

# A Palliative Care Approach to the Advanced Heart Failure Patient

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**Abstract:** Congestive heart failure can become a debilitating, terminal illness in many patients despite maximal medical therapy. Patients with advanced heart failure have persistence of severe clinical symptoms limiting their daily life, marked left ventricular systolic dysfunction, and poor exercise capacity. Although individual disease trajectory in these patients can be difficult to predict, overall mortality remains high despite recent advances in medical and surgical therapy. Palliative care should be considered for patients with high mortality estimates, especially those patients with a one-year survival estimate of less than 25% who are not candidates for cardiac transplantation or destination mechanical support. Palliative models for heart failure management shift the focus of care from curing this debilitating disease to managing symptoms and incorporating treatment based on patient quality of life and survival goals. This article discusses strategies for identifying and treating reversible causes of heart failure, for treating rhythm disturbances, and for maintaining hemodynamic stability. Confounding medical and psychological problems affecting overall patient energy levels and well-being are reviewed. Finally, various venues and sites of care are discussed.

**Keywords:** Palliative care, congestive heart failure, hospice.

## 1. INTRODUCTION

Nearly 5 million adults in the United States carry the diagnosis of congestive heart failure (HF). Of those diagnosed with HF, almost 75% are over the age of 65 years, making this chronic disease a major problem when caring for the expanding elderly segment of the population. Mortality rates have decreased with the use of agents blocking the renin-angiotensin-aldosterone system (RAAS) and sympathetic nervous system. However, regardless of aggressive therapy, HF can become a debilitating, terminal illness. Despite the publication of evidence-based therapies for HF, studies report that patients with advanced heart failure receive inadequate treatment for common HF symptoms [1-3]. Cardiologists have begun to recognize the need for palliative care in the management of heart failure [4]. With prognosis being difficult to predict, determining which therapies to implement for the advanced HF patient can be overwhelming. This paper will outline the major treatment choices when using a palliative care focus in the management of the advanced heart failure patient.

## 2. DETERMINING ADVANCED HEART FAILURE AND PROGNOSIS

There is not a consistent definition or set of criteria to identify patients having advanced heart failure. The new guidelines for HF management call for patients to be classified according to progressive stages of symptoms and structural heart disease [5, 6]. The new staging classification system uniquely pairs the patient's stage with advancing symptoms, progressive structural changes, and specialized treatments. Stage D patients have advanced structural heart disease and refractory symptoms that require specialized

treatment. These patients have the most advanced HF in the classification system. In addition to being categorized as Stage D heart failure, current literature suggests the definition for advanced heart failure should also include: 1) the persistence of severe clinical symptoms limiting daily life despite maximal therapy (classified as either New York Heart Association [NYHA] Class III or IV), and 2) marked left ventricular dysfunction (such as ejection fraction of 25% or less) [7, 8].

Terminal HF patients are at the end of the care continuum. In this review, terminal heart failure patients will be considered those patients who are close to dying. "End of life" for advanced heart failure is a subjective time assessment of the patient's final deterioration and can indicate a life span of days or many months. The paper will not discuss those patients who are considering heart transplant or ventricular remodeling as treatments for their advanced heart failure.

One of the most difficult problems in guiding care is estimating prognosis. Disease trajectory, or the rate of inevitable decline from heart failure, is unpredictable, unlike the charted prognostic course of most cancers. Survival has steadily improved with modern therapies, but the risk of death in patients with advanced CHF can be as high as 30-40% annually [9]. Scores to predict 1-year survival estimates have identified variables for dilated and ischemic advanced heart failure patients [10]. Other investigators have developed risk scores for patients hospitalized with advanced HF [11]. In general, older, symptomatic patients with a low ejection fraction and limited functional ability (whether measured by a six-minute walk, assessed with the NYHA classification or having limitations with activities of daily living) have a higher risk of dying. Though the listed criteria listed in (Table 1) are not definitive, they can give the care provider a basis for counseling the patient and agreeing on

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**Table 1. Variables Associated with Poor Prognosis for Patients with Advanced Heart Failure:**

