

A palliative care approach for patients with heart failure

Miriam J Johnson discusses the palliative care needs of heart failure patients, symptom control issues and end-of-life care

Heart failure patients have problems affecting many areas of their lives. In the last few years, there has been an increasing realisation that a palliative care approach with appropriate access to specialist palliative care services is required. Historically, such services have been accessed by cancer patients, but not by those with non-malignant disease. There are joint ventures developing in the UK between cardiology and palliative care, but barriers remain in many places.

As long ago as 1963, Hinton observed that, 'Discomfort was not necessarily greatest in those dying from cancer ... but that patients dying from heart failure and renal disease may also suffer great distress'.¹ In the UK, while palliative care provision for patients with cancer has subsequently developed, the similar needs of patients with heart failure have been largely ignored until recently. As therapeutic options for these patients have grown, so has recognition that their problems affect every domain of life. The importance of a palliative approach and the involvement of specialist palliative care services is now embedded in at least the rhetoric of the *National Service Framework for Coronary Heart Disease*.² However, although some collaborative ventures are developing, there is slow progress. This article will present some of the recent literature highlighting the experience of heart failure patients, describe some symptom control measures, discuss some specific issues regarding care of the dying and look at the barriers that prevent the development of services.

Key points

- In the UK, while palliative care provision for patients with cancer has subsequently developed, the needs of patients with heart failure have been largely ignored until recently.
- Pathways of care, such as the Liverpool Care Pathway, are transferable to patients with heart failure and are helpful.

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Patients with heart failure have many needs that can be helped by a palliative care approach and appropriate access to specialist services

Heart failure patients' experiences

In the last few years, interviews with patients with heart failure have brought forth a wealth of descriptions of what it is like to live with advanced disease.³⁻⁹ Some have compared symptom burden to lung cancer patients or patients known to palliative care clinics and confirmed that it is comparable, but yet less frequently addressed.^{6,7} The support network that has developed for cancer patients is all too frequently absent for heart failure patients, and patients and carers live in a contracting world of increasing exhaustion and uncertainty.

Breathlessness, fatigue, poor sleep and pain are common symptoms, as are nausea, anorexia and oedema. Depression seems to be a particular problem for patients and shares a common neurohormonal aetiology.¹⁰ Depression increases both morbidity and mortality, and affects how well the patient can engage with their own management and compliance with treatment.^{11,12} Cognitive difficulties, poor mobility and anxiety, coupled with a clinician's reluctance to accept that treatment is no longer maintaining good control, may lead to a poor understanding of the stage of disease.

Symptom control measures

Optimum tolerated heart failure treatment is a keystone in good symptom control, and the first thing that needs to be assessed. Thus, collaboration between cardiology and palliative care is mandatory. As the illness advances, a more pragmatic tolerance of renal dysfunction if a loop diuretic cannot be reduced is likely, and, in the end stages, rationalisation of medications, such as statins, aspirin or clopidogrel, would reduce the tablet burden given the polypharmacy of many.

Breathlessness

As with any symptom, a full assessment looking for reversible factors or other pathology is necessary. General measures, such as the use of a hand-held fan, breathing exercises and pacing or prioritising techniques, are likely to be helpful. There is little evidence to support the routine use of oxygen, as patients with compensated failure do not usually desaturate. Some patients may find it helpful, but individual assessment is recommended to prevent a patient from becoming psychologically dependent on an expensive and cumbersome treatment that may be having no benefit.¹³ Of course, many patients will have comorbid chronic obstructive pulmonary disease (COPD) and may require long-term oxygen therapy as part of their management.

Opioids are a promising option, but there is still very little published about their use. Small doses, such as 5 mg oral morphine four times daily, were beneficial in a pilot, placebo-controlled, crossover study, and were well tolerated. Care must be taken in patients with renal failure.¹⁴

Anxiety can exacerbate breathlessness, and benzodiazepines can be useful if judiciously used, particularly to help the control of panic attacks. The risk of respiratory depression is not a major concern, but sedation and subsequent risk of falling are, and those drugs with a long half-life, such as diazepam, are best avoided.

