Heart failure (HF) is a common condition affecting 1%–2% of the developed world, with a prevalence greater than 10% in elderly cohorts. While the disease trajectory is unpredictable, HF undisputedly has a poor prognosis, comparable to that of many cancers. The health economic cost of HF is increasing due to the ageing population and driven by recurrent, unscheduled and prolonged hospital admissions. A diagnosis of HF confers significant physical and psychological burdens for patients and their families, often over an extended period of time.

This article will discuss what is known with respect to palliative care for patients with HF, consider gaps in the evidence base and conclude with implications for clinical practice and directions for future research.

What is known
Models of care
It is well recognised that palliative care is important in patients with advanced HF. National and international guidelines for HF management recommend integrating palliative care into the overall provision for patients throughout the disease trajectory. Despite these guidelines, there is inequity with respect to a palliative approach to care and access to palliative care services for patients with HF, and possible barriers have been described. Clinicians are often unsure how to discuss the poor prognosis and unpredictable course of progressive HF including the risk of sudden death, fearing causing premature alarm and destroying hope; consequently, the conversations rarely take place.
This has been termed ‘prognostic paralysis’.16 Other factors such as the structure of ‘busy’ clinics which do not lend themselves to these types of conversations and a ‘medical model’ with a focus on prevention of death also contribute. Increasingly, it is recognised that as with cancer, many HF patients do wish to discuss end-of-life issues6 and guidance and training have been developed.17

A recent Cochrane review examined organisation of clinical services for HF. No palliative services or approaches to care were included, although two randomised controlled trials (RCT) considered multidisciplinary approaches to care, which reduced both HF-related and all-cause readmissions.18 The evidence for integrated cardiology and palliative care services is largely based on individual service evaluations,19–24 including only one RCT.24 Nevertheless, the benefits of an integrated service with respect to improvement in advanced care planning and reduction in hospital admissions have been consistently demonstrated. A further three RCTs comparing integrated palliative care with usual care are ongoing (trial identifiers: NCT01589601, NCT01519479 and NCT01304381).

Symptom control

HF patients require the same approach to symptom assessment and management as all palliative care patients, and the concepts of ‘total pain’ or ‘total breathlessness’25 remind us of the need to holistically assess all domains including psychosocial, spiritual, carer concerns and information and communication needs as well as physical. Good symptom control requires both recognising and treating any co-morbidities while optimising HF medical and device therapy management as appropriate depending on the stage of disease and the wishes of the patient.

Large randomised double-blind placebo-controlled trials have irrefutably demonstrated the prognostic benefit of HF medical therapy, such as angiotensin converting enzyme (ACE) inhibitors, beta blockers and mineralocorticoid receptor antagonists. These drugs have also been unequivocally shown to alleviate symptoms, reduce hospital admissions and improve quality of life.9 It follows that in HF patients with escalating palliative care needs, conventional HF medical therapy should be continued wherever possible. Medication should be reviewed regularly, and the relative benefits with respect to survival and symptom management considered. Decisions to reduce doses or discontinue drugs should be taken prospectively rather than only as a response to adverse effects (Table 1). Advanced HF patients are prone to hypotension and hypovolaemia, and this will directly influence which drugs are appropriate to continue. Diuretics remain important throughout the disease trajectory with respect to alleviating peripheral oedema and preventing pulmonary oedema.26 Intermittent intravenous diuretic therapy is often considered appropriate in advanced HF, but aggressive diuretic management in hospital is not recommended in the terminal stages. Subcutaneous infusion of diuretics may be of benefit.27,28 Continuing digoxin in end-stage HF may have symptomatic benefit by reducing heart rate and dyspnoea without adversely affecting blood pressure.29

Implantable cardiac defibrillators (ICD) and cardiac resynchronisation therapy defibrillators (CRTD) are now relatively commonplace within the HF population. Both devices reduce mortality in HF by preventing sudden cardiac death due to ventricular arrhythmia.9 In end-stage and terminal HF, consideration of deactivation of ICD or CRTD devices is of paramount importance. HF patients approaching death may have unstable ventricular rhythms causing recurrent shocks with pain and distress. It is therefore recommended that the defibrillator function of these devices is disabled.12 The exact timing of this will vary depending on the individual patient, their arrhythmia burden and previous device therapies. The concept of device deactivation must be conveyed sensitively to the patient and their carers. Patients may have misconceptions about how their device works and may even anticipate instantaneous death on deactivation of the defibrillator. Importantly, disabling the defibrillator function of an ICD or CRTD does not affect the pacing function of the device. A cardiac resynchronisation therapy (CRT) pacemaker, as well as improving survival, improves symptoms and quality of life while reducing hospital admissions9 and so should usually be continued.

