

Team-based Palliative and End-of-life Care for Heart Failure



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KEYWORDS

- Palliative care • Hospice care • Heart failure • Interdisciplinary communication • Patient care team
- Comprehensive health care

KEY POINTS

- Palliative care is one component of holistic, supportive care of patients throughout the course of disease, intensified at end of life and extending into the bereavement phase for their caregivers.
- Team-based palliative care for heart failure implies a multidisciplinary approach, including primary care, cardiology, and palliative care, each represented by various providers (eg, physicians, advanced practitioners, nurses, case managers, and pharmacists).
- 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, sometimes with consultation by palliative care and sometimes transitioning focus to palliative care at the end of life.

INTRODUCTION

Among an estimated 5.1 million Americans with heart failure, the prevalence of advanced disease is 5% to 10%.¹ As such, nearly half a million Americans struggle with significant symptom burden, psychosocial stressors, and difficult decisions imposed by their end-stage heart failure. Disease prevalence is expected to grow 25% by 2030, primarily because of improved survival, whereas costs are projected to increase from \$32 billion in 2013 to \$70 billion in 2030.¹ With increased emphasis on patient-centered care,^{2,3} and in response to unsustainable health care expenditures, there has been increasing attention placed on palliative and end-of-life care for patients with advanced heart failure.⁴

The 2013 American College of Cardiology Foundation (ACCF)/American Heart Association (AHA) guidelines support the use of palliative care in patients with end-stage heart failure as level 1B.⁴ Medicare's 2014 update to National Coverage Determination for mechanical circulatory support (MCS) even mandates a multidisciplinary team that includes a palliative care specialist.⁵ However, there is limited evidence to guide the content, implementation of, and integration of palliative care interventions into existing heart failure disease management. Therefore, this article explores evidence supporting a team-based approach to palliative and end-of-life care for patients with heart failure, comments on the current state of multidisciplinary care for such patients, identifies

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knowledge gaps, and discusses opportunities for future study.

Team-based Care Implies a Multidisciplinary Approach

Ample evidence shows that team-based care for patients with heart failure decreases rehospitalizations and improves survival through education, structured follow-up, patient self-care, and care-plan adherence.^{6,7} However, few pilot studies have assessed the efficacy of multidisciplinary palliative care in improving outcomes germane to end-stage heart failure (ie, quality of life, symptom control, decreased health care use, lower financial and caregiver burdens), in part because of heterogeneity in defining what palliative care is and how it should be delivered. **Table 1** details selected clinical trials and intervention studies that support a multidisciplinary palliative approach by incorporating specialties tailored to patient needs to facilitate the inevitable transitions in chronic heart failure care.

What's in a Name? Palliative Care is Supportive Care

Historically, the term palliative care was conflated with hospice care: a focused approach to dying patients for whom disease-targeted treatment or cure is 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 (**Fig. 1**). 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.²⁰⁻²² All health care 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.

Building on Experience or Diverging Pathways? Palliative Care in Cancer and in Heart Failure

Evidence and education have helped to normalize early, integrated palliative care approaches and improve outcomes for patients with advanced cancer.^{23,24} Because of a dearth of evidence in the cardiology literature, heart failure guidelines and consensus statements have partially relied on cancer care studies to recommend best practices for treating patients at end of life.^{4,22} However, despite similar or worse symptom

burden, depression, and spiritual well-being for patients with advanced heart failure compared with those with advanced cancer,²⁵ heart failure has been associated with less access to palliative care and use of hospice, and higher rates of resource use and aggressive treatment.^{26,27} This disparity highlights a need to better inform providers and patients of options for progressive and end-of-life heart failure.

Some clinicians have noted that translating the model of palliative cancer care to heart failure may not be feasible or appropriate, given a less predictable course of disease progression and less well-defined transition stages by which to time interventions.²² Even so, evidence-based cancer care provides a foundation from which integrated palliative heart failure care can expand. For example, the ENABLE: CHF-PC (Educate, Nurture, Advise, Before Life Ends: Comprehensive Heart Care for Patients and Caregivers) trial (see **Table 1**) evolved from a series of successful palliative cancer care trials, and its recently published feasibility pilot results were promising.¹¹

THE LOGISTICS OF TEAM-BASED PALLIATIVE CARE IN HEART FAILURE

Who Makes up the Clinical Palliative Care Team?

Various health care providers from multiple fields comprise the clinical component of a multidisciplinary palliative care team, along with patients and caregivers (**Fig. 2**). The 3 main specialties are 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.²⁸ Interdisciplinary care increases prescriptions for symptom control medication and decreases hospitalizations, length of stay, and cost of care.⁷ These 3 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 (**Fig. 3**).

This partnership can be challenging because of prognostic uncertainty, difficulty with optimal timing of consultation, the desire to save patients, and the fear of failing them. Such barriers stem from an inaccurate perception of palliative care as synonymous with hospice.^{29,30} Palliative care should not be seen as giving up or accepting death, but as 1 component of a collaborative, supportive approach to patient care (**Box 1**).

