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Reflections on ethical issues in palliative care for patients with heart failure

►► In a paper produced by a European Association for Palliative Care Taskforce,

Manuel Martínez-Sélles et al discuss the needs of patients with end-stage heart failure

as they receive palliative care, highlighting the importance of medical teams initiating timely discussions of a range of end-of-life issues at various points in the progression of the disease

Advanced heart failure is a life-limiting condition and, although prognostic uncertainty is a concern, discussion of end-of-life issues should be integrated early in disease management, particularly because advances in heart failure treatment during the last three decades have led to further ethical issues. The European Association for Palliative Care Taskforce undertook a review, presented here, to consider the complex ethical issues in the palliative care of people with advanced heart failure, incorporating a multidisciplinary perspective and including cardiologists, palliative care experts and ethicists from various European countries.

Prognostic uncertainty

The prognostication of disease progression for individual patients with heart failure is difficult, because there is no typical dying trajectory.¹ Loss of functional capacity or autonomy may occur either gradually or abruptly (see Figure 1), and sudden death is a frequent event. This information can guide a process of informed decision-making and choice of treatment between patients, their family carers and professionals.² The main variables associated with a poor prognosis are summarised in Table 1. Many of these variables are independent predictors of mortality in patients with heart failure and should be taken into account simultaneously. However, other conditions that should influence prognosis, such as frailty or some other impairment of a patient's functional status, are often not considered in currently available prognostic models, and this may limit the accuracy of prediction of survival.³ The patient's own perception of worsening health status is an independent predictor of

hospitalisations, mortality and consumption of resources, irrespective of the presence of other poor prognostic factors.⁴ Nevertheless, many patients with heart failure seem to have little knowledge of their disease or its treatment,⁵ and patients and their families frequently do not perceive it as being a serious disease.

These factors can lead to optimism on the part of the doctor when estimating a patient's risk and assessing life expectancy; they may also explain why patients in the final stages of heart failure frequently receive aggressive therapies. This prognostic uncertainty leads to ethical issues, because physicians are more likely to avoid discussing prognosis or to convey overly optimistic prognostic information, when there is considerable prognostic uncertainty.

Communication and decision-making

The care of people with advanced heart failure should be based on the principles of palliative care and involve both the person and their family in the decision-making process. Full communication throughout the disease progression is essential in order to ensure that the person is fully involved and able to make autonomous and clear decisions, or to plan ahead if they fear that they may lose their decision-making capacity.

Communication problems may make patients and their families unable to be involved in care planning, leading to deterioration in care at the end of life.⁶ Regular discussion should consider the patient's diagnosis and prognosis and will provide opportunities to discuss their care, including advance care planning and preparation for dying and death. Such discussions may become part of normal practice and thus, over time, become easier for all involved.⁷ Current evidence suggests that recognition and discussion of the end of life may be late, often too late to



Figure 1. The aim of treatment in relation to the duration of disease progression in end-stage heart failure is to regain functional capacity following organ failure at various points in the patient's dying trajectory¹

