



# SIGNS AND SYMPTOMS OF HEART FAILURE: ARE YOU ASKING THE RIGHT QUESTIONS?

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**CE** 1.0 Hour

## Notice to CE enrollees:

A closed-book, multiple-choice examination following this article tests your understanding of the following objectives:

1. Recognize signs and atypical symptoms that may be associated with worsening heart failure and functional class.
2. Define key elements of a patient teaching plan related to heart failure and response to treatment.
3. Define reliable indicators of functional class for heart failure patients.

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**Background** Patients may not verbalize common and atypical signs and symptoms of heart failure and may not understand their association with worsening disease and treatments.

**Objectives** To examine prevalence of signs and symptoms relative to demographics, care setting, and functional class.

**Methods** A convenience sample of 276 patients (164 ambulatory, 112 hospitalized) with systolic heart failure completed a 1-page checklist of signs and symptoms experienced in the preceding 7 days (ambulatory) or in the 7 days before hospitalization. Demographic and medical history data were collected.

**Results** Mean age was 61.6 (SD, 14.8) years, 65% were male, 58% were white, and 45% had ischemic cardiomyopathy. Hospitalized patients reported more sudden weight gain, weight loss, severe cough, low/orthostatic blood pressure, profound fatigue, decreased exercise, restlessness/confusion, irregular pulse, and palpitations (all  $P < .05$ ). Patients in functional class IV reported more atypical signs and symptoms of heart failure (severe cough, nausea/vomiting, diarrhea or loss of appetite, and restlessness, confusion, or fainting, all  $P \leq .001$ ). Sudden weight gain increased from 5% in functional class I to 37.5% in functional class IV ( $P < .001$ ). Dyspnea occurred in all functional classes (98%-100%) and both settings (92%-100%). Profound fatigue was associated with worsening functional class ( $P < .001$ ) and hospital setting ( $P = .001$ ); paroxysmal nocturnal dyspnea was associated with functional class IV ( $P = .02$ ) and hospital setting ( $P < .001$ ).

**Conclusion** Profound fatigue is more reliable than dyspnea as an indicator of functional class. Nurses must recognize atypical signs and symptoms of worsening functional class to determine clinical status and facilitate patient care decisions. (*American Journal of Critical Care*. 2010;19:443-453)

**H**eat failure is a clinical syndrome characterized by a group of signs and symptoms. The incidence of heart failure continues to increase, with 660 000 new cases diagnosed annually in adults aged 45 and over. For men and women at age 40, the lifetime risk of heart failure developing is currently 1 in 5.<sup>1</sup> Thus it is important for health care providers to better understand the signs and symptoms of heart failure so that diagnosis is not missed at first presentation and worsening status is identified early and treated promptly. Additionally, common signs and symptoms of heart failure may be well known to health care providers who treat heart failure routinely, but atypical signs and symptoms associated with worsening status may not be recognized at presentation.

Heart failure represents a substantial burden to the health care system, with estimated direct and indirect costs in 2008 expected to approach \$35 billion,<sup>1</sup> so it is important for health care providers and patients to quantify common and atypical signs and symptoms of heart failure in order to

optimize diagnostic testing and treatment decisions and facilitate appropriate monitoring of overall status. Because signs and symptoms of heart failure are important determinants of worsening status, learning their frequency relative to care setting and clinical status (New York Heart Association [NYHA] functional class) provides insight about determinants of current heart failure-related

health status that may affect decisions about the need for hospitalization, readiness for discharge, and frequency of monitoring.

Further, recognition of signs and symptoms of worsening heart failure may affect a patient's decision to seek treatment, follow self-care recommendations, and adhere to medications and other aspects of the treatment plan. In qualitative research, patients with heart failure did not recognize common but not heart-specific symptoms such as dyspnea and fatigue as important markers of worsening condition.<sup>2</sup> When

patients and nurses recognize signs and symptoms of heart failure and understand the management of heart failure, interconnections between bodily changes, sensations, and behaviors may become more relevant. Patients may not verbalize signs or symptoms to health care providers, either because providers do not ask or because patients believe or perceive the signs and symptoms to be unrelated to the heart. Alternatively, patients who have not been educated in symptom monitoring or those who are fearful or uncertain about taking actions when symptomatic may cope by ignoring signs and symptoms, taking action only when signs and symptoms are severe, or behaving in ways that ultimately exacerbate heart failure.

Many behavioral theorists include signs and symptoms as a precursor to coping or self-care behaviors. Behavioral models that directly or indirectly link the signs and symptoms of a disease or condition and behavior are the Common Sense Model of Illness,<sup>3-5</sup> the Health Promotion Model,<sup>6</sup> the Health Belief Model,<sup>7</sup> the Self-Regulation Model,<sup>8</sup> and the Symptom Management Model.<sup>9</sup> For example, in the Common Sense Model of Illness, implicit sensations and symptoms of illness are processed on both cognitive and emotional levels to form a conscious level of danger and threat that leads to goals for coping and coping actions. If acknowledgment of signs and symptoms is a precursor to coping by adhering to self-care behaviors, health care professionals need to better understand the scope of patients' signs and symptoms so they can adequately assess patients' status and provide education and counseling.