Table 1
Selected clinical trials and intervention studies of team-based palliative care in heart failure

Study	Study Type	Setting/Subject	Provider Training	Intervention Domains	Intervention Components	Intervention Development	Team Liaison	Team members	Outcomes/Results
Aiken et al, ⁸ 2006	Prospective, Single Center, Randomized Controlled Trial	Home-based COPD, NYHA IIIb/IV HF prognosis ≤ 2 y n = 190 (129 HF) 100 cases (67 HF) 90 controls (62 HF)	<ul style="list-style-type: none"> • Members chosen for EOLC/chronic disease care experience • 2 wk training session • Ongoing monthly presentations by experts on specific topics 	<ul style="list-style-type: none"> • Disease/Symptom Management • Self-care/knowledge of Illness/Resources • Preparation for EOLC/ACP • Physical/Mental Functioning • Utilization of Medical Services 	PhoenixCare Model <ul style="list-style-type: none"> • Average 1 to 6 home/clinic/phone care visits per month • Scheduled team meetings, referrals as needed • Unique protocols by disease & level of stability • Parallel with usual/curative treatment care 	<ul style="list-style-type: none"> • Based on expert opinion literature regarding case management of ill adults • Validated FairCare model used for communication training 	RN Case Manager	Medical Director SW Pastoral Counselor PCP Family Community Agencies	Among cases: <ul style="list-style-type: none"> • Better self-care, resource awareness, legal participation, vitality, physical function, self-rated health • Lower symptom distress • No difference in ED visits
Bekelman et al, ⁹ 2014	Prospective, Single Center, Mixed-Methods Feasibility Pilot	Outpatient HF (82% NYHA II/III) n = 17	<ul style="list-style-type: none"> • RN: 2 half-day workshops • SW/Psych: 1.5 workshop days 	<ul style="list-style-type: none"> • Symptom Management • Illness Adjustment/Depression 	CASA (Collaborative Care to Alleviate Symptoms & Adjust to Illness) <ul style="list-style-type: none"> • 6 to 8 RN-led phone/clinic visits for symptom management • 5 SW/Psych-led phone visits for adjustment/depression • Weekly team meetings with recommendations to PCP 	<ul style="list-style-type: none"> • Algorithm-based symptom management taught by PCS • Validated, manualized counseling protocol taught by psychologist • Collaborative care model validated in CAD patients with angina 	PCP	RN SW Psychologist Cardiologist PCS	<ul style="list-style-type: none"> • 1 early withdrawal • <5% missing data • 85% of recommendations implemented • All recognized depression treated • Patients reported positive experience, requested more program flexibility

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Study	Study Type	Setting/Subject	Provider Training	Intervention Domains	Intervention Components	Intervention Development	Team Liaison	Team members	Outcomes/Results
Brannstrom & Boman, ¹⁰ 2014 (Sweden)	Prospective, Single Center, Randomized Controlled Trial	Home-based NYHA III/IV HF n = 72 36 cases, 36 controls	—	<ul style="list-style-type: none"> • Disease Education • ACP • Symptom Management • Communication • Goals of Care 	PREFER (Palliative advanced home caRE and heart FailurE caRe) <ul style="list-style-type: none"> • Parallel with usual/curative treatment care, all needs met • Advanced, total home care unit providing services Monday-Friday • Phone/home visits with diuretics, as needed • Resume own provider at 6 mo w/ individual care plan • Bi-monthly team meetings 	<ul style="list-style-type: none"> • Based on “The 6 S’s,” a derived, person-centered PC model (Self-image, Self-determination, Social relationships, Symptom control, Synthesis & Surrender) • Relied on data collection from Swedish nationwide quality palliative registry aimed at improving EOLC • Care structure per ESC guideline recommendations 	—	PCS HF Cardiologist Cardiologist HF RN PC RN PT/OT	Among cases: <ul style="list-style-type: none"> • Improved QoL, total symptom, self-efficacy domains of KCCQ • Nausea was only improved symptom of 9 studied • NYHA class improved more often • 15 (vs. 53) hospitalizations • Nearly 5× more RN visits

