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Integrating palliative care into routine care of patients with heart failure: models for clinical collaboration

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Abstract Heart failure (HF) affects nearly 5.7 million Americans and is described as a chronic incurable illness carrying a poor prognosis. Patients living with HF experience significant symptoms including dyspnea, pain, anxiety, fatigue, and depression. As the illness advances into later stages, symptoms become more intense and refractory to standard treatments, leading to recurrent acute-care utilization and contributing to poor quality of life. Advanced HF symptoms have been described to be as burdensome, if not more than, those in cancer populations. Yet access to and provision of palliative care (PC) for this population has been described as suboptimal. The Institute of Medicine recently called for better access to PC for seriously ill patients. Despite guidelines recommending the inclusion of PC into the multidisciplinary HF care team, there is little data offering guidance on how to best operationalize PC skills in caring for this population. This paper describes the emerging literature describing models of PC integration for HF patients and aims to identify key attributes of these care models that may help guide future multisite clinical trials to define best practices for the successful delivery of PC for patients living with advanced HF.

Keywords Palliative care · Supportive cardiology · Early palliative care · Models of care

Background

Heart failure affects nearly 5.7 million Americans and is described as a chronic incurable illness carrying a poor prognosis [1]. The symptom burden in heart failure—including dyspnea, pain, anxiety, fatigue, and depression—can equal or exceed that in cancer populations [2]. As illness progresses into later stages, symptoms become more intense and refractory to standard treatments, and lead to poor quality of life, recurrent acute-care utilization, and suffering at the end of life [3]. Given the high symptom burden, variable illness trajectory, and uncertain prognosis, patients with advanced heart failure would benefit from primary and specialty level palliative care in multiple settings including inpatient, outpatient, and at home towards the end of life, yet evidence shows that heart failure patients have suboptimal access to and provision of palliative care and hospice [4–8]. Since the 2015 Institute of Medicine mandate to improve advance care planning and increase access to palliative care for all seriously ill patients [9, 10], there have been increasing calls for evidence-based guidance to improve advance care planning and integrate palliative care into the routine care of patients with advanced heart failure [11–13].

Leading professional societies have advocated for improved end-of-life care and access to palliative care for patients with advanced heart failure. The American College of

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Cardiology, American Heart Association, Heart Failure Society of America, and the International Society for Heart and Lung Transplant have published clinical guidelines related to the following: (1) intravenous inotrope therapy to palliate symptoms, (2) awareness of and continuing guideline-based medical therapy to palliate symptoms, (3) the use of intravenous diuretics to palliate symptoms, (4) referral to heart failure specialty clinic, (5) communication about deactivation of implantable defibrillators, (6) improved shared decision-making, and (7) improved access to hospice and palliative care for patients with advanced heart failure [14–20].

In addition, the Centers for Medicare & Medicaid Services and the Joint Commission now require all centers implanting left ventricular assist devices as destination therapy to include a palliative care clinician with experience and knowledge about advanced therapies as a member of the evaluating implant team [21, 22]. The establishment of this unique requirement (at the time of this review, no similar mandates for collaboration with specialty level palliative care exist for other disease states or patient populations) is based on emerging evidence of the unique palliative care needs of patients receiving mechanical circulatory support [23] and the benefits of palliative care consultation for these patients and their families [24]. Left ventricular assist devices have been shown to both improve quality of life and to prolong survival [25–27]. Because of the shortage of donor hearts, the majority of heart transplant recipients now receive mechanical circulatory support while awaiting transplant [28]. Palliative care issues specific to mechanical circulatory support include the unpredictable clinical trajectory and device deactivation at the end of life. The role of specialty level palliative care can include assessing patients' and families' understanding of the purpose and limitations of the device, exploring whether mechanical circulatory support aligns with the patient's goals, and supporting advance care planning and shared decision-making prior to implantation [29].

