

HOSPICE AND PALLIATIVE CARE: BENEFITS AND BARRIERS FOR PATIENTS DIAGNOSED  
WITH END STAGE HEART FAILURE



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**Learning objectives**

- 1. Describe the similarities and differences of hospice and palliative care for patients with advanced heart failure**
- 2. Identify three barriers to referral to hospice for patients with advanced heart failure**
- 3. Discuss the issue of timing of palliative interventions for patients with advanced heart failure**

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John Daniels is a 67 year old male with advanced heart failure being seen in his health care provider's office. He complains of shortness of breath. He was recently hospitalized for fluid overload from dietary excess. A week after discharge he attended a family party and consumed food and alcohol that is not on his normal low sodium diet. Over the past few days he has noted increased difficulty breathing and fatigue. His past medical history is positive for CAD and is status post two vessel CABG. His most recent LVEF is 20%. He also has Type II diabetes, hyperlipidemia, and hypertension. He is a full code. On physical exam you note his general appearance – overweight, barrel-chested male sitting upright on the examination table. He is alert and mildly short of breath.

Auscultation of his lungs reveals bilateral crackles in the bases. He has 1+ edema in his lower extremities. His goal of care is to optimize his functional status and avoid re-hospitalization. How can you help him achieve these goals? Would he benefit from referral to palliative care or hospice? His recent hospitalization and continuing symptom experience suggests that he may need more support in managing his disease at home. In consultation with Mr. Daniels you write a referral to a palliative care practice to support him in self care practices. You will continue to see him for his routine care. You note in his records to suggest hospice if the support of palliative care isn't enough to help him meet his goals.

Remarkable progress has occurred over the past 45 years as a result of extensive efforts to improve our understanding of the physiological progression of heart failure. Scientific breakthroughs in the 1990's better describe the impact of neurohormonal

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activation and cardiac remodeling, dramatically changing the way clinicians use medications to manage symptoms and delay progression of the illness<sup>1,2</sup>

Yet even with this significant progress, mortality rates for patients with heart failure have risen even as mortality rates for cardiovascular diseases in general have steadily declined<sup>3</sup>. Furthermore, the number of adults diagnosed with heart failure will continue to rise with the aging demographics as incidence increases with advancing age<sup>4,5</sup>. Heart transplantation, the only definitive surgical intervention for heart failure,<sup>6</sup> remains available to only a minority of patients as the transplant waiting list far exceeds the total number of donor hearts available.<sup>7</sup>

As a result, more and more individuals in the United States are living with and dying from heart failure. Without state-of-the-art palliative interventions, these patients face a variety of challenges including complex medication and dietary self-care regimens, poorly managed physical and emotional symptoms, social isolation, financial hardship, and diminishing quality of life even up to the time of death<sup>8-10</sup>

#### **Hospice and/or Palliative Care**

In the United States, hospices provided the earliest example of expert palliative care delivery. To palliate, by definition, means “to ease (symptoms) without curing the underlying disease” or “to moderate the intensity of.”symptoms.<sup>11</sup> During the 70’s and 80’s, interventions provided by hospices were primarily directed towards providing effective pain and symptom management as well as psychological and spiritual support for terminally ill cancer patients and their families.<sup>12</sup> Hospice care was in fact, palliative in nature.

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Nevertheless, while the notion of hospice and palliative care may be similar, even appearing to be conceptually identical to the outside observer, they are not synonymous (See Table 1). Both hospice and palliative care approaches stress a holistic approach to end-of-life care addressing physical, emotional, social, cultural, and spiritual needs for patients and their families often missing from traditional models of care.<sup>13-15</sup> Both emphasize expertise in symptom management, use of interdisciplinary care, and advanced communication skills in care of the chronically ill (i.e. palliative care) and dying (i.e. hospice) across multiple settings.<sup>14, 15</sup> Both emphasize the need to provide bereavement care to surviving loved ones.

So what is the difference? Perhaps the most salient difference between the two is within the realm of national funding guidelines.<sup>16</sup> In the United States, hospice is a specific system of care. As a system of care, many hospice patients are entitled to receive the Medicare Hospice Benefit (i.e. reimbursement for services). To receive the benefit, patients must: 1) be eligible for Medicare Hospital Insurance (Part A); 2) be certified by their health care provider to have a terminal illness with a life expectancy of 6 months or less; 3) sign a statement choosing hospice care instead of standard Medicare benefits for their terminal illness; and 4) receive care from a Medicare-approved hospice program.<sup>17</sup> When the person is certified as hospice appropriate by Medicare they are eligible to receive nursing care, physical, occupational, or speech pathology services, medical social services, home health aide services, homemaker services, medical supplies (drugs and equipment), physician services, short-term inpatient care, and counseling<sup>47</sup>. The Medicare requirement of a certified terminal illness with limited life expectancy has been the most problematic for

