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Using vignettes to understand heart failure self-care

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Abstract

Aims and objectives: We used vignettes to explore hospitalized HF patients' self-care decisions.

Background: Heart Failure (HF) self-care is integral to maintain and manage health, and may prevent unnecessary HF hospitalizations. Nevertheless, self-care remains challenging for patients, and using vignettes offers a new perspective to understand patient HF self-care decision making.

Design: This qualitative descriptive analysis was conducted as part of a mixed methods study.

Methods: We conducted semi-structured interviews (N=20) to elicit patient decisions about self-care in responses to three vignettes, which varied in symptom severity. Content analysis was used to extract quotes describing participant responses.

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Results: Participants were on average 60 years old, primarily male, African American, unemployed, and highly symptomatic (NYHA Class III or IV). Overall, participants were able to identify when symptoms required a decision to seek urgent medical attention, but had difficulty identifying the appropriate decision to make in response to less acute symptoms such as swelling.

Conclusions: Symptoms other than shortness of breath were challenging for patients to interpret and manage appropriately. Understanding how to apply HF knowledge to alleviate symptoms was also difficult.

Relevance to clinical practice: Vignettes may be a helpful tool to prompt patient-health care provider communication about self-care management, and prompt discussions about appropriate self-care decisions in response to varying levels of symptom severity.

Keywords

heart failure; self-care; decision making; symptom assessment; patient education

Introduction/Background

Heart failure (HF) is a global problem affecting 5.7 million Americans (Mozaffarian et al., 2014), and 26 million people worldwide (Savarese & Lund, 2017). HF self-care, which is defined as maintaining (e.g., daily medication taking), monitoring (e.g., checking weight) and managing (e.g., responding to symptoms) (Riegel, Jaarsma, & Strömberg, 2012) symptoms, is essential to promote and maintain health. Compared to patients with poor self-care, patients with more effective self-care experience better health outcomes such as quality of life and lower mortality (Lee et al., 2015; van der Wal, van Veldhuisen, Veegeer, Rutten, & Jaarsma, 2010; Vellone et al., 2017). Despite the importance of HF self-care on patient outcomes and clinician efforts to educate HF patients, HF self-care remains poor among HF patients (Holden et al., 2015; Sethares, Flimlin, & Elliott, 2014; Skaperdas et al., 2014). Patients struggle with following self-care advice because of a multitude of reasons, which are categorised in the literature as factors related to experience/skills, motivation, habits, beliefs/values, cognition/function, confidence, support and access to care (Jaarsma, Cameron, Riegel, & Stromberg, 2017). Symptom interpretation is especially challenging and difficult to assess as symptom interpretation typically occurs in a nonclinical environment. The purpose of our study was to understand HF symptom interpretation, using vignettes to describe the types of HF self-care decision HF patients make when faced with varying levels of HF symptom severity.

Vignettes are short stories given to individuals to elicit a response, either from their own perspective or the perspective of a character in the story (Barter & Renold, 1999). Historically, vignettes have been used in social and health science to gain information from individuals when observation is neither possible nor ethical (Barter & Renold, 1999). Vignettes are a valuable technique to explore perceptions, beliefs and meanings surrounding specific situations (Barter & Renold, 1999) and have not been used to assess HF self-care before. In this study, vignettes specific to HF self-care decision-making were used. Vignettes were presented to identify whether HF patients were able to make self-care decisions based on HF symptom education received from healthcare providers. Although symptoms can vary

among patients with HF, there are common elements to these symptoms (e.g., shortness of breath, swelling) that allow for the creation of vignettes representing varying levels of symptom severity and calling for different decisions in response.

