

THE NEED FOR PALLIATIVE CARE IN THE MANAGEMENT OF HEART FAILURE

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Patients with heart failure and those with advanced malignant disease, who are the main focus of palliative care specialists, share many physical, psychological, and social problems. However, it might be inferred from the respective standard textbooks that cardiology and palliative care are mutually exclusive disciplines; neither refers to the other, the former failing to mention palliative care even when detailing the management of end stage cardiac failure,¹ while the *Oxford textbook of palliative care*² does not envisage the extension of palliative care programmes beyond their present scope. There have, however, been a few articles from palliative care teams and cardiologists,³ epidemiologists,⁴ and psychiatrists⁵ which have begun to redress this situation by highlighting the problems faced by heart failure patients during the final months and days of life. The identified deficiencies in their care are compelling and need to be addressed. Conventional cardiological treatments are demonstrably inadequate or inappropriate for solving these problems, but some of the skills and experience acquired in palliative care could be adopted, or adapted to do so.

A common misconception is that palliative care is specifically for the management of patients in the terminal stages of malignant disease. This is, in effect, a paraphrase of the *Oxford textbook of palliative care* definition² and reflects the origins of palliative care in the hospice movement for the care of cancer patients. The World Health Organization, while also focusing exclusively on cancer patients, elaborates on the scope of the care which should be provided: “the active total care of patients . . . control of pain, of other symptoms and of psychological, social and spiritual problems is paramount”.⁶ It notes that “Many aspects of palliative care are also applicable earlier in the course of the illness” and that it “offers a support system to help the family cope during the patient’s illness”.

Medical and lay dictionary definitions are, on the other hand, mutually identical, succinct, and unconditional—“reducing the severity: denoting the alleviation of symptoms without curing the underlying disease”⁷ and “palliate and alleviate without curing”.⁸ Thus, collating these different definitions, palliative care is a patient management strategy which also recognises the needs of their carers, rather than simply providing disease specific treatments, and should be limited neither to cancer patients nor to those near to death. Terminal care, which is included in, but is not synonymous with, palliative care has been defined as “Turning away from active treatment . . . Concentrating on relief of symptoms and support for both patient and family”.⁹ All doctors caring for patients with progressive debilitating diseases will recognise the merits of the palliative approach, although they may not be familiar with the underlying concepts nor with the language used to describe them.

The cancer patients for whom treatments and communication skills have been developed in palliative care have diseases which are characterised by progressive limitations, a reduced life expectancy, intrusive symptoms and, terminally, by physical and mental distress. The objectives of this article are: (1) to present evidence which shows that these characteristics are shared by heart failure patients; (2) to identify the major needs of and the specific areas of palliative care most relevant to heart failure patients; and (3) to suggest strategies for their implementation.

HEART FAILURE: PROGRESSIVE DESPITE OPTIMUM TREATMENT

The pathophysiological responses to myocardial damage dictate that recovery from congestive cardiac failure is rare. Irrespective of aetiology it is the end result of the same initially adaptive process, ventricular remodelling¹⁰: global or localised left ventricular hypertrophy followed by dilatation combine to maintain the cardiac output (Starling’s law) in the face of an increasing afterload (for example, in hypertension) or of myocardial loss (for example, following myocardial infarction). But progressive dilatation leads to increasing wall stress (Laplace’s law) with resultant further dilatation and a currently irreversible downhill cycle. Timely surgery—for example, valve replacement—sometimes permits recovery, but although angiotensin converting enzyme (ACE) inhibitors and β blockers may delay the process in other cases, they are of only temporary benefit. This is reflected in the fragmented information we have on prognosis, recently reviewed.¹¹ The commonly quoted figures for the mortality of heart failure, 50% after one year in severe cases and 50% after five years

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in milder cases, reflect the finding of studies based on different populations with varied inclusion and diagnostic criteria and which were completed before the widespread use of ACE inhibitors. Subsequently the CONSENSUS (cooperative North Scandinavian enalapril study)¹² and SOLVD (studies of left ventricular dysfunction)¹³ trials showed unequivocally that ACE inhibitors improve quality of life and prognosis for patients with severe left ventricular systolic dysfunction (New York Heart Association (NYHA) functional class IV). In the CONSENSUS study the one year mortality for the enalapril treated group was 36% compared with 52% of the placebo group. This equates to a mortality reduction of 40% at six months and of 31% at one year.

