



University of Pennsylvania  
ScholarlyCommons

---

School of Nursing Departmental Papers

School of Nursing

---

5-2015

# "What Were They Thinking?": Patients' Cognitive Representations of Heart Failure Self-Care

Harleah G. Buck

Linda McAndrew


J. N. Dionne-Odom

Rachel Wion

Barbara Riegel

University of Pennsylvania, [briegel@nursing.upenn.edu](mailto:briegel@nursing.upenn.edu)

Follow this and additional works at: <https://repository.upenn.edu/nrs>

 Part of the [Behavioral Medicine Commons](#), [Cardiology Commons](#), [Cardiovascular Diseases Commons](#), [Circulatory and Respiratory Physiology Commons](#), [Medical Education Commons](#), [Medical Humanities Commons](#), [Neurology Commons](#), [Nursing Commons](#), and the [Preventive Medicine Commons](#)

---

## Recommended Citation

Buck, H. G., McAndrew, L., Dionne-Odom, J. N., Wion, R., & Riegel, B. (2015). "What Were They Thinking?": Patients' Cognitive Representations of Heart Failure Self-Care. *Journal of Hospice & Palliative Nursing*, 17 (3), 249-256. <http://dx.doi.org/10.1097/NJH.0000000000000156>

This paper is posted at ScholarlyCommons. <https://repository.upenn.edu/nrs/188>  
For more information, please contact [repository@pobox.upenn.edu](mailto:repository@pobox.upenn.edu).

---

# "What Were They Thinking?": Patients' Cognitive Representations of Heart Failure Self-Care

## **Abstract**

Heart failure (HF) is the largest palliative care population in the United States. Self-care patient education is a class I recommendation in HF clinical guidelines. Self-care is a 2-step decision-making process of maintenance and management, yet little is known about the thought processes or cognitive representations used. The purpose of this study was to identify and examine patients' cognitive representations in HF self-care with a unique, theoretically derived approach in a descriptive, exploratory study. Purposive sampling targeted hospitalized HF patients. Open-ended conceptual cognitive mapping approach elicited patient-generated items providing a visual display of cognitive representations. Recruitment continued until no new items were elicited. Thirteen white, primarily male (n = 11) patients reported 124 items when describing daily HF care. For self-care maintenance, diet, medication, and exercise were the most endorsed items. Patients also added items such as relaxation, distraction, or denial, not part of self-care guidelines. For self-care management, patient's items diverged widely from guidelines. A thematic analysis revealed a majority of the items were existential involving reflecting on their mortality and impact on families. Patients have an internal cognitive map with which they manage their HF. Palliative care nurses need to design care that takes this into account.

## **Keywords**

cognitive map, heart failure, patient education, self-care

## **Disciplines**

Behavioral Medicine | Cardiology | Cardiovascular Diseases | Circulatory and Respiratory Physiology | Medical Education | Medical Humanities | Medicine and Health Sciences | Neurology | Nursing | Preventive Medicine

Title: “What Were They Thinking?”: Patients’ Cognitive Representations of Heart Failure Self-care.

Author names and affiliations: Harleah G. Buck, PhD, RN, CHPN, FPCN<sup>a</sup>, Linda McAndrew, RN, MSN, CRNP, CCRN<sup>a</sup>, J. Nicholas Dionne-Odom, PhD, RN<sup>b</sup>, Rachel Wion, MS, RN<sup>a</sup>, and Barbara Riegel, DNSc, RN, FAAN, FAHA<sup>c</sup>

<sup>a</sup> College of Nursing, The Pennsylvania State University, University Park, PA, 16823, USA. HGB email: [hgb2@psu.edu](mailto:hgb2@psu.edu); LM: [imm30@psu.edu](mailto:imm30@psu.edu) ; RKW: [rkw12@psu.edu](mailto:rkw12@psu.edu)

<sup>b</sup> College of Nursing, University of Alabama at Birmingham, Birmingham, AL, 35294, USA. JNDO email. [dionneod@uab.edu](mailto:dionneod@uab.edu)

<sup>c</sup> School of Nursing, University of Pennsylvania School of Nursing, Philadelphia, PA 19104-4217, USA. BR email: [briegel@nursing.upenn.edu](mailto:briegel@nursing.upenn.edu)

Corresponding author: Harleah G. Buck, PhD, RN, CHPN, FPCN  
Assistant Professor, College of Nursing  
The Pennsylvania State University  
201 Health and Human Development East  
University Park, PA 16802, USA  
Phone: 814-863-3495  
Fax: 814-865-3779  
Email: [hgb2@psu.edu](mailto:hgb2@psu.edu)

**Funding:** HGB was supported by the National Palliative Care Research Center Career Development Award and a Penn State College of Nursing Pilot Award. JNDO was supported by the University of Alabama at Birmingham Cancer Prevention and Control Training Program (5R25CA047888). RW was supported by the Jonas Foundation <http://www.jonascenter.org/>.