Dionne-Odom et al, ¹¹ 2014	Prospective, Single Center Feasibility Pilot	Community-based/Rural HF (86% NYHA III/IV) n = 11 dyads (patient/caregiver)	<ul style="list-style-type: none"> • RN coaches had ≥24 h of training • Periodic fidelity checks • All interventionists in previous ENABLE studies 	<ul style="list-style-type: none"> • Problem-solving Management • Symptom Management • Self-care • Communication/Care Coordination • Local Community Resource Use • Decision-making/ACP • Life Review/Creating Legacy 	ENABLE (Educate, Nurture, Advise, Before Life Ends):PC-CHF <ul style="list-style-type: none"> • AP PC RN coached phone/in-person visits • 6 visits with patients; 3 with caregivers • Uses Charting Your Course guidebook • Monthly follow-up calls for reinforcement/coaching • In-person PC team assessment 	<ul style="list-style-type: none"> • Derived from previous ENABLE studies in oncology • Translated material to HF verbage • External advisors & clinician expert advisory groups (Cardiology, PCP, IM) 	AP PC RN coach	Caregiver PCP Internist Cardiologist	<ul style="list-style-type: none"> • Feasible from all perspectives • Clinicians concerns of prognostic uncertainty, poor patient understanding of disease severity, and parallel PC • Patients desired earlier intervention • Small to medium effect sizes of efficacy scores
Enguidanos et al, ¹² 2005	Prospective, Controlled Trial	Home-based HF, COPD, Cancer prognosis ≤1 y n = 298 (82 HF) 159 cases (31 HF) 139 controls (51 HF)	<ul style="list-style-type: none"> • MD, RN, SW "all with expertise in symptom management and bio-psychocial intervention" 	<ul style="list-style-type: none"> • Decision-making/ACP • Communication • Continuity of Care • Emotional/Practical/Spiritual Support • Symptom Control/Comfort Care • Clinician Emotional/Organizational Support 	KPPC (Kaiser Permanente Palliative Care) <ul style="list-style-type: none"> • Home visits by RN, MD, SW, et al, as needed • Parallel with usual/curative treatment care 	<ul style="list-style-type: none"> • KPPC domains derived from consensus statement by peer workgroup of field experts on ICU end-of-life care 	—	Family RN MD SW	<p>Among cases:</p> <ul style="list-style-type: none"> • No improved severity of illness in HF • More home deaths (less difference in HF patients) • Less days on service • 52% decrease in cost of care for HF

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Table 1
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Study	Study Type	Setting/Subject	Provider Training	Intervention Domains	Intervention Components	Intervention Development	Team Liaison	Team members	Outcomes/Results
Evangelista et al, ¹³ 2012	Prospective, Single Center, Cohort Study	Outpatient NYHA II/III HF, hospitalized n = 36	—	<ul style="list-style-type: none"> • ACP 	<ul style="list-style-type: none"> • Outpatient PCS consultation 1 wk after discharge • Phone interviews at baseline and 3 mo 	—	—	PCS or PC NP	<ul style="list-style-type: none"> • Perceived health better in AD completers • AD knowledge/attitude improved markedly • AD completion only increased 28% to 42%
Evangelista et al, ¹⁴ 2014	Prospective, Single Center, Cohort Study	Outpatient NYHA II/III HF, hospitalized n = 42 29 ≥ 2 PC visits 13 < 2 PC visits	—	<ul style="list-style-type: none"> • Symptom Management • Illness Understanding • Goals of Care • Decision-making/Care Coordination 	<ul style="list-style-type: none"> • PC program brochure and letter of explanation at discharge • Outpatient PCS consult 1 wk after discharge • Phone interviews at baseline and 3 mo • Encouraged to contact PC for ongoing services/support 	—	—	PCS or PC NP	<ul style="list-style-type: none"> • Significantly greater improvements in control, activation, & symptom distress with multiple PC visits

Schellinger et al, ¹⁵ 2011	Prospective, Multi-site/Single System Implementation Study	Outpatient HF, referred for ACP n = 1894 602 completed ACP 1292 did not complete	<ul style="list-style-type: none"> Facilitators (RN/SW) certified in 26-h competency-based communication skills training program Unquantified "staff time" to educate system employees about intervention/process 	<ul style="list-style-type: none"> ACP 	<p>"Respecting Choices:" Disease-Specific ACP</p> <ul style="list-style-type: none"> Call center to track referrals/schedule interviews Facilitated in-depth ACP interview with patient and proxy HF planning tools to accurately document goals, values, and treatment preferences accessible in medical record 	<ul style="list-style-type: none"> Based on established "Respecting Choices" program, which has been validated in multiple RCTs 	Certified Facilitator	Caregiver/Proxy RN SW Referral Coordinator	<ul style="list-style-type: none"> Completers were significantly older and referred more from clinics or home care Completers had significantly higher rates of appropriate documentation of ACP and hospice enrollment No difference in 60-d ED or admission rates
Schwarz et al, ¹⁶ 2012	Retrospective, Single Center Descriptive Study	Inpatient NYHA IV HF, referred for transplant & early PC n = 20	—	<ul style="list-style-type: none"> Symptom Management Goals of Therapy Clarification ACP Hospice Referral EOLC 	<ul style="list-style-type: none"> Chart review post-discharge Unstructured interviews to gauge impact of PC on patients, families, and care providers Non-standardized tool used in which 1 PCS & 1 HF cardiologist scored impact of PC on patients 	—	—	PCS HF Cardiologist NP SW Psychiatrist Hospital Chaplain	<ul style="list-style-type: none"> Reduced pain More holistic care (psychiatric assessment, spiritual counseling, etc.) Patient-reported increase in clarity & continuity of care 30% of patients completed ADs Moderate to significant impact scores

