

## Survey of specialist palliative care and heart failure: September 2004

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**Aims:** To describe English specialist palliative care (SPC) services' provision for, and attitude to, heart failure patients, and to identify developments of particular interest or expertise in this area. **Method:** Postal survey of all lead consultants of English SPC services, September 2004. **Results:** Of 397 services, 233 replied (response rate 59%); 222 (95%) thought SPC had a role in severe/end stage heart failure, while three (1%) did not. A total of 197 services (85%) accepted heart failure patients, 26 (11%) did not. The most common reasons for not accepting heart failure patients were lack of resources or beds, implications for staff training or an organizational decision. The mean number of heart failure patients currently under a service was 2.2, but 15 had more than five (maximum 53). Fifteen services (6%) had specific referral criteria for heart failure patients, including recurrent hospital admissions without symptomatic improvement, inappropriateness of further hospital admission and severity of heart failure. Twelve services (5%) had or were developing treatment guidelines for heart failure: five were end of life pathways, three covered breathlessness management and three were symptom control guidelines. Some 137 services (59%) described local collaborative initiatives between SPC, heart failure services and primary care, such as mutual education, joint working and working groups. A number of models of joint working practices were described in detail. Twenty-seven (12%) knew of national initiatives. **Conclusions:** The current situation of SPC services in England for patients with heart failure varies widely. One in 10 SPC services in this audit did not accept heart failure patients. Few have developed services of significant size. Local collaborative initiatives are common. Specific referral criteria and symptom control guidelines have been developed. Their role in promoting good palliative care in patients with heart failure remains unclear. Better dissemination of practical knowledge gained by these initiatives could significantly improve the provision of SPC services to heart failure patients. *Palliative Medicine* 2006; **20**: 603–609

**Key words:** advanced heart failure; end of life; hospices; palliative care; terminal care

### Introduction

Specialist palliative care (SPC) for people with diseases other than cancer, motor neurone disease and HIV/AIDS has been on the national agenda for a decade.<sup>1</sup> Initial fears of 'opening the floodgates' and overwhelming SPC services with referrals of patients with diseases other than cancer have proved unfounded. Hospice information service statistics show that, overall, the percentage of those receiving SPC who do not have a cancer diagnosis remains around 5%.<sup>2</sup>

Heart failure is a disease that has a survival akin to large bowel or ovarian cancer.<sup>3</sup> It causes approximately 60 000 deaths per annum in the UK. Studies have shown

that the level of need in heart failure patients, in terms of symptomatology and social, psychological and spiritual need, is at least equivalent to cancer.<sup>4–10</sup> Despite this, referral on to support services beyond the general practitioner and hospital doctor (such as district nurses, social workers, physiotherapists or SPC) is lower than for cancer patients.<sup>11</sup>

The cardiac community have started to take this issue on board. The Coronary Heart Disease National Service Framework of April 2000 and the NICE Management of Heart Failure guidelines of 2003 each comment on palliative care.<sup>12,13</sup> Palliative care is on the curriculum of at least one of the major heart failure nurse education programmes (Principles of care management for the patients with chronic heart failure: module of BSc in specialist nursing, Glasgow Caledonian University). At the time of this survey, there were no recommendations concerning the prac-

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tical implementation of palliative care in heart failure patients.

Anecdotally, some SPC services are known to have developed particular interests in heart failure,<sup>14–17</sup> but little has been published about these services. This survey aimed to describe in more detail the current state of SPC services for patients with heart failure in England and to identify development of particular interest or expertise in this area.

## Methods

A survey of lead practitioners of adult SPC services in England was conducted in September 2004. Adult SPC services in England, excluding those in cancer only hospitals, were identified from the Hospice Directory 2004.<sup>18</sup> Many services are listed separately, but are part of a wider organization based at multiple sites. In circumstances where identifying whether services were linked or separate was difficult, each listed service was contacted. Letters were sent to the consultant or lead clinician of each identified separate service, inviting them to complete a questionnaire about SPC for patients with heart failure. No reminders were sent to non-responders. Clinicians were given four months to return the questionnaire. Simple descriptive statistics were used to present the data.

The chair of the local ethics committee confirmed that ethics committee approval was not needed for this survey.