The primary aim of this study was to determine patients' perception of signs and symptoms of heart failure before an ambulatory visit or hospitalization. The secondary aims were to use a preprinted checklist of possible signs and symptoms of heart failure to examine if symptoms differed relative to demographics, NYHA functional class, and (for patients in NYHA functional class III or IV) care setting.

Recognizing signs and symptoms of worsening heart failure may affect a patient's decision to seek treatment.

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## Methods

### Setting and Sample

This descriptive, cross-sectional study was conducted at the Cleveland Clinic in Cleveland, Ohio, a large tertiary care medical center with both ambulatory care and hospital services, including cardiac transplantation, for patients with heart failure. The institutional review board approved the study protocol, and work was completed with the ethical standards set forth in the Helsinki Declaration of 1975. Study candidates were 276 adults: 164 scheduled for an ambulatory visit in the heart failure disease management program (a clinic led by an advanced practice nurse) and 112 patients being treated in the hospital for exacerbation of chronic heart failure. Convenience sampling was used to collect data for 11 months. Overall sample size was not predetermined. The enrollment goal was to achieve a minimum sample of 40 patients per NYHA functional class so that adequate assessment by functional class could be completed. Inclusion criteria were treatment for systolic heart failure, defined as an ejection fraction of 35% or less shown by echocardiography, age 18 years or older, alert and willing to participate, lived at home and cared for self, and understands written and spoken English. Patients were ineligible if they had a history of cognitive impairment, severe visual disability, or heart failure due to restrictive or hypertrophic disease in their medical record or were unable or unwilling to give written informed consent.

### Data Collection

A trained research nurse approached potential study participants while in the examination room of the ambulatory clinic or during the hospital episode of care. Patients who agreed to participate completed a short demographic questionnaire and a 1-page checklist of possible signs and symptoms of heart failure. A review of published reports from 1985 to 2000 produced no clinical studies of patients' perceptions or reports of signs and symptoms of heart failure and no studies of the spectrum and frequency of signs and symptoms of heart failure. Many references described studies of individual signs and symptoms, most often fatigue, breathlessness, edema, and exercise intolerance. Therefore, the principal investigator developed a checklist tool of 24 signs and symptoms of heart failure, 1 question with 4 options to determine heart failure functional class by using terminology from the NYHA,<sup>10</sup> and space to identify "other" symptoms that was based on available literature and expert clinical opinion and was

used in another study<sup>11</sup> before this research. The label NYHA functional class I is commonly thought of as asymptomatic heart failure; however, in this study it matched the original definition and reflected that symptoms did not prohibit or limit carrying out ordinary physical activities of daily living. Patients could have reported symptoms on the checklist and reported NYHA functional class I status if they believed ordinary physical activity did not cause undue dyspnea, fatigue, palpitations, or chest pain.

The checklist format prompted patients to report all signs and symptoms they were experiencing, rather than reporting only those that they thought were related to heart failure. Wording of items was simplified to enhance patients' understanding; for example, exercise intolerance was worded "decreased ability to exercise or carry out activities" and paroxysmal nocturnal dyspnea was worded "wake up from a sound sleep and unable to breathe." Additionally, some definitions were provided to enhance meaning; for example, change in urine output compared with normal was defined as "darker color, voiding less often or in small amounts," severe cough was defined as "keeps you awake at night or chest hurts when coughing," and orthostatic blood pressure was defined as "low blood pressure when shifting from a lying to sitting or standing position."

Content validity was demonstrated by a panel of 3 advanced practice nurses with expertise in heart failure and 1 master's prepared cardiac patient educator, using Lynn's method.<sup>12</sup> With 4 content experts, content validity beyond a .05 level of significance required 100% endorsement (content validity index of 100%) of each item by expert reviewers. Hospitalized patients were approached at any time during the hospital episode. Ambulatory patients were asked to check off all symptoms they had experienced in the preceding 7 days, and hospitalized patients were asked to consider signs or symptoms experienced during the 7-day period before hospital admission. Medical history was obtained by chart review.

The checklist format prompted patients to report all signs and symptoms they were experiencing, rather than only those they thought were related to heart failure.

The top 5 reported symptoms were shortness of breath, decreased ability to exercise, orthopnea, profound fatigue, and dizziness/lightheadedness.

