Role of the British Heart Foundation heart failure palliative care specialist nurse

A retrospective evaluation
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Chapter 1  Introduction

In 2006, the British Heart Foundation (BHF) invited health trusts and health boards across the UK to tender bids for innovative posts to manage cardiac patients. Eight trusts were successful in securing funding for a total of nine (8 WTE) heart failure palliative care specialist nurses (HFPCSNs) in Scotland and England for a three year period. These posts were established in response to the increasing recognition of unmet palliative and end of life care needs among patients with advanced heart failure, and those close to them. These needs had been highlighted by the BHF’s own heart failure nurses as well as in the wider academic literature (Rogers et al 2000, Hanratty 2002).

The posts were established on an individual basis between 2006 and 2009. Each post was set up in response to local healthcare settings, economies and concerns. The posts reflected a variety of ways of working, with some nurses working exclusively in acute or community based healthcare settings, and others operating in both settings or at the interface of care. In all but three of the posts, nurses had an active caseload and most combined this to a lesser or greater extent with formal and informal teaching and education for patients, carers and professional colleagues. In one site, the nurse acted in a purely advisory capacity, running two pilot projects of different nurse led interventions for patients with advanced heart failure.

This report provides a detailed process and outcome evaluation of these nine innovative posts, highlighting the impact of these posts on the care of patients with advanced heart failure in a variety of settings.
Chapter 2 Evaluation

2.1 Evaluation design and methods

2.1.1 Introduction
The evaluation was designed in response to an Evaluation Brief developed by the British Heart Foundation (BHF) and Marie Curie Cancer Care (MCCC) as part of the Caring Together Programme. Caring Together aims to develop an improved approach to management of palliative care for patients in the advanced stages of heart failure and their carers. The brief invited external evaluators to undertake an evaluation of the effectiveness of nine BHF (HFPCSNs). The evaluation was funded by the Caring Together programme.

2.1.2 Evaluation design
The evaluation was designed to focus on both the process and outcomes associated with each of the eight HFPCSN sites. The evaluation has two main aims:

1. To produce a detailed model or model(s) of the ways in which the HFPCSNs work, and their impact on local health and social care.
2. To detail the experiences of the HFPCSNs themselves and the impact of these posts on patients, carers, clinicians and other stakeholders.

The evaluation has two main outcomes:

1. A definition of a basic model for HFPCSN working:
Data to address this outcome was collected at a focus group of all nine HFPCSNs, process mapping for each of the pilot sites and analysis of routinely collected data. This data was supplemented with data from individual telephone interviews with each nurse.

2. The impact of the HFPCSN model on patients, carers, clinicians and other stakeholders:
Data to address this outcome was gathered from telephone interviews with stakeholders identified by each of the nine nurses. Information provided by nurses included written cases studies of two of their patients and nurse-led interviews with patients and carers.

The evaluation used a case study approach, a method particularly appropriate for the study of contemporary phenomena, which may be subject to unpredicted changes or have unexpected outcomes or consequences. A case study allows for data from a number of different sources to be incorporated in the description of a phenomenon, and for the triangulation of findings between various sources of data (Yin 2003).
2.1.3 Evaluation methods
The evaluation included five main sources of data collection, which are grouped below according to relevance to the evaluation aims:

2.1.3.1 HFPCSN experience
Focus group with BHF HFPCSNs:
A focus group was held at a planned meeting of all nine HFPCSNs in early November 2009. The focus group aimed to elicit information about barriers and facilitators faced by each of the nurses and the key elements of their working day. This included information about end of life decision making, use of standard tools, details of symptom management and areas of success and disappointment. The focus group was audio recorded and detailed notes were taken. The audio recording was transcribed and data was entered onto a coding framework that allowed both anticipated and emergent categories to be developed and included in the analysis (Ritchie and Spencer 1994).

Patient case histories:
Each nurse was asked to write two short patient case histories. One case study should illustrate a scenario in which they felt they had made a significant positive impact on patient care, and one in which they felt care could have been improved. The case histories were read and re-read and then coded directly onto a coding framework, allowing both anticipated and emergent themes to be developed and included in the final analysis.

Service descriptions and process mapping:
Prior to the focus group, the nurses were asked to complete a template for a process map in order to provide details of how patients are referred to them and where and how their service works in relation to the local health economy, including third sector or voluntary services (Appendix 1).

2.1.3.2 Stakeholder experience
Telephone interviews with local healthcare professional stakeholders:
Each nurse was asked to provide the names and contact details of two health or social care professionals they work with who would be willing to take part in a telephone interview about their experiences of working with a HFPCSN. These interviews were audio recorded, with the participants consent, and data was coded directly onto a coding framework that allowed both anticipated and emergent categories to be developed and included in the final analysis (Ritchie and Spencer 1994).

Interviews with patients or carers:
Each nurse was asked to undertake a short structured interview with two patients or carers from their current case load. These interviews aimed to collect basic demographic information about interviewees, as well as asking questions about the ways in which the HFPCSN had been helpful and ways in which their care might have been improved.

2.1.3.3 Additional data sources
Telephone interviews:
Telephone interviews with each HFPCSN were undertaken to clarify information gathered about their role.

Data collection:
Routinely collected data for each nurse was collated and analysed to provide further information relating to the HFPCSN role and its impact.
2.1.4 Analysis

In the first instance, the data collected for each HFPCSN was analysed using a constant comparative approach (Strauss and Corbin 1990), in which data relating to each HFPCSN was compared with all others to highlight situations or instances in which personal, organisational or external factors influenced the development and impact of the HFPCSN.

The data from each of the data sets was then combined into eight discrete case studies representing the eight HFPCSN pilot sites. Once the case studies were constructed, each case was compared with all the other cases to further investigate and develop a distinct model, or models, of working.
Chapter 3 Heart failure palliative care specialist nurse (HFPCSN) experiences

3.1 Focus group with BHF HFPCSNs

“I worked as a heart failure nurse but in a generic role, (and) found I didn’t have the time or the capacity to really provide good end of life care. When the job came up I was keen to take it on; I was passionate about filling those gaps. I could really see that we weren’t doing a good enough job within the generic role.”

3.1.1 Introduction

We needed to include information from the HFPCSNs themselves in the evaluation. As the pilot sites covered a wide geographic area, including sites in both Scotland and England, we decided to ask the nurses to take part in a focus group to discuss their roles. Recognising that each of the HFPCSNs were working in slightly different ways, a focus group would allow all the nurses to take part in a reflective discussion about their experiences of working as a HFPCSN, and to be able to compare their experiences with those of their peers. The focus group aimed to identify what the nurses felt were the key elements of their job, as well as facilitators and barriers to providing a successful and effective service.

3.1.2 Methods

The focus group was held in London as part of a scheduled regular meeting of all the HFPCSNs. The focus group was run by an independent researcher who used a topic guide to ensure key areas of interest were addressed by the group, but also allowed additional topics that arose during the focus group to be discussed in detail. The focus group was audio recorded with the nurses’ consent, and lasted for just over forty minutes.

3.1.3 Analysis

The audio recording of the focus group was transcribed. This data was entered into a coding framework that initially reflected the topic guide used for the group discussion. New codes were added as new areas emerged from the data. Due to difficulties in establishing exactly which nurse was speaking on the audio recording, it was difficult to accurately attribute much of this data to particular individuals, and thus to analyse them individually. As such, each category of comment was compared to all others to look for potential areas of triangulation or confirmation of results.

3.1.4 Results

Seven of the nine HFPCSNs were able to attend the focus group, representing six different localities. All the nurses took an active role in the focus group, with no individual appearing to dominate the group and everyone appearing to engage in the discussion. The data from the focus group is presented here under four key headings reflecting those used in the topic guide: choosing to become a heart failure palliative care specialist nurse; main tasks and greatest areas of impact; challenges and blocks to everyday working; and what would you have done differently?

3.1.4.1 Choosing to become a heart failure palliative care specialist nurse

All seven nurses present at the focus group answered the question regarding why they had chosen to take the post of HFPCSN. The nurses were unanimous in responding that previous experience of working
in either cardiology or palliative care had highlighted the need for dedicated end of life care for patients with chronic heart failure. Personal experiences had also influenced some of the nurses’ decisions:

“My background had always been oncology and palliative care but I had always been interested in heart failure problems from a personal experience because my father died quite young from that, and I’ve actually seen what the cancer population can get in comparison to people with heart disease or other non-malignant diseases get.”

Some nurses felt that the HFPCSN post gave them an opportunity to combine previous experience in palliative care and cardiology:

“I was interested in palliative care when I was working in coronary care, but the cardiac patients were not treated palliatively. I did a palliative care degree and heart failure came along later and I got the job (that) was putting those things together really.”

For others, the new post gave them the opportunity to concentrate in one area of care and/or develop clinical expertise:

“It’s something I’m passionate about, it was good to have cardiology palliative care rather than specialist palliative care and trying to cover it all as I was working as a single handed practitioner before in heart failure, oncology, MND, MS so dealing with a lot of different patient groups. So it was nice to concentrate on one specific patient group and also to get some clinical experience.”

Nurses with a background in cardiology reported that they had come to see the importance of palliative care only after they had come into contact with patients with heart failure:

“I came from a background in cardiology, it was very interventionist, looking at patients doing their obs and then in cardiac rehab. I never thought I’d be interested in palliative care until I saw heart failure patients and that’s what made me realise that it was probably as important as all the interventionist things we had if not more important.”

A number of nurses spoke of having a passion, or being passionate about, improving the care offered to patients with chronic heart failure, and some spoke as though this was a vocational role for them rather than just another nursing post:

“I was passionate about improving the care of patients and carers; I had identified that there were huge gaps in care.”

Nurses reflected on the apparent reluctance of many healthcare professionals working in cardiology to acknowledge and/or address the end of life care needs of patients with chronic heart failure. The HFPCSNs reported that there was often a reluctance among cardiologists, and cardiology in general, to be involved in end of life or palliative care, with these healthcare professionals often feeling they had “given up on patients” if they referred them to palliative care. Switching from a role aimed primarily at getting patients better, to one that aimed to help patients make the most of their lives, was reported as being difficult for many practitioners in this area, including at least one of the HFPCSNs:

“One of the hardest things I find in going from a general role to a palliative role is having to say I can’t make it better. I was used to making it better rather than the philosophy of living with this. It’s a very different philosophy.”

More specifically, the HFPCSNs felt that many healthcare professionals working within cardiology in general, and in chronic heart failure in particular, had a very disease focussed approach to caring for patients:
“I get told that the patient is fine from a heart failure view. They have got them optimised; they have done what they can do for them from a cardiology perspective, so it’s very much task orientated – what’s your weight?, what’s your blood pressure? Everything else around about that task.”

Many felt that this disease focus tended to preclude the more holistic assessments typical of a palliative care approach. Nurses in the focus group also argued that many healthcare professionals were reluctant to address heart failure patients more holistic needs because they were afraid of being unable to meet uncovered needs. They also had feelings of discomfort that perhaps resulted from lack of expertise to address issues raised by such assessments:

“Part of that is fear about not being able to provide the correct support for the patient. I think there is a lot of fear particularly from cardiologists that they are not doing their best for the patient if they give them palliative care; you have to keep treating them if you care.”

“When you do a holistic assessment, you unpick or uncover a whole lot of emotional and psychological issues which have never really been attended to.”

“You get a certain type of nurse; you get the certain type of personality that you are, and I think a lot of heart failure nurses are disease focused and that is what they want to focus on. And the psychosocial, all the softer bits, that’s what they don’t feel comfortable with.”

Time, or lack of time, was seen as a key constraint on the generalist in cardiology and heart failure providing quality end of life or palliative care assessments and/or care, even when the healthcare professionals themselves felt capable and wanted to provide such care:

“Time is an issue. Time constraints are issues for some heart failure colleagues engaging with the palliative care approach and I think that they have competing priorities between home visits and clinics.”

“I’m not going to drop something to go and deal with this which is what a lot of us do. It’s having the flexibility on the day, that freedom; it’s difficult when you have got other clinical commitments.”

The HFPCSNs also felt that cardiologists and other heart failure nurses found it difficult to prognosticate for patients with heart failure. As one nurse put it: “I think for some nurses it’s hard for them to identify when to say that’s enough for the patient”. For one of the nurses, time or spending an excess of time with a particular patient was seen as one way her colleagues acknowledged the patient should be considered palliative:

“I am part of a community and acute team who look after the NYHA I – III patients and I have the class IV. The problem is at what point do they refer? It’s often when they say: ‘It’s getting too much; I am spending too much time with them’.”

In this way, spending an ‘excess’ of time with a patient acted as a proxy for prognostication.

