

# Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology

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Heart failure is a serious condition and equivalent to malignant disease in terms of symptom burden and mortality. At this moment only a comparatively small number of heart failure patients receive specialist palliative care. Heart failure patients may have generic palliative care needs, such as refractory multifaceted symptoms, communication and decision making issues and the requirement for family support. The Advanced Heart Failure Study Group of the Heart Failure Association of the European Society of Cardiology organized a workshop to address the issue of palliative care in heart failure to increase awareness of the need for palliative care. Additional objectives included improving the accessibility and quality of palliative care for heart failure patients and promoting the development of heart failure-orientated palliative care services across Europe. This document represents a synthesis of the presentations and discussion during the workshop and describes recommendations in the area of delivery of quality care to patients and families, education, treatment coordination, research and policy.

**Keywords** Heart failure • Palliative care

## Introduction

Chronic heart failure (HF) is an important healthcare problem, associated with high morbidity and mortality rates; affected individuals often have a poor quality of life, even when treated with modern evidence-based therapy.<sup>1–4</sup> Although it is generally recognized that HF is a serious condition and equivalent to malignant disease in terms of symptom burden and mortality, only a comparatively small number of HF patients receive specialist palliative care.<sup>5–7</sup>

Having originated in the care of those with cancer, palliative care has now expanded to include the care of all individuals affected by

life-limiting conditions, including HF. As outlined in the latest definition of World Health Organization (WHO),<sup>8</sup> palliative care aims to improve the quality of life for patients and their families facing any life-threatening illness. Palliative care provides care in the relief of pain and other distressing symptoms; affirms life, and regards dying as a normal process; intends neither to hasten nor postpone death and offers a support system to help patients live as actively as possible until they die. This holistic approach also addresses the psychological and spiritual aspects of patient care and supports the family and informal carers during the illness and into bereavement. The core components of palliative care are itemized in Box 1.

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**Box 1: WHO definition of palliative care**

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems physical, psychosocial, and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families,
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life and includes those investigations needed to better understand and manage distressing clinical complications (<http://www.who.int/cancer/palliative/en/>).

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The term palliative care has long been synonymous with the support of those affected by advanced incurable malignancy and therefore cardiologists and cardiac nurses are frequently unfamiliar with the principles and practice of this clinical specialty.<sup>9</sup> A glossary of terms used to discuss the care that patients need during advanced stages of disease to the end of life are described in Box 2. Other barriers confounding the provision of palliative care to those with advanced HF include the inherent unpredictability of the condition, characterized by recurrent exacerbations, difficulties anticipating the terminal phase, and a high prevalence of sudden death. Complications linked to the multiple comorbidities typical of the elderly HF population may also disrupt the care plan.<sup>4,5</sup> Such problems have generally limited any consideration of the need for this form of support until the patient is obviously very close to death. However, in accordance with the WHO definition, a palliative care approach is no less applicable earlier in the course of HF in parallel with treatment options directed at improving cardiac function and prognosis.<sup>5,8</sup> In addition to the appropriateness of a palliative care approach for 'typical' older HF patients, a palliative approach may also become relevant for relatively younger patients being considered for heart replacement or mechanical circulatory

support. While some aspects of care may distinguish HF from cancer, particularly the potential salvage of some patients by surgical intervention or device therapy, it is accepted that many cancer and HF patients have similar generic palliative care needs, such as refractory multifaceted symptoms, communication, and decision-making issues and the requirement for family support. Both patient groups are also best served by tailored support service networks.<sup>10–15</sup>

**Box 2: Glossary of terms**

- *Palliative care*: defined in Box 1.
- *Terminal care*: care during the last days or weeks of the patient's life.
- *Supportive care*: care focusing on alleviating symptoms, complications, and side-effects of HF interventions, including supporting patients and families to cope with the disease and the effects of treatment.
- *End-of-life care*: a term variously used either signifying terminal care of dying patients and/or also interchangeably as 'palliative care'. End-of-life care may begin as soon as an irreversible progressive illness is diagnosed.
- *Hospice care*: a word describing service models, inconsistently used for mobile outpatient hospice teams, inpatient hospices, and also describing a financial model in some countries.

**The need for a statement**

Based on these features and the evolving access to this form of care, the Advanced Heart Failure Study Group of the Heart Failure Association (HFA) of the European Society of Cardiology (ESC) organized a workshop to garner the opinion of professionals interested in the development of palliative care in HF. The aims of this workshop were to:

- Increase awareness of the need for palliative care for patients with HF;
- Improve the accessibility and quality of palliative care for those with HF;
- Promote the development and enhance the availability of HF-oriented palliative care services across Europe.