Impressive though these figures are, they can be misleading as they do not indicate life expectancy—that is, months/years of remaining life. This is the most relevant figure for individual patients, but can only be derived from the mean or the median survival times.¹⁴ The formula for calculating mean survival incorporates the time for all patients to die, and that for median survival for 50% to die, but most trials are completed before this time has lapsed; average follow up in the CONSENSUS trial was only 188 days—less than six months—at which time approximately 75% of patients were still alive. However, a 10 year review of the original cohort has been published.¹⁵ No placebo group patients survived and only 4% of those on treatment did so. The mean increase in life span was only 260 days. Even this figure overestimates the prognosis of “real” patients. Excluded from the trial were patients with pulmonary disease, a creatinine concentration of > 300 mmol/L, an atypical presentation, and the 17% who were withdrawn “for various reasons”—and presumably also those who failed or were unable to attend hospital.

Furthermore, in practice, the majority of patients are still either prescribed an ACE inhibitor in what is regarded as a suboptimal dose or not at all. The use of ACE inhibitors was, however, credited with the observed increase in life expectancy of heart failure patients hospitalised in Scotland between 1986 and 1995 (from 1.23 years to 1.64 years—20 weeks).¹⁶ This is probably a more realistic figure than that from the CONSENSUS trial, although it also is likely to be inaccurate—in this case because of the vagaries of the *International Classification of Diseases* (ICD) diagnostic coding used and the exclusion of patients who were not hospitalised.

The results of β blocker trials are, like those with ACE inhibitors, both impressive and deceptive.¹⁷ The one year mortality in NYHA class II–IV patients was reduced by 30–65% by the addition of a β blocker to an ACE inhibitor, but many patients were excluded, follow up was for just 0.5 to 1.3 years, and only approximately 10% of eligible patients are currently treated. In reality the outlook for most patients with heart failure has probably changed little since these drugs were introduced and as the disease progresses, symptoms become more intrusive and the quality of life deteriorates.¹⁸

REPORTED SYMPTOMS AND ADEQUACY OF CONTROL

Cardiologists are used to documenting and quantifying the progressive breathlessness and fatigue in heart failure patients, but these objective clinical statements do not accurately portray quality of life (defined as “the difference between patient’s perceived expectation and achievement”).¹⁹ In the UK approximately 60 000 deaths per year are attributed to cardiac failure and for many patients their final months of life are characterised by distressing and poorly controlled

Table 1 Common inadequately treated symptoms in heart failure patients (%)

| Symptom | Terminally ill patients ⁴ Symptoms in final week in parentheses | Ambulant patients attending a heart failure clinic ³ |
|--------------------|--|---|
| Pain | 78 (63) | 41 |
| Breathlessness | 61 (51) | 83 |
| Mental disturbance | | |
| Low mood | 59 | 41 |
| Insomnia | 45 | |
| Anxiety | 30 | |
| Anorexia | 43 | 21 |
| Constipation | 37 | 12 |
| Nausea/vomiting | 32 | 17 |
| Tiredness | ND | 82 |
| Walking difficulty | ND | 65 |
| Oedema | ND | 33 |

ND, not documented.

symptoms. This is shown by a study in which a relative or other carer of 600 patients who died from heart disease, but not necessarily cardiac failure (ICD codes 391–429) were subsequently questioned.⁴ The most frequently reported symptoms are shown in table 1. It can be deduced from the report that:

- ▶ psychological or other non-cardiac symptoms were often the most distressing
- ▶ hospitalisation provided suboptimal or negligible symptom relief in 60–75% of patients
- ▶ in approximately a third of cases management plans ignored the patients wishes.

