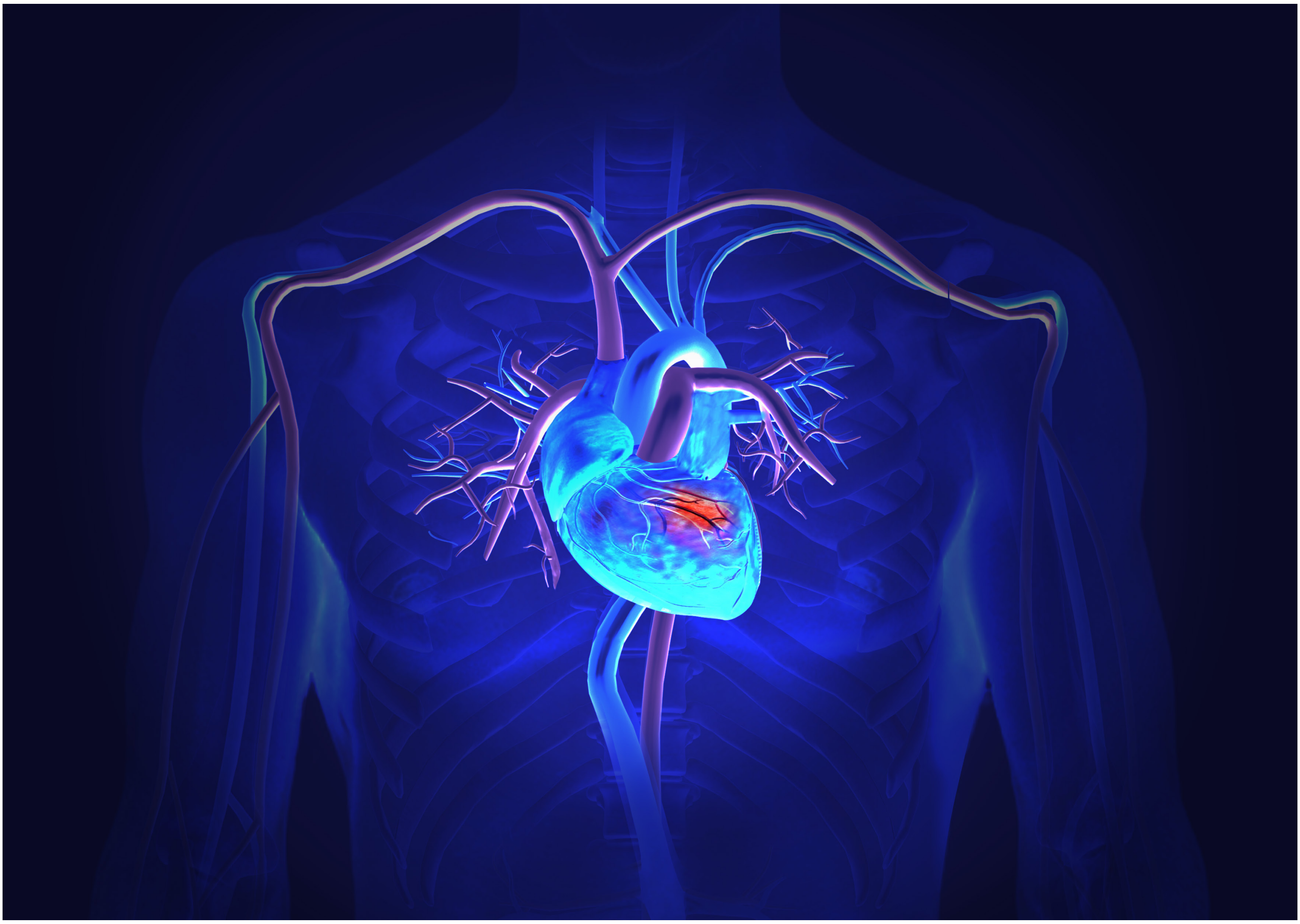
PALLIATIVE CARE FOR HEART FAILURE : ADVANCE CARE PLANNING PRIORITIES



APRNworld®

Disclaimer

The Nursing Continuing Professional Education materials produced by APRNWORLD® are made as an integrated review of current evidence available from multiple sources. The bulk of the information is taken from major scientific journals and other relevant publications. APRNWORLD® made every reasonable effort to cite these resources appropriately however, may have omissions made inadvertently due to the vast and generic nature of the scientific information available. APRNWORLD® does not hold copyright of any of such information. The copyright of such information belongs to the specific author/ publisher or their legal designee. Even though we made every reasonable effort in ensuring the quality and correctness of information, APRNWORLD® does not bear the responsibility of the accuracy of the information as it was taken from publicly available sources. The education material is meant for licensed professionals with a solid body of knowledge, experience and understanding of complex medical scenarios. The material presented here does not replace sound scientific and up-to-date guidelines from professional sources. Because of the dynamic nature of medical and scientific advancements, these training materials should not be used as the sole basis for medical practice. Individual practitioner should exercise their critical thinking and clinical reasoning skills in dealing with complex medical scenarios. APRNWORLD® does not bear any responsibility for the claims that the information presented through its platforms caused injury or unwanted outcomes in any clinical situations.

Palliative Care For Heart Failure : Advance Care Planning Priorities

ANCC Accredited NCPD Hours: 2.2hrs
Target Audience: RN/APRN

Need Assessment

Although recommended by all major cardiology societies for patients with advanced CHF, specialist palliative care for all eligible patients is currently neither a feasible nor a scalable strategy. Therefore, patients with CHF rarely receive specialist palliative care. Research 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 predicting prognosis; 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 and high mortality rate. In this article, 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.

Objectives

- Discuss the quality of life in people with Congestive Heart Failure.
- Describe the natural opportunities to integrate palliative domains in CHF Care.
- Identify the effective palliative care models in optimizing outcomes for patients with CHF.
- Describe the poorly controlled symptoms and psychosocial-spiritual distress in CHF.

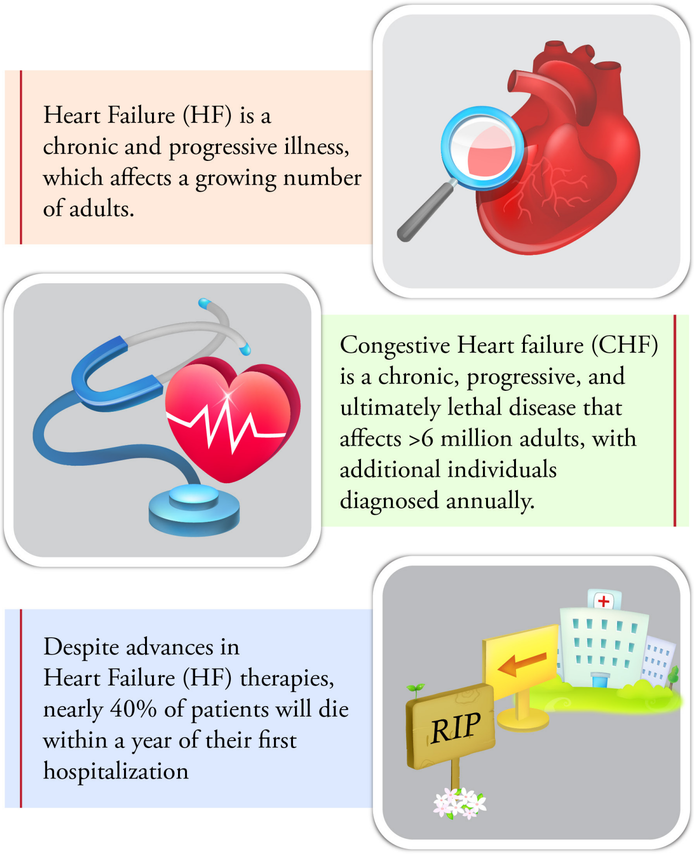
Goal

The goal of this article is to discuss the role of palliative care in the management of HF. The article also discuss the need for high-quality palliative care research to better understand the effect of integrating palliative care in the management of HF in view of current available evidence.

Introduction

Heart Failure (HF) is a chronic and progressive illness, which affects a growing number of adults. It is associated with a high morbidity, mortality, and significant physical and psychological symptom burden on both patients with HF and families.

Heart Failure



Heart Failure (HF) is a chronic and progressive illness, which affects a growing number of adults.

Congestive Heart failure (CHF) is a chronic, progressive, and ultimately lethal disease that affects >6 million adults, with additional individuals diagnosed annually.

Despite advances in Heart Failure (HF) therapies, nearly 40% of patients will die within a year of their first hospitalization

Figure 1 : Heart failure

Palliative care can be delivered as

(1) Specialist palliative care in which a palliative care specialist with palliative care training consults or co-manages patients to address palliative needs alongside clinicians who manage the underlying illness.

(2) 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.

Although there is little ***research on HF*** primary palliative care, primary palliative care in HF offers a key opportunity to ensure this ***population receives high quality palliative care in spite of the growing numbers of patients with HF and limited number of specialist palliative care providers.*** [1, Rank 5]

> **“ Heart Failure (HF) is associated with a high morbidity, mortality, and significant physical and psychological symptom burden on both patients with HF and families. ”**

Quality of Life in People with Congestive Heart Failure

Congestive Heart failure (CHF) is a chronic, progressive, and ultimately lethal disease that affects >6 million adults, with additional individuals diagnosed annually. Despite advances in Heart Failure (HF) therapies, nearly 40% of patients will die within a year of their first hospitalization.

During the course of CHF, patients typically experience debilitating physical and emotional symptoms, loss of independence, and disruptions to social roles, all of which severely degrade quality of life (QoL). Physical symptoms in advanced CHF, such as pain, are highly distressing for patients and caregivers, yet remain under-recognized and undertreated.

Patients and their caregivers often face decisions about high-risk and complex treatments(e.g., cardiac devices, transplantation) without adequate prognosis communication, decision support, or advance care planning. In addition, CHF management poses enormous financial and resource stress on families, healthcare systems, and society. Direct medical costs of HF are projected to be >$77 billion by 2030, a 215% increase from current spending.

