

## Section 8: Disease Management, Advance Directives, and End-of-Life Care in Heart Failure

### Education and Counseling

#### Overview

The majority of heart failure (HF) care is performed at home by the patient and family or caregiver. If these individuals do not know what is required, fail to see its importance, or face barriers to engagement in self-care, they will not participate effectively. For this reason, comprehensive education and counseling are the foundation for all HF management. The goals of education and counseling are to help patients, their families, and caregivers acquire the knowledge, skills, strategies, problem solving abilities, and motivation necessary for adherence to the treatment plan and effective participation in self-care. The inclusion of family members and other caregivers is especially important, because HF patients often suffer from cognitive impairment, functional disabilities, multiple comorbidities and other conditions that limit their ability to fully comprehend, appreciate, or enact what they learn.<sup>1-7</sup>

#### Recommendation

**8.1 It is recommended that patients with HF and their family members or caregivers receive individualized education and counseling that emphasizes self-care. This education and counseling should be delivered by providers using a team approach in which nurses with expertise in HF management provide the majority of education and counseling, supplemented by physician input and, when available and needed, input from dietitians, pharmacists, and other health care providers. (Strength of Evidence = B)**

**Teaching is not sufficient without skill building and specification of critical target behaviors. It is recommended that essential elements of patient education (with associated skills) are utilized to promote self-care as shown in Table 8.1. (Strength of Evidence = B)**

#### Background

**Self Care.** Self-care describes the process whereby a patient participates actively in the management of his or her HF, usually with the help of a family member or caregiver. Self-care includes both maintenance and management.<sup>8,9</sup> Self-care maintenance refers to healthy life-style choices (eg, exercising, maintaining a normal body weight) and treatment adherence behaviors (eg, monitoring weight changes, limiting dietary sodium, taking medications, getting routine immunizations). Self-care management is

**Table 8.1.** Essential Elements of Patient Education With Associated Skills and Target Behaviors

Elements of Education	Skill Building and Critical Target Behaviors
Definition of HF (linking disease, symptoms, and treatment) and cause of patient's HF	<ul style="list-style-type: none"> <li>• Discuss basic HF information, cause of patient's HF, and how symptoms relate to HF status</li> </ul>
Recognition of escalating symptoms and concrete plan for response to particular symptoms	<ul style="list-style-type: none"> <li>• Identify specific signs and symptoms (eg, increasing fatigue or shortness of breath with usual activities, dyspnea at rest, nocturnal dyspnea or orthopnea, edema)</li> <li>• Perform daily weights and know how to respond to evidence of volume overload</li> <li>• Develop action plan for how and when to notify the provider, changes to make in diet, fluid and diuretics</li> </ul>
Indications and use of each medication	<ul style="list-style-type: none"> <li>• Reiterate medication dosing schedule, basic reason for specific medications, and what to do if a dose is missed</li> </ul>
Modify risks for HF progression	<ul style="list-style-type: none"> <li>• Smoking cessation</li> <li>• Maintain blood pressure in target range</li> <li>• Maintain normal HgA1c, if diabetic</li> <li>• Maintain specific body weight</li> <li>• Understand and comply with sodium restriction</li> <li>• Demonstrate how to read a food label to check sodium amount per serving and sort foods into high- and low-sodium groups</li> <li>• Reiterate limits for alcohol consumption or need for abstinence if history of alcohol abuse</li> </ul>
Specific diet recommendations: individualized low-sodium diet; recommendation for alcohol intake	<ul style="list-style-type: none"> <li>• Comply with prescribed exercise</li> </ul>
Specific activity/exercise recommendations	<ul style="list-style-type: none"> <li>• Plan and use a medication system that promotes routine adherence</li> <li>• Plan for refills</li> </ul>
Importance of treatment adherence and behavioral strategies to promote	

a cognitive process that includes recognizing signs and symptoms, evaluating their importance, implementing a self-care treatment strategy (eg, diuretic administration), and evaluating its effectiveness. Self-efficacy, or confidence in one's ability to perform self-care, has been shown to influence self-care management abilities.<sup>10</sup>

Lack of knowledge and patient or caregiver misconceptions about how to participate in HF care is common.<sup>1,4,11-17</sup> The end result is non-adherence. HF patients, their families, and caregivers undertake the many behaviors involved in the care of HF in settings far removed from oversight by a health care provider. Teaching that emphasizes self-care is therefore a critical component of HF disease management programs.<sup>18</sup>

Knowledge alone is insufficient to promote adherence and effective self-care. An essential adjunct is skill building with target behaviors.<sup>14</sup> Skills needed include the ability to read food labels, adapt preferred foods to low-sodium versions, select low-sodium foods in the grocery store, prepare

palatable food with little or no added sodium, track sodium intake, and choose a low-sodium meal in a restaurant. Patients need guidance to develop an individualized system for medication adherence. Symptom management skills include the ability to monitor for and recognize a significant change in signs or symptoms and select an appropriate treatment strategy. Many HF programs advocate a self-directed diuretic scheme for managing significant increases in body weight.<sup>19,20</sup>

## Recommendation

**8.2 It is recommended that patients' literacy, cognitive status, psychological state, culture, and access to social and financial resources be taken into account for optimal education and counseling. Because cognitive impairment and depression are common in HF and can seriously interfere with learning, patients should be screened for these. Patients found to be cognitively impaired need additional support to manage their HF. (Strength of Evidence = B)**

## Background

A number of physical, cognitive, social, emotional, and environmental factors can affect an individual's learning ability and should be taken into account when planning education and counseling.<sup>1,4,6</sup> Patients often are not adept at communicating potential problems to their health care providers, who therefore must actively assess for them.

At least 20% of adults in the United States (US) cannot read at a fourth- or fifth-grade level.<sup>21</sup> Low literacy has been shown to be a major barrier to learning about illness.<sup>22</sup> Many patients in the US do not speak or read English.<sup>23</sup> Illiteracy and language barriers can be improved by including family members and caregivers in counseling; by using a variety of teaching methods, such as video and group discussion; by translating teaching materials; and by carefully constructing teaching materials at an accessible reading level, usually fifth or sixth grade.

