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A Mixed Methods Study of Symptom Perception in Patients with Chronic Heart Failure

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Abstract

Background—Early heart failure (HF) symptoms are frequently unrecognized for reasons that are unclear. We explored symptom perception in patients with chronic HF.

Methods—We enrolled 36 HF out-patients into a longitudinal sequential explanatory mixed methods study. We used objectively measured thoracic fluid accumulation and daily reports of signs and symptoms to evaluate accuracy of detected changes in fluid retention. Patterns of symptom interpretation and response were explored in telephone interviews conducted every 2 weeks for 3-months.

Results—In this sample, 44% had a mismatch between objective and subjective fluid retention; younger persons were more likely to have mismatch. In interviews, two patterns were identified: those able to interpret and respond appropriately to symptoms were higher in decision-making skill and the quality of social support received.

Conclusion—Many HF patients were poor at interpreting and managing their symptoms. These results suggest a subgroup of patients to target for intervention.

Keywords

self-care; heart failure; delay; symptom perception

Approximately 6.5 million adults in the United States have chronic heart failure (HF) and the prevalence is increasing.[1] Four of every five HF patients require hospitalization annually and at least one of every three are hospitalized repeatedly.[2] Hospitalizations typically result from fluid retention. The costs of these hospitalizations and the overall care of HF are draining our economy and costs are estimated to double by 2030 ($31 billion in 2012 to $70 billion in 2030).[3]

Once the cycle of fluid retention, subacute congestion, and hospitalization begins for HF patients, the sequence typically repeats until death.[4] Conversely, freedom from congestion has been shown to predict survival two years after hospital discharge.[5] Thus, detecting fluid retention early may prevent repeated hospitalizations, benefitting patients directly and decreasing health care costs for society. These findings illustrate the importance of helping HF patients to detect and interpret early indicators of fluid retention.

Symptom Perception

The ultimate goal of this study was to further our understanding of symptom perception, which can help to explain why some HF patients delay in seeking treatment for fluid retention. Symptom perception involves both the detection of physical changes and the interpretation of meaning.[6] Detection refers to the recognition of afferent physiological information. Interpretation refers to the attribution of a symptom experience to the appropriate source.[7]

Fluid retention is typically a slow process, and early indicators of congestion are often unrecognized for reasons that are unclear. HF patients are advised to weigh themselves and monitor their symptoms daily.[8] However, fewer than 50% of HF patients weigh regularly,[9, 10] perhaps because body weight is a gross measure of fluid retention with little sensitivity in detecting clinical deterioration.[11] There is little day-to-day correlation between daily symptom reports and daily weights.[12, 13] Further, patients often find it difficult to interpret whether weight changes are the result of fluid retention, or due to gains in adipose tissue.[14] Even in those who do weigh, lack of skill in evaluating weight gain[15] and managing signs and symptoms of fluid retention contribute to delays in treatment response.[16–18]

There is surprisingly little research addressing symptom detection and interpretation abilities in HF patients. Studies in HF and other populations suggest that disease severity, illness duration,[19] comorbid conditions,[20] cognitive decision-making ability, psychological state,[21] and symptom patterns influence somatic awareness or sensitivity to physical sensations.[22] Symptoms that are insidious, ambiguous, vague or non-specific[16, 23] lead to uncertainty. There is also evidence of sex-differences in somatic awareness.[24] In addition, self-care confidence influences the interpretation and response to symptoms.[25, 26] A growing body of research suggests age-related differences in interoception or the sense of the internal physiological condition of the body.[27–30]

At this point it is unclear if treatment seeking delay is related to erratic monitoring, inaccurate detection of fluid overload, mistaken interpretation, or poor decisions about response. Thus, the purpose of this study was to explore symptom perception in patients with chronic HF. We conducted a longitudinal sequential explanatory mixed methods study to explore these issues in HF patients with the goal of furthering our understanding of symptom perception in HF patients.

Materials and Methods

After obtaining Institutional Review Board approval, we enrolled a sample of community dwelling HF patients from outpatient settings affiliated with two university hospitals in Philadelphia, Pennsylvania. All participants gave written informed consent. We collected baseline and 3-month data during home visits. Biweekly, participants were telephoned to ask about their symptoms over the past week. Those who had experienced symptoms were interviewed.

