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Qualitative Analysis of Naturalistic Decision Making in Adults with Chronic Heart Failure

Abstract

Background:

Self-care of heart failure has been described as a naturalistic decision-making process, but the data available to defend this description are anecdotal.

Objectives:

The aim of this study was to explore the process used by adults with chronic heart failure to make decisions about their symptoms.

Methods:

This was a secondary analysis of data obtained from four mixed methods studies. The full data set held qualitative data on 120 adults over the age of 18 years. For this analysis, maximum variation sampling was used to purposively select a subset of 36 of the qualitative interviews to reanalyze.

Results:

In this sample, equally distributed by gender, 56% Caucasian, between 40 and 98 years, the overarching theme was that decisions about self-care reflect a naturalistic decision-making process with components of situation awareness with mental simulation of a plausible course of action and an evaluation of the outcome of the action. In addition to situation awareness and mental simulation, three key factors were identified as influencing self-care decision making: (a) experience; (b) decision characteristics such as uncertainty, ambiguity, high stakes, urgency, illness, and involvement of others in the decision-making process; and (c) personal goals.

Discussion:

These results support naturalistic decision making as the process used by this sample of adults with heart failure to make decisions about self-care.

Keywords

decision making, heart failure, self-care, symptoms

Disciplines

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

A Qualitative Analysis of Naturalistic Decision Making in Adults with Chronic Heart Failure

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Abstract

Background: Self-care of heart failure (HF) has been described as a naturalistic decision-making (NDM) process, but the data available to defend this description is anecdotal.

Objectives: The purpose of this study was to explore the process used by adults with chronic HF to make decisions about their symptoms.

Method: This was a secondary analysis of data obtained from four mixed methods studies. The full data set held qualitative data on 120 adults over age 18 years. For this analysis maximum variation sampling was used to purposively select a subset of 36 of the qualitative interviews to reanalyze.

Results: In this sample of mostly (56%) Caucasian men and women (50%) between 40 and 98 years, the overarching theme was that decisions about self-care reflect a NDM process with components of situation awareness with mental simulation of a plausible course of action and an evaluation of the outcome of the action. In addition to situation awareness and mental simulation, three key factors were identified as influencing self-care decision-making: 1) experience; 2) decision characteristics such as uncertainty, ambiguity, high stakes, urgency, illness characteristics, and involvement of others in the decision-making process; and 3) personal goals.

Discussion: These results support NDM as the process used by this sample of adults with HF to make decisions about self-care.

Key words: decision making; self-care; heart failure

A Qualitative Analysis of Naturalistic Decision Making in Adults with Chronic Heart Failure

Self-care of heart failure (HF) has been described as a naturalistic decision-making (NDM) process (Riegel & Dickson, 2008). The rationale for this description was recognition that adults with chronic HF rarely generate and compare options when making decisions about their symptoms. Instead, they use informal reasoning and prior experience to choose reasonable options, a process reflected in descriptions of NDM. Although NDM appears to be a good description of the real-world process used by HF patients, the data available to defend this thinking is anecdotal. Therefore, the purpose of this study was to explore the process used by adults with chronic HF to make decisions about their symptoms.

Decision-Making

Two major schools of thought drive the decision-making literature: normative and descriptive. Normative decision making is viewed as a deliberate and analytic process requiring a thorough search and analysis of available information (Lipshitz, Klein, Orasanu, & Salas, 2001). The choice among alternatives is made based on predictions about which option will best meet a particular goal based on analysis of a series of abstract, context-free models. In essence, normative decisions are believed to be rational choices of options assigned absolute and independent values which are weighed in terms of their advantages and disadvantages before choosing. Although perhaps ideal, this rational approach is a poor description of decisions made by laypersons in the everyday real world where situations are typically ambiguous, options are often vague, and decisions may need to be made quickly (Poon, Lal, Ford, & Braun, 2009).

Descriptive models evolved in response to a recognition that normative models fail to explain how people make decisions in the real world. These models acknowledge that decision-makers have limits on their time and options so mistakes are made when considering complex

and dynamic situations. The leading descriptive model is NDM. Although NDM has been used primarily to explain how experts make work-related decisions in the field (Bond & Cooper, 2006; Charles, Good, Hanusa, Chang, & Whittle, 2003; Helsloot & Groenendaal, 2011), the principles apply to individuals making real world personal decisions, as we will demonstrate.

