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.*

Manuscript received July 19, 2013; revised manuscript received December 5, 2013; revised manuscript accepted December 6, 2013.

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

See page 132 for disclosure information.

1071-9164/$ - see front matter



http://dx.doi.org/10.1016/j.cardfail.2013.12.003

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)

**Table 1.** ESCAPE Discharge Prediction Score

| Criteria (Based on Discharge Measurement) | Score if Yes (No = 0) |
|---|---|
| Age >70 y | 1 |
| BUN >40 mg/dL | 1 |
| BUN >90 mg/dL | 1 |
| 6-min walk <300 ft | 1 |
| Sodium <130 mEq/L | 1 |
| CPR/mechanical ventilation, yes/no | 2 |
| Diuretic dose >240 mg at discharge, yes/no | 1 |
| No beta-blocker at discharge | 1 |
| Discharge BNP >500 pg/mmol | 1 |
| Discharge BNP >1,300 pg/mmol | 3 |
| Total | 0−13 |

Reprinted with permission from O'Connor et al, Triage after hospitalization with advanced heart failure: the ESCAPE (Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheterization Effectiveness) risk model and discharge score, J Am Coll Cardiol 2010;55:872−8.[109]

and the patient population (eg, hospitalized, preserved systolic function). These algorithms are potentially useful for end-of-life HF care if they can identify patients at high risk of death during short-term follow-up (ie, 3−6 months), for whom the approach to management may be altered. The SHFM is the most widely used algorithm for predicting prognosis, but it should be recognized that it was not derived from an advanced HF population; therefore, like many models, it may underestimate risk in the advanced HF population. The online version of the SHFM allows one to determine the impact of different treatments on expected survival. The model has been validated in numerous HF patient populations, and it has been shown to be accurate for predicting risk of death for various patient groups,[14,15] including those referred for cardiac transplantation.[16] For individual patients, the discrimination for 1-year mortality has varied from 0.68 to 0.81 (ie, good to excellent, where 0.5 indicates no discrimination and 1.0 indicates perfect prediction) depending on the validation cohort. In the original cohort, the model accurately identified patients at the end of life who had a 1-year mortality of 84%, although only 0.4% of the population had such a high risk. A slightly larger group (3.3%) had a 1-year mortality of 51%, and though they are not clearly at the end of life, this information would be important for selecting device therapy.

With the Enhanced Feedback for Effective Cardiac Treatment (EFFECT) model,[17] patients with a score of <60 had only 8% 1-year mortality and those with a score of 121−150 had 59% 1-year mortality and therefore would not be candidates for ICDs. Those with a score of >150 had 79% 1-year mortality and would be considered to be at the end of life.

Patients with HFpEF tend to be older than patients with HFrEF, and they are more likely to have multiple comorbid illnesses that may affect prognosis. As a result, patients with HFpEF are less likely than patients with systolic HF to die from either progressive HF or ventricular tachyarrhythmias and more likely to die from a noncardiovascular cause, such as pneumonia or cancer.[18] For these reasons, it is more difficult to assess prognosis in patients with HFpEF than with HFrEF. Nonetheless, frequent hospitalizations and worsening symptoms, especially NYHA functional class IV, are markers of a downhill trajectory and high mortality within the ensuing 6−12 months, signaling the need to discuss prognosis and end-of-life care options.[19] Principles of managing symptoms in patients with advanced HF in the setting of preserved ejection fraction are generally similar to those in patients with reduced ejection fraction.

## Medical Management at the End of Life

In addition to dyspnea, patients with advanced HF often experience pain, weakness, fatigue, nausea, anorexia, constipation, edema, cough, altered mental status, anxiety, depression, and sleep disorders.[20−22] Management of these symptoms in patients approaching the end of life is briefly reviewed in the following sections.

### Dyspnea

Dyspnea, or the perception of difficulty breathing, is a hallmark of advanced HF, and may become increasingly severe in the terminal stage of illness. Management of dyspnea includes maintenance of euvolemia through judicious use of diuretics in conjunction with dietary sodium and fluid restrictions.[1,10] In patients with systolic HF, renin-angiotensin-aldosterone-system blockade (angiotensin-converting enzyme [ACE] inhibitors, angiotensin receptor blockers [ARB], mineralocorticoid antagonists) should be titrated as tolerated to optimize cardiac performance while minimizing adverse effects.[1,10] Digoxin is appropriate in patients with dyspnea persisting despite the above measures.[1,10] Similarly, intravenous inotropic therapy with dobutamine or milrinone may provide palliation of symptoms and improve quality of life in some patients, but this approach requires discussion with the patient and family about the potential for increased arrhythmia and mortality.[1,10]

Opioids have demonstrated efficacy and safety for alleviating dyspnea in patients with advanced HF and are considered to be first-choice adjunctive agents.[20,23,24] Relatively low dosages, such as 0.05 mg hydromorphone or 1 mg oxycodone, are often sufficient. Toxic metabolites excreted by the kidneys may accumulate, so patients requiring regular doses of opioids should be converted to fentanyl or methadone, which do not have renally excreted metabolites. Oxygen is appropriate in patients with hypoxemia, but it has not been shown to be helpful in patients with preserved oxygenation.[25] Benzodiazepines may be useful for reducing anxiety associated with dyspnea.[26] Other therapies, such as dietary supplements, relaxation techniques, and thermal therapy, are of unproven benefit.[21]

### Pain

Although pain is not usually considered to be a symptom of HF, pain is common in advanced HF.[27] When possible,

the underlying cause of pain should be treated appropriately (eg, antianginal agents for ischemic chest pain). For other pain, opioids are first-line agents, and the dose should be titrated to provide adequate relief, avoiding opioids with active metabolites that accumulate in renal impairment.[20,21] Fentanyl may be delivered via oral-buccal or topical routes for patients with moderate to severe pain; however, it is not FDA approved for noncancer pain. Nonsteroidal antiinflammatory drugs (NSAIDs) should generally be avoided owing to adverse effects on renal function, sodium and fluid retention, and gastrointestinal side effects.[20,21,28]

### Fatigue and Weakness

Fatigue and weakness in patients with advanced HF are usually multifactorial, related in part to cardiac insufficiency, loss of muscle mass, deconditioning, and comorbid conditions (eg, anemia, thyroid dysfunction, sleep disorders, depression). Cardiac performance should be optimized in accordance with current guidelines, and coexisting illnesses, if present, should be treated appropriately. Regular exercise, including aerobic exercise and resistance training with light weights, should be encouraged in patients who are able to exercise.[20,21] Stimulants, such as methylphenidate, may be beneficial in some cases.[20,21]

### Gastrointestinal Disorders

Advanced HF is often associated with increased catabolism in conjunction with anorexia, leading to cardiac cachexia.[29] HF therapy should be optimized, because there is some evidence that ACE inhibitors and carvedilol have favorable effects on energy metabolism and the manifestations of cardiac cachexia.[29] High-energy nutritional supplements may be useful for malnutrition, but there is no evidence that they improve clinical outcomes.[29] Similarly, appetite-promoting agents, such as megestrol acetate, are of uncertain benefit in HF patients, and they can promote fluid retention.[29]

Nausea occurs in some patients with advanced HF, likely due to a combination of reduced intestinal perfusion and medication side effects.[30] A careful review of medications should be performed, and all nonessential medications should be discontinued. Aspirin, a common cause of nausea, should be administered at low dosage (75−81 mg/d) and with food, and persistent unexplained nausea should prompt discontinuation of aspirin, at least temporarily. Antiemetic agents, such as prochlorperazine or ondansetron, should be considered in patients with intractable nausea, recognizing that these drugs have the potential for inducing significant side effects.

Constipation is also common in patients with advanced HF, due in part to decreased food intake, physical inactivity, and medication side effects (especially from opioids).[30] Treatment of constipation should include consumption of high-fiber foods, including vegetables, fruits, and whole grains.[31] Laxatives, such as polyethylene glycol 3350 and lactulose, should be administered as needed. In patients with severe constipation, an enema and/or manual disimpaction may be necessary to provide relief.

