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Symptom Perceptions and Self-care Behaviors in Patients Who Self-manage Heart Failure

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Abstract

Background—Patients with heart failure (HF) are at heightened risk for acute exacerbation requiring hospitalization. Although timely reporting of symptoms can expedite outpatient treatment and avoid the need for hospitalization, few patients recognize and respond to symptoms until acutely ill.

Objective—The purpose of this study was to explore patients’ perceptions of symptoms and self-care behaviors for symptom relief, leading up to a HF hospitalization.

Methods—To examine prehospitalization symptom scenarios, semistructured interviews were conducted with 60 patients hospitalized for acute decompensated HF.

Results—Thirty-seven patients (61.7%) said that they had a sense that “something just wasn’t quite right” before their symptoms began but were unable to specify further. Signs and symptoms most often recognized by the patients were related to dyspnea (85%), fatigue (53.3%), and edema (41.7%). Few patients interpreted their symptoms as being related to worsening HF and most often attributed symptoms to changes in diet (18.3%) and medications (13.3%). Twenty-six patients (43.3%) used self-care strategies to relieve symptoms before hospital admission. More than 40% of the patients had symptoms at least 2 weeks before hospitalization.

Conclusions—Despite the wide dissemination of HF evidence-based guidelines, important components of symptom self-management remain suboptimal. Because most of HF self-

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management occurs in the postdischarge environment, research is needed that identifies how patients interpret symptoms of HF in the specific contexts in which patients self-manage their HF. These findings suggest the need for interventions that will help patients expeditiously recognize, accurately interpret, and use appropriate and safe self-care strategies for symptoms.

Keywords

healthcare seeking behavior; heart failure; self-management

Introduction and Background

Despite the availability of evidence-based clinical practice guidelines on the treatment of patients with heart failure (HF)¹ and the American Heart Association's scientific statement on promoting self-care in HF,² unplanned HF hospitalizations are a major public health problem.^{3,4} Older persons are especially vulnerable to rehospitalization after an HF hospitalization. Nearly 30% of Medicare beneficiaries discharged from an HF hospitalization are readmitted within 30 days, and more than one-third of these readmissions are for HF.³ By 2015, the cost of HF in the United States is estimated to be \$44 billion.⁴ These figures are alarming because hospitalization alone is an independent risk factor of shortened survival in patients with HF.¹ Preventable causes of more than 70% of HF hospitalizations are attributed directly to ineffective HF self-management, including poor symptom recognition and delayed symptom reporting.^{5,6}

Intervention studies on HF self-management programs have produced varying results and failed to determine which components of care have the greatest impact on outcomes.⁷⁻⁹ Variable findings may be attributed in part to the wide range of symptoms experienced by patients with HF.¹⁰ Effective HF self-management is largely dependent on patient competence in the expeditious recognition, interpretation, and reporting of symptoms to healthcare providers.¹¹ However, HF signs and symptoms are often difficult to recognize because patients may not be alerted to or taught how to interpret evolving somatic changes leading to acute exacerbations. Further, evidence suggests that patients frequently confuse HF symptoms with other disorders or attribute symptoms to aging.^{1,12,13} Increasingly, patients are discharged from the hospital with unresolved HF symptoms, leaving them not only unable to recognize changes in existing symptoms but also challenged to detect new, reportable symptoms, which add to the complexity of HF self-management.^{14,15}

Patients with HF often report seeking care for worsening shortness of breath, fatigue, and swelling, all of which are symptoms of decompensated HF and associated with high risk for hospitalization.^{6,16} Less is known, however, about symptom perceptions and strategies patients use to alleviate or relieve symptoms in the pathway to clinical decline and hospitalization.¹⁷ This lack of knowledge is a critical problem because without an understanding of patients' perceptions of symptom scenarios and self-care treatment decisions for symptom relief, delivery of effective self-management interventions aimed at accurate and timely symptom interpretation, reporting, and healthcare seeking to reduce HF hospitalizations is unlikely. The purpose of this study was to explore symptom perceptions and self-care strategies used for symptom relief before hospitalization among patients who self-manage chronic HF.

