Title

Palliative Care for people living with heart failure – European Association for Palliative Care Task Force expert position statement.

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Short title
Palliative Care for People living with Heart Failure

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

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 recognise 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,

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 end-point in large multicentre randomised trials, and the added value of PC provided along with optimal cardiological treatment has only been shown recently in one single centre randomised study.[15] Access to PC throughout the whole course of HF, accordingly to needs, has been advocated.[16] The World Health Organisation has recently recognised 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 twenty 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 recognised, and less than 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 less than 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, recognising 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 ten 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. 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. This position statement paper has been approved by the EAPC Board for publication.

2. Basic definitions

A variety of terms meaningful for this paper 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 paper 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 quality of life, is universal. Ideally, PC should be introduced early on in the disease trajectory and increased as the disease progresses[1] 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 is facing the end of life (EoL) 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 US, 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 paper refers to a broad spectrum of PC.

End of life (EoL) is the period preceding a person's natural death, characterised 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 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 tenfold.[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, 52] so a needs and symptoms assessment based approach is a more suitable model for integration of PC into cardiac care, than recognising EoL.[53] Reliance on prognostication as a trigger for the consideration of PC is ineffective due to the poor utility of current prognostic tools[54] and because PC needs do not correlate with prognosis.[55] Prognostic uncertainty should trigger rather than block assessing of PC needs.[56] As discussed above, symptom assessment tools may be helpful in this regard.[57]

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 stages.[58] (Figure 3) Triggers for a PC approach or consultation should include distressing symptoms, existential distress, recurrent HF exacerbation and progressive frailty or caregiver concerns.

Table 1. Principles of Palliative Care for people living with heart failure

Topic	Description	Clinical implications for care 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 thirty 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 *vice versa* as part of their extended teams.

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

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.[57] 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.

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 optimising 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 10mg per day, given to provide a steady state according to preparation (2.5mg immediate release regularly four times daily; 5mg modified release twice daily or 10mg 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 10mg per day, 25% and 8% required dose escalation to 20mg or 30mg 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 hours, 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/24h 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 (stage 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 hospitalised 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 cancer[90]), 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[98]). Cardiac ischemic 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 versus 20%).[49, 110] Depression is an important, modifiable risk factor of HF related hospitalisation 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 SSRI (like citalopram) and mirtazapine can cause the prolongation of QT interval predisposing the development of ventricular tachycardia.[49]

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 optimised cardiologic treatment should be recognised 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 rehospitalisation 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.

6. Advance care planning

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 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 refocus goals of care.[54, 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 comorbidity[141] 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 outweigh 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 optimisation of HF therapy should be pursued, if only possible.[1, 9, 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 (for example, 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 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 resynchronisation component should be avoided, as the loss of pacemaker-mediated synchronisation 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 and 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 characterised 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]

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 optimised. 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[56] Services may be led by cardiologists, PC specialists, or jointly, and include common core components of care. [206-211]

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-	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.

	sustaining treatments. The conclusions can record advance directives or indicate personal representative for medical decision-making.	
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 beneficent 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).

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 palliative care for all patients with HF when needed regardless of prognosis should be the landmark of modern comprehensive care for people with heart disease.

