

The patient work system: An analysis of self-care performance barriers among elderly heart failure patients and their informal caregivers



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ABSTRACT

Human factors and ergonomics approaches have been successfully applied to study and improve the work performance of healthcare professionals. However, there has been relatively little work in “patient-engaged human factors,” or the application of human factors to the health-related work of patients and other nonprofessionals. This study applied a foundational human factors tool, the systems model, to investigate the barriers to self-care performance among chronically ill elderly patients and their informal (family) caregivers. A Patient Work System model was developed to guide the collection and analysis of interviews, surveys, and observations of patients with heart failure ($n = 30$) and their informal caregivers ($n = 14$). Iterative analyses revealed the nature and prevalence of self-care barriers across components of the Patient Work System. Person-related barriers were common and stemmed from patients’ biomedical conditions, limitations, knowledge deficits, preferences, and perceptions as well as the characteristics of informal caregivers and healthcare professionals. Task barriers were also highly prevalent and included task difficulty, timing, complexity, ambiguity, conflict, and undesirable consequences. Tool barriers were related to both availability and access of tools and technologies and their design, usability, and impact. Context barriers were found across three domains—physical—spatial, social—cultural, and organizational—and multiple “spaces” such as “at home,” “on the go,” and “in the community.” Barriers often stemmed not from single factors but from the interaction of several work system components. Study findings suggest the need to further explore multiple actors, contexts, and interactions in the patient work system during research and intervention design, as well as the need to develop new models and measures for studying patient and family work.

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“[C]linicians are not the only actors in health care; patients also play an important role in their own care ... the patient’s work must be examined in our efforts to reduce errors.” (Unruh and Pratt, 2007, p. S236)

1. Introduction

The healthcare industry undeniably recognizes, even embraces, the human factors/ergonomics (HFE) discipline, its concepts, and

methods (Carayon et al., 2014; Hignett et al., 2013; Russ et al., in press). HFE approaches to safety management, human–computer interaction, teamwork training, and design have become valued tools in international campaigns to improve the safety and quality of healthcare delivery since the turn of the century (Carayon, 2012; Institute of Medicine, 2000; Vincent, 2006; World Health Organization, 2009) and in some cases earlier (Weinger et al., 1994, 1998).

In a recent paper, Holden et al. (2013a) argued that maintaining HFE’s perceived value to an industry depends on the discipline’s ability to support the industry’s evolving practices and priorities. Addressing HFE in healthcare specifically, they and others (Unruh and Pratt, 2007; Vincent and Coulter, 2002) underscored the evolving role of the patient from passive recipient of care to “actor.” The authors accordingly promoted a branch of HFE that they call

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patient-engaged human factors, or the application of human factors theories and principles, methods and tools, analyses, and interventions to study and improve *work done by patients and families*, alone or in concert with healthcare professionals (Holden et al., 2013a; Holden and Mickelson, 2013).

1.1. Studying the patient work system: toward patient-engaged human factors

A majority of HFE applications in healthcare target “professional work,” or “work in which a healthcare professional or team of professionals are the primary agents, with minimal active involvement of patients, family caregivers and other non-professionals” (Holden et al., 2013a, p. 1676). Nevertheless, there are many good examples of HFE applied to the work of unpaid individuals, including patients (Fisk et al., 2009; Lipa et al., 2008; Morrow et al., 2005; Pak and McLaughlin, 2011). This means that there are already HFE models and tools available to support patient-oriented research and interventions but that they need to be better advertised and more widely applied in the healthcare arena. In this paper, we apply one of HFE’s foundational tools, the systems model (Carayon, 2006), to investigate the factors shaping self-care performance among elderly heart failure patients and their informal caregivers.