Health literacy, a related but different concept, is also a major problem for patients with HF. Health literacy refers to an individual's ability to understand and act upon health information. In a national survey, only 12% of American adults were considered proficient in health literacy; 22% of adults' health literacy was considered basic, indicating they were able to read simply worded material and solve one-step problems; while another 14% of adults had less than basic health literacy, meaning they had difficulty comprehending even simple instructions.<sup>24</sup> Low health literacy is associated with decreased knowledge of one's medical condition,<sup>22,25–29</sup> poor medication recall,<sup>30</sup> non-adherence to treatment plans,<sup>26,28</sup> poor self-care behaviors,<sup>22,28,31</sup> compromised physical and mental health,<sup>32,33</sup> greater risk of hospitalization,<sup>34,35</sup> and increased mortality.<sup>36,37</sup>

Although the literature specifically addressing issues of low health literacy in patients with HF is limited, it is

consistent with the larger body of health literacy literature.<sup>38–41</sup> In one study, 38% of patients could not read and understand their own medication bottle labels, and this poor health literacy was associated with increased emergency department use for cardiac related problems.<sup>42</sup> To ensure appropriate patient engagement in self-care, it is essential that clinicians treating patients with HF address low literacy by identifying patients at risk, documenting learning preferences, using appropriate teaching materials, and stressing effective communication.

Cognitive impairment is probably more prevalent than recognized in HF patients<sup>43–47</sup> and can seriously affect patients' ability to learn and retain information. Rates of cognitive impairment between 23% and 53% have been documented in community-dwelling elders with HF.<sup>43–46</sup> Depression is common in patients with HF, it is a significant predictor of mortality,<sup>48–64</sup> and it interferes with learning and successful adjustment to HF.<sup>65</sup> HF patients should be routinely screened for depression. (See Section 6, Nonpharmacologic Therapy, for screening guidelines and treatment recommendations).

Although depression is associated with poorer outcomes in HF patients, the treatment of depression has not been demonstrated to improve outcomes.<sup>66</sup> Patients with cognitive impairment or depression need the support and assistance of a family member or caregiver. Home health nurses are recommended to assess and assist patients who lack a caregiver. Such patients can benefit from more intensive physician or nurse monitoring.

To screen for depression, a standardized instrument such as the Patient Health Questionnaire-2 score,<sup>67</sup> Beck Depression Inventory,<sup>68</sup> DISH,<sup>69,70</sup> or STOP-D questionnaire<sup>71</sup> can be used. Asking patients to read and interpret the instructions from a prescription medication bottle or procedure preparation instructions provides a good literacy assessment.

## Recommendation

**8.3 It is recommended that educational sessions begin with an assessment of current HF knowledge, issues about which the patient wants to learn, and the patient's perceived barriers to change. Education sessions should address specific issues (eg, medication nonadherence) and their causes (eg, lack of knowledge vs cost vs forgetting) and employ strategies that promote behavior change, including motivational approaches. (Strength of Evidence = B)**

## Background

Effective education and counseling is individualized to what the patient needs and wants to learn, builds on prior knowledge and experience, involves the patient in discussion and skill practice, and provides feedback and reinforcement.<sup>72,73</sup> A major difference between patient teaching and formal didactic education is that patient

teaching focuses on what patients need to *do* rather than what they need to *know*.<sup>15</sup>

**Barriers to Change.** HF patients often face barriers when they try to implement recommended behaviors. For example, a lack of social support compromises patient self-care.<sup>74</sup> Barriers to medication adherence include medication cost, cost of transportation to the pharmacy and clinic, confusion caused by prescriptions from multiple providers, and pharmacies in unsafe neighborhoods.<sup>16,75</sup> Other adherence barriers include medication unpleasantness, difficulty remembering, having to take too many medications each day, restrictions on travel, forgetting, and night-time awakening to urinate.<sup>76</sup> Barriers to sodium restriction adherence include time, cost, taste, difficulty understanding the diet, significant others not eating low-sodium food, interference with social obligations, confusion with dietary restrictions from other comorbid conditions, limitations on eating out, and difficulty modifying diet habits.<sup>75–77</sup> A common misunderstanding among HF patients is that an increase in fluid intake is necessary to compensate for excess urination.<sup>15,77</sup>

**Readiness to Change.** Optimal patient education is more than imparting information. Counseling emphasizes individualized delivery of important information, taking into account factors that interfere with successful participation in care, as well as a patient's readiness to change. Many patients are not ready to engage in the recommended behaviors. According to one model, those in *precontemplation* are not considering change, those in *contemplation* are thinking about change but have yet to make a commitment, and those in *preparation* are planning to change in the future and may have already engaged in some early steps of change.<sup>78</sup> Few patients are in the *action* (change has occurred) or *maintenance* (change has been maintained for 6 months or more) phases of change, even when the need for behavioral change was stressed by previous counseling. Increasing motivation may be very effective in moving patients from an early stage to an active stage of change.

**Internal Motivation.** Motivation is an important contributor to successful self-care. Motivational techniques are extremely effective for individuals in the early stages of change. Motivation interviewing, a technique that helps the patient resolve ambivalence regarding change, is effective even in those facing difficult tasks, such as abstinence from drinking or weight loss.<sup>79,80</sup> Cognitive-behavioral techniques, which emphasize modifying barriers to change, are also quite useful with patients in the early stages of change.<sup>81</sup> Specific techniques have been suggested for moving patients forward in each of the stages of change.<sup>82</sup> For example, patients considering change need information. On the other hand, information is often irritating to individuals in the contemplation stages of change, who might respond to an emphasis on the benefits to be derived from

change. Those in the preparation stage benefit from comments that build confidence in their ability to make the necessary change or by suggestions that decrease perceived barriers.

**Educational Techniques to Avoid.** Fear and coercion are ineffective motivators because people who are pushed in one direction will resist change, even if the advocated approach is logical.<sup>80,82</sup> Paternalism, characterized by making decisions for or dictating decisions to patients, is rarely effective in the long-term because of lack of ownership by the patient over the decision.

## Recommendation

**8.4 It is recommended that the frequency and intensity of patient education and counseling vary according to the stage of illness. Patients in advanced HF or with persistent difficulty adhering to the recommended regimen require the most education and counseling. Patients should be offered a variety of options for learning about HF according to their individual preferences:**

- Videotape
- One-on-one or group discussion
- Reading materials, translators, telephone calls, mailed information
- Internet
- Visits

**Repeated exposure to material is recommended because a single session is never sufficient. (Strength of Evidence = B)**

## Background

Not all patients with HF have the same learning needs. Although one might argue that every patient could benefit from intensive education and counseling, current evidence suggests that those patients with few symptoms and less complicated HF may have worse outcomes in terms of health care resource use, costs, and quality of life when they receive intensive counseling.<sup>83</sup> Patients with more severe HF incur substantial benefit from an intensive intervention. Although most clinicians would argue for the value of face-to-face education and counseling, studies have shown that select patients who are motivated to learn and change can derive significant benefit from interventions delivered by mail, telephone, or technology.<sup>84–86</sup> These techniques are not likely to be successful with patients who suffer even mild cognitive impairment or have depressive symptoms, nor are they adequate for those with low literacy or low health literacy, poor social support, multiple comorbidities, or functional impairment. Regardless of the method used, it is imperative that information be covered more than once. Use of different methods may improve efficiency (eg, supplementing verbal with written materials).

