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NONPHARMACOLOGIC THERAPY: SURGERY, VENTRICULAR ASSIST DEVICES, BIVENTRICULAR PACING, AND EXERCISE (A HASAN, SECTION EDITOR)

Role of Palliative Care in the Outpatient Management of the Chronic Heart Failure Patient

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Abstract

Purpose of Review Patients with heart failure (HF) have an increased symptom burden and complex psychosocial and decision-making needs that necessitate the integration of palliative care. However, in the current era, palliative care is frequently evoked for these patients only at the end-of-life or in the inpatient setting; rarely is palliative care proactively utilized in outpatients with HF. The purpose of this review is to evaluate the current state of palliative care and heart failure and to provide a roadmap for the integration of palliative care into outpatient HF care.

Recent Findings Recent studies, including PAL-HF, CASA, and SWAP-HF, have demonstrated that structured palliative care interventions may improve quality of life, depression, anxiety, understanding of prognosis, and well-being in HF.

Summary HF is associated with high mortality risk, significant symptom burden, and impaired quality of life. Palliative care can meet many of these needs; however, in the current era, palliative care consultations in HF occur late in the disease course and too often in the inpatient setting. Primary palliative care should be provided to all outpatients with heart failure based on their needs, with referral to secondary palliative care provided based on certain triggers and milestones.

Keywords Heart failure · Palliative care · Outpatient · Clinic · Symptoms

Introduction

Heart failure (HF) affects more than 6 million Americans and its prevalence is increasing over time [1]. Despite increases in the use of guideline-directed medical therapy and advances in devices, HF remains a progressive disease that is associated with high mortality rates [2,3], increased cost of care [1,4], significant symptom burden [5,6], and impaired quality of life for both patients and caregivers [7].

Palliative care (PC) focuses on preventing and relieving suffering, supporting quality of life, and assisting with advance care planning, regardless of the stage of illness [8]. Given that HF is a highly symptomatic disease characterized by an often unpredictable clinical trajectory with a relatively high risk of death throughout its course, PC is highly relevant for those affected. Multiple cardiology practice guidelines recommend the use of PC in HF [9–12]. Despite this, PC remains underutilized [13,14] and is employed almost exclusively as an inpatient tool among these patients [15]. The lack of PC use in the outpatient setting may be partially responsible for the following observations: PC consultations among HF patients occur late in the disease course, often during the last month of

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life [15,16],; almost 30% of patients with cardiovascular disease referred for PC are bedbound [17]; and, despite a general preference among patients to die at home irrespective of their underlying condition [18], HF patients are more likely than patients with cancer to die in a medical facility and less likely to die at home [19].

Calls for integration of PC are growing in the care of HF patients, with the Joint Commission and Centers for Medicare and Medicaid Services mandating involvement of PC specialists in the managing team for patients considered for left ventricular assist device therapy [20]. However, there is little guidance on how to best implement PC in the care of HF patients. Nuances of optimal medical therapy, devices, and structural heart interventions, in addition to high symptom burden and complex needs of HF patients often necessitate the combined expertise of both cardiologists and PC specialists. Therefore, we will provide a roadmap for how to integrate PC into HF care, specifically in the outpatient setting. We will review the published literature and will address both barriers and future directions.

Definitions: Primary and Specialty Level Palliative Care, and Hospice

PC achieves its goals through symptom management, provision of psychosocial and spiritual support for both patients and caregivers, and delineation of patient goals and preferences. As the aims of PC are often concordant with disease-directed therapy, it is not appropriate to view PC as only needed when “there are no other options” or when the patient is at the end of life. Rather, PC can and should be provided alongside aggressive disease-specific treatment [21].

Supportive, palliative-type interventions and services can be provided by any healthcare provider, regardless of their training. When the PC is provided by a non-PC specialist, it is often termed “primary” palliative care in order to distinguish it from the “secondary” or “specialty” PC that may be provided by a PC specialist or PC team (Fig. 1). All clinicians should have communication skills that allow for basic management of symptoms and discussions regarding prognosis, preferences and goals for treatment options, and preferences for resuscitation procedures. PC specialists may be helpful in cases of refractory and/or complex symptoms, psychosocial and/or spiritual distress, and conflict resolution in regards to preferences and goals of treatment among family caregivers and/or treating clinical teams [22,23].

Palliative care teams may be comprised PC-certified physicians and nurse practitioners, nurse coordinators, counselors, and social workers or a multidisciplinary mix of members. Training for team members can range from board certification in Hospice and Palliative Medicine to focused training via continuing education programs. PC specialists can be members of interdisciplinary cardiology teams, be physically embedded within a cardiology clinic space, or serve as independent consultants.

Regardless of the make-up of PC teams, care coordination and collaboration among specialists are key in meeting the complex needs of HF patients. The three main medical specialties often involved in the care of HF patients are cardiology, PC, and primary care. Each specialty may take a leading role at different times along a patient’s trajectory. Effective collaboration is necessary for better communication, understanding of goals, and symptom management [24]. Teamwork allows for exchange of ideas and learning among professionals, dynamic prioritization of treatments to changes in patients’ preferences and disease status, coordination of services, and communication among team members and between patient and teams. Education of patients and caregivers via handouts or phone interviews may increase success of interventions. Trained members can utilize validated tools for assessment of symptoms and depression. Patients who screen positive can be referred for dedicated mental health services. Treatment algorithms for common symptoms will ensure timely management and standardization of practices. A multidisciplinary, team-based approach helps ensure holistic, patient-centered care.