## Abstract

Heart failure (HF) is the largest palliative care population in the US. Self-care patient education is a Class I recommendation in HF clinical guidelines. Self-care is a 2 step decision making process of maintenance and management, yet little is known about the thought processes or cognitive representations used. The purpose of this study was to identify and examine patients’ cognitive representations in HF self-care with a unique, theoretically derived approach in a descriptive, exploratory study. Purposive sampling targeted hospitalized HF patients. Open-ended Conceptual Cognitive Mapping approach elicited patient generated items providing a

visual display of cognitive representations. Recruitment continued until no new items were elicited. Thirteen white, primarily male (n=11) patients reported 124 items when describing daily HF care. For self-care maintenance- diet, medication, and exercise were the most endorsed items. Patients also added items such as relaxation, distraction, or denial; not part of self-care guidelines. For self-care management- patient's items diverged widely from guidelines. A thematic analysis revealed a majority of the items were existential involving reflecting on their mortality and impact on families. Patients have an internal cognitive map with which they manage their HF. Palliative care nurses need to design care that takes this into account.

*Keywords:* cognitive map; self-care; heart failure; patient education

## Introduction

In a major shift from earlier times, hospice nurses are more likely to care for non-cancer rather than cancer patients. Heart disease, primarily heart failure (HF), accounts for a growing number (13.4% in 2013) of hospice admissions.<sup>1</sup> In the next few years hospice and palliative care nurses will be caring for even greater numbers of HF patients with the current emphasis on increasing outpatient palliative care services. This is because HF, at present, affects 5.7 million individuals in the US<sup>2</sup> with the incidence and prevalence increasing with the aging of the population.<sup>3</sup> Current projections call for increases of 46% by 2030. Yet many hospice and palliative nurses may be more familiar with oncology patients, their clinical guidelines and self-care practices.

Patient education in HF self-care is a Class I recommendation in clinical guidelines and an important element of evidence based practice.<sup>3</sup> Nurses are the primary source of that education. It is imperative that hospice and palliative care nurses understand what HF patients think concerning self-care to be effective patient and family educators. Failure to do so may be one reason for the current state of poor patient self-care.<sup>4</sup> For example, in a recent study patient rates for a simple, self-care activity -daily weights- showed large geographic variations with 60% of patients in the northeastern US, 40% in the southeastern US, and less than 20% in the southwestern US reporting weighing themselves daily.<sup>5</sup> This is just one example of an endemic, nurse-sensitive problem.

HF self-care is a 2 step decision making process that results in behavior. Step 1 includes decisions related to adherence to treatment protocols and monitoring changes in condition ( or self-care maintenance); and Step 2 includes decisions related to recognizing symptoms, evaluating them, then implementing treatment and evaluating it (or self-care management).<sup>6</sup>

Self-care decision making is influenced by: 1) characteristics of the individual (such as age, gender, and education level), 2) self-care problem faced and 3) environment. All of these factors are influenced in turn by the patient's personal knowledge, experience, skill, and values.<sup>6,7</sup>

Knowledge and experience are particularly important as they are necessary in developing mental simulations to match the current situation with past situations.<sup>8</sup> People rely on a synthesis of prior experiences, or some sort of cognitive representations in decision making. Cognitive representations are internal pictures and thoughts that represent our external reality. They are learned and once developed are activated by internal or external stimuli. Over time they become associated with other representations resulting in larger and more intricate structures.<sup>9</sup> People use these structures like a map to find their way through life. For example, a patient might feel fatigued and lay down in bed. However, he/she then experiences orthopnea. The sensation may trigger a picture or thought of a recliner. Without giving further conscious thought, the patient then rises and moves to the recliner and falls asleep. Cognitive representations are efficient, unconscious, yet necessary for reflection and information accessing.<sup>9</sup> But HF self-care cognitive representations are currently unknown.