Despite reporting that other colleagues were often reluctant to address the palliative or end of life care needs of patients with heart failure, some of the nurses in the focus group acknowledged that non-specialist colleagues were also sometimes reluctant to hand over palliative patients, fearing they would lose their skills in caring for patients at this stage in their illness. Some of the nurses felt, however, that notwithstanding the risk of becoming de-skilled, there was not necessarily the commitment or indeed the skills amongst the current heart failure nurse workforce to deliver holistic palliative care to their patients:

“Heart failure nurses don’t want to lose the palliative patients because they see it as becoming de-skilled and they see this group of patients often can be more interesting than your standard heart failure patient so I think there is an element of not wanting to become de-skilled. But the flip side of that is they often don’t want to take on the effort and time that is involved in managing these patients properly; you can’t half do it; you can’t want the patient because you want the experience and seeing the complex patient management and then say I haven’t got the time.”
“Sometimes I have been told that a lot of problems heart failure patients have at the end of life are not heart failure specific, so they are very generalised palliative care symptoms. And it’s sometimes feeling well that’s not our problem now because it’s not heart failure. It’s trying to explain that if you are taking on a palliative care role then it’s all of the issues that are a problem; you can’t say well they are constipated, they need to go to specialist palliative care; you should be taking it on and dealing with it.”

3.1.4.2 Main tasks and greatest areas of impact

The HFPCSNs reported that offering practical advice for everyday living, or improving everyday life, was their key area of impact:

“Practical things you can bring, a whole assessment in terms of getting them to the appropriate people, social worker, benefits advice, specialist palliative care day services, that kind of thing, a wheel chair that just improve everyday living.”

Time or having the time to sit and listen to patients was also seen as a key area of work for all the nurses:

“That is what I am told quite frequently; you sit and listen and the doctor doesn’t have time; the doctor never listens but you will sit down and listen to what I am saying.”

One nurse cited helping patients stay out of hospital was her main area of impact, and that this had often been achieved through the provision of home oxygen:

“They keep waking up breathless at three o’clock in the morning as they have been for years, they call an ambulance. The oxygen prevents the 999 call; the oxygen might not be what they need clinically, but it does stop the 999 call.”

When asked specifically about which symptoms they addressed, the HFPCSNs reported that dry mouth and itching were those they most commonly addressed and that these had often not been adequately managed by other healthcare professionals. They also reported that bowel care, fatigue, anxiety often resulting from breathlessness, depression or low mood, general pain from co-morbid conditions and oedema were also common presenting problems. The nurses also identified ‘total pain’ as a common problem, which the nurses felt often resulted from a patient’s lack of understanding of their condition:

“Total pain and that’s where the feeling of loss and isolation sometimes it stems back to when they were first diagnosed; they are not told it’s a long-term problem, and when you go in they are still thinking you will get them better.”

3.1.4.3 Challenges and blocks to everyday working

The HFPCSNs reported a number of challenges to their everyday working. These challenges appeared to particularly reflect local working practices and local health economies. Their responses were therefore often more specific to their local context than the issues raised in response to other questions asked at the focus group.

Reported challenges included difficulties in getting appropriate and timely social care packages for their patients, lack of 24/7 support for people living or wishing to die at home, and politics (both national and local). Some nurses were unable to access home oxygen for patients. Others reported that both patients and healthcare professionals had unrealistic expectations of what they would be able to achieve in terms of admission avoidance and symptom control without the availability of appropriate community based services.

More general challenges related to working with hospices and establishing that heart failure patients have recognisable palliative care needs. In one hospice, while the senior nurses were happy to accept heart failure patients, other junior nurses seemed more reluctant to take on these patients. Another hospice
was willing to accept heart failure patients, but required a great deal of reassurance about managing their needs. The use of oxygen, policies on resuscitation, the use of medication and the extent to which patients could take part in exercise classes were all identified as areas of concern for hospices providing care for patients with heart failure.

Possibly, the most significant challenge in terms of establishing a palliative care service for heart failure patients was the lack of support from local cardiologists and senior members of local PCTs. Nurses felt that without this support, their service was unlikely or indeed unable to achieve its aims. One nurse reported that as one local cardiologist “did not acknowledge palliative care”, it had proved impossible to work with them and they had to work with other colleagues. Lack of support from the PCT had resulted in at least one case for a HFPCSN feeling that she would need to work “ridiculous hours” to ‘prove’ their post was worth keeping.

Nurses were asked if there were any significant blocks to them achieving what they wished to achieve in their role. Few nurses raised blocks to everyday working that had not been raised as challenges; however, the lack of time and having to spend seemingly undue amounts of time on administration and letter writing were identified as significant blocks. Some nurses felt there needed to be greater clarity over what specialist nurses should be doing with their time. As one nurse stated:

“There needs to be some reflection on the specialist nurse role and what aspects of their days work are concentrated on that specialist role, and what aspects are concentrated on administration which could quite clearly be done by someone else.”

3.1.4.4 What would you have done differently?

Not every nurse answered this question. Those who did reported they would have spent more time setting up or establishing their service before taking on an active caseload. Those nurses whose role was similar to the one they had held previously, or who had changed roles locally, felt they would have spent more time defining their new role to both themselves and to their colleagues.

Other nurses would have spent more time establishing a good working relationship with local cardiologists, or sought help from other sources to help champion the service locally. While some nurses reported spending three months setting up their services, most, on reflection, felt that a six month lead time would have been more appropriate.

It is important to note that at the end of the focus group all the nurses reported that they would like to stay in post when their initial funding came to an end in March 2010.

3.1.5 Discussion

The nurses taking part in the focus group were passionate about their BHF HFPCSN posts. All had been attracted to these posts because past experience working in either cardiology or specialist palliative care had highlighted the need for care, which focused on the palliative and/or end of life care needs of patients with heart failure. Some nurses reflected on the inequity of palliative care services for patients with non-malignant conditions compared to those with cancer. Others recognised that traditional cardiology services were unlikely to address the more holistic needs of heart failure patients and their families.

The nurses felt they were able to impact in both practical and clinical ways to improve patients’ quality of life. On referral, some patients were found to have unresolved symptoms, including dry mouth and itchy skin, which had not been successfully addressed by other healthcare professionals. The HFPCSNs felt that their specialist role allowed them the time to address patients’ needs in a more holistic way.
The nurses highlighted the importance of support, especially from local cardiologists and cardiology teams, but also from hospices and their staff. They also felt that their services needed to be recognised as important to local healthcare commissioners if they were going to be funded beyond their initial pilot phase. In practice, this meant that line managers and others had to be able and willing to champion the service through local PCT bureaucracies.

Discussion between the HFPCSNs underlined regional variations in practice that resulted in different levels and types of care being available to patients. This was especially true with regard to home-based interventions, such as oxygen and 24/7 nursing support. The HFPCSNs were only able to function within the limits of available services. This highlighted the varying degree to which the nurses could impact on admission avoidance, and enable people to die at home; consequently, there were notable disparities in the services being offered to patients and their families within the different pilots.

3.2 Patient case histories

“I felt that this was a very successful outcome and a good example of how my role could work. By developing a service which gave me the flexibility in my time to take on patients at short notice, provide crisis management as well as regular reviews, I felt I was providing an additional service to what I could as a generic heart failure nurse. I do not feel that I would have had such a successful outcome within the constraints of a generic role and additional responsibilities of fixed clinics and inpatient workload.”

3.2.1 Introduction

It was essential to know more about the everyday details of the HFPCSNs work and the ways in which they had an impact on individual patient care. We asked each nurse to write two patient case studies. The first case should illustrate a case in which they thought their intervention was as positive as it could be in the circumstances. The second case should reflect one in which the HFPCSN felt they had not achieved as much as they had hoped to for a patient or their family.

3.2.2 Methods

Each nurse was asked to write two case studies as described above. They were asked not to include any identifiable information about the patient or other individuals included in the case study. They were not given any other guidance on writing the studies, as we wanted the nurses to write in a way that felt comfortable to them and to feel able to discuss cases frankly, especially those in which they felt more could have been achieved.

3.2.3 Analysis

The case studies were read and re-read by the researcher. A coding frame was developed from these initial readings, and this was applied to each case study. Emergent codes and themes were added to the coding frame as they arose, and these were then applied to all other histories using a constant comparative method. In only three cases the HFPCSN indicated that the case study represented either a successful or less successful intervention. As such, the researcher analysed these three cases in the first instance, and using information from this analysis sought to assign the remaining case studies into the two categories. The resulting allocation yielded a total of six successful and ten less successful cases.
Chapter 3 Heart failure palliative care specialist nurse (HFPCSN) experiences

3.2.4 Results

The nurses returned 18 case histories to the researcher; two each from six pilot sites and three from two pilot sites. In the latter two instances, two cases histories were chosen at random to avoid giving undue representation to any particular pilot or model of service delivery.

As expected, the case histories were written in many different ways with some including a large amount of clinical information and specific details of interventions given or made, while others were more narrative in approach and provided a summary of events. The case histories varied in length from a less than one typed page to over three pages.

3.2.4.1 Successful cases

Successful or positive case histories were likely to include a number of common factors. These included examples of good communication, effective symptom management, a supportive family, partnership working, implementation of National End of Life tools and, in all but one case, a home death. These positive factors are well summarised in the case history presented below:

“A 69 year old lady was admitted to a ward with severe heart failure symptoms. She was known to acute and community based heart failure clinical nurse specialists, and had had several admissions over the previous year for LVSD; she had an ICD in place. When I arrived on the ward, I was told that a doctor (not the patient’s usual consultant) had written up a DNR without consulting the patient or her daughter. I visited the patient and found her physically, psychologically and socially distressed:

- Physically – very facially drawn, pale cachexic, features of someone in their last days of life;
- Psychologically – very withdrawn and not wishing to interact with me or her daughter;
- Socially – in a busy four bedded ward, disturbed by lights and sounds around her.

I advised the nursing and medical staff of all of the above, and in particular that this lady had a very poor prognosis that I doubted her or her daughter knew about. I said we needed to discuss her DNR status, the deactivation of her ICD and other end of life matters. We made a plan that included me and the consultant discussing with the daughter and the patient all the issues I had raised, which resulted in the ICD being turned off, (and) the cessation of all unnecessary medications, investigations and fluid restrictions. The patient was moved to a side room, and her daughter stayed with her to help with her care. The patient was put on the Liverpool Care Pathway and died peacefully five days after my initial visit with her daughter present.”

In all successful case studies the HFPCSNs gave details of effective symptom management, reflecting an often immediate and always ongoing positive impact on the patient and those around them. Effective and timely symptom management appeared to be the first step towards ensuring a successful outcome for patients:

“Brian’s main problems on my first visit were fluid leaking out of his oedematous leg, a swollen abdomen and an irritating cough at night. His GP had increased his Fursoemide by 40mg, he was already taking 80mg, so I suggested a further 40mg and increased his spironolactone to 50mg. His Ramipril had been stopped - if it was for the cough it had not helped; the surgery did not know why it had been stopped. I restarted it at 1.25mg and also prescribed co-codamol for pain from a sacral pressure sore. Asprin and Simvastatin were stopped as Brian’s condition was terminal and they are long term medications offering no symptom relief. His oxygen saturates were 90% at rest; he was breathless on exertion so oxygen was prescribed. He was briefly admitted to hospital for three units of blood because of a low Hb; on discharge he stated that he did not want to go back in. He was still taking co-codamol for pain; I further prescribed a small dose of Oromorph for shortness of breath with success, and oedema was much improved.”
Without exception, positive outcomes included details of effective communication with patients and relatives. However, successful communication and interventions depended on the patient and/or their informal carers acknowledging that they were entering the last phase or final stages of their life:

“I met Mrs S at home with her daughter present. They were aware of the reason for my visit, and Mrs S understood that she had a condition that was untreatable and becoming increasingly difficult to manage. I was able to have a very frank discussion with Mrs S, who made it clear that she understood that she was dying and did not wish to have any life saving interventions, hospital admissions or resuscitation attempts. Her main concern was when it was likely to be, as she simply felt that she ‘could not go on much longer like this’.”

Successful communication with other healthcare professionals was also essential in positive case studies. Being able to effectively engage with healthcare professionals in community and acute settings meant that treatments, interventions, care packages and care plans, which included timely monitoring of symptoms and medication review, allowed the patients to be optimally treated in the manner and place they preferred. Such successful communication included ensuring that any agreed plans were available to all health and social care professionals involved, or potentially involved, in the patient’s care. As a result, up to date written information was essential:

“I also requested that the GP add her to the Gold Standards Register and notify out of hours of her wishes not to be admitted to hospital again. I spoke to the district nurse to advise her of the situation and my involvement.”

Many of the HFPCSNs made reference to the importance of having attended a course on advanced communication skills. They felt the training allowed them to feel confident in initiating end of life discussions with patients and families, and with colleagues in health and social care. As a consequence of effective communication, the HFPCSNs felt more able to build up successful models of partnership working, which allowed patients to remain at home or in their preferred place of care despite increasing care needs and a worsening symptom burden:

“By utilising the Marie Curie nurses, community team, district nurses and GP, we were able to work together to ensure that her wishes were met, (and) that she died at home in comfort and pain free. There were some issues surrounding setting up CSSI, but I felt that my honest discussion with the patient gave me the confidence to act as the patients advocate in this matter and to go back to the GP again and question his decision.”

“I continued to see Mr G at home and liaised closely with his GP; this included joint visits. This partnership working proved to be very effective in terms of dealing with symptoms and problems as they arose, and improving communication between professionals. The partnership working prior to the need for the syringe driver certainly aided the process when one was required. I believe that an element of trust between the GP, district nurse and myself through this close working relationship (helped) make a difference in improving his end of life care. Since Mr G’s death, I have had two further patients from the same GP practice. The experience gained during Mr G’s death has helped to facilitate good practice and care for these patients.”

