patients hospitalized for decompensated HF who were not randomized into the main ESCAPE trial but still received PAC.[5] In the medical therapy arm of the Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart Failure (REMATCH) trial (a randomized trial of destination ventricular assist device therapy versus optimal medical management in end-stage patients), estimated 1-year survival was only 25%.[6] This range of outcomes likely reflects underlying differences in the populations studied, and it highlights the significant heterogeneity of patients classified as stage D.

Heart Failure With Preserved Ejection Fraction

Up to 50% of HF patients have preserved left ventricular systolic function, and this form of HF becomes increasingly more common with advancing age, especially in women.[7,8] Although symptom severity, hospitalization rates, and prognosis are similar in patients with HFpEF to those in patients with HFrEF,[9] management of patients with HFpEF is compromised by the lack of proven effective therapies. Thus, neither pharmacologic agents nor devices have been shown to reduce mortality in this population.[1,10]

Predicting Prognosis in Stage D Heart Failure

The optimal treatment of HF depends in part on the patient's expected survival. Although many medical treatments improve outcomes at all stages of HF, use of ICDs does not clearly improve survival unless life expectancy is ≥1 year. Accordingly, clinical guidelines recommend against, and some payers will not reimburse, the use of ICDs if a patient is expected to live <12 months. In addition, a patient may choose to discontinue treatments that are only life prolonging (ie, with no impact on symptoms), eg, turning off the ICD function of a device if life expectancy is markedly limited or if quality of life is poor. Therefore, knowledge of one's risk of dying in the next year may help patients and their families select the most appropriate treatment and optimal care setting. A patient with a markedly shortened survival and poor quality of life may wish to be managed outside of the hospital (eg, hospice).

Predicting the outcome for patients with stage D HF is challenging. One survey showed that physicians thought that they could predict 6-month mortality "most of the time" or "always" in only 16% of their HF patients.[11] Patients also have been poor at predicting their own survival. In a study using the Seattle Heart Failure Model (SHFM; see below) to estimate life expectancy, patients with chronic stable HF estimated a survival consistent with actuarial data for individuals without HF, 3 years longer than the model predicted. Younger age, increased New York Heart Association (NYHA) functional class, lower left ventricular ejection fraction (LVEF), and less severe depression were the most significant predictors of greater overestimation by patients. Actual survival was more accurately predicted by the SHFM than by the patient's estimate.

Given the difficulty in estimating prognosis, predicting survival for patients with HF has become a research priority. Many large studies have examined patient characteristics and treatments that are associated with a higher or lower risk of death.[12,13] Several of these investigations have yielded algorithms to predict survival for patients with HF with the use of information commonly available at the time of a clinical encounter (Table 1).[10−14] They differ in their outcome (survival to discharge or long-term survival)