Sample

We enrolled a small sample of 36 to allow depth rather than breadth in data collection.[31] Maximum variability was sought in participant age, gender, HF duration and severity, and comorbidity. In addition to HF confirmed by clinical examination and echocardiographic evidence of impaired ventricular function, all enrollees had a prescription for a loop diuretic as an indicator of prior fluid retention and an implantable cardioverter defibrillator (ICD) with continuous intrathoracic impedance monitoring capability (OptiVol® Medtronic, Minneapolis). ICDs are indicated for HF patients to prevent ventricular tachyarrhythmia if they are NYHA class II–III, have an ejection fraction ≤35%, and an expected survival of more than a year.[32] Anyone who had a major surgical procedure within the prior three months was excluded because surgery may interfere with impedance measurements. Participants had to speak English, be able to complete the protocol (e.g., adequate visual acuity and hearing), and live in an independent setting where self-care is an expectation (i.e. not institutionalized). Vision, hearing, and English proficiency were assessed by interview. Exclusion criteria included major untreated psychiatric illness documented in the medical record and cognitive impairment assessed using the Telephone Interview for Cognitive Status (TICS);[33] anyone with a score of < 25 was ineligible for inclusion. Those with poor health literacy were excluded after screening using three brief questions.[34]

Measurement

Continuous Intrathoracic Impedance Monitoring Capability—The OptiVol® device provides an objective measure of daily thoracic fluid status using an intrathoracic impedance-derived fluid index to measure changes in electronic resistance.[35] Increasing congestion within the lungs results in a reduction in the resistance/impedance to the electronic current from the device.[36] Average raw daily impedance is quantified, stored in the device, and typically downloaded in clinical practice at three month intervals. Changes in impedance have superior sensitivity (76%) over weight gain (23%) in predicting clinical events and lower false detection event rates than weight gain (1.9 vs. 4.3 per patient-year).[37] Changes in impedance are associated with a greater risk of hospitalization for HF[38] and all-cause mortality than weight gain.[39] We used devices produced by a single manufacturer (Medtronic) to ensure that impedance was measured in an identical fashion. Data extracted from the device included the precise date of onset, frequency, duration, and resolution of all episodes of congestion including threshold crossings. Device data were used as the gold-standard for fluid retention.

Monitoring Behaviors, Signs and Symptoms—Over a three-month period, participants kept a daily research diary where they noted fluid retention monitoring behaviors (e.g., weighing), symptoms (e.g. dyspnea, fatigue), and ratings of perceived fluid retention. Perceived fluid retention was measured using a 0–10 severity rating scale (*How much fluid do you think you retained today?*). Such scales are commonly used to rate symptoms.[40] The research diary was designed as a checklist that could be completed easily and rapidly to encourage adherence. Symptoms were assessed daily using the Heart Failure Somatic Perception Scale (HFSPS),[41] which asks how much the participant was bothered by 18 common HF symptoms, rated with six response options (0, not at all to 5, extremely bothersome). The HFSPS 6-item subscale for dyspnea (HFSPS Dyspnea), the primary symptom of fluid retention, has a Cronbach's α of 0.90, and is predictive of clinical events at 180 days and one year.[42] Additional items assessing inability to sleep and bendopnea (i.e., shortness of breath when leaning forward)[43] were assessed daily, as was the 7-item Multidimensional Fatigue Inventory.[44] All symptoms were assessed using the HFSPS 0–5 point rating scale to minimize confusion. Higher scores indicate greater acute physical symptoms.

Interviews—Interviews were used to identify symptom interpretation and response patterns. A major critique of qualitative symptom perception studies is reliance on recall, so participants were telephoned every two weeks to inquire about symptoms; interviews were completed only when symptoms were reported. A semi-structured interview guide was developed to explore the thought processes used by HF patients to interpret and respond to their symptoms: (*"Tell me about your symptoms in the past week"*). A series of open-ended questions and probes were used by trained research assistants to focus the interview while allowing participants to speak freely. To assess thoughts about signs, symptoms, and causes, participants were asked a series of open-ended questions around the following categories: *What did you experience (and is it a new experience)? How did it feel? What is the significance of the symptom? What is the major symptom you experience with fluid retention (e.g., shortness of breath, fatigue)? How do you usually respond to symptoms of this type?* Patients were encouraged to fully describe monitoring behaviors, symptoms, perceptions, and interpretations. To clarify any unclear descriptions, they were asked for examples. Two styles of probes were used to facilitate the interview: recapitulation was used to redirect for clarity and elaboration, and silent probes, thoughtful periods of silence were used to allow reflection.[45] Interviews were audiotaped, transcribed verbatim and the data were analyzed using Atlas.ti software (Berlin, Germany).

