The State of the Science on Integrating Palliative Care in Heart Failure

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Abstract

Background: Heart failure (HF) is a chronic progressive illness associated with physical and psychological burdens, high morbidity, mortality, and healthcare utilization. Palliative care is interdisciplinary care that aims to relieve suffering and improve quality of life for persons with serious illness and their families. It is offered *simultaneously* with disease-oriented care, unlike hospice or end-of-life care. Despite the demonstrated benefits of palliative care in other populations, evidence for palliative care in the HF population is limited.

Objective: The objective of this article is to describe the current evidence and the gaps in the evidence that will need to be improved to demonstrate the benefits of integrating palliative care into the care of patients with advanced HF and their family caregivers.

Methods: We reviewed the literature to examine the state of the science and to identify gaps in palliative care integration for persons with HF and their families. We then convened an interdisciplinary working group at an NIH/NPCRC sponsored workshop to review the evidence base and develop a research agenda to address these gaps.

Results: We identified four key research priorities to improve palliative care for patients with HF and their families: (1) to better understand patients' uncontrolled symptoms, (2) to better characterize and address the needs of the caregivers of advanced HF patients, (3) to improve patient and family understanding of HF disease trajectory and the importance of advance care planning, and (4) to determine the best models of palliative care, including models for those who want to continue life-prolonging therapies.

Conclusions: The goal of this research agenda is to motivate patient, provider, policy, and payor stakeholders, including funders, to identify the key research topics that have the potential to improve the quality of care for patients with HF and their families.

Keywords: heart failure; health services; palliative care in heart failure; quality and outcomes; uncontrolled symptoms

Scope of the Problem

HEART FAILURE (HF) is a disease of older adults; nearly 80% of inpatients with advanced HF are older than 65 years.^{1–6} HF is a chronic progressive illness marked by acute potentially life-threatening deteriorations superimposed on gradual functional decline.⁷ Deterioration is associated with hospital admissions and intensive treatment^{8–11}; for patients

with advanced HF, the 1-year freedom from hospitalization or death is only 33%.^{12,13} Approximately 80% of HF patients are hospitalized in the last 6 months of life.¹⁴ In addition, the care for these patients is costly. Medicare costs for HF patients exceed all other diagnoses at \$32 billion per year.^{1–6} By 2030, the total cost of HF care is projected to reach \$69.7 billion.¹⁵ For patients with HF, the prevalence of poor quality of life (QOL), the untreated HF symptom burden (dyspnea,

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pain, anxiety, and depression),¹⁶ and the high rate of acute care services use in the 30 days before death (emergency department [ED] visits: 64% vs. 39%, hospitalizations: 60% vs. 45%, and ICU admissions: 19% vs. 7%)¹⁷ exceeds that of cancer.^{16,18–21}

Optimal treatment for HF can vary greatly based on whether patients have preserved or reduced left ventricular ejection fraction. The prevalence and complexity of late-stage HF is, in part, the result of the effectiveness of HF therapies for reduced ejection fraction—in the past, death previously prevented progression to right-sided HF and cardiorenal syndrome. Effective neurohormonal antagonist therapies and implantable defibrillators have decreased sudden death, and, in turn, these therapies have made disease progression more complicated and less predictable (Fig. 1).²² Unlike many advanced illnesses, the HF interventions that most effectively treat many symptoms are the same therapies that prolong life.^{12,23–28} The best treatment for common HF symptoms is the treatment of HF itself. In late-stage disease, diuretics and in some cases vasodilators are commonly used to reduce symptoms of congestion. For some patients, relief of congestion is facilitated by improving cardiac output, for which our only current therapy is ongoing intravenous inotropic therapy, which requires an indwelling venous catheter and high daily costs. Most patients are not eligible for advanced therapies like mechanical circulatory support devices or heart transplantation.