It is important to underscore the distinction between PC and hospice. Hospice is an approach to care that aims to maximize quality of life when the estimated prognosis is less than 6 months. The Medicare Hospice Benefit, covers services in a per diem capitated arrangement in four levels of care including routine home care, continuous home care, general inpatient care, and respite care [25]. Despite the potential benefits of hospice including improved symptom control, increased patient and family satisfaction, hospice utilization for HF remains low and when used, implemented too late in the course. A recent study of discharged HF patients in the Get With The Guidelines–Heart Failure registry showed that a meager 4% of Medicare patients were discharged to hospice, with a median survival of only 11 days [26•].

Palliative Care Needs of Heart Failure Patients

Symptom Management and Quality of Life Needs

HF is associated with significant symptom burden and reduced quality of life, both throughout the disease course and during advanced stages, with multiple studies demonstrating that HF patients report greater symptom burden and lower quality of life than patients with cancer [27,28]. Physical symptoms are prevalent and are shown to be the strongest predictor of health-related quality of life [29,30]. Classically, breathlessness and fatigue are inquired about during clinic visits. However, other symptoms are also prevalent and may be underrecognized. In a cross-sectional

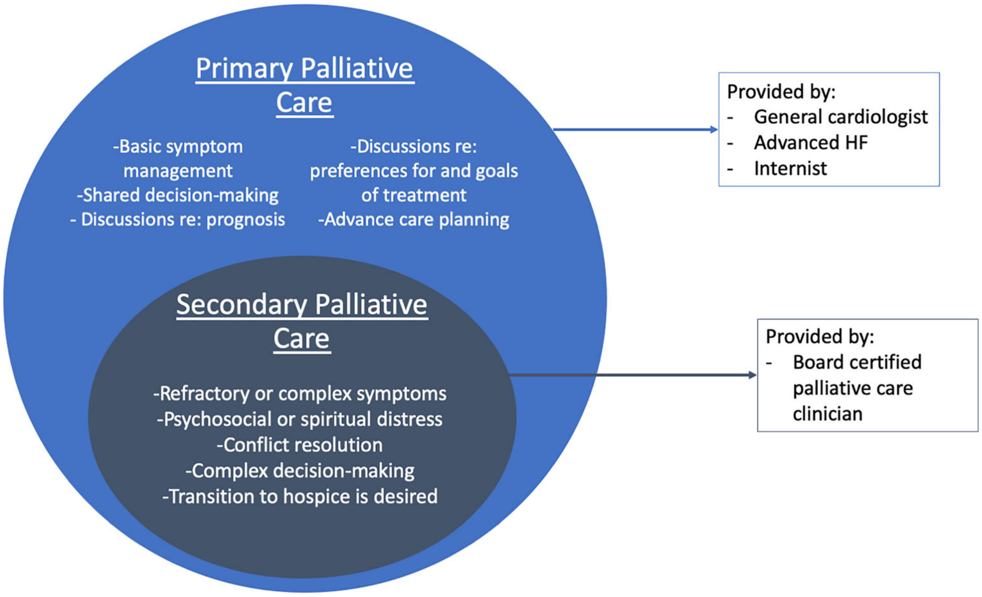

Fig. 1 Primary vs specialty (secondary) palliative care

study of 66 community-dwelling stable older adults with HF, the top three symptoms reported were limited activity (reported by 68% of patients), fatigue (42%), and physical discomfort (27%) [31]. Other than physical symptoms, approximately 30-40% of patients with HF experience depressive symptoms [32,33], despite not carrying a formal diagnosis of depression [34]. Finally, studies suggest that HF patients experience suboptimal symptom control and quality of life at the end of life, with 41% of patient surrogates reporting that their HF patient was in severe pain and 63% reporting that the patient was severely short of breath during the 3 days before death [35]. Thus, there is a significant need for interventions that palliate patients with HF, not only during the end of life but throughout the various stages of disease.

The Need for Shared Decision-Making Despite Prognostic Uncertainty

HF patients are often faced with complex decisions regarding treatment options for their disease. These therapies include interventions that may potentially improve cardiac function (such as bypass or valve surgery) or reduce the risk of sudden cardiac death (such as implantable defibrillators), adjunctive therapies that may be initiated in the midst of an acute decompensation such as intravenous inotropes or temporary mechanical circulatory support, and advanced surgical therapies such as durable LVAD or heart transplantation [9]. Shared decision making, in which the physician and patient allow the patient's values, goals, and preferences to guide the discussion regarding diagnostic and treatment options, and the cardiologist offers recommendations based on these goals, has been promoted in HF [9]. However, a number of factors can make decision-making challenging in these patients, including the sheer number of treatment options available, clinician uncertainty regarding prognosis, patients' poor prognostic awareness, the true risk/benefit calculus of the therapy being offered, and lack of consensus regarding the patient's goals and values.

