Palliative Care in Heart Failure
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ABSTRACT
Heart failure is the most common reason for hospital admission among older persons. The incidence and prevalence of heart failure are increasing as the population ages and becomes more obese. Patients who suffer from heart failure have a high mortality rate, even with modern treatment. The course of disease near the end of life is often marked by weight loss, breathlessness, anxiety, and pain. Although current evidence-based treatment allows patients to live longer after the onset of heart failure, the number of patients requiring end-of-life care for heart failure will continue to increase.

Patients with heart failure, who are in the terminal or advanced stages of their illness, require an approach to medical care that includes relief of pain in the broadest physical, emotional, and spiritual sense.

This approach to the treatment of the terminally ill patient, palliative care, differs from curative care by focusing primarily on symptom relief and patient preferences. Palliative care may be of great benefit to the patient when it is used to gradually supplant curative treatment as the patient's heart failure advances.

Successful palliative care for patients with end-stage heart failure is best provided by a multidisciplinary team led by the patient's primary care physician, who is often the first to see the patient who has symptoms of heart failure. The primary care physician frequently continues to coordinate the patient's healthcare team as heart failure becomes progressively severe or terminal. Palliative care for patients with advanced heart failure is good medical care.

HEART FAILURE

Victoria Hospital was organized to help reduce, or palliate, suffering in patients with terminal illness by honoring the patient’s preference to alleviate symptoms rather than attempt to cure the disease.4

DEFINING PALLIATIVE CARE

Palliative care is a therapeutic model that focuses on the relief of pain and suffering in patients with advanced, chronic, end-stage, or terminal illness—patients whose disease is not expected to respond to curative treatment.3 The palliative care model emphasizes a biopsychosocial approach to medical care that includes relief of pain in the broadest physical, mental, and spiritual sense, providing care appropriate for the patient who suffers from pain, and using narrative stories to help understand and better care for the patient.5 It may be defined as the subset of good medical care that is provided to patients who are dying. The main distinction between palliative and curative care is that in palliative care, death is accepted as a normal outcome of treatment.

The treatment of heart disease includes both curative and palliative interventions9 For example, aortic valve replacement in a patient with cardiac symptoms due to aortic valve stenosis is a curative intervention. This procedure confers an immediate mortality risk of approximately 1% to 2%. The postprocedural mortality rate corresponds with that of the age cohort, because the underlying problem, valvular aortic stenosis, has been cured. Coronary artery bypass surgery, by contrast, is a palliative intervention. It too has a 1% to 2% immediate surgical mortality rate, but postprocedural mortality is higher than that of the age cohort. With coronary artery bypass surgery, the underlying problem, coronary atherosclerosis, has not been cured but only palliated, and the clinical outcome depends on the patient’s ability to control the underlying risk factors for coronary heart disease (CHD), such as high blood pressure, dyslipidemia, smoking, and diabetes.

PALLIATIVE CARE AS “GOOD MEDICAL CARE”

Good medical care was defined in 1933 as “the kind of medicine practiced and taught by the recognized leaders of the medical profession at a given time or period of social, cultural, and professional development in a community or population group.”10 The operational definition of good medical care was based on specific “articles of faith.”10-12 According to this definition, good medical care should (1) be rational, based on medical science, and prevention oriented; (2) require the cooperation of the lay public and medical practitioners; (3) treat the individual as a whole; and (4) include developing a close and continuing personal relationship with the patient, coordinating social welfare and other support services, and providing all necessary services.

These articles of faith correspond almost point by point with the basics of palliative care as outlined by Kuebler et al.13 Palliative care is based on the social sciences (eg, sociology, psychology); is individualized, humanistic, and interpersonal; is interdisciplinary; focuses on the patient’s comfort by relieving symptoms; views the patient as a whole; and accepts death as a normal outcome.12

Although palliative care differs from curative care by focusing primarily on symptom relief and patient preferences rather than on curing the underlying disease, palliative care shares many features with the traditional concept of good medical care.