### Depression and Anxiety

Approximately 30%−35% of patients with advanced HF have clinical depression, and the presence of depression correlates with higher symptom burden and increased risk of adverse outcomes, including hospitalizations and mortality.[20,21] Depressed patients also tend to be less adherent to medications and behavioral interventions. Options for treating depression in patients approaching the end of life include cognitive behavioral therapy, spiritual support (eg, clergy), and medications.[20,21] Selective serotonin reuptake inhibitors (SSRIs) at low doses are generally considered to be first-line agents, but these drugs can induce fluid retention and hyponatremia in patients with renal insufficiency,[20] and some prolong the QTc interval. The efficacy of these agents in improving depression scores in patients with stage D HF remains to be established.[32] Tricyclic antidepressants, such as nortriptyline or desipramine, are alternatives to SSRIs, but side effects, including prolongation of the QT interval, are relatively common, especially at higher dosages.[20,21] The onset of antidepressant effect is 1−2 weeks or longer with both SSRIs and tricyclics, a major disadvantage in patients approaching the end of life. In contrast, the onset of action of psychostimulants, such as methylphenidate, is 1−2 days, and these agents may provide significant relief from depression in patients with advanced HF.[20]

Few studies have examined the prevalence and treatment of anxiety in patients with advanced HF, but it is likely that an increasing proportion of patients experience anxiety as HF symptoms progress.[20,33] Interventions that enhance patients' and spouses' sense of control over HF (ie, self-efficacy) have been shown to reduce emotional distress; such interventions include support groups and HF education.[34] Short-acting benzodiazepines, such as lorazepam, are effective in alleviating anxiety that does not respond to nonpharmacologic therapies.[20]

### Sleep Disorders

Approximately 50% of patients with HF have sleep-disordered breathing, including central and obstructive sleep apnea.[35] In addition, Cheynes-Stokes respirations become increasingly common in patients with advanced HF.[35] Continuous positive airway pressure (CPAP) is the mainstay of therapy for sleep-disordered breathing.[36] However, many patients with advanced HF are unable to tolerate CPAP, and hypoxia may precipitate worsening HF.[37] Nocturnal oxygen therapy has benefits nearly equivalent to those of CPAP for patients with obstructive sleep apnea.[38−40] The utility of other interventions, such as opioids and anxiolytic agents, in alleviating the distress associated with sleep-disordered breathing is unknown.

Insomnia also is a common problem in patients with advanced HF. It is often multifactorial, due to orthopnea,

nocturia, sleep-disordered breathing, and psychologic distress (ie, anxiety and depression).[41] Treatment of insomnia begins with appropriate management of the underlying cause(s) when feasible. Attention to sleep hygiene, including development of a regular routine before going to bed and avoidance of caffeine, alcohol, and excess fluid intake during the evening hours, is also appropriate.[42] Trazodone (25 mg) is effective for inducing sleep with minimal side effects but may cause delirium in older patients. Zolpidem (5 mg) is often effective in patients with more severe insomnia, but it may induce confusion, falls, or daytime fatigue. Other agents that may be useful in selected cases include mirtazapine and nortriptyline.

### Confusion and Delirium

Advanced HF has been linked to cognitive impairment, presumably due to impaired cerebral blood flow and/or repetitive microemboli.[43] HF is also one of the most common causes of delirium in hospitalized patients.[44] Medications, such as opioids and benzodiazepines, may contribute to confusion or delirium in HF patients. Treatment includes reducing the dosage or eliminating potentially offending medications if feasible. In patients with relatively low blood pressure (eg, $<100$ mm Hg), decreasing the dose of beta-blockers and/or ACE inhibitors to allow the blood pressure to rise may also be beneficial.[45] Regulating the environment to ensure adequate sunlight during the day and avoidance of sleep disturbance at night is also important. In patients with recurrent or persistent delirium, especially if associated with agitation or combativeness, small doses of haloperidol may be effective, but patients should be monitored closely for development of extrapyramidal side effects.

### Cough

Cough is another common symptom in patients with advanced HF.[30] Cough is often worse at night, interfering with sleep. Pulmonary congestion and ACE inhibitors are the most common causes of cough in HF patients. Other causes include aspiration pneumonitis and bronchitis.[46] Treatment of cough includes diuresis in patients with evidence of pulmonary congestion and substituting an ARB for an ACE inhibitor if appropriate. Cough suppressants, such as dextromethorphan, may be useful for some patients. In more severe cases, opioids, especially codeine, are often effective.[46] Excess secretions may also be problematic in patients with advanced HF. In most cases, secretions can be effectively managed with periodic suctioning with the use of a hand-held device.

### Edema

Patients with advanced HF may have persistent lower extremity edema and ascites, which, if severe, may be associated with considerable discomfort and interfere with activities, including performance of activities of daily living (eg, dressing, bathing, toileting). Treatment of marked edema and/or ascites in patients with advanced HF includes treatment of nocturnal hypoxia, aggressive diuresis, often with an intravenous loop diuretic alone or in combination with a thiazide (eg, metolazone), and optimization of other HF medications.[1,10] Dietary salt and fluid restriction is appropriate, and use of NSAIDs and other sodium/fluid retaining medications should be avoided.[1,10] Elevating the legs, when feasible, may afford some relief. Thigh-high support stockings may also be beneficial in some cases, but many patients find them to be uncomfortable and difficult to use.

### Inotrope Infusions

Continuous home inotrope infusions can be a palliative tool that allows advanced HF patients who are not candidates for, or who do not desire, a mechanical circulatory support device (MCSD) or transplantation to be discharged home. In patients who develop recurrent symptoms during attempts to wean inotropic therapy, discharge to home with continuous inotrope infusions are associated with an initial good level of functioning. In one study, although median survival was only 3.4 months, the majority of patients died at home and avoided repeated hospitalization.[47] Continuous home inotrope infusions may be an effective strategy for palliative management of selected end-stage patients. In a small cohort of patients, home inotrope infusions were associated with a 70% reduction of hospital days.[48]

In a risk-adjusted model, continuous milrinone and dobutamine infusions appeared to be associated with equivalent survival rates.[49] The combination of a beta-blocker and continuous intravenous milrinone is effective and may allow optimization of medications and eventual weaning of milrinone.[50] The combination of a beta-blocker with dobutamine yields opposing hemodynamic effects and is not recommended.[51–53]

In all published reports, continuous inotropic therapy was used only after attempts at optimization of noninotropic medications or weaning of inotropes failed. Candidates for continuous inotropic infusions include those who exhibit significant improvement in clinical status on inotropes and who can not be weaned without return of disabling symptoms. Patients should be counseled that inotropes are a palliative measure used to facilitate discharge home and improved out-of-hospital functioning in the period before death, but that inotropes are not associated with improved survival.

### Discontinuation of Medications

As HF progresses, goals of care may change from a principal focus on extending life to a primary emphasis on controlling symptoms and maximizing quality of life. In this context, the role of disease-modifying medications, such as ACE inhibitors and beta-blockers, may become less important than other therapies aimed primarily at palliation of symptoms. In such cases, it may be appropriate to reduce the doses or discontinue ACE inhibitors and/or beta-blockers, especially if these agents are causing adverse

effects or are otherwise contributing to impaired quality of life (eg, owing to polypharmacy or increased medication costs). However, ACE inhibitors may help to control symptoms through afterload reduction. The impact of discontinuing guideline-recommended therapies needs further research.

### Comorbid Conditions

Patients with HF often have ≥1 coexisting conditions, among the most common of which are coronary artery disease, hypertension, diabetes, renal insufficiency, atrial fibrillation, and chronic lung disease.[54,55] Although a detailed discussion of comorbid conditions is beyond the scope of this paper, in general, comorbidities in HF patients at the end of life should be managed in accordance with existing guidelines, keeping in mind that the principal goal of therapy is to minimize symptoms and maximize quality of life. Therefore, whereas treatment of ischemic chest discomfort and symptomatic atrial fibrillation is appropriate, aggressive management of hypertension and diabetes is usually not warranted.

## Review of Therapies for Advanced Heart Failure

In addition to GDMT, management of the patient with advanced HF often includes device therapy. Unique considerations exist for these therapies as patients progress toward end-of-life care.