## Recommendation

**8.5 It is recommended that during the care process patients be asked to:**

- **Demonstrate knowledge of the name, dose, and purpose of each medication**
- **Sort foods into high- and low-sodium categories**
- **Demonstrate their preferred method for tracking medication dosing**
- **Show provider daily weight log**
- **Reiterate symptoms of worsening HF**
- **Reiterate when to call the provider because of specific symptoms or weight changes (Strength of Evidence = B)**

## Background

Successful education is an interactive process in which patients and caregivers participate by asking questions and by demonstrating that they have comprehended and retained what they were told. Misperceptions by patients and family are very common, but they can be avoided when an interactive learning process is used.<sup>4</sup> Very few clinicians have strategies in place for assessing that patients have understood and retained the education given to them. Retention of learned material is poor among the elderly and any patient with a chronic disease, but it is enhanced when the learner shows mastery of the learned material by recitation of specific details or by demonstration.

## Recommendation

**8.6 During acute care hospitalization, only essential education is recommended, with the goal of assisting patients to understand HF, the goals of its treatment, and the post-hospitalization medication and follow-up regimen. Education begun during hospitalization should be supplemented and reinforced within 1–2 weeks after discharge, continued for 3–6 months, and reassessed periodically. (Strength of Evidence = B)**

## Background

The hospital is arguably the most difficult setting for patient and family education because patients are ill, anxious, and in circumstances that do not promote retention.<sup>13,87</sup> By many estimates, patients retain only a minority of information taught to them in the hospital.<sup>10</sup> One study showed that 46% of patients were noncompliant with their recently prescribed regimen and most demonstrated inadequate medication-related knowledge just 1 week after discharge, even when they received medication teaching.<sup>16</sup> In another study, half of all patients interviewed claimed they received no medication education before discharge, 70% claimed they received no written materials, only 43% of patients could name their discharge medications, and none could

**Table 8.2.** Modifiable Factors Leading to Hospital Readmissions for HF

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- Inadequate patient and family or caregiver education and counseling
  - Poor communication and coordination of care among health care providers
  - Inadequate discharge planning
  - Failure to organize adequate follow-up care
  - Clinician failure to emphasize nonpharmacologic aspects of HF care, such as dietary, activity, and symptom monitoring recommendations
  - Failure to address the multiple and complex medical, behavioral, psychosocial, environmental, and financial issues that complicate care, such as older age, presence of multiple comorbidities, lack of social support or social isolation, failure of existing social support systems, functional or cognitive impairments, poverty, presence of anxiety or depression
  - Failure of clinicians to use evidence-based practice and follow published guidelines in the prescription of pharmacologic and nonpharmacologic therapy
- 

name even one side effect of their prescribed medications, regardless of whether or not they reported receiving information from a clinician.<sup>88</sup> Further, there was little agreement between patients and their physicians as to whether or not they had or had not received medication education from the physician.

Patient and caregiver knowledge about their HF and medication regimen must be confirmed by responses. Education should be reinforced and additional teaching started within 1 week of discharge.<sup>89</sup> Systematic education and counseling should continue for 3 to 6 months according to the needs of the patient and family or caregiver.<sup>90</sup>

The difficult circumstances under which discharge education is provided do not diminish its importance. One randomized, controlled study of 223 HF patients using a structured 1-hour, one-on-one teaching protocol led to significantly fewer deaths, rehospitalizations, or days hospitalized during follow-up.<sup>91</sup> In addition to improving self-care adherence, cost of care in the patients receiving the intervention was lower than in control subjects.

## Disease Management Programs

Practitioners who care for patients with HF are challenged daily with preventing common, recurrent rehospitalizations for exacerbations. Most of the staggering cost associated with the care of HF patients is attributable to these hospitalizations.<sup>92–94</sup> As many as one-half to two-thirds of hospital readmissions are thought to be preventable with attention to modifiable factors,<sup>95–99</sup> which include those listed in Table 8.2.<sup>1,4,87,96,100–108</sup>

Recognizing the deficiencies in traditional or “usual care”<sup>109</sup> has led to the testing of comprehensive, integrated, interdisciplinary disease management models of care that demonstrate markedly improved outcomes.

## Recommendation

**8.7 Patients recently hospitalized for HF and other patients at high risk for HF decompensation should be considered for comprehensive HF disease management. High-risk patients include those with renal**

**insufficiency, low output state, diabetes, chronic obstructive pulmonary disease, persistent New York Heart Association (NYHA) class III or IV symptoms, frequent hospitalization for any cause, multiple active comorbidities, or a history of depression, cognitive impairment, inadequate social support, poor health literacy, or persistent nonadherence to therapeutic regimens. (Strength of Evidence = A)**

## Background

Disease management is "a comprehensive, integrated system for managing patients...by using best practices, clinical practice improvement...and other resources and tools to reduce overall cost and improve measurable outcomes in the quality of care".<sup>110</sup> A number of disease management programs have been studied. They fall into 3 broad categories: (1) HF clinics<sup>19,111–126</sup> (2) care delivered in the home or to patients who are at home<sup>18,83,90,105,127–139</sup> and (3) telemonitoring.<sup>140–146</sup> Clinics or services designed solely for the administration of intravenous infusions, or which consist of only a single component of HF care, are not considered HF disease management programs and generally have not provided evidence of effectiveness.

HF clinics are disease management programs in which service is provided primarily in an outpatient clinic setting where patients come to receive care from practitioners with expertise in HF. HF clinics provide optimization of drug therapy, patient and family/caregiver education and counseling, emphasis on self-care, vigilant follow-up, early attention to signs and symptoms of fluid overload, coordination of care with other providers, quality assessment, and increased access to the health care provider.

