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## Team-Based Palliative and End-of-Life Care for Heart Failure

Timothy J. Fendler, MD<sup>1</sup>, Keith M. Swetz, MD, MA<sup>2</sup>, and Larry A. Allen, MD, MHS<sup>3</sup>

Timothy J. Fendler: swetz.keith@mayo.edu; Larry A. Allen: larry.allen@ucdenver.edu

<sup>1</sup>Saint Luke's Mid America Heart Institute, University of Missouri-Kansas City School of Medicine, Kansas City, Missouri

<sup>2</sup>Section of Palliative Medicine, Division of General Internal Medicine, Department of Medicine, Mayo Clinic, Rochester, Minnesota

<sup>3</sup>Division of Cardiology, Department of Medicine, University of Colorado School of Medicine, Aurora, Colorado

### SYNOPSIS

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. Therefore, we will comment on the current state of multidisciplinary care for such patients, explore evidence supporting a team-based approach to palliative and end-of-life care for patients with heart failure, and identify high-priority areas for research. 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, sometimes transitioning leadership from primary care to cardiology to palliative care.

### Keywords

Palliative care; Hospice care; Heart failure; Interdisciplinary communication; Patient care team; Comprehensive health care

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Corresponding Author: Timothy J. Fendler, 4401 Wornall Road, SLNI, CV Research, Suite 5603, Kansas City, MO 64111, fendlert@umkc.edu.

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### DISCLOSURES

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## INTRODUCTION

Among an estimated 5.1 million Americans with heart failure, the prevalence of advanced disease is 5 to 10%.<sup>1</sup> 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 due primarily to improved survival, while costs are projected to balloon from \$32 billion in 2013 to \$70 billion in 2030.<sup>1</sup> With increased emphasis on patient-centered care,<sup>2,3</sup> and in the face of unsustainable health care expenditures, there has been increasing attention placed on palliative and end-of-life care for patients with advanced heart failure.<sup>4</sup>

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.<sup>4</sup> Medicare's 2014 update to National Coverage Determination for mechanical circulatory support (MCS) even mandates a "multidisciplinary team" that includes a "palliative care specialist."<sup>5</sup> However, there is limited evidence to guide the content, implementation, and integration of palliative care interventions into existing heart failure disease management. Therefore, we will explore evidence supporting a team-based approach to palliative and end-of-life care for patients with heart failure, comment on the current state of multidisciplinary care for such patients, identify knowledge gaps, and discuss opportunities for future study.

### **"Team-Based" Care Implies a Multidisciplinary Approach**

Ample evidence exists supporting team-based care for patients with heart failure to decrease rehospitalizations and improve survival through education, structured follow-up, patient self-care, and careplan adherence.<sup>6,7</sup> However, few pilot studies have assessed the efficacy of multidisciplinary palliative care in improving outcomes germane 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. 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 the Name? "Palliative Care" is "Supportive Care"**

Historically, the term "palliative care" had been conflated 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 (Figure 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.<sup>20–23</sup> 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.

## **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.<sup>24,25</sup> Due to a dearth of evidence in 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.<sup>4,23</sup> However, despite similar or worse symptom burden, depression, and spiritual well-being for patients with advanced heart failure compared to those with advanced cancer,<sup>26</sup> heart failure has been associated with less access to palliative care and use of hospice, and higher rates of resource utilization and aggressive treatment.<sup>27,28</sup> This disparity highlights a need to better inform providers and patients of options for progressive and end-of-life heart failure.

Some 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.<sup>23</sup> Even so, evidence-based cancer care provides a foundation from which integrated palliative heart failure care can expand. For example, the ENABLE CHF-PC trial (Table 1) evolved from a series of successful palliative cancer care trials, and its recently published feasibility pilot results were promising.<sup>11</sup>

## **THE LOGISTICS OF TEAM-BASED PALLIATIVE CARE IN HEART FAILURE**

### **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 (Figure 2). 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.<sup>29</sup> Interdisciplinary care increases prescriptions for symptom control medication and decreases hospitalizations, length of stay and cost of care.<sup>7</sup> 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 (Figure 3).

This partnership can be challenging due to 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.<sup>30,31</sup> Palliative care should not be seen as "giving up" or "accepting death," but as one component of a collaborative, supportive approach to patient care (Figure 4).

However, a national shortage of palliative care specialists exists along with the proliferation of heart failure in older patients with multimorbidity.<sup>33</sup> 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.<sup>34</sup>

### Who Takes the Lead?

The role of an appointed clinical team leader, or liaison, is important in coordination of multidisciplinary care.<sup>23</sup> 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.<sup>8,12,35–37</sup> 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.<sup>38</sup>

Referrals among patients with advanced heart failure are most commonly for allied health services and psychosocial support. Figure 2 includes all team members mentioned previously in controlled trials, pilots or reviews of multi-disciplinary heart failure palliative care programs. Data from two 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. Fortunately, while the multidisciplinary palliative care team should adopt a holistic, patient-centered perspective, not all patients require all services.

