Failing the Failing Heart: A Review of Palliative Care in Heart Failure

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Heart failure (HF) is the most common reason for hospital admission for patients older than 65 years. With an aging population and improving survival in heart failure patients, the number of people living with HF continues to grow. As this population increases, the importance of treating symptoms of fatigue, dyspnea, pain, and depression that diminish the quality of life in HF patients becomes increasingly important. Palliative care has been shown to help alleviate these symptoms and improve patients’ satisfaction with the care they receive. Despite this growing body of evidence, palliative care consultation remains underutilized and is not standard practice in the management of HF. With an emphasis on communication, symptom management, and coordinated care, palliative care provides an integrated approach to support patients and families with chronic illnesses. Early communication with patients and families regarding the unpredictable nature of HF and the increased risk of sudden cardiac death enables discussions around advanced care directives, health care proxies, and deactivation of permanent pacemakers or implantable cardioverter defibrillators. Cardiologists and primary care physicians who are comfortable initiating these discussions are encouraged to do so; however, many fear destroying hope and are uncertain how to discuss end-of-life issues. Thus, in order to facilitate these discussions and establish an appropriate relationship, we recommend that patients and families be introduced to a palliative care team at the earliest appropriate time after diagnosis.


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Published reviews of palliative care in HF have initiated discourse regarding its role and justification. These reviews include detailed analysis of the pathophysiology of HF symptoms and available treatment options in addition to stressing the importance of end-of-life communication with patients and families. Our aim is to provide an update on the role of palliative care in HF patients, including the current state of palliative care involvement in HF, potential impact on quality of care, palliative care models, and symptom management. In addition, we discuss guidelines regarding device deactivation and the role of palliative care in facilitating these discussions. This should be of interest to any practitioner who treats HF patients as palliative care involvement in those with life-limiting illnesses has been shown to improve quality of life, reduce symptoms, and increase patient and family satisfaction with the care they receive.

To identify studies of palliative care in HF, we searched the Medline database for literature with the subject headings “heart failure” and “palliative care” from 1996 to current, which led to 220 results. After limiting it to English language only, we were left with 209 results; 44 were nonrelated, 2 were based on costs, 4 on prognostication, 37 on management of HF, and 122 on palliative care/hospice in HF.

Current State of Palliative Care Involvement
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Palliative medicines’ role in HF treatment is beginning to gain recognition by national entities, which may improve its utilization going forward—the American College of Cardiology/American Heart Association (AHA) HF guidelines included palliative care referral as a class I recommendation (Level of Evidence C) for patients with HF at the end of life for the first time in their 2005 guideline update.27

Potential Impact on Quality of Care
Evidence of the impact of palliative care on quality of care is growing and spans from subjective metrics such as patient satisfaction to objective metrics such as length of stay. In a study of patients with multiple organ failure, palliative care involvement was associated with fewer invasive procedures and interventions at the end of life, decreased length of stay, and shorter admissions to intensive care units.28 A recent retrospective telephone survey with family members of veterans who received palliative care demonstrated higher scores for emotional and spiritual support, access to home care services, access to benefits after a patient’s death, and adequacy of communication.29

Studies in cancer patients and those with life-limiting illnesses suggest that the involvement of palliative medicine improves patient and family satisfaction with care and symptom management.15–17 In a recent cross-sectional study comparing symptomatic HF and cancer patients, the authors suggest that HF patients may benefit from palliative care as much as cancer patients.29 The study shows that end-stage HF patients had higher symptom burden (eg, fatigue, pain, dyspnea), depression scores, and lower spiritual well-being than cancer patients. Another study comparing HF and cancer patients suggests similar quality of life and emotional well-being; however, a lower satisfaction with information and communication among HF patients. These authors propose that there is a palliative transition point at which HF patients would benefit from palliative care.30

Palliative Care Model
The traditional palliative care model is based on patients with illnesses that have predictable trajectories, where patients have steady declines followed by a short terminal phase. This type of model allows for the initiation of palliative care at a planned time for all patients. The traditional model cannot be applied to HF due to the risk of sudden death and the natural history of disease, which is characterized by acute decompensations followed by periods of stability.31

Despite many prognostic models, we still cannot reliably predict who is at risk for sudden death or the terminal phase of HF. Many prognostic models and markers for survival are valuable at the population level but not at the individual level. The Seattle Heart Failure Model predicts 1-, 2-, and 5-year survival based on clinical, laboratory, and medication data without assessing hemodynamics or cardiac capacity.32 This model also allows one to predict effects on survival by adding or removing interventions such as a β-blocker or implantable cardioverter defibrillators (ICD) (online calculator available at: http://www.SeattleHeartFailureModel.org). Other prognostic measures range from single-item predictors, such as the 6-minute walk test,33 B-type natriuretic peptide,34 peak cardiac power,35 and maximal oxygen consumption,36 to multivariable models.37–39 The Heart Failure Survival Score38 is used for risk stratification in the evaluation for cardiac transplantation and has been shown to be effective for patients with or without β-blockade.39,40