### Implantable Cardioverter Defibrillators

Although it is clear that ICDs reduce mortality rates in patients with mild to moderate systolic HF,[56,57] the value of ICDs in patients with advanced HF is unproven. In the Sudden Cardiac Death in Heart Failure Trial (SCD-HeFT), the overall group had a significant mortality benefit, but the subgroup of patients with NYHA functional class III HF did not realize a statistically significant survival benefit.[56] To date, no study has demonstrated survival benefit in NYHA functional class IV patients. ICD therapy is therefore indicated for patients with left ventricular systolic dysfunction but is not indicated for patients who "do not have a reasonable expectation of survival with an acceptable functional status for at least 1 year, even if they meet ICD implantation criteria."[58] ICD implantation is also not indicated for "NYHA class IV patients with drug-refractory congestive HF who are not candidates for cardiac transplantation or CRT-D."[58]

Many physicians and patients overestimate the benefit of ICDs. For example, in one study, patients estimated a 50% survival benefit rather than the actual 7%−10% mortality reduction.[59] Therefore, clinicians should include an honest and evidence-based discussion of the risks and benefits of ICDs for patients with advanced HF. The risk of sudden cardiac arrest should be balanced against the risks of a nonarrhythmic death (eg, progressive HF with declining functional capacity) or death from a non-HF cause, the risks of ICD implantation, and the impact of ICD shocks on quality of life. For patients who have advanced symptoms (NYHA functional class IV) or poor prognostic factors, ICD implantation should be discouraged. Many patients will have had an ICD placed some time earlier and it is appropriate that these patients understand the option to deactivate the defibrillator when they approach the end of life.

### Cardiac Resynchronization Therapy

Cardiac resynchronization therapy (CRT) reduces symptoms in selected patients with NYHA functional class II−IV systolic HF.[60−64] However, patients with advanced HF accounted for only 4.2% of subjects enrolled in the CRT clinical trials.[65] Subsequent observational reports have had mixed findings. Left bundle branch block (LBBB) patients (n = 545) who met qualifications for being listed for heart transplantation and who instead underwent CRT implantation demonstrated 1- and 3-year freedom from HF death of 92.3% and 77.3%.[66] These data suggest that CRT implantation is reasonable in advanced HF patients with LBBB in lieu of or before listing for heart transplant.

Limited nonrandomized series reported benefit from CRT in inotrope-requiring or inotrope-dependent patients.[67] In one of these studies, 9 out of 10 inotrope-dependent patients were able to be weaned from inotropes after CRT implantation.[68] However, another series showed that mortality was still very high (60% after 9.5 months) in patients who were inotrope-dependent at the time of CRT implantation, raising concern about the cost-effectiveness of CRT implantation in inotrope-dependent patients.[69] Thus, CRT may provide benefit to selected patients with advanced HF, but the potential benefits and risks should be assessed on an individual basis.

### Cardiac Transplantation

Cardiac transplantation is an established therapy associated with good long-term survival and marked improvement in functional capacity in appropriate patients. About 5,000 patients worldwide receive heart transplants each year (2,000−2,200 annually in the USA). The median survival after heart transplant is 10 years. The overwhelming majority of heart transplant patients function without physical limitations.[3] These factors suggest that heart transplant should be considered as an option for appropriately selected patients with advanced HF.

Transplant patient selection has been summarized by Mancini and Lietz.[3] Patients who are inotrope dependent, have a peak oxygen consumption ($VO_2$) during cardiopulmonary exercise testing of $<10$ mL $min^{-1}$ $kg^{-1}$, or an SHFM-estimated survival of $<80\%$ at 1 year are potential transplant candidates. Those with a $VO_2$ of 10−14 mL $min^{-1}$ $kg^{-1}$ or an SHFM-estimated survival of 80%−90% are considered to be of intermediate risk andcan be considered on an individual basis for transplant candidacy. Best utilization of available donor organs dictates that patients selected for transplant should be both ill enough to require transplantation but well enough to have good long-term

outcome after transplantation. Most transplant centers exclude patients >70–75 years of age and those with advanced comorbidities.

### Mechanical Circulatory Support Devices

MCSDs serve as a bridge to heart transplantation, as destination therapy (DT) in patients who are not candidates for heart transplantation, or as a bridge to recovery in selected patients.[6,70–73] Outcomes have improved over time owing to technologic advances and increasing center experience.[74–76] Improved patient outcomes have led to significant growth in the use of MCSDs as DT. Consideration of this therapy in patients with high risk indicators is therefore appropriate. Illness severity indicators for selection of patients for MCSD are similar to those for cardiac transplantation and include patients who are inotrope dependent, have a maximal oxygen consumption during cardiopulmonary exercise testing of <14 mL $min^{-1}$ $kg^{-1}$, or have an estimated 1-year SHFM survival of <90%.[3]

Patient outcomes with MCSD are improved by appropriate patient selection.[77] Recognition of high risk features and calculation of a risk score can aid in patient selection by identifying individuals who are too sick (ie, HF is too far advanced or life-limiting comorbidities are present) to realize meaningful benefit. Some patients may be at such high risk that MCSD implantation would represent "procedural futility."[78] Risk scores have been developed to help assess likelihood of survival after MCSD. Details of patient selection and management are beyond the scope of this paper but have been summarized by Slaughter et al,[79] and guidance has been provided by the International Society for Heart and Lung Transplantation.[80] Clinicians involved in the care of patients with advanced HF should be familiar with the available risk stratification tools to appropriately discuss potential MCSD therapy with their patients. They should be able to use these tools to identify patients who do not meet criteria for MCS as well as those who are too ill to have sufficient likelihood of good outcome. Patients who might benefit from MCSD implantation should be educated about the potential risks and benefits to enable informed decision making. Palliative medicine consultation before MCSD placement can facilitate decision making and provide guidance if adverse events occur or when MCSD must be discontinued.

## Approaches to End-of-Life Communication in Heart Failure

Comprehensive HF care integrates education and support for the patient and family, as well as communication and decision making with evidence-based therapy throughout the course of illness.[20] Patients with HF are at risk for rapid clinical deterioration (eg, following a myocardial infarction or other acute illness) or sudden cardiac death, so the possibility of dying from HF should be acknowledged early in the course of management. As patients progress to advanced HF, discussions about planning for the end of life become more important, especially for patients who have declined, failed, or been deemed to be ineligible for advanced HF therapies.

Basic principles of communication should be applied to discussions regarding goals of care and end-of-life preferences, including the use of simple clear language, avoidance of euphemisms, and defining technical or medical terms as they are used. Communication should begin with a query to identify what the patient understands or feels in a given situation, followed by providing information to educate the patient or correct misunderstandings. The conversation should end by asking the patient to explain back what was said and by providing the patient an opportunity to ask questions. This "Ask-Tell-Ask" format (Table 2) is the foundation of patient-centered communication.[81] Conversations may need to be broken into a series of discussions, depending on patient and family needs. As many as 1 in 5 patients may not want to know their prognosis specifically, so asking what information patients want is an essential step.[82]

### Patient and Family Expectations

Many HF patients and their families are unaware of the life-limiting potential of HF.[83] Prognostic information should always be balanced with a statement of the physician's commitment to work with the patient to prolong life as well as improve the quality of life, and of the ability of medications and devices to achieve these goals. A conversation about the general course of HF gives clinicians an opportunity to motivate HF patients and their families to actively "fight" HF with medical management and lifestyle changes. Partnering with patients and their families to help them to identify warning signs of worsening status and offering them clear instructions about what to do when symptoms increase can empower patients and help them and their families to cope with the illness.

### Discussing Dying

Because communication skills for addressing end-of-life issues and death are often not incorporated into medical training, clinicians caring for HF patients need to acquire these skills to discuss dying with patients and families. At times when death is a greater threat, clinicians should have a conversation about the patient's status and available interventions to either allow natural death or attempt to

**Table 2.** "Ask-Tell-Ask" Methodology

| | |
|---|---|
| Ask | "Tell me what you believe is going on in your illness" |
| | "As you look back, what has been important in your life?" |
| | "What are your concerns and worries?" |
| Tell and Partner | "Heart failure is a disease that can last for years, but that most people die from. My goal is to work with you to do our best to help you ____" |
| Ask | "What are your questions?" |
| | "Tell me what you understood from our discussion." |

forestall death. Because the patient is often new to the clinician at such encounters, the conversation should begin by asking what the patient understands and expects.

A conversation about dying is nearly always a "bad news conversation."[84] Clinicians should acknowledge that the topic is sad or distressing, and learn to provide empathetic responses to patients or families. Examples of empathetic responses include identifying emotions both on the clinician's and patient's parts, and using "wish" statements such as "I wish things were different."

