



British Heart
Foundation

Heart failure nurse services in England: Executive summary



LOTTERY FUNDED

THE UNIVERSITY *of* York

Ten reasons to appoint a heart failure specialist nurse (HFSN):

- 1 Heart failure is common, costly, and impacts greatly on quality of life. HFSNs can work across primary, secondary and tertiary care teams, improving communication and resulting in a more integrated and seamless care pathway for patients.
- 2 It is known that multi-disciplinary team interventions benefit people living with heart failure by improving symptom control, reducing admissions and increasing survival. HFSNs can help improve access by patients to these interventions and achieve quality and outcome framework (QOF) targets by organising careful initiation and titration of heart failure medications.
- 3 HFSNs can extend knowledge in primary care of how to educate, support and manage stable patients, including uptitration of medications. This can be performed by the primary care staff they have trained, and will help keep stable patients out of hospital, while allowing HFSNs to focus on more complex patients with advanced heart failure.
- 4 HFSNs are in a position to co-ordinate care and clinically assess patients, take a concise history, adjust medication in response to clinical status, closely monitor blood chemistry following medication adjustment, and check for clinical and renal deterioration.
- 5 HFSNs can help patients understand and manage their condition, providing them and their carers with education and advice about heart failure, its treatment and what to do if they have a problem. They have a key role in enabling patients and carers to navigate the patient pathway.
- 6 HFSNs based in the community can rapidly access patients and ensure they get referred on to appropriate services. If there are good links with secondary care, an integrated approach will result in a seamless and efficient service.
- 7 HFSNs improve health-related quality of life in both patients and carers.
- 8 It is known that patients with heart failure have high levels of anxiety and depression, which are related to increased morbidity and poor prognosis. HFSNs can assess the mental health of patients and refer on appropriately.
- 9 HFSNs reduce all cause admissions by an average of 35%. Inappropriate unplanned admissions are avoided through close monitoring. Patients managed by HFSNs still require necessary planned admissions but fewer. A saving of approximately £1,826 per patient seen is gained after the costs of the HFSNs have been deducted.
- 10 HFSNs can co-ordinate a shared care approach to end of life care with other members of the MDT.



Foreword

Heart failure – the inability of the heart to perform its pumping function adequately – causes distressing symptoms and, at its most severe, has a worse outcome than many common cancers. Because of the increasing age of the population, and greater numbers surviving heart attacks, heart failure is becoming an ever increasing burden on our health services.

A number of clinical trials have shown that heart failure specialist nurses (HFSNs) can improve the management of patients with heart failure. Following the successful pilot of funding 16 HFSNs in 2001, the British Heart Foundation (BHF) approached the Big Lottery Fund (BIG) for additional funding. Consequently, 76 HFSNs were employed by primary care trusts (PCTs) in England, who were funded by BIG and managed and supported by the BHF. However, unlike the clinical trials where heart failure nurses were usually associated with, and supervised by specialist centres, our heart failure specialist nurses have been working in the “real world” in disparate areas of England.

This report records an independent evaluation of the work of these nurses which was undertaken by researchers at the University of York. It confirms that heart failure specialist nurses provide great benefit and much comfort for patients with heart failure, and their carers. Importantly, for our cost conscious health-care environment, it also confirms that these nurses save the NHS money by managing patients’ problems at home and preventing or delaying costly and distressing hospital admissions. Most importantly, the report also points to significant lessons that should inform the organisation of future heart failure services.

This report typifies the British Heart Foundation’s approach to heart health. We have pioneered a new service, demonstrated its effectiveness with the support of Big Lottery Fund, and identified important issues that need to be considered in establishing effective services. It is now up to the health services to use this information to rise to the challenge of delivering appropriate care to all heart failure patients in the UK.



Peter Weissberg
Medical Director – British Heart Foundation



Background

Heart failure affects about 2% of the population with an annual incidence of 0.5 -1%. There are approximately 63,000 new cases each year in the UK and 878,000 people who suffer from definite or probable heart failure. The prevalence is increasing due, in part, to improved survival following myocardial infarction, and in part because it is strongly associated with age. This is increasing demand on the health service.¹ The National Service Framework for Coronary Heart Disease (2000) highlighted that people of South Asian origin have a higher incidence of coronary heart disease, and younger age at first admission for heart failure, compared to their white counterparts, and are under-represented in research into heart failure management.

Patients typically have multiple medical conditions, complex medication regimens,² unpredictable exacerbations, disabling symptoms that include fatigue and breathlessness, limited functional status and a poor quality of life.³

Frequent rehospitalisation is common with as many as 40% of patients being re-hospitalised within six months of discharge after an acute event.⁴ Treatment costs take about 1.8% of the NHS budget, and heart failure accounts for around 5% of acute admissions, and 10% of bed occupancy. It is a leading cause of death in the UK with 40% mortality at one year, and 10% per year thereafter.⁵

Recent years have seen policies to expand the role of nursing, one of which has been the development of the role of specialist nurse.^{6,7} There has also been an improved balance between generalists and specialists to provide integrated networks of specialist and continuing care in the management and support of patients with long term conditions.⁷

Many heart failure specialist nurse services concentrate on early intervention with inpatients, optimising therapy prior to discharge. This is followed by effective discharge planning and providing continuity of care after discharge.