Conceptual Framework

This study was guided by an integrated theoretical approach using principles derived from the HF Self-Care Model¹⁸ and the Common Sense Models of Health and Illness.^{19–22} Illustrated in Figure, HF symptom recognition, interpretation, and self-care strategies used and evaluated by patients as well as symptom reporting are core HF self-management behaviors that lead to self-management outcomes, such as effective symptom monitoring, timely reporting and healthcare seeking, and adherence to prescribed treatments and recommended lifestyle changes.^{18,19,23,24} The level of confidence patients have and how well prepared patients are for managing their HF undergird core behaviors of self-management.

In this study, self-care behaviors posited in the framework guided the exploration of HF symptom recognition and interpretation, as well as the self-care strategies patients used to relieve symptoms, all of which fall under the rubric of self-management.

Methods

Study Design and Sample

We used a cross-sectional exploratory design to describe patients' symptom perceptions and self-care behaviors leading up to an HF hospitalization. The university institutional review board (IRB) approved this study (IRB 12400, October 12, 2010). The patients were introduced to the study by hospital staff nurses, and patient consent was obtained before conducting questionnaire interviews. The sample of 60 patients for this study was derived from a larger sample (n = 198) of patients enrolled in a 5-year, randomized clinical trial testing the effect of group appointments on HF outcomes (IRB 10415, 2006–2012) conducted at a large, urban Midwestern university hospital (NIH-R01HL085397).

The patients included in the current study met the inclusion criteria for participation in the larger clinical trial. The clinical trial included patients who (1) were hospitalized with acute decompensated HF; (2) were at least 18 years old; (3) were alert and oriented; (4) gave informed consent to participate; (5) were able to read and write in English; and (6) self-managed their HF, without in-home nursing care assistance. Patients excluded from clinical trial participation (1) were heart transplant recipients or those on a transplant waiting list; (2) had refractory HF unresponsive to treatment; (3) had end-stage renal disease; (4) had a terminal illness; (5) had acute myocardial infarction within 2 weeks of the index HF hospitalization; (6) had metastatic carcinoma; and (7) were discharged to a nursing home, a rehabilitation unit, or an extended care facility. These exclusion criteria controlled for patients with reversible HF, heart disease requiring surgical intervention or transplantation, or terminal condition. Also excluded were patients with conditions that precluded participation in the group discussions or use of the videotaped education materials, such as severe blindness, deafness, severe dementia, or cognitive impairment.

Measures

Medical Record Review—Medical record reviews were conducted by trained study nurses to verify inclusion criteria and to gather comorbidity and other clinically relevant

data. Clinical trial screening and enrollment procedures were previously described.²⁵ Comorbidity data were collected from medical discharge summaries and were based on the International Classification of Diseases, 9th Revision, Clinical Modification, diagnosis codes.²⁶

Interview Questionnaire—Prehospitalization symptom data were gathered using semistructured interviews designed to capture 6 symptom management domains: (1) symptom recognition, (2) symptom interpretation, (3) self-care strategies used for symptom relief, (4) social interactions for symptom evaluation, (5) timeliness of symptom reporting to healthcare providers, and (6) timeliness of response to patient reports of symptoms by healthcare providers. Heart failure self-management preparation^{27,28} and confidence²⁹ were embedded throughout the questionnaire domains. The interview questionnaire focused on patients' perceptions of evolving symptoms, leading to a hospitalization for acute decompensated HF. Patient interviews were conducted either in person during hospitalization or by telephone within 7 days of hospital discharge.

The trained study nurses conducted the questionnaire interviews and entered patient responses, verbatim on paper copies of the questionnaire. Interview approaches were based on the Day Reconstruction Method.³⁰ This process has been shown to reduce recall bias in retrospective data collection by segmenting typical daily activities (eg, while preparing to go to work, while on the job, while preparing dinner) to enhance accuracy in recall of events.³¹ In this study, the questionnaire interviews were structured to guide the patients in reconstructing symptom experiences as they went about their usual daily routine, from symptom onset to hospitalization. The interview questionnaire was composed of closed- and open-ended items. The open-ended questions elicited detailed patient descriptions of symptom experiences, whereas the closed-ended items required yes or no responses or ordinal scale ratings.

Questionnaire interview data were gathered on 60 patients hospitalized with acute decompensated HF between October 2010 and May 2012. Because of concern for the occurrence of or worsening dyspnea and fatigue commonly experienced by patients with HF, the patients were provided unlimited time to complete the questionnaire interview. The interview questionnaires were completed within a mean (SD) of 27 (10.78) minutes (range, 7–45 minutes).

