

Palliative Care and Decision Making in Advanced Heart Failure

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Opinion statement

The diagnosis of advanced heart failure (HF) is established in patients for whom symptoms are refractory to guideline-directed therapies. Palliative care (PC) is based on symptom management and support of the patient and family, making its integration into the care of those with advanced HF essential. Comorbidities including frailty, cognitive dysfunction, and depression are often under-recognized in patients with advanced HF and may correlate with outcomes. Decisions should be based on the patient's values, goals agreed upon by the clinician with the patient, and what is medically reasonable. Palliative Care should be integrated to help with both palliation of symptoms and support for families and patients.

Introduction

The American Heart Association (AHA) and American College of Cardiology (ACC) have defined advanced HF as the stage of HF in which severe symptoms are present despite medical optimization and the addition of guideline-directed medical therapy [1•]. Though

670,000 new cases of HF are diagnosed annually [2], the number of patients who reach the advanced stage of the disease process is relatively few, with estimates ranging from 6 % to 25 % of the HF population [3–5]. Because these patients have reached the limits of

what medical therapy can offer in terms of symptom relief and life prolongation, their care becomes highly specialized. Advanced HF was formally recognized as a secondary subspecialty in 2008 and has changed rapidly as treatment options for advanced HF have evolved to include numerous pharmacologic therapies, device-based therapies, and transplantation. As the therapies available to treat patients with advanced HF become more widely implemented, so does the complexity of the decision making for patients, healthcare providers, and caregivers. Decision making in advanced HF, both from the provider perspective and from a patient perspective, remains difficult and continues to be an area of active research. Consensus committees have been working to give providers recommendations for over a decade [6••, 7]; these guidelines are aimed at helping to facilitate patient-centered care.

As an integral part of a patient-centered approach to the care of individuals with advanced HF, palliative care seeks to improve the quality of life of patients facing this life-threatening illness while focusing on re-

lieving physical, psychosocial, and spiritual pain (<http://www.who.int/cancer/palliative/definition/en>). The burden of HF on patients and their families is significant throughout the course of the illness. Symptoms and psychosocial issues may increase as the health status of patients with HF deteriorates. Compared to patients in the advanced stages of cancer, HF patients have an increased burden of physical symptoms, higher depression scores, and lower spiritual well-being [8]. Palliative care can offer a holistic approach to patient care and the therapies offered by palliative care can be integrated at all stages of HF. Furthermore, palliative care can aid in critical transitions of care as patients and their families navigate the often turbulent course of the disease, and can also aid in the decision-making process. As the fields of advanced HF and palliative care collaborate to improve the care of patients with HF, practitioners within each of these fields will need to keep themselves abreast of the latest data. This paper will serve to update care-providers on the most recent primary literature published on decision making and palliative care in advanced HF.

General concepts in shared decision making

Shared decision making should integrate medically reasonable therapies with the patient's values and preferences. Physicians are thus challenged to explore these values and subsequently employ management strategies most likely to be consistent with mutually agreed upon goals. Examples of phrases that may help advance a decision-making conversation are listed in Table 1. The following three steps are important to achieve shared, patient-centered decisions:

1. Start the conversation – The basic framework for decision-making conversations should be “Ask-Tell-Ask” [7]. Using this format, the clinician begins by asking the patient and family what they understand, how they think they are doing, and what they would like to know. Also included in this “ask” portion of the conversation should be questions to help understand on what level the patient would like to be involved in making decisions, as some persons would rather have others make decisions on their behalf. The next step is to “tell” the patient and family the information that they desire and also to provide information that is important to set the stage for decisions. This is the time to correct misperceptions by the patient or family. Last in the Ask-Tell-Ask framework is to ask what the patient and family understood, and ask what questions they have.
2. Establish goals – Conversations about goals of care should begin by clarifying current HF and overall health status for the patient and

Table 1. Useful phrases to help forward decision-making conversations

Examples of Phrases	Intent
As you look back on your life, what things have been most important to you? What currently brings you joy in your life? What things do you look forward to?	Elicit patient values
How do you feel about spending time in the hospital? Would you be willing to have a machine in your body if it helped you live longer? When a person's heart and breathing stop we can either allow them to die naturally or we can try to revive them. Which do you prefer?	Identify health care preferences
Based on what you've told me, it sounds as if we should aim to help you live as long as possible with as good function as possible. Is that correct? It seems you want to avoid hospital stays, so we should focus on treatments outside of the hospital, is that right? You said you do not want to prolong your life artificially, should we avoid all life-prolonging machines, and not try to keep you alive with a machine at the end of your life?	Identify goals

involved family with the "Ask-Tell-Ask" approach. This allows clinicians to ask what is important to the patient at their current stage of illness and to set specific goals. How best to achieve those goals will depend on what is medically reasonable. Some goals may need to be modified when they are not likely to be achieved given the patient's health status and available treatment options. It is important to note that in asking about values, the clinician is not asking what the patient would *prefer*. Many people would *prefer* to live a long, healthy life, yet this may not be an achievable course in many patients with advanced HF.

