PEER REVIEWED FEATURE

Heart failure and palliative care

Are we there yet?

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Integrating a palliative approach with active management can help identify and address the significant needs of patients with advanced heart failure.

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Key points

- **Introducing a palliative approach to care of patients with heart failure while still attempting to modify the disease course through treatment can improve patients' quality of life.**
- **Patients who would benefit from a palliative approach can be better identified by tools that assess needs rather than prognosis.**
- **Optimal palliative care of patients with heart failure integrates ongoing active management with specific interventions to manage symptoms such as breathlessness and oedema.**
- **A plan for deactivation of implantable cardioverter defibrillators at the end of life should be devised and discussed with patients.**
- **Patients should be given the opportunity to reflect on and communicate their preferences for end-of-life care early in the disease process.**

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It is estimated that each year around 30,000 Australians are diagnosed with heart failure.[1] This clinical syndrome predominantly affects older people, with prevalence doubling every decade from the age of 75 years onwards.[2,3] Heart failure is a progressive, chronic condition with a poor prognosis and significant symptom burden. It is characterised by diverse symptoms, including breathlessness, fatigue and fluid overload. Although the survival of people with heart failure following first hospital admission is improving, prognosis remains poor, with annual mortality rates as high as 50% for patients with New York Heart Association (NYHA) class IV disease.

People living with advanced disease (NYHA classes III and IV) experience high rates of disability, severely limiting their ability to manage the day-to-day activities of living such as food preparation, bathing and household cleaning, and they often experience significant psychological and existential distress and social isolation.[4,5] This significant symptom burden mandates the integration of palliative care into a comprehensive evidence-based, disease-modifying heart failure management plan.[6]

Palliative care in heart failure

Palliative care is defined by the WHO as 'an approach that improves the quality of life of patients and their families facing the problem 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'.[6] Central to this definition is that palliative care is an approach rather than a service, and one that any healthcare professional can provide, with specialist palliative care input sought for those with persistent or complex problems.

Despite this emphasis on early identification of palliative care needs, healthcare professionals continue to be concerned that

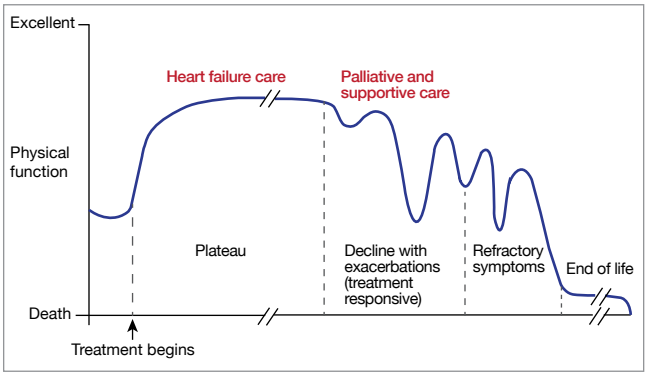

Figure. Conceptualised heart failure disease trajectory.
Adapted from Goodlin. Am J Coll Cardiol 2009; 54: 386-396.[20]

introducing palliative care 'too early' diminishes patients' hope.[7] An analysis of a UK national primary database showed that only 7% of decedents on the heart failure primary care register were also registered as needing a palliative approach and, of those who were, one third were entered onto the palliative care register within a week of death.[8]

The risk of reserving palliative care until it is obvious that a patient's deterioration is irreversible is that both the patient and their carers will be denied access to relevant physiological, psychological and social supports.[9,10] A lack of timely and appropriate palliative care frequently contributes to unnecessary patient suffering, as well as carer distress that can persist for months or even years after the patient's death.