Persons with serious illnesses such as HF and their families are eligible for palliative care, a form of interdisciplinary care that aims to relieve suffering and improve QOL. Unlike hospice or end-of-life care, palliative care is offered *simultaneously* with disease-oriented medical treatments. Despite the demonstrated benefits of palliative care in cancer, evidence for HF is sparse.^{29–31} Unlike cancer, the unpredictable nature of HF exacerbations, the increasing availability of expensive advanced therapies, the limited number of heart donors, the uncertainty of outcomes from invasive and intensive therapies, and a bias toward full cure versus focusing on improving QOL

make the integration of palliative care more challenging in HF.^{12,23–28} Improving integration of palliative care into HF care will require discovery, clinical dissemination, advanced study designs, instruments, analytics, education, and dedicated research funding.

With a goal of delineating research, practice, and policy priorities, a working group of palliative care and HF experts gathered in Birmingham, Alabama, for a symposium entitled: *Improving Palliative Care for Patients with Heart Failure and Family Caregivers: Creating an Agenda for Research and Clinical Priorities*. The symposium was supported by The John A. Hartford Foundation, the National Palliative Care Research Center, Mount Sinai's Claude Pepper Older American Independence Center, and University of Alabama at Birmingham Centers for Comprehensive Cardiovascular Care and Palliative and Supportive Care. Using a nominal group technique (NGT),³² a structured ranking process of important issues, we conducted three conference calls to create a ranked list of priorities (Table 1). Ten cardiology and six palliative medicine experts participated.

The highest ranked responses from the NGT calls were used to set the two-day symposium agenda. The agenda for the symposium in Alabama centered around a series of trigger talks and working groups on four distinct topics as follows: (1) Current Research Examining the Integration of Palliative Care and HF, (2) Clinical Models Integrating Palliative Care into the Care of Patients with HF, (3) Guidelines, Quality Metrics, and Policy, and (4) Development of an Action Plan and Commitment to Next Steps. From the symposium, the IMPACT-HF² (Improve Palliative Care Therapies for Patients with Heart Failure and Their Families) working group was developed; this group continues to work to advance the research, clinical models, and policy priorities at the intersection of palliative care and HF.

The symposium results were presented at the two-day National Institutes of Health/National Palliative Care Research

FIG. 1. Changing journeys with heart failure (HF) reduced ejection fraction (EF).²² This diagram contrasts the HF disease stages between the early days of heart transplantation and the current era. Because our modern therapies can prevent or delay disease progression, many patients in stage B and stage C HF may remain stable for many years. Although these patients are living longer, these modern therapies may also allow for a prolongation of these patients' inevitable deaths, which may include suffering.

TABLE 1. NOMINAL GROUP TECHNIQUE RANKED RESPONSES ABOUT INTEGRATION OF PALLIATIVE CARE AND HEART FAILURE

What are the challenges that you face in the care of your patients with HF? How can palliative care help?	Symptom management Goals of care Improved cross-training (HF training for palliative care clinicians and palliative care training for HF clinicians) Prognostic uncertainty Myths about palliative care (only end-of-life care) Optimal timing for palliative care Caregiver burden
What evidence would influence you and your colleagues about the role of palliative care in caring for your patients with HF?	Translation of guidelines to practice Recognize patient medical complexity Mandated guidelines Better symptom evidence Consensus on care model
What models have been successful in integrating palliative care into the care of patients with HF?	Triggered consults Palliative care embedded clinic model Primary palliative care models of training nurse practitioners within the HF clinic Palliative home care Trust and relationship building between palliative care and HF clinicians

This table represents the results (ranked in order of priority) from a nominal group technique exercise that used a series of questions asked to an interdisciplinary group of key stakeholders representing national leaders in the fields of HF and palliative care.
HF, heart failure.

Center (NIH/NPCRC) workshop, “Advancing and Extending a Palliative Care Research Agenda in the Specialties” in Bethesda, Maryland, in August 2016. This conference brought together thought leaders from chronic disease and palliative care specialties to outline the current research base and knowledge gaps and to create a consensus on the research priorities that were disease specific and crosscutting. The purpose of this article is to summarize the current research gaps and priorities at the intersection of palliative care and HF care that were brought forth from these two meetings.