Recent work supports the presence and importance of cognitive processes during HF self-care.<sup>7,10,11</sup> In one study<sup>7</sup> self-care was influenced by the person's knowledge (greater knowledge resulted in better self-care) and experience (more experience resulted in better self-care). In a subsequent study<sup>10</sup> if individuals were aware that their normal HF situation was changing (e.g. increased fatigued or shortness of breath) and interpreted the situation as needing action, they began to mentally simulate options before taking action. Personal experience with self-care influenced both their interpretation of the situation and the options they simulated. Patients were also influenced by the characteristics of the decision (e.g. how uncertain or

ambiguous the outcome) and whether the decision was in concordance with their own personal goals and prior experience.<sup>10</sup> A review of 19 studies on HF patients' attitudes, beliefs and experiences in developing HF management strategies also supports the importance of cognitive processes.<sup>11</sup> Newly diagnosed HF patients were unable to make meaning out of their HF situation since they lacked prior experience. Patients reported that it took time to build new cognitive representations from which to simulate self-care.<sup>11</sup>

But, to date, the actual cognitive representations utilized in HF self-care are unknown. Understanding patients' cognitive representations may help hospice and palliative nurses develop HF educational materials that are more effectively and efficiently transferred. The objective of this study was to identify and examine participants' cognitive representations in HF self-care with a unique, theoretically derived approach.

## **Methods**

### *Design*

A descriptive, exploratory design was used in this study as HF self-care cognitive representations are currently unknown. The Situation Specific Theory of HF Self-care<sup>7</sup> informed the participant interview guide and provided the framework to group items into domains and subdomains during data analysis (Table 2).

### *Sample and setting*

A purposive sample of patients was recruited from a community based hospital in the northeastern US. Participants, hospitalized for HF, were selected as having had a recent exacerbation which enabled them to discuss the cognitive representations used, particularly in symptom management, without the limitations of long term recollection. It was also

hypothesized that the participants would be more reflective about their HF self-care at this critical time. Recruitment continued until no new items were generated. Participants were invited to join the study if they were over the age of 18, had a documented diagnosis of HF on their medical record, and were English speaking.

### *Ethics approval*

The study was approved by the Institutional Review Boards of both the university and hospital. Participants were recruited in person by a trained research assistant (RA), informed consent was obtained and the interview began.

### *Procedures*

Conceptual Content Cognitive Map (3CM). The 3CM approach was developed by psychologists, Kearney and Kaplan, in the mid-1990s.<sup>9</sup> 3CM asks participants to identify important concepts (referred to in this paper as “items”) and then organize these items into groups, creating a map to depict how they perceive the concept.<sup>9</sup> This method has been used in multiple studies<sup>9</sup>, including those involving health care.<sup>12, 13</sup>

Because of the exploratory nature of this study the open-ended implementation of 3CM was used. Open-ended 3CM is a multi-step process which involved asking the participant to think about their daily HF routine and how they would explain it to someone unfamiliar with the topic. The RA then asked them to describe what they thought and did on a daily basis first, as it related to HF self-care maintenance (adherence and monitoring) and then, as it related to HF self-care management (symptom recognition and evaluation, treatment implementation and evaluation). Consistent with the method, the RA wrote down the participant-generated phrases or items on separate pieces of paper as the participant described their HF self-care. The



participant was then asked to confirm if the RA had accurately understood the participant's response by reviewing the items. The participant was instructed to add new items at any time in this process. There were no limits placed on the number of items or how they were grouped. When no new items were generated, the participant was asked to group the items and then rank each from 1=not very important to 5=extremely important. The 3CM was conducted in participant's hospital rooms and took approximately 30 minutes.

Demographic survey. Each participant also completed a brief sociodemographic survey assessing their age, gender, race/ethnicity, education level. HF type, severity, and duration was obtained from the medical record.

#### *Data analysis*

Items were transcribed from the separate pieces of paper, verbatim, into an excel spreadsheet retaining the groups and rank ordering created by the participant. Data were then visualized by the investigators during the analytic sessions using the spreadsheet. Frequency and importance of items were determined by a descriptive analysis. Participant grouping of items was analyzed as well. Two participants were selected to serve as examples for this paper at this point.

After this descriptive level of analysis a subsequent analysis was conducted to assess the degree of agreement of cognitive representations with current self-care theory and guidelines. This was intended to increase our understanding of the internalization of self-care education into participant's cognitive representations. Qualitative analytic strategies were used to analyze the items from the 3CM interviews.<sup>14, 15</sup> Three investigators (HGB, LM, RW) read through the items and groups to link items to the theoretical framework on which self-care education is built.

Items were coded according to the theory, but if the items were not linked to the theory a new code was developed. Trustworthiness was evidenced by the use of a theoretically derived interview guide, extensive training of a psychology graduate student RA, maintaining an audit trail of process and analytic memos and involvement of at least two investigators at all stages of the data analysis.

## **Results**

Thirteen participants were interviewed and reported a total of 124 items. These HF participants were white, primarily male, had completed at least high school and reported having enough or more than enough income to make ends meet. They had had HF on average three years (Table 1).