Despite professional guidelines and regulatory mandates for the inclusion of palliative care in the care of patients with advanced heart failure, there is little data offering guidance on how to best operationalize palliative care for this population. The aim of this paper is twofold: (1) to describe existing models of palliative care integration for heart failure patients from published literature and (2) to identify successful attributes of these care models to inform future palliative care integrative models of care for patients living with advancing heart failure.

Methods

The authors used PubMed and clinicaltrials.gov to search for relevant articles, with the goal to provide an overview of existing models of care, but not meant to be an exhaustive search. Search words included the following: "palliative care," "supportive cardiology," and "heart failure." Nine hundred sixty-three articles were retrieved from this search. Abstracts were reviewed and papers describing models of care delivery were included for full review. References from fully reviewed articles were used to retrieve additionally relevant literature. Articles describing models of care with outcome data were of particular interest. Descriptive articles were not reviewed in detail. Articles were separated into two groups: models describing general advanced heart failure populations with and without mechanical circulatory support.

Results

There is a limited but growing evidence base describing palliative care implementation for patients living with advancing heart failure. Selected models of palliative care integration are outlined in Table 1. All clinical innovations identified address core palliative care domains including communication about goals of care, shared decision-making, advance care planning [30–32, 34], symptom management [31, 32, 36], and coordination of complex care [30, 35]. Care are provided in a range of settings (inpatient, outpatient, and at home) and by various members of the interdisciplinary palliative care team.

Inpatient palliative care consultation

Sidebottom et al. described a brief and interdisciplinary specialty level consultation by a multidisciplinary team including a medical doctor, advanced practice nurses, social workers, and chaplain, for inpatients with advanced heart failure. This led to improved symptom control at 1- and 3-month follow-up [30]. Of note, the majority of patients did not have any follow-up palliative care beyond the initial consultation suggesting that a brief palliative care intervention may afford long-term benefits. Palliative care domains addressed included pain management and advance care planning [38]. Similarly, Swetz and his colleagues have shown that palliative care consultation for preparedness planning prior to implantation of a left ventricular assist device improved goals of care conversations and increased completion of advance care planning [24].

Telemedicine and home-based palliative care

Programs that offer continuity of care across multiple settings have also been shown to improve outcomes [33, 34]. The CASA (Collaborative Care to Alleviate Symptoms and Adjust to illness) trial [33] was a telephone-supported intervention that bridged acute care and community settings for rural or frail patients. Core elements of the intervention, offered concurrently with routine heart failure care, included the following: communication about goals of care and

Table 1 Models for integration of palliative care into care of patients with advanced heart disease