This document represents a synthesis of the presentations and discussion offered by the workshop participants (Appendix).

**Heart failure and palliative care****Disease trajectory of heart failure**

In this paper we focus on the different stages in the trajectory of HF and relate these to the WHO definition of palliative care (Box 1).<sup>8</sup> While the disease trajectory of each HF patient is different, a pattern of gradual decline is likely, punctuated by episodes of acute deterioration and eventually a seemingly unexpected death or death owing to progressive HF.<sup>11,12</sup> Thus, across the course of the illness, most HF patients will go through three phases:

**Table 1 Characteristics of the three stages in progressive heart failure****Stage 1: Chronic disease management phase (NYHA I–III)**

The goals of care include active monitoring, effective therapy to prolong survival, symptom control, patient and carer education, and supported self-management

Patients are given a clear explanation of their condition including its name, aetiology, treatment, and prognosis

Regular monitoring and appropriate review according to national guidelines and local protocols

**Stage 2: Supportive and palliative care phase: (NYHA III–IV)**

Admissions to hospital may herald this phase

A key professional is identified in the community to co-ordinate care and liaise with specialist heart failure, palliative care, and other services

The goal of care shifts to maintaining optimal symptom control and quality of life

A holistic, multidisciplinary assessment of patient and carer needs takes place

Opportunities to discuss prognosis and the likely course of the illness in more detail are provided by professionals, including recommendation for completing an advance care plan

Out-of-hours services are documented in care plans in the event of acute deterioration

**Stage 3: Terminal care phase**

Clinical indicators include, despite maximal treatment, renal impairment, hypotension, persistent oedema, fatigue, anorexia

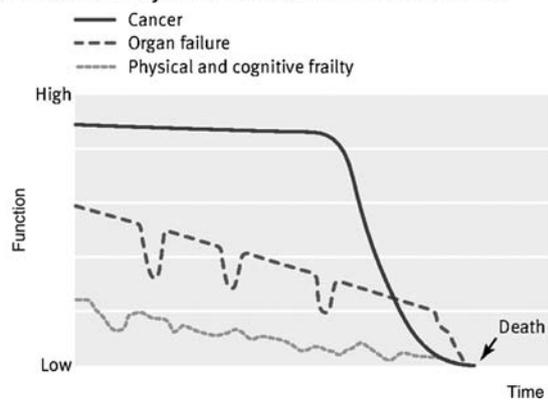
Heart failure treatment for symptom control is continued and resuscitation status clarified, documented, and communicated to all care providers

An integrated care pathway for the dying may be introduced to structure care planning

Increased practical and emotional support for carers is provided, continuing to bereavement support

Provision of and access to the same levels of generalist and specialist care for patients in all care settings according to their needs

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**The three main trajectories of decline at the end of life**

**Figure 1** Trajectories of decline. (Reproduced with permission from BMJ Publishing Group Ltd., Murray and Sheikh.<sup>12</sup>)

initially, a relatively stable primary phase needing routine chronic disease management; then one or more secondary phases of decline requiring increased utilization of hospital care, and a variety of supportive and palliative care strategies; and ultimately, a tertiary terminal phase of inexorable deterioration lasting for days or weeks (Table 1).<sup>11</sup> Although many patients with advanced HF will already have survived life-threatening decompensation or arrhythmias, when death does occur, this is often unanticipated (Figure 1).<sup>11,12</sup>

Therapy is often complex, as the common aetiological factors for HF such as ischaemic heart disease and hypertension still require treatment and a large proportion of patients also exhibit

concomitant arrhythmias and valvular heart disease. The mean age of patients hospitalized with HF in developed countries is 76 years, making the HF population vulnerable to the additional burden of general medical comorbidities and likely to be subject to the psychosocial problems that occur with ageing.<sup>4</sup> Common comorbidities include diabetes, renal dysfunction, anaemia, chronic obstructive pulmonary disease, depression, and cognitive impairment.<sup>16–19</sup> HF is the cause of 5% of acute hospital admissions and HF patients are often re-admitted; a diagnosis of chronic HF has already been established in more than 60% of those admitted with an acute HF syndrome.<sup>20</sup>

Although mortality is high in patients with HF, an increasing number of patients now live for many years following diagnosis, reflecting improvements in pharmacological, device, and cardiac surgical interventions. Combined with the changing demography, this improved survivorship will serve to increase the number of patients requiring palliative care. A greater proportion of patients will exhibit end-stage HF, for which the outcome remains poor.