We collected baseline sociodemographic data (e.g., age, gender, education) and socioeconomic status was assessed using the Barratt Simplified Measure of Social Status,[46] based on the dimensions of marital status, education and occupation. Decision-making was assessed using the computer administered version of the Iowa Gambling Task (IGT), which measures decision-making processes in the context of a mock gambling paradigm.[47] Depression was measured using the Patient Health Questionnaire (PHQ-9).[48] Self-care was measured with the Self-Care of Heart Failure Index (SCHFI v.6.2), which captures treatment adherence and self-monitoring, recognition of symptoms when they occur, symptom management strategies, and confidence in the ability to perform self-care. Scores are standardized 0–100 with higher scores indicating better self-care. A score ≥70 is considered adequate.[49] Perceived health (current and compared to last year) was measured using two items from the Short Form-36.[50]

Clinical characteristics (e.g. HF duration, type, ejection fraction) were abstracted from the medical record. New York Heart Association (NYHA) class was classified as I-IV by a single cardiologist using data from a standardized interview.[51] Comorbid conditions were abstracted from the medical record and summarized using the Charlson Comorbidity Index (CCI).[52] Global cognitive ability was tested with the Montreal Cognitive Assessment (MoCA).[53] Data on hospitalization was collected from the electronic medical record and augmented with patient interview to capture out-of-system events.

Analysis

After describing the sample, we evaluated the accuracy of HF patients' abilities to detect changes in fluid retention, aim 1, by comparing objective and subjective data. OptiVol® data were analyzed with latent class analysis. Specifically, the average fluid index (i.e. mean of fluid index over time) and variability in fluid index (i.e. within-person standard deviation of the fluid index over time) were used to identify naturally-occurring and distinct patterns of impedance over time. Impedance is used by the OptiVol device as a surrogate for fluid status in the chest. The fluid index ranges from 0 (no fluid accumulation) to 200 (truncated at high degree of fluid accumulation). Then we compared this objective evidence of fluid retention with subjective data on perceived fluid retention from symptom diaries and qualitative interviews to evaluate the accuracy of HF patients' abilities to detect fluid retention. After detection accuracy was determined, we explored factors associated with inaccurate detection, our second aim, using descriptive statistics because of the small sample size.

To address the third aim, to identify patterns of symptom interpretation and response, we explored how HF patients monitor, interpret, and respond to signs and symptoms of fluid retention in the qualitative data using content thematic analysis. Preliminary analysis of interview transcripts included a line-by-line review that yielded clusters of data that were labeled into brief headings. Codes derived from these data were linked to interview questions to yield coding categories. These coding categories were summarized across cases and subsequently cross-classified to yield a rich descriptive analysis. Within-case analysis was used to identify the key elements of each individual's account.[54] Methodological rigor was maintained through an audit trail, periodic peer debriefing and member checking to support credibility.[55] These analyses were done by qualitative research experts blinded to the quantitative data.

After the qualitative and quantitative data were fully analyzed, the first two authors used data integration techniques to identify patterns of symptom interpretation and response. Using triangulation methods, we compared qualitative evidence of symptom detection and interpretation with the quantitative OptiVol® and self-report data. Qualitative patterns of responses to signs and symptoms were integrated with the patterns derived quantitatively. Then, qualitative data were linked to the factors shown previously to contribute to symptom interpretation (e.g., age, comorbid conditions). Integrating these patterns helped illustrate how patients monitor and interpret symptoms of HF and provide insight into why HF patients delay in responding to fluid retention.

Results

The enrolled sample of 36 was predominately male (67%), older (64±15.2 years), White (61%), and functionally compromised (56% NYHA class III), with a moderate level of comorbidity (42%). See Table 1. Seven participants withdrew or were lost to follow-up before the final home visit, but only one withdrew early, so a rich data set was available on each of these participants.