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Table 1
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Study	Study Type	Setting/Subject	Provider Training	Intervention Domains	Intervention Components	Intervention Development	Team Liaison	Team members	Outcomes/Results
Wong et al, ^{17,18} 2013 (China)	Retrospective, Single Center Descriptive Study	Home-based NYHA III/IV HF n = 44	—	<ul style="list-style-type: none"> • Resource Utilization 	<ul style="list-style-type: none"> • Data had been collected prospectively in registry of all end-stage HF patients at site recruited into PC • Weekly to monthly home visits by team based on acuity • Patients also followed in hospital-based chronic HF management program at regular intervals 	—	—	MD RN Counsellor	<ul style="list-style-type: none"> • 68% died in 24 mo follow-up • Mean time to death was 5.5 mo • Significant reduction in all-cause & HF hospitalizations

Abbreviations: ACP, advance care planning; AP, advanced practice; CAD, coronary artery disease; CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; ED, emergency department; ENABLE, Educate, Nurture, Advise, Before Life Ends; EOLC, end of life communication; ESC, European Society of Cardiology; HF, heart failure; IM, internal medicine; KCCQ, Kansas City Cardiomyopathy Questionnaire; KPPC, Kaiser Permanente Palliative Care; MD, medical doctor; NP, nurse practitioner; NYHA, New York Heart Association; OT, occupational therapy; PC, palliative care; PCP, primary care physician; PCS, palliative care specialist; prn, as needed; PT, physical therapy; QoL, quality of life; RCT, randomized controlled trial; recs, recommendations; RN, registered nurse; Psych, psychologist; SW, social work.

Data from Refs.⁸⁻¹⁷

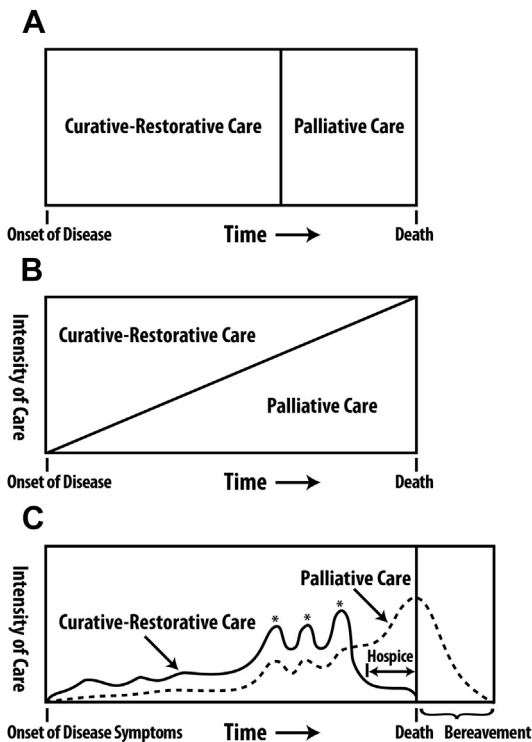


Fig. 1. Evolving models of integrating curative-restorative care with palliative care. (A) Curative-restorative care was previously seen as an all-or-none phenomenon, and palliative care was only initiated once curative-restorative care options were exhausted. (B) Palliative care principles were incorporated concurrently with curative-restorative care models, but because fewer curative-restorative care options existed palliative care was intensified. (C) This model shows why care trajectories rarely change at a constant, linear slope; instead, care intensity is augmented by punctuated exacerbations of illness over time.^{18,19} (Reprinted with permission of the American Thoracic Society. Copyright © 2015 American Thoracic Society. From Lankan PN, Terry PB, Delisser HM, et al. An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. *Am J Respir Crit Care Med* 2008;177(8):912–27. The American Journal of Respiratory and Critical Care Medicine is an official journal of the American Thoracic Society. Adapted from World Health Organization. Cancer pain relief and palliative care: report of a WHO expert committee. Geneva, Switzerland: World Health Organization; 1990. Technical Report Series No. 804; with permission.)

However, a national shortage of palliative care specialists exists along with the proliferation of heart failure in older patients with multimorbidity.³¹ Therefore, a shared-care approach is crucial. By improving clinician skills and allaying fears through interaction with and learning from palliative care specialists, general practitioners and cardiologists

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.³²

Who Takes the Lead?

The role of an appointed clinical team leader, or liaison, is important in coordination of multidisciplinary care.²² The team cannot function effectively without a clear understanding of organizational and leadership structure. Early in disease progression, lead input is more likely to pass 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 several studies and palliative care programs, the investigators described great success in appointing a heart failure or case management nurse to communicate with patients and delegate responsibility for different aspects of care.^{8,12,33–35} 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 ensure that medical decision making is tailored to patients' values, goals, and preferences.³⁶

Referrals among patients with advanced heart failure are most commonly for allied health services and psychosocial support. **Fig. 2** includes all team members mentioned previously in controlled trials, pilots, or reviews of multidisciplinary heart failure palliative care programs. Data from 2 descriptive studies on the frequency of referral types in a single palliative heart failure service is presented in **Table 2**. 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. However, although the multidisciplinary palliative care team should adopt a holistic, patient-centered perspective, not all patients require all services.