Prognostic uncertainty in HF makes decision-making about complex interventions especially challenging. In HF, patients who are at high risk for 1-year mortality based on prognostic models are often referred for consideration for advanced therapies [36]. Certain factors are shown to be markers for poor prognosis, including HF hospitalization [37], age [3,38], and comorbidities [3]. Further, risk models, such as the Seattle Heart Failure Model (SHFM) [39] and the Meta-Analysis Global Group in Chronic Heart Failure (MAGGIC) risk calculators [40] are validated and increasingly used. However, an important recent study by Allen and colleagues (2017) demonstrated that while these models perform reasonably well at the population level, they do not reliably predict which patients will die in the next year on the individual level, demonstrating sensitivity for 1-year death at 0.5% and 3.1% for the SHFM and MAGGIC models, respectively [41]. In fact, a recent study demonstrated that when doctors and nurses were asked to answer the "Surprise Question" for 129 HF patients ("would you be surprised if this patient were to die within the next year?"), there was both excellent sensitivity (0.85) and negative predictive value (0.88), identifying nearly all patients who were within their last year of life [42]. In contrast, studies have shown that ambulatory patients with HF tend to overestimate their life expectancy compared with model-based predictions for survival [43]. PC can assist patients in making complex treatment decisions in the context of their goals and values, especially when the disease trajectory and prognosis are uncertain.

The Need for Advance Care Planning

Advance care planning, a comprehensive approach to end-stage illness which includes documentation of surrogate decision-makers, earlier completion of advance care directives, and delineation of preferences for resuscitation and the location of end of life care, is critical in HF. It is especially important that this preparedness planning be broached in the outpatient setting. However, multiple studies have shown that detailed preparedness planning is suboptimal in HF patients. In a 2012 longitudinal study of 608 community HF patients, only 41% of these patients had an advance directive. Further, many of the completed advance directives did not address patient preferences regarding important end of life decisions, including cardiopulmonary resuscitation, mechanical ventilation, and artificial nutrition [44]. A study of 24,291 patients with HF hospitalized over a 5-year time period demonstrated similar findings. At the time of each patient's last admission, only 12.7% had a documented advance directive [45]. In this study, 32.5% patients with HF as a primary admission diagnosis who had a PC consultation had an advance directive, while only 10.0% of patients with HF as primary admission diagnosis had an AD if they did not have a PC consultation.

Place of death in HF is another area of potential improvement. Dying in the patient's preferred location is considered an important aspect of a personalized end of life experience [46], and many efforts to improve end of life care, such as hospice, focus on facilitating death at home or in a homelike surrounding if feasible [47]. While cancer patients have been most studied, multiple surveys have shown that a majority of patients state a preference to die at home irrespective of their underlying condition [18]. In particular, patients with HF may be more likely than patients with cancer to die in a medical facility and less likely to die at home [13,19]. Advance care planning and facilitating death in the patient's preferred location are central tenants of PC.

The Need for Caregiver Support

Living with HF is typically a shared experience, and caregiver well-being often declines during the disease course. Caregivers of patients with HF report impaired health status and emotional well-being [48], as well as a high prevalence of depressive symptoms which have been shown to relate to patient disease burden [49,50]. The burden has been associated with caregiver need for more help with daily tasks and with desire for greater communication with the patient [51]. Finally, caregivers not only report disruptions in their schedules and effects on their emotional health, but also significant financial burden [52].

Data Supporting Role of Outpatient PC in HF

The development and assessment of the impact of outpatient PC programs on HF care are still in infancy. However, recent studies have demonstrated that structured palliative care interventions may improve quality of life, depression, anxiety, and well-being in HF (Table 1).

Contemporary Trials

The Palliative Care in Heart Failure (PAL-HF) trial, a randomized, unblinded, single-center study of an interdisciplinary PC intervention in 150 patients with advanced HF showed that patients who were assigned to 6 months of PC plus usual care had improvements in HF-related quality of life as measured by the Kansas City Cardiomyopathy Questionnaire and overall health-related quality of life as measured by the Functional Assessment of Chronic Illness Therapy-Palliative Care scale. There were also improvements in depression and spiritual wellbeing [53••].

The Social Worker-Aided Palliative Care Intervention in High-risk Patients with Heart Failure (SWAP-HF) trial randomized 50 patients to a social-worker led palliative care intervention that began in the hospital and continued in the outpatient setting, versus usual care [54••]. The intervention was grounded in goals of care discussions guided by the Serious Illness Conversation Guide [55] conducted by a social worker with a background in PC. At 6 months, more patients in the intervention group had advance care preferences documented by non-study staff in the electronic medical record (65% vs 33%), and among patients who survived to 6 months, those in the intervention group were more likely to revise their baseline prognostic assessment in a direction consistent with the physician's assessment (94% vs 26%). Among these 6-month survivors, there was no difference in depression, anxiety, or quality of life scores between groups.

In the Collaborative Care to Alleviate Symptoms and Adjust to Illness (CASA) study, patients were randomized to a symptom and psychosocial collaborative care intervention provided by a multidisciplinary team that included a registered nurse, social worker, primary care physician, cardiologist, and PC specialist who jointly managed patients' care over structured telephone calls and visits. Patients in the intervention group showed improvements in depression, fatigue, and pain management, but no changes in HF-related quality of life scores [56].

