

Elements of effective palliative care interventions in advanced heart failure: A narrative review

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Abstract

People with advanced heart failure experience significant biopsychosocial needs and have a poor prognosis. International guidelines have called for integrating palliative care in heart failure management. This review explores the elements of effective palliative care interventions in advanced heart failure. PubMed, Embase, CINAHL and Cochrane Reviews were searched following an a priori review protocol for clinical trials of advanced heart failure and palliative care. The risk of bias was assessed using Risk of Bias 2 (RoB2). A qualitative, emergent approach was used to synthesize context + mechanism = outcome. Twenty-one papers from 18 studies were the data source. The efficacy of palliative care in advanced heart failure was mixed. Five studies reported significant improvement in health outcomes compared with the usual care control group. Timing may be necessary in accounting for improvement in quality of life (occurring on or about 3 months) and functional and symptomatic improvements (occurring on or about 6 months or longer). Effective models of secondary palliative care in advanced heart failure include interdisciplinary teams comprising primary care, cardiology and palliative care, routine check-ins, personalized care plans that explore goals, evidence-based symptom management and counselling. Integrating palliative care with heart failure management could improve patient outcomes. Future research and policy development may wish to consider when, how and what palliative care modalities are to be incorporated into the care of patients with advanced heart failure.

Keywords chronic disease; guideline; heart failure; palliative care; review

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Introduction

People with advanced heart failure (New York Heart Association Functional Class III or IV or the American Heart Association Heart Failure Stages C and D) experience a significant symptom burden, which includes a symptom constellation of breathlessness, fatigue, pain, anorexia, and psychological concerns of fear, anxiety and depression.^{1,2} Comparatively, this symptom cluster may impact quality of life to a greater degree than those living with advanced cancer.³ In addition, caregivers for people with advanced heart failure struggle with the uncertainty of illness trajectory and complex treatment regimes.^{4,5} Furthermore, following an index admission to a hospital with heart failure exacerbation, 40% of these pa-

tients may die within 12 months of hospital admission.⁶ Against this backdrop, some professional societies have advocated for early referral to and/or integration of palliative care.^{7–9}

The World Health Organization (WHO) defines palliative care as an approach to improving the quality of life for patients and families facing a life-limiting illness.¹⁰ Palliative care is a patient- and family-centred multidisciplinary approach, seeking to identify and treat symptoms (physical, emotional, spiritual or social) to improve individuals' quality of life or overall well-being across the phases of illness.¹¹ Models of palliative care vary. Primary palliative care is broadly defined as 'clinical management and care coordination including assessment, triage and referral, ... for the per-

son with uncomplicated needs associated with a life-limiting illness and/or end of life care'.¹² Thus, primary palliative care may be delivered at home, residential aged care facilities, or other community settings by primary healthcare providers (e.g., family physicians/general practitioners or nurses) and community providers with or without direct input from specialist palliative medicine physicians. The patients' needs in primary palliative care may be predictable or intermediate and fluctuating.¹³ By comparison, specialist palliative care includes but is not limited to the management of refractory pain¹⁴ or other more complex symptoms and assistance in addressing cases of near futility. In secondary palliative care, the care may be provided in consultation-liaison or shared care between primary healthcare providers and specialists in palliative care.¹⁵ The concept of palliative care can evoke strong emotions and concerns from patients and clinicians who may struggle with the concept of palliative care and what it may provide.¹⁶ Moreover, people with advanced heart failure markedly overestimated their prognosis and, hence, may underappreciate the need for support from an early incorporation of palliative care into their heart failure management.¹⁷ Despite nuanced differences between the European Society of Cardiology and the American guideline for managing heart failure,^{9,18} both highly referenced international guidelines call for integrating palliative care in advanced heart failure management.

A recent systematic review of palliative care in heart failure included 10 randomized controlled trials (published 2006–2019; $n = 921$ of whom 88% included participants had advanced heart failure) and found palliative care to reduce hospitalization [4 trials: odds ratio (OR) 0.56, 95% confidence interval (CI) 0.33–0.94, $I^2 = 27%$], some improvement to quality of life [7 trials: standardized mean difference (SMD) 0.25, 95% CI 0.06–0.45, $I^2 = 15%$] and some reduction in symptoms burden (3 trials: SMD -0.29 , 95% CI -0.54 to 0.03, $I^2 = 15%$), but no effects on anxiety, dyspnoea, pain and mortality.¹⁹ The positive findings somewhat concurred with the 2017 systematic review (15 studies: 10 prospective and 5 retrospective) findings of reduced risk of rehospitalization [relative risk (RR) 0.58, 95% CI 0.44–0.77; noting, however, $I^2 = 0%$] but mixed results in regard to quality of life, individual symptoms, symptom burden, costs and other resource utilization.²⁰ The subsequent 2019 systematic reviews (13 interventional and 10 observational studies, $n = 19\,891$)²¹ and the 2022 systematic review (18 randomized controlled trials, $n = 1642$ with chronic heart failure and $n = 175$ caregivers)²² both reported mixed findings regarding functions, symptoms, psychological, quality of life, mortality, self-care, satisfaction, costs and resource utilization, although the authors of the 2019 review concluded that multidisciplinary palliative care is effective for functions, symptoms, depression and quality of life. A more recent 2023 realist synthesis of 130 documents published between 2000 and 2022 attempts to provide insight to explain the observed heterogeneity across studies and sys-

tematic reviews.²³ The review found the complexity associated with heart failure illness trajectory, a lack of clarity on who is responsible for initiating palliative care, when this should happen and how often to be significant barriers.

In direct response to the call for greater clarity to the international guidelines addressing the complexities of palliative care provision in heart failure,¹⁸ this review explores the elements of effective palliative care interventions in advanced heart failure to inform the discourse on how palliative care could be effectively integrated into advanced heart failure management.