Real world decisions typically involve dynamically evolving conditions, uncertainty, ambiguity, missing information, time stress, and high stakes. These decisions may have ill-defined, shifting or competing goals. Sometimes multiple individuals are involved in the decision making process. For example, a patient with HF who has difficulty lying flat to sleep may not be able to easily label that symptom as one associated with HF. Yet, the decision about whether to take an extra diuretic dose is a high stakes decision. The situation will probably evolve, probably quickly; without intervention, the patient will probably be admitted to the hospital in the next few days. A thorough analysis of possible choices, advantages and disadvantages, is not typical in this situation. Instead, patients often use a ‘wait and see’ approach (i.e., do nothing until it is an emergency) or make a decision that can be described as NDM.

Naturalistic Decision-Making

NDM focuses on how people make decisions in real world contexts that are meaningful and familiar to them (Lipshitz et al., 2001). The original definition of NDM concentrated on the context, defining NDM as “how experienced people, working as individuals or groups in dynamic, uncertain, and often fast paced environments, identify and assess their situation, make decisions and take actions whose consequences are meaningful to them” (Zsombok, 1997, p. 5). More recently the emphasis has pulled away from context and onto experience, emphasizing that NDM is really about how people use their experience to make decisions (Lipshitz et al., 2001).

Several models of NDM have been proposed, but the Recognition-Primed Decision Model is the prototypical NDM model (Schulz, Lingle, Chubon, & Coster-Schulz, 1995).

Three variations of the Recognition-Primed Decision Model have been described. In a simple pattern match, recognition of the typicality of a situation would lead to a typical action (Bond & Cooper, 2006). In the second variation, if the situation is unclear the decision maker relies on a story-building strategy to mentally simulate and thereby understand the situation better. The third variation describes how the decision maker evaluates a course of action by mentally simulating it to see if the action will work and to look for unintended consequences. Experience is important to each of these variations. Prior experience is used to quickly identify patterns in situations. Once the situation is categorized, prior experience is recalled to guide decision-making about the issue at hand. Experience provides a repertoire of patterns that provide relevant cues, suggest expected outcomes associated with specific responses, and point to reasonable goals and actions in specific types of situations (Klein, 2008). Without the expertise provided by experience, the decision maker will not recognize a typical situation, may be unable to mentally simulate events, and will be unable to identify potential unintended consequences.

Descriptive models of decision making such as NDM emphasize situation awareness, defined as the perception of salient elements in the environment, the comprehension of their meaning, and the projection of their status in the near future (Endsley, 1996). True situation awareness involves comprehension of the significance of the situation. Expert naturalistic decision-makers comprehend the meaning of situational changes and are able to mentally simulate options and decide on a course of action. The purpose of this study was to explore the process used by adults with chronic HF to describe how they make self-care decisions about their

symptoms. If NDM is the process used, we would expect to see that expert naturalistic decision-makers with a chronic illness would detect symptoms early, understand the seriousness of the symptoms, and decide upon an action before the symptoms escalate.

Methods

This study was a qualitative secondary analysis of four primary data sets examining self-care practices among adults with HF. Qualitative data included in this analysis were collected between 2007 and 2011 from diverse HF populations living in the United States (Dickson, Deatrck, & Riegel, 2008; Dickson, McCarthy, Howe, Schipper, & Katz, in press; Riegel, Dickson, Goldberg, & Deatrck, 2007) and Australia (Riegel et al., 2010). A brief summary of the studies is provided in Table 1. The methodological approach for each study was similar. In brief, individuals were recruited from HF clinics by a trained research assistant. Inclusion criteria were the same across the four studies: 1) evidence of symptomatic HF for at least three months, 2) able to speak and read English, and 3) no history of a prior neurological event or other factor that could cause an inability to perform tests (e.g., diagnosed dementia, unable to write or read in English, major visual or hearing impairment). In accordance with the Declaration of Helsinki, appropriate institutional review board approvals were obtained for each of the U.S. studies and in Australia, from the appropriate institutional human research ethics committees prior to subject recruitment. Each participant provided written informed consent.