Methods

Study design

The qualitative data described are from a larger mixed methods study, in which 127 participants completed a quantitative survey between September 2013 to February 2015. The survey included demographic and psychosocial variables (i.e. HF knowledge, health literacy, depressive symptoms, social support, HF self-care, etc.). Participants were English speaking, hospitalized for HF, had a previous hospitalization for HF, and cognitively intact (Mini-Cog™ score > 3). Participants were excluded if hospitalized for acute conditions, had congenital heart disease, had a left ventricular assistive device (LVADS), and/or were on dialysis. After completing the quantitative data collection (demographics and psychosocial variables), participants were selected to complete qualitative semi-structured interviews to explore self-care decisions prior to hospitalization. To maximize perspectives on self-care, qualitative participants were purposively sampled based on their self-care ability and readmission status. Self-care was measured using the self-care maintenance subscale from the Self-Care of Heart Failure Index version 6 (high versus low scores, cut off being 70) (Riegel, Lee, Dickson, & Carlson, 2009). Readmission status was measured by patient self-report (current hospitalization within or beyond 30 days of their last hospitalization). Ultimately, there were 4 qualitative participant groups, those with: (1) high self-care and readmitted within 30 days, (2) high self-care and readmitted beyond 30 days, (3) low self-care and readmitted within 30 days, and (4) low self-care and readmitted beyond 30 days. Participants completed the survey (n=127) and interview (n=20) during their hospitalization. Interviews were conducted by a trained nurse researcher (JX), were 60–90 minutes long, audio-recorded, and transcribed verbatim. Interviews occurred until data saturation was reached. Vignettes were embedded within the semi-structured interview. Further details about the mixed methods study can be found in a previous publication (Xu et al., 2018).

Vignettes

Three clinically relevant vignettes were developed by a multidisciplinary team of clinicians and researchers based on past research delineating best practices in vignette development (Braun & Clarke, 2013). In order to generate situations that would be realistic and relevant to HF patients, the vignettes were developed with a team of two qualitative methods experts and six HF clinicians (one cardiologist, two heart failure nurse practitioners, two nurse managers of medical units with HF patients, and one HF educator). Drafts of the vignettes were written, discussed in team meetings, revised, and discussed until consensus was reached. The vignettes represented three clinical situations commonly observed in HF self-care: shortness of breath, weight gain, and edema. HF clinicians agreed the vignettes represented three different clinical situations: 1) urgent care, 2) contact with physician and/or increased self-care measures, or 3) usual self-care measures. Vignettes were then pilot tested among five HF patients to determine acceptability and applicability to the HF population. We asked patients if they could understand the vignettes, relate to the symptoms

in the vignettes, and report on how realistic the vignettes were. HF patients thought the vignettes were easy to understand, easily relatable, realistic. No edits to the vignettes were suggested; therefore, the vignettes did not change after the pilot.

During the interviews, participants were asked to envision themselves as the individual in the vignettes and describe how they would respond in each situation. Example questions included: “If you were in this situation, tell me what you would do. Start with what you would do first.” Participants responded by listing and describing what they would do in a sequential manner. The vignettes were read aloud, as many times as needed, to participants who indicated they struggled with reading.

Ethics

The study was approved by the Johns Hopkins University University’s Institutional Review Board (NA_00084946). Prior to enrollment, the study was described, informed consent obtained, and participants were advised of their rights including the ability to cease study participation without affecting their care. Each study participant received ten dollars as a token of appreciation.

Analysis

Transcripts were analyzed to describe the self-care decisions participants reported they would pursue in response to each vignette. Although codes were not specifically determined a priori and based on what arose from the data, we expected to see common HF self-care decisions from participants such as monitoring weight, decreasing salt intake, and taking medications. We identified participant’s self-care decisions through content analysis (Hsieh & Shannon, 2005) using Microsoft Excel, with the following protocol: (1) extracting blocks of text that represented self-care decisions, (2) summarizing each self-care decision quote with a descriptive code. Table 1 provides examples of self-care decision verbatim quotes and corresponding codes. To increase rigor, two qualitatively trained coders (JX and SA) completed the coding process independently, and a consensus approach was used to finalize codes (Morse, 2015). Coding decisions were discussed, reviewed, and revised as needed with HF content experts and qualitative methods experts to decrease bias (Cypress, 2017; Morse, 2015).

