

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

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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 speciality 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.¹ 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.² 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.³ 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%.⁴ 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.⁵ 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 RSCD 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.⁶ 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.⁷ 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 outpatients 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.⁷ 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.⁸ 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.^{9–11} Unlike patients with cancer, heart failure may be associated with episodes of acute decompensation resulting in hospital admission when patients present in

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
 - encompasses 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.²⁵ 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.²⁶

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).²⁷ 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 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.

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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: 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 incredibly safe to use in this situation and are only addictive if they are taken for recreational purposes. I think that we need

to look in the future at using morphine much more frequently in managing breathlessness. I've 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?

Dr Gibbs: Pain has been recognised now in the regional care of the dying study and in some 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.

Question: 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.

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