At enrollment, self-care was poor overall. Self-care maintenance scores were barely adequate (mean 69.8 ± 13.5, range 33–93). Self-care management scores (64.4 ± 18.9, range

35–90) and self-care confidence were low (mean 68.4 ± 19.1, range 17–100) as well. The HFSPS scale total score was low (mean 8.1 ± 10.6, range 0–51), the HFSPS Dyspnea subscale score was also low (mean 1.8 ± 3.7, range 0–15), as was the daily diary fatigue score (mean 4.1 ± 6.6, range 0–24), indicating that few were symptomatic on enrollment. Within the 3-month follow-up period, four participants were admitted to the hospital for HF; two of these four were admitted twice.

Accuracy of Fluid Retention Detection

Only 18 participants had OptiVol® data available for analysis; in the others, the data were not downloaded during the study interval. In the available data, we identified two patterns of lung water accumulation (latent class proportions 39% vs. 61%, entropy 0.96, posterior probabilities 0.97 and 1.00, parametric bootstrap likelihood ratio $p<.05$ all indicating a good model or analytic solution). As shown in the Figure, 7 participants (shown at the top) had substantial and highly variable thoracic fluid congestion over the 3 month study interval and 11 (shown at the bottom) had consistently limited congestion over 3 months with no major congestion events (average fluid index = 68.6 ± 29.3 vs. 11.8 ± 6.1; average variability = 70.2 ± 14.0 vs. 13.2 ± 8.8, both $p<0.001$).

To determine if the same people with objective thoracic fluid congestion were those who perceived fluid retention, we classified participants into one of two groups: 1) those who perceived minimal fluid retention, or 2) those who experienced significant variability and spikes in fluid retention. We used their daily ratings of perceived fluid retention (daily ratings of 0–10), interviews, and self-report data to classify them into these groups. Eleven participants perceived only minimal fluid retention (mean fluid retention .05 ± .46, range 0–3). Another seven experienced significant variability in fluid retention (mean fluid retention 2.96 ± .75, range 2–8). Then we examined their OptiVol data. We compared objective lung water accumulation obtained from the OptiVol with the subjective perceptions of fluid retention. When we did so, we found a distinct symptom-hemodynamic mismatch in some participants. Four of the seven patients in the high and variable thoracic congestion group (top figure) perceived little fluid retention. In the group with consistently limited congestion (bottom figure), four perceived high levels of fluid retention. In all, 8 of the 18 (44%) with OptiVol® data had a mismatch between objective and subjective measures of congestion. The other 10 participants appropriately reported perceived fluid retention when the OptiVol® detected congestion.

Factors Associated with Inaccurate Detection

The eight with a symptom-hemodynamic mismatch were compared to the 10 with a match between their symptoms and their hemodynamics. Only age differed significantly between the groups. Those with a mismatch were younger (53.9 ± 15.2 vs. 72.5 ± 7.9 years, partial eta squared effect size: .41, $p=.004$). There were no obvious differences between the groups in gender, depression, Charlson Comorbidity Index scores, MoCA cognition scores, Iowa Gambling Task decision-making scores, symptoms or symptom variability, or duration of HF. Mismatch patients were no less likely to weigh themselves daily than those with no mismatch.

Patterns of Monitoring, Interpretation and Response to Signs and Symptoms of Fluid Retention

When telephoned, 26 participants reported symptoms; one to three qualitative interviews were available for analysis on these 26. These participants reported using standard symptom monitoring strategies of daily weights (n=11) and ankle checks (n=7), as well as individualized approaches such as being attentive or *"listening"* to subtle changes such as waist fullness, wrist swelling, energy level, and activity tolerance *["…I have to walk about three blocks <to bus>…when I'm walking, I get winded… I have to stop"].* The most commonly reported signs were weight change and ankle edema, which were usually interpreted as HF related and specifically indicators of fluid retention. Shortness of breath (reported by 14) was interpreted as a symptom of fluid retention by 11 individuals; while 2 individuals interpreted it as activity intolerance *("...yesterday when I got to the top of the steps I was a little short of breath...it shouldn't be...")*. One person related his shortness of breath and fatigue to a cancer diagnosis and medication side effects *("my theory it's the medication, not the heart…")*.

