

THE BRITISH HEART FOUNDATION HEART FAILURE SPECIALIST NURSE

EVALUATION OF A NEW SERVICE

APRIL 2002 - DECEMBER 2003

EXECUTIVE SUMMARY

**Ms. J. F. Pattenden BA (Hons), MSc, PGCE
Prof. R. J. P. Lewin MA (Hons), MPhil
British Heart Foundation Care and Education Research Group
Dept of Health Sciences
University of York
April 2004**



CARER

“One of the best things she suggested was that [name] weigh himself every day. So he does it every day, writes it down, ...he knows, you know, if it goes up we phone [nurse] and she tells him the drugs to take, the diuretics. It is good because it stops him ending back up in hospital.” (carer 3)

PATIENT

“Well that gives you the confidence to be able to deal yourself with the illness really.” (patient 3)

PATIENT

“I’m so full of confidence with him [nurse]. I resigned from BUPA on the strength of him...you see that’s the other thing I mean, the attention I’m getting now is terrific,he’s got time to talk to me. He’s medicine himself.” (patient 27)

PATIENT

“...She’s our sort of link between ...the GP and the specialist and us, and she’ll do the leg work and telephone around because she knows who people are and she’ll get things done.” (patient 7)

NURSE

“I find the job is really rewarding, hard work there’s no getting away from that. It’s the reward of the fact you go and see the patient in their own home environment, they welcome you with open arms. You do something for them, they are so grateful.” (nurse 12)

NURSE

“There are patients that went in [to hospital] last year that won't have gone in this year because I'm more confident, and the GPs are more confident about ringing me.” (nurse 1)

ACKNOWLEDGEMENT

We’d like to thank the nurses and patients and research steering group who all gave generously of their wisdom and time.

The views expressed here are those of the researchers and not necessarily those of the BHF.

If you wish to know more, or to comment on this report, please contact Ms Jill Pattenden at the BHF Care and Education Research Group, Seebohm Rowntree Building, University of York, YO10 5DD. 01904 321335 JP30@york.ac.uk.

Background and study design

In recognition of the great burden that heart failure places on patients and their carers, the BHF funds posts for heart failure specialist nurses in hospital and Primary Care Trusts across the UK. The scheme started in April 2002 and between that month and December 2003 we conducted a study to

- assess the *impact* of these nurses from the patients' and carers' perspective
- examine the *processes* that helped or hindered nurses in their work
- make *recommendations* for future service development.

The *Impact Evaluation* was in two parts

1. A questionnaire study: Patients completed a general health related quality of life measure, the SF36, and a heart failure specific quality of life measure, the Minnesota Living With Heart Failure questionnaire (MLHF); a questionnaire designed to identify anxiety or depression, the Hospital Anxiety and Depression Scale (HAD); and a questionnaire to record how active they were, the Brief Leisure Time Exercise Questionnaire (BLT). Patients who felt well enough completed these at their first meeting with the nurse and again 3 months later. In addition, for one year, we collected audit statistics about readmissions to hospital and deaths.
2. An interview study: Patients and their carers, purposively selected to be representative of the whole group, were interviewed at home shortly after first seeing the nurse and again 5-6 months later.

The Process Evaluation

All of the nurses kept a diary in which they noted the factors that helped or hindered them as they developed their service. These were collected and collated in York every month. Following analysis of the diaries, findings were used to guide interviews with the nurses approximately 18 months after their appointment, to discover their perspective on the development and implementation of the service.

The Findings

The first awards were made in April 2002 to 6 centres: 1 teaching hospital, 2 rural and 3 urban. The teaching hospital was unable to recruit a nurse during the first year of the study and therefore was not included in this evaluation. Fourteen nurses were employed in the five participating centres.

By October 2003, the nurses had seen 923 patients. Their ages ranged from 24 to 95 years with a median age of 74, 66% were male, 57% were married or living with a partner and 29% lived alone; 90% were classified as white, 3 % as Afro-Caribbean and 7% as South Asian. 7% of patients were classified as having heart failure at NYHA Class I, 39% at Class II, 37% at Class III and 17% at Class IV.

The Impact Evaluation

The questionnaire study

These findings present a picture of the patients and how their health and quality of life changed during the time they were seeing a nurse. As there was no control group, no firm conclusions can be drawn from these changes.

Many of the patients felt too unwell to complete questionnaires, or their nurse felt reluctant to recruit them whilst they were recovering from an acute phase of the illness. As a result fewer of the more ill patients (21% of those in NYHA class 4) completed the questionnaires. Altogether 300 (44%) returned completed questionnaires at the first meeting with the nurse (Time 1) of whom 202 (30%) completed them again three months later (Time 2).

