

# Factors Associated With the Development of Expertise in Heart Failure Self-Care

Barbara Riegel ▼ Victoria Vaughan Dickson ▼ Lee R. Goldberg ▼ Janet A. Deatrck

- ▶ **Background:** Self-care is vital for successful heart failure (HF) management. Mastering self-care is challenging; few patients develop sufficient expertise to avoid repeated hospitalization.
- ▶ **Objective:** To describe and understand how expertise in HF self-care develops.
- ▶ **Methods:** Extreme case sampling was used to identify 29 chronic HF patients predominately poor or particularly good in self-care. Using a mixed-methods (qualitative and quantitative) design, participants were interviewed about HF self-care, surveyed to measure factors anticipated to influence self-care, and tested for cognitive functioning. Audiotaped interviews were analyzed using content analysis. Qualitative and quantitative data were combined to produce a multidimensional typology of patients poor, good, or expert in HF self-care.
- ▶ **Results:** Only 10.3% of the sample was expert in HF self-care. Patients poor in HF self-care had worse cognition, more sleepiness, higher depression, and poorer family functioning. The primary factors distinguishing those good versus expert in self-care were sleepiness and family engagement. Experts had less daytime sleepiness and more support from engaged loved ones who fostered self-care skill development.
- ▶ **Conclusion:** Engaged supporters can help persons with chronic HF to overcome seemingly insurmountable barriers to self-care. Research is needed to understand the effects of excessive daytime sleepiness on HF self-care.
- ▶ **Key Words:** cognition · family · mixed methods · naturalistic decision making · sleep

**H**ear failure (HF) is prevalent in developed countries worldwide (Gwadry-Sridhar, Flintoft, Lee, Lee, & Guyatt, 2004). As the syndrome advances, persons with HF begin a cycle of fluid retention, acute symptom exacerbation, and hospitalization that is best prevented with vigilant self-care (Bennett et al., 1998; Welsh et al., 2002). Yet, poor self-care remains extremely common

in this patient population (Bennett et al., 1998). Fewer than half of HF patients weigh themselves routinely to monitor fluid retention (Moser, Doering, & Chung, 2005). Eating a diet restricted in sodium is difficult for most patients, and investigators have documented that little more than half of HF patients are successful in this aspect of self-care (Hershberger et al., 2001). Symptom recognition is particularly challenging. In hindsight, patients realize that particular symptoms (e.g., shortness of breath, ankle swelling, fatigue) are related to HF, but at the time, most fail to recognize them as acute symptoms requiring early intervention (Carlson, Riegel, & Moser, 2001).

Self-care refers to the behaviors that patients use to maintain physiologic stability such as medication taking and the response to symptoms when they occur (Riegel, Carlson, et al., 2004). Much has been written about the importance of HF self-care, but clinicians and researchers remain perplexed about why some patients master self-care and others do not. In this study, the development of HF self-care expertise is described. Patients were grouped as poor, good, or expert in HF self-care based on interview data, and the factors associated with the development of self-care expertise were explored.

## Background

Although patient self-care is an essential and integral component of the management of chronic HF, surprisingly little is known about how patients learn self-care and those aspects of their lives that promote and inhibit its performance. Investigators have explored a wide variety of factors as potential predictors of self-care. Factors shown to influence HF self-care include comorbid conditions (Moser et al., 2005), functional impairment (Gary, 2006),

*Barbara Riegel, DNSc, RN, CS, FAAN, is Associate Professor; Victoria Vaughan Dickson, PhD, CRNP, is Lecturer; Lee R. Goldberg, MD, MPH, FACC, is Assistant Professor, School of Medicine; and Janet A. Deatrck, PhD, FAAN, is Associate Professor, School of Nursing, University of Pennsylvania.*

impaired cognition (Wolfe, Worrall-Carter, Foister, Keks, & Howe, 2006), depression (Moser et al., 2005), excessive daytime sleepiness (Riegel, Goldberg, & Weaver, 2004), and poor family support (Riegel et al., 2006). The study most illustrative regarding HF self-care was conducted by Horowitz, Rein, and Leventhal (2004), who interviewed HF patients and found that they commonly perceived HF as an acute rather than a chronic illness. Believing that HF could be cured, when symptoms were gone, the patients believed that their health was restored. Thus, subtle and insidious symptoms of an HF exacerbation were not recognized. As a consequence, the patients managed symptoms poorly and rarely engaged in effective self-care. Clinicians supported these patient misperceptions by failing to continually manage patients in the absence of symptoms.

Decision making is a critical component of HF self-care, which requires daily choices about lifestyle, symptom management, and treatment options. Naturalistic decision making helps explain these real-world decisions as based upon the interaction between the person, the problem, and the environment (Lipshitz, Klein, Orasanu, & Salas, 2001). Decisions about self-care are situation- and context-specific, influenced by knowledge about and experience with decision making in the particular context, skill to act on the decision made, and the compatibility of the decision and action with personal values (Figure 1). To understand HF self-care, we explored ways that available information shaped decision making about self-care, presumably through its influence on knowledge, experience, skill, and values.

