KEEPING HEART FAILURE PATIENTS AT HOME

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ABSTRACT

This qualitative study focused on the needs of heart failure patients in relation to staying at home and out of hospital. The patient's view was seen as critical as the literature predominantly identifies patients' needs from the health care professional's perspective.

The findings highlight the fact that people with heart failure do not identify they have 'needs' in terms of living, but rather they accomplish tasks in day to day living using the knowledge they have been given.

Recommendations from this research include re-evaluation and further development of current hospital based programs, extension of these programs into the community and greater communication between the heart failure patient and the health care team.

INTRODUCTION

Heart disease is the leading cause of death in New South Wales, Australia, with 13,331 deaths occurring in 1997 (Australian Bureau of Statistics 1999). Heart failure is one outcome of heart disease. A larger number of people in today's society are surviving cardiac events as a result of advanced medical and surgical interventions.

In Australia in 1998-9 there were 50,797 deaths from cardiovascular disease; 5% (2540) of these were from heart failure (Australian Institute of Health and Welfare, AIHW, 2001). The condition results in reduced exercise tolerance, breathlessness and tiredness which in the later stages severely limits a patient's lifestyle. There are often multiple admissions to hospital for symptom management and medication review. In 1998-9 heart failure accounted for 0.7% of all hospitalisations and 10% of those for all cardiovascular conditions (AIHW 2001). The cost to the health care system of these multiple admissions is significant (AUD$416 million in 1993-4) and will continue to be so with the trend in the ageing of the population (AIHW 2001).

These figures indicate there are more people in today's society who are living longer and requiring a range of health interventions from the nursing and medical professions, hospital and community support programs and groups. Given the substantial increase in individuals surviving cardiac events, attention must now centre on supporting the people in their own homes.

The literature provides evidence that problems do exist for patients who live with a chronic illness in the community (Winters 1997; McWilliam et al 1996), problems that if identified in hospital and addressed appropriately will provide a positive outcome for the patient. Studies have identified problems for heart failure patients that might affect them remaining in their own home (Hoskins et al 1999; Friedman 1997; Jaarsma et al 1997; Cameron 1996; Burke and Dunbar-Jacob 1995;

Fleury 1993). Strategies investigated to address these problems are the development of cardiac rehabilitation programs, heart failure clinics and support systems within community settings (Knox and Miscke 1999; Woodend 1999; Imich 1997; Martens and Mellor 1997).

The literature identifies a number of educational needs of patients with heart failure from the perspective of health professionals. However, there is little published literature related to the patient's perceptions of their illness or the conditions that are needed to reduce readmission episodes.

LITERATURE REVIEW

Knowles (1990) identified educational needs of the adult learner and differentiated between the perceived (felt) needs of the learner and needs that others have set for the learner (ascribed needs). Studies to date involving patients' contributions regarding needs on heart failure show that the health care profession does not adequately meet the needs of heart failure sufferers.

Bushnell's (1992) study on the evaluation of the knowledge of older patients with chronic congestive heart failure, concluded that in order to improve their quality of life, patients need to understand their illness and participate in their own health care. Bushnell's (1992) study revealed that only 3% of the participants were able to define congestive heart failure, with 6% able to give a partial definition. Hagenhoff et al (1994) found from their quantitative study that both patients and nurses agreed that medication was the most important aspect of education. However, the results showed nurses' perceptions on what education material was more important and realistic to learn about whilst in hospital differed to that of heart failure patients. The nurses rated risk factors, medications and diet as the most important but realistic learning foci. However, patients rated medication information, anatomy/physiology and risk factors as the most important and realistic to learn about. Interestingly, nurses rated psychological factors as least important and realistic learning foci. Patients rated activity information as the least important to learn about, with psychological factors as least realistic to learn about whilst hospitalised.

Two recent studies (Wehby and Brenner 1999; Hagenhoff et al 1994) identified the perceived learning needs of patients with heart failure. These studies found an imbalance between the perceived learning needs of those with heart failure and registered nurses' perceptions of their importance and patient's ability to learn about these needs during hospital stay. Furthermore, the studies supported the idea that there needed to be a comprehensive educational plan for patients with heart failure that was initiated in the hospital setting and extended into the community setting on discharge from hospital.

