

Heart failure and palliative care services working in partnership: report of a new model of care

Andrew Daley Bradford Marie Curie Hospice and Bradford Teaching Hospitals NHS Foundation Trust, **Christine Matthews** Bradford Marie Curie Hospice and **Anne Williams** British Heart Foundation Heart Failure Nurse Specialist, North Bradford Primary Care Trust

It is widely acknowledged that people with advanced heart failure have at least as great a need for supportive and palliative care as those with malignant disease. However, specialist palliative care services are seldom involved in their care in the UK. We describe a three-year collaboration between community-based heart failure nurse specialists and existing specialist palliative care services. In the model of care that has evolved, the heart failure nurses remain key workers throughout the illness. They run a regular support group for patients and carers in the setting of a hospice day therapy unit, referring patients for other palliative care involvement as necessary. Activity data and the results of patient interviews are presented. These suggest that the model is a cost effective, sustainable way of providing high quality care for people with heart failure. *Palliative Medicine* 2006; **20**: 593–601

Key words: day centre; day therapy; heart failure; palliative care; service model; support group

Background

Heart failure is a chronic, disabling condition which presents an increasing challenge to the health care system. The prevalence in the UK is currently 1–2% of the population¹ and the incidence is continuing to rise despite important advances in evidence-based treatments.^{1,2}

The personal burden of chronic heart failure (CHF) is great. Patients experience high levels of physical, functional and emotional distress.³ It is often characterized by slow decline, punctuated by episodes of rapid deterioration leading to acute hospital admission.⁴ These episodes may end in death with little warning: up to 50% of people with CHF may die suddenly.⁵ The uncertain trajectory and possibility of sudden death adds to the burden of coping with a major physical disability.

Evidence-based pharmacological therapy for CHF improves prognosis and, to a certain extent, quality of life.⁶ However, for many patients their final months (or even years) are characterized by distressing and poorly controlled symptoms.⁷ They also have a range of other needs that are poorly met.⁸ These include inadequate information about the disease; loss of autonomy and self esteem; poor co-ordination/continuity of care; social isolation and failure to support carers.

There is a growing acknowledgement that palliative and supportive care can play an important role in

improving quality of life for this group of patients and carers.^{6,9} A model of supportive care has been proposed by the National Institute for Clinical Excellence (NICE) in their recently published Guidelines on Supportive and Palliative Care for Adults with Cancer.¹⁰ Supportive care is used as an umbrella term for all services, including palliative care, that may be required to support people and their carers at any stage of the disease (Table 1). NICE suggests that supportive care is not a distinct speciality but the responsibility of all health and social care professionals delivering care.

A recent government report suggests that the principles of the NICE guidelines are broadly applicable to the care of people with conditions other than cancer.¹¹ However, specialist palliative care services in the UK still care predominantly for people with cancer. The services have legitimate concerns about the resource implications of extending care to other patient groups and about whether their skills are relevant and transferable. This paper describes the evolution of joint working between heart failure and specialist palliative care services in Bradford. Our experience leads us to suggest that such a model is effective and sustainable in providing high quality care.

How the Bradford Heart Failure Service evolved

Heart Failure Nurse Specialist Service

In 2002 the Bradford City, North, and South West Primary Care Trusts (PCTs) each appointed a Heart Failure Nurse Specialist (HFNS). Between them, these

Address for correspondence: Andrew Daley, Palliative Care Team, Bradford Royal Infirmary, Duckworth Lane, Bradford BD9 6RJ, UK.