Mandates for integrating palliative care in HF outpace the research base

The American College of Cardiology Foundation (ACCF),¹⁰ American Heart Association (AHA),³³ International Society for Heart and Lung Transplantation (ISHLT),³⁴ Heart Failure Society of America (HFSA),³⁵ and Canadian Cardiovascular Society (CCS)³⁶ encourage the incorporation of palliative care into the HF care (Table 2). The Joint Commission (TJC)³⁷ and the Centers for Medicare & Medicaid Services (CMS)³⁸ also require palliative care to be part of the team caring for patients with a ventricular assist device (VAD) as destination therapy (DT). Despite these multiple guidelines, there is little NIH funding support for HF-related palliative care research. A recent review of HF literature, conferences, and funding found that less than 1% of publications and less than 2% of conference sessions relate to palliative care. Furthermore, of the \$45 billion NIH budget directed to HF research, only \$14 million (0.03%) were related to palliative care.³⁹

Summary of Current Evidence

The current state of the science for palliative care in HF is limited, although the evidence that does exist demonstrates that further research is required to:

1. *Better understand advanced HF patients' limiting symptoms and focus treatment on their relief.* Patients with HF experience burdensome HF symptoms,⁴⁰ including pain, breathlessness, anxiety, fatigue, and depression,⁴¹ which can last for weeks to months⁴² with a prevalence¹⁶ exceeding that of many types of cancer.^{18–21} However, evidence for best practices in advanced HF symptom management is limited.
2. *Better characterize and address the needs of the caregivers of advanced HF patients.* HF patients' informal caregivers^{43–45} (e.g., spouse, children, other family members, and close friends) bear a large responsibility for HF caregiving hours and cost⁴⁶ and are at high risk of anxiety, depression, poor QOL, complicated grief, and great financial burden. The various responsibilities managed by the informal caregivers of HF patients^{43–45} amount to significant number of caregiving hours and cost.⁴⁶
3. *Improve patient and family understanding of HF disease trajectory and importance of advance care planning:* Although HF is a progressive disease, few patients actively participate in treatment decisions, advance care planning, or complete advance directives, and those that do, do so close to death.^{47–50} For example, decision making around initiation of many life-prolonging cardiac devices, like implantable cardioverter-defibrillators and mechanical circulatory support devices, rarely includes consideration of device deactivation.^{10,51–54} Despite benefits of goals of care discussions across a broad range of diseases, physicians are less likely to have these types of discussions with HF patients than those with other advanced illnesses.^{55–66} Patients are often unaware that their illness is life limiting,⁶⁷ and clinicians are unaware of patients' treatment preferences.^{9,48} Multiple models for improving advance care planning and

TABLE 2. SUMMARY OF KEY HEART FAILURE GUIDELINES ADVOCATING FOR THE INTEGRATION OF PALLIATIVE CARE

<i>Guideline title</i>	<i>Sponsoring society/ organization</i>	<i>Key palliative care domains covered in document</i>	<i>Notable specific mentions of palliative care</i>
2011 CCS HF Management Guidelines Update ³⁶	The CCS	<p>The provision of palliative care to patients with HF should be based on a thorough assessment of needs and symptoms, rather than on individual estimate of remaining life expectancy</p> <p>Clinicians looking after HF patients should initiate and facilitate regular discussions with patients and family regarding advance care planning</p> <p>In the presence of persistent advanced HF symptoms (NYHA III–IV) despite optimal therapy be confirmed, offer palliative care ideally by an interdisciplinary team with expertise in HF management, to ensure appropriate HF management strategies have been considered and optimized, in the context of patient goals and comorbidities.</p>	<p>CCS adapted WHO definition of palliative care:</p> <p>“Palliative care is a patient-centered and family-centered approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. It is applicable early, as well as later, in the course of illness, in conjunction with other therapies that are intended to prolong life, including but not limited to in the setting of heart failure, oral pharmacotherapy, surgery, implantable device therapy, hemofiltration or dialysis, the use of intravenous inotropic agents, and ventricular assist devices.”</p>
2012 AHA Scientific Statement “Decision Making in Advanced HF” ³³	American Heart Association	<p>Recommend referral to palliative care for assistance with difficult decision making, symptom management in advanced disease, and caregiver support even as patients continue to receive disease-modifying therapies</p> <p>The use of palliative care services should not be considered equivalent to the withdrawal of disease-modifying therapies</p> <p>Highly skilled communication is essential to shared decision making</p>	<p>“...[I]t is important to integrate palliative care into the care of patients with HF before they enter stage D. Even as patients are being considered for transplantation, mechanical circulatory support, or trials of novel therapeutics and pharmacological agents, palliative care can be increasingly integrated to ensure that patients’ symptoms are appropriately controlled and that patients understand the nature of these interventions, as well as the full complement of alternative therapies.”</p> <p>“Throughout the hospitalization as appropriate, before hospital discharge, at the first postdischarge visit, and in subsequent follow-up visits, the following should be addressed...consideration for palliative care or hospice care in selected patients.”</p>
2013 Guidelines for the Management of HF ¹⁰	American College of Cardiology Foundation and the American Heart Association Task Force on Practice Guidelines	<p>Comprehensive palliative care for HF delivered by clinicians should include expert symptom assessment and management</p>	

