

# Primary palliative care for heart failure: what is it? How do we implement it?

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**Abstract** Heart failure (HF) is a chronic and progressive illness, which affects a growing number of adults, and is associated with a high morbidity and mortality, as well as significant physical and psychological symptom burden on both patients with HF and their families. Palliative care is the multidisciplinary specialty focused on optimizing quality of life and reducing suffering for patients and families facing serious illness, regardless of prognosis. Palliative care can be delivered as (1) specialist palliative care in which a palliative care specialist with subspecialty palliative care training consults or co-manages patients to address palliative needs alongside clinicians who manage the underlying illness or (2) as primary palliative care in which the primary clinician (such as the internist, cardiologist, cardiology nurse, or HF specialist) caring for the patient with HF provides the essential palliative domains. In this paper, we describe the key domains of primary palliative care for patients with HF and offer some specific ways in which primary palliative care and specialist palliative care can be offered in this population. Although there is little research on HF primary palliative care, primary palliative

care in HF offers a key opportunity to ensure that this population receives high-quality palliative care in spite of the growing numbers of patients with HF as well as the limited number of specialist palliative care providers.

**Keywords** Heart failure · Palliative care

## Introduction

Heart failure (HF) is a chronic, progressive, and debilitating epidemic that afflicts more than six million American adults, while another 870,000 individuals are diagnosed annually [1]. Despite improved survival conferred by medical therapy [2], nearly 40% of patients will die within a year of first hospitalization [3]. During their course of illness, patients with HF suffer from major physical and psychological burdens [4–6], dramatic functional limitations [7], and an unpredictable trajectory [8, 9]—all of which impair patients' and caregivers' quality of life (QOL) [5, 7]. Physical symptoms in advanced HF, which include pain, breathlessness, fatigue, depression, and anorexia, among others, are highly distressing for patients and caregivers, yet remain under-recognized and undertreated [10, 11]. In fact, the symptom burdens among patients with advanced HF have been found to exceed those reported by patients with advanced cancer [6, 12–16]. Further, the management of HF poses enormous burden, both financial and non-financial, on families, healthcare systems, and society. In 2030, direct medical costs of HF are projected to be \$77.7 billion, a 215% increase from current spending [17]. Finally, patients and their caregivers often face decisions about high-risk and complex treatments [18, 19] (e.g., cardiac devices, transplantation) without adequate prognosis communication, decision support, or advance care planning [20, 21].

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Palliative care is the multidisciplinary specialty focused on optimizing QOL and reducing suffering for patients and families affected by serious illness, regardless of prognosis [22]. Palliative care includes pain and symptom management; psychological, spiritual, and social support; assistance with treatment decision-making; and complex care coordination [23]. In a systematic review and meta-analysis of randomized palliative care interventions [24], palliative care was found to be associated with improved survival [25], increased QOL [25, 26], decreased symptom burden [27], decreased healthcare expenditures [23], as well as improved caregiver outcomes such as burden and mood [28]; however, the overwhelming majority of this evidence emanates from oncology populations. It is only recently that several studies of palliative care interventions in HF have shown improvement in QOL [29, 30], symptom burden [29–32], mood [29, 33], and healthcare utilization [30, 32, 34] for patients with HF. Heightened recognition of the role of palliative care in the management of HF has called for high-quality palliative care research to better understand the effect of integrating palliative care in the management of HF [24, 35–37].

Palliative care can be delivered in one of two ways, distinguished by provider specialization [38]. First, specialist palliative care is the consultation or co-management of patients to address palliative needs alongside clinicians who manage the underlying illness by a clinician who completed a 1-year palliative care fellowship or certification. Alternatively, primary palliative care (aka “generalist palliative care”) involves the provision of essential palliative domains by a clinician without palliative care subspecialty training (i.e., an internist caring for patients with HF, a cardiologist, a cardiology nurse, or a HF specialist). To date, research in HF palliative care has been largely limited to specialist palliative care models, and no research exists on primary palliative care.

Although recommended by all major cardiology societies for patients with advanced HF, specialist palliative care for all eligible patients is currently neither a feasible nor a scalable strategy [36, 39–44]. Regrettably, patients with HF rarely receive specialist palliative care [45]. First, research [46–48], including ours [49, 50], has demonstrated barriers to referring patients with HF for specialist palliative care, such as the misperception that palliative care is only for patients at the very end of life, the unpredictable course of HF and related difficulty of prognostication, the lack of clear referral triggers across the HF trajectory, the ambiguity regarding what differentiates standard HF therapy from palliative care, and the uncertainty regarding the optimal time for referral to palliative care [49].

Second, and to the purpose of this article, there is a growing shortage of palliative care specialists [51]. It has been estimated that while there is approximately one cardiologist for every 71 persons experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one

palliative medicine physician for every 1200 persons living with a serious or life-threatening illness [52]. Approximately 18,000 additional palliative care physicians are needed to meet inpatient consultation needs alone [53]. While there is certification in palliative care for nurse practitioners, there is similarly an insufficient workforce to meet the growing needs of patients with serious illness and their families.

Specialist palliative care [38] comprises palliative care skills in the management of refractory symptoms and assistance with complex decision-making and conflict resolution. Specialist palliative care services are provided in a number of inpatient and outpatient settings with a variety of models. Although specialist palliative care has been demonstrated to improve quality of care for patients and their families and reduce cost, the workforce shortage limits the potential for specialist palliative care to meet the needs of this population. Innovations are needed to integrate palliative care principles within usual HF care—in other words, to promote the diffusion of primary palliative care into HF.