A recent systematic review and meta-analysis of palliative care interventions suggests that ***a palliative approach is associated with improved patient QoL, reduced symptom burden, and improved caregiver outcomes.*** However, most evidence for ***palliative care originates from research in oncology and the role of palliative care in chronic, non-malignant illnesses such as CHF is underdeveloped.*** [2, Rank 4]

> **“ Physical symptoms in advanced CHF, such as pain, are highly distressing for patients and caregivers, yet remain under-recognized and under-treated. ”**

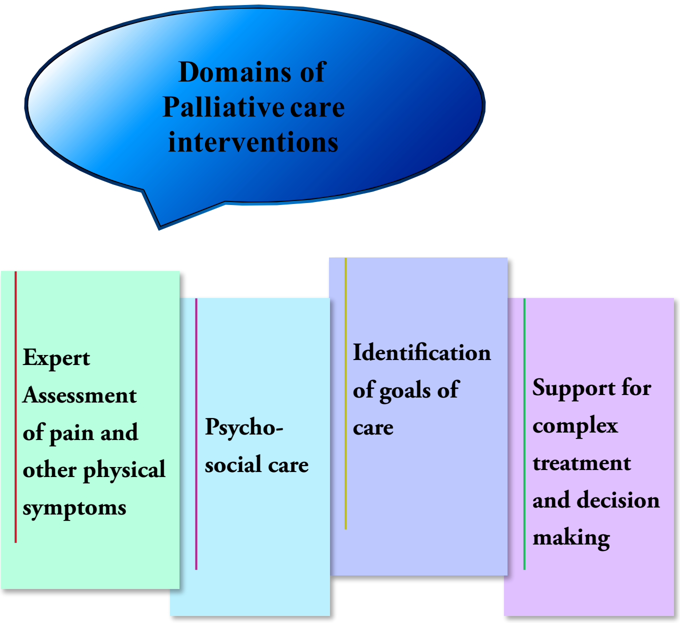


Figure: 2 Domains of Palliative care interventions

The Various Palliative Care Models

Palliative care takes many forms. Historically, ***a sub-specialty trained palliative care specialist works alongside patients' primary clinicians to consult on or co-manage patients' palliative needs.*** Alternatively, primary palliative care (or “basic” or “generalist” palliative care) is the concept that all clinicians, regardless of specialization, should be competent in funda-

> **“ 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. ”**

mental palliative skills (as shown in fig:3). These skills include basic physical and emotional symptom management, initial goals of care discussions, and patient referral to specialty palliative care or, for patients at the end of life, hospice care. Palliative care also varies by the location of service. More than 65% of U.S. hospitals have a specialty palliative care program which delivers services to inpatients. Community- and outpatient-based palliative care models have been regarded as the “new frontier” in supporting patients and families longitudinally and across a variety of care settings. [3, Rank 5]

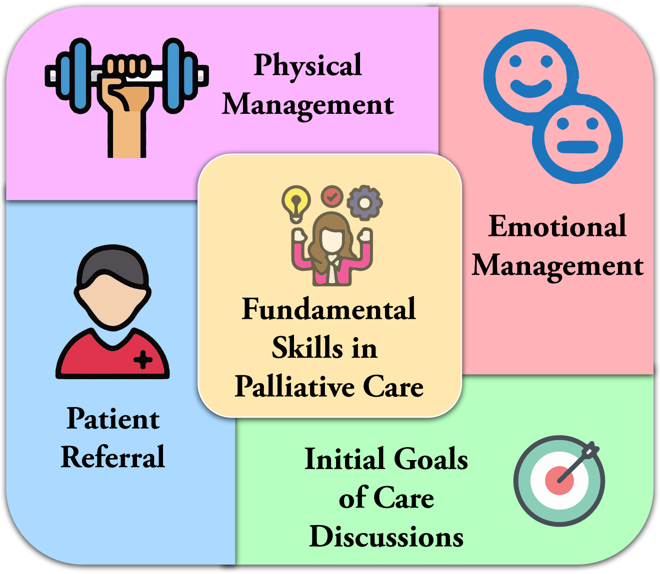


Figure 3: Palliative care skills

Natural Opportunities to Integrate Palliative Domains in CHF Care

Historically, the prevailing approach to palliative care has been one of a zero-sum game; palliative and curative therapies have been incorrectly regarded as contradictory options. ***It is no longer appropriate to assume that palliative care should be initiated only as a treatment of last resort when traditional HF management fails to fulfil a patient’s goals.*** Particularly given the unpredictable trajectory of HF, waiting for a “trigger” event to initiate a palliative approach – either primary palliative care or specialty palliative care consultation – perpetuates the false dichotomy of palliative versus (rather than palliative plus) life-prolonging therapy.

In fact, there are often multiple natural opportunities to consider integrating various palliative domains throughout the HF trajectory. ***Palliative care specialists can assist with the management of intractable symptoms, and more complex medical decision-making, such as instances of discordant patient-family goals or irresolvable unrealistic expectations of medical therapies.***

Recognizing the potential discordance between objective measures of disease severi-

> **“ Palliative and curative therapies have been incorrectly regarded as contradictory options. ”**

ty (e.g., ejection fraction) and patient-reported outcomes (e.g., symptom burden, QoL), it is important that patient-reported outcomes, such as ***symptoms and QoL be monitored regularly throughout the entire HF experience by primary care and/or cardiology providers to facilitate optimal patient-centered care.*** Ultimately, the optimal timing for integrating primary or specialty palliative care for patients with advanced HF will vary, reflecting patient need, not prognosis. [4, Rank 4]

Core domains of primary palliative care may be seamlessly integrated within usual HF disease and device management. (As shown in fig: 4).

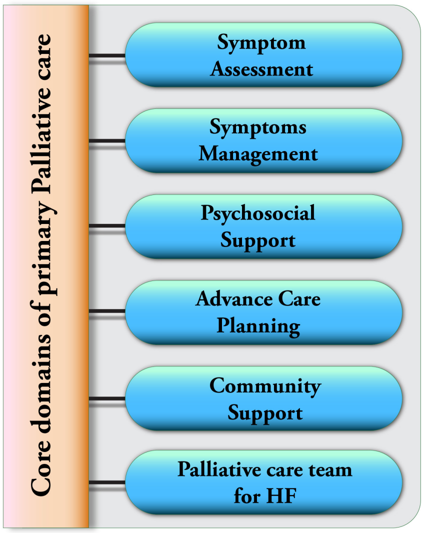


Figure 4: Core domains of primary Palliative care

When appropriate, ***specialty palliative care services may be initiated to address complex or intractable palliative needs.*** The timing of these referrals should be based on patient need, not prognosis. These measures can be initiated at any point during the HF trajectory. Given that symptoms, functional status, and QoL are not perfectly correlated, it is important that palliative needs such as symptoms and QoL be routinely and systematically monitored throughout the patient's HF care trajectory. [5, Rank 3]

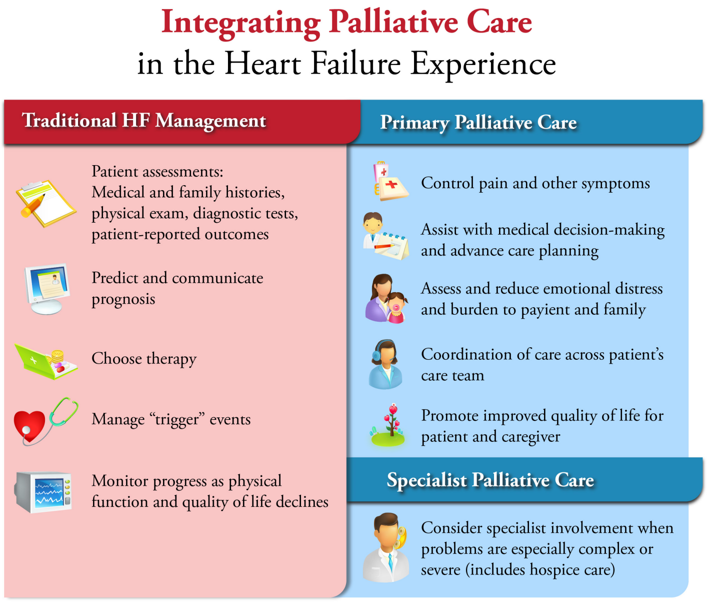


Figure 5 : Integrating palliative care in HF

> **“ For many patients, primary palliative care, such as basic symptom management and identifying a surrogate decision maker is provided by a primary care, cardiology, or HF clinician ”**

Poorly controlled symptoms and psychosocial-spiritual distress in CHF

Patients with HF often have a wide array of symptoms. (As shown in Figure 6)

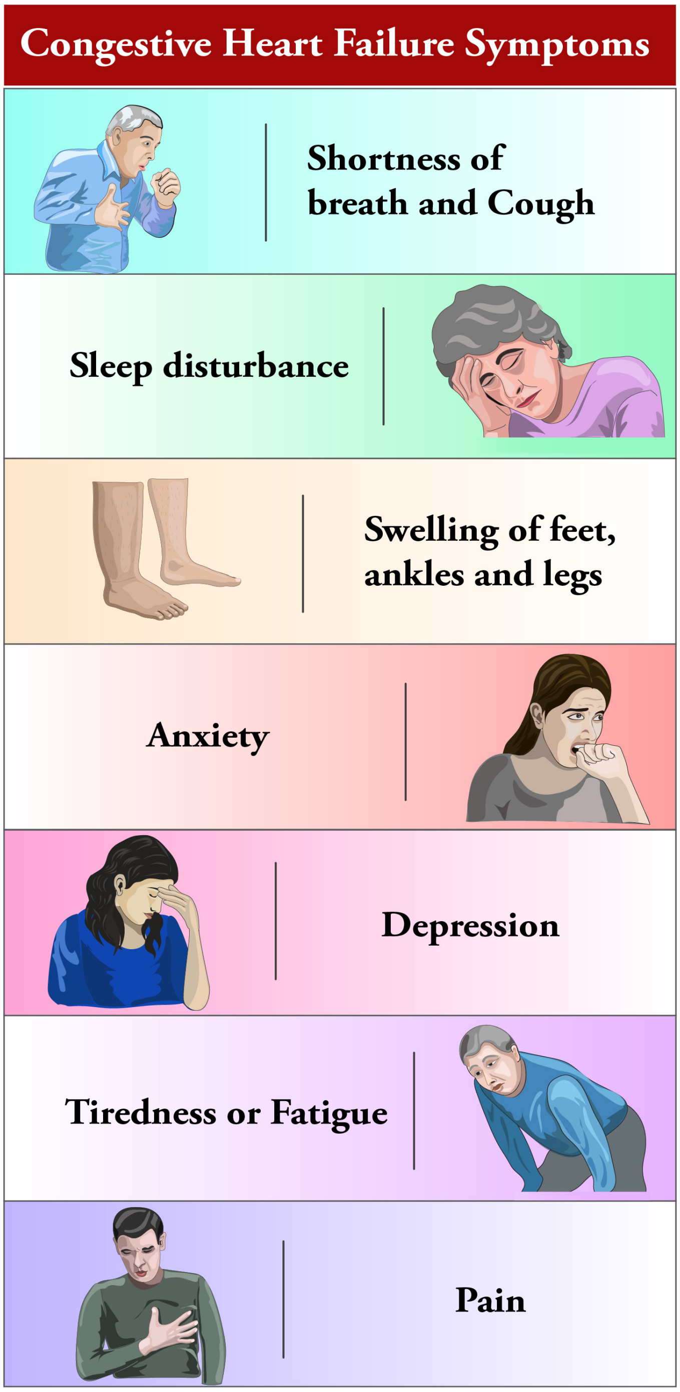


Figure 6: Symptoms of HF

There are varying levels of evidence for treating HF symptoms. Often, the ideal HF symptom management approach is treating the underlying HF condition (e.g., relieving dyspnea by addressing fluid overload). This is a clear example of the harmony between traditional HF disease management and a palliative approach. However, many symptoms persist despite optimal disease management. For example, ***pain is common, yet under-recognized and therefore undertreated in HF.*** Similarly, depression occurs in an estimated 1 in 5 patients with HF, and is associated with worse QoL and increased mortality; yet routine screening for depression in HF is rare. [6, Rank 5]