There have been several studies of the effectiveness of such nurse-led care. Those using multi-disciplinary, nurse-led home or clinic-based interventions⁸⁻¹⁰ have shown positive effects on readmissions. A reduction in adverse clinical outcomes and healthcare costs for patients with heart failure has been reported as a result of patient education and support.⁴

As part of a co-ordinated approach to patient care, the Department of Health¹¹ has endorsed the use of specialist nurse-led heart failure services in primary and secondary care. Initially, this tended to be a hospital-based service, with little provision of outpatient, community and home-based services. This was not ideal since cardiovascular disease, and specifically heart

failure, is chronic and well suited to management in the community, with many patients being very ill, elderly and housebound. In recognition of this, nurses with years of cardiology and general medical experience have more recently been employed to work in the community.

The Heart Failure Specialist Nurse Service for England is a collaborative project between two organisations. The British Heart Foundation (BHF) is a national charity funding research into the causes, diagnosis, prevention and treatment of heart disease, as well as funding specialist nurses. The Big Lottery Fund (BIG) is responsible for giving out half the money for good causes raised by the National Lottery. BIG is committed to bringing real improvements to communities and the lives of people most in need.

In recognition of the ever increasing numbers of people in England living with heart failure, and the need to provide community services nearer to where they live, BIG, working with their award partner the BHF, invited applications from primary care trusts for funding to employ heart failure specialist nurses based in the community in England for three years. In 2004, 76 nurses were allocated to 26 PCT groups in England. The BHF Care & Education Research Group at the University of York was invited to evaluate the development and impact of these services.

Our evaluation followed the project for three years and sought to answer eight questions. The key points and conclusions of each question follows.

1. Did the new services improve patient access to specialist heart failure care?

Overview

All centres have successfully developed their services, and although there are different models of service in each locality, all nurses have full caseloads. Most patients are referred from secondary care, from cardiology wards and clinics, general medical wards and medical admissions and, much less frequently, from care of the elderly wards. Most nurses aim to carry out at least one home visit, and will then see patients again at home or in a nurse-led community and/or secondary care clinic. More patients get seen when nurses run clinics, but home visits are still needed for people with less mobility to enable equal access to the nurses. Referrals also come from primary care but care has to be taken that these are appropriate and useful to the patient.

Many nurses are implementing palliative care groups and support groups, cardiac rehabilitation and exercise groups, and several have completed a non-medical prescribing programme, enabling them to provide a better service to patients. As the service has developed, many nurses report a tension between ever increasing caseloads and these other activities. An ideal "active" caseload is seen to be 50-60 patients, with the remainder of the caseload "inactive" and being managed and monitored by other community staff.

Key findings

- The 76 nurses see approximately 5,000 new patients a year. Most have an active caseload of over 60 patients each. Caseloads are increasing as more clinicians refer in to the service. In general, nurses see approximately 34% of all people with heart failure in the PCT, thus they report knowing they are only "scratching the surface". However, this compares well with the rest of the UK where 20-24% of patients receive specialist heart failure follow-up.
- Most referrals still come from cardiology but increasingly from other secondary care wards and GPs. This can lead to inequity of access for those patients not under the care of a cardiologist.
- Inequity of access to the HFSN service is created by geographical boundaries with lack of HFSN service provision in neighbouring PCTs.
- There is a tension between seeing as many patients as possible (ie in clinics) with the needs of patients who need home visits. However, all patients should have at least one long home visit post discharge from any ward to enable increased understanding of their condition and how to manage it.
- Most nurses operate some kind of discharge policy. In general, nurses tend to discharge stable optimised patients to primary care. If this is to work well, good links are needed with the primary care team, including community matrons. These staff need to be confident in managing stable heart failure patients, but call in HFSNs as necessary. Those patients with advanced heart failure tend to be kept in the active caseload and palliative care brought in to help with their management when appropriate.



Key findings

- Nurses are the key workers for their patients, supporting other professionals using a multi-disciplinary approach to managing heart failure across acute and community settings (see Model 1).
- Nurses are now implementing innovative new schemes to improve patient care and access to services needed. Examples of these include day therapy in hospices, support groups, one-stop heart failure clinics, cardiac rehabilitation, intravenous therapy in the community, early discharge support, and using heart failure health-care/support assistants for collecting bloods and checking on patients.