### 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 iterative intervention is preferred. This stems from the concept that “difficult discussions now simplify difficult decisions later.”<sup>40</sup> Nearly 20 years ago, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) 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.<sup>41</sup> 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.<sup>42</sup> The need for repetition stems from the unpredictable nature of heart failure progression,<sup>43</sup> the ensuing difficulty with accurate risk assignment and prognosis,<sup>40</sup> and the evolution of individual patient preferences over time.<sup>44</sup> Ultimately, these difficulties might be attenuated by earlier integration of supportive care that fosters improved patients' understanding and acceptance of their disease and mortality.<sup>45</sup> 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.<sup>46,47</sup> 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.<sup>48</sup> 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.<sup>49</sup> Early palliative heart failure interventions have been studied prospectively in outpatient<sup>9,15</sup> and post-admission settings<sup>13,14,50</sup> as well as among admitted patients undergoing their first heart transplant evaluation,<sup>16</sup> with varying results (Table 1).

Unfortunately, late referrals to palliative care are common. One single-center retrospective chart review of 132 advanced heart failure patients receiving inpatient palliative care consults over 5 years reported an actual median time from consultation to death of only 21 days.<sup>45</sup> 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.<sup>51</sup>

A number of 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, healthcare utilization, and cost (Table 1), though rate of death at home was higher in each of these studies.<sup>8,10,12,17</sup> 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.<sup>52</sup> The challenges of community-based rural palliative care have been reviewed<sup>53</sup> and tested in a feasibility pilot.<sup>11</sup> 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.<sup>53</sup> 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.

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 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.<sup>54,55</sup>

## 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.<sup>22,23,56,57</sup> 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.

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.<sup>58</sup> For example, depression is common and associated with worse outcomes in advanced disease.<sup>59</sup> However, anti-depressants had disappointing results when used in this setting.<sup>60</sup> 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, as well as exercise and cognitive behavioral therapy.<sup>61</sup> 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,<sup>62</sup> while a number of studies have shown dyspnea improvement through exercise and respiratory muscle training.<sup>56</sup> 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.<sup>63</sup>

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.<sup>64</sup> 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.<sup>40,65</sup> 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.<sup>66,67</sup> A number 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.<sup>8,9,11,15</sup> One pre/post-test design study even validated an interdisciplinary instructional seminar for non-physician heart failure providers on heart failure treatment guidelines and effective communication techniques.<sup>68</sup> 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.<sup>34</sup>

### **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. In fact, guidelines recommend palliative care consultation as part of a multidisciplinary approach<sup>5</sup> to all patients being considered for MCS or cardiac transplantation at an experienced center.<sup>4</sup> While MCS can offer extra years of life to a patient with terminal heart failure, it also creates new self-care<sup>69</sup> and financial burdens,<sup>70</sup> 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.<sup>71</sup> A number of reviews have helped to establish a consensus opinion regarding the importance of team-based care of the MCS patient before, during, and after device implantation.<sup>72,73</sup>

During the index admission for MCS, experts have advocated for a much more comprehensive advance care planning intervention. This has been referred to as “preparedness planning,” and takes into account multiple MCS-specific factors that are not addressed in traditional advanced directives (Table 4). Preparedness planning also requires open communication to establish realistic expectations and address difficult topics such as triggers for device withdrawal.<sup>75</sup> In one single-center study, using a multidisciplinary approach, length of stay was decreased, and costs and 30-day readmissions were reduced,<sup>76</sup> 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,<sup>77</sup> and were associated with post-traumatic stress disorder in caregivers.<sup>78</sup> Successful models of outpatient, community-based care of MCS patients rely on significant contributions from multiple team members, as well as dedication to adherence from patients and caregivers.<sup>79</sup> Finally, device deactivation at end-of-life for patients with MCS is often necessary to allow death. Navigating this ethically complex and challenging issue with patients calls for assistance and support from palliative care specialists.<sup>80</sup>

### **GAPS IN KNOWLEDGE; FUTURE DIRECTIONS**

Although a fair amount of 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 utilizing 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: we must change the culture such that all providers of healthcare services embrace palliative care, not as terminal or comfort care of the dying patient, 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 inter-disciplinary conferences that met regularly to discuss their patient cohort.<sup>8–10,81</sup> This team-based conference model allows for: 1) a healthy exchange of ideas and reciprocal learning among professionals, 2) prioritization of competing treatment preferences based on that which most benefits 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 would not just be a temporal concept across the patient's lifespan, but also an interdisciplinary one across various specialty providers of holistic healthcare. The hierarchy of the heart failure medical home would have both 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 would 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,<sup>40</sup> might offer the ideal setting for periodic re-assessment 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 intra-disciplinary 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 multi-disciplinary heart failure care.