### *Self-care maintenance items*

*Frequency.* Participants reported a total of 67 items when asked to describe their daily self-care maintenance (treatment adherence and symptom monitoring). On average they contributed 5 items (range 2 to 10 items) in 2 groups (range 1-4 groups). Number of items, while reflective of the richness and complexity of the participant's self-care cognitive representations did not necessarily assure quality or appropriateness of content items. For example, one participant reported 10 items (maximum number reported in the sample) but the items reported were: *pray, go to the doctor, go to the hospital, eat fruit, exercise, limit salt and fluid, rest, vitamins, keep busy, and napping* (in descending order of importance). Only three of the 10 items, *go to the doctor, exercise, and limit salt and fluid* are in current guidelines. A second participant who reported 9 items reported *do nothing fast, get up and move* (in response to chest pressure), *take medication, get tired and stop, prioritize time, know what you can do, cook on*

*occasion, go to bed after dinner, eat lots of nuts and berries* in descending order as his/her self-care practices. Once again, only 1 item *take medication* would be considered self-care maintenance. Only 1 of the 13 participants mentioned the need to *weigh self* as an item. While items related to dietary adherence were the most frequently mentioned (n=11), they were rarely placed in groups ranked as first. Generally participants kept them as a single item or placed them in groups which they ranked as second (n=4), third (n=3) or lower (n=4) in order of importance. Of the 9 individuals who mentioned medication, most group-ranked it first. The group-ranking of exercise mirrored dietary adherence with only 1 participant ranking it first while the others ranked in lower groups. However, smoking cessation, and non-prescription medications were each ranked first by two different participants reflective of the level of importance of this activity to the individual's cognitive representation of self-care maintenance.

*Examples of cognitive representations.* One participant, "Al" (not his real name) was a retired nurse. Al was selected to serve as an example because he reported more items than others in the study. Al's items were first compared to the situation specific theory and then were compared to another participant, "Joe", chosen for having fewer items (Figure 1). Al mentioned 8 items in 4 groups making his map one of the more complex. The group with the most items (also ranked 1st) were monitoring activities such as *monitoring salt intake, pedal edema, and breathing*. The theory suggests 10 categories under self-care maintenance such as medication taking and symptom monitoring. When compared with the theory, Al's cognitive representations contained 4 of the 10 categories in the theory (or 40%) suggesting that even an individual with professional education may still have cognitive representations that are inadequate according to self-care guidelines. Joe only reported 2 items (20% of the theory items), *take medications and watch salt*, both of which matched the theory and items in the Al's cognitive representations.

*Degree of agreement with current self-care theory and guidelines.* In the Situation Specific Theory of HF Self-care<sup>4,7</sup> treatment adherence and symptom monitoring are the two subdomains of self-care maintenance. When the participant items were theoretically categorized and then examined, dietary adherence was the most frequently endorsed category (n=11 items) followed by medication and exercise (n=9) and then symptom monitoring (n=6). See Tables 2 and 3 for further breakdown of item analysis. In addition to items generally understood to constitute self-care maintenance, participants also reported practicing self-determined forms of self-care maintenance such as resting (n=7), hobbies or activities (n=3), thinking/prayer (n=2) or depending on a caregiver to take care of things (n=2). In addition, there were a number of items reported by multiple participants that appeared counter intuitive or idiosyncratic (Table 3). These activities generally involved ignoring their heart and getting on with their daily lives.

#### *Self-care management items*

*Frequency.* Participants reported a total of 57 items when asked about self-care management, 10 less than self-care maintenance. On average, each participant contributed 4 items (range 2-7) in 2 groups (range 1-4). Once again, number of items did not assure the appropriateness of the items. When asked to describe what they thought about when they recognize, evaluate and treat their symptoms, one participant with 7 self-management items reported in descending order of importance that he/she was fearful of *passing out* and labeled this an *Extreme Indicator*. The next 6 items reported were *breathless walking, slower walking, taking it easy, knew that I had to be more conscious about what I was doing, wondering how far I can go, and was not sensibly conscious of what was going on*. These cognitive representations would seem to suggest that the response to the presence of symptoms was to focus on the physiologic changes (particularly cognitive changes) that accompany cardiac decompensation

without taking the next step of deciding to address them. A participant with 6 items described his/her self-management as consisting of: their caregiver *taking them to the doctor, putting a pill under their tongue, not worrying about finances, doesn't think of much – caregiver handles things, symptom just comes and goes, and doesn't really do anything*. While this describes what the participant actually is thinking and doing, it does not begin to address the need to take thoughtful and decisive action in response to HF symptoms.