A reduction in unplanned hospital admissions was also seen as a positive outcome by the HFPCSNs:

“During the time the palliative care heart failure nurse was involved in Alan’s care management, many milestones were passed during his last few months of life; he was managed at home well despite recurrent chest infections and a poor response to antibiotics and steroids. Unplanned hospital admissions decreased from seven in six months prior to palliative care support to two during the six months known to the HFPCSN. Both admissions occurred over weekends when the HFPCSN was not available.”

Some successful cases indicated that the patient had been referred to the HFPCSN at an ‘early’ stage, prior to the last phases of advanced heart failure. In these cases, success centred on interventions that improved the patient’s quality of life, maximised their independence and reduced stress for their informal carers:
“After a referral to occupational therapy, several aids were delivered after an assessment; grab rails, raised seating, perching stool, back rest support, and a commode in her bedroom. These helped maintain her level of independence. One nurse asked me to organise a wheelchair, which I was glad to do, enabling Mrs G to go outside with her nurses or family, lessening her social isolation. Why I had not thought of something so simple; I had concentrated on things to improve her quality of life in the home and had not considered how (she) was to get out.”

3.2.4.2 Less successful outcomes

Less successful case studies were associated with two key factors: Healthcare professionals’ and the lay public’s unrealistic expectations of a patients ability to “bounce back” from acute exacerbations of their heart failure; and difficulties in communication between the HFPCSNs and individuals, as well as across organisations. Each of these difficulties contributed to all the other factors that the HFPCSNs identified as being associated with less successful outcomes. These other factors included a reluctance to provide or accept social service support; inappropriate hospital admissions, treatments and deaths; concerns about the use of morphine, and confusion about medical devices used in heart failure.

The less successful case histories provided an indication that both healthcare professionals and the lay public have unrealistic expectations of patients with advanced heart failure, and the poor prognosis associated with it. Some HFPCSNs could appreciate the importance that some healthcare professionals and the lay public attach to remaining optimistic, particularly if a patient has previously had severe acute episodes from which they have ‘recovered.’ However, this optimism was often a barrier to accepting the need for and implementing effective end of life care:

“He had a significant previous medical history (that) included an out of hospital cardiac arrest for which (he) had had an internal Cardioverter Defibrillator inserted two years ago. Mr M had lived with heart failure for around eight years, and over that time had had at least two spells in intensive care, and had been very unwell on at least four occasions. Therefore, both Mr M and his family held the belief that he would always “bounce back” and that Mr M was a fighter.”

Amongst healthcare professionals, undue optimism or indeed lack of expertise in prognostication could result in patients continuing to be actively treated by some clinicians, while the HFPCSN might simultaneously be instigating palliative treatment aimed at improving quality of life, and ensuring end of life or advanced care plans had been discussed:

“The GP had known Mr B for many years and felt that I was unnecessarily concerned about his heart failure – this made me feel that I was being too pessimistic. I was also made to feel guilty that I had been unfair in my approach with Mr B, as I had told him I was concerned about this lack of progress and tried to discuss his care preferences.”

Differences between healthcare professionals were particularly acute when consultant cardiologists working in the same hospital held different views about the use of palliative interventions in heart failure. As one nurse stated:

“One cardiologist is very pro palliative care, whilst the other is very acute focused and does not agree with metolazone therapy being managed in the community. This then puts me in a very awkward situation when you’re following a clinical management plan from one consultant, and then the other might follow up the patient in clinic! It is also very confusing for the patients who are getting mixed messages.”

An unwillingness to acknowledge a patient’s poor prognosis can often lead to difficulties in communication. A belief that a patient will get better precludes any need to address issues related to end of life care. The HFPCSN case studies powerfully illustrated that some patients and families refused to enter into conversations about end of life and advanced care planning:
“We discussed that he recognised that he was deteriorating and was not responding to treatment; however, trying to explore this more in-depth was quite difficult and I was often met with yes and no answers from him. I tried to discuss advanced care planning and preferred priority of care, but Mrs E did not want me to discuss this with her husband saying he would ‘give up’.”

“As a throw away comment, he said if his time was up he would rather be at home but asked me not to continue with the conversation. Regardless of what and how I tried to approach the delicate issue of death and dying, it was very obvious that because his GP had not been of the same opinion as me he was not going to take my concerns too seriously.”

One nurse reported that a patient’s faith or culture could also be a major barrier to effective end of life discussions and planning:

“His strong Sikh belief ‘that it was god’s will and therefore what was the point’ made it very difficult to engage in end of life discussions, as he would just stop the conversation.”

The case studies also indicated that it was difficult to address issues relating to end of life and advanced care planning with patients who had poor short term memory. One nurse questioned whether it was kind and, by implication, ethical do so:

“It became apparent that Mrs W had a very poor short term memory and was unable to recall any of the information I had previously provided. She would ask ‘Why is my breathing so bad?’ and ‘why can’t I breathe/walk anymore?’ I would reply honestly and she would become upset, yet ten minutes later or on my next visit she would ask the same questions again.”

Lack of an advance care plan could result in the HFPCSNs being unable to complete out of hours forms for patients, which in turn could result in unplanned hospital admissions. Once in hospital, lack of communication between healthcare professionals, often due to inadequate transfer of information, could result in patients being given unnecessary and unwanted interventions and treatments:

“This was discussed with both Mr M and his family, and he was discharged home with an advanced care plan; this included Mr M’s wish to die at home. Unfortunately this care plan was not added to his out of hours medical notes, and as a result he ended up being readmitted four days later.”

“Abdul’s symptoms exacerbated and his family called the out of hours GP who proceeded to arrange an ambulance. Abdul was admitted to hospital with no visit from the GP. This resulted in him being actively treated for twenty-four hours with IV fluids, investigations and blood tests until he was reviewed by the heart failure nurse and cardiologist; on Sunday it was agreed that Abdul was terminal; this was discussed with his family and he was moved out of active monitoring and into a side room where he died twenty-four hours later without his family present.”

Less successful case studies often included deaths in hospital. As illustrated above, these could be the result of poor communication, but equally they were sometimes the result of inadequate availability of care services in the community. In these cases, there was little the HFPCSNs could do to ensure a patient was cared for at home or in their preferred place of care:

“Despite pressure from various professionals, the local social services could not provide a care package (lack of funding) … Marie Curie support was increased but a care package could still not be put in place … Although it was Mr M’s wish to die at home, he agreed to admission to a local hospice; this was planned for the next day. … Unfortunately Mr M died within ten minutes of being admitted to the hospice. As a result, his family felt as though they had let him down. They intimated that they wished they had kept him at home.”

The HFPCSNs felt that deaths preceded by attempts to resuscitate the patient were cases in which their intervention had been less successful. The case studies illustrated that the nurses felt such a death would,
by necessity, be undignified, and not wanted by either patients or their families. In these cases, the nurse’s recounting of the story suggested that they felt they had let patients down:

“Despite having a DNR in place, the medical and nursing decision was that if he had a ‘shockable’ rhythm he would be resuscitated. This happened and the patient died in CCU two days later following twenty-four hours of intensive investigation without his family being present.”

“When I spoke to her (patient’s wife) later, she said it was dreadful and undignified; all the things we strive to avoid.”

Three less successful cases referred to commonly held beliefs about morphine that nurses felt impacted on the care and symptom management they were able to offer patients. In one case, a patient’s husband whose first wife had died of cancer was reluctant to allow the use of morphine, saying that “morphine is a killer.” In the second case, a patient’s wife refused to give him the prescribed dose of morphine as she was concerned her husband would become addicted. It transpired that their son had been a drug addict. In the third case, a GP had refused to prescribe opiates for a syringe driver as he believed the drugs would hasten the patient’s death.

Less successful case studies were also associated with the need to turn off implanted devices, which are being used more frequently in the management of patients with advanced heart failure. The case studies indicated that there could be confusion over the immediate and long-term effects of turning off the devices, and about who was responsible for their de-activation:

“I had got a combined defib and pacemaker; I rung CCU about switching it off and why they had not considered turning it off; the sister that answered said it turns off his pacemaker! I did try to tell her that I was sure this was not so; luckily the consultant was on the unit and she spoke to him. He said it would be OK to turn it off. I asked if they would contact the company to get a rep to come out and turn it off. They agreed but of course it was all too late.”

Some case studies indicated that the HFPCSN was ambivalent about the success or otherwise of their interventions. While they may not have achieved all they might have wanted for a particular patient, they had nonetheless made a positive impact on their care and last stages of life, and in this way they felt their input was of value:

“In conclusion, I felt that I had not fulfilled my role as a palliative care nurse because he had not died at home. However, on reflection (of) my role and its impact I looked back on the number of hospital admissions in the year before he was referred to me in the seven months he was known to me. From April to October 2008, he had four unplanned admissions lasting 21, 22, 17 and 39 days respectively. He was referred to me in December 2008. In June 2009, he had one planned admission lasting half a day, which I had organised for a cardiology assessment. The second admission was in July 2009, which was unplanned when I was on annual leave, and he died peacefully three days later.”

The less successful case studies often included reflections that growing expertise and specific education and training events meant that the HFPCSNs would be more able to address some of the challenging issues raised in their case studies; particularly, those relating to managing difficult discussions about end of life care and prognostication with patients, families and health and social care professionals.

3.2.5 Discussion

The patient case studies provided by the HFPCSNs highlighted the diversity of situations they face in everyday practice. The fact that so few case studies were identified as successful or less successful by the HFPCSNs was an indication of how difficult it was to categorise a patient’s care in this way. In all cases the nurses’ interventions had at some level been successful in that they had impacted positively on the
patient and those close to them. However, most of the nurses used some implicit criteria in judging success. The most prominent of these criteria was undoubtedly the achievement of either a home death or a peaceful hospital death in which all those involved were aware that the patient had been, and was dying, and that the patient’s preferences for care were being met.

The case studies also emphasised the degree to which the aims of the HFPCSNs were reliant on other health and social care providers, and to a lesser extent patients’ own families, in achieving the sort of care and deaths that patients valued. Individual preferences and beliefs of GPs and cardiologists were also identified as having an impact on patient care, and to limit or enhance the HFPCSNs ability to work effectively with patients. Similarly, local policies and practices influenced what nurses were able to achieve in providing end of life care.

The nurses valued the tools advocated as part of the National End of Life Care Strategy, particularly the GSF and the process of advanced care planning as ways of improving patient care. However, some nurses found that patients refused to acknowledge the severity of their condition or engage in discussion about end of life care. In some cases, this held equally true for healthcare professionals. Such reluctance has been noted in other studies of patients with heart failure (Rogers et al 2000) and COPD (White et al in press), and calls into question the impact that advance care planning will have on end of life care for patients with conditions other than cancer.

Concerns from both the lay public and at least one healthcare professional about the use of morphine at the end of life were shown to have a negative impact on patient care, indicating the continued need for public and professional education about the appropriate use of opiates. Similarly, lack of knowledge and probably experience of caring for patients fitted with implanted devices resulted in less than optimal care in some instances.

3.3 Service descriptions and process mapping

3.3.1 Introduction

We wanted the nurses to describe the way in which their individual services worked. We wanted to know what they considered to be key aspects of their role, and about the main ways in which they were able to improve patients’ quality of life and the care provided in the last months, weeks and days of life. We also wanted to know what the HFPCSNs felt were the main barriers to developing their service further.

3.3.2 Methods

Prior to taking part in the focus group, the HFPCSNs were asked to draw a simple map of their service. The map was to start with a list of all the healthcare professions who referred patients to them, followed by a list of the key aspects of the service they provided, and then detail of the services to which the HFPCSNs commonly referred patients. The nurses were also asked to list “anything they felt would improve the service they were currently able to offer”. Having drawn up the service map, the nurses were asked to plot a recent patient journey from referral to onward referral, thus providing a simple process map.