## Results

A total of 452 letters and questionnaires were sent out. Many services were, in fact, linked or part of a larger organization, and sent back one combined reply (56/452). This was counted as one reply. One consultant sent back two replies for services that had not been identified as being distinct. In total, 233 questionnaires were returned

and 164 services did not reply (total 397), giving a response rate of 59%.

### Is there a role for SPC services in heart failure management?

Some 222 services (96%) thought that SPC services had a role in providing care for patients with severe/end stage heart failure. Three (1%) did not; eight (3%) did not reply to this question. A total of 197 services (85%) currently accepted referrals for patients with heart failure as their main diagnosis. Twenty-six (11%) did not; 10 (4%) did not reply to this question.

Reasons given for refusing or restricting access to SPC for heart failure patients are given in Table 1. The most common reasons were lack of resources, implications for staff training in heart failure and limited bed availability.

### Numbers of heart failure patients under SPC

Of the 233 services, 225 gave details of their service components, ie, whether hospice inpatient, community or day care, hospital inpatient or out patients (Table 2). The mean number of patients whose main problem was heart failure, currently under a SPC service was 2.2, with a range of 0–53. Fifteen of 233 services (6%) had five or more patients. Table 2 shows a detailed breakdown of results for inpatient, day care, community and hospital service components. In total, 501 patients with heart failure were identified as under a SPC service on the day of the survey.

### Referral criteria

Specific referral criteria/guidelines for patients with heart failure were in use by 15 services (6%), four services providing a copy of them. A further 20 (9%) stated that these were not necessary because their general referral criteria were adequate for all diagnoses. Many services provided details of their general referral criteria, which were very similar: patients should be suffering from advanced/progressive, life threatening/life limiting disease; patients or their families should have symptom control and/or physical/psychological/emotional/social/

**Table 1** Reasons given for refusing or restricting access to SPC by heart failure patients

	Heart failure patients not accepted ( <i>n</i> = 26)	Heart failure patients accepted ( <i>n</i> = 15)	Acceptance status unknown ( <i>n</i> = 10)	Total ( <i>n</i> = 51)
Lack of resources	20	12	2	34
Implications for staff training	15	7	1	23
Limited bed availability	10	3	2	15
Specific organizational position	4	1	1	6
None/few referred	1	3	1	5
Cardiac professionals can do this	2	1	0	3
Our lack of expertise	1	0	0	1
Other	2	1	0	3
Ethical reasons	0	0	0	0

**Table 2** Numbers of patients with heart failure under SPC on day of survey

	Number of specific SPC services (Total answers to this question = 225/233)	Mean number of patients with heart failure	Range in number of patients with heart failure
(i) SPC inpatient	127	0.4	0–20
(ii) SPC home care	140	1.3	0–12
(iii) SPC day hospice	128	0.8	0–39
(iv) Hospital inpatient support	154	0.4	0–4
(v) Hospital outpatient review	110	0.6	0–6

spiritual needs, which are complex, poorly controlled and require SPC input. Table 3 combines and summarizes the heart failure specific referral criteria/guidelines from the 15 services. The two services that included medical information, such as echocardiography results or blood tests, cited the criteria for referral to palliative care from an article by Ellershaw and Ward.<sup>19</sup> One other service stated a useful trigger phrase for referrers – ‘A patient who is sick enough that dying in the next year would not be a surprise’ – quoting the Macmillan Gold Standards Framework (a standardized organizational framework of multi-professional care developed for the palliative care needs of cancer patients).<sup>20</sup> There appeared to be no relationship between the use of heart failure specific referral criteria and having five or more patients with heart failure currently under the service (only one of the 15).

### Treatment guidelines and pathways

Specific treatment guidelines or pathways for patients with heart failure were in use or being developed by 12 services (5%). Five of these were end of life pathways. Two were breathlessness management programmes, akin to pulmonary rehabilitation. One was a guideline for the use of opiates for breathlessness. Three services were currently writing symptom control guidelines. One gave the title ‘Toptips’ but did not elaborate. In addition, two services stated that certain heart failure treatments could be continued under inpatient SPC (both mentioned intravenous furosemide). One service provided a copy of its draft treatment guidelines, which consisted of a one page table with brief guidance covering the management

of dyspnoea, pain, constipation, depression, insomnia, anxiety, anorexia, nausea and agitation. There appeared to be no relationship between the presence of specific treatment guidelines or pathways and having five or more patients with heart failure currently under the service (only one of the 12). Four of the services who had (or were developing) specific treatment guidelines or pathways also had heart failure specific referral criteria.