In each of the four primary studies, the research assistant used a semi-structured interview guide and each interview began with two open-ended questions (“Tell me about your heart failure” and “What do you do on a daily basis to take care of your heart failure?”). To gain insight into how self-care was practiced, we also asked open ended questions about the self-care decision making process (e.g., “Tell me about the last time you had <symptom>”). Each

interview was transcribed verbatim and checked for accuracy. The qualitative data from these four studies yielded a rich description of self-care practices and insightful narratives about the decision making process used in self-care.

In each study we used the same investigator-developed survey to collect sociodemographic data about participants including age, gender, race, education, and socioeconomic status. New York Heart Association (NYHA) functional class was collected in three of the studies using a standardized interview format (Kubo et al., 2004) and by health care provider assessment in one study.

Sample

The full collective data set held qualitative data on 120 adults over age 18 years. For this analysis we used maximum variation sampling to purposively select a subset of 36 of the qualitative interviews to reanalyze. This purposive sampling strategy ensured a diverse mix of participants with the age, race, gender, and NYHA class characteristics known to be associated with HF self-care (Riegel, Lee, & Dickson, 2011).

Qualitative Data Collection and Analysis

Qualitative secondary analysis uses existing qualitative data sets in order to answer additional research questions (Sandelowski, Docherty, & Emden, 1997). In this study we were interested in examining if self-care decisions made by patients with HF were consistent with the NDM process. The research questions driving each of the primary studies had focused on factors influencing self-care and subjects had described their daily self-care practices including symptom management and adherence decisions. Therefore, we were able to reexamine the qualitative accounts for evidence of the characteristics of NDM in order to answer a new

research question (McCormick, Rodney, & Varcoe, 2003). That is, to more fully describe the process used by patients with HF making self-care decisions.

In this secondary analysis of qualitative data, we used a qualitative descriptive approach. Two researchers (VVD and MT) trained in qualitative analysis each coded the narrative accounts of self-care decisions from two separate studies. Inter-coder reliability was assured by dual coding of a subset of files (n=10). Then coding was reviewed for similarities and variations by comparing level of agreement between the two coders. Discrepancies were discussed. Final inter-coder reliability was determined to be greater than 95% agreement.

Preliminary coding was based upon *a priori* codes derived from the theoretical framework guiding the study. The initial coding scheme resulted in data clusters related to evidence of self-care decision making. After preliminary coding, within-case analysis was used to identify the key components of each individual's self-care decisions (Ayres, Kavanaugh, & Knafl, 2003). Evidence of the self-care decision making process was then examined across cases to identify commonalities and variations of the process. This within-study and across-study analysis was an iterative process (Ayres et al., 2003) for each of the four data sets. Finally, we constructed an informational matrix (Dickson, Lee, & Riegel, 2011) to organize and analyze the themes about decision-making in self-care across the four studies. In this way we were able to explore similarities and differences in decision making (e.g., situation awareness) across the samples, to explore variation by population characteristics (e.g., gender, race), and to identify exemplars of NDM self-care decision making.

Methodological rigor of the qualitative data analyses was maintained through an audit trail and periodic debriefing with the co-investigators who are experts in HF self-care and knowledgeable about each of the four primary studies. Reliability was measured by consistency

of interpretation and coding of the qualitative data (Byrne, 2001). As is typical of a qualitative analysis, an audit trail of process and analytic memos and coding books was maintained, which support the credibility of the results.

Results

Sample demographic and clinical characteristics are shown in Table 2. Our final sample consisted of 36 participants, half of whom were female (50%). Ages ranged from 40 to 98 years with approximately one third (36%) older than 65 years. Most (56%) participants were Caucasian, one third were African American, and the rest (11%) identified themselves as Hispanic or Latino. Most participants had NYHA class II (39%) or class III (56%) HF.

Self-Care Decisions as a Naturalistic Decision-Making Process

The overarching theme that emerged from the analysis was that decisions about self-care reflected a NDM process as described in the Recognition-Primed Decision Model. Components of situation awareness and mental simulation of a plausible course of action and possible outcomes were evident. For example, individuals who recognized a symptom and assessed its importance described mentally “thinking through” the possible options including active management versus a passive response. This mental simulation including considering the desired results as well as an evaluation of the actual outcome of the action (i.e., did it work and would s/he make that decision again). The two components of situation awareness and mental simulation are illustrated below.