(continued)

TABLE 2. (CONTINUED)

<i>Guideline title</i>	<i>Sponsoring society/ organization</i>	<i>Key palliative care domains covered in document</i>	<i>Notable specific mentions of palliative care</i>
2013 ISHLT Guidelines for Mechanical Circulatory Support ³⁴	International Society for Heart and Lung Transplantation	Palliative care consultation should be a component of the treatment of end-stage HF during the evaluation phase for mechanical circulatory support	“Palliative care consultation should be a component of the treatment of end-stage heart failure during the evaluation phase for MCS. In addition to symptom management, goals and preferences for end of life should be discussed with patients receiving MCS as DT.”
		Goals and preferences for end-of-life care should be discussed with patients receiving mechanical circulatory support as destination therapy	“A multidisciplinary team led cooperatively by cardiac surgeons and cardiologists and composed of subspecialists (i.e., palliative care, psychiatry, and others as needed) ...is indicated for the in-hospital management of MCS patients.”
The 2015 Statement from the HFSA Guidelines Committee on Advanced (Stage D) HF ³⁵	Heart Failure Society of America	Incorporation of palliative care and hospice care into the care plans for patients with advanced HF Specifying that decision making should involve incorporating the patient's wishes for survival versus quality of life.	“The optimal approach [to advance care planning] involves shared decision making, where options for medical care are discussed with acknowledgment and legitimization of the complex trade-offs behind each choice....Involving palliative care specialists can facilitate the [advance care planning] conversation and, for patients who prioritize comfort over longevity, help to ensure access to necessary resources for enactment of a less aggressive path. Ideally, such conversations should be initiated before the transition to terminal stages of HF...”
2015 HF Management in Skilled Nursing Facilities ⁸⁷	American Heart Association and Heart Failure Society of America	Advance care planning Symptom management End-of-life care Hospice Transitions Care management Device management Caregiver support	“Decisions to balance palliative and disease-directed treatments may include withholding treatments of marginal potential efficacy, withdrawal decisions after treatments have been started, hospice referral for palliation, and determining whether end-of-life care will occur in the SNF or elsewhere. End-of-life care plan quality measures may be very important considerations for HF patients and potentially of value for improving patterns of care... These measures should be strongly considered for application in HF patients in SNFs.”