## Prognostication

There is a plethora of prognostic data in advanced HF, ranging from clinical indicators such as the New York Heart Association (NYHA) classification, through simple biochemical markers to more complex investigative tools. These include measures of cardiac performance, exercise capacity, and neurohormonal markers, in particular B-type natriuretic peptide (BNP) and N-terminal pro-BNP.<sup>21–23</sup> As no single parameter is a perfect predictor of outcome, numerous clinical scoring systems have been developed. The most commonly used in this setting are the HF Survival Score (HFSS)—employed in the selection of patients for cardiac transplantation, and the Seattle HF Score which has a wider application and is accessible as a

practical web-based tool (<http://depts.washington.edu/shfm/>),<sup>24,25</sup> Many of these scoring systems use a variety of different clinical markers (e.g. age, aetiology of HF, QRS duration, serum creatinine, and serum sodium levels), which are combined to derive a prognostic score. Unfortunately, neither the HFSS nor the Seattle HF Score include BNP as one of the parameters; neither do they acknowledge the effects of other illnesses. Scoring systems such as that used in the EFFECT study<sup>26</sup> or the CardioVascular Medicine Heart Failure (CVM-HF) index<sup>27</sup> do incorporate comorbidities into the prognostic estimation.

However, the use of these complex scoring systems is probably not required for prognostication in the vast majority of our elderly patients with advanced HF. Simple clinical acumen and the appearance of features such as progressive renal dysfunction, a greater than 5% non-fluid-related weight loss (cachexia), and escalating diuretic dose requirements, usually provide us with sufficient evidence of an irreversible and ever declining health status.<sup>28,29</sup> While prognostication is difficult and will remain so, there are points on the HF disease trajectory that could act as triggers for a palliative care discussion. These include recurrent episodes of decompensation within 6 months despite optimal tolerated therapy, the occurrence of malignant arrhythmias, the need for frequent or continual intravenous therapies, chronic poor quality of life, intractable NYHA class IV symptoms, and signs of cardiac cachexia.

## Patient and carer expectations

Importantly, the perception of patients and their families might be at odds with those of the clinicians faced with these objective predictors of poor survival.<sup>30</sup> However, chronic HF patients have frequent thoughts about death, both during acute exacerbations and also in the more chronic stable phase of the illness.<sup>10,31,32</sup> Some patients feel uncomfortable about considering or talking about their mortality,<sup>31</sup> but a sensitive approach from a member of the HF team with good communication skills may be helpful in initiating discussion about prognosis in the face of advanced disease. HF patients often fear suffering at the end of their lives and are concerned with the control of pain, dyspnoea, and other disease-related symptoms.<sup>31,33,34</sup> Concerns may also lie in perceptions of the inappropriate prolongation of life, maintaining autonomy, caregiver burden, and relationships with their loved ones.<sup>7,31</sup>

Both patients and carers may lack understanding about the basis of symptoms of HF, their management, and the anticipated disease trajectory. The possibility of disease progression and prognosis seem to be subjects rarely broached in discussion during clinical encounters.<sup>10,35,36</sup> Views about the preferred place of care and death also differ. Some patients would prefer to die at home; however, other patients are concerned that dying at home would put too much stress upon their family or family members may balk at the prospect of a loved one dying there.<sup>10,31,37</sup>

Patient preferences, as well as their information needs and choices about care, may change over the course of HF.<sup>38,39</sup> Resuscitation preferences and willingness to undergo burdensome therapy are inconstant and may vary over time. It should also be recognized that younger patients dying of HF may have different perspectives and trajectories.<sup>12,38–40</sup> Such patients may be

particularly subject to feelings of guilt because of physical incapacity and denial of their role as a breadwinner that may impose financial pressures on their families.<sup>34,37</sup>

## Palliative care in heart failure

### Definition and key constituents of palliative care

In this document palliative care is defined according to the WHO (Box 1).<sup>8</sup>

The aim of palliative care in HF is to prevent and relieve suffering and to promote the best quality of life for patients and their families.

Steps in the provision of palliative care for patients with HF (Table 2):

- optimizing evidence-based therapy;
- sensitively breaking bad news to the patient and family;
- establishing an advanced care plan including documentation of the patients' preferences for treatment options;
- education and counselling on relevant optimal self-management;
- organizing multidisciplinary services;
- identifying end-stage HF;
- re-exploring goals of care;
- optimizing symptom management at the end of life;
- care after death including bereavement support.