Fatigue

Fatigue is a major problem for patients with advanced heart failure and is difficult to manage. Reversible factors, such as over-diuresis and hypokalaemia, may be found. Poor sleep is common and will impact on daytime somnolence. Nocturnal apnoea and Cheyne-Stokes respiration may result in morning headache and daytime somnolence. Symptoms

may improve with continuous positive airway pressure ventilation (CPAP) overnight. Anaemia is also common and may contribute to fatigue. Muscle bulk is integrally important to the symptoms of heart failure, especially with regard to breathlessness and fatigue. Exercise programmes appear to be effective in helping both symptoms to some extent.¹⁵

Pain

The application of the WHO analgesic ladder is appropriate in heart failure. Patients can experience pain not only from angina, but also from musculoskeletal pain and arthritis. However, non-steroidal anti-inflammatory drugs (NSAIDs) should be avoided as there is an increased risk of decompensated heart failure with their use.¹⁶ Gout is another common problem, and as NSAIDs are contraindicated, colchicine is the treatment of choice. Low-dose steroids are very effective for gout, but have the same side-effect of fluid retention. Optimisation of anti-anginal therapy is important.

Other symptoms

Nausea can occur due to gut oedema, liver congestion, constipation or medication such as spironolactone or digoxin toxicity. Good skincare of oedematous legs is mandatory. Itch is fairly common and may respond to simple measures such as menthol in aqueous cream or may need systemic medication. Depression needs to be addressed holistically, but may respond to antidepressant medication such as selective serotonin reuptake inhibitors or mirtazepine. Tricyclics should be avoided because of their proarrhythmic potential.

End of life issues

Most patients would prefer to die at home, but few with heart failure get that option. This is partly due to the difficulties in estimating prognosis, and establishing whether a particular episode of decompensation is a terminal event. It is also partly due to a reluctance on the part of some healthcare professionals to recognise and discuss that the role of active treatment is now very limited. This can be particularly difficult with younger patients waiting for transplantation, where the risk is that palliative care is not accessed and discussions about end of life preferences do not take place because the patient is going to be 'cured'. However, this situation is improving and awareness is growing that these issues need to be explored.

Fatigue is a major problem for patients with advanced heart failure and is difficult to manage

If a patient has an implantable cardioverter device, then discussion as to whether the time has come to turn it to pacemaker mode is needed. Repeated shocks in a dying patient can be greatly distressing, not only for patients, but also their carers and involved healthcare professionals.¹⁷ Local protocols should be in place to prevent patients having to travel miles to a tertiary centre for this procedure in the late stages of illness.

Although a patient's fluid intake is inevitably restricted in the dying phase, pulmonary oedema may still occur, and diuretics may need to be continued. If the intravenous route is difficult, repeated injections can be prevented by administering furosemide by continuous subcutaneous infusion.¹⁸ Pathways of care, such as the Liverpool Care Pathway, are transferable to patients with heart failure and are helpful.¹⁹

Barriers to service development

Many palliative care services deal primarily with cancer patients. Thus, it is understandable that there is a concern that the skills needed to manage heart failure patients are lacking or out of date. Where services have developed, however, although there has been a 'learning curve' regarding fluid balance and weight monitoring, the skills needed have been those of palliative care.²⁰ Collaboration with cardiology services has provided the knowledge and skills that may be lacking. Mutual education is the result, which, in turn, upgrades the generic palliative care skills needed by cardiologists.

There is concern that many palliative care services will not cope with the demand. Where services are developing, it would appear that the main impact is on day-care services, where patients can respond well to weekly care and can stabilise. What has been found is that, as generic palliative care skills improve in both primary and secondary care, only 8–10% of the heart failure nurse specialist caseload requires referral to specialist palliative care services.^{20,21}

Lack of resources is a serious issue and collaboration with cardiology and primary care should take this into account. Education and the development of local relationships are often the start of a joint service and will improve skills. The lack of an evidence base on symptom control and a model of service provision is a problem, and it is hoped that as interest grows, this issue will be redressed.

