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Medication Management Strategies Used by Older Adults with Heart Failure: A Systems-Based Analysis

Robin S. Mickelson^{1,2}, Richard J. Holden^{3,*}

¹Vanderbilt School of Nursing, Vanderbilt University, Nashville, TN, United States

²Department of Veterans Affairs, Tennessee Valley Healthcare System Nashville, TN

³Department of BioHealth Informatics, Indiana University School of Informatics and Computing, Indianapolis, IN, United States

Abstract

Background: Older adults with heart failure use strategies to cope with the constraining factors impeding successful medication management. Strategies are behavioral adaptations that allow goal achievement despite these constraining conditions. When strategies do not exist, are ineffective or maladaptive, medication performance and health outcomes are at risk. While constraining factors to medication adherence are commonly described in literature, strategies used by patients to manage medication in natural setting are less well-described or understood.

Aim: Guided by cognitive engineering concepts, the aim of this study was to describe and analyze the strategies used by older adults with heart failure to achieve their medication management goals.

Methods: This qualitative descriptive study employed an empirical strategies analysis method to elicit strategies older adults with heart failure use in natural settings to manage medications. Observation and interview data collected from 61 older adults with heart failure and 31 accompanying caregivers were analyzed using qualitative content analysis to derive strategic categories and patterns and themes within and across cases.

Results: Stable and unstable thematic sub-categories derived from the data described proactive, planned, and ad hoc methods of medication management adaptations. Stable strategies proactively addressed constraints by adjusting the medication management process (simplification, consolidation, managing scarce resources), the sociotechnical system environment (offloading task requirements to people, physical space, tools and technologies), or the patient themselves (re-framing mental models). Situational strategies were either planned (rules from providers, previous experience), or ad hoc decision-making (pattern matching, imitation, seeking help, mental simulation) methods of responding to situational constraints. Medication non-adherence was a process adjusting strategy employed when other life goals conflicted with adherence goal. The

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^{*}Corresponding Author: Richard J Holden, PhD, Department of BioHealth Informatics, Indiana University School of Informatics and Computing, Walker Plaza — WK 319, 719 Indiana Avenue, Indianapolis, IN, 46202, United States, Phone: 1 317 278 5323, Fax: 1 317 278 5323, rjholden@iupui.edu.

health system was a source of medication management constraints without providing many strategies to assist patients.

Conclusions: Patients strived to control their medication management system and achieve goals, similar in nature to the work of healthcare professionals. The study of patient medication management could benefit from research methods and theories used in professional work settings – such as strategies analysis. Insights gained from this new perspective can benefit patient performance of medication management and other health-related activities.

Keywords

chronic heart failure; medication management; self-medication; patient strategies; medication adherence; self-care

Introduction

The health—i.e., physical, mental, and social well-being [1]—of older adults with heart failure requires them to manage often complex medication regimens. Many experience problems as research reports 40 to 60% do not take medications as prescribed [2] indicating medication mismanagment is especially high in this population. Multilevel constraints are known to impede the safe and effective use of medications by patients with heart failure. These constraints, or barriers, can be attributes of persons or their surrounding system, as summarized in Table 1 [2–8]. Over time, patients and their informal caregivers develop adaptive methods and strategies to cope with these constraints [9]. When strategies do not exist, are ineffective, or are maladaptive, medication performance and health outcomes are at risk. While extensive current literature addresses patients' constraints, specific strategies used by patients for the safety-critical processes of medication management are less well described and understood.

Constraints and strategies

In systems science and engineering, constraints are obstacles that threaten goal achievement by blocking workflow, or decreasing the effectiveness or increasing the effort required to carry out a goal-directed process [17–19]. Systems models classify constraints as interacting attributes of persons, tasks, tools, and the environment [20, 21]. Constraints can be stable, continual, situational, irregular, and unexpected [22]. For example, the complexity of a medication regimen is a stable and continually present task constraint. Misunderstanding unclear instructions on the label of a new medication is an irregular, unexpected tool constraint. These constraints make reaching a goal 'impossible, difficult, or unsatisfying in light of standards for timely and effective performance' [19]. Successful goal achievement is judged using performance criteria that set the boundaries of acceptable outcomes by a system, team, or individual [23]. Success criteria and goals of the healthcare system, health team, and families may differ from those of the patient.