## Methods

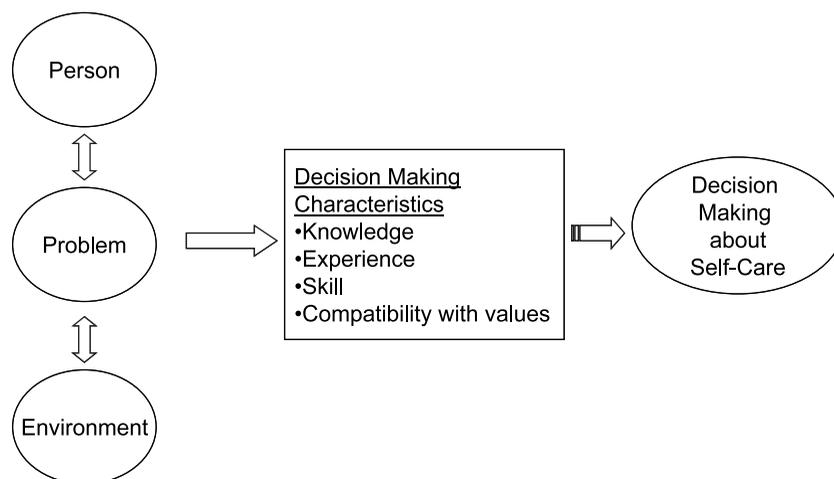
Using a mixed-methods (qualitative and quantitative) design (Tashakkori & Teddlie, 2002), evidence of exper-

tise in HF self-care, factors that facilitate and impede the performance of self-care, and the decision-making processes used by patients were explored. Data were collected primarily by interview to provide insight into the process by which self-care expertise develops. Standardized instruments were used to quantify the level and type of self-care in which the patients engaged and to gather data on factors anticipated to influence self-care. Objective testing of cognition was performed because self-care is a decision-making process requiring the ability to think, reason, and remember. Many of the deficits in cognition associated with HF are now recognized as subtle, requiring specific testing to detect (Bennett, Sauve, & Shaw, 2005).

## Participants

After the protocol was approved by the university Institutional Review Board, a purposeful sample of 29 persons with chronic HF was enrolled. All participants provided written informed consent.

As the objective of this study was to describe and understand, the sampling plan emphasized saturation of themes rather than sample size. Participants were recruited from an HF clinic associated with a large urban medical center in the northeastern United States. Patients were invited to participate if they had documentation of chronic symptomatic HF diagnosed with echocardiographic evidence of an abnormal left ventricular ejection fraction and a physician diagnosis of chronic HF. All participants spoke English and were judged by the HF clinic staff to be outliers (i.e., extreme case sampling) in terms of HF self-care. Specifically, physicians and nurses who work closely with the patients were asked to identify those patients judged to be particularly good or predominantly poor in HF self-care. Patients with severely impaired cognition, a complicating serious comorbidity such as psychosis or HIV/AIDS,



**FIGURE 1.** Conceptual model of the manner in which laypersons make decisions regarding self-care. Self-care requires daily choices about lifestyle, symptom management, and treatment options. According to naturalistic decision making, these decisions are based upon interaction between the person, the problem, and the environment. Decisions are influenced by knowledge about and experience with decision making, decision-making skill, and compatibility between the decision and personal values. Model reprinted from Riegel, B., Dickson, V. V., Hoke, L., McMahon, J. P., Reis, B. F., & Sayers, S. (2006). A motivational counseling approach to improving heart failure self-care: Mechanisms of effectiveness. *Journal of Cardiovascular Nursing*, 21, 232–241 (used with permission of Lippincott, Williams & Wilkins).

or an uncorrected hearing loss that could interfere with data collection were excluded.

### Procedure

Patients were paid US\$50 for completing the interview, cognition testing, and surveys. Most testing was done in the home, and loved ones were welcome to attend and contribute to the discussion if desired. The interview was structured using a guide designed to capture knowledge, experience, skill, and values to reflect the naturalistic decision-making model underlying the study. The interview guide consisted of open-ended questions and probes that focused the interview while allowing the participant to speak freely about self-care. All interviews began with a general question: "Tell me about your heart failure...," after which participants were encouraged to describe fully their experiences of managing HF (e.g., "Tell me about a time you managed your heart failure symptoms...") and factors affecting their ability to practice self-care (e.g., "Who are your resources for help and support?"). Interviews were audiotaped, transcribed verbatim, augmented with field notes, and analyzed using Atlas software (Atlas.ti Scientific Software Development, Berlin, Germany).

### Measurement

Scales were used to measure those factors anticipated to influence HF self-care (e.g., comorbid conditions, functional impairment, cognition, depression, excessive daytime sleepiness, and social support). When an important factor was identified in the qualitative data, scores on the instrument measuring that factor were analyzed (i.e., data triangulation). Only those instruments used in this analysis are summarized here.