When and 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 iterative intervention is preferred. This preference stems from the concept that difficult discussions now simplify difficult decisions later.³⁸ Nearly 20 years ago, the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of

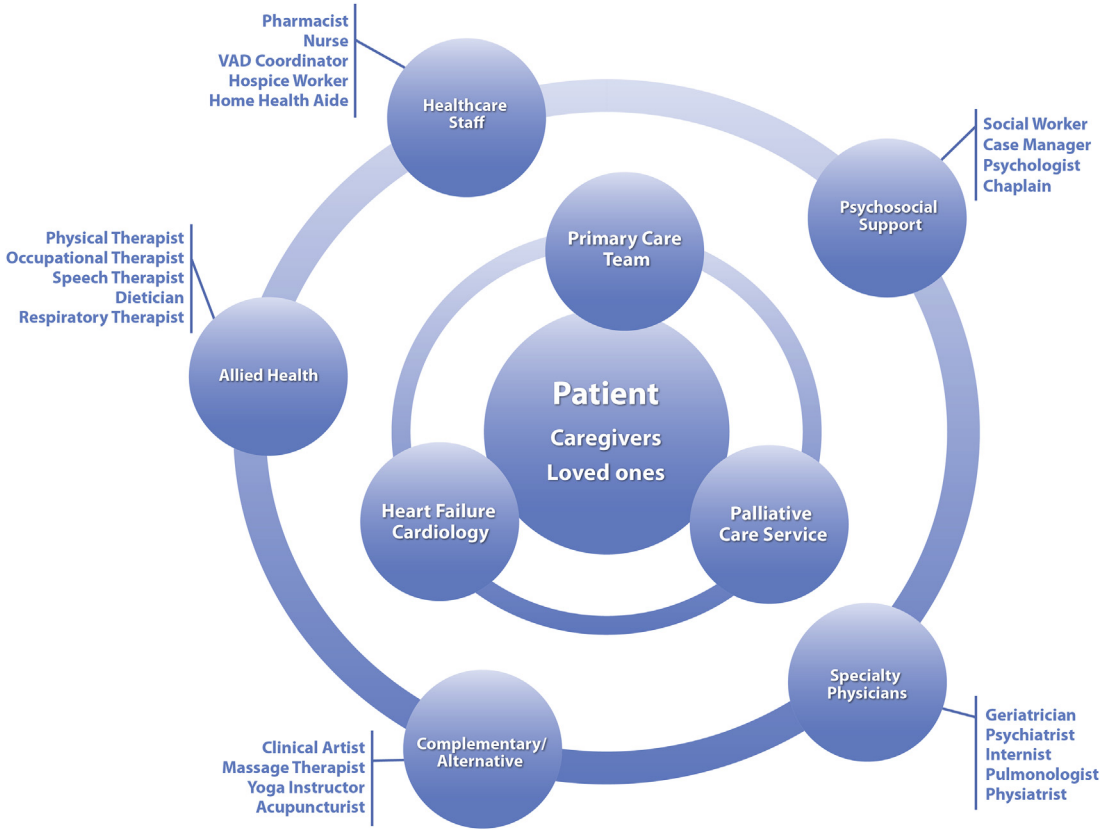


Fig. 2. Layered model of team-based palliative care in heart failure. This integrated, multidisciplinary model keeps the patient and caregivers central to the plan of care, and they are supported by layers of clinicians and providers whose support can vary over time. The core clinical team is composed of primary care, cardiology, and palliative care, with many secondary supportive and consultative services. The included providers are likely partial, and other team members may exist in individual teams to support patients as much as possible. VAD, ventricular assist device.

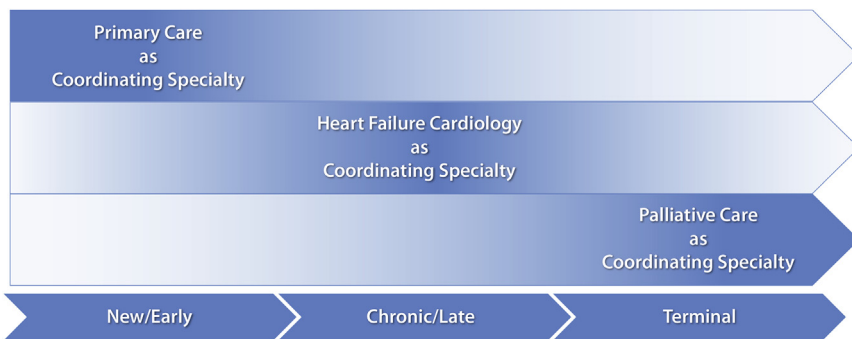


Fig. 3. Evolution of central care coordination at different stages of heart failure. In a team-based approach to advanced heart failure and palliative care, the responsibility and contribution of each core specialty may grow or decrease as the patient's disease progresses. This pattern of care coordination is likely to differ for all patients, according to their individual trajectory and needs.

