






Palliative care for people living with heart failure: European Association for Palliative Care Task Force expert position statement

Piotr Z. Sobanski ^{1*}, Bernd Alt-Epping², David C. Currow^{3,4}, Sarah J. Goodlin⁵, Tomasz Grodzicki⁶, Karen Hogg ⁷, Daisy J. A. Janssen ^{8,9}, Miriam J. Johnson ¹⁰, Małgorzata Krajnik¹¹, Carlo Leget ¹², Manuel Martínez-Sellés¹³, Matteo Moroni¹⁴, Paul S. Mueller ¹⁵, Mary Ryder ¹⁶, Steffen T. Simon^{17,18}, Emily Stowe ¹⁹, and Philip J. Larkin^{20,21}

¹Palliative Care Unit and Competence Centre, Department of Internal Medicine, Spital Schwyz, Waldeggstrasse 10, 6430 Schwyz, Switzerland; ²Department of Palliative Medicine, University Medical Center Göttingen Georg August University, Robertkochstrasse 40, 37075 Göttingen, Germany; ³University of Technology Sydney, Broadway, Ultimo, Sydney, 2007 New South Wales, Australia; ⁴Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT), Faculty of Health, University of Technology Sydney, Ultimo, Sydney, New South Wales, Australia; ⁵Department of Medicine-Geriatrics, Portland Veterans Affairs Medical Center and Patient-centered Education and Research, 3710 SW US Veterans Rd, Portland, 97239 OR, USA; ⁶Department of Internal Medicine and Gerontology, Jagiellonian University Medical College, 31-531 Kraków, Śniadeckich 10, Poland; ⁷Glasgow Royal Infirmary, Glasgow, UK; ⁸Department of Research and Education, CIRO, Hornerheide 1, 6085 NM Horn, The Netherlands; ⁹Department of Health Services Research, CAPHRI School for Public Health and Primary Care, Faculty of Health Medicine and Life Sciences, Maastricht University, Doboisdomein 30, 6229 GT, Maastricht, the Netherlands; ¹⁰Wolfson Palliative Care Research Centre, Allam Medical Building University of Hull, Cottingham Road, Hull, HU6 7RX, UK; ¹¹Department of Palliative Care, Collegium Medicum in Bydgoszcz, Nicolaus Copernicus University in Torun, Skłodowskiej-Curie 9, 85-094 Bydgoszcz, Poland; ¹²University of Humanistic Studies, Chair Care Ethics, Kromme Nieuwegracht 29, Utrecht, the Netherlands; ¹³Department of Cardiology, Hospital Universitario Gregorio Marañón, CIBERCV, Universidad Europea, Universidad Complutense, C/ Dr. Esquerdo, 46, 28007 Madrid, Spain; ¹⁴S.S.D. Cure Palliative, sede di Ravenna, AUSL Romagna, Via De Gasperi 8, 48121 Ravenna, Italy; ¹⁵Mayo Clinic Health System, Mayo Clinic College of Medicine and Science, 700 West Avenue South, La Crosse, 54601 Wisconsin, USA; ¹⁶School of Nursing, Midwifery & Health Systems, University College Dublin, Ireland St. Vincent's University Hospital Dublin, Belfield, Dublin 4, Ireland; ¹⁷Department of Palliative Medicine, Medical Faculty of the University of Cologne, Köln, Germany; ¹⁸Centre for Integrated Oncology Cologne/Bonn (CIO), Medical Faculty of the University of Cologne, Kerpen Strasse 62, 50924 Köln, Germany; ¹⁹St Clare Hospice, Hastingwood, Essex, UK; ²⁰Service des soins palliatifs Lausanne University Hospital, CHUV, Centre hospitalier universitaire vaudois, Lausanne Switzerland; and ²¹Institut universitaire de formation et de recherche en soins – IUFERS, Faculté de biologie et de médecine – FBM, Lausanne, Switzerland

Received 7 September 2018; revised 19 April 2019; editorial decision 2 July 2019; accepted 2 August 2019; online publish-ahead-of-print 29 August 2019

Abstract

Contrary to common perception, modern palliative care (PC) is applicable to all people with an incurable disease, not only cancer. PC is appropriate at every stage of disease progression, when PC needs emerge. These needs can be of physical, emotional, social, or spiritual nature. This document encourages the use of validated assessment tools to recognize such needs and ascertain efficacy of management. PC interventions should be provided alongside cardiologic management. Treating breathlessness is more effective, when cardiologic management is supported by PC interventions. Treating other symptoms like pain or depression requires predominantly PC interventions. Advance Care Planning aims to ensure that the future treatment and care the person receives is concordant with their personal values and goals, even after losing decision-making capacity. It should include also disease specific aspects, such as modification of implantable device activity at the end of life. The Whole Person Care concept describes the inseparability of the physical, emotional, and spiritual dimensions of the human being. Addressing psychological and spiritual needs, together with medical treatment, maintains personal integrity and promotes emotional healing. Most PC concerns can be addressed by the usual care team, supported by a PC specialist if needed. During dying, the persons' needs may change dynamically and intensive PC is often required. Following the death of a person, bereavement services benefit loved ones. The authors conclude that the inclusion of PC within the regular clinical framework for people with heart failure results in a substantial improvement in quality of life as well as comfort and dignity whilst dying.

Keyword

Palliative care • Heart failure

* Corresponding author. Tel: 0041 41 818 43 38; fax: 0041 41 818 40 12, E-mail: psoban@wp.pl

Disclaimer: The editors acknowledge that this position statement represents the opinion of the author and does not represent the opinions of the European Society of Cardiology, nor is it endorsed by the European Society of Cardiology.

Published on behalf of the European Society of Cardiology. All rights reserved. © The Author(s) 2019. For permissions, please email: journals.permissions@oup.com.

1. Introduction

Heart failure (HF) affects about 1–2% of the general adult population in high-income countries.¹ At least 5% of this group suffers from symptoms at minimal exercise or at rest [Class III or IV of HF according to New York Heart Association (NYHA) classification] despite optimal cardiologic management.^{2–4} People with advanced HF have a risk of premature death (80% of people with advanced HF die within 5 years) and report physical symptoms, psychosocial burdens, and spiritual needs similar to those reported by people with other advanced diseases, including cancer.^{5–7}

Scientific societies representing palliative care (PC), including the European Association for Palliative Care (EAPC), and cardiology, including the European Society of Cardiology recommend PC for people with advanced HF in order to improve their quality of life (QoL) and dying.^{1,8–14} QoL has hardly been considered as an endpoint in large multi-centre randomized trials, and the added value of PC provided along with optimal cardiologic treatment has only been shown recently in one single centre randomized study.¹⁵ Access to PC throughout the whole course of HF, accordingly to needs, has been advocated.¹⁶ The World Health Organisation has recently recognized access to PC for all people who need it as an essential criterion of Universal Health Coverage.¹⁷ Although heart disease has been included in the 20 health conditions most commonly resulting in either death or suffering severe enough to require PC intervention,¹⁸ and circulatory disease is the leading cause of death (34% of all deaths),¹⁹ only a minority of people with HF across Europe receive PC^{20–22} (merely 7% HF decedents compared with 50% of cancer patients had their PC needs recognized, and <1% of patients dying in hospices have HF as the primary diagnosis),²³ for a very short time (the mean time from PC referral to death is <2 weeks; significantly shorter than for people with cancer).²⁴ Improving access to PC for people with advanced HF might reduce their suffering and that of their loved ones, as well as decrease hospital readmissions.^{15,25–29}

The Board of the EAPC, recognizing the urgent need to improve the provision of PC for people with HF, has endorsed the initiative of professionals providing such care and approved the Task Force on Palliative Care for People with Heart Disease.³⁰ A group of multi-professional experts working in the field of PC and cardiology (physicians, nurses, ethicists, allied health professionals, and spiritual carers) from 10 countries has been charged on behalf of the EAPC with evaluating the existing data and current clinical practices with respect to PC for people living with HF. This position statement presents agreed opinions of these experts and has been approved by the EAPC Board for publication. The following topics will be discussed: basic definitions, symptom assessment, triggers for initiating PC, symptom management (breathlessness, pain, depression, and anxiety), advance care planning, spirituality and whole person care, addressing ethical dilemmas, adjustment of medical therapy, care for dying, and PC services.

2. Basic definitions

A variety of terms meaningful for this article are used internationally with varying interpretations. This, and a misperception amongst the lay public, patients, their families, and non-PC clinicians, often leads to belief that PC is only relevant to the last few weeks or days of life. This misperception is a major barrier to access PC for people with heart disease. A main aim of this article is to facilitate the correct understanding of the broad nature and wide applicability of PC for people living with HF. For clarity, key definitions for this document are therefore presented:

Palliative care is the active, total care for a person with incurable disease; that is, disease which may still respond to *disease-modifying* treatments, but is nonetheless progressive and life-shortening.³¹ PC is neither limited to a specific diagnosis, nor to a particular prognosis, and even if decline trajectories and patient characteristics differ among specific disease, the principle of PC, focusing on the improvement of the QoL, is universal. Ideally, PC should be introduced early on in the disease trajectory and increased as the disease progresses¹ or reduced/withdrawn if the condition improves (*Figure 1*). PC addresses symptoms and social, psychological, and spiritual problems.³¹ It affirms life and regards dying as a normal process; it aims to neither hasten nor postpone death. PC should be provided *alongside* optimal disease specific management and care.^{1,8,32}

Hospice care is a specific form of PC service dedicated to the whole person who approaches death and for those who love her/him. Care is focused on the individual's needs and personal choices, striving to offer freedom from pain, dignity, peace, and calm. It is not primarily aimed at saving life or finding a cure.³³ In Europe, hospice care is often provided by freestanding centres offering care in the patient's home or in a home-like in-patient setting. In the USA, a hospice is a specific insurance benefit dedicated to people who forgo life-prolonging therapies. In several countries 'hospice care' is used interchangeably with 'specialist PC'. This article refers to a broad spectrum of PC.

End of life (EoL) is the period preceding a person's natural death, characterized by the progression of a disease, which cannot be arrested by medical treatment. Depending on the person, her/his characteristics, the underlying disease and comorbidities different durations of expected survival are understood in the literature and policy in different countries as EoL—from several months until the last few days of life. EoL should be distinguished from active dying—a short period preceding imminent death, characterized by the waning of the physiological functions of a person and, limited to the last days or hours of life.³⁴

Transition of care is a change in the place, level, or goals of care. The main domains of care goals can be: cure, prolonging survival, optimizing function, improving comfort, achieving life goals, and supporting the family/caregiver. Transition of care is common and important during advanced disease.³⁴

Heart failure is the common end-pathway of many structural and functional cardiac diseases, which impair the ability of the ventricle(s) to fill and/or eject the blood. It is a clinical syndrome characterized by typical symptoms (e.g. breathlessness, ankle swelling, and fatigue) that may be accompanied by signs (e.g. elevated jugular venous pressure, pulmonary crackles, and peripheral oedema) caused by a structural and/or functional cardiac abnormality.¹

Comprehensive HF care is the integration of PC with guideline-directed HF management applied concurrently, with the focus varying according to needs, which change across time. It should be available to affected people and their caregivers throughout the whole course of patient's HF journey.³⁵ (*Figure 1*).

Advance care planning (ACP) is a process that enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate,³⁶ for the case of the loss of decision-making capacity.

3. Symptom assessment

The symptoms suffered by people with HF can be caused by HF itself [e.g. breathlessness, fatigue, and weakness (*Figure 2*)], comorbidities (e.g. musculoskeletal pain) and patients' general condition or treatment side

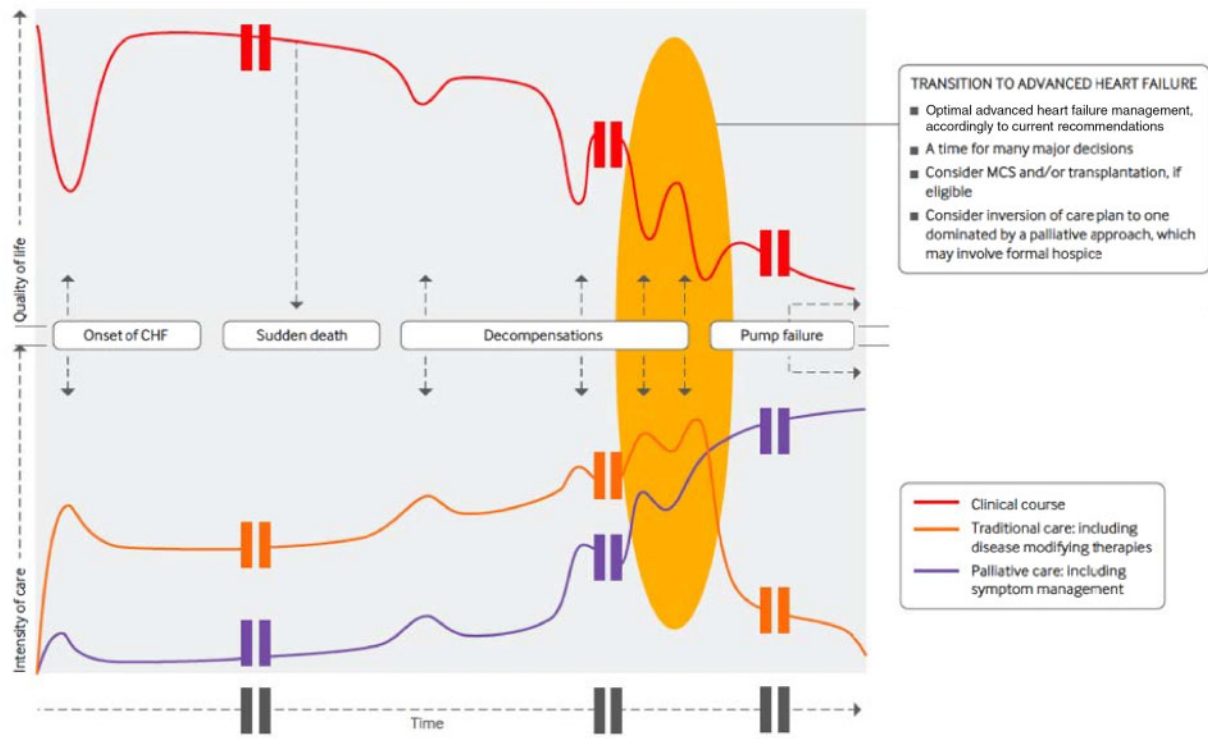


Figure 1 The clinical course of heart failure with associated types and intensities of available therapies (modified from reference 57 with further modification from reference 58). Reprinted with permission of the American Thoracic Society. Copyright © 2019 American Thoracic Society.