Results

Participant Characteristics

Most participants were male (80%, n=16), African American (60%, n=12), not working (unemployed, disabled, or retired, 80%, n=16), highly symptomatic (NYHA Classification III and IV, 70%, n=14), and an average of 60 years old (60.6 ± 12.68). Nearly half had a high school education or less (40%, n=8); half were married (50%, n=10). A majority (70%, n=14) of participants had another chronic disease in addition to heart failure, and the average self-care score was low at $63.16, \pm 20.44$. Due to purposive sampling, half were readmitted within 30 days of their last hospitalization (50%, n=10), and approximately half had high self-care scores (40%, n=8).

Response to Vignettes

Table 2 reports the most common self-care actions participants would take in response to each vignette. Participant responses are represented by self-care action codes with corresponding participant quotes. The quotes are predominately verbatim, but have been slightly edited to remove identifiers and increase readability. These responses were similar across participants, even when comparing participants who were readmitted within or beyond 30 days of their last hospitalization.

Vignette A represented a clinical situation clinicians agreed required urgent care. Participants reported the following self-care actions in response to this vignette: contact health care provider (35%, n=7), go to ER or call 911 (35%, n=7), self-treat (20%, n=4), contact a family member (5%, n=1), and do nothing (5%, n=1). Half the participants identified the situation as urgent and stated the expected action of seeking help by going to the hospital or calling 911 either immediately or that this would be the follow-up action after self-treatment attempts did not work. Participants were able to recognize acuity in the situation by the presence of shortness of breath, using phrases such as: “I think the first instinct would be to call now, to call my doctor’s office” and “[participant restating the vignette] If I have a cough that won’t go away, if I have a hard time breathing sitting up on a chair?...Just go to the ER”.

Vignette B represented a situation requiring contact with a physician and increased self-care measures. While 75% (n=15) realized the need to contact a physician or increase self-care measures, 80% (n=16) did not identify the need to monitor their weight more carefully. Participants were uncertain if the symptoms in the situation were due to HF, and cited the use of self-directed treatments without the guidance of a health care professional - “if I’m more tired than usual I’m thinkin’ I’m holdin’ fluid, probably take more Lasix when I got to work, to try to pee out the fluid. Salty foods I know makes me hold fluid.” Other responses included going to the ER or calling 911 (5%, n=1), doing nothing (5%, n=1), and self-medicating with non HF medications like nebulizers and hypertension pills (10%, n=2).

In Vignette C, which represented a situation requiring usual self-care measures, participants did not recognize the connection between ankle swelling and weight monitoring. Consequently, no participants reported weight monitoring activities. Two other participants thought they should continue taking Lasix and monitor their sodium intake. Five participants (25%) reported palliative measures to relieve symptoms immediately without considering the long term consequences of the symptoms (e.g. immediately relieve excessive pressure on feet by wearing slippers). The most common patient response to Vignette C was calling a health care provider (35%, n=7).

Discussion

We used vignettes to understand how patients interpreted symptoms and which self-care actions they would pursue in acute/ non-acute situations. Responses from the vignettes indicated participants had difficulty making decisions and identifying appropriate action steps. Often, patients did not realize the situation acuity, or identify when it was appropriate to contact their primary care provider/cardiologist. The lack of action may be partially due to

the HF symptoms not being clear indications of worsening HF to the patient, with symptoms interpreted as everyday symptoms or attributed to other chronic conditions. This is similar to previous research reporting poor HF symptom identification and response due to confusion over HF symptoms (Riegel et al., 2018; Zaverntnik, 2014).