Study/author	Setting	Population	Intervention	Outcomes
I. General heart failure (non-transplant, no mechanical circulatory support)				
A. Inpatient consultation				
Sidebottom et al. [30] -Single-center randomized study	Inpatient tertiary care hospital, USA	-$n = 80$ -Admitted w/ ADHF -NYHA not reported	-Traditional inpatient PC consultation +/− follow-up based on need -Referral to site-specific ACP process -Delivered by multidisciplinary team (4 PC MDs, 2 PC APNs, SW, chaplain)	-Most patients received consultation without follow-up -Consultation led to improved symptom control at 1 and 3 months
B. Outpatient consultation				
Bekelman et al. [31] -Retrospective chart review	Outpatient tertiary care hospital, USA	$n = 50$ NYHA III/IV (70%)	-Co-management; embedded specialist in advanced heart failure clinic -Half-day clinic/week, staffed by 1 PC MD	-Majority of referrals received from embedded cardiac clinicians working on same day as PC MD -Main symptoms addressed: depression, anxiety, pain, fatigue, dyspnea, insomnia -ACP addressed 48% of the time -Developed site-specific referral criteria
Evangelista et al. [32] -Prospective, case control, single-center study	Outpatient USA	-$n = 36$ -NYHA II (71%) -Recruited from inpt admission	-PC consult after hospital discharge by PC MD or APN that received extensive PC training	-PC consult duration 75 min avg. (50–120 min) -PC consult domains addressed: ACP 100%, symptoms 81%, illness understanding 69%, patient/family coping 50% -29% comorbid major depression, 20% of patients treated with an antidepressant -Improvement in fatigue, well-being, depression, dyspnea, and nausea
C. Outpatient consultation and telephone supportive care				
Bekelman et al. [33] -Prospective mixed-methods feasibility study	Outpatient USA	-$n = 16$ -NYHA III/IV (41%)	-"CASA" telephone support intervention -3 domains: (1) RN symptom management (2) SW or psychologist led supportive care (3) multidisciplinary meetings to discuss care plans	-85% of team recommendations implemented -Most common recommendations addressed pain and fatigue -Most patients enjoyed this model of care
Dionne-Odom et al. [34] -Prospective, single center, feasibility study	Outpatient rural, USA	-$n = 22$ (11 pt./caregiver dyads) -NYHA III/IV (81%)	-Concurrent PC led by PC RN using a structured framework for patients and caregivers -3 domains: (1) in-person PC consultation by PC RN (2) phone-based structured coaching/education/support by PC RN (3) satisfaction interviews	-Both patient and caregiver reported satisfaction with intervention and felt earlier intervention would have been even more helpful -Clinician concerns with phone intervention: challenge to create trusting environment, establish and maintain rapport over phone, difficult for those with hearing impairment
D. Home-based care				
Wong et al. [35]	Inpatient, home-based,	-$n = 84$ (43 intervention)	-Transitional care program delivered primarily	-Intervention associated with: reduced readmission rates, improved QoL and

Table 1 (continued)

Study/author	Setting	Population	Intervention	Outcomes
-Multi-center, randomized control trial	Hong Kong	-NYHA III/IV (93%)	by a PC nurse case manager (supported by a PC MD) and trained volunteers -Initial consultation prior to discharge, followed by 4 weekly in-home or telephone follow-up visits, then monthly in-home or telephone follow-up care × 12 weeks	improved symptom control (dyspnea, depression, total ESAS score)
Brannstrom and Boman [36] -Prospective, single center, randomized non-blinded controlled study	Home-based, Sweden	-*n* = 72 (36 intervention, 36 control) -NYHA III/IV (100%) -Recent ADHF -Frequent need for IV diuretic	-"PREFER" intervention -In-home management of HF Mon–Fri with ability to administer IV/SC diuretic -Telephone management of symptoms and support -Delivered by multidisciplinary team: PC MD, HF MD, PC RN, PT, and OT	-Improved QoL, fewer hospitalizations and decreased length of stay for intervention group
II. Advanced therapies (transplant or mechanical circulatory support)				
A. Inpatient setting				
O'Connor et al. [37] -Prospective feasibility study	Inpatient tertiary care hospital, USA	-*n* = 37 -Convenience sample of patients undergoing LVAD evaluation	-Scripted PC assessment tool administered by a trained RN during LVAD implantation evaluation process -RN shadowed PC MD at bedside twice, completed three consults in the presence of PC MD, and then practiced independently with ongoing feedback from PC MD based on RN documentation	-Majority of consults took place in the hospital a few days prior to LVAD implantation -Few patients required full PC consultation -Consult duration 30 to 60 min
Swetz et al. [24] -Retrospective chart review	Inpatient tertiary care hospital, USA	-*n* = 19 -NYHA III/IV (100%) -patients undergoing DT-LVAD evaluation	-Inpatient PC consultation addressing ACP specific to DT scenarios -Delivered by multidisciplinary team -"Preparedness Plan" = PC MD consultation + SW consultation + advance care planning -Follow-up post LVAD implant	-68% of pts. receiving DT LVAD received pre-implant PC consultation -Median time of palliative care consultation was 1 day prior to LVAD implantation -68% of pts. had new/revised advance directives after the consultation

