

Medication Nonadherence or Self-care? Understanding the Medication Decision-Making Process and Experiences of Older Adults With Heart Failure

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Background: More than half of all patients with heart failure (HF) do not take medications as prescribed, resulting in negative health outcomes. Research has shown that medication adherence may be intentional rather than the ability to follow prescribed regimens, yet very little is known about medication-taking decisions in older patients with HF.

Objective: The purpose of this qualitative study was to gain insight into the decision-making processes and experiences of older patients with HF by exploring the different aspects in choosing to take or not take medications as prescribed in the community setting. **Methods:** Using a narrative inquiry approach, the personal narratives of 11 adults 65 years or older who took at least 2 daily medications for HF were gathered using in-depth, semistructured interviews. The data in this study were organized and analyzed using Riessman's framework for narrative analysis.

Results: Participants made intentional decisions to take particular medications differently than prescribed. A worrisome symptom prompted a naturalistic decision-making process. When a medication interfered with attaining a personal goal, participants coped by individualizing their medication regimen. Participants did not consider taking a medication differently than prescribed as nonadherence but a necessary aspect of maintaining a personal level of health, which could be seen as self-care. **Conclusions:** The older patient with HF should be carefully assessed for nonadherence. The development of interventions that are patient specific, target medications with the greatest potential for nonadherence, and use easy-to-access resources may promote decisions for medication adherence. More research is needed to develop interventions that promote decisions for medication adherence.

KEY WORDS: Medication adherence, Decision-making, Heart failure, Narrative inquiry

The American College of Cardiology and the American Heart Association guidelines recommend medications to reduce morbidity and mortality in patients with heart failure (HF).¹ Although these medications are effective treatments, their full benefits are not attained because approximately half of older adults 65 years or older do not take their HF medications as prescribed; this could result in substantial negative health outcomes.^{2,3}

Medication management in older adults is often more challenging because of multimorbidity, polypharmacy, and cognitive/function decline.⁴ Despite efforts to ensure that patients with HF take their medications as prescribed, individuals have choices about when or whether to take a medication. Although most would agree that unintentional nonadherence (forgetting to take a medication) exists, medication nonadherence to chronic medications is thought to be primarily intentional, involving deliberate decisions to take medications differently than prescribed.^{5,6}

Of the few published studies regarding decision-making in the patient with HF, the majority are in the generalized area of self-care.⁷⁻¹⁰ Although medication taking is considered a self-care activity, there is a lack of research specifically examining medication-taking decisions in those with HF. This study proposed that medication-taking decisions should be investigated as a separate component of self-care for 3 reasons. First, the relationship between clinical HF outcomes and medication adherence is clearly defined in the existing research.¹¹

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Second, adherence to medications is a different behavioral phenomenon than other aspects of self-care (eg, daily weight, smoking cessation, and diet changes).^{12,13} Different from other aspects of self-care, medication-taking behaviors are initiated and driven by a prescription that includes defined actions of filling the prescription, taking doses at specified intervals, and monitoring for good and bad effects. Third, adherence to medications poses unique challenges that may negatively impact the individual, such as cost and medication side effects.² Therefore, future interventions for medication adherence are likely to be different from other self-care adherence interventions. A better understanding about the medication-taking decisions of older patients with HF is needed to give nurses insight into their role in improving medication adherence, inform the development of evidence-based interventions to improve medication management, and improve health outcomes.

The purpose of this qualitative study was to gain understanding and insight into older adults' decision-making processes, experiences, and perceptions by exploring the different aspects in choosing to take or not take HF medications as prescribed in the community setting. The central question of this study was as follows: What are the storied decisions of patients with HF about choosing to take and not take HF medications as prescribed? The specific aims of the study were (a) to identify the role of decision-making in medication adherence, (b) to elicit descriptions regarding how individuals make medication-taking decisions, and (c) to understand what the patient with HF considers medication adherence and medication nonadherence.