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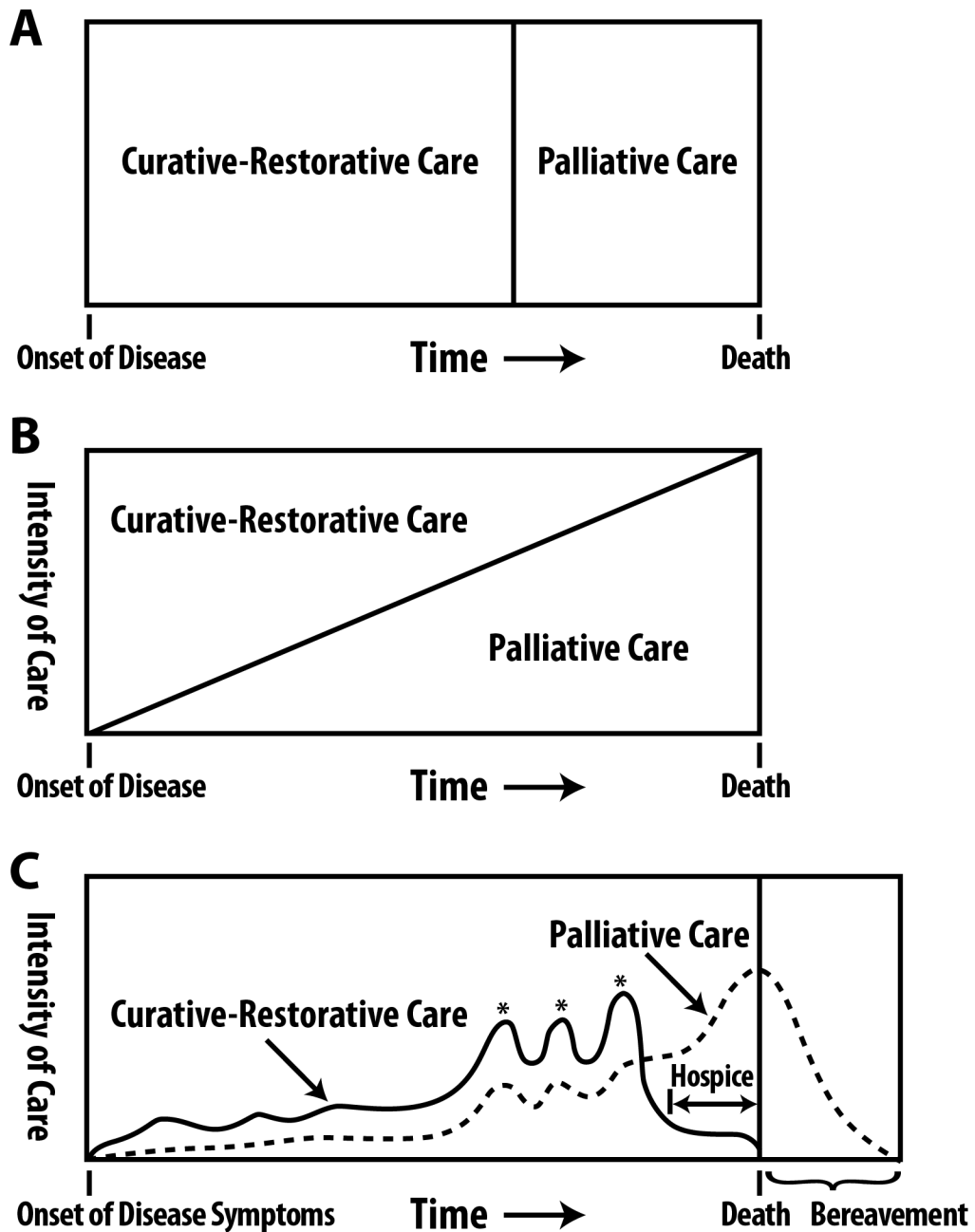
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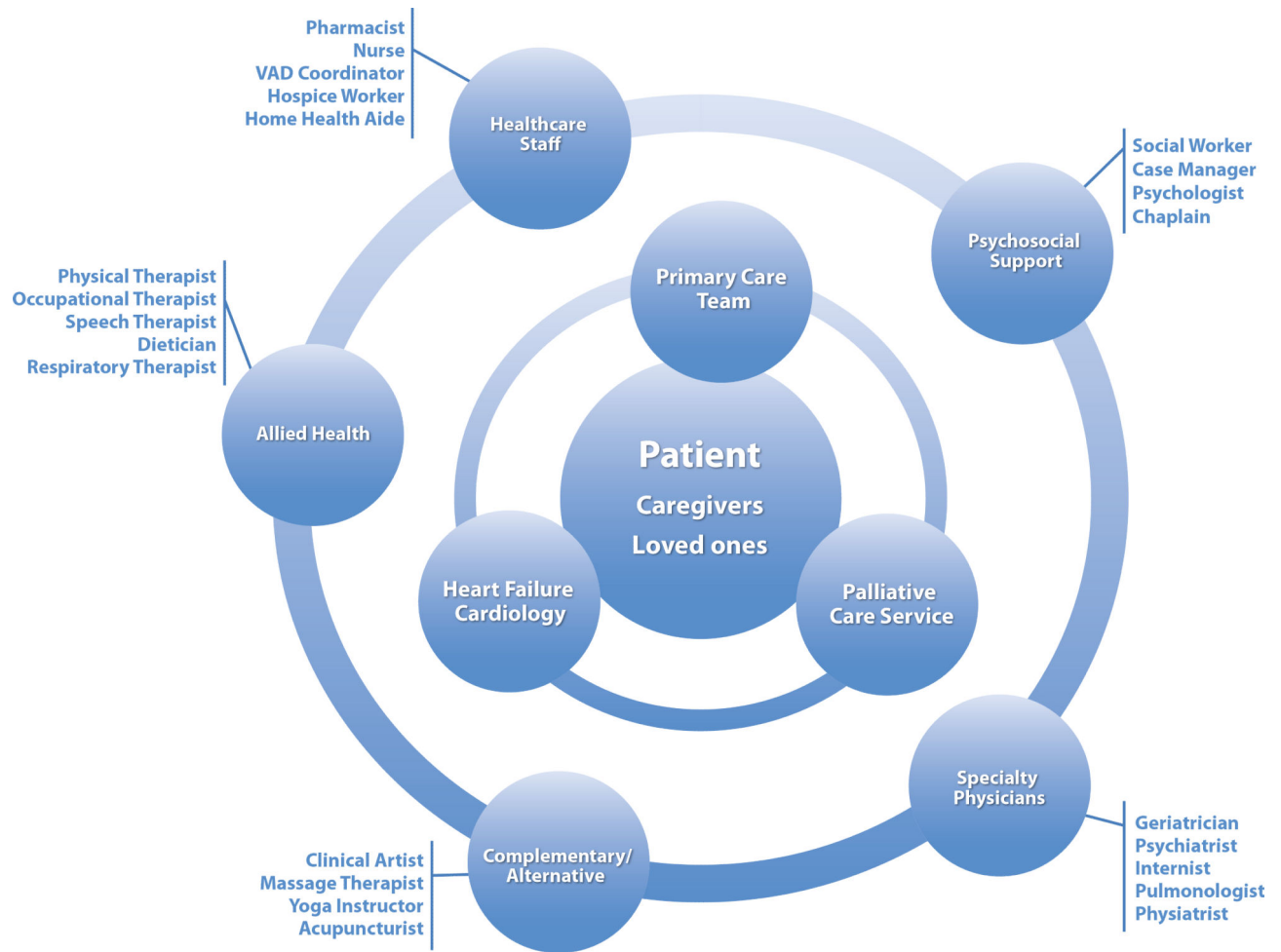
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**KEY POINTS**