Primary palliative care is a potentially feasible, scalable, and generalizable solution to meet the needs of patients with HF [38, 54]. Traditional HF disease management strategies represent potential vehicles through which to infuse palliative principles into usual HF care. Primary palliative care, including symptom management, communication, psychosocial support, and care coordination, with overall goal of alleviating suffering, should arguably be a part of comprehensive HF care (see Table 1); yet, these processes are often not the focus of HF management. Indeed, multiple aspects of primary palliative care (e.g., care coordination, decision support) align with principles of disease management [55]. Furthermore, many patients with HF may not have complex or intractable needs requiring a palliative care specialist (see Table 1), yet still would benefit from the integration of primary palliative care in their HF treatment program [38]. Research is needed to examine the outcomes from the integration of primary palliative care into internal medicine and cardiology clinics, while reserving specialist palliative care for patients with complex needs.

### **Need for primary palliative care training for patients with HF**

Due to the limitations in the numbers of the specialist palliative care workforce, there is a growing demand for primary palliative care training for those who care for patients with serious illness and their families. A recent paper outlines the core competencies in palliative care for cardiology fellows training to include (1) prognostication; (2) communication; (3) discussing goals of care, end-of-life care, and resuscitation status; (4) understanding what palliative care is; (5) timely referral to palliative care; (6) symptom palliation; and (7)

**Table 1** Primary palliative care versus specialist palliative care for patients with HF and their families

Domains		Primary palliative care (PPC)	When to refer to specialist palliative care (SPC)
Symptom management	Shortness of breath	Maximize HF therapies to relieve congestion	Debilitating refractory dyspnea despite PPC interventions
	Pain	-Maximize antianginal medications and recommend activity modification for anginal pain -Acetaminophen or single-agent opioid therapy for somatic pain -Referral to physical therapy for musculoskeletal pain if patient is possible	-Pain refractory to PPC interventions -Neuropathic pain
	Depressed mood	Treat low mood from an adjustment reaction by referral for psychotherapy or initiation of antidepressant medication if appropriate	- Symptoms of major depressive disorder such as incapacitating hopelessness and anhedonia requiring medical management
	Anxiety	Treat mild anxiety with referral to psychologist for help with relaxation techniques and psychotherapy or initiation of anxiolytic medication if appropriate	Debilitating anxiety or panic symptoms that prevent the patient from participating in regular activities
	Nausea	-Adjust HF therapies -Consider adding single-agent antiemetic	Ongoing symptoms despite PPC interventions
	Fatigue	-Maximize HF therapies -Referral to cardiac rehabilitation -Evaluate and treat for insomnia -Evaluate for sleep disordered breathing if indicated	-Ongoing symptoms despite PPC -Patients unable to participate in cardiac rehabilitation -SPC can provide pharmacotherapy for fatigue.
	Insomnia	-Education on sleep hygiene -Treat mild associated anxiety with psychotherapy and relaxation techniques	-Refractory to PPC interventions -SPC can provide pharmacotherapy for insomnia and/or associated anxiety and advanced education on sleep hygiene
Communication	Discussing code status	Patients with clear wishes and an understand of prognosis after CPR	-Patients unable to verbalize understanding of their illness and prognosis after CPR
	Advance care planning	Patients with clear wishes have already identified a surrogate and family/surrogates who support those wishes.	-Patients unable to verbalize understanding of their illness and prognosis -Patients and families who are in disagreement about the patient's end-of-life choices -Disagreement about the chosen surrogate or the patient is ambivalent about choice
	Discussions to withdraw life-sustaining therapies	Patients and/or surrogates who verbalize a clear understanding of the patient's prognosis with and without therapy and can base decisions made on patient's goals and values.	-Patients and/or surrogates unable to verbalize clear understanding of prognosis -Patients and/or surrogates who are in disagreement (conflict) about the treatment that best matches patient's goals and values -Surrogates with lack of insight into patient's goals and values
Psychosocial support	Request for assisted suicide	Referral to specialist level palliative care	SPC to navigate complex request and explore other options
	Patient support	-Supportive listening -Referral to HF team social worker	Refer to SPC when needs exceed the expertise of HF social worker, especially around issues of end-of-life care such as counseling parents on how to talk to their children
Care coordination	Caregiver support	-Supportive listening -Referral to HF team social worker	Refer to SPC when needs exceed the expertise of the HF social worker, especially when caregiver has significant needs or the patient and caregiver are in conflict
	Care coordination	-Communication with other providers caring for the patient -Straightforward referral for home hospice for patients with good support at home and without complex medical or social needs	Complex hospice or home care referral for patients who require placement in facilities with need for complex medical management (e.g., palliative home inotropes)

deactivation of rhythm control devices [56]. Similarly, the recent 2015 American College of Cardiology (ACC) Core

Cardiology Training Statement recognizes the need for training in primary palliative care. Specifically, under *Medical*

*Knowledge*, the training guidelines include the “need to know the principles, modalities, and appropriate indications for palliative care” [57]. Under *HF Disease Management*, training in end-of-life care is recommended including communication of care options and participation in an interdisciplinary palliative care team [57]. Finally, under *Professionalism*, there is discussion that trainees should be able to clearly and objectively discuss the therapies available for advanced HF, including palliative care, transplant, or mechanical circulatory support [57]. Guidelines as to how palliative care training is to be integrated for the advanced HF fellow are not specified. While there is specialty training available for physicians, nurses, and nurse practitioners in cardiology and in HF, none of those programs has a formal component that provides training in primary palliative care.