Box 1 Palliative care versus hospice care

Consultative palliative care

- Addresses goals of care and focuses on quality of life, family support, and symptom management
- Can begin with onset of symptoms from a serious, life-limiting disease

Hospice

- A specific type of palliative care provided when a patient is terminally ill (ie, life expectancy <6 months if the disease runs its expected course)
- Provides team-based support services to the patient, family, and caregivers in the home or an institution

Adapted from Swetz KM, Kamal AH. In the clinic. Palliative care. Ann Intern Med 2012;156(3):ITC2-2; with permission.

Table 2
Services accessed in 2 team-based palliative heart failure programs

	Bekelman et al, ³⁷ 2011	Evangelista et al, ¹⁴ 2014
Number of patients	50	36
Study Type	Case series	Descriptive study
Study Location	Aurora, CO	Irvine, CA
Rate of Services Used	—	—
Chaplain (%)	—	45
Home Health (%)	—	83
Hospice (%)	16	7
Neurology (%)	4	—
Other (%)	10	—
Alternative Medicine (%)	2	—
Pain Clinic (%)	2	—
Pulmonary Clinic (%)	2	—
Speech Therapy (%)	2	—
Weight Loss Clinic (%)	2	—
Palliative Care Specialist (%)	100	100
Nurse Practitioner (%)	—	83
Physician (%)	—	27
Pharmacist (%)	—	100 ^a
Physical and Occupational Therapy/Rehabilitation (%)	20	66
Psychiatry (%)	8	55
Psychology/Counseling (%)	4	—
Social Work (%)	26	69
Support Groups (%)	—	31

^a Mandatory referral.

Data from Bekelman DB, Nowels CT, Allen LA, et al. Outpatient palliative care for chronic heart failure: a case series. *J Palliat Med* 2011;14(7):815–21; and Evangelista LS, Liao S, Motie M, et al. On-going palliative care enhances perceived control and patient activation and reduces symptom distress in patients with symptomatic heart failure: a pilot study. *Eur J Cardiovasc Nurs* 2014;13(2):116–23.

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.³⁹ The investigators suggested that repeated exposure throughout the disease span might be needed to effect positive change, in addition to a more developed health care infrastructure to support interventions. Subsequent literature confirmed the importance of constantly readdressing goals and expectations for care with patients with heart failure.⁴⁰ The need for repetition stems from the unpredictable nature of heart failure progression,⁴¹ the ensuing difficulty with accurate risk assignment and prognosis,³⁸ and the evolution of individual patient preferences over time.⁴² Ultimately, these difficulties might be attenuated by earlier integration of supportive care that fosters improvement in patients' understanding and acceptance of their disease and mortality.⁴³ Early and iterative 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.^{44,45} In a controlled trial of early outpatient palliative care for patients with various chronic diseases, 69% would have preferred the intervention regarding future plans to have occurred earlier.⁴⁶ 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.⁴⁷ Early palliative heart failure interventions have been studied prospectively in outpatient^{9,15} and postadmission settings^{13,14,48} as well as among admitted patients undergoing their first heart transplant evaluation,¹⁶ with varying results (see **Table 1**).

However, late referrals to palliative care are common. One single-center retrospective chart review of 132 patients with advanced heart failure receiving inpatient palliative care consults over 5 years reported an median time from consultation to death of only 21 days.⁴³ Late hospice referrals were associated with worse family satisfaction with hospice, unmet needs, poor awareness about expectations for when death would occur, low confidence in being part of care, and perceived lack of care coordination.⁴⁹

Several locations for palliative heart failure interventions have been studied. Home-based palliative care was explored in multiple studies with

mixed results regarding symptom burden, quality of life, health care use, and cost (see **Table 1**), although rate of death at home was higher in each of these studies.^{8,10,12,17} These findings reflect the priorities of patients with end-stage heart failure, who prefer to be at home during the terminal stage of the disease, if possible.⁵⁰ The challenges of community-based rural palliative care have been reviewed⁵¹ and tested in a feasibility pilot.¹¹ 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.⁵¹ In addition, 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.

One of the best models for an early, iterative, and efficacious supportive care intervention in patients with chronic disease was pioneered by medical ethicist Bernard (Bud) Hammes at Gundersen Health System in La Crosse, Wisconsin. His program, *Respecting Choices*, entails in-depth discussions about advance directives, facilitated by trained providers. Discussions are encouraged with all adults whenever they interact with health care professionals, whether inpatient or outpatient, primary care or specialty, physicians or other providers. Although the intervention only addresses 1 domain of supportive care, it has been associated with very high rates of advance directive completion, higher patient satisfaction, and lower rates of health care use and costs in the last year of life.^{52,53}

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

Several different supportive care stages have been put forth in expert reviews to delineate how the role of the multidisciplinary palliative heart failure team changes with disease progression.^{21,22,54,55} 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 (**Table 3**). 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.