**Table 1**  
Patient characteristics

| Variable <sup>a</sup>                 | Total (N = 276) | Ambulatory (n = 164) | Hospital (n = 112) | Between-group P values |
|---------------------------------------|-----------------|----------------------|--------------------|------------------------|
| Age, mean (SD) y                      | 61.6 (14.8)     | 62.9 (15.2)          | 59.7 (13.9)        | .09                    |
| Male                                  | 180 (65.2)      | 94 (57.3)            | 86 (76.8)          | .002                   |
| Ethnicity                             |                 |                      |                    |                        |
| White                                 | 161 (58.3)      | 68 (41.5)            | 93 (83.0)          | <.001                  |
| African American                      | 110 (39.9)      | 93 (56.7)            | 17 (15.2)          | <.001                  |
| Cause of heart failure                |                 |                      |                    |                        |
| Ischemic cardiomyopathy               | 123 (44.6)      | 64 (39.0)            | 59 (52.7)          | .03                    |
| Dilated cardiomyopathy                | 75 (27.2)       | 49 (29.9)            | 26 (23.2)          | .28                    |
| Valvular disease                      | 17 ( 6.2)       | 7 (4.3)              | 10 (8.9)           | .18                    |
| Hypertension                          | 34 (12.3)       | 34 (20.7)            | 0 (0.0)            | —                      |
| Married                               | 156 (56.5)      | 85 (51.8)            | 71 (63.4)          | .08                    |
| Living alone                          | 56 (20.3)       | 39 (23.8)            | 17 (15.2)          | .11                    |
| Diabetes                              | 101 (36.6)      | 64 (39.0)            | 37 (33.0)          | .38                    |
| Asthma                                | 35 (12.7)       | 26 (15.9)            | 9 (8.0)            | .08                    |
| Chronic obstructive pulmonary disease | 40 (14.5)       | 22 (13.4)            | 18 (16.1)          | .66                    |
| Myocardial infarction                 | 92 (33.3)       | 42 (25.6)            | 50 (44.6)          | .002                   |
| Hypertension                          | 93 (33.7)       | 85 (51.8)            | 8 (7.1)            | <.001                  |
| Atrial fibrillation                   | 69 (25)         | 28 (17.1)            | 41 (36.6)          | <.001                  |

<sup>a</sup> Values are expressed as number (%) of patients unless otherwise indicated.

### Data Analysis

Baseline characteristics, signs and symptoms of heart failure, and NYHA functional class were reported as means (standard deviations) for continuous variables and percentages for categorical variables. Data were analyzed by  $\chi^2$  test for categorical variables and Wilcoxon rank sum test for continuous variables. To estimate effect of care settings, age, sex, race and NYHA functional class, linear regression analysis was used for total number of signs and symptoms, and multivariable logistic regression was applied to individual signs and symptoms. All tests were

2-sided; a *P* value of .05 or less was designated as statistically significant. SAS version 9.2 (Cary, North Carolina) and statistical package *R* were used to conduct analyses.

### Results

#### Characteristics of Patients

Two hundred seventy-six patients with systolic heart failure were included in the study. Patients' characteristics are provided in Table 1. Mean age of the

sample was 61.6 (SD, 14.8) years, 65.2% were male, and 58.3% were white. When ambulatory (n = 164) and hospitalized (n = 112) patients were compared, hospitalized patients were more likely to be male (76.8% vs 57.3%, *P* = .002) and white (83% vs 41.5%, *P* < .001). Ischemic cardiomyopathy was the most frequent cause of heart failure, present in 44.6% (n = 123) of patients, followed by dilated cardiomyopathy (27.2%). Common comorbid diseases were similar in the 2 care settings, except that hospitalized patients were more likely than outpatients to have a history of myocardial infarction (44.6% vs 25.6%, *P* = .002) and atrial fibrillation (36.6% vs 17.1%, *P* < .001) and were far less likely to have a history of hypertension documented in the medical record (7.1% vs 51.8%, *P* < .001).

#### Signs and Symptoms

Range of symptoms reported per patient was 1 to 15, and the mean and median were 5. Not surprisingly, patients reported symptoms of heart failure much more often than they reported signs of heart failure (Table 2). Of 24 items, the top 5 reported symptoms were shortness of breath, decreased ability to exercise, orthopnea, profound fatigue, and dizziness/lightheadedness. The 5 most

The 5 most frequently reported signs were edema, ankle or leg edema, palpitations, irregular pulse, and abdominal edema.

frequently reported signs were edema (no site specified), ankle or leg edema, palpitations, irregular pulse, and abdominal edema (Table 2). No patients reported having whole-body edema.

### Age, Race, and Sex

Neither the total number of signs and symptoms of heart failure reported per patient nor the prevalence of individual signs and symptoms differed by patient's age; however, fewer signs and symptoms were reported among whites ( $P = .02$ ) and men ( $P < .001$ ). When individual signs and symptoms of heart failure are examined, in addition to the care setting, whites were less likely than African Americans to report experiencing severe cough ( $P < .001$ ), orthopnea ( $P < .001$ ), and nausea, vomiting, or diarrhea ( $P = .04$ ). Likewise, men were less likely than women to report experiencing orthopnea ( $P = .03$ ); wheezing ( $P = .03$ ); nausea, vomiting, or diarrhea ( $P = .003$ ); dizziness ( $P = .02$ ); exercise intolerance ( $P = .008$ ); and restlessness ( $P = .005$ ). Older patients were less likely to report feeling fullness in the right side of the abdomen in addition to the influence of the care setting.

### Functional Class

Signs and symptoms of heart failure were compared by functional class for the 261 patients who completed data collection on functional status. In all, 17 of 23 signs and symptoms increased significantly as functional class worsened from I to IV (Table 3). Nearly all patients reported dyspnea regardless of functional class. Orthopnea, profound fatigue with exertion or generalized weakness, and decreased ability to exercise increased from less than 25% of patients in functional class I to more than 80% of patients in functional class IV (all  $P \leq .001$ ). The differences remained for orthopnea and profound fatigue when care setting was taken into consideration (both  $P \leq .001$ ). Similarly, paroxysmal nocturnal dyspnea and restlessness/confusion or fainting were rarely reported by patients in functional class I (<5% of participants), but frequency increased to greater than 45% in patients reporting functional class IV status (both  $P \leq .001$ ).

