

Palliative Care for Patients With Heart Failure

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The Patient's Story

Mr R is a 74-year-old married, retired professional who emigrated to the United States in the 1950s. He has New York Heart Association (NYHA) class II to III heart failure due to idiopathic cardiomyopathy and type 2 diabetes mellitus. In 1991, at age 62, Mr R complained to his primary care physician that he could no longer sleep horizontally. His physician referred Mr R to Dr J, a cardiologist who diagnosed him with a nonischemic dilated cardiomyopathy with an ejection fraction below 35%. Dr J initiated therapy with an angiotensin-converting enzyme inhibitor (ACE-I), a diuretic, and digoxin. Mr R's clinical symptoms improved. When Mr R returned to Dr J's care in 1999, digoxin was stopped and carvedilol added. One year later he returned for evaluation with more severe symptoms and had an ejection fraction of 19%. Mr R now had NYHA class III to IV symptoms, resting tachycardia, Cheyne-Stokes respirations, limited energy, weight loss, and poor glycemic control. Dr J increased Mr R's ACE-I dose and instituted a home monitoring system through which a nurse could adjust diuretics by telephone.

Dr J told Mr R that she was concerned that he was not doing all that he could to take care of himself. He responded that he was not sure he wanted to continue the intensive monitoring and medication regimen required for optimal management. Dr J then raised the option of hospice. Shortly after this discussion, Mr R came to a shared medical appointment with other heart failure patients and declared that he was not depressed, had accepted what could happen, and wanted to enroll in hospice. At that point, even minimal activity caused symptoms, despite treatment with benazepril, carvedilol, bumetanide, and digoxin. Mr R agreed to a do not attempt to resuscitate (DNR) order. In hospice, Mr R began adhering fully to his medication, diet, and self-monitoring regimens and his symptoms improved. After several months he was discharged from hospice. Mr R can now walk for 30 minutes on level ground. He has no pedal edema. He continues to take his medicines, has kept his DNR order, and follows up regularly with Dr J.

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Heart failure accounts for more hospitalizations among Medicare beneficiaries than any other condition. Its symptoms, including shortness of breath, fatigue, and edema, can be frightening and diminish quality of life. Although treatment advances have allowed patients to live longer with a better quality of life, heart failure remains a leading cause of death in the United States. Half of heart failure patients die within 5 years of diagnosis, and for many patients, death is sudden. Given the availability of effective treatments, the prevalence of distressing symptoms, and a persistent high risk of death that may occur suddenly, physicians must simultaneously treat the underlying condition while helping patients plan for future needs and complete advance directives. Using the case of Mr R, a 74-year-old man with heart failure, we illustrate ways that physicians can address these issues to improve the care of patients with heart failure, including symptom management and discussing advance directives, prognosis, and hospice care. By combining optimal medical management with palliative care, physicians can best care for heart failure patients and their families.

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Mr and Mrs R and Dr J were interviewed by a Perspectives editor in September 2002.

PERSPECTIVES

MR R: *I went to see Dr J because I had a cough . . . and had trouble recovering. So, my family doctor asked, "What happened?" I said, "I can't really sleep or lay horizontal."*

MRS R: *We were in denial. I told Dr J, "This is one of the diseases that I don't want to read about, I don't want to know."*

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DR J: In 1991, I thought that he would ultimately need a heart transplant and told him so pretty early on. Then he got so much better that that has completely gone by the wayside.

Palliative Care and Heart Failure

Heart failure accounts for more hospitalizations among Medicare beneficiaries than any other condition. Its prevalence is increasing, currently affecting 6% to 10% of the US population aged 65 years and older.¹ As Mr R's case demonstrates, heart failure can cause frightening symptoms that diminish quality of life, including shortness of breath, fatigue, and edema. Exacerbations and repeated hospitalizations are characteristic of heart failure. Although most patients survive these episodes and return to their baseline, each one can result in lower functioning. However, as Dr J observes, treatment advances have greatly improved both quality of life and survival. While Mr R initially presented with NYHA class II to III heart failure (TABLE 1), which had worsened, he stabilized at class I after adhering to his medical regimen. Nevertheless, any exacerbation may be fatal, and about 50% of heart failure patients die within 5 years of diagnosis.¹ In addition, up to half of deaths from heart failure are sudden.^{4,6,7} Given the availability of effective treatments, but distressing symptoms and persistent high risk of death that may occur suddenly, physicians must simultaneously treat the underlying condition while discussing and attending to palliative care issues. Recent guidelines for the management of patients with heart failure reflect this duality.^{8,9} Finally, although Dr J is a cardiologist, most patients are cared for by primary care physicians; thus, up-to-date information on palliative care for patients with heart failure is important to all physicians.¹⁰

Palliative care, including discussion of prognosis and advance directives, management of symptoms and comorbidities, and hospice, should be integrated with optimal medical management as described in guidelines such as the one developed by the American College of Cardiology/American Heart Association and other organizations.^{8,9,11} ACE-Is, β -blockers, spironolactone, diuretics, and digoxin as indicated and self-care education have the potential to alleviate patient's symptoms and improve quality of life; therefore, all are appropriate components of palliative care for patients with heart failure.