It is noted that none of these three trials showed differences in mortality or hospitalization rates between intervention and control arms. However, we would argue that these "hard" endpoints are overstressed, while the other patient-centered outcomes such as symptoms and understanding of prognosis are often not emphasized enough. This is not to say that PC interventions do not have the potential to reduce hospital

Table 1 Selected clinical trials and studies of outpatient palliative care for heart failure patients

Study	Design	Timing	Team members	Intervention	Population	Outcomes	Results
Rogers et al. Pal-HF, 2017 [53••]	Prospective, RCT, single site	Pre discharge from ADHF hospitalization, 6 months post-discharge, followed up to 4 years	PC NP lead PCS Counselor Cardiology team	Interdisciplinary team, algorithm-driven symptom management, psychosocial and spiritual care, outlook intervention for end of life preparation, advance care planning	$N = 150$ (intervention 75) Patients admitted or within 2 weeks of discharge for ADHF	HF-related QOL (KCCQ, FACIT-Pal)	Improvement of KCCQ by 9.5 points(CI0.94-18.05, p 0.03), FACIT-Pal by 11.8 points (CI 0.84-22.71, p 0.035)
Desai et al. SWAP-HF, 2018	Prospective, RCT, single site	Pre-discharge from ADHF admission, 6 months post discharge	PC SW and/or SW + PC MD	Structured goals of care discussions based on Serious Illness Conversation Guide	$N = 50$ (intervention 26) Patients admitted for ADHF at the time of discharge planning	%patients with advance care preferences documented by the primary cardiology team at 6 months, %patients with improvement in prognostic alignment	65% intervention patients with documented ACP (vs 33%), 94%patients with improved prognostic alignment (vs. 26%)
Bekelman et al, CASA, 2018	Prospective, RCT, multisite	Eligibility confirmed via HER for HF diagnosis, diuretic dosing, LVEF $\leq 40\%$, BNP ≥ 100 pg/ml, NT-proBNP ≥ 500 pg/ml, reduced KCCQ, 1 target symptom	RN SW PCP, PCS, cardiologist	Algorithm-driven symptom management by RN, psychosocial care by SW	$N = 314$ (intervention 157)	HF-specific health status (KCCQ) baseline vs. 6 months	No significant change in KCCQ scores
Evangelista et al., 2014	Prospective, cohort study, single site	Pre-discharge from ADHF admission	PCS	PC brochure and letter, outpatient PC visit 1 week after discharge, additional visits as needed	$N = 42$	Perceived control (CAS-R), self-related ability (PAM), symptom burden (ESAS)	Improved perceived control ($p < 0.001$), activation $p < 0.001$), less symptom burden (p 0.040)
Evangelista et al., 2012	Prospective, cohort study, single site	Pre-discharge from ADHF admission	PC MD or NP	PC visit 1 week after discharge, subsequent phone interviews	$N = 36$	Symptom burden (ESAS), depression (PHQ9), QOL (MLHFQ)	Lower symptom burden ($p < 0.001$), lower level of depression ($p = 0.002$), improved QOL ($p < 0.001$)

ACP advance care planning, *ADHF* acute decompensated heart failure, *CAS-R* Control Attitude Scale, *ESAS* Edmonton Symptom Assessment System, *FACIT-Pal* Functional Assessment of Chronic Illness Therapy–Palliative Care, *KCCQ* Kansas City Cardiomyopathy Questionnaire, *MLHFQ* Minnesota Living with Heart Failure Questionnaire, *PAM* Patient Activation Measure, *PC* palliative care, *PCS* palliative care specialist, *PHQ9* 9-item Patient Health Questionnaire, *QOL* quality of life readmissions, or to decrease mortality, as they did in metastatic non-small cell lung cancer [57]. In 2018, Koser and colleagues documented their experience with an outpatient heart failure clinic dedicated to close monitoring after admission for acute heart failure exacerbation through structured telephone calls and acute visits after discharge, with referrals to PC as indicated [58]. In a retrospective analysis of 415 adults who had been enrolled in this clinic, 17.1% had been referred to PC, a higher percent than that reflected in national data. Seventy percent of the study patients who were referred to PC died in the outpatient setting. Further, this clinic achieved a reduction in the 30-day readmission rate (13.3%, vs 22% national average) and a lower inpatient mortality rate (1.2%, vs 11.6% national average). Study investigators attributed palliative care involvement as a contributor to both of these outcomes.

Recommended Strategies for Integrating PC Into Outpatient HF Care

Who Should Receive Palliative Care and When

Because of the symptomatic burden and unpredictable clinical nature of HF, we suggest that all patients with HF receive primary palliative care in the early phases of disease. PC skills and interventions are best provided by the primary provider (i.e., the cardiologist or primary care physician) in the early stages, as there are not enough palliative care specialists to provide consultation to the millions of patients living with HF. Further, HF patients develop relationships with the practitioners who provide the majority of their HF care and this therapeutic alliance can facilitate difficult discussions.