Strategies are behavioral adaptations that allow goal achievement despite constraining conditions [17–19, 24]. These adaptations can be stable and pre-planned (Figure 1a) or 'in the moment' responses (Figure 1b) to unexpected situations and conditions [17, 19, 25]. Strategies involve short term fixes or long term habits and remove, manipulate, or work

around a constraint [19]. Workarounds involve going outside of a usual, accepted process of goal achievement and increase risk [26].

Medication management in heart failure

Medication management is the most commonly performed self-care behavior of patients with heart failure [27]. Heart failure is a chronic condition affecting primarily older adults and is the leading cause of death among persons with cardiovascular diseases [28]. Heart failure patients' adaptation to medication constraints and strategy development is regarded as a naturalistic decision-making process [9, 29] relying on previous experience, situational factors, and whether self-care goals conflict with personal goals [29].

There is a dearth of research, however, addressing the medication management strategies of patients in response to constraining factors. Harkness et al. [30] identified two categories of strategies for heart failure self-care: perception- and action-based. Swanlund [15] described general strategies used by older adults with cardiovascular disease to administer medications: help from others, cues, simplification, determination, routines, knowledge, education, and alertness. Other research addressed strategies to remember medication administration [31–34]. These studies have provided high-level categories and descriptions but have lacked detail and a theoretical underpinning. We identify a need for detailed, analysis of strategies specifically related to medication management, including how the use of strategies affects patient performance.

This article describes and analyzes the nature of strategies used by older adults with heart failure to manage medications. We adopt cognitive systems engineering concepts to interpret our data [35, 36]. This approach introduces a new way to understand the ubiquitous heart failure self-care phenomena of managing medications.

Methods

This study employs a mixed methods design and an empirical strategies analysis method [24, 37]. This method elicits strategies individuals use in natural settings and describes patterns across cases [24, 37].

Sample and setting

We analyzed data from 61 patients living with heart failure in a larger study of heart failure self-care collected between 2012–2014. Thirty-one informal caregivers also participated during patient interviews by adding comments to patient responses. Patient participants were aged 65, NYHA class II and III (mild to moderate), and lived in a 200-mile radius of a large academic medical center in the Southern USA. Participants fitting inclusion criteria with an upcoming cardiology appointment were contacted by telephone (~ 30% non-participation rate) and informed about the study goals and procedures. Half were recruited from an outpatient cardiology clinic specializing in heart failure. The other half were recruited within 60 days of discharge from a hospital admission for acute heart failure.

Data collection

Data were collected by the authors (PhD-level) and two Masters prepared PhD students representing human factors engineering (RJH), psychology (RJH, AMS), social science (CT), and nursing (RSM). Data were collected through (1) audio-recorded clinic appointment observations with field notes, (2) either a short (30-min) audio-recorded clinic interview with a video-recorded home follow-up (90-min) interview or one extended videorecorded home interview (90–120 minutes), (3) self-administered surveys, (4) photographs extracted from in-home or in-clinic video-recordings, and (5) review of medication lists from the electronic medical record. Interviews made up the bulk of strategy-related data. Scripted interview questions specifically addressed medication processes such as daily administration routines, storing medications, refill management, organizational strategies, and difficulties with adhering to the medication regimen. Patients completed and returned by mail a standardized, self-administered paper survey (n = 58, 95% response rate). The survey assessed cardiovascular health [38] and self-care behavior [39]. A heart failure knowledge scale [40] was completed by patients at the follow-up or extended interview (n=48, 100%response rate). Follow-up interviews took place approximately one week after the initial interview, though not all of patients completed a follow-up. Participants provided consent and received up to \$65 for participation. The Vanderbilt University Institutional Review Board and Human Research Protection Program reviewed and approved the study (IRB #120950). The study conforms with the principles outlined in the Declaration of Helsinki [65]. Detailed descriptions of data collection procedures and instruments are reported elsewhere [41, 42].

