



Health and wellbeing for people living with heart failure

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Project background

Heart failure is a chronic long-term condition that affects 800,000 people in the UK and accounts for 141,500 hospital inpatient episodes a year. The debilitating nature of the physical symptoms means they have a significant psychological and social impact on those living with the condition. The community-based cardiac follow-up service in north-east London gives all new patients an initial one-hour appointment with a nurse, but this is often not long enough to provide them with the emotional support required, along with education such as self-help information and explanation of medication and treatment options. One solution that the project team at the North East London NHS Foundation Trust wanted to consider was a structured education programme.

Aim and objectives

The aim of the project was to develop and implement an education programme for people diagnosed with heart failure, to promote choice, self-management and individual patient-centred care. To achieve this aim, the objectives identified were to:

- Identify and engage with the key stakeholders
- Understand the patient experience through a patient focus group
- Use the patient experience to design a new patient education programme
- Implement the education programme
- Evaluate the programme

Implications for practice

- Listening to patient experiences within a focus group can be a powerful way of understanding the impact of chronic disease on a person's life
- It is important to embrace support and advice from outside the immediate team
- It is important not to focus solely on the end result and to appreciate the process of reflection, while being open minded to creative approaches to develop and analyse practice along the way

This project was supported by the FoNS Patients First Programme in partnership with the Burdett Trust for Nursing

Key activities and outcomes

• Developing a shared vision

The project team wanted to develop a shared vision with the wider nursing team in relation to patient-centred care. To achieve this, the team decided to use a values clarification exercise at one of the monthly community cardiac service (CCS) meetings, in January 2013. After initial explanation and brainstorming of ideas, the nursing team members at the meeting were each invited to complete statements eliciting their interpretation of patient-centred care. These were then themed by the project team, and fed back at a later CCS meeting.

• Identification and canvassing of wider stakeholders

At one of the regular CCS nursing meetings, the project team began to identify key stakeholders, including consultants and GPs, psychologists and specialist secondary care nurses. These were contacted for their views on the potential make-up and benefits of a patient education programme. Most stakeholders responded and supported the establishment of such a programme. However, it was noted that the responses were largely 'clinical' and 'medical', whereas the focus needed to be more on how patients can manage their condition. The project leaders subsequently met the team clinical psychologist, who talked about how patients might feel about their condition. This strengthened the case for a patient focus group.

• Patient focus group

After informal chats with individual patients at their regular consultations, 100 invitations were sent out to patients and 13 attended the focus group. The project team decided to use an adapted emotional touchpoint activity to explore how patients felt about their initial diagnosis and how it was to live with heart failure. Various cards displaying 'emotion' words were laid out on a table to give patients a prompt to describe their feelings. The facilitator took notes and these were fed back to a subsequent team meeting. Patients identified a lot of frustration about their diagnosis and its impact on their lives. The stories that they shared were very powerful for both the nurses and other patients, who showed each other a great deal of support within the group.

• Effects on practice

The stories shared at the patient focus group, combined with the input from the psychologist, enabled the project team to develop an education programme that centred on the impacts of heart disease and how to cope with them. Severe staffing shortages have delayed the implementation of the programme but there have been various positive 'knock-on' effects from the project, including staff starting to focus more on how their service might feel from the patients' point of view. For instance, clinic letters should be consistent and more informative – less 'clinical' and more about self-help. In addition, the project team realised that they needed a variety of approaches they could use with patients to help explain their condition. The team put in an application to a trustwide innovation fund for iPads to enable the cardiac service team to provide a three-dimensional view of how the heart works and what heart failure means, which patients have responded to positively.