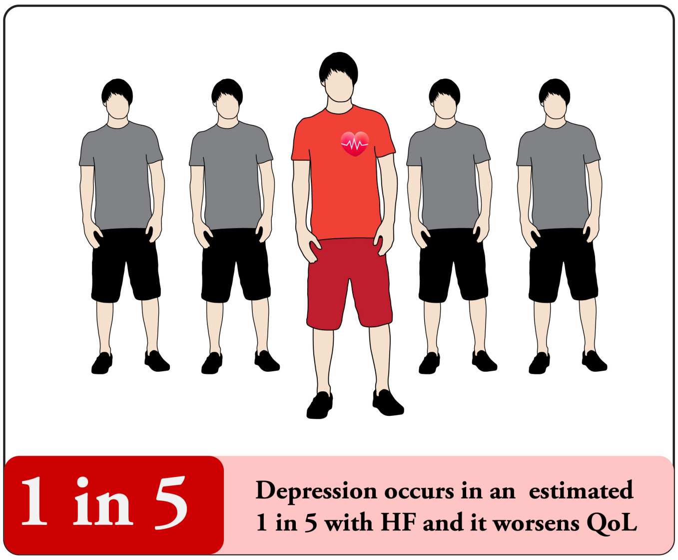


Figure 7: Depression and HF

The ***psychosocial-spiritual context*** of HF beyond depression and anxiety is understudied. The HF experience is common with uncertainty, existential distress, and adjustment to modified social and professional roles. ***Additionally, patients considering advanced therapies such as Vascular Assistive Devices (VAD) and cardiac transplantation face additional anxieties as they anticipate or adjusting to a new life after treatment.*** In addition to limitations in personal roles, patients experience wide variability in social support and the availability of informal caregivers (e.g., friends, spouses, children). Regarding spirituality, patients with HF and poor health status report worse spiritual well-being compared to patients with metastatic lung and pancreatic cancer.

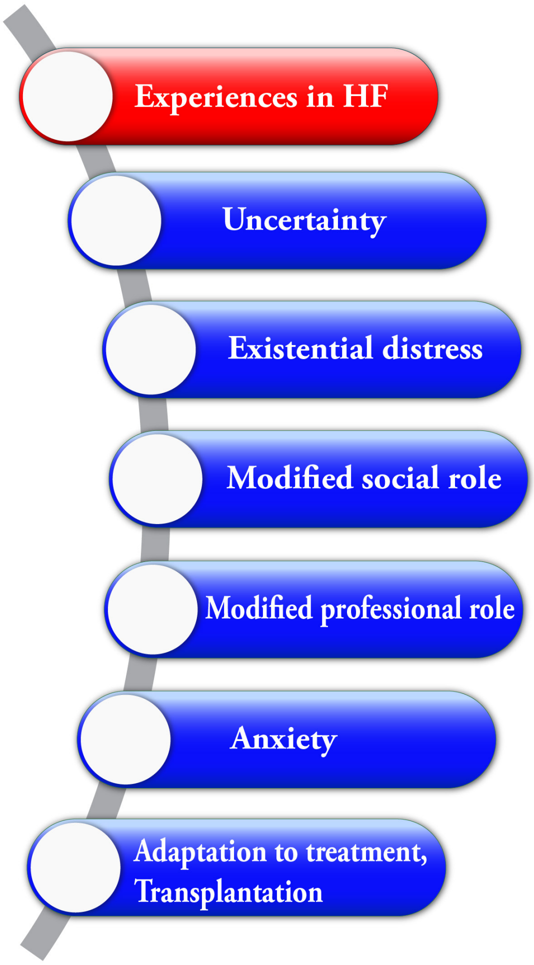


Figure 8: HF Experience to address in the Psychosocial-spiritual domain of palliative care

> **“ Palliative care is an interdisciplinary approach and a clinical subspecialty that focuses on improving quality of life and reducing suffering among patients with serious illness and their families. ”**

The assessment and treatment of physical symptoms and psychosocial-spiritual distress in HF should be the responsibility of patients’ ongoing care providers (i.e., primary care, cardiology, mental health) and community supports. Yet the assessment and treatment of HF symptoms need not wait until the point of intractability. Therefore, ***palliative care principles should be integrated throughout the HF management continuum, allowing cardiology and primary care clinicians to serve as primary palliative care providers.*** Although the role of palliative care specialists is still being defined, if patient distress persists and palliative care specialists are available, referral should be considered. [7, Rank 3]

The Various Palliative Care Models

Patients with HF have a higher rate of acute care service utilization in the 30 days before death than patients with cancer. Each hospital admission is an opportunity to discuss goals of care, as this is most likely when the treatment regimen for a patient with HF may escalate. As the risk for mortality increases with each subsequent hospitalization, hospital discharge planning is an opportunity to discuss what is most important, what QoL means to the patient/family, and under what circumstances they would and would not want life prolonging treatments.

> **“ On discharge, HF patients require assistance on homecare, physical therapy, cardiac rehabilitation and family role in patient care. ”**

Furthermore, depending on the treatments initiated, the patient may require further assistance on discharge, such as home care, physical therapy, or cardiac rehabilitation. In addition, many families are intimately involved in patient care. Therefore, ***clinicians should screen for caregiver burden and stress and help by providing support and counselling.*** [9, Rank 5]

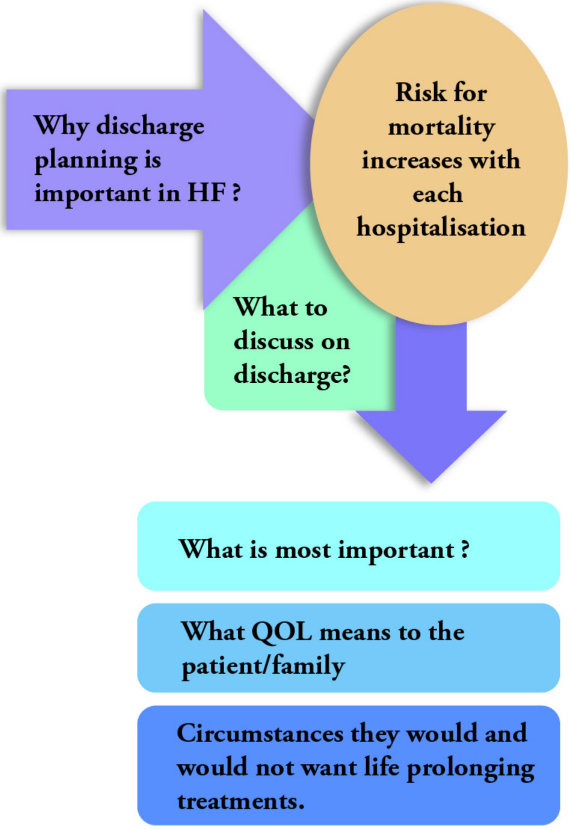


Figure 9: Discharge Discussion in HF

Although commonly combined, palliative care and hospice are related but conceptually distinct services. Hospice care is a specific delivery mechanism of palliative care reserved for individuals at the end of life. In contrast to palliative care, hospice eligibility requires an estimated life expectancy of six months or less, and an agreement to forego life-sustaining procedures. One exception is the U.S. Veterans Health Administration, which allows for hospice care concurrent with life-sustaining treatments. Addressing a patient’s physical, psychosocial, and existential distress need not wait until the very end of life. Therefore, ***Palliative care should be seamlessly integrated throughout the HF experience, with referral to hospiceservices if and when its philosophy aligns with patient and family goals.***

Despite this high morbidity and mortality, hospice utilization has remained low with about one-third of patients with HF receiving hospice at time of death. Patients with advanced HF enroll in hospice at lower rates than those with cancer. Compared to patients with cancer, patients with HF were more likely to enroll in hospice late in the course of their disease (usually within three days before their death). Nevertheless, numerous cardiology professional societies have called for the continued and earlier integration of hospice care for patients with advanced heart disease. Further training is needed to assist primary care and HF clinicians to identify patients who are eligible for hospice, to describe what hospice care can provide in different settings (i.e. home, inpatient and residence), and to introduce hospice as a treatment recommendation when appropriate.When conflict arises between patients and/or families or between clinicians about a hospice recommendation, specialty palliative care may be helpful in facilitating future treatment care planning. [8, Rank 3]

Existing Clinical Guidelines Regarding Palliative Care in CHF

There are growing numbers of guidelines from major cardiology societies, including the American College of Cardiology Foundation (ACCF), American Heart Association (AHA), International Society for Heart and Lung Transplantation (ISHLT), the Heart Rhythm Society, and Heart Failure Society of America (HFSA), encouraging the incorporation of palliative care into the care of patients with HF. Historically, most of these ***guidelines have focused on end-of-life decision making with respect to device management, including implantable cardiac defibrillators (ICD) and mechanical circulatory support, or referral to hospice.*** More recently, there has been an acknowledgement of the benefits of palliative care earlier in the disease trajectory.

> **“ For effective rendering of hospice care and to recommend hospice as a treatment of recommendation, settings like home, inpatient and residence can be utilized. ”**

Several guidelines also advocate that the HF and specialty palliative care teams jointly help patients and families decide on treatment options, with an emphasis on decision-making in the context of advanced HF. For example, the ISHLT statement recommended that specialty palliative care consultation should be included in the treatment of end-stage HF during the evaluation phase for mechanical circulatory support. ***In addition to managing symptoms, clinicians should be having discussions about goals and preferences for end-of-life care with patients receiving mechanical circulatory support as destination therapy.***

Later, AHA experts recommended referral to specialty palliative care for assistance with difficult decision making, symptom management in advanced disease, and caregiver support.

An HFSA statement also recommended incorporating specialty palliative and hospice care into patients with advanced HF care plans, specifying that decision making should include the patient's wishes for survival improvement versus QoL optimization. [11, Rank 4]

The above recommendations have recently expanded into The Joint Commission (TJC) and the Centers for Medicare & Medicaid Services (CMS) mandates. TJC revised its requirements for disease-specific advanced certification program for Ventricular Assist Device (VAD) for Destination Therapy (DT). They specifically added a requirement to include a specialty palliative care representative to the core interdisciplinary team. Following TJC updates, CMS published its final memorandum for VADs for Bridge-to-Transplant (BTT) and DT, again mandating the inclusion of palliative care specialists in the multidisciplinary team of medical professionals caring for beneficiaries receiving VADs as DT.