ADHF acute decompensation of heart failure, *HF* heart failure, *MD* medical doctor, *APN* advance practice nurse, *RN* registered nurse, *SW* social worker, *PT* physical therapist, *OT* occupational therapist, *NYHA* New York Heart Association class, *PC* palliative care, *DT-LVAD* destination therapy left ventricular assist device, *QoL* quality of life, *ESAS* Edmonton Symptom Assessment Scale decision-making, psychosocial support, and life review or legacy work. The patient and caregiver interventions resulted in increased patient and family satisfaction and less caregiver burnout over time. Of note, the patients and families also expressed a wish to have received a similar intervention earlier in the trajectory of illness, which supports the need to integrate palliative care throughout the trajectory of serious illness [34]. This study also highlights the importance of interventions to focus on both the patient and caregiver.

The PREFER (Palliative caRE heart FailurE clinic caRe) study evaluated a comprehensive intervention in Sweden pairing telemedicine with in-home palliative care. In this study, heart failure physicians, palliative care physicians, nurses, a physiotherapist, and an occupational therapist provided telemedicine as well as home visits Monday through Friday during daytime hours. Patients could receive subcutaneous or intravenous diuretics for treatment of symptoms refractory to an oral regimen. No intravenous inotropes were utilized. In-home blood work was obtained to help direct care. In addition to heart failure care, patients received comprehensive evaluation and management of non-cardiac illnesses described by this team as “total care of the patient.” All patients had New York Heart Association class III or IV symptoms. Patients who were prospectively randomized in an open non-blinded study to receive this intervention reported improved quality of life and had fewer hospitalizations compared to a control group receiving standard care [36].

New models for team-based palliative care

Recent studies have explored new models of interdisciplinary teamwork to improve access to palliative care for patients with heart failure. One recent study demonstrated the feasibility and acceptability of an in-person and telephone-supported intervention delivered by a registered nurse using symptom evaluation and management algorithms, and a social worker and psychologist who provided psychosocial care. Care plans were discussed during weekly interdisciplinary rounds that included a palliative care physician [33].

In a different study, a registered nurse utilized a scripted tool to assess goals of care for patients being evaluated for left ventricular assist device placement as destination therapy. This nurse was trained and given longitudinal feedback by a palliative care physician, based on clinical observation and review of documentation [37]. All patients approached by the nurse agreed to and completed the scripted visit, and multidisciplinary feedback from the cardiac team was uniformly positive. The results of this study concluded that this intervention was feasible and again highlights a practicable model of care delivery using a palliative care physician in more of a guiding non-frontline role.

Outpatient palliative care

Assistance with decision-making is a fundamental skill in supporting patients and families facing progressive clinical decline from advancing heart failure. A common theme from the available literature suggests that meaningful advance care planning happens over a series of conversations and is improved when patients have continuity with their outpatient clinicians. Bekelman et al. evaluated an “early” palliative care co-management intervention over 3.5 years that focused on exploring goals of care and end-of-life care preferences while at the same time pursuing disease-modifying treatment for heart failure. One significant finding was that the incidence of advance care planning conversations for an individual patient increased over time [31]. Initial consultations focused on acute symptom management, and goals of care were often addressed in follow-up visits once symptoms were stabilized. Thus, longitudinal outpatient palliative care may improve advance care planning for patients with heart failure. In another model that identified patients from the inpatient setting likely to benefit from outpatient palliative care consultation, advance care planning was addressed in 100% of the follow-up outpatient palliative care visits [32], highlighting again that the iterative nature of these conversations makes them well suited to a care delivery model that spans multiple settings. The benefit of outpatient palliative care, provided in non-emergent situations when patients and families are not faced with making critical in-the-moment decisions, allows patients to build rapport and trust over time that facilitates information sharing and exploring goals and wishes as heart failure progresses.