Vignette responses allowed us to examine HF patients' ability to interpret symptom changes and their plan for action. Our findings are consistent with reported challenges in HF symptom interpretation (Lee et al., 2018; Riegel et al., 2018), and add a new perspective in how clinicians or researchers could elicit HF patient symptom interpretations. Similar to our sample, previous studies have found that HF patients often seek help emergently when they have difficulty breathing (Altice & Madigan, 2012), however the importance of seeking help with other HF symptoms (i.e. fatigue, weight gain, edema) is less clear for HF patients (Clark et al., 2012). Two literature reviews examining help seeking and self-care behavior among HF patients, found interpretation of the presence and significance of symptoms to be a struggle for this population (Clark et al., 2012; Zaverntnik, 2014). Interpretation of HF symptoms can be especially challenging amongst older adults who are at higher risk for comorbidities, age-related changes, and cognition concerns (Zaverntnik, 2014). Given our findings of poor symptom response, and the association between poor HF symptom response behaviors with increased clinical event frequency (i.e. mortality, hospitalization, emergency room visit) (Lee et al., 2018), future intervention research is warranted to specifically improve symptom interpretation. A recent HF typology study identified four HF patient self-care clusters that were different by adherence to self-care and health care provider consulting behaviors (Vellone et al., 2017). These typologies may be useful in targeting and tailoring symptom management interventions by helping to identify what factors to intervene on.

In addition to HF symptoms, other factors influence how patients approach HF self-care, such as the presence of comorbidities, severity of HF, functional limitations, memory and cognitive deficits (Holden et al., 2015). Indeed, the majority of our participants had another comorbidity, and some reported the use of non-HF medications and treatments to alleviate their HF symptoms. The inability or difficulty in identifying and distinguishing HF symptoms from symptoms due to other chronic illnesses is a common concern among HF patients (Jurgens et al., 2009; Riegel et al., 2018). It is possible that HF patients who experience comorbidities may be undertreated for their HF and other non-HF specific symptoms (Janssen, Spruit, Uszko-Lencer, Schols, & Wouters, 2011). Clinicians may benefit from utilizing patient-centered approaches tailored to specific patient challenges in identifying appropriate self-care actions within the context of comorbidities. For example, a systematic review of interventions for managing patients with multiple chronic conditions found the most effective interventions targeted specific functional challenges or risk factors for patients such as functional ability or medication management (Smith, Soubhi, Fortin, Hudon, & O'Dowd, 2012). Future research is necessary to continue improving how HF patient's interpret their symptoms within the context of multiple chronic conditions.

Although vignettes have been criticized for their potential inability to portray real situations that participants can identify with (Gould, 1996), our participants reported that they could personally relate to the study vignettes. HF patients may have been especially receptive to the self-care vignettes we employed, as they were created in collaboration with HF

clinicians, expert researchers, and HF patients. Despite attempts by clinicians to increase the type and extent of HF education, HF patients still have difficulty interpreting their symptoms and determining when assistance is needed. Although many of our participants had received HF education in varying formats through hospital education or community programs, they still had challenges as evidenced by confusion over which self-care decisions were appropriate.

Several study limitations need to be discussed. The data reflect the participants' reactions to hypothetical situations; therefore, it is possible participants may reason or act differently when faced with real-life HF symptom exacerbations. Their own symptoms of worsening HF may be somewhat different from those portrayed in the vignettes. Social desirability bias may have influenced how participants responded to the vignettes. Participants reported having previously received HF education during the qualitative interviews, but the content, format, and quantity of education was not assessed. Findings may not be relevant to the overall HF population due to the sample being predominately elderly, urban, male, and African American. However, this particular sample is also a strength, because this population segment is understudied in HF.