> **“ Caregivers suffer physical, psychological and financial consequences associated with care, they should be screened for caregiver burden and get counselling. ”**

> **“ AHA emphasizes that "the use of palliative care services should not be considered equivalent to the withdrawal of disease-modifying therapies." ”**

As mentioned, multiple guidelines

advocate for the involvement of specialty palliative care in decisions regarding high-technology interventions and end-of-life care. However, there is little emphasis on (1) addressing the many domains of patient and family QoL aside from functional status, (2) integrating palliative care earlier in the HF trajectory, or (3) providing palliative care concurrently with HF-directed therapies, particularly for patients who are ineligible for or who prefer not to receive cardiac devices. [10, Rank 3]

Priorities for Future Research and Clinical Implementation of Palliative Care in CHF

To date, the rationale for palliative care in HF has largely been one of analogy from the benefits reported from studies of palliative care in oncology. Yet, it is neither likely nor appropriate to assume that the framework of palliative care used in oncology is optimal for patients living with chronic, non-malignant illnesses, such as HF. Indeed, the next era of palliative care research and clinical implementation will challenge the status quo of palliative care, both in terms of content and structure, to maximize impact and uptake in chronic illness. Whereas few randomized trials of palliative care interventions exist in HF, these trials are an important yet imperfect starting point for future investigation. Three critical questions remain unanswered in the literature representing the next priorities in clarifying the role of palliative care in HF, as given in the below table. (Table 1)

Sl No.	Role Identification in Palliative Care
1.	First, how do we build capacity in addressing the unmet palliative needs of patients with HF?
2.	Which palliative care models and delivery methods are most effective in optimizing outcomes for a particular patient with HF?
3.	Which treatments are most effective for addressing symptom burden in payients with HF?

Table 1: Critical questions on the role of Palliative care in HF

True innovation regarding the ability to disseminate and sustain palliative care will disrupt the prevailing reliance on the increasingly scarce resource of palliative care specialists. Indeed, all clinicians caring for patients with serious illness, like HF, should possess a fundamental palliative proficiency to alleviate suffering (e.g., basic management of physical and psychological symptoms, eliciting goals of care, responding to family concerns). Initial efforts to educate cardiology fellows in palliative care competencies, such as communication, are underway.

Research is needed to understand how to improve education regarding primary palliative care domains that are relevant to patients with advanced HF, such as elicitation of goals of care, advance care planning, and caregiver support. Undeniably, multiple aspects of palliative care (e.g., symptom self-management, care coordination, decision support and patient activation) align with principles of disease management and HF self-care. [12, Rank 3]

Effective Palliative Care Models in Optimizing Outcomes for Patients with CHF

Trials are needed to identify the comparative effectiveness of various combinations of palliative care delivery in HF, specifically across two characteristics: ***provider specialization (e.g., primary care vs. cardiology vs. palliative care) and delivery method (e.g., in person vs. telephonic vs. video-based).*** First, although more studies are needed to confirm the effectiveness of primary palliative care in HF, subsequent trials must directly compare this model with specialty palliative care management.

Whereas intuition would argue for the relative superiority of specialty palliative care over a primary palliative approach, this assumption remains untested, and, access to specialty care for all HF patients is considerably limited. While evidence suggests that telephone-based palliative care is effective in oncology, no head-to-head trial has evaluated this model against in-person palliative care. It is unclear whether palliative care delivered remotely is equivalent to the arguably more resource-intensive method of in-person consultation. To ensure maximal relevance, these studies must simultaneously assess patient (e.g., QoL, symptom burden), caregiver (e.g., burden, mood), and health system outcomes (e.g., utilization, costs). [11, Rank 4]

> **“ Prognostic paralysis has been described, whereby clinicians of patients with uncertain illness trajectories prevaricate when considering end of life issues..” ”**

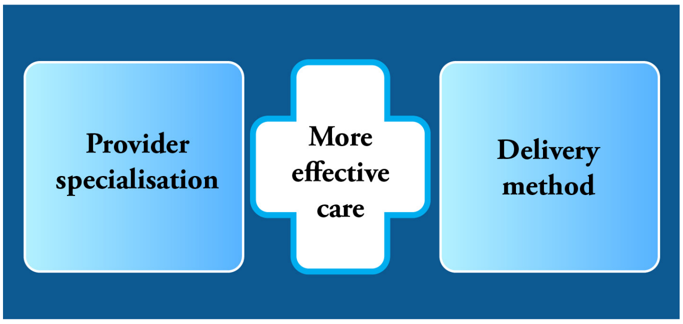


Figure 10: Components to be synchronised for Effective Palliative care in CHF

Although the most common symptoms for patients with HF are well known to be depression, anxiety, sleep disturbance, fatigue, dyspnea, and pain, additional studies are needed to expand the range of effective treatment modalities for these symptoms. For example, recent intervention studies of psychiatric comorbidity in HF have failed to yield a clear conclusion of the effectiveness of treatments. This is likely due to differences in the underlying pathophysiology of these symptoms, which may differ in cardiac versus non-cardiac conditions.

Given this gap in the literature, it remains challenging to effectively treat these very burdensome symptoms. Furthermore, ***due to often extreme medical complexity and frailty in this population, it can often be additionally difficult to discern a distinct symptom from progression of the overall disease process*** (e.g. fatigue due to depression or due to HF). Moreover, ***the severity of perceived symptoms does not reflect the degree of underlying cardiac pathophysiology.*** For example, dyspnea is experienced in up to 90% of patients with HF, yet this is frequently in the absence of hypoxemia or hypercapnia. ***In addition, physiological measures of disease severity, such as ejection fraction, may be inadequate proxies for health status and other subjective markers of well-being.*** These factors further complicate studies of potential palliative treatments due to the difficulty of establishing appropriate subject inclusion and response criteria for these symptoms. [13, Rank 5]

> **“ Clinical research in the field of Palliative care for HF remains challenging and puzzling. ”**

Prognostic Uncertainty of Patients with CHF

Compared to the well-established mortality curve for cancer, ***mortality is far more variable in chronic non-malignant conditions like CHF.*** This is a consequence of the exacerbating-remitting course of the disease. In one study, only 15.7% of surveyed physicians reported that they could confidently predict patients' clinical trajectories within a 6-month time frame, thus making it exceedingly challenging for clinicians to recognize the transition to end-of-life; this phenomenon that has been referred to in the literature as ***"prognostic paralysis"*** Further properties of advanced CHF make prognosis prediction evermore challenging. Sudden Cardiac death (SCD) from dangerous ventricular arrhythmias or myocardial infarction can occur at any time. ***Implantable left/bi-ventricular assist***

devices and Implantable Cardioverter-Defibrillators (ICDs) have the potential to substantially alter disease course. The same can be said for cardiac transplantation. [15, Rank 4]

> **“ Heart Failure Survival Score (HFSS) was originally developed as a risk-stratification model for patients with severe CHF (NYHA class III/IV symptoms) to aid in selecting candidates for cardiac transplant. ”**

Use of ICDs in the Setting of Advanced CHF

In the setting of advanced CHF, the use of ICDs for primary prevention of SCD raises important ethical considerations. ***ICD shocks can cause patients significant discomfort, calling into question the benefits of life prolonging measures vs. preserving quality of life.*** The decision of whether existing ICDs should be deactivated or left on (thereby prolonging the dying process) at the end-of-life presents a unique ethical dilemma, but is a consideration that should be addressed prior to device implantation.

The class, number of hospitalizations and functional capacity (as determined by VO2 max testing) have been used as clinical indicators to evaluate prognosis in CHF. (as shown in fig 11). Biochemical markers such as N-Terminal prohormone of brain natriuretic peptide (NT-BNP) have also been shown to correlate with in beta-blockade, ACE-inhibitor/ angiotensin II (AT1) receptor blocker use, aldosterone antagonists, etc.) so its predictive value may not be as applicable to modern clinical practice [14, Rank 4]

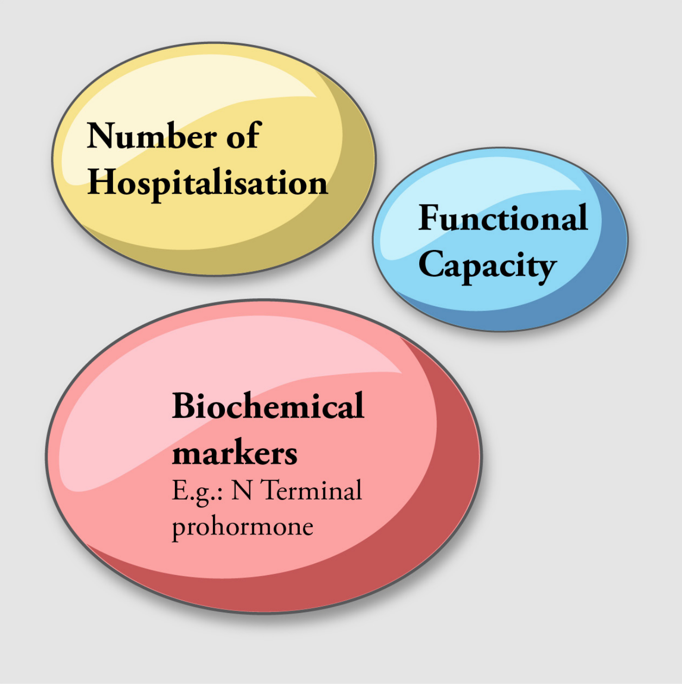


Figure11: Indicators of CHF Prognosis

Provider Education and Training in Palliative Care for CHF

Healthcare providers often do not recognize that CHF is an incurable, progressive, and terminal disease. This recognition is made more difficult from the standpoint of cardiologists because modern treatments and therapies have dramatically altered the clinical course of end-stage CHF over the last twenty years.

There is a striking discrepancy among providers between perceived and actual knowledge of what palliative care is and where it fits in the spectrum of managing advanced CHF. When surveyed, most non palliative care physicians reported that they could define palliative care but incorrectly identified palliative care as mandating the cessation of life-prolonging therapies. Physicians recognized the importance of initiating conversations about Advanced Care Planning (ACP) and involvement of a palliative care physician but frequently acknowledged not knowing what services were provided or how to access them. It is conceivable that these provider attitudes are a factor in the low referrals to hospice in the last six months of life, despite recent data associating hospice enrolment to decreased hospital re-admission rates, use of acute medical care resources and improved symptom control. [17, Rank 3]

Shared Responsibility for Patients with Advanced CHF

Delivery of palliative care as it relates to end-stage heart failure still suffers from disconnectedness – and with it, poor quality and continuity of care. In fact, the term "heart failure care teams" is a misnomer as the phrase falsely implies coherence and stability. Systematic barriers to palliative care discussion and limited advanced care planning discussion make patients with heart failure more likely to die in acute care settings than patients with cancer. ***Compared to the relatively smooth and unified relationship that exists between palliative care physicians and oncologists, there is a developmental gap in the relationship between palliative are physicians and cardiologists with clear room for improvement.*** There is a strong need for shared responsibility among Cardiology and Palliative care system. (as shown in fig:9)Part of the disconnection likely arises from the difficulty in assigning responsibility for patient care to a single provider. Because standard medical therapies for CHF play a role in controlling symp-