Abdominal bloating was described by 5 as a sign of fluid retention *("when I'm aware that I am retaining fluid…I feel it first in my abdomen").* Fatigue was detected by 12; but not always interpreted as related to HF. Some (n=5) linked their fatigue to conditions like diabetes, spinal stenosis, and atrial fibrillation. However, fatigue in combination with other signs (e.g., weight gain) or symptoms was more likely to be interpreted as HF. Activity intolerance followed by fatigue was mentioned as a signal of worsening symptoms (*"some days everything is an effort…then I get tired…super tired…it's different").*

We identified two patterns based on the ability to interpret and respond to symptoms. One person was so brief in response to interview questions that we were unable to judge his ability to interpret symptoms, so only 25 people were classified.

Group 1—Thirteen participants had difficulty detecting and interpreting their symptoms. Five of these experienced bodily sensations but vacillated in calling them symptoms. For example, one 83-year-old white woman who reported having symptoms in the daily diary (HFSPS total 15; HFSPS dyspnea 8; daily diary fatigue scale 22) reported in the qualitative interview that she had not had any symptoms *("I don't huff and puff"*). On subsequent interviews, she was noted to have labored breathing by the research assistant, which was consistent with her symptom diary (HFSPS total 30, HFSPS dyspnea 16, daily diary fatigue scale 28). However, she reported qualitatively that she did not have symptoms but was just *"not as perky"* as she used to be. In this group, inability to interpret symptoms resulted in ineffective actions *("rest and try to breathe normally"*) and even potentially dangerous actions *("I just don't feel like myself…I think it is my kidneys…so I try to drink more and flush them"*). Three of these five had OptiVol® data, but no symptom-hemodynamic mismatch was found.

Another 8 people detected symptoms but could not interpret or label them correctly. Although they described symptoms like shortness of breath, fatigue and ankle edema, these symptoms were attributed to comorbid conditions rather than HF. As a result, treatment was delayed as they tended to *"wait and see"* before taking action. For example, one 72-year-old white man described wrist swelling as a sign of fluid retention, which he assessed by *"twisting his watch"* and checking his ankles for swelling. Although he reported *"evidence of carrying fluid"* he attributed it to his diabetes, which he felt was compounded by stress. He feared taking an extra diuretic that would *"dry him out too much"*. Misconceptions about causes and consequences of worsening symptoms were evident in this group. A 76-year-old White man described symptoms of shortness of breath and activity intolerance (HFSPS total 16, HFSPS Dyspnea 18), worsening shortness of breath *("panting")* and fatigue (daily diary fatigue scale 14). However, he attributed the worsening of his symptoms over the course of 10 days to the weather *("not my heart")* until he developed a cough, which prompted him to contact his doctor. When asked about this delay, he had been monitoring his weight daily and concluded that his symptoms could not be related to his HF since his weight had not changed. He planned to *"give it a few days"*.

Those who struggled with labeling their symptoms as HF-related discussed overlap with other comorbid conditions *("the ankles swell…but I have had arthritis forever…")*. They linked their symptoms to environmental factors (e.g., stress, weather) and failed to connect these factors with their heart. They were particularly confused when symptom patterns varied from past experience. They did not articulate a prescribed plan of *"what to do"*. No one discussed taking an extra diuretic as part of their personal plan to ameliorate symptoms or intent to contact their healthcare provider, which are typical self-care management strategies. Even the person who planned to *"give it a few days"* discussed his only option as going to the emergency room.

Patterns of ongoing but fluctuating symptoms may have contributed to the inability of this group to interpret their symptoms and respond effectively. When symptom patterns were different than expected (*"I did not eat anything with salt so I know it was not that")*, patients had difficulty in interpretation and reported waiting to see if the expected pattern emerged. Uncertainty was described by those who *"wait and see"* and sometimes delayed treatment for days. For example, a 67-year-old white male who monitored for symptoms with daily weights and checking his ankles described fluctuating symptoms of shortness of breath but no weight gain (HFSPS total 12), which he interpreted as a respiratory problem. Then he noticed a 5-pound weight gain without shortness of breath (HFSPS total 4), but did not take any action because his breathing had improved. When he noticed that his clothes were tighter indicating fluid retention and the shortness of breath had returned, he interpreted the symptoms as related to his HF, but at this point treatment had been delayed for more than a week. In these eight patients, two had evidence of a symptom-hemodynamic mismatch.