<p><b>1. Laboratory data:</b></p> <p>a. Presence of serum sodium less than 136mEq/liter (Alla, 2000, Lee, 2003).</p> <p>b. Serum creatinine of greater than 2.0mg/dL, increased blood urea nitrogen (BUN) (Lee, 2003).</p>
<p><b>2. Functional status:</b></p> <p>a. Six minute walk distance less than 300 meters (Bittner, 1993).</p> <p>b. Dependency with activities of daily living (Walsh, 1997)</p> <p>c. Peak oxygen consumption during exercise testing of less than 14ml/kg/min (4 METS) (Adams, 1998).</p> <p>d. NHYA class III or IV for 3 months (Adams, 1998).</p>
<p><b>3. Symptoms:</b></p> <p>Persistent orthopnea (Lucas, 2000).</p>
<p><b>4. Medical history:</b></p> <p>Comorbid illnesses including chronic obstructive pulmonary disease (COPD), dementia, hepatic cirrhosis, cancer, cerebrovascular disease (Lee, 2003).</p>
<p><b>5. Demographics:</b></p> <p>Age greater than 70 years (Alla, 2000).</p>
<p><b>6. Vital signs:</b></p> <p>Tachycardia, increased respiratory rate, abnormal blood pressure reading (Alla, 2000, Lee, 2003).</p>
<p><b>7. Procedures:</b></p> <p>Ejection fraction of 25% or less (Nohria, 2002, Adams, 1998).</p>

levels of treatment which can include a palliative care focus [7, 8, 12-14].

Patients with high mortality estimates as well as those who have less than a 25% one-year survival estimate can be considered patients who would benefit from palliative care.

### 3. CONSIDERING PALLIATIVE CARE

All patients who are considering adding palliative care to their treatment should be on maximal HF therapy since inappropriate dosing of HF medications can contribute to poor control of symptoms and decreased functional ability. As advanced HF patients begin to experience more hospitalizations and aggressive rescue efforts for HF exacerbations, these patients and their families may want to re-direct the focus of care. Goals to aggressively treat symptoms will remain intact but specifics regarding how and where to treat these patients may be altered. As the patient declines with more severe symptoms and becomes more of a burden to caregivers, goals of care can shift to quality of life rather than quantity of life. This transition can be subtle or drastic, depending on patient preferences, clinical evaluation and social situation. The ultimate goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms, and improvement of functional capacity [15].

Common HF symptoms requiring palliative care management include problems such as breathlessness, activity limitations, fluid retention, nausea, constipation, anxiety, and depression. Palliative measures in heart failure focus on relieving symptoms and improving quality of life and have less emphasis on curing and improving survival. Symptom relieving measures must be evaluated for their impact on survival, overall risk, efficacy and patient preference. Outcome measurements and endpoints become patient-centered and evaluate the effectiveness of treatments on QOL, symptom relief and functional status. Traditional endpoints such as survival, cardiac events and rates of hospitalizations become less important.

Varying levels of palliative care can be incorporated into the patient's treatment plan, depending on patient preferences and clinical assessment. General discussion highlighting palliative choices through enrollment in a hospice program can be appropriate palliative care measures. Incorporation of palliative care into advanced HF treatment is evolving. In general, the estimated chance of death should reflect the amount of time dedicated to planning palliative or end of life care. Even though no guidelines exist to guide the palliative care approach to advanced HF, this paper will review current therapies available and their role in palliative care.

### 4. DISCUSSING TREATMENT GOALS

Symptom control for HF involves a wide variety of treatments ranging from dietary recommendations to invasive procedures. Discussions regarding treatment should include factors such as symptom outcome, burden on patient/caregiver, financial burden, availability of treatment and impact on survival.

Besides gender and cultural differences, patient preferences concerning treatment can be biased depending on their 1) perception of their condition; 2) trust in the health care system or provider and 3) belief in the benefit of life sustaining measures [16]. Advanced HF patients tend to polarize preference either for survival or QOL, with the most symptomatic patients willing to trade time for symptom relief [17, 18].