Because there is a limited number of specialist palliative care clinicians, it is not feasible to provide specialist palliative care to patients with HF by an interdisciplinary care team. Given this gap in workforce, future research will need to determine how high-quality palliative care can be delivered by general cardiologists, HF specialists, as well as nurses, social workers, and other clinicians who are integrated within the HF team. The development of high-quality primary palliative care is particularly important for HF given its rapidly increasing incidence, high morbidity and mortality, and the complex decision-making in advanced stages involving consideration of ventricular assist device therapies, cardiac transplant, and hospice. Because the vast majority of these patients are cared for by primary cardiologists in the community and not advanced HF teams in academic medical centers, new models will need to address how to treat patients across a variety of healthcare settings. Finally, research is required to identify ways to motivate HF clinicians to devote the time and resources to integrate training in primary palliative care into their education. By improving the evidence base and providing education, HF clinicians will likely be prompted to receive primary palliative care training, as we have seen in the field of oncology.

### Primary palliative care domains for patients with HF

The domains of primary palliative care include management of basic symptoms, communication regarding goals of care and advanced care planning, and psychological support and care coordination. These individual domains are discussed in detail in the paragraphs that follow and are outlined in the middle column of Table 1.

#### Management of basic symptoms

The most common symptoms of HF are pain, breathlessness, anxiety, fatigue, and depression, of which the majority of

patients describe at least one symptom as burdensome [58]. Many of these patients leave the hospital with suboptimal symptom control due to lingering congestion, which can last for weeks to months [59]. Because addressing symptoms is often the mainstay of HF management, with basic education, HF clinicians can also be alerted to identify and treat other symptoms, such as uncomplicated depression, anxiety, and pain. Specialist palliative care may still be appropriate for complex or refractory symptoms.

#### Communication regarding goals of care and advance care planning

Patients with HF rarely complete advance directives. In one study of community-dwelling patients with HF, only 41% had an advance directive; the vast majority (90%) of these was durable powers of attorney for healthcare (healthcare proxy) [60]. In another study assessing the presence of advanced directives in electronic medical records of adult patients admitted with HF to two large tertiary care hospitals, only 12.7% had a documented advance directive at the time of the last admission [61].

Unfortunately, even when completed, these documents rarely address patients' goals of care. The forms are often completed without a conversation about patient's preferences for treatment [62]. Identification of a healthcare proxy is an important aspect of advance care planning, but it is not sufficient without a discussion about treatment preferences, especially given the myriad therapies available to patients with HF.

Unfortunately, a lack of early communication about prognosis and goals leads to unwanted treatment in some cases and very late decisions near the time of death. For patients with HF, data demonstrate that decisions about preferences for resuscitation are made close to death. Among community-based patients with HF, at enrollment, 73.4% were full code, and at death, 78.5% had do not resuscitate (DNR) orders. These orders are placed a median time of 37 days before death [63]. These orders may mean that conversations about end-of-life care may be occurring only weeks before death for community-based patients with HF. There is even less evidence regarding the use of out of hospital physician orders for life-sustaining treatment (“out of hospital DNRs”) in the HF population.

Patients with HF and their caregivers face an additional layer of complexity in decision-making at the end of life given the various cardiac devices that are used to prolong life including automatic implantable cardioverter defibrillator and mechanical circulatory support. Therefore, decision-making for this population includes not only the implementation of these devices but also discussions about deactivation of these devices in the appropriate clinical circumstances. Ideally, patients should be encouraged to execute advance directives with device-specific language to ensure that they receive care

consistent with their preferences [64–66]. Efforts to foster completion of comprehensive advance directives that address goals of care are needed desperately for patients with HF well in advance of death.

Under the primary palliative care domain of communication and advance care planning, two key tasks include identification of a surrogate decision-making, guidance about filling out an advance directive (healthcare proxy, living will), and exploring goals and values and discussing prognosis. The goal of these discussions is to assure that treatments, such as defibrillator, mechanical circulatory support, inotropes, and resuscitation, are aligned with patient's goals and values. It is important to acknowledge that leading these discussions can be both emotionally taxing and time consuming.

As medical school, medical residency, and nursing curricula have evolved, many HF clinicians are likely to have been exposed to basic education in communication skills, as a means to facilitate having these discussions. Nevertheless, there are many instances in which there is added complexity, which could serve as a signal to involve specialist palliative care. Such signals might include conflict between the patient and family, conflict among the clinical care team, or ambiguity about which treatment options might best match goals and values due to existential distress. In these instances, the involvement of specialist palliative care can offer the necessary communication skills to navigate these more complex and challenging conversations.

### Psychosocial support and care coordination

Caregivers of patients with advanced HF also face a tremendous burden. Indeed, the estimated annual informal caregiving cost attributable to HF was \$3 billion in 2010 [67]. In addition to partnering in complex medical decisions, family members or friends often take on the responsibilities of assessing symptoms, administering medications, assisting in the management of advanced HF therapies and devices (e.g., mechanical circulatory support, wearable defibrillators, and/or heart transplants), and providing emotional support. Likewise, they coordinate care and assist with activities of daily living, such as transportation to office visits and diagnostic procedures. Ultimately, they will need bereavement support following their loved ones' death. Overall data about the caregiving burdens related to HF are limited.

One qualitative study of caregivers of patients with a destination therapy LVAD demonstrated the burdens of caregivers; specifically, participants described a process of adjusting and adapting to their new roles, amid persistent worry and stress, and eventually accepting caregiving as part of life [68]. In another qualitative study of bereaved caregivers of patients with an LVAD, the participants shared a high level of confusion at the end of life [69]. These caregivers are at high risk for the hazards of caregiving for patients with serious

illness, including anxiety, depression, poor quality of life, complicated bereavement, and high costs of care.