Seven nurses from six pilot sites drew up service maps and process maps (Figures 1-6). The following case studies are incorporated below:

- Case 1: Community based
- Case 2: Community and hospital based
- Case 3: Hospital based but with community based clinics
Chapter 3  Heart failure palliative care specialist nurse (HFPCSN) experiences

- Case 4: Community based palliative care
- Case 7: Joint post community and hospital based
- Case 8: Hospital and community based

Key information from the other two sites is provided in Figures 7 and 8. This information has been supplemented by data from HFPCSNs quarterly progress reports, and a final questionnaire sent out by the BHF in October 2009 (Appendix 11.6).
3.3.2.1 Case 1: Community based

Figure 1

Caseload: Palliative and supportive patients only
Post not funded in 2010

People referring to service
- Cardiologist
- Acute heart failure nurse
- Community heart failure nurse
- District nurses
- GPs
- Community matrons

NB: All referrals have to meet referral criteria

Key aspects of service
- Holistic patient assessment
- Clinical Assessment
- Medication and treatment review
- Psychological and emotional support of patients and carers
- Education

Onward referral
- Social services
- Community healthcare co-ordinators
- Respite care (day and night sitters)
- DS1500
- Wheel chair loans
- Hospice
- Day care
- Respite care
- District Nurses
  - Equipment
  - Syringe drivers
  - Dressings
- Phlebotomy

Total number of patients seen: 23
Patients died: 13 (57%)
Home deaths: No
Non-medical prescriber: No
Community IV diuretics: No
Heart failure training: Yes
Palliative care module: Yes
Advanced communication skills: Yes

Things that would improve service
- To see patients earlier - NHYA III
- IV Diuretics in the community
- A regular MDT meeting
- Good database
3.3.2.2 Case 2: Community and hospital based

FIGURE 2

Caseload: 20-30% generic, 70-80% supportive and palliative
In post 33 months – continues to be funded as a substantive hospital based post

People referring to service
- Heart failure nurse
- GP
- Cardiologist
- Ward staff
- Palliative care team
- Physicians
- Other specialist nurses – e.g. respiratory

Key aspects of service
- Holistic Assessment
- Symptom control – medication review
- Facilitate significant discussions
- Identify patients entering palliative end of life phase of illness
- Psychological assessment
- Documentation
- Liaise with GP and other health care professionals
- Education – Patient and families
  Healthcare professionals

Onward referral
- Occupational therapist
- Social services
- Benefits advisor
- Physiotherapist
- Cardiologist
- DN
- Community hospital
- Bereavement Support
- Marie Curie team
- Hospice
- GP
- Dietician
- Equipment – Home oxygen

Total number of patients seen: 193
Patients died: 90 (47%)
Home deaths: 40 (44%)
Nurse prescriber: No
Community IV diuretics: No
Heart failure training: Yes
Palliative care module: Yes
Advanced communication skills: Yes

Things that would improve service
- To see patients earlier - NHYA III
- IV Diuretics in the community
- A regular MDT meeting
- Good database
3.3.2.3 Case 3: Hospital based but with community based clinics

Figure 3

Caseload: 2006-2008: 30% generic 70% palliative  
2008-2009: 90% generic 10% palliative

In post 36 months – continues to be funded by the acute trust

Key aspects of service

- Holistic patient assessment
- Patient advocacy
- Review of treatment options with HF cardiologist
- Symptom management and medication review
- Psychological support
- Discharge planning
- DS1500
- Education and teaching
- Other healthcare professionals
- Service development

Onward referral

- Specialist palliative care
- Cardiology and other specialist teams
- Devices, transplantation
- Other quality of life interventions
- Community services
- Assertive case managers
- District nurses
- Community HF teams
- Day care services

Total number of patients seen: 620

Patients died: 65 (10%)
Home Deaths: 19 (29%)
Non-medical prescriber: No
Community IV diuretics: No
Heart failure training: Yes
Palliative care module: Yes
Advanced communication skills: Yes

Things that would improve service

- Formal Heart failure clinics run jointly with heart failure consultant
- Support group for patients and families
- Formal MDT meetings
- Jointly funded secondary/primary care role to enable seamless cross over IV Diuretics in the community
3.3.2.4 Case 4: Community based palliative care

Figure 4

Case load: 25% generic 75% supportive/palliative
In post 39 months – continues to be funded for the next 12 months by local hospice

**People referring to service**
- HGPs
- DN
- Cardiac specialist nurses
- Heart failure nurses
- Consultants
- Community matrons

**Key aspects of service**
- Holistic assessment
- Concentrate on keeping patients in their PPC
- Assessment of benefits
- Symptom management
- Treatment and medication review
- Counselling and support for families
- Bereavement support

**Onward referral**
- Fast response team
- Physiotherapy
- Occupational therapy
- Dietician
- Social Services
- Mental health team
- Day hospice
- Hospice
- Tai Chi group
- Patient and family support group

**Total number of patients seen:** 309
- Patients died: 109 (35%)
- Home deaths: 63 (58%)
- Non medical prescriber: Yes
- Community IV diuretics: Yes
- Heart failure training: Yes
- Palliative care module: Yes
- Advanced communication skills: Yes

**Things that would improve service**
- More involvement with cardiologists
- Quicker access to physiotherapy assessments
- IV Diuretics in the community
- A driver
3.3.2.5 Case 7: Joint post community and hospital based

In post 18.75 hours/week 33 months
1.5 days/week 11 Months

Funding ceased for one post as planned in original bid, funding for other post continues for a further 12 months

People referring to service
- Heart Failure Liaison Nurse Team
- Hospital consultants
  - Cardiologists
  - Care of the elderly

Key aspects of service

Pilot 1
- Six week supportive palliative care programme in partnership with HFLN, palliative care specialists nurse, social worker, OT, dietician, benefit advisor, pharmacist, counsellor, days service hospice.

Pilot 2
- HF/ palliative care clinic model
- With cardiologist – HF and palliative care specialist nurses – 8 week programme with Marie Curie Hospice MDT
- Supporting staff in identifying patients, supporting care of identified patients
- Joint working
  - Home visits
  - Clinic revises
  - District nurses
  - Hospices

Onward referral
- Community services
- GP
- DN
- Pharmacist
- Nursing homes
- Acute hospital
- Specialist palliative care
- Social worker
- Occupational therapy
- District nurses
- Marie Curie services
- Social worker
- Benefits advice
- Occupational therapy
- Wheel chair
- Blue Badge
- Physiotherapy
- Hospice for medical assessment
- Dietician

Total number of patients seen: Not applicable
Patients died: Not applicable
Home deaths: Not applicable
Non-medical prescriber: No
Community IV diuretics: Not applicable
Heart failure training: Yes
Advanced communication skills course Yes

Things that would improve service
- Change of mind set with HFLN and Cardiologists towards holistic assessment and proactive follow up
- From disease to person centred approach
- More time – for role modelling
- Re-design current service provision
- Identify local champions to support out work
### 3.3.2.6 Case 8: Hospital and community based

**Figure 6**

*Caseload: Only patients with supportive and palliative care needs*

In post 18 months – late in joining the scheme, BHF pilot funding will cease in April 2011

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**People referring to service**
- Cardiologist
- Heart failure specialist nurse
- GPs (occasionally)

**Key aspects of service**
- Joint home visits with HF nurse
- Holistic assessment
- Clinical assessment
- Treatment and medication review
- Bereavement visits
- Advice to:
  - HF Nurses
  - Nurses
  - GPs
  - Cardiologists
- Education
  - Informal sessions
  - Formal sessions
- Service development

**Onward referral**
- District nurses
- Marie Curie services
- Social worker
- Benefits advice
- Occupational therapy
- Wheel chair
- Blue Badge
- Physiotherapy
- Hospice for medical assessment
- Dietician

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**Total number of patients seen:** 17

- Patients died: 11 (64%)
- Home deaths: Missing data
- Non-medical prescriber: Yes
- Community IV diuretics: No
- Heart failure training: No
- Palliative care module: Yes
- Advanced communication skills: Yes

**Things that would improve service**
- Increased support from cardiologist
- Consultant palliative care support
- To be more integrated with specialist palliative care services
- Administrative Support
3.3.2.7 Service summary - Case 5 Community based

Figure 7

Caseload: Only patients with palliative care needs
In post thirty-one months – continued funding secured from PCT post based at local hospice.

“I manage patients with advanced heart failure considered to be in the palliative phase and their carers in the community. The main principles of the role are to improve communication, choice and access to specialist palliative care, symptom management and social and psychological support with the aim of reducing hospital admissions and delivering care in the patients preferred place of care. I have close working relationships across the interface of primary and secondary care with GPs, cardiologists, heart failure specialist nurses and palliative care nurses to improve continuity and enhance patient care and experience. I also have key working relationships with multi-professional teams improving access to services across the PCT.”

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</tr>
<tr>
<td>Community IV diuretics:</td>
<td>No</td>
</tr>
<tr>
<td>Heart failure training:</td>
<td>Yes</td>
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<td>Palliative care module:</td>
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<tr>
<td>Advanced communication skills course</td>
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3.3.2.8 Figure 7: Service summary - Case 5 Community based

Figure 8

Caseload: 60% generic 40% palliative
In post thirty-six months – continued funding secured from the PCT at a community base

- To provide holistic care for a caseload of complex chronic heart failure patients within their own place of residence.
- To provide educational, emotional and social support to patients and their carers.
- To maintain health and control of symptoms, and promote self management.
- To improve overall quality of life for patients, families and carers.
- To provide palliative and supportive care to ensure they are cared for in their preferred place of care.
- To help reduce avoidable admissions and improve overall management of patients in line with the evidence base.
- To support GP practices and primary care services and educate as required. Point of contact for patients and their families.

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<td>No</td>
</tr>
<tr>
<td>Community IV diuretics:</td>
<td>No</td>
</tr>
<tr>
<td>Heart failure training:</td>
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<td>Palliative care module:</td>
<td>No</td>
</tr>
<tr>
<td>Advanced communication skills course</td>
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</table>

3.3.3 Results

Information from the nurses’ quarterly reports indicated that, by October 2009, they had been in post for between 18 and 39 months (with the exception of one of the nurses who had been recruited only seven months ago as she replaced a nurse who had left post in June 2008). However, six of the nurses had been in post for longer than thirty months. As already noted, nurses at one site did not have an active caseload. Of the other seven sites, three accepted only patients with recognised palliative or supportive care needs, and the other four had mixed caseloads of generic heart failure patients and those with palliative or supportive care needs.

The total number of patients seen by each nurse by October 2009 ranged from 17 to 620. The nurses who had been in post for the shortest period of time reported the lowest number of total patients, and a nurse who reported that 90% of her patient caseload was generic patients had seen the most patients.

The number of patients who had died ranged from 11 to 109, and the percentage of patients who had died ranged from 10% to 64%. Nurses with exclusively palliative and supportive care caseloads had the greatest proportion of deaths, and the nurse with a large generic caseload had the least.

One nurse reported that none of her patients had died at home; two other nurses provided incomplete data by counting all “deaths in the community”. Of the four other sites with active patient caseloads, the number of home deaths ranged from 11 to 63 (29% to 63%) of all deaths.
The HFPCSNs were asked in quarterly progress reports “how many unplanned hospital admissions do you think have been avoided by your care?” For the year 2009, the nurses reported avoiding between three and 57 such hospital admissions. The nurses who were newest to their roles reported the least number of avoided admissions, while a nurse who was a non-medical prescriber who had access to IV diuretic provision in the community and worked closely with their local hospice reported the greatest number of avoided hospital admissions.

3.3.4 Analysis

In all but one of the pilot sites, nurses descriptions of the key aspects of their service centred on a holistic assessment, including identification of patients entering the palliative or end of life phase of their illness, symptom control, treatment and medication reviews, patient and family support and bereavement care. In addition, most nurses described education, both formal and informal, and service development as key aspects of their post. The exceptional site was one of those in which the HFPCSN did not have an active or ongoing patient case load, but acted in advisory capacity to acute and community based healthcare professionals.

Regardless of their particular service configuration, the HFPCSNs reported receiving referrals from a wide range of healthcare professionals from both the acute and community settings. There were some reported differences in the perceived number of referrals from different groups of healthcare professionals, which seemed to be associated with the HFPCSNs predominant area of work - either an acute or community base.

Onward referrals to new services or for new treatments or interventions were very similar across all the pilot sites. However, referrals to very specific services or interventions such as Tai Chi groups, to assertive case managers or community healthcare co-ordinators, for home based oxygen or intravenous diuretics, reflect the availability of these services within a local health care economy rather than the service provided by individual HFPCSNs. The process maps were easy to follow, and showed the diverse way in which an individual patient’s needs might be met within each service.

Nurses identified a number of ways in which the services they offered might be improved, and it is this data that highlights the degree to which wider healthcare provision, health policies and common cultures can inhibit or enhance the services of the HFPCSN. Four HFPCSNs felt their service could be improved through the provision of intravenous diuretics in the community, and four would have liked more active support from local cardiologists, either for the HFPCSNs role in general or for a more holistic person centred approach to patients with end stage heart failure. Other nurses requested better administrative support, improved access to clinical psychologists, physiotherapy, benefits advice, more effective or any multi-disciplinary team meetings, patient and/or family support including respite care, and more consistent support from specialists in palliative care, including local hospices.

3.3.5 Discussion

The number of total patients seen by each of the HFPCSNs varied widely. This may be accounted for by the significantly different length of time in post for two of the nurses. However, these differences may also be attributable to differences in referral criteria, local case mix and the willingness or otherwise of healthcare professionals to make referrals to the HFPCSNs.

Although the data about home deaths was incomplete, the number and proportion of patients dying at home, in all correctly reporting sites, was well above national figures for home deaths even among cancer patients. Information relating to the number of hospital admissions that were avoided should perhaps be treated with caution, as nurses used non-objective criteria to assess admission avoidance and may therefore have unconsciously increased these figures. However, even if there was some exaggeration in
the numbers, the potential for HFPCSNs to have a positive impact on the number of patients to stay at home when they suffer deterioration in their illness, as well as at the end of life, has important implications for patients and commissioners alike.

Both the service maps and the information from the final questionnaire revealed that despite being established to work in different ways, the HFPCSN services were very similar in terms of the key aspects of their roles and in the interventions and onward referrals they made on behalf of patients. This was also true for the sites in which the HFPCSNs worked in a purely advisory capacity.

The similarity of interventions and onward referrals suggests that heart failure patients have a common core set of unmet needs that can be identified during a holistic assessment. These needs include symptom management and the consideration of wider psycho-social needs, such as support with activities of everyday living, help in claiming benefits and improved access to psychological and/or bereavement support.