Reviewing poor prognostic indicators with the patient can generate discussions about their perception of HF stage. The patient will more likely engage in difficult treatment discussions if the provider listens, uses open ended questions and allow them to express their feelings [19, 20]. Patient and family members value nontechnical explanations that are delivered with compassion and kindness. There is no data to support whether a certain discipline or provider should be leading these discussions. Candid discussions on the low survival rates after receiving CPR and rare hospital discharge after resuscitation should be initiated [21]. Outcomes with treatments therapies would be based on patient goals such as satisfaction with symptom relief or improved coping with advancement of chronic HF. Over 75% of chronically ill patients responded that they would not want an offered treatment if the outcome were survival with severe functional and cognitive impairment [22].

Treating symptoms with invasive procedures such as surgery or devices is very challenging, especially with limited trials to guide care. Regarding choice of procedures

in the elderly, we need to be clear on the outcomes they can expect whether it is survival or QOL indicators [23, 24]. For example, patients may opt for a less invasive procedure such as percutaneous coronary intervention (PCI) for treatment of intractable angina because of less caregiver burden and faster rehabilitation even though survival may not be as high.

Not all treatment options are available throughout the country and some do not have enough research to help guide patient care. These variables all have an impact on patient decisions. Frequent treatment discussion outlining goals of care should happen through all phases of advanced HF. (Table 2) highlights points to be considered during treatment discussions.

**Table 2. Discussing Treatment Preferences**

1. Reviewing the poor outcomes associated with advanced heart failure patients receiving CPR can guide advanced directives discussions.
2. All patients should have frequent updates on prognosis, goals of care, and treatment planning including preferable sites of care.
3. Key questions are "Where should care be delivered?" and "What procedures should be done?"
4. Key factors to include during discussion are treatment outcomes, burden of treatment and treatment impact on QOL.
5. Question which provider should discuss these issues: Cardiologist, primary care clinician, in-patient hospital staff, gerontologist.

#### 4.1. TREATMENT FOR PHYSICAL COMPLAINTS

One of the challenges with advanced HF management is to evaluate whether there is a reversible cause for worsening symptoms. Targeting and treating reversible causes can improve symptoms and functional status, both major goals of palliative care. Adherence to basic diet recommendations and maximizing standard HF therapy is always warranted for the treatment of symptoms.

##### 4A. Angina and Ischemia

Coronary artery disease is present in 50% to 70% of patients with advanced heart failure and can precipitate worsening of HF. Certainly revascularization, either surgical or percutaneous, should be considered for those with medically refractory angina and suitable coronary anatomy [25, 26]. Several randomized trials regarding this issue are in progress. Other possibilities include transmyocardial laser therapy [27], and enhanced external counterpulsation [28]. Guiding treatment discussions around activity limitations from angina may help the patient and provider with the decision to consider non-medical therapy, especially if maximal anti-anginal medication has not been effective.

If a patient with limiting angina has suitable coronary anatomy for PCI, this may be a good treatment choice. It is a less aggressive procedure with faster recovery periods than Coronary Artery Bypass Grafting (CABG), especially in older patients [24]. Patients with multi-vessel or left main coronary artery disease and LV dysfunction have better survival with CABG compared with PCI, but their peri-procedure morbidity and mortality is also higher. These

outcomes should be considered when making revascularization decisions.

Nitrates and beta-blocker therapy can be used to medically manage angina, but non-dihydropyridine calcium channel blockers should be avoided due to their negative inotropic effects. Other precipitating causes of angina such as emotional stress, anemia, hypervolemia, and oxygen desaturation with activity should be addressed concomitantly. If standard therapies are not effective, low dose narcotics such as morphine can be considered for pain relief.

#### 4B. Palpitations and Rhythm Disturbances

##### Atrial Fibrillation

Nearly 40% of patients with advanced HF have atrial fibrillation. Rate control of atrial fibrillation with AV nodal suppression is critical to prevent heart failure exacerbation and can usually be accomplished with a combination of digitalis, beta-blockers and amiodarone [29]. Non-dihydropyridine calcium channel blockers should be avoided due to their negative inotropic properties. An attempt at cardioversion and rhythm control should be made because of the difficulty with rate control in these patients. Chronic coumadin use is recommended for patients with chronic or frequent paroxysmal atrial fibrillation due to the high risk of embolic stroke in this patient population group. AV nodal ablation therapy and pacemaker implantation should be considered in patients whose heart rate is difficult to control medically.