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patients with heart failure due to the high degree of uncertainty in the illness trajectory.<sup>17</sup> There is also hospice coverage available for those eligible for Medicaid but what is covered is determined on a state by state basis<sup>46</sup>. Private insurers often offer reimbursement for hospice services similar to those covered by the Medicare Hospice Benefit<sup>15</sup> but patients with private insurance need to confirm their coverage with their provider. Provision of palliative care, on the other hand, is not bound by specific funding guidelines.<sup>16</sup> Receiving palliative care does not require an established, well-articulated prognosis (i.e. written certification of “six months to live” is not required). Patients with any life-threatening or debilitating illness that requires additional informal or formal care should be eligible to receive palliative care.<sup>14, 18</sup> While there is currently no general package of benefits for palliative care, specific services may be covered within the context of various Medicare, Medicaid and private insurances.<sup>15</sup>

Additionally, national experts assert that palliative care can and should be delivered *concurrently* with “active” or “disease-modifying” (also may be described as “curative”) therapies in patients with life-threatening illness.<sup>14</sup> This is often described as “upstreaming palliative care”.<sup>17</sup> This factor is critically important for those patients with heart failure where boundaries between palliative and disease-modifying care are not clear-cut when compared to diseases such as cancer. For example, in the cancer patient chemotherapy may be effective for a definitive period of time after which it no longer alters the course of the disease and comfort care alone may be a reasonable option.<sup>15, 19</sup> Alternatively, patients with advanced heart failure can be responsive to disease-modifying care until the day of death.<sup>19</sup>

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<sup>20</sup> For example, diuretics actively treat pulmonary edema and as a result palliate shortness of breath. Beta-blockers can actively slow disease progression as well as reduce hospitalizations and overall mortality.<sup>21,22</sup> Even patients who undergo life-prolonging device therapy (such as ventricular assist devices) to manage severe symptoms are also at risk of dying secondary to their heart failure and should be approached using principles of palliative care.

According to the National Hospice and Palliative Care Organization, the test of palliative care vs. disease-modifying (or curative) care is that the expected outcome of palliative care is relief of distressing symptoms, the easing of pain, and/ or enhancing quality of life.<sup>15</sup> The vast majority of heart failure therapies can meet that test. Though titration of drug dosages may be required, considering benefits versus burden, these patients may receive their full regime of cardiac medications until death as effective symptom management tools.

### **When and Where Should Patients Receive End-of-life Care?**

Two critical questions remain for providers developing plans of care for patients with heart failure. The first is exactly when “end-of-life” interventions should be initiated. Second is whether or not patients with advanced heart failure should be referred to hospice for their care (in other words, certification of the six-month prognosis) or should they receive palliative care within a specialty heart failure disease management program?

There are a number of barriers related to prognostication and perception that make referral to hospice for patients with heart failure problematic. First and foremost, has been

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the issue of timing: the belief that the “end of life” is a precise time interval that can be clearly defined by prognostic models.<sup>18</sup> Heart failure’s illness trajectory is incongruent with the notion of the six-month prognosis. Goodlin et al’s schematic representation of Stages C and D heart failure plainly indicates the unpredictable illness trajectory of heart failure characterized by exacerbation and remissions of symptoms with occasional symptom plateaus resulting from changing medical and surgical therapies.<sup>23</sup> Throughout the illness trajectory is the possibility of sudden death as patients with heart failure are 6-9 times more likely to experience sudden death than the general population.<sup>3</sup>

Major efforts have been made to improve the ability of clinicians to predict the end of life for patients with heart failure.<sup>24-26</sup> Prognostic markers that have been used to identify “end-stage” heart failure include NYHA Functional Class IV, older age, persistent resting tachycardia, reduced serum sodium, higher diuretic dose, or multiple recent emergency visits or hospitalizations to name only a few.<sup>24, 26, 27</sup> Guidelines have been developed by the federal government to aid providers in determining a patient’s prognosis for heart disease in general (See Table 2)

The recently published *Clinical Practice Guidelines for Quality Palliative Care, Second Edition*, however, stresses that the goal of palliative care is to prevent and relieve suffering and support the best quality of life for patients and families *regardless* (italics our own) of the specific stages of a disease.<sup>20</sup> This is in keeping with the evidenced based guidelines developed by the 2009 task force of the American College of Cardiology Foundation/American Heart Association practice guidelines.<sup>6</sup> While this does not eradicate

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the responsibility of researchers to provide more substantive prognostic criteria, it does demonstrate that a poor prognosis is not the cue to begin palliative interventions.