Given the inability to predict prognosis at the individual level and the natural history of HF, patients and their families should be introduced to the palliative care team at the earliest appropriate time after diagnosis. Although the involvement of palliative care specialists will not likely be required at the onset of diagnosis, establishing a relationship can be beneficial for future interactions. When the disease course progresses, the palliative care team initiates the appropriate care and assistance in collaboration with the life-prolonging treatments offered by cardiologists. This departure from the traditional model—initiating discourse with patients and families regarding the natural course, prognosis, and inevitable end-of-life issues as early as at the time of diagnosis41—is reinforced by the World Health Organization (WHO). The WHO states that palliative care should be used “early in the course of illness, in conjunction with other therapies that are intended to prolong life,” as it “improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering.”42

In addition to the timing of consultation, there is the question as to who should be providing palliative care. Palliative care describes a multidisciplinary approach that addresses both the symptomatic and psychosocial aspects of HF therapy with the assistance of physicians, nurses, and social workers.
specifically trained in palliative medicine. The multidisciplinary team can be expansive, including chaplains, massage therapists, pharmacists, and nutritionists. Although likely most effective, this model may not be practical in many care settings. In the long term, cardiologists may have to learn aspects of the palliative care skill set to ensure optimal treatment of HF patients, relying on the multidisciplinary teams for more intensive interventions.

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Role in HF Symptomatology

HF patients have a myriad of symptoms, including dyspnea, fatigue, pain, and depression, that lead to a diminished quality of life. Multiple therapies have proven to be effective in alleviating these symptoms. With a focus on improving patient satisfaction and quality of life, palliative care involvement can assure that HF patients receive the appropriate available palliative treatments to minimize symptoms.

A recent review by West and colleagues recommends that the Likert scale and Visual Analog Scale be used to measure dyspnea in acute HF syndromes as they have been established as being the best combination of valid, reliable, and easy-to-use instruments. Loop diuretics given for volume overload improve exertional capacity and decrease dyspnea. Oral opioids have been shown to improve dyspnea both acutely and chronically in patients who are New York Heart Association (NYHA) class II to IV. Opioids have improved ventilatory response to exercise, both by causing vasodilation and through their anxiolytic properties. In addition, actions on opioid receptors in the brain can change patients' perception of dyspnea. Benzodiazepines may also be useful in patients with panic attacks associated with breathlessness. For those patients who develop resistance to diuretics or suffer from acute decompensations with fluid overload, ultrafiltration may be a safe and effective alternative. The use of angiotensin-converting enzyme inhibitors has been shown to improve a HF patient’s duration of exercise in addition to also improving patient ratings of dyspnea, fatigue, orthopnea, and edema when compared with placebo in a double-blind, randomized trial using captopril. In addition, data from the Prophylaxis of Thromboembolism in Critical Care Trial (PROTECT) suggest that the adenosine A receptor antagonist rolifylline improves weight loss and achieves early dyspnea relief compared with placebo—potentially surfacing as another viable treatment option in the near future.

Patients with symptoms of fatigue should be evaluated in the same manner as those without HF: treat anemia, infection, dehydration, electrolyte imbalances, thyroid dysfunction, and depression. When appropriate, patients should be screened for sleep-disordered breathing, given its high prevalence among HF patients. If present, patients should be placed on continuous positive airway pressure while sleeping to minimize fatigue and improve their emotional function. Testosterone supplementation therapy has been shown to improve exercise capacity, muscle strength, and peak oxygen consumption in men and women with NYHA functional class II or III HF. Opioids have been suggested for use as first-line agents for treatment of moderate to severe pain. Therapy should be initiated with a short-acting agent to determine total daily requirements and then transitioned to long-acting agents. Opioids are traditionally avoided or used sparingly for risk of addiction; however, studies demonstrate that the risk of addiction in terminally ill patients is low. Other treatment methods, including acupuncture, music, and exercise, may be beneficial, but have not been validated in HF patients. Nonsteroidal anti-inflammatory agents should be avoided due to potential precipitation of acute renal failure, fluid retention, and the risk of gastrointestinal bleeding.

It is estimated that approximately 30% of patients with HF have depression. These patients have also been shown to have poorer HF outcomes. Recent guidelines from the AHA Science Advisory Committee advocate screening patients with coronary heart disease for depression with the two-question Patient Health Questionnaire (PHQ-2). Studies have suggested that a score ≥ 3 in the PHQ-2 is 83% sensitive and 92% specific for major depression; thus, those with a score ≥ 3 should then be given the nine-item PHQ. Patients with a score < 10 on PHQ-9 can be offered support and follow-up within 1 month; those with a score ≥ 10 should be referred to a mental health specialist. In general, nonpharmacologic treatments for depression, such as psychotherapy,
cognitive behavioral therapy, and exercise, should be attempted and may be beneficial. However, when pharmacologic agents are initiated, selective serotonin reuptake inhibitors (SSRIs) are generally used as first-line agents. SSRIs are effective and have fewer side effects and medication interactions than alternative agents—critical attributes in a population that is burdened by polypharmacy.