3. Discuss options – Only after the patient's health status has been clarified, and their goals are better understood, can a conversation about options may take place. After these framework conversations have taken place, the provider can introduce the idea that there may be options in their care. Once the clinician understands patient and family values they can present options for care that are consistent with those values, and also identify options that are contrary to the values. For example, spending as little time as possible in the hospital may not be consistent with mechanical circulatory support, an intervention in which up to 80 % of all patients experience a complication requiring hospitalization within the first year [9•].

Clinical issues to guide decisions for providers

Decision making within the field of advanced HF is fraught with difficulties for practitioners. The challenges facing the provider include highly variable disease progression, a multitude of treatment modalities which can be used independently or in concert, as well as wide variations in patient and care-giver goals and preferences.

Decision making in advanced HF

Predicting the course of advanced HF can be challenging as many patients live with physical frailty for several years, while others precipitously worsen. Prognosis is often thought of as the fundamental point from which decisions are made in life-threatening illnesses. However, it is arguably only a component of the decision-making process. As discussed previously, patient values should be explored independent of their estimated longevity; prognosis should be used to help designate specific, time-sensitive goals (such as attending a wedding).

The two most commonly used tools for prognostication in AHF, the Seattle Heart Failure Model [10] and the Heart Failure Survival Score [11] may have low predictive ability for individual patients [12]. Recently, an alternative model demonstrates superior risk prediction compared to the aforementioned risk models [13•]. This model was derived from a cohort of 2,255 continuous patients referred for HF management and evaluation for advanced therapies between January 2000 and June 2007 and was validated in consecutive patients presenting from July 2007 to June 2011. Four variables, ACEI/ARB use, NHYA class, peak VO_2 , and levels of BNP are entered into a formula to calculate a score, with the highest score imparting the highest mortality. This scoring system more is a more accurate predictor of all-cause mortality when compared to retrospectively assigned SHFM and HFSS scores (c-indices of 0.791 versus 0.758 and 0.607, respectively). Though not included in standard risk models, other variables are important determinants of outcomes. These include physical frailty, cognitive impairment and comorbid conditions. Particularly in older HF patients, such factors influence both the course of HF and the likely success of interventions. Frailty, defined as “a state of increased vulnerability to adverse outcomes” [14], or a loss of physiological resilience, is common in both advanced HF and advanced age. Frailty can be assessed by functional tools or diagnostic codes [15], and has been identified as an independent predictor of risk in elderly patients with all forms of cardiovascular disease [16••]. In elderly patients with HF, assessment of frailty and cognitive impairment as part of a comprehensive geriatric assessment yields better mortality risk prediction than most tools [17••].

Cognitive impairment is associated with worsened outcomes in advanced HF [18••]. Though both cognitive impairment and HF tend to affect patients >65 years of age disproportionately, cognitive impairment often goes under-recognized. In a study conducted on 282 patients admitted with a primary diagnosis of HF who underwent cognitive testing, 46.8 % of patients had cognitive impairment, with 21.6 % found to have moderate or severe impairment. Yet, cognitive impairment was documented in the chart in only 22.7 % of the cases. Patients who did not have chart documentation of their cognitive impairment were at a higher risk of 6-month mortality or hospital readmission ($p=.04$). Because patients with cognitive impairment are at greater risk of worse outcomes, and because their cognitive impairment may limit their ability to make decisions for themselves, screening for cognitive impairment in patients with advanced HF is important.

Decision making in mechanical circulatory support

While the annual number of heart transplants in the US has been stagnant, the number of mechanical circulatory support device implantations is on the rise. The most recent Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACS) report is an accrual of information on more than 7,000 patients who have received these devices since 2006 [19]. This report has shown that the proportion of patients receiving devices as destination therapy (DT), compared to bridge to transplant, has increased to >40 %. However, this technology is prone to significant complications which include, but are not limited to, bleeding, clotting complications, and infection. Given the current imperfections of LVAD technology, careful selection of the appropriate patient population to receive this therapy is crucial to successful outcomes and improved quality of life.

Patient selection for DT LVAD implantation is complex and includes both medical and psychosocial evaluation. A modified version of the PACT (psychosocial assessment of candidates for transplantation) tool, originally developed to help assess psychosocial candidacy for transplant, can be used for LVAD candidacy [21••]. The mPACT tool evaluates eight qualities: support stability and availability, personality and psychological health, lifestyle factors and substance abuse, adherence and understanding transplant, and follow-up [20••]. In a retrospective study of 48 patients undergoing LVAD implantation at one center, patients with higher mPACT scores had decreased 30-day readmission rates (26 % vs. 67%, $p=0.045$) after device implantation.