*Examples of cognitive representation.* As in the previous analysis, we compared Al's items with both the theory and with Joe's (Figure 2). This time the number of items per participant was flipped. Al reported 2 items (*concerned about breathing and thinking about family*) neither of which are related to the theory while Joe who had fewer cognitive representations in self-care maintenance now had far more cognitive representations for self-care management, but half of the items were not theoretically related. Only rest (*try to sleep*) and oxygen (*sit down and put on oxygen*) could be thought of as treatment implementation. Both participants reported that the recognition of symptoms stimulated thoughts of other people, whether their loved ones or others with life-limiting illness.

*Degree of agreement with current self-care theory and guidelines.* Symptom recognition and evaluation, followed by treatment implementation and evaluation are the subdomains of self-care management in the Situation Specific Theory of HF Self-care.<sup>7</sup> Here the participant's cognitive representations diverged widely from the theory. Few of the items could be mapped to the theory making a comparison with the theory, as was done with self-care maintenance, impossible. According to the theory, it is currently expected that when the participant recognizes a change in their condition (e.g. pedal edema, shortness of breath, or fatigue) that they will respond by reducing the salt in their diet and their fluid intake, taking an extra diuretic, and

calling a clinician, for example. But this was not what was reported suggesting that our self-care management education is not penetrating. Instead a thematic analysis of the items showed that a majority of the participants' cognitive representations were existential, involving reflection on their mortality and the impact on their families (Table 4). This existential response to the changes in their condition could result in either their taking action or becoming passive. However, even when they took action, rarely were the actions in concordance with current evidence based practice related to fluid volume overload, the most common source of symptoms in HF. *Sit down and put on oxygen, putting a pill under my tongue or go to the hospital* were the only recognizably efficacious activities reported. Other reported items generally could be categorized as related to resting and waiting for the symptom to pass. The third theme that arose from the items was of the family response.

Because we could examine number of endorsements of the thematically group items we could assess how common the subtheme was. For example, participants reported items that could be categorized as "Action Taken" (n=16 items) which suggests that they are implementing a treatment protocol in response to the recognition of changes in condition. However, when the individual items were analyzed few of these actions, such as *take it easy, or I use positive thinking* would impact their cardiac decompensation. The next 3 subthemes with the greatest number of endorsements (n=11, 11, 9 respectively for a total of 31 items) after "Action Taken" appear to be existential or affective responses to the perception of possible death. The recognition of symptoms appears to engage the self-reflective or affective domain to the degree that further action is precluded and passivity results.

## **Discussion**

The purpose of this study was to identify and examine participants' cognitive representations in HF self-care using open-ended conceptual cognitive mapping. From this study it is clear that patients have an internal cognitive map from which they manage and make meaning of their HF, however, few of the cognitive representations include items that would be recognized as guideline directed or evidence based.

The number of endorsements for self-care maintenance suggest that HF education has made an impact in diet, medication and exercise. However, the percentages of reported items dropped off markedly from there with few participants discussing equally important areas such as alcohol and smoking cessation; fluid restriction; or preventive behaviors such as routine wellness visits or immunizations. This raises the question as to whether some aspects of HF education are better received than others. Currently diet, exercise, and medication may be viewed positively in the current wellness oriented culture and therefore integrated into their cognitive representations, whereas restrictions such as of alcohol, smoking, and fluid may be viewed negatively and therefore ignored.

Particularly concerning in this study is the finding that only one participant mentioned *weigh self* as part of their self-care maintenance activities. This lack of daily weights suggests that nurses need to be even more persuasive in this area. The deficits uncovered in this study are supported by a recent, large comparison study of HF self-care behaviors across 15 countries<sup>5</sup> which found suboptimal self-care across the globe, with *taking medications as prescribed* the most consistently practiced self-care behavior while other equally important behaviors are practiced inconsistently at best. Daily weighing may have negative connotations in our culture which stigmatizes overweight individuals. There may be a need to develop new means for assessing individual fluid volume that does not involve the currently ignored bathroom scale.

What this study suggests is that self-care behavior may be inconsistent because self-care, as operationalized by clinicians, has not become part of the internal cognitive representations of HF patients. Palliative care, with its focus on patient goals of care may be particularly suited to address this pressing issue. Assessing patient's goals of care before beginning HF self-care education may help palliative care nurses link a particular activity with a patient's goal thereby increasing the likelihood of adherence.