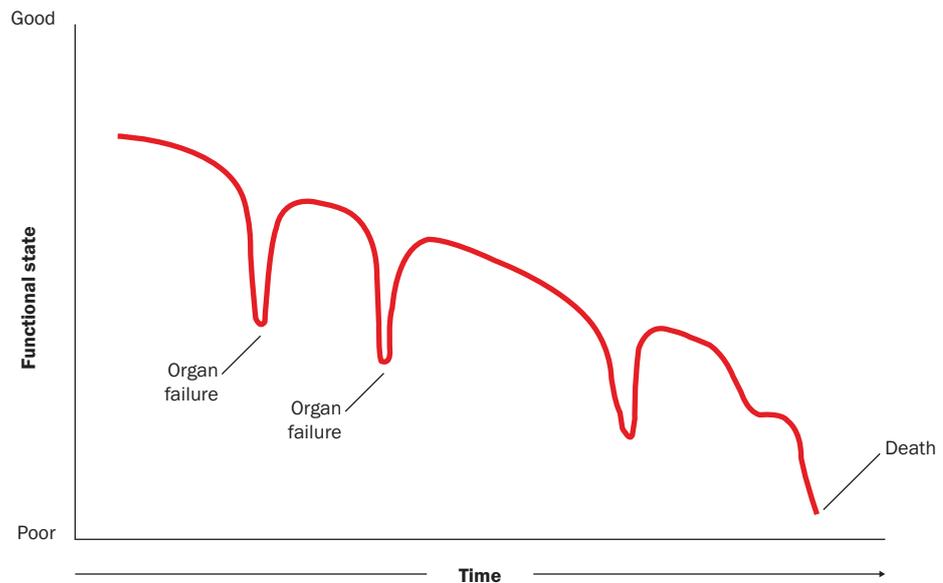


Table 1. Main prognostic parameters in patients with heart failure

- Advanced age
- Left ventricular systolic dysfunction
- Ischaemic aetiology
- Functional class
- Severe hyponatremia
- Low peak oxygen consumption during exercise
- Low hematocrit
- Wide QRS complex
- Hypotension
- Sinus tachycardia at rest
- Renal insufficiency
- Intolerance to conventional therapy
- Refractory volume overload
- Persistently elevated natriuretic peptides
- Co-morbidity
- Frailty

allow for proper discussion and planning for end-of-life care.⁶ In particular, late referral to palliative care leads to late discussion of these issues.⁶ Specific protocols have demonstrated effectiveness in maintaining communication throughout the process of disease progression and may be helpful in improving communication. One example, by Baile *et al*, is given in Table 2.⁸

Advance care planning

In order to ensure that patient autonomy is respected, even if the patient loses their decision-making capacity, it is essential to know their opinion on treatment options and to make sure that they are fully involved in the decision-making process. Patients can express their wishes for treatment options while they are able to do so, and if they lose capacity, these views are then well known and the care team can comply with them.

Table 2. SPIKES – a six-step protocol for delivering bad news⁸

Setting	<ul style="list-style-type: none"> • Privacy • Involve significant others • Sit down • Look attentive and calm • Adopt listening mode
Perception	<ul style="list-style-type: none"> • Before you tell, ask • Assess the gap between the patient's expectations and the actual medical situation
Invitation	<ul style="list-style-type: none"> • Do not assume that all patients want to know all • Ask about preferences regarding information
Knowledge	<ul style="list-style-type: none"> • Give a warning that bad news is coming • Give the information in small chunks • Use clear language
Empathy	<ul style="list-style-type: none"> • Acknowledge and address the patient's emotions • Let them know that showing emotion is normal
Strategy and summary	<ul style="list-style-type: none"> • Ensure that the patient understands the information • Summarise the information and give an opportunity for the patient to voice concerns

Advance care planning may produce a clear plan for future care that outlines what treatments the person may or may not wish to receive, such as an Advance Directive, or it may involve the discussion and recording of their resuscitation wishes, such as a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) or Allow Natural Death (AND) order.^{7,9} This planning, if correctly and legally undertaken, should be respected – in some countries this is already required by law. It is also possible, in many countries, to appoint a proxy who can make decisions on behalf of the patient, should the patient lose their capacity to do so themselves. The proxy should then be involved in decision-making



in the same way as the patient themselves. Advance care planning should be revisited throughout the disease progression. The early start of such discussion normalises the addressing of such difficult areas and allows more people to be involved. Currently, even with careful assessment and encouragement, few hospitalised patients have an advance care plan.¹⁰

Withdrawal of treatment and resuscitation status

As a person deteriorates, treatments that have been appropriate at less advanced disease stages may become less appropriate or ineffective and may be deemed 'futile' when they provide no benefit or are detrimental to the patient's well-being and quality of life.⁹ If a new treatment is considered by the physician to be futile or of little benefit, the physician is not compelled to start it, although careful discussion and explanation with the patient and family is needed.