effects (e.g. deconditioning, nausea, constipation, depression, anxiety, sleep problems, confusion, and delirium).^{25,37,38} Symptoms that persist despite optimal guideline-directed cardiologic treatment should trigger a PC approach or involvement.³⁹ These symptoms should be treated with as much attention as improving heart function and prolonging survival. This is particularly pertinent in advanced disease, including those awaiting transplantation or ventricular assist device (VAD) implantation.^{40–42} Several symptoms that cause substantial suffering (e.g. depression, fatigue, tiredness, and poor appetite) may be regarded as unimportant given the seriousness of HF and, as a result, may be unaddressed. To ensure that patient-relevant causes of distress are identified and addressed, symptoms should be assessed systematically.⁴³ Extending the usual history by validated assessment tools increases the identification of symptoms 10-fold.⁴⁴ Any symptom can be assessed using the Numeric Rating Scale (NRS). Multi-symptom [the Edmonton Symptom Assessment Scale (ESAS)],^{6,43,45,46} or multidimensional [the Integrated Palliative care Outcome Scale (IPOS)⁴⁷] tools can be used to assess symptoms comprehensively. Repeating the assessments helps quantify changes in symptom burden and the effectiveness of treatment. The simplicity and widespread distribution of the ESAS favours its broader use in clinical practice. The burden caused by a given symptom depends on its intensity, impact on functional capacity, and on QoL. For breathlessness, unpleasantness (reflecting affective distress it causes) should be assessed additionally to its intensity.⁴⁸ Anxiety and depression can be assessed using the Hospital Anxiety and Depression Scale (HADS).^{1,49–51} Disease specific tools like the Kansas City Cardio-myopathy Questionnaire (KCCQ) (for which there is a short-form of 12 questions) or PC-specific

like Functional Assessment of Chronic Illness Therapy–Palliative Care scale (FACIT–Pal), can be used to evaluate factors that limit wellbeing and monitor the efficacy of management.^{15,45}

4. Triggers for initiating PC provision

HF guidelines reinforce the focus on PC as an option for patients with advanced/end-stage HF, or those who are at the EoL, indicating however that ideally, PC should be introduced early in the disease trajectory and increased as the disease progresses,^{1,8} so a needs and symptoms assessment-based approach is a more suitable model for integration of PC into cardiac care, than recognizing EoL.⁵² Reliance on prognostication as a trigger for the consideration of PC is ineffective due to the poor utility of current prognostic tools⁵³ and because PC needs do not correlate with prognosis.⁵⁴ Prognostic uncertainty should trigger rather than block assessing of PC needs.⁵⁵ As discussed above, symptom assessment tools may be helpful in this regard.⁵⁶

Conversations about the goals of care, assessment of PC needs and considerations of the need to include PC in the ongoing care can be initiated at annual HF review visits in less advanced stages of HF, or after each significant health-related events in more advanced stages⁵⁸ (Figure 3). Triggers for a PC approach or consultation should include distressing symptoms, existential distress, recurrent HF exacerbation, and progressive frailty or caregiver concerns.

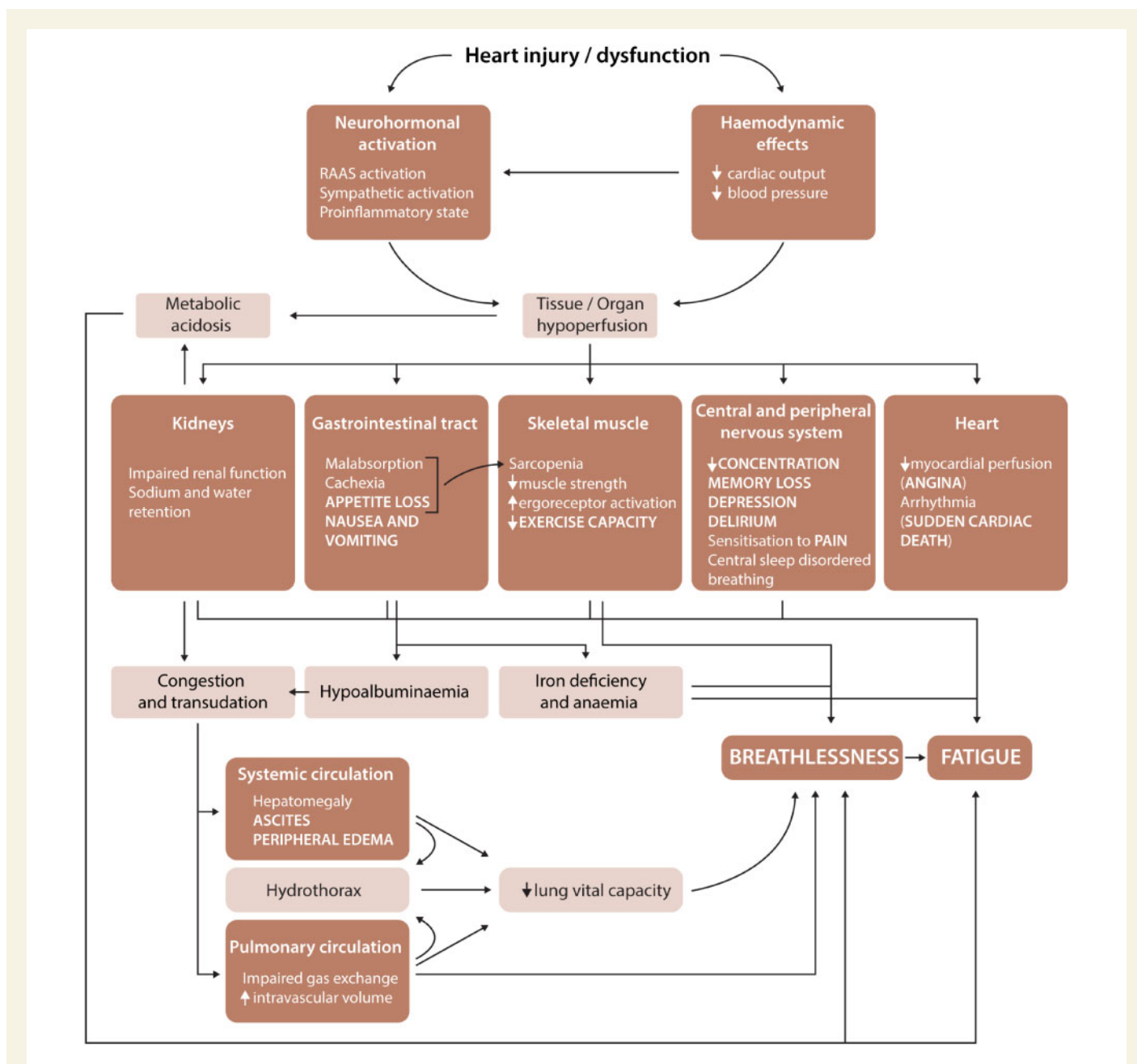
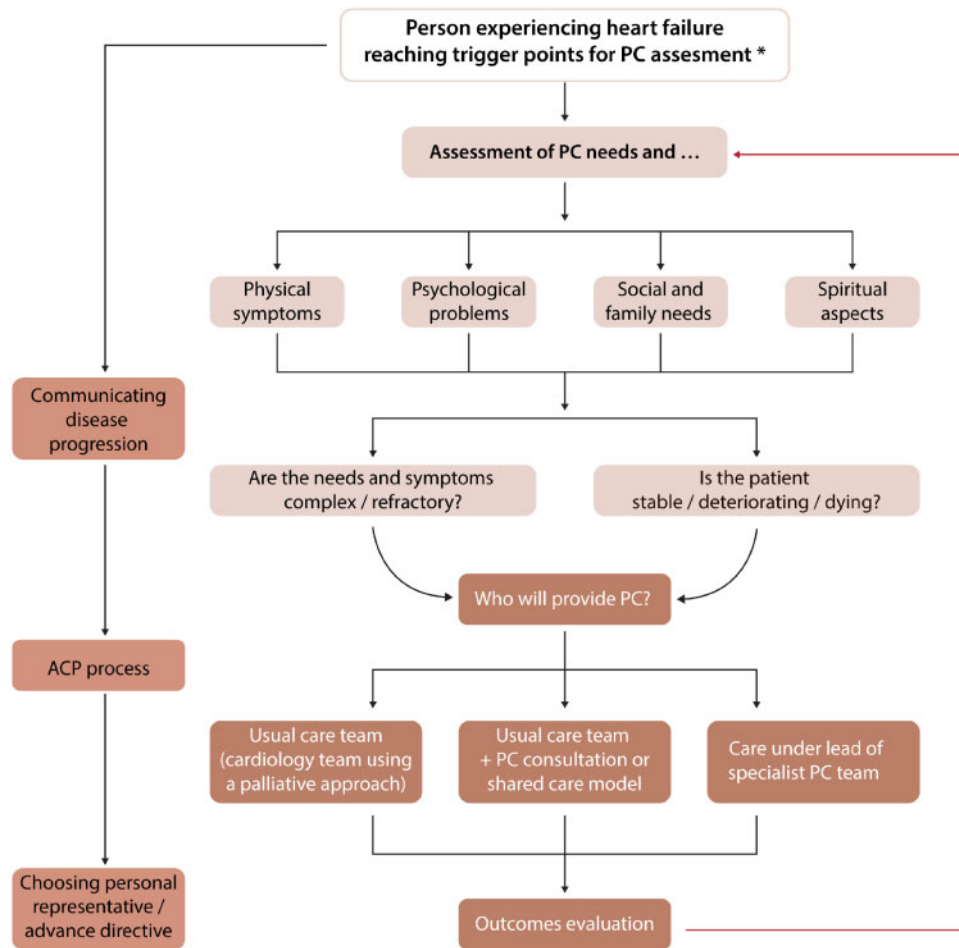


Figure 2 The pathophysiology of main heart failure symptoms, related to palliative care. (Most relevant symptoms marked with bold upper case.)

PC integration should start when the symptoms and problems begin to emerge and persist and be provided alongside disease modifying treatments. A needs assessment tool validated for people with HF: the Needs Assessment Tool: Progressive Disease-HF (NAT: PD-HF) can help to identify people who can benefit from PC.⁶⁰ This tool includes four major sections: the patient’s wellbeing; the caregiver’s ability to provide care; the caregiver’s wellbeing; and issues that should raise consideration of referral to specialist services such as the lack of a caregiver.⁵⁶ Each section has a series of prompts, which act as an aide to assess the level of concern about unmet needs (none, some, significant) and identify the action taken by the clinician (managed by the clinician, managed within the team, referral to other resources). People with HF are deemed to have important needs if they were assessed as

having ‘significant concern’ on any of the NAT:PD-HF patient wellbeing domains.³² This assessment tool is designed to be completed in less than a minute at the end of a consultation and, in cancer patients, has been shown to reduce the level of unmet needs without prolonging consultations. It has recently been translated and validated in Dutch, and translations into other languages are in progress.⁶¹ Supportive and PC Indicators Tool (SPICT) can help to identify people who may have PC needs based on the risk of deterioration and dying, although it neither identifies what those needs are nor triages corresponding action.⁶² A combination of tools allows for a variety of triggers to flag the need for re-negotiating goals of care.

Basic PC related definitions and key principles of PC relevant for care for people with HF are summarized in *Table 1*.



*Triggers for PC assessment

I. Significant change in heart failure trajectory:

- New HF (incidental HF) with refractory, severe symptoms before discharge
- Before ICD / CIED implantation or replacement
- Qualification for heart transplantation or mechanic circulatory support
- Consideration of high risk or high burden intervention or treatment
- After resuscitated sudden cardiac death
- Signs or symptoms of advanced HF: especially with risk markers or fulfilling criteria for referral to tertiary cardiac centres e.g., NYHA class III/IV, appetite/weight loss, physical wasting, initiation of intravenous inotropes, more than one unplanned hospitalization or visit due to decompensated HF within 12 months.

II. Periodic HF follow up or significant changes in health status :

- Periodic HF visit (in stable condition at least yearly check up)
- Essential changes in health status (new significant comorbidity)

III. Patient / family related factors:

- Desire for additional communication
- Request for excessive medical interventions
- Request by or excessive burden of relatives/informal caregivers
- Patient declining/dying with difficulties in acknowledging it
- Request to hasten death/suicidal statements
- Request of family or team caring for patient
- Substantial change in next of kin circumstances (like new illness or death of spouse, or caregiver)
- Declining ability to provide self-care

Figure 3 Palliative care provision for people with heart failure—flow chart.

Table 1 Principles of palliative care for people living with heart failure

Topic	Description	Clinical implications for care of people with heart failure
Palliative care	Active care often provided alongside disease modifying management; it should be introduced early in the disease trajectory and increased as the disease progress, on the basis of patient's and caregivers' needs.	Palliative care supplements optimal cardiologic treatment strategies by introducing interventions focused on addressing physical symptoms, psychosocial, and spiritual problems.
Hospice care	A specific form of PC service, providing care for people approaching death and those who love them	People with advanced heart failure, for whom further hospitalizations are no longer appropriate/not wanted, can receive appropriate care provided by specialist PC team in home like institutions.
End-of-life	Period of from several months until the last few days of life, characterized by continuous disease progression despite optimal cardiologic treatment.	Process of treatment goals adjusting, focusing more on care than curing. Stepwise preparedness for dying could be appropriate for some people with as their heart failure worsens.
Symptoms and problems assessment	Using validated symptoms/problems assessment tools: -increases the detectability of symptoms/problems, -allows evaluation effectiveness of treatment/interventions focused to alleviate them.	Multi-symptom ESAS (free available in over 30 languages ⁵⁹), multidimensional IPOS (evaluating physical symptoms, psychological and social problems), HADS, and PHQ-9 are validated tools that can be used to assess symptoms and problems in people with heart failure.
Triggers for initiating palliative care	Recognition of persisting symptoms or existence of unaddressed PC needs helps to recognize need for intensification of PC involvement.	Persistence of ongoing troublesome symptoms/problems despite optimal HF therapy should imply to start/intensify PC provision (as approach, involvement of specialist PC or referral). Tools assessing symptoms/problems (like ESAS, IPOS, HADS, PH-9) or comprehensive palliative care needs assessment tools (like NAT: PD-HF) can help to identify those with unmet needs, including caregivers.
Palliative Care services	PC may be delivered in any clinical care setting including inpatient and outpatient units and at the patient's own home: it encompasses a palliative approach, specialist PC consultation or involvement of specialist PC multi-disciplinary team.	Collaboration between cardiology and PC is pivotal to ensuring access to PC to all people living with HF throughout the whole course of disease, irrespective of their current place of care, accordingly to their needs. In the absence of any agreed service model, the cardiac team should at least have access to a PC specialist and <i>vice versa</i> as part of their extended teams.