Group 2—Twelve people described monitoring, interpreting, and responding appropriately to symptoms. They reported consistent monitoring strategies like daily weights and checking ankles. Six described body listening as important to symptom detection *("it is an internal feeling"*). They described using their knowledge about and experience with symptoms to interpret and manage their symptoms. Specifically, they recalled past episodes of similar symptom experiences; recounted prior or familiar situations ("*I know when I have social obligations…the salt")*. Some described that a rating of severity ("*red light goes off*"), number of days with symptoms, or the progression of symptoms influenced how they responded. Those who discussed weight changes and ankle edema were able to describe their understanding of the relationship of these symptoms to fluid retention *("I check my legs and weight…they got a little big…fluid…I watch my body. It dictates to me all the time how I feel…'*"), which supported their interpretation of symptoms as HF-related.

In this group, treatment of symptoms included altering activity levels (*If <activity> is more than I can deal with, then I don't do it…or I plan for it…give myself extra time…rest")* and use of a diuretic either independently or in consultation with the provider. Social support by family and friends helped them with daily self-care maintenance behaviors and at times reinforced their symptom perception and interpretation *("…my children would say '...your ankles look a little big'…so I am aware that fluid retention is with my feet swelling…*"). Five of these 12 had OptiVol® data so we could judge symptom-hemodynamic mismatch; two had mismatch and three did not.

In the quantitative data, those who were able to interpret and respond appropriately to symptoms were higher in decision-making skill and the quality of social support received (Table 2). The groups did not differ in age, cognition, functional status, or depression scores. Of the four participants hospitalized over the 3-month period, two were in the first group and two were in the second group. Length of hospital stay did not differ between the groups.

Discussion

The purpose of this study was to evaluate the accuracy of HF patients' abilities to detect changes in fluid retention, identify patterns of symptom interpretation and response, and explore factors related to inaccurate detection, interpretation and response. We found a distinct mismatch between symptoms and hemodynamics in a subset of patients, with some of those with objective evidence of congestion failing to detect fluid retention. Others perceived fluid retention but had little objective evidence of congestion. The only factor distinguishing those with a symptom-hemodynamic mismatch was younger age. In the qualitative analysis we identified two groups based on their varied abilities to interpret and respond to symptoms. These groups illustrate the differential etiologies involved. The group experiencing difficulty interpreting their symptoms often could not recall situations in which they had experienced symptoms, they failed to perceive worsening HF, or they attributed their HF symptoms to some other illness. This group was lower in decision-making skill and reported less social support than the group with more expertise in symptom interpretation. Surprisingly, symptom-hemodynamic mismatch and hospitalization were not limited to the group poor in symptom detection and interpretation.

An enduring clinical dilemma is that many HF patients have hemodynamics that are much worse or much better than their symptoms,[56] so the finding of a distinct symptom-hemodynamic mismatch is important. In a prior study we identified specific profiles when data on physical and psychological symptoms and hemodynamics were integrated.[57] Three profiles were identified in that study, with 18% of patients having severe symptoms and average hemodynamics, 64% having mild symptoms and poor hemodynamics, and only 18% having concordant symptoms and hemodynamics. Similarly, in the current study we again found that a large proportion of participants had a symptom-hemodynamic mismatch. Only younger age distinguished these patients from those without a mismatch, which differs from our prior research suggesting that older HF patients had trouble perceiving symptoms.[29] The prior mismatch study[57] demonstrated that HF patients with a symptom-hemodynamic mismatch have a greater risk of poor outcomes, illustrating the need for further study to understand symptom-hemodynamic mismatch and determine if symptom monitoring and interpretation interventions can lessen this mismatch.

The fact that decision-making skill was lower in patients who on interview struggled to interpret their symptoms is consistent with prior studies suggesting that healthy adults with lower cardiac awareness (interoceptive awareness) had reduced decision making ability.[58] The somatic marker hypothesis posits that neural interpretation of somatic information influences decision-making.[59] Neural interpretation depends on brain structures closely tied to models of interoceptive ability including the orbital prefrontal cortex, amygdala, and insular cortex. The right insula, an area of the brain known to be impaired in HF patients,[60] has been shown to be more active in people who make accurate judgments about stimuli produced within the body during decision-making.[61] Together these findings support the interpretation that the cognitive impairment commonly seen in HF patients contributes to poor decisions about symptom response.