Data Analysis

The specific data analysis method was descriptive qualitative content analysis with iterative category development [43]. This method systematically derives trends, patterns, and themes from large amounts of textual data revealing the underlying meaning [44]. It accommodates both deductive (conceptual model-driven) approaches and inductive (data-driven) category development. All interviews were transcribed verbatim and entered into and analyzed in NVivo 10 (QSR International). During first-pass structural coding [45], researchers RSM & RJH identified broad passages of data mentioning medication management in the interviews. During second-pass coding, RSM identified strategies described by participants to manage medications. Patient medication management was defined as the process and related activities required for the optimal use of medications to achieve the maximum health benefits with the minimal harm for a specific patient [46]. Strategies were defined as any method used by a patient or informal caregiver to adapt to medication management constraints to achieve goals [23, 24]. Constraints identified in illustrative instances of strategy use were categorized using the Patient Work System model [3], a systems engineering framework including person(s) (individual or team), task, tool/technology, organizational context, social context, and physical context factors [20, 21]. Sub-categories and cross-cutting themes regarding strategies and constraining factors were derived from the data and informed by concepts from extensive literature review of strategies from medical and non-medical sources [19, 23–25, 32, 47–49]. Authors RSM & RJH achieved analytic agreement regarding themes, subthemes, and core category emergence using regular coding discussions [50, 51].

Results

All patient participants had a diagnosis of heart failure and were managing the disease with medications. Table 2 describes detailed demographic information and selected survey results from the 61 older adult participants. Patients had on average 16.9 medications including prescribed, over the counter, and herbal supplements documented in the medical record. All patients had at least one comorbidity and the majority reported fair to moderate amounts of disability from their disease. Analysis of data revealed four overarching themes: the nature of stable strategies, the nature of unstable strategies, strategies involving non-adherence, and the healthcare system as a source of constraints and potential provider of strategies. Participant age and gender are added to quotes below to differentiate participants.

Theme 1: The nature of stable strategies

Participants developed and proactively used various stable strategies. These strategies became integrated, even automated, into people's routines and were relatively successful under standard conditions. Stable strategies were adaptive responses to consistent constraints such as medication management task difficulty, healthcare system complexity, and a lack of resources (e.g. tools, social support, access to medications). Stable strategies adapted the medication management process, the environment, or the self.

Sub-theme 1a: Strategies adapting medication management process.—A

common strategy (90%, 55/61) was to simplify, reorganize, or otherwise modify the medication management process itself. For example, filling a pillbox could be simplified by marking prescription bottles with pertinent information: 'Do you see on top of those bottles? you've got the BM, that's bedtime and AM... all I have to do is look at the top and... take them out of here and put them in my little container.' ^{80/M} Participants also adjusted medication schedules (67%, 41/61) and synchronized medications into daily events such as meals, waking. Consolidating medication tasks (e.g., the weekly pillbox filling ritual) or precompleting tasks (e.g. preparing medication management: 'I put my medicine out at night, what I'm gonna take the next morning. All I have to do is just get me some water.'^{74/M}

Another process-related adaptation was managing limited medication supplies (49%, 30/61). Some patients borrowed medications from family members, stockpiled unused medications (*'I have a cache'* ^{V025/68/F}), or found alternative supply sources: *'Our druggist we've been there so long now they'll give me two or three pills to get me by till I get my prescription comes in.* ^{'68/F}

Sub-theme 1b: Strategies adapting the sociotechnical environment.—

Participants operated in a *sociotechnical system* or environment, which they often adapted to accomplish goals. These strategies included offloading medication management tasks onto other people (84%, 51/61), physical spaces (57%, 35/61), or tools and technologies (77%. 47/61) in one's environment (Table 3). For instance, patients recruited others' assistance, for example having a spouse track one's medications. Other people were also relied on for information: '[My sister] *has had heart problems for a long time... and she knows all the tricks, all the tricks of the trade.* '^{84/M} Physical spaces were also exploited and often used as

Patients also created tools. For example, a patient made a chart to track administration: *'That was confusing to try to keep everything. Did I take it or didn't I take it? And so, we made a little chart.* ^{'70/M} Medication lists were commonly carried in wallets to communicate the medication regimen across people and settings. Patients also modified existing tools, for example, combining several written logs into one:

'I've got just got a little chart I write it all down on. Cause they gave it to me up in diabetes. But then I've sort of added some things [weight, blood pressure]. Didn't have room, but I sort of added some things to write it down and everything.' ^{70/M}