Prognosis

DR J: In 1991 . . . I was thinking months based on . . . [his] poor nutritional status and cardiac cachexia When we finally got around to talking about hospice . . . , I made note of the fact that I'd been wrong about him before and that I was saying that he probably had a very limited prognosis but that I certainly wasn't counting out that he might not improve substantially if he did all of the self-care things . . . [When he improved,] I was able to say, "Well, I was wrong again."

Addressing prognosis establishes a context for palliative care issues for patients with heart failure. However, physi-

Table 1. New York Heart Association Class and Prognosis*

Class	Definition	Prognosis†
I	No limitation of physical activity	20% Mortality at 5 years ²
II	Slight limitation of physical activity and symptoms with ordinary activity (eg, climbing stairs)‡	3% to 25% Mortality per year ³
III	Marked limitation of physical activity and symptoms with less than ordinary activity (eg, bathing, walking across room)‡	10% to 45% Mortality per year ³
IV	Inability to carry on any physical activity without discomfort and symptoms at rest‡	40% to 50% Mortality at 1 year ⁴

*Based on *Nomenclature and Criteria for Diagnosis of Diseases of the Heart and Great Vessels*.⁵

†For patients with heart failure who are receiving optimal medical management and are not experiencing an exacerbation.

‡Symptoms include fatigue, dyspnea, palpitations, or anginal chest pain.

Table 2. Discussing Challenging Topics With Patients With Heart Failure

Topic	What the Physician Could Say
Hope	"When you think of the future, what do you hope for?"
Prognosis	"Most people with heart failure ultimately will die from it. That can be gradual and anticipated, or sudden and unexpected." "We know that half of people with heart failure like yours will die in the next year. We will work together to try to help you become one of the people that lives longer than that." As prognosis becomes even more limited use estimates, eg, "weeks to months," "days to weeks," or "hours to days."
Advance directives	"If you were to get so sick that you could not talk to me directly, whom should I talk with to help me make decisions about your medical care?" "When you think about the future, what worries you the most?" "What is most important in your life right now?" "I would like to talk with you about the kind of care you would want if you became more ill. In particular, I wanted to talk with you about [hospitalization, intubation, CPR]"
Hospice	"It sounds like you think your spouse could use more help caring for you at home. Hospice is one way that we could get you more help at home. Have you heard of hospice?"

cians may dislike discussing prognosis with patients, believing that patients expect too much certainty^{12,13} and will become angry if the prognosis is incorrect. Yet, patients often think about their prognosis and many welcome opportunities to talk about it.¹⁴ Contrary to fears that discussions of prognosis will destroy patients' hope, such discussions can refocus hope more realistically and prevent false hope (TABLE 2).

A realistic understanding of prognosis allows patients to make informed decisions about their care^{15,16} and to attend to legal and financial matters, complete advance directives, designate a medical decision maker, emphasize participating in pleasurable activities, and focus on life closure and legacy issues.¹² If given only a year to live, many people would likely live that final year differently than they were planning otherwise.

When is it appropriate to raise the issue of prognosis or advance directives? Certainly, when the patient raises the issue,¹⁷ but during a hospital stay or at an outpatient appointment after a hospital stay are also appropriate times. One author¹⁸ suggests that physicians who would not be surprised if their patient died within the next year should initiate discussions about prognosis and advance directives. Because sudden death is common, physicians should address prognosis and initiate discussions of patient wishes and goals for treatment early in the course of illness.

Physicians can begin a discussion about prognosis by asking, "When you think about the future, what do you hope for?" If the patient has hopes that are unlikely to be realized, the physician should be supportive while encouraging the patient to consider alternatives. For example, attending a grandchild's graduation may be unrealistic, but the patient could write a letter to be read at graduation.

In heart failure, survival is best predicted by the severity of symptoms after treatment and not during an exacerbation.^{19,20} For patients receiving optimal therapy with NYHA class I symptoms, mortality is 5% to 10% per year and increases to 40% to 50% per year for those with NYHA class IV symptoms⁴ (Table 1). Another sign of poor prognosis is cardiac cachexia, defined as nonintentional, nonedema weight loss of 7.5% of previous normal weight over 6 months.²¹ Other predictors of poor prognosis include hypotension, renal insufficiency, anemia, depression, and older age.²²⁻²⁸

Prognosis is best presented as a range estimate, with caveats about the physician's ability to accurately predict what will happen to any single individual (Table 2). Such caveats are critical in heart failure because the course of the disease is inherently difficult to predict^{18,29} and prognosis can be greatly affected by response to therapy. Once Mr R began adhering to his medical regimen, he improved considerably, as did his prognosis. In such circumstances, physicians can simply admit that their prognosis was incorrect, as did Dr J.