1. Palliative care is one component of holistic, supportive care of the patient throughout the course of disease, intensified at end-of-life and extending into the bereavement phase for their caregivers.
2. Team-based palliative care for heart failure implies a multidisciplinary approach, including primary care, cardiology, and palliative care, each represented by various providers (e.g. physicians, advanced practitioners, nurses, case managers, and pharmacists).
3. 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.



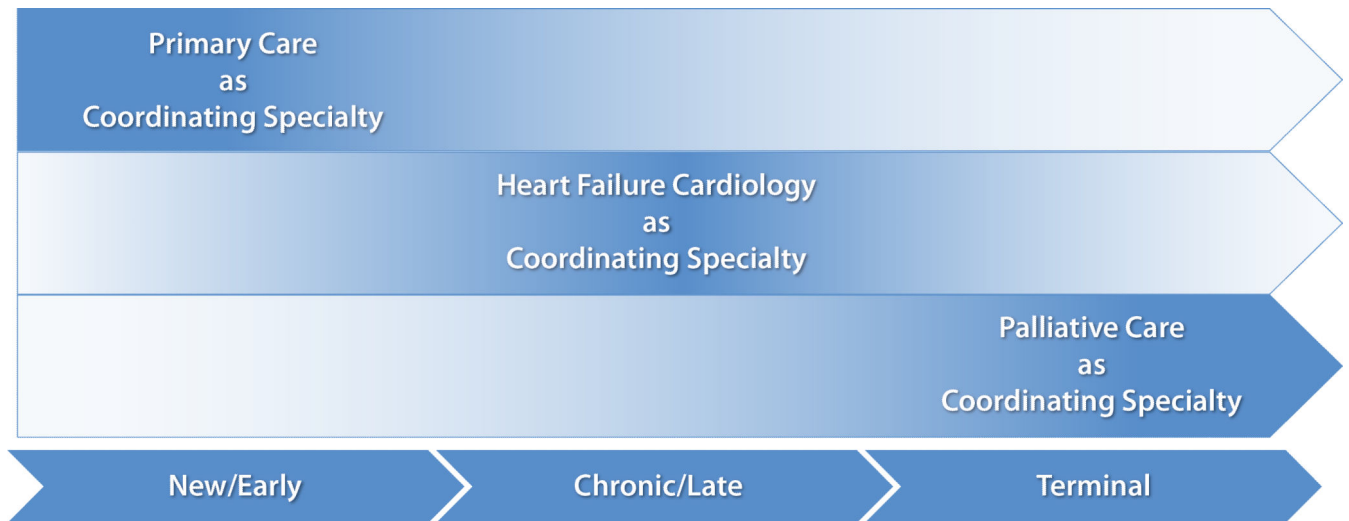
**Figure 1. Evolving models of integrating curative-restorative care with palliative care**  
 A) Previously, curative-restorative care was seen as an “all or none” phenomenon, and palliative care was only initiated once curative-restorative care options were exhausted. B) Palliative care principles were incorporated concurrently with curative-restorative care models, but as less curative-restorative care options existed palliative care was intensified. C) This model accounts for the fact that care trajectories rarely change at a constant, linear slope; rather, care intensity is augmented by punctuated exacerbations of illness over time. 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.* Apr 15 2008;177(8):912–927; with permission.



