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Palliative care for patients with heart failure: description of a service

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Over the past 10 years, there has been an increasing demand for heart failure patients to have access to palliative care services. The concerns of this group have been highlighted and there is growing recognition in national palliative care and cardiology bodies that these concerns should be addressed. In spite of this, there is little improvement. There are concerns about the acceptability of hospice services to heart failure patients, worries about service overload, lack of appropriate knowledge and skills and difficulty in knowing when to refer a heart failure patient for palliative care.

In Scarborough, a joint approach by a cardiologist and palliative care physician was set up in September 2000. This paper describes the service so far in an attempt to address some of the above reservations and to provide a catalyst and encouragement to others beginning a similar venture. *Palliative Medicine* 2006; **20:** 211–214

Key words: heart failure; palliative care

Introduction

The understanding and management of heart failure has changed dramatically over the last 20 years.[1,2] Medication has expanded and advances in technology have provided additional treatment options with various devices. Cardiac surgery techniques continue to develop, and research progresses in molecular and genetic approaches to management. With so many options, it is unsurprising that cardiologists can forget that patients will die from their disease, and that even while active treatment is appropriate, patients will benefit from good supportive care, taking into account the effects of illness on all domains of life. It is difficult to recognize deterioration despite optimum treatment and when a change of goal is needed; the end stage trajectory is not as clear as for cancer.[3]

There is growing recognition in both palliative care and cardiology communities that the distress, psychosocial and spiritual concerns suffered by this group of patients should be addressed.[4–12] In spite of this, there is little improvement. Progress is patchy and dogged by the difficulties of historical approaches, and working with voluntary sector organizations whose funding is often precarious, cancer-focused and who are worried about potentially overloading the service. There is concern that precious beds in short stay acute units will become blocked by patients with severe debility, but not imminently dying.

Other concerns have centred on the acceptability of 'hospice' or 'palliative care' to patients with heart failure, although where patient satisfaction has been assessed, this has not appeared to be a problem.[13,14] There is also doubt that hospice staff have the necessary skills for such patients. In a hospital-based questionnaire, Dharmasena and Forbes,[15] reported that if the palliative care service extended to non-malignant patients, then 94% of responding physicians would consider referral, but with a shared care approach to address such concerns.

In the Scarborough area (population: 220 000) a joint approach from cardiologist and palliative physician was set up in September 2000 with some simple referral criteria (see Box 1). Patients have access to all specialist palliative care (SPC) services except community palliative care nurse specialists, although at the time of writing, this has now been added. This paper describes the service so far, in an attempt to address some of the above reservations.

Box 1 Referral criteria

- NYHA III/IV with continuing symptoms and deterioration despite optimum treatment
- Social isolation; consideration for day hospice attendance
- Consideration for hospice as alternative venue for inpatient admission if required
- Help with difficult communication issues
- *Trial of opioid
- *Care of the dying – Liverpool Care Pathway

*Now, usually carried out without referral to specialist palliative care, unless complex issues.

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Methods

Two reviews were performed. Firstly, the case notes of patients with heart failure who had been admitted to the hospice inpatient unit between September 2000 and February 2005 were independently reviewed by a consultant cardiologist and a palliative care consultant, noting problems during admission, and interventions given. The two lists were then combined to give as full a picture as possible.

If a patient was admitted more than once, these details were recorded for each admission. Gender, average length of hospice stay, number of admissions, and outcome was also recorded.

Secondly, a retrospective review of heart failure patients referred to the SPC services by May 2005 (the first review took until May to complete – hence a longer time period for the second review) was carried out. Source of referral and services accessed were noted. Patient outcome with regard to discharge from the service or death was also documented.

Results

Inpatient admissions

A total of 22 patients (14 female, eight male) had been admitted to the hospice 41 times between September 2000 and February 2005. Although one patient was admitted seven times, most were only admitted once. The average age was 71.8 years (range: 64–90 years). The average length of stay was 13.75 days (range: 1–37).

Many problems were presented, the most frequent of which was breathlessness or cough. This was a presenting symptom in 34 of the admissions to the hospice. Fatigue was the second most common problem, described by patients in 26 admissions. Other reported symptoms and issues can be seen in Table 1.

Interventions during the inpatient stay were wide-ranging, involved the whole multi-professional team and focused on control of symptoms, rationalization of medication, spiritual issues, family anxieties and planning for bereavement (Table 2). Management of breathlessness was not specifically documented, but implicit in many interventions including drug treatment (antibiotics, opioids, benzodiazepines), drainage of effusion, physiotherapy, provision of fan, etc. In selected patients, management with intravenous diuretics, fluid restriction and daily weighing was carried out with help, if necessary, from the cardiology team.

The problems and interventions listed independently by cardiologist and palliative physician were largely the same. The differences were mainly seen in the interventions, where there was a tendency for the cardiologist to under-report psychological support, discharge and end-of-life planning, and for the palliative physician to under-report fluid balance and daily weights.