With primary palliative care training, HF clinician caring could better identify those patients and caregivers at risk for these symptoms of anxiety, depression, and complicated grief and ensure that they are referred to appropriate sources of support such as social workers and chaplains. By conducting earlier goals of care discussions and providing prognostic information, caregivers and families can prepare for increasing care needed at home and can mobilize necessary resources. Exploration of patient and caregiver spiritual, religious, and existential suffering is certainly best left to specialist palliative care teams into which chaplaincy is well integrated. Specialist palliative care may be required when the distress of caregiver becomes more complex, including complicated bereavement.

By understanding the goals and values of patients with HF and their caregivers, HF clinicians with primary palliative care training can coordinate care in line with patients' preferences. Furthermore, for those patients with clear goals focused on comfort, a social worker could arrange for hospice care either in the home or in a facility and a referral to a social worker.

### Case examples of primary palliative care

The following cases highlight the ways that the HF team is able to provide primary palliative care in terms of treating symptoms, exploring goals and values, and helping make decisions that align with the patient's overall desired care.

#### Case 1: exploration of goals and values and initiating caregiver support

Mr. S is a 67-year-old man with ischemic cardiomyopathy and type II diabetes who has been followed by a HF cardiologist, Dr. M, for several years. He has been married for over 40 years and lives with his wife. He has adult children who live out of state. Over the past 6 months, his HF has progressed from stable New York Heart Association (NYHA) class II symptoms to class IV symptoms. Despite the addition of cardiac resynchronization therapy and maximizing oral HF therapies, he continued to decline and was admitted for volume overload. He was started on a continuous milrinone infusion with improvement of symptoms and was sent home on that therapy. Dr. M referred him for evaluation for both heart transplant and mechanical circulatory support, and he was deemed ineligible for both due to morbid obesity, history of two prior bypass surgeries, and significant chronic kidney disease. Dr. M met with Mr. S and his wife during a follow-up visit and relayed that he was ineligible for advanced therapies, including heart transplant and discussed prognosis on destination milrinone. Mr. S's wife shared her difficulties in caring for Mr. S at home with the intravenous medication. She shared that she was

hoping it would be temporary until he could receive a transplant. Learning their current situation would continue indefinitely was a shock to her. She asked if there was a way for her to have more help caring for him at home. Dr. M offered to have the social worker from the HF program speak to Mr. S and his wife to investigate how they might add more supports at home. She also explained increased risk of sudden cardiac death on continuous milrinone and explored his goals and values. She learned that Mr. S was feeling better on his current therapy and would be willing to continue on the milrinone for as long as it would be helpful but would like his death to be peaceful and does not want to a lot of time in the hospital or be a burden on his family. In accordance with Mr. S' wishes, the milrinone was continued and Dr. S recommended deactivation of his defibrillator.

### Case 2: alignment of patient preferences with medical therapies

Ms. C is an 80-year-old woman with metastatic pancreatic cancer diagnosed during a recent hospital admission. She lives alone in an apartment with her daughter. She presented to the emergency department several days after her initial appointment with oncology with chest pain and was found to have non-specific EKG changes and elevated cardiac enzymes. She was admitted to the cardiology service, and a stress echo showed reversible ischemia. Ms. C was referred for cardiac catheterization. In light of her diagnosis of advanced cancer, the interventional cardiologist, Dr. G, initiated a code status conversation with the patient and her daughter prior to the procedure and learned that Ms. C did not want to undergo CPR under any circumstances and had actually decided during her oncology evaluation not to pursue chemotherapy. Dr. G suggested that she forego catheterization and treat her anginal symptoms medically. He discussed the option of hospice referral with Ms. C and her daughter, and they were in agreement that hospice would be helpful in managing her symptoms and supporting her family. Dr. G asked the nurse case manager on the cardiology floor to place a referral for home hospice.

### Models for primary palliative care training

Because the distinction of primary palliative care and specialist palliative care is new to the field of palliative medicine, many of the features are still being defined. Nevertheless, there are primary palliative care training models available with a focus to educate physicians, physician assistants, nurses, case managers, and social workers who care for patients across all diagnoses (Table 2). Specifically, the Center to Advance Palliative Care (CAPC) has developed a web-based clinical skills curriculum, with a focus on pain

management, communication skills, symptom management, and training in whole patient care. These online modules ([www.capc.org](http://www.capc.org)) offer clinical training for clinicians from all disciplines and specialties who care for patients with serious illness. In addition, the Education in Palliative and End-of-Life Care (EPEC) Program, which began in 1997, has developed curriculum to educate healthcare professionals of all backgrounds in the essential clinical competencies of palliative and end-of-life care with the goal to ensure that all patients receive the primary palliative care they need (<http://bioethics.northwestern.edu/programs/epec/>). The EPEC curriculum combines didactic sessions, video presentations, interactive discussions, and practice exercises. It teaches fundamental palliative care skills in communication, ethical decision-making, psychosocial considerations, and symptom management. There are also specialized EPEC programs for professionals in emergency medicine, oncology, and pediatrics and those who care for veterans as well as a program for caregivers. These courses offer both in-person conferences and workshops, as well as distance learning with online modules.