Recent studies have demonstrated that early access to specialist palliative care alongside active management of the underlying disease improves cancer patients' experiences.[11-13] A randomised controlled trial (RCT) comparing usual care with in-home palliative care in addition to usual care for people who were housebound and deemed to be terminally ill (33% of whom had heart failure) found benefits of palliative care.[14] Participants in the palliative care arm were more satisfied with their care, had reduced use of medical services and healthcare costs, and were more likely to die at home than those in the control arm.[14] A recently reported pilot RCT of palliative care interventions in patients with advanced heart failure confirms a benefit for those in the palliative care arm.[15]

Integrating a palliative approach

There is international consensus that a palliative approach to care is appropriate for people with heart failure.[1,16-18] Guidance statements, including the National Heart Foundation recommendations for best practice, also highlight the importance of timely conversations to pave the way for difficult decisions as the disease progresses.[1,19] The heart failure disease trajectory can be conceptualised as a series of transitions (Figure).[20] This allows integration of a tailored palliative approach and provides opportunities for patients, carers and the clinical team to:

- acknowledge disease progression
- implement appropriate self-management strategies
- identify when the ceiling of medical management of episodes of decompensation associated with progressive heart failure has been reached
- respond to increasing symptom burden and dependency
- recognise deterioration, especially in the last days to weeks of life
- receive appropriate death and bereavement support.[20]

Although the pattern of transition in heart failure is likely to change as the use of implantable cardioverter defibrillators (ICDs) and other assistive devices increases, reducing the risk of sudden cardiac death, it remains relevant to current clinical practice.[21]

1. GSF clinical indicators specific for heart failure to identify people nearing the end of life[23,25]

Presence of at least two of the indicators below suggests a person is nearing end of life and may benefit from a palliative approach:

- NYHA class III or IV chronic heart failure – shortness of breath at rest on minimal exertion
- Patient thought to be in the last year of life by the care team – the 'surprise question' ('Would you be surprised if the patient were to die in the next few months, weeks, days?')
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychological symptoms despite optimal tolerated therapy

Abbreviations: GSF = Gold Standards Framework; NYHA = New York Heart Association.

Identifying people who would benefit from a palliative approach: prognostication versus need

A consequence of the unpredictable illness trajectory of heart failure is that it may not be easy to recognise the moment when heart failure transforms from a chronic complex problem to a chronic progressive problem.[22] Even with severe episodes of deterioration, patients may recover to resume independent living at home but continue to have significant unmet palliative needs.

Prognosis-based assessment

Despite numerous policies that encourage the identification of patients thought to be in the last year of life, there appears to be no useful way to use estimated prognosis as the trigger to initiate a palliative approach. A prospective study showed that neither the Seattle Heart Failure (SHF) Model nor the Gold Standards Framework (GSF) Prognostic Indicator Guide have acceptable utility in identifying patients in the last year of life; sensitivity and specificity were 83% and 22%, respectively, for the GSF, and 12% and 99% for the SHF.[23,24]

Of these two guides, the GSF Prognostic Indicator Guide may be more applicable in clinical practice, as it identified most of those with palliative care problems (86%) and has good face validity for recognising patients who are less well and likely to have unmet palliative care needs, without allowing prognostication to be a barrier (Box 1).[25]

Needs assessment

An approach to palliative care based on needs rather than prognosis or diagnosis appears more fit for purpose, and is likely to avoid the need for palliative care being recognised only in the last few weeks, or even days, of life. Implementing a palliative approach while still attempting to modify the course of the disease through treatment assists with timely identification and management of unmet needs.[26]

An Australian team has developed a practical tool – the Needs Assessment Tool: Progressive Disease-Heart Failure (NAT:PD-HF) – to help GPs and cardiology teams identify the unmet palliative needs of their patients with heart failure.[27] This tool allows care to move beyond diagnosis and prognosis, and to be tailored according to the level of concern about and complexity of the patient's and carer's needs. The NAT:PD-HF prompts referrals to relevant community and home-based care services, which are important for optimising the patient's independence and functioning, better supporting care at home. Initiating these community services and supports in a timely manner can help prevent unnecessary hospitalisations as physical care needs escalate.

Configuring the palliative care team

The primary care and cardiology team, in which heart failure nurse specialists often play a key role, is central to initiating a palliative approach as the patient's heart failure progresses.[28] GPs and primary care nurses play a pivotal role in helping patients with heart failure and their carers make the transition to a palliative approach, alongside ongoing titration of optimally tolerated cardiac treatments. The primary care team often has a long association and in-depth knowledge of the patient and their family, which assists with continuity of care.