Method

Design

Narrative inquiry was used to view explore the different aspects of medication-taking decisions from the patient's point of view. Using a narrative inquiry approach, stories that are lived and told have the capacity to render life experiences in relevant and meaningful ways, offering insight into the reality of the individual.¹⁴ Storytelling is a natural and nonthreatening way for older adult participants to convey their unique experience of making medication-taking decisions. The Naturalistic Decision-Making Model (NDM), a descriptive theoretical framework to explain how people make decisions in real-world contexts, was used to guide this investigation. Theorists of NDM recognize that real-world decisions are intentional, situation specific, and made under conditions of high stakes, uncertainty, and competing goals.¹⁵ The decisions that individuals make do not always adhere to prescriptions, but rather based on past experiences, intuition, and information that is available at the time of the decision even if that information is incomplete

or unreliable.^{9,15,16} The NDM is used in previous research to help explain why individuals make inconsistent decisions about HF self-care^{9,17} and was a good fit for this investigation.

Riessman's narrative inquiry approach was used to develop interview questions.^{14,18} Interview questions were open-ended, storytelling invitations, giving participants the freedom to recount experiences in their own way. Riessman's thematic, structural, and performance analyses were used to systematically evaluate the narrative data, examining not only *what* was said but also *how* and *to whom* a story was told.^{14,18}

Participant Recruitment

Purposive sampling and snowball sampling were used to recruit older community-dwelling adults with personal knowledge of taking daily medications for HF. Potential study participants were identified through advertising to the general public via flyers at 9 institutional review board–approved recruitment sites located in the southwest United States. Recruitment sites included 3 senior adult independent living communities, 2 churches, 2 senior community centers, an indigent care clinic, and a physician's office. The researcher was not a member or affiliated with any of the agencies chosen for participant sampling. Because it was anticipated that a large amount of in-depth data would be collected from each study participant and that data redundancy would be reached, the estimated sample size of this study was 10 to 15 participants. The study was institutional review board approved, and all participants completed informed consent before enrollment. See Table 1 for study inclusion criteria.

Data Collection

This study used in-depth, semistructured interviewing that was conversational in nature. Before the interview, participants completed a self-report demographic questionnaire that was investigator developed. Interviews began with an open-ended question similar to “Tell me the story of when you first started taking medications for your heart.” Subsequent questions included “Describe your daily medication-taking routine” and “Tell

TABLE 1 Inclusion Criteria

1. 65 years or older
2. Take at least 2 daily medications for heart failure (HF)
3. Self-administer daily medications
4. Have experience making a decision to take a HF medication differently than prescribed
5. Live independently in the community setting
6. Speak and read English
7. Have no history of a previous neurological event or other factor that could cause an inability to effectively answer interview questions

me about a time when you chose to take one of your heart medications differently than prescribed.” Participants were encouraged to expand their accounts with probes, such as “tell me more about that.” Interviews were informal, and participants were given the freedom to direct the flow of the dialogue and explore new topics. After each interview, field notes were used to capture observations and reflections. Participants chose interviewing locations that were convenient to them, such as their home or a private meeting room in their living community. Interviews were audio-taped and lasted approximately 60 minutes.

Data Analysis

Different from other qualitative forms of inquiry, the unit for analyses was the complete stories of each case rather than selected component themes across cases. Data transcription was performed by the researcher. Interviews were transcribed verbatim to include pauses, nonlexicals, and emotions of how the narrative was delivered, such as laughing, crying, and tone of voice. After multiple readings, conversation unrelated to the study topic was removed and transcripts were condensed to the essential components of each medication-taking story. Interview transcriptions were evaluated again by story element, identifying the story introduction, problem, plot, climax, resolution, and characters. Stories were compared to discover commonalities in themes and structure.

The NDM was used as the starting point for making decisions about emerging themes and interpreting meaning in the data. Thematic analysis asks, “What is the point to the story?” giving focus to *what* was said. Structural analysis evaluates *how* the story was told and constructed to depict the intended message. Structural analysis asks, “What was the sequence of events?,” “Why were the events configured in that way?,” “Were there gaps and inconsistencies?,” “What characters did the story refer to?” Performance analysis asks *to whom* the story is directed, evaluating the effect of the listener on the told story. Performance analysis asks, “What body language was used?” and “What effect did the listener have on the story?” Through these methods of evaluation, the analysis generated a deeper understanding and insight into the different aspects of medication-taking decisions. The qualitative data analysis software NVivo (released 2016, NVivo Qualitative Data Analysis Software for Windows, Version 11; QSR International Pty Ltd, Doncaster, Victoria, Australia) was used to organize study data and assist with data analysis.