ESAS, Edmonton Symptom Assessment System; HADS, Hospital Anxiety and Depression Scale; IPOS, Integrated Palliative care Outcome Scale; NAD: PD-HF, Assessment Tool: Progressive Disease-Heart Failure; PHQ-9, brief Patient Health Questionnaire.

5. Symptom management

5.1 Breathlessness

Breathlessness (dyspnoea) is the subjective experience of breathing discomfort or difficulty in breathing that consists of qualitatively distinct sensations that vary in intensity.⁴⁸ It can be acute, chronic, or episodic with the episodes usually superimposing on chronic (constantly present with usual fluctuations) difficulties in breathing. Episodic breathlessness is a severe worsening of breathlessness intensity or unpleasantness, beyond the usual fluctuations in the patient's perception.^{63–65} Breathlessness that persists despite optimal treatment of the underlying pathophysiology and results in disability is defined as a chronic breathlessness syndrome, which requires symptomatic management.^{66,67} Breathlessness is reported by almost 90% of people experiencing advanced HF and is usually present at minimal exertion or at rest, substantially limiting the patients' QoL and daily activities such as bathing or dressing.⁶⁸ Chronic breathlessness in people with HF can be related to haemodynamic status, skeletal myopathy and sarcopenia, chronic or acute comorbidities.^{16,69} In the case of breathlessness exacerbation, potentially reversible aggravating factors should be sought and if appropriate, specifically treated. After or parallel to optimizing the guidelines recommended treatment of HF (re-establishing and/or maintaining optimal volume status)^{1,9,12,14} and/or concomitant

disease, non-pharmacological and pharmacological symptomatic treatment should be pursued. Most studies on symptomatic/palliative breathlessness management have been performed on unselected cohorts, so conclusions with respect to efficacy and safety specific in a HF population should be drawn with caution. Appropriately tailored exercise helps to improve functional capacity and skeletal myopathy. A physiotherapeutic approach, including breathing training, neuro-electrical leg muscle stimulation, or use of a hand-fan and walking-aids are considered as potentially helpful. Relaxation, breathing-relaxation training, and psychological interventions can be tried.⁷⁰ Oxygen therapy can ameliorate breathlessness in hypoxemic patients, but the data do not support use in those who are only mildly hypoxemic or normoxaemic.⁷¹ Pharmacological symptomatic treatment of breathlessness is based on opioids. The evidence for their efficacy is strongest for people with stable chronic obstructive pulmonary disease (COPD).⁷² The beneficial effect of opioids on breathlessness probably does not depend on its aetiology,⁷³ but data on the short-term use of opioids in people with HF are conflicting and data for longer-term use are promising, but inconclusive.^{74–76}

Most studies on symptomatic breathlessness management have been performed using oral low-dose morphine. Oral low-dose sustained release morphine has recently had its licensed indication extended to chronic breathlessness due to COPD, HF or cancer by the Therapeutic

Goods Administration of Australia. Therefore this is the only drug and drug preparation anywhere in the world with a license for use in chronic breathlessness. Although the studies of morphine in HF give conflicting findings, based on the licensed dosing schedule morphine should be started at 10 mg per day, given to provide a steady state according to preparation (2.5 mg immediate release regularly four times daily; 5 mg modified release twice daily or 10 mg modified release once daily). In a dose increment study of people with a range of causes of breathlessness, a clinically important improvement occurred in 63% participants, 67% of responders benefited by 10 mg per day, 25% and 8% required dose escalation to 20 mg or 30 mg of morphine per day respectively.^{77,78} After the start of treatment or dose increment, the initial response, if present, is seen in the first 24 h, however the magnitude of improvement may grow during a week (up to doubling the effect). If the response is inadequate, dose increases should not occur for at least one week. Doses can be titrated to a maximum of 30 mg/24 h of oral morphine (or equivalent dose of other opioid) if appropriate; a dose which appears to be unrelated to excess mortality or hospital admission, at least in people with severe COPD.⁷⁹ In significant renal impairment (Stages 4 and 5 of chronic kidney disease i.e. GFR <30 mL/min), something quite common among people with advanced HF and older adults, morphine should be avoided, used with caution, and/or switched to another opioid not having active metabolites with renal excretion.⁸⁰ Other opioids are sometimes used for breathlessness management, but there are no published adequately powered, placebo-controlled data in people with HF for this indication for any, other than oxycodone, where there was no benefit over placebo.⁷⁴ Phase 2 studies with fentanyl show promise.⁸¹ It is unknown if the alleviation of breathlessness is a specific feature of morphine or a class effect.

The most recent Cochrane review of benzodiazepines demonstrated a lack of evidence either for or against benzodiazepines. None of the published studies were done in people with HF. As the use of benzodiazepines has been associated with increased risk of all-cause mortality in severe COPD and other morbidity such as falls, caution is advised. Benzodiazepines, if at all, should be used as second- or third-line therapy, in acute episodes when other measures have failed and anxiety significantly aggravates distress.^{79,82–85}

5.2 Pain

Pain is present in most patients with advanced HF. The prevalence of pain increases with age and functional class, reaching 89% in those with NYHA Class IV HF.^{86–88} At least moderate pain is reported by 61% of hospitalized HF patients, and pain at more than one site by 40%.^{6,89} Chronic pain, if inadequately treated (which occurs more frequently for people with HF than for those with cancer⁹⁰), degrades QoL^{87,91} and correlates with fatigue and depression.⁹² Untreated pain is also associated with more frequent hospital admissions due to HF-decompensation.⁹³ The involvement of PC services improves the burden of pain in in- and out-HF-patients.^{26,89} Pain can be of cardiac (ischaemic) or non-cardiac (musculoskeletal, or caused by dyspepsia, gout, peripheral vascular disease, oedematous legs, or tense ascites) origin.^{94–97} Appropriate management should be based on the likely pathophysiological mechanism of the pain, such as neuropathic, ischaemic, nociceptive, or inflammatory (for review see reference 98). Cardiac ischaemic pain is usually controlled with anti-anginal medication, but there are patients for whom this remains a severe problem despite optimal cardiologic treatment. Spinal cord stimulation might be considered in chronic refractory angina.^{99–102} Intravenous strong opioids, such as morphine, are recommended for the relief of severe anginal pain related to acute coronary

syndromes.¹⁰³ Opioids slow gastric emptying and might delay the absorption of orally administered antiplatelet agents. Administration of crushed tablets, prokinetic drugs, or parenteral loading are proposed to overcome this undesirable effect.^{104–106}

For chronic non-cancer pain, non-pharmacologic and non-opioid pharmacologic therapy are preferred.¹⁰⁷ Non-steroidal anti-inflammatory (NSAIDs) drugs increase fluid retention and should be avoided in patients with HF. Previously stable patients started on a NSAID have an increased risk of worsening HF.¹⁰⁸ Many people with HF also have renal dysfunction and take a loop diuretic and ACE inhibitor—adding NSAID increases renal strain, particularly in the older adult. Paracetamol appears to be safe in HF.¹⁰⁹ Topical NSAIDs might be tried; however, their safety has not been studied in HF patients. Data regarding the long-term use of strong opioids in chronic non-cancer pain are mixed overall and very limited in people with HF, and the risk of side effects and addiction should be carefully balanced in the decision to prescribe them. The opioids, if appropriate should be considered if pain persists despite non-pharmacological and non-opioid pharmacologic therapy and in the lowest dose for the shortest duration. In people with severely impaired renal function opioids with a safer metabolic profile, such as methadone, buprenorphine, or fentanyl, are preferred.

5.3 Depression and anxiety

The prevalence of depression among people with HF, especially in its advanced stage, is significantly higher than in the general population (up to 42% and 70% respectively vs. 20%).^{49,110} Depression is an important, modifiable risk factor of HF-related hospitalization and death, and independent negative prognostic indicator. It also contributes to overall poor QoL.^{1,49,110–112} The co-existence of depression results in poor self-care, decreased medication adherence, increased smoking, and decreased activity leading to deconditioning and weight gain.⁴⁹ In contrast, anxiety often considered in connection with depression, does not seem more prevalent in HF than in the general population and does not pose the same risks as depression.^{49,110,111,113,114} Anxiety is associated with poor physical functioning due to the inability of individuals to implement effective coping strategies.¹¹⁵

Depressive symptoms may overlap with HF symptoms, making the diagnosis of depression more complicated.¹¹⁶ A vicious cycle ensues between depression and HF. Depression causes the activation of the hypothalamus-pituitary-adrenal (HPA) axis, resulting in elevation of cortisol level.⁴⁹ Due to the association of depression with reduced functional performance and HF instability, it is recommended that all HF patients be assessed for depression and treated if appropriate.^{92,114,117,118} To date, there are no published guidelines on the treatment of depression for people with HF but a number of approaches have demonstrated the improvement of depressive symptoms, physical function, QoL, and self-management skills, but not overall outcome. An integrated approach from a multidisciplinary team is recommended. Cognitive behavioural therapy and aerobic exercise training seem to give promising results. Pharmacological interventions may be necessary for some patients to treat depression but also to inhibit excessive activation of the neuroendocrine HPA axis related to the depression.⁴⁹ The selection of efficient and safe antidepressants, however, is challenging. Selective serotonin uptake inhibitors (SSRI) and alfa2-antagonists (mirtazapine) are thought to be the safest group of antidepressants for patients with HF, but the evidence is limited.¹ However, similarly to Monoamine Oxidase Inhibitors (MAOIs), they can cause hypertension.⁴⁹ Tricyclic antidepressants (TCA) can provoke orthostatic hypotension, worsening of HF and arrhythmias, and should be avoided in HF.^{1,49} TCA and several

Table 2 Elements of palliative care management most relevant in care for people with heart failure

Topic	Description	Clinical implications for care people with heart failure
Breathlessness— palliative management	Breathlessness (at rest or at slight exertion) persisting despite continuously optimized cardiologic treatment should be recognized as indication for symptomatic management.	Multi-modal PC management including breathing-relaxation training, cognitive-behavioural therapy, walking aids, hand-held fans, and low-dose oral morphine may improve breathlessness intensity, unpleasantness and/or its impact of the functional capacity.
Pain management	Pain is a common symptom among people with HF, often being caused by concomitant disease and requires symptomatic management.	Local and non-pharmacological therapies should be applied if applicable. Opioids should be considered for pharmacologic pain management in people with heart failure, taking into account renal function. Systemic non-steroid anti-inflammatory drugs are contraindicated. Paracetamol is considered as free of undesirable cardiovascular side effects.
Depression management	Depression as common comorbidity, increasing risk of rehospitalization, and limiting the QoL	Depression should be actively sought. The management should be based on multi-modal interventions (including cognitive behavioural therapy) with the pharmacotherapy based on selected SSRI or mirtazapine, as second line intervention.

SSRI (like citalopram) and mirtazapine can cause the prolongation of QT interval predisposing the development of ventricular tachycardia.⁴⁹

Elements of PC management most relevant in care for people with HF are summarized in *Table 2*.

6. Advance care planning

ACP is an essential component of PC, it increases the completion of advance directives, discussion of EoL preferences, improves the concordance between preferred and received care and might decrease rehospitalizations at the EoL.^{119,120} Yet, ACP is often not done or poorly conducted in patients with HF. Preferences for life-sustaining treatments are often not discussed and documented resuscitation orders may differ from patient preferences.^{121,122} Clinicians caring for patients with HF report as important barriers to ACP: reluctance of patients or family members to accept a poor prognosis, difficulty of patients or family members to understand limitations or adverse effects of life-sustaining treatments, and discordance among family members about the goals of care.¹²³ Patients and family members report as important barriers to ACP: uncertainty about care they would desire, a preference to concentrate on staying alive than talking about EoL care and uncertainty about which doctor is responsible for EoL care.¹²⁴ Overcoming these barriers is important for the delivery of high-quality PC. In fact, ACP leads to open communication and may give patients feelings of relief and more control about their care.¹²⁵ ACP can be initiated at any stage of a person's life.³⁶ HF has an unpredictable trajectory. Moreover it increases the risk of cognitive impairment.^{126,127} Therefore, timely ACP, when the patient is able to participate in decision-making process should be a standard element of clinical care of people with HF and ACP should not be postponed until a patient approaches the end stage of his or her disease.³⁹ Nevertheless, identifying the appropriate moment in the course of the disease trajectory to start ACP can facilitate the process.¹²⁸

ACP should be considered at transition points during the course of the disease like hospital admission, symptom burden or functional decline despite optimal disease specific treatment, and the exhaustion of disease-oriented treatment options.¹²⁸ ACP should to be adapted to the patient's readiness to engage in ACP and should not be limited to discussing and recording life-sustaining treatment preferences.³⁶ Indeed,

communication about the goals of care and addressing the concerns of the patient and loved ones about the EoL are paramount. Communication with PC consultants or teams can help to identify or re-focus goals of care.^{53,129,130} Furthermore, previously documented goals of care and preferences regarding (life-sustaining) treatments and care should be updated regularly.^{131,132} Disease-specific aspects need to be addressed where appropriate, such as fear of dyspnoea at the EoL, reprogramming of an implantable cardioverter-defibrillator (ICD), so that it does not deliver shocks or withdrawing mechanical circulatory support delivered by VADs in the dying phase.¹³³

7. Whole person care and spirituality

The 'Whole Person Care' concept is based on treating the patient as an integral human being consisting of an inseparable body, mind, and spirit. Providing the very best medical service adjusted by psychological and spiritual care ensures that the person is addressed as an integral individual, even if optimally fixed medical issues cannot cure the disease. Addressing medical, psychological, and spiritual needs facilitates the process of growing personal integrity in response to even incurable disease or injury. This growth of the sense of integrity or wholeness is known as the process of healing. This concept recognizes the meaning of relations between all those participating/involved in the care for a person: a patient her- or himself, her or his family, friends and caring team,^{134,135} and reinforces the role of spirituality in a person's life in addition to physical and mental dimensions.