Inadequate symptom control is not confined to patients with severe heart failure. We compared the needs of patients attending South Manchester University Hospital NHS Trust heart failure clinic, two thirds of whom were in NYHA class I or II, with those of cancer patients (table 1).³ Many problems were common to both groups. In the heart failure patients non-cardiac symptoms were attributable to: (1) the frequently documented co-morbidities including chronic obstructive pulmonary disease, arthropathies, and diabetes; (2) side effects of medications; and (3) the psychological and social consequences of a chronic progressive illness. We observed that even in a well established multidisciplinary clinic, approximately 60% of patients felt that one or more of their problems (cardiac, non-cardiac or psychological) were inadequately addressed. Although in some instance this occurred because of non-disclosure of a problem, it was usually because of non-documentation or from a failure to treat documented symptoms. However, appropriate action was taken in 71% of cases as a result of the study. The simple expedient of asking “What are your three most troublesome problems?” often exposed previously unrevealed symptoms.

A report from the USA, but confined to the terminally ill, provides complementary data.²⁰ Close relatives or other carers of 236 patients who died in hospital from cardiac failure were interviewed about symptoms during the last 48–72 hours of life. Severe symptoms had been experienced by the majority of patients (breathlessness 66%, pain 45%, and severe confusion 15%) and during the same period of time, almost 40% had had at least one major therapeutic intervention; tube feeding, ventilation or cardiopulmonary resuscitation. Many patients would have preferred comfort to aggressive treatment, but communication with patients about this was uncommon. Poor communication about patients wishes is a common theme of reports into the care of the terminally ill as was noted above.

STRATEGIES FOR IMPROVING SYMPTOM CONTROL

Conventional cardiological drugs demonstrably fail to control the predominant cardiac symptoms of heart failure patients (fatigue and dyspnoea), are not relevant for the control of the non-cardiac symptoms, and are inappropriate for terminal care. However, palliative care specialists are adept at treating many of the identified (non-cardiac) gastrointestinal problems and genitourinary and psychological symptoms for which well tried management protocols have been summarised.²¹ But for many patients the distressing breathlessness of chronic pulmonary oedema remains dominant. The physiological actions of the opioids morphine and, in the UK and Canada, heroin are still poorly understood but several actions, beneficial for the treatment of left ventricular failure, have been identified²²:

- ▶ depression of sympathetic vascular reflexes and histamine release cause arteriolar and venodilatation with resultant reduction in pre- and afterload
- ▶ reduced responsiveness of the dominant respiratory control centre, which is the carbon dioxide sensitive medullary reflex; as a result, the increase in respiratory rate in response to afferent stimuli from the lungs is decreased
- ▶ a central narcotic action reduces the usually associated mental distress.

The value of opioids in the treatment of acute left ventricular failure is unchallenged. They are also extensively employed in the palliative management of dyspnoea caused by lung tumours and by chronic obstructive pulmonary disease, but their use is not mentioned in detailed discussions of management options for intractable cardiac failure found in cardiology textbooks.¹ The reasons for this omission are unclear, but are probably related to concerns about one or more of three properties of the drugs: psychological dependence, tolerance, and physical dependence. Extensive experience in palliative care shows that such concerns are, in practice, misplaced.²³ Psychological dependence (“addiction”) rarely if ever occurs in the palliative care setting. Tolerance—that is, the need for increasing the dosage of opioid to control symptoms—if it does occur, usually results from worsening of pain rather than tolerance in the pharmacological sense. It is not cited as a problem when prescribed for relief of chronic dyspnoea. Physical dependence is inevitable but irrelevant if the patient remains on treatment and is easily managed using standard detoxification protocols if continuation is not required.²⁴

A dosage regimen similar to that used for long term pain control is effective²⁵:

- ▶ initially 2.5 mg morphine every four hours (“by the clock”) and as required at the same dose if necessary
- ▶ recalculate the four hourly dose after 1–2 days based on previous 24 hour total (four hourly dosage plus as required)
- ▶ recalculate as necessary.