### Clarifying Goals of Care for Heart Failure Patients

Communication to define the goals of care for an individual patient, and then to identify options and make decisions about interventions, are fundamental to patient-centered care. Goals for care must be set in light of the patient's clinical condition, and they need to be reevaluated at turning points in care, such as decompensation, stabilization, and adverse events.

Clinicians should begin a conversation about goals of care by specifically identifying the situation and the need to clarify goals. Statements such as "we have choices, and which direction we go will depend on what is important to you, as well as what is medically possible" or "we need to make a decision about what path to take now" help to frame the conversation.

Beginning a discussion of treatment goals by understanding what a patient has valued in their life allows the clinician to integrate that information into the care plan. Treatments that are appropriate to the patient's health state and HF status can be identified as consistent with their values, and presenting these gives the clinician a chance to check back with the patient.

In advanced HF, some patients may specifically wish to avoid surgery or to not be hospitalized again, and these preferences clearly direct the path of care, as well as help to set goals. A useful concept in conversations to set goals of care is "Hope for the best, and plan for the worst." This allows clinicians to identify what a patient or their family hope for, as well as to acknowledge that a plan is needed for a variety of undesired conditions, such as death, stroke or unconsciousness, prolonged hospitalization in intensive care, or multisystem organ failure.

## Advance Care Planning

As part of the "planning for the worst" conversation, the topic of advance care planning can be addressed. A general approach to either sudden or progressive HF death can be discussed at the time of HF diagnosis or in association with an event such as hospitalization or hospital discharge. The increased risk of sudden cardiac death in HF patients makes it important to have a plan for whether to allow natural death or attempt cardiopulmonary resuscitation (CPR) when the heart stops. This conversation can be normalized by saying "all HF patients and their families should have a plan for what to do in an emergency." The decision about CPR is best initially presented as a big-picture decision of whether to "allow natural death" or "try to revive you" "when your heart stops." Clinicians should avoid presenting a menu of interventions. Rather, a general approach should be identified, with boundaries for limiting therapies. Many patients want all potentially effective therapeutic measures as long as they have a chance to return to independent function. However, many patients prefer being allowed to die rather than being kept alive in a condition in which they would not be cognitively intact, eg, after having had significant brain injury after CPR. When a patient prefers an attempt at CPR, then it is reasonable to ask about conditions under which the patient would not want prolonged life support.

Some patients will have considered resuscitation preferences at an earlier stage of their illness. For other patients, advance care planning has been avoided, so the topic can be introduced and the patient and family can be provided written material along with a promise that the clinician will revisit the subject at a later date. Patients who choose to not state a preference should be informed that the default intervention in the United States is to attempt CPR. Some patients will not want to consider the topic, and these individuals should be asked to designate a proxy who can make decisions on their behalf. Even when a surrogate decision maker is identified, patients should be encouraged to indicate global preferences, if possible.

As the patient's health status evolves throughout their illness, preferences for an attempt at CPR may change.[85] Clinicians should revisit preferences for resuscitation with changes in status and with changes in what is medically reasonable to offer the patient. Table 3 summarizes commonly used advance directives for expressing end-of-life care preferences.

Designation of a health care proxy, also called "Durable Power of Attorney for Health Care," assigns one or more persons to make decisions on the patient's behalf (using what is known of the patient's views and values, or "substituted judgment") should they lose capacity, even temporarily.

Living Will and 5-Wishes (www.agingwithdignity.org/five-wishes.php) documents provide statements about the patient's philosophy for medical treatment if they lose capacity in the future and are not likely to regain it. These directives usually include a statement about life-sustaining therapy, although some Living Will documents are restricted to "terminally ill" states. Newer directives often stipulate undesired states, such as "unable to communicate or interact with others," and indicate which therapies might be continued or discontinued.

Many states also have a legal order form for interventions, the Physician Order for Life-Sustaining Treatments (POLST), which is a transportable order signed by a physician that stays with the patient and is to be followed by emergency personnel wherever the patient is living or receiving health care. This document stipulates whether CPR should be attempted or not, whether the patient should be hospitalized and under what circumstances, and

**Table 3.** Advance Directives

| Directive | Purpose | Nuances | Content |
|---|---|---|---|
| Durable Power of Attorney for Health Care or Healthcare Proxy (DPOA/HC) | Designates one or more individuals to make decisions on the patient's behalf should she or he lose capacity | Form set by state statute or law; usually requires a witnessed signature | Assigns decision making when the person is not capable |
| Living Will | A statement of preferences for care in future states | Language varies by state, but may require 2 physicians to state that the patient is "terminally ill" | Usually specifies life-prolonging treatment such as ventilation or nutrition and hydration |
| Five Wishes | Legal advance directive in 42 states | May provide guidance even if not a legal advance directive | Includes DPOA/HC and preference for types of treatment, level of comfort, approach to care, and information for loved ones |
| Physician Order for Life-Sustaining Treatments (POLST) | Transportable order for emergency care; stays with the patient, to be followed wherever the patient is living or receiving health care; some states have a registry that can be accessed by emergency or medical personnel | Must be signed by a licensed physician, nurse practitioner, or physician assistant; designed for patients with high likelihood of dying but in some states broadly used in long-term care settings | Stipulates whether or not cardiopulmonary resuscitation should be initiated, the patient should be transported to the hospital, and intensity of interventions |

addresses treatments such as feeding tubes or fluids and antibiotics. Some states also permit a written physician order regarding resuscitation, such as "Do Not Resuscitate" on an official prescription. Completing a POLST document or other order set involves identifying the patient's preferences for specific interventions in the future; however, a POLST form is not a substitute for a careful discussion of preferences and planning for future care.

## Palliative Care and Hospice

### Characteristics and Reimbursement

Hospice and palliative care both improve quality of life through symptom and pain management using a holistic, multi-disciplinary approach. This organized, comprehensive philosophy addresses typical issues that arise throughout care and at end-of-life including psychosocial and emotional responses to the diagnosis, spiritual issues, patient and family education, and bereavement.[86] Palliative care (nonhospice) services can be used throughout the course of care for patients with a life-limiting illness.

Hospice is an insurance benefit and specialized service in the USA. Hospice referral should be considered when patients with advanced HF have recurrent HF hospitalizations, worsening functional status, or need for continuous intravenous inotropic therapy despite attempts to optimize overall management.[87,88] If the clinician anticipates that the patient might die within 6 months, consideration of hospice care may be appropriate.[89]

Patients electing the hospice benefit agree to care focused on palliation. The referring physician and the Hospice Medical Director must certify that the patient has an approximate life expectancy of 6 months or less at the time of referral, and care is recertified every 90 days for 6 months, then every 60 days thereafter. The majority (87%) of hospice services are paid for by the Medicare Hospice Benefit at a per diem rate. Hospice services may also be paid for by Medicaid, private insurance or managed care programs, or charity/donations.[90] Although hospice patients are often cared for in the home, patients can also be cared for in nursing homes or specialty hospice units. Brief "general inpatient care" in hospitals or nursing homes contracting with the hospice agency is also permitted.

### Hospice Referral in HF: Statistics and Barriers

Historically, hospice has been underutilized for HF patients, and heart disease has accounted for only 11.4% of hospice admissions in recent years.[91] In one study, hospice utilization in the last 6 months of life for Medicare patients with HF increased from 19% to 40%.[92] Yet in the AHA Get With the Guidelines program, the utilization of hospice services among all patients was $<10\%$, even among those in the highest decile of mortality risk.[93] Factors associated with hospice referral included increased age, low systolic blood pressure, and impaired renal function. In an earlier study, patients who died in the hospital had similar characteristics to those discharged to hospice but had more procedures or invasive therapies.[94]

In HF, many factors contribute to the difficulty in forecasting 6-month life expectancy, including sudden cardiac death, comorbidities, and the ability of individuals to survive with a low functional status for years. Before considering hospice, patients should be optimized on HF medications (or have a contraindication or intolerance documented) and evaluated for devices or transplant if appropriate. Ancillary services should be offered or intensified if desired (eg, dietary counseling, case management, occupational or physical therapy, home health services, home-based primary care, assisted living facility, or nursing home placement). All patients considered for MCSD or transplant, and perhaps CRT (because up to 30% of patients do not respond),[10,95–97] should be made aware that hospice care is an option either instead of or if they continue to decline despite the intervention.