PALLIATIVE CARE IN HEART FAILURE

HEART FAILURE: DEFINITION AND EPIDEMIOLOGY

Heart failure is a pathophysiological syndrome in which the heart’s ability to eject or to fill with blood is impaired and cardiac tissue is remodeled; variable degrees of chamber thickening and dilatation may be present.14,15 Chronic heart failure (CHF) is also recognized as a systemic chronic inflammatory disease. Chronic inflammation is associated with production of cytokines, which are thought to mediate cardiac cachexia, with associated muscle wasting, weight loss, and altered ventilatory control.15 A hallmark of heart failure is that it is a progressive disorder in both its cardiac and systemic manifestations.16-17 According to American Heart Association (AHA) estimates, the prevalence of heart failure in adults older than age 45 is 2.3%. Prevalence increases to 10% in persons older than age 75.18 The prevalence of heart failure is expected to increase further as more people survive coronary events, and as the population ages and becomes more obese.19,20

Improvements in the diagnosis and treatment of heart failure have been associated with an improvement in case fatality rates (CFRs).20,21 A study of CFRs in the general population of Scotland between 1986 and 1995 showed the effect of angiotensin-converting enzyme (ACE) inhibitors on survival.21 ACE inhibitors were introduced into routine clinical practice in Scotland in 1986; by 1995, the 30-day CFRs for patients with heart failure decreased by 26% for men and 17% for women. Longer-term CFRs decreased by 18% for men and 15% for women. These results are even more significant in light of recently published data from the Framingham Heart Study. The results showed that the incidence of heart failure has decreased in women but not in men.20
However, both men and women now survive longer after the onset of heart failure.20

**Clinical Course of Heart Failure**

Although only about 5% of patients die during an index hospital admission for heart failure, the mortality rate after hospital discharge is high. Philbin et al found that the 6-month mortality rate following discharge was 23%; more than one half (55%) of patients died or were readmitted to the hospital within 6 months.21 Most deaths were due to pump failure. Other studies have shown that during a 2-year follow-up, about one third of deaths from heart failure were sudden and occurred earlier than deaths from pump failure.22

Patients with heart failure experience a slow decline in functional level. The course of disease is punctuated by frequent hospital admissions for decompensated heart failure.24 Uncertainty regarding time and mode of death is an important feature of heart failure. Levenson et al found that when physicians were asked to estimate how long their patients who suffered from heart failure would live, the median estimate given for 6-month survival was 54%, even when the patient was within 3 days of death.25

Left ventricular stiffness is especially marked in the hearts of elderly patients who have a history of hypertension, CHD, and diabetes. As a result, patients with these commonly comorbid conditions often present to the emergency department acutely ill with decompensated heart failure. They typically respond rapidly to treatment and, after 3 to 5 days of hospitalization, return to their previous lifestyle and level of functioning. As symptoms return—often because of volume expansion caused by nonadherence to dietary restrictions or medications—patients may schedule an appointment with their primary care physician or cardiologist. The timing of the appointment is often based on the patient’s estimate of a linear rate of decompensation. However, heart failure symptoms typically develop in a nonlinear fashion, and the patient’s level of distress can change dramatically over a short period of time. The reason this occurs is that as the left ventricular end-diastolic pressure in the heart increases, the pulmonary venous pressure increases, causing the lungs to become stiffer and the respiratory rate to increase, thereby increasing the work of respiration.26

M odels of palliative care (Figure 1) compare end-of-life care in patients with cancer with the different time course of end-of-life care in patients with heart failure.27 The patient with heart failure often moves up and down the “continuum of care,” whereas the patient with cancer usually has a unidirectional and more predictable progression toward death. In patients with cancer, active care can be administered until a short time before death, when palliative care is administered as terminal care (Section A). This is the traditional model of palliative care. In the alternative model, palliative care is part of active care from the onset and, as disease progresses, plays an increasingly larger role until it preempts all other medical care at the time of death (Section B).