Conclusions

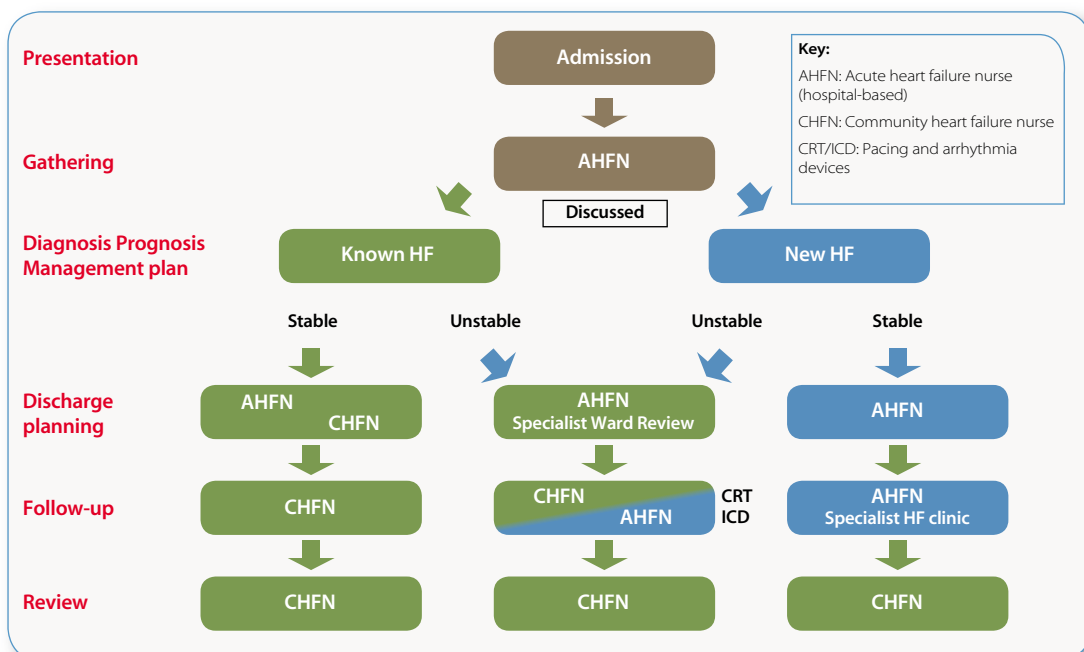
Nurses as key workers are having a significant impact on quality of life for patients, who are receiving better access to other services and much needed continuity of care.

Although based in primary care, nurses need strong links with cardiology and other staff in secondary care who can ensure referrals are made from all wards.

Recommendations

- This study shows that at present, most patients are referred from cardiology wards. This disadvantages the majority of patients who are not under the care of cardiology. Every service should develop a referral pathway to ensure that these patients are not excluded.
- All services should adopt an individualised approach to assessment and intervention.
- All patients should have the opportunity to access clinic or home-based care.
- A national guideline on discharge from the nurse service should be developed to avoid an ad hoc and inconsistent approach.

Model 1: An example of an integrated heart failure care pathway (adapted from the Hastings, Bexhill & Rother PCT model)



2. Did introducing a service extend the wider healthcare team's knowledge about effective methods of managing heart failure?

Overview

In their quarterly monitoring reports, and at interview in the case study sites, nurses report having taught many staff to manage stable heart failure patients. Some nurses are not only teaching district nurses, community matrons and others in primary care, but also teach on post-registration modules for nurses at local universities.

Key findings

- Where there are good links with the primary care team, the nurses have been able to extend knowledge of how to manage stable optimised patients, but retain links to ensure they will be contacted by either the patient or his/her primary care team should there be a problem.
- Many clinicians and managers acknowledge the special contribution of the heart failure specialist nurses as “adding value” to services.
- The key message from medical colleagues was that rather than fitting into existing multi-disciplinary teams in primary care, the HFSNs were the main link between different professionals among primary, secondary and community care services, facilitating better communication between GPs and cardiologists, resulting in better quality of life for patients and continuity of care across sectors.
- Nurses took varying amounts of time to feel confident in their role, and need support while learning, as do junior doctors. They now feel they have enough expertise to carry out their role effectively and share their knowledge across the primary care team.
- It appears that in most areas, the HFSNs have managed to develop a model of holistic care that is patient focused and yet sustainable in the long run.
- There was some evidence that where the management of patients was passed on to the primary care team, patients were not always referred back to the HFSN when they started to deteriorate, leading to unnecessary readmissions.

Conclusions

As heart failure nurses are a limited resource, they have to manage their caseloads to ensure they see those most in need of their skills. They can do so by involving other professionals such as heart failure support nurses, or healthcare assistants in the more routine checks. Once stable, patients can be managed in primary care but should be referred back to the care of the HFSN if their condition deteriorates.

Recommendation

Nurses must be seen as the key worker across settings in order to improve communication and patient management. The skills of the HFSN are best utilised when the service has a broad skill mix, including health-care assistants.

3. How should services be organised?

Overview

As with all new services, trust has been gained slowly from some professionals in both primary and secondary care. Having a GP, cardiologist or geriatrician with an interest in heart failure acting as a champion for the service helps considerably. It has been a challenge to develop a new service within an increasingly complex and fluid healthcare system. The new models of commissioning services and PCT reorganisation have had some negative impacts on the development of the role. For example there may be conflict between the roles of community matrons and HFSNs.