Sub-theme 1c. Strategies adapting the self—Although less commonly described, multiple patients described adapting themselves by adjusting their attitudes. For example, a patient accepted his frequent trips to the bathroom as a sign that his diuretic was working: '*I know what i s doing, and to me, tha s something good pretty much. And so, it doesn bother me.* 'S010/66/M A previously non-adherent patient became adherent after re-framing the purpose of her medications:

'I'm realizing medication is a form of preparation, you know, and builds your system up to fight off what may come in the future. So, after this last hospitalization I became a little bit more devoted in taking my meds.'^{73/F}

Theme 2: The nature of situational strategies

While stable strategies were adequate for routine conditions, any change or disruption required adaptation. For example, a patient^{S003/81/M} eliminated a step (not consuming a nutritional supplement) from his morning routine and subsequently forget to take his morning medications. A patient^{S004} added a new medication that looked similar to an old medication and confused the two medications. In both cases, the patients experienced a medication-related adverse event. In many other cases, patients developed situational strategies to prevent these disruptions from causing harm. These situational strategies were sometimes planned and used in recurring situations. Other times, these strategies were created ad hoc.

Sub-theme 2a. Planning for the situation.—For expected or recurring situations, many patients (67%, 41/61) had rules-based strategies, allowing them to deploy the specific strategy when a condition was met. The most common examples of this were rules-of-thumb about not 'doubling up' when medications were forgotten or taking an as-needed diuretic upon detecting weight increases: '*Yeah, i s, what, what the doctor's instructions are if, if you gain three pounds, uh, in a short period of time, take a diuretic. Well, I don let it wait that [long].* '^{84/M} Many patients learned these rules from healthcare professionals.

On the other hand, patients also developed situational strategies based on personal experience. For example, patients brought extra medications while on vacation in case they were delayed in returning home: *'You always wonder if you're going to be stranded while you're traveling. I always have a few extra days' supply.* ^{'84/M}

Sub-theme 2b. Responding to the unexpected.—In responding to unexpected and unplanned for situations, patient participants described a variety of spontaneous strategies. Some (25%, 15/61) applied (or misapplied) a strategy from the past to the new situation, as one caregiver described: *T'll tell you what she does when she had, is having a problem breathing- She's got on these menthol cough, cough drops----and sometimes she'll take up to Ten or eleven of them.* 'husband of 65/F In other cases (10%, 6/61), they experimented with strategies they observed from healthcare practitioners, for example, adjusting diuretic dosing:

'I was foolin' around with it [Lasix] trying to say, well, I, I won't bother anybody... I observe and I read and what have you, but, uh, being in the hospital, I can pick up quick... I'm not a dummy... I can pick up things like that.'^{80/M}

Other spontaneous situational strategies were to seek help (48%, 29/61) from family, friends, and healthcare providers: '*I could see that I was getting out of breath and everything so I called my daughter up and I told her.*'^{V005} Yet others avoided a decision or delayed their response (16%, 10/61) until further evaluation: '*I could feel it come on and usually I run around in denial for about four or five days. You know, then finally I say yeah, this, this is, you know, a problem now.*'^{74/M}

The selection of a situational strategy appeared to be a complex process, depending on patients' awareness and interpretation of the situation as well as preferences. For example, concerned that contacting her physician would result in hospitalization, a patient administered twice the dosage of nitroglycerin, citing: *'I did not want to be going to the* [hospital].' ^{65/F}

Theme 3: Strategic non-adherence

Patients sometimes faced situations wherein personal goals conflicted with their or the provider's medication adherence goals. Sometimes (57%, 35/61), patients would implement a strategy to achieve the personal goal, resulting in nonadherence from a medical point of view. Table 4 provides several examples, including cases of patients reducing and skipping doses or self-administering additional doses of medications in response to acute symptoms, perceived medication ineffectiveness, or after consuming salty foods. In some cases, patients were aware of the goal conflict and trade-offs; this patient who skipped diuretic medication to avoid disruptions to personal travel goals was clearly aware of the consequences: 'And when we're traveling I just don't take it [medication]... Well, for several days I can notice edema in my leg. Gain some weight, so I, it's a balance.'⁸¹/M