Methods

A narrative review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (see Table S1).²⁴ The protocol was registered with PROSPERO (CRD 42020202923).

Eligibility criteria

To be consistent with previous reviews,^{25–27} we focused on peer-reviewed, published primary and pilot studies employing randomized or clinical trials with a comparator. To be included, the studies needed to be

- available in English;
- published after 1980—this index year was selected to coincide with the advancement in heart failure treatment, especially with the move away from the passive treatment regimen of bed rest, inactivity and fluid restriction;
- the patient population aged more than 18 years and had advanced heart failure as classified as New York Heart Association Functional Class III or IV or equivalent; and
- received palliative care as defined by the WHO.

The reference list of systematic reviews was hand-searched for any primary studies not discovered in the initial searches.

Information sources and search strategy

Databases examined included PubMed [National Library of Medicine (NLM)], Embase (Ovid), CINAHL (EBSCO) and Cochrane Reviews (Wiley). The main concepts of the search terms included heart failure, cardiac failure, palliative care, terminal care and hospice care (see Table S2). The last search was conducted in August 2024.

Study selection and data extraction

Search results were imported into Covidence™ systematic review software (Veritas Health Innovation, Melbourne, Australia) for data management. PA, IA-D and DL independently conducted screening by title and abstract. PA and IA-D assessed the full text of potentially relevant records. Any disagreements were resolved through discussion with MRA. IA-D and DL extracted data using a Microsoft Excel proforma that incorporates the Template for Intervention Description and Replication (TIDieR) reporting checklist²⁸ with the following headings: author, country and year, study design, patient population, interventions delivered (why, what, how, where and when), who delivered and outcomes (how well). PA and DL used the Cochrane Risk of Bias 2 (RoB2) tool to assess the risk of bias in the included studies.²⁹ The reliability of the RoB2 assessment was measured against published reviews that included the primary studies.

Synthesis of results

We adopted a qualitative, emergent approach to synthesize the information and to answer the review question.³⁰ First, the extracted data were freely coded. PD and DL read the full texts of the included studies and coded each fragment that provided information to answer the review question. Second, the codified data were organized and grouped based on descriptive aspects using a context-lined causality approach represented by 'context + mechanism = outcome'.³⁰ Reflection and debriefing with MRA and CGDP ensured the credibility of the analysis.

Results

Study selection

Figure 1 outlines the search results for this review. After removing duplicates, 10 849 records were screened, and 21 papers from 18 trials were included in this review. Characteristics of these included papers are summarized in Table 1. Our assessment of the quality (see Table S3) was in concordance with other systematic reviews' assessment^{22,27,52} ($\kappa > 90\%$). We did not formally assess reporting bias using funnel plots or statistical testing for study effects, as no meta-analysis was undertaken due to the methodological and clinical heterogeneity of the included studies.

Outcome

The reported primary and secondary outcome variables and outcomes are tabulated in Table S4. The primary outcome

measures included changes to the quality of life,^{35,36,40,41,46–49} mood (depression^{34,37,43,46–48} and anxiety^{34,47,48}), pain,^{34,46,47} the burden of the condition,^{43,48,49} dyspnoea,^{31,46} global health status,^{43,47} heart failure symptoms,^{41,43,51} preferences,^{17,38,50} readmission³⁹ and hospitalization.^{35,36} Only seven papers from five studies had a statistically significant improvement compared with the usual care control group.^{34–37,39,40,51} Four papers from three trials reported significant improvement in both test and control groups before and after interventions.^{32,39,40,44}

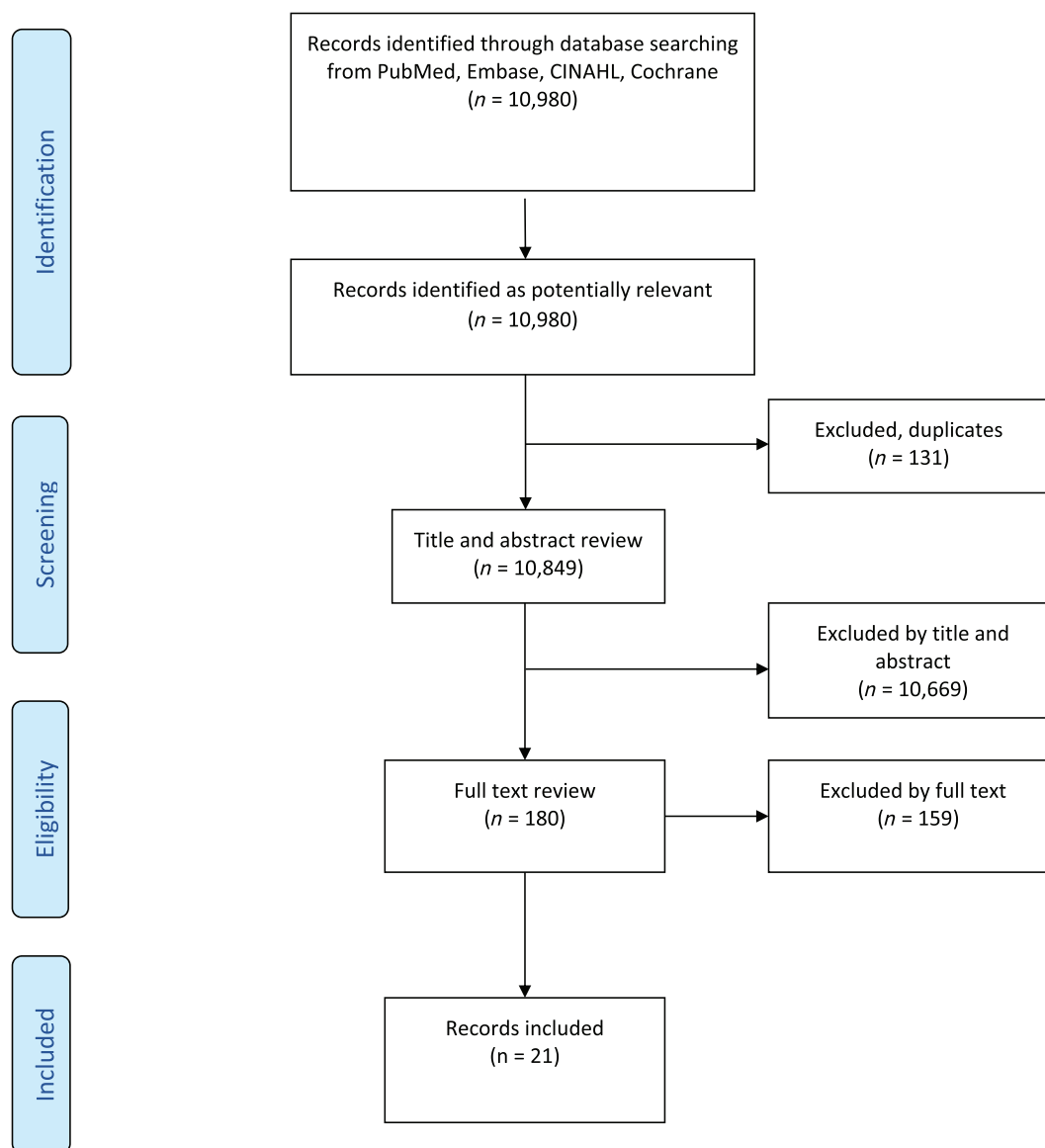
Different quality-of-life measures were employed across the studies. The most common being the Kansas City Cardiomyopathy Questionnaire (KCCQ). Compared with the control group, the quality-of-life measures improved after intervention in four studies.^{35,37,40,41} Four studies reported improved quality of life before and after intervention in the treatment group.^{35,37,40,50}