(continued)

TABLE 2. (CONTINUED)

<i>Guideline title</i>	<i>Sponsoring society/ organization</i>	<i>Key palliative care domains covered in document</i>	<i>Notable specific mentions of palliative care</i>
JCAHO Advanced Certification Program for VAD for Destination Therapy ³⁷	Joint Commission for the Accreditation of Hospital Organizations	Revised requirements for the DSC advanced certification program for VAD for Destination Therapy Specifically added a requirement to have a palliative care representative to the core interdisciplinary team.	“The Joint Commission announced revisions to requirements for the DSC advanced certification program for VAD for Destination Therapy... to add a palliative care representative to the core interdisciplinary team.”
CMS Memorandum for VADs for Bridge-to-Transplant and Destination Therapy ³⁸	Centers for Medicaid and Medicare Services	Mandated the inclusion of palliative care specialists in the multidisciplinary team of medical professionals caring for beneficiaries receiving VADs for DT.	“Beneficiaries receiving VADs for DT must be managed by an explicitly identified cohesive multidisciplinary team of medical professionals with the appropriate qualifications, training, and experience. The team embodies collaboration and dedication across medical specialties to offer optimal patient-centered care. Collectively, the team must ensure that patients and caregivers have the knowledge and support necessary to participate in shared decision-making and to provide appropriate informed consent. The team members must be based at the facility and must include individuals with experience working with patients before and after placement of a VAD.” “The team must include a palliative care specialist.”

AHA, American Heart Association; CCS, Canadian Cardiovascular Society; CMS, Centers for Medicare & Medicaid Services; DSC, disease-specific care; DT, destination therapy; HFSA, Heart Failure Society of America; ISHLT, International Society for Heart and Lung Transplantation; MCS, mechanical circulatory support; VAD, ventricular assist device; WHO, World Health Organization.

preparedness planning exist;^{68,69} however, few are tailored to patients with HF and their families.

4. *Determine the best models of palliative care, including models for those who want to continue life-prolonging therapies:* The models that exist for specialist palliative care for HF focus on triggers that indicate patients have unmet needs through the use of specific clinical criteria are expanding nationally. For example, at the University of North Carolina, all patients who are being evaluated for destination therapy-left ventricular assist devices (DT-LVADs) are seen by palliative care consultation services. At St. Luke's Mid America Heart Institute, all candidates for LVAD are automatically seen by palliative care specialists, and all HF inpatients have at least one palliative care consult per year. At Brigham and Women's Hospital, all patients with DT-LVAD receive a palliative care consult, referred to as "supportive cardiology." In addition to consulting on all patients evaluated for LVAD, the University of Colorado palliative care team members participate in HF rounds on a weekly basis. At the University of Alabama, Birmingham, the *ENABLE-HF*⁷⁰⁻⁷² (Educate, Nurture, Advise, Before Life Ends) randomized clinical trial is using a concurrent telehealth approach to reach rural and underserved minorities, through in-person palliative care consultation and patient and family caregiver phone coaching to encourage activation and communication and decision-making skill building.³⁰

Currently, there are efforts to develop comanagement models for patients with advanced HF in the outpatient setting. One model that existed at the University of Washington Medical Center was a dedicated cardiology outpatient palliative care clinic providing initial evaluation and longitudinal follow-up for the VAD population. The model at the Icahn School of Medicine at Mount Sinai includes a palliative care physician, embedded in the outpatient advanced HF practice, who sees patients longitudinally who are undergoing DT-LVAD evaluation and those with palliative care needs. When these patients are admitted to the hospital, the inpatient palliative care consultation team will follow them as needed. The University of Pittsburgh has a particularly innovative model that had its origins in an inpatient team that originally used triggers for consultation. These initial triggers resulted in a 20% increase of the overall palliative care consult volume for patients with HF. Based on the success of this trigger program, the team developed an outpatient HF-palliative care clinic in 2005. The hiring of a dedicated nurse practitioner allowed the palliative care team to bridge the gap between outpatient and inpatient palliative care services, and ultimately, helped several complex patients to avoid serial readmissions and die peacefully at home. Given the prevalence of HF, more research is needed about models of telehealth and telemonitoring to meet palliative care needs.⁷³⁻⁷⁶ Despite the growing evidence for specialist palliative care for patients with HF, there are little data on developing primary palliative care models⁷⁷ tailored for HF. Finally, although more HF patients utilize hospice,¹⁴ patients with advanced HF enroll in hospice at lower rates and closer to death than those with cancer.^{17,78-80}