Another resource for primary palliative care training is the End-of-Life Nursing Education Consortium (ELNEC) project [70–73], a national education initiative to improve palliative care by training nursing faculty in palliative care, so they can teach this essential information to nursing students and practicing nurses (<http://www.aacn.nche.edu/elneec>). In addition to ELNEC-Core, which is appropriate for all nurses, there are specialty ELNEC courses for advanced practice RNs, as well as specialty nurses in pediatrics, oncology, critical care, and geriatrics. Currently, a cardiac specific training is being developed. While there is not a primary palliative care training curriculum tailored to HF clinicians, there are models under development to address this growing need.

Kavalieratos and colleagues are developing a primary palliative care intervention for patients with NYHA class III–IV HF being cared for in community-based outpatient cardiology clinics. This intervention is informed by the Chronic Care Model [55], a well-established model of disease management that is commonly utilized in cardiology, to concomitantly provide primary palliative care early within patients' usual outpatient, community HF care experiences. Indeed, multiple aspects of palliative care (e.g., care coordination, decision support) align with principles of disease management, as conceptualized by the Chronic Care Model. After receiving a 2-day training in core palliative care topics, an existing cardiology nurse will deliver a manualized intervention to patients during regularly scheduled outpatient cardiology office visits; additional telephone contacts will serve to reinforce content. The intervention will span five domains: symptom management, psychosocial support, advance care planning (e.g., understanding prognosis and electing a proxy), care coordination, and self-management. With funding from the National Heart,

**Table 2** Primary palliative care training opportunities

Program	Target population	Modules	Costs	Time commitment	Format
CAPC Online Curriculum	Healthcare professionals who care for patients with serious illness	<ul style="list-style-type: none"> <li>• Pain management</li> <li>• Communication skills</li> <li>• Symptom management</li> </ul>	Part of CAPC membership for all staff (~\$3500 per organization)	40+ modules	Online
EPEC	Healthcare professionals and caregivers	<ul style="list-style-type: none"> <li>• Communication skills</li> <li>• Ethical decision-making</li> <li>• Psychosocial considerations</li> <li>• Symptom management</li> </ul>	<ul style="list-style-type: none"> <li>• Conference ~\$750</li> <li>- Each online module \$30</li> </ul>	<ul style="list-style-type: none"> <li>- 1.5 days (in-person)</li> <li>- 16 modules with 30 screens per module (online)</li> </ul>	<ul style="list-style-type: none"> <li>- In-person workshops and conferences</li> <li>- Online</li> </ul>
ELNEC	<ul style="list-style-type: none"> <li>• Undergraduate and graduate nursing faculty</li> <li>• CE providers and staff development educators</li> <li>• Hospice nurses</li> <li>• Homecare nurses</li> <li>• APRN/staff nurses working in acute care settings</li> </ul>	<ul style="list-style-type: none"> <li>• Nursing care at the end of life</li> <li>• Pain management</li> <li>• Symptom management</li> <li>• Ethical/legal issues; cultural considerations in end-of-life care</li> <li>• Communication</li> <li>• Loss, grief, bereavement</li> <li>• Preparation for and care at the time of death</li> </ul>	\$625 plus travel and lodging	2 days with optional additional half day	<ul style="list-style-type: none"> <li>- In-person trainings</li> <li>- ELNEC online for undergraduate nursing students</li> </ul>
CardioTalk	Physicians and advanced practice RNs	<ul style="list-style-type: none"> <li>• Giving bad news</li> <li>• Conducting family conferences</li> <li>• Defining goals of care</li> <li>• Responding to emotion</li> <li>• Discussing code status</li> <li>• Respecting and supporting religious and spiritual beliefs</li> <li>• Withdrawing life-sustaining therapies</li> </ul>	\$600 plus travel and lodging	2 days	In-person

Lung, and Blood Institute, this intervention [74] will undergo pilot testing to establish its feasibility and acceptability; future research will compare the effectiveness of this intervention against usual care.

### CardioTalk communication skills training

Another model specifically for development of communication skill training for cardiology physicians is CardioTalk [75], which is based on VitalTalk ([vitaltalk.org](http://vitaltalk.org)) (originally Oncotalk), a communication skills training program which has demonstrated effectiveness with an increase in a mean of 5.5 new communication skills per participant [76–78]. This communication training consists of brief didactic sessions, practice sessions using new skills, and reflection on skills used [76]. By building off the experiential learning model [79] and deliberate practice [80], learners improve their ability to respond to emotion, elicit patient goals and values, thereby create a more patient-centered encounter [76].

CardioTalk has been part of fellow and attending physician education at a large academic medical center since 2014. Cardiology fellows and attending faculty were surveyed prior to the workshop on their level of prior education in communication as well as their willingness to participate. All of the

fellows reported having received at least some education in communication, while close to 60% of the faculty reported having some prior education. Given this information, many cardiologists may have a basic framework for communication but may still benefit from additional communication training. In the group surveyed, providers welcomed the opportunity to improve basic communication skills.

Additional data examining participant level of perceived preparedness collected after the workshop demonstrated that cardiology fellows and faculty reported feeling more prepared to perform basic communication skills after the training. These skills included giving bad news, conducting family conferences, defining goals of care, expressing empathy, responding to emotion, discussing code status, respecting and supporting religious and spiritual beliefs, and withdrawing life-sustaining therapies.

### Future directions

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 [81]. A more nuanced understanding of the impact of different aspects of palliative care is required to export these models to other settings where the entire breadth of palliative care expertise may not be readily available.

In order to meet the growing need for palliative care for patients with advanced HF, funding is needed to develop optimal models of primary and specialist palliative care. Unfortunately, in spite of multiple guidelines advocating palliative care for patients with advanced HF, the NIH funding support for HF research related to palliative care is lacking. A recent review of published literature, HF-related conference proceedings and NIH funding from 2009 to 2013 found that of the journals reviewed, less than 1% of their publications related to palliative care. Less than 2% of HF-related sessions in conference proceedings mentioned palliative care. Of the NIH's \$45 billion directed to HF research, only \$14 million (0.03%) was spent on palliative care research [82].