It is important to emphasize that general palliative care is an approach that is applicable to all care settings and is not dependent on a specific health-care team. Similarly, a palliative care approach should not be reserved only for those who are expected to die over a short period. Instead, it should be available to all patients needing comprehensive and integrated treatment along the whole disease trajectory. Transition from general HF disease management to a potentially terminal care phase may be appropriate at several stages of crisis in HF, a feature that distinguishes HF care from the usual pattern of care applicable to those with cancer (Figure 1).<sup>11</sup>

### Managing symptoms

A high proportion of patients with advanced HF suffer from refractory symptoms such as pain, breathlessness, persistent cough, fatigue, and limitation in physical activity, anxiety, depression, sleeping problems, nausea, and constipation.<sup>9,28,40–46</sup> Studies describing the last months of HF patients lives report a considerable amount of discomfort and confusion in the final days before death.<sup>40,42</sup>

#### Symptomatic assessment

Symptoms need to be effectively evaluated not only because symptom alleviation is a primary target for treatment in the relief of suffering, but also because symptom prevalence and intensity may offer prognostic guidance in HF patients.<sup>35,46</sup> Few patients have sufficient understanding of their condition, the origin of the resultant malaise and their required disease management.<sup>14,35,45</sup> As with cancer, data on the full multidimensional spectrum of the symptom burden associated with HF are increasingly available, acknowledging differences between patients', carers' and the

**Table 2 Goals and steps in the process of providing palliative care in patients with heart failure**

Patient features	>1 episode of decompensation/6 months despite optimal tolerated therapy Need for frequent or continual i.v. support Chronic poor quality of life with NYHA IV symptoms Signs of cardiac cachexia Clinically judged to be close to the end of life
Confirm diagnosis	Essential to ensure optimal treatment
Patient education	Principles of self-care maintenance and management of heart failure
Establish an advanced care plan	Designed with the patient and a family member. Reviewed regularly and includes the patients' preferences for future treatment options
Services should be organized	The patients' care within the multidisciplinary team, to ensure optimal pharmacological treatment, self-care management, and to facilitate access to supportive services.
Symptom management	Requires frequent assessment of patients' physical, psychological, social, and spiritual needs Patients frequently have multiple co-morbidities that need to be identified
Identifying end-stage heart failure	Confirmation of end-stage heart failure is advisable to ensure that all appropriate treatment options have been explored and a plan for the terminal stage of illness should be agreed upon
Breaking bad news to the patient and family	Explaining disease progression and a change in treatment emphasis is a sensitive issue and must be approached with care
Establishing new goals of care	End-of-life care should include avoidance of circumstances which may detract from a peaceful death. All current pharmacological treatment and device programmes should be considered. Resuscitation orders should be clear

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health-care professionals' perceptions.<sup>45,46</sup> Quantifiable features are also evolving. Different aspects of symptoms should be considered separately, such as contributory elements of fatigue in a lack of energy and the perceived degree of physical dysfunction, as well as drowsiness, irritability, and low mood.<sup>44–46</sup> Other symptoms are often inter-related, for example breathlessness is associated with sleep deprivation and depression.

### Psychological and spiritual issues

Depressive symptoms are common in HF patients, particularly in those with several concomitant conditions.<sup>17,18</sup> It is important to recognize that feeling sad about the impact of disease is to be expected and should be distinguished from clinical depression. The prevalence of clinically significant depression in patients with HF is more than 20% and mortality rates are increased in HF patients suffering depression.<sup>47–49</sup> Although there is no evidence that treating depression reduces morbidity and mortality, in the context of palliative care, both pharmacotherapy with selective serotonin re-uptake inhibitors as well as psychotherapy might be helpful in alleviating symptoms.

As in other life-threatening illnesses, the chronic and progressive nature of HF may have a significant impact on patients' sense of self and other spiritual aspects. Spiritual contentment is an important modifier of the degree of depression in elderly HF patients and enhancement of patients' sense of spiritual well-being might positively impact on depression and thus improve quality of life.<sup>50</sup> It is important to enquire about patients' spiritual concerns and needs without questioning their beliefs, and to afford them the opportunity to find comfort and closure near the end of life.<sup>51</sup> Health-care professionals do not always feel comfortable or skilled in discussing religious or spiritual concerns with patients.

In some facilities other professionals, including chaplains, spiritual advisers, and pastoral counsellors may be approached to talk to patients and address these issues.

Interventions aimed at alleviating symptoms should offer a holistic approach and be directed not only at the patients' physiological and psychological symptoms, but also address their social and spiritual needs.

