Recognizing Symptoms: An Essential First Step in Self-Care

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Introduction

Self-care is integral to effective management of chronic heart failure. Self-care includes daily weight and symptom monitoring, consistent medication and diet adherence and knowledgeable decision-making about symptoms when they occur. The goals of self-care are to maintain an acceptable quality of life and avoid emergent (or unplanned) hospital admissions for symptom management. However, hospitalization is common with readmission rates over 30% 3 months after initial hospitalization and as high as 47% at 6 months.[1-4]High readmission rates have been attributed to avoidable causes such as poor adherence to dietary restrictions and medications.[5, 6] Increasing the risk of readmission further is evidence that heart failure symptom monitoring and symptom management have been reported as the least frequently performed self-care behaviors.[7] In an effort to decrease the frequency of admission and improve quality of life, heart failure disease management strategies typically incorporate patient education. Patient education promotes self-care when it helps patients focus on adherence to therapy, symptom monitoring, and decision-making in response to symptoms when they occur.

Self-Care Concept

Self-care for patients with heart failure is a "naturalistic decision-making process involving the choice of behaviors that maintain physiologic stability (*self-care maintenance*) and the response to symptoms when they occur (*self-care management*)." [8] p.350.(Figure 1). Examples of *self-care maintenance* behaviors are adherence to healthy lifestyle practices (e.g., exercise),dietary restrictions, and pharmacological therapy. *Self-care management*, an active, deliberate decision-making process, occurs in response to heart failure symptoms. Both self-care

maintenance and management are positively influenced by confidence. The first step of *self-care management,* and the key to the process of decision-making in response to symptoms, is symptom recognition.

Challenges in Heart Failure Symptom Recognition

Symptom recognition is challenging for patients with heart failure. Poor recognition skills are associated with faulty expectations about normal aging, previous illness experiences, comorbid illness with overlapping symptom profiles, and side effects of medications. These factors increase the difficulty for patients to discriminate which symptoms are expected (i.e. increased respiratory effort with activity) and which are related to heart failure. The nonspecific nature of heart failure symptoms further complicates symptom recognition for patients. In addition, heart failure symptoms can increase insidiously, which hampers symptom awareness and appropriate self-care. Finally, patients with heart failure may experience minimal or symptom free periods, which impairs their perception of heart failure in terms of a chronic illness which requires ongoing self-care.[9]

The most defining symptoms of heart failure are dyspnea and fatigue.[10, 11] Other common symptoms of heart failure include weight gain, cough, edema, increased abdominal girth, palpitations, weakness, dizziness, and sleep disturbance. Symptoms are the result of volume overload or decreased cardiac output (see Table 1). Taken singly, these symptoms are not particularly anxiety provoking or perceived as life-threatening by many patients. As a result, patients may miss the significance of their symptoms and attribute them to normal aging believing “I am tired because I am old.” Alternatively, previous experience with non life threatening illnesses like the common cold may lead patients to discount the importance of their symptoms. “My cough is due to a cold”. Furthermore, over time patients adapt to and come to

accept chronic symptoms as normal. Slowly escalating symptoms are accommodated by reflexively decreasing activity, which delays recognition of their meaning and often leads to another hospital admission.

Surprisingly, a history of hospital admission for heart failure symptom management is *not* associated with better self-care. In one study, patients who experienced a previous admission had longer duration of symptoms and delayed care-seeking on subsequent admissions.[11] A hospital admission for heart failure symptom management did not improve subsequent symptom recognition and response. Severity of symptoms also affects self-care. Patients have been reported to seek care for the more acute symptoms of heart failure after early symptoms of heart failure decompensation were missed. If symptoms are not severe, they are not attended to. Potential explanations for the lack of response to the early symptoms of heart failure decompensation like fatigue and weight gain are that these symptoms are well tolerated and do not evoke patient concern. Fatigue and weight gain may not be considered serious and worthy of emergent medical care. In addition, individuals vary in their ability to feel physical sensations[12] suggesting that symptom severity will not uniformly predict detection and response of patients.

Lack of patient understanding of heart failure as a chronic illness associated with particular symptoms also has been linked to poor self-care.[9] In a qualitative study of 19 patients, symptoms were not connected with an illness (heart failure) resulting in lack of reaction to symptoms of worsening heart failure. Symptoms were considered unimportant vague sensations with multiple unknown causes.

Symptom recognition is often complicated by comorbid illnesses that are typical among patients diagnosed with heart failure. A recent study of 34,587 older patients admitted to the hospital with heart failure reported comorbidities that included coronary heart disease (56%),

hypertension (61%), diabetes (38%), atrial fibrillation (30%), chronic obstructive pulmonary disease (33%), and stroke (18%).[13] Similarly, dyspnea secondary to volume overload in heart failure may be difficult to distinguish from dyspnea associated with chronic obstructive lung disease. Comorbid illnesses and the associated treatments may cause symptoms that mimic or mask the symptoms of heart failure and complicate symptom recognition. It therefore is not surprising that patients may be unable to differentiate the fatigue of heart failure from that associated with beta blocker therapy.