Spirituality has a multidimensional nature, and encompasses existential questions, values, and religious matters.¹³⁶ Although spirituality is recognized as one of the four dimensions in PC, research in this area is underdeveloped in terms of people with HF. Studies have shown that spirituality is an important and integral component of QoL and affects the person's ability to place their difficulties in perspective.¹³⁷ The spiritual needs of people with HF and their carers are influenced by hopelessness, isolation and altered self-image (loss of confidence, dependency, being a burden) associated with chronic illness and disability.¹³⁸ In advanced HF, spiritual wellbeing remains stable over time and varies

according to race and symptom distress.¹³⁹ Social and psychological decline both tend to track the physical decline, while spiritual distress fluctuates independently.¹⁴⁰ Experiencing spiritual peace better predicts mortality than functional status and comorbidity¹⁴¹ and greater spiritual well-being is associated with a lower incidence of depression.¹⁴² Hope and hopelessness are constructs conceptually linked with depression and spirituality. One study indicates that expression of hope positively affects cardiovascular outcomes.¹⁴³ Adjunct spiritual counselling appears to have a positive impact on QoL.¹⁴⁴

Besides the openness to the spiritual dimension of the patient, the whole person care approach focuses the clinician additionally on curing the illness, acknowledging the simultaneous process of internal healing, i.e., 'becoming psychologically and spiritually more integrated and whole; a phenomenon which enables persons to become more completely themselves and more fully alive'.¹⁴⁵ As the relationship between clinician and the patient has a mandatory meaning for healing, medical professionals should be therapeutically present (be on hand i.e. 'here and now'); enhance the patient's dignity and his or her sense of being a unique human being; be open to the spiritual needs of the patient and cooperate with specialists in spiritual care such as chaplains; be ready to assist in the patient's quest for meaning; and take care of her- or himself (including self-development, as a person and as a professional).

Spiritual care, which addresses an essential aspect of humanity, should be integrated into care for people with HF within a wide range of interventions and attitudes (from the therapeutic presence of clinicians to the professional help offered by specialists in spiritual care/chaplains, pastoral care workers).¹⁴⁶

8. Addressing ethical dilemmas

Four ethical principles encompass dilemmas that arise during the care of people with advanced HF: beneficence, non-maleficence, respect for patient autonomy, and justice.¹⁴⁷

Beneficence refers to the clinician's duty to act for the good or benefit of patients. Non-maleficence refers to the clinician's duty to prevent or avoid harming patients. Clinicians should weigh the anticipated benefits and harms of tests and treatments in the context of the patient's prognosis and health care-related goals. 'Double effect' is a well-established concept that allows clinicians to prescribe potentially harmful medications, procedures, or other treatments if the intent is good, the harmful effect is not intended, and the potential benefit of the treatment outweighs the harms.^{148,149}

Respect for patient autonomy requires that clinicians inform patients about their diseases and prognoses and the risks, benefits and alternatives to tests and treatments. Regarding patients with advanced HF, clinicians should inform those with implantable cardiac devices (e.g. ICDs) of the option of withdrawing device therapies or 'device's function deactivation' (e.g. reprogramming an ICD so that it does not deliver shocks).^{150,151} Clinicians should ensure patients' decisions to refuse or request the withdrawal of therapies are informed and respect such decisions.¹⁵¹ Respect for patient autonomy also underlies the process of ACP; clinicians should encourage patients with advanced HF to articulate and document their health care-related values, goals, and preferences.¹⁴⁹

Justice requires that clinicians base their testing and treatment recommendations on medical evidence and need, not on patient-specific characteristics (e.g. race and sex).¹⁵²

Ethical dilemmas that arise when caring for patients, occur when two or more of the aforementioned ethical principles conflict with each other. In patients with advanced HF decision making regarding

withholding or withdrawing life-sustaining treatments commonly precipitates these dilemmas. For example, if a patient's request for deactivation of an implantable cardiac device (i.e. withdrawal of device therapies) conflicts with the clinician's perceived beneficence and non-maleficence duties, the clinician should strive to resolve the dilemma (e.g. care conference). For situations in which such dilemmas cannot be resolved, ethics consultation and/or PC consultation should be considered. There are multiple approaches to ethics consultation.¹⁴⁹ However, most involve systematically reviewing the patient's medical situation and health care-related values, goals and preferences, QoL concerns, contextual features associated with specific case, and other factors. This approach usually defines the ethical dilemma and suggests a solution to resolve it.

9. Adjustment of medical therapy

Transition of the goals of care towards improving comfort and focusing on alleviating symptoms requires compassionate communication with patients and their families and loved ones and should be connected with a review of ongoing therapies with respect to their applicability. The validity of former indications for their use, after setting new goals, should be evaluated. Continuous optimization of HF therapy should be pursued, if only possible.^{19,14} Treatments relevant for symptom management or prevention should be continued if well tolerated and the dose regularly reviewed. Medicines prescribed for indications that are becoming no longer relevant should be considered for withdrawal. Therapies causing undesirable side effects and preventive drugs, especially those with a long delay in showing their benefits, such as statins, should be stopped.¹⁵³ However, routinely stopping any HF treatment when starting PC is inappropriate as many HF treatments, like angiotensin-converting enzyme inhibitors (ACEI) and angiotensin II type I receptor blockers (ARB) or angiotensin receptor-neprilysin inhibitors (ARNIs) as they may be important for symptom control.¹ Diuretics help maintain euvolaemia and control breathlessness and should not be withdrawn unless there is a clear reason to do so.¹⁵⁴ If the patient's condition deteriorates and fluid intake decreases, diuretic dose reduction could be appropriate. ACEI, ARB, or ARNI may help prevent pulmonary congestion but can cause symptomatic hypotension or the worsening of renal function. Dose reduction or discontinuation should be individually tailored.¹⁵⁵ Beta-blockers prevent tachycardia and/or angina, especially in patients with atrial fibrillation (and) prone to rapid ventricular rate. If they need to be reduced or stopped due to symptomatic hypotension or low cardiac output, this should be done gradually and digoxin may become an alternative.¹⁵⁵ In the case of significant bradycardia, beta-blockers should be reduced or stopped. Inotropic drugs may provide symptomatic benefits in advanced HF as part of a PC approach.^{1,14,156} The intermittent infusion of intravenous inotropes might sometimes be considered as PC intervention in inpatient institutions or even in home care to improve both symptoms and QoL.^{157–161} Inotropic drugs should not be started or continued in patients who are actively dying as they usually no longer provide any symptomatic benefits in such situations.¹⁶² If HF status improves, re-adjustment of therapy is then needed, including both restarting or increasing previously reduced doses of HF medication, and/or reducing or withdrawing PC medications (e.g. opioids after breathlessness or pain has improved).

In patients with an active ICD, the option of reprogramming the device at the EoL, to avoid potentially painful and usually futile shocks should be discussed in advance and, if agreed, performed timely.^{163,164} Anti-tachycardia pacing (ATP), which is generally well tolerated can be left active if the patient does not wish to deactivate all anti-tachyarrhythmic

Table 3 Palliative care interventions relevant in supporting people with heart failure

Topic	Description	Clinical implications for care people with heart failure
Advance care planning (ACP)	Process of compassionate communication on disease progression, helping individuals to define goals of care and preferences for future medical treatment and care, especially life-sustaining treatments. The conclusions of the ACP can be: the recording of advance directives or the indication of a personal representative for medical decision-making.	Disease-specific aspects need to be addressed as part of ACP, such as fear of breathlessness or uncontrolled pain at the end of life or management of an implantable cardioverter-defibrillator in the dying phase.
Addressing ethical dilemmas	Four ethical principles guide decision making that arise during the care of patients with advanced HF: beneficence, non-maleficence, respect for patient autonomy, and justice. Ethical dilemmas that arise when caring for patients usually occur when two or more ethical principles are in conflict with one another.	Respect for patient autonomy requires that clinicians inform people with advanced HF about their disease, prognosis and the risks, benefits and alternatives to tests and treatments including, in those with implantable cardiac devices, the option of withdrawing device therapies or 'device deactivation'. Respect for patient autonomy also underlies the process of ACP. For situations in which such dilemmas cannot be resolved, ethics consultation and/or PC consultation should be considered.
Spiritual care	Address religious needs, values, and the existential quest.	Spiritual care involves a wide range of interventions from the therapeutic presence of clinicians to the professional help offered by specialists in spiritual care/chaplains and pastoral care workers.
Adjusting medical therapy	The validity of former indications for drugs use, after setting new goals, should be continually evaluated.	Adjustment of medical therapy is a dynamic process that might include reducing doses/withdrawing of ongoing medication if it is no longer beneficial especially if causing unpleasant side effects or restarting/up-titrating previously withdrawn/reduced doses of drugs after improvement of clinical situation. The rule is: harm, burden or long-term effect = stop; symptom improvement = continue/adjust dose.
Care for the dying	Dying is a medical diagnosis and diagnosing it should be neither neglected nor postponed. Dying is a dynamic process, with changing symptoms and signs, requires if complex intensive palliative care.	Patients and their families should receive appropriate counselling, support, and reassurance. All interventions and therapies that do not contribute to the aim of preserving the highest level of comfort should be discontinued or not initiated. This also includes the deactivation of ICDs and other devices (if not performed previously).

therapies or if it might be in the patient's best interests. More complex are requests for pacemaker deactivation. Some patients fear that an active pacemaker can prolong dying. However, this therapy neither prolongs dying nor causes symptoms, furthermore anti-bradycardia pacing can improve QoL, even in patients who are dying, by preventing symptoms caused by low heart rate and/or pauses in heart rhythm (e.g. dizziness, presyncope, and breathlessness).^{165–167} Likewise, discontinuing the resynchronization component should be avoided, as the loss of pacemaker-mediated synchronization can precipitate HF-related symptoms.^{151,168} A multidisciplinary approach should be considered including PC and cardiology, and ethics if needed, when patients or their caregivers request deactivation of antibradycardia or resynchronization pacing.

10. Care for dying

About 60–70% of deaths in patients with HF have a cardiovascular cause, with HF-related death being either sudden or caused by progressive pump failure.^{169–171} For this reason, a team caring for people with HF should be familiar with diagnosing dying, caring for the dying, looking after the bereaved, and communicating about these issues. Diagnosing dying should be based on a multidisciplinary team discussion, in order to align the clinical perceptions of different professions.^{172,173} During the dying phase, progressive weakness and immobilization, loss of interest in

eating and drinking, cognitive impairment with diminishing verbal communication, changes in breathing pattern, and existential suffering might occur.^{174–176} Dying is a dynamic process characterized by changes in diagnostic appraisal, as well as physical, psychosocial, and/or spiritual needs of the patient and their family and loved ones.

Many people prefer to die at home, but 60–80% of all patients will die in institutions like hospitals, nursing homes, residential homes, and hospices.^{177–179} The preference with respect to place of care whilst dying can change during the course of the disease.^{180,181} The presence of a family caregiver who supports a patient's wish to die at home is one of the most important factors enabling a home death.^{177,182–184} Therefore, counselling, support, reassurance, and encouragement of relatives should be a major component of psychosocial care for patients and their families.¹⁸⁵ Earlier ACP contributes to realizing patient preferences.^{186–190}

When dying occurs, moist breathing (a 'death rattle') and confusion are common.¹⁹¹ If for any reason ICD has not been deactivated previously, and unwanted ICD shocks occur, a magnet can be taped over the device generator to prevent further shocks and perform electronic deactivation if possible.^{150,151,192–195}

All diagnostic, therapeutic, and nursing interventions that do not contribute to the aim of preserving the highest level of comfort should be discontinued or not initiated.^{185,196}

Palliative Care interventions most relevant in supporting people living with HF are summarized in *Table 3*.

11. PC services

An interdisciplinary approach encompasses the patient, her or his family, and loved ones and addresses PC needs wherever the patient is—at home or in institution. PC is divided into generic and specialist PC.^{18,31} Generic PC, termed the 'PC approach', is provided by all health professionals, who have basic PC training and incorporate PC principles into routine patient care. Specialist PC is provided by a multi-professional team for whom PC is the core practice and who has specialist training in PC. Specialist PC is needed for patients with needs or problems that are complex and/or persist despite generic PC.¹⁹⁷ PC should be provided alongside optimal disease specific management and care.^{1,8,32}

The complex nature of the needs and symptoms experienced by people with HF require multi-disciplinary collaboration between cardiology and PC.^{1,198} Both HF and palliative management need to be regularly reviewed and optimized. Most PC concerns should be within the skills of the usual care teams (cardiology, primary care, care of older adults), supported by a specialist PC for education, training, and clinical care if needed. For this reason, it could be reasonable to have a PC team, or at least a PC specialist in the cardiac team, and a cardiologist in the PC team. The PC team usually encompasses physicians, nurses, allied health professionals (AHPs), and chaplains, sometimes being supported by pharmacists and ethicists. The term AHP includes psychologists, pharmacists, physiotherapists, dietitians, speech and language therapists, occupational therapists, and social workers. Each discipline/profession plays a role in addressing patients' and relatives' PC needs. AHPs provide a rehabilitative approach, energy conservation techniques, enablement, self-management, and self-care.¹⁹⁹ Physiotherapy and occupational therapy-led interventions are especially important for non-pharmacological breathlessness management^{199–201} and the improvement of functional ability.^{202–204} Occupational therapists have core skills in non-pharmacological fatigue and anxiety management, along with the assessment and provision of equipment to maintain function and optimize QoL.²⁰⁵ PC provides as well bereavement service to support these who lost a loved one.

Despite the promising evidence supporting the involvement of multi-disciplinary PC in the care of people with HF,^{15,26,28,29} there have been no trials to test which model of service provision is the most effective, although the use of an integrated approach based on the identification and triage of problems is promising.⁵⁵ Services may be led by cardiologists, PC specialists, or jointly, and include common core components of care.^{206–211}

12. Conclusions

PC improves the QoL of many people living with HF, their families and loved ones. For most, generic PC along with optimal HF care is all that is required and can be provided by the core team (cardiology, primary care, or care of older adults) with access to specialist PC as needed. The most important step in the improvement of PC provision for people with HF is the proper understanding of a broad spectrum of PC services and the recognition of the PC needs they have. Symptom management, support in decision-making, communication including disease progression and EoL issues, advance care planning as well as addressing psychosocial and spiritual problems are the fields PC is focused on. PC should complement cardiologic care, and not be seen as an alternative to it. A responsive integrated cardiac and PC for all patients with HF when

needed regardless of prognosis should be the landmark of modern comprehensive care for people with heart disease.