One intriguing finding from this study is the patient's perception of the role of the informal caregiver in self-care management. There is a clear signal that patients perceive that their informal caregivers will intervene by taking them to health care providers. This leaves the interesting question, however, as to why the informal caregivers are not intervening earlier or more actively responding to symptom management education. It could be that patients do not recognize or think to report the caregivers' involvement at an earlier stage or it could reflect that the caregiver is equally unlikely to understand or remember information that they have given during education sessions. Other studies support the importance of the informal caregiver in self-care.<sup>16, 17</sup> but until patient/caregiver dynamics of in HF self-care are fully understood informal caregivers may not be activated to their full capacity.

A unique finding of this study is that complexity of self-care cognitive representations signified by number of items does not equate to quality of cognitive representations— more is sometimes just more and not necessarily better. If anything, this analysis raises the interesting question as to whether a patient with a very rich and complex cognitive representation of HF self-care which does not include any information from current guidelines, may be more resistant to new information, particularly if that information conflicts with already established cognitive representations. A second unique finding of the study is that we are given a glimpse into what



patients' are *really* thinking when they do recognize HF symptoms. The large number (n=31) of items in self-care management that could be categorized as existentially oriented suggest that symptoms mean something very different to the patient than to the clinician. While for the clinician, symptoms suggest poor adherence or possible disease progression, for the patient it is possible that they suggest death and loss. One hypothesis is that this activation of the affective domain seemingly distracts patients from responding to the symptoms in a proactive, directed way. When this affective activation is coupled with the minimal cognitive impairment common in this population, it is perhaps understandable that passivity or ineffective actions are taken. Palliative care nurse's expertise in assessing and addressing psychosocial and spiritual domains may help patients in this process.

#### *Strengths and Limitations*

When reviewing our findings keep in mind the homogeneity of our sample, the limited geographic area that is represented, and the exploratory nature of our study. Future work is required in larger, more diverse populations before we can begin to approximate the full complexity of these interesting findings.

## References

1. NHPCO. NHPCO's facts and figures-hospice care in America. 2014.
2. Mozaffarian D, Benjamin EJ, Go AS, et al. Heart Disease and Stroke Statistics—2015 Update: A Report From the American Heart Association. *Circulation*. 2014.
3. Yancy CW, Jessup M, Bozkurt B, et al. 2013 ACCF/AHA Guideline for the Management of Heart Failure: Executive Summary: A Report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. *Journal of the American College of Cardiology*. 2013.
4. Riegel B, Moser DK, Anker SD, et al. State of the science: promoting self-care in persons with heart failure: a scientific statement from the American Heart Association. *Circulation*. 2009;120:1141-1163.
5. Jaarsma T, Strömberg A, Ben Gal T, et al. Comparison of self-care behaviors of heart failure patients in 15 countries worldwide. *Patient education and counseling*. 2013.
6. Riegel B, Lee CS, Dickson VV. Self care in patients with chronic heart failure. *Nat Rev Cardiol*. 2012;8:644-654.
7. Riegel B, Dickson VV. A situation-specific theory of heart failure self-care. *Journal of Cardiovascular Nursing*. 2008;23:190-196.
8. Klein G. Naturalistic Decision Making. *Human Factors: The Journal of the Human Factors and Ergonomics Society*. 2008;50:456-460.
9. Kearney AR, Kaplan S. Toward a Methodology for the Measurement of Knowledge Structures of Ordinary People. *Environment and Behavior*. 1997;29:579-617.
10. Riegel B, Dickson VV, Topaz M. Qualitative analysis of naturalistic decision making in adults with chronic heart failure. *Nurs Res*. 2013;62:91-98.
11. Wingham J, Harding G, Britten N, Dalal H. Heart failure patients' attitudes, beliefs, expectations and experiences of self-management strategies: A qualitative synthesis. *Chronic Illness*. 2013.
12. Van Hulle Vincent C, Gaddy EJ. Pediatric nurses' thinking in response to vignettes on administering analgesics. *Research in Nursing and Health*. 2009;32:530-539.
13. Vincent CVH, Wilkie DJ, Szalacha L. Pediatric Nurses' Cognitive Representations of Children's Pain. *The Journal of Pain*. 2010;11:854-863.
14. Sandelowski M. Real qualitative researchers do not count: the use of numbers in qualitative research. *Research in nursing & health*. 2001;24:230-240.
15. Sandelowski M. Whatever happened to qualitative description? *Research in nursing & health*. 2000;23:334-340.
16. Sebern M, Riegel B. Contributions of supportive relationships to heart failure self-care. *European Journal of Cardiovascular Nursing*. 2009;8:97-104.
17. Ågren S, Evangelista LS, Hjelm C, Strömberg A. Dyads Affected by Chronic Heart Failure: A Randomized Study Evaluating Effects of Education and Psychosocial Support to Patients With Heart Failure and Their Partners. *Journal of cardiac failure*. 2012;18:359-366.