Quality of life. The scores on the general measure of quality of life (SF36) showed that these patients had a worse quality of life and greater comorbidity than those who are typically enrolled in research trials. At Time 2 there was an improvement in the scales measuring 'social functioning' and 'change in health'. None of the other sub-scales showed a significant change. The scores on the heart failure specific quality of life questionnaire (MLHF) revealed a significant change in a positive direction, a greater number of people showing improved scores after seeing the nurse than showed either deteriorating scores or

remained the same. The greatest improvement was seen in patients with the most severe heart failure.

Anxiety and depression. At Time 1 approximately 50% of patients scored above the level that indicates that a person might benefit from treatment. This was true for both anxiety and depression. There was no significant change in these scores at Time 2.

Physical activity. At the first meeting the questionnaire indicated the median level of activity to be equivalent to 4 sessions (a session was fifteen minutes or more) of 'mild' activity per week, mild refers to activities like slow walking. Only a few patients reported any activity at the moderate level which equates to brisk walking, gardening, or light housework. The largest number of people were almost completely inactive. This did not change significantly at Time 2.

The interview study

We interviewed 36 patients and 20 carers. Five months later 16 of the patients and 6 carers were interviewed again. The main areas of concern for both patients and carers were:

- coping with the symptoms of heart failure
- coping with comorbidity
- having to take multiple medications
- having to adapt their lifestyle due to chronic ill health
- psychological difficulties (anxiety, depression, confusion)
- carer issues of responsibility and isolation.

Patients and carers greatly valued the nurses. The nurse provided them with many benefits these included:

- better communication about their illness
- improved knowledge and understanding of heart failure
- improved self-management of heart failure
- care that was easily accessible 'on the end of the phone'
- easier access to monitoring, tests and other health services
- having a key nurse with whom they could build a good relationship
- co-ordination of multi-disciplinary care
- referral to, and arranging help from, other agencies
- relief of carer responsibility and isolation
- a reduction in the need for GP and clinic visits

The interviews revealed areas which some patients felt could be improved. These included:

- advice on physical activity
- warning of unpleasant side effects of medications
- more information about their prognosis
- the timing of information giving to avoid overload
- the possibility of an out-of-hours service
- concerns that, as the service grew, the nurses might be over-stretched

Special needs of ethnic minority groups. There was a noticeable difference in the way that people in minority ethnic groups talked about their condition, treatment and prognosis. For many patients communicating with health professionals was a serious problem. A trained interpreter was essential in order for them to benefit from the heart failure nurse. In some centres, deep poverty and an inability to access health services were particularly marked in the patients from minority ethnic groups.

Medication, readmissions and deaths. The percentage of patients taking an ACE inhibitor or beta-blocker at the nurse's first visit ranged from 77–92% and 26-70% respectively. No data was obtained on the number achieving an 'optimal' dose and nurses reported that there was often a need to arrive at a pragmatic dose that balanced side effects against recommended levels, particularly with older people.

The average all cause readmission rate was 35%. This varied greatly across centres from 14–57% reflecting the case mix. Centres that accepted more elderly or complex patients had higher readmission rates.

Deaths rates (all cause) varied from 5-17%, with an overall rate of 13%. In general it would appear that patients managed by the heart failure specialist nurses had lower unplanned readmission and mortality rates than the published national averages for patients with heart failure.

Process Evaluation

All of the nurses reported that this was both the most challenging and the most rewarding job they had ever had. The majority reported that they felt valued and respected by patients and colleagues alike. The service was most effective in settings where individual or teams of nurses worked across the primary/secondary care interface.

There were some commonly experienced problems setting up the service. These were generally due to a lack of preparation in organisations receiving the nurses. Many arrived to find they had no desk, phone, computer, clerical or managerial support. The areas from which the nurses reported the least problems were those that had multi-disciplinary steering groups in place and a history of collaborative working prior to the nurse being appointed.

A common problem was not having agreement amongst all of the patients' doctors about the nurse altering a patient's medication. This led to a significant degree of wasted time communicating the problem to the patient's doctor and waiting to receive permission to make the change or obtain a new prescription. A number of nurses felt that they had experienced cases where the delay resulted in an acute hospital admission that might have been avoided.

Initially gaining referrals was a problem in some areas, for example from general medical wards or care of the elderly wards. Some GPs were indifferent and a few overtly hostile to the new service: medico-legal responsibility for patients, prescribing budgets and cynicism about the value of non-pharmacological interventions were the most common sources of friction. In general the post holders felt that they gradually overcame these reservations.

Although some nurses experienced a slow start in patient referrals, as the study progressed caseloads increased and many became time-pressured. Factors related to this were lengthy visits to very ill patients, travelling time to widely dispersed patients and having no assistance with clerical and administrative tasks. Nurses reported that the majority of patients were seen 6 or 7 times, however these ranged from 1 – 56 contacts. As nurses became more confident and experienced, the average number of visits to patients declined and they became better at allocating differing amounts of time to different groups of patient.

Patients with more complex problems and those who chose to die at home received the most visits.