Ideally, palliative care should be initiated at the time of diagnosis of any life-threatening illness.<sup>20</sup> Accordingly, patients with Stage C and Stage D should have palliative care interventions implemented (ranging anywhere from initiating conversations about advanced directives, to administering morphine derivatives, to having discussions regarding the possibly of deactivating automatic internal cardiac defibrillators in hospice).

Furthermore, all patients with Stage D heart failure who remain significantly symptomatic with minimal exertion or at rest despite maximal medical therapy should be considered priority candidates for palliative care interventions whether provided by hospice or within a comprehensive heart failure disease management setting.

Beyond the issue of timing to initiate palliative care interventions, is the issue of who should deliver those interventions. As mentioned earlier, the notion of the certified six-month prognosis has been one of the greatest stumbling blocks to hospice enrollment. Furthermore, consensus opinions for referral to hospice as an option for advanced heart failure patients are mixed. Goodlin et al. recommended hospice as potentially effective in meeting the needs of patients with advanced heart failure all the while recognizing a clear lack of evidence to fully endorse its use.<sup>23</sup> However, the 2009 American College of Cardiology and American Heart Association Guidelines recommended “end of life care, such as hospice” (pg.1982) for patients with symptoms refractory to treatment.<sup>20</sup> The guidelines recommend referral to heart failure programs with expertise in management of refractory symptoms and discussion of end-of-life

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options with the patient and family when there are no further appropriate therapies. The Heart Failure Society of America also explicitly recommends that patients requiring end-of-life care be considered for hospice services.<sup>28</sup>

Lack of adequate data on effectiveness of hospice to affect priority heart failure outcomes including quality of life has contributed to the reluctance to endorse hospice and must be addressed.<sup>29</sup> In order to make a referral to hospice, providers must be assured that their patients will receive expert heart failure management that meets the standards of cardiovascular experts across the entire illness trajectory until the time of death. To meet this need, hospices across the country must continue to develop expertise in caring for heart failure patients with clear understanding of the unique needs of these patients when compared to patients with cancer.<sup>19</sup>

In addition, for many people, the hospice label is of itself inherently “toxic” representing imminent death and therefore may never even be considered as an alternative model of care.<sup>30</sup> Patients may assume that to agree to hospice is to hasten death or to surrender treatment.<sup>29</sup> In fact, patients do not have to forego cardiopulmonary resuscitation or discontinue interventions such as tube feedings to qualify for hospice.<sup>31</sup> A recent study of over 4,000 patients showed that mean survival times increased from 321 days to 402 days for heart failure patients admitted to hospice.<sup>15</sup> One hypothesis for this finding is that the expert symptom management provided by hospice prolongs life.

Researchers have shown that heart failure patients may have a higher preference for resuscitation than patients with cancer.<sup>32</sup> Caution must be noted however, when compared to

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patients with metastatic cancer, advanced heart failure patients received do not resuscitate (DNR) orders significantly later in their hospitalization even when there was no significant difference with preferences for resuscitation.<sup>33</sup> They were also more likely to receive significantly more life-sustaining treatments in the acute care setting than the patients with cancer even though the heart failure patients were significantly older. Nearly 20% of heart failure patients received cardiopulmonary resuscitation before receiving their do not resuscitate (DNR) orders. It is critical to ask the question: Was that due to high preferences for resuscitation<sup>32</sup> or a potential deficiency in health care providers' ability to effectively communicate with patients and their families?

Patients should have the opportunity to receive hospice services where the clear focus is palliative in nature. Hospices have been in the business of delivering quality end of life care for patients facing end of life for nearly four decades in the United States. Cancer is no longer the most common diagnostic category in hospice. Non-cancer diagnoses now account for almost 60% of admissions. Heart disease accounted for 12% of these non-cancer diagnoses in 2008 (latest year available).<sup>15</sup> Efforts to increase the percentage of patients with heart failure who are referred to hospice are slowly increasing. For the time being, national hospice enrollment statistics for patients with heart failure range has stabilized from roughly 8% to 12%.<sup>15, 34, 35</sup>

For patients with heart failure who are admitted to hospice, the national median length of stay is only 15 days (mean is 58 days). In other words, 50% of the heart failure patients received roughly 2 weeks or fewer days of hospice care. To judge the effectiveness