Addressing patients' needs

Patients with heart failure have many needs that can be helped by a palliative care approach and appropriate access to specialist services. The current imbalance between these patients and those with cancer has been highlighted, but progress to tackle it has been slow. As more palliative care units gain experience and confidence in the care of heart failure patients, and as cardiologists become aware of the benefits of involving a wider team, it is to be hoped that the lot of such patients will improve, and that future studies will demonstrate that supportive and palliative care is accessible.

References

1. Hinton JM. The physical and mental distress of the dying. *Q J Med* 1963; **32**: 1–21.
2. Department of Health. *National Service Framework for Coronary Heart Disease*. London: DoH, 2000. www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4094275&chk=eTaccC (last accessed 10/08/06)
3. Buetow SA, Coster GD. Do general practice patients with heart failure understand its nature and seriousness, and want improved information? *Patient Educ Couns* 2001; **45**: 181–185.
4. DIPex. www.dipex.org (last accessed 10/08/06)
5. Rogers A, Addington-Hall JM, McCoy AS *et al*. A qualitative study of chronic heart failure patients' understanding of their symptoms and drug therapy. *Eur J Heart Fail* 2002; **4**: 283–287.
6. Murray SA, Boyd K, Kendall M *et al*. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002; **325**: 915–916.
7. Anderson H, Ward C, Eardley A *et al*. The concerns of patients under palliative care and a heart failure clinic are not being met. *Palliat Med* 2001; **15**: 279–286.
8. McCarthy M, Lay M, Addington-Hall J. Dying from heart disease. *J R Coll Physicians Lond* 1996; **30**: 325–328.
9. Willems DL, Hak A, Visser FC, Cornel J, van der Wal G. Patient work in end-stage heart failure: a prospective longitudinal multiple case study. *Palliat Med* 2006; **20**: 25–33.
10. Joynt KE, Whellan DJ, O'Connor CM. Why is depression bad for the failing heart? A review of the mechanistic relationship between depression and heart failure. *J Cardiac Failure* 2004; **10**: 258–271.
11. De Denus S, Spinler SA, Jessup M, Kao A. History of depression as a predictor of adverse outcomes in patients hospitalised for decompensated heart failure. *Pharmacotherapy* 2004; **24**: 1306–1310.
12. Junger J, Schellberg D, Muller-Tasch T *et al*. Depression increasingly predicts mortality in the course of congestive heart failure. *Eur J Heart Failure* 2005; **7**: 261–267.
13. Booth S, Wade R, Johnson MJ *et al*. The use of oxygen in the palliation of breathlessness. A report of the expert working group of the scientific committee of the Association for Palliative Medicine. *Respir Med* 2004; **98**: 66–77.
14. Johnson MJ, McDonagh TA, Harkness A *et al*. Morphine for the relief of breathlessness in patients with chronic heart failure – a pilot study. *Eur J Heart Fail* 2002; **4**: 753–756.
15. Beniaminovitch A, Lang CC, LaManca J *et al*. Selective low-level leg muscle training alleviates dyspnoea in patients with heart failure *J Am Coll Cardiol* 2002; **40**: 1602–1608.
16. Heerdink E, Leufkens H, Herings R *et al*. NSAIDs associated with increased risk of congestive heart failure in elderly patients taking diuretics. *Arch Intern Med* 1998; **158**: 1108–1112.
17. Nambisan V, Chao D. Dying and defibrillation: a shocking experience. *Palliat Med* 2004; **18**: 482–483.
18. Verma AK, da Silva JH, Kuhl DR. Diuretic effects of subcutaneous furosemide in human volunteers: a randomised pilot study. *Ann Pharmacother* 2004; **38**: 544–549.
19. www.lcp-mariecurie.org.uk (last accessed 10/08/06)
20. Johnson MJ, Houghton T. Palliative care for patients with heart failure – description of a service. *Palliat Med* 2006; **20**: 211–214.
21. Davidson PM, Paull G, Introna K *et al*. Integrated, collaborative palliative care in heart failure: the St George Heart Failure Service experience 1999–2002. *J Cardiovascular Nursing* 2004; **19**: 68–75.

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