In order to meet the growing palliative care needs of patients with HF and their caregivers, dedicated funding is required to ensure that high-quality research examines the optimal models for providing primary palliative care to this population. In addition, further collaboration between palliative care and HF societies is necessary.

## Conclusion

Palliative care is a critical addition to the care of patients with HF and their families, yet the resources to provide specialist palliative care to the vast number of patients living with HF and their families is not feasible due to the limited resource allocation and workforce of palliative care clinicians. Primary palliative care training for clinicians caring for patients with HF offers an opportunity to fill this gap and ensure that these patients are receiving both the highest quality of care across the spectrum of their serious illness, from diagnosis to death. In spite of the vast needs, there is little data to support primary palliative care models for this population; therefore, research is needed to advance this nascent field. Fortunately, with the increasing demand for palliative care in this population from clinicians, specialty societies, and regulatory bodies, including CMS, there are growing opportunities to develop successful models for primary palliative care in this population and to better clarify the role of specialist palliative care for the most complex needs of this population.

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**Ethical standards** The manuscript does not contain clinical studies or patient data. This article does not contain any studies with human participants or animals performed by any of the authors.

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## References

- Ziaieian B, Fonarow GC (2016) Epidemiology and aetiology of heart failure. *Nat Rev Cardiol* 13(6):368–378
- Writing Committee M, Yancy CW, Jessup M et al (2013) 2013 ACCF/AHA guideline for the management of heart failure: a report of the American College of Cardiology Foundation/American Heart Association Task Force on practice guidelines. *Circulation* 128(16):e240–e327
- Liu L, Eisen HJ (2014) Epidemiology of heart failure and scope of the problem. *Cardiol Clin* 32(1):1–8 vii
- Solano J, Gomes B, Higginson I (2006) A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manag* 31(1):58–69
- Bekelman DB, Havranek EP, Becker DM et al (2007) Symptoms, depression, and quality of life in patients with heart failure. *J Card Fail* 13(8):643–648
- Kavalieratos D, Kamal AH, Abemethy AP et al (2014) Comparing unmet needs between community-based palliative care patients with heart failure and patients with cancer. *J Palliat Med* 17(4):475–481
- Juenger J, Schellberg D, Kraemer S et al (2002) Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. *Heart* 87(3):235–241
- Allen L, Yager J, Funk M et al (2008) Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure. *JAMA* 299(21):2533–2542
- Bakitas M, Macmartin M, Trzepkowski K et al (2013) Palliative care consultations for heart failure patients: how many, when, and why? *J Card Fail* 19(3):193–201
- Goebel J, Doering L, Shugarman L et al (2009) Heart failure: the hidden problem of pain. *J Pain Symptom Manag* 38(5):698–707
- Evangelista L, Sackett E, Dracup K (2009) Pain and heart failure: unrecognized and untreated. *Eur J Cardiovasc Nurs* 8(3):169–173
- Hunt SA, Abraham WT, Chin MH et al (2009) Focused update incorporated into the ACC/AHA 2005 Guidelines for the Diagnosis and Management of Heart Failure in Adults: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines: developed in collaboration with the International Society for Heart and Lung Transplantation. *Circulation* 119(14):e391–e479
- Johnson MJ, Booth S (2010) Palliative and end-of-life care for patients with chronic heart failure and chronic lung disease. *Clin Med* 10(3):286–289
- O'Leary N, Murphy NF, O'Loughlin C, Tiernan E, McDonald K (2009) A comparative study of the palliative care needs of heart failure and cancer patients. *Eur J Heart Fail* 11(4):406–412