PC provided by the primary provider should focus on strategies for addressing symptoms (such as dyspnea, pain, depression) and quality of life, while also touching on discussions around prognosis and goals of care and early completion of advance directives. Dyspnea is the most common symptom experienced by HF patients, and providers should be aggressive with their prescription of loop diuretics, remembering that many centers have the option of offering subcutaneous or intravenous furosemide in the outpatient setting. Other HF therapies, such as ACE inhibitors and beta-blockers, not only improve mortality but can also improve symptoms and quality of life, and these medications should be aggressively prescribed as well. In addition to classic HF symptoms such as dyspnea, leg swelling, and fatigue, other symptoms experienced by HF patients such as pain, anorexia, and depression should be inquired about during appointments. Practitioners may benefit from the use of tools used to quantify symptoms that have been validated for use in HF patients, such as the Edmonton Symptom Assessment Scale [59] or the Memorial Symptom Assessment Scale [60]. Depression should also be prospectively screened using screening tools as such as Patient Health Questionnaire 9 [61].

Completion of detailed advance directives is also crucial in early HF care, although too often the patient's wishes are not documented in this form as described above. Regular discussions about prognosis and goals (with concomitant completion of advance directives) can allow patients and their families to express their wishes about future care, including life-sustaining treatments, limits of care or unacceptable states, and surrogate decision makers. It is the primary provider's responsibility to have these discussions proactively, even if the patient is well at the time, so that the patient and family are prepared for the kinds of decisions that may arise in acute life-threatening situations.

In contrast, referral to a palliative care specialist may be indicated in select scenarios (Fig. 2). Despite the shortcomings of prognostic risk models as described previously, we suggest that patients who are deemed to have poor prognosis based on a combination of risk models and clinical gestalt (i.e., the surprise question) be referred for more formalized palliative care consultation. Patients with significant comorbidities

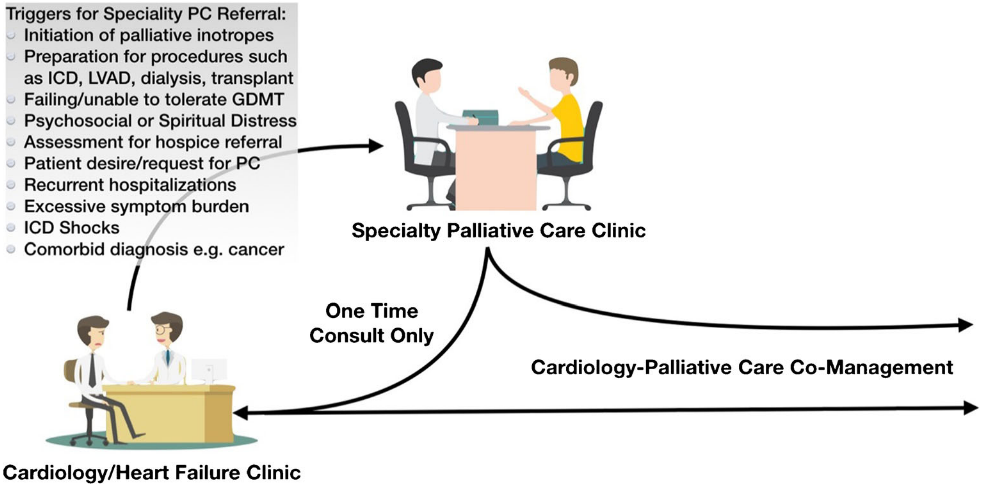

Fig. 2 Cardiology/heart failure clinic

(such as cancer, dementia, or lung disease, frailty), who are New York Heart Association (NYHA) functional class IV, or who are struggling with decision making may also benefit from specialty palliative care. Finally, certain clinical milestones or triggers should also prompt consideration of palliative care consult. These include repeated hospitalizations which is a strong predictor of mortality in community HF patients [62], or consideration of therapies such as VAD, OHT, or intravenous inotropes at home.

How to Incorporate Primary Palliative Care Into Outpatient HF Care

Providing PC can be difficult in today's busy clinical practice environment. The following suggestions may be helpful for providers who wish to incorporate primary and specialty-level PC into the care of HF patients:

1. Utilize the annual HF review: The American Heart Association has proposed an "annual HF review" with the patient's primary HF provider. This should occur during a scheduled clinic visit, and would allow the patient to summarize their symptom burden, quality of life, and goals for the coming year. This would also be an opportunity for the provider to review current and potential medications and devices, discuss a range of prognoses, and update advance directives. In order to maximize patient comfort and willingness to engage in these discussions, we encourage providers to emphasize that these visits are a routine part of their practice.
2. Use milestones as triggers: Primary providers should revisit advance directives and goals of care both at regular intervals (i.e., every 6 months or annually) and also at major milestones. We and others suggest the following potential milestones as triggers for these discussions: hospitalizations, ICD shocks, serial increases in the dose of maintenance diuretic or loss of ability to tolerate guideline-directed medical therapy, consideration of renal replacement therapy, important diagnoses/comorbidities (i.e., cancer), or other major life events such as the death of a spouse. And also recommend coordination of care at the time of discharge to include palliative care referral when appropriate [9]
3. Seek opportunities to further PC skills: Even though much of conventional HF care can be considered to be "palliative" in nature, primary HF providers often do not have formalized training in PC skills [63]. A number of training workshops exist that introduce PC skills to non-PC clinicians such as the Serious Illness Care Program (https://www.ariadnelabs.org/areas-of-work/serious-illness-care/) or VitalTalk (www.vitaltalk.org) provide evidence-based trainings that empower clinicians to hold difficult discussions [64••].
4. Involve caregivers: Caregiver involvement is extremely important in HF care. We recommend both inviting caregivers to patient appointments and involving them in the discussions about the current state of the disease and the patient's goals of care. Caregivers can both serve as patient advocates—assisting with medications and drawing attention to symptoms that the patient may not want to disclose—and can also bear witness to some of the difficult goals of care discussions that take place. In addition, assessing and addressing caregiver burden may benefit both patient and caregiver. Caregiver burden can easily be assessed with a few simple questions, such as: "We know that caregivers often neglect their own health. When was the last time you saw your primary care provider? (assessing Caregiver Health)"; "I know that many family caregivers find the role to be very stressful. How are you coping with these responsibilities? (Assessing Quality of Life)"; "Many caregivers don't want to burden others, especially children. Are there times when you really need help but don't ask for fear of being a burden? (Assessing Support)"; "We work with a social worker who is an expert in assisting caregivers. May I refer you to this individual? (Referring)"
5. Introduce PC team as part of the HF team: If the primary provider decides that referral to PC is necessary, it is important that this be broached in a sensitive way, as both patients and providers may have negative perceptions of PC teams. It should be emphasized that PC consultants work in tandem with HF teams to help maximize quality of life for patients with HF and help determine what values and goals are important to them as they battle this disease. While not always feasible, we recommend that a PC physician or nurse clinician be co-located within the HF clinic for maximal integration.

Conclusion

Patients with HF have significant needs that could be alleviated through timely primary and specialty-level PC and the outpatient setting remains underutilized for the delivery and integration of this care model. The evidence weighs heavily in favor of developing and testing models to overcome this gap in care so that patients with HF can access palliative care at any stage of their illness and in any care setting.

Compliance with Ethical Standards

Conflicts of Interest Dr. Desai reports personal fees from Abbott, grants and personal fees from Alnylam, grants and personal fees from AstraZeneca, personal fees from Boston Scientific, personal fees from Boehringer Ingelheim, grants and personal fees from Biofourmis, personal fees from DalCor Pharma, grants and personal fees from Novartis, personal fees from Relypsa, and personal fees from Regeneron, outside the submitted work.

Human and Animal rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors

References

Papers of particular interest, published recently, have been highlighted as:
- • Of importance
- •• Of major importance