E-mail Andrew.daley@bradfordhospitals.nhs.uk

Table 1 Components of supportive care as recommended in NICE guidelines (2004)

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- Self help and support
 - User involvement
 - Information giving
 - Psychological support
 - Symptom control
 - Social support
 - Rehabilitation
 - Complementary therapies
 - Spiritual support
 - Palliative care
 - End-of-life and bereavement care
-

PCTs care for a largely urban population of 394 000 people, 19% of who describe themselves as of South Asian origin. The posts were pump prime funded by the British Heart Foundation. Their role is to support patients in the community following a hospital admission for heart failure. The primary aims are to improve quality of life and reduce hospital readmission rates through provision of psychosocial support, liaison between health and social care services and optimization of cardiac medication (working to locally agreed protocols). Blue *et al.* have demonstrated that specialist nurses can be effective in achieving these aims.¹² By definition, patients ill enough to require hospital admission for heart failure are likely to have advanced disease and Table 2 confirms that this was the case for most of those referred to the Bradford HFNSs.

The three nurses who were appointed believed that a supportive and palliative care approach was key to both achieving the aim of reducing hospital readmission and to generally improving care. They all had extensive cardiology experience but lacked confidence in providing palliative care. They approached the local specialist palliative care service with a view to gaining the relevant skills.

Specialist palliative care service

The district is fortunate in being served by two hospices, community and hospital palliative care teams and hospice at home teams, which all work in a closely integrated manner. An increasing proportion of their referrals are for non-malignant disease (currently 16%)

and one-third of these are for heart failure. However, in 2002 less than 2% of referrals were for heart failure and palliative care staff felt anxious about caring for people with the disease: it was clear that a two-way learning process was desired. Those parts of the service collaborating with the HFNSs have been primarily:

- Marie Curie hospice comprising 16 beds (330 admissions/year), Day Therapy (200 referrals/year) and outpatient clinics.
- Community palliative care team comprising six clinical nurse specialists, medical consultant, psychology, social work and ethnic liaison professionals (640 referrals/year).

Collaboration and components of care

Shared learning was initially achieved as follows:

- The HFNSs were invited to attend the community palliative care team's regular multidisciplinary team meetings (MDTs). Hearing discussions about cancer patients proved valuable and they were also given the opportunity to discuss their own cases.
- Attendance of the HFNSs at formal educational events organized by the palliative care service and vice versa.
- Practice-based education for primary care staff was delivered jointly by the HFNSs and a palliative care consultant. This allowed discussion of symptom control issues that the HFNSs did not feel competent to facilitate.

The HFNSs adopted the idea of conducting a holistic supportive and palliative care assessment, encouraging the patient to prioritize their problems, identify coping strategies and express preferences for care. The assessor acts as a key worker to personally address the problems if they have the relevant skills and resources, or to co-ordinate provision of support from elsewhere: this is how our hospital and community specialist palliative care nurses work. The heart failure nurses quickly gained confidence in this model. They were keen to act as key workers, continuing to support their patients until death wherever possible. This fitted well with the palliative care

Table 2 Severity of heart failure at time of referral to Bradford HFNS

New York Heart Association (NYHA) Class		Percentage of referrals to Bradford HFNS (n = 491)
NYHA I	No limitations on activity. Asymptomatic.	4
NYHA II	Slight limitation of physical activity. Ordinary activity results in fatigue, dyspnoea, palpitations or angina.	27
NYHA III	Marked limitation of physical activity. Comfortable at rest.	58
NYHA IV	Inability to carry on any activity without discomfort. Symptoms of congestive cardiac failure are present even at rest.	10
Not recorded		1

service's view that they did not have the resources to care directly for large numbers of people with heart failure.

Collaboration over patient care evolved naturally from the conducting of holistic assessments and took various forms:

Advisory care.

- Telephone advice from palliative care consultants about specific symptom problems.
- Joint case discussion at MDTs.

Direct care.

- Joint visiting with a Macmillan nurse.
- Medical assessment at a hospice-based outpatient clinic.
- Hospice admission for symptom control or terminal care.

The pattern of collaboration was consistent with the district referral criteria for specialist palliative care: a referral is accepted for any patient with progressive life-limiting illness who has needs that their professional carers are unable to adequately meet. These generally fall into one or more of the following categories:

- difficult physical symptoms,
- complex emotional/social needs,
- social isolation,
- practical support needed to allow dying at home,
- carers with high risk of bereavement difficulties.