Table 1 Problems noted during admission

Problem	No. of admissions
Breathlessness/cough	34
Fatigue	26
Nausea/vomit/weight loss/anorexia	25
Leg oedema/cellulitis/leg ulceration	18
Pain	16
Constipation/diarrheoa	13
Anxiety/distress	11
Reduced mobility	11
Depression	10
Insomnia	10
Carer exhaustion	10
Itch	6
Others (overdiuresis, pleural effusion, dry mouth, drug related, co-morbidities, nose bleed, dysphagia)	17

Referrals to SPC services

From initiation of the service in 2000 to May 2005, 62 patients were referred to the palliative team. Of these patients, two had died before they could be seen (within 24 hours of referral); a further 43 had died by the time of

Table 2 Interventions during admission

Intervention	No. of admissions
Rationalization of medication[a]	22
Change of diuretic	19
Antibiotic	14
Anti-emetics	13
End-of-life care	13
Bowel care	13
Pain control	11
IV diuretics	7
Catheter care	7
Treatment of itch	6
Others (drain pleural effusion, rehydration, denture care, chiropody, hairdresser, fan, diabetes management, warfarin control)	15
OT/physiotherapy	24
Aromatherapy	10
Cardiology review	10
Others (tissue viability nurse, rheumatologist, ENT surgeon, vascular surgeon)	4
Discharge planning	12
Communication issues[b]	22
Family support	21
Psychological support	18
Management of anxiety	9
Social support	8
Chaplaincy/spiritual support	8
Antidepressant	4
Benefits advice	3

[a]Ceasing all but the medication necessary for comfort for the dying, streamlining polypharmacy if possible for those not imminently dying.

[b]Understanding end stage of illness, wishes regarding resuscitation and place of care, addressing collusion and denial.

Table 3 Source of referral

Year	Consultant	GP	Already known to service	Unknown
2001 (part year)	2		1	1
2002	8	4	3	
2003	8	2		
2004	18	5		
2005 (part year)	4	5		1

data collection. Five had been discharged and 11 have continued involvement with the palliative care team. One patient was lost to follow up.

Table 3 details the source of referral for patients to the palliative team. The number of referrals from both hospital consultants and general practitioners is increasing annually, but not dramatically so. The appointment of a second cardiologist and heart failure nurse specialists (HFNS) in 2004 has had an impact on the referral pattern.

A wide range of both inpatient and outpatient services were accessed by patients referred to palliative care and are shown in Table 4.

Discussion

Patients with end stage heart failure need access to supportive and palliative care. We have adopted a shared care approach, with the HFNS acting as the key worker liaising between primary, secondary and hospice services. Hospice and hospital are in close proximity and the consultant palliative physician has an honorary contract with the Acute Trust. These factors facilitate co-working and the establishment of professional relationships. We appreciate that this may be more of a challenge in a larger centre, and a different model may be required.

The referral criteria appear to be appropriate in that the number of ongoing patients is manageable. Some patients have stabilized during regular review at the day hospice or clinic; some well enough to be discharged. Referral to SPC services should only be necessary for patients with difficult symptoms or psychosocial issues, with the majority being well cared for by their general practitioner and cardiologist.[16] The Gold Standards Framework,[17] and the Liverpool Care Pathway,[18] should encourage good care without requiring the specialist team. Concerns regarding the numbers of patients requiring specialist services may be unfounded,[19] although our data suggest that there is a significant impact on the day therapy service. In Australia, a collaborative approach found that only 8.3% of heart failure patients in the programme needed SPC referral,[20] which is similar to our own figures; 10% of patients known to the HFNSs.

Our hospice admission review shows that what is performed is indeed palliative care, with its special emphasis on time for communication, psychological, spiritual and social support to both patient and carer. The main difference being that symptom control remains closely related to fluid balance and optimum cardiac medication. Access to cardiology support enables suitable patients to be admitted for intravenous diuretics as well as end-of-life care. This is probably why patients have the opportunity to die in the hospice if this is their wish, as it can be difficult to judge whether or not an episode of decompensation is a terminal event. Patients admitted to the hospice are aware of the available resources, and that if the clinical situation required the facilities of the hospital, then transfer would be recommended. The concern that heart failure patients will require long admissions has not been borne out; the average length of stay is a little longer than that for our cancer patients (14 days compared with 9.5 days).

Invariably with retrospective case note reviews, our information is limited to what has been documented. Therefore, it is difficult in particular to quantify the amount of time spent on psychological support for patients and families. Likewise, the full extent of cardiology team support received by the palliative care team is not known, as telephone calls, or informal visits from the heart failure nurse specialists were not recorded. We are currently planning prospective evaluation of the service.

This description is presented in the hope that others will be encouraged to develop local solutions for extending palliative care to patients with heart failure. We

Table 4 Services accessed by NEW referrals, by year of referral (beginning of service to May 2005)

Year	Home visit	Seen as hospital inpatient	Seen in coronary care unit	Hospital palliative outpatient clinic	Day hospice	Hospice inpatient	Hospice outpatient	Lymph oedema clinic
2001 (part year)		3		2	2	3	1	1
2002	3	7		1	2	7	2	3
2003		5	3	2	5	2	2	
2004		13	1	4	7	9	3	
2005 (part year)		3	1	3	1	4		

Service accessed only noted for the year the patient was referred – patient may have continued going to day hospice into the following year etc.

expect that different models will be needed in different settings, but recommend a shared care approach. A mutual understanding and respect of the different skills of each team is the first step, and this can be taken without additional resource.

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