Cardiopulmonary arrest is frequent in patients with advanced heart failure. However, patients with heart failure are 10 times less likely than those with cancer to have a do-not-resuscitate order, despite having a similar prognosis.¹¹ Studies consistently show that most patients with heart failure opt to continue with resuscitation.¹² It is unclear why patients with heart failure and their doctors are resistant to do-not-resuscitate orders¹² and physicians rarely seem to initiate discussions as to patients' end-of-life preferences.¹⁴ The prognosis of patients with heart failure remains variable and rapidly changeable, and decisions regarding medical options and resuscitation status therefore need to be revisited frequently. Unfortunately, DNACPR orders, which apply only to cardiopulmonary resuscitation manoeuvres, are often associated with a reduction of other therapies. This may be of concern to patients and families and reduce their likelihood of accepting a DNACPR. In addition, they, and sometimes their physicians, are unaware that the success rate of resuscitation after cardiopulmonary arrest is low (15–20% for patients who have been discharged home and less than 10% in the community).^{15,16}

Palliative sedation

In certain circumstances, palliative sedation may be considered for the relief of severe distress and very distressing symptoms.¹⁷ In Cherny and Radbruch's EAPC white paper on sedation in palliative care, palliative sedation is defined as "the monitored use of medications intended to induce a state of decreased or absent awareness

(unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health-care providers in patients that are imminently dying".¹⁷ The American Academy of Hospice and Palliative Medicine published a position paper on palliative sedation supporting its use, as do many critical care organisations. The goal of palliative sedation is to provide comfort and the relief of refractory symptoms without intentionally reducing lifespan. In heart failure patients, these symptoms would typically be uncontrollable dyspnoea, delirium or pain. Such an approach would be considered only if all other means of symptom control had been attempted; the patient or responsible surrogate should be fully informed about the rationale for palliative sedation and agree to its use. The level of sedation should be proportionate to the patient's level of distress, and their alertness be preserved as much as possible. The patient may deteriorate and die during this treatment, but the aim is to alleviate suffering and manage symptoms, and not to shorten life.¹⁸ Under the doctrine of double effect, the use of sedation can be justified, even if life is shortened.¹⁹

The use of devices in the management of heart failure

The introduction into medical practice of devices that improve functional capacity, quality of life and survival has considerably changed the outlook for patients with heart failure. Such technology includes:

- implantable cardioverter-defibrillators (ICDs), which detect and terminate life-threatening ventricular tachyarrhythmia
- implantable cardiac resynchronisation devices, which are used in cardiac resynchronisation therapy (CRT) and can improve left ventricular function in patients with left bundle branch block
- CRT defibrillators (CRT-Ds), which perform both functions listed above
- ventricular assist devices (VADs), which are mechanical pumps that support heart function in patients with circulatory failure.

Although clinical guidelines recommend against their use in patients with a life expectancy of less than one year, even elderly or treatment-refractory patients may benefit from these therapies.²⁰ Clinicians should discuss the risk and benefits of these therapies in patients with heart failure, and the decision-making process and the measures adopted should follow the principle of proportionality, balancing the benefits and risks to inform the decisions.



As patients deteriorate, the use of such devices needs to be reassessed. Patients reaching the end of life, if competent and well informed, should also participate in decision-making related to the withholding or withdrawal of these therapies. Discussion about device deactivation should take place prior to implantation and be frequently reinitiated, especially in the case of a heart failure hospitalisation or an ICD shock or if a patient with an ICD reaches the terminal stage of an advanced non-cardiac disease. A discussion, similar to that prior to the first implantation, should also be held in the case of device replacement, an intervention that is never mandatory.

The ICD should be deactivated during the dying process, which will prevent unnecessary suffering and the prolongation of life at the cost of significant discomfort.²¹ Unfortunately, this is clearly not always standard practice, and many patients may receive multiple shocks at the end of life.²¹ In most cases, it is reasonable to turn off only the ability to provide a shock. However, few clinicians address these talks personally in their daily practice, and discussions about ICD deactivation prior to death are rarely held. Device deactivation has been addressed in an expert consensus statement,²² which suggests that principles of autonomy and self-determination ought to be respected and complied with if a patient or surrogate requests that a device be turned off or has, in advance care planning, defined when they wish the device to be turned off. ICD deactivation should be considered under the following circumstances:

- when a DNACPR order is discussed
- in patients with disease deterioration whose quality of life has worsened
- when the patient is expected to die
- if a well-informed and competent patient requests it.²²

Patients should be informed that ICD deactivation will not make death imminent and that cardiac resynchronisation therapy may continue, even if defibrillation has been deactivated, as resynchronisation improves left ventricular contraction and reduces symptoms.