Strategies to Improve Symptom Recognition

Optimally, symptom recognition involves patients detecting a change in symptom status and knowing if the change is linked to their heart failure. To improve symptom recognition, the typical symptoms of heart failure and their cause are reviewed with patients. Several educational strategies have been tested for this purpose including formal education programs, teaching booklets[14-16], symptom diaries[17], telephone follow-up[15, 16, 18, 19], home visits[20, 21], and multidisciplinary care.[22] Unfortunately, strategies to improve self-care have not consistently translated into fewer hospital admissions or appropriate response to a change in symptom status.

Monitoring body weight is emphasized for patients with heart failure. Patients are encouraged to weigh themselves daily and to watch for a 2 to 4 pound gain over their baseline weight. Should this occur, they are instructed to take additional diuretics or contact their health care provider for guidance. Symptom and weight diaries have been used as adjuncts for weight monitoring with varying degrees of success. Higher symptom diary use has been reported in those who attend heart failure education programs and have fewer symptoms. Regular self-weighing is associated with owning a scale, attending heart failure educational sessions, and

having a left ventricular ejection fraction > 30%.[17] Failure to perform daily weights has been cited as a common omission in self-care among patients with heart failure.[23]

Clearly, knowledge of heart failure symptom monitoring is an important component of self-care, but it does not guarantee reliable adherence by patients to recommendations from their health care providers. Targeting interventions to improve self-care knowledge and the confidence to be an active participant in managing one's heart failure may require a combination of strategies. Ni suggests the gap between knowledge and behavior change can be enhanced by ongoing, repeated patient education and by including family members in the educational process whenever possible.[23] Recognizing and treating depression and other psychological illnesses may improve self-care. Comprehensive and holistic assessment - including psychosocial evaluation - is necessary to avoid missed opportunities for educational interventions to improve self-care.

Measurement of Self-Care

The effectiveness of disease management strategies is often measured in terms of readmission rates, morbidity, mortality, cost, or length of stay. However, it is equally important to measure the direct effect of the interventions on patient's self-care abilities. Measurement of self-care is challenging. Challenges arise from variations in conceptualization (i.e. limiting self-care to treatment adherence), assuming that knowledge alone is sufficient for self-care, or using evaluation methods with poor reliability and validity (i.e. health diaries).

Several instruments have been developed to specifically measure self-care among patients with heart failure.[7, 8, 20, 24, 25] Jaarsma and colleagues developed the European Self-Care of Heart Failure Scale. It is a self-reported 12-item scale which emphasizes self-care maintenance or adherence with recommended behaviors (i.e. sodium restriction). [20, 24]The Revised Heart Failure Self-Care Behavior Scale [7] is a 29-item Likert scale revision of Jaarsma's

original self-care scale.[20] The revised scale, based on Orem's Theory of Self-Care, addresses 3 dimensions; complying with the medical regimen, asking for help, and adaptation activities including immunizations, alcohol restriction, smoking cessation, and physical activity. The Self-Care in Heart Failure Index, a 15-item scale, encompasses both self-care maintenance (treatment adherence) and the decision making process for the self-care management of heart failure symptoms as well as a self-care confidence scale.[8] The choice of instrument for clinical or research use is related to the definition of self-care one uses and the outcome of interest.

Measurement of self-care indices in clinical practice can be used to identify where in the process of self-care difficulties occur. Although lack of adherence to therapy (self-care maintenance) has often been cited as problematic, self-care management skills beginning with symptom recognition are also important targets for intervention. Knowing where the problems occur fosters individually appropriate patient education interventions.

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Figure 1. Self-Care Process [8]

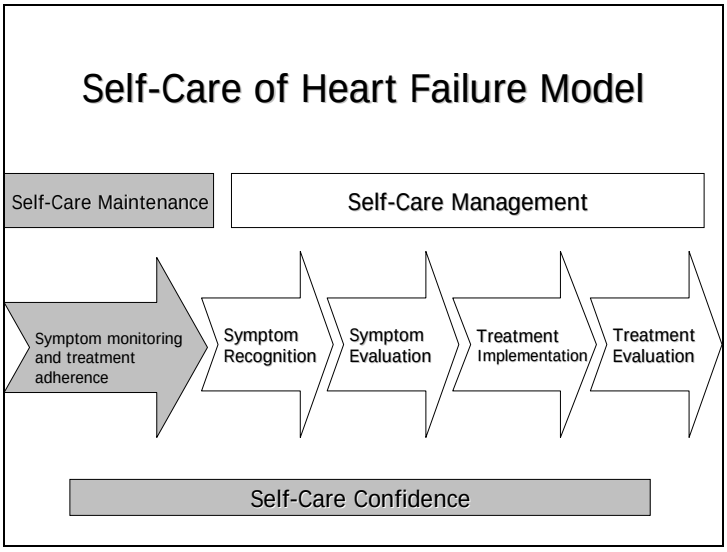

Table 1. Common symptoms of heart failure

Dyspnea
Dyspnea on exertion
Fatigue
Orthopnea
Paroxysmal nocturnal dyspnea
Cough
Edema
Increased abdominal girth
Weight gain
Palpitations
Chest pain
Nausea
Nocturia
Sleep disturbance
Weakness