Analysis of the ways in which services might be improved highlighted the range of services that HFPCSNs were able to access. In some cases, the HFPCSNs were unable to either provide or access services or interventions that they felt would benefit patients. These included providing intravenous diuretics at home and domiciliary oxygen, which had been identified by other pilot sites as having a positive impact on reductions in unplanned hospital admissions and an increase in home death rates.

### 3.3.6 Conclusion

Despite many differences in the way each of the HFPCSN posts were established, both the qualitative and the routinely collected quantitative data indicate that nurses work in remarkably similar ways and report very similar facilitators and blocks to good practice.

Active support of local cardiologists was a key factor in improving the HFPCSN service. The absence of such support necessarily affects the way in which the HFPCSNs are able to work, either by reducing the number of referrals they receive by limiting the extent to which palliative interventions are seen as credible and in patients’ best interest, or by restricting the range of interventions that can be offered at home.

While different service configurations may have resulted in the HFPCSNs working in slightly different ways and settings, the needs of end stage heart failure patients seem to be remarkably similar, calling for similar interventions. It is this core area of need that dictates the way in which HFPCSNs work. There are, however, factors associated with the wider health economy that determine to a large extent the way in which nurses are able to meet the needs of this patient group.
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4.1 Telephone interviews with local healthcare professional stakeholders

“Doctors provided what care they could; what would happen is there would be a tremendous scramble every single time to get this organised and that organised, and different doctors trying to do it. We didn’t have a co-ordinated team. So if you are trying to evaluate the BHF palliative care nurse, they have enabled us to bring some quality of life to patients in death.”

4.1.1 Introduction

The evaluation needed to know about the ways in which the HFPCSNs had an impact on health care provision in the pilot sites. This required more information regarding the experience of working with HFPCSNs, rather than just data on caseloads or teaching commitments. In order to identify how the HFPCSNs were perceived within the wider health and social care team, telephone interviews were undertaken with local stakeholders.

4.1.2 Methods

Each nurse was asked to identify two health or social care professionals with whom they work, and to ask if they would be willing to take part in a short telephone interview as part of the evaluation of the HFPCSN service. Having identified appropriate interviewees, the nurses passed on contact details to the researcher who in turn contacted the participants to arrange suitable times for interview.

The nurses identified 15 potential interviewees 11 of whom were interviewed, including at least one stakeholder for each of the pilots. One potential interviewee was on sick leave and four others failed to contact the researcher despite three reminders. The interviewees included specialist nurses from acute and community settings, individuals employed in specialist palliative care provision, hospital consultants and GPs. The interviews were semi-structured with a list of questions that all participants were asked, but other themes were explored and discussed as they arose (Appendix 3). Nine of the eleven interviews were audio recorded with the participants consent, and were between 15 and 45 minutes in length. Extensive notes were taken during the two unrecorded telephone interviews, and these were re-written for inclusion in the analysis.

4.1.3 Analysis

The interviews were listened to and re-listened to, and notes were read and re-read in order to ensure familiarisation. Data was then entered directly on to a coding frame. The data was analysed using a framework approach, as this allowed information from each case to be easily compared both within and between all categories and cases (Richie & Spencer 1994). Data from the interviews was incorporated into a coding framework under the five broad categories reflecting the interview schedules:

- Interviewees role and the perceived role of the HFPCSN
- Interviewees view of the management of the palliative and end of life care needs of heart failure patients prior to the HFPCSN
- How the HFPCSNs helped the interviewee in their job
- How the HFPCSNs improved patient care locally
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- What would they miss most should the post cease to be funded tomorrow

This data was then re-coded into six overarching themes:
- Expert knowledge
- Continuity and time
- Access to and co-ordination of care
- Education
- Protocols
- Previous experience and personal qualities

4.1.3.1 Expert knowledge

All stakeholders reported that HFPCSNs had a high degree of specialist knowledge about the palliative care needs of heart failure patients. The nurses combined this specialist knowledge with skills and experience from past posts to provide a level of specialist care, which the interviewees themselves felt unable to provide:

“I think it is the breathlessness, oedema, the general inability and I think it’s the fine tuning of the symptoms. I think there are a great number of needs and it’s a very complex condition and getting the medication right… And it is getting the balance of the medication right. I think it is a speciality on its own; I think although we are looking at end of life care these patients have special needs.”

Some stakeholders felt that the palliative care needs of heart failure patients were in many ways different to those of the cancer patients more usually seen by specialists in palliative care. Some felt that specialists in palliative medicine were reluctant to take on the care of heart failure patients, with one interviewee stating: “sure palliative care teams are getting more involved with heart failure patients, but there is a definite apprehension”. Others felt that specialists in palliative care lack the knowledge to provide quality care to heart failure patients. However, others felt the HFPCSNs needed knowledge of both specialist palliative care and heart failure: “the expertise comes with the blending of heart failure knowledge with palliative care”.

Stakeholders also felt that generalists in the community, such as district nurses, community matrons and GPs, were unable to provide appropriate or similar quality care for patients’ with advanced heart failure: “we are trained to fire fight so when somebody is unwell and breathless and we see them, we are not good at forward thinking, planning or management.”

Expert knowledge was seen as particularly important in two key areas: symptom control and skills in identifying patients who were nearing the end of their lives.

Symptom control

Every stakeholder reported that the HFPCSN was an expert in symptom control, which was recognised as difficult to achieve for patients with advanced heart failure. Expert knowledge of symptom management and appropriate use of medications were seen as essential in achieving quality end of life care:

“…also to ensure that drug reduction rather than optimisation is done and make sure palliation drugs are introduced; we have certainly seen far more patients receiving a very different drug regimen towards the end of life, which I think is a huge advantage.”

“I have got trained staff who know to look out for signs and symptoms (that) I notice when I’m on ward rounds. The girls notice things I wouldn’t like mouth care, bowel care. Doctors aren’t interested in that as a general rule; we are but we don’t think to ask. Our palliative care team look at it holistically.”
Managing symptoms and using appropriate drugs were particularly appreciated by stakeholders when the HFPCSN was a nurse prescriber:

“(Name) can prescribe for the patients and that is great for them so they can get the medication there and then, rather than having to wait for the surgery to produce a piece of paper.”

At least one stakeholder felt that the HFPCSN was better at promoting self management with patients than most healthcare professionals, and that these measures themselves improved patients’ symptom burden and prevented contacts with both acute and primary care health services:

“One patient in particular who I am sure would be a frequent A&E (attendee) were it not for (HFPCSN), this person’s carers are now confident to add an extra (drug name) or oramorph when needed. …… I can’t think of the last time one of my colleagues recorded a patient’s weight with heart failure (HFPCSN name) - (it) is fantastic.”

Skills in the identification of patients at increased risk of dying

Stakeholders reported that a HFPCSN’s ability to identify patients at increased risk of dying was a key and unique skill. This was especially so when the nurses were able to agree an appropriate protocol for identification:

“It’s quite difficult to know with these patients when they are coming towards the end of life. I think that is quite hard and sometimes (PCFHN name) will help with interpreting all the results and investigations over a period of time, especially if she had known the person, she can see if things are not going so well.”

Stakeholders also appreciated the nurse’s expert knowledge in breaking bad news, sometimes wanting the nurses to accompany them when they were about to talk with patients or families about end of life care. In some cases stakeholders also felt it was important that the local HFPCSN had completed the Verification of Death training, as this saved families the anxiety of an often lengthy wait for a doctor’s visit to certify the death.

4.1.3.2 Continuity and time

Most stakeholders felt that the HFPCSNs offered greater continuity of care to patients than had previously been the case. Stakeholders also reported that the HFPCSNs were able to offer and spend more time with patients and their families, thus enhancing the quality of care they received.

Almost all stakeholders reported that they and the HFPCSNs were part of a team - part of a service that sought to provide “seamless care”, or to care for the patient “throughout their heart failure journey”. Each of these is a way of describing a service that is seeking to improve continuity of care. Stakeholders identified a number of ways in which continuity of care could be provided or improved. Continuity of information was improved when HFPCSNs were able to contribute to some sort of integrated care records, whether these were hand written, patient held or electronic records:

“(HFPCSN name) is IT literate so she is able to use our shared care patient records; she can see the GP records and I can see what she is putting in her records. The out of hours service also has access to the same network. (Name) is very well knitted into the local health economy.”

Continuity of place of care was improved by the HFPCSNs help in preventing crisis admissions. Advance care planning, anticipatory prescribing and good symptom control were all reported as significant in preventing crisis admissions:

“Better management for the patients and their family. Whereas if (name) wasn’t in post, the patient would go home and then get a degree of breathlessness and the next day the family would dial 999; the person who is very poorly would just be brought straight back in again and I think it is so important that patients and
families actually know where they are with their illness, and actually what is the plan and I think (HFPCSN name) is instrumental in doing this."

“The patients who are under (name)’s care are enormously grateful for the continuity that (name) offers, and the availability she offers, and the expert knowledge on symptoms and their conditions; it saves them negotiating our appointment system and out of hours and the A&E department. Because it is a scheduled service, they know when (name) is going to contact them. If they know somebody is coming then they can manage.”

Another stakeholder made a similar comment reflecting the importance of easy access to expert advice in maintaining continuity: “Having someone at the end of the telephone for patients, it’s vital to them; they feel so safe knowing she is there to call on”.

For many stakeholders, helping a patient achieve their preferred place of care or enabling a patient to die at home was evidence that the HFPCSNs were increasing continuity: “Our biggest achievement though is we have deaths at home that we didn’t have before. The patients are actually selecting where they want to die.”

Continuity of healthcare professionals was also seen as important to stakeholders with many reporting that HFPCSNs were often able to work within both the acute and community settings. This had two important aspects. First, it allowed nurses to see patients in both environments, to gather and offer advice to specialists in both settings, and to follow the patient from one setting to another. This was seen as especially important when patients were admitted to hospital very close to death:

“Sometimes if it’s not avoidable she will even go into the hospital and follow them there, and give them support there so she doesn’t just dismiss them if they go into hospital.”

Second, working in both environments also allowed trust to be built up within teams and across different disciplines, with acute sector nurses reporting that they liked to know “what they were sending patients out to”. Importantly, one stakeholder who worked in a local hospice reported increased confidence in caring for patients with heart failure, stating that frequent visits by the HFPCSN had “made it very easy for us to look after heart failure patients, we know we have support and that makes us confident that we can meet their needs”.

Stakeholders were almost universally of the belief the HFPCSNs had more time than either they or other local healthcare professionals had available to spend with patients. This perception of available time allowed the nurses to provide the more holistic care and assessment normally associated with specialist palliative care. This included talking to patients about their preferences for end of life care and more general psychosocial and spiritual needs. Time was also seen as important as it allowed the HFPCSNs to support patients’ families, both prior to and following bereavement:

“Obviously because of the caseload she has more time to look at additional needs rather than just symptom; it’s very much holistic care, exploring all the aspects of palliative care that she has been able to focus on.”

4.1.3.3 Access to and co-ordination of care

Stakeholders reported that the HFPCSNs improved patient access to care in a number of ways, including a more timely access to care or equipment, access to new services or health and social care advice.

At least one stakeholder reported that the HFPCSN was able to admit patients directly to hospital or hospice under service level agreements for advanced practitioners, which ensured more timely admissions where necessary. Other nurses reported having more informal agreements with colleagues in secondary care that allowed patients to be admitted directly to hospital wards, bypassing normal A&E admission procedures which can cause unnecessary delays in treatment and distress to patients and their carers. A number of stakeholders reported that the HFPCSNs were able to access hospice services either on behalf of patients, by enabling hospice or other specialists in palliative care to gain skills in caring for patients with heart failure, or by extending the number of services willing to care for these patients.
Stakeholders also reported that HFPCSNs were able to negotiate more prompt access to equipment, as well as occupational therapy and physiotherapy for patients:

“(HFPCSN name) has worked in the community and she has made an awful lot of connections with existing resources in the community so we can access them a lot quicker (and) a lot speedier than we did before, (such as) occupational therapy, physios, DNs, community pharmacists, so we can actually get people home a lot quicker because we can get equipment into the houses a lot quicker. Whereas before we had to wait three or four days, with (HFPCSN name) it’s almost the following day and if we didn’t have someone championing that through we couldn’t offer home as a place of death to be honest.”

Promoting more timely access to appropriate services and equipment were all seen as ways in which the HFPCSNs had improved the co-ordination of care for heart failure patients. Increased co-ordination of service provision was seen as a key aspect of the HFPCSNs role, particularly when patients were nearing the end of life or dying. This was a time when their input was seen as especially important regardless of the location of care.

One stakeholder explained that a course they had developed with the local HFPCSN for patients with heart failure and their carers had been so successful that a similar course was being developed for other patient groups. In this way, the HFPCSN had a positive impact on the care and services offered to patients with other long term life-threatening conditions, including those with cancer.

4.1.3.4 Education

Education was seen by many stakeholders as an important part of the HFPCSN role. While all nurses reported running formal education sessions, many stakeholders felt they had an important role in ‘up-skilling’ other specialist or generalist staff in both the acute and community settings. Joint visits and/or assessments meant that these specialist nurses were able to teach by example, and opportunities for joint working were particularly valued by community based cardiology nurses:

“(The HFPCSN) has done a lot of education with other members of staff in the team so their understanding of the needs of heart failure has changed, and their appreciation of this stage has changed, and the way we treat (patients) has changed.”