Discussion about future disablement of a VAD should also take place before device implantation and be revised periodically. Deactivation may be considered under the following circumstances:

- at the request of the patient, either as a direct request or from an advance directive, if they have lost capacity to make the decision
- at the request of the patient's surrogate following serious, non-fatal complications or the development of a terminal condition caused by concomitant disease.

The discontinuation of VAD support is emotionally challenging because this is usually a life-terminating event, and patients often die shortly after the therapy withdrawal. Thus the use of medication to manage symptoms and possible distress, including palliative sedation, may be considered before withdrawal.

Medication and intensive care

The majority of medications for heart failure should be maintained, provided they are tolerated, as they may improve symptoms. Inotropic infusions do not lengthen survival but can be used as part of palliative care at the end of life, while intermittent infusion of intravenous inotropes can be safely administered and can improve both symptoms and quality of life.²³ In patients hospitalised in intensive care units, identifying patients' values and goals, which should be reviewed daily, ensures that the decision-making process respects patients' autonomy.

Legal issues

There may be ethical discussions about the most appropriate use of limited resources, including consideration of rationing of services, fairness and distributive justice.²⁴ Advanced therapies, for example, may need to be rationed and offered to those patients who are expected to have better prognosis and outcomes. It is also important that patients who require palliative care have access to it, and this can be considered as a human right.²⁴ However, policies may differ among European countries, which may lead to differences in the treatment received by these patients – in some countries, palliative care services may be restricted or unavailable for those with heart failure.²⁵

Ethical decisions related to withholding or withdrawing therapies should take into account the law and guidelines within the specific country, as well as the evidence base for the intervention and resources available. Resolution 1859 (2012) of the Parliamentary Assembly of the Council of Europe, 'Protecting human rights and dignity by taking into account previously expressed wishes of patients',²⁶ clarifies the role of advance directives for patients in all European countries. There is a need for all countries to consider this imperative to respond to the wishes of patients and at the same time ensure that there is ready availability of palliative care.

Social and spiritual support

Advanced heart failure is a critical illness resulting in emotional, social and spiritual needs, including feelings of hopelessness, isolation and altered self-image of both patients and their



families, all of which have ethical implications. Social and spiritual support reduces depression and anxiety.²⁷ Assessment of patients with end-stage heart failure should incorporate evaluation of the patient and families' psychosocial support, financial resources, emotional state and well-being, and spiritual and religious needs. Continuing care is valued by patients and families, and families appreciate contact following the death. Bereavement is a normal process, and clinicians should acknowledge and appreciate this, with empathic responses and requests for help from chaplains, social workers, counsellors and others who can offer assistance. Grief after sudden death can be especially challenging, and a broad support system may be needed to meet the needs of the bereaved family members. A sudden death may also be felt emotionally by the professionals involved, and support and ongoing supervision is helpful.²⁸

Conclusion

Advanced heart failure is a life-shortening condition and, although prognostic uncertainty is an issue, planning for adverse events and the end of life should be integrated into care early in the course of the condition. Consequently, regular revisiting of these discussions during the process of the disease is necessary to allow for adjustment to changing circumstances. Communication is essential to inform patients about the potential benefits and burdens of interventions, to understand patient goals and to facilitate decision-making regarding withdrawal of

treatment, resuscitation status, use of palliative sedation and other end-of-life decisions. The involvement of families throughout the progression of the disease is also recommended, together with social and spiritual support ■

Note

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Declaration of interest

The authors declare that there are no conflicts of interest.

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Key points

- ▶ **Advanced heart failure is a life-shortening condition; planning for adverse events and the end of life should be integrated into care at an early point in the illness.**
- ▶ **Advances in treatment have increased the ethical complexity in the care provided by clinicians, particularly at the end of life.**
- ▶ **Communication is essential to inform patients about potential outcomes and the realistic benefits and burdens of interventions, and to understand patient goals and values.**
- ▶ **Involving patients and families in the process of decision-making is crucial.**
- ▶ **Social and spiritual support is extremely important, as is knowledge of legislation.**
- ▶ **Patients with implanted devices merit special attention; regular revisiting during the disease process is necessary to allow adjustment to changing circumstances.**