Participants completed a brief sociodemographic survey. Comorbidity was assessed using the interview format of the Charlson Index (Katz, Chang, Sangha, Fossel, & Bates, 1996) in which responses are summed, weighted, and indexed into one of three categories (low, moderate, or high) according to the published method (Charlson, Pompei, Ales, & MacKenzie, 1987). Validity was demonstrated by the instrument authors when comorbidity category predicted mortality, complications, healthcare resource use, length of hospital stay, discharge disposition, or cost.

Seven structured questions about symptoms and physical limitations were used to assign New York Heart Association (NYHA) functional class (Kubo et al., 2004). This questionnaire, developed based on the standard definitions of NYHA classes and used in major NIH-funded clinical trials, provides approximately 60% concordance in classification and 90% reproducibility.

Heart failure self-care was quantified using the Self-Care of HF Index (SCHFI; Riegel, Carlson et al., 2004). The 17-item SCHFI is measured on a 4-point Likert scale and grouped to form three scales: self-care maintenance, management, and confidence. Maintenance items assess treatment adherence behaviors and self-monitoring performed to prevent an acute exacerbation of HF (e.g., daily weighing). Management items assess the ability to recognize symptoms when they occur, treatments implemented

by the patient (e.g., taking an extra diuretic for shortness of breath), and ability to evaluate the effectiveness of the treatments implemented. Items measuring confidence address the patient's perceived ability to engage in each phase of self-care (e.g., recognize symptoms). Raw scores on the scales and scores standardized to 100 are reported; higher scores reflect better self-care. Coefficient alpha for the SCHFI was .77 in a sample of 760 HF patients (Riegel, Carlson et al., 2004). Construct validity was demonstrated with confirmatory factor analysis. The SCHFI has been shown to be sensitive to subtle behavioral changes in a variety of HF samples (Riegel, Carlson et al., 2004; Riegel & Carlson, 2004).

To assess cognitive status, two brief neurobehavioral tests were administered. These tests were chosen because of their brevity and sensitivity to subtle impairments in memory, attention, and executive function. Short-term memory and learning ability were assessed using the Probed Memory Recall Test in which four word pairs were shown to the patient for 30 seconds (Cavanaugh, 1984). Ten minutes were allowed to pass with other tasks and then one word of the pair was presented and the participant was asked to fill in the second word from memory. The task is to recall all four of the paired words within 1 minute. List learning is a common and highly sensitive test of decline in anterograde memory, and the Probed Memory Recall Test has shown good construct and discriminant validity in prior testing (Kuslansky, Buschke, Katz, Sliwinski, & Lipton, 2002).

Attention and cognitive processing were measured using the Digit Symbol Substitution Test (Joy, Kaplan, & Fein, 2003). In this test, participants were shown a list of numbers and associated symbols and were asked to draw the simple symbols below each corresponding number (out of sequence) during a 90-second interval. This test has demonstrated discriminant validity (Joy et al., 2003). The number completed in 120 seconds was used in analysis.

Persons with HF commonly complain of daytime sleepiness (Redeker & Stein, 2006). Thus, excessive daytime sleepiness was measured with the Epworth Sleepiness Scale (ESS; Johns, 1991). Respondents rate the likelihood of falling asleep in eight soporific situations using a 4-point Likert scale ranging from 0 (*never dozing*) to 3 (*high chance of dozing*). The ESS correlates significantly with the frequency of brief breathing pauses or apneas (Johns, 1992). Test-retest reliability ( $r = .82$ ) and internal consistency ( $\alpha = .88$ ) have been established (Johns, 2000). Scores are summed, with higher scores indicating higher daytime sleepiness, or categorized as sleepy ( $\geq 11$ ) or not sleepy ( $< 11$ ).

Support is recognized widely as essential in this patient population (Molloy, Johnston, & Witham, 2005), but it has been difficult to find an instrument sensitive enough to measure what is seen clinically. In this study, family functioning was assessed with the McMaster Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983), a 60-item self-report instrument that yields scores in seven subscales: problem solving, communication, roles, affective responsiveness, affective involvement, behavior control, and general functioning. Participants rate the

extent to which the statement describes their family from 1 (*strongly agree*) to 4 (*strongly disagree*); higher scores indicate poorer functioning. Families can be categorized into lower or higher family functioning groups based on standardized cut-points (shown below). The FAD is used widely; internal consistency of the scale ranges between .86 and .92, and the test-retest reliability is reported to be .71 (Miller et al., 1994). In this study, internal consistency was .96.

Depression was assessed using the 4-point Patient Health Questionnaire PHQ-9, a brief measure of the full range of symptoms that are part of the *DSM-IV* diagnosis of major depression (Kroenke, Spitzer, & Williams, 2001). The PHQ-9 is unique because it assesses symptom duration and can be used as a provisional diagnostic tool for major or minor depression, not just depressive symptoms. The PHQ-9 had a sensitivity of 88% and a specificity of 88% for detecting major depression when a score of 10 was compared to the professional interviews as the criterion standard.