Stakeholders felt that the HFPCSNs were in a strong position to introduce and support best practice, as they were part of a national network of similar nurses with ongoing education and training sessions. This was seen as especially important when services were making bids for more financial resources, or trying to increase service provision. At least one stakeholder reported that the HFPCSN was seen as “the local expert” within the area.

4.1.3.5 Protocols

While only a few stakeholders directly included developing protocols as a key aspect of the HFPCSNs role, it was clear that establishing protocols for end of life care, the use of intravenous drugs in the community and the introduction of so called ‘hot-boxes’, which held end of life care drugs, were all important areas of impact:

“Also (HFPCSN name) has done a lot of ‘protocolising’ things, written the end of life protocol, she has written the intravenous frusimide protocol.”

Providing guidance on anticipatory prescribing and the use of National End of Life Care documents, such as the Gold Standards Framework and Preferred Place of Care, were also seen as important ways in which the HFPCSNs helped to improve patient care.
4.1.3.6 Previous experience and personal qualities

Some, but not all, stakeholders made reference to the HFPCSNs previous nursing experience and ways in which their knowledge and skills had an impact on their current role. Stakeholders reported that previous experience of end of life care, work in community settings, work in acute settings and work in discharge planning and case management all played an important part in the success of the HFPCSN post.

Stakeholders often commented on the dedication and determination of individual HFPCSNs in their day-to-day work, with some reporting that these nurses worked above and beyond their job descriptions, and often worked many more hours than they were paid to. Some nurses were reported to have taken work mobile telephones on holiday with them and/or be on call to patients “all the time”. Personal qualities such as “being a good communicator”, “always being there for patients and families”, and being happy to “champion things through” were common among stakeholder views of HFPCSNs. One stakeholder reported of a HFPCSN: “She is a fabulous nurse, it’s a pleasure to work with her; I think the whole project would have fallen on its face without her, she is so knowledgeable; we wouldn’t have been able to do this without (her).”

4.1.4 Discussion

Without exception, the stakeholders interviewed for this part of the evaluation reported that the HFPCSNs had increased the quality of patient care regardless of how a particular service was set up or worked on a day-to-day basis. It was felt that providing quality palliative or end of life care for patients with heart failure was a specialist skill, with the HFPCSNs having some unique areas of specialist knowledge especially in identification and prognostication, symptom control and end of life medication. While it was felt that both generalists and specialists in palliative care could provide adequate care for patients with advanced heart failure, HFPCSNs provided better quality care and were more able to address the needs of patients and families. Stakeholders also reported, however, that HFPCSNs needed to and had learnt from specialists in cardiology and in end of life care, and that the success of some posts was reliant on this synergy or blending of skills.

Stakeholders particularly valued the apparent improvements in co-ordination of services between primary and secondary care that HFPCSNs afforded. This was especially so when patients were able to die in their preferred place, usually home, either because of timely discharge from hospital and/or the timely provision of equipment, aids, care packages and medication within the community.

All the HFPCSNs were seen as working as part of a team, and the transfer of skills or the up-skilling of colleagues were seen as key achievements of the nurses, especially when this allowed other staff to improve the quality of care they provided or allowed patients to access new services.

While some stakeholders reported that the HFPCSNs had more time to address the needs of patients than other members of hospital or community based healthcare teams, this was tempered by suggestions that many of the nurses worked long hours and/or over and above what was expected of them to set up and maintain a high quality service. These conflicting reports suggest that while time is important in providing high quality end of life care services to patients with advanced heart failure, such time may have been given to date on the basis of goodwill on the part of HFPCSNs rather than factored properly into job descriptions and expectations.
4.2 Interviews with patients or carers

“Advice and information have been invaluable. Everything has been explained in words that I can understand. I feel I am able to speak directly to you about any problems or worries I have with Mum. At times it has been difficult getting through to the GP surgery, but you have always got back to me if I left a message on your answer-phone.”

4.2.1 Introduction

The evaluation needed to include information from patients and carers about their experiences of being cared for or working with the HFPCSNs. The scope of this evaluation did not allow for an independent researcher to identify patients and carers, and then conduct face to face interviews under rigorous conditions. Instead, each HFPCSN was asked to identify and interview two patients or carers from their current caseload. This method does have potential weaknesses. The nurses could choose only those patients and carers who have had a positive experience of their care; they might avoid asking patients who they feel are too ill or unlikely to want to take part in an interview; and the patients and carers might feel unable to give negative comments about the nurses work for fear of upsetting their relationship, or concerns they may have about the future funding of the nurse’s post. Notwithstanding these weaknesses, patient and carer views are essential in any service evaluation and asking the nurses to undertake the interviews offered a practical and timely way forward.

4.2.2 Methods

The nurses were instructed to choose the “next suitable” patient or carer for interview, but to avoid asking patients or carers who were or would be distressed or fatigued by the interview.

The interviews were structured (Appendix 3) and included questions on socio-demographics and length of time patients had been known to the service, which the nurses would know from patient records. The interview included two questions seeking information on the interviewee’s experience of using the service:

1. What are the three things that I have done that have been most helpful to you? (Prompt: Why was that particularly helpful?)

2. What three things could I have done to improve things for you? (Prompt: Why would that have been helpful?) Has anything been unhelpful?

These questions were designed to encourage the interviewee to concentrate on the practical or tangible aspects of the HFPCSN work rather than their personal qualities.

Nurses from six localities each returned two completed questionnaire schedules, while two did not return any interview schedules. Two of the interviews were with bereaved carers, one included both a patient and carer, five of the interviews were with female patients and six of the interviewees were over 71 years old. The interviewees had been known to the service for between three months and two years, with eight being in contact with the service for 10 months or less.

Data from the 12 completed questionnaires was entered on to a framework and analysed using a constant comparative approach.
4.2.3 Results

Analysis of the data revealed five common categories of comment from patients and carers. Four categories related directly to the service the nurses offered. These included:

1. Improved quality of service
2. Better access to other services
3. Access to specialist knowledge and advice
4. Addressing or supporting end of life or bereavement needs.

The other category reflected patient and carer experiences of their or their loved one’s illness, and is best described as improving confidence and reducing anxiety. It is important to note that implicit in much of the patient and carer data in any of the categories were issues related to quality of life and a desire to stay or to have loved ones remain at home, regardless of the stage or severity of their illness.

4.2.3.1 Improved quality of service

Patients and carers felt that the HFPCSNs offered a “better service” than they had received previously. Both patients and carers reported that the HFPCSNs ability to visit patients at home on a planned basis, or when necessary due to a perceived emergency, was a key improvement to the service they received. Both groups of interviewees reported that the specialist nurses were able to offer more time than other healthcare practitioners:

“Listening to me and not rushing your visit. As I sometimes feel the ‘heart nurse’ is only interested in my heart.”

Improved co-ordination of services was also reported as a major improvement:

“You keep the doctors and other nurses who look after me up-to-date. You pass on information to them and it’s good that you all work together.”

The interviewees also appreciated having easy access to the HFPCSNs over the telephone. Being able to get directly through to the nurse or their answer phone was seen as much easier than trying to get through to the GP practice or hospital clinics:

“Telephone contacts between visits, being able to call you and you responding on the same day have been a great comfort.”

4.2.3.2 Improved access to other sources of help

The interviewees reported that arranging new equipment and aids, and helping them access adaptations to their homes had been an important help to them, as had help in getting their “benefits sorted out”. Through the HFPCSNs’ interventions, patients had accessed stair lifts, walk-in showers and ramps, all of which had directly improved patients quality of life:

“You have also arranged social services, occupational therapy assessment for adaptations to our flat for mum, and district nurses for leg dressing and bloods very quickly. This is very reassuring.”

Arranging for home-based medical equipment was also reported as an important role of the HFPCSNs:

“You arranged for me to have oxygen and a nebuliser at home, this has kept me out of hospital. I can breathe easier and feel less anxious as I know they are there.”

The HFPCSNs also helped patients to access services from local hospices. This was greatly appreciated, often more than the interventions of the nurses themselves:
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“Socially I am not getting out much so visits to the hospice are good and I had a back massage this morning, it’s great.”

4.2.3.3  Access to specialist help and advice
Both patients and carers reported that the HFPCSNs offered them a level of specialist help and advice that other healthcare professionals were not able to offer. The interviewees reported that it was helpful knowing that someone ‘qualified’ or ‘experienced’ in heart failure was visiting them, and offering practical and timely advice on problems they had seen before:

“General advice supplements such as fortisips and juices because she lost so much weight and lost her appetite. We were really worried she wouldn’t eat; you discussed portion sizes and to try not to ‘overface’ her with big portions. We would never have known about supplements like fortisips and it was very reassuring.”

The interviewees reported that the specialist nurses gave advice in a way that was easy to understand, and introduced interventions that improved the patient’s symptom burden. The HFPCSNs were able to offer effective advice on ‘changing’ and or organising patients’ medications:

“I will never forget that time when you first started coming and she was so poorly, she had not been out of hospital long; we thought she needed to go back in but you cut back her water tablets and she picked up very quickly.”

Two patients saw HFPCSNs at a heart failure clinic held at a local hospice. One reported that “it made me feel special, I had a good check up the staff were interested in me”.

4.2.3.4  End of life and bereavement care
As already stated, patients and carers reported that the HFPCSNs had more time to talk and listen than other healthcare professionals. When conversations were focussed on end of life or bereavement, they also reported that the nurses were more likely to act on issues raised than others. The HFPCSNs also spent time with patients and carers, both before and following patients’ deaths. This was reported as a unique and beneficial aspect of the role:

“Talking to me, preparing me for the next stage of my condition.”

“You visited me and rang me after my wife died, and helped me sort things out as though I was not alone.”

“(The HFPCSN) made sure she was contactable and there when my husband needed to speak to her, and time was never an issue even when she was off duty she insisted she was only a phone call away. My husband’s consultant discharged him into (HFPCSN’s name) care. I honestly look back now and do not know how my husband and myself would have coped if he had not put us in touch with (HFPCSN’s name). She allowed my husband to remain at home and die.”

4.2.3.5  Increased confidence and reduced anxiety
Both patients and carers reported that the HFPCSNs interventions had reduced their anxiety about their illness. This was often through improving symptom burden or offering useful ways of managing symptoms, all of which improved patients’ quality of life. While this was explicit in some answers, it was implied in others:

“Saved my life, I was very down arguing with the wife; I felt so bad because I was full of water. Then you sorted me out so I was able to get out of the chair and house, and start my hobbies again.”
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“You will take blood and do investigations and will tell me the results. This puts my mind at rest. You make changes to my care after tests; this makes me feel better. You explain things and are willing to listen to my questions. This makes me feel less anxious. I know you are reliable and don’t hide things from me; this gives me confidence. When I feel better (name of wife) feels better too. I know that you are always on the end of phone for advice and reassurance.”

Six interviewees reported that there was nothing the PCFHN could have done to improve the care they had received. One patient reported that their care would have been improved if the HFPCSN had been able to “take the illness away”, and more effectively improving their breathing: “My breathing is a constant reminder that I am ill”. Other interviewees reported that they would have liked intravenous diuretics at home, as this may have avoided hospital admissions. They would have liked to see the HFPCSN more often. Others reported that there should been more HFPCSNs as it was difficult to access appropriate help when the HFPCSN was off duty. One carer reported that he had not been prepared for his wife’s sudden death.

4.2.4 Discussion

Patients and carers valued the many unique aspects of the HFPCSNs care. By having sufficient time to address and coordinate optimum care for these patients, using their specialist knowledge about heart failure, effective interventions and end of life issues, patients and carers felt the HFPCSNs offered a better quality of service than they had experienced previously. The benefits of HFPCSN care were reported not only in improved symptom management, but also in access to aids and adaptations. Patients and carers reported that these resources improved quality of life, confidence and an improved ability to cope with the illness, and in some cases death.

It is notable that half of all the interviewees were unable to think of any ways in which the HFPCSN could have improved their care, and the majority reported potential service improvement related to having greater access to HFPCSNs. A notable example of possible service improvements was a request for provision of home based intravenous diuretics. This reflects an acknowledged variation in practice throughout the UK, and an area for future service development.

The patient and carer interviews provided good information on the ways in which individual services and personnel had made an impact on care. All those interviewed referred repeatedly to the benefits of the HFPCSN. This data, however, does not allow us to compare different service models, as the interviewees had only experienced one type of service about which they could comment, and different service models could potentially have been more or less beneficial to different individuals. Nevertheless, the data does suggest that interventions from HFPCSNs make a unique contribution to the care of patients regardless of how a service is configured.
Chapter 5  Discussion

This evaluation shows that the eight HFPCSN sites have been successful in improving the care of patients with heart failure requiring palliative or end of life support. The nurses have improved the appropriateness, timeliness and continuity of patient care by providing specialist holistic assessment.