Most of the nurses found the transition from working in secondary care to working alone in the community very challenging. All reported a huge increase in their confidence over the first 18 months. A common remark was that they had been trained as nurses but in their new role needed to think like doctors. Several reported a need for better clinical and personal supervision during the first year. Specific training and educational needs were reported and have been listed in the recommendations.

Most nurses felt they were effective and probably cost effective through reducing the number of people readmitted. Some nurses felt that there were patients who benefitted less from the service: these were often those with severe heart failure, multiple comorbidities, poor material and personal resources and those in the minority ethnic groups. Teaching self-management skills to this group of patients was particularly difficult and nurses reported making weekly visits and a continual need for crisis management.

As the nurses became established their new role, they often realised the need to go beyond visiting and helping patients on an individual level to improving facilities and solving problems for their patients at a group level. We found more than 20 instances where they had initiated innovative local solutions. Some examples included:

- establishing a weekly heart failure support group in a hospice providing day therapy, palliative care, education and support for patients and carers
- liaising with rehabilitation teams to provide services including psychology and physiotherapy for patients and carers
- building capacity within Primary Care by training District, Practice and CHD lead nurses to manage uncomplicated patients
- providing star-coded medication dosette boxes for patients unable to read instructions
- establishing joint home visits with Diabetes or Palliative care nurses
- establishing ways of speeding social services assessment visits for the more urgent cases

Conclusions

- patients and carers greatly valued the heart failure specialist nurse service which provides them with many benefits
- patients were reassured by regular monitoring, having a key nurse with whom they could build a relationship, who provided continuity of care and who was easily accessible
- patients had high levels of anxiety and depression and very low levels of activity
- carers welcomed having the nurse with whom they could share responsibility for the patient
- in some centres a lack of preparation or local agreement about the role of the nurse caused difficulties in establishing an effective service
- after initially feeling challenged by the role, the nurses have become assured practitioners, feeling respected by patients, GPs and consultants
- nurses are having an impact on patient health and well being by providing support and co-ordinating multi-disciplinary care
- the nursing role calls for considerable knowledge and a number of skills. The nurses valued the training they received and identified a number of additional needs
- nurses are improving local services for heart failure patients in general as well as at an individual level

Recommendations

Our recommendations fall into 3 main areas:

1. Organisational

- there should be professional support; a managed clinical network or multi-disciplinary steering group; referral and treatment protocols and a set of roles and responsibilities for nurses agreed locally prior to the appointment of nurses
- there should be a structured induction period including an introduction to the local community systems and key stakeholders in primary and secondary care
- there should be a phased approach to building a caseload
- the service should span the primary/secondary care divide. This can be achieved by PCT based nurses spending some time in secondary care
- patients in general medical or care of the elderly wards are often missed and there is a need for a person based there to identify and refer relevant patients to the service
- the current ad hoc method for developing integrated assessment and clinical skills should be replaced with regular, structured occasions for learning with an experienced mentor
- there should be regular clinical supervision with a cardiologist, registrar or GP with special interest to discuss difficult cases. It is helpful if these doctors act as 'champions' for the specialist nurse service
- access to consultant advice via a mobile phone would be very helpful
- all nurses should have mentoring and support allowing the discussion of issues around concerns such as, feelings of failure if patient does not improve, the death of a patient, maintaining appropriate boundaries of care
- IT, clerical and administrative support should be available
- consideration should be given to developing a career pathway for heart failure specialist nurses.

2. Training

Education and training needs reported by the nurses included:

- communication skills to enable discussion of prognosis & patient expectations
- more on palliative care and helping patients with 'end-of-life' issues
- the skills to identify and meet psychological and rehabilitative needs

- training in simple cognitive-behavioural techniques, particularly to promote physical activity, problem solving and psychological self-help
- training in cultural awareness
- training to use assessment measures to determine the patient's needs and provide an audit of outcomes

3. Service delivery

- the treatment components provided should be based on an assessment of each patient's individual needs and risk stratification to create a care plan discussed and agreed with the patient and carer. Whenever possible this should take place at the first visit
- services should be organised to optimise patient education and rehabilitation, enhancement of self-management skills, optimising medications, symptom control and maintaining close follow up
- nurses acting as 'case managers' could be expanded
- less information could be imparted in the first visit and education could be spread over several visits
- some patients and carers were unable to read and video or audio-taped information should be made available in appropriate languages
- patients revealed significant unmet psychological needs. Simple cognitive behavioural management provided by the nurses may be helpful. Otherwise patients should be referred on to psychology or psychiatry services
- resources and training should be made available to enable nurses to coordinate a multi-disciplinary team approach
- caseloads should reflect the case mix of mild and severe disease and travelling times
- a more flexible approach to when and where patients are seen using a mixture of home, clinic and telephone support according to the patients needs, might reduce time pressure on nurses