1.1.1. Self-care in chronic illness and heart failure

Chronic illness is a controllable, but not curable illness lasting more than one year that often limits activities of daily living and requires continuous medical attention (National Center for Health Statistics, 2013). Chronic illness is globally prevalent, especially among the elderly. In the US, 80% of older adults have at least one chronic disease and 50% have two or more, accounting for 75% of healthcare expenditures (Centers for Disease Control, 2009). Annually over half of all deaths in the US are related to chronic illness (Kung et al., 2008). Controlling and managing the symptoms and progression of chronic illness is hardly a task for clinical professionals alone (Bodenheimer et al., 2002) because it depends critically on the performance of recommended self-care behaviors such as medication taking and nutrition management by patients or their informal (lay) caregivers (for an HFE-oriented review, see Mitzner et al. (2013)).

This study focuses on those managing heart failure, a chronic illness described in Table 1. Heart failure is a prevalent, costly, progressive illness characterized by impairment of the pumping or filling functions of the heart. This impairs the delivery of oxygen to the body (causing shortness of breath and fatigue) and limits the body’s ability to expel wastes, particularly water, whose accumulation can cause harm. Multiple self-care activities are recommended to heart failure patients. Adherence is limited, despite the designation of self-care as a Class I recommendation—i.e., having the highest benefit-to-risk ratio—in professional guidelines for managing heart failure (Yancy et al., 2013). Non-adherence is estimated at 40–60% for medication taking, 12–92% for dietary and fluid restriction, 25–88% for daily weighing, and 41–58% for exercise (Moser and Watkins, 2008; van der Wal et al., 2005; Wu et al., 2008). This is problematic because excessive fluid congestion can lead to sudden death and non-adherence is associated with increased mortality and hospitalizations, reduced quality of life, and decline in health status (Ditewig et al., 2010; Jovicic et al., 2006; Lee et al., 2009).

Several studies identify barriers to performing recommended heart failure self-care (McEntee et al., 2009; Oosterom-Calo et al., 2012; Siabani et al., 2013; Zaveritnik, 2014). Most of the studied barriers are patient-related factors such as age, lack of knowledge, and low self-efficacy (Oosterom-Calo et al., 2012). Person-level

Table 1

Heart failure and heart failure self-care.

<p><i>Summary (Remme and Swedberg, 2001; Rich, 2001; Yancy et al., 2013)</i></p> <ul style="list-style-type: none"> • Heart failure is a group of symptoms (breathlessness, fatigue, and/or ankle swelling) that occur when the ability of the heart to eject or fill with blood is impaired. • Caused by heart attack, prolonged uncontrolled hypertension (high blood pressure), and other chronic cardiovascular diseases that progressively change the physical structure of the heart. • Leading and fastest growing cause of death in the US among all cardiovascular diseases. • Also known as chronic heart failure or congestive heart failure. <p><i>Prevalence and costs (Chaudhry et al., 2010; Curtis et al., 2008; Go et al., 2014)</i></p> <ul style="list-style-type: none"> • 5.1 million Americans aged ≥ 20 have heart failure, projected to increase 25% by 2030 • 12% prevalence rate in adults aged ≥ 65; 80% of heart failure patients are aged ≥ 65 • Projected US costs of heart failure: \$32 billion (2013), \$61.4 billion (2020) <p><i>Recommended self-care behaviors (Riegel et al., 2009, 2011; Yancy et al., 2013)</i></p> <ul style="list-style-type: none"> • Medication adherence (scheduled and as needed) • Symptom monitoring, including daily weighing (and appropriate response) • Restriction of dietary sodium intake • Restriction of fluid intake • Smoking cessation, alcohol restriction • Regular exercise (for cardiac fitness) of 30 min or more • Weight loss • Keeping regular appointments, communicating with clinicians