### Availability of Palliative and Hospice Care

Availability of hospice care and the services provided in the USA vary by region and between agencies. Areas with a younger population, higher education, and higher economic status are more likely to have hospice services.[98] Many hospices do not have staff education, procedures, or policies in place to manage various aspects of HF care, including ICDs, MCSDs, or inotropic agents.

Not all hospice agencies accept patients on continuous inotrope infusions, particularly milrinone, owing to the high cost and deleterious impact on hospice fixed pharmacy benefits. Clinicians should work to establish relationships with hospice agencies to promote the use of inotrope infusions as palliative care agents.[99] Due to the reimbursement structure that fixes drug payments once a patient is enrolled in hospice care, more expensive therapies tend to be provided by larger agencies that can tolerate the financial loss associated with their use.[100] Although hospices should provide all therapies related to the hospice diagnosis and all therapies directed at managing symptoms and other sources of distress, there is no standard for HF care in hospice.

Many aspects of palliative care for HF patients can be provided by primary care, palliative care, or HF clinicians. Many HF providers do not have a comfort level with palliative care[101] and could benefit from training in communication skills and management of common symptoms.

### Needs Assessment for Palliative and Hospice Care

To incorporate palliative care into HF care, a system needs assessment may be helpful. Online tools for hospital palliative care programs to assist clinicians in systematically beginning a hospital palliative care program are available at www.capc.org/building-a-hospital-based-palliative-care-program/designing/system-assessment. A framework for the provision of comprehensive HF care integrating palliative care has been published.[20]

### Spiritual Aspects of Palliative and Hospice Care

Spirituality can affect patient opinions regarding offered therapies and is an important resource for many patients, particularly in times of serious illness. Supporting a patient spiritually can include listening, performing a Faith Importance Community Address Spiritual Assessment, prayer, chaplaincy involvement, and providing realistic hope.[102] The goal is to guide patients toward a peaceful journey at the end of life.

### Device Management and Withdrawal of Therapy

As patients progress toward the end of life, clinicians should continue to actively discuss goals of care, especially regarding to device therapies. Implantable devices, including standard pacemakers, ICDs, and CRT, play an increasingly important role in the management of HF patients, especially those with severe left ventricular systolic dysfunction (LVEF $\leq$30%−35%). Decisions regarding MCSDs also need to be addressed as the patient nears the end of life. Requests for MCSD discontinuation appear to be more common than expected, occurring in 21% of patients in one case series.[103] Furthermore, some patients are found dead with their MCSD disconnected from a power source. In these cases, it is unclear whether an accidental death occurred or if the patient had chosen to withdraw MCSD support on their own.[104]

Management of devices in patients approaching the end of life has recently been addressed in 2 consensus documents.[105,106] Optimally, discussions about future device disablement should occur before device implantation and revisited periodically, especially when there has been a significant deterioration in the patient's condition and prognosis. Clinicians should have a detailed discussion with their patients requesting withdrawal of support about the likely outcomes of their requests as well as the variety of options that are available. Palliative care or hospice support should be arranged to coincide with withdrawal of device therapies where an abrupt worsening of symptoms might be anticipated. In one series, patients who had their MCSDs deactivated died on average within 20 minutes of discontinuation.[107]

Clinically, the most common issue that arises is determining if and when a device should be disabled. Several studies have documented that ICDs are infrequently disabled, even during the final 24−48 hours of life.[105,106,108] As a result, patients may experience repetitive shocks that are a source of distress for both patients and families. Therefore, patients (or their surrogates if appropriate) should be offered the option of disabling the ICD when it appears that death is near. All centers that implant ICDs should have a process for deactivating them, and all patients should understand the option of deactivating the ICD at a future date.

In general, the legal, ethical, moral, and medical principles governing device disablement are similar regardless of the nature of the device (eg, ICD, pacemaker).[105,106] MCSD discontinuation does present a more challenging ethical consideration, because the presence of the MCSD has caused a different physiologic situation than what would have resulted as part of the natural disease process. In the case of deactivation of a continuous-flow MCSD, the patient may experience retrograde flow through the pump and die instantly. It has also been argued that the MCSD is functioning as an "artificial organ" or that it is an integral part of the patient (such as a porcine valve prosthesis) and as such is unlike other device therapies.[104] Others argue that for the MCSD to achieve such status, it would have to be under the independent control and power of the body. The external power source and need for external expert control makes the MCSD a medical intervention that can be ethically removed if the burden of treatment outweighs the benefit.[103] If the decision is made to deactivate an MCSD, appropriate support should be provided, including opioids and benzodiazepines for patient comfort.

**Table 4.** Research Agenda for End-of-Life Care in Patients With Heart Failure

| Topic | Specific Issues | Examples of Research Questions |
|---|---|---|
| Identifying the "end of life" for patients with HF | 1. Characteristics to reliably define the last 6−12 months in patients with HF<br>2. Cause of death in patients with stage C or D HF<br>3. HFrEF vs HFpEF | Are the features of the last 6−12 months of HF patients' lives related to clinical findings, health services utilized, venue of care, or other issues?<br>What proportion of deaths in HF patients are due to HF versus other illnesses?<br>Are descriptors of the end of life different for patients with HFrEF vs HFpEF? |
| Prognosis and trajectory of HF | 1. End-stage HF course<br>2. Predicting the end of life<br>3. Prevalence of symptoms and functional issues | What interventions and treatments improve prognosis in patients with advanced HF at end of life?<br>Can a predictive model for prognosis be validated prospectively?<br>What symptoms and cognitive and physical impairments occur, and at what intervals, as HF patients approach the end of life? |
| Treatment options for HF patients at the end of life | 1. Treatments for symptoms<br>2. Models of care<br>3. Medication management at the end of life<br>4. Sleep-disordered breathing | In HFrEF, what medications improve symptoms at the end of life?<br>What models of care enhance symptoms and quality of life at the end of life?<br>What aspects of interdisciplinary care benefit symptoms, quality of life, and patient/family needs in end-stage HF<br>Which medications can be discontinued without adverse impact on quality of life at the end of life?<br>Does treatment of sleep-disordered breathing (with oxygen or CPAP) benefit function or alter the course for HF patients near the end of life? |
| Symptom management | 1. Assessment of symptoms<br>2. Interventions to improve symptoms | How should symptom severity and frequency be assessed?<br>What treatments benefit dyspnea, fatigue, and pain in HF patients at the end of life? |
| Communication with patients and families about the end of life | Skills training for physicians and other clinicians | What training positively affects patient and family outcomes?<br>Which outcomes related to communication should be measured? |
| Devices | 1. Defibrillators<br>2. MCSD | At what point should defibrillators be deactivated near the end of life? What processes work to perform deactivation?<br>Does palliative care consultation alter patient choice about MCSD? |
| Education of clinicians | 1. Clinicians in hospice<br>2. Clinicians in home care | What education of clinicians about end-stage HF improves patient and family outcomes in hospice or home care? |
| Patient and family education | 1. Self-management<br>2. Withdrawal of therapy | What self-management techniques improve patient outcomes at the end of life?<br>What education facilitates patient-family decision making about withdrawal of therapy at the end of life? |

CPAP, continuous positive airway pressure; HF, heart failure; HFpEF, heart failure with preserved ejection fraction; HFrEF, heart failure with reduced ejection fraction; MCSD, mechanical circulatory support device.

The fundamental tenet underlying all such decisions is patient autonomy, ie, the right of the patient to refuse treatment when he or she perceives that such treatment is no longer in accordance with his or her wishes. Once the patient or proxy has decided to forgo device therapy, it is incumbent on the treating physician to disable the device or to transfer the patient's care to another physician who is comfortable complying with the patient's requests. Note that the principle of patient autonomy is applicable even in situations when a pacemaker-dependent patient asks that the pacemaker be turned off. Though it is appropriate for the physician to discuss the likely effect of disabling the pacemaker (ie, death, potentially within minutes) with the patient and family, the final decision resides with the patient.