Patients also described strategic nonadherence events while pursuing goals of comfort or quality of life:

'But my other goal is what I call palliative... it doesn't matter how much diet, how much medication, how much exercise, how much this, that or the other, I am not gonna get through this, I am dying of heart disease. So ... whatever I can do to physically feel better daily whether that means sleeping, whether that means getting up and walking around, whether that means taking a ride out to the Buddhist temple for recre-, whatever, palliative makes me feel better that day.'^{68/M}

Theme 4: The healthcare system as a source of constraints and provider of strategies

Comments from 92% (56/61) of the participants indicated that the healthcare system was often a source of stable and situational constraints. This was due to inadequate informational integration, complex medication regimens, limited access to resources, insurance rules, and high medication costs; some of these constraints being specific to the U.S. healthcare system. Such constraints prompted various, sometimes very effortful strategies:

'I'm real careful with my meds as far as I've got about 4 medications that are on \$4, um, drug list and I get them at Wal-Mart like that, they're not filed through my insurance so that's not accounting toward my doughnut hole [an insurance coverage gap in US federal drug plans for seniors] but so I keep, check to see what I've got that's not you know that is on a \$4 list somewhere, um, the rest of them I get, I get through my, um, regular drug store. But, um, um, I do my research on that.' ^{66/F}

However, the healthcare system seemingly offered few new strategies or assistance implementing existing strategies. Nevertheless, some strategy support was reported by patients (51%, 31/61) in the form of refill reminder calls, mail-order delivery, 90-day refill intervals, secure messaging with providers, and health information access through a patient portal. Many of these supports are also specific to the U.S. healthcare system, but exemplify the value of strategic support at the organizational level. Participants uniformly expressed appreciation for these supports.

Patients also received strategic support from healthcare professionals, though a few patients (8%, 5/61) expressed that this support was minimal. A patient explained: *'There's not a magic list of instructions that they lay out.'*^{74/M} Clinic observations, however, offered several examples of nurse practitioners helping patients adapt their medication management process to their individual context.

Discussion

These results suggest the support of strategic adaptations as an important new priority for research to improve the medication management performance of older adults. There is little research addressing patient strategies, especially the strategies of older adults. More work is needed to expand our understanding of the relationship between patient strategies and health outcomes.

The importance of strategies to medication management performance

In this study, participants often adapted the environment or the task, rather than the self. Participants streamlined task processes and used environmental supports to make medication management easier, quicker, and less effortful. Stable strategies also aimed to improve safety and prevent known errors such as forgetting medications or confusing look-a-like medications.

Other research validates strategies as important elements of successful medication management in older adults. Laboratory research reports cognition declines with age [53], yet work-related performance did not decline in real world settings [54]. Methods used in laboratory research failed to capture compensatory factors such as environment supports and

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strategies used by older adults in real world settings. Improved diabetes treatment adherence was related to the *number of strategies mentioned* in a study by Lippa et al. [55] analyzing the self-management practices of 18 diabetic patients. Other research reports a greater number of medications improved medication adherence [56–58], suggesting increasing complexity necessitates more attention and stronger strategies. A lack of strategies or ineffective strategies may enable medication mismanagement. Improving strategy use by patients is an important focus for practice and future research.

Situational constraints are less easily planned for or anticipated. In this study, some of the resulting situational strategies tested the boundaries of safety. Taking a greater dose of a medication in response to a perceived lack of effect resulted in hospitalization for one participant. Supporting resilience, the ability to adapt and respond to unexpected change, disruptions, and disturbances [59], can guide new interventions and tool and technology design. For example, improving the speed and quality of communication channels between patients and healthcare professionals may reduce the need to make unsafe decisions without provider input. Decision-support tools for patients could also offer support when situations are difficult to interpret and act on. Actions can also be guided by providing patients a repertoire of safe situational strategies in the form of rules and "what to do if" scenarios, as some studies show patients' medication management decisions often follow learned rules [42].

Strategic non-adherence

The results of this study reveal medication management to be a goal-driven process aimed to achieve physical, mental, and social well-being for that patient through the control of a complex system of people, tasks, tools, and environments [66]. In several ways, patients' health work is similar to the work of healthcare professionals; both are goal-driven, share the common goal of improving patient health, and are often constrained by system factors and complex interdependencies that require integration, coordination, and strategic adaptation [19, 61, 62]. Unlike the work of health professionals, however, patient work takes place within the context of everyday life, where conflicting goals commonly impede safe and effective performance.