The response to a referral is to either give advice or to make a face-to-face assessment. Following assessment the need for continuing specialist palliative care involvement and the appropriate level of intervention is negotiated with the patient, informal carers and professionals involved.

To our surprise, direct care for heart failure patients was seldom required. Service activity data are presented later in the paper.

Hospice-based Heart Failure Support Group. Like most UK hospices, the Bradford Marie Curie hospice provides a Day Therapy service. This offers multifaceted care which can include assessment, symptom control, monitoring, creative activities, complementary therapies, emotional support, social interaction and respite. Evidence is starting to confirm the major quality-of-life benefits that this kind of service provides, particularly due to its social dimension.^{13–15} The heart failure nurses had witnessed these benefits and were keen to establish something similar for their own patients.

In 2003 successful bids were made to the PCTs and Big Lottery fund to develop care for non-cancer patients. The bids funded a full-time psychologist and a 20% increase in Day Therapy capacity. The psychologist joined the existing psychology service in the hospice and community palliative care team but also had a specific remit to develop care for people with non-malignant disease, including heart failure.

These developments allowed the establishment of a Heart Failure Support Group, which is organized and run by the HFNSs but takes place in the pleasant environment of the hospice day therapy unit. The HFNSs offer attendance to those who are socially isolated, interested in complementary therapies, have carers needing respite or who are starting to struggle with symptoms. Just under half the patients referred to them are offered attendance. The programme has a number of components:

- An opportunity for social interaction between patients and carers.
- Regular, informal emotional support from the psychologist.
- Access to individual consultation with heart failure and palliative care nurses, psychologist, benefits advisor or palliative care consultant as necessary.
- Multidisciplinary programme of education talks covering the disease process, medication, nutrition, psychological wellbeing, benefits advice and how to exercise.
- Complementary therapies including reflexology and acupuncture.
- Regular group relaxation session led by the psychologist.

The Support Group is run as a two-hour session on a fortnightly basis, exclusively for heart failure patients and their carers. The rolling education programme is repeated every three months. Volunteer transport is available for those patients who need it. Patients with greater needs may also attend the normal Day Therapy service for a full day spent alongside cancer patients and those with other non-malignant diagnoses.

Data collection methods

The HFNS and palliative care service perform continuous data collection, audit and evaluation, which are used to inform the NHS commissioners and charities involved in funding them. The palliative care services use a shared electronic clinical record system, which allows centralized reporting of activity data across the district. The HFNSs record key information on a database and, for this study, supplemented this with data from the patients' paper records.

Qualitative data on patients' experiences of the support group were available from interviews conducted by one of the authors as part of a Masters Degree research project.¹⁶ The research explored the wider subject of the experiences of older adults with CHF. This was in order to gain a deeper understanding of their palliative and supportive needs and the value of possible interventions, including their experiences at the Support Group. The full research will be reported in a separate paper but the methodology is briefly summarized here. The study design was qualitative, using a grounded theory approach to data collection and analysis. Interviews were audiotaped and transcripts were analysed using constant comparative analysis. Local NHS Research Ethics Committee approval was obtained.

Initially patients who had been or were still under the care of an HFNS and who had attended/were attending the support group were eligible for the study. They were approached collectively at the group (or by post for those not attending anymore) to reduce potential feelings of coercion due to the role of the researcher as an HFNS involved with the group. They were given the patient information sheet to consider and facility was made to reply by post, rather than directly to the researcher. The voluntary nature of participation, as well as assurances that care would not be affected by participation, non-participation or withdrawal was stressed in both verbal and written form. As is the case in grounded theory, initial data collection and analysis guided further sampling and, from a pool of 15 willing participants, 10 patients aged 80 years or older were sampled based on emerging themes associated with older age and coping. Five patients chose to be interviewed with their spouse or carer and five were interviewed alone. Interviews were conducted in patients' own homes where the balance of power is more equal and comfort can be more easily attained given the frail nature of the participants.