The HFPCSN played a significant role in identifying when patients were entering the last phase of their illness. There is evidence that healthcare professionals have widely differing views about what constitutes end of life care and palliative stages of illnesses (Shipman et al 2006). The skills of the HFPCSNs in identifying the need for palliative and end of life care was particularly valued by professional stakeholders; however, often neither the HFPCSNs nor the healthcare professional stakeholders were able to say if and what formal criteria were used in making these judgements. Often, a number of strategies for identification were deployed, including holistic assessments, interpretation of medical investigation results, prior knowledge of the patient, and reports of a noticeable increase in the time generalist healthcare professionals spent with a patient or their family. How these factors were weighed up by the HFPCSNs was not always evident, although some did use a well-articulated approach to patient identification. This is consistent with the recognised challenges in accurate prognostication among patients with advanced heart failure, and that generalist healthcare professionals may lack the knowledge, time and skills to cope effectively with the complexity of this task without specialist support. The HFPCSNs appear to play a key role in bridging the specialist-generalist divide, particularly around the accurate identification of patients nearing the end of life.

Being able to correctly identify this group of patients is the essential first step in determining and meeting their needs. Our findings suggest that patients with advanced heart failure have a consistent and common set of core end of life or palliative care needs that can usually be uncovered and addressed by holistic assessment, which is seen as one of the central tenants of palliative care. The HFPCSNs have unique knowledge that blends aspects of cardiology and palliative care, allowing them to effectively meet these needs. In addition to this blend of knowledge, having sufficient time and flexibility to meet the needs of patients and their families was seen as a key benefit of the HFPCSN service.

The HFPCSNs were keen to use the end of life care tools advocated in the National End of Life Care Strategy, including the completion of advanced care plans and/or documenting preferred priorities for care. However, a number of patients were reluctant to accept that they were nearing the end of their lives, or indeed that they were unlikely to recover from another acute episode. Such reluctance to acknowledge or recognise the likely outcome of their condition has been noted elsewhere (Rogers et al 2000, White et al in press); however, it does raise particular questions about the use of advanced care planning for patients with conditions with an uncertain trajectory, such as heart failure. It is important that the HFPCSNs accept that patients and families will vary in their willingness to discuss issues related to the end of life, and to view this variability as appropriate and not necessarily an indication of failure of the service.

The increasing use of implanted devices raises important clinical issues for advance care planning, and requires further work to develop protocols, policies and ethical statements regarding their de-activation.

Most importantly, it is vital that there is consistency and continuity between key healthcare professionals when talking with patients and families about prognosis and planning. Conflicting messages at such an uncertain time will create significant difficulties for patients and families who may already be struggling to manage the difficult feelings that can be present at the end of life. Communication between the multi-professional team is critical to help patients and families feel confident that there is a shared understanding and approach to care.
Some generic heart failure nurses had reported their concerns to the HFPCSNs that their presence would deskill them in caring for patients with palliative or end of life care needs. Our evaluation yielded no direct evidence of such deskilling; however, this nonetheless remains a risk of introducing another ‘sub-specialist’ role into the community setting. Arguably, palliative care should be a legitimate area of care and expertise of all specialist heart failure nurses, as it is unlikely that the sub-specialist HFPCSN role will become as widespread as the heart failure nurse role. Generalist cardiologists and primary care stakeholders reported that the HFPCSNs had ‘up-skilled’ cardiology teams, most particularly the hospital based cardiology nurses.

Further work is required to explore whether palliative and end of life care should be part of the scope of the heart failure nurse role, or whether a sub-specialism should be developed in its own right. This requires development of a strategic vision regarding the HFPCSNs role. The six service models described in this evaluation, which revolve largely around direct patient contact by the HFPCSNs through an assigned caseload, may not be a viable model in the longer term, particularly as the needs of heart failure patients at the end of life become more widely recognised. The HFPCSNs may need, for example, to adopt a model often seen in specialist palliative care with three different levels of intervention, including advice to colleagues; one-off or intermittent face to face consultations with patients with particular issues requiring a more specialist input; or the offer of an ongoing package of palliative care to patients with the most complex needs.

Stakeholder and lay feedback stressed that patients would benefit from the HFPCSN service providing cover for weekends and out of hours. Many community services face similar challenges around providing an adequate level of 24/7 support for patients, particularly those services which aim to help patients avoid hospital admission. Further work to understand the nature of out of hours needs, effective mechanisms for communicating advance care plans to out of hours services and improved co-ordination with generic services, such as community nursing, may be worth exploring if a 24/7 hour service is not financially viable.

Like all services, the HFPCSNs had to function within national and local health service imperatives. Their work was influenced by local service provision, policies and cultures, and all these local factors had an impact on the type of service it was possible to provide. The provision of 24/7 home based care, community based oxygen and IV diuretics at home were all subject to local differences in practice and policies. These interventions were all seen as essential in reducing unplanned hospital admissions and/or increasing the number of home deaths. Support from cardiologists, nurse managers and commissioners were also factors that affected what the HFPCSNs were able to achieve, with the absence of any one of these resulting in less than optimal service provision. Any lack of support often inevitably gave rise to increased concerns about future funding, not at all surprising when piloting a new service.

Certain key elements are identified as important to the success of the HFPCSN role. These include completing a course in advanced communications, being a non-medical prescriber, and being able to admit patients directly to hospital or hospice. These skills all help to ensure a flexible service, which is better able to deliver high quality care that takes account of patients’ preferences about where they would like to be cared for and to die.

The HFPCSNs rarely mentioned teaching or education as an important part of their job; however, professional stakeholders particularly valued their educational role. While the evaluation revealed few accounts of formal education sessions, informal or practice based learning that arose while working alongside, or in conjunction with, the HFPCSNs was reported as a key way of improving patient care. In future, the HFPCSNs may need to consider how to optimise these educational opportunities as a way of increasing the skills of other healthcare professionals, and potentially decreasing demand for and reliance on their own services. For example, the reported reluctance of some hospice staff to accept referrals for patients with heart failure has been highlighted by other authors (Frankland et al, 2007). This demonstrates a need for education that is tailored to the needs of the different healthcare professionals, who may be involved in the care of patients with heart failure at the end of life.
Irrespective of their professional backgrounds, all the HFPCSNs were passionate about their posts, and were committed to improving end of life care for heart failure patients. This passion led, in many cases, to the nurses working long hours in order to deliver a high quality and responsive service. Such commitment is hard to cost, may be difficult to replicate nationally, and indeed no service model can be predicated on assumptions about staff working significantly longer hours to deliver the service aims. The issue of time – including time required as patients’ needs become more complex; time commitments of staff to meet those needs and patients’ appreciation of an unhurried service where there is time to explore and express many of the complex feelings that are present at the end of life – will benefit from further exploration to improve our understanding of how best to meet the needs of this patient group.

Stakeholders provided good information on the ways in which individual services and healthcare professionals benefitted from contact with the HFPCSNs. The data collected, however, does not allow us to compare the HFPCSN model with other services, as the interviewees only had experience of one type of service. Other service models could potentially have been more or less beneficial to different individuals. Nevertheless, the data does suggest that interventions from HFPCSNs made a unique contribution to the care of patients, regardless of how a service was configured. Further work comparing this type of specialist service to ‘usual care’ would be welcome.

This evaluation has some acknowledged limitations. It was heavily reliant on the HFPCSNs themselves to provide information about their service, and to identify suitable lay and professional stakeholders to provide insights into the impact of the service. The strength of the evaluation, however, lies in the triangulation of information from different data sources, and different methods of data collection. The findings from each discrete element of the evaluation suggest that all eight pilot HFPCSN sites have been consistently successful in improving the care of patients with advanced heart failure.
Chapter 6  Key findings

6.1 Models of service delivery

- It was not possible to distinguish one superior model of service delivery for the HFPCSN. Factors identified as core to a successful model include:
  a. Consistent support from local cardiologists and cardiology teams, with strong continuity in communications with patients, families and primary care.
  b. Support from local managers, particularly commissioners.
  c. Configurations of local health and social care services that support excellent end of life care.
- The HFPCSNs can come to post from either cardiology or palliative care backgrounds, but all found specialist training in advanced communication skills and understanding of the heart failure disease trajectory an essential requirement for the post. Sensitivity to patient and family comfort, and willingness to discuss issues related to end of life care, are key, as is the willingness to accept that not all patients will choose to engage in these discussions.
- Being a non-medical prescriber and having access to community IV diuretics are important for successful symptom management, and may be key in admission avoidance.
- Nurses like to use the national End of Life Care tools, such as the PPC documents, GSF and LCP, and tend to measure their own success in the number of patients they enable to die at home.
- The long term viability of the HFPCSN role depends, in part, on further testing of models of both a generalist and specialist approach to meeting the palliative care needs of patients with heart failure. It may be that a small cadre of HFPCSNs will provide the specialist learning and experience that can be shared with generalist colleagues, and deliver an overall improvement to care across all settings and service models.

6.2 Impact of HFPCSNs

- This evaluation has gathered a good deal of information that suggests it is possible to identify patients with advanced heart failure who are entering the palliative or terminal phase of their illness, though more work in this area is needed.
- This group of patients have been shown to have a core set of end of life care needs that are not dissimilar to those of other dying patients, and which the HFPCSNs are expert in addressing.
- Education should be a key part of the HFPCSNs role. The nurses should aim to increase the skills of all those they work with, and to directly address concerns about deskilling of the generic heart failure nurse.
- Both professional stakeholders and patients and carers value the HFPCSNs, and see them as making a positive contribution to patient care.
- Patients and carers in particular would like a better level of cover from HFPCSNs, including weekend and out of hours access and alternative cover when their own nurse is away.
Chapter 7  Conclusion

The HFPCSNs have been successful in improving the quality of end of life care for patients with advanced heart failure. Despite having different nursing backgrounds, and working in slightly different ways, the nurses have been able to identify and address a core set of end of life needs for patients with heart failure. Our findings suggest that the HFPCSN role could be delivered as a dedicated post that allowed sufficient time and flexibility to meet the complex and often rapidly changing needs of patients and their families. This would be dependent, inevitably, on local resource availability. Alternative models where the palliative care needs of heart failure patients became part of the core role of heart failure nurses would, arguably, help to contain additional service costs, but would present considerable challenges in both the time and training required to deliver a high standard service.

While external factors clearly influence both the manner and type of care the HFPCSNs are able to provide, personal qualifications and qualities also influence the delivery of care. To be most successful, HFPCSNs would ideally have a background in cardiology with experience of heart failure management. For those coming from a palliative care background, a good and increasing knowledge of heart failure and its treatment is crucial. Nurses need excellent communication skills, and it seems that completing a course in Advanced Communication Skills may be an essential requirement of the post. Being a non-medical prescriber also appears to be helpful, as does having admitting rights to hospital and/or hospice.

The success of the HFPCSN post is absolutely reliant on the support of local cardiologists, nurse managers and commissioners. The absence of the support of any of these three sources will compromise the effectiveness and viability of the role. Additionally, clear policies and operational guidelines for the delivery of key aspects of care in a community setting, such as intravenous diuretics and the deactivation of implanted devices, are vital for enabling more patients to receive more care at home, if that is their choice.

To be truly successful, the HFPCSNs need to press for a change in some long held views about the nature of heart failure, and the purpose of dedicated palliative care. The lay public and healthcare professionals, especially those working in cardiology and specialist palliative care, need to acknowledge the nature of advanced heart failure in the terminal phase with an often heavy symptom burden, but responsive to palliative interventions usually associated with the care of cancer patients. However, optimisation of medical therapy for heart failure throughout is essential and is best managed by a cardiology consultant or heart failure specialist nurse.

Following the conclusion of the project, funding for all but one of the innovative palliative care posts came to an end in March 2009. The nurse in this post will continue to be funded until April 2011 and the post has a clear remit to up-skill the local heart failure specialist nurse team in palliative and supportive care and to work on improving links with and the skills and knowledge among local health care providers.

One nurse has left her post and the local PCT has decided not to replace her due to the present economic climate. The nurses from one site will return to their former posts having established a framework that will help to identify patients likely to benefit from palliative care and up-skilled local healthcare professionals in caring for patients with advanced heart failure.

One nurse has secured substantive funding from a local hospice to work exclusively with heart failure patients with supportive and palliative care needs. The four other nurses have substantive funding to continue their work with patients with advanced heart failure, based largely on the models of working outlined in their original bids to the BHF.
Chapter 8  Abbreviations

BHF  British Heart Foundation
BHF HFPCSN  British Heart Foundation heart failure palliative care specialist nurse
DN  District nurse
GP  General practitioner – Family doctor
GSF  Gold Standard Framework
LCP  Liverpool Care Pathway
PCC  Preferred priorities for care
HFPCSN  Heart failure palliative care specialist nurse
HFPCSNs  Heart failure palliative care specialist nurses
Chapter 9 References


Yin RK. *Applications of Case Study Research.* Sage Publications 2003
## Appendices

### Appendix 1  Service model template

<table>
<thead>
<tr>
<th>Name</th>
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</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>List all the people who refer patients to your service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>List all the services, interventions and treatments you offer as part of your service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>List three or four things that you feel would improve the service you are able to provide</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>List all the services, health and social care professionals you refer patients on to</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Why did you choose the job?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>How do you spend the majority of your time, what are your main tasks or</td>
</tr>
<tr>
<td>main part of your role? (Prompt for symptoms)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>What is your biggest challenge in your everyday working?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>What are the blocks to doing what you would really like to do in this</td>
</tr>
<tr>
<td>post?</td>
</tr>
</tbody>
</table>
Appendix 3  Healthcare professionals telephone interview guide

1. What does BHF HFPCSN (nurse’s name) do?

2. What did you do before (nurse’s name) was in post?

3. Has having (nurse’s name) in post improved patient care?

4. How has she achieved that?

5. Has (nurse’s name) made your job easier?

6. I’m not saying this will happen, but what would you miss most if (nurse’s name) left tomorrow?
Appendix 4  Patient and carer questionnaire

Evaluation of BHF heart failure palliative care specialist nurse project

Patient and carers interviews

The aim of these interviews is to gather some basic information from patients and their carers about their experiences of having a BHF HFPCSN involved in their care. I would like you to ask two and/or carers if they would feel able to complete a short interview with you about the care you have provided and ways in which you have been able to help them. Please explain that information from the interviews will be included in an evaluation of your service. Please make it clear that all the information they provide will be anonymous and that you will not pass on any personal or identifiable details to the evaluator. Additionally please make sure that patients or carers know that they do not have to complete an interview as it is entirely voluntary.