Although some of the studies evaluating disease management in HF clinics were randomized, controlled trials,<sup>113,114,119,123,126</sup> most compared data before and after program implementation. These studies consistently show that HF patients receiving care in a HF clinic experience a reduction in subsequent hospitalizations and hospital days, higher quality of life, and an improvement in functional status. This model appears to be cost-effective, because the increased costs of specialty care are offset by fewer rehospitalizations and/or improvements in quality of life endpoints.<sup>147–149</sup> Improved survival was seen in one of the randomized, controlled trials.<sup>123</sup> The largest study of clinic-based disease management to date, the Coordinating Study Evaluating Outcomes of Advising and Counseling in Heart Failure (COACH) demonstrated a non-statistically significant 15% reduction in mortality in 1049 patients randomized to a nurse-based HF disease management intervention as compared to usual care. However, no differences between groups were observed in the primary endpoints of all-cause mortality or HF hospitalization, or the number of days lost because of death or hospitalization over 18 months of follow-up.<sup>126</sup> The lack of effect on the primary endpoints in this study may have been due to a lower than anticipated event rate, and closer

follow-up than anticipated in the usual care group. In a meta-analysis of 29 randomized trials of multidisciplinary HF disease management programs involving 5039 patients, disease management programs were associated with significantly lower mortality and hospitalization rates. The majority of the trials included in this meta-analysis that analyzed cost-effectiveness (15 of 18) demonstrated that the strategies were cost saving.<sup>150</sup> Another meta-analysis included 54 studies, 27 of which were randomized and 27 of which were not randomized.<sup>151</sup> The findings of this analysis revealed that among the randomized studies, disease management programs were associated with reductions in all-cause hospitalizations, cardiovascular and HF specific hospitalizations, and the combined endpoint of hospitalization or death.<sup>151</sup>

Another model features HF-specific care delivered in the home or to patients at home. Many of these programs use a case management approach. Included in this group are examples of true multidisciplinary and collaborative HF care.<sup>83,90,131,152</sup> Characteristics shared by these programs include patient and family/caregiver education and counseling, emphasis on self-care, vigilant follow-up, early attention to signs and symptoms of fluid overload, coordination of care with other providers, increased access to the health care provider, and attention to social and financial barriers to adherence.

Studies of patients receiving care in the wide variety of home-based programs showed significantly fewer total and HF rehospitalizations, fewer days per hospitalization, improved quality of life, lower health care costs, and improved survival.<sup>83,90,105,127–129,131,133–136,152,153</sup> Several were randomized controlled trials that showed positive results for endpoints such as time to first hospitalization, days in the hospital, unplanned readmissions, and deaths out of the hospital.<sup>127,129,131,134,153</sup> In the meta-analysis by McAlister et al, disease management programs that focused on enhancing patient self-care activities reduced HF hospitalizations by 34%, and all-cause hospitalizations by 27%, but they had no effect on all-cause mortality.<sup>150</sup>

In the third category of disease management programs, computer technology and telephone data transmission are used to monitor patients' weight, blood pressure, heart rate, and in some cases other physiologic parameters. These programs have much less personal contact with a health care provider than the home-based programs, and many lack an educational component. Most of the studies conducted using telemonitoring techniques were small, with one exception.<sup>146</sup> Because of these study limitations, findings concerning this category of disease management programs remain equivocal. In the meta-analysis by McAlister et al, disease management strategies using telephone contact were associated with a reduction in HF hospitalizations, but not mortality or all-cause hospitalization.<sup>150</sup>

Studies of HF disease management using the clinic and home-based care models provide convincing evidence that it is possible to significantly reduce rehospitalization rates

and costs and improve functional status and quality of life for HF patients. Although evidence of a clinical benefit was not demonstrated statistically in the COACH trial, a potentially clinically relevant reduction in all-cause mortality was noted, and it is plausible that a higher than expected level of care was provided in the usual care arm, thus limiting the ability to detect significant between-group differences.<sup>126</sup> A growing number of adequately powered studies and published meta-analyses have demonstrated a positive effect on survival by HF disease management.<sup>123,127,136,150,151</sup> This effect appears to be due to improved patient self-care. Programs focusing on self-care skills demonstrate gains equal to or greater than those seen with programs that improve drug therapy.<sup>18,123</sup>

## Recommendations

**8.8 It is recommended that HF disease management programs include the components shown in Table 8.3 based on patient characteristics and needs. (Strength of Evidence = B)**

**Table 8.3.** Recommended Components of a HF Disease Management Program

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- Comprehensive education and counseling individualized to patient needs
  - Promotion of self care, including self-adjustment of diuretic therapy in appropriate patients (or with family member/caregiver assistance)
  - Emphasis on behavioral strategies to increase adherence
  - Vigilant follow-up after hospital discharge or after periods of instability
  - Optimization of medical therapy
  - Increased access to providers
  - Early attention to signs and symptoms of fluid overload
  - Assistance with social and financial concerns
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**8.9 It is recommended that HF disease management include integration and coordination of care between the primary care physician and HF care specialists and with other agencies, such as home health and cardiac rehabilitation. (Strength of Evidence = C)**

**8.10 It is recommended that patients in a HF disease management program be followed until they or their family/caregiver demonstrate independence in following the prescribed treatment plan, adequate or improved adherence to treatment guidelines, improved functional capacity, and symptom stability. Higher risk patients with more advanced HF may need to be followed permanently. Patients who experience increasing episodes of exacerbation or who demonstrate instability after discharge from a program should be referred again to the service. (Strength of Evidence = B)**

## Background

**Essential Elements of Disease Management.** Every successful HF disease management program has a comprehensive education and counseling component. Programs

should include intensive guideline-based education and counseling with emphasis on behavioral strategies to increase adherence and counseling to address patients' individual barriers to engaging in self-care. Education should include diet, medications, weighing, symptoms heralding worsening HF, and the importance of seeking early treatment for these symptoms. Promotion of self-care is a fundamental component of successful programs and the foundation upon which disease management is based. Frequent follow-up in some form and increased access to health care providers also appear to be vital components. Optimization of medical therapy is an important aspect. Because the majority of rehospitalizations for exacerbation are the result of fluid overload<sup>98</sup> some mechanism for addressing early signs of fluid overload is essential. In many programs, educating patients about flexible diuretic regimens is successful. When patients or their family or caregiver are unable or unwilling to assume significant responsibility, home visits by a nurse or "drop-in" visits to a HF clinic are options. Assistance with social and financial concerns and coordination of care among all agencies involved are additional important components of HF disease management.

A recent meta-analysis examined randomized controlled trials of disease management programs from 1995–2005 in order to determine the characteristics that were common to successful programs.<sup>154</sup> They found that successful disease management always had multiple components, including an in-hospital phase of care, intensive patient education, self-care supportive strategy, optimization of the medical regimen, and ongoing surveillance and management of clinical deterioration. It was considered fundamental that a cardiac nurse and cardiologist be actively involved and that the delivery of follow-up care was flexible.

## Advance Directives and End-of-Life Care

### Overview

HF has a worse prognosis than many common cancers,<sup>155</sup> and premature death from progressive decompensated HF or sudden cardiac death (SCD) is frequent. Recent advances in HF treatment have resulted in substantial reductions in annual mortality from these modes of death. Nevertheless, the mortality rate in HF remains high, making advance directives and end-of-life care important issues for patients with this condition.

