Living with and dying from heart failure: the role of palliative care


The aim of palliative care is to improve the quality of life in the broadest sense for patients with incurable disease. It also aims to improve the quality of dying (to achieve a “good” death) and to ameliorate the devastating effect of dying on the family and carers.

Specialist palliative care is a young specialty in the UK. Many of the modern concepts were put in place by Dame Cicely Saunders when she opened St Christopher’s Hospice in 1967, creating not only inpatient hospice beds but a large multi-professional home care outreach service.

HEART FAILURE
Living with and dying from heart failure

The work of John Hinton in 1963 recognised the physical and mental distress of dying in the wards of a London teaching hospital. He described high levels of physical and mental distress which were more pronounced in patients dying from heart or renal failure than with cancer. He showed that considerable suffering remained unrelieved and observed that the symptom of breathlessness was more difficult to manage than that of pain.

Most of the contemporary evidence for the experience of living with and dying from heart failure comes from two major studies. The first study to investigate symptoms in terminal heart disease in the UK was the regional study of care for the dying (RSCD). This was a population based retrospective survey of a random sample of people dying in 20 English health districts during 1990. This study included 675 patients dying from heart disease of all causes. Heart failure was not analysed separate from other cardiac causes of death. The study to understand prognoses and preferences for outcomes and risks of treatment (SUPPORT) was a prospective study undertaken in the USA at five academic medical centres. This study included nine diagnostic groups of hospitalised patients with an aggregate mortality rate of 50% within six months. Out of a total of 9105 patients 1404 had heart failure.

The RSCD found that people who died from heart disease were reported to have experienced a wide range of symptoms, which were frequently distressing and often lasted for more than six months. Pain was the most commonly reported symptom and was very distressing in 50% of patients. The site of the pain was not identified. Dyspnoea was the second most common symptom and was very distressing in 43%. Low mood was reported in 59%, and 45% were reported to have been anxious; these symptoms ranked with pain and urinary incontinence in their cause of distress. Management of these symptoms in hospital brought little or no relief in between a quarter and a third of the sample. At least one in six had symptom severity comparable to those of cancer patients managed by specialist palliative care services.

The SUPPORT study reported that functional impairment, depression scores, and the percentage of heart failure patients reporting severe pain or dyspnoea increased as death approached. Forty one per cent of patient surrogates reported that patients were in severe pain and 63% reported that patients were severely short of breath during the three days before death. This study therefore confirmed that pain was a symptom of severe heart failure although this is not well recognised.

Mental health problems have been largely overlooked in heart failure patients and can lead to significant psychological distress. In particular, depression is common. Koenig has shown that in a hospital based population of heart failure patients major depression was present in 36.5% and minor depression in 25.5%. Importantly, these patients had no greater access to mental health services than patients without depression. Depression has been shown to increase the hospital readmission rate of patients with heart failure, both at three months and one year, as well as causing a significant increase in mortality at the same time periods. The mechanism for this is uncertain and interestingly depression causes similar neuroendocrine activation to chronic heart failure itself. In addition depression could result in poor patient compliance with medication and a failure to seek medical help at an appropriate time.

The SUPPORT study showed half the patients had been unable to get adequate information about their condition. Although many patients were thought to have known that they were dying, 82% of patients were reported to have “worked this out for themselves” although it is unclear how they did this. Health-care professionals rarely discussed dying with their patients.

In a recent qualitative study, patients with heart failure believed that doctors were reluctant to talk about death or dying and some would have welcomed timely and frank discussion concerning prognosis. They reported barriers to asking questions and felt unable to raise certain issues with their doctors. While physicians may not be best placed to provide these patients with all the information they would like, other health care professionals such as specialist heart failure nurses may be able to contribute if they use effective communication strategies. In addition, patients reported confusion, short term memory loss, and mobility problems which made attendance at hospital outpatient difficult. This highlights the importance of effective community management of heart failure. This is illustrated, for example, by the fact that many patients treated for heart failure experience worsening symptoms for a relatively long time before they seek medical advice.

Patients tend to attribute symptoms of heart failure to advancing age and decreasing physical and mental capacities, and this may reinforce their beliefs that nothing can be done to improve their symptoms. This lack of everyday knowledge of chronic heart failure serves to highlight the importance of patient education and information as well as the need for raised public awareness.

The findings reported from these studies suggest that we are failing to care adequately for our patients with heart failure. These patients might benefit not only from coordinated heart failure team management of their disease but also from some input from specialist palliative care.