### Symptom control interventions

Symptom control in HF poses specific challenges. For example palliation of dyspnoea underscores the need to maintain patients on optimal active HF medication.<sup>4</sup> Although morphine has been shown to be effective in palliating the dyspnoea of end-stage HF, protocols to guide dose titration, particularly for non-intravenous administration, are not yet established.<sup>52</sup> Research needs to address the question of optimally palliating dyspnoea with morphine while continuing to use this symptom as a marker to best guide HF management. Evidence is also lacking on the application of many other symptom control interventions established in palliative (cancer) care to those suffering from HF.<sup>46</sup> Until translational research provides that evidence base, a practical approach has been adopted that proposes several interventions to be used on an empirical basis in daily practice.<sup>13,53–55</sup>

Since the majority of patients with end-stage HF have multiple medical conditions, strategies for optimal symptom management need to accommodate both cardiovascular and non-cardiovascular conditions. Addressing these issues is challenging, particularly the requirement to treat multiple medical conditions in those already burdened with complex polypharmacy. Prospective research may facilitate the development of protocols specifically relevant to HF as proposed in the PAIN-HF study.<sup>56</sup>

## Co-ordination of care

A recent qualitative telephone survey of professionals involved in chronic HF palliative care in the UK underlines the need for optimization of services involving joint working between cardiologists, community HF nurses, and palliative care professionals.<sup>57</sup> Another systematic review exploring attitudes to palliative care at the end of life showed strong support for the development of multi-component interventions and to improve continuity of care in advanced HF.<sup>58</sup>

Co-ordination of care within hospital and primary care settings still needs to be improved in many countries. A designated health-care professional might be appointed to co-ordinate care and liaise between HF specialists, general internal medicine, palliative care, and other services. In some countries this might be the role of the general practitioner, while in others care may be co-ordinated by a HF nurse, an internist, a geriatrician, or a palliative care specialist.

## Communication and decision-making

It seems that communication about prognosis and death in HF is intrinsically more complicated than it is in cancer care. HF patients often have little insight into the nature of their disease, or their prognosis and rarely initiate or are offered discussion on end-of-life issues with their professional carers.<sup>59,60</sup> This lack of communication between health-care professionals and patients is particularly lacking in the terminal phase. In one retrospective study based on interviews with the next of kin of deceased patients who had been recipients of an implantable cardioverter defibrillator (ICD), deactivation of the device before death was discussed in only 27% of cases. Even when an active 'Do-Not-Resuscitate' (DNR) order was in place, such discussion took place <45% of the time.<sup>61</sup>

In addition to issues on medical management and self-care behaviours, education of patients and their families should include the anticipated course of the illness, resuscitation preferences, advanced care planning, the possibility of exacerbations, and functional decline.<sup>4,5,28</sup>

The general themes of the many communication and decision-making issues in palliative cancer care such as 'prepare for the worst but hope for the best' or 'how best to break bad news to patients' might be equally applicable in advanced HF.<sup>62,63</sup> The effects of improved communication skills have been demonstrated in oncology,<sup>64</sup> but even in this setting, such studies have revealed continuing gaps in information exchange, disclosure, prognosis, and empathic communication. Research on the specific application of such communication interventions in HF is scarce.

As discussed above, patients' preferences, their information needs, and choices about care may change over the course of HF, necessitating regular open discussions. Clinicians may be reluctant to discuss advance directives and resuscitation preferences, fearing that these interactions may be distressing for patients. However, as evident in the SUPPORT study, resuscitation preferences are inconstant and therefore discussion on end-of-life issues should be undertaken and frequently revisited.<sup>38</sup> Patients' goals of care need to be reviewed and reaffirmed on a regular basis to better ensure that these are consistent with those of their

professional carers. Cognitive impairment, confusion, and other comorbidities often complicate such conversations and therefore staff members working with HF patients require good communication skills.<sup>11,60</sup> The use of a palliative care specialist, a hospital ethicist, or a patient advocate may be helpful at such times if locally available.

## Consequences for heart failure treatment

Algorithms to facilitate the incorporation of illness-guided palliative care principles within disease-guided pharmacological protocols developed for symptom management and prognosis remain to be established. Those that have been developed in the care of cancer patients require further research to ensure that they also apply to palliative HF care.<sup>65</sup> Treatment may require modification for patients with advanced HF and multiple life-limiting comorbidities. Data supporting the use of clinical guidelines have usually been based on studies that have often excluded the elderly or patients with significant non-cardiovascular disease. Therefore, these guidelines offer little insight into how best to adjust individualized therapy for patients with advanced disease and comorbidity that substantially affects life-expectancy. Patient preferences gain increased importance in the face of any advanced disease state.

Clinical decision tools, as in the Seattle HF Model (<http://depts.washington.edu/shfm/app.php?accept=1&enter=Enter>),<sup>25</sup> have been designed to allow estimation of the prognostic benefit of adding medications or devices to an individual patient's therapeutic regimen. These tools may provide a rational basis for developing individualized strategies for the comprehensive management of the advanced HF patient with multiple comorbid conditions, and facilitate decision-making concerning initiating or augmenting palliative care.