Hospice services or other end-of-life care should only be implemented after full and appropriate application of evidence-based pharmacologic and cardiac device therapies (ie, cardiac resynchronization therapy [CRT]), unless documentation of intolerance or contraindication to such treatments is present. For critically ill patients, clinicians should acknowledge to the patient and their family the potentially life-threatening nature of their condition, and supportive care should be implemented as indicated. In most

cases, adequate time (weeks to months) must be given to allow medical therapies to exert a beneficial therapeutic effect. In addition, issues such as access to care, adherence to medications and other self care behaviors, and knowledge about HF must be addressed. End-of-life care most often includes continuing HF therapies, which may effectively ease symptoms and stabilize or improve quality of life. Failure to implement evidence-based therapies or to comply with quality measures for HF is associated with higher patient mortality.<sup>156</sup> In one hospital system, HF patients with do-not-resuscitate (DNR) orders were less likely to receive quality measures including ACE-inhibitor/angiotensin receptor blocker (ARB) use, non-pharmacologic counseling, or assessment of left ventricular (LV) function as compared to patients without DNR orders, after adjustment for other factors.<sup>157</sup> Discontinuation of medications at the end of life may be considered when taking them becomes burdensome (eg, the patient has difficulty swallowing) or if they do not impact symptoms (eg, statins). Drugs should be discontinued one at a time so that worsening symptoms can be correctly attributed to discontinuation of a specific drug.

A discussion about HF course and prognosis should be conducted with all patients to the extent that they are willing to participate in such a conversation. Several tools, including the Enhanced Feedback for Effective Cardiac Treatment (EFFECT) score<sup>158</sup> and the Seattle HF Score,<sup>159</sup> may help clinicians identify the patient's general prognosis. Secondary analyses of registries and trials have identified several common predictors of death, including low sodium, elevated BUN or serum creatinine, advanced age, and low hemoglobin.<sup>160–164</sup> Data generated from these scores should be presented to the patient and family as an estimated range of times, with the caveat that patients may live longer or shorter than expected.

A discussion of prognosis should acknowledge the fact that death in HF may occur suddenly and unexpectedly in patients who are otherwise well compensated, so patients should be educated on the available strategies to reduce the risk of SCD. In the Candesartan in Heart Failure: Assessment of Reduction in Mortality and Morbidity (CHARM) Preserved study that enrolled patients with NYHA Class II-III HF and preserved left ventricular ejection fraction (LVEF), 29% of subjects died of SCD while 20% died of progressive HF. Non-cardiovascular causes accounted for 30% of deaths, and the remaining 21% died of other cardiovascular causes.<sup>165</sup> In CHARM-Added, 40% of patients with NYHA Class II-III HF and reduced LVEF died of SCD, 28% died of progressive HF, and 20% died of non-cardiovascular causes. However, in subjects with a reduced LVEF, mortality was double that observed in those with a preserved LVEF so the absolute mortality from SCD was much higher in patients with reduced LVEF compared to those with preserved LVEF.<sup>166</sup> In the Metoprolol CR/XL Randomised Intervention Trial in Congestive Heart Failure (MERIT-HF), the mortality in subjects randomized to the metoprolol CR/XL group was

5.3%, 8.1%, and 16.7% per patient-year of follow-up for NYHA class II, III, and IV, respectively. The deaths due to progressive HF increased from 12% to 26% to 56% in NYHA Class II, III, and IV, respectively, while SCDs declined from 64% of deaths in NYHA Class II subjects to 59% in class III and to 33% in Class IV subjects.<sup>167</sup> The absolute number of SCDs was 6, 11, and 19 per 100 subjects in NYHA classes II, III, and IV. In the Comparison of Medical Therapy, Pacing, and Defibrillation in Chronic Heart Failure (COMPANION) Trial, NYHA Class IV CRT subjects experienced about 15 SCDs per hundred.<sup>168</sup> Thus, while the percentage of deaths due to SCD is lower in patients with NYHA Class IV HF, the absolute number of SCDs is quite large. This general concept of a decline in the absolute percentage of SCD but a high absolute number has been confirmed recently.<sup>169</sup>

Patients and families may want more specific information about their likely course. A greater proportion of patients with less severe symptoms tend to die from SCD, whereas death is attributed to progressive HF more often in patients with more symptomatic disease.<sup>167</sup> In young patients, progressive HF death typically is heralded by a period of severe symptoms, frequent hospitalizations, and obvious, unremitting clinical deterioration. Some individuals, especially, older, frail individuals, may have severe fatigue as a sign of progressive HF. Shortness of breath can be well managed for most patients and should not be presented as inevitable.

Discussion of end-of-life care can occur when the patient has progressed to a state of severe, refractory HF. This discussion is easier if the patient and family are aware early in the course of HF care that HF leads to death, often over a period of many years. Early in the course of care, clinicians should discuss dying from HF with patients. This conversation should include a discussion about the effectiveness of medication management, the use of CRT (if indicated) to modify the course of illness, and the potential risks and benefits of implantable defibrillators to reduce the chance of a SCD. Some data suggest that patients prefer to be informed about issues related to their disease and its prognosis when they are relatively well.<sup>170</sup> In addition, patients want to be aware of the prognosis of their condition, but they desire that this information be balanced with hope that they have the potential to respond to available therapeutic measures.<sup>170</sup> To optimize interventions and approaches to care, it is important to understand whether a patient would want an attempt at resuscitation or natural death.<sup>171</sup>

In considering these issues, it is important to understand the distinction between advance directives and end-of-life care. Advance directives are decisions or legal documents made or created by individuals and shared with loved ones and health care providers that identify desired or undesired treatments if an individual becomes incapacitated and incapable of making decisions about care. Examples of legal advance directives are shown in Table 8.4. All patients with HF should be encouraged to have advance directives in place before the end-of-life is imminent and should

**Table 8.4.** Examples of Legal Advance Directives

Legal Advance Directive	Description
Living Will	This document uses standard language in the patient's state of residence, identifying whether specific or general life-prolonging interventions should be initiated (or continued) in the face of imminent death. Some states require 2 physicians to certify that the patient has a "terminal illness" for a living will to be enacted.
Durable Power of Attorney for Health Care (DPOA/HC)	This document designates one or more individuals to make health care decisions on behalf of the person at a future time if the person is unable to speak independently. While the DPOA/HC does not typically identify specific interventions or approaches to care desired by an individual, patients should be encouraged to make their proxy aware of undesired states and/or generally preferred approaches to care. Patients with HF should be encouraged to appoint a DPOA/HC. Clinicians should discuss with patients with HF general preferences for care, including preferences for an attempt at resuscitation versus allowing natural death.

designate proxy decision makers in the event they are not able to speak for themselves. The use of advance directives has not been well-studied in patients with HF. End-of-life care refers to care designed to provide symptom relief, comfort, and support for patients and their families when optimal treatments have failed to halt progression of the illness or relieve symptoms and the likelihood is high that death is imminent within the coming weeks to months.

