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Contents lists available at ScienceDirect

Heart & Lung

journal homepage: www.heartandlung.com

A mixed methods study of symptom perception in patients with chronic heart failure

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ARTICLE INFO

Article history:

Received 6 September 2017

Received in revised form

31 October 2017

Accepted 5 November 2017

Available online

Keywords:

Self-care

Heart failure

Delay

Symptom perception

mixed methods

fluid retention

decision-making

social support

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.

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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,

Funding: Funded by a grant from the Biobehavioral Research Center, School of Nursing, University of Pennsylvania. Dr. Streur's training is supported by the National Institute of Nursing Research of the National Institutes of Health under award number T32NR014833. Dr. Irani's training is supported by the National Institute of Nursing Research of the National Institutes of Health under award number T32NR015433.

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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 gain¹⁵ 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 in depth.

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 New York Heart Association (NYHA) class II–III, have an ejection fraction $\leq 35\%$, 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 HF³⁸ 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.

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