The demographic data collected in this study were analyzed to describe the characteristics of the study sample. The Statistical Package for the Social Sciences (released 2016, IBM SPSS Statistics for Windows, Version 24.0; IBM Corp, Armonk, New York) software

was used to conduct descriptive statistics, including frequencies, means, and percentages.

Sample

Eleven older adults participated in the study. All participants took medication doses at least 2 times per day, and 4 of those reported taking medications 3 or more times each day. Although 10 of the 11 participants described their HF as well controlled, the majority reported recently experiencing 1 or more symptoms of HF. Characteristics of the study sample are presented in Table 2.

Findings

The narrative analysis revealed 5 themes: I don't do it just 'cause the doctor said to, that worried me, connect the dots, how I feel, and I am not nonadherent. These themes illuminated a deeper understanding of the role of decision-making in participants' medication-taking behaviors, the sequence of events in making a medication-taking decision, and what participants considered medication adherence and medication nonadherence. See Tables 3 and 4 for example narratives.

I Don't Do It Just 'Cause the Doctor Said to

The theme “I don't do it just 'cause the doctor said to” describes participants' intentional decisions to take medications differently than prescribed. The theme was captured with the following statement, “Well I listen to them—what they've got to say to start with. How it affects me is the thing. If what they tell me proves to be true then I'll go along with it, but I don't do it just 'cause they said do it.”

Shared in the narratives recounting medication-taking experiences were stories of making a decision to adjust medication doses, skip doses, or stop a medication altogether. Participants reported trusting their doctor but felt they knew their body best and decisions for medication nonadherence were necessary to maintain a personal standard of well-being. Study participants did not describe forgetting medications or taking all medications differently than prescribed. Instead, they told stories of making intentional decisions to stop or adjust particular medications. Example statements include “...those are the only two that I mess with because they affect me the most” and “I take about half a dozen medications and I take them as prescribed, except for the furosemide, which I've cut down to 1 every day rather than 2 every other day and 1 opposite days.” Participants based their medication-taking decisions on physical symptoms (ie, blood pressure, diuresis, bruising) and personal values (ie, enjoying an activity). Some made a 1-time decision to discontinue a medication, whereas others continually adjusted the dose and timing of selected medication(s). Some adjusted their medications

TABLE 2 Participant Demographics (N = 11)

Age, mean (SD, range), y	80.73 (7.39, 69–92)
Gender, male	6 (54.45)
Race, white	11 (100)
Highest level of education	
High school or equivalent	1 (9.1)
College, ≤2 years	2 (18.2)
Bachelor's degree	6 (54.5)
Graduate degree	2 (18.2)
Current marital status	
Married	7 (63.6)
Widowed	2 (18.2)
Divorced	2 (18.2)
Living arrangements	
Live alone	5 (45.4)
With spouse	6 (54.5)
Retired	11 (100)
Annual income (household income if married)	
0–30 000	2 (18.2)
30 001–60 000	2 (18.2)
60 001–80 000	1 (9.1)
80 001–100 000	1 (9.1)
>100 000	4 (36.4)
Do not wish to answer	1 (9.1)
Supplemental drug insurance plan, yes	7 (63.6)
Number of daily medications, mean (SD, range)	11.45 (4.414, 6–17)
Number of participants taking each medication	
Beta-blocker	7 (63.6)
Calcium channel blocker	6 (54.5)
Digoxin	1 (9.1)
ACE inhibitor	5 (45.5)
Angiotension receptor blocker	4 (36.4)
Diuretic	9 (81.8)
Antihyperglycemic	3 (27.3)
Anticoagulant	11 (100)
Thyroid medication	3 (27.3)
Antidysrhythmic	3 (27.3)
Pulmonary medication	3 (27.3)
Nitrate	1 (9.1)
Antidepressant	3 (27.3)
Cholesterol medication	7 (63.6)
Sleeping medication	4 (36.4)

Data are presented as n (%), unless otherwise stated.
Abbreviation: ACE, angiotension-converting enzyme.

so often, they journaled their medication-taking decisions: “I took it today [Lisinopril-hydrochlorothiazide]. That's the reason why I wrote down that I took it... If I don't take this [antihypertensive], I put a line through that too. And the water pill up here—I did not take a water pill today so out here beside it you see where I put my little minus sign.”

