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Improving the care of patients dying of heart failure

ABSTRACT

Patients with heart failure have special palliative care needs, but palliative measures for treating the symptoms of end-stage heart failure have been largely ignored. A formal disease-management program for heart failure should include palliative care.

KEY POINTS

Although it is more difficult to determine when the end of life is near in heart failure than in other terminal diseases, algorithms based on multivariate analysis can help.

Before declaring a patient has end-stage heart failure, drug therapy must be optimized.

Patients want and deserve to be free of pain and dyspnea at the end of life; treatment algorithms can help guide therapy.

Frequent firing of an implanted defibrillator is a criterion for initiating palliative care. Discussions with the patient and family must include the difficult issues of turning off an implanted defibrillator.

Caregivers need to learn to communicate openly and clearly with their patients who are approaching the end of life. Doing so helps patients and their families make important decisions.

TOO MANY heart failure patients die in pain, short of breath, and with too much left unsaid. We can do better for them.

Despite advances in its treatment, heart failure is still a lethal disease. As the graying of America continues and the prevalence of heart failure increases, we need to refocus our priorities to include palliative care as a part of the spectrum of services we provide. Specifically, we believe that a formal disease-management program, supervised by physicians, staffed by nurses, and based on evidence, can ease the suffering of patients in the end stage of heart failure.

In this article, we evaluate what has been done so far and describe the approach we use in the heart failure disease-management program at The Cleveland Clinic Foundation.

HEART FAILURE ON THE RISE

The incidence and mortality rate of heart failure due to systolic left ventricular dysfunction are increasing in the United States, for several reasons. More people are surviving to old age with conditions that place them at risk of heart failure, such as hypertension, coronary artery disease, diabetes, and obesity. Paradoxically, advances in the treatment of myocardial infarction and unstable angina are also to blame—more people are surviving heart attacks only to develop heart failure later.

Most research in heart failure is directed at treating the earlier stages. We have seen exciting advances in drug treatments (eg, angiotensin-converting enzyme [ACE] inhibitors, beta-blockers, aldosterone inhibitors, natriuretic peptides), cardiac devices (biventricular pacing, left ventricular assist devices), and surgery (infarct exclusion, endoventricular reconstruction).

Unfortunately, palliative measures for treating the symptoms of end-stage heart failure have been largely ignored.

■ PALLIATIVE CARE WHEN DEATH IS NEAR—OR NOT SO NEAR

Historically, palliative medicine has been specialized and designed to relieve or reduce uncomfortable symptoms and suffering in anticipation of imminent death when a cure or amelioration is no longer possible.

But what if death is not so imminent? In recent years, palliative care has expanded to include coordinated services to meet the health needs of people with life-limiting chronic conditions, such as cancer, who may survive for months to years.

Heart failure is a continuum, and so is its care. For some patients, the focus of care should be on aggressive prolongation of life, while for others the focus should be on quality of life. Most patients fall somewhere between the extremes and should be encouraged to attend to important life events and closure, but also should be reassured that they might yet live a long time.

For patients who move in and out of the latter half of the continuum, a palliative medicine program should attempt to maximize their well-being—physical, psychological, social, spiritual, and cultural—in a compassionate way. The emphasis should be on keeping the patient comfortable by controlling and alleviating symptoms, and on restoring or maintaining function.

■ WHEN IS IT TIME TO CONSIDER PALLIATIVE MEDICINE?

In any terminal disease, palliation becomes a larger part of the care plan as time passes, but there is no point at which only curative care is appropriate and no point at which only palliative care is appropriate. Thus, palliative medicine should not be thought of as a program that only deals with the transition from aggressive treatment to “care.”

This is especially true for heart failure, since predicting when death is near is difficult: patients often do not have clinically predictable phases of overt decline as they do in

cancer, bronchopulmonary conditions, or liver failure.

Function and symptoms do not predict death

Burns et al¹ found that many Medicare patients still alive 1 year after being hospitalized for heart failure had substantial impairment in activities of daily living, became short of breath when walking less than 1 block, and needed formal care at home or in an institution. The percentages, however, were not significantly different from data collected at 6 weeks or 6 months after discharge. This underscores the difficulty in projecting the need for and duration of palliative care on the basis of function and symptoms.