A relationship between frailty and outcomes after destination therapy LVAD has recently been identified [21••]. When compared with those who were not frail, patients who were frail were at increased risk for death ($p=0.004$) and readmission (adjusted $p=0.024$) after the index hospitalization. The mean number of days alive out of hospital the first year after LVAD was 293 for patients who were not frail, 266 for intermediately frail patients, and 250 days for frail patients.

Patient decision making in advanced HF

The challenges with decision making in advanced HF are not unique for providers, but also contribute to difficulty making decisions for patients. A wide spectrum of therapeutic options ranges from hospice to LVAD (either as a bridge to transplant or as destination therapy) and transplant. Other treatments, such as home inotropes, may serve a variety of purposes including palliation or optimization prior to advanced therapies. The stakes are high and the time to make these decisions may be short because of rapid disease progression. This is precisely why values-based, participatory decision making is needed. Offering a menu of choices is not effective for most patients, and identifying values allows the clinician to then offer treatments consistent with patient values.

In order to help guide patients with their decision-making process, it is important to understand how decisions are made by patients. This issue was recently studied via interviews with a total of 22 patients who had been offered (DT) LVAD implantation, 15 of whom proceeded and seven of

whom declined [22••]. The decision-making process was emotionally charged for all patients. The prevailing means by which patients reached their decision could be explained by “Dual –Process Theory” which states that people either rely on intuition or reasoning to make decisions. Specifically, investigators described some patients as “automatic decision makers” who felt there was no alternative other than the life-prolonging therapy. This group of patients was found to have a strong fear of death. Alternatively, the other group of patients went through a prolonged, reflective decision-making process where the risks and benefits were carefully considered. This patient group contained patients who accepted the device and others who declined.

Patients are often faced with uncertainty about what impact a device or transplant can offer to their quality of life. As a provider it is important to understand the quality of life outcomes from a patient perspective, particularly when the therapies being offered carry high risk of morbidity and mortality. A group from the UK has recently conducted a study comparing LVAD and transplant on quality of life and physical activity [23]. These investigators chose 40 patients with advanced HF and 14 age- and sex-matched controls to follow over a period of 1 year. Fourteen patients underwent LVAD implantation, two patients underwent heart transplantation, and 14 patients were treated with optimal medical therapy. Patients with optimal medical therapy demonstrated a significant decline in their physical activity and quality of life scores over the course of the year, whereas LVAD and transplant patients were able to increase significantly their activity from baseline within 3 months of surgery ($p < 0.05$). The quality of life measures improved in both LVAD and transplant ($p < 0.01$), but the transplant patients had higher quality of life scores relative to LVAD patients. Notably, none of the patients who underwent LVAD in this study experienced significant adverse outcomes, such as stroke, which would be likely to impact quality of life scores negatively. These findings are helpful to have in mind when framing a conversation of goals of care and quality of life with patients.

With the increasing number of device-based therapies offered for life prolongation, end-of-life planning can become complex for practitioners, patients, and care-givers. Many similarities can be drawn between patients with terminal cancer and patients with advanced HF, but significant differences between how end-of-life planning and decision making between these two patient groups can be found. A study of Korean patients with terminal cancer and other terminal diagnoses (including advanced HF) has highlighted glaring differences in end-of-life care for cancer and other terminal diagnoses. For example, patients with cancer were much more likely to have written advance directives than non-cancer patients ($p < .001$). Patients with non-cancer diagnoses were much more likely to receive care in ICUs ($p < .001$) and to receive life-prolonging therapies such as intubation and mechanical ventilation ($p < .001$), cardiopulmonary resuscitation ($p = .005$), and surgery under general anesthesia ($p < .001$). Equally striking was that cancer patients were much more likely to request pain medications than non-cancer patients ($p = .001$).

Although all patients should be encouraged to have an advance care plan (ACP), it may difficult for some to do so. The SMiLE survey (Schedule for Meaning in Life Evaluation) helps hospitalized patients identify the meaning of life while facilitating communication between the patient and provider

[24]. This survey was a useful adjunct to improve communication surrounding end-of-life care issues and help the practitioner guide the patient develop care plans consistent with their priorities and preferences. We believe that advance care planning should be an essential component of HF treatment. ACPs should be in place for end-of-life care, as well as frequently encountered complications of treatment modalities employed for advanced HF. Table 2 suggests common complications of these respective therapies that ACPs should address.