### Collaborative initiatives

Of 233 services, 137 (59%) were aware of local collaborative initiatives between SPC, heart failure services and primary care.

One area of collaboration was mutual education. Educational initiatives described commonly involved SPC professionals teaching cardiac and community/primary care health care professionals and/or heart failure professionals (mainly nurse specialists) teaching SPC professionals, often as ‘one off’ sessions. Larger educational events had been organized by primary care or hospital trusts (four), or at cardiac and cancer network level (one), the latter aiming to promote interest and establish a working group.

The second area of collaboration was in terms of specific service developments. Of 233 services, 62 (27%) stated that local specialist heart failure services had an interest in end of life care. Of 233 services, 50 (21%) stated that local SPC services had an interest in heart failure. Twelve respondents mentioned local or regional/network task forces or steering/working groups. A further 12 respondents mentioned specific projects, ranging from respite/hospice at home services focusing

**Table 3** Heart failure specific referral criteria for specialist palliative care ( $n = 15$  services with specific criteria already in use)

	$n = 15$ (%)
First three points covered by ‘general criteria’:	
Specific detail regarding severity and/or complexity of patients’ symptom control needs	10 (67)
Specific detail regarding severity and/or complexity of patients’ other needs (psychological, emotional, spiritual, social)	10 (67)
Specific detail regarding severity and/or complexity of carers/families’ needs (including high bereavement risk)	9 (60)
Heart failure specific criteria:	
Recurrent hospital admissions with decompensated heart failure, usually without symptomatic improvement	11 (73)
Symptomatic severity of heart failure (NYHA functional classes III and/or IV)	10 (67)
Lack of further treatment options making hospital admission inappropriate	9 (60)
Specific further medical information (eg, echocardiogram results, blood results)	2 (13)

on non-malignancy, through single nurse appointments to focus on non-malignancy, to complex projects of collaborative mutual education and support, joint working and service provision. The latter all involved heart failure clinical nurse specialists. Six of these 12 respondents submitted documents describing their projects, which included some of the following: SPC contact details, symptom control guidelines, service use statistics, referral criteria and joint working practices.

A number of models of joint working practices were described. The three broad types of model are summarized in Table 4. Two respondents described similar joint initiatives with hospital cardiology colleagues, based around mutually agreed referral criteria and initial assessment by a palliative care consultant. The SPC professionals' expertise in managing these patients gradually increased, so that more of their cardiac management could be taken on by SPC, even resulting in the use of intravenous furosemide with daily weighing and regular blood tests in one hospice. A second model was that of SPC training and supporting heart failure clinical nurse specialists as the key supportive care workers. Details provided about these initiatives were scanty. Types and levels of training and support in palliative care were varied. Close collaborative working, with SPC offering informal telephone advice, heart failure nurse attendance at multi-disciplinary meetings to discuss difficult cases, joint assessments or 'full' SPC referral, were described. One service had a SPC nurse spending one day a week working alongside the community heart failure nurses, who already had substantial training on palliative care courses.

In a third model, in addition to the collaborative working described above, a hospice worked with its local heart failure nurses, allowing the hospice day centre to be used for a regular programme of heart failure patients (and their carers) education and support.

Of 233 services, 27 (12%) were aware of a national initiative/s. Specific national initiatives/bodies were: national study days, the Liverpool Care Pathway (LCP), Pursuing Perfection, the British Heart Foundation, the Coronary Heart Disease National Service Framework and the NICE heart failure guidelines.

## Discussion

The evidence for symptom control, psychological, emotional and social need in heart failure is at least as compelling as in cancer. The paucity of published evidence for the benefit of SPC in heart failure makes planning response to that need difficult.

This survey has confirmed that wide variations in SPC practice with regard to heart failure exist around the country. At one extreme, more than one in 10 of the SPC services who participated in the survey would not take on a heart failure patient at all, whatever their demonstrated need. At the other extreme, more than one in five SPC services expressed a particular interest in heart failure.