Research Gaps and Priorities

Table 3 outlines the key research gaps, as well as the potential research topics and objectives that would help to advance the science of palliative care research for patients with advanced HF. The priorities are as follows:

1. *Gap: To better understand advanced HF patients' limiting symptoms and focus treatment on their relief.* Symptoms of HF, which are ameliorated by HF therapies (dyspnea, severe edema, and hepatic congestion), are distinct from symptoms common to many advanced diseases, such as pain, anxiety, and insomnia. This distinction in symptoms is common to HF and end-stage lung disease, but less applicable in cancer. In addition, fatigue, a prevalent symptom for patients with HF, has little evidence on targeted therapies. *Priority:* (1) To better understand treatments (pharmacologic and non-pharmacologic) for symptoms of patients with advanced HF (pain, fatigue, anxiety, and depression) and (2) to assess both improvement in symptoms and function and also tolerability of side effects and relationship to HF exacerbations.
2. *Gap: To better characterize and address the needs of the caregivers of advanced HF patients.* Informal caregivers suffer greatly with this disease; care-taking responsibilities include assessing symptoms, administering medications, assisting with managing advanced HF therapies and devices (e.g., mechanical circulatory support), partnering in complex health and medical decisions, and providing emotional support. *Priority:* (1) To better characterize the burdens of caregivers of patients with HF and (2) to test interventions to address these caregiver needs.
3. *Gap: To improve patient and family understanding of the HF disease trajectory and the importance of advance care planning.* Multiple models for improving advance care planning and preparedness planning exist; however, few are tailored to patients with HF and their families. In addition, there are a limited number of clinical models of how palliative care can be combined with other medical care for HF, and even those that have demonstrated effectiveness and improvements in patient care have not been able to demonstrate exactly which of the elements of palliative care are directly related to better outcomes.⁸¹ Without a more nuanced understanding of the impact of different aspects of palliative care, it will be difficult to export these models to other settings where the entire breadth of palliative care expertise may not be readily available. *Priority:* To create effective and timely communication techniques focused on advance care planning for patients with HF and their caregivers.
4. *Gap: To determine the best models of palliative care, including models for those who want to continue life-prolonging therapies.* Unfortunately, the limited number of clinical models in HF has not been well tested and even those that have demonstrated effectiveness and improvements in patient care have not been able to demonstrate exactly which of the elements of palliative care are directly related to better outcomes.⁸² Without a more nuanced understanding of the impact of different aspects of palliative care, it will be

TABLE 3. PROPOSED RESEARCH PRIORITIES AND SAMPLE TRIAL DESIGNS FOR IMPROVING THE SCIENCE OF PALLIATIVE CARE FOR PATIENTS WITH ADVANCED HEART FAILURE

No.	Research priority	Study objective	Study setting	Sample	Study design
1	To better understand advanced HF patients' limiting symptoms and focus treatment on their relief	To better understand treatments (pharmacologic and nonpharmacologic) for symptoms of patients with advanced HF (pain, fatigue, anxiety, depression)—assess both improvement in symptoms but also tolerability of side effects and relationship to HF exacerbations	Academic and community/inpatient and outpatient	Stage C and D HF Patients	RCT of medications/treatments for symptoms, with detailed assessment of medication side effects (as applicable)
2	To better characterize and address the needs of the caregivers of advanced HF patients	To create interventions to improve caregiver burden and distress	Academic and community/inpatient and outpatient	Caregivers of patients with advanced HF	Cohort study to better elucidate needs and then interventions to improve burdens and increase caregiver activation
3	To improve patient and family understand of disease trajectory and importance of advance care planning	To create effective and timely communication techniques focused on advance care planning for patients with HF and their caregivers	Academic medical centers may be the place to begin this work	Stage C and D HF patients	Innovative RCTs of interventions to improve advance care planning, as well as determine effect of interventions on patient-centered outcomes
4	To determine the best models of palliative care, including models for those who want to continue life-prolonging therapies	To better understand the individual elements of a specialist palliative care intervention and determine the impact of each of these elements on outcomes important to clinicians, patients, and family caregivers. (i.e., what's in the palliative care syringe?) To determine effective models to empower and teach primary cardiology staff to better apply principles of palliative care in the domains of symptom management, communication, and psychosocial support	Needed in both inpatient and outpatient settings, as the syringe might be different Outpatient academic and community settings	Stage C and D HF patients Clinicians caring for patients with HF: Physicians (HF specialists, general cardiologists, primary care); nurses (NP and RN); physician assistants, social work Patients with Stage D HF	Cohort study or adaptive trial design with data collection designed to determine exposure to each of the individual elements conveyed in the delivery of specialty level palliative care Pre-post education intervention or RCT of intervention delivery
		To determine the best models to deliver care to patients who may not want advanced therapies but also are not ready for hospice	Academic medical centers may be the place to begin this work		Adaptive trial design using predetermined patient and family centered outcomes