The association between functional status and paroxysmal nocturnal dyspnea remained significant for patients in the hospital setting ( $P = .02$ ). In addition, each of the following was reported by more than 33% of patients in functional class IV, representing a significant increase in frequency from patients with higher functional class: any edema; sudden weight gain; ankle edema; chest pain; severe cough; nausea/vomiting, diarrhea, or loss of

**Table 2**  
Signs and symptoms of heart failure (N = 276)

| Variable  | Number of patients (%) |
|---|------------------------|
| <b>Heart failure signs</b>                                |                        |
| Edema/swelling  | 126 (45.7)             |
| Ankle/leg edema   | 90 (32.6)              |
| Palpitations  | 57 (20.7)              |
| Abdomen edema   | 55 (19.9)              |
| Irregular pulse   | 55 (19.9)              |
| Sudden weight gain  | 54 (19.6)              |
| Change in urine output compared with normal               | 40 (14.5)              |
| Weight loss   | 32 (11.6)              |
| Low blood pressure or orthostatic blood pressure          | 25 (9.1)               |
| Heart rate <60/min or >120/min                            | 19 (6.9)               |
| Cool, pale, or mottled skin                               | 13 (4.7)               |
| Whole-body edema  | 0 (0.0)                |
| <b>Heart failure symptoms</b>                             |                        |
| Shortness of breath; trouble breathing                    | 276 (100.0)            |
| Exercise intolerance                                      | 168 (60.9)             |
| Orthopnea   | 125 (45.3)             |
| Profound fatigue with exertion or generalized weakness    | 119 (43.1)             |
| Dizziness/lightheadedness                                 | 82 (29.7)              |
| Nausea/vomiting; diarrhea or loss of appetite             | 67 (24.3)              |
| Paroxysmal nocturnal dyspnea                              | 65 (23.6)              |
| Restlessness, confusion, or fainting                      | 62 (22.5)              |
| Right-sided abdominal fullness, discomfort, or tenderness | 52 (18.8)              |
| Severe cough  | 52 (18.8)              |
| Chest pain  | 51 (18.5)              |
| Wheezing  | 42 (15.2)              |

appetite; right-sided abdominal pain; irregular pulse; and palpitations (Table 3). Weight loss, low or orthostatic blood pressure, cool/pale or mottled skin, and low or high heart rate were rarely reported by patients, regardless of the functional class.

### Care Setting: Ambulatory Care Versus Hospital

The ambulatory care and hospital groups differed significantly in number of symptoms reported per patient ( $P < .001$ ), with 4.1 (SD, 3.2) for the ambulatory group and 8 (SD 3.5) for the hospital group. In patients with NYHA functional class III-IV status, signs and symptoms of heart failure were compared between ambulatory ( $n = 89$ ) and hospitalized ( $n = 73$ ) patients who had provided information on functional class in the survey. Of the signs and symptoms of heart failure identified by patients in NYHA functional class III-IV, significant differences in frequency by care setting were found for 43% of the signs and symptoms on the checklist (Table 4). For signs and symptoms that differed by care setting, frequencies were consistently higher in hospitalized patients. Finally, differences by care setting were

Nearly all patients reported dyspnea regardless of functional class.