The main barriers to accepting patients with heart failure were stated to be issues of SPC resources and beds, closely followed by concerns over the implications of training staff in an unfamiliar area. Evidence from those services that do accept heart failure patients suggests that these barriers are surmountable. As such, achieving a state of 100% of SPC services accepting heart failure patients seems possible. There was very little support for the suggestion that cardiac services should be expected to deliver all palliative care for heart failure patients.

The good response rate to this survey suggests that interest within SPC is high, and many respondents requested to be kept informed of any new knowledge or developments. Nearly 60% already knew of some local collaboration in this area. In contrast, the mean number

**Table 4** Three models of joint working practice described by respondents

Model	Initiators	Site of initial patient contact	Process	Outcomes/comments
1	Joint SPC/hospital cardiology initiative	Initially hospital in/out-patient based	SPC consultant assessed referrals from cardiology consultant/heart failure nurse in hospital/hospital outpatients/community. Patients referred on for SPC community/day hospice/inpatient services as appropriate.	Referrals deemed to be appropriate. Numbers not over-whelming. Mutual increase in knowledge and skills.
2	Cardiology (mainly heart failure nurses)	Hospital/community	Heart failure nurses acting as key supportive and palliative care workers for patients.	Initial training and some experience in palliative care required. Continuous support described by some respondents. One respondent described joint working one day a week.
3	Joint SPC/Primary Care Trust cardiology initiative	Hospice day centre	Heart failure patient support group (six structured education sessions), run by heart failure nurses, held in hospice day centre with access to full SPC services.	Popular with patients and professionals. Efficient use of professional time. Future of group/discharge policy to be discussed.

of patients currently under a SPC service was 2.2, suggesting that local interest had frequently not translated into many patient referrals to SPC. It is recognized that the slow progression of heart failure discourages health care professionals from referring patients to SPC and patients and their carers from accepting it.<sup>21</sup> It is not known what the appropriate level of referral to SPC is for any disease, and heart failure is no exception.

The survey did not reveal the extent to which heart failure patients were receiving palliative care from general or cardiac professionals, augmented by training, support or joint working practices from/with their SPC colleagues. It did collect a few examples of different models of joint working practice that are in current use around England. No evidence currently exists to define which models deliver effective and cost effective palliative care, are feasible on a large scale and are sustainable. Such data is likely to be necessary in order to secure a funded future for palliative care in heart failure, be it general or specialist.

The three models described in more detail reveal fundamentally different care planning. These models had clearly been shaped as much by local relationships and NHS/voluntary sector configuration as patient need. At one end of the spectrum, model 1 involved SPC starting by accepting patients with heart failure according to jointly agreed referral criteria. Both services that described this model had started it as a hospital-based initiative, but the service had grown and developed out into hospice and/or community. As interest and experience increased, more heart failure management had been taken on by SPC, even to the extent of fluid overload being managed in one SPC inpatient unit with intravenous furosemide. A service described under model 2 had a community specialist heart failure service reaching out to deliver a high level of supportive and palliative care itself. This service has published its experience.<sup>22</sup>

Delivering this service has required both extensive initial training and regular, frequent and ongoing joint working with an experienced community palliative care nurse. With this model, the numbers of referrals on to full SPC services was quoted as low. These extreme models, of heart failure services delivering palliative care, or SPC services delivering relatively acute cardiac care, both required a high level of training and support from the other service. Model 2 – heart failure nurses becoming the key supportive care workers – requires SPC involvement in terms of education. It is also likely to require ongoing flexible working between the two specialties, with a range of services, including telephone advice, difficult case discussion and joint assessments, as well as ‘full’ SPC referral. Model 3, the use of a hospice day centre as the site for a heart failure support group and, therefore, a specific bridge between cardiac and SPC, may be reproducible elsewhere. Issues of patient numbers and discharge arrangements from the hospice day centre may need to be addressed. The survey did not provide enough detail to recommend any particular model as a blue print for others to follow.

The areas of local initiatives, education, joint working practices, referral criteria and written guidelines were inter-related. Whilst a majority of services (59%) were aware of local collaborative initiatives between SPC, heart failure services and/or primary care, the proportion involved in such initiatives was much lower. A small minority had matured from fledgling beginnings, with the development of a combination of referral criteria, treatment guidelines, steering/working groups and new models of care. This ‘pyramid’ of service interest and development is depicted in Figure 1.