Advance Directives

MR R: *Many times Dr J asked me how I felt and I said, "It's fine if I die. I have lived already more than 70 years."*

DR J: *I talked with him about his code status. He agreed that he did not want to have any further invasive procedures, any surgeries, and would not accept cardiopulmonary resuscitation. We talked about the role of a prehospital DNR order that he would sign and have at home.*

Advance directives can be oral or written and, beyond documenting the patient's preferences, may also name a surrogate to make medical decisions if required (Table 2). The identification of a surrogate also offers an opportunity for the physician to ask about what the patient has told, or would want to tell, the surrogate about his preferences.

Conversations about advance directives often include decisions about code status and the patient's desire for cardiopulmonary resuscitation. Explicit consideration of car-

diopulmonary resuscitation is appropriate for patients with heart failure because it may become relevant. However, discussions of advance directives should also include other issues, such as invasive procedures, surgery, and even hospitalizations. These discussions should focus on the patient's values and goals. Open-ended questions are an ideal way to begin to understand a patient's preference (Table 2).³⁰

Physicians periodically need to rediscuss advance directives because patients like Mr R may live for many years and experience many exacerbations and recoveries that influence their preferences, ideas, and goals.³¹ Physicians in the outpatient and inpatient settings must communicate to each other the outcomes of discussions they have about patient preferences.³² Finally, physicians should ensure that patients do not incorrectly view discussions of advance directives and prognosis as signs that the physician is "giving up." Saying "I will care for you whatever happens" and scheduling patients for return appointments with the physician can allay patients' fears of abandonment.³³ Physicians can further reassure patients and their families by providing their pager number or direct telephone line to patients who are imminently dying.

Palliation of Symptoms and Comorbidities

MR R: *I felt always weaker and I kept losing weight. I had shingles and that was really painful.*

Optimal medical management is the first step in ameliorating heart failure symptoms. However, as the disease progresses, medications directed at the underlying pathophysiology of heart failure may not completely relieve symptoms. Palliative treatments directed toward comfort are often needed alongside medical management. Their indication is the presence of symptoms, not a poor prognosis.

Dyspnea. Dyspnea is a greatly feared symptom and is commonly experienced during acute exacerbations. Of patients dying of advanced heart disease, 60% experience significant dyspnea.^{34,35} In addition to maximizing diuretic and vasodilator treatments, physicians can evaluate patients for other treatable causes of dyspnea, such as pleural effusions that can be relieved by thoracentesis. When dyspnea persists despite treatment, opioids may be used. In opioid-naïve patients, morphine sulfate in small doses, eg, 2 mg orally every 2 to 3 hours, can offer significant relief.^{36,37} The dose can be slowly titrated upward as needed. In addition, in our experience, oxygen, even for patients who are not hypoxemic, fans, and fresh air may provide relief.

Pain. Most physicians do not think of heart failure as a painful condition and Mr R did not experience pain. However, a study of patients dying of advanced heart disease found that pain was the most common distressing symptom, affecting 78% of patients.³⁵ Among seriously ill, hospitalized patients, 41% of patients with heart failure experienced moderate to severe pain in the last 3 days of life, a percentage comparable with those dying from lung or colon cancer.^{34,38} Although these studies do not describe the etiology

of the pain, cardiac causes including angina and edema, comorbidities such as osteoarthritis, diabetic neuropathy or shingles, or interventions such as chest tubes all can cause pain. Regardless of its cause, pain should be assessed and treated, with opioids if necessary. For patients who have never used opioids, the same doses recommended for relief of dyspnea can be effective. Physicians should avoid nonsteroidal anti-inflammatory drugs including cyclooxygenase 2 (COX-2) inhibitors because they directly antagonize the effects of ACE-Is and diuretics and can lead to exacerbations of heart failure by decreasing renal function and increasing fluid retention (TABLE 3).³⁹⁻⁴¹ If nonsteroidal anti-inflammatory drugs are necessary, patients must be alerted to the potential for fluid retention and instructed to call for advice or to increase their dose of diuretics if it occurs.

Depression. Although it is common and normal for patients to experience sadness and grief with the progression of heart failure, clinical depression is pathological and should be treated. Mr R said, "I never believed that I had any depression. Even so, Dr J gave me some pills for depression, but I didn't take any." Mrs R viewed it differently: "He had depression, and he didn't recognize it . . . he was depressed most of the time." Dr J diagnosed Mr R with depression based on his poor appetite, anhedonia, tearfulness, suicidal ideation, and hopelessness. Depression leads to diminished quality of life and may contribute to poorer outcomes,⁴⁹ perhaps through medical nonadherence. In seriously ill patients, the common vegetative symptoms of depression, such as poor sleep, decreased appetite, and anhedonia, may arise from underlying disease. For such patients, feelings of guilt, worthlessness, and hopelessness may be more specific for depression.^{50,51} Although Dr J prescribed a selective serotonin reuptake inhibitor, Mr R refused to take it. Treatment with selective serotonin reuptake inhibitors is preferred over tricyclic antidepressants in patients with heart failure due to the latter's potential to cause orthostatic hypotension and arrhythmias.