Seven functional scales were employed, and only one study reported improvement after intervention.⁴¹ Two studies reported improved functional scales before and after intervention in the treatment group.^{32,40} Three studies reported statistically significant improvement in depressive symptoms compared with the control group,^{37,41,43} and one further study reported improvement after intervention in the treatment group.⁵⁰ One study reported improvement in anxiety before and after intervention in the treatment group,⁵⁰ and one other study found statistically significant improvement compared with the control group.³² Three studies reported statistically significant improvement in symptoms compared with the control group,^{37,44,51} and two other studies reported improvement in the treatment arm after intervention.^{35,40} Notable pain reduction (test vs. control) was reported in one study.⁴⁷ Improvement in dyspnoea (test vs. control) was reported in two studies.^{32,43} Spiritual well-being improved in two studies (test vs. control).^{32,41} Readmission was reduced (test vs. control) in two studies.^{35,40}

Study and intervention determinants: Context + mechanism

By 'context', the trial settings included inpatient,^{34,38} outpatient^{32,33,37,46,49,50} and community.^{35,36,39,40,43,44,47,48,51} Whilst the majority of the trials were conducted in the United States,^{17,32,34,37,38,41,43,46–49,51} other countries included the United Kingdom,^{31,33,44,45} Sweden,^{35,36} Hong Kong Special Administrative Region of the People's Republic of China (Hong Kong)^{39,40} and Singapore.⁵⁰ There were no international collaborative studies.

The age and gender of the test and control were consistently somewhat similar (not statistically significant) within the various studies (one paper did not report on the patients' demographic,³³ and two papers had more female than male participants in the intervention group^{32,46}). Across the stud-

Figure 1 PRISMA flow chart.²⁴

ies, the mean age of the participants ranged from 53 to 82 years old (group means 68.9 years old), and the proportion of males ranged from 13% to 100% (group means 55.4%). Other sociodemographic and social determinants of health covariates and confounders were not consistently reported across the included papers to enable reasonable comparison.

The majority of the studies involved multidisciplinary teams, and nurses were most frequently involved in the delivery of care,^{32,35–41,43,44,46–49,53} followed by social workers,^{17,32,38,46} psychologists or counsellors,^{32,41,43} primary care physicians,^{35,36,43} palliative care physicians,¹⁷ chaplains,^{32,38,46} volunteers^{32,39,40} and non-clinical facilitator.⁵⁰

The predominant intervention modalities of the included studies were case management,^{32,35,36,39–41,43,44,47–51} followed by a palliative care consult,^{17,33,34,37,38} and two studies focused on medication (opiate).^{31,45} Most studies also included telehealth in the delivery of the intervention.^{32,39,40,43,46–49,51} However, the care structure did not solely explain or account for the observed mixed effectiveness.

The different study time frames (i.e., 4 days,³¹ 2 weeks,³⁴ 3 months,^{37,39,40,45,51} 4 months,⁴⁴ 5 months,³³ 6 months,^{17,35,36,38,41,43,46} 9 months,^{47,48} 1 year^{32,49} and 2 years⁵⁰) did not alone account for the mixed effectiveness results observed ~~per second~~ (compared with the control group). However, the timing of when palliative care was intro-

Table 1 Characteristics of the included randomized controlled trials.