characteristics of the informal caregivers who help co-manage the disease are rarely considered and relatively few studies address barriers associated with healthcare professionals (Siabani et al., 2013). Characteristics of self-care tasks (e.g., treatment complexity, regimen side-effects) and tools (e.g., medication packaging, documentation systems) are less commonly studied but quite pertinent to self-care (Wu et al., 2008). Contextual or “environmental” barriers have been studied with variable regularity and often reveal self-care difficulties due to lacking social, financial, and community resources (e.g., transportation, access to care) (Arbaje et al., 2008; McEntee et al., 2009). The emphasis on barriers related to patient characteristics may explain why so many heart failure self-care interventions involve education, intensified contact with clinicians, or both (Ditewig et al., 2010; Molloy et al., 2012). Interventions focused on redesigning the patient’s work and work system (e.g., beyond educating the patient) are rare and could be promoted by considering self-care from a whole-systems human factors perspective.

Another limitation of the literature on heart failure self-care barriers is the relative shortage of studies with elderly patients (Zaveritnik, 2014). Further, quantitative studies have been limited in scope (i.e., measuring fewer barriers, concurrently) and ability to understand how barriers operate in practice. Qualitative studies, in contrast, have used general probes to elicit a broader range of barriers (e.g., Riegel and Carlson, 2002; van der Wal et al., 2010); however, these rarely probed about specific categories of barriers nor provided reliable information about barrier prevalence. Critically, *no single empirical study has used a systems model to elicit barriers to heart failure self-care*. This is problematic because systematic reviews that have used systems frameworks to synthesize the barriers literature clearly demonstrated that self-care performance is shaped by multiple factors at and above the individual level of analysis (McEntee et al., 2009; Wu et al., 2008). Furthermore, conceptual models of geriatric self-care recognize that self-care is shaped by an interaction of patient characteristics, home and community factors, aspects of the healthcare system, and tool design (Murray et al., 2004). Indeed, applying a human factors framework depicting the entire system in a single study has the added benefit of showing how multiple system factors combine and interact to shape self-care performance (Carayon et al., 2014;

Holden et al., 2013a). Accordingly, heart failure self-care is a fitting target for our present application of a human factors whole-systems model to understand the barriers to patient (and family)-engaged work performance.

1.1.2. Study objectives and conceptual model

This study aimed to apply a systems model to investigate patient work performance and more specifically to use a human factors systems model to understand the nature and prevalence of barriers to self-care performance by elderly heart failure patients and their informal caregivers.

Fig. 1 presents the **Patient Work System** model (PWS), integrating aging-specific (Fisk et al., 2009; Rogers and Fisk, 2010) and healthcare-specific (Holden et al., 2013a; Karsh et al., 2006) human factors systems models. In the PWS, work performance is shaped by four interacting components: Person(s); Tasks; Tools (or Technologies); and Context. Person(s) in the PWS can be patients, healthcare professionals (HCPs), and informal caregivers—individuals who voluntarily carry out or assist patients in health- or disease-related activities. Context factors are ones that exist at higher levels of analysis, including physical–spatial, social–cultural, and organizational characteristics. Performance processes in the model refer to the physical, cognitive, and social–behavioral activities that are aimed at accomplishing a health-related goal or outcome. For patients, these might include purchasing, organizing, and taking medications; gathering information about a disease; communicating with a clinician; or shopping for groceries (Holden et al., 2013a; Karsh et al., 2006).

It is important to go beyond this general model and further specify the nature and definitions of the factors in the PWS for specific patient groups (e.g., elderly heart failure patients) and instances of performance (e.g. self-care). Some have attempted to do so, drawing examples and suggesting definitions based on prior research (Henriksen et al., 2009; Holden et al., 2013a; National Research Council, 2011; Zayas-Cabán and Valdez, 2012). In this study, we applied the general model in Fig. 1 to gather and analyze empirical data from heart failure patients and their caregivers to further develop both the idea of the patient work system and to identify the work system factors specific to heart failure self-care. As a result, this paper produces a refined framework that is comprehensive, conceptually sound, empirically derived, and can

be used across multiple studies. Notably, the framework is inclusive of individual-level and task, tool, and context-level factors, as well as the interactions between these factors. Therefore, when applied to study self-care performance, the framework and its development represent an advance over biomedical studies that have had a narrow focus on the factors shaping self-care (i.e., mostly individual-level ones) and have not used or produced a distinct framework of self-care barriers that can be used across multiple studies.