Key findings

- Cardiologist and medical support is crucial to the development of the HFSN service caseload and to promote equity of access to the service by all people with heart failure.
- Links into the multi-disciplinary team (MDT) vary by locality, with some having more success than others. This can be influenced by the way the nurse is perceived and where he/she is located. For example, the term specialist nurse can lead to a perception of her/him belonging to secondary care, even though based in the community. The background and experience of the nurse also influenced the speed at which links were made with the MDT.
- Nurses are able to work across the primary/secondary care divide. There have been pressures of legitimising a new role and competencies across a vertical and horizontal hierarchy.
- The existing systems of care vary from area to area. There may be some overlap with community matrons in some areas, so joint working needs to be encouraged.
- Although some GPs were slow to accept HFSNs, they are now seen as valuable assets to the primary care team. There are still some GPs with anxieties about HFSNs prescribing.

- Nurses up-titrating and monitoring medications are a valuable tool for both GPs and cardiologists, and can help GPs meet their quality and outcome framework (QOF) targets for this patient group.

Conclusions

There are significant benefits to having heart failure nurses based in the community and “owned” by the PCT. Care needs to be taken to ensure these posts are seen as part of the community team. Being based in the community gives much better access to the MDT. There are some drawbacks; in particular, referral pathways appear to largely favour those being discharged from cardiology wards. There is some evidence of an unhelpful lack of joint working between chronic disease management teams and specialist nurses.

Recommendation

Heart failure specialist nurses should be included in the management of the heart failure patient by the MDT.







4. Did the service meet the needs of the South Asian patients?

Overview

Since people without English as their first language were likely to be excluded, by default, from completing health-related quality of life (HRQoL) and satisfaction with care measures, a sample of patients and carers of South Asian origin were interviewed to gain their views of the service and whether it is improving their HRQoL. We did not find any “essential” (overriding) cultural or religious features in any of the South Asian groups that we could identify as underpinning their experience of heart failure and the HFSN service. We found three main “scenarios” resulting in qualitatively different levels of access to HFSN services. These varied from excellent medical and psycho-social support in one site, to another where support focused largely on medical issues and drug titration, and in one extreme case, to minimal medical support and no direct involvement of an HFSN.

Key findings

- In general, the needs and experiences related to heart failure, and the benefits of the HFSN service, are similar for the minority ethnic participants and white participants who took part in the larger survey.
- More than gender, it seems, the socio-economic background and “social capital” (ie access to English and alternate sources of information) mark internal differences within each ethnic group.
- In general, most people found the nurses very helpful in understanding their condition, optimising their medication, and getting speedy access to services they needed. Participants felt reassured by the fact that they could contact the nurse whenever they needed and s/he had time to listen to their problems and point them in the right direction.
- It appeared that, at times, assumptions were made by some professionals. For example, some professionals assumed that South Asian patients couldn’t speak English and/or would not use the specialist heart failure nursing service due to “cultural issues”, and hence were not offered the services that were available to the white patients.
- In one particular area, all of the patients interviewed, except one, had no direct contact with a heart failure specialist nurse until recently, even for titration of medications and even though three of them spoke English. They were seen by a bilingual cardiac community nurse who provided them with basic information and contact with the service based in the hospital, providing little sense of continuity or psycho-social support, resulting in patients feeling neglected and discriminated against.

- Equally importantly, we found examples of good practice suggesting that it is possible to provide an equitable service to people of ethnic minority backgrounds, given the commitment of nurses and leadership within local teams.

Conclusions

It is possible to provide an equitable service to people of ethnic minority backgrounds without predefining their needs as special or different. At the same time, one of the important findings from this work suggests that even where the resources are available, stereotypical assumptions about ethnicity and difference can structure services to exclude patients and carers who are from minority ethnic groups in a manner that leads to neglect and feelings of discrimination.

Recommendations

- More attention should be paid to training NHS staff to help them understand and engage with issues of providing services for people of different ethnic and socio-economic backgrounds.
- Training must incorporate sharing models of good practice and challenging assumptions about minority ethnic groups as homogenous communities whose needs and experiences are predefined by religious and cultural norms.
- Care should be taken to monitor the quality of services provided to minority ethnic and other marginalised groups, to ensure equity of services as envisaged in the National Service Framework.

5. Did the service affect the patients' health-related quality of life? How satisfied were they with the service?

Overview

Overall, the nurses appear to have had a significant positive impact on health-related quality of life, and patients and carers are highly satisfied with the care they provide.

Key findings

- 10% of patients seen by nurses completed our survey, but the sample of 954 patients and 342 carers exceeded our target. The demographics were similar to those patients who did not complete the survey, but when compared to the non-participants the nurses gave us details for (297), non-participants were more likely to be older, male and NYHA IV. Survey patients were also more likely to have had more contacts with the nurses and have fewer co-morbidities.
- Looking at other studies using the Minnesota Living with Heart Failure (MLHF) questionnaire, which measures the impact of heart failure on daily living, our study patients had much higher baseline scores, showing worse levels of health-related quality of life. There was significant improvement from baseline at six months and 12 months in both the disease specific (MLHF) and generic HRQoL measure the Short Form 12 (SF 12) used (Figure 1).