The total daily dose is usually less than that used for pain control. It is essential to use concurrently a standard protocol for the management of constipation which inevitably occurs.²⁶

IDENTIFICATION OF THE TERMINAL STAGE OF HEART FAILURE AND ITS MANAGEMENT

Patient management should be tailored to reflect prognosis. This is especially so when life expectation is very limited and a change from active (including palliative) treatment to terminal care is or should be considered appropriate. Palliative care specialists acknowledge that it is often difficult to judge when to do this,²⁷ a difficulty made worse in heart failure

because of the numerous pathological scenarios, an unpredictable response to treatment, and a high incidence of sudden death. This is compounded by a valid concern that a reversible precipitant may be overlooked or that various combinations of inotropes, vasodilators, and diuretics may initiate a remission.

There has been no concerted attempt using objective criteria to identify when the end of life is imminent in individual heart failure patients, but encouraged by the need to prioritise patients for heart transplant waiting lists, efforts have been made to evaluate potential markers of long term and short term survival groups. The predictive accuracy of more than 80 variables has been assessed and comprehensively reviewed.²⁸ Several sources of error were identified, each common to a number of studies: small sample size, selected populations, interrelated variables (that is, different tests measuring the same phenomenon), short period of follow up, and data handling problems. The reviewers concluded that “few variables predicted consistently”. Some markers, such as circulating concentrations of cytokines, endothelin-1, and hormone assays (renin noradrenaline (norepinephrine), atrial natriuretic peptide (ANP)), although useful, either have limited availability or their assay is difficult and time consuming. Some simple routine tests have, however, provided useful information.

A low serum sodium, which is inversely proportional to serum renin, has consistently predicted outcome. In a study of NYHA class IV patients²⁹ the median survival of those with a serum sodium less than 137 mEq/l (pre-ACE inhibitor treatment) was 164 days compared with 373 days for those with higher values. If the serum sodium was less than 130 mEq/l survival was only 99 days.

Prognosis is related to functional capacity irrespective of how it is measured: NYHA class,³⁰ six minute walk test,³¹ or peak $\dot{V}O_2$.³²

Assessed by echocardiography, left ventricular dilatation is predictive of outcome, but ejection fraction is not, probably because of inaccuracies inherent in the calculation used to measure it. However, its measurement by radionuclide ventriculography is useful. In one study,³³ the mortality for patients with mild (81% in NYHA II) cardiac failure was 27% after 16 months if ejection fraction was less than 20%, but only 7% with higher values.

Unfortunately, the use of these tests is often limited in clinical practice. The prognosis of hyponatraemic patients may be improved by ACE inhibitors,²⁹ although to a lesser extent than in the normonatraemic. Facilities for radionuclide screening are limited, and the assessment of functional capacity is often precluded by non-cardiac impairment of mobility—for example, because of chronic obstructive pulmonary disease or arthritis. Study of prognostic markers is important because it increases our understanding of the pathophysiology of heart failure and may aid treatment; however, those which have been assessed to date, while they may identify high and low risk groups, lack the predictive accuracy to indicate the imminent end of life of individual patients.

An alternative approach to the problem is therefore required. Published protocols for the management of resistant cardiac failure consist, in practice, of “check lists” to ensure that a reversible aetiology or precipitant has not been overlooked, and that all reasonable treatment options have been considered.¹³⁴ Cardiologists will recognise that the typical patient for whom this process is used has a very poor quality of life, with increasingly frequent hospitalisations or outpatient attendances characterised by worsening oedema and progressive renal failure in the absence of an iatrogenic

cause. By this stage, the views of patient and carer on the merits of continuing active treatment should have been sought. Empirical observations (as there is no relevant objective data) suggest that assimilating these three sources of information (simple prognostic indicators, a “check list”, and the patient’s wishes) and their implications would be an improvement on the present situation. The findings of the SUPPORT (study to understand prognoses and preferences for outcomes and risks of treatment) group,²⁰ suggest that either such a strategy is not used or that if it is, its inference is ignored. The latter may be the result of a reluctance to acknowledge that a patient is terminally ill because of the implicit finality and failure. This, however, is to misunderstand the dying process which, when well managed, is a gradual and overlapping progression from active through palliative to terminal care; it does not require a sudden treatment change as active measures are often continued to aid patient comfort. This is a positive approach of doing everything possible, not a negative “there is nothing more to be done”.