Figure Captions:

Figure 1 Theory – Interview Guide- Item Linkage

Figure 2 Self-care maintenance Examples

\*groups indicated by circles and circles ranked from extremely important (top of figure) to not very important (bottom) by the participant

Figure 3 Self-care management Examples

\*groups indicated by circles and circles ranked from extremely important (top of figure) to not very important (bottom) by the participant

Figure 1

**Self-care Maintenance**

- Medication taking
- Symptom monitoring
- Dietary adherence
- Fluid restriction
- Alcohol restriction
- Weight loss
- Exercise
- Smoking cessation
- Preventative behaviors (e.g immunizations, dental care, etc)
- Nonprescription medications

Theory<sup>4,7</sup>

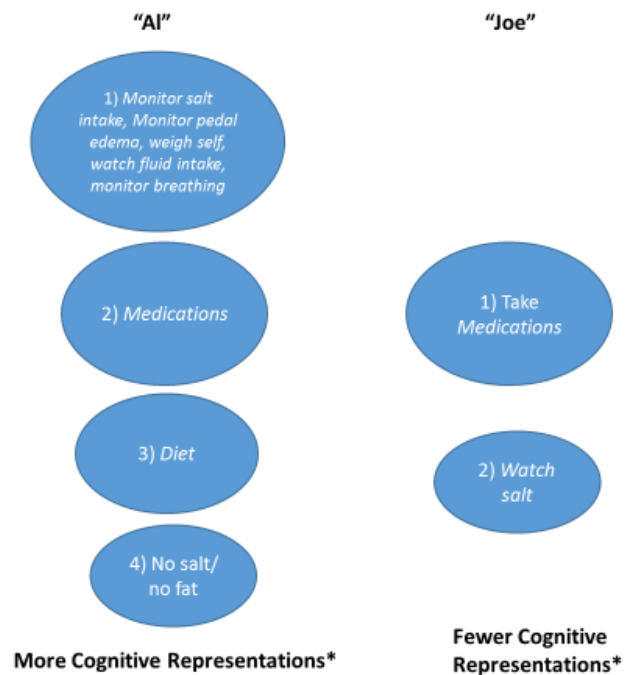


Figure 2

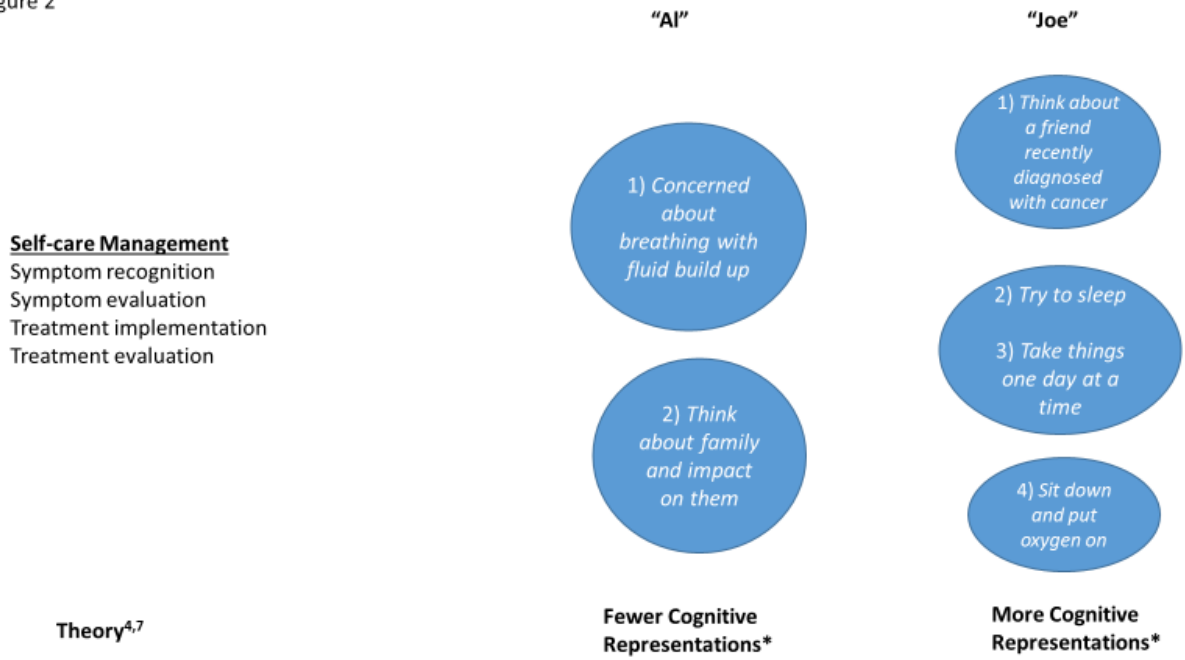


Table 1. Sociodemographic Characteristics of the Sample

| <b>Characteristics</b>            | n (%)     | Mean (SD)         |
|-----------------------------------|-----------|-------------------|
| Age (in years)                    |           | 71.19 (12.45)     |
| Gender (% male)                   | 11(85%)   |                   |
| Race/Ethnicity†                   |           |                   |
| White                             | 13 (100%) |                   |
| Black                             |           |                   |
| Education                         |           |                   |
| HS degree or less                 | 9 (69%)   |                   |
| Some college                      | 2 (15%)   |                   |
| College or advanced degree        | 2 (15%)   |                   |
| Income to make ends meet          |           |                   |
| More than enough                  | 2 (15%)   |                   |
| Enough                            | 8 (62%)   |                   |
| Not enough                        | 3 (23%)   |                   |
| Heart failure duration (in years) |           | 3.07(4.8)         |
| BNP level                         |           | 1575.93 (1977.88) |

BNP- brain natriuretic peptide

Table 2. Theoretical Analysis of Self-care Maintenance Items

| <b>Theoretical Category</b>                          | <b>Example Item</b>   | <b>Number of Endorsements</b> |
|--|---|-------------------------------|
| Dietary Adherence                                    | <i>Watch what you eat/ no salt<br/>Try to watch the amount of fatty foods I eat</i> | 11                            |
| Medication taking                                    | <i>Take medication</i>  | 9                             |
| Exercise   | <i>Walk<br/>Treadmill</i>   | 9                             |
| Symptom monitoring                                   | <i>Weigh self<br/>Monitor breathing</i>   | 6                             |
| Alcohol Restriction                                  | <i>Watch what I drink</i>   | 3                             |