Figure 1: Minnesota Living with Heart Failure overall scores at baseline, six and 12 months. A lower score indicates a better HRQoL.

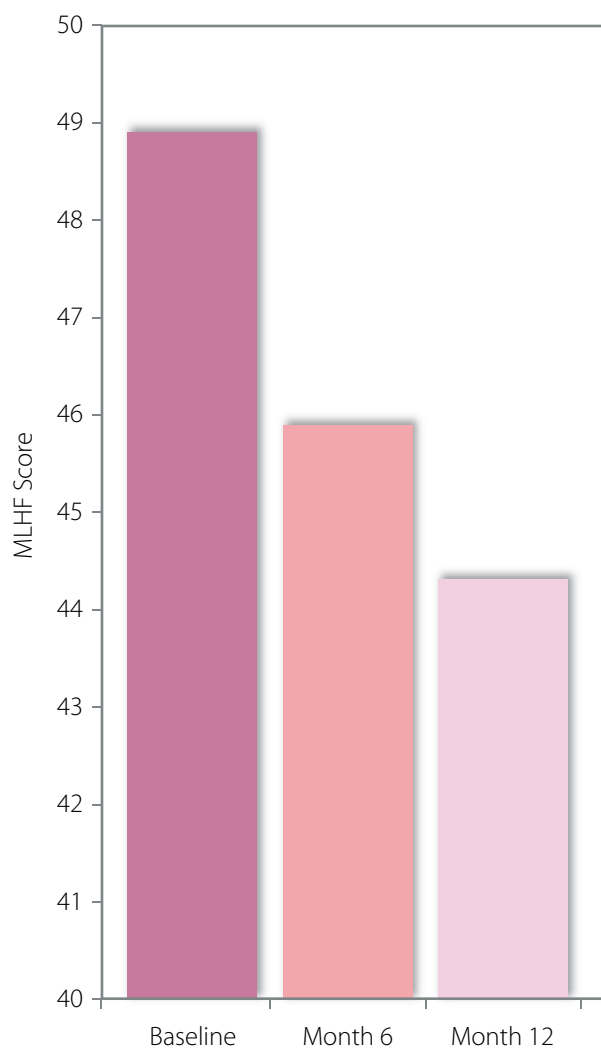


Table 1: Survey patient outcomes at baseline, six months and 12 months

	Baseline (n= 954)	Month 6 (n = 801)		Month 12 (n=729)	
	Mean (SD)	Mean (SD)	Mean diff (SE)	Mean (SD)	Mean diff (SD)
Self-care behaviour (0 – 60; 0 = better self care)	21.2 (8.0)	23.2 (7.7)	0.98 (0.25)**	23.9 (8.1)	1.63 (0.28)**
Minnesota Living with Heart Failure (0-105; 0 = fewer problems)					
Overall score	48.8 (24.4)	45.9 (24.3)	-2.84 (0.68)**	44.3 (24.2)	-3.60 (0.78)**
Physical dimensions	23.2 (11.3)	22.1 (11.2)	-1.12 (0.33)**	21.6 (11.3)	-1.28 (0.38)**
Emotional Dimensions	11.3 (7.5)	10.9 (7.5)	-0.39 (0.22)	10.4 (7.4)	-0.59 (0.24)*
SF12 Quality of Life (0 – 100; 0 = poor, 50 population mean)					
Physical health	28.0 (7.7)	28.6 (7.4)	0.6 (0.25)*	29.3 (7.3)	1.0 (0.28)**
Mental health	45.8 (12.6)	47.1 (12.4)	1.3 (0.38)**	47.0 (12.5)	0.84 (0.40)*
Hospital anxiety & depression (HAD) (0-21; 0=low)					
Anxiety	9.0 (1.6)	9.0 (1.6)	0.02 (0.07)	9.0 (1.5)	0.05 (0.07)
Depression	8.0 (1.7)	8.0 (1.6)	0.02 (0.07)	8.2 (1.7)	0.18 (0.07)*
Borderline cases (HAD > 8) %					
Anxiety	83.7	83.5	na	84.8	na
Depression	62.8	64.0	na	66.4*	na
Confirmed cases (HAD > 11) %					
Anxiety	14.1	14.9	na	15.4**	na
Depression	5.3	5.3	na	7.8**	na
Satisfaction with service (0-100) 100 = total satisfaction					
General satisfaction	na	78.8 (14.9)	na	76.4 (14.9)	-2.4 (0.47)**
Professional care	na	82.6 (14.1)	na	79.7 (16.2)	-2.9 (0.55)**
Depth of relationship	na	78.1 (17.6)	na	76.6 (17.9)	-1.5 (0.64)*
Perceived time	na	62.1 (24.0)	na	61.1 (23.7)	-1.0 (0.94)

* significant at the 0.05 level

** significant at the 0.01 level



- Self-care scores were good at baseline and did not improve overall. It would appear that there were improvements in uptake of flu jab and increased exercise, but a slight decrease in the score on other items in the questionnaire.
- Anxiety and depression scores did not improve.
- Patients were highly satisfied with the care from the HFSN. But over the 12-month follow-up, satisfaction decreased slightly. This may be linked to discharge from the service.