Evidence for managing specific symptoms refractory to conventional cardiac therapies is variable (Table 2). Pain is the most researched symptom in palliative care.30 In HF, it is important to consider and treat co-morbidities while being mindful of medications which may exacerbate HF symptoms.

Management of refractory dyspnoea in palliative care has an emerging evidence base. Exercise has been clearly shown to improve quality of life in HF.31,32 However, studies of patients with the most severe symptoms are lacking.31 Evidence for other non-pharmacological interventions for dyspnoea in HF is mostly extrapolated from trials in patients with chronic obstructive pulmonary disease (COPD),33 although one study, considering the benefits of a handheld fan, did include some patients with HF.34 Psychological interventions, specifically in HF patients, have shown some benefit.35,36

A Cochrane review of opioids for the palliation of breathlessness did demonstrate evidence of a beneficial effect although it was noted many of the trials were small and only one included patients with HF.37 A subsequent adequately powered RCT of morphine compared with placebo demonstrated an improvement in breathlessness in those taking morphine.38 There are fewer studies specifically in HF populations and the results are mixed,39–41 and perhaps beneficial effects may take several days to become apparent.31 Therefore, extrapolating from evidence in other populations,
low dose opioids are both efficacious and safe\textsuperscript{42} and effectiveness should be assessed over several days.\textsuperscript{41}

Benzodiazepines are commonly used to palliate refractory dyspnoea, but a recent Cochrane review demonstrated insufficient evidence and concluded that until more adequately powered studies were conducted, benzodiazepines should be considered second- or third-line treatment only.\textsuperscript{43}

Despite being commonly prescribed, there is no evidence for supplementary oxygen in the palliation of refractory dyspnoea in the absence of significant hypoxaemia.\textsuperscript{44,45} However, very few patients with HF were included in these studies. HF is complicated by the fact that up to one-third of patients may have episodic hypoxia due to sleep disordered breathing, which may respond to nocturnal oxygen therapy.\textsuperscript{46} Clinical trials are in progress.\textsuperscript{46}

The HF population is not well represented in studies considering the palliation of pain and refractory dyspnoea. However, it is reasonable to extrapolate from evidence in other palliative care populations, unless there is evidence of contraindication.\textsuperscript{47} Often with palliative care patients, it is important to consider multi-morbidity rather than single disease guidelines.\textsuperscript{48} This may be particularly pertinent in advanced HF where multi-morbidity is commonplace.

What is yet unknown

Evidence base for symptom control

The evidence base for management of pain and refractory dyspnoea in advanced HF is improving. However,
management strategies for other symptoms such as nausea, oedema and fatigue in advanced HF are mostly based on ‘good practice points’ (Table 2). Strategies include optimising cardiac management, minimising adverse effects of medical therapies and applying symptom control measures that are helpful in other palliative care populations.

**Table 2.** Specific symptoms and suggested management in advanced heart failure (HF).

<table>
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<tr>
<th>Symptom</th>
<th>Management Strategies</th>
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| Dyspnoea | - Non-pharmacological management: exercise, breathing training, walking aids, psychological interventions, handheld fan  
- Opioids  
- Benzodiazepines not recommended as first-line treatment, may consider if other interventions are not effective  
- Oxygen not currently recommended for routine palliation of breathlessness, a clinical uncertainty |
| Oedema | - Appropriate fluid restriction  
- Weight monitoring  
- Early diuresis  
- Good skin care |
| Fatigue | - HF is a multi-system disorder and causes a skeletal myopathy, which contributes to both breathlessness and fatigue; interventions such as exercise may help  
- Consider episodic hypoxia due to sleep disordered breathing, either obstructive sleep apnoea or central sleep apnoea and other causes of poor sleep, such as poorly controlled symptoms.  
- Consider other causes of fatigue such as poor nutritional intake, side effects of medications such as beta blockers, anaemia, hypokalaemia, hypothyroidism or depression |
| Pain | - Consider multi-factorial nature of pain in HF including refractory angina, gastrointestinal congestion, gross oedema, gout, immobility, diabetic neuropathy, osteoarthritis  
- Avoid medications with anti-cholinergic activity (pro-arrhythmogenic) and non-steroidal anti-inflammatory drugs (increase salt and water retention) if possible |