## Pharmacological treatment

HF medication is important in maintaining symptom relief and improving quality of life. It follows that most active cardiac therapies should continue even if the patient's palliative care needs are escalating. Medications should be reviewed regularly and decisions to adjust or discontinue drugs should be taken prospectively rather than only as a response to adverse effects. It is also important to reconsider the relative merits of therapies that have been prescribed for symptomatic relief and those offered primarily to improve prognosis.

## Pacemakers and defibrillators

Implantable cardioverter-defibrillators and their use in combination with cardiac resynchronization therapy (CRT-D) are becoming increasingly common in HF management. Patients with palliative treatment for end-stage HF should have their ICD inactivated, because repeated ICD firing (ICD storm) can occur and be very distressing in the terminal phase.<sup>66</sup> In addition, it may be appropriate to sensitively inform patients for whom the treatment of arrhythmias may unnecessarily prolong the dying process and succumbing to a lethal arrhythmia may be a better mode of dying. Patients and their families should be reassured that ICD inactivation is not expected to immediately result in the death of the patient.<sup>66,67</sup> If a CRT-D device has been implanted, it may be

preferable to disable only the defibrillator function and to maintain pacing activity to avoid symptomatic deterioration.

Discussions about ICD inactivation should be conducted early in the follow-up of end-stage HF patients, ideally before being confronted with a dilemma at the end of life. Patients should be considered for ICD inactivation when it is clinically obvious that they are about to die, when a DNR order is in force, and when the impairment of quality of life is such that a sudden cardiac death might be considered a relief. In addition, in compliance with basic ethical principles, ICDs may require deactivation when fully informed competent patients spontaneously request this.<sup>66,68</sup>

### Heart transplantation and assist devices

Although still limited in terms of accessibility, an increasing number of patients with advanced HF are assessed for heart replacement and short- or long-term mechanical circulatory support. The nature of such intervention demands reconsideration of the goals of care and open discussion on the benefits and burdens of such therapy. These may include additional symptoms, infection risk, thrombo-embolic complications, and the possibility of graft rejection or neoplasia. Alternatively, cardiac transplant recipients may survive for more than 25 years and heart transplantation is currently considered as a potential curative treatment for end-stage HF.<sup>4,69,70</sup> In many countries it is accepted that protocol-derived consideration for heart transplantation is triggered for advanced HF patients if it is likely that the recipient will achieve a gain in life-expectancy of at least 5 years.

At variance with the layman's perspective, this intervention is rarely available. Worldwide, only about 5000 heart transplants are carried out annually. This number has remained relatively stable or even decreased over the last 15 years, making heart transplantation an unattainable option for most.<sup>71</sup> As comorbidities may significantly impact on possible survivorship, these have to be carefully considered before active listing for this intervention.<sup>5,72</sup>

Left ventricular assist devices (LVAD) are increasingly used in patients with severe HF. Their use is often linked with transplant programmes where they may provide mechanical circulatory support as a 'bridge' until a suitable cardiac homograft becomes available. However, given the significant technical development in recent years, they may also be considered for long-term implantation as 'destination therapy' (LVAD-DT). Following the publication of data such as that from the REMATCH study,<sup>73</sup> LVAD-DT is a feasible consideration in those ineligible for cardiac transplantation. Although this treatment option is still not widely available, the use of these devices is expected to increase in the near future, limited only by access to an experienced cardiac surgical centre and cost constraints that will eventually reduce as implant rates increase. One of the major problems is optimal timing for VAD implant as destination therapy.<sup>34</sup> The use of the INTERMACS classification of advanced HF that offers several clinical profiles ranging from NYHA grade III patients to those in cardiogenic shock, may help to inform the decision on timing.<sup>74</sup> The presence of these devices presents significant ethical and logistic dilemmas in those with end-stage HF.<sup>75</sup> Close liaison with palliative care professionals to assist in device management may be particularly helpful if withdrawal is being considered

because of progressive HF, device-related complications, or the occurrence of other life-limiting conditions.<sup>73,76</sup>

## Development of heart failure palliative care in Europe

A general statement on palliative care for HF that would apply across Europe is difficult given the spectrum of health-care systems, local legislation, and varying cultural attitudes. No single service model will fit all health-care systems. However, as most of the challenges relevant to the care of patients who are living and finally dying with advanced HF cross national boundaries and are transcultural, a uniform structured strategy is applicable in most regions.

Optimal end-of-life care for HF should be available across the range of health-care structures and the components of such service provision that might be applicable on a pan-European basis and linked to HF management programmes are summarized in the tri-phase model proposed in *Table 2*. The European Association for Palliative Care (EAPC; [www.eapcnet.org](http://www.eapcnet.org)) might offer a useful platform for collaboration and facilitate such service development.