**Table 3**  
Signs and symptoms by New York Heart Association functional class (N = 261)

| Variable   | Functional class |             |               |             | Between-groups<br>P values |
|--|------------------|-------------|---------------|-------------|----------------------------|
|  | I (n = 43)       | II (n = 56) | III (n = 114) | IV (n = 48) |                            |
| <b>Heart failure signs</b>                               |                  |             |               |             |                            |
| Edema/swelling   | 8 (18.6)         | 17 (30.4)   | 63 (55.3)     | 33 (68.8)   | <.001                      |
| Ankle/leg edema  | 7 (16.3)         | 14 (25.0)   | 47 (41.2)     | 19 (39.6)   | .009                       |
| Palpitations   | 6 (14.0)         | 8 (14.3)    | 21 (18.4)     | 19 (39.6)   | .004                       |
| Abdomen edema  | 3 (7.0)          | 8 (14.3)    | 25 (21.9)     | 16 (33.3)   | .01                        |
| Irregular pulse  | 5 (11.6)         | 6 (10.7)    | 23 (20.2)     | 16 (33.3)   | .02                        |
| Sudden weight gain                                       | 2 (4.7)          | 6 (10.7)    | 26 (22.8)     | 18 (37.5)   | <.001                      |
| Change in urine output compared with normal              | 3 (7.0)          | 5 (8.9)     | 20 (17.5)     | 11 (22.9)   | .08                        |
| Weight loss  | 5 (11.6)         | 6 (10.7)    | 9 (7.9)       | 8 (16.7)    | .43                        |
| Low blood pressure or orthostatic blood pressure         | 1 (2.3)          | 5 (8.9)     | 7 (6.1)       | 7 (14.6)    | .14                        |
| Heart rate <60/min or >120/min                           | 2 (4.7)          | 4 (7.1)     | 9 (7.9)       | 2 (4.2)     | .78                        |
| Cool, pale, or mottled skin                              | 1 (2.3)          | 1 (1.8)     | 7 (6.1)       | 3 (6.3)     | .49                        |
| <b>Heart failure symptoms</b>                            |                  |             |               |             |                            |
| Shortness of breath                                      | 43 (100.0)       | 56 (100.0)  | 112 (98.2)    | 48 (100.0)  | .46                        |
| Exercise intolerance                                     | 10 (23.3)        | 23 (39.3)   | 88 (77.2)     | 40 (83.3)   | <.001                      |
| Orthopnea  | 5 (11.6)         | 14 (25.0)   | 60 (52.6)     | 39 (81.3)   | <.001                      |
| Profound fatigue with exertion or generalized weakness   | 4 (9.3)          | 8 (14.3)    | 61 (53.5)     | 41 (85.4)   | <.001                      |
| Dizziness/lightheadedness                                | 5 (11.6)         | 15 (26.8)   | 36 (31.6)     | 23 (47.9)   | .002                       |
| Nausea/vomiting; diarrhea or loss of appetite            | 6 (14.0)         | 4 (7.1)     | 34 (29.8)     | 19 (39.6)   | <.001                      |
| Paroxysmal nocturnal dyspnea                             | 2 (4.7)          | 8 (14.3)    | 28 (24.6)     | 24 (50.0)   | <.001                      |
| Restlessness, confusion, or fainting                     | 2 (4.7)          | 9 (16.1)    | 26 (22.8)     | 22 (45.8)   | <.001                      |
| Right-sided abdominal fullness, discomfort or tenderness | 3 (7.0)          | 7 (12.5)    | 23 (20.2)     | 17 (35.4)   | .003                       |
| Severe cough   | 3 (7.0)          | 5 (8.9)     | 24 (21.1)     | 19 (39.6)   | .001                       |
| Chest pain   | 3 (7.0)          | 5 (8.9)     | 24 (21.1)     | 17 (35.4)   | <.001                      |
| Wheezing   | 2 (4.7)          | 6 (10.7)    | 20 (17.5)     | 12 (25.0)   | .04                        |

**In the hospital setting, functional status was significantly associated with paroxysmal nocturnal dyspnea.**

more common in frequently reported signs and symptoms related to heart failure (eg, orthopnea and profound fatigue) rather than more atypical signs and symptoms (cool, pale, or mottled skin and wheezing), except that shortness of breath and ankle and abdominal edema did not differ by care setting.

### Discussion

When given a checklist, patients were able to report many different signs and symptoms of heart failure. Although the most prevalent signs and symptoms were consistent with findings reported in the literature,<sup>13-</sup>

<sup>19</sup> patients in our study reported some rarely discussed signs and symptoms, such as change in urine output; cool, pale, or mottled skin; and irregular pulse. Our findings may be more comprehensive as a result of our use of the checklist format. Patients may have recognized signs and bothersome symptoms on the checklist that they may not have thought to verbalize because they did not believe them to be associated with their heart or with heart failure.

Of 12 signs and 12 symptoms, edema was the sign and shortness of breath was the symptom reported most often. Of patients reporting themselves as being

in NYHA functional class III or IV, more than 50% reported experiencing a collection of at least 5 factors: shortness of breath, orthopnea, edema, profound fatigue, and decreased ability to exercise. Although these results may not seem surprising, some results require further discussion.

First, dyspnea was universally reported, regardless of functional class or care setting. Although dyspnea was common in symptomatic ambulatory patients (functional class II or higher),<sup>16,20</sup> patients before or during hospitalization for exacerbation of heart failure,<sup>21-23</sup> patients being treated in an emergency care setting,<sup>24</sup> and patients with advanced heart failure,<sup>25</sup> this study presents new findings that dyspnea is highly prevalent in patients in NYHA functional class I (patients reporting no limitations in ordinary physical activity).

The presence of dyspnea in ambulatory and presumably asymptomatic patients has implications for nursing care. Ultimately, asking about dyspnea during assessment may yield little value. Dyspnea may be a poor marker of change in heart failure condition unless the assessment includes other subjective or objective factors, such as functional capabilities, results of a 6-minute walk test, or activity level. Some telehealth remote monitoring and internal cardiac monitoring systems ask patients simple

**Table 4**  
**Sign and symptoms by care setting (ambulatory vs hospital) in patients with heart disease in New York Heart Association functional class III or IV**