Conclusions

There was significant improvement in patients' health-related quality of life over a one-year follow-up period and patients were very satisfied with the care they received. An important role of HFSN services is to provide education and support to patients and their carers about the condition and its management, which may need to be done more regularly to maintain high levels of self-care behaviours.

Recommendation

Anxiety and depression should be routinely assessed using recognised standardised measures. When appropriate, patients should be referred to their GP for onward referral to psychology services or medication.

6. How does the caring role impact on family carers, and is this role and their quality of life affected by the new service?

Overview

The majority of carers are spouses and female. Carer age is about six years younger than the patient's age. As we know, caring can be exhausting for some carers. We assessed the physical demands of caring, the impact caring had on the carer's perceived role and the financial demands of caring. We also assessed general health-related quality of life and satisfaction with the care provided by the HFSN service.

Key findings

- Carers' physical health score at baseline was better than that of the patients but poor compared with population norms, and the score did get worse over the year (Figure 2).
- Carers' SF12 mental health component score was similar to that of the person they were caring for.
- Although improved at 12 months, physical aspects of care giving are more difficult than for patients with other chronic conditions.
- Role alteration and financial aspects of care giving are similar to carers for patients with other chronic conditions.
- Physical demands of caring, role alteration and financial alteration are associated with worse mental health components of quality of life.

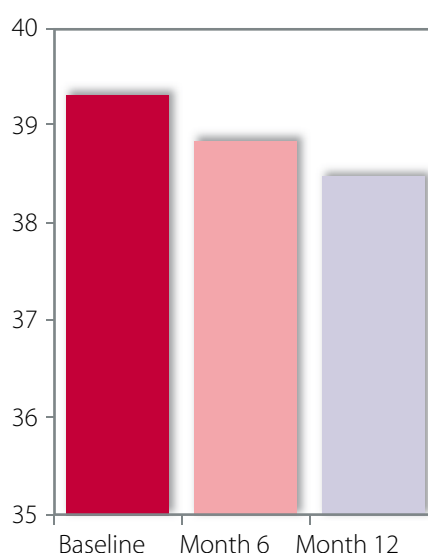
Conclusions

Carers may have poor physical health which is getting worse over time. They appear to have found the HFSN service helpful in relieving some of the aspects of care giving.

Recommendation

Carers' needs should be regularly assessed to see if they have adequate support and respite to enable them to carry out their role.

Figure 2: Physical components of the SF12 at baseline, six and 12 months for carers. A higher score indicates better physical health.



7. Did the service reduce all cause admissions to hospital?

Overview

By comparing hospital episode statistics over a one-year period on all cause admissions for patients with a diagnosis of heart failure with nurses' data on their patients' all cause admissions in the same period, we have been able to model the difference in admission rates between patients with or without an HFSN.

We also compared the admission rates in the same 12-month period when heart failure nurses were in post, with a 12-month period prior to them being in post.

Key findings

- Heart failure nurses saw 34% of all patients discharged with a diagnosis of heart failure in the 12-month period.
- For those patients seen by a heart failure nurse, the number of readmissions, on average, was 18 per 100. For those patients not seen by a heart failure nurse, the average was 97 per 100 (Figure 3). Patients seen by heart failure nurses were far less likely to be readmitted than the overall heart failure population. Our analysis indicates that this result is statistically significant, is unlikely to have occurred by chance and is due to the heart failure nurse service.
- The number of readmissions during this period was 35% less than the previous 12 months.
- Patients seen by heart failure specialist nurses were less likely to be readmitted, but when they were they tended to be admitted for a longer duration (11.6 nights compared to 8.6 nights before the nurses were in post). This may reflect the fact that admissions were for more serious events.
- Nurses reported that they were aiming to reduce inappropriate emergency admissions but may plan necessary admissions.
- Nurses suggest that fewer unnecessary admissions are due to the close monitoring of blood chemistry to avoid blood urea and potassium imbalance, medication changes including diuretics, and close liaison with other members of the MDT.
- Heart failure specialist nurses have the potential to save significant sums of monies through reductions in readmissions. This is estimated as £1,826 per patient seen over and above the cost of the heart failure nurse.