Demographic and questionnaire data were coded, double entered into the study database, and analyzed using the International Business Machines Statistical Package for the Social Sciences, Windows version 21.0 software (Armonk, New York). Central tendencies for skewed data were reported as median, rather than mean. Data cleaning procedures and double-entry comparisons were performed systematically to ensure data accuracy and completeness. Content and construct validity were verified, and the interview questionnaire was pilot tested before use in this study.

Results

This report includes findings on symptom recognition, symptom interpretation, and self-care strategies used to relieve symptoms. The patients' age ranged from 25 to 88 years, with a mean (SD) age of 63 (14) years. Nearly half of the patients were women, black, married, retired from work, had a high school education, and received Medicare benefits (Table 1). The median length of time the patients had lived with HF was 4 years (mean, 7.73 years; range, 4 days to 38.75 years). The patients had a mean of 3 (range, 1–7) comorbid conditions, in addition to HF. No significant associations were found between symptoms experienced and comorbidities typical of HF, including hypertension (92.9%), mitral regurgitation (87.5%), coronary artery disease (66.1%), diabetes (50%), and chronic lung disease (37.5%). More than one-third ($n = 21$, 35%) of the patients for whom data were available reported having had a previous HF hospitalization. Of these, 14 patients stated that they understood their hospital discharge instructions and had everything they needed to self-manage their HF at home.

Symptom Experience Perspectives

Symptoms—Thirty-seven patients (61.7%) reported feeling a vague sense that something was “just not quite right” before their symptoms began but were unable to specify or name actual signs or symptoms. When asked what symptoms the patients had before going to the hospital, shortness of breath, fatigue, and swelling were most commonly reported (Table 2). The patients experienced a mean (SD) of 3.77 (1.67) (range, 0–8) symptoms before being hospitalized. Nearly two-thirds of the patients indicated that they were “very bothered” or “constantly bothered” by their symptoms; yet, more than 40% of the patients experienced symptoms 2 weeks or longer (median, 3 days) before being hospitalized.

Symptom Interpretation—Most of the participants ($n = 56$, 93.3%) did not realize before hospitalization that their symptoms represented an exacerbation of HF. Twenty-five patients (41.7%) interpreted symptoms as being related to recent changes in their self-management regimens. The most frequently reported self-management reasons for symptoms were changes in diet (18.3%) and medications (13.3%), followed by changes in weight (6.7%), sleep (5%), or exercise (3.3%). Less frequently, the patients related symptoms to (1) a recent hospitalization, (2) a change in usual routine due to vacation or holidays, (3) an increase in fluid intake, (4) lack of motivation, (5) doing yard work, (6) a drastic change in weather, or (7) unstable housing.

Self-care Strategies Used for Symptom Relief—When asked whether the patients tried to relieve their symptoms on their own before being hospitalized, 26 patients (43.3%) reported that they used strategies at least once each day in their attempt to relieve symptoms. Self-care strategies initiated by the patients to relieve symptoms included self-medicating, raising the head of the bed, resting, walking, and dietary changes. The patients who self-medicated reported using lasix, nitroglycerin, prescription pain medications, oral medication prescribed to control diabetes, aspirin, oxygen, and prescription breathing treatments.

Discussion

The primary focus of this study was to describe symptom perceptions and self-care strategies used for symptom relief by patients who self-manage chronic HF, before hospitalization. Characteristics of this sample were consistent with those of other HF studies.^{32,33} The number and type of signs and symptoms reported by the patients before hospitalization were also similar to those in previous studies.^{10,34} We were able to elicit from patient interviews salient symptoms related to shortness of breath, fatigue, and swelling. However, responses to questions about earlier subtle, somatic changes revealed that although the patients sensed that something was “just not quite right” before being hospitalized, the initial signs were too vague to name and interpret. Thus, further research should focus on conducting in-depth patient interviews to identify whether patients have prodromal signs before symptoms and, if they do, include instruction on how to recognize, interpret, and engage in self-care action behaviors, including expeditious reporting to avoid hospitalization.