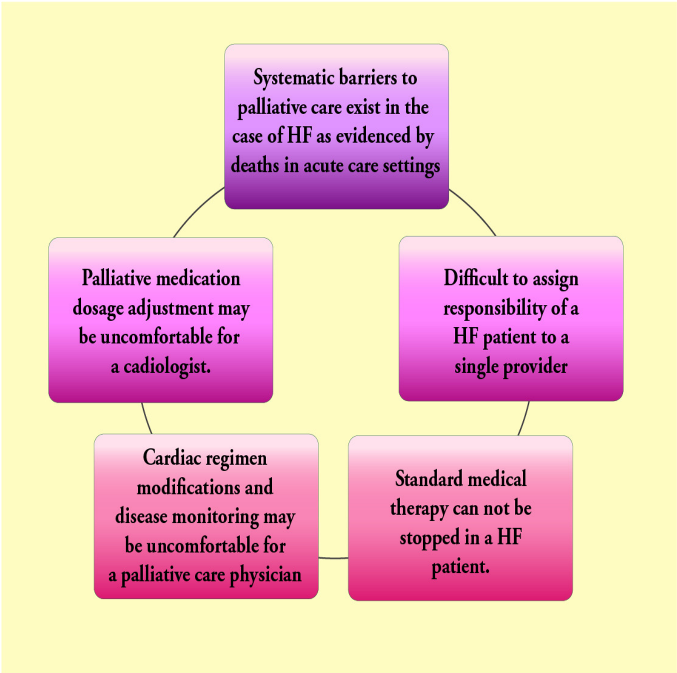


Figure 12: Need for shared responsibility among Cardiology and Palliative care in Advance CHF

toms, they should not be stopped unless they are causing adverse side effects (hypotension, presyncope, acute kidney injury, etc.). Palliative care physicians may feel uncomfortable modifying cardiovascular medications, especially when daily volume assessment and fine tuning of patients' diuretic regimens is required to maintain euvolemia. Similarly, cardiologists may be uncomfortable adjusting doses of the medications (e.g. opioids, neuroleptics) that are routinely used in palliative care. This brings to attention the need for a shared approach with division of desponsibility when caring for patients with advanced/end-stage CHF. [16, Rank 5]

Shared Challenges in Delivering Effective Palliative/End-of-life Care in Advanced CHF

It is not surprising that, given the relatively underdeveloped role of end-of-life/ palliative care in non-malignant chronic diseases as opposed to cancer, the end-of-life needs for patients with advanced CHF are sadly under-recognized and under-addressed in the community. In one study, patients with advanced CHF were less likely to be identified as end-stage requiring palliative care despite greater levels of functional impairment and caregiver burnout. Further to this sentiment is the observation that patients with CHF are often ineligible for certain community services (e.g. subsidized equipment, support groups, and transportation programs) which are normally afforded to those receiving palliative care support for cancer. From a community standpoint, this leaves a significant population subgroup underserved.

The AHA recommends revisiting prognosis on an annual basis at a yearly "heart failure review", although in practice this is seldom done. One study reported as few as 12% of physicians, nurse practitioners, and physician's assistants discussed prognosis annually with their heart failure patients, with 4% never discussing prognosis at all. Consequently, palliative care referrals for patients with advanced CHF remain the exception rather than the norm. Reasons for this are multifactorial but likely stem from misconceptions about the role of palliative care in chronic non-malignant terminal disease.

The intricacies surrounding communication regarding prognosis, preferences and ACP in heart failure are complex, but at this stage still possess many gaps. As previously described, a significant component underlying providers' reluctance to have "the conversation" is prognostic uncertainty. Further to this, for clinicians who are traditionally focused on curative and disease-modifying interventions to improve quantity of life, there exists to some degree the notion that “palliative care” implies treatment failure – and extending this line of thinking – failure of the clinician. Challenges are to be addressed and managed by community, Cardiologist and palliative care team. (as shown in fig:13) Especially in the realm of heart failure management with its rapid advances in medical care, there seems to always be “one more thing to try”, which makes shifting the focus of care from life extension to symptom relief difficult to accept. As was previously discussed, ***providers generally have limited knowledge with regards to what palliative care is, how to access it, and how it can complement traditional heart failure management – leaving a strong role for provider education in the end-of-life care of these patients*** [18, Rank 4]

Challenges in Effective palliative care delivery to HF patients

- **Under recognised needs**
- **Failure to address the problem at community level.**
- **Lack of support groups.**
- **Ineligibility for subsidized equipments.**
- **Lack of community services as for other palliative services.**
- **Lack of referral as done in malignant conditions.**
- **Prognostic paralysis and uncertainty.**
- **Misconceptions about the role of palliative care in chronic non-malignant terminal disease.**
- **Need for equal importance to both quantity of life and quality of life.**

Figure 13: Challenges in Effective palliative care delivery to HF patients

For patients and their families, initiating a palliative care discussion has been likened to the “beginning of the end” and is thought by some to take away patients’ hope. It is usually noted that, patients do not give up because he/she wanted to live.

Interestingly, however, at least one study has found that engaging patients in end-of-life discussions led to less aggressive intervention (a decision made by the patient), improved quality of life, and improved post-mortem adjustment for families. It is plausible that if the graveness and severity of the patient’s illness had been recognized and communicated with the family earlier in his/her admission, the patients may have been more prepared for comfort-focused care and less aggressive intervention including admission to the CICU.

In light of the overall poor prognosis of advanced CHF, it is of particular concern that advance directives and Advanced care planning are seldom discussed. Less than half of patients with advanced CHF have documented advanced directives/goals of care, whether in the community or in hospital. Conversations about these issues frequently occur in emergent circumstances. Major barriers including time, not knowing what to discuss, and general discomfort with initiating this discussion are often cited as reasons for putting off this conversation. [19, Rank 5]

Knowledge Sharing as a Clinical Barrier in CHF Management

A final barrier to delivering and receiving effective palliative care services revolves around the sharing of knowledge. Too often, patients and their families are not on the same page as their physicians – and moreover – not on the same page with each other. ***Many patients have little understanding of CHF as a terminal, progressive and irreversible condition and – not uncommonly – attribute their declining functional status to old age.***

The sharing of knowledge regarding the clinical course of CHF is complex, for which the communication of truths and uncertainties must be balanced with hope. Research also indicates that between patients and family caregivers, there exists a certain level of disagreement about symptom severity and satisfaction with medical care. This makes the caregivers tending towards the perception that their loved ones' condition is more severe and that their medical care is more unsatisfactory. Recent qualitative data shows that while most caregivers do not understand the severity of patients' CHF symptoms, or that they are dying – in caregivers who did, patients had a higher likelihood of receiving palliative care services. With special attention to shared discussion around topics that are traditionally avoided it is conceivable that this barrier – as it pertains to patients and their families – to the provision of palliative care services can be removed. [20, Rank 3]

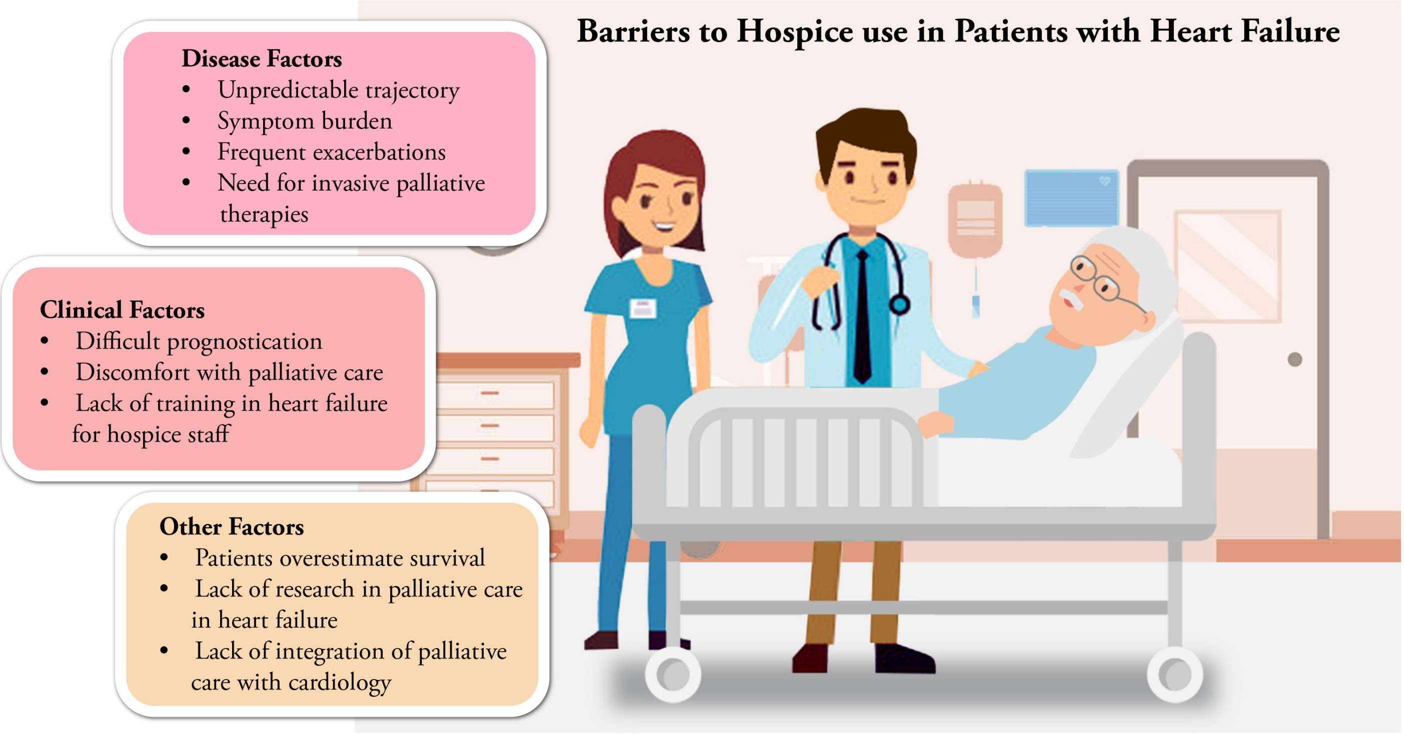
Addressing Barriers to Accessing Palliative Care in CHF

Addressing barriers to accessing palliative care services for patients with heart failure is a complex discussion. Education is certainly part of this discussion; there is a definite need to inform families and address pre-existing notions about what palliative care is and is not. ***Deciding when to involve palliative care services is also a challenge as the disease***

course and prognosis of heart failure is highly variable. Nonetheless, there is resounding agreement that providers should make it clear to patients and families that heart failure is a terminal diagnosis. Dying comfortably can be one of the most fulfilling contributions one can make to enrich the lives of patients and their families. When discussing goals of care and advance care planning in CHF, ***we must abandon the false dichotomy of curative vs. palliative care as the two approaches.***

Palliative care has a role in managing heart failure symptoms, addressing spiritual and emotional needs, and assisting with caregiver burnout. It is not just about care of the dying or care that is provided when curative efforts have been exhausted. It is based on current recommendations and an ever-evolving evidence base that should be involved early in the course of heart failure. The confusion that led to an unnecessary cardiac intensive care unit admission in a patient's final days could have been avoided if more attention had been invested earlier to eliminate any ambiguity about the severity of the disease, and rather, to acknowledge the reality that the patient was approaching the end of life. This would have enabled the patient's passing to be peaceful, more dignified, and much easier for all affected parties. [21, Rank 5]

> **" Limitations exist in the specialist palliative care work man power and palliative care training. "**



Barriers to Hospice use in Patients with Heart Failure

Disease Factors
- Unpredictable trajectory
- Symptom burden
- Frequent exacerbations
- Need for invasive palliative therapies

Clinical Factors
- Difficult prognostication
- Discomfort with palliative care
- Lack of training in heart failure for hospice staff

Other Factors
- Patients overestimate survival
- Lack of research in palliative care in heart failure
- Lack of integration of palliative care with cardiology

Figure 14: Barriers in palliative care delivery in HF

The Necessity for Primary Palliative Care Training for Patients with Congestive Heart Failure

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 (as shown in Figure: 15).