That Worried Me

The theme “that worried me” describes participants' uncertainty about a medication. When recounting experiences of medication nonadherence, participants introduced and concluded their story by sharing uncertainty about the safety, need, or reason for a medication.

Participants shared, “I don't know why that [diuretic] was prescribed to begin with” and “I'm so dry in my mouth... Why? Which medication or is it all of them? That bothers me.” Another worried about the bruising and bleeding from her anticoagulant when she stated, “I am wondering, is there a benefit for me to still be on it?”

Worry about a medication was most prominent in stories about the excessive therapeutic effect of diuretics. Each participant worried about dehydration, the number of times they awoke to urinate, and “wetting” themselves in public places. Many participants tracked their fluid intake and output: “I measure. I try to drink the amount of water they tell me to all the time...I count the times when I get up to pee.” It was common for participants to express that the cycle of drinking to quench their thirst and “expelling more water” did not “make sense.” Very often, participants feared they were taking too much diuretic and made routine decisions to adjust their prescribed dose: “But if I'm getting 12.5 water pill because I had to take a Lisinopril then I won't take a whole 40 mg water pill.”

Most participants reported that a nurse or physician was “not easy to contact” or too busy to discuss medication concerns. Participants relied, instead, on information that was available at the moment to inform medication-taking decisions, particularly the Internet for this study sample: “The first thing I do is head for the Internet to find out what they are and what do they do. I know what the doctor told me but I still want to know.” Although participants described the Internet as a “helpful” resource for medication information, finding conflicting information was common. Participants frequently ended stories by expressing a desire for more medication information to support their medication-taking decisions.

Connect the Dots

The theme “connect the dots” describes how participants made medication-taking decisions. Consistent with naturalistic decision-making, an unusual symptom or event triggered concern and prompted a complex decision-making process (see the Figure 1). Participants investigated each medication to connect the symptom to a medication effect. One participant described how she came to a decision to adjust her diuretic:

When I had these occurrences with IBS I think that I feel dehydrated. I figured this is what that pill [diuretic] is for and therefore if I don't take it then I should recover faster. And, I'll go back on it because I have recovered and it makes sense...You connect the dots. This happens, then this (demonstrating 'connecting the dots' with hand gestures)...And then I will be ok. And then I get back on it and here we go again. It is a cycle.

Influenced by past experiences, bodily symptoms, and information that was available at the moment, participants experimented with adjusting or stopping a

TABLE 3 Naturalistic Decision-Making Characteristics and Themes With Example Narrative

Theme	Naturalistic Decision-Making Model Characteristic	Narrative
That worried me	Decisions are preceded by concerning symptom(s) or event(s) and made with incomplete or conflicting information.	"You know I have that dry mouth. It was worse last night than it's ever been and I got to where when I'm up I take a swig of water. Of course that's gonna make me go again but it was so severe it was almost choking me. And when I got my drink, the lining inside my lips and all were sticking together inside my mouth..."
Connect the dots	Decisions are situation specific and influenced by past and present experiences. Consequences of decisions are continually evaluated to inform future decisions. Decisions are made individually or in consultation with others.	"I had got that down to 2 times per night. Now I'm up 6, 8, 10 times per night. That's almost every hour!... I stand up and just wet my pants. It's just awful. But that's the reason I just take half a water pill."
How I feel	Decisions are dynamic and made under the conditions of shifting, poorly defined, or competing goals.	"Now if I'm going to be around home here then I might take the whole water pill. I have my journal here. Over here is my medicines. Over here is how I feel and what I'm doing today... I am very careful about where I go to the bathroom... I did not take a water pill today... I trust the medication but how I feel is going to come first..."
I don't do it just 'cause the doctor said to	Decisions are intentional and lead to purposeful actions. People do not always adhere to algorithms, policies, rules, or prescriptions	"I listen to them [health providers]—what they've got to say to start with. How it affects me is the thing. If what they tell me proves to be true then I'll go along with it but I don't do it just 'cause they said do it... You know your body better than anybody.
I am not nonadherent	Decisions are high-stakes and made to avoid threats or consequences.	You know what works for one person wouldn't work for the other... I got to know why I'm doing something so I can give it my all... If you don't take your medicine then you don't believe in them [health provider] or something? I tell you I don't care what they think. I'm looking out for me. My health comes first to me."

medication and monitored for a change. For instance, 1 participant experimented with an antianginal medication before stopping it completely: "So, I cut it back to 1 in the morning and 1 at night... Then I got to thinking and if I didn't feel too good that day I might take one. So, I'm going to try it and see what happens and I did. I did that 2 or 3 times. But I just finally weaned myself off that." Like many other cases, the decision to stop the medication was supported by reading in a pharmacy flyer and on the Internet that "if you got this and this don't take this medicine."