## Conclusion

The number of patients with advanced HF is increasing, due in part to the aging of the population and in part to therapeutic advancements leading to increased survival among patients with stage C HF. However, despite an expanding armamentarium of HF therapies, for many patients HF is ultimately a fatal illness. It is therefore essential to ensure

that treatment of all HF patients incorporates discussions of overall goals of care and an assessment of individual patient preferences for management in the terminal stages of illness, as well as in the event that a sudden change in health status occurs (eg, cardiac arrest with cerebral hypoxemia). Optimally, these discussions should begin early in the course of treatment and recur as the patient's condition evolves. Additional research is needed (Table 4) to more accurately assess prognosis in HF patients, to develop strategies for routinely defining patient preferences, to optimize the role of palliative care and hospice services in patients with advanced HF, and to ensure that care of all HF patients is equitable, timely, and patient centered.

## Acknowledgment

The authors acknowledge Bart Galle, PhD for his contributions to the development of this manuscript.

## Disclosures

Sarah J. Goodlin, MD, reports research support from Medtronic. Wendy Gattis Stough, PharmD reports support from the Heart Failure Society of America. None of the other authors report any potential conflict of interest.

## References

1. Hunt SA, Abraham WT, Chin MH, Feldman AM, Francis GS, Ganiats TG, et al. 2009 focused update incorporated into the ACC/AHA 2005 guidelines for the diagnosis and management of heart failure in adults: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines Developed in collaboration with the International Society for Heart and Lung Transplantation. J Am Coll Cardiol 2009;53:e1−90.
2. Roger VL, Go AS, Lloyd-Jones DM, Benjamin EJ, Berry JD, Borden WB, et al. Heart disease and stroke statistics—2012 update: a report from the American Heart Association. Circulation 2012;125:e2−220.
3. Mancini D, Lietz K. Selection of cardiac transplantation candidates in 2010. Circulation 2010;122:173−83.
4. Costanzo MR, Mills RM, Wynne J. Characteristics of "stage D" heart failure: insights from the Acute Decompensated Heart Failure National Registry Longitudinal Module (ADHERE LM). Am Heart J 2008;155:339−47.
5. Allen LA, Rogers JG, Warnica JW, DiSalvo TG, Tasissa G, Binanay C, et al. High mortality without ESCAPE: the registry of heart failure patients receiving pulmonary artery catheters without randomization. J Card Fail 2008;14:661−9.
6. Rose EA, Gelijns AC, Moskowitz AJ, Heitjan DF, Stevenson LW, Dembitsky W, et al. Long-term use of a left ventricular assist device for end-stage heart failure. N Engl J Med 2001;345:1435−43.
7. Borlaug BA, Redfield MM. Diastolic and systolic heart failure are distinct phenotypes within the heart failure spectrum. Circulation 2011;123:2006−13.
8. Kitzman DW, Gardin JM, Gottdiener JS, Arnold A, Boineau R, Aurigemma G, et al. Cardiovascular Health Study Research Group. Importance of heart failure with preserved systolic function in patients ≥65 years of age. Am J Cardiol 2001;87:413−9.
9. Kitzman DW, Little WC, Brubaker PH, Anderson RT, Hundley WG, Marburger CT, et al. Pathophysiological characterization of isolated diastolic heart failure in comparison to systolic heart failure. JAMA 2002;288:2144−50.
10. Lindenfeld J, Albert NM, Boehmer JP, Collins SP, Ezekowitz JA, Givertz MM, et al. HFSA 2010 comprehensive heart failure practice guideline. J Card Fail 2010;16:e1−194.
11. Hauptman PJ, Swindle J, Hussain Z, Biener L, Burroughs TE. Physician attitudes toward end-stage heart failure: a national survey. Am J Med 2008;121:127−35.
12. Fonarow GC, Adams KF Jr, Abraham WT, Yancy CW, Boscardin WJ. Risk stratification for in-hospital mortality in acutely decompensated heart failure: classification and regression tree analysis. JAMA 2005;293:572−80.
13. O'Connor CM, Abraham WT, Albert NM, Clare R, Gattis SW, Gheorghiade M, et al. Predictors of mortality after discharge in patients hospitalized with heart failure: an analysis from the Organized Program to Initiate Lifesaving Treatment in Hospitalized Patients With Heart Failure (OPTIMIZE-HF). Am Heart J 2008;156:662−73.
14. Diercks DB, Peacock WF, Kirk JD, Weber JE. ED patients with heart failure: identification of an observational unit-appropriate cohort. Am J Emerg Med 2006;24:319−24.
15. Kalogeropoulos AP, Georgiopoulou VV, Giamouzis G, Smith AL, Agha SA, Waheed S, et al. Utility of the Seattle Heart Failure Model in patients with advanced heart failure. J Am Coll Cardiol 2009;53:334−42.
16. Goda A, Williams P, Mancini D, Lund LH. Selecting patients for heart transplantation: comparison of the Heart Failure Survival Score (HFSS) and the Seattle Heart Failure Model (SHFM). J Heart Lung Transplant 2011;30:1236−43.
17. Lee DS, Austin PC, Rouleau JL, Liu PP, Naimark D, Tu JV. Predicting mortality among patients hospitalized for heart failure: derivation and validation of a clinical model. JAMA 2003;290:2581−7.
18. Zile MR, Gaasch WH, Anand IS, Haass M, Little WC, Miller AB, et al. Mode of death in patients with heart failure and a preserved ejection fraction: results from the Irbesartan in Heart Failure With Preserved Ejection Fraction Study (I-Preserve) trial. Circulation 2010;121:1393−405.
19. Pocock SJ, Wang D, Pfeffer MA, Yusuf S, McMurray JJ, Swedberg KB, et al. Predictors of mortality and morbidity in patients with chronic heart failure. Eur Heart J 2006;27:65−75.
20. Goodlin SJ. Palliative care in congestive heart failure. J Am Coll Cardiol 2009;54:386−96.
21. Adler ED, Goldfinger JZ, Kalman J, Park ME, Meier DE. Palliative care in the treatment of advanced heart failure. Circulation 2009;120:2597−606.
22. Jaarsma T, Beattie JM, Ryder M, Rutten FH, McDonagh T, Mohacsi P, et al. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. Eur J Heart Fail 2009;11:433−43.
23. Abernethy AP, Currow DC, Frith P, Fazekas BS, McHugh A, Bui C. Randomised, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnoea. BMJ 2003;327:523−8.
24. Jennings AL, Davies AN, Higgins JP, Gibbs JS, Broadley KE. A systematic review of the use of opioids in the management of dyspnoea. Thorax 2002;57:939−44.
25. Booth S, Wade R, Johnson M, Kite S, Swannick M, Anderson H. The use of oxygen in the palliation of breathlessness. A report of the Expert Working Group of the Scientific Committee of the Association of Palliative Medicine. Respir Med 2004;98:66−77.
26. Currow DC, Abernethy AP. Pharmacological management of dyspnoea. Curr Opin Support Palliat Care 2007;1:96−101.
27. Goodlin SJ, Wingate S, Albert NM, Pressler SJ, Houser J, Kwon J, et al. Investigating pain in heart failure patients: the Pain Assessment, Incidence, and Nature in Heart Failure (PAIN-HF) study. J Card Fail 2012;18:776−83.
28. Page J, Henry D. Consumption of NSAIDs and the development of congestive heart failure in elderly patients: an underrecognized public health problem. Arch Intern Med 2000;160:777−84.