Situation Awareness. Situation awareness encompassed the individual’s recognition and interpretation of a symptom with an assessment of its severity or importance. This situation awareness was essential for the subsequent steps of initiation and implementation of a decision. For example, individuals who recognized a symptom but not its importance were unlikely to

describe mentally simulating a plan of action: "... I knew I had a problem (postural dyspnea)... I just did not want to accept that this could be a serious problem". On the other hand, individuals who recognized the importance of the situation at hand and that a decision was needed were more likely to mentally simulate options and take action. For example, one man described how he decided that an extra diuretic dose was needed to manage his symptoms. First, he recognized his dyspnea, its severity, and mentally processed that a self-care decision was needed ("If I just start coughing and if I can't lay down for probably five or six minutes... that's when I know"). Then he formulated his plan ("...weigh myself to see...") and took an extra diuretic because that is how he effectively managed similar situations in the past.

Mental Simulation. Mental simulation was used to explore possible options, to develop plans of action when faced with self-care needs, and to evaluate outcomes. This mental simulation seemed to be based on situation awareness and was clearly influenced by prior personal experience with the situation. When discussing a possible course of action participants most often described deciding "what to do" and "why" by recalling what they had done in the past when experiencing a particular symptom. For example, "If my weight increased by 2 kilos... I would check my ankles.... 2 kilos would not be enough to bother me at this stage... But certainly if it continues to go up, I would go to see the doctor".

This mental simulation of plausible action also included a component of evaluation. As individuals formulated their decision, they contemplated what should happen based on the action and what to do should the expected outcome not occur as well as what not to do in the future. Participants described how they "knew" their decision had been correct, usually with symptom alleviation (e.g., after diuretic titration) or symptom prevention (i.e., low-salt diet adherence). Evaluating the outcome of a self-care decision provided reinforcement for future decisions

(“...you limit what you do...because I have learned that I will get these symptoms”). In some cases, the assessment of outcomes after a decision led to a decision modification. For example one individual described how his plan to “wait it out” was not effective and required re-evaluation of the situation and a new decision. “I had a very dry cough...I just tried waiting...thinking it will get better...it just got worse and worse and worse....at that point I thought it was something serious and went to the ER”.

Besides situation awareness and mental simulation, the narrative accounts of self-care revealed three key factors influencing the self-care decision-making process: 1) experience with the situation (i.e., the symptom and/or the behavioral response) and the decision (i.e., action and outcome), 2) decision characteristics such as uncertainty, ambiguity, high stakes, urgency, illness characteristics, and involvement of others in the decision-making process; and 3) conflict or synergy with personal goals (e.g., competing goals). Table 3 provides an exemplar of this self-care decision making process with illustrative quotes.

Experience with the Situation and the Decision. Experience was a key factor helping individuals to recognize and interpret symptoms, mentally formulate a plan, and decide on an action. For example, one participant described that when he was first diagnosed with HF, he did not recognize his shortness of breath as a HF symptom: “...we were on the elevator... and a doctor was on there... he heard my cough and he told me, “You need to go to the emergency room...”. Over time he learned from his experiences with worsening HF symptoms to recognize and act on HF symptoms much faster “now I know...I can tell before they <doctors> even listen to my lungs... if there’s gonna [sic] be fluid...so I take another <diuretic>”.

In this sample, individuals specifically described the value of their past experience in helping them be proactive in self-care decision-making. For example, one participant described

what experience had taught him about fluid retention and reducing sodium in his diet: “I have learned how not to build the fluid up. I know the different signs when my fluid is up too high. I know the ankles puffing up where I can’t walk...” Past experiences with life-threatening situations prompted vigilance and timely decisions about self-care for many (“...I used to wait....now I don’t wait...”).

Experience improved situation awareness by helping participants interpret external cues. These external cues were often unique to the individual. For example, one participant assessed the severity of his fluid retention based upon his past experience (“...not able to close that belt buckle”). Another patient reported that the distance she was able to walk without HF symptoms helped her assess the severity of her symptoms; a shorter distance suggested increased fluid retention and edema. Other external cues reported by our sample were the number of pillows used for sleep (“...the more pillows I need; the worse it is...”).