Figure 15: Core competencies in palliative care training for cardiology fellows

Similarly, the recent ***American College of Cardiology (ACC) Core Cardiology Training Statement recognizes the need for training in primary palliative care.*** The training guidelines are specified, (as shown in Table 2)

Training Guidelines for Primary Palliative Care in CHF	
Areas of Training	
Medical Knowledge	**HF Disease Management**
Principles, Modalities & Appropriate indication for palliative care.	Training in end-of-life care, Communication of care options & Participation in an interdisciplinary palliative care team.

Table 2: ACC Core Cardiology Training guidelines for Primary Palliative care

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.”*** 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. [22, Rank 5]

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 devices 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 health care 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. [24, Rank 3]

Primary Palliative Care Domains for Patients with CHF

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.

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. Many of these patients leave the hospital with suboptimal symptom control due to lingering congestion, which can last for weeks to months. 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. [23, Rank 4]

2. 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 health care (healthcare proxy). In another study assessing the presence of advanced directives in electronic medical records of adult patients admitted with HF to 2 large tertiary care hospitals, only 12.7% had a documented advance directive at the time of the last admission.

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. 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. [28, Rank 3]

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 enrolment 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. 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. [26, Rank 5]

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. ***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-maker, guidance about filling out an advance directive (healthcare proxy, living will) and exploring goals and values and discussing prognosis. (as shown in Fig:16) 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. [29, Rank 5]

Communication & Advance care planning

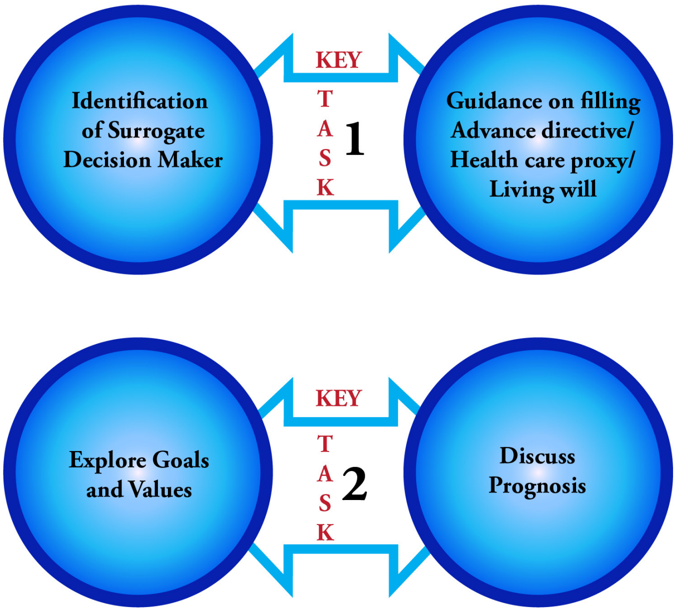


Figure 16: Key tasks under Communication in Palliative care

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. [30, Rank 4]

3. 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 very high in 2010. In addition to partnering in complex medical decisions, ***family members or friends often take on the responsibilities of assessing symptoms, administrating 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. 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. These caregivers are at high risk for the hazards of caregiving for patients, with serious illness (as shown in Fig:17), [31, Rank 4]

Figure 17: Common hazards to caregivers of HF patients

With primary palliative care training, HF clinicians 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 chaplain service 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 or a referral to a social worker. [32, Rank 5]

Team-Based Palliative Care as a Multi-disciplinary Approach

Clinical practice guidelines endorse the use of palliative care in patients with symptomatic heart failure. Palliative care is no longer seen as "giving up" or "accepting death," but is now conceptualized as "supportive care" afforded to most patients with chronic, life-limiting illness. However, the optimal content and delivery of palliative care interventions remains unknown and its integration into existing heart failure disease management continues to be a challenge. Ultimately, patients require a "heart failure medical home", where various specialties may take a more central role in coordination of patient care at different times in the disease span.

Ample evidence exist supporting team-based care for patients with heart failure to decrease rehospitalisation and improve survival through education, structured follow-up, patient self-care, and care plan adherence. However, few pilot studies have assessed the efficacy of multidisciplinary palliative care in improving outcomes appropriate to end-stage heart failure (i.e., quality of life, symptom control, decreased healthcare utilization, lower financial and caregiver burden). This is in part due to heterogeneity in defining what palliative care is and how it should be delivered. [42, Rank 3]

Historically, the term "palliative care" had been confused with hospice care - a focused approach to dying patients for whom disease-targeted treatment or cure are no longer viable. However, this narrow restriction has given way to a more holistic view of disease management in which "supportive care" is afforded to all patients with chronic or life-threatening illness. Optimal palliative care ideally begins early in the course of the disease and continues in parallel with heart failure-targeted therapy in an integrative, multidisciplinary manner. Essentially, all healthcare providers should strive to treat the whole patient collaboratively with a team of colleagues. Likewise, heart failure clinicians should maintain concurrent foci on treating disease, extending survival and optimizing quality of life for patients with chronic heart failure at all disease stages.

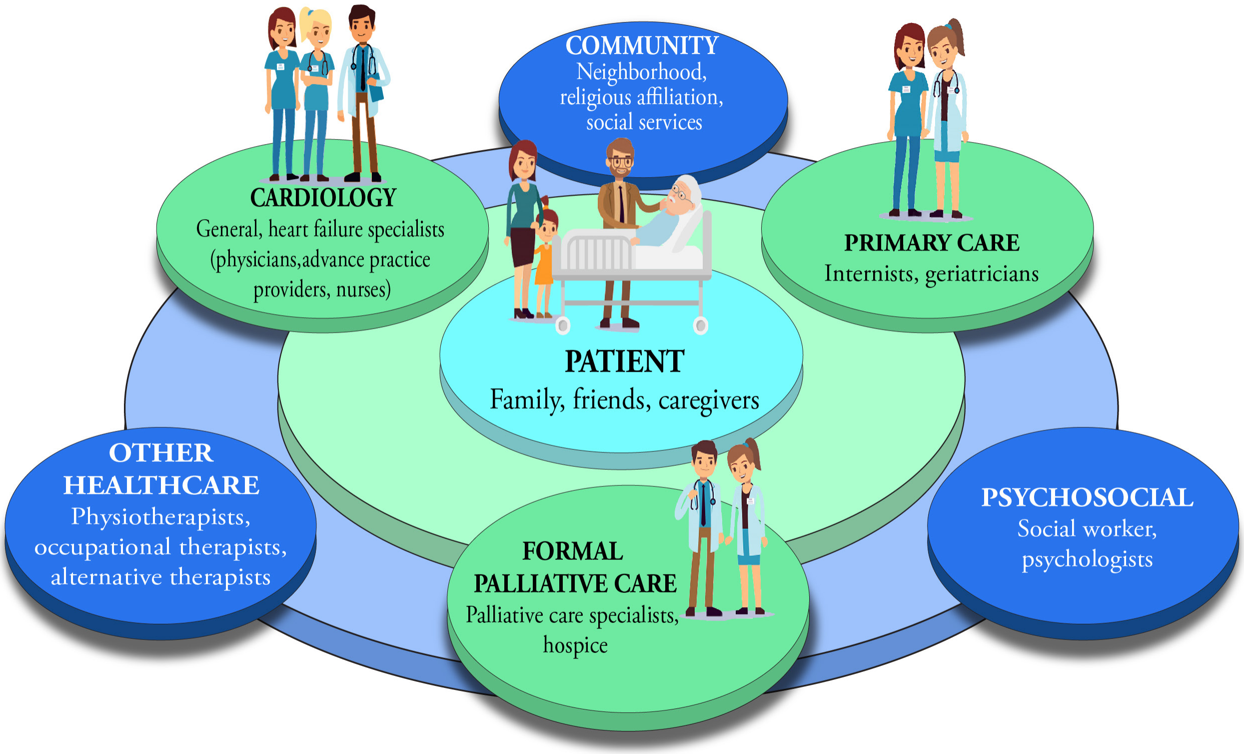
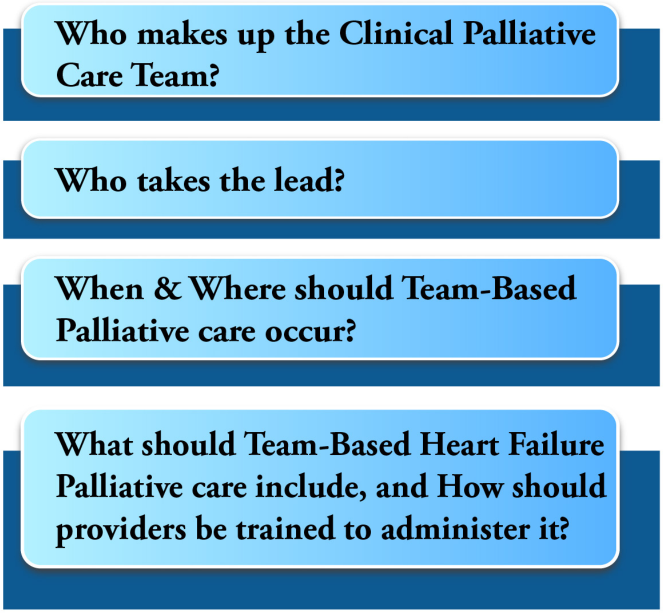


Figure 18: Multidisciplinary team approach in palliativecare for HF patient

The Logistics to Team-Based Palliative Care in Congestive Heart Failure

The logistics can be better analysed by answering and intervening according to certain questions. (as shown in fig: 19)



Who makes up the Clinical Palliative Care Team?

Who takes the lead?

When & Where should Team-Based Palliative care occur?

What should Team-Based Heart Failure Palliative care include, and How should providers be trained to administer it?

Figure 19: Logistics to Team based Palliative care

1. Who makes up the Clinical Palliative Care Team?

Various healthcare providers from multiple fields comprise the clinical component of a multi-disciplinary palliative care team, along with patients and caregivers. ***The three main specialties include primary care, cardiology, and palliative care,*** each represented by various physicians, advanced practitioners, and nurses. A collaborative interface between these specialties leads to improved communication and understanding of patients' goals, more streamlined referrals to specialists, and better end-of-life experiences. Interdisciplinary care increases prescriptions for symptom control medication and decreases hospitalizations, length of stay and cost of care. In a sense, ***these three***

specialties should constitute the core of the patient's "heart failure medical home." Each specialty may take a more central role in coordination of patient care at different times in the disease span.

