

Chapter 12

Palliative Care of the Right Heart



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Case

A 57 year-old male with long-standing non-ischemic cardiomyopathy with left ventricle ejection fraction (LVEF) of 10% presented with acute decompensated heart failure (HF) in the setting of atrial fibrillation with rapid ventricular response. Initially, he required inotropic support (milrinone), which was successfully discontinued after atrioventricular node (AVN) ablation with biventricular pacemaker-defibrillator implantation.

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L. Tsao, M. E. Afari (eds.), *Clinical Cases in Right Heart
Failure*, Clinical Cases in Cardiology,

https://doi.org/10.1007/978-3-030-38662-7_12

12.1 What Are the Indications for Palliative Care Referral?

Palliative care enables patients to receive goal-directed therapies consistent with their values and preferences. A diagnosis of HF portends an increased mortality risk, high symptom burden, and frequent need for complex medical decision-making throughout the course of the illness. Historically, palliative care and curative treatments have been mutually exclusive, but best practice would involve the provision of symptomatic and disease-directed treatments concurrently. Therefore, palliative care should be integrated early in the disease course and becomes increasingly more important as the illness progresses and/or as the intensity of proposed disease-directed interventions increases [1]. Specific indications for specialty palliative care referral include New York Heart Association (NYHA) Class IV disease, multiple comorbid illnesses (including renal failure, metastatic cancer, and dementia), and frailty or worsening functional status (Fig. 12.1). Another indication for specialty palliative care referral would be at important decision points along the illness trajectory, such as when considering major invasive interventions such as mechanical circulatory support [2] or shifting the focus of care to emphasize the quality of life rather than life prolongation. The patient featured in this case would qualify for palliative care based on multiple factors, including: his acute presentation of symptomatic HF; high mortality risk on the basis of low LVEF; the need for inotropic support; and consideration of invasive procedures and device implantation.

12.2 What Is the Role of Palliative Care in the Management of ACC-AHA Stage C Patients?

Palliative care has a role throughout the trajectory of heart failure regardless of patients' goals of care, and becomes more important as HF progresses [3]. Palliative care in cardiology is unique as the goals of even the most aggressive treat-

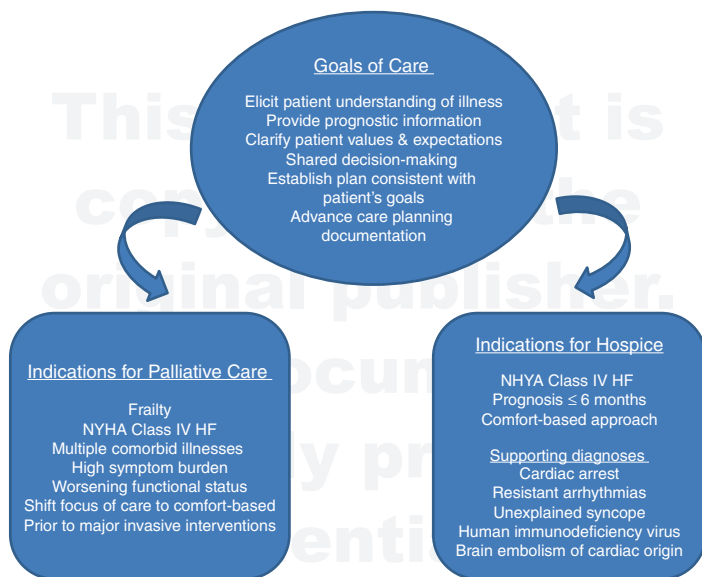


FIGURE 12.1 Description of components of goals of care discussions and indications for palliative care and hospice care in patients with HF

ment of HF are often palliative in nature. Patients classified as ACC-AHA Stage C may benefit from specialty palliative care to help treat symptoms commonly reported in this population, including but not limited to fatigue, dyspnea, depression, and anxiety. Palliative care is also indicated in this stage of disease to help the patient identify surrogate medical decision-makers and complete advance directives, provide anticipatory guidance regarding illness trajectory and prognosis, and participate in shared decision-making around complex medical decisions. Our patient would benefit from early palliative care to assist with both symptom management and medical decision-making, and would continue to benefit from palliative care at varying levels of involvement throughout the disease trajectory (Fig. 12.2) [4].