Studies should account for differences in terms of patients who may or may not be candidates for advanced therapies. NP, nurse practitioner; RCT, randomized control trial; RN, registered nurse.

difficult to export these models to other settings where the entire breadth of palliative care expertise may not be readily available. In addition, no information exists to characterize how often patients classified objectively as facing imminent mortality seek to retain the option for life-sustaining interventions, because even advanced HF stages often associated with interludes of relative comfort and activity.

Furthermore, overcoming HF and palliative care integration research gaps is compounded by palliative care workforce deficits.^{82,83} There are no realistic estimates of the shortages of nurse practitioners specializing in palliative care. Therefore, it is unrealistic to provide full interdisciplinary specialist palliative care team consultations for all HF patients. Future research is needed to delineate how palliative care specialist and generalist physicians, nurses, social workers, and others who care for patients with HF can work together to provide high-quality palliative care to patients and family caregivers in need.

Care models must be tailored to patients' specific needs and disease stage. For example, the care models for patients wishing to pursue all life-prolonging treatments solely focused on comfort and those in an "in-between" or transitional stage will likely require different approaches. For example, patients in a transitional phase may wish to receive antibiotics for pneumonia, but decline craniotomy for intracranial hemorrhage or surgery to resect ischemic bowel. This transitional stage is the most complex because goals of care may be in flux due to periods of acceptable QOL that are interspersed with exacerbations and hospitalizations that may call into question if and when to begin to limit life-prolonging therapies. Evidence about patterns of hospice use to the HF population remains limited.^{84,85} Likewise, there are no interventions in the literature that are known to increase hospice utilization among patients with advanced HF. *Priority:* (1) To better understand the individual elements of a specialist palliative care intervention and determine the impact of each of these elements on outcomes important to clinicians, patients, and family caregivers. (i.e. what's in the palliative care syringe?); (2) to determine effective models to empower and teach primary cardiology staff to better apply principles of palliative care in the domains of symptom management, communication, and psychosocial support; (3) to determine the best models to deliver care to patients who may not want advanced therapies but also are not ready for hospice.

Conclusions

Solving these problems will involve innovative research studies across a variety of settings that incorporate new and novel methodologies. Study designs for interventions and education should engage patient and family caregiver stakeholders and clinicians representing the related specialties and disciplines. It is critical that research to fill these gaps account for and examine the disparities that exist for patients with HF and their families. First, research needs to account for the fact that these disparities are present on multiple levels.⁸⁶ For patient and caregiver, disparities involve sociodemographics, illness severity, acculturation, health literacy, cultural beliefs, values, and preferences; for providers, they include knowledge, attitudes, bias, and communication; and for health systems, they include the

context in which palliative care is provided, models of care, financials of palliative care services, and organizational culture. Next, interventions need to be developed to eliminate the disparities so that patients can access resources that support palliative care delivery. To date, little data exist to describe how disparities limit access to palliative care for those patients with HF and their families.

In conclusion, there is clearly an unmet need for palliative care in patients with HF. However, there is a dearth of evidence from which to establish the best symptom management, caregiver support, advance care planning, and palliative care models. The goals of palliative care research should be to design and integrate palliative care with recommended HF treatments to maximize the quality and length of survival in accordance with the patients' goals and preferences.

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