Body listening appears to be an advanced symptom monitoring skill that we only identified in those who were adept at symptom interpretation and response. We have referred to these patients as "experts" in our prior studies.[25, 62] These experts are individuals who can recognize linkages, make changes, and adapt to situations. These body listening behaviors reflect a naturalistic decision making process with person, problem, and environmental factors influencing the everyday self-care decisions made by patients.[6] When symptoms or patterns of symptoms were interpreted within the context of predisposing situations that were different than expected, patients had difficulty because the expected pattern failed to emerge. Interventions designed to improve body listening are needed. It is notable that the average scores on the HFSPS and the dyspnea and fatigue subscales indicated few were symptomatic, yet self-care maintenance scores were low. One would assume that patients with poor self-care maintenance would be symptomatic but this was not the case in this sample. It may be that those with poor self-care maintenance were still early enough in the disease trajectory to be able to practice poor self-care and still avoid having symptoms.

Fatigue is a cardinal symptom of HF but these results confirm that patients have great difficulty interpreting this particular symptom. Fatigue was interpreted best when it was experienced in combination with other HF symptoms (e.g., weight gain), confirming the importance of understanding symptom clusters. In a prior HF study, fatigue clustered with shortness of breath with activity.[63] In another study, a volume overload cluster was identified with fatigue, shortness of breath, and sleep problems.[64] Knowledge of symptoms that typically cluster with fatigue could be used to teach HF patients about symptom perception.

Finally, those patients better at interpretation and response to symptoms reported that the quality of the support their received was higher. This result confirms that of prior studies demonstrating the importance of social support in self-care.[25, 65–68]

Limitations of this study include a small sample size, although it was adequate for a mixed methods study[31] and the sample characteristics were typical of those of HF patients in the community. OptiVol® data were not available on all participants, and some with OptiVol® data were not able to be interviewed, which resulted in unequal sample sizes for various analyses. Further, without objective hemodynamic data on everyone, we cannot be certain that individual reports of fluid retention were due to HF. Another limitation is that impedance can be influenced by conditions other than HF. False positive detections do occur. Future research should combined diagnostics (impedance, posture, respiratory, activity, heart rate, arrhythmia and heart sounds) to improve sensitivity and decrease the risk of false positive events.

In summary, in this study we determined that although some HF patients had systems in place for monitoring their symptoms, problems with symptom detection were evident, interpretation was poor, and problems in management delayed response. Even those who were comfortable in their self-care abilities had evidence of a symptom-hemodynamic mismatch and did not avoid HF hospitalization. Notably, even the most savvy patients in this sample were not able to avoid a HF hospitalization. Further research is greatly needed on this topic if we are to achieve the goal of rapid response to signs and symptoms and early medical intervention in patients with HF, thereby decreasing HF hospitalization.

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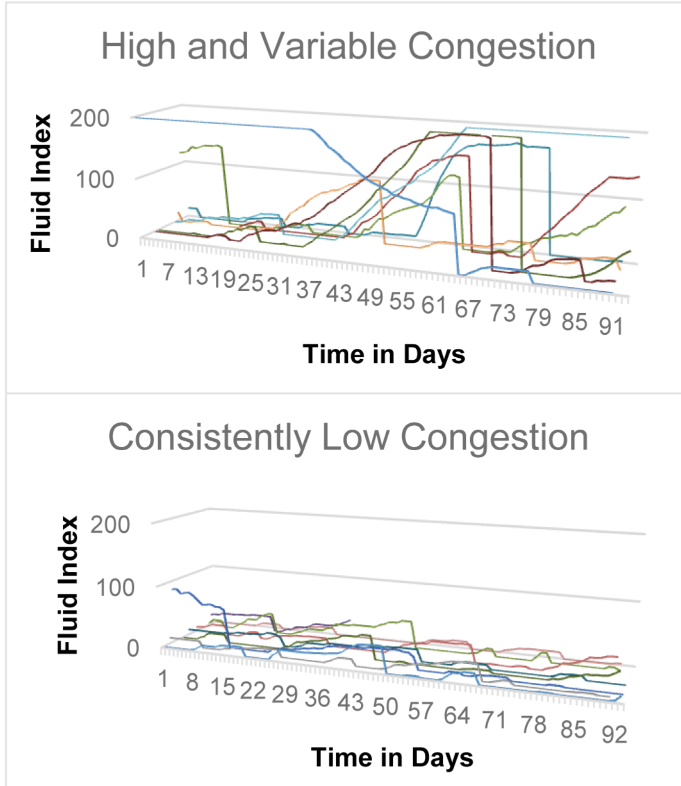

Figure.