It is interesting that there was no apparent relationship between a high number of heart failure patients (>5) currently under a services, and the use of either heart failure specific referral criteria or specific treatment

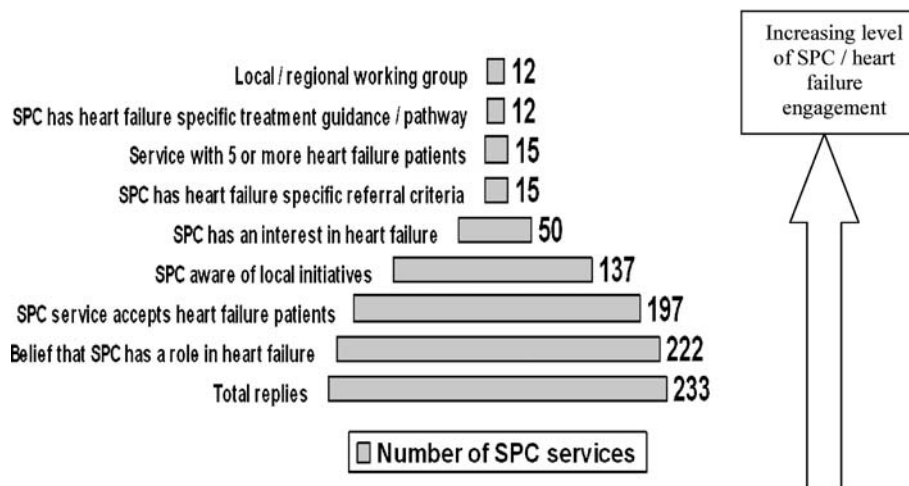


Figure 1 Pyramid of SPC interest in, and involvement with, heart failure patients.

guidelines. Drawing any conclusion from this is not possible from this survey. We speculate that referral criteria or treatment guidelines help ensure appropriate referral without overwhelming services, but we also recognize that a lack of specific referral criteria does not appear to be a barrier to developing a bigger service for heart failure patients. Whether specific referral criteria for individual diseases should, therefore, be encouraged as one means of opening up services to this patient group needs further investigation.

Heart failure specific treatment guidance, including symptom control and end of life care, was in use by only a handful of services. The LCP,<sup>23</sup> originally developed for patients dying from cancer, is widely known to be used for other dying patients in a variety of settings. A specific LCP project, researching the use of the LCP in heart failure, is ongoing. In this project, the generic pathway is being used, with some minor additions covering cardiac specific areas, such as turning off internal cardiac defibrillators. Four different symptom control guidelines were identified in this survey. Since this survey was completed, Cheshire and Mersey cancer and cardiac networks have published symptom control guidelines.<sup>24</sup>

A number of national bodies are now showing a particular interest in palliative care in heart failure. The National Council for Palliative Care (NCPC) has a Circulatory and Respiratory Policy Group. Part of this group's remit is to gather and disseminate knowledge on palliative care and heart failure. Since this survey was conducted, the NCPC has undertaken and published a survey of heart failure nurses in England, regarding their involvement with palliative care services.<sup>25</sup> The Heart Improvement Programme (formally the Coronary Heart Disease Collaborative) has produced a document paralleling the NICE guidance on supportive and palliative care in cancer,<sup>26,27</sup> and a CD-ROM, 'Supportive and palliative care in heart failure: a resource kit for cardiac networks'.<sup>28</sup>

## Conclusions

Despite the publication of influential guidelines and recommendations on heart failure over the past five years, which have promoted the role of SPC, referrals to SPC have not risen dramatically. The current situation of SPC services for patients with heart failure varies widely. In this survey, one in 10 services that responded, currently did not accept any such referrals, creating a complete barrier to heart failure patients and their family and professional carers seeking SPC. Most of the SPC services that do accept these patients currently have very little experience, and only two of three of these SPC services know of local interest or initiative in this area. In a minority of cases, SPC services have developed

with clear particular heart failure interest. This interest does not mean that these services now have a high number of heart failure patients on their books. Local collaborative initiatives are common. Different models of joint working described could act as a useful resource for other services. The effectiveness, cost effectiveness and sustainability of these different models are not known. The role for disease specific referral criteria or treatment guidelines in promoting good palliative care in patients with heart failure is also unclear.

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