Utilizing decision aids in the outpatient setting may also help to promote advance care planning and informed decision-making. Recent print and video decision aids were developed to assist patients and families with decision-making for ventricular assist device for destination therapy. They were designed using evidence-based standard tools (e.g., the International Patient Decision Aid Standards, the Ottawa Decision Support Framework) and a rigorous need assessment involving 24 advanced heart failure patients, 20 caregivers, and input from 24 clinicians from medical centers across the USA. These tools attend to both cognitive and emotional aspects of complex decision-making, highlight the dichotomous choice to accept or decline mechanical circulatory support, and endorse palliative care and hospice as part of, instead of an alternative to, advanced heart failure care. The majority of patients and families felt the decision aids were helpful in assisting with decision-making and would recommend their use [39]. A more recent randomized controlled study demonstrated that utilization of a video decision-support tool for patients undergoing left ventricular assist device therapy led to increased future planning conversations with the patient’s doctor [40].

In addition to decision-aid tools, various communication techniques can be taught to help elicit patient preferences for goals of care. Jackson et al. describe communication strategies designed to improve goals of care conversations and shared decision-making in the ambulatory setting. Their step-by-step approach to cultivating prognostic awareness can likely be learned and utilized by both specialist and generalists alike [41].

Intraprofessional collaboration and generalist palliative care

A recent qualitative study interviewing 13 multidisciplinary non-palliative care clinicians from eight advanced heart failure teams across the USA demonstrated that most heart failure clinicians report positive experiences working with palliative care clinicians and perceive palliative care to improve care delivery and outcomes for their patients [42].

There is general consensus that all clinicians caring for patients with mechanical circulatory support should take an active role in goals of care discussions and should possess the skills to communicate information regarding potential device complications, prognosis, and quality of life [43]. In addition, intraprofessional communication between the medical and surgical teams can lead to decreased hospital length of stay and reduced healthcare cost [44]. A recently published reflective piece written by a cardiology fellow in the USA highlighted the basic palliative care competencies that could be taught as part of routine cardiac training including the following: prognostication, communication skills for engaging in goals of care and advance care planning conversations, symptom management, device deactivation, and understanding how to define palliative care and when to refer [45]. Generalist palliative care training has been described in the primary care setting. In one study, generalists received 5 h of training using two tools; the first assisted in the identification of patients that would benefit from palliative care, and the second offered a structured approach in developing a palliative care management plan. Generalists were interviewed 2 years after their training and mostly reported an increased recognition for patients requiring palliative care and an increased confidence with communication skills. However, many still found it challenging to discuss end-of-life issues with their chronically ill patients because most of their patients did not understand the terminal nature of their illness [46]. Future work is needed to examine effective intraprofessional models of care.

Discussion

Despite guidelines advocating for palliative care to be a part of comprehensive heart failure care, there remains no clear direction on how to operationalize the ideal care model. This article reviews a growing body of literature describing existing models for the provision of palliative care for patients with advancing heart failure. It confirms that palliative care clinicians may specifically add value through expert symptom management, facilitation of advance care planning, and by optimizing transitions and end-of-life care. The evidence base is growing at a swift rate. The results of the first prospective, single-center randomized control trial, PAL-HF (Palliative Care in Heart Failure Trial), which investigates longitudinal outpatient palliative care for this patient population [47] will be published later this year. Preliminary results demonstrate that longitudinal palliative care delivered by a specialty level nurse practitioner and physician, in addition to routine cardiac care, led to improvement in symptoms and quality of life [48].