Outcomes

Service data

Referral demographics. A total of 491 patients were referred to the HFNS service from its start in November 2002 until March 2005. The rate of referral has remained stable except for a slight increase in winter and spring months, as might be expected. The numbers referred were: 206 in Year 1; 196 in Year 2; 109 in Year 3 (first six months).

Information relating to the demography of the heart failure patients is shown in Table 3, together with comparative data for all patients (including those with cancer and other non-malignant diseases) referred to the community palliative care team during the same period.

Table 3 Demography of HFNS and specialist palliative care referrals

	HFNS referrals (n=491)	Community palliative care team referrals (n=1500)
Age (years)		
Mean age on referral	76	71
Age range	27–95	19–97
Gender (%)		
Male	59	49
Female	41	51
Ethnicity (%)		
White British	78	93
Asian	16	5
Eastern European	3	1
Other European	2	<1
Black Caribbean		<1

Care from specialist palliative care services. Only 17% of the HFNS patients attended the Support Group or were referred on for direct care from the specialist palliative care service. Details of this care are presented in Table 4.

There are approximately 800 Support Group attendances each year (93% by patients, 7% by relatives). This equates to a notional cost of £47 per attendance (ie, the cost of general staffing, transport and hospice overheads). This figure does not include the psychologist's time devoted to heart failure patients (estimated at eight hours per week, including home visits when necessary).

Six patients had seven hospice admissions, four of which ended in death. These represent 1.1% of all hospice admissions during the period and accounted for 80 occupied bed days (0.9% of total used). The average length of stay for heart failure patients was 11 days, compared with 15 days for all admissions during the period.

Table 4 Number of patients attending support group and/or requiring specialist palliative care services

Total number of patients referred to HFNS service (Nov 2002–Mar 2005)	491
Total number of patients (% of HFNS referrals) attending Support Group and/or requiring a palliative care service	85 (17%)
Number attending the Support Group	46 (9%)
Number requiring a specialist palliative care service (± Support Group)	51 (10%)
Specialist palliative care services required (% of HFNS referrals)	
Day Therapy	17 (3%)
Psychology (individual therapy)	15 (3%)
Palliative care consultant	14 (3%)
Hospice at Home team (practical nursing when prognosis only weeks)	13 (3%)
Community palliative care nurse (joint visits)	10 (2%)
Hospice inpatient care	6 (1%)

Table 5 Place of death

	Percentage of referrals to HFNS (n = 118)	Percentage of referrals to community palliative care team (n = 998)
Hospital	58	18
Home	28	35
Other (including care home, community hospital, overseas, unknown)	11	13
Hospice	3	34

Place and timing of death. To date, 24% of patients referred to the HFNS service have died. Their place of death is shown in Table 5. As a comparison, the table also presents place of death data for all patients (including those with cancer and other non-malignant diseases) who were referred to the community palliative care team during the same period.

The length of time from HFNS referral until death ranged from 2 days to 23 months, with a mean of 5.3 months. The distribution is shown in Figure 1 alongside comparative data for all patients (including those with cancer and other non-malignant diseases) cared for by the community palliative care team during the period. The distribution for the two services is surprisingly similar.

Figure 2 compares the time from referral for hospice Day Therapy until death/discharge for heart failure and cancer patients. The results reflect the differing trajectories of the two diseases with prolonged attendance occurring more often for patients with heart failure. It is also notable that 50% of heart failure referrals ended in discharge ($n=17$) compared with only 19% of cancer referrals ($n=134$).