Timely engagement of the specialist cardiac and palliative care specialists to address complex symptoms that have not responded to usual care ensures that patients' and carers' physical, psychological, social and spiritual needs are addressed.

Optimising symptom management and minimising burden

Optimal palliative care combines:

- ongoing active management of heart failure (the basis for improved survival and quality of life)
- specific symptom management interventions (individually tailored cardiac-directed treatments, including device therapies such as resynchronisation pacemakers).

All patients should be treated with an ACE inhibitor and beta-blocker specific for heart failure, unless these are not tolerated. Ideally patients should be euvolaemic when a beta-blocker is commenced.

Symptom management is a priority for the multidisciplinary heart failure team, including primary care practitioners. The approach to symptom control includes:

- full assessment of all domains to seek and address reversible factors, followed by
- palliation of refractory symptoms, irrespective of the underlying cause of the disease.

A range of evidence-based treatment options are available for improving the symptoms experienced by people with advanced heart failure (Box 2).[29]

Breathlessness

Breathlessness is a cardinal feature of heart failure. Exercise training improves the quality of life in people with chronic heart failure, but many patients with advanced heart failure may be unable to tolerate the focus on aerobic exercise.[30] Tailored exercise helps at least partially to reverse generalised skeletal myopathy, which is integral to the genesis of breathlessness in heart failure.[31] Use of a range of other nonpharmacological techniques (breathing training, pacing and prioritising, anxiety management, relaxation and mobility aids), although not specifically tested in heart failure populations, is supported by moderate to strong evidence in the management of breathlessness and can be provided by most teams that include physiotherapists and occupational therapists.[32]

Despite oxygen supplementation being an intuitive and commonly used intervention, most evidence indicates that oxygen is of no more benefit than medical air to patients with breathlessness in the absence of significant hypoxaemia.[33] Any observed benefit could be due to

2. Palliative management of common heart failure symptoms[29]

Breathlessness

- Nonpharmacological management includes exercise, breathing training, walking aids, psychological interventions and handheld (battery-operated) fans
- Pharmacological management comprises regular low-dose opioids
- Interventions not recommended include the following
  - Benzodiazepines are not recommended as first-line treatment but may be considered if other interventions are not effective, especially in the terminal hours or days of life, or when panic is a significant driver of breathlessness
  - Oxygen supplementation is not recommended for routine palliation of breathlessness in the absence of hypoxaemia because of mixed evidence for its effectiveness

Oedema

- Nonpharmacological management includes weight monitoring and good skin care
- Pharmacological management comprises diuresis as appropriate, including sequential nephron diuresis and parenteral administration

Fatigue

- Note that heart failure is a multisystem, systemic disorder causing skeletal myopathy, which contributes to both breathlessness and fatigue
- Nonpharmacological management comprises gentle graded exercise
- Consider the possibility of:
  - episodic hypoxia due to sleep disordered breathing (e.g. obstructive sleep apnoea or central sleep apnoea)
  - other causes of poor sleep (e.g. poorly controlled symptoms)
  - other causes of fatigue (e.g. poor nutritional intake, side effects of medications such as beta-blockers, anaemia, hypokalaemia, hypothyroidism or depression)

Pain

- Consider the multifactorial nature of pain in heart failure; causes can include refractory (stable) angina, gastrointestinal congestion, gross oedema, gout, immobility, diabetic neuropathy and osteoarthritis
- Avoid if possible:
  - medications with anticholinergic activity (pro-arrhythmogenic)
  - NSAIDs (these increase salt and water retention)

the cooling effect of airflow over the nasal passages, and simpler devices, such as a handheld battery-operated fan, should be trialled first.[34] Few patients in trials of oxygen supplementation had heart failure, and thus oxygen use remains a clinical uncertainty.[35] However, some people with heart failure may have sleep-disordered breathing, in which case nocturnal oxygen may be helpful.

Although opioids relieve breathlessness in patients with chronic obstructive pulmonary disease and cancer, the evidence is mixed for those with heart failure.[36-38] However, opioids appear to increase exercise tolerance, which may reduce breathlessness over time as skeletal muscle improves.[38-40] Therefore, assessment of short-term response should relate to activity rather than breathlessness intensity.[41]

Benzodiazepines are also commonly used to treat breathlessness, but there is inconclusive support for their use.[42] In practice, to avoid tolerance and adverse events such as falls and memory impairment, benzodiazepines should be restricted to situations where panic is a major cause of severe episodes. Other approaches should be used for anxiety states, such as anxiolytic serotonin reuptake inhibitors.