## Recommendations

- 8.11 It is recommended that patient and family or caregiver discussions about quality of life and prognosis be included in the disease management of HF. (Strength of Evidence = C)**
- 8.12 It is recommended that:**
- Seriously ill patients with HF and their families be educated to understand that patients with HF are at high risk of death, even while aggressive efforts are made to prolong life.**
  - Patients with HF be made aware that HF is potentially life-limiting, but that pharmacologic and device therapies and self-management can prolong life. In most cases, chronic HF pharmacologic and device therapies should be optimized as indicated before identifying that patients are near end-of-life.**
  - Identification of end-of-life in a patient should be made in collaboration with clinicians experienced in the care of patients with HF when possible.**
  - End-of-life management should be coordinated with the patient's primary care physician.**

- As often as possible, discussions regarding end-of-life care should be initiated while the patient is still capable of participating in decision-making. (Strength of Evidence = C)**

**8.13 End-of-life care should be considered in patients who have advanced, persistent HF with symptoms at rest despite repeated attempts to optimize pharmacologic, cardiac device, and other therapies, as evidenced by 1 or more of the following:**

- HF hospitalization<sup>172,173</sup> (Strength of Evidence = B)**
- Chronic poor quality of life with minimal or no ability to accomplish activities of daily living (Strength of Evidence = C)**
- Need for continuous intravenous inotropic therapy support<sup>174,175</sup> (Strength of Evidence = B)**

## Background

**Identification of Patients Who Are Near the End of Life.** Some patients with HF exhibit episodes of frequent decompensation requiring hospitalization. Although a roller-coaster pattern of decompensation may occur in advanced HF despite aggressive therapy, in some patients, events will be related to reversible causes, such as dietary sodium or fluid indiscretion, medication nonadherence, contraindicated medications, inadequate medical therapy, new onset atrial fibrillation, or acceleration of ventricular rate in patients in chronic atrial fibrillation.

After identifiable causes of decompensation are eliminated and proven therapies have been aggressively applied, end-of-life care should be considered if patients still experience a marked decline in functional ability and quality of life. Typically, these patients have severe LV systolic dysfunction or severe restrictive diastolic dysfunction and evidence of marked cardiac decompensation. They often have significant renal insufficiency and hypotension that may limit the application of effective therapy. This clinical picture persists despite intensive attempts at pharmacologic management both in inpatient and outpatient settings. Elderly patients with HF may also approach the end of life in the context of progressive frailty or with other significant medical problems. HF in this population is often accompanied by cognitive problems and increasing need for assistance with care.

**Recognition of End-stage HF.** Patients with HF and their caregivers often do not appreciate the life-limiting nature of their illness.<sup>176</sup> HF is a chronic disorder and often progresses to death.<sup>177</sup> Despite the concern that a discussion of prognosis might be discouraging and have a negative impact on psychological and physical morbidity,<sup>178</sup> discussions about dying should occur in the course of care for patients with HF. These conversations should be coupled with discussions on ways patients can manage HF (i.e.,



through self-care maintenance and management behaviors (see sections 8.1–8.6).<sup>179</sup> Early in the course of illness and in the context of a discussion of the importance of self management, the clinician should acknowledge that HF is rarely curable and will ultimately lead to death. This information should be partnered with encouragement that good quality of life can often be achieved with evidence-based pharmacologic and device therapies. Patients should be educated on the possibility of SCD and available strategies to reduce the risk of this event, and clinicians should assess the patients' wishes regarding the implementation of these strategies (i.e. placement of implantable cardioverter defibrillator (ICD), cardiopulmonary resuscitation [CPR]). When patients develop refractory HF despite aggressive medical therapy, clinicians should discuss their worsened prognosis and options for care. It is reasonable to have discussions about the possibility of death with the patient and their family during any period of severe instability (i.e. during hospitalizations for HF, and/or in the setting of hemodynamic compromise or hypoxemia). Recent evidence has shown that the majority of family members or surrogate decision makers of critically ill patients wanted physicians to accurately inform them of the patient's prognosis.<sup>180</sup>

**Decision-Making at End of Life.** Experience from HF centers caring for patients dying from progressive HF suggests that decisions about termination of life-prolonging therapy are usually made by the patient and family after discussions with their health care provider about prognosis and goals, although such open discussions can be challenging for patients and clinicians.<sup>171,181,182</sup> Decisions related to end-of-life care may be made during periods of relative compensation; however, clinicians should be prepared to guide patients and families in decision making in situations of decompensation as well. Because patients with HF approaching end of life may have periods of confusion, delirium, somnolence, or inattention and need someone else to make decisions, a designated surrogate decision maker or durable power of attorney for health care is especially important at this time.

## Recommendations

- 8.14 It is recommended that end-of-life care strategies be individualized and include core HF pharmacologic therapies, effective symptom management and comfort measures, while avoiding unnecessary testing. New life-prolonging interventions should be discussed with patients and care-givers with careful discussion of whether they are likely to improve symptoms. (Strength of Evidence = C)**
- 8.15 It is recommended that a specific discussion about resuscitation be held in the context of planning for overall care and for emergencies with all patients with HF. The possibility of SCD for patients with**

**HF should be acknowledged. Specific plans to reduce SCD (for example with an ICD) or to allow natural death should be based on the individual patient's risks and preferences for an attempt at resuscitation with specific discussion of risks and benefits of inactivating the ICD. Preferences for attempts at resuscitation and plans for approach to care should be readdressed at turning points in the patient's course or if potentially life-prolonging interventions are considered. (Strength of Evidence = C)**

- 8.16 It is recommended that, as part of end-of-life care, patients and their families/caregivers have a plan to manage a sudden decompensation, death, or progressive decline. Inactivation of an implantable defibrillation device should be discussed in the context of allowing natural death at end of life. A process for deactivating defibrillators should be clarified in all settings in which patients with HF receive care. (Strength of Evidence = C)**

- 8.17 Patients with HF receiving end-of-life care should be considered for enrollment in hospice that can be delivered in the home, a nursing home, or a special hospice unit. (Strength of Evidence = C)**