**Prognostication**

Being able to recognise when patients are approaching end of life is desirable with respect to conversations regarding patient priorities. Prognostication in HF, however, is extremely difficult. Over 300 individual prognostic markers have been described, with neurohormones such as B-type natriuretic peptide (BNP) showing the greatest prognostic potential. Composite scoring systems have been developed and include the Enhanced Feedback for Effective Cardiac Treatment (EFFECT) model, Heart Failure Survival Score and the Seattle Heart Failure Model (SHFM). These tools are predominantly derived from trial data or restricted cohorts such as transplant waiting list patients and therefore lack generalisability, known as spectrum bias. They are often not externally validated and become out of date as new therapies are introduced.

UK guidance recommends identifying when a HF patient is in the last year of life using the Gold Standards Framework (GSF) Prognostic Indicator Guide. This indicator does not have any published data supporting its accuracy. A recent study has clearly demonstrated the difficulty in accurately predicting the last year of life in patients with advanced HF, with neither the GSF nor the SHFM being useful.

**Implications for clinical practice**

A palliative care approach can and should run in parallel with conventional HF management. The level of palliative care intervention at different stages in a patient’s disease process will vary from patient to patient depending on their individual need and as such is a dynamic and responsive process. This is distinct from the more historical model of palliative care whereby HF management would end and palliative care begins once death was considered to be approaching. This integrated strategy permits continued optimisation of HF therapy with palliative care intervention or referral to an integrated HF and palliative care service based on unmet need. It has been suggested that points along the disease trajectory, such as diagnosis and first hospital admission, should trigger an assessment that includes holistic symptom control, carer’s needs, education and communication including decision-making about future medical care. Recent guidelines from the American Heart Association summarise the need for timely conversations: ‘difficult discussions now will simplify difficult decisions in the future’. These conversations require time, training and an individualised approach and may appear daunting to some clinicians but enable patients, if they wish, to discuss their poor prognosis and be involved in decisions about their future care despite uncertain disease trajectories by ‘hoping for the best, and preparing for the worst’.
Despite the difficulties in prognostication, the study by Johnson has demonstrated effective end-of-life care planning within integrated shared-care models, with more people dying in their preferred place of care.

An integrated team can be formed comprising clinicians (cardiologists, palliative care specialists, geriatricians and General Practitioners/family doctors), specialist nurses (HF, palliative care and community nurses), physiotherapists/physical therapists, occupational therapists and dieticians with mutual exchange of skills and education. Collaborative working is key and necessitates excellent communication between team members generally with a key worker such as HF specialist nurse or General Practitioner/family doctor to ensure good coordination of care.

Implications for future research

Despite the challenges of research in palliative care, adequately powered RCTs regarding effectiveness of specific strategies for symptom control in palliative care patients are possible and have been conducted. Further trials including HF patients and in under-researched symptoms are required. Studies should be pragmatic as HF patients as well as palliative care patients are a heterogeneous group with multiple co-morbidities. Future challenges for research include moving away from mortality-based studies to considering patient-relevant outcomes such as quality of life and timing of palliative care interventions. In terms of research, the debate has moved on from whether palliative care is appropriate in this group of patients to asking what is the most effective way of delivering palliative care and novel means of evaluation that may be required.

Conclusion

HF is a common condition, and many patients and their carers are living with significant symptoms and unmet need. There are challenges to research in this area, although recommendations for symptom control are becoming increasingly evidence-based. Integrated models of care, which are based on need, are recommended. At the centre is excellent communication both with the patient and between services to ensure the best possible care.

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