##### Sinus Node Dysfunction

Almost 70% to 80% of all permanent pacemakers are placed in patients 65 years or older to optimize heart rate control [30]. Implantation is generally considered a low risk procedure. Rate responsive ventricular pacing can improve QOL measures better than fixed rate devices since heart rate adjusts with activity. The recent Dual Chamber and VVI Implantable Defibrillator (DAVID) trial demonstrated that over riding sinus activity with RV pacing could lead to HF so it is important to set the lower rate limit and A-V delay below the intrinsic sinus rate and A-V conduction delay whenever possible [31]. Dual chamber pacemakers can reduce the symptoms of pacemaker syndrome and recurrence of atrial fibrillation but they do not improve stroke free survival when compared to single ventricular chamber pacing [32].

##### Ventricular Arrhythmias

Most antiarrhythmic drugs, with the notable exception of amiodarone, are contraindicated for the HF patient because of their proarrhythmic effects. Initiation of beta-blocker therapy is indicated provided the patient does not have signs of fluid retention. The use of the implantable cardioverter defibrillator (ICD) has improved survival in patients with impaired LV function and a history of cardiac arrest, or post myocardial infarction. Survival rates with ICD therapy are higher than those with antiarrhythmic therapy alone. However, the guidelines do not recommend ICD therapy for terminally ill patients or for NYHA class IV, drug-refractory HF patients who are not candidates for heart transplantation [33].

Treatment goals for the NYHA class III patient, especially regarding prolongation of life, become a core issue when discussing ICD placement. Patients may decline ICD placement if this modality might prolong suffering while living with a debilitating disease. Anxiety may surface as patients realize their mortality [34]. Patients contemplating ICD placement should be warned about possible frequent appropriate and inappropriate ICD discharges. Ethical concerns may arise if and when the device needs to be deactivated as the patient deteriorates. As a patient enters into the terminal phase of heart failure, most providers agree it is ethical to withdraw the pacemaker and ICD functions [35].

#### 4C. Fluid Retention Despite Maximal Oral Diuretics

Since patients with refractory congestive heart failure and renal insufficiency may become resistant to high doses of diuretics, other therapies have been used to manage fluid retention. Use of intravenous diuretics is usually restricted to the inpatient setting or outpatient infusion unit. They can be administered in home care or hospice, but policies vary with each agency. Peritoneal dialysis (PD) has been used to achieve euvolemia in patients with refractory congestive heart failure [36]. This type of management can be used for short-term fluid removal or long-term palliative care therapy and can be helpful in patients who have limited vascular access. Extracorporeal ultrafiltration has also been used to manage fluid retention in patients with advanced HF [37]. Up to 4 liters have been safely removed over several hours in small, non-randomized studies with intravascular volumes remaining stable. The procedure is usually conducted in a hospital setting.

#### 4D. Dyspnea

Optimization of therapy such as diuretics, digoxin, and ACE inhibitors can relieve dyspnea by decreasing left ventricular filling pressures and pulmonary congestion. Anxiety can precipitate dyspnea and should be treated as a possible underlying cause. Morphine has been the most studied opioid for relieving dyspnea, but other agents such as oxycodone, fentanyl, and methadone can also provide good relief [38]. Benzodiazepines are helpful in relieving anxiety associated with dyspnea and generally have little effect on the QT interval [39]. When using opioids or benzodiazepines, initial doses should be low, and titration should be done slowly to prevent suppression of the respiratory drive.

Oxygen therapy can improve hypoxia in patients with concomitant pulmonary disease. Patients can be assessed for home oxygen use to treat exercise-induced desaturation by performing a six-minute walk with pulse oximetry.

#### 4E. Fatigue

General complaints of fatigue and weakness should be medically evaluated for etiologies other than HF. Providers should be aware of the high prevalence of anemia and depression in the advanced HF patient population. Treatment of anemia, malnutrition and depression may improve overall energy levels.

Anemia can contribute to HF exacerbations and has been associated with increased mortality in patients with advanced heart failure [40]. Thus its etiology should be determined and appropriate therapy should be instituted. Hemoglobin levels

above 12.0g/dL in hospitalized HF patients have been associated with less in-hospital deaths [41]. Possible therapies for correction include erythropoietin injections and iron supplementation [42].