Many patients progress to being symptomatic at rest despite medical therapy. With few alternatives available, studies have evaluated the role of inotropes in chronic treatment of HF and their impact on morbidity and mortality. A study using continuous outpatient inotropic agents in 36 patients with end-stage HF (ie, AHA stage D) demonstrated improved ability to ambulate. In addition, attempts to discontinue inotropes led to worsening dyspnea, hypotension, and renal dysfunction, leading the authors to conclude that continuous outpatient treatment with inotropes may be acceptable for patients with stage D disease.

In a retrospective study, chronic intravenous (IV) inotropes (dobutamine and milrinone) were associated with reductions in days hospitalized at 30, 60, and 180 days after drug initiation, but were associated with high mortality rates of 42.6% and 56.8% at 6 and 12 months, respectively. Another retrospective study comparing mortality of patients discharged on chronic IV milrinone versus milrinone showed no statistically significant difference in mortality at mean follow-up of 95 days, 77% and 74%, respectively. Data suggesting that continuous chronic inotrope use may increase mortality do not clearly document if these patients have an ICD in place. Because of improvement in symptoms, inotropic therapy is listed as a IIb indication for patients with refractory symptoms in the 2009 updated AHA/American College of Cardiology Foundation (ACCF) guidelines for diagnosis and management of HF. Continuous IV support may provide palliation of symptoms as part of an overall plan to allow the patient to die comfortably at home.

End-of-Life Decisions

Traditionally, goals of therapy are to provide life-extending therapies and to alleviate symptoms related to HF. However, goals of treatment must be readdressed as HF progresses. Medical devices such as permanent pacemakers (PMs) and ICDs that are beneficial early in the course of disease may no longer be indicated or desired by patients with disease progression. Discontinuation of such therapies may actually improve quality of life for some patients. The 2009 AHA/ACCF guidelines for diagnosis and management of HF recommend that patients with refractory end-stage HF and implantable defibrillators should receive information about the option to inactivate the defibrillator (class I, Level of Evidence C). Palliative care specialists can assist with providing the appropriate information and providing patients and families with the resources necessary to make the most informed decisions.

With a growing number of patients having a PM or ICD inserted and an increasing proportion of our population being > 65 years, there has been much discussion about the ethical and legal implications of deactivating such devices at the patient’s request. Surveys completed by electrophysiologists and device manufacturer representatives suggest that practitioners are more likely to deactivate ICDs than PMs, presumably because ICD deactivation does not result in immediate death, whereas PM deactivation can be followed by bradycardia and imminent death. Retrospective reviews of requests by patients or their surrogates to withdraw PM or ICD demonstrated how assistance of ethical consultation and reinforcement of the ethical and legal permissibility of withdrawing PM or ICDs decreased clinician reluctance to grant patients’ wishes.

It has been > 50 years since the first implantation of a PM and 30 years since the ICD has been used clinically, and there have been no consensus statements published regarding deactivating these devices until recently. With evidence suggesting that about 20% of ICD patients receive painful shocks that decrease their quality of life and research acknowledging that physicians possess a limited understanding of the ethical and legal implications of deactivating a device, the Heart Rhythm Society recently published a consensus statement. Example principles read as follows:

- A patient with decision-making capacity has the legal right to refuse or request the withdrawal of any medical treatment or intervention, regardless of whether she or he is terminally ill, and regardless of whether the treatment prolongs life and its withdrawal results in death.
- Ethically and legally, there are no differences between refusing cardiovascular implantable electronic devices (CIED) therapy and requesting withdrawal of CIED therapy.
- Legally, carrying out a request to withdraw life-sustaining treatment is neither physician-assisted suicide nor euthanasia.

VADs have resulted in clinically meaningful survival benefit and...
that is associated with a multitude of symptoms and increased risk of sudden cardiac death. Studies in cancer patients and those with chronic illnesses have shown that palliative care involvement has been shown to improve quality of care (eg, decrease the number of interventions and length of hospitalization, and potentially improve morbidity). Despite its benefits, studies have shown that palliative care is underutilized and, when used, tends to be late in the course of disease, decreasing its effectiveness and patient and family satisfaction. Palliative care should be initiated early in the course of the disease process to help with symptom relief, enhance communication, provide patients and families with realistic goals, and discuss withdrawing of care when appropriate. Palliative care education and awareness for health care workers must be expanded and possibly be made as the standard of care for HF patients.

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management approach for patients with severe HF. However, patients with VADs are still at risk for serious complications, and discussion of end-of-life care and reassessment of goals must be addressed. A retrospective study performed at the Mayo Clinic (Rochester, MN) reviewed cases of patient requests to withdraw VADs. The authors concluded that the right to request VAD withdrawal is part of a patient’s right to refuse or request to withdraw any unwanted treatment and is no different than withdrawing mechanical ventilation or hemodialysis.

Conclusions

HF is a multifaceted syndrome with a prolonged course of illness. By not offering HF patients the benefits of palliative care, we are failing to provide them and their families with the best therapeutic options for symptom management and optimal communication about their disease state. This leads to suboptimal quality of care, irrespective of the life-prolonging treatments that these patients are receiving; in short, we are failing the failing heart.

The authors report no conflicts of interest.

References

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