Work is never performed as described in processes and procedure manuals because constraints and conditions require adaptation [63]. Rather than trying to control behavior with a rigid pre-defined path, parameters of performance made explicit and strategies adapted to keep patient behavior within these parameters would improve safety [64]. In aviation research, air traffic controllers switched strategies and relaxed performance criteria when the number of planes to track increased in number [24]. Similarly, when situational demands of medication management increased (e.g. being away from home, experiencing acute symptoms), patients described relaxing adherence criteria as a strategy. However, patients were not always able to judge 'safe' boundaries of these adaptations.

Healthcare system as a source of strategies

As a major source of constraints, the healthcare system could also offer more tools, technologies, and strategies to support effective and efficient medication management. Many

of sources of strategic support are specific to the U.S. Healthcare system but. Participants appreciated pharmacy tools such as mail-order delivery and automatic refills. They also mentioned the patient portal as a source of information and an easy communication tool. There are many potential areas of improvement when the support of medication management becomes a priority. Participants in this study had difficulty tracking information over time such as medication history or the cost of medications across pharmacies. Crowd-sourcing and social media tools facilitating sharing of strategies between patients could also go far to improve medication management performance.

Limitations

Although ours was a relatively large sample for a study of its kind, it was performed in one region of the U.S. and was limited to older adults with heart failure. Generalizing across conditions, age groups, and geographic locations will require additional studies. Data used for this analysis was gathered from a larger study of heart failure self-care, with only a subset of data collection methods designed to measure medication-related strategies. Infrequently used strategies were not identified, and the situational strategy descriptions were limited. The longterm effects of strategy use were unknown as patients were not followed over time. This could be a valuable topic for future research. Also, descriptive statistics document participants mentioning the specific strategy or constraint. Other participants' medication management may also be constrained by those factors, and they may use strategies they did not mention.

Conclusions

Patients strive to control their system and achieve goals using strategies; they are not simply adherers/non-adherers and followers of directions. As goal directed work, patient work has much in common with professional work than previously assumed, and likely could benefit from the same tools and research methods used in professional work settings. Through the application of an empirical strategies analysis method previously applied to professional work, this study revealed new insights into medication management constraints and strategies. Future applications of these methods can further our understanding how to improve the performance of health activities of patients.

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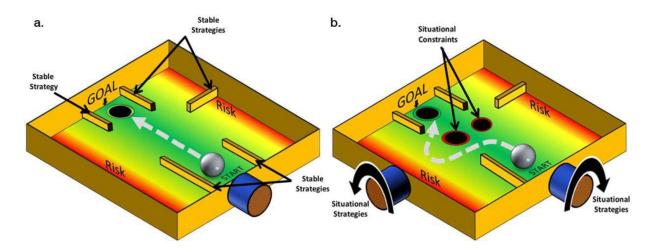


Figure 1. Relationship between Constraints, Strategies, and Goals [67]. (a) Stable Constraints & Strategies (b) Situational Constraints & Strategies

Table 1.

Medication Management Constraints [3–6, 10–16].

Patient

- Sleep quality
- · Coping and emotional response
- Cognitive, physical, perceptual limitations and condition state
- Experience, time since diagnosis
- Multiple comorbidities

Task

- Medication regimen complexity
- Medication effects
- Frequent medication changes
- Conflicting goals

Tool

- Portability
- Accuracy
- Durability
- Usability
- Effectiveness

Organizational environment

- · Living arrangements
- Disruptions
- Financial, healthcare, and family resources
- · Rules, roles, routines
- · Communication channels
- Other workload

Social environment

- Interpersonal influence
- Judgement of others
- Cultural beliefs, norms
- · Social resources and engagement

Physical environment

- · Distance to pharmacy
- Workspace attributes

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Table 2.