Acknowledgements

The authors thank Lourdes Rexach from the Unidad de Cuidados Paliativos Hospital Universitario Ramón y Cajal, Madrid, Spain, and Luis Parente Martins from the Centro Hospitalar Lisboa Norte-Portugal for their participation in the reviewing process of the position statement. The authors also thank Louise Bellersen from Radboud University Nijmegen the Netherlands, David Oliver from the University of Kent, UK, Otmar Pfister from the University Hospital in Basel, Switzerland, and Ruthmarijke Smeding from Switzerland for their contribution to the earlier stages of the Taskforce work.

Conflict of interest: The authors P.Z.S., B.A.-E., S.J.G., K.H., M.J.J., C.L., M.M.-S., M.M., S.T.S., E.S., and P.J.L. have nothing to disclose. D.C.C. reports he is an unpaid member of an advisory board for Helsinn Pharmaceuticals, is a consultant to Specialised Therapeutics and Mayne Pharma, and received intellectual property payments from Mayne Pharma. T.G. reports personal fees from Servier, Krka, Polpharma, Abbott, outside the submitted work. D.J.A.J. reports personal fees from Boehringer Ingelheim, Novartis, AstraZeneca, outside the submitted work. M.K. reports personal fees from Mundipharma, Takeda, Teva, Stada, Angellini, Molteni, Pfeizer, outside the submitted work. P.S.M. reports other fees from Boston Scientific Patient Safety Advisory Board, other from NEJM Journal Watch General Medicine, other fees from Medtronic Medical Education, outside the submitted work. M.R. reports she is member of International Committee of Medical Journal Editors.

References

1. Ponikowski P, Voors AA, Anker SD, Bueno H, Cleland JG, Coats AJ, Falk V, Gonzalez-Juanatey JR, Harjola VP, Jankowska EA, Jessup M, Linde C, Nihoyannopoulos P, Parissis JT, Pieske B, Riley JP, Rosano GM, Ruilope LM, Ruschitzka F, Rutten FH, van der Meer P; Authors/Task Force Members. 2016 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure: the Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC) developed with the special contribution of the Heart Failure Association (HFA) of the ESC. *Eur Heart J* 2016;**37**:2129–2200.
2. Abouezzeddine OF, Redfield MM. Who has advanced heart failure? Definition and epidemiology. *Congest Heart Fail* 2011;**17**:160–168.
3. Chaudhry SP, Stewart GC. Advanced heart failure: prevalence, natural history, and prognosis. *Heart Fail Clin* 2016;**12**:323–333.
4. Creamer A, Homer S, Pudlo M, Daniel C, Bionat S, Bhimaraj A. Prevalence of advanced heart failure utilizing the latest published definitions yields higher than previously published data. *J Card Fail* 2015;**21**:S68.
5. Luddington L, Cox S, Higginson I, Livesley B. The need for palliative care for patients with non-cancer diseases: a review of the evidence. *Int J Palliat Nurs* 2001;**7**:221–226.
6. O'Leary N, Murphy NF, O'Loughlin C, Tiernan E, McDonald K. A comparative study of the palliative care needs of heart failure and cancer patients. *Eur J Heart Fail* 2009;**11**:406–412.
7. Norton C, Georgiopoulou VV, Kalogeropoulos AP, Butler J. Epidemiology and cost of advanced heart failure. *Prog Cardiovasc Dis* 2011;**54**:78–85.
8. Yancy CW, Jessup M, Bozkurt B, Butler J, Casey DE Jr, Drazner MH, Fonarow GC, Geraci SA, Horwich T, Januzzi JL, Johnson MR, Kasper EK, Levy WC, Masoudi FA, McBride PE, McMurray JJ, Mitchell JE, Peterson PN, Riegel B, Sam F, Stevenson LW, Tang WH, Tsai EJ, Wilkoff BL. 2013 ACCF/AHA guideline for the management of heart failure: executive summary: a report of the American College of Cardiology Foundation/American Heart Association Task Force on practice guidelines. *Circulation* 2013;**128**:1810–1852.
9. Yancy CW, Jessup M, Bozkurt B, Butler J, Casey DE Jr, Colvin MM, Drazner MH, Filippatos G, Fonarow GC, Givertz MM, Hollenberg SM, Lindenfeld J, Masoudi FA, McBride PE, Peterson PN, Stevenson LW, Westlake C; Writing Committee Members. 2016 ACC/AHA/HFSA Focused Update on New Pharmacological Therapy for Heart Failure: an Update of the 2013 ACCF/AHA Guideline for the Management of Heart Failure: a report of the American College of Cardiology/

- American Heart Association Task Force on Clinical Practice Guidelines and the Heart Failure Society of America. *Circulation* 2016;**134**:e282–293.
10. Fang JC, Ewald GA, Allen LA, Butler J, Westlake Canary CA, Colvin-Adams M, Dickinson MG, Levy P, Stough WG, Sweitzer NK, Teerlink JR, Whellan DJ, Albert NM, Krishnamani R, Rich MW, Walsh MN, Bonnell MR, Carson PE, Chan MC, Dries DL, Hernandez AF, Hershberger RE, Katz SD, Moore S, Rodgers JE, Rogers JG, Vest AR, Givertz MM. Advanced (stage D) heart failure: a statement from the Heart Failure Society of America Guidelines Committee. *J Card Fail* 2015;**21**: 519–534.
 11. Jaarsma T, Beattie JM, Ryder M, Rutten FH, McDonagh T, Mohacs P, Murray SA, Grodzicki T, Bergh I, Metra M, Ekman I, Angermann C, Leventhal M, Pitsis A, Anker SD, Gavazzi A, Ponikowski P, Dickstein K, Delacretaz E, Blue L, Strasser F, McMurray J. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail* 2009;**11**:433–443.
 12. Ezekowitz JA, O'Meara E, McDonald MA, Abrams H, Chan M, Ducharme A, Giannetti N, Grzeslo A, Hamilton PG, Heckman GA, Howlett JG, Koshman SL, Lepage S, McKelvie RS, Moe GW, Rajda M, Swiggum E, Virani SA, Zieroth S, Al-Hesayen A, Cohen-Solal A, D'Astous M, De S, Estrella-Holder E, Frenes S, Green L, Haddad H, Harkness K, Hernandez AF, Kous S, LeBlanc MH, Masoudi FA, Ross HJ, Roussin A, Sussex B. 2017 Comprehensive update of the Canadian Cardiovascular Society guidelines for the management of heart failure. *Can J Cardiol* 2017;**33**:1342–1433.
 13. National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand (Chronic Heart Failure Guidelines Expert Writing Panel). *Guidelines for the Prevention, Detection and Management of Chronic Heart Failure in Australia. Updated October 2011*. https://www.heartfoundation.org.au/images/uploads/publications/Chronic_Heart_Failure_Guidelines_2011.pdf (2 August 2019, date last accessed).
 14. Crespo-Leiro MG, Metra M, Lund LH, Milicic D, Costanzo MR, Filippatos G, Gustafsson F, Tsui S, Barge-Caballero E, De Jonge N, Frigerio M, Hamdan R, Hasin T, Hulsmann M, Nalbantgil S, Potena L, Bauersachs J, Gkouziouta A, Ruhparwar A, Ristic AD, Straburzynska-Migaj E, McDonagh T, Seferovic P, Ruschitzka F. Advanced heart failure: a position statement of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail* 2018;**20**:1505–1535.
 15. Rogers JG, Patel CB, Mentz RJ, Granger BB, Steinhauser KE, Fiuzat M, Adams PA, Speck A, Johnson KS, Krishnamoorthy A, Yang H, Anstrom KJ, Dodson GC, Taylor DH Jr, Kirchner JL, Mark DB, O'Connor CM, Tulsy JA. Palliative care in heart failure: the PAL-HF randomized, controlled clinical trial. *J Am Coll Cardiol* 2017;**70**: 331–341.
 16. Goodlin SJ. Palliative care in congestive heart failure. *J Am Coll Cardiol* 2009;**54**: 386–396.
 17. https://www.who.int/health_financing/universal_coverage_definition/en/ (2 August 2019, date last accessed).
 18. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, Arreola-Ornelas H, Gómez-Dantés O, Rodriguez NM, Alleyne GAO, Connor SR, Hunter DJ, Lohman D, Radbruch L, del Rocio Sáenz Madrigal M, Atun R, Foley KM, Frenk J, Jamison DT, Rajagopal MR, Knaul FM, Farmer PE, Abu-Saad Huijjer H, Alleyne GAO, Atun R, Binagwaho A, Bošnjak SM, Clark D, Cleary JF, Cossio Díaz JR, De Lima L, Foley KM, Frenk J, Goh C, Goldschmidt-Clermont PJ, Gospodarowicz M, Gwyther L, Higginson IJ, Hughes-Hallett T, Hunter DJ, Jamison DT, Krakauer EL, Lohman D, Luyirika EBK, Medina Mora ME, Mwangi-Powell FN, Nishtar S, O'Brien ME, Radbruch L, Rajagopal MR, Reddy KS, del Rocio Sáenz Madrigal M, Salerno JA, Bhadelia A, Allende S, Arreola-Ornelas H, Bhadelia N, Calderon M, Connor SR, Fan VY, Gómez-Dantés O, Jiménez J, Ntizimira CR, Perez-Cruz PE, Salas-Herrera IG, Spence D, Steedman MR, Verguet S, Downing JD, Paudel BD, Elsner M, Gillespie JA, Hofman KJ, Jiang Kwete X, Khanh QT, Lorenz KA, Méndez Carniado O, Nugent R, Rodriguez NM, Wroe EB, Zimmerman C. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *The Lancet* 2018;**391**:1391–1454.
 19. Writing Group M, Mozaffarian D, Benjamin EJ, Go AS, Arnett DK, Blaha MJ, Cushman M, Das SR, de Ferranti S, Despres JP, Fullerton HJ, Howard JV, Huffman MD, Isasi CR, Jimenez MC, Judd SE, Kissela BM, Lichtman JH, Lisabeth LD, Liu S, Mackey RH, Magid DJ, McGuire DK, Mohler ER, 3rd Moy CS, Muntner P, Mussolino ME, Nasir K, Neumar RW, Nichol G, Palaniappan L, Pandey DK, Reeves MJ, Rodriguez CJ, Rosamond W, Sorlie PD, Stein J, Towfighi A, Turan TN, Virani SS, Woo D, Yeh RW, Turner MB; American Heart Association Statistics Committee, Stroke Statistics Subcommittee. Heart Disease and Stroke Statistics-2016 Update: a report from the American Heart Association. *Circulation* 2016;**133**:e38–360.
 20. den Herder-van der Eerden M, Ebenau A, Payne S, Preston N, Radbruch L, Linge-Dahl L, Csikos A, Busa C, Van Beek K, Groot M, Vissers K, Hasselaar J. Integrated palliative care networks from the perspectives of patients: a cross-sectional explorative study in five European countries. *Palliat Med* 2018;**26**:29216318756812.
 21. Cheang MH, Rose G, Cheung CC, Thomas M. Current challenges in palliative care provision for heart failure in the UK: a survey on the perspectives of palliative care professionals. *Open Heart* 2015;**2**:e000188.
 22. Gadoud A, Kane E, Macleod U, Ansell P, Oliver S, Johnson M. Palliative care among heart failure patients in primary care: a comparison to cancer patients using English family practice data. *PLoS One* 2014;**9**:e113188.
 23. Sleeman KE, Davies JM, Verne J, Gao W, Higginson IJ. The changing demographics of inpatient hospice death: population-based cross-sectional study in England, 1993–2012. *Palliat Med* 2016;**30**:45–53.
 24. Beernaert K, Cohen J, Deliens L, Devroey D, Vanthomme K, Pardon K, Van den Block L. Referral to palliative care in COPD and other chronic diseases: a population-based study. *Respir Med* 2013;**107**:1731–1739.
 25. Evangelista LS, Lombardo D, Malik S, Ballard-Hernandez J, Motie M, Liao S. Examining the effects of an outpatient palliative care consultation on symptom burden, depression, and quality of life in patients with symptomatic heart failure. *J Card Fail* 2012;**18**:894–899.
 26. Sidebottom AC, Jorgenson A, Richards H, Kirven J, Sillah A. Inpatient palliative care for patients with acute heart failure: outcomes from a randomized trial. *J Palliat Med* 2015;**18**:134–142.
 27. Wiskar K, Celi LA, Walley KR, Fruhstorfer C, Rush B. Inpatient palliative care referral and 9-month hospital readmission in patients with congestive heart failure: a linked nationwide analysis. *J Intern Med* 2017;**282**:445–451.
 28. Brannstrom M, Boman K. Effects of person-centred and integrated chronic heart failure and palliative home care. PREFER: a randomized controlled study. *Eur J Heart Fail* 2014;**16**:1142–1151.
 29. Wong FKY, Lee P, Lam P-T, Ng JSC, Sham M. Effects of a transitional palliative care model on patients with end-stage heart failure: a randomised controlled trial. *Heart* 2016;**102**:1100–1108.
 30. European Association for Palliative Care Task Force on Palliative Care for People with Heart Disease. <https://www.eapcnet.eu/eapc-groups/task-forces/heart-disease> (2 August 2019, date last accessed).
 31. <https://www.eapcnet.eu/about-us/what-we-do> (May 2019, date last accessed).
 32. Campbell RT, Petrie MC, Jackson CE, Jhund PS, Wright A, Gardner RS, Sonecki P, Pozzi A, McSkimming P, McConnachie A, Finlay F, Davidson P, Denvir MA, Johnson MJ, Hogg KJ, McMurray J. Which patients with heart failure should receive specialist palliative care? *Eur J Heart Fail* 2018;**20**:1338–1347.
 33. Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe. *Eur J Palliat Care* 2009;**16**:278–289.
 34. Hui D, Nooruddin Z, Didwaniya N, Dev R, De La Cruz M, Kim SH, Kwon JH, Hutchins R, Liem C, Bruera E. Concepts and definitions for “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care”: a systematic review. *J Pain Symptom Manage* 2014;**47**:77–89.
 35. Goodlin SJ, Hauptman PJ, Arnold R, Grady K, Hershberger RE, Kutner J, Masoudi F, Spertus J, Dracup K, Cleary JF, Medak R, Crispell K, Pina I, Stuart B, Whitney C, Rector T, Teno J, Renlund DG. Consensus statement: palliative and supportive care in advanced heart failure. *J Card Fail* 2004;**10**:200–209.
 36. Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Driekamer MA, Droger M, van der Heide A, Heyland DK, Houttekier D, Janssen DJA, Orsi L, Payne S, Seymour J, Jox RJ, Korffage IJ; European Association for Palliative Care. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol* 2017;**18**:e543–e551.
 37. Bekelman DB, Rumsfeld JS, Havranek EP, Yamashita TE, Hutt E, Gottlieb SH, Dy SM, Kutner JS. Symptom burden, depression, and spiritual well-being: a comparison of heart failure and advanced cancer patients. *J Gen Intern Med* 2009;**24**:592–598.
 38. Janssen DJ, Spruit MA, Wouters EF, Schols JM. Daily symptom burden in end-stage chronic organ failure: a systematic review. *Palliat Med* 2008;**22**:938–948.
 39. Whellan DJ, Goodlin SJ, Dickinson MG, Heidenreich PA, Jaenicke C, Stough WG, Rich MW; Quality Of Care Committee, Heart Failure Society of America. End-of-life care in patients with heart failure. *J Card Fail* 2014;**20**:121–134.
 40. McKenna M, Clark SC. Palliative care in cardiopulmonary transplantation. *BMJ Support Palliat Care* 2015;**5**:427–434.
 41. Schwarz ER, Baraghoush A, Morrissey RP, Shah AB, Shinde AM, Phan A, Bharadwaj P. Pilot study of palliative care consultation in patients with advanced heart failure referred for cardiac transplantation. *J Palliat Med* 2012;**15**:12–15.
 42. Goldstein NE, May CW, Meier DE. Comprehensive care for mechanical circulatory support: a new frontier for synergy with palliative care. *Circ Heart Fail* 2011;**4**: 519–527.
 43. Alpert CM, Smith MA, Hummel SL, Hummel EK. Symptom burden in heart failure: assessment, impact on outcomes, and management. *Heart Fail Rev* 2017;**22**:25–39.
 44. Homs J, Walsh D, Rivera N, Rybicki LA, Nelson KA, Legrand SB, Davis M, Naughton M, Gvozdzian D, Pham H. Symptom evaluation in palliative medicine: patient report vs systematic assessment. *Support Care Cancer* 2006;**14**:444–453.
 45. Ezekowitz J, Thai V, Hodnefeld T, Sanderson L, Cujec B. The correlation of standard heart failure assessment and palliative care questionnaires in a multidisciplinary heart failure clinic. *J Pain Symptom Manage* 2011;**42**:379–387.
 46. Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991;**7**:6–9.
 47. Kane PM, Daveson BA, Ryan K, Ellis-Smith CI, Mahon NG, McAdam B, McQuillan R, Tracey C, Howley C, O'Gara G, Raleigh C, Higginson IJ, Koffman J, Murtagh F. Feasibility and acceptability of a patient-reported outcome intervention in chronic heart failure. *BMJ Support Palliat Care* 2017;**7**:470–479.
 48. Parshall MB, Schwartzstein RM, Adams L, Banzett RB, Manning HL, Bourbeau J, Calverley PM, Gift AG, Harver A, Lareau SC, Mahler DA, Meek PM, O'Donnell DE; American Thoracic Society Committee on Dyspnea. An official American Thoracic