15. Steinhilber KE, Arnold RM, Olsen MK et al (2011) Comparing three life-limiting diseases: does diagnosis matter or is sick, sick? *J Pain Symptom Manage*
16. Currow DC, Smith J, Davidson PM, Newton PJ, Agar MR, Abernethy AP (2010) Do the trajectories of dyspnea differ in prevalence and intensity by diagnosis at the end of life? A consecutive cohort study. *J Pain Symptom Manage* 39(4):680–690
17. Heidenreich PA, Albert NM, Allen LA et al (2013) Forecasting the impact of heart failure in the United States: a policy statement from the American Heart Association. *Circ Heart Fail* 6(3):606–619
18. Cain CJ, Wicks MN (2000) Caregiver attributes as correlates of burden in family caregivers coping with chronic obstructive pulmonary disease. *J Fam Nurs* 6(1):46–68
19. Dracup K, Evangelista LS, Doering L, Tullman D, Moser DK, Hamilton M (2004) Emotional well-being in spouses of patients with advanced heart failure. *Heart Lung* 33(6):354–361
20. Harding R, Selman L, Beynon T et al (2008) Meeting the communication and information needs of chronic heart failure patients. *J Pain Symptom Manage* 36(2):149–156
21. Lemond L, Allen LA (2011) Palliative care and hospice in advanced heart failure. *Prog Cardiovasc Dis* 54(2):168–178
22. Morrison RS, Meier DE (2004) Palliative care. *N Engl J Med* 350(25):2582–2590
23. Morrison RS, Dietrich J, Ladwig S et al (2011) Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. *Health Aff* 30(3):454–463
24. Kavalieratos D, Corbelli J, Zhang D et al (2016) Association between palliative care and patient and caregiver outcomes: a systematic review and meta-analysis. *JAMA* 316(20):2104–2114
25. Temel JS, Greer JA, Muzikansky A et al (2010) Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 363(8):733–742
26. Bakitas M, Lyons KD, Hegel MT et al (2009) Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the project ENABLE II randomized controlled trial. *JAMA* 302(7):741–749
27. Rabow M, Dibble S, Pantilat S, McPhee S (2004) The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. *Arch Intern Med* 164(1):83–91
28. Abernethy AP, Currow DC, Fazekas BS, Luszcz MA, Wheeler JL, Kuchibhatla M (2008) Specialized palliative care services are associated with improved short- and long-term caregiver outcomes. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer 16(6):585–597
29. Sidebottom AC, Jorgenson A, Richards H, Kirven J, Sillah A (2015) Inpatient palliative care for patients with acute heart failure: outcomes from a randomized trial. *J Palliat Med* 18(2):134–142
30. Brannstrom M, Boman K (2014) Effects of person-centred and integrated chronic heart failure and palliative home care. PREFER: a randomized controlled study. *Eur J Heart Fail* 16(10):1142–1151
31. Aiken LS, Butner J, Lockhart CA et al (2006) Outcome evaluation of a randomized trial of the PhoenixCare intervention: program of case management and coordinated care for the seriously chronically ill. *J Palliat Med* 9(1):111–126
32. Wong F, Ng A, Lee P, et al (2016) Effects of a transitional palliative care model on patients with end-stage heart failure: a randomised controlled trial. *Heart*
33. Bekelman DB, Plomondon ME, Carey EP et al (2015) Primary results of the patient-centered disease management (PCDM) for heart failure study: a randomized clinical trial. *JAMA Intern Med* 175(5):725–732
34. Brumley R, Enguidanos S, Jamison P et al (2007) Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *J Am Geriatr Soc* 55(7):993–1000
35. Fendler TJ, Swetz KM, Allen LA (2015) Team-based palliative and end-of-life care for heart failure. *Heart Fail Clin* 11(3):479–498
36. Braun LT, Grady KL, Kutner JS et al (2016) Palliative care and cardiovascular disease and stroke: a policy statement from the American Heart Association/American Stroke Association. *Circulation*
37. Kavalieratos D, Corbelli J, Ernecoff N, Arnold R, Schenker Y (2016) Identifying the impact of palliative care interventions: a systematic review (SA538D). *J Pain Symptom Manage* 51(2):406
38. Quill TE, Abernethy AP (2013) Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med* 368(13):1173–1175
39. Fang JC, Ewald GA, Allen LA et al (2015) Advanced (stage D) heart failure: a statement from the heart failure society of america guidelines committee. *J Card Fail*
40. Yancy CW, Jessup M, Bozkurt B et al 2013 ACCF/AHA Guideline for the Management of Heart Failure: a report of the American College of Cardiology Foundation/American Heart Association Task Force on practice guidelines. *Circulation*
41. Feldman D, Pamboukian SV, Teuteberg JJ et al (2013) The 2013 International Society for Heart and Lung Transplantation Guidelines for mechanical circulatory support: executive summary. *J Heart Lung Transplant* 32(2):157–187
42. Dans M, Garcia K (2015) Palliative care and hospice in patients with advanced cardiovascular disease. *End-of-Life Care in Cardiovascular Disease: Springer*:33–49
43. Jurgens CY, Goodlin S, Dolansky M et al (2015) Heart failure management in skilled nursing facilities: a scientific statement from the American Heart Association and the Heart Failure Society of America. *Circulation: Heart Failure* 8(3):655–687
44. Allen LA, Stevenson LW, Grady KL et al (2012) Decision making in advanced heart failure: a scientific statement from the American Heart Association. *Circulation* 125(15):1928–1952
45. Andersen J (2009) NHPCO 2009 facts and figures. 1–15
46. Dunlay SM, Foxen JL, Cole T et al (2015) A survey of clinician attitudes and self-reported practices regarding end-of-life care in heart failure. *Palliat Med* 29(3):260–267
47. Brännström M, Forsell A, Pettersson B (2011) Physicians' experiences of palliative care for heart failure patients. *Eur J Cardiovasc Nurs* 10(1):64–69
48. Hanratty B, Hibbert D, Mair F et al (2002) Doctors' perceptions of palliative care for heart failure: focus group study. *BMJ* 325(7364):581–585
49. Kavalieratos D (2014) Attitudes and perceptions regarding a generalist plus specialist model of palliative care in heart failure. *J Am Coll Cardiol* 63(12\_S)
50. Kavalieratos D, Mitchell EM, Carey TS et al (2014) “Not the ‘grim reaper service’”: an assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. *J Amer Heart Assn* 3(1):e544–e544
51. Kamal AH, Maguire JM, Meier DE (2015) Evolving the palliative care workforce to provide responsive, serious illness care. *Ann Intern Med*
52. A Call to Action: Policy Initiatives to Support Palliative Care. <https://reportcard.capc.org/recommendations/>. Accessed 5/12, 2016
53. Lupu D (2010) American Academy of H, Palliative Medicine Workforce Task F. Estimate of current hospice and palliative medicine physician workforce shortage. *J Pain Symptom Manage* 40(6):899–911
54. Schenker Y, Arnold R (2015) The next era of palliative care. *JAMA*:1–2
55. Krumholz HM, Currie PM, Riegel B et al (2006) A taxonomy for disease management: a scientific statement from the American Heart Association Disease Management Taxonomy Writing Group. *Circulation* 114(13):1432–1445