**Figure 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, while supported by layers of clinicians and providers whose support can vary over time. The core clinical team is comprised 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 best as able.





**Figure 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 would likely differ for all patients, according to their individual trajectory and needs.

## **Palliative Care vs. Hospice**

### 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 (i.e., 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

**Figure 4. Palliative care vs. hospice**

Adapted from Swetz KM, Kamal AH. In the clinic. Palliative care. *Ann Intern Med.* Feb 7 2012;156(3):ITC2-2-ITC2-16; with permission.

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 Members (Team Liaison in bold)	Outcomes/Results	Limitations
Aiken 2006 <sup>8</sup>	Prospective, Single Center, Randomized Controlled Trial (Blinded Enrollers & Interviewers)	Home-based COPD or NYHA IIIb/IV HF, prognosis n = 190 (129 HF) 100 case (67 HF) 90 control (62 HF)	<ul style="list-style-type: none"> <li>Providers had chronic disease &amp; EOLC experience</li> <li>2 week workshop</li> <li>Monthly lectures by content experts</li> <li>Communication training with validated modules</li> </ul>	<ul style="list-style-type: none"> <li>Disease Awareness</li> <li>Symptom Management</li> <li>Self-care</li> <li>Knowledge of resources</li> <li>EOLC/ACP</li> <li>Physical/Mental Functioning</li> <li>Medical Service Utilization</li> </ul>	<p><b>PhoenixCare Model</b></p> <ul style="list-style-type: none"> <li>1–6 clinic/home/phone visits/month</li> <li>Scheduled meetings</li> <li>Referrals prn</li> <li>Protocol customized to disease/morbidity</li> <li>Parallel with usual, curative treatment</li> </ul>		<p><b>RN Case Manager</b> Medical Director SW Chaplain PCP Family Community Agencies</p>	<p>Among cases:</p> <ul style="list-style-type: none"> <li>Better self-care, resource use, legal documents, vitality, physical function, self-rated health</li> <li>Lower symptom distress</li> <li>No difference in ED visits</li> </ul>	<ul style="list-style-type: none"> <li>Single center</li> <li>Did not achieve planned enrollment</li> <li>High early death rate</li> <li>Non-HF enrollees</li> </ul>
Bekelman 2014 <sup>9</sup>	Prospective, Single Center, Mixed-Methods Feasibility Pilot	Outpatient HF (82% NYHA II/III) n = 17	<ul style="list-style-type: none"> <li>2 day workshop</li> <li>algorithm for symptom management</li> <li>manualized counseling protocol</li> </ul>	<ul style="list-style-type: none"> <li>Symptom Management</li> <li>Illness Adjustment</li> <li>Depression</li> </ul>	<p><b>CASA</b> (Collaborative Care to Alleviate Symptoms &amp; Adjust to Illness)</p> <ul style="list-style-type: none"> <li>6–8 RN-led phone/clinic visits for symptom control</li> <li>5 SW/Psych-led phone visits for adjustment/mood</li> <li>Weekly meetings, recs relayed to PCP</li> </ul>	<ul style="list-style-type: none"> <li>Use of “collaborative care model,” validated in CAD patients</li> </ul>	<p><b>PCP</b> RN SW Psychologist Cardiologist PCS</p>	<ul style="list-style-type: none"> <li>1 withdrawal</li> <li>&lt;5% missed data</li> <li>85% of recs implemented</li> <li>All depression treated</li> <li>Patients gave (+) feedback, requested more program flexibility</li> </ul>	<ul style="list-style-type: none"> <li>Single center</li> <li>Small cohort</li> <li>No control</li> <li>Protocol changed throughout study</li> <li>Limited domains</li> </ul>
Branstrom 2014 <sup>10</sup> (Sweden)	Prospective, Single Center, Randomized Controlled Trial	Home-based NYHA III/IV HF n = 72 36 case 36 control	--	<ul style="list-style-type: none"> <li>Disease Education</li> <li>ACP</li> <li>Symptom Management</li> <li>Communication</li> <li>Goals of Care</li> </ul>	<p><b>PREFER</b> (Palliative advanced home care and heart Failure care)</p> <ul style="list-style-type: none"> <li>Parallel with usual curative treatment</li> <li>Total home care unit, comprehensive services Mon–Fri</li> </ul>	<ul style="list-style-type: none"> <li>Based on “The 6 S<sup>8</sup>” PC model (Self-image, Self-determination, Social interaction, Symptom control, Synthesis, Surrender)</li> </ul>	<p>PCS HF Cardiologist Cardiologist HF RN PC RN PT/OT</p>	<p>Among cases:</p> <ul style="list-style-type: none"> <li>Improved QoL, total symptom, &amp; self-efficacy domains of KCCQ</li> <li>Only nausea improved (of 9 symptoms)</li> </ul>	<ul style="list-style-type: none"> <li>Single center</li> <li>Small cohort</li> <li>Non-blinded</li> <li>Patients knew providers before enrollment</li> </ul>