- Society statement: update on the mechanisms, assessment, and management of dyspnea. *Am J Respir Crit Care Med* 2012;**185**:435–452.
49. Ghosh RK, Ball S, Prasad V, Gupta A. Depression in heart failure: intricate relationship, pathophysiology and most updated evidence of interventions from recent clinical studies. *Int J Cardiol* 2016;**224**:170–177.
 50. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;**67**:361–370.
 51. Holly D, Sharp J. Distress thermometer validation: heart failure. *Br J Cardiac Nurs* 2012;**7**:595–602.
 52. McKelvie RS, Moe GW, Cheung A, Costigan J, Ducharme A, Estrella-Holder E, Ezekowitz JA, Floras J, Giannetti N, Grzeslo A, Harkness K, Heckman GA, Howlett JG, Kouz S, Leblanc K, Mann E, O'Meara E, Rajda M, Rao V, Simon J, Swiggum E, Zieroth S, Arnold JM, Ashton T, D'Astous M, Dorian P, Haddad H, Isaac DL, Leblanc MH, Liu P, Sussex B, Ross HJ. The 2011 Canadian Cardiovascular Society heart failure management guidelines update: focus on sleep apnea, renal dysfunction, mechanical circulatory support, and palliative care. *Can J Cardiol* 2011;**27**:319–338.
 53. Bakitas M, Macmartin M, Trzepakowski K, Robert A, Jackson L, Brown JR, Dionne-Odom JN, Kono A. Palliative care consultations for heart failure patients: how many, when, and why? *J Card Fail* 2013;**19**:193–201.
 54. Girgis A, Johnson C, Currow D, Waller A, Kristjanson L, Mitchell G, Yates P, Neil A, Kelly B, Tattersall M, Bowman D. *Palliative Care Needs Assessment Guidelines. The Centre for Health Research & Psycho-Oncology*. Newcastle, NSW; 2006.
 55. Braun LT, Grady KL, Kutner JS, Adler E, Berlinger N, Boss R, Butler J, Enguidanos S, Friebert S, Gardner TJ, Higgins P, Holloway R, Konig M, Meier D, Morrissey MB, Quest TE, Wiegand DL, Coombs-Lee B, Fitchett G, Gupta C, Roach WH Jr. Palliative care and cardiovascular disease and stroke: a policy statement from the American Heart Association/American Stroke Association. *Circulation* 2016;**134**:e198–225.
 56. Waller A, Girgis A, Davidson PM, Newton PJ, Lecathelinais C, Macdonald PS, Hayward CS, Currow DC. Facilitating needs-based support and palliative care for people with chronic heart failure: preliminary evidence for the acceptability, inter-rater reliability, and validity of a needs assessment tool. *J Pain Symptom Manage* 2013;**45**:912–925.
 57. Lanken PN, Terry PB, Delisser HM, Fahy BF, Hansen-Flaschen J, Heffner JE, Levy M, Malarski RA, Osborne ML, Prendergast TJ, Rocker G, Sibbald WJ, Wilfond B, Yankaskas JR. An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. *Am J Respir Crit Care Med* 2008;**177**:912–927.
 58. Allen LA, Stevenson LW, Grady KL, Goldstein NE, Matlock DD, Arnold RM, Cook NR, Felker GM, Francis GS, Hauptman PJ, Havranek EP, Krumholz HM, Mancini D, Riegel B, Spertus JA. Decision making in advanced heart failure. *Circulation* 2012;**125**:1928–1952.
 59. Edmonton Symptom Assessment Score. <http://www.palliative.org/NewPC/professionals/tools/esas.html> (2 August 2019, date last accessed).
 60. Needs Assessment Tool: Progressive Disease—Heart Failure (NAT: PD-HF). <https://www.eapcnet.eu/Portals/0/PDFs/NATPDHF.pdf> (June 2019, date last accessed).
 61. Janssen DJ, Boyne J, Currow DC, Schols JM, Johnson MJ, La Rocca HB. Timely recognition of palliative care needs of patients with advanced chronic heart failure: a pilot study of a Dutch translation of the Needs Assessment Tool: progressive Disease—Heart Failure (NAT: pD-HF). *Eur J Cardiovasc Nurs* 2019;**18**:375–388.
 62. Hight G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICt): a mixed-methods study. *BMJ Support Palliat Care* 2014;**4**:285–290.
 63. Weingartner V, Scheve C, Gerdes V, Schwarz-Eywill M, Prenzel R, Otremba B, Muhlenbrock J, Bausewein C, Higginson IJ, Voltz R, Herich L, Simon ST. Characteristics of episodic breathlessness as reported by patients with advanced chronic obstructive pulmonary disease and lung cancer: results of a descriptive cohort study. *Palliat Med* 2015;**29**:420–428.
 64. Berliner D, Schneider N, Welte T, Bauersachs J. The differential diagnosis of dyspnea. *Deutsches Arzteblatt Int* 2016;**113**:834–845.
 65. Simon ST, Weingartner V, Higginson IJ, Voltz R, Bausewein C. Definition, categorization, and terminology of episodic breathlessness: consensus by an international Delphi survey. *J Pain Symptom Manage* 2014;**47**:828–838.
 66. Mahler DA, Selecky PA, Harrod CG, Benditt JO, Carrieri-Kohlman V, Curtis JR, Manning HL, Malarski RA, Varkey B, Campbell M, Carter ER, Chiong JR, Ely EW, Hansen-Flaschen J, O'Donnell DE, Waller A. American College of Chest Physicians consensus statement on the management of dyspnea in patients with advanced lung or heart disease. *Chest* 2010;**137**:674–691.
 67. Johnson MJ, Yorke J, Hansen-Flaschen J, Lansing R, Ekstrom M, Similowski T, Currow DC. Towards an expert consensus to delineate a clinical syndrome of chronic breathlessness. *Eur Respir J* 2017;**49**:1602277.
 68. Currow DC, Abernethy AP, Johnson MJ. Activity as a measure of symptom control. *J Pain Symptom Manage* 2012;**44**:e1–e2.
 69. Johnson MJ, Clark AL. The mechanisms of breathlessness in heart failure as the basis of therapy. *Curr Opin Support Palliat Care* 2016;**10**:32–35.
 70. Bausewein C, Booth S, Gysels M, Higginson I. Non-pharmacological interventions for breathlessness in advanced stages of malignant and non-malignant diseases. *Cochrane Database Syst Rev* 2008;CD005623.
 71. Clark A, Johnson M, Fairhurst C, Torgerson D, Cockayne S, Rodgers S, Griffin S, Allgar V, Jones L, Nabb S, Harvey I, Squire I, Murphy J, Greenstone M. Does home oxygen therapy (HOT) in addition to standard care reduce disease severity and improve symptoms in people with chronic heart failure? A randomised trial of home oxygen therapy for patients with chronic heart failure. *Health Technol Assess* 2015;**19**:1–120.
 72. Ekstrom M, Nilsson F, Abernethy AA, Currow DC. Effects of opioids on breathlessness and exercise capacity in chronic obstructive pulmonary disease. A systematic review. *Ann Am Thorac Soc* 2015;**12**:1079–1092.
 73. Johnson MJ, Bland JM, Oxberry SG, Abernethy AP, Currow DC. Opioids for chronic refractory breathlessness: patient predictors of beneficial response. *Eur Respir J* 2013;**42**:758–766.
 74. Oxberry SG, Torgerson DJ, Bland JM, Clark AL, Cleland JG, Johnson MJ. Short-term opioids for breathlessness in stable chronic heart failure: a randomized controlled trial. *Eur J Heart Fail* 2011;**13**:1006–1012.
 75. Oxberry SG, Bland JM, Clark AL, Cleland JG, Johnson MJ. Repeat dose opioids may be effective for breathlessness in chronic heart failure if given for long enough. *J Palliat Med* 2013;**16**:250–255.
 76. Johnson MJ, McDonagh TA, Harkness A, McKay SE, Dargie HJ. Morphine for the relief of breathlessness in patients with chronic heart failure—a pilot study. *Eur J Heart Fail* 2002;**4**:753–756.
 77. Currow DC, McDonald C, Oaten S, Kenny B, Allcroft P, Frith P, Briffa M, Johnson MJ, Abernethy AP. Once-daily opioids for chronic dyspnea: a dose increment and pharmacovigilance study. *J Pain Symptom Manage* 2011;**42**:388–399.
 78. Currow DC, Quinn S, Greene A, Bull J, Johnson MJ, Abernethy AP. The longitudinal pattern of response when morphine is used to treat chronic refractory dyspnea. *J Palliat Med* 2013;**16**:881–886.
 79. Ekstrom MP, Bornefalk-Hermansson A, Abernethy AP, Currow DC. Safety of benzodiazepines and opioids in very severe respiratory disease: national prospective study. *BMJ* 2014;**348**:g445.
 80. Erweiterte S3-Leitlinie Palliativmedizin für Patienten mit einer nicht-heilbaren Krebskrankung. https://www.leitlinienprogramm-onkologie.de/fileadmin/user_upload/Downloads/Leitlinien/Palliativmedizin/Version_2/LL_Palliativmedizin_2.01_Langversion.pdf (June 2019, date last accessed).
 81. Pilkey J, Pedersen A, Tam JW, Malik A, Wong J. The use of intranasal fentanyl for the palliation of incident dyspnea in advanced congestive heart failure: a pilot study. *J Palliat Care* 2018;**825859718777343**.
 82. Simon ST, Higginson IJ, Booth S, Harding R, Weingartner V, Bausewein C. Benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases in adults. *Cochrane Database Syst Rev* 2016;**10**:Cd007354.
 83. Obiora E, Hubbard R, Sanders RD, Myles PR. The impact of benzodiazepines on occurrence of pneumonia and mortality from pneumonia: a nested case-control and survival analysis in a population-based cohort. *Thorax* 2013;**68**:163–170.
 84. Vozoris NT. Do benzodiazepines contribute to respiratory problems? *Expert Rev Respir Med* 2014;**8**:661–663.
 85. Vozoris NT, Wang X, Fischer HD, Bell CM, O'Donnell DE, Austin PC, Stephenson AL, Gill SS, Rochon PA. Incident opioid drug use and adverse respiratory outcomes among older adults with COPD. *Eur Respir J* 2016;**48**:683–693.
 86. Bhattarai P, Hickman L, Phillips JL. Pain among hospitalized older people with heart failure and their preparation to manage this symptom on discharge: a descriptive-observational study. *Contemp Nurse* 2016;1–12.
 87. Evangelista LS, Sackett E, Dracup K. Pain and heart failure: unrecognized and untreated. *Eur J Cardiovasc Nurs* 2009;**8**:169–173.
 88. Goodlin SJ, Wingate S, Albert NM, Pressler SJ, Houser J, Kwon J, Chiong J, Storey CP, Quill T, Teerlink JR. Investigating pain in heart failure patients: the pain assessment, incidence, and nature in heart failure (PAIN-HF) study. *J Card Fail* 2012;**18**:776–783.
 89. Evangelista LS, Liao S, Motie M, De Michelis N, Ballard-Hernandez J, Lombardo D. Does the type and frequency of palliative care services received by patients with advanced heart failure impact symptom burden? *J Palliat Med* 2014;**17**:75–79.
 90. Kavalieratos D, Kamal AH, Abernethy AP, Biddle AK, Carey TS, Dev S, Reeve BB, Weinberger M. Comparing unmet needs between community-based palliative care patients with heart failure and patients with cancer. *J Palliat Med* 2014;**17**:475–481.
 91. Dansie EJ, Turk DC. Assessment of patients with chronic pain. *Br J Anaesth* 2013;**111**:19–25.
 92. Conley S, Feder S, Redeker NS. The relationship between pain, fatigue, depression and functional performance in stable heart failure. *Heart Lung* 2015;**44**:107–112.
 93. Godfrey C, Harrison MB, Medves J, Tranmer JE. The symptom of pain with heart failure: a systematic review. *J Card Fail* 2006;**12**:307–313.
 94. Anderson H, Ward C, Eardley A, Gomm SA, Connolly M, Coppinger T, Corgie D, Williams JL, Makin WP. The concerns of patients under palliative care and a heart failure clinic are not being met. *Palliat Med* 2001;**15**:279–286.
 95. Levenson JW, McCarthy EP, Lynn J, Davis RB, Phillips RS. The last six months of life for patients with congestive heart failure. *J Am Geriatr Soc* 2000;**48**:S101–109.
 96. Nordgren L, Sorensen S. Symptoms experienced in the last six months of life in patients with end-stage heart failure. *Eur J Cardiovasc Nurs* 2003;**2**:213–217.
 97. Gilbert CJ, Cheung A, Butany J, Zywiwiel MG, Syed K, McDonald M, Wong F, Overgaard C. Hip pain and heart failure: the missing link. *Can J Cardiol* 2013;**29**:e631–632.