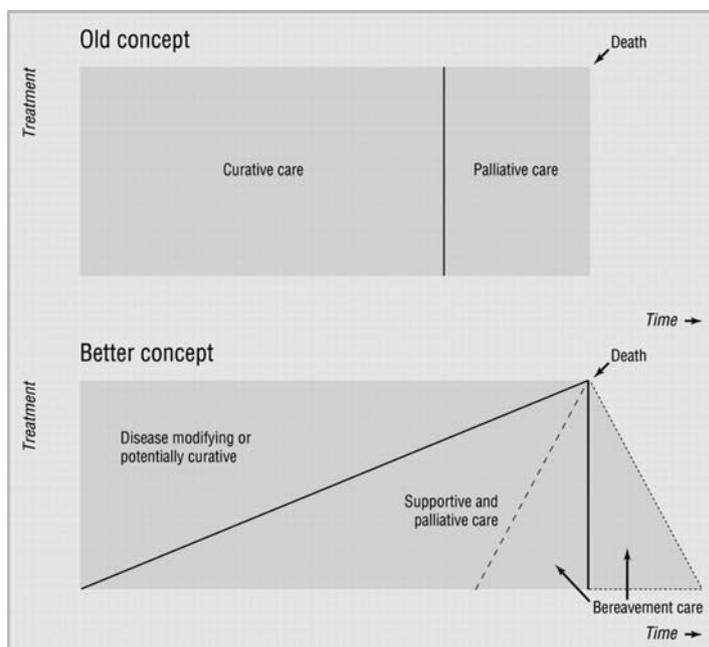
### Role of heart failure management programmes

While we must acknowledge that HF management programmes are not well-established across the whole of Europe, over the last two decades these programmes have been developed in several countries with evolving roles for cardiologists, general practitioners, and HF nurses. Fifteen years ago, nurse-led HF clinics for patient education and follow-up were initiated, and since then several different models have been utilized in the organization and delivery of HF care, adapted according to local and national health-care needs.<sup>5,77</sup> The optimal HF management model is not yet defined but the majority of existing programmes are based in outpatient clinics staffed by nurses and physicians.<sup>77-79</sup>

These programmes may involve primary care settings and collaboration with general practitioners is particularly important in the co-ordination of care for those patients needing input from several specialties, or who are unable to visit hospital outpatient departments.<sup>77,80</sup> In several countries, integration and cooperation with general practitioners and primary care nurses are already established and fundamental to the delivery of care to patients with advanced HF. Although the severity of symptoms and prognosis will differ for individual patients, the elements of their palliative care requirements may be similar to the essential components offered in HF management programmes. Thus, it should be possible to integrate palliative care into HF management.

### Integrating cardiology and palliative care

Lessons on how to integrate cardiology and palliative care can be gleaned from the experience of those in oncology. The European Society of Medical Oncology (ESMO) and the American Society of Clinical Oncology (ASCO) have established working groups on palliative cancer care and developed position statements. The ESMO has embarked on an incentive programme to facilitate the



**Figure 2** Model for palliative care. (Reproduced from Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *Br Med J* 2005;**330**:1007–1011, with permission from BMJ Publishing Group Ltd.)

integration of palliative care within the care of those with cancer, based on 13 key points of integration.<sup>81</sup> The ESMO palliative care working group has proposed that oncologists should maintain their key role as providers of care to their patients over the whole trajectory of illness, and that there should be a concomitant linkage with specialized palliative care professionals in a shared-care strategy for these patients. An ASCO task force on palliative care concurred that palliative cancer care is the integration of palliative care principles in the disease trajectory of cancer patients, that this should not be confined to the terminal phase, and posed specific challenges to the specialties of oncology and palliative care in the collaborative development of palliative cancer care services.<sup>82</sup> In larger cancer centres these joint palliative cancer care services are already established, typically staffed by palliative care specialists, who are also oncologists or have had enhanced training in oncology. The EAPC is in the process of drafting a white paper to define palliative care services and has raised the issue of developing subspecialty palliative care. Early examples include palliative paediatric care, palliative cancer care as described above, and others such as palliative cardiac care are likely to follow.

The success of such initiatives requires that the existing high-quality treatment provided by specialists in palliative care, largely confined to terminal care, needs to be assured while this is extended to the earlier stages of life-limiting diseases as proposed in the WHO policy. It is unlikely that either palliative care or medical specialists, working in isolation, will be sufficiently experienced to provide for the complex disease or symptom-related care needs of their patients relevant to these various disease states, including those with HF. A collaborative approach is required to address these unmet care needs with the development

of formal professional alignments. While successful examples of shared care practices already exist, the development of this approach for HF demands a robust evidence base to facilitate implementation, and further research on such integrated care models is mandated.