### Analysis

Over 780 pages of transcription were analyzed using content analysis to obtain data clusters (Hsieh & Shannon, 2005). Coding of the interview data was then linked to the factors shown previously to contribute to HF self-care (e.g., cognitive impairment). After this preliminary coding, within-case analysis was used to identify the key elements of each individual's account of HF self-care (Ayres, Kavanaugh, & Knafl, 2003).

Patients were coded as engaging in self-care maintenance if there was qualitative evidence of daily weight monitoring, checking ankles, exercise, medication adherence, or diet adherence. Self-care management was coded when patients described monitoring symptoms, recognizing the importance of a symptom, and using and evaluating active approaches to treating symptoms (e.g., taking an extra water pill, calling the provider, restricting salt or fluid intake in response to a specific symptom). Some patients used energy conservation maneuvers so this also was coded as a management behavior if done in response to symptoms.

Using the interview and field note data, one investigator, blinded to the quantitative data, classified participants as poor, good, or expert in HF self-care. The primary factor differentiating these groups was self-care management. Specifically, patients judged to be *poor* in HF self-care were lacking in the ability to manage symptoms and were also inconsistent in their routine performance of maintenance behaviors. Alternately, patients who were poor in self-care performed most of the desirable maintenance behaviors but had little understanding of how to manage symptoms. Those deemed to be *good* at HF self-care adequately managed indiscretions in the treatment regimen and symptoms, and routinely performed most but not all maintenance behaviors. These patients were neither consistent in their self-care practices nor skilled in their implementation. *Experts* in HF self-care had a high degree of knowledge and skill in self-care management. They adeptly managed HF symptoms when they occurred or described how they kept themselves symptom-free despite having a moderate or high level of comorbidity. Experts

also routinely performed maintenance behaviors (e.g., followed a low sodium diet, had a system for assuring that medications were taken).

Factors that impeded and facilitated the development of expertise in HF self-care were identified from the qualitative data and corroborated with the quantitative data, to determine (a) the contributors to poor HF self-care and (b) what differentiates experts in HF self-care from those merely good in self-care.

Descriptive statistics were used to depict the sample. Analysis of variance and chi-square analyses, depending on the level of measurement, were used to compare groups formed on the basis of the qualitative categorization of self-care expertise. All analyses were done using SPSS 13.0 (SPSS, Chicago, IL).

### Results

The sample of 29 participants was predominately male, elderly, married, Caucasian, educated at a high school level or above, retired from active employment, and reported having HF for an average of 6 years (range 1–20 years; Table 1).

Only three (10.3%) of the 29 participants were rated as expert in HF self-care. These three experts were women, none lived alone, and all were homemakers. All were NYHA class III or IV. All had been diagnosed with HF within the past 3–6 years. Two of the three had cared for spouses who had died of heart disease. Comparing socio-demographic characteristics among the groups, experts were older, had less formal education, and higher levels of comorbid illnesses. Body mass index was lower in the experts and the proportion with a history of sleep disordered breathing was lower. Experts were more likely to rate their health as good rather than fair, but overall quality of life was poor for them.

Self-care maintenance, management, and confidence scores were adequate, on average, and different among the three groups (Table 2). Self-care scores rose in a linear fashion as expertise increased, except for confidence, which was highest in patients judged to be good but not expert in self-care.

### Contributors to Poor Heart Failure Self-Care

All participants had received routine education through the HF clinic physicians and nurses. The education on diet, the importance of daily weights, and exercise was reinforced during each routine clinic visit. However, misconceptions and lack of knowledge were common among those poor in self-care: "If I do eat something salty, I try to flush it out of myself with a lot of water..." Patients failed to recall instructions: "No one ever told me." Those who were poor in self-care did not have the skill to solve problems or manage dietary indiscretions: "They put me on 2,400 (calorie diet). I could handle that but still you know—my heart diet said don't eat that, diabetes says eat because of the medication that I'm taking and my sugar..."

As shown in Table 2, the characteristics or traits held in common by patients poor in HF self-care were impaired memory, attention, and cognitive processing; excessive daytime sleepiness; depression; and impaired family functioning.

TABLE 1. Demographic and Clinical Profile of the Sample of Heart Failure Patients (N = 29)

	Poor in Self-Care (n = 10)	Good in Self-Care (n = 16)	Expert in Self-Care (n = 3)
Age in years, mean (SD)	59.4 (9.8)	63.9 (15.4)	69.0 (6.2)
Caucasian (%)	50	68.8	66.7
Female (%)	30	31.2	100
Married or live with someone (%)	90	81.3	33.3
Mean years of education, mean (SD)	13.5 (3.6)	14.2 (2.3)	12.7 (1.1)
Household income sufficient to meet needs (%)	20	25	33.3
Years with HF, mean (SD)	5.4 (3.2)	6.8 (4.8)	5.0 (1.7)
Receive most care in an HF clinic (%)	80	46.7	66.6
Charlson Comorbidity score, mean (SD)	2.9 (1.7)	3.2 (1.7)	4.7 (2.3)
Medications (%)			
ACE inhibitor	88.9	87.5	100
Beta-blocker	88.9	100	100
NYHA functional class (%)			
Class II	20	37.5	0
Class III or IV	80	62.5	100
History of diagnosed sleep disordered breathing (%)	70	43.8	33.3
Body mass index, mean (SD)	32.6 (4.0)	28.5 (7.9)	26.6 (5.7)
Perceived health (%)			
Fair	50	13.3	33.3
Good	30	40	66.7
Perceived overall quality of life rated as poor (%)	10	6.3	33.3

Note. HF = heart failure; ACE = angiotensin converting enzyme; NYHA = New York Heart Association.