98. Light-McGroary K, Goodlin SJ. The challenges of understanding and managing pain in the heart failure patient. *Curr Opin Support Palliat Care* 2013;**7**:14–20.
99. Tsigaridas N, Naka K, Tsapogas P, Herios Pelechas E, Damigos D. Spinal cord stimulation in refractory angina. A systematic review of randomized controlled trials. *Acta Cardiol* 2015;**70**:233–243.
100. Bueno EA, Mamtani R, Frishman WH. Alternative approaches to the medical management of angina pectoris: acupuncture, electrical nerve stimulation, and spinal cord stimulation. *Heart Dis* 2001;**3**:236–241.
101. Taylor RS, De Vries J, Buchser E, Dejongste MJ. Spinal cord stimulation in the treatment of refractory angina: systematic review and meta-analysis of randomised controlled trials. *BMC Cardiovasc Disord* 2009;**9**:13.
102. Andrell P, Yu W, Gersbach P, Gillberg L, Pehrsson K, Hardy I, Stahle A, Andersen C, Mannheimer C. Long-term effects of spinal cord stimulation on angina symptoms and quality of life in patients with refractory angina pectoris—results from the European Angina Registry Link Study (EARL). *Heart* 2010;**96**:1132–1136.
103. Roffi M, Patrono C, Collet J-P, Mueller C, Valgimigli M, Andreotti F, Bax JJ, Borger MA, Brotons C, Chew DP, Gencer B, Hasenfuss G, Kjeldsen K, Lancellotti P, Landmesser U, Mehilli J, Mukherjee D, Storey RF, Windecker S. 2015 ESC Guidelines for the management of acute coronary syndromes in patients presenting without persistent ST-segment elevation: Task Force for the Management of Acute Coronary Syndromes in Patients Presenting without Persistent ST-Segment Elevation of the European Society of Cardiology (ESC). *Eur Heart J* 2016;**37**:267–315.
104. Kubica J, Kubica A, Jilma B, Adamski P, Hohl E-L, Navarese EP, Siller-Matula JM, Dąbrowska A, Fabiszak T, Kozłowski M, Gurbel PA. Impact of morphine on antiplatelet effects of oral P2Y₁₂ receptor inhibitors. *Int J Cardiol* 2016;**215**:201–208.
105. Kubica J, Adamski P, Ostrowska M, Sikora J, Kubica JM, Sroka WD, Stankowska K, Buszko K, Navarese EP, Jilma B, Siller-Matula JM, Marszałł MP, Rosc D, Kozinski M. Morphine delays and attenuates ticagrelor exposure and action in patients with myocardial infarction: the randomized, double-blind, placebo-controlled IMPRESSION trial. *Eur Heart J* 2016;**37**:245–252.
106. Tavenier AH, Hermanides RS, Ottervanger JP, Ter Horst PGJ, Kedhi E, van 't Hof A. Risks of opioids in ST-elevation myocardial infarction: a review. *Drug Saf* 2018;**41**:1303–1308.
107. Dowell D, Haegerich TM, Chou R. CDC guideline for prescribing opioids for chronic pain—United States, 2016. *JAMA* 2016;**315**:1624–1645.
108. Heerdink ER, Leufkens HG, Herings RM, Ottervanger JP, Stricker BH, Bakker A. NSAIDs associated with increased risk of congestive heart failure in elderly patients taking diuretics. *Arch Intern Med* 1998;**158**:1108–1112.
109. Sudano I, Flammer AJ, Periat D, Enseleit F, Hermann M, Wolfrum M, Hirt A, Kaiser P, Hurlimann D, Neidhart M, Gay S, Holzmeister J, Nussberger J, Mocharla P, Landmesser U, Haile SR, Corti R, Vanhoutte PM, Luscher TF, Noll G, Ruschitzka F. Acetaminophen increases blood pressure in patients with coronary artery disease. *Circulation* 2010;**122**:1789–1796.
110. Chapa DW, Akintade B, Son H, Woltz P, Hunt D, Friedmann E, Hartzung MK, Thomas SA. Pathophysiological relationships between heart failure and depression and anxiety. *Crit Care Nurse* 2014;**34**:14–24; quiz 25.
111. Sokoreli I, de Vries JJ, Pauws SC, Steyerberg EW. Depression and anxiety as predictors of mortality among heart failure patients: systematic review and meta-analysis. *Heart Fail Rev* 2016;**21**:49–63.
112. Jani BD, Mair FS, Roger VL, Weston SA, Jiang R, Chamberlain AM. Comorbid depression and heart failure: a community cohort study. *PLoS One* 2016;**11**:e0158570.
113. Gustad LT, Laugsand LE, Janszky I, Dalen H, Bjerkeset O. Symptoms of anxiety and depression and risk of heart failure: the HUNT Study. *Eur J Heart Fail* 2014;**16**:861–870.
114. Easton K, Coventry P, Lovell K, Carter LA, Deaton C. Prevalence and measurement of anxiety in samples of patients with heart failure: meta-analysis. *J Cardiovasc Nurs* 2016;**31**:367–379.
115. Eisenberg SA, Shen BJ, Schwarz ER, Mallon S. Avoidant coping moderates the association between anxiety and patient-rated physical functioning in heart failure patients. *J Behav Med* 2012;**35**:253–261.
116. Wallenborn J, Angermann CE. Depression and heart failure—a twofold hazard? Diagnosis, prognostic relevance and treatment of an underestimated comorbidity. *Herz* 2016;**41**:741–754.
117. Lefteriotis C. Depression in heart failure patients. *Health Sci J* 2013;**7**:349.
118. Johnson TJ, Basu S, Pisani BA, Avery EF, Mendez JC, Calvin JE, Jr, Powell LH. Depression predicts repeated heart failure hospitalizations. *J Card Fail* 2012;**18**:246–252.
119. Houben CHM, Spruit MA, Groenen MTJ, Wouters EFM, Janssen D. Efficacy of advance care planning: a systematic review and meta-analysis. *J Am Med Dir Assoc* 2014;**15**:477–489.
120. Kernick LA, Hogg KJ, Millerick Y, Murtagh FEM, Djahit A, Johnson M. Does advance care planning in addition to usual care reduce hospitalisation for patients with advanced heart failure: a systematic review and narrative synthesis. *Palliat Med* 2018;**32**:1539–1551.
121. Janssen DJ, Spruit MA, Schols JM, Wouters EF. A call for high-quality advance care planning in outpatients with severe COPD or chronic heart failure. *Chest* 2011;**139**:1081–1088.
122. Brunner-La Rocca HP, Rickenbacher P, Muzzarelli S, Schindler R, Maeder MT, Jeker U, Kiowski W, Leventhal ME, Pfister O, Osswald S, Pfisterer ME, Rickli H. End-of-life preferences of elderly patients with chronic heart failure. *Eur Heart J* 2012;**33**:752–759.
123. You JJ, Aleksova N, Ducharme A, MacIver J, Mielniczuk L, Fowler RA, Demers C, Clarke B, Parent MC, Toma M, Strachan PH, Farand P, Isaac D, Zieroth S, Swinton M, Jiang X, Day AG, Heyland DK, Ross HJ. Barriers to goals of care discussions with patients who have advanced heart failure: results of a multicenter survey of hospital-based cardiology clinicians. *J Card Fail* 2017;**23**:786–793.
124. Van den Heuvel LA, Spruit MA, Schols JM, Hoving C, Wouters EF, Janssen DJ. Barriers and facilitators to end-of-life communication in advanced chronic organ failure. *Int J Palliat Nurs* 2016;**22**:222–229.
125. Andreassen P, Neergaard MA, Brogaard T, Skorstengaard MH, Jensen AB. The diverse impact of advance care planning: a long-term follow-up study on patients' and relatives' experiences. *BMJ Support Palliat Care* 2017;**7**:335–340.
126. Gott M, Barnes S, Parker C, Payne S, Seamark D, Gariballa S, Small N. Dying trajectories in heart failure. *Palliat Med* 2007;**21**:95–99.
127. Doehner W, Ural D, Haeusler KG, Celutkienė J, Bestetti R, Cavusoglu Y, Pena-Duque MA, Glavas D, Iacoviello M, Laufs U, Alvear RM, Mbakwem A, Piepoli MF, Rosen SD, Tsiyogoulis G, Vitale C, Yilmaz MB, Anker SD, Filippatos G, Seferovic P, Coats AJS, Ruschitzka F. Heart and brain interaction in patients with heart failure: overview and proposal for a taxonomy. A position paper from the Study Group on Heart and Brain Interaction of the Heart Failure Association. *Eur J Heart Fail* 2018;**20**:199–215.
128. Reinke LF, Engelberg RA, Shannon SE, Wenrich MD, Vig EK, Back AL, Curtis JR. Transitions regarding palliative and end-of-life care in severe chronic obstructive pulmonary disease or advanced cancer: themes identified by patients, families, and clinicians. *J Palliat Med* 2008;**11**:601–609.
129. Chuang E, Kim G, Blank AE, Southern W, Fausto J. 30-Day readmission rates in patients admitted for heart failure exacerbation with and without palliative care consultation: a retrospective cohort study. *J Palliat Med* 2017;**20**:163–169.
130. Goodlin S, Smusz TL, Stark GL. Identifying heart failure patients appropriate for palliative care: experience from the trenches (323). *J Pain Symptom Manage* 2009;**37**:476.
131. Janssen DJA, Spruit MA, Schols J, Cox B, Nawrot TS, Curtis JR, Wouters E. Predicting changes in preferences for life-sustaining treatment among patients with advanced chronic organ failure. *Chest* 2012;**141**:1251–1259.
132. Houben CHM, Spruit MA, Schols J, Wouters EFM, Janssen D. Instability of willingness to accept life-sustaining treatments in patients with advanced chronic organ failure during 1 year. *Chest* 2017;**151**:1081–1087.
133. Sherazi S, McNitt S, Aktas MK, Polonsky B, Shah AH, Moss AJ, Daubert JP, Zareba W. End-of-life care in patients with implantable cardioverter defibrillators: a MADIT-II substudy. *Pacing Clin Electrophysiol* 2013;**36**:1273–1279.
134. Puchalski CM, Vitillo R, Hull SK, Reller N. Improving the spiritual dimension of whole person care: reaching national and international consensus. *J Palliat Med* 2014;**17**:642–656.
135. Hutchinson TA. *Whole Person Care. A New Paradigm for the 21st Century*. New York: Springer; 2011.
136. Nolan S, Saltmarsh P, Leget C. Spiritual care in palliative care: working towards an EAPC Task Force. *Eur J Palliat Care* 2011;**18**:86–89.
137. Beery TA, Baas LS, Fowler C, Allen G. Spirituality in persons with heart failure. *J Holist Nurs* 2002;**20**:5–25; quiz 26–30.
138. Murray SA, Kendall M, Boyd K, Worth A, Benton TF. Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliat Med* 2004;**18**:39–45.
139. Strada EA, Homel P, Tennstedt S, Billings JA, Portenoy RK. Spiritual well-being in patients with advanced heart and lung disease. *Palliat Support Care* 2013;**11**:205–213.
140. Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. *J Pain Symptom Manage* 2007;**34**:393–402.
141. Park CL, Aldwin CM, Choun S, George L, Suresh DP, Bliss D. Spiritual peace predicts 5-year mortality in congestive heart failure patients. *Health Psychol* 2016;**35**:203–210.
142. Bekelman DB, Dy SM, Becker DM, Wittstein IS, Hendricks DE, Yamashita TE, Gottlieb SH. Spiritual well-being and depression in patients with heart failure. *J Gen Intern Med* 2007;**22**:470–477.
143. Davidson PM, Dracup K, Phillips J, Daly J, Padilla G. Preparing for the worst while hoping for the best: the relevance of hope in the heart failure illness trajectory. *J Cardiovasc Nurs* 2007;**22**:159–165.
144. Tadwalkar R, Udeoji DU, Weiner RJ, Avestruz FL, LaChance D, Phan A, Nguyen D, Bharadwaj P, Schwarz ER. The beneficial role of spiritual counseling in heart failure patients. *J Relig Health* 2014;**53**:1575–1585.
145. Kearney M. *A Place of Healing. Working with Suffering in Living and Dying*. Oxford: Oxford University Press; 2000.
146. Mueller PS, Plevak DJ, Rummans TA. Religious involvement, spirituality, and medicine: implications for clinical practice. *Mayo Clin Proc* 2001;**76**:1225–1235.
147. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 7th ed. New York: Oxford University Press; 2012.