56. Munoz-Mendoza J (2015) Competencies in palliative care for cardiology fellows. *J Am Coll Cardiol* 65(7):750–752
57. Fuster V, Halperin JL, Williams ES et al (2015) COCATS 4 task force 1: training in ambulatory, consultative, and longitudinal cardiovascular care. *J Am Coll Cardiol* 65(17):1734–1753
58. Bekelman DB, Nowels CT, Allen LA, Shakar S, Kutner JS, Matlock DD (2011) Outpatient palliative care for chronic heart failure: a case series. *J Palliat Med* 14(7):815–821
59. Khan RF, Feder S, Goldstein NE, Chaudhry SI (2015) Symptom burden among patients who were hospitalized for heart failure. *JAMA Intern Med* 175(10):1713–1715
60. Dunlay SM, Swetz KM, Mueller PS, Roger VL (2012) Advance directives in community patients with heart failure. *Circ Cardiovasc Qual Outcomes*. 5(3):283–289
61. Butler J, Binney Z, Kalogeropoulos A et al (2015) Advance directives among hospitalized patients with heart failure. *JACC Heart Fail*. 3(2):112–121
62. Stevenson LW, O'Donnell A (2015) Advanced care planning: care to plan in advance. *JACC Heart Fail* 3(2):122–126
63. Dunlay SM, Swetz KM, Redfield MM, Mueller PS, Roger VL (2014) Resuscitation preferences in community patients with heart failure. *Circ Cardiovasc Qual Outcomes* 7(3):353–359
64. Buchhalter LC, Ottenberg AL, Webster TL, Swetz KM, Hayes DL, Mueller PS (2014) Features and outcomes of patients who underwent cardiac device deactivation. *JAMA Intern Med* 174(1):80–85
65. Goldstein NE, Mehta D, Teitelbaum E, Bradley EH, Morrison RS (2008) “It’s like crossing a bridge” complexities preventing physicians from discussing deactivation of implantable defibrillators at the end of life. *J Gen Intern Med* 23(Suppl 1):2–6
66. Goldstein NE, Lampert R, Bradley E, Lynn J, Krumholz HM (2004) Management of implantable cardioverter defibrillators in end-of-life care. *Ann Intern Med* 141(11):835–838
67. Joo H, Fang J, Losby JL, Wang G (2015) Cost of informal caregiving for patients with heart failure. *Am Heart J* 169(1):142–148 e142
68. Marcuccilli L, Casida JJ, Bakas T, Pagani FD (2014) Family caregivers’ inside perspectives: caring for an adult with a left ventricular assist device as a destination therapy. *Prog Transplant* 24(4):332–340
69. McIlvennan CK, Jones J, Allen LA, Swetz KM, Nowels C, Matlock DD (2016) Bereaved caregiver perspectives on the end-of-life experience of patients with a left ventricular assist device. *JAMA Intern Med* 176(4):534–539
70. Sherman DW, Matzo ML, Rogers S, McLaughlin M, Virani R (2002) Achieving quality care at the end of life: a focus of the End-of-Life Nursing Education Consortium (ELNEC) curriculum. *Journal of professional nursing : official journal of the American Association of Colleges of Nursing* 18(5):255–262
71. Sherman DW, Matzo ML, Pitorak E, Ferrell BR, Malloy P (2005) Preparation and care at the time of death: content of the ELNEC curriculum and teaching strategies. *Journal for nurses in staff development : JNSD : official journal of the National Nursing Staff Development Organization* 21(3):93–100 quiz 101–102
72. Matzo ML, Sherman DW, Penn B, Ferrell BR (2003) The end-of-life nursing education consortium (ELNEC) experience. *Nurse Educ* 28(6):266–270
73. Matzo ML, Sherman DW, Sheehan DC, Ferrell BR, Penn B (2003) Communication skills for end-of-life nursing care. Teaching strategies from the ELNEC curriculum. *Nurs Educ Perspect* 24(4):176–183
74. 2016 Health NIo. integrating palliative care with disease management to improve outcomes among patients with advanced heart failure: interventional research career development. [https://projectreporter.nih.gov/project\\_info\\_description.cfm?aid=9162916&icde=31188392&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC](https://projectreporter.nih.gov/project_info_description.cfm?aid=9162916&icde=31188392&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC). Accessed September 28, 2016
75. Berlacher K TW, Reitschuler-Cross E, Arnold RM (2015) CardioTalk: the future of communication training in cardiovascular medicine. Paper presented at: American College of Cardiology Annual Assembly; San Diego, CA
76. Back AL, Arnold RM, Baile WF et al (2007) Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Arch Intern Med* 167(5):453–460
77. Back AL, Arnold RM, Tulskey JA, Baile WF, Edwards K (2010) “Could I add something?”: teaching communication by intervening in real time during a clinical encounter. *Acad Med* 85(6):1048–1051
78. Lenzi R, Baile WF, Berek J et al (2005) Design, conduct and evaluation of a communication course for oncology fellows. *J Cancer Educ* 20(3):143–149
79. Armstrong E, Parsa-Parsi R (2005) How can physicians’ learning styles drive educational planning? *Acad Med* 80(7):680–684
80. Ericsson KA (2004) Deliberate practice and the acquisition and maintenance of expert performance in medicine and related domains. *Acad Med* 79(10 Suppl):S70–S81
81. Stevenson LW, Davis RB (2016) Model building as an educational hobby. *Circ Heart Fail* 9(8)
82. Xie K, Gelfman L, Horton JR, Goldstein NE (2017) State of research on palliative care in heart failure as evidenced by published literature, conference proceedings, and NIH Funding. *J Card Fail* 23(2):197–200