Although the patients were very or constantly bothered by their symptoms, nearly half of the patients experienced symptoms at least 14 days before seeking treatment. In an earlier study, the median treatment-seeking delay time for patients hospitalized for acute decompensated HF was 4 days.¹² These findings suggest the need for including instructional information focused specifically on early warning signs of worsening HF in customized self-management interventions for patients who contend with continuous or unresolved symptoms and multiple chronic conditions. Symptom management regimens that include an established time-line for the length of time the patients experience symptoms before they need to seek care may help to expedite early reporting and receiving outpatient treatment and effectively reduce the need for hospitalization. Other situational and contextual factors that facilitate or impede symptom recognition, accurate interpretation, and deployment of safe and effective symptom relief strategies and healthcare seeking need to be identified and addressed as well.

In this sample, the patients most often attributed symptoms to external phenomena. For example, a variety of alterations in self-management routines (ie, changes in diet and medications), rather than body parts (eg, heart, kidney), organ systems (eg, respiratory, gastrointestinal), or medical conditions (eg, arthritis, diabetes), were cited in the patients' interpretations of symptoms. Similar findings were reported by other investigators.³⁵⁻³⁸ Variations in the patients' symptom interpretations may have contributed to differences in self-care strategies used for symptom relief, and these differences may be, in part, attributable to the socialization of lifelong patterns of illness perceptions and self-care treatment decision making. Additional research is needed to identify underlying reasons for diet and medication changes as well as how decisions are made about self-care strategy choices used for symptom relief.

Self-medicating was the most commonly reported strategy used for symptom relief by the participants. However, self-care safety and quality related to the independent use of patient-selected medications and other nonpharmacologic strategies are unknown. Taking extra doses of prescription medications that control diabetes and pain may be inappropriate for

self-treating symptoms of worsening HF and may even contribute to adverse outcomes. Of particular interest is that most of the patients who had been hospitalized for HF before the study hospitalization reported that they understood their hospital discharge instructions on diet, medications, and symptom reporting. Together, these findings illustrate the need for additional research on HF self-management, with particular emphasis on not only the timeliness and accuracy of symptom recognition and interpretation and safety and quality of self-care but also the context in which most HF self-management occurs, namely, the postdischarge environment.^{1,39} Unlike hospital settings in which standard approaches to acute care of patients with HF are well established, a distinctive characteristic of the postdischarge environment is that self-care by patients occurs in the home, with environmental and social factors unique to each individual.

The postdischarge environment and the social stability of that postdischarge environment together have critical roles in HF rehospitalization.³⁷⁻⁴¹ Inadequate postdischarge environments, coupled with lack of self-management skills, increase patients' risk for rehospitalization.³⁹⁻⁴¹ It is important to understand environmental and other contextual factors that enhance or deflect patients' ability to effectively self-manage their chronic HF, including the ability to accurately and expeditiously recognize, interpret, and report symptoms, as well as select, have access to, and use safe and appropriate self-care strategies for symptom relief. Thus, research that includes the postdischarge environment will uncover factors related to symptom self-management of chronic HF that might otherwise remain obscured.

Limitations

Conclusions from the data are limited to the recall, specificity, and authenticity of participant responses. The participants were encouraged to candidly answer questions to elicit the most factual and precise data available. However, questions about the context or content of the patients' thinking when interpreting symptoms were not used and will be used in future studies. Using the Day Reconstruction Method³⁰ aided in enriching accuracy of responses. Although recollection is subjective to each patient's perceptions, their insights are undoubtedly made valid in the realm of patient satisfaction.

Although the patients who were previously hospitalized for HF reported that they understood their discharge instructions on diet, medications, and symptom reporting, these participants were not asked about the actual content and source of information received in their discharge instructions. The patients in this study were also enrolled in a larger clinical trial and, as such, were selected on the basis of strict inclusion and exclusion criteria. Future studies are needed that include a broad range of patients who self-manage their HF.

Conclusions

This research begins to address a major gap in the literature by characterizing personal perspectives of symptom experiences and self-care behaviors among persons hospitalized with acute decompensated HF. Several studies have addressed various aspects of HF self-care, including symptom monitoring, management, and reporting.^{10,33-37} This study, however, provides the most comprehensive examination of symptom experiences, including

how symptoms were interpreted and managed before hospitalization. This investigation attempts to better understand the scope of patients' symptom experiences and symptom management during the pre-hospitalization period in the postdischarge environment.