Study	Study Type	Setting/Subject	Provider Training	Intervention Domains	Intervention Components	Intervention Development	Team Members (Team Liaison in bold)	Outcomes/Results	Limitations
Dionne-Odom <sup>11</sup> 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"> <li>24 or more hours of training</li> <li>Periodic audits</li> <li>All providers from previous ENABLE studies</li> </ul>	<ul style="list-style-type: none"> <li>Problem-solving</li> <li>Symptom Management</li> <li>Self-care</li> <li>Communication</li> <li>Care Coordination</li> <li>Community Resource Use</li> <li>Decision-making/ACP</li> <li>Life Review</li> <li>Creating a Legacy</li> </ul>	<ul style="list-style-type: none"> <li>Phone/home visits for diuretics, prn</li> <li>Resume care with PCP at 6 months with individual care plan</li> <li>Bi-monthly meetings</li> </ul>	<ul style="list-style-type: none"> <li>Relied on data from Swedish palliative registry</li> <li>Care structure per ESC guidelines</li> </ul>	<p><b>AP PC RN Coach</b> Caregiver PCP Internist Cardiologist</p>	<ul style="list-style-type: none"> <li>NYHA class improved more often</li> <li>15 (vs. 53) hospitalizations</li> <li>Nearly 5x more RN visits</li> </ul>	<ul style="list-style-type: none"> <li>Non-US study</li> </ul>
Enguidanos 2005 <sup>12</sup>	Prospective, Controlled Trial	Home-based HF, COPD, Cancer prognosis n = 298 (82 HF) 159 case (31 HF) 139 control (51 HF)	<ul style="list-style-type: none"> <li>providers had expertise treating symptoms and biopsychosocial intervention</li> </ul>	<ul style="list-style-type: none"> <li>Decision-making/ACP</li> <li>Communication</li> <li>Continuity of Care</li> <li>Psychosocial Support</li> <li>Spiritual Support</li> <li>Symptom Control</li> <li>Comfort Care</li> <li>Healthcare Team Support</li> </ul>	<p><b>ENABLE</b>(Educate, Nurture, Advise, Before Life Ends);<b>PC-CHF</b></p> <ul style="list-style-type: none"> <li>In-person team PC assessment</li> <li>AP PC RN coached phone visits</li> <li>6 with patients</li> <li>3 with caregivers</li> <li><i>Charting Your Course</i> guidebook</li> <li>Monthly follow-up calls for reinforcement</li> </ul>	<ul style="list-style-type: none"> <li>Based on cancer ENABLE studies, translated to HF</li> <li>External clinician expert advisory (Cardiology, IM)</li> </ul>	<p>Among cases:</p> <ul style="list-style-type: none"> <li>No improved HF severity</li> <li>More home deaths (less difference in HF)</li> <li>Less days on service</li> <li>52% decrease in cost of HF care</li> </ul>	<ul style="list-style-type: none"> <li>Non-randomized</li> <li>May only be generalizable to managed care organizations</li> <li>Non-HF enrollees</li> </ul>	
Evangelista 2012 <sup>13</sup>	Prospective, Single Center, Cohort Study	Outpatient	--	ACP	<ul style="list-style-type: none"> <li>Outpatient PCS consultation 1</li> </ul>	--	PCS or PC NP	<ul style="list-style-type: none"> <li>AD completers had better</li> </ul>	<ul style="list-style-type: none"> <li>Single center</li> <li>Small Cohort</li> </ul>