End of life care

It is now recognised that the terminal phase of heart failure may be as bad as cancer, both in terms of symptoms and distress. These disturbing findings might be improved if the end of life was recognised by doctors and nurses. Unfortunately attempts to predict prognosis in heart failure have proved unsatisfactory. Unlike patients with cancer, heart failure may be associated with episodes of acute decompensation resulting in hospital admission when patients present in...
Role of palliative care in heart failure

New York Heart Association (NYHA) functional class IV. Most of these patients recover to be discharged from hospital with improvement in their symptoms and functional class, only to have a high chance of being readmitted in the subsequent 3–6 months. There is the additional complication that 25% of patients with heart failure die without worsening of their heart failure symptoms and there is no accepted marker to determine which patients will die suddenly. Further difficulties with establishing a realistic prognosis are a consequence of over optimism on the part of physicians.

These difficulties with prognostication create a barrier to good end of life care since a diagnosis of dying is not made and thus the end of life is not identified. This may explain at least in part why patients with heart failure (and indeed other serious chronic conditions) reported in the SUPPORT study had a high rate of major intervention such as cardiopulmonary resuscitation, ventilation or the insertion of a feeding tube in the last three days of life.

ROLE OF PALLIATIVE CARE

Lessons from cancer

A recent review found five randomised control trials of the effect of palliative care on outcomes in patients with cancer involving 925 patients. Only one trial showed no significant effect. The others showed that palliative care caused patients to spend more time at home and reduced the number of hospital inpatient days. Palliative care improved symptom control, the likelihood of patients dying where they wanted, and the satisfaction of the patient and carers. Palliative care appeared to reduce the overall cost.

In cancer there is increasing recognition that palliative care plays an important role not just at the end of life but also earlier in the disease trajectory. In patients with heart failure palliative care may also have an important role irrespective of whether death is believed to be imminent.

Little data exist detailing the effect of specialist palliative care in heart failure. Specialist palliative care can alter outcomes for patients with heart failure. A small scale retrospective study of patients with heart failure managed by St Christopher’s Hospice has shown that specialist palliative care can manage heart failure using generic palliative care skills. The needs of these patients included overcoming communication difficulties, psychological, spiritual, and social support, symptom control, end of life care, and subsequent bereavement support for carers. For more than half of the patients the place of death was probably transferred from hospital to the hospice.

Palliative care intervention in heart failure

To determine the role of palliative care in heart failure it will first be necessary to evaluate the palliative care needs of heart failure patients (fig 1). Only then can an appropriate assessment tool be developed. With this tool it will be possible to assess the outcomes for heart failure patients for palliative care interventions and then to deliver interventions that have been proven to be effective. These interventions will include symptom control and communication strategies, and the management of anxiety and depression, together with a randomised controlled trial of the effect of specialist palliative care in addition to best practice involving a heart failure team.

Alternative models of palliative care in the management of patients are shown in fig 2. The traditional concept that active care discontinues when palliative care starts near the end of life (A) was that adopted by Medicare in the USA. Patients opted for active treatment or palliative care but do not receive both simultaneously. In the UK a more phased approach for palliative care in cancer, starting close to the point of diagnosis, has been adopted (B). Furthermore the role of palliative care continues after the patient’s death in managing bereavement care, in particular for family and carers identified as being at high risk. We propose a modified pathway for patients with heart failure (C). Early palliative care intervention might help to improve communication and could also address the issues surrounding sudden death in this illness. Early intervention may also be indicated because of the high early mortality of newly diagnosed heart failure. At the end of life, palliative care may play a greater role, but it is likely in most patients that at least some of their active heart failure treatments will continue.

The hospice model of care of the dying patient is regarded as a model of excellence. An integrated care pathway, the Liverpool care of the dying pathway, has recently been developed based upon principles of hospice care. It sets standards of care for symptom control in the dying phase of a patient’s life. The pathway also provides a means to measure symptom control and has been shown to be effective in the dying patient. The challenge in patients with heart failure will be to identify the end of life.

If the problems of dying of heart failure are to be addressed then the wider issue of the quality of dying from other illnesses must be assured also. Issues surrounding the care of the dying and the National Health Service have been addressed by the Nuffield Trust. The Buckinghamshire declaration resulted from a Nuffield conference in September 2000 examining how dying could be improved, and the key elements of this are reported in table 1. In particular it was recognised that care of the dying must be seen as an essential part of disease management—not as an “add-on” extra. Health care professionals must not routinely regard the death of a patient as a failure in care.

![Figure 1](https://www.heartjnl.com)

**Figure 1** Approach to evaluating the role of palliative care in heart failure.

**Figure 2** Models showing involvement of palliative care in cancer (A and B) and a proposed model for heart failure (C).
Table 1  The Buckinghamshire declaration: the care of the dying and the NHS. Brief summary of selected points (www.nuffieldtrust.org.uk)

1. An authoritative document, based on best practice, should be produced and made nationally available for use by health professionals wherever they practice.
2. The quality of services to the dying needs to be audited.
3. Attitudes, both public and professional, need to change.
4. Central government should take a lead in setting national standards for provision and training in care of the dying.
5. In each hospital, and healthcare setting, there should be clear lines of responsibility for ensuring that basic equipment and drugs needed to care for dying patients are available in adequate quantities, every day of the year.
6. Attitudes among staff need to change, replacing the spirit of paternalism/maternalism to one of partnership with patients.
7. The nursing profession must continue to encourage its members to prove that they are safe to practise and safe to teach others, both nurses and care staff.
8. Further beacon sites of excellence should be identified, and used to disseminate good practice to staff throughout the NHS.
9. Risk assessment of the bereaved can enable special help to be made available to those who most need it; it should be offered more widely.