Reference	Why	What	Who provided	How
-	To determine the efficacy of morphine for the relief of breathlessness in patients with chronic heart failure	Double-blind; 5 mg oral morphine for 4 days	Not explicitly informed	5 mg oral morphine or placebo over 4 days, then 2 days washout followed by crossover for 4 days; venous blood taken by nurse
Johnson et al. ³¹				Researchers provided a list of eligible patients; care management
Comprehensive Care Team (CCT)	To compare physical, psychological, social and spiritual outcomes between multifaceted outpatient care	(i) In-depth consultation by social worker with recommendations relating to physical symptoms, psychological well-being, social support, spiritual well-being and advanced care planning; (ii) social worker provided case management and psychological support in person or by phone; (iii) nurse provided family caregiver training through formal class and individual consultation; (iv) pharmacist conducted medical review; (v) chaplain offered spiritual and psychological support; (vi) monthly support groups; and (vii) medical and pharmacy students provided patient support through weekly phone contacts	Social worker, nurse, chaplain, pharmacist, psychologist, art therapist, volunteer co-ordinator, three physicians and health student volunteers	
Rabow et al. ³²				
-	To evaluate the effectiveness of an outpatient palliative care intervention for heart failure patients	1 h palliative care consultation followed by 30 min consultations for 5 months with the same doctor	Doctor	Palliative care consultation and monthly meeting
Paes ³³				
-	To evaluate the impact of a proactive palliative medicine consultation on the care of chronically ill,	Proactive palliative care consultation every weekday during hospitalization	Palliative care physicians	Assessment of symptoms, psychosocial and spiritual needs, and discussed treatment preferences
Pantilat et al. ³⁴				(Continues)

Table 1 (continued)

Reference	Why	What	Who provided	How
PREFER	To evaluate the outcome of the programme concerning patient symptoms, health-related quality of life and hospitalizations	Non-blinded, integrated palliative and heart failure care	General practitioners and nurses	(i) The responsible doctor and nurse identified for each patient; (ii) the patient underwent thorough medical examination for comorbidities and assessment of physiological, social and spiritual needs; (iii) the development of a palliative care plan with the nurse; (iv) regular meetings twice a month; and (v) discussion between the team Ibid
Sahlen et al. ³⁶	To assess the cost-effectiveness of person-centred integrated heart failure and palliative home care	Ibid	Ibid	Ibid
Evangelista et al. ³⁷	To examine the feasibility and effectiveness of a palliative care consultation along with standard heart failure care in an outpatient setting regarding symptom burden, depression and quality of life	Palliative care consult at discharge	Palliative care physicians and advanced practice nurses; nurse completed 40 h didactic and 6 month clinical mentored practicum with a physician	Palliative care consult before discharge to ascertain needs, goals and preferences to develop a treatment plan
Hopp et al. ³⁸	To investigate whether hospital-based palliative care consultation was associated with increased 'do not resuscitate'	Palliative care consult vs. usual care	A physician and advanced nurse practitioner	Palliative care consult
TCP-ESHF	To examine the effects of home-based transitional palliative care for patients with end-stage heart failure after hospital discharge	(i) Case management with periodic review; (ii) discussion of end-of-life issues; (iii) multidisciplinary approach; (iv) staff development for communication, cardiovascular and palliation; (v) discussion of treatment preferences; and (vi) integrated model of care Ibid	Nurse case manager, palliative care physicians and volunteers (training not explicitly informed)	Week 1: The care manager and trained volunteers conducted a home visit together. Week 2: The care manager provided a telephone follow-up. Week 3: The volunteers conducted a home visit in pairs. Week 4: The care manager provided a telephone follow-up Ibid
PAL-HF	To investigate whether an interdisciplinary palliative care intervention improves health outcomes	Unblinded; shared goal setting to combine heart failure symptoms management with palliation Ibid	Certified palliative care nurse practitioner, palliative care physician, counsellor and usual	After discharge, nurse practitioners engaged in ongoing management in the outpatient environment (Continues)

Table 1 (continued)

Reference	Why	What	Who provided	How
CASA Bekelman et al. ⁴³	To determine whether a symptom and psychosocial collaborative care intervention improves heart failure-specific health status, depression and symptom burden in patients with heart failure	Single-blinded nurses provided six follow-up assessments by telephone (1–2 per month). Social workers provided six telephonic counselling sessions	Nurses, social workers, primary care clinicians, cardiologists and palliative care physicians. Nurses and social workers trained to provide CASA intervention: Social workers received 8 h of psychosocial intervention training and follow-up supervision	The nurse and social worker met weekly as part of a collaborative care team with a primary care clinician, cardiologist and palliative care physician. The nurse addressed symptoms, the social worker provided structured psychosocial care, and the team reviewed care and provided orders for tests and medications (i) Patient identification and referral, (ii) holistic assessment, (iii) care management and co-ordination, (iv) training and education and (v) multidisciplinary work and joint working
Caring Together intervention Johnson et al. ⁴⁴	To assess the feasibility of a clinical trial of palliative cardiology effectiveness	Cardiology and holistic assessment for identification of individually tailored solutions; care manager assigned to co-ordinate care	Care manager (usually heart failure nurse specialist); training provided to all stakeholders delivering the programme	Consultation with a social worker before discharge and consultation with the social worker at each visit for 24 weeks
SWAP-HF O'Donnell et al. ¹⁷	To determine if early initiation of goals of care conversations by social workers would improve prognostic understanding, elicit advanced care preferences and influence care plans for high-risk patients discharged after hospitalization	Single-blind; structured evaluation of prognostic understanding, end-of-life preferences, symptom burden and quality of life with routine review by a palliative care physician; communication of this information to treating clinicians; and longitudinal follow-up in the ambulatory setting	Palliative-trained social worker	Physicians
BreatheMOR-HF Johnson et al. ⁴⁵	To determine the effectiveness and cost-effectiveness of 12 week morphine therapy for the relief of chronic breathlessness in people with chronic heart failure compared with placebo	Double-blind; 10 mg oral modified release morphine twice daily	Physicians	Morphine vs. placebo
- O'Riordan et al. ⁴⁶	To pilot a randomized clinical trial of a palliative care intervention for people with heart failure	Palliative care consultation provided by a multidisciplinary team	Nurse practitioners, physicians, social workers and chaplains	First consultation during hospitalization, follow-up 1 week and then five monthly consultations either in person or teleconference <i>(Continues)</i>