Study	Study Type	Setting/Subject	Provider Training	Intervention Domains	Intervention Components	Intervention Development	Team Members (Team Liaison in bold)	Outcomes/Results	Limitations
Evangelista 2014 <sup>14</sup>	Prospective, Single Center, Cohort Study	NYHA II/II HF, hospitalized NYHA II/II HF, hospitalized NYHA II/II HF, hospitalized n = 36	--	<ul style="list-style-type: none"> <li>Symptom Management</li> <li>Illness Understanding</li> <li>Goals of Care</li> <li>Decision-making</li> <li>Care Coordination</li> </ul>	<ul style="list-style-type: none"> <li>week after discharge</li> <li>Phone interviews at baseline, 3 months</li> </ul>			<ul style="list-style-type: none"> <li>perceived health</li> <li>Greatly improved AD knowledge</li> <li>AD completion only increased 28% to 42%</li> </ul>	<ul style="list-style-type: none"> <li>No control</li> <li>Limited domains</li> </ul>
Schellinger 2011 <sup>15</sup>	Prospective, Multi-site/Single System Implementation Study	Outpatient HF, referred for ACP n = 1894 602 completed ACP 1292 did not	<ul style="list-style-type: none"> <li>Certified, 26-hour training in skills for communication</li> <li>Un-quantified 'staff time' to educate system employees</li> </ul>	<ul style="list-style-type: none"> <li>ACP</li> </ul>	<ul style="list-style-type: none"> <li>PC program brochure &amp; explanation letter at discharge</li> <li>Outpatient PCS consult 1 week after discharge</li> <li>Phone interviews at baseline, 3 months</li> <li>Ongoing PC contact encouraged</li> </ul>	--	PCS or PC NP	<ul style="list-style-type: none"> <li>Significantly better control, activation, &amp; symptom burden with &gt; 1 PC visit</li> </ul>	<ul style="list-style-type: none"> <li>Single center</li> <li>Small Cohort</li> <li>No control</li> </ul>
			<ul style="list-style-type: none"> <li>Certified, 26-hour training in skills for communication</li> <li>Un-quantified 'staff time' to educate system employees</li> </ul>	<ul style="list-style-type: none"> <li>ACP</li> </ul>	<ul style="list-style-type: none"> <li>Call center to track referrals, schedule interviews</li> <li>In-depth ACP talk with patient &amp; proxy</li> <li>documentation of goals, values, and preferences in medical record</li> </ul>	<ul style="list-style-type: none"> <li>Based on "Respecting Choices" program, validated in multiple RCTs</li> </ul>	<b>Certified Facilitator</b> Caregiver/Proxy RN SW Referral Coordinator	<ul style="list-style-type: none"> <li>Completers were older &amp; referred more from clinics or home care</li> <li>Completers had higher rates of good ACP documentation &amp; choosing hospice</li> <li>No difference in 60-day admission</li> </ul>	<ul style="list-style-type: none"> <li>Non-randomized</li> <li>Limited domains</li> <li>May only be generalizable to systems using "Respecting Choices."</li> </ul>

Study	Study Type	Setting/Subject	Provider Training	Intervention Domains	Intervention Components	Intervention Development	Team Members (Team Liaison in bold)	Outcomes/Results	Limitations
Schwartz 2012 <sup>16</sup>	Retrospective, Single Center Descriptive Study	Inpatient NYHA IV HF, referred for transplant & early PC n = 20	--	<ul style="list-style-type: none"> <li>Symptom Management</li> <li>Goals of Therapy</li> <li>ACP</li> <li>Hospice Referral</li> <li>EOLC</li> </ul>	<ul style="list-style-type: none"> <li>Chart review</li> <li>Interviews re: impact of PC on patients, caregivers, providers</li> <li>Non-standardized tool (1 PCS &amp; 1 HF cardiologist scored impact of PC)</li> </ul>	--	PCS HF Cardiologist NP SW Psychiatrist Hospital Chaplain	<ul style="list-style-type: none"> <li>Reduced pain</li> <li>More holistic care (spiritual, psychosocial)</li> <li>Increased patient clarity, continuity</li> <li>30% with ADs completed</li> <li>Medium-to-large impact scores</li> </ul>	<ul style="list-style-type: none"> <li>Single center</li> <li>Small cohort</li> <li>Retrospective</li> <li>No control</li> <li>Non-standardized assessment tool</li> </ul>
Wong 2013 <sup>17</sup> (China)	Retrospective, Single Center Descriptive Study	Home-based NYHA III/IV HF n = 44	--	<ul style="list-style-type: none"> <li>Resource Utilization</li> </ul>	<ul style="list-style-type: none"> <li>Scheduled, hospital-based HF visits</li> <li>Home visits, prn</li> </ul>	<ul style="list-style-type: none"> <li>Data from single center registry of all HF patients recruited to PC</li> </ul>	MD RN Counselor	<ul style="list-style-type: none"> <li>68% died at 2 yr</li> <li>Mean time to death 5.5 months</li> <li>Reduced HF/all-cause admission</li> </ul>	<ul style="list-style-type: none"> <li>Single center</li> <li>Small cohort</li> <li>Retrospective</li> <li>No control</li> <li>Non-US study</li> <li>Limited domains</li> </ul>