Since end stage heart failure can be associated with weight loss and cachexia, patients are at risk for general malnutrition. A multivitamin may be beneficial, but supplementation with other micronutrients such as vitamins C and E, vitamins B6 and B12 and co-enzyme Q10 has not been demonstrated to be helpful [43] and are not recommended by the HF guidelines.

#### 4F. Limited Activity

Fatigue and weakness are hallmark symptoms that contribute to activity limitations. In addition to maximizing HF medications, education should be provided on energy conservation and daily activity recommendations. Topics such as energy expenditure, energy flow, prioritizing activities and establishment of energy saving routines should be discussed. Strength training, assistive device recommendations and home exercise programs can all be safely implemented. Progressive home walking exercise programs have been associated with improved rating of symptoms [44].

#### 4G. Nausea and Constipation

Nausea can be caused by hepatic and gastric congestion as well as by medication side effects. Patients must be screened for reversible causes such as digoxin toxicity or intolerance to certain analgesic agents. Avoiding fluid overload can improve gastrointestinal symptoms as well as appetite. Constipation can have many causes depending on the fluid status and concomitant illnesses, but agents such as magnesium salts and fleet enemas should be avoided due to their high salt content.

#### 4H. Pain

Regardless of etiology, patient discomfort or pain should be aggressively treated. Non-steroidal anti-inflammatory drugs should be avoided since they can worsen renal function and promote fluid retention.

### 5. ADDITIONAL THERAPIES

#### 5A. Obstructive Sleep Apnea (OSA)

Obstructive sleep apnea (OSA) is a common associated diagnosis in patients with HF. HF patients should be screened using specific questions eliciting symptoms of OSA and/or using validated questionnaires. The use of continuous positive airway pressure (CPAP) has been shown to reduce left ventricle afterload and heart rate and can also improve arterial oxygenation during stage 2 sleep [45]. This therapy should be encouraged for all HF patients with OSA. A well fitting mask with specific patient education can improve adherence with wearing the mask during sleep. Better oxygenation during sleep can decrease episodes of waking during the night and lessen daytime fatigue and napping.

#### 5B. Inotropic Therapy

Inotropic therapy for patients with advanced HF has been available since the 1970's but chronic use of these agents (greater than 48-72 hours) has been associated with high

mortality rates, exacerbation of underlying ischemia, and ventricular arrhythmias [46]. Despite these shortcomings, continuous intravenous inotropic therapy may allow HF patients to leave the hospital and thus have a role for palliation in end stage HF. With intermittent infusion provided through hospice, improved HF symptoms ranged from 201 to 489 days after treatment [47]. The patient and provider must accept the possibility of sudden cardiac death, infectious complications and the possibility of not being able to wean inotropic therapy. If a patient becomes dependent, mortality rates are poor, with 61% at 6 months and 79% by one year [48]. If the intravenous inotropic agents are being solely used for comfort care, then judicious use of agents such as narcotics and anxiolytics should be considered in lieu of inotropic agents to avoid the need for intravenous catheters.

IV administration of inotropic therapy can be performed in outpatient infusion units or through home care agencies. If utilized, guidelines for Medicare reimbursement must be followed, especially if a home care agency is involved [49].

### 5C. Cardiac Resynchronization Therapy (CRT)

Not all of the CRT randomized trials have shown CRT to improve ventricular function and exercise capacity in patients with QRS prolongation and LV dysfunction [50-52]. Enrollment criteria was similar for all three trials and included advanced HF patients with NYHA III or IV classification, EF of less than 35% and QRS duration of greater than 130-150 msec. In the Comparison of Medical Therapy, Pacing and Defibrillation in Heart Failure (COMPANION) trial, reduction of death from or hospitalization for heart failure was reduced by 40% in the pacemaker-defibrillation group. Both device groups (pacemaker only and combination pacemaker-defibrillation) had improvement in 6 minute walk time, QOL and NYHA class symptoms at 3 and 6 months after insertion. Changes in variables were similar for both CRT groups at 3 months and remained sustained at 6 months. There was no benefit seen in QOL measures in the optimal medical therapy group.