Demographics, self-report health status, knowledge, adherence (N=61)

Age, mean (SD, range)	73.31 (6.73, 65–86
Gender Male	31 (51%)
Race White, non-Hispanic	45 (74%)
Annual Household Income (U.S. dollars)	
Less than \$25,000	19 (31%)
\$25,000 to \$49,999	18 (30%)
\$50,000 to \$99,999	14 (23%)
\$100,000 and over	5 (8%)
Did not report	5 (8%)
Education	
Less than high school	9 (15%)
High school	21 (34%)
Some university	13 (21%)
University graduate	18 (30%)
Years since heart failure diagnosis	
Less than 1	14 (23%)
2 to 9	24 (39%)
10 and over	14 (23%)
Not known	9 (15%)
Other medical diagnoses	
Hyperlipidemia (high cholesterol)	50 (82%)
Hypertension (high blood pressure)	55 (90%)
Diabetes Mellitus	37 (60%)
Number of medications, mean (SD, range)	16.9 (5.53, 3–34)
Living arrangements	
Alone	19 (31%)
With spouse	33 (54%)
With sibling	7 (11%)
With adult child/grandchild	2 (4%)
Retired	55 (90%)
Heart failure specific health status $a^{(n=58)}$	
Little to no disability	2 (3%)
Fair amount of disability	29 (50%)
	. /

Severe disability 2 (3%)

Heart failure knowledge ^b (n=47)	
0–9	4 (8%)
10–13	38 (81%)
14–15	5 (11%)
Memory strategies ^C (n=56)	
Use a system to help you remember your medications?	
Rarely	5 (11%)
Sometimes	2 (4%)
Frequently	3 (5%)
Always	46 (82%)
Remember medications ^C (n=56)	
Forget to take one of your medications?	
Always	6 (11%)
Sometimes	12 (21%)
Frequently	0 (0%)

^aKansas City Cardiomyopathy Questionnaire (overall clinical summary scale) [38, 52]

Rarely

38 (68%)

 $b_{\mbox{Dutch}}$ Heart Failure Knowledge Scale, range 0 (low)-15 (high) [40]

^CSelf-care of Heart Failure Index [39]

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Table 3.

Examples of Strategies Leveraging People, Physical Space, and Tools and Technologies in One's Environment.

People		
Outsourcing tasks to family members	'She, she [wife] keeps all my medication up. She knows more about now what I take than I do. I used to take, know what I done, but she keeps it in a little, uh, what do you call those things?' ^{72/M}	
Community assistance	'We have one of our members [church] is a med student so she made that chart for him so that has a lot it's been a, a team effort to keep him, to get him stable.' son of 79/M	
• Pharmacists and healthcare provider assistance	'I think they [physicians and nurses], they keep everything pretty straight for me, you know like the medicine and stuff and if they feel like there needs to be a change or something other they take can of that [send change to pharmacy].' ^{70M}	
Physical Space		
• Home structures to organize medication administration (e.g. cabinets, drawers, tables)	T've got, I've got a, got a little plastic basket I've got all my bottles and meds in, and I've got one for me and one for my husband. ' $^{68/F}$	
• A medication management space proximate to place of administration	'So, in the morning time when I roll over I just keep water right there by the bed because when I roll over, take the shots, then reach back and get the pills and then I can get up.' ^{65/F}	
• Spatial and visual cues indicating an action was completed	'I keep all, it takes ten syringes out of the little bag and I put them in, with the rest of my in-, with my insulin and stuff and if, if I've got an even amount that means I haven't taken the morning one, but if I s-, if later on if I've got an odd amount it means I didn't take that evening medicine.' ^{70/M}	
Tools and Technologies		
• Tools to externalize memory requirements (e.g., medication lists, mobile phone reminders)	'I just always keep a list because I can't remember all that, there's so many of them [medications].' 68/F	
• Tools to evaluate fluid status based on numerical values (e.g., bathroom scales, pulse oximeters)	'The doctor won't tell you to buy one of these [pulse oximeter] Uh, but I used it as a trigger [for diuretic administration], you know. I don't want to go through another thing like I went down in Birmingham.' ^{84/M}	
• Tools to detect and prevent errors (e. g. post-administration checklists, problematic medication lists)	Tve got another list that ha-, that had medications I take and that did have side effects like I'm allergic to penicillin. Then, uh, the Metformin that I used to take for my diabetes, that stuff messed with my kidneys. So, I st-, had to stop taking that. A couple other ones start giving me, uh, make n making my muscles weak. ⁶⁶ M	
• Tools to communicate with providers about refills (e.g. secure messaging).	'When I need a prescription or something I can write in" [through patient portal].' ^{81/M}	
• Tools to acquire medication information (e.g., portal, websites, medication package inserts).	'Well if, if I'm there if I'm at an appointment I, I ask him [provider], otherwise if I have questions I would do it [at] My Health at Vanderbilt.'75/F	
 Tools that facilitate refills, maintaining medication supply 	I can drive to it and I have driven to it, but they, they will automatically deliver it, no problems at all.' $^{68/M}$	