Fatigue. In many cases, weakness—which may be related to heart failure itself, heart failure-associated cachexia, depression or other causes—will respond to more intensive medical management and increased physical activity if the patient is capable of doing so. However, as heart failure progresses, patients may become weaker and lose weight. If the fatigue and weight loss are due to depression, it is important to treat it as described above.

Treating Comorbidities. Small studies have suggested that using erythropoietin and iron to treat the mild anemia common in severe heart failure may reduce symptoms, increase exercise capacity, and prevent hospitalizations.^{52,53} Larger studies are ongoing to define the safety and long-term effects of such treatment, but correction of anemia may be an option for symptom relief in selected patients. Similarly, sleep apnea is common in heart failure. Small trials have shown that continuous positive airway pressure improves cardiac function.⁵⁴ Again, larger trials are ongoing to assess the long-

Table 3. Some Medications to Avoid in Patients With Heart Failure

Medication	Deleterious Effect
Nonsteroidal anti-inflammatory drugs, including cyclooxygenase 2 selective inhibitors ^{40,41}	Increased edema can precipitate heart failure exacerbations
Calcium channel blockers ^{42,43}	Can worsen symptoms of heart failure, principally in patients with systolic heart failure (amlodipine, felodipine acceptable)
Metformin ⁴⁴	Risk of lactic acidosis in renal insufficiency
Thiazolidinediones ⁴⁴	Increased edema
Antiarrhythmics ⁴⁵⁻⁴⁸	Increased sudden death (amlodarone, dofetilide acceptable if indicated)

term effects on symptoms and outcomes, but treating sleep-disordered breathing may relieve symptoms for some patients.

Intravenous Therapy for Refractory Symptoms. Although Mr R's symptoms improved while taking an oral medication regimen, many patients with heart failure continue to be symptomatic despite maximal medical therapy. For some patients hospitalized with heart failure and low cardiac output, intravenous inotrope infusions with dobutamine or milrinone may provide symptomatic relief. If patients cannot be weaned off these medications, home intravenous inotrope therapy becomes an option. Patients must be involved in the decision because the benefits are uncertain and carry risks, including increased risk of sudden death.^{55,56} Some hospices can provide home intravenous inotrope therapy.⁵⁷ In patients hospitalized for heart failure without severe hypotension, the intravenous vasodilator nesiritide has been shown to relieve symptoms,⁵⁸ but its role in outpatients has not been determined.

OTHER MANAGEMENT STRATEGIES

Self-care Education

MR R: [My health declined] only after I started this medication...these pills caused me completely to lose my appetite. . . .

MRS R: The medication was beginning to wear him down.

DR J: It was pretty clear that he wasn't doing all he could to take care of himself including a low-salt diet, paying attention to his blood glucose, making sure that he did some activity every day, taking his medications as scheduled.

Although Mr and Mrs R attributed many of his symptoms to adverse effects from his medication, they were most likely due to his decompensated heart failure. This misconception may explain why, as Dr J observed, Mr R did not adhere to his medication and self-care regimen.

Patients often end up on bewilderingly complex medical regimens for both heart failure and comorbid conditions, are burdened by lifestyle restrictions and multiple pills, and are concerned about adverse effects. The perceptions of Mr R and his wife are not uncommon. Comprehensive patient education is essential, including alerting patients and caregivers to the symptoms of heart failure, early signs of deterioration,

Box. National Hospice and Palliative Care Organization General Medical Guidelines for Determining Prognosis in Selected Noncancer Diseases*

The Patient Should Meet All of the Following Criteria

- I. The patient's condition is life limiting, and the patient and/or family knows this.
- II. The patient and/or family have elected treatment goals directed toward relief of symptoms rather than the underlying disease.
- III. The patient has either of the following:
 - A. Documented clinical progression of the disease, which may include
 1. Progression of the primary disease process as listed in the disease-specific criteria, as documented by serial physician assessment and laboratory, radiologic, or other studies.
 2. Multiple emergency department visits or inpatient hospitalizations over the prior 6 months.
 3. For homebound patients receiving home health services, nursing assessment may be documented.
 4. For patients who do not qualify under 1, 2, or 3, a recent decline in functional status should be documented. Clinical judgment is required.
 - B. Documented recent impaired nutritional status related to the terminal process:
 1. Unintentional, progressive weight loss of more than 10% over the prior 6 months.
 2. Serum albumin <2.5 g/dL may be a helpful prognostic indicator but should not be used in isolation from other factors above.

Patients With Heart Disease Should Also Meet the Following Criteria

- I. Intractable or frequently recurrent symptomatic heart failure or intractable angina pectoris with heart failure.
- II. Patients should already be optimally treated with diuretics, vasodilators, β -blockers, and spironolactone as indicated and tolerated.[†]
- III. Other factors contributing to a poor prognosis: symptomatic arrhythmias, history of cardiac arrest and resuscitation or syncope, cardiogenic brain embolism, or concomitant HIV disease.