However, a national shortage of palliative care specialists exists along with the proliferation of heart failure in older patients with multimorbidity. Therefore, a ***shared-care approach is crucial.*** By improving clinician skills and learning from palliative care specialists, general practitioners can be empowered to provide primary palliative care to their patients with heart failure. Palliative care could then be consulted for more challenging issues, such as complex symptom control or complicated advance care planning. [41, Rank 4]

2. Who Takes the Lead?

The role of ***an appointed clinical team leader, or liaison, is important in coordination of multidisciplinary care.*** The team cannot function effectively without a clear understanding of organizational and leadership structure. Early in disease progression, lead input is more likely to fall to a general practitioner or cardiology service, with palliative care consultation as needed. In end-stage disease, palliative care specialists might take more central ownership of the patient's care.

In a number of studies and palliative care programs, authors described great success in appointing a heart failure or case management nurse to communicate with patients and delegate responsibility for different aspects of care. A single team member who acts as the liaison in coordinating primary and referral services thereby offers continuity of care, a reliably recognizable team contact, and a source of trust and comfort for patients. ***The clinical team leader can assure that medical decision-making is tailored to patients' values, goals, and preferences.***

Referrals among patients with advanced heart failure are most commonly for allied health services and psychosocial support. The needs of patients with advanced heart failure can be universal, but may also have patient, site, and regional variation. Meeting such patient needs may also challenge financial and staffing sustainability. The multidisciplinary palliative care team should adopt a holistic, patient-centered perspective as not all patients require all services. [44, Rank 4]

3. When & Where Should Team-Based Palliative Care Occur?

There is no clear consensus on the optimal timing and location of supportive care for patients with heart failure, except that ***early and frequent intervention is preferred.*** This stems from the concept that "difficult discussions now simplify difficult decisions later." Nearly 20 years ago, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments trial, investigators identified substantial inadequacies in end-of-life care, but were unable to improve outcomes via a nurse-led, in-hospital, palliative care intervention. The authors suggested that repeated exposure throughout the disease span might be needed to affect positive change, in addition to a more developed healthcare infrastructure to support interventions.

Indeed, subsequent literature solidified the importance of constantly readdressing goals and expectations for care with heart failure patients. The need for repetition stems from the unpredictable nature of heart failure progression, difficulty with accurate risk assignation and prognosis, and the evolution of individual patient preferences over time. Ultimately, these difficulties might be attenuated by earlier integration of supportive care that fosters improved patients' understanding and acceptance of their disease and mortality. ***Early and frequent supportive care integration might be more easily accomplished by a team of physicians, nurses, psychologists, and chaplains*** with skills different from but complementary to those of heart failure clinicians.

Early discussions regarding advance care decisions are preferable, primarily because they allow more time for coping and planning by patients and caregivers, alike. In a controlled trial of early outpatient palliative care for patients with various chronic diseases, majority would have preferred the intervention regarding future plans to have occurred earlier. ***Provisional planning can help patients avoid struggling with unpredictable deteriorations in health status*** and mitigate the isolation and dependency that can accompany these declines, in part by identifying resources and support in advance. Early palliative heart failure interventions have been studied prospectively in outpatient and post-admission setting as well as among admitted patients undergoing their first heart transplant evaluation, with varying results [48, Rank 4]

A number of locations for palliative heart failure interventions have been studied. ***Home-based palliative care was***

> **“ Palliative care has a role in managing heart failure symptoms, addressing spiritual and emotional needs, and assisting with caregiver burnout. ”**

explored in multiple studies with mixed results regarding symptom burden, quality of life, healthcare utilization, and cost, though rate of death at home was higher in each of these studies.

This reflects the priorities of patients with end-stage heart failure, who prefer to be at home during the terminal stage of the disease, if possible. The challenges of community-based rural palliative care have been reviewed and tested in a feasibility pilot. When rural patients with heart failure face geographic barriers to access, the importance of a team leader or liaison, telephone communication support, and definitive, concrete, end-of-life plans are vital to success. Finally, although it seems intuitive that patients would prefer to face difficult decisions about their future in the outpatient setting, as opposed to during the stress of a hospitalization for acute decompensation, this concept has not been thoroughly explored.

Discussions are encouraged with all adults whenever they interact with healthcare professionals, whether inpatient or outpatient, primary care or specialty, physicians or other providers. Although the intervention only addresses one domain of supportive care, ***it has been associated with very high rates of advance directive completion, higher patient satisfaction and lower rates of healthcare utilization and costs in the last year of life.*** [49, Rank 4]

4.What Should Team-Based Heart Failure Palliative Care Include, and How Should Providers be Trained to Administer It?

A number of different supportive care stages have been put forth in expert reviews to delineate how the role of the multi-disciplinary palliative heart failure team changes with disease progression. From these and other studies, we have consolidated supportive care of the patient with heart failure into 6 domains and identified team members associated with service provision in each domain. (as shown in Table 3)

Figure 19: Palliative care team

Palliative care Team for HF

	Domain	Members
1.	Physical well being	Physician, APP, Pain Specialist, Palliative Care Specialist(PCS) , Pulmonologist, Respiratory Therapist, Pharmacist, Physical & Occupational Therapy-(PT/OT) ,Yoga Acupuncture Therapist
2.	Psychosocial support	Physician, APP, Psychiatrist, Psychologist, Pharmacist, Chaplain, PCS, Support Group, Social Work, Case Management (SW/CM), Home Health, Support Group Facilitator, Hospice Team, Chaplain
3.	Advance care planning	Physician, APP, SW/CM, PCS, Caregiver, Hospice
4.	Communication	Physician, APP, Caregiver, Team Liaison, PCS, Psychologist, Psychiatrist
5.	Caregiver Focus	Caregiver, SW/CM, Support Group, Psychologist, Psychiatrist
6.	Education	Physician, APP, Pharmacist, Dietician, Physiatrist, PT/OT

Table 3: Palliative care Team for HF

The expectation should be that different team members provide varying amounts of support at different times in the progression of disease, with the medical home (cardiology or primary care) and an appointed team liaison involved in coordination and continuity of care throughout.

Much work is needed to identify which supportive care interventions are most effective at different time points in heart failure progression. In one review, multidisciplinary interventions improved continuity of care, but there was little direct evidence supporting improved outcomes. For example, depression is common and associated with worse outcomes in advanced disease.

However, anti-depressants had disappointing results when used in this setting. Therefore, ***depression in the setting of heart failure is likely to be most responsive to multi-modality interventions,*** including pharmacotherapy for cardiac dysfunction and other comorbidities, along with exercise and cognitive behavioural therapy. Likewise, dyspnea is a common symptom that affects quality of life in patients with advanced heart failure. An often-quoted but small pilot study described ***improved shortness of breath in patients treated with opioids,*** while a number of studies ***have shown dyspnea improvement through exercise and respiratory muscle training.*** Even more promising is the Breathlessness Support Service, a UK-based intervention for patients with advanced diseases, including heart failure. ***In a randomized controlled trial, the intervention used behavioral***

therapy, fans/ cooling techniques, and pulmonary therapists, in addition to common treatments, to improve outcomes. [46, Rank 5]

Device-Related Span of Palliative Care

One of the challenges in provision of staged supportive care throughout the disease span is a lack of provider training to facilitate holistic care of the patient. In qualitative studies, providers avoided broaching palliative care issues with patients for a number of reasons, such as lack of time and resources, discomfort or self-perceived skill deficit in discussing sensitive issues, unpredictable disease course and uncertainty with timing of conversations, fear of negative effects on the patient, and perception of palliative care as synonymous with terminal care.

However, patients mostly preferred hearing the truth, as long as they were asked permission to broach such topics, and such conversations did not take away their hope.

As with other skill sets, providers need to develop comfort with communication of difficult content. Given the shortage of palliative care providers in the US, ***structured educational interventions need to be tested to ensure that all team members are both able and willing to perform their duties,*** so that non-palliative care specialists can be empowered to excel in providing primary palliative care. [50, Rank 2]

The Importance of Family Care-Giving

Support provided by family caregivers is critical to maintaining the health and quality of life (QoL) of individuals worldwide affected by heart failure (HF).

Several Institute of Medicine (IOM) reports have described the toll that performing tasks for persons with serious illnesses can have on family caregivers' health and well-being, which may consequently hinder their ability to provide high quality care to patients.

These reports stress the imperative of ensuring that family caregivers are kept healthy and functioning, particularly in the advanced stages of illness when both patient

> **" Strong communication skills are of utmost importance in creating open, trusting patient-provider relationships, and palliative care communication training has been shown to be effective. "**

care demands and the risk of caregiver burden increase. Among patients with advanced HF, specialist palliative care clinicians play an important role for HF caregivers because a ***core component of palliative care practice is the assessment of family caregivers and the development of care plans that specifically address caregivers' unique needs.*** Moreover a recent American Heart Association and American Stroke Association policy statement stress the importance of including caregivers in palliative HF treatment to assist with managing patients' complex needs and thereby reduce caregiver burden.

Despite an increased general awareness of the need to support family caregivers, the extent and quality of research and the evidence-base that it has produced to guide clinical care of this population has yet to be comprehensively assessed. Several reviews have evaluated particular aspects of HF family caregiving, including general experiences, relationship quality, needs, burden, roles in patient self-care and left ventricular assist device management. [36, Rank 3]

Several qualitative studies noted that caregivers stated feeling that these unmet needs were ignored by the formal healthcare system, which further intensified the strain and burden of the role and engendered distrust of the healthcare system. In one of these studies, caregivers expressed this type of distrust in the healthcare system when they felt the role they were expected to fulfill exceeded or was incompatible with their ability to perform that role. Frustration with healthcare providers providing a lack of information was another theme identified in another study in which "providers conveyed a sense that they were busy, and partners [caregivers] said they had few opportunities to ask questions and to get them answered in an understandable manner" [40, Rank 1]

> **" Having HF is associated with functional impairment; debilitating symptoms; and complex medication, device, and self-care regimens that often require the regular assistance of unpaid family caregivers. "**

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.

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 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 was spent on palliative care research.

In order to meet the growing palliative care needs of patients with HF and their caregivers, ***dedicated funding is required to ensure 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.*** [38, Rank 3]

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.