| Variable  | Ambulatory<br>(n = 89) | Hospital<br>(n = 73) | Between-groups<br>P values |
|---|------------------------|----------------------|----------------------------|
| <b>Heart failure signs</b>                                |                        |                      |                            |
| Edema/swelling  | 44 (49.4)              | 52 (71.2)            | .008                       |
| Ankle/leg edema   | 33 (37.1)              | 33 (45.2)            | .38                        |
| Palpitations  | 14 (15.7)              | 26 (35.6)            | .006                       |
| Abdomen edema   | 18 (20.2)              | 23 (31.5)            | .14                        |
| Irregular pulse   | 10 (11.2)              | 29 (39.7)            | <.001                      |
| Sudden weight gain  | 13 (14.6)              | 31 (42.5)            | <.001                      |
| Change in urine output compared with normal               | 11 (12.4)              | 20 (27.4)            | .03                        |
| Weight loss   | 6 (6.7)                | 11 (15.1)            | .14                        |
| Low blood pressure or orthostatic blood pressure          | 4 (4.5)                | 10 (13.7)            | .07                        |
| Heart rate <60/min or >120/min                            | 6 (6.7)                | 5 (6.8)              | .77                        |
| Cool, pale, or mottled skin                               | 4 (4.5)                | 6 (8.2)              | .51                        |
| <b>Heart failure symptoms</b>                             |                        |                      |                            |
| Shortness of breath                                       | 89 (100.0)             | 71 (97.3)            | .39                        |
| Exercise intolerance                                      | 63 (70.8)              | 65 (89.0)            | .008                       |
| Orthopnea   | 45 (50.6)              | 54 (74.0)            | .004                       |
| Profound fatigue with exertion or generalized weakness    | 43 (48.3)              | 59 (80.8)            | <.001                      |
| Dizziness/lightheadedness                                 | 26 (29.2)              | 33 (45.2)            | .05                        |
| Nausea/vomiting; diarrhea or loss of appetite             | 23 (25.8)              | 30 (41.1)            | .06                        |
| Paroxysmal nocturnal dyspnea                              | 21 (23.6)              | 31 (42.5)            | .02                        |
| Restlessness, confusion, or fainting                      | 17 (19.1)              | 31 (42.5)            | .002                       |
| Right-sided abdominal fullness, discomfort, or tenderness | 17 (19.1)              | 23 (31.5)            | .10                        |
| Severe cough  | 16 (18.0)              | 27 (37.0)            | .01                        |
| Chest pain  | 16 (18.0)              | 25 (34.3)            | .03                        |
| Wheezing  | 14 (15.7)              | 18 (24.7)            | .22                        |

yes/no questions about dyspnea to ascertain current status. Patients may not recognize dyspnea as something that changed if it occurred regularly or continuously. Additionally, patients often describe dyspnea on the basis of their ability to physically adapt to it.<sup>20</sup> If patients eliminate activities that exacerbate dyspnea, they may be unaware of worsening heart failure. To add value to reports of dyspnea, qualifiers should be added when questioning patients; for example, one could ask: Compared with yesterday, do you have more shortness of breath when you perform everyday activities? or Did you decrease regular activities because of increased breathlessness yesterday?

In addition, it may be important to focus on monitoring signs or symptoms that exhibit a large increase in frequency from one functional class to the next. Thus, monitoring questions should be individualized to a patient's current status. For example, in this study, the frequency of orthopnea doubled (100% increase) from functional class I to II and again from class II to III, making it a good question for assessing symptoms in patients with asymptomatic or mild heart failure. However, orthopnea was a less sensitive marker when prevalence was compared in patients

with heart failure of functional class III and IV. Even though the frequency of orthopnea increased significantly as functional class worsened, and the prevalence in patients in functional class IV was 55% higher than the prevalence in patients in functional class III, other symptoms of heart failure increased more in frequency from functional class III to IV. Assessment questions related to new onset of paroxysmal nocturnal dyspnea and new onset of restlessness, confusion, or fainting might be more likely to provide evidence of worsening heart failure because these symptoms more than doubled in frequency in patients in functional class IV compared with functional class III (paroxysmal nocturnal dyspnea increased by 103%, from 24.6% to 50.0%; and restlessness, confusion, or fainting increased by 101%, from 22.8% to 45.8%).

Second, significantly more hospitalized patients than outpatients with functional class III or IV heart failure reported irregular pulse, low or orthostatic blood pressure, and sudden weight gain as signs they experienced, even though the prevalence of

**Patients may describe dyspnea on the basis of their ability to physically adapt to it.**

each was fewer than 45%. Researchers<sup>25</sup> found that many of the 21 signs or symptoms that indicated that patients had end-stage heart failure were related to tissue or organ hypoperfusion. In our study, signs that were reported significantly more often in hospitalized patients were signs reflecting fluid overload (eg, sudden weight gain) or hypoperfusion (change in urine

output and restlessness, confusion, or fainting). Ultimately, signs that reflect fluid overload and hypoperfusion are important indicators to health care providers when assessing and compiling all evidence and when developing a diagnosis or treatment plan, but such signs should be assessed as a group and used together to provide support for worsening heart failure.

Third, findings of edema were both consistent and inconsistent with published reports of edema. In patients treated in an emergency department for heart failure, 47% had lower extremity edema detected on physical examination,<sup>26</sup> similar to our patients' reported rate of 45.2%;

however, in 2 large registries that used review of medical records to report findings on physical examination of patients with acute heart failure decompensation, 65% to 66% had lower extremity edema.<sup>22,27</sup> When Jurgens<sup>28</sup> assessed patient-reported signs and symptoms before admission for acute heart failure, increased abdominal girth was reported by 33%, compared with a rate of 31.5% in hospitalized patients with NYHA functional class III or IV heart disease in this study; however, in Jurgens's study, fewer patients reported having any edema (50%) compared with patients in our study (71.2%).