Table 1 (continued)

Reference	Why	What	Who provided	How
ENABLE CHF-PC Bakitas <i>et al.</i> ⁴⁷	To determine the effect of an early palliative care telehealth intervention over 16 weeks on the quality of life, mood, global health, pain and resource use of patients with advanced heart failure	Single-blind; in-person palliative care consultation and six nurse-coach telephonic sessions (30–40 min) and monthly follow-up for 48 weeks (<i>n</i> = 208) vs. usual care (<i>n</i> = 207); 50 years or older with Functional Class III or IV or Stage C or D advanced heart failure	Nurse-coach training provided with weekly supervision by investigators	Session 1 introduced the programme, elicited patients' understanding of illness and discussed problem-solving and the COPE framework. Session 2 reviewed self-care topics. Session 3 addressed physical and emotional symptom management. Session 4 introduced values elicitation, advanced care planning and decision aids. Sessions 5 and 6 included a life review and creating a legacy Ibid
Dionne-Odom <i>et al.</i> ⁴⁸	To determine the effect of nurse-led palliative care telehealth intervention on the quality of life and mood of family caregivers of persons with advanced heart failure	Ibid	Four registered nurses underwent 28 h of structured orientation and training	Ibid
PENPal-HF Kavaliaratos <i>et al.</i> ⁴⁹	To develop and test the intervention as part of routine care	Training to cardiology clinic nurse manager to enhance skillset regarding palliative needs and advanced care planning	Cardiology nurse with ≥15 years' experience; training included primary palliative care skills, review of a 79-page study manual and 10.5 h of training with palliative care educators	(i) Patients received four quarterly visits from the nurse; (ii) the nurse made monthly semi-scripted calls between visits to reinforce palliative principles; and (iii) the nurse communicated patient concerns with physicians Patient and family referred to facilitator, facilitator to provide emotional support, advanced care document dated and specified patient's preference Telephonic consult on problem-solving and coping skills: (i) identifying the symptoms, (ii) what needs to be done and formulating strategies, (iii) choosing and testing best strategies and (iv) evaluating effectiveness
- Malhotra <i>et al.</i> ⁵⁰	To examine the effect of an advanced care planning programme in facilitating end-of-life care consistent with the preferences of patients	Advanced care planning	Non-clinician facilitators trained in a 3 day workshop in Respecting Choice Model followed by mentoring for 3 months	
COPE-HF Graven <i>et al.</i> ⁵¹	To examine the effectiveness of the intervention on heart failure symptom frequency, severity, and symptom-related degree of interference with physical activity and enjoyment of life	One home visit and then weekly (first month) and bi-weekly (second and third months) phone calls	Advanced practice nurse; trained through observation and demonstration initially and every 3 months	

Abbreviations: BCOS; Bakas Caringiving Outcomes Scale; CI, confidence interval; COPE, creativity, optimism, problem-solving, and expert information; EORTC, European Organisation for Research and Treatment of Cancer; ESAS, Edmonton Symptom Assessment Scale—Palliative-14; HADS, Hospital Anxiety and Depression Scale; HRQL, health-related quality of life; KCCQ, Kansas City Cardiomyopathy Questionnaire; MD, mean difference; QOL, quality of life.

Table 1 (continued)

Reference	Where	When; how much	Tailoring	Modifications	How well
-	Not explicitly informed	4 days; blood tests for brain natriuretic peptide, adrenaline and noradrenaline	Not explicitly informed	2.5 mg morphine if creatine >200 µmol/L	6 out of 10 patients reported that morphine improved breathlessness; the median breathlessness score fell 23 mm ($P = 0.022$)
Comprehensive Care Team (CCT)	A 70-general medicine physician practice, location not explicitly informed	1 year; data collection at enrolment, 6 months and 12 months for functional status and psychological and spiritual well-being measures	Not explicitly informed	Not explicitly informed	The intervention group had less dyspnoea and anxiety, improved sleep quality and spiritual well-being, but no change in pain, depression or quality of life
-	Not explicitly informed	Date not explicitly informed; before and after HADS and EORTC	Not explicitly informed	Not explicitly informed	13 randomized, 9 completed (6 in intervention and 3 in control); improvement in anxiety, depression, global health status, physical functioning and social functioning
-	Not explicitly informed	Not explicitly informed; before and after and 2 week follow-up after discharge	Included pharmacist and chaplain as required	Not explicitly informed	107 patients enrolled (54 in intervention and 53 in control), 81 completed the 2 week post-discharge follow-up (41 intervention and 40 usual care); no statistically significant differences in the level of pain, dyspnoea and anxiety between groups
PREFER	Skellefteå, northern Sweden	January 2011 to October 2012; assessment at 1, 3 and 6 month follow-up	Phone calls and home visits varied from several times per day to every other week	Not explicitly informed	75 000 population; 517 eligible; 72 included (36 intervention and 36 control); improved HRQL (57.6 ± 19.2)
-	Ibid	January 2011 to 2013	Ibid	Ibid	0.25 quality-adjusted life year; cost reduction of SEK 600 000 over 6 months
-	Single university-affiliated medical centre, location not explicitly informed	March to July 2008: Phone survey before and 3 months after intervention	Palliative consults varied from 50–120 min	Tailored medication, counselling and education	36 matched pairs selected from 157 pools: Greater improvement in symptoms, depression and quality of life
-	Not explicitly informed	September 2006 to June 2008; baseline vs. 3–6 months' choice of 'do not resuscitate'	Involvement of chaplains and social workers as required	Number of palliative care consults	85 recruited (43 intervention and 42 control); 9.3% intervention vs. 0% control choose 'do not resuscitate'
TCP-ESHF		May 2013 to December 2014; readmission at 4 and	Discharge advice on symptom management,	Not explicitly informed	389 were assessed for eligibility, 84 were