Section C shows that management of heart failure has aspects of both active and palliative care. In a typical scenario, the patient with heart failure presents to the emergency department acutely ill with decompensated heart failure. They typically respond rapidly to treatment and, after 3 to 5 days of hospitalization, return to their previous lifestyle and level of functioning. As symptoms return—often because of volume expansion caused by nonadherence to dietary restrictions or medications—patients may schedule an appointment with their primary care physician or cardiologist. The timing of the appointment is often based on the patient’s estimate of a linear rate of decompensation. However, heart failure symptoms typically develop in a nonlinear fashion, and the patient’s level of distress can change dramatically over a short period of time. The reason this occurs is that as the left ventricular end-diastolic pressure in the heart increases, the pulmonary venous pressure increases, causing the lungs to become stiffer and the respiratory rate to increase, thereby increasing the work of respiration.26

_**Diagnosis**_ | _**Death**_
---|---
**A: Cancer-Traditional Model** | **Palliative care**
Active care |  
**B: Cancer-Alternative Model** | **Palliative care**
Active care |  
**C: Heart Failure Model** | **Palliative care**
Active care |  

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**Figure 1. Models of End-of-Life Care for Patients With Cancer or Heart Failure**

Management of patients with heart failure is tailored to reflect prognosis at every stage of illness. This is especially true as patients enter the refractory stage, when emphasis shifts from cura-
tive to palliative care. For heart failure, prognostic indicators of mortality include: age older than 70 years, the presence of comorbidities, an advancing need for care, the underlying precipitants of heart failure, nonadherence to medication regimens, environmental extremes, treatment options such as heart transplantation, and the patient's preferences regarding intensity of care.34,36,37

Much is known about how to administer palliative care to patients with cancer; the types of medical specialists who will be involved and the medical and insurance infrastructure to support palliative care in these patients is well defined. This is not the case with respect to providing palliative care for patients with heart failure. For example, whether patients with advanced heart failure are cared for by a cardiologist or general internist may be linked to the perceived severity of illness or to social and demographic factors.12

However, the situation improved in 1996, when the US government assigned a code to each diagnosis and type of service.38 (For example, the International Classification of Diseases code for palliative care is V66.7, which is described as follows: “Encounter for palliative care—end of life, hospice care, terminal care.”) This code must be used in conjunction with the code for the underlying diagnosis, in this instance, heart failure.) Before then, few, if any, articles in US medical journals discussed palliative care for heart failure.

Recently, focus groups of British physicians from various specialties (eg, primary care, cardiology, geriatrics, general medicine, and palliative care medicine) have provided insights into the way palliative care in patients with heart failure is viewed and addressed in the United Kingdom.39 The groups noted that aspects of palliative care that have been developed for patients with cancer are often not available for patients with heart failure, either because patients and physicians are not aware or do not remember that these patients qualify for palliative care (Table 1).39

As noted above, the difficulty of predicting the clinical course of heart failure is a major reason why planning for end-stage care in patients with heart failure is overlooked. Patients oscillate between poor health status (often near death) and a reasonable or good functional status and quality of life. Continuously moving between 2 extreme clinical states can be demoralizing for the patient, family, and their care providers, and is associated with frequent and expensive hospital admissions. Although approximately 25% of patients hospitalized with severe heart failure had previously stated their preference not to be resuscitated, it is not surprising that 40% of these patients changed their minds within 2 months of discharge because of the uncertainty about short-term outcomes.36

Planning for end-of-life care in patients with heart failure may be improved because of recently developed diagnostic tests that quantify the degree of heart failure decompensation. Brain natriuretic peptide (BNP) is produced in the myocardium in response to volume stretch. Recent studies have shown that the presence of BNP in patients with heart failure predicts poor outcome with high sensitivity and specificity.37,42 BNP levels fall to near normal after patients with decompensated heart failure are given diuretics. A rising BNP level despite evidence-based treatment of heart failure is an important prognostic indicator of poor outcome. Patients with rising BNP levels despite vigorous treatment should be apprised of curative treatment options— the possibilities of which may be limited—and the availability of palliative care.