Variation in patients' reports of edema and in findings between health care providers and patients' self-reports could be due to many factors. Patient-related factors include heterogeneity in characteristics, medical history, use and dosing of diuretics and other drugs that facilitate removal of excess fluid or are associated with edema (eg, calcium channel blockers or thiazolidinedione drugs), and comorbid conditions; factors related to health care providers include expertise in examination and diligence in documentation. Additionally,

patients' knowledge and self-efficacy about assessing edema and recognizing subtle changes could affect reporting frequency. Of note, prevalence of sudden weight gain was much lower than orthopnea and

edema/swelling in both ambulatory and hospital functional class III/IV groups, possibly reflecting that (a) patients failed to weigh themselves, (b) patients had a decreased appetite and food intake due to edema, so volume overload was offset by decreased caloric intake, or (c) volume overload was offset by cachexia and loss of muscle mass.

Fourth, in our patients, profound fatigue was associated with worsening NYHA functional class whereas dyspnea was not, and profound fatigue was also a reliable indicator of being hospitalized. Only a few studies have been done on fatigue in patients with heart failure. Researchers<sup>29</sup> found that in ambulatory older women with heart failure, fatigue was the most frequently experienced symptom, and although it was only mildly bothersome, the fatigue had increased in intensity at a second assessment 18 months later. Further, at the second assessment, fatigue was associated with dyspnea. In another study,<sup>30</sup> women with heart failure had more problems with fatigue than did men. In patients with stable, chronic systolic dysfunction, fatigue was not associated with self-reported NYHA functional class,<sup>31,32</sup> but fatigue was associated with other clinical factors (dyspnea and sleep disturbance) and psychological factors (depressive symptoms and type-D personality).<sup>32</sup> In this study, reported frequency of fatigue was not based on patients' sex, race, or age, making it a reliable indicator of status in a broad group of patients. Our results may have differed because we used the adjective *profound* to describe fatigue instead of "exertional or general fatigue."

Paradoxically, men and whites reported fewer signs and symptoms, yet were hospitalized more often than women and nonwhites. Many factors could potentially explain these findings. Although fewer in number, signs and symptoms among men and whites could have been more intense or irritating, prompting health care. Men may be more sensitive to bodily changes than are women or men may be quicker to communicate changes in signs and symptoms as heart failure worsens.

Alternatively, when signs and symptoms were present, female caregivers of male patients and whites may have been more assertive in seeking treatment. In a substudy of OPTIMIZE-HF (Organized Program to Initiate Lifesaving Treatment in Hospitalized Patients With Heart Failure), a large national registry for patients hospitalized for heart failure,<sup>33</sup> and in a report of consecutive patients treated in a special care unit for acute decompensated heart failure at our site from January 2000 through December 2006,<sup>34</sup> patients with left ventricular systolic dysfunction were more often male and more likely to have ischemic

Questions related to new onset of paroxysmal nocturnal dyspnea and new onset of restlessness, confusion, or fainting might be more likely to provide evidence of worsening heart failure.

Profound fatigue was a reliable indicator of being hospitalized.



cardiomyopathy. Research is needed to determine if the cause of heart failure plays a role in the number of signs and symptoms that patients report or if another rationale emerges.

Finally, the number of symptoms did not differ relative to the patient's age. Our sample was younger than patients with left ventricular systolic dysfunction in an outpatient cardiology registry<sup>35</sup> (mean [SD] age, 68.7 [13.2] years) and in 2 hospital-based registries<sup>22,27</sup> (mean [SD] age, 72.4 [14.1] and 73.1 [14.2] years). Future research with older patients is needed to learn if signs and symptoms are blunted with older age and if findings from this study are similar in older patients with heart failure who have medical conditions with signs and/or symptoms that often mimic worsening heart failure (eg, atrial fibrillation, chronic obstructive pulmonary disease, renal disease, valvular disease, anemia, vascular disease).

Limitations of this study are that data were collected by using a convenience sample at 1 Midwest health care setting. Results may not be applicable to community-dwelling and hospitalized adults in other geographic regions, patients of ethnicity other than white or African American, very elderly patients, or patients with causes of heart failure different than the causes among our patients. Our sample included only patients with systolic heart failure; thus, these results cannot be used to draw conclusions about people with heart failure and preserved systolic function.

Our data collection tool was not exhaustive. Patients could have had other signs or symptoms and failed to report them in the space provided; for example, our tool did not include difficulty sleeping as a symptom of heart failure. In 1 study,<sup>29</sup> difficulty sleeping was only mildly bothersome and its intensity remained stable at 18 months when patients were resurveyed. We collected data on paroxysmal nocturnal dyspnea and restlessness, and, although related, those factors are not equivalent surrogates of difficulty sleeping. Besides difficulty sleeping, our tool did not include signs or symptoms associated with aging, such as nocturnal polyuria, even though this also may be associated with heart failure. Moreover, our tool did not include signs or symptoms associated with depression, such as worrying or feeling nervous, sad, or irritable, even though these could be perceived as psychological symptoms of heart failure. Future research should examine signs or symptoms of heart failure that are associated with both heart failure and depression to determine their independent effects on heart failure.