(Continues)

Table 1 (continued)

Reference	Where	When; how much	Tailoring	Modifications	How well
	Three hospitals in Hong Kong, locations not explicitly informed	12 weeks after index hospital discharge; intention to treat	medication and referrals, if appropriate		randomized (43 intervention and 41 control), and 41 intervention and 41 control completed follow-up. Lowered readmission (33.6% vs. 61.0%), relative risk 12 week readmission for intervention 0.55 (0.35–0.88) Ibid; intervention had a higher McGill QOL total score, with no significant differences with symptoms of distress or functional status 150 randomized (75 intervention and 75 control); improved KCCQ (9.49) and FACIT-Pal (11.77)
PAL-HF	Ibid	May 2013 to June 2015; baseline, 4 weeks and 12 weeks after discharge; intention to treat	Ibid	Ibid	Ibid; intervention had a higher McGill QOL total score, with no significant differences with symptoms of distress or functional status 150 randomized (75 intervention and 75 control); improved KCCQ (9.49) and FACIT-Pal (11.77)
	Not explicitly informed in this paper or the protocol ⁴²	August 2012 to June 2015; assessment at Weeks 2, 6, 12 and 24; 6 months and follow-up until death or end of study	Not explicitly informed	Not explicitly informed	4100 were assessed, 317 were randomized (157 intervention and 157 control), and 124 intervention and 124 control completed a 6 month follow-up. Improved KCCQ (2.6), depressive symptoms (–0.29) and fatigue (–0.30) 77 recruited (43 intervention vs. 34 usual care); the intervention group scored lower in ESAS (43.5 vs. 35.2) and KCCQ (35.4 vs. 39.9)
CASA	Three sites, location not explicitly informed	August 2012 to April 2015; intention to treat	Social workers provided support to patients' informal caregivers as needed	Not explicitly informed	4100 were assessed, 317 were randomized (157 intervention and 157 control), and 124 intervention and 124 control completed a 6 month follow-up. Improved KCCQ (2.6), depressive symptoms (–0.29) and fatigue (–0.30) 77 recruited (43 intervention vs. 34 usual care); the intervention group scored lower in ESAS (43.5 vs. 35.2) and KCCQ (35.4 vs. 39.9)
Caring Together intervention	Two heart failure outpatient groups, location not explicitly mentioned	April to December 2015, 10 months	Not explicitly informed	Not explicitly informed	265 assessments (26 intervention and 24 control); more patients in the intervention group than in the control group had documentation of advanced care preferences 65% vs. 33%
SWAP-HF	Brigham and Women's Hospital in Boston, Massachusetts	September 2014 to December 2015; Percentage of patients with documentation of advanced care at 6 months and percentage of patients with improvement in prognostic alignment	Not explicitly informed	Not explicitly informed	386 assessed, 45 randomized (21 to intervention and 24 to
BreatheMOR-HF	13 centres in England and Scotland, locations not explicitly informed	12 weeks; numerical rating scale average breathlessness at Week 4; other outcome	Not explicitly informed	The trial closed early due to the recruitment	386 assessed, 45 randomized (21 to intervention and 24 to

(Continues)

Table 1 (continued)

Reference	Where	When; how much	Tailoring	Modifications	How well
-	An academic medical centre, location not explicitly mentioned	data at Days 2, 4 and 7 and Weeks 2, 3, 4, 8 and 12 January 2012 to December 2013	Nine received additional contacts (range 1–4) as needed	Not explicitly informed	control); 20 in intervention and 24 in control completed follow-up 1757 assessed, 39 randomized (22 to intervention and 18 to control); 16 in intervention and 14 in control analysis; no differences between study groups over time 785 potential patients (>50 years old) were screened, 573 were approached, 461 consented, and 415 were randomized; 86 out of 208 in the intervention group completed follow-up; 99 out of 207 in usual care completed follow-up. At Week 16, KCCQ improved 1.6 ± 1.7 in the intervention group over the usual care group. FACIT-Pal improved 1.2 ± 0.8 in the intervention group over the usual care group
ENABLE CHF-PC	University of Alabama at Birmingham and Birmingham Veterans Affairs Medical Center	October 2015 to May 2019; outcome measures collected by blinded data collectors every 8 weeks for 48 weeks; intention to treat employed in the analysis	Not explicitly informed	Not explicitly informed	371 caregivers were screened, 314 were approached, 189 consented, and 158 were randomized (82 to intervention and 76 to usual care); 32 completed follow-up in intervention, and 50 completed follow-up in usual care No difference in BCOS (-0.4 ; 95% CI -5.1 to 4.3 ; $d = -0.03$)
PENPal-HF	Not explicitly informed	October 2015 to August 2018 Study period not explicitly mentioned; eight weekly follow-ups for 56 weeks; feasibility and acceptability	All sessions were digitally recorded; 10% were randomly selected every 4 months for audit; no protocol non-adherence was noted	Not explicitly informed	5154 screened, 30 randomized (20 intervention and 10 control); 7 in intervention and 6 in control completed assessment; 94% satisfied with care

(Continues)

Table 1 (continued)

Reference	Where	When; how much	Tailoring	Modifications	How well
	National Heart Centre Singapore and Singapore General Hospital, Singapore	March 2015 to June 2018; survey every 4 months and 1 year follow-up	Not explicitly informed	Not explicitly informed	282 randomized (93 intervention and 189 control); decreased in intervention more likely to have wishes followed (35% vs. 44%, $P = 0.47$)
COPE-HF	Two North Florida hospitals, location not explicitly mentioned	Not explicitly informed; surveyed at baseline and 5, 9 and 13 weeks	Not explicitly informed	Not explicitly informed	126 recruited (34 intervention, 35 control and 38 attention-control); completion at 13 weeks: 19 intervention, 23 control and 24 attention-control; improvement in symptom severity [MD -2.59 (-3.65 , -1.53)]