Peripheral and pulmonary oedema

Loop diuretics are the mainstay of oedema management.[43] However, as heart failure worsens, oedema can become challenging and require the addition of thiazides (sequential nephron diuresis), at least intermittently, or other options such as changing to a three times daily loop diuretic regimen or replacing frusemide with bumetanide, which is better absorbed from the gastrointestinal tract. There is emerging evidence to suggest that fluid restriction has only a limited role, even in decompensated NYHA class IV heart failure, and it requires regular monitoring if trialled.[44] Parenteral administration of a loop diuretic may become necessary, often necessitating hospital admission as home intravenous administration is unavailable in many areas. For patients who otherwise do not need to be in hospital, a continuous subcutaneous infusion of frusemide may allow them to stay at home.[45]

Deactivating implantable cardioverter defibrillators

It is challenging for clinicians and patients to initiate conversations about resuscitation status and device therapy. The challenge is often compounded by patients' and carers' unrealistic expectations of the success of cardiopulmonary resuscitation and limited knowledge about ICDs. A recent Swedish registry survey found that 85% of ICD recipients believed that 'switching off' the device equated to immediate death.[46]

The importance of addressing these issues is illustrated by a recent prospective analysis of intracardiac electrograms from 125 explanted ICDs, which showed that 31% of patients had received shock therapy in the last 24 hours of life.[47] Robust protocols for deactivation of ICDs and communication when a patient with a 'do not attempt cardiopulmonary resuscitation' order is approaching death, particularly out of hours, are important in the acute, aged care and community settings. A deactivation plan needs to be devised in partnership with the heart failure team when an ICD is inserted.[48] As GPs will increasingly be called upon to support conversations about ICD deactivation, it is essential they are familiar with what is involved.[48]

Clarifying the goals of care and aligning treatment

Although people with advanced heart failure have similar palliative care needs to those with other life-limiting illnesses, a significant point of difference is that they and their carers need to be aware of the possibility of sudden cardiac death and to plan accordingly.[20] Indeed, recent studies of adults with congenital heart disease found that they report a greater willingness to discuss end-of-life issues than their clinicians, often some years before death is expected.[49,50] Patients with heart failure need to have an opportunity to reflect on and communicate their personal values and preferences for future care in the event they become unable to speak for themselves, through advance care planning.[51] As cognitive impairment is a potential problem for people with heart failure, it is important to initiate these conversations earlier in the illness trajectory so that the patients can actively participate in the care planning process.[52]

As GPs have often known their patients over an extended period, they are ideally placed to support their patients in expressing their values and end-of-life care preferences. Some patients may wish to formalise such directives as legal documents that include the appointment of a substitute decision-maker for health and/or financial matters. State and territory legislation and jurisdictional advance care planning resources are available as point-of-care resources from a national website (http://advancecareplanning.org.au/advance-care-planning/for-professionals the-law-of-advance-care-planning).[53]

Supporting carers

With shorter hospital stays, informal care in the community is needed more often, with family members, friends or neighbours assuming more caregiving responsibilities.[54] If the carer is a spouse then they are often also coping with their own emotional responses to loss and grief, which can lead to carer burden. Similarly, older children who have taken on the carer role can also find this stressful, especially if they are still working and have other family responsibilities. It is crucial to proactively identify and address carers' needs, and to involve them in care planning and decision making to decrease carer strain.

Conclusion

A palliative approach to care for people living with advanced heart failure is important to identify and address the significant needs of this group and their carers. GPs and practice nurses play a pivotal role in helping patients with heart failure and their carers make the transition to a palliative approach to care, integrated with ongoing titration of optimally tolerated cardiac treatments. Engagement with specialist cardiac and palliative care specialists allows a team approach to complex symptoms that have not responded to usual care. **CT**

References and further reading

A list of references and further reading are included in the website version (www.medicinetoday.com.au) of this article.

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