Palliative care

The need for integration of palliative care into the care of patients with advanced HF has been well documented [25, 26]. The integration of symptom management, advance care planning and psychosocial support that comprise palliative care is still lagging in HF care [27, 28]. All members of the patient's team should continuously address symptoms requiring palliation as they arise. However, providers differs in comfort-level administering palliative therapies, and specialized palliative care is likely under-used. In one academic hospital only 6 % of patients admitted for decompensated HF were referred for a palliative care consultation [29]. Factors predicting referral included worsened disease severity scores ($p < 0.0001$), advanced age ($p = 0.0074$), and prior HF admission ($p < 0.0001$). A qualitative study of 30 patients, 20 care-givers, and 65 professionals who had experience with advanced HF identified poor patient understanding, difficulty with prognostication, and poorly coordinated and fragmented care as barriers to access and delivery of palliative services.

Palliative care can facilitate a good death. A good death means different things to different patients. However, one of the key principles to a good death is to die at one's preferred location [30]. Preferences for site of death can be dynamic as the disease progresses. One study found that 61 % of patients with advanced HF, COPD, or renal failure changed their preferred site of death at least once during their follow up of 1 year, and only 39.4 % of these patients died at the site that they previously designated as their preferred site of death. Thus, end-of-life issues can be dynamic and should be addressed at multiple stages of the disease progression, as patient preferences may vary with illness severity.

Symptom management

Symptoms of dyspnea, pain, and fatigue are common throughout the course of HF. Therefore, all patients with advanced HF should have a plan in place to manage symptoms. Few data inform management in advanced HF, but extrapolation from studies in chronic HF guides therapy. In general, because HF symptoms arise from the diffuse myopathy characterizing the HF syndrome, medications and treatments that address the renin-angiotensin-aldosterone and beta-adrenergic disarray should be continued through the end of life. Sleep-disordered breathing should be identified and treated [31]. Thigh muscle strengthening exercises are warranted to combat fatigue and dyspnea [31]. Other treatments

Table 2. Suggestions for topics to be included in advanced care plans sorted by therapy

End of Life issues for all people

- Dyspnea and pain
- Parenteral nutrition and enteral feeding
- Ventilatory support
- CPR
- Location of death
- Surrogate decision maker

Issues to plan for an ICD – Would you want us to turn off your device to avoid shocks if you experienced the following:

- Disabling stroke
- Incurable infection
- Inevitable death from another cause (e.g. cancer)

Issues to plan for a destination LVAD – Would you want your pump turned off if you experienced the following:

- Disabling stroke
- Incurable infection
- Inevitable death from another cause (e.g. cancer)

to specifically address fatigue include caffeine [32], and opioids for dyspnea, pain and fatigue.

Device management of the end of life

Although guidelines recommend that advance directives be completed in patients that have implantable cardioverter defibrillators, these directives rarely address the management of these devices. Physicians often fail preemptively to address deactivation and that patients have not considered the possibility of turning off these devices when they reach end of life. In one study of patients with ICDs in place, 30 % of all patients surveyed stated that they would not deactivate the device in any scenario [33]. Factors that predicted device deactivation at the end of life included being Caucasian ($p=0.03$), and having at least one IADL disability ($p=0.03$).

A study by Kinch Westerdahl et al addressed the frequency of ICD shocks at the end of life by post-mortem interrogation of ICDs in 130 patients that died between 2003 and 2010 [34••]. They found that 35 % had ventricular arrhythmias in the hour before death and 31 % received a shock in the last 24 h. Some patients received multiple shocks. Importantly, 65 % of patients with do-not-resuscitate orders had the ICD programmed on 24 h before death and 51% were programmed on 1h before death. This study underscores the need for effective communication between providers and patients to prevent unnecessary and painful shocks at the end of life. To this end, the WISDOM (Working to Improve Discussions about Defibrillator Management) study will evaluate the effects of a communication intervention to improve conversations between physicians and patients regarding ICD deactivation. The study objectives are to increase the number of conversations about ICD deactivation, to increase the number of ICDs deactivated, and to improve

psychological outcomes [35••]. These goals emphasize the importance of discussing this aspect of care within the context of a patient's values and overall goals of care.

Summary

Decision making in advanced HF is complex and can be dynamic depending on the patient's values, goals of care, and course of treatment. There are many factors that should be considered when patients and providers are participating in shared decision making including patient values, comorbidities, and psychosocial support. These issues have been the subject of ongoing investigation and it is important for care-providers to keep themselves abreast of the current literature. Palliation of symptoms should be a consideration throughout the course of heart failure, but the delivery of this type of care is highly patient- and situation-specific. Fundamental principles of decision making are outlined in the preceding text, as well as a sampling of some contemporary primary data on decision making and palliative care.

Compliance with Ethics Guidelines

Conflict of Interest

Dr. Lisa LeMond and Dr. S. Albert Camacho each report no potential conflicts of interest. Dr. Sarah J. Goodlin reports a research grant from Medtronic.

Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by any of the authors.

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