*Adapted with permission from National Hospice Organization.⁶⁰

[†]This criterion is modified from the published guideline to reflect current, optimal medical management of heart failure.

and knowing when to call for help; the potential benefits, actions, and adverse effects of medications; and the importance of lifestyle modifications including medication adherence, daily activity, maintaining a low-salt diet, and monitoring for fluid retention with daily weights. Although many patients think they should conserve energy, exercise can be beneficial for patients with heart failure and can increase exer-

cise tolerance and decrease mortality.⁵⁹⁻⁶² Education about these topics, independent of any changes in medications, has been shown to reduce hospitalizations for exacerbations of heart failure by 39%⁶³ and gives patients a sense of control over their health. Education should be a routine part of care for patients with heart failure at any stage. A home health aide or visiting nurse can assist in patient education, monitor adherence to medications and lifestyle changes, and help patients and their families manage complex medication regimens. For Mr R, the help hospice provided, as well as the apparently empowering decision to enter hospice, increased his adherence to his treatment and improved his overall health and functioning.

Shared Appointments

DR J: *A shared medical appointment is a group meeting of 5 to 10 of my own patients. The questions that one patient asks may answer another patient's questions. Things may come up that patients are reluctant to ask about themselves, but are very interested to hear.*

MR R: *This is a very interesting program . . . to listen to some other patients that have, not the same thing, but similar things, how they cope with it.*

MRS R: *The shared medical appointment is the best thing.*

When asked to make recommendations to other physicians caring for patients with heart failure, Mr and Mrs R both cited Dr J's innovative group visits. Studies suggest that such visits offer benefits to patients.⁶⁴ Group visits may be an effective forum for raising palliative care issues in a more general and less threatening way. The physician might say, "Others of my patients have wondered what happens in the future and what they can expect. I am wondering if anybody here today has questions about this?" Of course, individual visits remain essential for ongoing treatment and patient confidentiality.

Nonpharmacologic Therapy

Although Mr R has told Dr J that he does not want any more invasive interventions, there are patients for whom such interventions are appropriate. A detailed discussion of these interventions is beyond the scope of this article, but they include cardiac resynchronization therapy with biventricular pacemakers, implantation of an internal cardioverter defibrillator or ventricular assist device, and a variety of emerging surgical procedures. Indications for these therapies are evolving rapidly, and referral to a cardiologist is appropriate. The choice of whether to use these interventions must be made in the context of the patient's overall goals. For example, internal cardioverter defibrillators have been shown to reduce mortality in patients with heart failure who are at risk of sudden death⁶⁵ and are very appropriate for many such patients. But for patients with poor quality of life, severe comorbidities, or limited life expectancy, avoiding sudden death may not be a goal of therapy. Patients who choose these treatments should also realize that they could be turned off at any time. If and when they should be turned off should be ad-

dressed as part of advance directives. Finally, heart transplantation may be appropriate for younger patients without major comorbidities. Because the need for cardiac transplantation vastly exceeds the supply of donor hearts, patients who are accepted to a transplant waiting list should receive palliative care in addition to optimal medical management.

Hospice and Concurrent Care Programs

MRS R: *Dr J was giving him 6 more months. What was he going to choose? Would we go to extremes to keep him alive? He decided not to . . . And that's what hospice is about.*

DR J: *He said that he knew how sick he was, but that he really wasn't sure that he wanted to do all of what it would entail to stay stable. So, at that point I said, "Well, we can go in the other direction." . . . I then talked with him about hospice.*

MR R: *She said why don't you make a choice. So we tried this hospice that is paid for by Medicare.*

Through Dr J's guidance, Mr R is the unusual heart failure patient who enrolled in hospice. In 2001, only 10% of patients enrolled in hospice nationally were admitted with a diagnosis of heart failure.⁶⁶ In the United States, hospice is most commonly provided as an at-home service for people with life-threatening illness. Hospice care addresses physical, emotional, psychological, spiritual, and existential suffering for the patient and family. To enroll in hospice, a patient must have a physician who will direct his or her care and be expected to survive 6 months or less, though due to late referrals, the average length of stay in hospice is much shorter.⁶⁷ The BOX presents the National Hospice and Palliative Care Organization guidelines for enrollment, modified to reflect current optimal management of heart failure.⁶⁶

Many heart failure patients who would benefit from hospice may survive longer than 6 months and may even improve under hospice care, as did Mr R.⁶⁸ His experience corrects 2 common misconceptions. First, many people falsely believe that hospice connotes forgoing all treatments.¹⁸ Mr R not only continued taking his medications, he became more adherent. Many patients with heart failure would be expected to continue taking their medications until the day of death because medication helps manage symptoms such as dyspnea and edema. Second, although most people who enroll in hospice die, a significant number improve under the comprehensive care provided by hospice and, like Mr R, graduate. Patients who subsequently need to reenroll are eligible to do so if they meet hospice criteria. Because some patients who might benefit from hospice may be reluctant to enroll or do not meet hospice criteria, some health care systems have established specialized home care or concurrent care programs for patients with heart failure to provide them with similar services.¹⁸

Importantly, hospice also provides caregiver support.⁶⁹ When asked for suggestions about how physicians can better care for people with heart failure, Mrs R replied, "My suggestion would be to have a support system for the care-

givers." The availability of respite care and caregiver support is an appealing and important benefit to appeal to patients and families.