One patient reported: "...the only thing that bothers me with my brain is.....the little things that I can't figure out right now." In the qualitative data, cognition was linked to difficulties with dietary and medication adherence as well as symptom management.

Depression was highest among those poor in self-care. "Considering how I used to be and now...that has changed drastically... I find it very hard sometimes to deal with... it's very emotional. This morning after I got into the office for a while I just, uh, cried for a little bit, a sense of hopelessness...I'm not capable of doing the walking that I used to do...I feel a sense of inadequacy..." Depression interfered with patients' motivation for self-care: "Sometimes you just get fed up and I think that was just a day that I had a real down spiraling. I just ate what I wanted. I put salt on everything and just didn't care." Another stated: "It feels exactly like the word: failure."

Excessive daytime sleepiness was associated with poor self-care: "I find that by the time I get home and get my shower and take the rest of my meds...I start to get kind of sleepy...It sometimes feels like I could sleep forever, so I don't know if that's just part of the symptom or what it is..." Scores on the Epworth Sleepiness Scale were highest in those poor in self-care and significantly more of them were categorized as sleepy ( $\geq 11$ ).

Although most participants reported feeling supported, a few lived alone or the support available negatively contributed to their self-care: "...we would go to parties and they wouldn't have anything low-salt for me to eat..." Scores on the Family Assessment Device consistently reflected poorer family functioning for patients rated poor in HF self-care. These patients often lacked a family member to rely on: "I basically have alienated myself from my family over the years." Without adequate support, patients felt isolated and reported difficulty with managing day-to-day tasks.

#### Differentiating Experts From Those Merely Good in Heart Failure Self-Care

As shown in Table 2, many of the quantitative scores were similar in patients good and expert in HF self-care. Depression was actually higher in the self-care experts, and self-care confidence was lower when compared to those good in self-care. The primary factor distinguishing participants who were expert versus good in self-care was excessive daytime sleepiness; experts were less sleepy than those rated good in self-care. Experts were less likely to have a history of sleep disordered breathing such as sleep apnea and more likely to have a normal body weight—a major contributor to sleep disordered breathing (Maislin et al., 1995).

**TABLE 2. Multidimensional Typology of Heart Failure Patients (N = 29) Based on Self-Care Qualitative Rating**

	Poor in Self-Care (n = 10)	Good in Self-Care (n = 16)	Expert in Self-Care (n = 3)
<i>Self-Care</i>			
Self-Care Maintenance			
Standardized	70.0 ± 16.9	80.0 ± 12.2	85.0 ± 5.0
Raw	14.0 ± 3.4	16.0 ± 2.4	17.0 ± 1.0
Self-Care Management*			
Standardized	62.0 ± 12.9	73.2 ± 11.6	87.6 ± 5.9
Raw	14.9 ± 3.1	17.5 ± 2.8	21.0 ± 1.4
Self-Care Confidence*			
Standardized	62.1 ± 10.3	77.7 ± 12.9	72.3 ± 12.0
Raw	14.9 ± 2.5	18.6 ± 3.1	17.3 ± 2.9
<i>Cognition</i>			
Probed Memory Recall Task	2.0 ± 1.2	2.3 ± 1.2	2.3 ± 0.3
Digit Symbol Substitution Task	39.5 ± 15.9	43.6 ± 16.7	44.0 ± 8.7
<i>Excessive Daytime Sleepiness</i>			
Epworth Sleepiness Scale <sup>a</sup> (cut-point = 10)	11.4 ± 5.9	8.9 ± 5.1	6.7 ± 5.7
	6 (60.0%) sleepy	5 (31.3%) sleepy	1 (33.3%) sleepy
<i>Depression</i>			
PHQ-9 score	8.2 ± 6.9	2.4 ± 2.4	8.0 ± 1.0
<i>Family Functioning<sup>a</sup></i>			
Problem Solving Function (cut-point 2.2)	2.1 ± 0.6	1.7 ± 0.3	1.8 ± 0.4
Communication (cut-point 2.2)	2.2 ± 0.3	1.9 ± 0.3	1.9 ± 0.5
Roles (cut-point 2.3)	2.4 ± 0.4	2.0 ± 0.3	2.0 ± 0.2
Affective Responsiveness (cut-point 2.2)	2.4 ± 0.7	1.8 ± 0.5	1.9 ± 0.2
Affective Involvement (cut-point 2.1)	2.2 ± 0.5	1.9 ± 0.4	2.1 ± 0.2
Behavior Control (cut-point 1.9)	1.9 ± 0.3	1.7 ± 0.3	1.9 ± 0.3
General Family Functioning (cut-point 2.0)	2.2 ± 0.5	1.6 ± 0.3	1.8 ± 0.5

Note. \* $p < .05$ . <sup>a</sup>Lower scores are better.