The protocols for patient management during these last days of life are better established than is the timing of their initiation.

Palliative care teams have devised comprehensive integrated care pathways which simply ensure that the physical and psychological problems of the dying and of their carers are conscientiously addressed. Concerns that inflexibility in these programmes may not cater for the patient who has an unanticipated remission of symptoms are unfounded since they deliver optimum care, not euthanasia. Provided cardiologists can broadly agree a process which will identify those heart failure patients who appear to be close to the end of life, there is no reason why they should not then benefit from the care and attention offered by the above protocols.

REQUIREMENTS FOR IMPROVED CARE

The quality of life of patients with all grades of heart failure could be significantly improved by applying the management principles advocated in palliative care, fundamental to which is good communication. As noted above, communication with heart failure patients is often inadequate, whereas in palliative care good communication with patients is regarded as a pre-requisite for optimum patient care. Clearly this concept of communication is not synonymous with simply asking the correct questions and taking an adequate history. In brief, there are considered to be three main components to good communication³⁴: (1) active listening (not a universal attribute of doctors), the specific task of (2) breaking bad news, and (3) therapeutic dialogue. The objective of this process is to ensure that the patient understands the implications of his illness and that his concerns and aspirations are addressed. The skills required to achieve these outcomes sensitively will have to be learned. The fact that so much time is devoted to writing about and studying this topic reflects its perceived importance: “No-one who hasn’t time for chat knows anything about terminal care”.³⁵ The other relevant aspects of established palliative care, treatment schedules for the control of non-cardiac symptoms, and the management of the final days of life will need to be integrated into cardiologist practice through collaboration between cardiologists and palliative care specialists.

In addition there is a need for research into the use and actions of opioids in chronic left ventricular failure. This should include the evaluation of different treatment regimens, the use of alternative opioid delivery systems (for example, nasal sprays which have been shown to relieve

Palliative care in heart failure: key points

- ▶ Heart failure and the conditions managed by palliative care specialists share many features: inexorably progressive debilitation, a deteriorating quality of life and, unless conscientiously addressed, distressing symptoms, especially at the end of life
- ▶ In end stage heart failure a strategy is urgently needed to ensure a timely progressive move away from invasive treatment towards supportive terminal care
- ▶ The views of heart failure patients on how they would prefer to be treated are often either not sought or are unheeded
- ▶ Palliative care specialists have developed treatment strategies which effectively control many of the distressing symptoms reported by heart failure patients and for which conventional cardiologist treatments are ineffective or inappropriate
- ▶ There is no practical reason why the regular use of morphine should not be considered as routine for the treatment of the dyspnoea of chronic heart failure
- ▶ The basic principles of palliative care—good communication and close attention to symptom control—should be adopted to improve the quality of life of heart failure patients
- ▶ The teaching of these techniques and skills should be included in training programmes for prospective cardiologists

anxiety rapidly), and the role of newer opioids such as fentanyl. These changes are not only necessary to improve patient care, but are also important for an often ignored group—the relatives and the carers. It is a tenet of palliative care that the way in which people die remains in the memories of their survivors.³⁶

It is unrealistic to expect every cardiologist to become proficient in the various aspects of palliative care. It is, however, important to acknowledge the benefits which palliative care has to offer and to encourage their adoption, either by interested cardiologist colleagues, by professionals with a palliative care training, or by a combination of the two. To ensure adequate expertise among cardiologists an educational module in palliative care should be developed and incorporated into cardiology training courses. Currently many cardiologists with a major interest in heart failure devote considerable time to research. The demonstrated increasing burden of treating heart failure will dictate the need to develop heart failure as a clinical subspecialty whose practitioners would logically take on the role of developing and providing a palliative care service.

Cardiology is a speciality in which interventional treatments continue to make dramatic improvements to patient’s prognosis and quality of life. At the same time, however, we should remember that: “The terminally ill fear the unknown more than the known, professional disinterest more than professional ineptitude, the process of dying rather than death itself”.³⁷

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