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Illness perception, self-care behaviour and quality of life of heart failure patients: A longitudinal questionnaire survey

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ABSTRACT

Objectives: To examine the associations between illness perception, self-care behaviour, and quality of life in patients admitted to hospital with a primary diagnosis of heart failure (HF), and the changes in these at 2 and 6 months after discharge.
Design: Longitudinal questionnaire-based study.
Setting: Three London hospitals with specialist heart failure services.
Participants: A convenience sample of 88 patients (70% male, mean age 70) admitted to hospital with a primary diagnosis of heart failure were recruited prior to discharge. Participants were over the age of 18, able to understand English, and with the cognitive ability to complete the questionnaires. Thirty-eight patients did not provide follow-up data: 21 (24%) died during the 6-month follow-up period, and 17 (19%) did not return their post-discharge questionnaires.
Methods: The Revised Illness Perception Questionnaire, the Self-Care Heart Failure Index, Hospital Anxiety and Depression scale, and the Minnesota Living with Heart Failure (MLHF) Questionnaires were completed prior to discharge from hospital, and 2 and 6 months after discharge.
Results: HF symptoms improved over time (MLHF score co-efficient [95%CI] −0.915 [−1.581, −0.250], $P < 0.001$). Patients appeared to believe that many of the causes of their illness were outside their control. Although self-care maintenance (e.g. weighing daily) improved over time, this did not translate into increased involvement in self-care management (e.g. adjusting diuretic dose) or the ability to act on changes in symptoms. Self-care confidence was lower in those who reported a more negative emotional impact of their illness, but was higher in those who had high scores on illness coherence.
Conclusions: Six months following hospital discharge, patients' symptom control had improved. Many continued to believe that their illness was outside their control, and although self-care maintenance improved this was not associated with greater self-care management, particularly if the patient's emotional state was negative, and their understanding of their condition was poor. Our data suggest that a more participative person-centred approach, tailoring the disease management programme to address the patient's illness beliefs and emotional state, assisting the individual to identify barriers and solutions, may help increase self-care confidence and management.

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What is already known about the topic?

- Heart failure is a chronic condition that undergoes intermittent decompensation: symptom control can be improved by self-monitoring and self-management, where appropriate
- Providing education is not sufficient to ensure adequate self management and behaviour change
- Understanding a patient's perception of their illness facilitates a more tailored approach to an individual's anxieties, and possible misconceptions about their illness and treatment

What this paper adds

- Many patients may think that their heart failure is caused by factors outside their control
- There is a strong association between a patient's emotional representation of their illness (anxiety, depression and emotional symptoms) and their attitude towards self-care
- Patients' confidence in self-care and self-care monitoring increase in the 6 months after hospital admission, but self-care maintenance does not
- The effectiveness of a heart failure disease management programme may be improved by taking a more person-centred approach: using a more formal assessment of an individual's beliefs, behaviour and emotional state to tailor the healthcare professional's input.

1. Background

Heart failure is one of the most common reasons for bed occupancy, emergency medical admission and readmission to hospital (NICOR, 2012). The most recent national audit in England by The National Institute For Cardiovascular Outcomes Research (NICOR) reports a median length of stay of 9 days, a 12% inpatient mortality, and a mortality of around 35% at 12 months in those who survive to leave hospital (NICOR National Audit 2012). Additionally, the readmission rate is high with 51% of patients either dead or readmitted at 10 months after discharge (NICOR, 2012). Access to a HF management programme runs at around 50% of all patients, with access poorer in older patients.

In the high-risk period following hospital discharge, guidelines from the National Institute for Health and Clinical Excellence (NICE) suggest that patients should be followed up, and supported to self-care, if that is what they wish to do (NICE, 2003, 2010). International guidelines, such as those from the European Society of Cardiology (McMurray et al., 2012), suggest that multidisciplinary management programmes are fundamental to improving patient outcomes, with structured follow-up and patient education, optimisation of medical treatment, psychosocial support and improved access to care. There is emphasis on co-ordination of care, and the provision of 'adequate' patient education, with special emphasis on adherence and self-care, and patient involvement in symptom monitoring and flexible diuretic use (McMurray et al., 2012).

At policy level, many healthcare systems are keen to empower people living with long-term conditions, such as heart failure, to self-care if they so wish. It is recognised that a patient's 'journey' with a long-term condition involves the development of an understanding of their needs for internal resources and external support, so that the condition and its management can be integrated into their lives in such a way that their quality of life is maximised (Department of Health, 2006).

The impact of any long-term condition on an individual, and that individual's ability to optimise self-care, are related to many factors, including: (a) the perception or actual severity and nature of the underlying condition; (b) the short, medium and long-term impact of the condition on the individual's ability to undertake normal activities of daily living; (c) the persons' beliefs, understandings and expectations around the condition, and the perceived role health and social care can play in providing a cure, care or support; (d) how much the patient participates in or avoids self-caring as a result of these beliefs; (e) the effect of symptoms, loss of control and loss of role on a patient's morale and mental health and they way in which they want to live their lives; and (f) healthcare professionals beliefs and expectations in providing care, cure or support (Department of Health, 2006).

It is increasingly recognised that a more person-centred approach – working to support self-care where appropriate and desired – requires a change in professional role for doctors and nurses. Currently, there is a tendency for professional guidelines to focus on identifying an illness or medical problem, deciding how to treat it, and making sure a treatment regime is followed. In contrast, increasingly confident and well-informed patients living with a long-term condition are recognised as an 'expert' in their own right – they know more about living with their condition than anyone else – and the relationship between the patient and professional is considered a meeting between two experts, sharing knowledge (Tuckett et al., 1985). A motivational style of discussion can then help modify the way people seek help by challenging their beliefs about their health and condition, and treatment, supporting them to identify barriers and solutions as they move towards optimal self-care. A more 'person-centred' approach may improve the outcome and experience of care for patients, with evidence for benefit for a range of conditions, including coronary disease (Ekman et al., 2012), asthma (Effing et al., 2007) and diabetes mellitus (Warsi et al., 2004).

There is growing evidence that an individual's health related beliefs are modifiable and contribute to positive patient outcomes (Broadbent et al., 2009). Effective patient education should address individual beliefs about illness and its treatment, and provide strategies to promote patient confidence to manage self-care (Bandura, 1997; Lorig et al., 1999; Mullen et al., 1992; Baker et al., 2005).

Self-care management for heart failure includes maintenance of weight, diet, physical activity, symptom management, and compliance with medication, and requires confidence and the ability to manage specific symptoms. Little is known about why some people master heart failure self-care and others do not: teaching patients