Conclusion

We found participants understood when a situation was acute/emergent and clearly related to HF, but were less certain when addressing symptoms that were more vague. Participants had difficulty identifying appropriate self-care decisions, suggesting the need for clinicians to help HF patients practice making self-care decisions and apply self-care knowledge. Further study is needed to develop approaches to help HF patients understand how symptoms such as sudden weight gain and leg swelling may be signs of worsening HF. Since patients had difficulty identifying the clinical significance of sudden weight gain and leg swelling, clinicians may need to clearly emphasize symptoms requiring medical attention. Special attention should be paid to developing educational materials for individuals who have lower health literacy and a poor understanding of HF. Vignettes may be especially helpful in promoting patient-provider communications, highlight educational gaps, and serve as a prompt for targeted discussions about self-care management.

Relevance to Clinical Practice

Since participants in our study had difficulty responding appropriately to worsening symptoms, even when symptoms were severe, clinicians should be attentive to how patients are processing and evaluating symptoms at home. The patients had exposure to HF education during their hospitalization. The problem with appropriate self-care appears to be less of a knowledge issue. Rather, patients' ability to apply knowledge and problem solve, particularly in the context of comorbidities and worsening function, needs further support and attention. Clinicians should carefully consider patient understanding of HF symptoms as well as their ability to apply knowledge and adequately respond to worsening HF symptoms. Identification of and appropriate self-care actions for less acute symptoms such as weight gain and edema should be addressed explicitly, as many of our participants had trouble responding to these symptoms.

Using vignettes as a patient-centered education tool to assess how HF patients understand HF, interpret symptom exacerbations, and make decisions regarding appropriate action can open doors for discussing and addressing areas of uncertainty (Barter & Renold, 1999). Because HF patients were able to relate to our vignette scenarios, HF nurse educators may find the vignettes developed in this study a practical symptom assessment and teaching tool for HF patients. Although the vignettes have not been tested as an educational tool, future clinical studies could consider testing the vignettes as such and further describe the clinical applicability of vignettes as a HF patient self-care tool.

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What does this paper contribute to the wider global clinical community?

- Participants understood when a situation was acute/emergent and clearly related to HF but were less certain with making a self-care decision when addressing symptoms that were vaguer and/or when they had multiple comorbidities
- HF self-care vignettes could be used in patient education to assist with symptom interpretation

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Table 1.

Examples of participant quotes and corresponding action codes

Participant quotes	Action codes
"I would call my cardiologist and make an appointment that day to see him."	Call cardiologist & make appointment
"Well, I had all that. The only thing to do is go see your primary doctor. That's what I did. He made a lot of money off of me."	See primary care doctor
"I would call my practi-, my, um, my everyday doctor, I forget what you call them. [Primary care doctor] Thank you. I would call her and inform her of it and the three pounds, and then take the advice that's given to me from her, or by her. Whether it's "check yourself in a couple of hours, see if" or, or, "come to my office or either go to the hospital." I don't know what she, I, I mean, I'm assuming now. I don't know what she would say."	Call primary care doctor and follow advice
"I went and bought a black pair and a brown pair. And I wore slides everywhere I went because I couldn't fit my shoes no more. That's what I did."	Wear "slides" (aka slippers)
"I think the first instinct would be to call now, to call Doctor 2's office, talk to either Doctor 2 or his assistant, Nurse 3. Um, if it was a really hard time breathing, I guess, panicking, I guess I would be going to the emergency room at Hospital A"	Call doctor or go to ER depending on severity
"But I know when it's 3 to 5 pounds overweight ... over your weight, that you probably should get in touch with your doctor or go to the hospital..."	Call doctor or go to hospital
"first thing I would do is make sure to keep a good eye on my weight."	Monitor weight
"I would probably weigh myself in the morning and at night. I probably wouldn't eat much, to see if it is the fluid or the food."	Weigh self in the morning and night

Table 2.Data Display of Vignettes: Participants Self-Care Actions[†] with participant quotes