How I Feel

The theme "how I feel" describes the personal values that participants used to guide their medication-taking decisions. The story element, *conflict* (the challenge that characters encounter in achieving their goals), emerged from the narratives as a power struggle between personal values and treatment/prescriber goals. Influenced by what was perceived as important to them at the time, participants established personal priorities and values in life such as feeling well, uninterrupted sleep, or enjoying an activity.

Frequent in the narratives were statements of "hurrying" to the bathroom and the "embarrassment"

of wetting themselves. "And it's so uncomfortable that you know I am unsure of just wearing underwear—whether I'll be able to make it to the bathroom. I don't have much time." Some participants shared that the effects of a diuretic prevented them from going places. "I've been wanting to get back in church. Well there's no way you can go to church and have to get up every 15 minutes and go pee." Others told of skipping diuretic doses for long car rides, such as doctor's appointments, or on days that a bathroom was not convenient. Many described mobility issues as justification for skipping a diuretic dose on days away from home: "I'm very careful about where I go to the bathroom when I go out because you don't know if you are going to be able to open the door or you got a place to get up off the pot."

Most participants shared frustration about a medication side effect or therapeutic effect, such as diuresis, that made them feel worse instead of better. The flow of the narrative followed participants' thought processes as they grappled with feeling as if they should take their medications as prescribed but struggling to justify the consequences. For example, 1 participant started having problems breathing after starting a new beta-blocker: "It is blood pressure control and I understand it..."

TABLE 4 Naturalistic Decision-Making Characteristics and Themes With Example Narrative 2

Theme	Naturalistic Decision-Making Model Characteristic	Narrative
That worried me	Decisions are preceded by concerning symptom(s) or event(s) and made with incomplete or conflicting information.	"Well one morning I realized that something is wrong."
How I feel	Decisions are dynamic and made under the conditions of shifting, poorly defined, or competing goals.	"I wet myself. I wet myself a couple of times which was very embarrassing. I woke up every morning and discovered that my pajamas were wet. Ok why?"
Connect the dots	Decisions are situation specific and influenced by past and present experiences. Consequences of decisions are continually evaluated to inform future decisions.	"I'm an engineer. One of the first things you learn as an engineer is go find out what the hell is wrong. So, I looked up every one of these. The first thing I do is head for the Internet to find out what they [medications] are and what they do. I know what the doctor told me but I still want to know. I want to see it. I don't trust anything I can't read..."
I don't do it just 'cause the doctor said to	Decisions are intentional and lead to purposeful actions. People do not always adhere to algorithms, policies, rules, or prescriptions Decisions are made individually or in consultation with others.	"So that's when I said, 'Let's cut this one [bladder antispasmodic] out.' I waited 2-3 days to see if that worked and it does. That is a problem. I don't know exactly why that was prescribed to begin with...I put off going to the doctor because he would charge me \$180 bucks to tell me the same thing I knew. So, I went by it [computer] and it works...We lived in a retirement center and cottages. Across the street was a man who had been a scientist. He had education dripping out his ears...He was on medications and we would compare notes. We took a lot of the same meds. The wonderful part of all this was his wife was a retired RN. I had her check everything that I didn't think was quite right." "I may tell them [health providers] I quit taking the pill and why. They may want to know. They may say, 'so what.' That's his problem not mine. For now, I'm satisfied."
I am not nonadherent	Decisions are made to avoid threats or consequences.	

You are panting and struggling to breath and it's not normal...I stopped taking that." In many other cases, participants experienced an unwanted medication effect that caused personal disruptions. One participant complained about the bruising from an anticoagulant: "I want to wear short sleeves. I can't wear shorts." Another shared, "I take a medication that makes you not care about sex...I kinda in a way miss that..."