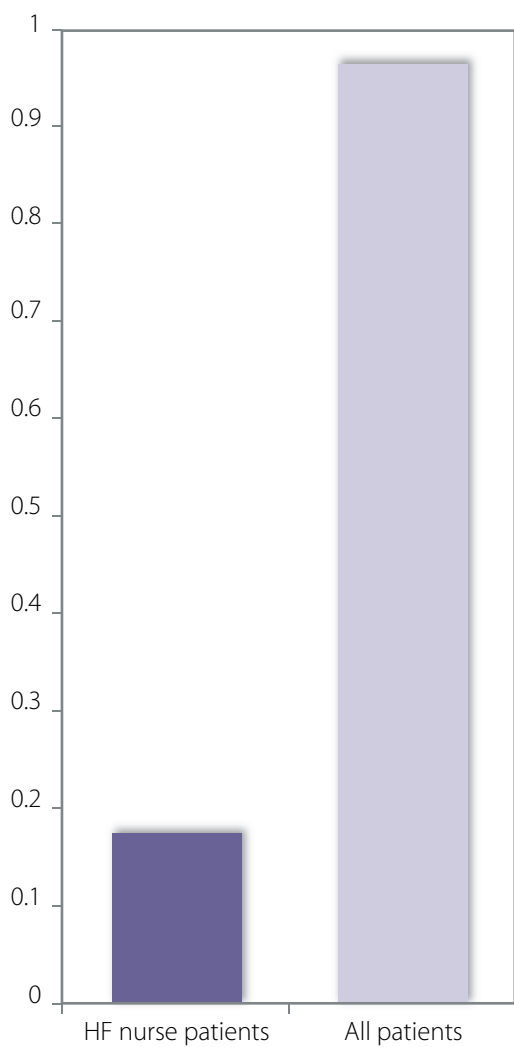
Conclusions

Nurses had a significant impact on all cause admissions to hospital for their heart failure patients. Patients are less likely to have unplanned admissions, but once admitted may stay in longer. This is similar to the national average (12.7 nights) and may reflect the planned nature of the intervention or local policies rather than the patient needing to be there.

Recommendation

All heart failure patients should have a heart failure specialist nurse as part of their management team.

Figure 3: The probability of readmission for heart failure nurse patients compared with all patients diagnosed with heart failure.



8. What was the impact of the service on healthcare costs?

Overview

Establishing whether the use of heart failure specialist nurses benefits heart failure patients is only one aspect of the overall evaluation process. Decision makers have to consider the relative costs of providing heart failure specialist nurses, and establish whether these costs benefit the overall use of National Health Service resources. In order to assess this aspect of the project we assessed both the overall costs of providing the HFSN service, and then compared this with the potential cost savings that the heart failure nurse service brings to the NHS.

Key findings

- The total cost of a nurse including salary, overheads, management and training costs was £35,000 per year at the time of analysis.
- Economic modelling of PCT level hospital episode statistics data showed that patients who were able to see an HFSN had a median cost saving of £1,826 compared to patients from the same PCT diagnosed with heart failure but not seen by an HFSN. This figure is over and above the costs of providing the HFSN service. The median is used to obtain an average where there is a large variation in costs.

Conclusion

Heart failure specialist nurses may have the potential to save significant sums of money through reductions in admissions. HFSNs in this project were associated with a total saving to the NHS of £8,050,834 over the year sampled.

Recommendation

As HFSNs have a potentially significant impact on reducing healthcare costs for the heart failure patients they see, it would seem sensible to ensure that a greater proportion of heart failure patients than the current 34% are seen by an HFSN.

Table 2: Main findings.

Average reduction in heart failure admissions	43%
Average reduction in all cause admissions	35%
Average length of stay	11.6 nights
Average proportion of patients in the PCT discharged with coding of heart failure seen by HFSNs	34%
Average estimated saving per patient	£1,826
Estimated saving to a PCT if nurse sees 100 patients per year over and above cost of salary	£182,600



What people said...

...nurses

HFSN 6: *"I seem to be getting the patients passed to me that are definitely struggling to get to clinics, definitely struggling to manage their heart failure, definitely the neglected population... I sometimes think if I wasn't there, where would they go to? I think deep down I know the answer would be, they would go to their GPs and the GP would admit them. So I suppose I am making a difference."*

HFSN 59: *"When they've been told that they've got heart failure, they just think, well that's the end; they just almost go home desperate. And then suddenly [an HFSN] comes along and we're looking at treatment and everything. We don't give them false hope obviously, but it's just giving them the support... you've taken the time to explain things and that's what they're really appreciative about. Just having somebody go through things in simple terms explaining what's happened and how you're going to treat it and then of course it pays off because they're more compliant with the medication because they understand why they're taking it and how it's working."*

HFSN 5: *"I feel what I can give is slightly more than what the cardiologist can give and that's time. And I believe that these patients need a lot of time to explain, voice their concerns, because obviously it is a debilitating life threatening illness and I think these patients need a lot of psychological support."*

HFSN 4: *"He has been a revolving door type patient where he's been in hospital all the time, and this is the first time he's actually been picked up and followed up at home. I went through his medication with him and he was complaining of cold hands and feet and I said, I think you're on a beta-blocker medication, let's look through your medication and he said, I'm not on a beta-blocker my doctor said I wasn't. And when I went through his pills he was on a beta-blocker. We went through life style modifications, he was drinking things like lots of Bovril and stuff and just little things like that and his wife was quite happy. And he was like, Pet will you call again? I said I would leave him a few weeks and then call him but said contact us if you need to. He was really pleased."*