Experience influenced the self-care decision making process itself, however similar past experiences did not necessarily lead to the same decision among different individuals or even in the same individual. Although, several participants described that they had experienced multiple hospitalizations caused by ‘shortness of breath’ (dyspnea and pulmonary edema), recurrent episodes prompted varying decisions. For example, one participant described that based upon his experience, when he feels severe shortness of breath, he mentally urges himself: “Something’s wrong with you; go to the doctor!” even if there are obstacles. On the other hand, another participant experiencing severe shortness of breath described entering the “defensive mode” in which she restricts her activities and waits. Contextual factors also seemed to influence this process, as described in more detail below.

Decisions Characteristics. Decision characteristics of uncertainty, ambiguity, high stakes, urgency, illness characteristics, and involvement of others contributed to the process of decision making. Uncertainty and ambiguity because of insufficient or missing information contributed to the mental simulation of a plan of action, mostly in a negative way. Individuals who were uncertain as to the meaning or importance of symptoms (“when I don’t feel so well...I can’t tell...it could be the diabetes...or the heart...”) often decided to “wait and see...” or to ignore the situation. Conversely, those who assessed the situation as “high stakes” (“...I felt like I was going to die”) or with a sense of urgency or time stress (“I couldn’t breathe. I could hardly walk”) described a decision to act quickly.

Illness characteristics such as sleepiness and depression affected decision-making by confounding symptom recognition and altering decision characteristics. That is, when someone was depressed, symptoms were not easily recognized and decision-making was more tentative, more uncertain (“... when I am tired...I look at everything .. there is so much to do...I don’t know where to start. So I don’t.”)

In some cases, a caregiver or significant other was first to become aware of a situation and to contribute to the decision. For example, one participant reported that he knows that his HF symptoms are severe and a decision about going to the emergency room has to be made when his wife tells him “If you are that ill, call an ambulance!”

Conflict or synergy with personal goals. Generally, most of the sample described positive personal goals that supported self-care behaviors (e.g. “I want to see my grandchildren grow up... so I take those pills”). However, when faced with specific self-care scenarios that presented a conflict in goals, self-care decisions were affected. Several individuals described competing goals related to employment or family that forced prioritization of that commitment

over self-care. For example, one man described “powering” through his HF symptoms of shortness of breath and fatigue when caring for his 3 year old child. Although he recognized the situation and the symptom as important and described a mental plan of options for action such as rest and dietary change that would alleviate the situation, his priority to care for his active daughter altered his decision. Another woman described her conflict surrounding a self-care decision for fluid retention when she needed to be out of the house at work: “even if I have gained 5 pounds overnight...if I have an important meeting, the water pill stays in the <pill>box and I hope I don’t regret it...” Inability to manage competing goals increased the vulnerability of some to self-care decisions with unfavorable outcomes. The process is shown in Figure 1.

Discussion

The results of this study support NDM as the process used by adults with HF to make decisions about self-care. Evidence was presented of the important contributions of situation awareness and mental simulation in decision-making. In addition, three key factors were identified as influencing decision-making: 1) experience; 2) decision characteristics such as uncertainty, ambiguity, high stakes, urgency, illness characteristics, and involvement of others in the decision-making process; and 3) personal goals. Together, these factors support the proposition that adults with HF use a NDM process to make decisions about self-care.

Experience was found to be foundational to the process, as proposed by the originators of NDM. Those without experience were poor in both situation awareness and mental simulation, a finding consistent with prior work (Cameron, Worrall-Carter, Page, & Stewart, 2010; Francque-Frontiero, 2002). For example, Cameron et al. (2010) found that HF patients diagnosed within the prior 2 months had poorer self-care maintenance (treatment adherence and symptom

monitoring) and made poorer decisions about symptoms compared to HF patients who had experience with the illness.

We found that situation awareness initiated the decision-making process and that experience with HF promoted situation awareness by facilitating the mental simulation of situations and decision options. Situation awareness has not been discussed previously in adults with HF, although somatic awareness has been studied. Jurgens describes somatic awareness as sensitivity to physical sensations and bodily activity secondary to physiological change (Jurgens, 2006). In her study of HF patients, Jurgens found that somatic awareness was a significant predictor of delay in response to HF symptoms and patients with a previous history of HF demonstrated less delay time compared to those without experience. These prior results are consistent with our finding that situation awareness is vital and experience promotes situation awareness in adults with HF.