The traditional model of palliative care involved patients receiving curative care (example: diuresis, inotrope support,

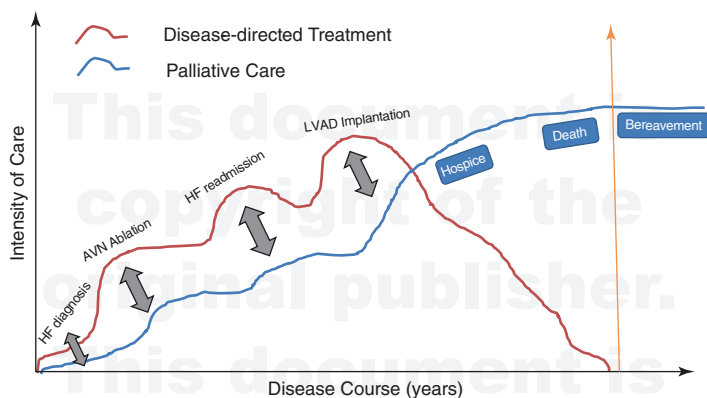


FIGURE 12.2 The contemporary overlapping model of palliative care requires the involvement of palliative care concurrently with disease-directed treatment. The timeline of the patient's disease process is shown with a highlight of the many opportunities that the palliative and supportive care team could be engaged. The x-axis indicates the disease progression over time and the y-axis signifies the intensity of care. The blue line indicates palliative care involvement and the red line indicates heart failure disease trajectory. Arrows indicate opportunities for palliative care involvement

devices for HF patients) until treatment failure, at which point patients received palliative care. The more contemporary overlapping model entails involvement of palliative care concurrently with disease-directed treatment upon diagnosis with a serious illness, with varying involvement of palliative care throughout the disease process (more involvement during disease exacerbations, important decision points, and as disease progresses) [5].

12.3 Which Resources Are Available for Heart Failure Patients and Caregivers?

Caring for patients with HF is time and resource-intensive. The patient in this case may need assistance with instrumental

activities of daily living, transportation to and from appointments and procedures, assistance with medication management, and emotional support as he grapples with adjusting to limitations resulting from his medical condition. Caregivers must be vigilant to avoid caregiver burnout and have access to appropriate resources to support both the patient and themselves. This support may take the form of peer support, palliative and supportive care, and community and governmental resources to help care for patients in the home.

For more information about how to find palliative care: <https://getpalliativecare.org/resources/>

For information for caregivers: <https://www.cardiosmart.org/For-Caregivers/Resources-for-Caregivers>

For information on how to get more help in the home: <https://eldercare.acl.gov/Public/Index.aspx>

For information about planning for advanced heart failure: <https://www.heart.org/en/health-topics/heart-failure/living-with-heart-failure-and-managing-advanced-hf/planning-ahead-advanced-heart-failure>

Case Continued

Over the next 6 months, the patient was readmitted monthly for decompensated HF. He was typically admitted with worsening shortness of breath and lower extremity edema. His wife noted that he has been depressed lately. On his most recent admission, he was diagnosed with severe biventricular failure requiring milrinone support, and the heart failure specialists initiated a discussion with the patient and his wife regarding whether to place a left ventricular assist device (LVAD).

12.4 What Is the Role of Palliative Care in the Management of Symptoms for ACC-AHA Stage D Patients?

Symptom management is a central tenet of palliative care. The patient in our case is likely to experience a range of

symptoms including depression, anxiety, fatigue, and dyspnea. These symptoms can be optimally managed with a multidisciplinary approach including but not limited to the patient's primary cardiologist, specialty palliative care providers, and a psychosocial support team.

The palliative care team can collaborate with the HF team to facilitate interventions designed to both improve symptoms and optimize treatment of heart failure. As the patient in our case experiences more frequent hospitalizations throughout his illness trajectory, he may benefit from ambulatory intravenous furosemide and or ambulatory inotropes to enhance his quality of life through reduced symptom burden and avoidance of hospitalizations. In clinical practice, subcutaneous furosemide has been used in the hospice population for symptom amelioration for many years and has been helpful to prevent hospital readmission in the palliative care population. There is emerging data to suggest that ambulatory subcutaneous furosemide may benefit patients with decompensated HF [6]. Limited data suggests that ambulatory inotropes may improve ACC-AHA functional class without impacting survival [7]. For patients who are interested in a more comfort-based approach to care and wish to avoid further aggressive disease-directed treatments, we advocate for Palliative Care involvement, including discussion of transition to hospice care [8, 9].

12.5 What Is the Process for Obtaining Informed Consent and Initiating Shared Decision Making for Cardiac Device Implantation?

Ideally, pre-implantation palliative care consultation would result in a comprehensive evaluation of the patient's values and preferences for care along with identification of surrogate decision-makers. These discussions should lead to completion of advance care planning documents such as a healthcare proxy/durable power of attorney for healthcare

(HCP/DPOA) and physician orders for life-sustaining treatment (POLST). Such consultation would also allow for discussion of the tenets of informed decision-making (assessment of patient understanding, involvement of surrogate decision-makers where indicated, discussion of impact of interventions on daily life, and risks, benefits, side effects, and alternatives to the procedure) [10].