Experts were characterized by their ability to describe their specific HF symptoms, and they could link their symptoms with HF physiology and their self-care behavior. "I came to realize that salt retains fluid...And when I retain fluid I don't feel good...so we cook with very little or no salt and mild food..." Another expert stated: "...I'm bloated today...I feel it in my stomach... I weigh myself every morning and I was 2½ pounds up in weight...It makes you breathe a little harder...But still you need that water pill to get that fluid off...It works right away...It starts to like open up...the fluid just starts coming out."

In addition, experts were able to verbalize their understanding of treatments. One expert described why controlling her weight was important: "so the heart

doesn't have to work any harder..." and the importance of exercise: "strengthen the heart muscle." Although medication adherence was found among all those that were good and expert in self-care, experts had a more comprehensive understanding of their medication regimen. A daughter described her expert mother: "She recognizes what they (pills) are, too. So it's not like she's just taking a pill and she doesn't know what it is. She can look at every pill and she can tell you exactly what medicine that pill is and what it does."

As patients recounted their stories of living with HF, they described how knowledge, experience, skill, and values—key concepts in naturalistic decision making— influenced their proficiency in HF self-care: "I got some diet stuff from the doctor. I went to the library, I got some

books...I read up on the heart failure. I ask a lot of questions when I go to my clinic appointment." Experience in dealing with HF self-care, either during the course of their illness or as a caregiver for a family member, enhanced self-care skill development: "I have worked with these medications and diet for so long now...my husband and now me..." Vigilance was an important part of the process of developing proficiency in HF self-care: "It is a routine...I feel like everyday my main concentration is on...let's see what's due now." Belief in the importance of self-care contributed to its consistent performance. Experts believed that the benefits of self-care exceeded its burden either through a positive outcome ("I'm finding that I enjoy food more knowing that it doesn't have the salt...") or averting a relapse and symptoms ("I haven't been hospitalized for four years").

Family functioning scores were higher in patients who were good or expert in self-care compared to those poor in self-care. Experts, however, had supporters who were engaged in their HF self-care. As one expert explained, when she does not feel well she has difficulty concentrating, remaining alert, and finds herself "making silly mistakes" with her medication. Her daughter observed: "when she's feeling lousy you really need to have somebody else helping to monitor it (medication)." Regarding symptom management, this expert described, "...there's just times when I'm just...I'm a noodle. ...she's doing everything for me. She has to stay home with me." Her daughter elaborated that at those times "... (I need) an outside set of eyes saying well this has gone on for too long of a period of time" and they seek professional help. These data suggest that a key difference between persons merely good at self-care and those truly proficient or expert in HF self-care is having family members and supporters actively engaged to assist them as needed.

## Discussion

This study is an account of how HF self-care proficiency develops and how empirical information is used by patients to shape their decisions. The rich description of the women who had mastered self-care reveals the importance of knowledge, experience, skill and values—key constructs in naturalistic decision making—in helping patients make the links between information provided by clinicians and the self-care decisions made on a daily basis. The fact that so few in this sample had mastered self-care is not surprising, considering how commonly poor self-care is noted in the literature (Artinian, Magnan, Sloan, & Lange, 2002; Riegel & Carlson, 2002).

Others have written about how challenging it is for HF patients to manage a treatment regimen because of multiple comorbid conditions, poor functional status, and age-related changes (De Geest et al., 2004). However, in this study, the experts had more comorbid illness, poorer functional class, and were older than those with less self-care expertise. This finding is consistent with prior research demonstrating that patients who are relatively more symptomatic are better at HF self-care (Rockwell & Riegel, 2001). This finding suggests that perhaps the progression

in HF motivates some patients to attend more closely to self-care to keep their condition stable.

Sleepiness was highest in those poor in self-care, suggesting that excessive daytime sleepiness may decrease learning, decision making, motivation to perform self-care, or a combination of these. This is consistent with research illustrating that when subjects are purposefully deprived of sleep, decrements in sustained attention and concentration, working memory, executive functioning, and decision making are evident (Killgore, Balkin, & Wesensten, 2006). Repeated sleep interruptions and chronic sleep deprivation are common in persons with HF due to nocturia, age, comorbid illnesses, excess body weight, poor exercise patterns, alcohol use, and chronic insomnia (Roth & Drake, 2004). Sleep disordered breathing is one of many causes of excessive daytime sleepiness (Kaneko et al., 2003), and sleep disordered breathing was diagnosed more commonly in those poor in self-care than others. This finding underscores the importance of screening for, diagnosing, and treating sleep disordered breathing in this patient population.