**Delivery of Palliative Care in Heart Failure**

**Multidisciplinary Teams**

A source of confusion in managing patients with heart failure, as UK focus group members noted, is the definition of roles.38 Management of symptoms may be handled by physicians, advanced practice nurses, physician assistants, or pharmacists. Nurses traditionally manage care, and social workers may manage psychosocial support. The use of team management coordinated by the primary care physician may help to reduce this confusion. In his review on

<table>
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<tr>
<th>Table 1. Aspects of Palliative Care That May Not Be Available for Patients With Heart Failure*</th>
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<td><strong>SERVICES</strong></td>
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<tr>
<td>• Multidisciplinary support in the community</td>
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<tr>
<td>• Specialist nurse-practitioners</td>
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<tr>
<td>• Access to inpatient beds for palliative care</td>
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<td>• Professional training in the principles of palliative care</td>
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<td>• Social and financial support</td>
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<tr>
<td><strong>APPROACHES</strong></td>
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<tr>
<td>• A strategy for a timely move from invasive treatment to supportive care</td>
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<tr>
<td>• Optimization of treatment of the underlying disease</td>
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<tr>
<td>• Improved symptom control and attention to comorbidities</td>
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<tr>
<td>• Emphasis on quality of life</td>
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<tr>
<td>• Discussion of prognosis early in the course of disease, seeking patients' views</td>
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<tr>
<td>• Acknowledgement of disease-specific barriers to effective communication</td>
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<tr>
<td>• Adequate information about palliative care for patients</td>
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the need for palliative care in the management of heart failure, Ward states, "It is unrealistic to expect every cardiologist to become proficient in the various aspects of palliative care. It is, however, important to acknowledge the benefits that palliative care has to offer and to encourage their adoption, either by interested cardiological colleagues, by professionals with a palliative care training, or a combination of the two."43

The American College of Cardiology and the AHA, in their joint updated guidelines for managing heart failure in adults, include a special section on end-of-life care.14 The guidelines make no formal recommendations; however, specific interventions for providers and the usefulness of disease-management strategies that include the entire team of caregivers are discussed—especially a collaborative model between a generalist and a cardiologist.14

A multidisciplinary team can offer benefits that improve clinical outcomes in patients with heart failure. A randomized controlled clinical trial of 200 hospitalized patients with demonstrated the benefits of a multidisciplinary program for managing outpatient care.44 Patients were randomized to a group receiving multidisciplinary team care (protocol-based care administered by a telephone nurse coordinator, a cardiologist with training and experience in the care of patients with heart failure, and the patient's primary physician) or to a group receiving standard care. The program was designed to implement evidence-based medical therapy, increase patient understanding and compliance, and reduce financial barriers to care, as well as to provide frequent telephone monitoring and clinical follow-up. The investigators sought to determine if multidisciplinary team care led to decreased deaths and hospital readmissions for heart failure, and improved treatment adherence and quality of life at no extra cost. In the patients receiving team care, significant improvements were observed in quality-of-life scores, percentage of patients on target vasodilator therapy, and percentage of patients adhering to dietary recommendations. The team care group had fewer hospital admissions for any reason compared with the control group. Figure 2 shows the difference in first-event rates for death and hospital readmission for CHF in patients who received team care vs standard care.45 (The primary outcome measure was the composite of the number of CHF hospital admissions and deaths over 6 months.)

Table 2 summarizes some of the clinical data from this study. New York Heart Association (NYHA) functional class improved from level II or level III to primarily level II, indicating a shift toward stable and improved patient-assessed symptoms, a decreased frequency of ankle edema, and average or good adherence to diet. There was a trend toward a statistically significant improvement in the use of ACE inhibitors in the team-management group. Quality-of-life scores showed significant improvement overall. There were no significant differences between the study groups regarding inpatient cost or use of inpatient or outpatient resources. The greatest overall cost was for readmission. These results and several recent meta-analyses of multidisciplinary care in heart failure demonstrate the effectiveness of this approach.45

Multidisciplinary care requires coordinated care. Most participants in the British heart failure focus group agreed that the primary care physician is a central figure in providing palliative care for patients with heart failure. However, other care providers—cardiologists, specialty nurses, social workers, and palliative care specialists—also play important and interdependent roles.36 Cardiologists typically see the most seriously ill patients with heart failure, but only a few studies define their role in palliative care for these patients.33