...cardiologists

Lead cardiologist 30: *"So, I think they do that [uptitration] really well and that's a very important thing because most of the evidence for saving people's lives and improving quality of life is about the drugs. And then, the second thing that they do for me, which doctors don't do, is spend time just talking about the pathology, you know, "this is what it means" and things about life; driving, sexual intercourse, all of the other stuff that might be affected – that doctors just tend not to have time for and not want to, you know, they're not going to go there."*

Lead cardiologist 39: *"They've improved the care across the board. We get patients now who have much better access to evidence based care for heart failure. I mean, the guidelines are very important because they have improved patients' access to, you know, not only appropriate therapies particularly beta-blockers and ace-inhibitors, but all the therapies really. So, I think, we would be lost without them at this stage."*

...patients

(taken from letters of support for HFSNs)

Wife of heart failure patient 1: "[Nurse name] was an absolute lifeline for us both, providing support, advice and practical assistance on many occasions. I am sure she helped us far above and beyond what you would expect of her as an employee. [Nurse name's] career is clearly her vocation and we are privileged to have benefitted from her expertise. Although dealing with such serious illness, she had a wonderful sense of humour and could always bring a smile to [patient's] face."

Patient 2: "I am also very thankful for the support I have received from the BHF HFSN [nurse name]. On several occasions I felt it would be necessary to be readmitted to hospital, but with her knowledge and support, I was able to overcome the immediate problems at home. Her professional guidance immediately gave me confidence that the reactions I was experiencing were from some of the drugs prescribed which could have that effect. This backup was invaluable to my recovery and I am pleased to be able to benefit from her continued support by attending her clinic at [hospital name]."

Patient 3: "I feel as though sometimes there's somebody there to help me and if I need them I've just got to make a telephone call and somebody will be there, if it's not [nurse name] it will be somebody else. The heart failure nurses they explain to you things better and they get to know what your symptoms are, how you feel, because they see you quite a lot when you first start going there and then it eases off but they know how you feel."

Wife of heart failure patient 4: "She is a heart nurse and she treats him and she asks him about everything. She checks all the medicines and, if required, she increases or decreases his dose. She looks after him well and we are happy with her."





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Ten key points you need to know about setting up heart failure nurse services as part of the multi-professional heart failure team:

- 1 Clinical and management leadership and involvement are crucial both in primary and secondary care. A multi-professional steering group is essential for developing agreed referral protocols and patient pathways. These should include evidence based drug therapies, systems of communication with "Out of hours services" and clarifying the nurse's role to avoid inappropriate referrals.
- 2 Nurses benefit from having access to secretarial support and ongoing training. Cover for sickness, annual or study leave should be considered. There needs to be adequate budgeting, to include the cost of mobile phones, travel, databases, office space and equipment.
- 3 No "one size fits all" model of service exists. Services should be tailored to meet the specific needs of particular health-care environments and patients. An integrated patient pathway with the provision of home visits, community clinics or hospital clinics according to patient needs, will increase access for both stable and unstable patients to the service. The use of interactive methods to monitor patients should also be considered.
- 4 Due to variations in geographical area, age of patients, numbers of co-morbidities and severity of heart failure, no ideal "caseload" can be recommended. Nurses report that an active caseload of 50 is a safe number to have when doing home visits. Nurse-led clinics enable more patients to be seen.
- 5 A policy on when to discharge stable patients to primary care helps reduce nurses' caseloads allowing more high risk patients to be seen, with referral back to the HFSN service if the patients' condition deteriorates.
- 6 Education and training should be provided for all staff involved in the management of stable patients, and those at end of life, in the community and nursing homes. These staff can then regularly reinforce self-care strategies and monitor stable patients discharged from HFSNs, or assist in the palliation of symptoms at end of life.
- 7 There must be good communication between the HFSNs and health and social services within primary and secondary care. Patients with suspected heart failure in the community should have an early accurate and definitive diagnosis. In some areas this may be at a rapid access heart failure clinic. Patients with heart failure can then be started on appropriate medications and added to the heart failure register.
- 8 There are core elements that need to be considered when setting up a heart failure nurse service. A good model is where a cardiologist, or physician with a heart failure subspecialty, work with the hospital-based and community HFSNs and the MDT. These staff would develop a care plan for inpatients and then discharge to the community HFSNs for follow-up and review, or to outpatient clinics as appropriate. This co-ordinated approach would avoid fragmented care.
- 9 Good practice such as direct access to consultants by mobile phone, weekly meetings to discuss cases, direct admissions and intravenous diuretics in the community can improve patient outcomes.
- 10 There needs to be a pathway in place to enable patients to have a palliative approach if they remain symptomatic, despite maximum tolerated therapy, at end of life, and for the safe cessation of unnecessary medication and implantable devices.

BEATING HEART DISEASE TOGETHER

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