Sociodemographic group differences support prior findings that higher education is not associated necessarily with better self-care (Rockwell & Riegel, 2001). The experts in this study were the least educated overall. They also actively sought information about HF, proficiently communicated with providers, and developed specific routines to manage their symptoms. Those who were poor in self-care had no action plan for maintaining stability or for managing their HF symptoms. The lack of consistency in linking HF symptoms and self-care was a distinguishing feature between those expert and poor in self-care. Prior experience appears to have promoted self-care skill development, consistent with prior research (Franque-Frontiero, Riegel, Bennett, Sheposh, & Carlson, 2002) and the naturalistic decision-making model underlying this study.

Triangulation of the qualitative and quantitative data illustrated the essential nature of support from engaged family members. Experts had better family functioning and an engaged family supporter; those who were poor in self-care had neither. Molloy et al. (2005) note the need for instrumental assistance (e.g., transportation, shopping, housekeeping), but these results suggest that the value of support extends beyond tangible support to true engagement or commitment. It may be that assistance in day-to-day monitoring and managing of symptoms supports the acquisition of knowledge and skills, which are important to HF self-care.

Although the small sample size used in this study was adequate for the qualitative analysis, it limited the use of the quantitative data to description. Another study limitation was enrollment from a single setting in which all the patients were cared for by the same physician. Without variability in providers, it was not possible to identify characteristics of the healthcare system that promote or inhibit the mastery of HF self-care.

Future research is needed to confirm the factors found to be associated with the development of expertise in HF self-care. Intervention research testing the effect of screening and treating sleep disordered breathing, depression, and subtle impairments of cognitive ability is needed to determine if

such an approach can improve HF self-care. Approaches designed to engage family members are especially needed.

In summary, the results of this study support those of prior investigators who have shown that self-care is poor in persons with HF. The fact that only one in 10 HF patients can be expected to master self-care illustrates the importance of finding ways to develop this expertise. ▼

Accepted for publication March 26, 2007.

Funded by program grant no. 30-NR05043, Center for Nursing Outcomes Research, National Institute of Nursing Research, NIH, University of Pennsylvania.

Corresponding author: Barbara Riegel, DNSc, RN, CS, FAAN, School of Nursing, University of Pennsylvania, 420 Guardian Drive, Philadelphia, PA 19104-6096 (e-mail: briegel@nursing.upenn.edu).