Qualitative data on benefits of the Support Group

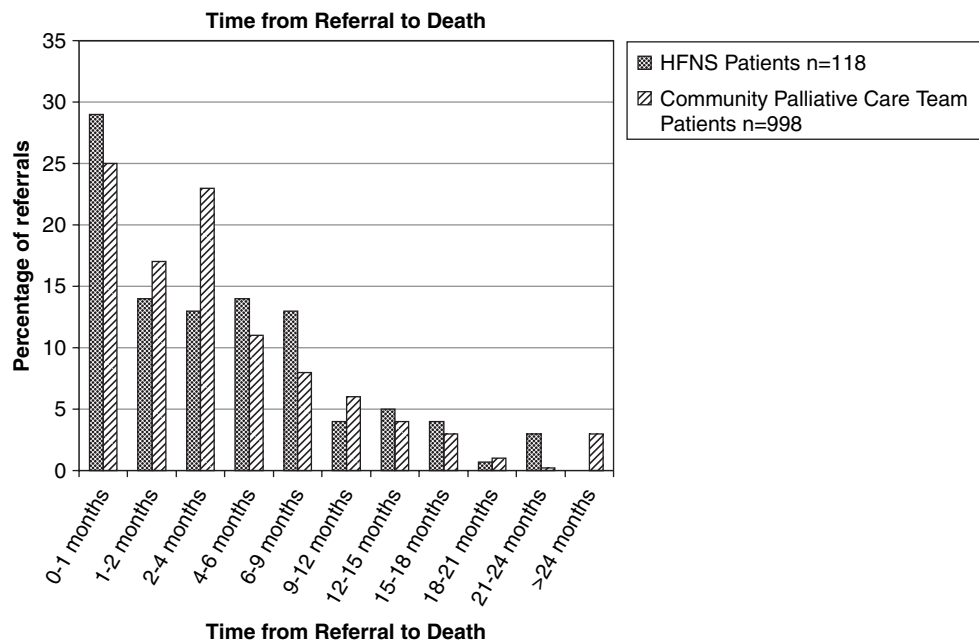
Characteristics of the interview participants are summarized in Table 6. Attendance at the group was cited as beneficial in helping patients cope in a number of key areas. Quotes from the patients illustrate these well:

Physical, psychological and social isolation.

Well I'm getting older now, as you know, and you feel your mind's not as strong as it should be. Just stuck here on your own if you don't go anywhere like that (ie, the Group) you deteriorate, you're forced to do.

The Group is an interest that gets me out of just ordinary routine, or being penned up and getting sorry for myself.

It was more a question of being with a group which is in the same boat as you are. My spouse doesn't come into this as I think it's a help to be able to talk to people who've got the same problems.

**Figure 1** Time from referral to death.

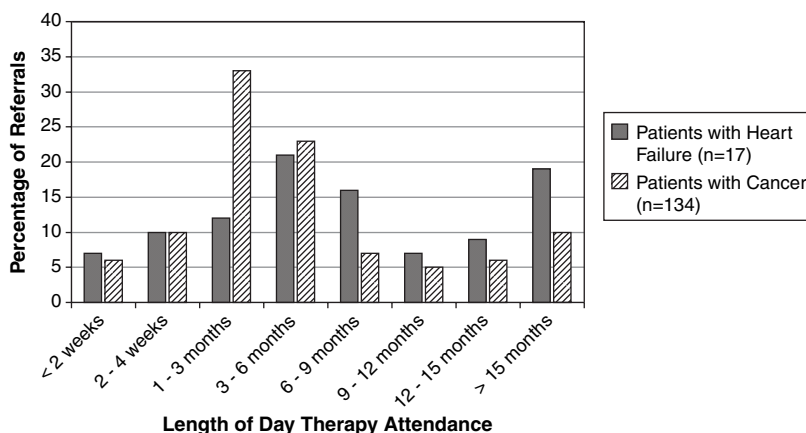


Figure 2 Length of day therapy attendance for heart failure and cancer patients.

You're among people aren't you? I mean when you come back home here you shut the door and you're on your own.

Loss of self-esteem and self-worth.

Everybody seemed to have time for you. . . you know in the back of your mind they're all so busy. There's so

much to do these days with elderly people and you sort of talk to somebody and think you're taking up their time but you didn't get that at the Group did you?

I was getting a bit depressed at that time. I felt that I needed something to help me I think.

This time last year I wouldn't have sat and talked to you like this. I would have just said 'oh, I'm too poorly I can't be bothered'.