Situation awareness was prompted by external cues. This finding is consistent with the theoretical underpinnings of the theory of Uncertainty in Illness, which explains how patients construct meaning from their pattern of symptoms, the familiarity of the situation, and congruence between that which is expected and that which is experienced (Mishel, 1988). External cues are what make the situation familiar. We found that the external cues were often unique to each individual, illustrating the importance of building on individual experiences rather than expecting every individual to experience the same cues. Awareness of the uniqueness of cues could lead clinicians to tailor instructions more than current practice reflects. For example, HF patients are routinely instructed to weigh themselves daily, but adherence to such advice is low (van der Wal, Jaarsma, Moser, van Gilst, & van Veldhuisen, 2010). Recognition of the

uniqueness of external cues would prompt the clinician to help the patient identify a different cue to monitor if daily weighing is not useful to him or her.

Mental simulation was as important to the process of NDM as situation awareness. Mental simulation was used to explore possible options, to develop plans of action when faced with self-care decisions, and to evaluate outcomes. The process we identified is consistent with that proposed by Leventhal in the Common Sense Model of illness representation (Leventhal & Cameron, 1987). Leventhal proposed that people form lay representations or mental schema when confronted with illness-related information and that these schema influence the manner in which symptoms are interpreted and decisions are made. These processes mirror the conscious simulation processes described as useful for exploring options in complex decisions (Baumeister & Masicampo, 2010).

Mental simulation is discussed in professional training (Fisher, Orkin, & Frazer, 2010; Round, Conradi, & Poulton, 2009) and attributed to patients choosing between specific health care options (Evans-Lacko, Baum, Danis, Biddle, & Goold, 2011). But, little evidence was located to support that clinicians recognize that patients use mental simulation to facilitate everyday decision-making. Recognition that mental simulation is used routinely by patients was particularly interesting to us because the situation-specific theory of HF self-care specifies that evaluation is a component of the self-care management process of symptom management (Riegel & Dickson, 2008), but little research has addressed this specific phase of the self-care process. Using mental simulation in patient teaching sessions may facilitate the ability of patients to learn how to think through issues before they occur.

Decision characteristics such as uncertainty, ambiguity, high stakes, urgency, illness characteristics, and involvement of others were found to influence the decision-making process.

These characteristics can be linked through recognition of the contribution of others to decisions as described by Mishel and Braden (1988), who noted that social support decreased the level of ambiguity associated with illness. We previously demonstrated that family dynamics influenced symptom interpretation and self-care decisions, especially in men (Riegel, Dickson, Kuhn, Page, & Worrall-Carter, 2010). In this prior study we also found women to be tentative in response to symptoms, a result we interpreted in light of research suggesting that women are more influenced by uncertainty and social pressure when making decisions (Sanz de Acedo Lizarraga, M.L., Sanz de Acedo Baquedano, & Cardelle-Elawar, 2007).

Decisions that are consistent with personal goals promote decision-making. According to the premises of NDM, options for a particular decision scenario are selected or rejected based upon compatibility with the decision-maker's values and personal goals, not necessarily just the perceived merit of an action (Lipshitz et al., 2001). Our study confirms this important and often ignored characteristic of decision-making. We found that when faced with competing personal goals, for example childcare versus managing symptoms, participants chose the action most compatible with their personal goals. This finding is consistent with our prior work in which we found that when other roles and responsibilities compete with self-care, decisions are affected (Dickson, Kuhn, , Worrall-Carter, & Riegel, 2011; Dickson, McCauley, & Riegel, 2008). Others have described how roles and responsibilities linked to personal values and goals challenge preventive health behaviors (Bach Nielsen, Dyhr, Lauritzen, & Malterud, 2005; Cohen & Kataoka-Yahiro, 2009; Dunn, 2008) and treatment seeking (Turriss & Johnson, 2008). Our study extends this finding and helps explain why decisions are situational. This analysis contributes to the growing evidence that self-care decisions are likely to be imbedded in broader tasks and driven by larger personal goals.

Limitations of this study include a sample that is younger than many community-based HF populations. The relative youth of this sample may well have influenced the decision characteristics because work and family obligations could have contributed to the time stress surrounding decisions. Relatively fewer older adults may have prevented us from identifying cognition as a factor influencing decision-making, although impaired cognition also could be considered an illness characteristic. It is also important to note that as a secondary analysis of qualitative data, our analysis was limited to the data as collected. Strengths of the study include the use of purposive sampling to draw a balanced sample from a rich and large qualitative database, with adequate representation of ethnic minority patients.