148. Sulmasy DP, Pellegrino ED. The rule of double effect: clearing up the double talk. *Arch Intern Med* 1999;**159**:545–550.
149. Snyder L, American College of Physicians Ethics P, Human Rights Committee. American College of Physicians ethics manual: sixth edition. *Ann Intern Med* 2012; **156**:73–104.
150. Padeletti L, Arnar DO, Boncinelli L, Brachman J, Camm JA, Daubert JC, Hassam SK, Kassam S, Deliens L, Glikson M, Hayes D, Israel C, Lampert R, Lobban T, Raatikainen P, Siegal G, Vardas P, Kirchhof P, Becker R, Cosio F, Loh P, Cobbe S, Grace A, Morgan J. EHRA Expert Consensus Statement on the management of cardiovascular implantable electronic devices in patients nearing end of life or requesting withdrawal of therapy. *Europace* 2010;**12**:1480–1489.
151. Lampert R, Hayes DL, Annas GJ, Farley MA, Goldstein NE, Hamilton RM, Kay GN, Kramer DB, Mueller PS, Padeletti L, Pozuelo L, Schoenfeld MH, Vardas PE, Wiegand DL, Zellner R; American Heart Association. HRS Expert Consensus Statement on the Management of Cardiovascular Implantable Electronic Devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy. *Heart Rhythm* 2010; **7**:1008–1026.
152. ABIM Foundation, American Board of Internal Medicine, ACP-ASIM Foundation, American College of Physicians-American Society of Internal Medicine, and European Federation of Internal Medicine. Medical professionalism in the new millennium: a physician charter. *Ann Intern Med* 2002;**136**:243–246.
153. Kutner JS, Blatchford PJ, Taylor DH, Ritchie CS, Bull JH, Fairclough DL, Hanson LC, LeBlanc TW, Samsa GP, Wolf S, Aziz NM, Currow DC, Ferrell B, Wagner-Johnston N, Zafar SY, Cleary JF, Dev S, Goode PS, Kamal AH, Kassner C, Kvale EA, McCallum JG, Ogunseitan AB, Pantilat SZ, Portenoy RK, Prince-Paul M, Sloan JA, Swetz KM, Von Gunten CF, Abernethy AP. Safety and benefit of discontinuing statin therapy in the setting of advanced, life-limiting illness: a randomized clinical trial. *JAMA Intern Med* 2015;**175**:691–700.
154. Vicent L, Nunez Olarte JM, Puente-Maestu L, Oliva A, Lopez JC, Postigo A, Martin I, Luna R, Fernandez AF, Martinez SM. Degree of dyspnoea at admission and discharge in patients with heart failure and respiratory diseases. *BMC Palliat Care* 2017;**16**:35.
155. Joyce E, Nohria A. Therapeutic adjustments in stage D heart failure: challenges and strategies. *Curr Heart Fail Rep* 2015;**12**:15–23.
156. Hashim T, Sanam K, Revilla-Martinez M, Morgan CJ, Tallaj JA, Pamboukian SV, Loyaga-Rendon RY, George JF, Acharya D. Clinical characteristics and outcomes of intravenous inotropic therapy in advanced heart failure. *Circ Heart Fail* 2015;**8**: 880–886.
157. Altenberger J, Parisis JT, Costard-Jaeckle A, Winter A, Ebner C, Karavidas A, Sihorsch K, Avgeropoulou E, Weber T, Dimopoulos L, Ulmer H, Poelzl G. Efficacy and safety of the pulsed infusions of levosimendan in outpatients with advanced heart failure (LevoRep) study: a multicentre randomized trial. *Eur J Heart Fail* 2014; **16**:898–906.
158. Gorodeski EZ, Chu EC, Reese JR, Shishebor MH, Hsieh E, Starling RC. Prognosis on chronic dobutamine or milrinone infusions for stage D heart failure. *Circ Heart Fail* 2009;**2**:320–324.
159. Nanas JN, Tsagalou EP, Kanakakis J, Nanas SN, Terrovitis JV, Moon T, Anastasiou-Nana MI. Long-term intermittent dobutamine infusion, combined with oral amiodarone for end-stage heart failure: a randomized double-blind study. *Chest* 2004;**125**: 1198–1204.
160. Rich MW, Shore BL. Dobutamine for patients with end-stage heart failure in a hospice program? *J Palliat Med* 2003;**6**:93–97.
161. Lopez B, Querejeta R, Gonzalez A, Sanchez E, Larman M, Diez J. Effects of loop diuretics on myocardial fibrosis and collagen type I turnover in chronic heart failure. *J Am Coll Cardiol* 2004;**43**:2028–2035.
162. Ruiz-Garcia J, Diez-Villanueva P, Ayesta A, Bruna V, Figueiras-Graillet LM, Gallego-Parra L, Fernandez-Aviles F, Martinez-Selles M. End-of-life care in a cardiology department: have we improved? *J Geriatr Cardiol* 2016;**13**:587–592.
163. Stoevelaar R, Brinkman-Stoppelenburg A, Bhagwandien RE, van Bruchem-Visser RL, Theuns DA, van der Heide A, Rietjens JA. The incidence and impact of implantable cardioverter defibrillator shocks in the last phase of life: an integrated review. *Eur J Cardiovasc Nurs* 2018;**17**:477–485.
164. Kirkpatrick JN, Gottlieb M, Sehgal P, Patel R, Verdino RJ. Deactivation of implantable cardioverter defibrillators in terminal illness and end of life care. *Am J Cardiol* 2012;**109**:91–94.
165. Mueller PS, Hook CC, Hayes DL. Ethical analysis of withdrawal of pacemaker or implantable cardioverter-defibrillator support at the end of life. *Mayo Clin Proc* 2003; **78**:959–963.
166. Buchhalter LC, Ottenberg AL, Webster TL, Swetz KM, Hayes DL, Mueller PS. Features and outcomes of patients who underwent cardiac device deactivation. *JAMA Intern Med* 2014;**174**:80–85.
167. Kapa S, Mueller PS, Hayes DL, Asirvatham SJ. Perspectives on withdrawing pacemaker and implantable cardioverter-defibrillator therapies at end of life: results of a survey of medical and legal professionals and patients. *Mayo Clin Proc* 2010;**85**: 981–990.
168. Datino T, Rexach L, Vidán MT, Alonso A, Gándara Á, Ruiz-García J, Fontecha B, Martínez-Sellés M. Guidelines on the management of implantable cardioverter defibrillators at the end of life. *Revista Clínica Española (Engl Ed)* 2014;**214**:31–37.
169. Klein L, Hsia H. Sudden cardiac death in heart failure. *Cardiol Clin* 2014;**32**:135–1ix.
170. Rickenbacher P, Pfisterer M, Burkard T, Kiowski W, Follath F, Burckhardt D, Schindler R, Brunner-La Rocca HP; TME-CHF Investigators. Why and how do elderly patients with heart failure die? Insights from the TIME-CHF study. *Eur J Heart Fail* 2012;**14**:1218–1229.
171. Hamaguchi S, Kinugawa S, Sobirin MA, Goto D, Tsuchihashi-Makaya M, Yamada S, Yokoshiki H, Tsutsui H; JCARE-CARD Investigators. Mode of death in patients with heart failure and reduced vs. preserved ejection fraction: report from the registry of hospitalized heart failure patients. *Circ J* 2012;**76**:1662–1669.
172. Kennedy C, Brooks-Young P, Brunton Gray C, Larkin P, Connolly M, Wilde-Larsson B, Larsson M, Smith T, Chater S. Diagnosing dying: an integrative literature review. *BMJ Support Palliat Care* 2014;**4**:263–270.
173. Taylor P, Dowding D, Johnson M. Clinical decision making in the recognition of dying: a qualitative interview study. *BMC Palliat Care* 2017;**16**:11.
174. Domeisen Benedetti F, Ostgathe C, Clark J, Costantini M, Daud ML, Grossenbacher-Gschwend B, Latten R, Lindqvist O, Peternelj A, Schuler S, Tal K, van der Heide A, Eychmüller S. Opcare International palliative care experts' view on phenomena indicating the last hours and days of life. *Support Care Cancer* 2013; **21**:1509–1517.
175. Eychmüller S, Domeisen Benedetti F, Latten R, Tal K, Walker J, Costantini M. Diagnosing dying in cancer patients—a systematic literature review. *Eur J Palliat Care* 2013;**20**:292–296.
176. Nauck F, Klaschik E, Ostgathe C. Symptom control during the last three days of life. *Eur J Palliat Care* 2000;**7**:81–84.
177. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013;**12**:7.
178. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;**284**:2476–2482.
179. Pinzon LCE, Claus M, Zepf KI, Letzel S, Fischbeck S, Weber M. Preference for place of death in Germany. *J Palliat Med* 2011;**14**:1097–1103.
180. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev* 2013;**6**:CD007760.
181. Agar M, Currow D, Shelby-James T, Plummer J, Sanderson C, Abernethy A. Preference for place of care and place of death in palliative care: are these different questions? *Palliat Med* 2008;**22**:787–795.
182. Cantwell P, Turco S, Brenneis C, Hanson J, Neumann CM, Bruera E. Predictors of home death in palliative care cancer patients. *J Palliat Care* 2000;**16**:23–28.
183. Grande G, Ewing G. Death at home unlikely if informal carers prefer otherwise: implications for policy. *Palliat Med* 2008;**22**:971–972.
184. Hauser JM, Kramer BJ. Family caregivers in palliative care. *Clin Geriatr Med* 2004;**20**: 671–688. vi.
185. Muller K, Gamba G, Jaquet F, Hess B. Torasemide vs. furosemide in primary care patients with chronic heart failure NYHA II to IV—efficacy and quality of life. *Eur J Heart Fail* 2003;**5**:793–801.
186. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, Mitchell SL, Jackson VA, Block SD, Maciejewski PK, Prigerson HG. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;**300**:1665–1673.
187. Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med* 2009;**169**:480–488.
188. Mack JW, Cronin A, Keating NL, Taback N, Huskamp HA, Malin JL, Earle CC, Weeks JC. Associations between end-of-life discussion characteristics and care received near death: a prospective cohort study. *J Clin Oncol* 2012;**30**:4387–4395.
189. Mack JW, Paulk ME, Viswanath K, Prigerson HG. Racial disparities in the outcomes of communication on medical care received near death. *Arch Intern Med* 2010;**170**: 1533–1540.
190. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 2010;**28**:1203–1208.
191. Nauck F. Symptom control in the terminal phase. *Schmerz* 2001;**15**:362–369.
192. Dodson JA, Fried TR, Van Ness PH, Goldstein NE, Lampert R. Patient preferences for deactivation of implantable cardioverter-defibrillators. *JAMA Intern Med* 2013; **173**:377–379.
193. Carlsson J, Paul NW, Dann M, Neuzner J, Pfeiffer D. The deactivation of implantable cardioverter-defibrillators: medical, ethical, practical, and legal considerations. *Dtsch Arztebl Int* 2012;**109**:535–541.
194. Fromme EK, Stewart TL, Jeppesen M, Tolle SW. Adverse experiences with implantable defibrillators in Oregon hospices. *Am J Hosp Palliat Care* 2011;**28**:304–309.
195. Waltzenberger J, Schöne-Seifert B, Friedrich DR, Alt-Epping B, Bestehorn M, Dutzmann J, Ertl G, Fateh-Moghadam B, Israel CW, Maase A. Verantwortlicher

- Umgang mit ICDs. Stellungnahme der DGK und ihrer Schwester-Gesellschaften. *Der Kardiologe* 2017;**11**:383–397.
196. Alt-Epping B. Choosing wisely at the end of life: recommendations of the German Society for Palliative Medicine (DGP). *Internist (Berl)* 2017;**58**:575–579.
 197. Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med* 2013;**368**:1173–1175.
 198. Fendler TJ, Swetz KM, Allen LA. Team-based palliative and end-of-life care for heart failure. *Heart Fail Clin* 2015;**11**:479–498.
 199. Cahalin LP, Arena RA. Breathing exercises and inspiratory muscle training in heart failure. *Heart Fail Clin* 2015;**11**:149–172.
 200. Higginson IJ, Bausewein C, Reilly CC, Gao W, Gysels M, Dzingina M, McCrone P, Booth S, Jolley CJ, Moxham J. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *Lancet Respir Med* 2014;**2**:979–987.
 201. Booth S, Moffat C, Burkin J, Galbraith S, Bausewein C. Nonpharmacological interventions for breathlessness. *Curr Opin Support Palliat Care* 2011;**5**:77–86.
 202. Arena R, Cahalin LP, Borghi-Silva A, Phillips SA. Improving functional capacity in heart failure: the need for a multifaceted approach. *Curr Opin Cardiol* 2014;**29**:467–474.
 203. Zwisler AD, Norton RJ, Dean SG, Dalal H, Tang LH, Wingham J, Taylor RS. Home-based cardiac rehabilitation for people with heart failure: a systematic review and meta-analysis. *Int J Cardiol* 2016;**221**:963–969.
 204. Cornelis J, Beckers P, Taeymans J, Vrints C, Vissers D. Comparing exercise training modalities in heart failure: a systematic review and meta-analysis. *Int J Cardiol* 2016;**221**:867–876.
 205. Rehabilitative palliative care: enabling people to live fully until they die. <https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/rehabilitative-palliative-care/resources-for-rehabilitative-palliative-care> (June 2019, date last accessed).
 206. Daley A, Matthews C, Williams A. Heart failure and palliative care services working in partnership: report of a new model of care. *Palliat Med* 2006;**20**:593–601.
 207. Davidson PM, Paull G, Introna K, Cockburn J, Davis JM, Rees D, Gorman D, Magann L, Lafferty M, Dracup K. Integrated, collaborative palliative care in heart failure: the St. George Heart Failure Service experience 1999–2002. *J Cardiovasc Nurs* 2004;**19**:68–75.
 208. Johnson MJ, Houghton T. Palliative care for patients with heart failure: description of a service. *Palliat Med* 2006;**20**:211–214.
 209. Johnson MJ, Nunn A, Hawkes T, Stockdale S, Daley A. Planning for end of life care in people with heart failure: experience of two integrated cardiology-palliative care. *Br J Cardiol* 2012;**19**:71–75.
 210. Bouamerane M-M, Mair F. *Caring Together Manualisation Report*. British Heart Foundation/Marie Curie Cancer Care; 2014. <https://www.mariecurie.org.uk/global-assets/media/documents/commissioning-our-services/current-partnerships/caring-together/caring-together-manualisation-report.pdf> (2 February 2019, date last accessed).
 211. Denvir MA, Cudmore S, Highet G, Robertson S, Donald L, Stephen J, Haga K, Hogg K, Weir CJ, Murray SA, Boyd K. Phase 2 randomised controlled trial and feasibility study of future care planning in patients with advanced heart disease. *Sci Rep* 2016;**6**:24619.