Device insertion should only be considered after maximal HF therapy has been implemented, and if the patient is not considered to be terminal. CRT appears to improve symptoms and QOL, but the long term benefits with advanced HF patients have not yet been demonstrated. Patients with dyspnea performing ADLs, other co-morbid diseases limiting activity and an inability to achieve at least 300 meters with a six minute walk test may not benefit from CRT. If the patient meets criteria for combination therapy with defibrillation, an in-depth discussion would be required to identify the patient's view regarding shock treatment for lethal arrhythmias at his/her current clinical status.

### 5D. Mechanical Support

Patients who are ineligible for heart transplantation and who have end stage heart failure can be considered for implantation of a left ventricular assist device (LVAD) as destination therapy. In the Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart failure (REMATCH) trial, survival rates after one year were significantly higher in the group of patients randomized

to LVAD therapy compared with those treated with optimal medical management (52% vs. 25%, respectively) [53]. At 2 years, only 23% in the LVAD group were alive vs. 8% in the medical group. Despite the survival benefits in the LVAD group, serious adverse events such as infection, bleeding and stroke, were twice as high in the LVAD group over the follow up period. The use of LVADs is associated with overall high morbidity and mortality rates and would not generally be recommended for use in the advanced HF patient seeking palliative care [54].

## 6. PSYCHOLOGICAL ISSUES

Advanced heart failure patients can be plagued with the theme of uncertainty. The patient can experience uncertainty regarding inaccurate prognosis estimates, development of debilitating symptoms and general lack of control over disease progression. Other problems such as depression and anxiety can negatively affect self-efficacy behaviors and general outlook. Mood, morale and coping styles must be addressed in HF management to help improve QOL measures. Cognitive impairment is frequent in advanced HF and can be associated with depression.

### 6A. Depression and Anxiety

Disease specific questionnaires, such as the Kansas City Cardiomyopathy Questionnaire (KCCQ), that review social patterns, mood status and acceptance of limitations can be used to initiate discussions that screen for depression and anxiety [56]. Depression has been associated with increased morbidity and mortality as well as worsening functional decline in patients with HF [57-59]. Lengthening of the QT interval, which can lead to torsades de pointes and sudden death, is one of the greatest concerns when using older antidepressive agents. Serotonin reuptake inhibitors such as sertraline have been found to be safe and effective treatment for patients with ischemic heart disease [60].

Anxiety disorders are higher in HF patients compared with the normal population [61]. Anxiety can exacerbate symptoms such as dyspnea and can be associated with fear of dying. Medical treatment and psychological counseling should be included in the general management of the heart failure patient with anxiety. Symptoms should be relieved without undue sedation.

### 6B. Mood, Morale and Adaptation

Coping with advanced heart failure can be difficult as functional losses become more imminent. Many patients with HF eventually experience depression, anxiety, uncertainty regarding prognosis, feelings of loss due to decline in physical status, hostility, anger and grief [62]. Patients with greater perceived control and use of active behavioral coping styles benefited with improved QOL measures [63]. Counseling patients to use adaptive coping styles, identifying barriers to adherence, discussing treatment preferences to enhance quality of life, and encouraging development of social support systems are all positive interventions. Exploring the role of spirituality in advanced HF patients with appropriate tools can be beneficial since these activities enhance hope, comfort, and inner peace; and, at times, improve health outcomes [64, 65].

## 6C. Cognitive Impairment

Cognitive impairment has been reported to be almost two times greater in patients with HF than those without HF [66]. Trojano and colleagues reported that abnormal performance on neuropsychological tests was prevalent in 58% of NYHA class III-IV HF patients [67]. Poor cognitive performance was associated with depression, HF severity and hypertension.

This impairment can limit self-care behaviors and increase caregiver burden. Aides to improve medical adherence such as medicine boxes and written medication lists can be implemented.

## 7. PROVIDING PALLIATIVE CARE

If symptom management is the cornerstone of treatment for the advanced HF patient, disease management programs with cardiology input have consistently shown to be effective by offering close follow up of the patient [68]. Recent consensus papers outlining stepped therapy for stage C and D HF are recommending the incorporation of multidisciplinary disease management programs and hospice care along the continuum of care.