More evidence of the difficulty of predicting survival on the basis of symptoms and ability to perform activities of daily living comes from SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments).^{2,3} Of 1,312 heart failure patients discharged from the hospital, 77% survived more than 6 months, even though 73% had an ejection fraction of 20% or less, 68% were readmitted within 2 months, 76% required home care services, 79% experienced a 5-lb weight loss within 2 months of discharge, and 75% had a documented arrhythmia. Of patients given a 50% or less chance of surviving 6 months (predicted on the basis of multivariate analysis), 53% were actually alive at 6 months, but of those with a predicted chance of survival of 10% or less, 38% were still alive at 6 months.²

Sudden cardiac death: Living with ambiguity

One reason that imminent death is not as predictable in heart failure as in other terminal diseases is that many of the deaths in heart failure are in the category of sudden cardiac death.

Studies of cardiac reserve and electrophysiology can predict the probability of death. For example, maximum oxygen consumption or heart rate variability can be used to determine prognosis and to guide changes in medical management that include palliation. However, many of these tests are expensive, time-consuming, invasive, and not readily available, and

Length of survival is difficult to predict in heart failure



they may cause patient discomfort.

The palliative medicine team can help patients learn to live with the ambiguity of the situation, ie, knowing that they might die suddenly even though they may feel relatively well.

National Hospice Organization criteria

In 1998, the National Hospice Organization⁴ published medical guidelines for determining prognosis in heart disease. According to these guidelines, prognosis is poor and the patient qualifies for palliative care if he or she has any of the following:

- Recurrent or persistent congestive symptoms at rest (New York Heart Association [NYHA] functional class IV) despite optimal use of vasodilators and diuretics
- Symptomatic ventricular or supraventricular tachycardia resistant to drugs
- Cardiac arrest and subsequent resuscitation
- Unexplained syncope
- Cardiogenic brain embolism
- Concomitant human immunodeficiency virus (HIV) infection.

The guidelines did not take into account recent advances in heart failure and HIV treatment, however, perhaps making them outdated from the outset. Particularly, they did not address:

- Specific vasodilator therapy
- Angiotensin-converting enzyme inhibitors, which are the current treatment of choice and should be given in the doses used in large, randomized, placebo-controlled trials^{5,6}
- Aldosterone inhibitor (spironolactone)
- Beta-blockers.

Beta-blockers are beneficial in advanced heart failure

Beta-blockers deserve special mention. Originally contraindicated in heart failure, beta-blockers were shown only a few years ago to improve left ventricular ejection fraction, symptoms, and exercise capacity, and reduce the combined risk of death and hospitalization when given long-term in mild or moderate heart failure.⁷⁻⁹

And now, in advanced heart failure too. In the COPERNICUS (Carvedilol Prospec-

tive Randomized Cumulative Survival) study,¹⁰ 2,289 patients with ejection fractions below 25% and in NYHA class III or IV received either carvedilol or placebo, in addition to standard therapy. Those receiving carvedilol had a 35% lower rate of death and a 24% lower combined risk of death or hospitalization. The rate of withdrawal due to adverse effects was less in the beta-blocker group than in the placebo group.

Therefore, before we declare that a patient has end-stage systolic heart failure, drug therapy needs to be optimized. The right drugs must be given at the right doses, and drugs that could worsen heart failure, such as nonsteroidal anti-inflammatory drugs, first-generation and second-generation calcium channel blockers, and some oral type 2 diabetic agents (eg, rosiglitazone, pioglitazone), must be stopped.

The EPICAL study: Refining the prognosis

In the EPICAL (Épidémiologie de l'Insuffisance Cardiaque Avancée en Lorraine) study, Alla et al¹¹ used multivariate analysis to examine 28 readily available factors, and developed algorithms for predicting prognosis in patients with ischemic or dilated cardiomyopathy.

According to their findings, patients with ischemic cardiomyopathy have a 25% or less chance of surviving 1 year if they have any three of the following four factors:

- Serum sodium level below 138 mmol/L
- Resting heart rate greater than 100 beats per minute
- Serum creatinine level greater than 2.0 mg/dL
- History of prior decompensation.

Similarly, patients with dilated cardiomyopathy have a 25% or less chance of surviving 1 year if they have at least four of the following seven factors:

- Serious comorbidity (ie, cancer, cirrhosis, arteritis, cerebral vascular accident, or bronchopneumopathy)
- Known cardiopathy
- Institutionalization or dependence on assistance from relatives
- Serum sodium level less than 138 mmol/L
- Resting heart rate greater than 100 beats per minute

Before saying a patient is in end-stage heart failure, optimize the treatment

Is your heart failure patient ready for palliative care?