Table 2  The palliative care approach: the duty of all health care professionals

- Promotion of physical, psychological, social, and spiritual well being
- Emphases: quality of life including good symptom control
- Whole person approach
- Encourages patient and carers
- Respect for patient autonomy and choice
- Open and sensitive communication

DELIVERING PALLIATIVE CARE IN HEART FAILURE

A survey of the activity of UK palliative care services during 1997–98 showed that 1084 patients with heart disease received specialist palliative care compared to 62 499 patients with cancer. It follows that since about 155 000 patients per annum die from cancer, just over 40% received palliative care. The number of deaths from heart failure is difficult to obtain, but if it is estimated conservatively at 30 000 per annum (Cowie MR, personal communication) then only about 4% received palliative care. The need for palliative care in heart failure has been recognised in the National Service Framework for coronary artery disease which has recommended access to palliative care for patients with end stage heart failure. In 1996 an executive letter from the NHS Executive determined that it was the duty of all health care professionals to adopt a palliative care approach to their patients with life threatening diseases (table 2). Only patients with a need beyond this should be considered for specialist palliative care. Specialist palliative care is delivered by a multiprofessional team equipped with specialist training who provides physical, psychological, social, and spiritual support. This service is provided either directly or through advice and specialist palliative care plays an important role in education.

The issue of delivering palliative care is something that must depend on local arrangements between specialist palliative care (still largely funded from outside the NHS), primary care, and the heart failure team. Between them, they should provide supportive and palliative care for the patient and their carers. The development of local palliative care strategies may be the way ahead in the immediate future.

Palliative care for patients with heart failure has the potential to play an important role in relieving suffering and distress, both for the patient and their carers. It is imperative that high quality evidence is gathered to assess how this benefit may be best derived and delivered to the many patients with this condition.
Role of palliative care in heart failure

Dr Gibbs: Pain has been recognised now in the regional care of the dying study and in other studies, so the first thing to say is that I really think it is there. The pain in some of the milder classes of heart failure may be related to withdrawing non-steroidal drugs, because these patients are in an age group where they have arthritis. We are currently constructing a body map of where the pain is in our patients. Although I can’t tell you the result of that yet because we have not yet finalised the data collection, it really is throughout the body. One thing we should bear in mind in NYHA class IV is that oedema is painful. Leg oedema is something that is painful so it might be that; but it may be also that as symptoms get very bad in any disease, patients tend to start complaining of pain. It is exactly the same in cancer, in HIV and AIDS—it is very unclear what it is and there is no reason why they should have all this pain but they have it. We see pain in dementia as well.

Dr Gibbs: There are various problems with morphine and the opioids as a whole in heart failure. The first is that we don’t know the pharmacokinetics, and there are no satisfactory trials to show whether it really works or not. The big problem with morphine in breathlessness—not pain control—in chronic disease is that the randomised trials that have been done tend to show nothing; some patients benefit and some patients do not, so we need more data. The other problem is that a lot of doctors are stuck with the old concept that the opioids are addictive and dangerous. They are not; they are not yet finalised the data collection, it really is throughout the body. One thing we should bear in mind in NYHA class IV is that oedema is painful. Leg oedema is something that is painful so it might be that; but it may be also that as symptoms get very bad in any disease, patients tend to start complaining of pain. It is exactly the same in cancer, in HIV and AIDS—it is very unclear what it is and there is no reason why they should have all this pain but they have it. We see pain in dementia as well.

Dr Gibbs: As a palliative medicine registrar who sees mainly cancer patients, I have found from doing a study in hospital that we not only don’t get a lot of referrals, but when we do get referrals the advice we are offering is often overlooked by the medical or surgical teams looking after the patient. The patients who are generally terminally ill that we see are often cared for by the most junior staff, who often misunderstand the advice we are giving or don’t know how to use it, and are often unsupported by the senior staff. How can this be improved in heart failure?

Dr Gibbs: I have one simple piece of advice for people who work in heart failure in hospital, and that is to arrange to have lunch with the palliative care team.

QUESTION AND ANSWER SESSION

Question: This area of palliative care is clearly very important. I just wonder if you get further if you try to define the point at which you start to use morphine as a treatment for breathlessness.

Dr Gibbs: I have certainly tried to do it and we are doing some work in this at the present time.

Question: I’m very interested in the number of patients who experience pain. Can you say a few more words about the nature of pain in heart failure?

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