In 2013, Centers for Medicare & Medicaid Services (CMS) in the United States of America, issued a national coverage determination with the requirement that patients undergoing surgery for destination LVAD therapy must have access to palliative care prior to device implementation [11]. This mandate has resulted in the widespread integration of palliative care consultation into the workflow at heart transplant centers across the country. Unfortunately, however, palliative care consultation during the pre-implantation period is frequently limited to a perfunctory one-time palliative care encounter, which has not been shown to improve advanced care planning as desired [12].

12.6 How Should Goals of Care Be Approached in this Patient?

All patients with life-limiting or serious illness benefit from goals of care conversations. Early goals of care conversations, preferably with a clinician who is familiar with the patient, are associated with multiple favorable outcomes including improved quality of life and an increase in care concordant with patient wishes [13]. The general approach to a goals of care conversation centers on eliciting patient understanding of illness, providing accurate prognostic information, clarifying patient values, expectations, and hopes, and establishing a plan consistent with patient goals in the context of medical reality.

Unfortunately, initial palliative care consultation frequently occurs in the hospital setting when patients are actively dying or have nearly reached end-of-life. Delayed

TABLE 12.1 Common barriers to initiation of goals of care conversations related to patient, physician, and system-specific factors

Barriers to goals of care conversations		
Patient	Physician	System
Lack of knowledge	Lack of training	Lack of infrastructure and training
Unaware of need for conversation	Perceived lack of time	Lack of financial incentive
Cultural barriers	Cultural barriers	Cultural barriers
	Fear of taking away hope	

consultation can deprive patients and their families of the time to build rapport with palliative care providers and comprehensively contemplate, discuss, and document advance directives. The delay in timely palliative care consultation may be due to barriers to effective patient-physician communication stemming from physicians, patients, and the health-care system (Table 12.1). Medical providers are often hesitant to discuss goals of care for fear of taking away hope or upsetting their patients or families and because of their own discomfort with the conversation due to inadequate training in communicating about goals of care [14]. Physicians also avoid such conversations because of a perceived lack of time or failure to recognize opportunities to have goals of care conversations (such as a significant change in clinical status or important clinical decision point) [15]. Individual physicians may have their own cultural barriers to discussing end-of-life and also frequently lack prognostic awareness. Patients and their families typically do not broach goals of care conversations because they perceive that it is the physicians' responsibility to initiate the conversation; they are unaware of the need for goals of care conversations; or there are cultural barriers to discussing death [16]. Within the United States healthcare system, work is being done to appropriately train

and reimburse clinicians for having goals of care conversations, but currently there are no systematic practices in place to ensure that patients with life-limiting illness consistently engage in advance care planning [17]. The consequences for not discussing goals of care may be emotionally and financially costly to the patient, family, and healthcare system. Negative sequelae include patients receiving burdensome and non-beneficial care at the end of life that is not concordant with their wishes; families experiencing moral distress, depression, and complicated grief as they are forced to make complex medical decisions for their actively dying relatives without their input, and a huge financial burden to the healthcare system as patients receive costly, aggressive treatments at the end of life [18].

In the case of our patient, goals of care conversations should have been initiated early and repeated frequently throughout the clinical course. Upon diagnosis with HF, goals of care conversations to discuss illness trajectory, overall prognosis, and to assign surrogate decision-makers would have been appropriate. Throughout his course, our patient has had several decision points and changes in clinical status where further goals of care conversations would have been appropriate, including prior to pacemaker implantation, during initiation of inotropes, or simply during one of his many inpatient hospital stays (Fig. 12.2). The focus of goals of care conversations changes over time as patients' clinical scenarios and values shift, so frequent re-examination of goals of care is warranted in patients with chronic life-limiting illnesses such as our patient.

Case Continued

Our patient received an LVAD for biventricular failure refractory to inotrope support. His post-operative course was complicated by persistent right ventricular failure despite maximum medical therapy. The patient and his family subsequently decided to avoid further aggressive interventions, including heart transplant.

12.7 What Are the Indications for Hospice in Patients with Heart Failure?

The indications for hospice are, in general, a desire to pursue a comfort-based approach to care and a prognosis of 6 months or less if the disease runs its expected course (Fig. 12.1). Patients with heart disease who meet criteria for hospice care have typically already been optimally treated for heart disease, are not candidates for surgical procedures, or decline these procedures and are NYHA Class IV along with a prognosis of 6 months or less. Supporting diagnoses include history of cardiac arrest, treatment for resistant symptomatic arrhythmias, history of unexplained syncope, history of brain embolism of cardiac origin, and concomitant human immunodeficiency virus. In the United States, criteria for hospice eligibility for cardiac diseases are guided by Medicare and depend on Local Coverage Determination guidelines, which vary regionally.