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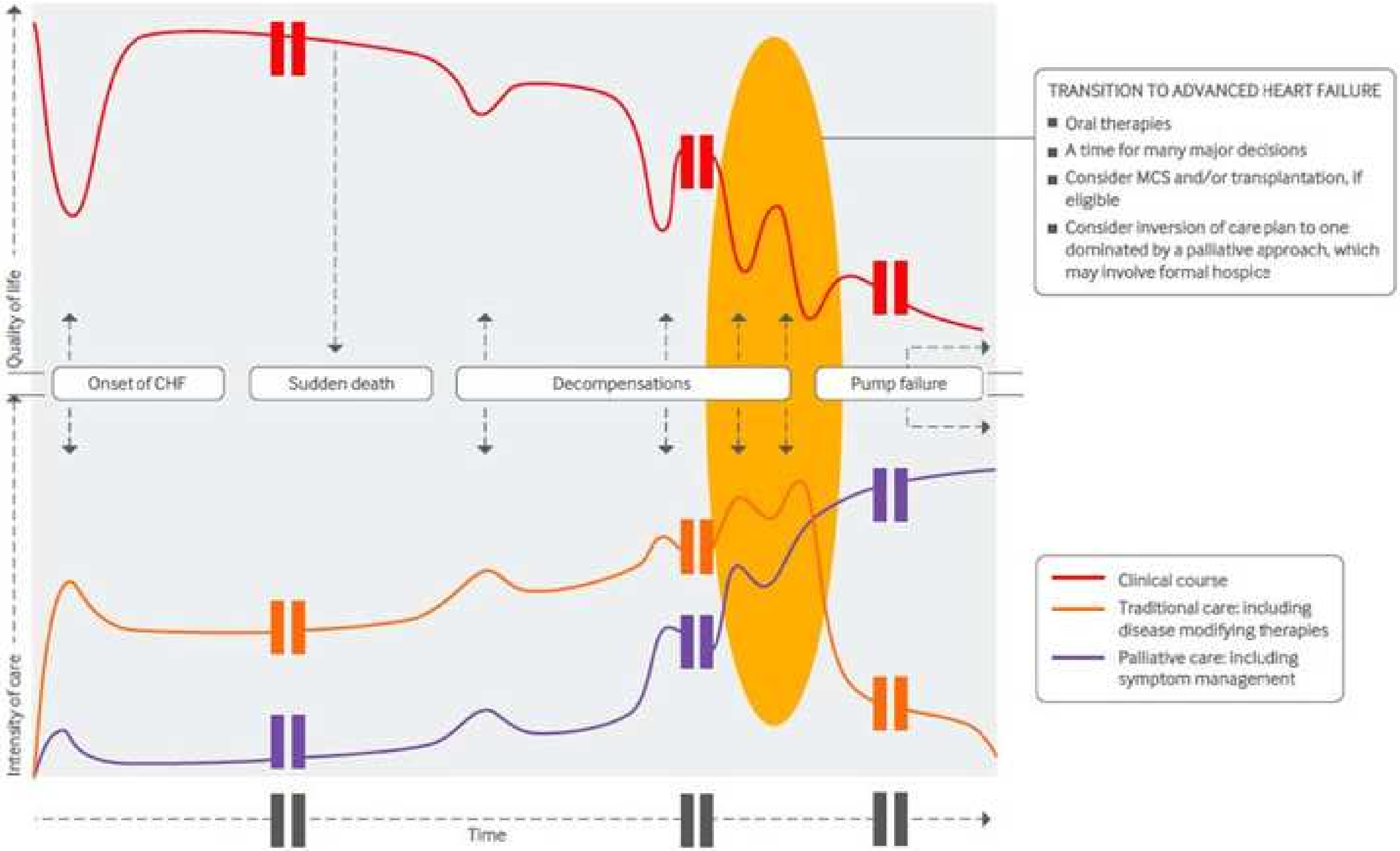
Figure Legend

Figure 1. The clinical course of heart failure with associated types and intensities of available therapies. (Modified from[58])

Figure 2. The pathophysiology of main heart failure symptoms, related to Palliative Care. (Most relevant symptoms marked with green colour)

Figure 3. Palliative Care provision for people with heart failure – flow chart.

Figure 1



TRANSITION TO ADVANCED HEART FAILURE

- Oral therapies
- A time for many major decisions
- Consider MCS and/or transplantation, if eligible
- Consider inversion of care plan to one dominated by a palliative approach, which may involve formal hospice