<p>Vignette A</p> <p>Last night you had a hard time sleeping because of breathing problems. You ended up falling asleep only after propping yourself up with two pillows. This morning you're feeling very tired, have a cough that won't go away, and have a hard time breathing sitting on a chair.</p> <hr/> <ul style="list-style-type: none"> • <i>Go to ER/call 911</i> <p>"To be honest, ER."</p> <p>"I guess go to the hospital. I'm going to go and I know it's something that's not right."</p> • Contact health care provider <p>"OK. First of all, I'd try to contact my primary physician. And let him know that I had difficulty falling asleep and I would only go to sleep after being propped up on a pillow. See what he thinks. And that this morning I was extremely tired and see what he would recommend."</p> <p>"Probably try to do something about this breathing problem, you know, and being able to sleep, and that would be priority thing. And, uh, you know, I guess I just go in there and let the doctor know what I had to do in order to get some sleep. See what his suggestion is -- is that okay, would that work or should I try something else?"</p> • Take medications (e.g. nitro, metoprolol, aspirin) <p>"Take nitro and medication when it's severe. The metoprolol helps the heart, baby aspirin, but reduce the stresses in the chest area."</p> 	<p>Vignette B</p> <p>A few days ago, you went out with friends to a birthday party. You had a lot of fun and ended up eating more salty foods than expected. This morning you're feeling more tired than usual, and when you weighed yourself you find out you have gained 3 pounds from yesterday.</p> <hr/> <ul style="list-style-type: none"> • <i>Contact health care provider</i> <p>"This has happened, yes. Going to a friend's house, um, birthday party, graduation party...or friend got a promotion his job at work and I over-drink alcoholic beverages, mostly beer. Um, that has salt in it, too. Um, and I've eaten a lot of salty foods and the next day I wake up feeling more tired than usual and weigh myself and I have gained more than three pounds. If I'm not in acute distress, I would call my everyday doctor, I forget what you call them. [Primary care doctor] Thank you. I would call her and inform her of it and the three pounds, and then take the advice that's given to me from her, or by her."</p> • <i>Monitor weight</i> <p>"I would probably weigh myself in the morning and at night. I probably wouldn't eat much, to see if it is the fluid or the food."</p> • Take medications (i.e. lasix, diabetes and blood pressure medications) <p>"make sure that I took my water pills, you know, cause usually when I get to that point, I probably skipped a day or two you know. Pills at home won't work as good as the intravenous they give you here."</p> <p>"I'd take my med ... take more medication that deals with diabetes. To try to take the pressure off, take the high blood pressure pill that takes pressure off, exercise and drink some water, drink water. That's all you can do."</p> 	<p>Vignette C</p> <p>You notice your feet feel tight in your shoes, but you feel better after taking your shoes off. You see that your ankles are little bigger than usual and remember you have gained 2 pounds in the last week.</p> <hr/> <ul style="list-style-type: none"> • Contact health care provider <p>"Would call the cardiovascular and the diabetic doctor. The cardiovascular doctor probably the first person because that's [symptoms] gonna trigger and if anything is off, it can trigger a stroke."</p> <p>"The main concern would be to get the fluid out. And the only way to do that, you got to go to the doctor ... your hospital or have your primary doctor recommend the hospital that you be taken care immediately; you are an emergency case."</p> • Take off shoes prop up feet Wear slippers <p>"I take my shoes off and put on a pair of sandals, like this, or socks or sandals at work."</p> <p>"I went and bought a black pair and a brown pair. And I wore slides everywhere I went because I couldn't fit my shoes no more. That's what I did."</p> • Take medications (i.e. lasix) <p>"My cardiologist already said if I'm gaining too much weight, I can take an extra fluid pill. [interviewer asked - How do you know how much extra you're supposed to take?] That's at my own judgement, and also she said I can do that."</p>
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[†]The self-care actions clinicians expected from participants are in ***bold and italicized font***.

The clinician expectations were for patients to go to the ER or call an ambulance (Vignette A), contact a health care provider for advice and monitor weight carefully (Vignette B), and monitor weight (Vignette C).

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