Table 6 Characteristics of interview participants

Characteristic	Number of interview participants (n = 10)
Age (years)	Range: 80–90 Mean: 83 Median: 81.5
Gender	
Male	5
Female	5
Marital status	
Married	4
Widowed	6
Living situation	
Live alone	5
Live with spouse	4
Live with family	1
NYHA Class	
II	2
III	4
IV	4
Length of time with heart failure	Range: 10 months–3 years Mean: 21.8 months Median: 18 months
Number of co-morbidities	
1	2
2	2
3	5
>3	1
Number of attendances at support group	Range: 5–19 Mean: 11 Median: 12

The support of the psychologist appeared to have been valuable to many of the participants. They felt they could talk about their concerns confidentially but also valued the group relaxation sessions. One described how the session had enabled her to 'swim' again (in her imagination):

The psychologist talked about 'where would you fancy being?' and at that time I must have gone out, and well, I didn't go anywhere else. I went to the swimming pool and I had the time of me life. I had a good swim and a shower, and I'd gone off to sleep and that's what was on me mind. I just miss the pool so much.

Learning coping skills. One participant who suffered with insomnia described the relaxation skills "...like another thing to use when I go to bed". Three participants explained that the Support Group environment enabled them to do some exercise in the form of walking which they were unable to do otherwise.

Monitoring and reassurance. Most participants needed to know that their heart failure was being monitored and that someone would notice if things weren't right. One described how he felt no one 'in authority' was overseeing him, which caused him concern, but by coming to the group '... you knew that somebody was there to look after you... you're in "no worry depot" there you see.'

Generating hope and purpose.

It gives me a willingness to carry on. That's what it does do. Oh yes.

One participant had found a willing audience for his poetry:

Well it's made me feel a little bit, as far as they're concerned, you could tell by me poems if you like it's made me feel I belong a little bit.

Oh yes . . . the feeling that people with this condition are worth bothering about you know. Going to the trouble of getting a group together.

People gained strength from seeing other people with heart failure, often perceived as being worse than they were, who appeared to be coping:

Well I think it gives you a sense of continuing. That your life is still important and it's worth something. And you learn about the characters of people and how they attack it and how they make their lives worth while.

Because I think about it and I think, well, all these other people have got the same problem and there's nobody moaning, they're all cheerful whereas you probably wouldn't be if you weren't going anywhere. So I look forward to it. I'd go every week.

Transport. Volunteer transport is a vital element to the success of the Support Group, with 37 patients (80%) being reliant on it. Many positive comments about the care, consideration and pleasant disposition of the volunteer drivers emerged in the qualitative interviews. A small number of patients who were wheelchair or oxygen dependent were brought by ambulance, funded by the NHS.

Discussion

Level of specialist palliative care support needed

Our experience shows that community-based HFNSs can function as effective key workers, providing support throughout the illness and maintaining continuity of care. Use of a standardized, formal assessment of patients' problems, coping strategies, values and care preferences has proved crucial to this – as has easy access to support from the specialist palliative care service.

In our experience, few patients have needed direct care from the specialist palliative care service. The only additional costs directly incurred by the palliative care service in collaborating over heart failure care are those for the Support Group (£37.5k pa) and regular psychologist input (eight hours per week).

In particular, there has been little demand for hospice beds. This is the finite resource that services most fear may become swamped if non-cancer care becomes a significant part of their workload. Whilst the home death rate for heart failure patients was similar to that for the palliative care team's patients (predominantly having cancer diagnoses), the hospital death rate was dramatically higher for people with heart failure. Given that the HFNSs were aware of the possibility of hospice admission and that they often complete handover forms for out-of-hours services, we suspect that this is a reflection of the differing disease trajectories. Unpredictable crises commonly occur in heart failure and many patients and their professionals continue to opt for hospital admission in the hope that an acute deterioration might be reversible.