I Am Not Nonadherent

The theme "I am not nonadherent" describes what participants considered medication adherence and medication nonadherence. Participants indicated in their narratives that they did not view their decisions to adjust a medication dose, adjust their medication regimen, or quit taking a single medication as being nonadherent, but rather logical decisions to maintain a personal level of health. Participants described medication nonadherence as "stupid" and "not very smart." Of note, the same participants who described medication nonadherence as foolish also reported not taking a medication as prescribed. Participants chose to include details in their stories to demonstrate competent decision-making ability, such as their profession as a teacher, engineer, or manager. Nearly all participants spoke about not fully disclosing their medication nonadherence to providers. Many stating, "There is no point" because they were satisfied with

their medication-taking decisions and did not intend to change.

Discussion

Different from other decision-making research in the patient with HF, this study specifically explored the medication-taking decisions of older adults with HF. In this study, medication nonadherence was not a consequence of forgetting to take a medication, nor

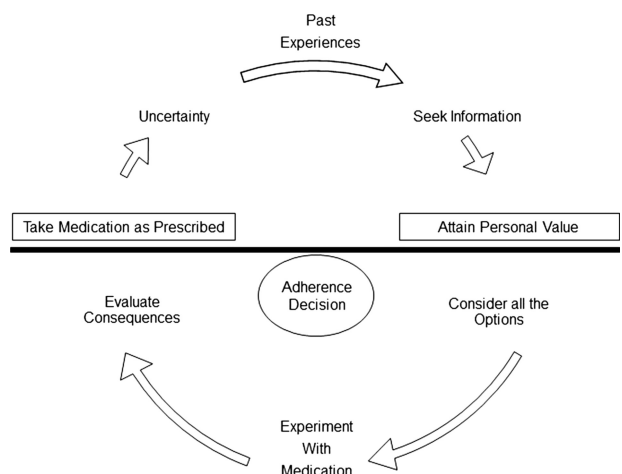


FIGURE 1. Medication adherence decision-making process.

were participants nonadherent to all prescribed medications. This study found that medication nonadherence was the result of intentional decisions to take particular HF medications differently than prescribed. Overall, this finding supports previous studies suggesting that much of medication nonadherence in those taking medications for chronic conditions, including HF, is intentional.^{5,6,17,19,20} The finding that medication-taking decisions are triggered by a concerning symptom or worry about the safety or need of a medication is consistent with those of others who found that patients with HF experience high levels of uncertainty about their symptoms and medications.^{2,6,21}

This study adds to the literature in many ways. First, the findings of this study suggest that when older patients with HF experience a concerning symptom and health providers are not easily accessed, they will seek information from resources that are readily available, such as the Internet. This finding is similar to an investigation by Ekman and colleagues,²² who also reported that patients with HF sought medication-taking information on the Internet when questions were unanswered by professionals. Different from Ekman, this study had a much older study sample, with a mean age of 80.73 versus 60.24 years, suggesting that the Internet should not be disregarded as a resource for older patients' medication-taking decisions.

Adding to previous work regarding medication management strategies in older patients with HF,²⁰ information from the Internet helped these participants feel comfortable taking medication decision-making into their own hands. Because Internet information may be unreliable, informing medication-taking decisions with online information places the patient at risk for medication-taking mistakes and/or poor health outcomes. The convergence of limited provider access and readily available information from the Internet poses a serious phenomenon in modern-day healthcare and should provide direction to the nurse for the development of effective teaching strategies.

Second, the findings from this study add to the body of knowledge about what motivates older patients with HF to take their medications differently than prescribed. Study participants were constantly monitoring their body and had standards for what they considered normal. When something was perceived as unusual, it generated concern at individualized levels. For example, all study participants reported taking anticoagulants, but only 1 described bruising as bothersome enough to spur decisions for routinely adjusting the prescribed dose. Those who took diuretics worried about dehydration, hypotension, and distance from a bathroom. In contrast, participants reported taking medications they did not worry about automatically or without question.