There is also a growing evidence base supporting involvement of palliative care specialists in serious illness conversations for patients with advanced heart failure. Two studies reviewed in this paper demonstrated that providing care by physician or advance practice nurse palliative care specialists in an outpatient clinic led to increased completion of advance care planning documentation. Additionally, a small randomized controlled study of a palliative care social worker led intervention focusing on goals of care communication in the outpatient setting led to an increase in patient reported prognostic awareness as well as an increase in goals of care documentation by the primary cardiac team [49]. It may be that these discussions are best done outside of the hospital when no urgent decisions are required to be made. The outpatient setting affords an opportunity for relationships to build over time that may allow patients and caregivers to feel more comfortable in discussing end-of-life issues. Given the unpredictable nature of the heart failure trajectory, iterative discussions are required to address and readdress evolving goals of care. Palliative care teams may be best suited to assist primary cardiology teams with these tasks and the embedded co-management model, maximizing face time between specialties, may assist in this education and refining of the primary team's basic palliative care skill set. Specific language must be developed and taught that is relevant to specific palliative care issues in heart failure such as uncertainty in prognosis and goals of care [50, 51]. There remains an opportunity to explore how best to impart this communication skill set to primary teams caring for heart failure populations and to understand how this finesse in language affects clinical outcomes. As clinicians continue to work together and celebrate successes in improving their patient care, the cardiology team can better appreciate the unique palliative care skill set, which may lead to earlier and more appropriate referrals. Future research should determine how to identify heart failure patients at high risk of dying [52] and optimize interdisciplinary teamwork to improve advance care planning in the outpatient setting.

In addition to outpatient care, models describing telephone supportive care may also help to inform future directions of study. Patients with progressive, advanced heart failure may be unable to easily attend clinic appointments, which may increase burden onto their caregivers who try to arrange for services or who dedicate their personal time to help loved ones to be seen in person for supportive care. Telephone support is convenient and is welcomed by patients and caregivers. Studies evaluating this model of care show that non-specialists can be trained to provide basic evaluation and management of symptoms in addition to providing education and coaching centering upon coping and advance care planning.

Telephone supportive care can be combined with home-based palliative care to help patients live comfortably in their own home. A California-based study of home-based palliative care for a mixed patient population (including cancer, heart failure, chronic lung disease, and other) demonstrated a reduction in 30-day readmission rates. [53]. Similarly, for patients with heart failure, emerging evidence suggests that home-based palliative care improves quality of life and reduces hospital admissions for uncontrolled symptoms. Future studies are needed to better understand how to most effectively use the interdisciplinary palliative care team to produce value-based home care for homebound patients with advanced heart failure. It is interesting to note that in Sweden, patients can receive subcutaneous and intravenous medications for symptom management in the home setting [36], which likely contributed to their favorable outcomes. This should be further studied in the USA to observe if similar outcomes can be achieved in a multi-payer health care system. Home-based programs should also be evaluated for patients living with mechanical circulatory support to see if these benefits can be extended to this vulnerable population.

Finally, in order to meet the palliative needs of patients with advanced heart failure, primary care and cardiac clinicians will need to be able to provide basic palliative care to their patients and families, calling upon specialist-trained clinicians for more complex needs. This has been described as a *primary or generalist* vs. *specialist* palliative care skill set [54]. The primary skill set includes basic management of pain and other symptoms in addition to engaging in discussions on prognosis, goals of care, and advance care planning. Two studies reviewed in this paper demonstrate that basic palliative care skills may be implemented using a scripted or semi-structured tool. This puts the palliative care physician in more of a guiding role while empowering other interdisciplinary team members to deliver frontline supportive care to patients in need. Future studies should focus on determining the types of methodologies that can best deliver this primary skill set and should evaluate outcomes to determine its value.

Palliative care has traditionally been offered in the inpatient setting when patients and families are facing rapid changes in care needs. In order to meet the needs of patients and families living with chronic relapsing serious illness, palliative care has moved outside of hospital walls into outpatient clinics and patients' homes providing longitudinal supportive care. Although the evidence base is limited, emerging data reviewed in this paper may help guide a task force in thinking about how to set up multi-site clinical trials that can assist in the creation of best practices for the successful delivery of palliative care for patients and caregivers living with advanced heart failure.

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