Abbreviations: BCOS, Bakas Caregiving Outcomes Scale; CI, confidence interval; COPE, creativity, optimism, problem-solving, and expert information; EORTC, European Organisation for Research and Treatment of Cancer; ESAS, Edmonton Symptom Assessment Scale—Palliative-14; HADS, Hospital Anxiety and Depression Scale; HRQL, health-related quality of life; KCCQ, Kansas City Cardiomyopathy Questionnaire; MD, mean difference; QOL, quality of life.

duced and the outcome measured appears to be important. Improvement in quality-of-life measures (test vs. control) seemed to occur approximately on or about 3 months,^{35–37,40,41} whilst functional and symptomatic improvement (test vs. control) generally took some 6 months or longer.^{33,41,43,47}

Whilst studies conducted in the United States reported mixed effectiveness results (test vs. control), the included studies from Hong Kong^{39,40} and Sweden^{35,36} reported statistically significant positive palliative, physical and functional effectiveness results (test vs. control). The Chinese and Swedish studies employed a case management approach to delivering palliative care intervention. Other studies that employed such an approach had reported mixed effectiveness results (test vs. control).^{32,41,43,44,47–51}

Some of the studies explicitly articulated the philosophy or framework for the intervention. These were as follows:

- 4C transitional care [comprehensiveness, continuity, co-ordination and collaboration in alignment with palliative care principles of (i) case management with periodic review; (ii) discussion of end-of-life issues; (iii) multidisciplinary approach; (iv) staff development for communication, cardiovascular and palliative care; (v) discussion of treatment preferences; and (vi) integrated model of care]^{39,40};
- 6S model (self-image, self-determination, social relation, symptom control, synthesis and surrender)^{35,36};
- Chronic Care Model^{48,49}; and
- Respecting Choice Model.⁵⁰

Whilst all the control groups in the included studies received evidence-informed heart failure management, the palliative care aspect of the control groups varied from having no concurrent palliative care^{17,31–38,45,46,50,51} to having social aspects of palliative care included in their usual care⁴⁴ to the usual care control group receiving inpatient^{39–41,43,47,48} and/or outpatient^{39,40,49} palliative care consult. The presence of palliative care components in the control group did not solely account for the observed mixed effectiveness findings reported across the included studies.

We attempted to stratify the positive outcome variables by the Quality Palliative Care domains.⁵⁴ All included studies had a clear structure and palliative care process (Domain 1 of the Quality Palliative Care domains). The majority of the studies explicitly included physical aspects of care (Domain 2),^{31,33–37,39–41,43–50} care for nearing the end (Domain 7),^{17,32,34–41,44,46–50} psychological aspects (Domain 3),^{32–37,39–41,43,44,46–48} social aspects (Domain 4),^{32,33,35,36,39–41,43,44,46–48,51} and spiritual and existential aspects (Domain 5).^{17,32,34–36,39–41,44,47}

Only one study explicitly included ethical and legal aspects (Domain 8),¹⁷ and no studies explicitly reported on cultural aspects (Domain 6).

We further differentiated the palliative care intervention in the included studies into primary and specialist palliative

care to account for the efficacy of the positive studies. Most of the included studies were classified as specialist palliative care^{28,30,38,39,41,46,48–50} and did not account for the mixed effectiveness results observed. We noted, however, that process indicators such as completing an advanced care plan were generally associated with primary palliative care intervention.^{49,50} Likewise, primary palliative care appeared effective in aligning patients' acceptance of one's prognosis.¹⁷

The frequency and intensity of early palliative care intervention did not account for the observed mixed effectiveness result. Of the studies that reported efficacious health outcomes,

- the Chinese study^{39,40} employed weekly follow-up in the first month (Week 1 home visit, Week 2 phone call, Week 3 home visit and Week 4 phone call) followed by monthly home visits supplemented by further social visits and phone call follow-up with ad hoc referrals to primary care physicians and other health services;
- the US-based PAL-HF study^{41,42} employed follow-up at Weeks 2, 6 and 12, but in delivering the end-of-life preparation component of the intervention, three 1 h sessions spaced a week apart were delivered at the inception of the intervention (i.e., Week 2, Week 3 and Week 4);
- in the COPE-HF partnership study,⁵¹ participants had weekly and bi-weekly phone sessions over 12 weeks; and
- the Swedish PREFER study^{35,36} employed frequent home visits and phone calls that varied from several times a day to every other week, coupled with structured fortnightly meetings among the multidisciplinary team.

Conversely, similar intense frequencies were deployed in the ENABLE CHF-PC study^{47,48} (weekly phone follow-up in the first month followed by monthly phone call check-in), CASA trial⁴³ (twice monthly), O'Riordan et al.⁴⁶ (1 week after charge and then five monthly consults), Comprehensive Care Team³² (at least monthly) and Paes³³ (monthly), but did not find a statistically significant improvement in palliative care health outcomes between the intervention and control groups.

In summary, the context of timing appears to be the only variable that is associated with positive efficacy outcomes.

Elements of effective palliative care intervention: Outcomes = context + mechanism

Focusing on the studies that reported statistically significant improvement compared with the usual care control group^{holistically},^{35–37,39–41,51} we found that the general improvements were observed with depression, anxiety, breathlessness, readmission and spiritual well-being on the Edmonton Symptom Assessment Scale. All the trials involved an

interdisciplinary team of nurses, primary care physicians, cardiologists, counsellors or volunteers working collaboratively with specialist palliative care clinicians in an outpatient setting using a secondary palliative care case management approach. There were routine and frequent phone check-ins with the patients and care plans that explored goals of care, symptom management and counselling, personalized for each patient.