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of hospice care for patients with heart failure based on a 15 day “dose” of hospice is hazardous: to judge effectiveness of a program is premature. A short hospice length of stay may preclude thorough assessment and adequate symptom management. Further research is essential to determine the length of stay that will have the most impact on heart failure patients and their families as well as to determine key heart failure outcomes.<sup>36, 37</sup> From the perspective of bereaved family members, being admitted to hospice “too late” resulted in deficiencies in the desired physical and psychological comfort for the patients, lower coordination of services, and less satisfaction with care.<sup>37</sup> It is unlikely that patients with short-length of stays will receive the full range and benefits of hospice services.<sup>38</sup>

In one study of hospice and heart failure patients, 37% were admitted the last week of life with 9% admitted actively dying.<sup>39</sup> Functional status was extremely poor at admission and in many cases, patients’ required total care. Examination of the patient’s hospice records revealed that while the pharmacological management was not consistent with national standards, patient symptoms were routinely managed with morphine derivatives. There was small evidence of potential benefit for heart failure patients in hospice. The patients in hospice had fewer episodes of pain than demonstrated in previous studies.<sup>10, 39</sup> Whether or not this was due to the pharmacological management or merely to the poor functional status of the patients was unclear. Nevertheless, morphine derivatives commonly prescribed in hospice settings has been also shown to be effective as a palliative agent when used to relieve dyspnea in patients with advanced heart failure.<sup>40, 41</sup>

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All of these, problems with timing, perceptions of hospice, and limited length of stay have resulted in the charge to improve palliative care for heart failure patients in general, that would be provided outside formal hospice agencies.<sup>23, 30, 42</sup> Key components of palliative care traditionally associated with hospice can be and must be delivered outside of hospice settings. Symptom management strategies commonly used in hospice (such as use of morphine derivatives for pain and dyspnea), may be effective outside of hospice settings and should be considered.

The Center to Advance Palliative Care (CAPC) has developed protocols to improve palliative care across the continuum of care regardless of the healthcare setting.<sup>43</sup> These protocols can facilitate hospice-hospital partnerships, develop palliative care in critical care units and create fiscally viable palliative care programs in long term care and community based programs. Each of these can help improve care for patients with serious illnesses and their families. CAPC has also developed a website (<http://www.getpalliativecare.org/home>) that provides comprehensive palliative care information for people coping with serious illnesses. At this site is a detailed description of palliative care and an interactive questionnaire for use in determining whether palliative care would help. A directory of palliative care programs nationwide is provided.

Clinicians who wait for dramatic signals that indicate the end of life prior to referral for palliative care may deny patients and their families the care they should receive. Palliative care for patients with advanced heart failure is vitally important whether or not death is believed to be imminent.<sup>44</sup> To improve care for patients with advanced heart failure,

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there is the opportunity to utilize a palliative care approach whether or not the patient meets the six month prognosis marker required to receive the hospice benefit. Systems of care that provide the best outcomes should guide practice. As palliative care programs mesh with hospice programs, there can be a seamless transition for patients to receive best practice care from the time of diagnosis to death, regardless of setting or prognosis.

Table 1: Broad Comparison of Hospice and Palliative Care

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Provision	Hospice	Palliative Care
Holistic approach	Initiated at enrollment in the hospice system of care	Initiated at onset of a life-threatening illness
Expertise in symptom management	Yes	yes
Use of interdisciplinary care	Yes	yes
Advanced communication skills through home, nursing home, and hospital settings	Yes	yes
Emphasize importance of bereavement care	Yes	yes
Prognosis	Requires written certification of estimated six month prognosis for reimbursement. Patients may be recertified at the end of the six month period or discharged from hospice if no longer declining in health.	Does not require estimate of prognosis.

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**Heart Disease**

Patients will be considered to be in the terminal stage of heart disease (life expectancy of six months or less) if they meet the following criteria. (1 and 2 should be present. Factors from 3 will add supporting documentation.):

1. At the time of initial certification or recertification for hospice, the patient is or has been already optimally treated for heart disease or are patients who are either not candidates for surgical procedures or who decline those procedures. (Optimally treated means that patients who are not on vasodilators have a medical reason for refusing these drugs, e.g., hypotension or renal disease.)
2. The patient is classified as New York Heart Association (NYHA) Class IV and may have significant symptoms of heart failure or angina at rest. (Class IV patients with heart disease have an inability to carry on any physical activity without discomfort. Symptoms of heart failure or of the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.) Significant congestive heart failure may be documented by an ejection fraction of  $\leq 20\%$ , but is not required if not already available.
3. Documentation of the following factors will support but is not required to establish eligibility for hospice care:
  - a. Treatment resistant symptomatic supraventricular or ventricular arrhythmias;
  - b. History of cardiac arrest or resuscitation;
  - c. History of unexplained syncope;
  - d. Brain embolism of cardiac origin;
  - e. Concomitant HIV disease.

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