Table 3
Domains of supportive care and team members involved in early and late phases of heart failure progression

Domains	Early Phase	Late Phase	Team Members
Physical Well-being	Life-prolonging Heart Failure Therapies (Medications, Interventional Procedures)	Symptom Management (Pain, Dyspnea, Fatigue, Insomnia, Anorexia, Pruritis, Side Effects of Heart Failure Treatments or Interventions)	Physician, APP, Pain Specialist, Palliative Care Specialist (PCS), Pulmonologist, Respiratory Therapist, Pharmacist, PT/OT
		Complementary & Alternative Medicine (as desired by the patient)	Acupuncturist, Clinical Art Therapist, Message Therapist, Yoga Instructor
	Exercise/Weight Control/Nutrition	Rehabilitation/Strengthening	Physiatrist, PT/OT, Nutritionist
	Psychosocial Support	Quality of Life	ALL Team Members
Psychosocial Support	Community Resources (Insurance, Financial Aid, Support Groups)	Community Resources (Transportation, Home Care, Hospice)	Social Work, Case Management (SW/CM), Home Health, Support Group Facilitator, Hospice Team
		Spirituality	Chaplain
		Depression, Anxiety	Physician, APP, Psychiatrist, Psychologist, Pharmacist, Chaplain, PCS, Support Group
Communication	Emotional Support, Coping	Loss of Control, Autonomy, Legacy Building	
	Appoint Team Liaison	Maintain Open, Trusting Relationship (“Meet patients where they are”)	Physician, APP, Caregiver, Team Liaison, PCS, Psychologist, Psychiatrist
		Continuity of Care	
		Shared-decision Making, Assess Goals of Care	
Advance Care Planning	Disease Understanding	Prognostic Understanding (As patient wishes to know)	
		Addressing Fears & Concerns	
		Legal (Assess Preferences and Goals of Care Frequently)	Physician, APP, SW/CM, PCS, Caregiver
Advance Care Planning	Legal (Advance directives—including living wills, appointment of alternate decision maker (health care power of attorney))	Difficult Issues (Choosing a Place of Death; Avoiding Prolonged Suffering; Code status; Considering Hospice; De-escalation of Care;	Physician, APP, PCS, Caregiver, Hospice

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Table 3
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Domains	Early Phase	Late Phase	Team Members
		Preferences for Rehospitalization, Device Deactivation	
Education	Self-management/Self-care (Adherence to Medication, Diet; Exercise)		Physician, APP, Pharmacist, Dietician, Physiatrist, PT/OT
	Understanding heart failure and the implications of the diagnosis	Understanding Unpredictable Course	Physician, APP, RN
		Knowledge of Potentially Life-limiting Nature of Illness	
Caregiver Focus		Preserve/Foster Relationships Caregiver Agreement with/Acceptance of Patient Preferences	Caregiver
		Prevention of Caregiver Fatigue and Burnout	SW/CM, Support Group, Psychologist, Psychiatrist
		Avoid Leaving Financial Burdens	Caregiver, SW/CM
		Bereavement Support	Caregiver, Psychologist, Psychiatrist, SW/CM, Chaplain

Abbreviations: APP, advanced practice provider; CM, case management.

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.⁵⁶ For example, depression is common and associated with worse outcomes in advanced disease.⁵⁷ However, antidepressants had disappointing results when used in this setting.⁵⁸ Therefore, depression in the setting of heart failure is likely to be most responsive to multimodality interventions, including pharmacotherapy for cardiac dysfunction and other comorbidity, exercise, and cognitive behavior therapy.⁵⁹ 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,⁶⁰ whereas several studies have shown dyspnea improvement through exercise and respiratory muscle training.⁵⁴ Even more promising is the Breathlessness Support Service, a United Kingdom-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.⁶¹

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 several 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.⁶² 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.^{38,63} 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.^{64,65} Several of the heart failure-specific pilots and trials listed in **Table 1** relied on at least some level of training for facilitators of palliative interventions.^{8,9,11,15} One pretest/posttest design study even validated an interdisciplinary instructional seminar for nonphysician heart failure providers on heart failure treatment guidelines and effective communication techniques.⁶⁶ As with other skill sets, providers need to develop comfort with communication of

difficult content. Given the shortage of palliative care providers in the United States, 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.³²

Device-related, Team-based Palliative Care

Evaluation for potential long-term MCS represents a decision point at which a formal palliative care consultation should be considered, if circumstances allow. Guidelines recommend palliative care consultation as part of a multidisciplinary approach⁵ to all patients being considered for MCS or cardiac transplantation at an experienced center.⁴ Although MCS can offer extra years of life to a patient with terminal heart failure, it also creates new self-care⁶⁷ and financial burdens⁶⁸; necessitates a strong infrastructure of provider and caregiver support; and imparts high risk for adverse events such as stroke, recurrent gastrointestinal bleed, chronic infection, and pump failure, all of which can seriously affect quality of life.⁶⁹ Several reviews have helped to establish a consensus opinion regarding the importance of team-based care of patients with MCS before, during, and after device implantation.^{70,71}

During the index admission for MCS, experts have advocated a much more comprehensive advance care planning intervention. This intervention has been referred to as preparedness planning, and takes into account multiple MCS-specific factors that are not addressed in traditional advance directives (**Table 4**). Preparedness planning also requires open communication to establish realistic expectations and address difficult topics, such as triggers for device withdrawal.⁷² In 1 single-center study, using a multidisciplinary approach, length of stay was decreased, and costs and 30-day readmissions were reduced,⁷³ but larger controlled trials are needed to establish efficacy and patient satisfaction.