The literature serves to highlight a definite need exists for developing and implementing an educational package which will respond to the needs of heart failure sufferers and their changing condition. This is not an easy task given the variations in presentation of heart failure. The Agency for Health Care Policy and Research (AHCPR 1994) recommended eight areas for patient and family education and counselling. These are (1) general information; (2) prognosis; (3) activity recommendations; (4) dietary recommendations; (5) medications; (6) risk factors; (7) symptoms; and, (8) psychological factors. Prior to this, most studies had focused on the learning needs of medical patients with some form of cardiac disease. These studies revealed there was a difference of opinion between nurses and patients on what aspects were more important to learn first (Chan 1990; Karlik et al 1990; Grady et al 1988).

Luniewski, Reigle and White (1999) support the idea that adequate education in hospital can lay the foundations for improved self management of the heart failure patient at home. This conclusion was the result of the use of a card sort assessment tool they designed which measured the educational needs of heart failure patients.

Variation in educational needs occurred between the patients depending on the duration of time they had lived with the illness. The researchers argue that involving the patient in a card sort assessment process would lead to meeting their individual needs. These concepts are supported by McWilliam et al (1996) in their phenomenological study which explored the meanings, motives, intentions, emotions and feelings that were identified as part of their health and health promotion by individuals with chronic illness.

McWilliam et al (1996, p.4) defined chronic illness as any illness of three or more months duration and concluded that the focus could be shifted towards a patient's individual life and health, where the chronic illness was only one component. They stated that further research needed to be conducted in order to obtain more knowledge about health promotion strategies pertinent to specific chronic illnesses.

These studies address the needs of patients in hospital, but until a study conducted by Rogers et al (2000), there was little research aimed at the needs of heart failure patients in the home setting.

Stull et al (1999) studied the transition of becoming a patient with heart failure. In their qualitative study, they found five distinct phases emerged from the data in relation to acquiring a new identity from the diagnosis of heart failure. These phases were: (1) a crisis event; (2) the diagnosis; (3) the patients' and family's response to the diagnosis; (4) their acceptance and adjustment to life with this condition; and, (5) making the decision to get on with life. The key implications from their findings were that patients and their families needed information about heart failure and the normality of emotions, behaviours and changes in family life. This information can come from a variety of sources such as previous experience with heart problems, clinicians, friends or other family members.

Rogers et al (2000) explored the patients' understanding of chronic heart failure, investigating their needs related to information and issues concerning communication. Their in-depth interviews produced the results depicted in Table 1.

Table 1: Results of Rogers et al (2000) study

- Patients tend to attribute symptoms of heart failure to advancing age and believe nothing can be done about their symptoms.
- Patients have questions about their illness they feel unable to ask their doctors.
- Patients believe that doctors are reluctant to talk about death or dying.
- Some patients would welcome timely and frank discussion about prognosis.

Rogers et al (2000) believe there is little public understanding of chronic heart failure and of patients' needs. Both of these areas require more research.

The emphasis, from the small amount of research conducted to investigate the perspective of people living with heart failure, supports the involvement of the patient in the discussion and management of their condition in order to achieve the best outcome for everyone (Rogers et al 2000; Luniewski et al 1999; Wehby and Brenner 1999). This involvement includes discussion and information about the illness, medications, lifestyle changes, risk factors, availability of support if required, prognosis and death and dying issues (Davies and Curtis 2000).

Strategies aimed at decreasing the readmission rate for heart failure patients include the work of Hoskins et al 1999 and Martens and Mellor 1997. Other studies by Riegel et al 2000; McCormick 1999; Naylor and McAuley 1999; Knox and Miscke 1999; Imich 1997; Jaarsma et al 1998; Jaarsma et al 1997 and Paul 1997 support the importance of keeping patients at home. These studies show that if programs are properly implemented, the patient is included in the management plan and the programs supported by all members of the multidisciplinary team, then the patient will benefit from remaining in their own home and maintaining their quality of life.

In order to best utilise the knowledge health professionals hold in regard to heart failure, we must learn from the people who live with the condition and then appropriately implement changes in conjunction with them to improve their lifestyle and quality of living.

Evidence from the literature supports the importance of involving the person in the management of their illness, allowing them to feel in control and empowering them to choose how they live their life rather than being instructed by medical and other allied health professionals (Winters 1997).