In summary, we have provided evidence that HF patients use a NDM process to make decisions about self-care. Further understanding of this process has provided insights that can be used to improve decision-making in chronically ill individuals.

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Table 1: Summary of Studies

Study Purpose	Sample Demographics	Key Results
To describe how expertise in self-care develops. (Riegel et al., 2007)	N=29 60% male, 60% Caucasian Mean age 63.37 (\pm 13.12) years; 60% NYHA III Length of time with HF: 6 (range 1-20) years	Patients with poor HF self-care had worse cognition, more sleepiness, were more depressed and had poorer family functioning.
To examine the contribution of biobehavioral variables of cognition, self-efficacy and attitudes to HF self-care. (Dickson et al., 2008)	N= 41 63.4% male, 68.3% Caucasian Mean age 49.17 (\pm 10.51) years; 58.5% NYHA III Length of time with HF: 6.6 \pm 4.7 years	A self-care typology characterized by variance in cognition, self-efficacy and attitudes, was constructed from the integrated data: experts, novices, and inconsistent.
To explore age-related differences in the ability to perceive symptoms of heart failure. (Riegel, Dickson, Cameron et al., 2010)	<u>Sample:</u> N=29 72.4% Male, Mean age 68.69 (\pm 14.40); 58.6% NYHA II Length of time with HF: 5.2 \pm 5.8 years	Older patients had more difficulty in detecting and interpreting shortness of breath than younger patients.
To describe the self-care	<u>Sample:</u> N=30	Self-care, which was very

<p>practices and sociocultural influences of self-care in an ethnic minority black population with HF. (Dickson et al., in press)</p>	<p>60% male, 100% Black Mean age 59.63 (\pm 15.19) years; 66.6% NYHA III Length of time with HF: 5.33 (\pm7.03)years</p>	<p>poor in the sample, was influenced by cultural beliefs, including the meaning ascribed to HF, and by social norms that interfered with willingness to access social support.</p>
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Table 2: Socio-demographic characteristic of the sample

Characteristics	N (%)
Gender	
Male	18 (50%)
Female	18 (50%)
Age	
<65	23 (64%)
>65	13 (36%)
Race	
White	20 (56%)
African American	11 (31%)
Hispanic or Latino	5 (13%)
NYHA class	
II	14 (39%)
III	20 (56%)
IV	2 (5%)

Table 3: Exemplars of Self-Care Naturalistic Decision Making Process

Exemplar	Situational Awareness	Experience	Mental Simulation of Plan	Decision Characteristics	Self-Care Decision
65 y/o AA women	“the breathing is bad”	“I knew from the past...this was not good...it comes on fast...”	When I have this...there really are no options. Other times...like if my weight is up... I know I can take the extra pill...and see if it helps...”	High stakes and urgency “I felt like I would die...I <u>could not</u> breathe” Multiple Individuals “...my grandson took one look and said, Gram, I’m calling 911”	Called 911
40 y/o Hispanic male	“I had weakness... and was so tired...”	“I’ve had it before and I know what I need to do as far as	“I had to just sit...stay on the floor with <baby> and wait...wait ‘til it	Competing personal goal: childcare “I couldn’t just leave her... and	“Wait it out”

		<seeking care>...but..."	passed or until my wife got home...I knew if I was not better then I would go to emergency ...and she<wife> would make me"	I couldn't lift her up... I was weak. So I had to be strong for her"	
74y/o white male	"I can't really tell...I have pretty bad arthritis and have to work to walk..."	"...but <wife> knows...she's seen it <dyspnea> and knows what's coming..."	"... the last time, my weight went up cause <wife> didn't see what I ate...next day, she gave me the extra water pill and it helped... but her hand can reach for that phone to call <for help> pretty fast..."	Multiple individuals: "I count on her ..."	Diuretic titration

Figure 1. Figure representing the importance of situation awareness and mental simulation of action in making naturalistic decisions about self-care. Experience is important in terms of improving situation awareness and facilitating the process of mental simulation. Decision characteristics and personal goals influence the decisions made.