INITIAL SCREENING CRITERIA

If the following three criteria are met, proceed to secondary criteria based on type of cardiomyopathy

- New York Heart Association class IV function (dyspnea at rest) despite using, when applicable:
- Vasodilators and beta-blockers at target doses, digoxin and spironolactone at low doses, diuretics
- Surgery, drugs, and devices to treat conditions related to heart failure have already been discussed

Additional criteria when applicable:

- Requires long-standing dobutamine or milrinone intravenously to maintain hemodynamic control
- Other findings have not responded to optimized treatment:
 - Ventricular tachycardia, supraventricular tachycardia, syncope, palpitations, firing of implantable defibrillator
 - Neurological deficits such as confusion or mental obtundation
 - Appearance or worsening of a related condition: cardiogenic brain embolism, human immunodeficiency virus, bronchopulmonary disease, peripheral vascular disease
 - Signs of low-flow state: symptomatic hypotension and sequela, nausea, abdominal distention, poor appetite
 - Unexplained weight loss

FOR PATIENTS WITH ISCHEMIC CARDIOMYOPATHY, USE THESE SECONDARY CRITERIA

Palliative care is recommended if three of the following four criteria are met:

- Serum sodium concentration < 138 mmol/L
- Heart rate > 100 beats per minute
- Serum creatinine concentration > 2.0 mg/dL
- Prior decompensation

Patients who do not have three of the above four criteria qualify for palliative care if they score > 21 points by the following criteria:

Serum sodium < 134 mmol/L	_____	16 points	
Serum sodium > 134 but < 138 mmol/L	_____	7 points	
Heart rate > 100 beats per minute	_____	9 points	
Serum creatinine level > 2.0 mg/dL	_____	10 points	
Age > 70 years	_____	5 points	
Prior decompensation	_____	6 points	TOTAL _____

FOR PATIENTS WITH DILATED CARDIOMYOPATHY, USE THESE SECONDARY CRITERIA

Palliative care is recommended if four of the following seven criteria are met:

- Serum sodium concentration < 138 mmol/L
- Heart rate > 100 beats per minute
- Serum creatinine concentration > 2.0 mg/dL
- Comorbid condition: cancer, stroke, arteritis, chronic obstructive pulmonary disease
- Age > 70 years
- Lives in institution or needs assistance from relatives
- Has confirmed cardiopathy

Patients who do not have four of the above seven criteria qualify for palliative care if they score > 19 points by the following criteria:

Serum sodium < 134 mmol/L	_____	4 points	
Serum sodium > 134 but < 138 mmol/L	_____	2 points	
Heart rate > 100 beats per minute	_____	8 points	
Serum creatinine level > 2.0 mg/dL	_____	6 points	
Comorbid condition (as above)	_____	4 points	
Age > 70 years	_____	5 points	
Lives in institution or needs assistance from relatives	_____	7 points	
Has confirmed cardiopathy	_____	7 points	TOTAL _____

TABLE 1



- Serum creatinine level greater than 2.0 mg/dL
- Age greater than 70 years.¹¹

This system is especially useful when patients have dyspnea due to hypervolemia, a factor in determining NYHA functional class III or IV.

A combined approach to prognosis

We use an algorithm that combines the National Hospice Organization guidelines⁴ (based on symptoms but modified to include optimized medical management) with specific findings of the EPICAL study¹¹ (TABLE 1).

Ideally, palliative care should be part of the plan from the beginning and should be discussed with the patient and family well in advance. If not, the topic must be broached once the prognosis is determined to be poor and treatments such as cardiac transplantation, left ventricular assist devices, or surgery are deemed inappropriate and a decision must be made to change the focus of care from life-sustaining to supportive measures.

■ WHAT DOES PALLIATIVE MEDICINE INCLUDE?

Patients and their families especially want and need two things from palliative medicine: effective control of symptoms and open communication (TABLE 2).¹²

Symptoms are common

Patients with advanced heart failure have many symptoms (TABLE 3), but pain and dyspnea are the most troubling. In the SUPPORT study,¹³ of 92 patients who died during the index hospitalization, 35% had severe pain and 43% had dyspnea. Of 865 patients alive 1 year after enrollment, 18% had severe pain and 32% had dyspnea.¹³

Patients with heart failure did not have as much pain as patients with cancer. However, in the last 3 days of life, the number of patients with pain increased significantly to 43%, and the number with dyspnea increased significantly to 65%. Exactly what the pain represented remains elusive, but physicians caring for patients with end-stage heart failure need to be aware of the problem.