1. Benjamin EJ, Muntner P, Alonso A, et al. Heart disease and stroke statistics—2019 update: a report from the American Heart Association. Circulation. 2019;139:e56–e528.
2. Curtis LH, Greiner MA, Hammill BG, et al. Early and long-term outcomes of heart failure in elderly persons, 2001-2005. JAMA Intern Med. 2008;168:2481–8.
3. Jong P, Vowinckel E, Liu PP, Gong Y, Tu JV. Prognosis and determinants of survival in patients newly hospitalized for heart failure: a population-based study. JAMA Intern Med. 2002;162:1689–94.
4. van Diepen S, Tran DT, Ezekowitz JA, et al. Incremental costs of high intensive care utilisation in patients hospitalised with heart failure. Eur Heart J Acute Cardiovasc Care 8(7),660–666. https://doi.org/10.1177/2048872619845282.
5. Bekelman DB, Havranek EP, Becker DM, et al. Symptoms, depression, and quality of life in patients with heart failure. J Card Fail. 2007;13:643–8.
6. McCarthy M, Lay M, Addington-Hall J. Dying from heart disease. J R Coll Physicians Lond. 1996;30:325–8.
7. Chung ML, Lennie TA, Mudd-Martin G, Dunbar SB, Pressler SJ, Moser DK. Depressive symptoms in patients with heart failure negatively affect family caregiver outcomes and quality of life. Eur J Cardiovasc Nurs. 2016;15:30–8.
8. Sepúlveda C, Marlin A, Yoshida T, Ullrich A. Palliative Care: The World Health Organization's global perspective. J Pain Symptom Manag. 2002;24:91–6.
9. Allen LA, Stevenson LW, Grady KL, et al. Decision making in advanced heart failure: a scientific statement from the American Heart Association. Circulation. 2012;125:1928–52.
10. Braun Lynne T, Grady Kathleen L, Kutner Jean S, et al. Palliative care and cardiovascular disease and stroke: a policy statement from the American Heart Association/American Stroke Association. Circulation. 2016;134:e198–225.
11. Jaarsma T, Beattie JM, Ryder M, et al. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. Eur J Heart Fail. 2009;11:433–43.
12. Yancy Clyde W, Jessup M, Bozkurt B, et al. 2017 ACC/AHA/HFSA focused update of the 2013 ACCF/AHA Guideline for the management of heart failure: a report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines and the Heart Failure Society of America. Circulation. 2017;136:e137–61.
13. Warraich HJ, Hernandez AF, Allen LA. How medicine has changed the end of life for patients with cardiovascular disease. J Am Coll Cardiol. 2017;70:1276–89.
14. Warraich HJ, Mentz RJ, Hernandez AF. Paving a better path for patients dying of heart disease. Circulation. 2018;137:1216–7.
15. Bakitas M, MacMartin M, Trzepkowski K, et al. Palliative care consultations for heart failure patients: how many, when, and why? J Card Fail. 2013;19:193–201.
16. Alsalem AB, Zheng Z, Huang Y, et al. Palliative care consultations for advanced heart failure patients: experience from a safety-net hospital. J Card Fail. 2018;24:S94.
17. Warraich HJ, Wolf SP, Mentz RJ, Rogers JG, Samsa G, Kamal AH. Characteristics and trends among patients with cardiovascular disease referred to palliative carecharacteristics and trends among patients with cardiovascular disease referred to palliative carecharacteristics and trends among patients with cardiovascular disease referred to palliative care. JAMA Netw Open. 2019;2: e192375–5.
18. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care. 2013;12:7.
19. Weitzen S, Teno JM, Fennell M, Mor V. Factors associated with site of death: a national study of where people die. Med Care. 2003;41: 323–35.
20. Services CfMaM. Proposed decision memo for ventricular assist devices for bridge-to-transplant and destination therapy (CAG-00432R).
21. Bekelman DB, Hutt E, Masoudi FA, Kutner JS, Rumsfeld JS. Defining the role of palliative care in older adults with heart failure. Int J Cardiol. 2008;125:183–90.
22. Quill TE, Abernethy AP. Generalist plus specialist palliative care — creating a more sustainable model. N Engl J Med. 2013;368:1173–5.
23. Kavalieratos D, Gelfman LP, Tycon LE, et al. Palliative care in heart failure. rationale, evidence, and future priorities. 2017;70:1919–1930. https://doi.org/10.1016/j.jacc.2017.08.036.
24. Fendler TJ, Swetz KM, Allen LA. Team-based palliative and end-of-life care for heart failure. Heart Fail Clin. 2015;11:479–98.
25. Nakagawa S, Garan AR. Hospice use and palliative care for patients with heart failure: never say never in medicine, but it is never too early to start the conversationpalliative care and hospice for patients with heart failure research. JAMA Cardiol. 2018;3:926–8.
26. • Warraich HJ, Xu H, DeVore AD, et al. Trends in hospice discharge and relative outcomes among medicare patients in the get with the guidelines–Heart Failure Registry Trends in Hospice Discharge and Outcomes Among Medicare Patients in the GWTG-HF Registry Trends in Hospice Discharge and Outcomes Among Medicare Patients in the GWTG-HF Registry. JAMA Cardiol. 2018;3:917–26 **This registry review of Medicare-linked claims data of HF patients showed infrequent hospice utilization among HF patients. When referred, patients were often referred too late with brief hospice enrollment.**
27. Xu J, Nolan MT, Heinze K, et al. Symptom frequency, severity, and quality of life among persons with three disease trajectories: cancer, ALS, and CHF. Appl Nurs Res. 2015;28:311–5.
28. Bekelman DB, Rumsfeld JS, Havranek EP, et al. Symptom burden, depression, and spiritual well-being: a comparison of heart failure and advanced cancer patients. J Gen Intern Med. 2009;24:592–8.
29. Rumsfeld JS, Alexander KP, Goff DC, et al. Cardiovascular health: the importance of measuring patient-reported health status. Circulation. 2013;127:2233–49.
30. Heo S, Doering LV, Widener J, Moser DK. Predictors and effect of physical symptom status on health-related quality of life in patients with heart failure. Am J Crit Care. 2008;17:124–32.
31. Walke LM, Gallo WT, Tinetti ME, Fried TR. The burden of symptoms among community-dwelling older persons with advanced chronic disease. JAMA Intern Med. 2004;164:2321–4.
32. Rumsfeld JS, Havranek E, Masoudi FA, et al. Depressive symptoms are the strongest predictors of short-term declines in health status in patients with heart failure. J Am Coll Cardiol. 2003;42: 1811–7.