METHOD

This qualitative descriptive study sought to discover ways of meeting the needs of heart failure patients that would facilitate them staying at home. The participants were all patients affiliated with a large public teaching hospital located in the Sydney, Australia, metropolitan area. They were recruited either from the Cardiology Step-Down Ward or the Heart Failure Clinic attached to the hospital.

Participants were selected by using a purposive sampling technique, which facilitated exploration of the views of a particular group of people (Grbich 1999) - those diagnosed with heart failure and living at home. The inclusion criteria for selecting the participants were:

- 20-90 years of age.
- Male or female.
- Diagnosed with heart failure.
- Aware of diagnosis.
- Patient in Cardiology Step-Down Ward. or attending the Heart Failure Clinic.
- Able to understand and speak English.

The participants ranged in age from 62-89 years. Eight lived with another person (spouse, relative or friend) and four lived alone. All participants had a support network (family, friends, community groups, government groups) on which they could rely if they required help. Time spent living with heart failure since diagnosis ranged from a few months to 20 years. All participants were classified under one of the four New York Heart Association Classification groups. Three were Graded I, four Graded II, two Graded IV and two Graded II-III or III-IV.

Semi-structured interviews were conducted to collect data because this approach allowed the interviewer to gain insight into the participant's perspective, but still maintain some control over the interview, so the purpose of the study could be achieved and the research topic fully explored (Clarke 1999; Holloway and Wheeler 1996). The interviews were audio taped, preserving the words of the participants as accurately and completely as possible (Holloway and Wheeler 1996). In conjunction, field notes were made by the interviewer at the completion of the interview to add clarity and depth to interview data. Interviews were transcribed and analysed by theme extraction. Ethical clearance was obtained from participating institutions and consent sought from participants prior to commencement of data collection.

RESULTS

The major and minor themes emerging from the data are depicted in Table 2.

Table 2: Major and minor themes identified

Major theme	Minor theme
Trying to make sense of their illness	- Taking a philosophical approach to the illness - Frustration with their illness - The impact of other conditions on living with heart failure
Measures of wellness	- Activities of living/exercise - Social functions/interactions/commitments - Shortness of breath and tiredness
Maintaining independence and control over illness	- Recognition of one's own limitations and working around them - Support systems - Information
The finality of death	- Reference to death - Near death experiences - Preparing/organising to die
Doctor/patient relationship	- Patient expectations/listening to the patient - Gratitude/respect/trust - Conflicting advice/polypharmacy

When 'Trying to make sense of their illness', the participants explored the effect their illness had on their activities of living and social functions. The minor themes identified the philosophical approaches that the participants used in dealing with and understanding their illness, the frustration they experienced from the heart failure and the way in which other conditions impacted on living with heart failure.

'Measures of wellness' was a representation of what each participant was physically able to achieve depending on how well or sick they felt. This was demonstrated by their ability to perform activities of living or exercise independently, the social functions they could attend, interactions with other people and being in a position to keep commitments made to other people (ie family, friends, doctors' appointments). The influence of shortness of breath and tiredness on their activities was a measure of whether to seek readmission to hospital or medical treatment.

'Maintaining independence and control over their illness' represented dignity, self-esteem and respect for themselves. Through knowing one's own limitations and working around them, having support systems in place and having the information concerning and relating to heart failure helped this group of participants achieve independence and control over their illness.

The recognition of 'the finality of death' emerged from the data because each participant knew that it would eventually happen to them and they had to accept this reality. Each participant approached this in a different way, some philosophically, others by organising their affairs and achieving goals before their death.

The 'doctor/patient relationship' was seen as an important aspect of participants' management of their illness. Participants were concerned their doctor was treating them correctly, according to the patient's expectations and expected appropriate communication between themselves and the doctor. However, although there were feelings of gratitude, respect and trust between the doctor and the participants, confusion remained as a result of conflicting advice to the patient from doctors relating to polypharmacy.

The findings from the data indicated that a number of factors had influenced the person living with heart failure in their own home. These factors related to the participant's acceptance of the illness, how they were feeling on a daily basis, whether they were experiencing symptoms of shortness of breath or tiredness, and the expectations they placed on themselves. Other factors related to the family, health care team and community support the participant received, plus the perceptions of the community at large toward people with heart failure and their lack of understanding about this illness. Helping identify these factors allows the health care professional to act accordingly to increase patient's knowledge, understanding and acceptance of their illness, and to increase the awareness, understanding and implications of heart failure in the larger community.