Like other patients with terminal illness,

TABLE 2

Elements of a patient-centered model of care in end-stage heart failure

- Pain control
- Effective symptom management
- Bedside presence by physicians and other essential healthcare providers
- Clear communication about the current condition
- Autonomy preservation; control
- Avoidance of prolonged suffering/dying
- Minimization of family burden
- Strengthening of relationships with significant others
- Addressing spirituality issues
- Discussion of the site of death
- Terminal sedation, if necessary

TABLE 3

Common symptoms and syndromes of end-stage heart failure

Symptoms

- Dyspnea
- Pain
- Abdominal fullness
- Nausea
- Early meal satiety
- Palpitations, racing heart
- Easily fatigued, leg weakness, lack of energy; inability to carry out activities of daily living
- Persistent cough
- Weight loss
- Sleep problems
- Memory problems; mental obtundation
- Edema

Syndromes

- Malignant ascites, anasarca
- Anorexia, cachexia
- Pleural effusion

Patients want and need good symptom control and open communication

patients with heart failure suffer from psychological problems as a result of their symptoms and treatment. These include:

- Distress of living with a fatal condition

TABLE 4

Palliative treatments for end-stage heart failure

Pain, severe dyspnea

Try a nonopioid drug: acetaminophen 650 mg every 4 hours or 975 mg every 6 hours

If pain is still moderate or severe, try acetaminophen (300 mg) with codeine (30 mg), once or twice every 4 hours as needed

If pain persists, start morphine, controlled or immediate release, plus a laxative

If dyspnea causes anxiety, give an anxiolytic (eg, clonazepam, diazepam, lorazepam)

Dyspnea due to hypervolemia

Follow algorithm for diuretic therapy in end-stage heart failure (TABLE 5)

Persistent, severe cough

Guaifenesin-dextromethorphan as needed, or hydrocodone-homatropine 5 mL every 6 hours as needed

Drugs that worsen heart failure must be stopped

- Disruption of social life, personal goals, income, faith, and daily function
- Increasing dependence on others, need for assistance with activities of daily living, and the accompanying effects on self-esteem.¹⁴

While the rate of mental confusion among SUPPORT patients remained fairly consistent (9% to 16%) in the last 6 months of life, anxiety and depression increased and peaked between 1 month and 3 days before death.¹³

Controlling symptoms of heart failure

Common physical symptoms must be aggressively evaluated and managed. Once recurring symptoms are identified, they must be assessed individually, and the causes and possible mechanisms must be determined.

Drugs (including over-the-counter medications or herbs) and foods that increase sodium and water retention can worsen heart failure and must be altered or eliminated. Nonsteroidal anti-inflammatory drugs, decongestants, sodium-based antacids, ginseng, or ginkgo can exacerbate heart failure symptoms by worsening hypervolemia.

Management of symptoms requires a

diverse approach (TABLE 4), with multiple drugs to relieve pain, persistent severe cough, progressive dyspnea, anxiety, and constipation.

Pain. The World Health Organization's three-step analgesia ladder is a good guide for pain management.

Respiratory distress due to hypervolemia is managed with a combination of loop and adjunct diuretics (TABLE 5). A key part of therapy is educating the patient and family about diet and fluid restriction, the importance of adherence, and home management of sudden weight gain and other fluctuating symptoms.

Intravenous inotropic (dobutamine) or inotropic vasodilator (milrinone) therapy may need to be continued after hospital discharge if oral drugs fail to control hemodynamics (ie, keep the pulmonary artery wedge pressure down and the arterial blood pressure up) and symptoms during hospitalization (TABLE 5). A Hickman catheter or PICC (peripherally inserted central catheter) line should be inserted for this purpose.

In palliative medicine, these drugs should *not* be titrated on the basis of blood pressure, but rather on how the patient feels; the goal is to improve functional ability and quality of life.

Of note, these drugs do not increase survival—in fact, continuous inotropic therapy may shorten survival time if arrhythmias occur.^{15–17}

Home care services

Economic and caregiver limitations may require social work intervention: high cost and poor functional status can affect compliance with diet, drug, and other therapies, and families may be incapable of providing the necessary care or assistance.

Home care services by registered nurses trained in both heart failure and palliative care can be an important asset to care of patients with heart failure and their families. Self-care education offered as part of home care may ease symptoms, and the mobilization of collaborative services to the home may decrease stress and anxiety. Home caregivers can foster discussions about making plans to turn off ICD defibrillator function when it fires repeatedly, and about how to



deal with dying at home. This can decrease the need for an ambulance and emergency resuscitation.

**The importance of communication:
Facilitating discussion of end-of-life issues**

Communication is perhaps the most important part of a patient-centered model of care (TABLE 6).¹⁸ Communication improves patient and family satisfaction with care, which in turn improves compliance.