12.8 What Are the Challenges Associated with Managing an Advanced Heart Failure Patient on Hospice?

Once patients have elected the hospice benefit, they opt to forgo disease-directed treatments in favor of focusing on symptom palliation. Somewhat unique to the field of cardiology is the concept that many interventions that are aggressive disease-directed treatments also result in symptom palliation. Some of these interventions are costly, which can be challenging for hospice agencies to sustain. Additionally, patients who are on hospice typically wish to avoid re-hospitalization, which can be complex as some of the interventions for symptom palliation can only be performed on an inpatient basis or require significant involvement of the primary team. In our patient, for example, continuing to manage his LVAD while on hospice would require seamless communication between

the hospice team and the mechanical support team to ensure appropriate symptom management, device management, and transparency regarding prognosis and goals of care. Furthermore, such management would be costly to the hospice agency, who would bear the full burden of financial responsibility for the patient's care.

12.9 Discuss the Ethical Dilemma Surrounding Cardiac Device Deactivation or Explant?

Whenever considering an intervention, risks and benefits must always be considered. Ethically, discontinuing an intervention is considered to be equivalent to never initiating the intervention in question [19]. Therefore, deactivating an automatic implantable cardioverter-defibrillator (AICD) at the end of life is considered ethically acceptable, and is not considered euthanasia or physician-assisted suicide. When discussing preferences around device deactivation, it is important to be sensitive to cultural considerations and religious beliefs around end-of-life care.

12.10 Palliative Care in Pulmonary Arterial Hypertension and Right Heart Failure

An increasing, though less common, presentation of right heart failure is isolated pulmonary arterial hypertension (PAH) with initiating pathologic changes inherent to the pulmonary vasculature in the absence of precedent left HF. Diagnosis is frequently delayed, as early nonspecific symptomatology of fatigue, anorexia, bloating, dyspnea, and tachycardia may be confused for more common illnesses, adding potential for care provider distrust by the patient and family. Progressive symptom burden, low cardiac output, and mortality have been ameliorated by the advent of disease-

targeting therapies (including endothelin-receptor antagonists, phosphodiesterase-5 inhibitors and prostacyclin analogues), which carry a high burden of side effects and cost. The average survival from the time of diagnosis may reach 7–10 years, with wide variation based upon a variety of biometric factors. Early clinical improvement and sense of well-being despite low physical reserve and overall poor prognosis with such disease-modifying therapies can be accompanied by unrealistic hopes and expectations by the patient and family, as the disease course and trajectory remains unpredictable. The patient in Chap. 7 also needs an early palliative care consult for the reasons enumerated in this chapter.

Patients with right heart failure in the setting of PAH face disease-related symptoms, loss of hope and emotional changes, and waxing and waning functional debility. These challenges are prevalent, yet remain under-recognized, under-reported and under-treated. The progression of PAH is frequently met with multiple-organ system decline, and these patients are considered high-risk for organ transplantation.

Longitudinal palliative care involvement for patients with PAH has been suggested to assist in iterative patient and family prognostic awareness and determination of goals of care and decision-making, development and implementation of coping tools, mood assessment and therapy, non-disease-targeting symptom management, and advanced care planning [20, 21]. Lack of formal PAH-specific criteria for hospice enrollment and the inherent complexities of maintaining or de-prescribing PAH-targeting pharmacotherapies, suggest that palliative care involvement to assist throughout clinical deterioration would be a high-value intervention.

Case Conclusion

After shared decision-making between the patient, his family and the medical staff, he was transitioned to hospice. He reported significant improvement of his quality of life. His family managed his diuretic therapy at home, and despite an overall poor anticipated prognosis of weeks to months, he was still alive 1 year later.

Clinical Pearls

- Palliative Care is indicated upon diagnosis of heart failure and should be provided concurrently with disease-directed treatment.
- Palliative Care is an integral part of the multidisciplinary team caring for patients with HF. Palliative Care can contribute to the interdisciplinary team by providing psychosocial support to the patient and family; initiating symptom management for a range of symptoms including depression, anxiety, fatigue, and dyspnea; and engaging the patient in early and frequent discussion of goals of care.
- Hospice care is appropriate for patients with HF who have a prognosis of 6 months or less who have already been optimally treated for heart disease, are not candidates for surgical procedures, or decline these procedures and have NYHA Class IV disease.
- CMS has issued a requirement that patients undergoing surgery for destination LVAD therapy must have access to palliative care prior to device implementation, which has resulted in palliative care consultation during the preimplantation period that is frequently limited to a perfunctory one-time palliative care encounter and has not been shown to improve advanced care planning as desired. Patients qualifying for mechanical support benefit from early, longitudinal palliative care involvement.
- Patients with right heart failure in the setting of PAH face a high mortality risk, burdensome symptoms, and an unpredictable disease trajectory, and would benefit from early involvement of palliative care.

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