33. Rutledge T, Reis VA, Linke SE, Greenberg BH, Mills PJ. Depression in heart failure: a meta-analytic review of prevalence, intervention effects, and associations with clinical outcomes. J Am Coll Cardiol. 2006;48:1527–37.
34. Warraich HJ, Kitzman DW, Whellan DJ, et al. Physical function, frailty, cognition, depression, and quality of life in hospitalized adults ≥60 years with acute decompensated heart failure with preserved versus reduced ejection fraction. Circ Heart Fail. 2018;11:e005254.
35. Levenson JW, McCarthy EP, Lynn J, Davis RB, Phillips RS. The last six months of life for patients with congestive heart failure. J Am Geriatr Soc. 2000;48:S101–9.
36. Feldman D, Pamboukian SV, Teuteberg JJ, et al. The 2013 International Society for Heart and Lung Transplantation Guidelines for mechanical circulatory support: executive summary. J Heart Lung Transplant. 2013;32:157–87.
37. Solomon SD, Dobson J, Pocock S, et al. Influence of nonfatal hospitalization for heart failure on subsequent mortality in patients with chronic heart failure. Circulation. 2007;116:1482–7.
38. Pulignano G, Del Sindaco D, Tavazzi L, et al. Clinical features and outcomes of elderly outpatients with heart failure followed up in hospital cardiology units: data from a large nationwide cardiology database (IN-CHF Registry). Am Heart J. 2002;143:45–55.
39. Levy Wayne C, Mozaffarian D, Linker David T, et al. The Seattle Heart Failure Model. Circulation. 2006;113:1424–33.
40. Pocock SJ, Ariti CA, McMurray JJV, et al. Predicting survival in heart failure: a risk score based on 39 372 patients from 30 studies. Eur Heart J. 2012;34:1404–13.
41. Allen LA, Matlock DD, Shetterly SM, et al. Use of risk models to predict death in the next year among individual ambulatory patients with heart failurepredicting death among ambulatory patients with heart failurepredicting death among ambulatory patients with heart failure. JAMA Cardiol. 2017;2:435–41.
42. Straw S, Byrom R, Gierula J, et al. Predicting one-year mortality in heart failure using the 'Surprise Question': a prospective pilot study. Eur J Heart Fail. 2019;21:227–34.
43. Allen LA, Yager JE, Funk MJ, et al. Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure. JAMA. 2008;299:2533–42.
44. Dunlay Shannon M, Swetz Keith M, Mueller Paul S, Roger VL. Advance directives in community patients with heart failure. Circulation. 2012;5:283–9.
45. Butler J, Binney Z, Kalogeropoulos A, et al. Advance directives among hospitalized patients with heart failure. JACC: Heart Fail. 2015;3:112–21.
46. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. J Clin Oncol. 2003;21:1133–8.
47. Hoyer T. A History of the Medicare hospice benefit. Hosp J. 1998;13:61–9.
48. Janssen DJA, Spruit MA, Wouters EFM, Schols JMGA. Family caregiving in advanced chronic organ failure. J Am Med Dir Assoc. 2012;13:394–9.
49. Hooley PJD, Butler G, Howlett JG. The relationship of quality of life, depression, and caregiver burden in outpatients with congestive heart failure. Congest Heart Fail. 2005;11:303–10.
50. Bidwell JT, Lyons KS, Lee CS. Caregiver well-being and patient outcomes in heart failure: a meta-analysis. J Cardiovasc Nurs. 2017;32:372–82.
51. Garlo K, O'Leary JR, Van Ness PH, Fried TR. Burden in caregivers of older adults with advanced illness. J Am Geriatr Soc. 2010;58: 2315–22.
52. Dunbar Sandra B, Khavjou Olga A, Bakas T, et al. Projected costs of informal caregiving for cardiovascular disease: 2015 to 2035: A Policy Statement From the American Heart Association. Circulation. 2018;137:e558–77.
53.•• Rogers JG, Patel CB, Mentz RJ, et al. Palliative care in heart failure. The PAL-HF Randomized, Controlled Clinical Trial. J Am Coll Cardiol. 2017;70:331–41 **The PAL-HF studied and demonstrated that palliative care involvement in patients in addition to usual care led to improvement in HF-related quality of life, depression, and spiritual wellbeing.**
54.•• O'Donnell AE, Schaefer KG, Stevenson LW, et al. Social worker–Aided Palliative Care Intervention in High-risk Patients With Heart Failure (SWAP-HF): a pilot randomized clinical trial. JAMA Cardiol. 2018;3:516–9 **This study showed that intervention led by social work resulted in increased documentation of patient preferences and increased concordance between physician and patient assessment of prognosis.**
55. Gandesbery B, Dobbie K, Gorodeski EZ. Outpatient palliative cardiology service embedded within a heart failure clinic: experiences with an emerging model of care. Am J Hosp Palliat Med. 2017;35: 635–9.
56. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non–small-cell lung cancer. N Engl J Med. 2010;363:733–42.
57. Koser KD, Ball LS, Homa JK, Mehta V. An outpatient heart failure clinic reduces 30-day readmission and mortality rates for discharged patients: process and preliminary outcomes. J Nurs Res. 2018;26:393–8.
58. Ezekowitz JA, Thai V, Hodnefield TS, Sanderson L, Cujec B. The correlation of standard heart failure assessment and palliative care questionnaires in a multidisciplinary heart failure clinic. J Pain Symptom Manag. 2011;42:379–87.
59. Zambroski CH, Moser DK, Bhat G, Ziegler C. Impact of symptom prevalence and symptom burden on quality of life in patients with heart failure. Eur J Cardiovasc Nurs. 2005;4:198–206.
60. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med. 2001;16:606–13.
61. Setoguchi S, Stevenson LW, Schneeweiss S. Repeated hospitalizations predict mortality in the community population with heart failure. Am Heart J. 2007;154:260–6.
62. Dabbouseh NM, Kaushal S, Peltier W, Johnston FM. Palliative care training in cardiology fellowship: a national survey of the fellows. Am J Hosp Palliat Med. 2017;35:284–92.
63. Back AL, Arnold RM, Baile WF, et al. Faculty development to change the paradigm of communication skills teaching in oncology. J Clin Oncol. 2009;27:1137–41.
64.•• Bekelman DB, Allen LA, et al. Effect of a collaborative care intervention vs usual care on health status of patients with chronic heart failure: the CASA Randomized Clinical Trial. JAMA Intern Med. 2018;178(4):511–9 **This study showed that though focused symptom and psychosocial intervention did not result in difference in health status, secondary outcomes including depression and fatigue improved.**