CONCLUSION

As with Mr R and Dr J, physicians can offer patients with heart failure a great deal to help them live longer with a better quality of life. Nevertheless, the reality is that heart failure exacts a significant toll on patients and their families and is a leading cause of death. Remembering that half of patients diagnosed with heart failure die within 5 years of diagnosis and that half of all deaths from heart failure are sudden should encourage physicians to address personal treatment goals and advance directives and pursue palliative care alongside optimal medical therapy. As Dr J found, honest and compassionate discussions, focused on optimizing treatment while preparing for an uncertain future, can reap rewards for the patient and physician. As physicians, we gain satisfaction from knowing that we have provided the best possible care to our patients, and by helping our patients make the most of each day, we may learn to do the same for ourselves.

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Other Sources: For a list of relevant Web sites, see the article on the JAMA Web site at <http://www.jama.com>.

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REFERENCES

1. *Heart Disease and Stroke Statistics—2004 Update*. Dallas, Texas: American Heart Association; 2000. Available at: <http://www.americanheart.org/downloadable/heart/1079736729696HDSStats2004UpdateREV3-19-04.pdf>.
2. McAlister FA, Teo KK, Taher M, et al. Insights into the contemporary epidemiology and outpatient management of congestive heart failure. *Am Heart J*. 1999; 138(1 pt 1):87-94.
3. Costanzo MR, Augustine S, Bourge R, et al. Selection and treatment of candidates for heart transplantation. *Circulation*. 1995;92:3593-3612.
4. Stevenson WG, Stevenson LW. Prevention of sudden death in heart failure. *J Cardiovasc Electrophysiol*. 2001;12:112-114.
5. *Nomenclature and Criteria for Diagnosis of Diseases of the Heart and Great Vessels*. 9th ed. Boston, Mass: Little Brown Medical Division; 1994.
6. Berger R, Huelsman M, Strecker K, et al. B-type natriuretic peptide predicts sudden death in patients with chronic heart failure. *Circulation*. 2002;105:2392-2397.
7. La Rovere MT, Pinna GD, Maestri R, et al. Short-term heart rate variability strongly predicts sudden cardiac death in chronic heart failure patients. *Circulation*. 2003; 107:565-570.
8. Hunt SA, Baker DW, Chin MH, et al. ACC/AHA guidelines for the evaluation and management of chronic heart failure in the adult: executive summary. *J Heart Lung Transplant*. 2002;21:189-203.
9. *Summary of the Evidence-Based Guidelines for the Management of Heart Failure*. Oakland, Calif: Care Management Institute Kaiser Permanente; 2002.
10. Philbin EF, Jenkins PL. Differences between patients with heart failure treated by cardiologists, internists, family physicians, and other physicians: analysis of a large, statewide database. *Am Heart J*. 2000;139:491-496.
11. Liu P, Arnold JM, Belenkie I, et al. The 2002/3 Canadian Cardiovascular Society consensus guideline update for the diagnosis and management of heart failure. *Can J Cardiol*. 2003;19:347-356.
12. Lamont EB, Christakis NA. Complexities in prognostication in advanced cancer. *JAMA*. 2003;290:98-104.
13. Christakis NA, Iwashyna TJ. Attitude and self-reported practice regarding prognostication in a national sample of internists. *Arch Intern Med*. 1998;158:2389-2395.
14. McCormick TR, Conley BJ. Patients' perspectives on dying and on the care of dying patients. *West J Med*. 1995;163:236-243.

15. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA*. 1998;279:1709-1714.
16. Murphy DJ, Burrows D, Santilli S, et al. The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. *N Engl J Med*. 1994;330:545-549.
17. Quill TE. Initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room." *JAMA*. 2000;284:2502-2507.
18. Lynn J. Serving patients who may die soon and their families: the role of hospice and other services. *JAMA*. 2001;285:925-932.
19. Effect of metoprolol CR/XL in chronic heart failure. *Lancet*. 1999;353:2001-2007.
20. The SOLVD Investigators. Effect of enalapril on survival in patients with reduced left ventricular ejection fractions and congestive heart failure. *N Engl J Med*. 1991;325:293-302.
21. Anker SD, Chua TP, Ponikowski P, et al. Hormonal changes and catabolic/anabolic imbalance in chronic heart failure and their importance for cardiac cachexia. *Circulation*. 1997;96:526-534.
22. Murberg TA, Bru E, Svebak S, Tveteter R, Aarsland T. Depressed mood and subjective health symptoms as predictors of mortality in patients with congestive heart failure. *Int J Psychiatry Med*. 1999;29:311-326.
23. Ho KK, Anderson KM, Kannel WB, Grossman W, Levy D. Survival after the onset of congestive heart failure in Framingham Heart Study subjects. *Circulation*. 1993;88:107-115.
24. Felker GM, Adams KF, Jr, Konstam MA, O'Connor CM, Gheorghide M. The problem of decompensated heart failure: nomenclature, classification, and risk stratification. *Am Heart J*. 2003;145(suppl 2):S18-S25.
25. Dries DL, Exner DV, Domanski MJ, Greenberg B, Stevenson LW. The prognostic implications of renal insufficiency in asymptomatic and symptomatic patients with left ventricular systolic dysfunction. *J Am Coll Cardiol*. 2000;35:681-689.
26. Mitka M. Researchers probe anemia-heart failure link. *JAMA*. 2003;290:1835-1838.
27. Szachniewicz J, Petruk-Kowalczyk J, Majda J, et al. Anaemia is an independent predictor of poor outcome in patients with chronic heart failure. *Int J Cardiol*. 2003;90(2-3):303-308.
28. Felker GM, Gattis WA, Leimberger JD, et al. Usefulness of anemia as a predictor of death and rehospitalization in patients with decompensated heart failure. *Am J Cardiol*. 2003;92:625-628.
29. Field MJ, Cassell CK, eds. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press; 1997.
30. Pantilat SZ. Care of dying patients. *West J Med*. 1999;171:253-256.
31. Krumholz HM, Phillips RS, Hamel MB, et al. Resuscitation preferences among patients with severe congestive heart failure. *Circulation*. 1998;98:648-655.
32. Pantilat SZ, Alpers A, Wachtler RM. A new doctor in the house: ethical issues in hospitalist systems. *JAMA*. 1999;282:171-174.
33. Quill TE, Cassel CK. Nonabandonment: a central obligation for physicians. *Ann Intern Med*. 1995;122:368-374.
34. 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(suppl 5):S101-S109.
35. McCarthy M, Lay M, Addington-Hall J. Dying from heart disease. *J R Coll Physicians Lond*. 1996;30:325-328.
36. Williams SG, Wright DJ, Marshall P, et al. Safety and potential benefits of low dose diamorphine during exercise in patients with chronic heart failure. *Heart*. 2003;89:1085-1086.
37. Johnson MJ, McDonagh TA, Harkness A, McKay SE, Dargie HJ. Morphine for the relief of breathlessness in patients with chronic heart failure—a pilot study. *Eur J Heart Fail*. 2002;4:753-756.
38. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA*. 1995;274:1591-1598.
39. Bleumink GS, Feenstra J, Sturkenboom MC, Stricker BH. Nonsteroidal anti-inflammatory drugs and heart failure. *Drugs*. 2003;63:525-534.
40. Heerdink ER, Leufkens HG, Herings RM, Ottervanger JP, Stricker BH, Bakker A. NSAIDs associated with increased risk of congestive heart failure in elderly patients taking diuretics. *Arch Intern Med*. 1998;158:1108-1112.
41. Page J, Henry D. Consumption of NSAIDs and the development of congestive heart failure in elderly patients. *Arch Intern Med*. 2000;160:777-784.
42. Kizer JR, Kimmel SE. Epidemiologic review of the calcium channel blocker drugs. *Arch Intern Med*. 2001;161:1145-1158.
43. Elkayam U, Amin J, Mehra A, Vasquez J, Weber L, Rahimtoola SH. A prospective, randomized, double-blind, crossover study to compare the efficacy and safety of chronic nifedipine therapy with that of isosorbide dinitrate and their combination in the treatment of chronic congestive heart failure. *Circulation*. 1990;82:1954-1961.
44. Masoudi FA, Wang Y, Inzucchi SE, et al. Metformin and thiazolidinedione use in Medicare patients with heart failure. *JAMA*. 2003;290:81-85.
45. Waldo AL, Camm AJ, deRuyter H, et al. Effect of d-sotalol on mortality in patients with left ventricular dysfunction after recent and remote myocardial infarction. *Lancet*. 1996;348:7-12.
46. Heidenreich PA, Keefe B, McDonald KM, Hlatky MA. Overview of randomized trials of antiarrhythmic drugs and devices for the prevention of sudden cardiac death. *Am Heart J*. 2002;144:422-430.
47. Sim I, McDonald KM, Lavori PW, Norbutas CM, Hlatky MA. Quantitative overview of randomized trials of amiodarone to prevent sudden cardiac death. *Circulation*. 1997;96:2823-2829.
48. Torp-Pedersen C, Møller M, Bloch-Thomsen PE, et al. Dofetilide in patients with congestive heart failure and left ventricular dysfunction. *N Engl J Med*. 1999;341:857-865.
49. Jiang W, Alexander J, Christopher E, et al. Relationship of depression to increased risk of mortality and rehospitalization in patients with congestive heart failure. *Arch Intern Med*. 2001;161:1849-1856.
50. Block SD. Assessing and managing depression in the terminally ill patient. *Ann Intern Med*. 2000;132:209-218.
51. Block SD. Psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA*. 2001;285:2898-2905.
52. Mancini DM, Katz SD, Lang CC, LaManca J, Hudaihed A, Androne AS. Effect of erythropoietin on exercise capacity in patients with moderate to severe chronic heart failure. *Circulation*. 2003;107:294-299.
53. Silverberg DS, Wexler D, Sheps D, et al. The effect of correction of mild anemia in severe, resistant congestive heart failure using subcutaneous erythropoietin and intravenous iron. *J Am Coll Cardiol*. 2001;37:1775-1780.
54. Kaneko Y, Floras JS, Usui K, et al. Cardiovascular effects of continuous positive airway pressure in patients with heart failure and obstructive sleep apnea. *N Engl J Med*. 2003;348:1233-1241.
55. Stevenson LW. Clinical use of inotropic therapy for heart failure: looking backward or forward, II: chronic inotropic therapy. *Circulation*. 2003;108:492-497.
56. Oliva F, Latini R, Politi A, et al. Intermittent 6-month low-dose dobutamine infusion in severe heart failure. *Am Heart J*. 1999;138(2 pt 1):247-253.
57. Cross KL. The use of dobutamine in hospice patients. *AAHPM Bulletin*. 2000;1:6-7. Available at: <http://www.nah.org/physicians/dobutamine.html>.
58. Publication Committee for the VMAI Investigators (Vasodilatation in the Management of Acute CHF). Intravenous nesiritide vs nitroglycerin for treatment of decompensated congestive heart failure. *JAMA*. 2002;287:1531-1540.
59. Corvera-Tindel T, Doering LV, Woo MA, Khan S, Dracup K. Effects of a home walking exercise program on functional status and symptoms in heart failure. *Am Heart J*. 2004;147:339-346.
60. Pina IL, Apstein CS, Balady GJ, et al. Exercise and heart failure. *Circulation*. 2003;107:1210-1225.
61. Pozehl B, Duncan K, Krueger S, VerMaas P. Adjunctive effects of exercise training in heart failure patients receiving maximum pharmacologic therapy. *Prog Cardiovasc Nurs*. 2003;18:177-183.
62. Piepoli MF, Davos C, Francis DP, Coats AJ. Exercise training meta-analysis of trials in patients with chronic heart failure (ExTraMATCH). *BMJ*. 2004;328:189.
63. Krumholz HM, Amatruda J, Smith GL, et al. Randomized trial of an education and support intervention to prevent readmission of patients with heart failure. *J Am Coll Cardiol*. 2002;39:83-89.
64. Beck A, Scott J, Williams P, et al. A randomized trial of group outpatient visits for chronically ill older HMO members. *J Am Geriatr Soc*. 1997;45:543-549.
65. Ezekowitz JA, Armstrong PW, McAlister FA. Implantable cardioverter defibrillators in primary and secondary prevention. *Ann Intern Med*. 2003;138:445-452.
66. *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diagnoses*. Arlington, Va: National Hospice and Palliative Care Organization; 1996.
67. Christakis NA, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. *N Engl J Med*. 1996;335:172-178.
68. Fox E, Landrum-McNiff K, Zhong Z, Dawson NV, Wu AW, Lynn J. Evaluation of prognostic criteria for determining hospice eligibility in patients with advanced lung, heart, or liver disease. *JAMA*. 1999;282:1638-1645.
69. Rabow MW, Hauser JM, Adams J. Supporting family caregivers at the end of life: "They don't know what they don't know." *JAMA*. 2004;291:483-491.