Figure 2

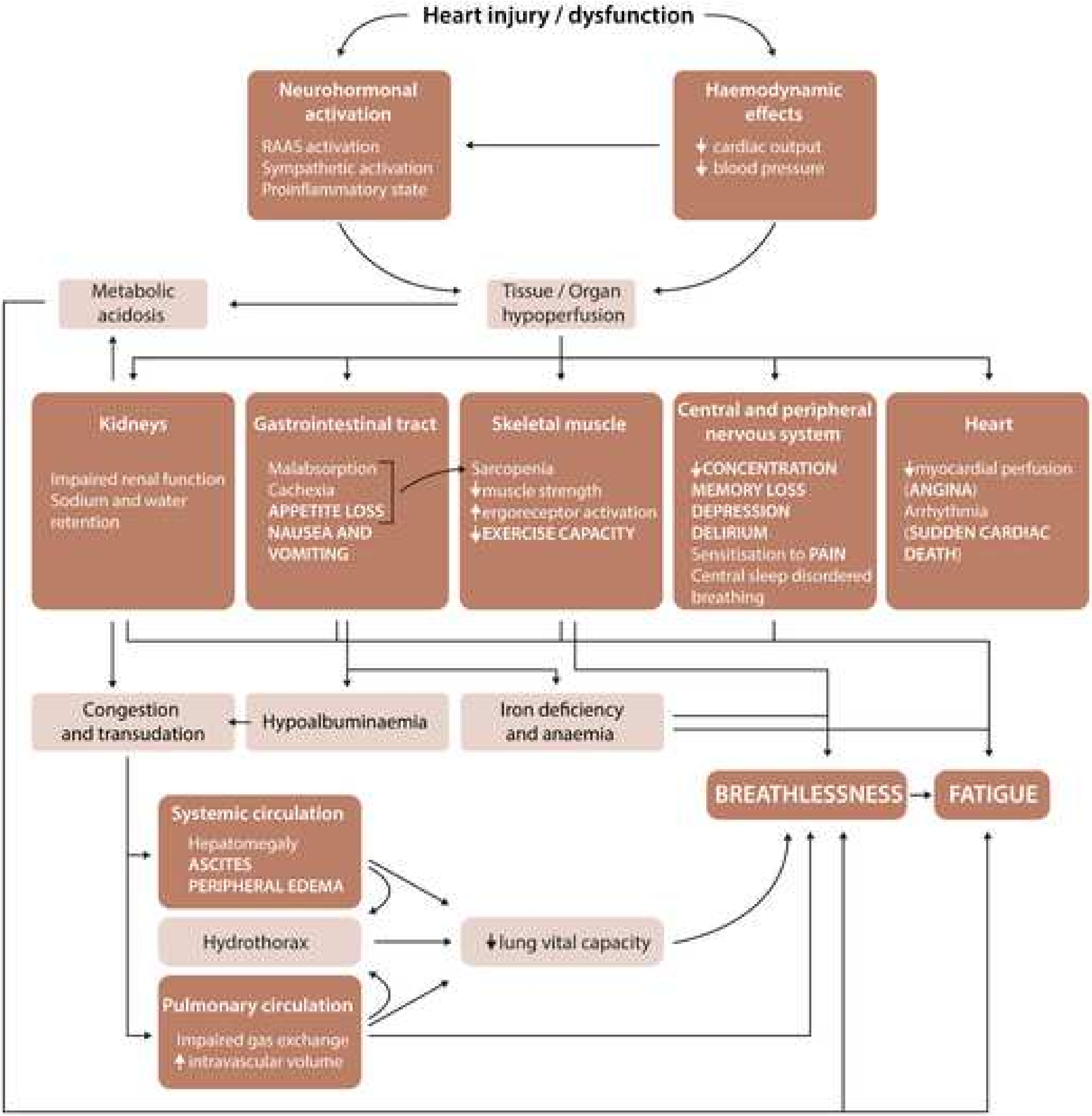
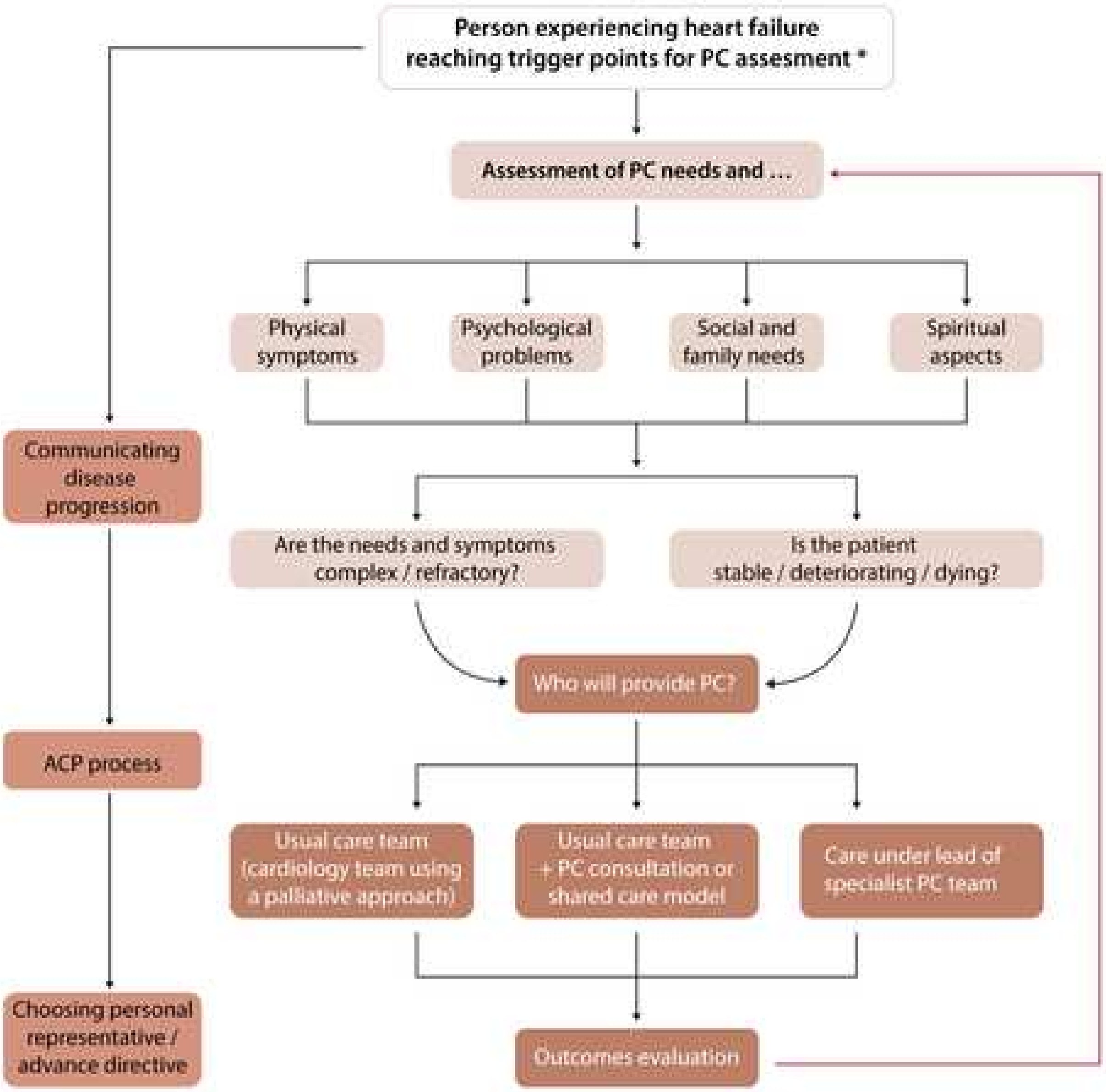

Heart injury / dysfunction
Neurohormonal activation
RAAS activation
Sympathetic activation
Proinflammatory state
Haemodynamic effects
↓ cardiac output
↓ blood pressure
Metabolic acidosis
Tissue / Organ hypoperfusion
Kidneys
Impaired renal function
Sodium and water retention
Gastrointestinal tract
Malabsorption
Cachexia
APPETITE LOSS
NAUSEA AND VOMITING
Skeletal muscle
Sarcopenia
↓muscle strength
↑ergoreceptor activation
↓EXERCISE CAPACITY
Central and peripheral nervous system
↓CONCENTRATION
MEMORY LOSS
DEPRESSION
DELIRIUM
Sensitisation to PAIN
Central sleep disordered breathing
Heart
↓myocardial perfusion
(ANGINA)
Arrhythmia
(SUDDEN CARDIAC DEATH)
Congestion and transudation
Hypoalbuminaemia
Iron deficiency and anaemia
BREATHLESSNESS
FATIGUE
Systemic circulation
Hepatomegaly
ASCITES
PERIPHERAL EDEMA
Hydrothorax
↓lung vital capacity
Pulmonary circulation
Impaired gas exchange
↑ intravascular volume

Figure 3



***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