Some US clinics have developed step-by-step protocols for determining whether a patient is eligible for palliative care.45 Applying these protocols requires the coordination of professionals in various medical disciplines; the primary care physician is essential for coordinating and managing those resources. In 2001, California's legislature passed a law requiring every licensed physician to take courses in pain management and end-of-life care.46
A provider’s view of his or her own mortality may impede the introduction of appropriate palliative care measures for patients with heart failure. Discomfort with death and the failure it implies may prevent caregivers from meeting the needs of dying patients (eg, by not helping to obtain do-not-resuscitate orders or by not heeding patient preferences about end-of-life care). The same fear and discomfort about death may prevent healthcare teams from integrating palliative measures with active care early enough for the patient to benefit.4

Trust is an important aspect of the physician-patient relationship, especially when the patient is receiving palliative care. Patients and their family members need to feel that the physician is acting as an advocate for the patient.47

It is critical that the process of palliative care is skillfully explained to patients and their families. For the surviving relatives, the final weeks and moments of a family member’s life may be filled with frustration and anger that can impede the bereavement process, or they may be a source of inspiration and strength. Communicating with patients and their families about death and dying and skillfully addressing the needs of both are fundamental aspects of primary care. Methods of communication developed in the practice of oncology have great utility when caring for patients with end-stage heart failure and other comorbid conditions.48,49

Hockley presents an important overview of the psychosocial aspects of palliative care, particularly regarding the importance of openness in communication with patients and family, factors that enable families to cope with the dying of a loved one, and the way in which the healthcare provider can assess how a family is coping.49 Hockley suggests viewing the family and the patient as a “unit of care.” Organizing family meetings that include the patient can establish open communication with the physician. During these meetings, all can frankly address the issue of dying, which may help the family to function as a cohesive unit. Any barriers to family cohesion may also be identified (eg, previous problems in handling stress, other concurrent or recent stressful events in a family member’s life, and each member’s attitudes toward his or her changing role in the family). Hockley also suggests that the healthcare team sketch a family tree to help them identify family members whose relevant experiences they can also note. In addition she provides useful methods for broaching the subject of death with small children. Hockley recognizes that physicians can gain the trust of the family by controlling symptoms but urges physicians not to remain strictly “symptomatologists.”

Spiritual care plays a major role in palliative care, and all persons who care for the patient can benefit from it.3,4,50 Spiritual care is independent of religious denomination.41 Narrative stories also play an important role in caring for patients who are dying.3,51 In an effort to rectify misunderstanding or miscommunication between the physician and patient, Ward suggests asking the patient, “What are your 3 most troublesome problems?”44 A similar formulation using single-syllable words may also be used: “Of all the things in your life right now, what is the one thing that you don’t like the most?” These plain questions are easily understood, even by those with limited skills in speaking English. They invite patients to express their feelings and help care providers to understand and better assist the patient.

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) was a large and well-powered trial of a palliative approach to end-of-life care.52 The study

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<th>Table 2. Clinical Data at 6 Months From a Randomized, Controlled Trial of Multidisciplinary Care in CHF</th>
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<tr>
<td>Intervention Group (%)</td>
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<td>(n = 102; data available: 94)</td>
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<tr>
<td>NYHA functional class</td>
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<tr>
<td>I 8 11</td>
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<tr>
<td>II 67 10</td>
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<tr>
<td>III 20 41</td>
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<tr>
<td>IV 5 8 P = .03</td>
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<tr>
<td>Patient-assessed CHF symptoms</td>
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<tr>
<td>Stable 44 35</td>
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<tr>
<td>Improved 43 31</td>
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<tr>
<td>Worse 12 35 P = .003</td>
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<tr>
<td>Ankle edema 20 41 P = .003</td>
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<tr>
<td>At goal weight 50 20 P = .001</td>
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<tr>
<td>Diet compliance</td>
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<tr>
<td>Good 34 14</td>
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<tr>
<td>Average 35 31</td>
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<tr>
<td>Poor 27 52 P = .002</td>
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<tr>
<td>Medications</td>
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<tr>
<td>ACE inhibitor 83 71 P = .07</td>
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<tr>
<td>Angiotensin II blocker 13 8 P = .33</td>
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<tr>
<td>Beta-blocker 46 38 P = .27</td>
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<tr>
<td>Digoxin 71 60 P = .11</td>
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<tr>
<td>Diuretic 93 88 P = .32</td>
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<td>Hydralazine 5 8 P = .44</td>
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<tr>
<td>Long-acting nitrate 15 20 P = .37</td>
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included 41 patients in the control group and 50 patients in an intervention group who suffered from acute exacerbations of cirrhosis, chronic obstructive pulmonary disease, or CHF. There were no differences in outcomes regarding pain control or resource use. The results show that even established programs of palliative care can be ineffective if the important aspects of care, such as involving the entire care team, addressing the provider's own fear of mortality, and paying attention to essential issues of trust and open conversation, are not considered. Larger studies that focus on the special care needs of patients with heart failure as the primary condition in the setting of other comorbidities will need to be undertaken before the palliative care principle can be moved beyond the voicing of "articles of faith."53