Other Online Resources

ACC/AHA Guidelines for the Evaluation and Management of Chronic Heart Failure in the Adult

<http://www.americanheart.org/presenter.jhtml?identifier=3000656>

Detailed, evidence-based guidelines for management of heart failure with graded evidence.

Evidence-Based Guidelines for the Management of Heart Failure: Care Management Institute, Kaiser Permanente

http://members.kaiserpermanente.org/kpweb/pdf/feature/247clinicalpracguide/CMI_HeartFailureGuideline_public_web_061003.pdf

Detailed, evidence-based guidelines for management of heart failure with graded evidence and many tables and charts.

The 2002/2003 Canadian Cardiovascular Society Consensus Guideline Update for the Diagnosis and Management of Heart Failure

<http://www.ccs.ca>

Detailed, evidence-based guidelines for management of heart failure with graded evidence.

Use of Dobutamine in Hospice Patients at Home and Protocol; Nathan Adelson Hospice

<http://www.nah.org/physicians/dobutamine.html>

Provides a sample order set for home infusion of dobutamine used by a hospice agency.

Heart Failure Online

<http://www.heartfailure.org/index.htm>

An online resource directed at patients that explains heart function, defines heart failure, and explains treatments and prevention of heart failure as well as answers common questions.

End of Life/Palliative Resource Education Center

<http://www.eperc.mcw.edu>

An online repository of educational materials for clinicians and teachers about a wide variety of topics in end-of-life care.