Competency in managing heart failure is the other issue that frequently concerns specialist palliative care professionals. However, mutual respect and a willingness to admit to areas of ignorance resulted in palliative care staff feeling well supported and necessary skills were rapidly acquired. The HFNSs work to detailed protocols for adjustment of medication. These have been agreed with the local cardiologists, who are happy to be telephoned for advice by either the HFNSs or palliative care service. Staff in the hospice inpatient unit have grown in experience and confidence in using parenteral diuretics and monitoring fluid balance. Our recent impression is that the number of patients admitted to the hospice rather than hospital with acute deterioration may therefore be going to increase somewhat. This is the subject of ongoing monitoring.

Support Group

Previous studies have described the value of support groups following myocardial infarction, cancer and other areas of chronic disease.^{18–23} The patients and carers attending our Support Group clearly find it very helpful. However, many others who are offered attendance (particularly younger patients) choose not to attend. This may be because they have adequate social support, are pursuing aggressive treatment options or because their coping strategies are not compatible with Support Group membership eg, 'not thinking about the illness'.²⁴ Interestingly, the fact that the group meets in a hospice setting has never been cited as a reason for patients declining to attend.

Asian community

The Bradford Asian community is a young population (only 6.6% aged 65 or over, compared with 22% of the white community). It currently has a high prevalence of heart disease and a low prevalence of cancer. The proportion of HFNS referrals who are Asian (16%) is similar to their proportion in the whole community

(19%), suggesting that the service is culturally acceptable to them. The low proportion of specialist palliative care referrals from the Asian community reflects the fact that 84% of the service's referrals are for cancer. Death certificate data strongly suggest that the palliative care service sees at least as high a proportion of Asian patients with cancer as white patients (ie, >80% of all those with advanced cancer). Many Asian people with heart failure value home-based support from the HFNSs but few of them have attended the Support Group. Many have limited English language skills and it has not yet been possible to organize alternative language support for the group. The fact that the group has to meet on a Friday may also be a factor for some who normally attend a mosque for prayers on that day of the week.

Length of involvement in care

NYHA stage IV disease is often quoted as having a 12-month survival rate as low as 50%. Many patients referred to our HFNSs have lived considerably longer than this. Some were referred relatively early in their illness (31% were NYHA I or II at referral) but it may also reflect the fact that patients receive optimization of their cardiac drugs and high quality supportive care. Either way, it means that the number attending the Support Group has been gradually increasing, such that the group is now run weekly with two separate cohorts of patients. Staff have been reluctant to consider discharge when patients are benefiting from attendance but this issue may need to be addressed with those who have relatively stable disease. Similarly, the appropriateness of continuing attendance for those referred to Day Therapy needs to be kept under close review. It is notable that a greater proportion of heart failure than cancer patients are discharged from Day Therapy.

Future developments

New concepts of palliative care are emerging in which supportive care is offered alongside active treatment throughout the course of serious chronic illness, possibly over many years.⁴ This would seem to be an appropriate model for people living with CHF.

The West Yorkshire Cardiac Network has recently drafted guidelines for minimum standards of care that include a six-monthly review of all heart failure patients.¹⁷ Partly as a result of our experience in Bradford, the guidelines state that at each review it should be considered whether an assessment of supportive and palliative care needs has become appropriate. Triggers for this would be one or more of the following:

- A negative answer to the question 'Would it be a surprise if this person died within the next 12 months?'

- NYHA stage III/IV disease.
- A hospital admission arising from worsening symptoms of existing heart failure.
- Poor response to treatment.
- Rapidly worsening quality of life.

Each PCT is asked to identify appropriate individuals to conduct such assessments and to co-ordinate care thereafter. Clearly, in our own area, the HFNSs are those individuals. The elements of support provided should be based on an assessment of individual problems and coping resources. Existing specialist palliative care services are unlikely to be able to provide all the necessary support but our experience demonstrates that they can do so effectively in partnership with key workers such as HFNSs. A hospice-based support group can form one element of care and enhance the coping resources of patients and carers.

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