CONCLUSION

Prior to the study, the researcher had believed the participants would know what they needed in order to make living with heart failure at home easier. The findings show participants generally did not think about 'needs' in relation to living, but rather accomplished tasks, and managed on a day-to-day basis using information they already had or what they felt was the best way to deal with life for them personally. This was achieved by working out their limitations through a process of trial and error.

When looking closely at the findings, areas of need could be identified by comments the participants made.

Those identified by the researcher were generally supported in the literature, mainly from the health care team's perspective, and included: educational needs, information on lifestyle changes, consultation by the health care team with the participant about how they are treated (Donovan 1995; Donovan and Blake 1992) and lastly an area which has not received much recognition in the literature, that of death and dying.

This was an unexpected finding and one not identified in the literature. The interviews did reveal there was little discussion, if any, occurring between the patient and the doctor or other members of the health care team concerning death and dying. It was an area that caused concern and anxiety and something that was perceived as inevitable which had to be dealt with and accepted in some way. Further communication between patients and members of the health care team in relation to death and dying may assist the patients to develop a more positive outlook on life and toward their illness. If the patient developed a more positive attitude to their illness, then this may have positive repercussions on their lifestyle management and compliance to treatment.

Death and dying is a psychological issue which warrants further research to discover whether addressing patient needs for psychological care would benefit the patient in the long term and whether that would influence their coping mechanisms with the disease process. Through addressing psychological needs, the patient may feel a sense of hope, develop the confidence to manage their condition, not become too frustrated with their limitations and maintain their quality of life. If patients have hope, they may manage heart failure more effectively at home even though they know there is no current cure.

No studies have been conducted involving patients with heart failure in terms of hope, but parallels could be drawn with other chronic illnesses (Foote et al 1990; Miller 1989; Greene, O'Mahony and Rungasamy 1982). Gibson (1999) conducted a study determining the level and predictors of hope involving people diagnosed with a condition of uncertain cause and prognosis and for which little treatment was currently available. This study highlighted that the contributions of perceived social support, medical intervention, fatigue associated with the illness, personal growth since diagnosis of the illness, and the person's age were significant in fostering hope. Such studies for patients with heart failure may reveal similar findings.

There have not been many studies on the patient's perspective of living with heart failure (Rogers et al 2000; Luniewski et al 1999; Stull et al 1999). This research study moves one step closer to discovering, from the perspective of the heart failure patient, what they perceive they need in order to stay at home and out of hospital. There are still areas of need to be addressed for this patient population: greater communication between the patient and health care team; discussion on death and dying; and, providing details of programs that exist for heart failure patients.

Recommendations include the need to evaluate the current cardiac rehabilitation programs for capacity to meet the needs of heart failure patients. Utilising what is already in place and building on this may assist the heart failure patient to maintain independence and control over their lives. Programs commenced in hospital should continue in the community to provide ongoing support. In a controlled environment within the hospital, help is always available, but at home that security does not exist. This is when the patient with heart failure becomes most vulnerable. If the support continues in the community, then the transition from hospital life to home life could become smoother.

Part of the problem for some of the participants in this study was the communication of treatment and management options between various doctors and the patient, which lead to confusion. Inclusion of the patient in discussion about treatment and greater communication between health care workers, especially doctors, may lead to less confusion for the patient. Improving the communication between the patient and the health care team regarding diagnosis, medications and death and dying would help the patient's transition from hospital to home. Effective communication with the health care team may also reduce the number of readmissions to hospital.

Given the nature of this qualitative research study, the findings may not be generalised to the wider population. The limitations of this study were that it did not include the needs of family members and/or their support people and it was limited to English speaking participants.

Recommendations for future research would be to conduct a study aimed at identifying the needs of heart failure patients from non-English speaking backgrounds as their needs may be confounded by language and cultural issues.

Further study is needed to determine what it is like for family members or support people, what their needs entail and whether this is beneficial in helping the person live with heart failure.

Another issue requiring attention is increasing public knowledge about heart failure and what it represents, as supported by the Rogers et al (2000) study. Greater community awareness may generate more positive and accepting opinion of heart failure and allow people diagnosed with this condition to feel all is not lost and there is treatment available.

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