Discussion

Building on the earlier reviews,^{19–23} our updated review included 21 papers from 18 trials that sought to identify elements of effective palliative care in advanced heart failure that were associated with improved health outcomes, using a realist-focused approach on context + mechanism = outcome. We could not attribute the statistically significant differences in efficacy across studies to notable determinants between groups (test vs. control); this may be partly explained by the inclusion of some elements of palliative care in the control group (which affected the fidelity of the trials) as well as the underreporting of interventions and comparator models. The latter is also observed in other reviews of palliative care in other chronic conditions.^{19,25,26,55–57} We did, however, observe that the timing of when palliative care is integrated may be an important determinant in influencing the success of health outcomes in advanced heart failure, as well as the key constituents of effective secondary palliative care. Our findings are congruent with the European statement advocating for a flexible, interdisciplinary approach to heart failure management to account for the individualized needs and preferences of the patients and their families.⁵⁸

Recent changes to international heart failure management guidelines advocated the early concomitant inclusion of multidisciplinary palliative care.^{53,59} The European guidelines identified the importance of palliative care in advanced heart failure end-of-life symptomatic control,^{18,53} and the American guidelines emphasized aspects of palliative care, namely, communication and conveyance of prognosis, goals of care, shared decision-making, symptom management and caregiver support in improving the quality of life and relieving suffering.^{18,59} It is hypothesized that palliative care, when offered alongside heart failure management early, would significantly improve quality of control, symptomatic control, communication and caregiver satisfaction.⁶⁰ However, unlike the European guideline, the American Heart Association guideline explicitly differentiated between primary and specialist palliative care, with the latter offered selectively by palliative care specialists.^{18,59} The proposed segregation of care may be well-intended and is designed to make primary palliative care more readily accessible and available to patients with all

stages of heart failure,¹⁸ especially regarding physical, psychosocial, social, cultural and occupational well-being and logistics such as advanced care plans. In our review, the capacity of primary care to provide primary palliative care was bolstered through the provision of resources, training, protocols and referral pathways. This, indeed, had been shown to be successful in increasing the rate of advanced care directives; however, the translation to efficacy in sustaining quality of life, improved symptoms and reduced readmission was not linear nor causal, reflective of the complexity of the disease prognosis and trajectory.

In analogous to when is the best time to incorporate palliative care in heart failure management, early integration of palliative care in oncology care has long been shown to lead to improved health outcomes, including improved quality of life, improved symptom control, fewer intensive care admissions, and greater median survival for those patients who had early palliative care involvement and dying in their choice of location.^{61–64} Whilst attempting to define the critical timing of introducing palliative care interventions in advanced heart failure management, consideration of some of the implementation barriers is essential to this discourse. These include communicating and co-ordinating services beyond the healthcare sector, including social services and pastoral care. In some countries, there is a lack of consensus and a confusing array of referral criteria for the involvement of palliative care in patients with heart failure.¹¹ The provision of palliative care for heart failure may also be limited by the lack of specific funding and integration across and within the continuum of care.⁴² A systematic, thoughtful approach to considering key strategic elements in consultation with patients, families, communities, service providers, organizations, funders, policymakers and decision makers is necessary to deliver an effective realist palliative care programme. Complex behaviour change supported by implementation science methods may be needed.

Limitations of the study

Including the full variety of different models of care is a limitation of this review's sensitivity to detect unique differences. The heterogeneity of the study designs and measurement tools further reduced the ability to conduct a meaningful and rigorous meta-analysis, draw definite conclusions, or identify definitive causal associations between the interventions delivered, the delivery method, the frequency of delivery and the setting with the efficacy measures. However, such limitations may also be conceived as a potential strength, especially in terms of transferability, because our review reflects the diversity and pragmatism of real-world experience and constraints, thereby increasing specificity to support further discourse, especially in considering *how* to bridge the efficacy-effectiveness gap in designing, delivering

and evaluating palliative care in advanced heart failure across the different healthcare settings.

Several of the studies enrolled patients with moderately high KCCQ scores (indicating reasonable performance status and quality of life) or directly from an acute admission for advanced heart failure; this may have contributed to potentially non-statistically significant findings between groups in these studies because participants in both groups may be on a trajectory of improvement following adjustments to their clinical management in the hospital and a period of recuperation.

The delivery of healthcare services has been dramatically impacted by the recent COVID-19 pandemic, which has led to the increased incorporation of telehealth in treatment modalities. Whilst some studies had explicitly mentioned telehealth, these were restricted to phone consultation. We cannot ascertain from this review how different telehealth modalities may impact and facilitate greater palliative care in advanced heart failure.

Implications for clinical practice, policy and research

It is predicted that there will be a substantial rise in the heart failure burden in the Western world over the next 20 years. The key to improving outcomes for patients with heart failure is integrating palliative care with heart failure management.

We recommend the following:

- Consistency between international guidelines (e.g., American and European guidelines) about how and when palliative care should be integrated with cardiological care in advanced heart failure.
- Authors to include more nuanced, in-depth descriptions of the palliative care interventions, elements, theory/philosophy and models of care in advanced heart failure.
- Coupled with advancements in enabling technologies, future studies may wish to consider how complex multicomponent interventions may be facilitated with the support of digital, virtual and artificial intelligence.

Conclusions

People with advanced heart failure have a high mortality and complex symptom burden that lends itself to palliative care. Integrating palliative care into advanced heart failure management may significantly benefit patients and their carers whilst ensuring limited health resources are spent effectively and efficiently.

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Conflict of interest statement

This review forms part of PA's PhD thesis. The authors declare no other actual or potential conflict of interest with re-

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Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Table S1. PRISMA 2020 checklist.

Table S2. Search strategies.

Table S3. Quality assessment of the included studies.

Table S4. Reported primary and secondary outcome measures.

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