COPD - chronic obstructive pulmonary disease; HF - heart failure; NYHA - New York Heart Association; PC - palliative care; ACP - advance care planning; EOLC - end of life communication; RN - registered nurse; Psych - psychologist; MD - medical doctor; NP - nurse practitioner; SW - social work; PCP - primary care physician; AP - advanced practice; PCS - palliative care specialist; CAD - coronary artery disease; ESC - European Society of Cardiology; IM - internal medicine; RCT - randomized controlled trial; ED - emergency department; PT - physical therapy; OT - occupational therapy; KCCQ - Kansas City Cardiomyopathy Questionnaire; AD - advance directive; prn - as needed; QoL - quality of life; yr - year

Data from Refs 8–17.

**Table 2**

Services accessed in two team-based palliative heart failure programs

	<b>Bekelman 2011<sup>39</sup></b>	<b>Evangelista 2014<sup>14</sup></b>
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%*
Physical & Occupational Therapy/Rehabilitation	20%	66%
Psychiatry	8%	55%
Psychology/Counseling	4%	--
Social Work	26%	69%
Support Groups	--	31%

\* Mandatory referral

Data from Bekelman DB, Nowels CT, Allen LA, Shakar S, Kutner JS, Matlock DD. Outpatient palliative care for chronic heart failure: a case series. *J Palliat Med.* Jul 2011;14(7):815–821; and Evangelista LS, Liao S, Motie M, De Michelis N, Lombardo D. 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.* Apr 2014;13(2):116–123.

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

DOMAINS	EARLY PHASE	LATE PHASE	TEAM MEMBERS
Physical Well-being	Life-prolonging Heart Failure Therapies (Medications, Interventional Procedures)		Physician, Advanced Practice Provider (APP)*, Pharmacist
	Symptom Management (Pain, Dyspnea, Fatigue, Insomnia, Anorexia, Pruritus, Side Effects of Treatments/Interventions)		Physician, APP, Pain Specialist, Palliative Care Specialist (PCS), Pulmonologist, Respiratory Therapist, Pharmacist, Physical & Occupational Therapy (PT/OT)
	Complementary & Alternative Medicine (as desired by the patient)		Acupuncturist, Clinical Art Therapist, Massage Therapist, Yoga Instructor
	Exercise/Weight Control/Nutrition	Rehabilitation/Strengthening	Physiatrist, PT/OT, Nutritionist
	Community Resources (Insurance, Financial Aid, Support Groups)	Quality of Life Community Resources (Transportation, Home Care, Hospice)	ALL Team Members
Psychosocial Support		Spirituality	Chaplain
		Depression, Anxiety	Physician, APP, Psychiatrist, Psychologist, Pharmacist, Chaplain, PCS, Support Group
	Emotional Support, Coping	Loss of Control, Autonomy, Legacy Building	
	Appoint Team Liaison	Maintain Open, Trusting Relationship ("Meet patients where they are")	
Communication		Continuity of Care	
		Shared-decision Making, Assess Goals of Care	Physician, APP, Caregiver, Team Liaison, PCS, Psychologist, Psychiatrist
	Disease Understanding	Prognostic Understanding (As patient wishes to know)	
		Addressing Fears & Concerns	
Advance Care Planning	Legal (Advance directives—including living wills, appointment of alternate decision maker [health care power of attorney])	Legal (Reassess Preferences and Goals of Care Frequently)	Physician, APP, SW/CM, PCS, Caregiver
		Difficult Issues (Choosing a Place of Death; Avoiding Prolonged Suffering; Code status, Considering Hospice; De-escalation of Care; Preferences for Rehospitalization, Device Deactivation)	Physician, APP, PCS, Caregiver, Hospice
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	
	Knowledge of Potentially Life-limiting Nature of Illness		Physician, APP



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DOMAINS	EARLY PHASE	LATE PHASE	TEAM MEMBERS
Caregiver Focus	Preserve/Foster Relationships, Caregiver Agreement with/Acceptance of Patient Preferences	Prevention of Caregiver Fatigue and Burnout	Caregiver
		Avoid Leaving Financial Burdens	SW/CM, Support Group, Psychologist, Psychiatrist
		Bereavement Support	Caregiver, SW/CM Caregiver, Psychologist, Psychiatrist, SW/CM, Chaplain

\* „Advanced Practice Provider” refers to nurse practitioners or physician assistants

**Table 4**

Common differences between traditional advance directives and preparedness plans in patients receiving left ventricular assist devices 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	++	++
Post-operative 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, AbouEzzeddine OF, et al. Palliative medicine consultation for preparedness planning in patients receiving left ventricular assist devices as destination therapy. *Mayo Clin Proc.* Jun 2011;86(6):493–500.