18 study participants had OptiVol data and reports of fluid retention available for analysis. Of these, 7 participants experienced considerable and highly variable thoracic fluid congestion over the 3 months. This is illustrated in the top figure showing that the fluid index rises and lowers in a variable fashion. In the bottom figure, we show the 11 who experienced consistently limited congestion and little variability over 3 months. These 11 had no major congestion events.

Table 1

Demographic and Clinical Characteristics of the Full Sample (N=36)

Patient Characteristics	Mean ± SD	N, Percentage
Age (years)	63.8 ± 15.2	
Socioeconomic status (Barratt Simplified Measure of Social Status)	43.8 ± 11.1	
Depression (PHQ-9)	4.5 ± 4.1	
MoCA Score	25.28 ± 3.1	
Charlson Comorbidity Index (CCI) score	3.36 ± 2.0	
Ejection Fraction (%)	37.4 ± 16.8	
HF duration	135.4 ± 102.2	
Total number of medication	10.9 ± 4.8	
Male		• 24 (66.7)
Race		
• African American		• 9 (25.0)
• Caucasian		• 22 (61.1)
• Mixed or other		• 5 (13.9)
Education		
• High school or less		• 6 (16.7)
• Some trade or college education (e.g. vocational, associate degree)		• 16 (44.4)
• College (bachelor degree or higher)		• 14 (38.9)
Employment		
• Employed full or part-time		• 12(33.3)
• Unemployed (sick Leave, disability, retired)		• 23 (63.9)
• Other (e.g. student)		• 1 (2.8)
Marital status		
• Single		• 4 (11.1)
• Married		• 24 (66.7)
• Divorced or Separated		• 6 (16.7)
• Widowed		• 2 (5.6)
Self-reported income		
• More than enough to make ends meet		• 20(55.6)
• Enough to make ends meet		• 13 (36.1)
• Not enough to make ends meet		• 3 (8.3)
Quality of support		

	Mean ± SD	N, Percentage
• Satisfactory		• 2(5.6)
• Good		• 6 (16.7)
• Very Good		• 28 (77.8)
Perceived health		
• Poor		• 5 (14.3)
• Fair		• 16 (45.7)
• Good		• 8(22.9)
• Very Good		• 6 (17.1)
Abnormal MoCA score (< 26)		• 19 (52.8)
Categorized Charlson Comorbidity (CCI) score		
• Low level (CCI 1–2)		• 13 (36.1)
• Moderate level (CCI 3–4)		• 15 (41.7)
• High level (CCI≥5)		• 8 (22.2)
Common Comorbid Conditions		
• Atrial fibrillation		• 15 (41.7) *
• Myocardial Infarction		• 14(38.9)
• Sleep disordered breathing		• 14 (38.9)
• Diabetes		• 13 (36.1)
• Chronic pain		• 8 (22.2)
• Chronic Obstructive Pulmonary Disease		• 8 (22.2)
• Cerebrovascular Accident		• 7 (19.4)
• Renal Disease		• 6 (16.7)
NYHA class		
• I		• 3 (8.6)
• II		• 11 (31.4)
• III		• 20 (57.1)
• IV		• 1 (2.9)

Key: HF=heart failure; PHQ-9=Patient Health Questionnaire; MoCA=Montreal Cognitive Assessment; NYHA=New York Heart Association

* Percentages were calculated by the formula: n/36*100 (each disease was treated individually, so the sum of percentages under "common comorbidity conditions" are not 100)

Table 2

Differences between the Two Patterns of Symptom Detection, Interpretation and Response Groups (N=25)

	Group 1: unable to interpret or label symptoms correctly (n=13)	**Group 2: able to interpret and respond to symptoms (n=12)**	**Group differences (p value and effect size)**
Iowa Gambling Task Total T-scores	47.0 ± 3.0	52.9 ± 9.5	P=0.04 Partial eta squared = .166
Quality of support received (1–4 scale)	3.4 ± .77	3.9 ± .29	P=0.03 Partial eta squared= .181