## Basic models of palliative care for heart failure

Generic models of palliative care are illustrated in *Figure 2*. Two models of palliative care for HF patients are outlined below, both of which are relevant to inpatient or community-care settings and might also be useful at times of care transition.

### Heart failure specialist care aligned with palliative care consultancy

In this model, the patient is cared for primarily by the HF specialists, be it the HF interdisciplinary care team or the cardiologist. General palliative care is provided by the general practitioner or general community nurses, with specialist palliative care input by the palliative care physician or specialist teams as required. Interdisciplinary education is central to the success of this model, integrating principles of palliative care in training programmes for HF professionals and including HF care for palliative care professionals. While palliative care specialists may be either hospital or hospice based, a flexible approach is required as palliative care consultations need to be accessible for both hospitalized and community-based patients. The provision of assessment at home may be particularly applicable to this group of patients in facilitating support for the patient and their family in a familiar setting, in advising

the primary care physicians on optimal symptom management and in avoiding unnecessary admissions.

One example of this model is an initiative in the UK where the British Heart Foundation has recently funded HF nurses who will be specifically trained in palliative care and in advanced communication skills. This should enhance the support of both patients and their families and facilitate co-ordination with other health-care professionals. A second example of this model is in Switzerland where mobile palliative care teams based in the community provide symptom management for the patient at home and support families in their caring role.

### Heart failure-oriented palliative care services

The second care pathway is one in which palliative care services assume responsibility for the basic care of the patient and their family, and HF specialists serve as consultants for specific issues relating to the treatment of HF. The provision of HF-specific protocols and guidelines can be helpful in informing and reassuring palliative care specialists who are caring for such individuals. Palliative care services may be located as inpatient departments in general hospitals, as independent inpatient hospice care centres, or as community-based support programmes for patients cared for at home with nurses or trained nursing assistants providing basic care for the patient and support or respite care for the family.

## Conclusions

A palliative care approach is applicable to HF patients and is particularly relevant to those with advanced disease. This approach is aimed at improving the quality of life of patients and their families facing the problems associated with refractory symptomatic HF, through the prevention and relief of suffering by means of early identification and treatment of physical and psychological symptoms and attention to social and spiritual needs. Palliative care should be integrated as part of a team approach to comprehensive HF care and should not be reserved for those who are expected to die within days or weeks. Rather, this should be considered for the general clinical cohort as part of a comprehensive care provision over the whole disease trajectory. Patients' individual needs are important in care planning, including age and family-related issues. Three phases can be conceptualized to guide modelling of clinical services for HF patients along their disease trajectory and clinicians should prepare for a 'change in gear' from a chronic stable disease management approach, to enhancement of the supportive and palliative care elements at times of crisis, and then to terminal care when death is imminent.

## Major recommendations

### Delivery of quality care to patients and their families

- The expected or anticipated course of the illness, final treatment options, treatment preferences, living wills, and advance directives should be discussed with patients and their families at an early stage of the disease.

- Goals of care should be evaluated repeatedly during disease progression, anticipating that patients may frequently want to modify their decisions.
- Close to the end of life, any life-prolonging treatment not contributing to symptom control should be carefully evaluated and possibly withdrawn and additional palliative care measures introduced as appropriate.
- Patients should understand that withdrawal of previously applicable conventional treatment does not mean withdrawal of care.
- Discussion with patients and families should focus on what will be provided rather than what will be discontinued.
- Optimal co-ordination and continuity of care for those patients who are often re-admitted under a variety of medical specialties or who are unable to visit the outpatient department. Collaboration with primary care services is vital.

### Education

- Patient education should be regularly reinforced.
- Communication skills should be included in staff training.
- Joint educational opportunities should be available for HF and palliative care professionals working with patients with advanced HF.
- Cardiac palliative care should be incorporated in the postgraduate palliative care training of general practitioners.

### Treatment co-ordination

- Treatment co-ordination for patients with advanced HF is essential to help reduce the risk of care fragmentation and potential conflicts commonly encountered when many health professionals and multiple agencies are involved.

### Research

- Further research is required to assess how patients needing a palliative care approach can best be identified and how that care can best be planned and co-ordinated throughout their illness.
- Further research is needed to determine optimal treatment strategies and care models for end-stage HF patients across the whole spectrum of those affected from young individuals to the elderly with comorbidity.
- Research gaps in pharmacological and non-pharmacological treatment of symptoms have been identified and should be addressed<sup>46</sup>

### Policy

- On the advice of participants, the HFA incorporated a section on palliative care in the recently updated ESC Heart Failure Guidelines.<sup>4</sup>

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