## References

- Artinian, N. T., Magnan, M., Sloan, M., & Lange, P. (2002). Self-care behaviors among patients with heart failure. *Heart & Lung, 31*, 161–172.
- Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research, 13*, 871–883.
- Bennett, S. J., Huster, G. A., Baker, S. L., Milgrom, L. B., Kirchgassner, A., Birt, J., et al. (1998). Characterization of the precipitants of hospitalization for heart failure decompensation. *American Journal of Critical Care, 7*, 168–174.
- Bennett, S. J., Sauve, M. J., & Shaw, R. M. (2005). A conceptual model of cognitive deficits in chronic heart failure. *Journal of Nursing Scholarship, 37*, 222–228.
- Carlson, B., Riegel, B., & Moser, D. K. (2001). Self-care abilities of patients with heart failure. *Heart & Lung, 30*, 351–359.
- Cavanaugh, J. C. (1984). Effects of presentation format on adult's retention of television programs. *Experimental Aging Research, 10*, 51–53.
- Charlson, M. E., Pompei, P., Ales, K. L., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of Chronic Diseases, 40*, 373–383.
- De Geest, S., Steeman, E., Leventhal, M. E., Mahrer-Imhof, R., Hengartner-Kopp, B., Conca, A., et al. (2004). Complexity in caring for an ageing heart failure population: Concomitant chronic conditions and age related impairments. *European Journal of Cardiovascular Nursing, 3*, 263–270.
- Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster family assessment device. *Journal of Marital and Family Therapy, 9*, 171–180.
- Franque-Frontiero, L., Riegel, B., Bennett, J., Sheposh, J., & Carlson, B. (2002). Self-care of persons with heart failure: Does experience make a difference? *Clinical Excellence for Nurse Practitioners, 6*, 23–30.
- Gary, R. (2006). Self-care practices in women with diastolic heart failure. *Heart & Lung, 35*, 9–19.
- Gwadry-Sridhar, F. H., Flintoft, V., Lee, D. S., Lee, H., & Guyatt, G. H. (2004). A systematic review and meta-analysis of studies comparing readmission rates and mortality rates in patients with heart failure. *Archives of Internal Medicine, 164*, 2315–2320.
- Hershberger, R., Ni, H., Nauman, D. J., Burgess, D., Toy, W., Wise, K., et al. (2001). Prospective evaluation of an outpatient heart failure management program. *Journal of Cardiac Failure, 7*, 64–74.
- Horowitz, C. R., Rein, S. B., & Leventhal, H. (2004). A story of maladies, misconceptions and mishaps: Effective management of heart failure. *Social Science & Medicine, 58*, 631–643.
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*, 1277–1288.
- Johns, M. W. (1991). A new method for measuring daytime sleepiness: The Epworth sleepiness scale. *Sleep, 14*, 540–545.
- Johns, M. W. (1992). Reliability and factor analysis of the Epworth Sleepiness Scale. *Sleep, 15*, 376–381.
- Johns, M. W. (2000). Sensitivity and specificity of the multiple sleep latency test (MSLT), the maintenance of wakefulness test and the Epworth Sleepiness Scale: Failure of the MSLT as a gold standard. *Journal of Sleep Research, 9*, 5–11.
- Joy, S., Kaplan, E., & Fein, D. (2003). Digit Symbol—Incidental Learning in the WAIS-III: construct validity and clinical significance. *Clinical Neuropsychologist, 17*, 182–194.
- Kaneko, Y., Floras, J. S., Usui, K., Plante, J., Tkacova, R., Kubo, T., et al. (2003). Cardiovascular effects of continuous positive airway pressure in patients with heart failure and obstructive sleep apnea. *New England Journal of Medicine, 348*, 1233–1241.
- Katz, J. N., Chang, L. C., Sangha, O., Fossel, A. H., & Bates, D. W. (1996). Can comorbidity be measured by questionnaire rather than medical record review? *Medical Care, 34*, 73–84.
- Killgore, W. D., Balkin, T. J., & Wesensten, N. J. (2006). Impaired decision making following 49 h of sleep deprivation. *Journal of Sleep Research, 15*, 7–13.
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine, 16*, 606–613.
- Kubo, S. H., Schulman, S., Starling, R. C., Jessup, M., Wentworth, D., & Burkhoff, D. (2004). Development and validation of a patient questionnaire to determine New York Heart Association classification. *Journal of Cardiac Failure, 10*, 228–235.
- Kuslansky, G., Buschke, H., Katz, M., Sliwinski, M., & Lipton, R. B. (2002). Screening for Alzheimer's disease: the memory impairment screen versus the conventional three-word memory test. *Journal of the American Geriatrics Society, 50*, 1086–1091.
- Lipshitz, R., Klein, G., Orasanu, J., & Salas, E. (2001). Taking stock of naturalistic decision making. *Journal of Behavioral Decision Making, 14*, 331–352.
- Maislin, G., Pack, A. I., Kribbs, N. B., Smith, P. L., Schwartz, A. R., Kline, L. R., et al. (1995). A survey screen for prediction of apnea. *Sleep, 18*, 158–166.
- Miller, I. W., Kabacoff, R. I., Epstein, N. B., Bishop, D. S., Keitner, G. I., Baldwin, L. M., et al. (1994). The development of a clinical rating scale for the McMaster model of family functioning. *Family Process, 33*, 53–69.
- Molloy, G. J., Johnston, D. W., & Witham, M. D. (2005). Family caregiving and congestive heart failure. Review and analysis. *European Journal of Heart Failure, 7*, 592–603.
- Moser, D. K., Doering, L. V., & Chung, M. L. (2005). Vulnerabilities of patients recovering from an exacerbation of chronic heart failure. *American Heart Journal, 150*, 984.
- Redeker, N. S., & Stein, S. (2006). Characteristics of sleep in patients with stable heart failure versus a comparison group. *Heart & Lung, 35*, 252–261.
- Riegel, B., & Carlson, B. (2002). Facilitators and barriers to heart failure self-care. *Patient Education and Counseling, 46*, 287–295.
- Riegel, B., & Carlson, B. (2004). Is individual peer support a promising intervention for persons with heart failure? *Journal of Cardiovascular Nursing, 19*, 174–183.
- Riegel, B., Carlson, B., Moser, D. K., Sebern, M., Hicks, F. D., & Roland, V. (2004). Psychometric testing of the self-care of heart failure index. *Journal of Cardiac Failure, 10*, 350–360.

- Riegel, B., Dickson, V. V., Hoke, L., McMahon, J. P., Reis, B. F., & Sayers, S. (2006). A motivational counseling approach to improving heart failure self-care: Mechanisms of effectiveness. *Journal of Cardiovascular Nursing, 21*, 232–241.
- Riegel, B., Goldberg, L., & Weaver, T. E. (2004). How sleepiness influences self-care in persons with heart failure. *Journal of Cardiac Failure, 10*(4, supplement), Abstract 378.
- Rockwell, J. M., & Riegel, B. (2001). Predictors of self-care in persons with heart failure. *Heart & Lung, 30*, 18–25.
- Roth, T., & Drake, C. (2004). Evolution of insomnia: Current status and future direction. *Sleep Medicine, 5*(Suppl. 1), S23–S30.
- Tashakkori, A., & Teddlie, C. A. (2002). *Handbook of mixed methods in social and behavioral research*. Thousand Oaks: Sage.
- Welsh, J. D., Heiser, R. M., Schooler, M. P., Brockopp, D. Y., Parshall, M. B., Cassidy, K. B., et al. (2002). Characteristics and treatment of patients with heart failure in the emergency department. *Journal of Emergency Nursing, 28*, 126–131.
- Wolfe, R., Worrall-Carter, L., Foister, K., Keks, N., & Howe, V. (2006). Assessment of cognitive function in heart failure patients. *European Journal of Cardiovascular Nursing, 5*, 158–164.