Please complete the basic information questions and then go on to ask the questions. Please record as accurately as possible the patient’s or carers responses to the questions in the spaces provided. If the patient or carer gives a one word or short answers for example “help with benefits” or “would have liked to see you more often” - ask them why that has or would have been particularly helpful and detail their response. Please complete by hand at the time of interview and type up and send to me via email angie.rogers@blueyonder.co.uk

Please circle as appropriate

<table>
<thead>
<tr>
<th>Is the interviewee:</th>
<th>A patient</th>
<th>A carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are they:</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>How old are they?</td>
<td>Less than 40</td>
<td>41 – 50</td>
</tr>
<tr>
<td></td>
<td>51 – 60</td>
<td>61 – 70</td>
</tr>
<tr>
<td></td>
<td>71 – 80</td>
<td>Over 81 years old</td>
</tr>
<tr>
<td>How long has the patient or family been known to your service?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What are the three things that I have done that have been most helpful for you? (Prompt: “Why has that been particularly helpful?”)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What three things could I have done to improve things for you? (Prompt: “Why would that have been helpful”) Has anything been unhelpful?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td></td>
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<tr>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Appendix 5  BHF heart failure palliative care specialist nurses final questionnaire 2009

<table>
<thead>
<tr>
<th>Name</th>
<th>Date post started</th>
</tr>
</thead>
</table>

## Work location / Base
- Community
- Hospital
- Other
- Please specify below

## Database
- Athena
- Other
- Please specify below

## Training/Professional development

1. Have you completed an accredited heart failure training programme?
   - Yes
   - No
   - In progress

2. Have you undertaken a palliative care module?
   - Yes
   - No
   - In progress
   - If yes, specify module and where undertaken:

3. Have you undertaken an Advanced Communication skills course?
   - Yes
   - No
   - If yes, please specify:

4. Are you a non-medical prescriber?
   - Yes
   - No
   - In progress

5. If yes, are you prescribing in your role?
   - Yes
   - No

6. Please identify any additional professional development you require to support you in this role

## Role, supervision and referrals

1. Which of the following would you identify as descriptive of your role? (please tick all that apply)
   - Advisory
   - Clinical
   - Teaching
   - Strategic
   - Other
   - Please specify

2. Who is your clinical supervisor?
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. What is his/her speciality?</td>
<td>Cardiology □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □</td>
</tr>
<tr>
<td>4. Do you have direct access to a cardiologist for advice?</td>
<td>Yes □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □</td>
</tr>
<tr>
<td>5. What additional supervisory support would be helpful in your role?</td>
<td>Cardiology □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □</td>
</tr>
<tr>
<td>6. How are patients referred to you?</td>
<td>GP □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □</td>
</tr>
</tbody>
</table>
Collaboration within your role

1. Are you functioning as part of a multi-disciplinary team?
   Yes [ ] No [ ]

For each of the following types of healthcare professionals, please describe the extent of your collaboration.

**Part of MDT:** Please tick if this type of healthcare professional is part of your core multi-disciplinary team

**Degree of collaboration:** Please indicate the degree of interaction you have with each healthcare professional (Frequent, occasional, rare, never)

<table>
<thead>
<tr>
<th>Healthcare professional</th>
<th>Part of MDT</th>
<th>Degree of collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generic heart failure nurse</td>
<td>Hospital</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community</td>
<td></td>
</tr>
<tr>
<td>Nursing team (hospital)</td>
<td>Cardiology</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Medical admission unit</td>
<td></td>
</tr>
<tr>
<td></td>
<td>General medicine</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Accident and emergency</td>
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<tr>
<td></td>
<td>Care of the elderly</td>
<td></td>
</tr>
<tr>
<td>Community nurses</td>
<td>Community matron</td>
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<tr>
<td></td>
<td>District nurse</td>
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<tr>
<td></td>
<td>Practice nurse</td>
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<tr>
<td>Palliative care nurses</td>
<td>Hospital</td>
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<tr>
<td></td>
<td>Community</td>
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<tr>
<td></td>
<td>Hospice</td>
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<tr>
<td>Physicians</td>
<td>Cardiologist</td>
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<tr>
<td></td>
<td>General medicine</td>
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<td></td>
<td>Elderly care</td>
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<tr>
<td></td>
<td>Accident and emergency</td>
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<tr>
<td>Palliative care physicians</td>
<td>Hospital</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community</td>
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<tr>
<td></td>
<td>Hospice</td>
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Appendix 5
<table>
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<th>Service</th>
<th>Hospital</th>
<th>Community</th>
<th>Hospice</th>
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<td>Physiotherapist</td>
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<td></td>
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<tr>
<td>Dietician</td>
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<td></td>
<td></td>
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<tr>
<td>Occupational therapist</td>
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<tr>
<td>Counsellor</td>
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<tr>
<td>Pharmacist</td>
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<tr>
<td>Social services</td>
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<tr>
<td>Bereavement services</td>
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<tr>
<td>Other: Specify</td>
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</tbody>
</table>
### Caseload

1. Which type of heart failure patients does your caseload include?
   - Only patients with supportive and palliative care needs
   - Generic caseload and patients with supportive and palliative care needs
   - If yes specify: percentage generic
   - Percentage requiring supportive and palliative care

2. Total no. of patients seen while in post:
   - No. of active patients:
   - Average caseload size:
   - No. of patients who have died:

### Broader support environment

1. Do you have access to hospice care?
   - In-patient
   - Day care
   - Other

2. Do you have access to carer respite support?
   - Hospice
   - Day hospice
   - Hospice at home
   - Other

3. Do you have access to bereavement services for your patients and their carers?
   - Yes
   - No

4. Do you have links with specialist palliative care services in your area?
   - Yes
   - No
   - Please describe

5. Do you have links with ‘Out of Hours’ care providers for your patients?
   - Yes
   - No
   - Please describe

### Broader contextual environment

1. Is there an integrated care pathway being used in your area?
   - Yes
   - No

2. Is advanced care planning used in your area?
   - Yes
   - No

3. Are clinical management plans being used in your area?
   - Yes
   - No
<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>4. Are patients able to receive IV diuretics outside the acute hospital setting?</td>
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<td></td>
</tr>
<tr>
<td>5. Is the Gold Standards Framework being used in your area for heart failure patients?</td>
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<td></td>
</tr>
<tr>
<td>6. Is the Preferred Priorities of Care document being used in your area?</td>
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<td></td>
</tr>
<tr>
<td>7. Is the Liverpool Care Pathway being used in your area for heart failure patients?</td>
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</table>

8. Give a brief description of your role:

9. Highlight key developments and innovations in your role:

10. Describe any barriers/challenges to performing your role:
Appendix 6  Data from BHF Final Questionnaire 2009

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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
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<td>01/10/2006</td>
<td>01/03/2007</td>
<td>19/03/2007</td>
<td>23/10/2006</td>
<td>06/12/2006</td>
<td>01/04/2008</td>
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<td>Months in Post</td>
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<td>33</td>
<td>36</td>
<td>29</td>
<td>31</td>
<td>36</td>
<td>Post 1: 34</td>
<td>Post 2: 11</td>
<td>18</td>
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<td>Forth Valley</td>
<td>Heart of England</td>
<td>South Yorkshire</td>
<td>Sandwell PCT</td>
<td>Bradford &amp; Airedale</td>
<td>Glasgow &amp; Clyde</td>
<td>Glasgow and Clyde</td>
<td>6</td>
</tr>
<tr>
<td>Base</td>
<td>Community</td>
<td>Commn/ Hosp</td>
<td>Hospital</td>
<td>Community</td>
<td>Community</td>
<td>Hospital base working in the community</td>
<td>Hospital base working in the community</td>
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<td>Access to cardiologist?</td>
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<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>8</td>
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<tr>
<td>Patients Seen / Caseload</td>
<td>33</td>
<td>193</td>
<td>620</td>
<td>309</td>
<td>'60</td>
<td>132</td>
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Frequency of collaboration with other healthcare professionals

(F - Frequent, O – Occasional, R – Rare, N – Never)

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<td>F</td>
<td>8</td>
</tr>
<tr>
<td>Hospice at home</td>
<td>F</td>
<td>F</td>
<td>F</td>
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<td>8</td>
</tr>
</tbody>
</table>
Appendix 7  Overview of funding costs for the BHF heart failure palliative care nurse role

Aim
The aim was to obtain an estimate of the cost to fund a NHF HFPCSN for the first year in post and on an annual basis thereafter.

Sources of information
Information regarding the role of each HFPCSN, and likely costs incurred to support that role, were obtained from Lynda Blue. Details of courses and conferences attended by each HFPCSN and funded by the BHF were obtained from Cynthia Curtis and Sonja Tengwall. Bianca Heggeland provided information on salary and other upfront costs.

Costs included
Base salary, upfront costs for office equipment, training costs and associated travel expenses were included in the overall cost estimate. It was determined that no additional costs are incurred for cardiologist advice, clinical supervision, office stationary or ongoing office costs. It is assumed that these costs are met by the respective NHS trusts.

The details of each cost item are described below.

Salary
The BHF pay a block grant of £40,000 per year to each NHS Trust to cover salary, on-costs and travel. These funds are not monitored anymore closely and in some cases they would not be covering the full cost of the post.

Office equipment
BHF funds up to £5,000 per post upfront to cover office equipment (laptop, desk, phone).

Training costs (based on the clinical roles)
Training costs varied widely by role and full details are included in the Appendix. The average cost of training was estimated for the six clinical roles only. The average cost incurred to date across these six roles was £975.

All of the nine HFPCSN’s had attended the Advanced Communications Skills Course, the average cost of training is £1373 per nurse.

Training expenses (for the clinical roles)
Discussion with BHF training coordinators revealed many of the courses require accommodation of up to four nights, along with travel expenses. Assuming accommodation costs of £100 /night, and travel = £50; and that on average each HFPCSN will require 2 x 4 nights, and 1 x 2 nights accommodation and travel:

The best estimate of training expenses per HFPCSN = £1200
Total costs

The average cost of funding a clinical HFPCSN post is approximately £47,573 during the first year and approximately £40,000 per year thereafter. This includes the following costs:

<table>
<thead>
<tr>
<th>Item</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salary</td>
<td>£40,000</td>
</tr>
<tr>
<td>Office equipment</td>
<td>£5,000</td>
</tr>
<tr>
<td>Training costs</td>
<td>£1,373</td>
</tr>
<tr>
<td>Training expenses</td>
<td>£1,200</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>£47,573</strong></td>
</tr>
</tbody>
</table>
Details of training received

<table>
<thead>
<tr>
<th>Nurse/site</th>
<th>Role</th>
<th>Training costs</th>
</tr>
</thead>
</table>
| 1          | Clinical | GSF Fifth Annual Conference £145  
End of life workshop £20  
Clinical assessment – Caledonian University £340  
Total = £505 |
| 2          | Clinical | Enhanced care practice MSc (Advanced practice) £425  
Enhanced care practice MSc (Advanced practice) £750  
Palliative care for people with non-malignant conditions £70  
Total = £1245 |
| 3          | Clinical | Annual Cardiovascular Disease Conference course fee £300  
Looking forward to the end of life care strategy - £255.50  
Total £555 |
| 4          | Clinical | Heart Failure 2009 - Heart Failure Association of the ESC  
Total £153 |
| 5          | Clinical | Evidence based practice proposal, Evidence based practice project £1728 – BHF supporting £850 of this  
Core planning module Wolverhampton University- £319.60  
Advanced communication course – 3 day BHF run - £597  
Total £1767 |
| 6          | Clinical | Caledonian heart failure module – £660  
Clinical assessment course – Caledonian University £340  
Conference – palliative care, broadening our horizons - £25  
Advanced communication – 3 day course run by BHF approx £597  
Total £1622 |
| 7a         | Project role | BSc Cancer & palliative care 2006-07  
Total £530 |
| 7b         | Project role | PG Certificate in teaching & learning £560 x2 + £526  
Total £1646 |
| 7c         | Project role | Advanced communication course  
Not run by BHF. Glasgow University £250 |
| 8*         | Project role | Palliative care module – Caledonian University  
Total £320 |

*started 1 year later

Nurse 7b replaced Nurse 7a. 7b and 7c job share one full-time position.
BEATING HEART DISEASE TOGETHER