Overall, personal goals, values, and individual standards for comfort were important to medication-taking

decisions, as others have found.^{6,9,20,22} The advantages and the disadvantages of taking a medication differently than prescribed were balanced against what was valued at that time, such as feeling well or uninhibited activity. Participants appraised each medication individually, in that one medication was deemed worth taking as prescribed whereas another was not. Decisions were dynamic, with some participants continually weighing the advantages and disadvantages of a medication and making a different decision each day based on the situation. Participants reported using their own health data to help them understand the consequences of their decisions.

The findings of this study suggest that when a concerning symptom interferes with attaining a personal goal or standard for comfort, patients make a naturalistic and situation-specific medication-taking decision, pointing to previous work regarding the Situation-Specific Theory of HF Self-care.^{9,17} Based on this theory, when the burden of a symptom interfered with attaining a personal goal, participants responded with medication nonadherence, which could be seen as self-care. Although participants in this study believed their medication-taking decisions as beneficial, medication nonadherence as a HF self-care strategy could have serious consequences.¹¹ Based on the results of this study, it is possible that patient-centered interventions that consider the unique circumstances and desires of the individual may promote HF self-care that includes decisions for medication adherence over medication nonadherence.

Perceived negative medication effects were important to medication-taking decisions, even if the effect was therapeutic. Very often, a concern over what was perceived as a negative medication effect stimulated doubt about the medication worth. When participants perceived a medication to be both bothersome and unnecessary, they made the decision to stop it. When a medication was bothersome but believed to have benefits, participants continually adjusted the dose, hoping to gain control over the negative effects of the medication and satisfy a personal value.

This study supports the findings of previous research suggesting that patients are less adherent to medications with perceived negative side effects.^{2,5,21} This study adds to the findings of other research suggesting that compared with other HF medications, patients may find diuretics more bothersome.²³⁻²⁵ Recent research indicates that even small increases in medication adherence in the patient with HF could result in reductions in hospital visits and all-cause mortality.²⁶ Targeting interventions to medications that have the greatest potential for medication nonadherence, such as diuretics, may have far reaching benefits for patients with HF.

Lastly, this study suggests that patients with HF may consider their decisions to take medications differently than prescribed as necessary to maintaining health and

What's New and Important

- When the burden of a symptom interfered with attaining a personal goal, older patients with HF may respond with medication nonadherence, which could be seen as a strategy for HF self-care.
- Information from the Internet helped older patients with HF feel comfortable taking medication decision-making into their own hands.
- Patients with HF may consider their decisions to take medications differently than prescribed as necessary to maintaining a personal level of health and not medication nonadherence.

not medication nonadherence. It was evident in the narratives that participants in this study wanted to be perceived as discerning and making warranted medication-taking decisions, insisting throughout their story that they had a reason for their medication nonadherence and that they are experienced decision-makers. This may help to explain why in this and other studies,²⁰ patients do not fully disclose medication nonadherence to health providers. A critical first step to improving medication adherence is identifying its presence. In clinical practice, assessing medication adherence is typically self-report. Studies have consistently shown that patients tend to overestimate their medication adherence.²⁷ When asking patients if they are taking their medications, a true representation of adherence may depend on how the question is asked and who is asking. Nurses have a significant role in documenting and reconciling medications that patients are taking. This is an opportunity to carefully assess whether the older patient is taking HF medications differently than prescribed.

This narrative qualitative study was strengthened by the systematic evaluation of the narrative data. However, several limitations need to be acknowledged. The experiences described by participants provided insight into decisions, yet their stories were retrospective and may not be free from error or bias. Although widely accepted for narrative research, the small sample size is a limitation. Furthermore, the sample is relatively homogeneous and limited to older adults with HF in 1 region of the United States. Further research is needed to examine medication-taking decisions in patients with HF who are younger or have different demographic variables.

Conclusions

The findings of this narrative study suggest that older patients with HF make intentional decisions to take selected medications differently than prescribed. When a medication interferes with a goal or lifestyle preference, patients may cope by individualizing prescribed medication regimens to try and live as comfortably as possible, which could be seen as self-care. Participants

did not consider taking a medication differently than prescribed as medication nonadherence but rather a necessary aspect of maintaining a personal level of health. Because medication nonadherence can result in poor health outcomes, nurses should carefully assess the older patient with HF for medication nonadherence. The development of interventions that are patient specific, target medications with the greatest potential for medication nonadherence, and use resources that are readily accessible, such as the Internet, may promote decisions for medication adherence and should be the focus of future research.

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