Our tool contained some symptom clusters; for example, restlessness, confusion, or fainting and nausea, vomiting, diarrhea, or loss of appetite, that

prevented determining the frequency of individual symptoms in the cluster. Our findings reflected signs and symptoms that occurred at any time during a 7-day period. Reports of occurrence of dyspnea, fatigue, palpitations, chest pain, and NYHA functional class could have been mismatched if symptoms were infrequent or did not occur at times when patients were physically active.

Finally, our tool did not assess intensity, or, when applicable, location, duration, or precipitating factors of signs and symptoms of heart failure. These variables may be important qualifiers of some signs and symptoms of heart failure, and these details may help interpret overall satisfaction with life, perceived health, adherence to self-care behaviors for heart failure, and health-related quality of life. Future research should examine relationships between signs and symptoms of heart failure and outcomes, including the effects of increasing somatic awareness through education about the signs and symptoms of heart failure and what to do to control worsening signs and symptoms.

## Conclusion

It is up to health care providers to ask the right questions to illuminate the sometimes subtle changes that indicate worsening heart failure. When patients use a checklist to report signs and symptoms of heart failure, both common and more atypical signs and symptoms emerge, some that can be used in isolation and others that can be used as part of a group of signs and symptoms to determine current heart failure status and readiness for discharge, if hospitalized. Dyspnea was found in most ambulatory and hospitalized patients and in patients classifying themselves as having no limitations in activity (functional class I); therefore, health care providers should not use the symptom dyspnea in isolation to monitor for improvement or worsening of heart failure, as dyspnea appears to be insensitive to heart failure status. A checklist may overcome patients' reluctance to report signs and symptoms believed to have little meaning in relation to heart failure.

FINANCIAL DISCLOSURES  
None reported.

Men and whites reported fewer signs and symptoms, yet were hospitalized more often than women and nonwhites.

This tool did not include psychological signs or symptoms such as those associated with depression.

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**CE Test** Test ID A101905: Signs and symptoms of heart failure: Are you asking the right questions?

*Learning objectives:* 1. Recognize signs and atypical symptoms that may be associated with worsening heart failure and functional class. 2. Define key elements of a patient teaching plan related to heart failure and response to treatment. 3. Define reliable indicators of functional class for heart failure patients.

**1. Which of the following is the current lifetime risk of developing heart failure for men and women at age 40?**

- a. 1 in 10
- b. 1 in 5
- c. 1 in 25
- d. 1 in 3

**2. Which of the following was the expected direct and indirect cost associated with heart failure in 2008?**

- a. \$35 billion
- b. \$6 million
- c. \$53 million
- d. \$5 billion

**3. Which of the following symptoms below are so global that patients with heart failure may not recognize them as important markers of worsening condition?**

- a. Edema and weight gain
- b. Tachycardia and nocturia
- c. Vertigo and memory loss
- d. Dyspnea and fatigue

**4. What does the Common Sense Model of Illness include as a precursor to coping or self-care behaviors?**

- a. Recognizing signs and symptoms to form a conscious level of danger and threat
- b. Ignoring signs and symptoms as an initial coping mechanism
- c. Resisting initial patient teaching efforts due to fear and uncertainty
- d. Engaging in behavior that is known to cause exacerbation of symptoms

**5. What was the primary aim of the study?**

- a. To test the accuracy of a preprinted checklist in describing of signs and symptoms
- b. To compare the symptoms of heart failure to the NYHA functional class
- c. To determine patients' perception of signs and symptoms of heart failure
- d. To describe the most frequently reported symptoms associated with heart failure

**6. Which of the following was the most frequent etiology of heart failure in the study sample?**

- a. Dilated cardiomyopathy
- b. Ischemic cardiomyopathy
- c. Valvular disease
- d. Hypertension

**7. Which of the following heart failure signs was 1 of the 5 most frequently reported by patients in the study?**

- a. Shortness of breath
- b. Whole body edema
- c. Dizziness/lightheadedness
- d. Ankle/leg edema

**8. During the study, which of the following heart failure symptoms did patients universally report regardless of functional class or care setting?**

- a. Dyspnea
- b. Edema
- c. Profound fatigue
- d. Activity intolerance

**9. What symptom of heart failure was associated with worsening NYHA functional class and also was a reliable indicator of being hospitalized?**

- a. Edema
- b. Decreased appetite
- c. Profound fatigue
- d. Dyspnea

**10. Which of the following did the study investigators identify as a limitation of the study data collection tool?**

- a. The tool was not exhaustive in listing heart failure symptoms.
- b. The tool included signs and symptoms associated with depression.
- c. The tool contained descriptions of symptoms associated with aging.
- d. The tool assessed intensity of heart failure symptoms.

**11. Which of the following conclusions did the study investigators reach related to the use of a checklist for assessment of symptoms associated with heart failure?**

- a. Patients may report expected signs and symptoms of heart failure.
- b. Patients are likely to inaccurately describe the signs and symptoms of heart failure.
- c. Patients may report atypical signs and symptoms of heart failure.
- d. Patients are unlikely to accurately describe the signs and symptoms of heart failure.

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