Addressing barriers to accessing palliative care services for patients with heart failure is a complex discussion. Education is certainly part of this discussion; there is a definite need to inform families and address pre-existing notions about what palliative care is and is not. Deciding when to involve palliative care services is also a challenge as the disease course and prognosis of heart failure is highly variable. Nonetheless, there is resounding agreement that providers should make it clear to patients and families that heart failure is a terminal diagnosis. Dying comfortably can be one of the most fulfilling contributions one can make to enrich the lives of patients and their families. When discussing goals of care and ACP in CHF, we must abandon the false dichotomy of curative vs. palliative care as the two approaches necessarily exist simultaneously. [55, Rank 5]

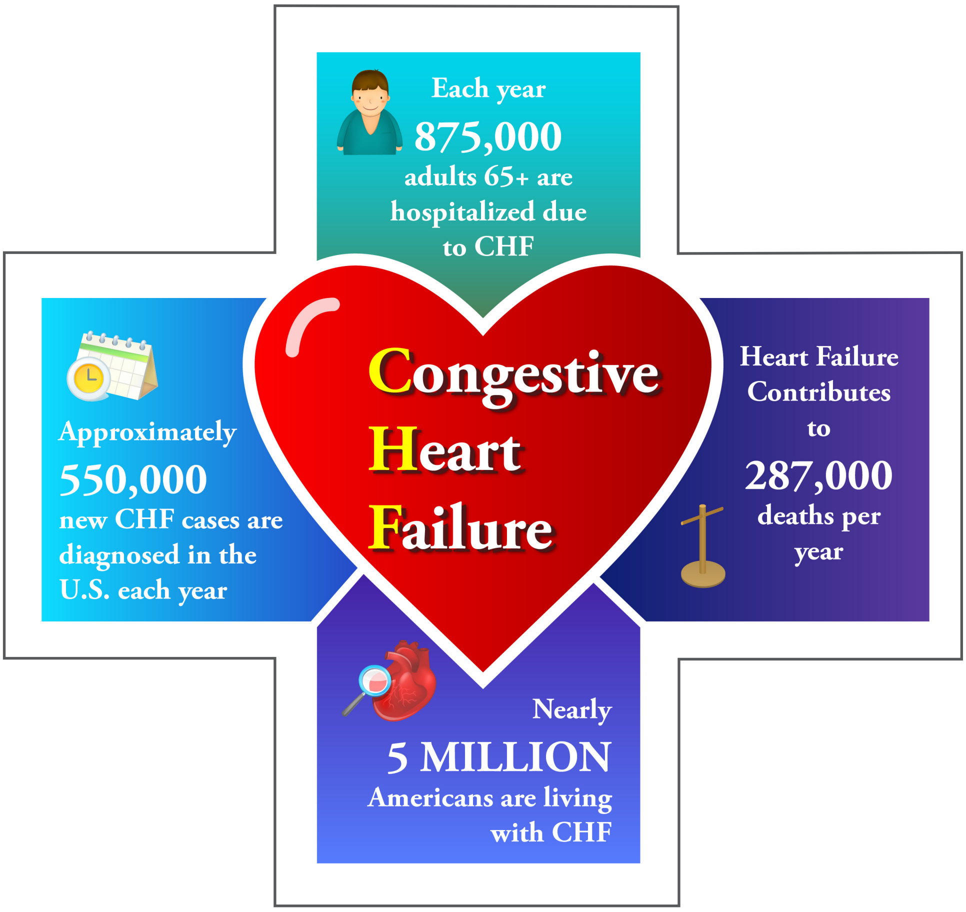


Figure 20: Data about Congestive Heart Failure

***Important information for post-test are highlighted in red letters, boxes and diagrams.**

References

1. Ziaeian B, Fonarow GC. Epidemiology and aetiology of heart failure. Nat Rev Cardiol. 2016

2. Yancy CW, Jessup M, 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. 2015

3. Liu L, Eisen HJ. Epidemiology of heart failure and scope of the problem. Cardiol Clin. 2015

4. Solano J, Gomes B, Higginson I. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. J Pain Symptom Manage. 2016

5. Bekelman DB, Havranek EP, Becker DM, et al. Symptoms, depression, and quality of ife in patients with heart failure. J Card Fail. 2017

6. Kavalieratos D, Kamal AH, Abernethy AP, et al. Comparing unmet needs between community-based palliative care patients with heart failure and patients with cancer. J Palliat Med. 2016

7. Juenger J, Schellberg D, Kraemer S, et al. Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. 2018

8. Allen L, Yager J, Funk M, et al. Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure. JAMA: The Journal of the American Medical Association. 2018

9. Bakitas M, Macmartin M, Trzepkowski K, et al. Palliative care consultations for heart failure patients: how many, when, and why? J Card Fail. 2019

10. Goebel J, Doering L, Shugarman L, et al. Heart failure: the hidden problem of pain. Journal of pain and symptom management. 2019

11. Evangelista L, Sackett E, Dracup K. Pain and heart failure: unrecognized and untreated. Eur J Cardiovasc Nurs. 2016

12. 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. 2017

13. Johnson MJ, Booth S. Palliative and end-of-life care for patients with chronic heart failure and chronic lung disease. Clin Med. 2015

14. O'Leary N, Murphy NF, O'Loughlin C, Tiernan E, McDonald K. A comparative study of the palliative care needs of heart failure and cancer patients. Eur J Heart Fail. 2016

15. Steinhauser KE, Arnold RM, Olsen MK, et al. Comparing Three Life-Limiting Diseases: Does Diagnosis Matter or is Sick, Sick? J Pain Symptom Manage. 2016

16. Currow DC, Smith J, Davidson PM, Newton PJ, Agar MR, Abernethy AP. 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. 2017

17. Heidenreich PA, Albert NM, Allen LA, et al. Forecasting the impact of heart failure in the United States: a policy statement from the American Heart Association. Circ Heart Fail. 2018

18. Cain CJ, Wicks MN. Caregiver attributes as correlates of burden in family caregivers coping with chronic obstructive pulmonary disease. Journal of Family Nursing. 2017

19. Dracup K, Evangelista LS, Doering L, Tullman D, Moser DK, Hamilton M. Emotional well-being in spouses of patients with advanced heart failure. Heart Lung. 2016

20. Harding R, Selman L, Beynon T, et al. Meeting the communication and information needs of chronic heart failure patients. J Pain Symptom Manage. 2018

21. Lemond L, Allen LA. Palliative care and hospice in advanced heart failure. Prog Cardiovasc Dis. 2019

22. Morrison RS, Meier DE. Palliative care. The New England Journal of Medicine. 2015

23. Morrison RS, Dietrich J, Ladwig S, et al. Palliative Care Consultation Teams Cut Hospital Costs For Medicaid Beneficiaries. Health Affairs. 2018

24. Kavalieratos D, Corbelli J, Zhang D, et al. Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis. JAMA. 2016

25. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. The New England journal of medicine. 2017

26. Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. JAMA: The Journal of the American Medical Association. 2019

27. Rabow M, Dibble S, Pantilat S, McPhee S. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. Arch Intern Med. 2016

28. Abernethy AP, Currow DC, Fazekas BS, Luszcz MA, Wheeler JL, Kuchibhatla M. 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. 2018

29. idebottom AC, Jorgenson A, Richards H, Kirven J, Sillah A. Inpatient palliative care for patients with acute heart failure: outcomes from a randomized trial. J Palliat Med. 2015

30. Brannstrom M, Boman K. Effects of person-centred and integrated chronic heart failure and palliative home care. PREFER: a randomized controlled study. Eur J Heart Fail. 2014

31. Aiken, Butner LS, Lockhart J, et al. 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. 2016

32. Wong F, Ng A, Lee P, et al. Effects of a transitional palliative care model on patients with end-stage heart failure: A randomised controlled trial. Heart. 2016

33. Bekelman DB, Plomondon ME, Carey EP, et al. Primary Results of the Patient-Centered Disease Management (PCDM) for Heart Failure Study: A Randomized Clinical Trial. JAMA Intern Med. 2015

34. Brumley, Enguidanos R, Jamison S, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. J Am Geriatr Soc. 2017

35. Fendler TJ, Swetz KM, Allen LA. Team-based Palliative and End-of-life Care for Heart Failure. Heart Fail Clin. 2015

36. Braun LT, Grady KL, Kutner JS, et al. Palliative Care and Cardiovascular Disease and Stroke: A Policy Statement From the American Heart Association/American Stroke Association. Circulation. 2016

37. Kavalieratos D, Corbelli J, Ernecoff N, Arnold R, Schenker Y. Identifying the Impact of Palliative Care Interventions: A Systematic Review (SA538D) Journal of Pain and Symptom Management. 2016

38. Quill TE, Abernethy AP. Generalist plus specialist palliative care--creating a more sustainable model. N Engl J Med. 2016

39. Fang JC, Ewald GA, Allen LA, et al. Advanced (Stage D) Heart Failure: A Statement from the Heart Failure Society of America Guidelines Committee. Journal of cardiac failure. 2015

40. Yancy CW, Jessup M, Bozkurt B, et al. 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. 2015

41. Feldman D, Pamboukian SV, Teuteberg JJ, et al. The International Society for Heart and Lung Transplantation Guidelines for mechanical circulatory support: executive summary. J Heart Lung Transplant. 2015

42. Dans M, Garcia K. End-of-Life Care in Cardiovascular Disease. Springer. Palliative Care and Hospice in Patients with Advanced Cardiovascular Disease 2015

43. Jurgens CY, Goodlin S, Dolansky M, et al. 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. 2015

44. Allen LA, Stevenson LW, Grady KL, et al. Decision making in advanced heart failure: a scientific statement from the American Heart Association. Circulation. 2017

45. Khan RF, Feder S, Goldstein NE, Chaudhry SI. Symptom Burden Among Patients Who Were Hospitalized for Heart Failure. JAMA internal medicine. 2015

46. Dunlay SM, Foxen JL, Cole T, et al. A survey of clinician attitudes and self-reported practices regarding end-of-life care in heart failure. Palliat Med. 2015

47. Brännström M, Forssell A, Pettersson B. Physicians' experiences of palliative care for heart failure patients. European Journal of Cardiovascular Nursing. 2016

48. Hanratty B, Hibbert D, Mair F, et al. Doctors' perceptions of palliative care for heart failure: focus group study. BMJ. 2017

49. Kavalieratos D. Attitudes and perceptions regarding a generalist plus specialist model of palliative care in heart failure. Journal of the American College of Cardiology. 2018

50. Kamal AH, Maguire JM, Meier DE. Evolving the Palliative Care Workforce to Provide Responsive, Serious Illness Care. Ann Intern Med. 2015 Aug 11; [PubMed] [Google Scholar]

51. Dunlay SM, Swetz KM, Redfield MM, Mueller PS, Roger VL. Resuscitation preferences in community patients with heart failure. Circ Cardiovasc Qual Outcomes. 2014

52. Buchhalter LC, Ottenberg AL, Webster TL, Swetz KM, Hayes DL, Mueller PS. Features and outcomes of patients who underwent cardiac device deactivation. JAMA internal medicine. 2014

53. Goldstein NE, Mehta D, Teitelbaum E, Bradley EH, Morrison RS. "It's like crossing a bridge" complexities preventing physicians from discussing deactivation of implantable defibrillators at the end of life. J Gen Intern Med. 2018

54. Goldstein NE, Lampert R, Bradley E, Lynn J, Krumholz HM. Management of implantable cardioverter defibrillators in end-of-life care. Ann Intern Med. 2018

55. Joo H, Fang J, Losby JL, Wang G. Cost of informal caregiving for patients with heart failure. American heart journal. 2015

56. Kavalieratos, D., Gelfman, L. P., Tycon, L. E., Riegel, B., Bekelman, D. B., Ikejiani, D. Z., ... & Arnold, R. M. Palliative care in heart failure: rationale, evidence, and future priorities. Journal of the American College of Cardiology. 2017