Prehospitalization symptoms, symptom perceptions, and self-care strategies used to relieve symptoms are important aspects of HF self-management that can influence outcomes, including hospital readmission. Misinterpreting symptoms and using potentially unsafe strategies for symptom relief are areas of self-management nurses can address by customizing HF self-management interventions. Imperative to the success of HF self-management programs are attention to and impact of the postdischarge environment. Research is needed to further identify and explain how the postdischarge environment influences the timeliness of symptom recognition and interpretation, as well as the safety and quality of self-care strategies deployed for symptom relief, to effectively reduce recurrent HF hospitalizations.

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What's New and Important

- Many patients who self-manage chronic HF fail to recognize and interpret cardiac-related signs and symptoms.
- Customized self-management interventions are needed that focus on accurate symptom interpretation and deployment of safe and effective self-care strategies for symptom relief.
- Research is needed on identifying postdischarge environment factors that influence self-management decision making and outcomes, including rehospitalization.

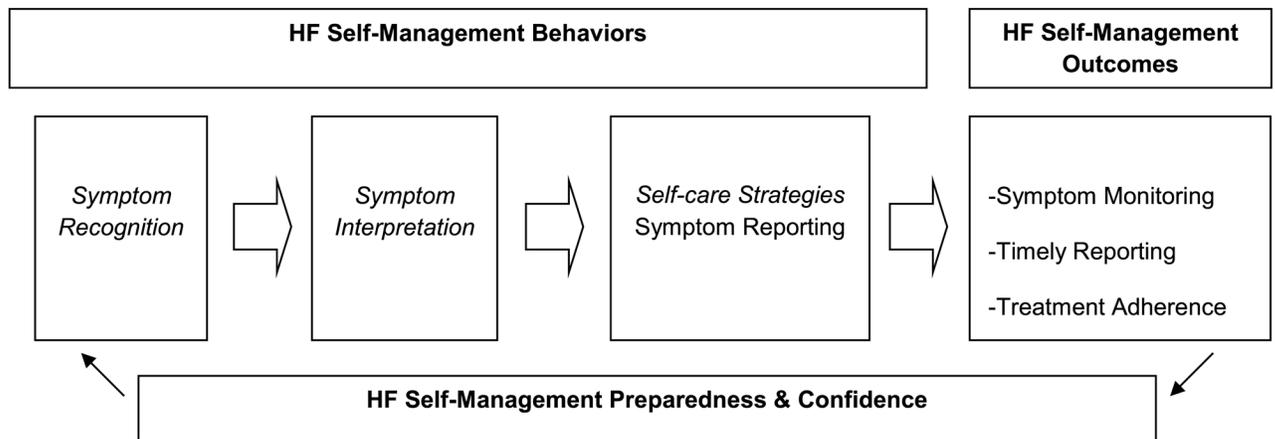


FIGURE. Heart failure symptom recognition, interpretation, and reporting framework.

TABLE 1

Sample Characteristics (N = 60)

Variable	n	%
Gender		
Male	33	55.0
Female	27	45.0
Age		
18–64	32	53.3
65–89	28	46.7
Race		
White	33	55.0
Black	25	41.7
Multiracial	2	3.3
Hispanic/Latino/Spanish		
Yes	4	6.7
No	56	93.3
Education		
High school or lower	26	43.3
Some college or higher	33	55.0
Marital status		
Married	29	48.3
Not married	31	51.7
Children <18 y		
Yes	12	20.0
No	47	78.3
Employment status		
Yes	8	13.3
No	48	80.0
Income adequacy		
Cannot make ends meet or enough, no more	31	51.7
Enough with extra or always extra	25	41.7
Health insurance		
Private: employer or out-of-pocket	11	18.3
Medicare/Medicaid/military/other	43	71.7

TABLE 2

Symptoms Before Current Hospitalization (N = 60)

Variable	n	%
Shortness of breath	51	85.0
Dyspnea		
Orthopnea		
Paroxysmal nocturnal dyspnea		
Fatigue	32	53.3
Exercise intolerance		
Feeling tired/fatigued		
Edema	25	41.7
Swelling of lower extremities		
Excessive weight gain		
Feeling bloated		
Alteration of sensorium	12	20.0
Dizziness		
Giddiness		
Difficulty concentrating		
Difficulty in sleeping		
Alteration of psychosocial status	12	20.0
Feeling "blue" or depressed		
Feeling anxious		
Chest pain or discomfort	12	20.0
GI distress	11	18.3
Loss of appetite		
Nausea, vomiting, indigestion		
Change in taste		
Constipation		
Diarrhea		

Abbreviation: GI, gastrointestinal.