29. von HS, Lainscak M, Springer J, Anker SD. Cardiac cachexia: a systematic overview. Pharmacol Ther 2009;121:227−52.
30. Levenson JW, McCarthy EP, Lynn J, Davis RB, Phillips RS. The last six months of life for patients with congestive heart failure. J Am Geriatr Soc 2000;48:S101−9.
31. Hsieh C. Treatment of constipation in older adults. Am Fam Physician 2005;72:2277−84.
32. O'Connor CM, Jiang W, Kuchibhatla M, Silva SG, Cuffe MS, Callwood DD, et al. Safety and efficacy of sertraline for depression in patients with heart failure: results of the SADHART-CHF (Sertraline Against Depression and Heart Disease in Chronic Heart Failure) trial. J Am Coll Cardiol 2010;56:692−9.
33. De Jong MJ, Chung ML, Wu JR, Riegel B, Rayens MK, Moser DK. Linkages between anxiety and outcomes in heart failure. Heart Lung 2011;40:393−404.
34. Sullivan MJ, Wood L, Terry J, Brantley J, Charles A, McGee V, et al. The Support, Education, and Research in Chronic Heart Failure Study (SEARCH): a mindfulness-based psychoeducational intervention improves depression and clinical symptoms in patients with chronic heart failure. Am Heart J 2009;157:84−90.
35. Sharma B, Owens R, Malhotra A. Sleep in congestive heart failure. Med Clin North Am 2010;94:447−64.
36. Arzt M, Bradley TD. Treatment of sleep apnea in heart failure. Am J Respir Crit Care Med 2006;173:1300−8.
37. Gottlieb JD, Schwartz AR, Marshall J, Ouyang P, Kern L, Shetty V, et al. Hypoxia, not the frequency of sleep apnea, induces acute hemodynamic stress in patients with chronic heart failure. J Am Coll Cardiol 2009;54:1706−12.
38. Sasayama S, Izumi T, Seino Y, Ueshima K, Asanoi H. Effects of nocturnal oxygen therapy on outcome measures in patients with chronic heart failure and cheyne-stokes respiration. Circ J 2006;70:1−7.
39. Toyama T, Seki R, Kasama S, Isobe N, Sakurai S, Adachi H, et al. Effectiveness of nocturnal home oxygen therapy to improve exercise capacity, cardiac function and cardiac sympathetic nerve activity in patients with chronic heart failure and central sleep apnea. Circ J 2009;73:299−304.
40. Seino Y, Imai H, Nakamoto T, Araki Y, Sasayama S. Clinical efficacy and cost-benefit analysis of nocturnal home oxygen therapy in patients with central sleep apnea caused by chronic heart failure. Circ J 2007;71:1738−43.
41. Redeker NS, Jeon S, Muench U, Campbell D, Walsleben J, Rapoport DM. Insomnia symptoms and daytime function in stable heart failure. Sleep 2010;33:1210−6.
42. Silber MH. Clinical practice. Chronic insomnia. N Engl J Med 2005; 353:803−10.
43. Qiu C, Winblad B, Marengoni A, Klarin I, Fastbom J, Fratiglioni L. Heart failure and risk of dementia and Alzheimer disease: a population-based cohort study. Arch Intern Med 2006;166:1003−8.
44. Rockwood K. Acute confusion in elderly medical patients. J Am Geriatr Soc 1989;37:150−4.
45. Zuccala G, Onder G, Pedone C, Carosella L, Pahor M, Bernabei R, et al. Hypotension and cognitive impairment: Selective association in patients with heart failure. Neurology 2001;57:1986−92.
46. Dalal B, Geraci SA. Office management of the patient with chronic cough. Am J Med 2011;124:206−9.
47. Hershberger RE, Nauman D, Walker TL, Dutton D, Burgess D. Care processes and clinical outcomes of continuous outpatient support with inotropes (COSI) in patients with refractory end-stage heart failure. J Card Fail 2003;9:180−7.
48. Sindone AP, Keogh AM, Macdonald PS, McCosker CJ, Kaan AF. Continuous home ambulatory intravenous inotropic drug therapy in severe heart failure: safety and cost efficacy. Am Heart J 1997;134:889−900.
49. Gorodeski EZ, Chu EC, Reese JR, Shishehbor MH, Hsich E, Starling RC. Prognosis on chronic dobutamine or milrinone infusions for stage D heart failure. Circ Heart Fail 2009;2:320−4.
50. Zewail AM, Nawar M, Vrtovec B, Eastwood C, Kar MN, Delgado RM III. Intravenous milrinone in treatment of advanced congestive heart failure. Tex Heart Inst J 2003;30:109−13.
51. Bristow MR, Shakar SF, Linseman JV, Lowes BD. Inotropes and beta-blockers: is there a need for new guidelines? J Card Fail 2001;7:8−12.
52. Lowes BD, Simon MA, Tsvetkova TO, Bristow MR. Inotropes in the beta-blocker era. Clin Cardiol 2000;23:III11−6.
53. Lowes BD, Tsvetkova T, Eichhorn EJ, Gilbert EM, Bristow MR. Milrinone versus dobutamine in heart failure subjects treated chronically with carvedilol. Int J Cardiol 2001;81:141−9.
54. Braunstein JB, Anderson GF, Gerstenblith G, Weller W, Niefeld M, Herbert R, et al. Noncardiac comorbidity increases preventable hospitalizations and mortality among Medicare beneficiaries with chronic heart failure. J Am Coll Cardiol 2003;42:1226−33.
55. Rich MW. Heart failure in the oldest patients: the impact of comorbid conditions. Am J Geriatr Cardiol 2005;14:134−41.
56. Bardy GH, Lee KL, Mark DB, Poole JE, Packer DL, Boineau R, et al. Amiodarone or an implantable cardioverter-defibrillator for congestive heart failure. N Engl J Med 2005;352:225−37.
57. Moss AJ, Zareba W, Hall WJ, Klein H, Wilber DJ, Cannom DS, et al. Prophylactic implantation of a defibrillator in patients with myocardial infarction and reduced ejection fraction. N Engl J Med 2002; 346:877−83.
58. Epstein AE, DiMarco JP, Ellenbogen KA, Estes NA III, Freedman RA, Gettes LS, et al. ACC/AHA/HRS 2008 guidelines for device-based therapy of cardiac rhythm abnormalities: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Revise the ACC/AHA/NASPE 2002 Guideline Update for Implantation of Cardiac Pacemakers and Antiarrhythmia Devices): developed in collaboration with the American Association for Thoracic Surgery and Society of Thoracic Surgeons. Circulation 2008;117:e350−408.
59. Stewart GC, Weintraub JR, Pratibhu PP, Semigran MJ, Camuso JM, Brooks K, et al. Patient expectations from implantable defibrillators to prevent death in heart failure. J Card Fail 2010;16:106−13.
60. Abraham WT, Fisher WG, Smith AL, Delurgio DB, Leon AR, Loh E, et al. Cardiac resynchronization in chronic heart failure. N Engl J Med 2002;346:1845−53.
61. Bristow MR, Saxon LA, Boehmer J, Krueger S, Kass DA, De MT, et al. Cardiac-resynchronization therapy with or without an implantable defibrillator in advanced chronic heart failure. N Engl J Med 2004;350:2140−50.
62. Cazeau S, Leclercq C, Lavergne T, Walker S, Varma C, Linde C, et al. Effects of multisite biventricular pacing in patients with heart failure and intraventricular conduction delay. N Engl J Med 2001; 344:873−80.
63. Cleland JG, Daubert JC, Erdmann E, Freemantle N, Gras D, Kappenberger L, et al. The effect of cardiac resynchronization on morbidity and mortality in heart failure. N Engl J Med 2005;352: 1539−49.
64. Young JB, Abraham WT, Smith AL, Leon AR, Lieberman R, Wilkoff B, et al. Combined cardiac resynchronization and implantable cardioversion defibrillation in advanced chronic heart failure: the MIRACLE ICD trial. JAMA 2003;289:2685−94.
65. Herweg B, Barold SS. When is it too late for cardiac resynchronization therapy? Pacing Clin Electrophysiol 2008;31:525−8.
66. Hansky B, Vogt J, Zittermann A, Guldner H, Heintze J, Schulz U, et al. Cardiac resynchronization therapy: long-term alternative to cardiac transplantation? Ann Thorac Surg 2009;87:432−8.
67. Cowburn PJ, Patel H, Jolliffe RE, Wald RW, Parker JD. Cardiac resynchronization therapy: an option for inotrope-supported patients with end-stage heart failure? Eur J Heart Fail 2005;7:215−7.
68. Herweg B, Ilercil A, Cutro R, Dewhurst R, Krishnan S, Weston M, et al. Cardiac resynchronization therapy in patients with end-stage inotrope-dependent class IV heart failure. Am J Cardiol 2007;100: 90−3.
69. Konstantino Y, Iakobishvili Z, Arad O, Ben-Gal T, Kusniec J, Mazur A, et al. Urgent cardiac resynchronization therapy in patients with decompensated chronic heart failure receiving inotropic therapy. A case series. Cardiology 2006;106:59−62.