## Background

**Reassessment of Decision-Making.** The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) evaluated 936 patients with severe HF and showed a 19% change in resuscitation decisions over a 2-month period among patients who survived their enrollment hospitalization.<sup>183</sup> In 50% of the cases, the physician's perception of the patient's preference was inaccurate. An analysis of the SUPPORT and Hospitalized Elderly Longitudinal Project (HELP) showed that a HF diagnosis was an independent predictor of attempted resuscitation, whereas other severe diseases (chronic obstructive pulmonary disease, cirrhosis, coma, colon or lung cancer, or multi-system organ failure) were independent predictors of not receiving resuscitation.<sup>184</sup>

**End-of-Life Care.** The goals of end-of-life care are to meet patients' and their families' goals for length and quality of life to the extent possible, manage debilitating symptoms, and provide support for emotional, social, and spiritual distress. Bereavement support should be provided during the patient's illness and for the family after the patient's death. In most cases, evidence-based HF care or even aggressive treatment should be continued to meet these goals. In some cases, time-limited trials of aggressive treatment can be used to help providers and patients understand whether or not a patient may be responsive to such treatment. Hospitalization for management of congestion or a trial of intravenous treatment at home or under hospice

care to reduce symptoms are examples of appropriate end-of-life medical care for HF.

**Symptom Management.** Patient-centered care dictates that symptoms be managed to the level desired by patients and families when possible. Inadequate symptom relief is distressing to patients and their families and negatively affects quality of life, as well as the ability of patients to complete life closure tasks.<sup>185</sup>

Since some therapies to manage HF symptoms may influence duration of survival, it is important for physicians to fully assess a patient's desires regarding the balance of symptom management and prolongation of life. In a time-trade-off study of 287 patients with advanced HF in the ESCAPE (Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheter Effectiveness) study, 49% indicated they would not be willing to trade survival time to feel better. In the subgroup of patients who survived for <105 days, 31% reported they would trade almost all of their remaining days to feel well for the time they had left. In contrast, only 6% of patients who survived for 180 days were willing to trade most of their survival days to feel well ( $P=0.0015$ ).<sup>186</sup>

In an analysis of 91 HF patients (48 with NYHA class II symptoms and 43 with NYHA class IV symptoms), treatment preferences were assessed in relationship to the time trade off score. In this analysis, two specific patient groups were identified. Treatments that improved quality of life at the expense of survival were preferred by 55% of the patients, whereas 45% preferred medical management that prolonged survival time.<sup>187</sup> The description of end-of-life symptoms that may occur with medical management (severe shortness of breath or gasping for air) may have influenced the outcome of this study. Interestingly, these preferences correlated poorly with quality of life, symptom, and overall health scores.<sup>187</sup> This evidence suggests that for some patients, treatment preferences can be decided early in the course of the illness.

As compared to patients with other manifestations of coronary heart disease, patients with HF have a worse health status at the end of life and tend to have more hospitalizations, and more commonly rate their health as fair or poor, have activity restrictions, and report symptoms.<sup>188</sup> An array of symptoms are seen among patients with end stage HF,<sup>189-191</sup> including pain (78%), dyspnea (61%), low mood (59%), sleeplessness (45%), loss of appetite (43%), confusion (40%), constipation (37%), nausea and vomiting (32%), anxiety (30%), and urinary incontinence (29%).<sup>192</sup> Families rated pain, dyspnea, low mood, anxiety, urinary incontinence, and confusion as being the most distressing to patients in the last year of their lives. In the SUPPORT study of patients admitted for acute HF who were considered to have end-stage HF, the three most common symptoms reported by family members in the last 6 months of life were dyspnea, pain, and confusion.<sup>189</sup> The percentage of patients experiencing escalating rates of perceived severe dyspnea and pain increased significantly as death

approached. In the last 3 days of life, 63% of all patients with HF experienced severe dyspnea. Current experience may differ as a result of advancements in medical therapies since the early 1990s when SUPPORT was conducted, but nonetheless, adequate symptom management is a high priority for patients and their families. In one study, during the last week of life, 70% of patients' families rated their quality of life as poor to fair. Increases in emotional symptoms, such as anxiety and depression, were reported by families during the 3 days before death. Other studies have confirmed these findings.<sup>193</sup> Analysis of medical records of 80 patients diagnosed with HF revealed that the most common symptoms experienced in the last 6 months of life were breathlessness (88%), followed by pain (75%) and fatigue (69%). Investigators concluded that end-stage patients with HF experience similar symptoms to end-stage cancer patients. In two studies of HF programs, the course to death for patients with advanced HF was frequently progressive metabolic disarray and decreased consciousness.<sup>194,195</sup>

One of the most important components of end-of-life care is good listening and open communication, with particular attention to patients' concerns about management of symptoms, attitudes about dying,<sup>177</sup> ease to access of services, and emotional and spiritual concerns. Symptoms should be treated to the level of comfort desired by the patient and family, recognizing that in some situations a compromise is required between alertness and decreased symptoms.

As previously discussed, pain is present in two-thirds or more of patients with HF, and it is common for patients to have multiple sites of pain. Non-steroidal anti-inflammatory drugs should be avoided in patients with HF, so interventions for arthritis pain should include local steroid injections, low-dose opioids, and physical therapy. Pain related to ischemia is most effectively treated with nitrates and opioids. Dyspnea can be managed with diuretics and opioids. Morphine is inexpensive and effective for dyspnea, but active metabolites can accumulate in patients with end-stage disease because of poor renal function. This accumulation may lead to myoclonus, agitation and delirium. In addition, recent evidence from the Acute Decompensated Heart Failure National Registry (ADHERE) suggests that morphine use may be associated with higher risk of mortality, even after adjustment for other important risk factors.<sup>196</sup> Clinicians should be vigilant for confusion or delirium and attempt to avoid medications or other insults that precipitate or worsen delirium. Antidepressants, sleep aids, sedatives, and complementary therapies can worsen confusion, particularly if pharmacokinetic or pharmacodynamic changes related to HF (i.e. poor hepatic or renal perfusion) or age are not considered. Dose adjustments or extended dosing intervals may be needed to optimize the benefits from these drugs while minimizing cognitive side effects. Gastrointestinal problems, such as loss of appetite, constipation, nausea/vomiting, and fecal incontinence can be managed with diet modifications, appetite enhancers, laxatives, or other medications. Urinary

incontinence is often related to diuretic use and weakness of the urinary sphincter. It may be addressed with a change in the timing of diuretic doses, a urinary catheter, pads or incontinence underwear. Management of fatigue and activity intolerance may require lifestyle modifications including periods of rest with feet elevated or rescheduling of activities to take advantage of changing energy levels. Energy conservation techniques, such as breathing retraining, spacing activities, meditating, or using assistive devices, may be helpful. A low-level exercise program may have both physical and psychological benefits. Home health aides and homemakers can be very helpful in assisting patients to manage activities of daily living and thus conserve energy.