Table 4.

Example task strategies involving non-adherence

Patient Goal	Constraint	Strategy	Example Quote
intensity of medication side-effects	 Frequent waking at night due to increased urine volume Fear of falling Desire for rest 	Reduced the dose of a diuretic before bedtime.	'Half one? So, I don't have to get up so many times. It puts you up about three times if you take a whole one, and if you just take a half one, you don't have to get up about twice.' 76M
	 Increased in urine volume Unavailability of bathroom facilities Difficulty walking 	Spread the medication dose over time.	'I take the Furosemide in the morning usually. Well right now [when away from home] I took part of it and I'll take the rest [later]. Stretching it out seems to work better.' ^{81/M}
	 Perceived negative medication side-effects Difficulty speaking up Desire for autonomy 	Reduced the frequency of administration.	'I have to take it twice a day, it's supposed to be three times, I take it twice a day I couldn't take it 3 times a day because it was making me sick.' ^{65/F}
	 Anxiety about medication effects (kidney damage) Cultural beliefs (distrust of Western medicine) Lack of knowledge 	Administered medications only when symptoms occurred.	⁶ If I'm not swelling, I'm not holding water, and I'm watching my weight on the scales then I don't take it [Lasix]. ^{79M} 'He doesn't take those water pills as often since you told him it will affect his kidney. So, he doesn't take them like every week. ^{* son 79M}
	 Lethargy due to medications Medication task difficulty (insulin management) Recent hypoglycemic events Lack of social support 	Administered twice a day medication once a day to avoid daytime sleepiness.	'We took it upon ourselves to change it where everything she takes that makes you sleepy you take it at night and she's sleeping more at night. ' daughter of 70/F
relief or • La avoidance • Ar • Ar • La • La to c • Pa • Ea • Ea • Ea • Ar	 Acute symptoms Lack of expected effects Anxiety 	Administered an extra dose of a medication.	'So, this morning I took two doses instead of one and still waiting for it to kick in.' $^{74/M}$
	 Acute symptoms Lack of prescribed medication to control symptoms Pain 	Administered a discontinued medication.	'They took my gout medicine away from me and I told (husband), I said you just get that right back and said it out there, I said if you don't want to give it to me I'll take it from myself and so, so I did, because I can feel it coming on.' ^{74,F}
	 Eating high-salt food the previous evening Eating preferences 	Administered a larger dose of a medication.	'It's only when I've been a bad boy and gone out to a Mexican restaurant that I have to take the 60 [mg of Lasix].'
	AnxietyRecent hospitalization	Administered a medication early.	'So, it was so close [to the weight threshold] and it was bothering me so I knew the signs of my congestive heart failure [and took medication early]' ^{67/F}
Avoid social judgement, incontinence	 Perceived ineffective bowel prep Patient history of bowel incontinence Next day colonoscopy 	Administered an extra dose of a medication.	'I got prepped, it, uh, I didn't think I got a good reaction so I doubled up on it and took an extra package of that laxative [resulting in hospitalization].' ^{81/M}
Avoid effects on job performance	 Increased urine volume Time pressure Availability of bathroom facilities 	Omitted multiple doses of a medication.	'So, I didn't want to be, uh, be stopping on the road every fifteen minutes. So, I didn't take it then for several days in a week or two-week time.' ^{67/M}
Preserve financial resources	 Income limitations High cost of medications Family responsibilities 	Omitted multiple doses of a medication.	'I get through down through the money I don't have anything left. So that's why I felt like the tablet wasn't going to be that important to me.' ^{65/F}