The complexities of living with MCS necessitate continued team-based care after discharge. Adjusting to new limitations, fear of device malfunction, and conflicting feelings of hope and uncertainty for the future all created great psychosocial stress for patients,⁷⁴ and were associated with posttraumatic stress disorder in caregivers.⁷⁵ Successful models of outpatient, community-based care of patients with MCS rely on significant contributions from multiple team members, as well as dedication to adherence from patients and caregivers.⁷⁶ In addition, device deactivation at end of life for patients with MCS is often necessary

Table 4
Common differences between traditional advance directives and preparedness plans in patients receiving left ventricular assist devices (LVADs) as destination therapy

Measure to Be Considered	Advance Directive	Preparedness Plan
Antibiotics: long-term role	+	++
Artificial nutrition	+	++
Blood transfusions	+	++
Goals and expectations	–	++
Hemodialysis	+	++
Hydration	+	++
Intracranial hemorrhage	–	++
LVAD failure	–	++
LVAD infection	–	++
Organ donation	++	++
Mechanical ventilation	++	++
Postoperative plans for rehabilitation	–	++
Power of attorney appointed	++	++
Psychosocial assessment	–	++
Review of perioperative morbidity and mortality	–	++
Social dynamics reviewed	–	++
Spiritual and/or religious preferences	++	++
Stroke	–	++

Notation: –, not generally found in document; +, may be found in document; ++, often found in document.

Data from Swetz KM, Freeman MR, AbouEzzedine OF, et al. Palliative medicine consultation for preparedness planning in patients receiving left ventricular assist devices as destination therapy. *Mayo Clin Proc* 2011;86(6):495.

to allow death. Navigating this ethically complex and challenging issue with patients calls for assistance and support from palliative care specialists.⁷⁷

GAPS IN KNOWLEDGE: FUTURE DIRECTIONS

Although extensive expert opinion and consensus has been published regarding the importance of a team-based approach to palliative care in heart failure, prospective studies are lacking. Important gaps include the feasibility and effectiveness of using non-palliative care specialists as purveyors of primary palliative care, optimal components of comprehensive palliative interventions, and long-term outcomes associated with early and iterative advance care planning. The greatest challenge is less tangible: the culture must be changed such that all providers of health care services embrace palliative care, not as terminal or comfort care of dying patients but as supportive, holistic care of all patients. Those who treat patients with heart failure must take up the cause of treating not just the disease but the person with the disease.

To that end, the same team-based approach that we believe can optimize outcomes for patients with

heart failure should be applied to optimizing delivery of palliative heart failure care. In line with the concept of a medical home that provides and coordinates continuous care throughout the disease span for patients with heart failure, many successful trials, pilots, and single-center programs used interdisciplinary conferences that met regularly to discuss their patient cohort.^{8–10,78} This team-based conference model allows (1) a healthy exchange of ideas and reciprocal learning among professionals, (2) prioritization of competing treatment preferences based on the preferences that most benefit patients, (3) coordination of services to minimize redundancy, (4) mutability of individualized treatment plans as the disease progresses, and (5) streamlined communication between patients and the team to maximize understanding and trust.

Continuity of care in a heart failure medical home is not just a temporal concept across the patient's lifespan but also an interdisciplinary one across various specialty providers of holistic health care. The hierarchy of the heart failure medical home would have stability, in that appointed team liaisons would consistently provide a reliable interface between team and patient, and fluidity, in that central/primary and peripheral/consultative

patient care roles might vary by individual patient and change over time. We contend that the concept of an annual heart failure review, put forth previously in a statement from the AHA on decision making in heart failure,³⁸ might offer the ideal setting for periodic reassessment of patients' goals, values, and preferences as they change, whether it occurs in the office of a primary care doctor, heart failure cardiologist, or palliative care specialist.

SUMMARY

Palliative care in heart failure should no longer be thought of as comfort administered to dying patients; it should instead refer to team-based, holistic, supportive care of patients across the span of heart failure progression, beginning early in the disease process, intensifying at patients' end of life, and extending into the bereavement phase for their caregivers. It must iteratively address patients' values, goals, and preferences regarding treatment, quality of life, and survival. As such, the team will change and grow in a manner reflective of changes and growth in patients during the span of the disease. A broad range of providers must be trained in communication techniques and interdisciplinary collaboration skills to ensure their confidence and ability in approaching the whole patient. How best to deliver such care will require further research to establish cost-effective, feasible, and sustainable models of multidisciplinary heart failure care.

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