| Smoking Cessation                                    | <i>Do not smoke</i>   | 3                             |
| Preventative Behavior<br>(immunization, dental care) | <i>Go to the doctor regularly</i>   | 3                             |
| Non-prescription Medication                          | <i>Vitamins</i>   | 2                             |
| Fluid Restriction                                    | <i>Watch fluid intake</i>   | 1                             |

\*in descending order of endorsement

Table 3. Self-Determined Self- care Maintenance Items

| <b>Category</b>      | <b>Example Item</b>  | <b>Number of Endorsements</b> |
|----------------------|--|-------------------------------|
| <b>Rest</b>          | <i>Get tired and stop, feel tired, quit no matter what</i>                                     | 7                             |
| <b>Hobbies</b>       | <i>Gardening<br/>Lots of hobbies</i>   | 3                             |
| <b>Think/Pray</b>    | <i>I pray about my heart<br/>I think about it</i>  | 2                             |
| <b>Wife</b>          | <i>Wife takes care of everything</i>   | 2                             |
| <b>Idiosyncratic</b> | <i>When sitting chest gets heavy so get up and get moving<br/>Eat lots of nuts and berries</i> | 6                             |

\*in descending order of endorsement

Final pre-publication version

**Table 4. Thematic Analysis of Self-care Management Items**

| <b>Theme</b>   | <b>Subtheme</b>                      | <b>Example Items</b>   | <b>Number of Endorsement</b> |
|--|--------------------------------------|--|------------------------------|
| <b>Existential Response to Changes in Condition (n=31 items)</b> | Reflection                           | <i>Think about family and impact on them<br/>Hope to get better<br/>Wondering how far I can go</i>                   | 11                           |
|  | Explicit thoughts of death and dying | <i>Worry about living and dying<br/>Thought that I was going to die<br/>Didn't think that I was going to make it</i> | 11                           |
|  | Generalized Concerns Felt            | <i>Scared<br/>Concerned about breathing with fluid buildup</i>   | 9                            |
| <b>Psychomotor Response to Changes in Condition (n=21 items)</b> | Action Taken                         | <i>I use positive thinking<br/>Sit down and put on oxygen<br/>Go to the hospital<br/>Put a pill under my tongue</i>  | 16                           |
|  | Detachment/Passivity                 | <i>Don't really do anything<br/>Not wanting to get out of bed</i>  | 5                            |
| <b>Family Response to Changes in Condition (n=5 items)</b>       | Family Action                        | <i>Wife took me to doctor<br/>Didn't give my wife much trouble about going to the hospital</i>                       | 5                            |