**Use of Continuous Intravenous Inotropic or Vasoactive Support and End-of-Life Care.** Patients undergoing end-of-life care may respond to continuous intravenous inotropic agents with temporary symptomatic improvement. Utilization of inotropic agents must be undertaken with the understanding that these drugs likely will reduce survival due to an increase in SCD. Health care providers skilled in HF management may use intravenous inotropic infusions for end-of-life care when oral HF pharmacologic therapies fail to stabilize symptoms. The use of inotropic therapy in this population is highly variable.<sup>197</sup> Patients should be informed about the potential risks of inotropic therapy including proarrhythmia and other adverse clinical outcomes such as sepsis due to chronic indwelling venous catheters that might reduce life expectancy despite a possible period of symptomatic improvement.

Periodic reevaluation of continuous intravenous inotropic support is mandatory, because the patient's response to treatment may diminish over time, or the patient may decide that the quality of life gained is offset by the intensity of therapy required. Continuous intravenous inotropic therapies must not be considered as acceptable alternatives to core evidence-based HF pharmacologic and cardiac device based treatments. They should be applied only after careful attempts to manage patients with evidence-based drug and cardiac device therapies. Hospices vary in their provision of intravenous and other therapies, based on agency size and staff education.

**Referral to Hospice.** Data from 2000 indicate that 8% of all hospice patients have a diagnosis of HF.<sup>198</sup> A survey of hospice centers published in 2005 reported similar findings, with an average of 9% of patients under hospice care having a primary diagnosis of HF.<sup>199</sup> Patients with cancer are routinely referred for hospice care and comprise the majority of hospice patients nationally. Only 1.6% of the 182,898 hospitalization episodes from 2001–2005 in ADHERE resulted in hospice referral; however, ADHERE enrollment was not limited to an end-stage population.<sup>200</sup> Hospices vary in their expertise and practice caring for patients with HF.<sup>201</sup> Clinicians providing care to patients with HF should partner with local hospice agencies to create

a plan of care to meet patients' needs. For select patients, referral for hospice services may be an appropriate method of providing palliation when symptoms are refractory, quality of life is poor, and there is functional decline.<sup>202</sup> The Medicare hospice benefit was developed so that individuals could choose such supportive care and still receive Medicare funding.

To be eligible for the hospice benefit, the patient's physician and hospice medical director must certify that the patient has a likely life expectancy of 6 months or less, and the patient must consent to receive hospice in lieu of Medicare A-reimbursed care for his or her terminal illness. This agreement does not preclude other treatments for illnesses or injuries not related to HF, nor does it necessitate abandonment of appropriate HF medical therapy. Patients may withdraw from the hospice program and reenroll at a later date with no penalty. Hospice care is not limited to 6 months; however, the patient's prognosis must be identified as approximately 6 months at specified certification periods (the first two periods are 90 days, followed by an unlimited number of 60 day certifications).

The Medicare hospice benefit includes coverage for all medications and treatments associated with the hospice diagnosis, symptom management, homemaker and home health aide assistance, and chaplain and bereavement support for patients and families. Nursing care, medical supplies and appliances, therapy services and a wide variety of other professional support services necessary to improve quality of life are covered. Physician oversight of care may be provided by the hospice medical director or by a physician of the patient's choice.

There are four levels of hospice care. In the United States, 70% of hospice care is delivered in patients' homes or place of residence (including nursing homes).<sup>203</sup> Respite care up to 5 days per certification period is generally provided in nursing homes under contract. "General inpatient care" is provided to manage symptoms or provide services that cannot be provided in other settings—in either a hospital or nursing home. "Continuous care" provides 8–24 hours of licensed nursing care in the home for brief periods of time to manage complex problems or provide caregiver education. Hospice care is reimbursed by Medicare and most insurances at a specified daily rate, regardless of the medications, treatments or services provided.

**Advance Directives and Risk of Sudden Death.** SCD in a patient with compensated HF is a relatively common cause of death. Most SCDs occur outside the hospital, often at home or in the presence of a family member. Families commonly express the need to know how to respond in a cardiac emergency and report that this learning need is often unmet by health care professionals.<sup>204</sup> Patients report wanting their families to know what to do in an emergency.<sup>204,205</sup> A discussion with patients and families about the patient's wishes regarding resuscitation can include information about the effectiveness of resuscitation and its

sequelae.<sup>206</sup> Patients' wishes need to be clear to all health-care providers and family care givers, and they should be documented in a written advance directive when possible. Discussions regarding patient and family preferences should be undertaken before an acute crisis develops.

### Information on Cardiopulmonary Resuscitation.

When patients and families make the choice to attempt resuscitation, family members can be advised how to obtain CPR training. Many clinicians express concern over the ability of families of high-risk cardiac patients to learn CPR, and the potential guilt they might feel if resuscitation fails. In fact, the majority of family members of patients at risk for SCD can successfully learn CPR, are not burdened by responsibility or guilt, and use CPR appropriately when the occasion arises.<sup>207,208</sup>

**Choice to Allow Natural Death.** When patients and families decide against resuscitation attempts, they need to be told what to do when death occurs outside the hospital. Without prior information, most people call 911 or a similar emergency medical system number. In some states, this action may end in unwanted resuscitation and prolonged life support efforts. Many states have statutes directing emergency response personnel to comply with written physician orders for resuscitation (such as the Physician Order for Life Sustaining Treatment originally developed in Oregon).<sup>209</sup> A better option is to have a family member call a health care provider who knows the patient, has been informed of the patient's preference to not attempt resuscitation, and is willing to certify the cause of death.

As more patients with HF have ICDs implanted, it is important to plan what actions to take when patients are near the end of life. Defibrillation devices can be inactivated for those end-stage patients who do not desire resuscitation. A clear process for defibrillator deactivation should be identified to facilitate this step in advance of imminent death. A recent survey revealed that roughly 60% of cardiologists, 88% of geriatricians, and 95% of family physicians or internists had 2 or fewer conversations with patients and families about deactivation of implanted defibrillators.<sup>210</sup> Kelley et al reported the results of a similar survey designed to assess physician management practices regarding ICD use near the end of life.<sup>181</sup> Only 13% of the physician respondents accepted primary responsibility for discussions regarding device inactivation, 10% responded that another doctor should discuss, and 7% felt the patient or family should bring it up first.<sup>181</sup> These data suggest that communication among patients and physicians regarding ICD therapy at the end of life is needed.

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