Managed care organizations have a unique opportunity to apply palliative care principles to the treatment of patients with heart failure and improve patient outcomes. Brumley recently observed that managed care organizations have a financial incentive to identify high-risk patients with chronic illnesses because coordinating care can avoid expensive outcomes. Managed care organizations also have the infrastructure in place to take advantage of coordinated care systems.54 Although no published studies on the role of managed care in administering palliative care are currently available, Brumley describes a palliative care program developed by Kaiser Permanente to evaluate the use of a blended model of hospice and curative care in patients with chronic obstructive pulmonary disease, congestive heart failure, or cancer.55

In an issue of the Journal of the American Medical Association devoted to palliative care, the introductory editorial by Lynn is a useful summary.56 While calling for an "era of innovation, evaluation, and learning," she underscores that widespread reforms are necessary among provider organizations, government agencies, healthcare researchers, policy makers, and clinicians. Lynn encourages physicians to learn the communication skills that will enable them to support seriously ill patients and their families. She urges healthcare professionals and lay people to identify some current routine practices as unacceptable, including allowing patients to suffer from unrelieved pain, ignoring the need for caregiver support, and failing to prepare advanced care plans. In response, many medical centers have instituted pain committees to more effectively address the issue of pain management.56

**Research Agendas for Palliative Care**

In addition, the Institute of Medicine has published an agenda for research in palliative care.57 The goal is to better understand and manage symptoms such as pain and dyspnea. The Canadian agenda for palliative care includes simultaneously approaching symptoms, ethics, clinical decision making, communications, family and family caregiving issues, interdisciplinary team issues, health systems and services, and existential and spiritual concerns.58

**Conclusion**

Primary care physicians, who often see patients at the onset of heart failure and care for them throughout the course of the illness, play a pivotal role (Table 3). As part of the care team, the primary care physician is in a unique position to coordinate care for these patients. Although it is difficult to arrive at a prognosis for patients with heart failure, elderly patients with multiple comorbidities and frequent hospital admissions may be considered leading candidates for palliative care. Patients with heart failure may alternate between the need for curative and palliative care before clearly entering the terminal stage of heart failure.

As the population ages, the number of patients with heart failure will increase. The basic concepts of palliative care for patients with heart failure are the same as those for patients with other terminal diseases. However, patients with heart failure may benefit more from palliative care when it is begun almost concurrently with standard care, because of the unpredictable course of the syndrome. Studies suggest that multidisciplinary teams may provide the most skillful palliative care to patients with heart failure. The proper approach to palliative care not only improves the patient's quality of life, but also enables family members to have more comforting memories of their loved one in the final stages preceding death.59 Palliative care for patients with heart failure is good medical care.

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<tr>
<th>Table 3. Recommendations for Providing Palliative Care</th>
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<tr>
<td>• View the family as a “unit of care” that includes the patient.</td>
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<tr>
<td>• Involve the entire care team (cardiologists, specialty nurses, social workers, and palliative care specialists) in the disease-management strategy.</td>
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<tr>
<td>• Maintain open communication with the patient and family members.</td>
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<tr>
<td>• To prevent misunderstanding or miscommunication, occasionally ask the patient a question such as, &quot;Of all the things in your life right now, what is the one thing that you don't like the most?&quot;</td>
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<tr>
<td>• Address your own fears about death by taking a course on end-of-life care.</td>
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<tr>
<td>• Recognize the importance of trust. The patient and family members need to feel you are advocating on the patient's behalf, based on the patient's wishes.</td>
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REFERENCES