Close follow up can be administered through heart failure clinics, telephone care, home visits, and combinations of all modalities. Coordinated care for the advanced HF patient seeking a palliative approach can be difficult to implement. Problems such as different programs throughout the country, various admission criteria, program limitations, and varying reimbursement plans all effect continuity of care. Geriatric long-term programs have been designed to address the full spectrum of medical, social and rehabilitative services, but they may not offer 24-hour coverage or be affiliated with cardiac experts. Unpredictable illness trajectories and inability to accurately predict prognosis can influence which follow up program to consider.

Alternative programs such as the Medicaring Collaborative Project offer comprehensive care with creative combinations of aggressive and supportive care instead of curative care [69]. This experimental model allows for home care that is not time-limited or restricted by hospice criteria. Frail, elderly patients with advanced HF who are not strictly homebound and have a probable prognosis of more than six months can consider long-term home care if they are enrolled in Medicare Part B [70].

## 8. MOVING TO TERMINAL PHASE

### 8A. Definition

Patients have usually moved into the terminal phase of HF when functional status impacts minimal daily activities, and symptoms are more difficult to control. This transition is usually a gradual process and becomes more evident after frequent hospitalizations or emergency room visits.

### 8B. Hospice Programs

In order to meet the hospice criteria, an advanced HF patient must have a prognosis of less than six months, an EF less than 20%, be identified as NYHA class III or IV, have refractory symptoms of HF, and have continued functional decline [71]. Presence of multiple, poor prognostic variables

(see Table 1) can assist the patient and provider with planning long term care. Posing the question, "Would you be surprised if the patient died in 6 months" can lead the discussion toward offering hospice services.

If the patient and family are not ready for hospice, enrollment into pre-hospice "bridge programs" is selectively available throughout the country. The home care agency, affiliated with a hospice program, provides home care for patients with advanced diseases who still request life-prolonging treatment. To receive this service, the HF patient must be homebound, have a skilled nursing need and a prognosis of less than one year.

If patients meet these criteria, home care programs that provide coverage during off hours can prevent unplanned emergency room visits or hospitalizations and support the patient with close follow up.

Patients are eligible for hospice services related to their advanced HF through Medicare Part A. Hospice can be ordered through a community agency, or patients can be admitted to an in-patient hospice unit. Hospice care offers comprehensive palliative care that includes symptom management; support for psychological, spiritual, and social needs; as well as bereavement services.

## 8C. Discussing End of Life Goals

Two key questions arise when discussing treatment preferences in patients with advanced illness: where should care be delivered, and what procedures should be done? Although 43% of older adults would prefer to die at home, only 19% actually do so, with many older adults dying in the hospital [72]. Providing comprehensive services, such as hospice, in the home is complex and requires social support. With the expected exacerbations of heart failure and caregiver challenges in managing these patients, it can be difficult to find a suitable venue for care that provides good coverage without repeated hospitalizations for relief of symptoms. Choosing where treatment will be provided becomes very personal and will vary depending on the medical situation, finances, family care giving abilities, and available programs. At a minimum, patients should be offered hospice care before death is imminent since this is a standard benefit through Medicare Part A.

General agreement on the components of a "good death" may be identified [73], but the process of achieving this goal can be quite varied between patients and their families. Ambivalence can lead to wanting all available treatments, and this may constitute a "good death". Dying is a process, not a specific moment in time. Patient-provider communication should explore situations that allow the patient to understand the interaction between severity of symptoms, medical choices, and disease trajectory. Frequent discussion regarding prognosis and treatment seems to be the only feasible, practical solution at present time until never advanced therapies have been rigorously studied. This can allow for death with dignity and a balance between technology and spirituality at the end of life [74].

## 9. CONCLUSIONS

Management of advanced or terminal HF is complex. Palliative models for HF shift from curing this debilitating

disease to managing symptoms and incorporating treatment based on patient QOL and survival goals. Palliative care attempts to preserve functional status, promote adaptation strategies, and relieve symptoms. Care should ultimately be guided by patient preferences and treatment goals. A good rule to guide care is that the estimated probability of death should reflect the amount of time dedicated to planning palliative or end of life care. That is, if the patient has a 50% chance of dying in the following year, then 50% of the effort in his/her care during that year should be directed towards this goal.

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