Caregivers must learn to be comfortable with talking with patients about dying and must learn to communicate with them with compassion. At a time when many patients worry about being abandoned by the health care team, caregivers need to build trust and convey genuine concern when communicating important information. Being at ease with the dying process enables caregivers to communicate in a direct, straightforward manner that aids decision-making, and compassionate discourse reduces patients' fear and anxiety about dying.

Communication should include a discussion of the patient's preferences, goals, and hopes. In addition, attentive listening and focused attention promote mutual shared plans for care.

When to turn off the ICD?

Combination biventricular pacemaker-implantable cardioverter-defibrillators (ICDs) and stand-alone ICDs are becoming more common in heart failure management. It is beyond the scope of this article to discuss the issue of whether to implant an ICD in a patient with nonsustained ventricular tachycardia observed during the escalation of hospitalizations that occurs in end-stage heart failure. However, frequent firing of an ICD is one of the criteria for initiating palliative care.

In palliative care, discussions with patients and families must include turning off the ICD's defibrillator function. Specific problems and benefits associated with disabling the ICD should be communicated openly so that complex religious considerations regarding the morality of a decision can be fully explored and the fear of immediate death or fear and anxiety associated with frequent firings can be discussed openly.

TABLE 5

Management of respiratory distress and weight gain in end-stage heart failure

Paroxysmal nocturnal dyspnea

Nitroglycerin ointment (1 inch) at bedtime as needed

Respiratory distress at rest during waking hours with edema and respiratory congestion

If systolic blood pressure is > 80 mm Hg:

Give extra furosemide (Lasix) dose equal to 1/2 of total 24-hour dose,

Double the daily dose of potassium supplement and obtain metabolic panel in 7 days

If systolic blood pressure is < 80 mm Hg: No treatment

If on milrinone drip:

Increase drip rate by 1 increment per 24-hour period (milrinone increments: 0, 0.375, 0.5, 0.75 µg/kg/minute)

If on dobutamine drip:

Increase drip rate by increment per 24-hour period (dobutamine increments: 0, 2.5, 5, 7.5, 10 µg/kg/minute)

If volume-depleted:

Decrease diuretics by 1/2

Maintain lower diuretic dose until systolic blood pressure rises above 80 mm Hg

If fluid overload develops, resume prior diuretic dose

Weight gain 3–6 lb consistent with fluid overload

If total daily dose of furosemide is < 120 mg:

Double today's dose x 1

Double the daily dose of potassium supplement and obtain metabolic panel in 7 days

If total furosemide dose is 120 mg or more:

Give usual daily furosemide dose

Add metolazone (Zaroxolyn) 5 mg by mouth x 1

Double the daily dose of potassium supplement and obtain metabolic panel in 7 days

Weight gain of ≥ 6 lb consistent with fluid overload

Consult cardiologist: Patient may require intravenous diuretics, vasodilator therapy, or nesiritide, especially if there is evidence of complex decompensation (increased afterload, fluid overload, and/or hypoperfusion)

ADDITIONAL RESEARCH

The American Heart Association and American College of Cardiology joint report on heart failure management quality assurance¹⁹ outlines the critical elements of high-quality care. Further research in palliative medicine is necessary to provide stronger

TABLE 6

Patient-centered approach to end-of-life issues in palliative care

Advance planning

- Determine patient's priorities and home support system; consult social workers as needed
- Discuss living will or durable power of attorney, naming a health care proxy
- Document patient's wishes and relevant documents in the medical chart

Do-not-resuscitate orders

- Discussion of this should emerge naturally from a discussion of the approaches and interventions taken to achieve the overall goals of comfort, living each day to the fullest, quality of life at the end of life, and a peaceful, dignified death

Maintain good communication


- Use open-ended questions to prompt communication
- Use clear, simple language
- Use the word "dying" in conversation; avoid such words as "terminal" and "fatal"
- Once dying is discussed, be compassionate and focus on what can be done for the patient

Discuss emotional, spiritual, cultural, social, and family needs

- Ask what is important to the patient to deal with stress
- Arrange meeting with pastoral care team, if patient desires
- Ask about the need to inform any family members
- Discuss life goals and other life-closure issues
- Discuss the meaning of illness and the suffering it creates
- Discuss concerns about one's ability to cope
- Listen attentively; acknowledge the patient's emotions

Promote patient autonomy and control

- Offer choices related to diet and fluids, and discuss the medical plan
- Reassure the patient that the health care team will continue to oversee the care for heart failure
- Be prepared for anticipatory mourning

evidence-based direction for health care providers, patients, and families dealing with advanced heart failure, especially regarding transitions in care, eg, from life-sustaining to symptom management, and optimal drug and nondrug therapies for end-stage heart failure. 

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