70. Farrar DJ, Holman WR, McBride LR, Kormos RL, Icenogle TB, Hendry PJ, et al. Long-term follow-up of Thoratec ventricular assist device bridge-to-recovery patients successfully removed from support after recovery of ventricular function. J Heart Lung Transplant 2002;21:516–21.
71. Miller LW, Pagani FD, Russell SD, John R, Boyle AJ, Aaronson KD, et al. Use of a continuous-flow device in patients awaiting heart transplantation. N Engl J Med 2007;357:885–96.
72. Pagani FD, Miller LW, Russell SD, Aaronson KD, John R, Boyle AJ, et al. Extended mechanical circulatory support with a continuous-flow rotary left ventricular assist device. J Am Coll Cardiol 2009; 54:312–21.
73. Rogers JG, Aaronson KD, Boyle AJ, Russell SD, Milano CA, Pagani FD, et al. Continuous flow left ventricular assist device improves functional capacity and quality of life of advanced heart failure patients. J Am Coll Cardiol 2010;55:1826–34.
74. Lietz K, Long JW, Kfoury AG, Slaughter MS, Silver MA, Milano CA, et al. Impact of center volume on outcomes of left ventricular assist device implantation as destination therapy: analysis of the Thoratec Heartmate Registry, 1998 to 2005. Circ Heart Fail 2009;2:3–10.
75. Long JW, Kfoury AG, Slaughter MS, Silver M, Milano C, Rogers J, et al. Long-term destination therapy with the Heartmate XVE left ventricular assist device: improved outcomes since the REMATCH study. Congest Heart Fail 2005;11:133–8.
76. Long JW, Healy AH, Rasmusson BY, Cowley CG, Nelson KE, Kfoury AG, et al. Improving outcomes with long-term "destination" therapy using left ventricular assist devices. J Thorac Cardiovasc Surg 2008;135:1353–60.
77. Lietz K, Long JW, Kfoury AG, Slaughter MS, Silver MA, Milano CA, et al. Outcomes of left ventricular assist device implantation as destination therapy in the post-REMATCH era: implications for patient selection. Circulation 2007;116:497–505.
78. Bieniarz MC, Delgado R. The financial burden of destination left ventricular assist device therapy: who and when? Curr Cardiol Rep 2007;9:194–9.
79. Slaughter MS, Pagani FD, Rogers JG, Miller LW, Sun B, Russell SD, et al. Clinical management of continuous-flow left ventricular assist devices in advanced heart failure. J Heart Lung Transplant 2010;29:S1–39.
80. Feldman D, Pamboukian S, Teuteberg J. The 2013 International Society for Heart and Lung Transplantation guidelines for mechanical circulatory support: executive summary. J Heart Lung Transplant 2013.
81. Goodlin SJ, Quill TE, Arnold RM. Communication and decision-making about prognosis in heart failure care. J Card Fail 2008;14:106–13.
82. Goodlin SJ, Hauptman PJ, Arnold R, Grady K, Hershberger RE, Kutner J, et al. Consensus statement: palliative and supportive care in advanced heart failure. J Card Fail 2004;10:200–9.
83. Remme WJ, McMurray JJ, Rauch B, Zannad F, Keukelaar K, Cohen-Solal A, et al. Public awareness of heart failure in Europe: first results from SHAPE. Eur Heart J 2005;26:2413–21.
84. Allen LA, Yager JE, Funk MJ, Levy WC, Tulsky JA, Bowers MT, et al. Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure. JAMA 2008;299:2533–42.
85. Krumholz HM, Phillips RS, Hamel MB, Teno JM, Bellamy P, Broste SK, et al. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Resuscitation preferences among patients with severe congestive heart failure: results from the SUPPORT project. Circulation 1998;98:648–55.
86. National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. 2nd ed. 2009. Available at: www.nationalconsensusproject.org.
87. Goodlin SJ, Schaefer K, Kovner V, Reznickova N, Smusz T. Referral of heart failure patients to hospice: is it time for new guidelines?. [abstract]. J Pain Symptom Manage 2012;43:417.
88. National Hospice Organization. Medical guidelines for determining prognosis in selected noncancer diseases. Hosp J 1996;11:47–63.
89. Lynn J. Sick to death and not going to take it anymore!: reforming health care for the last years of life. University of California Press; 2004.
90. Connor SR. U.S. hospice benefits. J Pain Symptom Manage 2009;38: 105–9.
91. National Hospice and Palliative Care Organization. Hospice care in America. NHPCO facts and figures. 2012. Available at: http://www.nhpco.org.
92. Unroe KT, Greiner MA, Hernandez AF, Whellan DJ, Kaul P, Schulman KA, et al. Resource use in the last 6 months of life among medicare beneficiaries with heart failure, 2000–2007. Arch Intern Med 2011;171:196–203.
93. Whellan DJ, Cox M, Hernandez AF, Heidenreich PA, Curtis LH, Peterson ED, et al. Utilization of hospice and predicted mortality risk among older patients hospitalized with heart failure: findings from GWTG-HF. J Card Fail 2012;18:471–7.
94. Hauptman PJ, Goodlin SJ, Lopatin M, Costanzo MR, Fonarow GC, Yancy CW. Characteristics of patients hospitalized with acute decompensated heart failure who are referred for hospice care. Arch Intern Med 2007;167:1990–7.
95. Derfler MC, Jacob M, Wolf RE, Bleyer F, Hauptman PJ. Mode of death from congestive heart failure: implications for clinical management. Am J Geriatr Cardiol 2004;13:299–304.
96. Bax JJ, Abraham T, Barold SS, Breithardt OA, Fung JW, Garrigue S, et al. Cardiac resynchronization therapy: part 1—issues before device implantation. J Am Coll Cardiol 2005;46:2153–67.
97. Bax JJ, Gorcsan J III. Echocardiography and noninvasive imaging in cardiac resynchronization therapy: results of the PROSPECT (Predictors of Response to Cardiac Resynchronization Therapy) study in perspective. J Am Coll Cardiol 2009;53:1933–43.
98. New study shows significant gaps in the availability of hospice care. Hosp Manage Advis 2008.
99. Goodlin SJ. End-of-life care in heart failure. Curr Cardiol Rep 2009; 11:184–91.
100. Goodlin SJ, Kutner JS, Connor SR, Ryndes T, Houser J, Hauptman PJ. Hospice care for heart failure patients. J Pain Symptom Manage 2005;29:525–8.
101. Goodlin SJ, Trupp R, Bernhardt P, Grady KL, Dracup K. Development and evaluation of the "Advanced Heart Failure Clinical Competence Survey": a tool to assess knowledge of heart failure care and self-assessed competence. Patient Educ Couns 2007;67:3–10.
102. Gillian R, Puchalski C. Spiritual support is important to heart failure patients. Supportive care in heart failure. Oxford University Press; 2008. p. 299–317.
103. Mueller PS, Swetz KM, Freeman MR, Carter KA, Crowley ME, Severson CJ, et al. Ethical analysis of withdrawing ventricular assist device support. Mayo Clin Proc 2010;85:791–7.
104. Simon JR. Case study. "Doctor, will you turn off my LVAD?" Commentary. Hastings Cent Rep 2008;38:14–5.
105. Lampert R, Hayes DL, Annas GJ, Farley MA, Goldstein NE, Hamilton RM, et al. HRS expert consensus statement on the management of cardiovascular implantable electronic devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy. Heart Rhythm 2010;7:1008–26.
106. Padeletti L, Arnar DO, Boncinelli L, Brachman J, Camm JA, Daubert JC, et al. EHRA expert consensus statement on the management of cardiovascular implantable electronic devices in patients nearing end of life or requesting withdrawal of therapy. Europace 2010;12:1480–9.
107. Brush S, Budge D, Alharethi R, McCormick AJ, MacPherson JE, Reid BB, et al. End-of-life decision making and implementation in recipients of a destination left ventricular assist device. J Heart Lung Transplant 2010;29:1337–41.
108. Marinskis G, van Erven L. Deactivation of implanted cardioverter-defibrillators at the end of life: results of the EHRA survey. Europace 2010;12:1176–7.
109. O'Connor CM, Hasselblad V, Mehta RH, Tasissa G, Califf RM, Fiuzat M, et al. Triage after hospitalization with advanced heart failure: the ESCAPE (Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheterization Effectiveness) risk model and discharge score. J Am Coll Cardiol 2010;55:872–8.