We note two additional novel aspects of this work. First, the notion of patients performing *work* shaped by a *work system* is not trivial: it represents a different way of thinking about who is involved (patients *and* caregivers), what they do (goal-driven work *not* compliance), the cause of patient outcomes (poor work system design *not* personal failings), and the useful avenues for intervention (whole-systems redesign to support work *not* individual-level reinforcement of knowledge or motivation) (Valdez et al., *in press*). Second, our mixed-method research approach combines thick description with quantification of prevalence, rare in the heart failure self-care literature: one review reports 3% of studies (2/60) using mixed methods versus 82% (49/60) purely quantitative and 22% (13/60) purely qualitative (McEntee et al., 2009).

2. Methods

Data were collected from and about elderly heart failure patients ($N = 30$) and their informal caregivers ($N = 14$) using research interviews, observations, surveys, and medical record review (see Fig. 2). Multiple and mixed methods were used to achieve a triangulated (i.e., multi-source, multi-perspective) understanding of the patient work system (Cresswell and Plano Clark, 2011). Semi-structured interviews and clinic visit transcripts yielded the largest and most useful set of data and therefore were the primary sources for model development, with other data sources used in a complementary fashion. All initial interviews had the same general set of items, augmented with ad hoc probes, while follow-up interviews had some standard items and some questions that were created specifically for that participant, based on their initial interview responses (see Appendix A). In-clinic visit observations were focused on learning the content of self-care related information exchanged between patients, caregivers, and clinicians

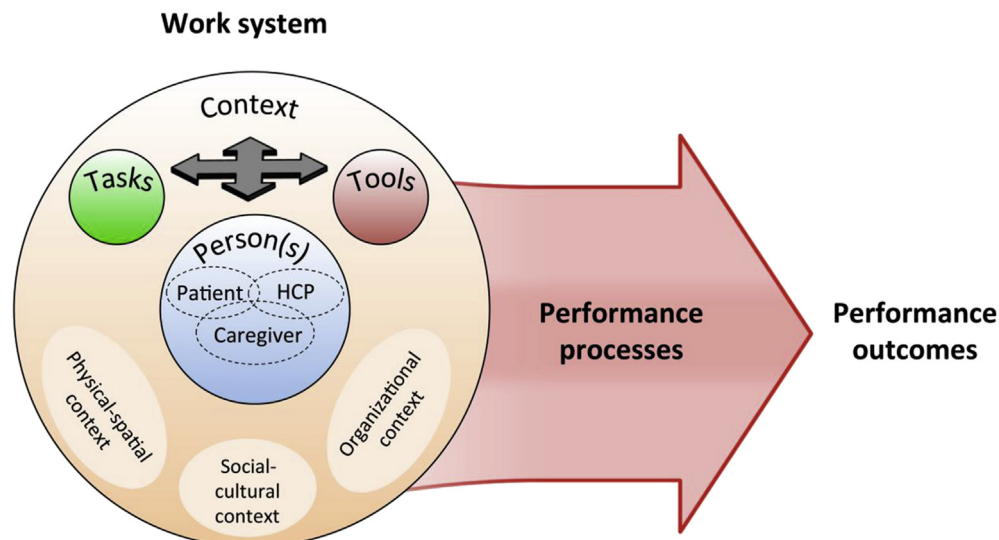


Fig. 1. Patient Work System model (PWS) depicting interactions between person(s), tasks, tools, and context. Person(s) include patients, informal caregivers, and healthcare professionals (HCPs). Context includes physical–spatial, social–cultural, and organizational environments. In combination, the work system factors shape performance processes and outcomes.

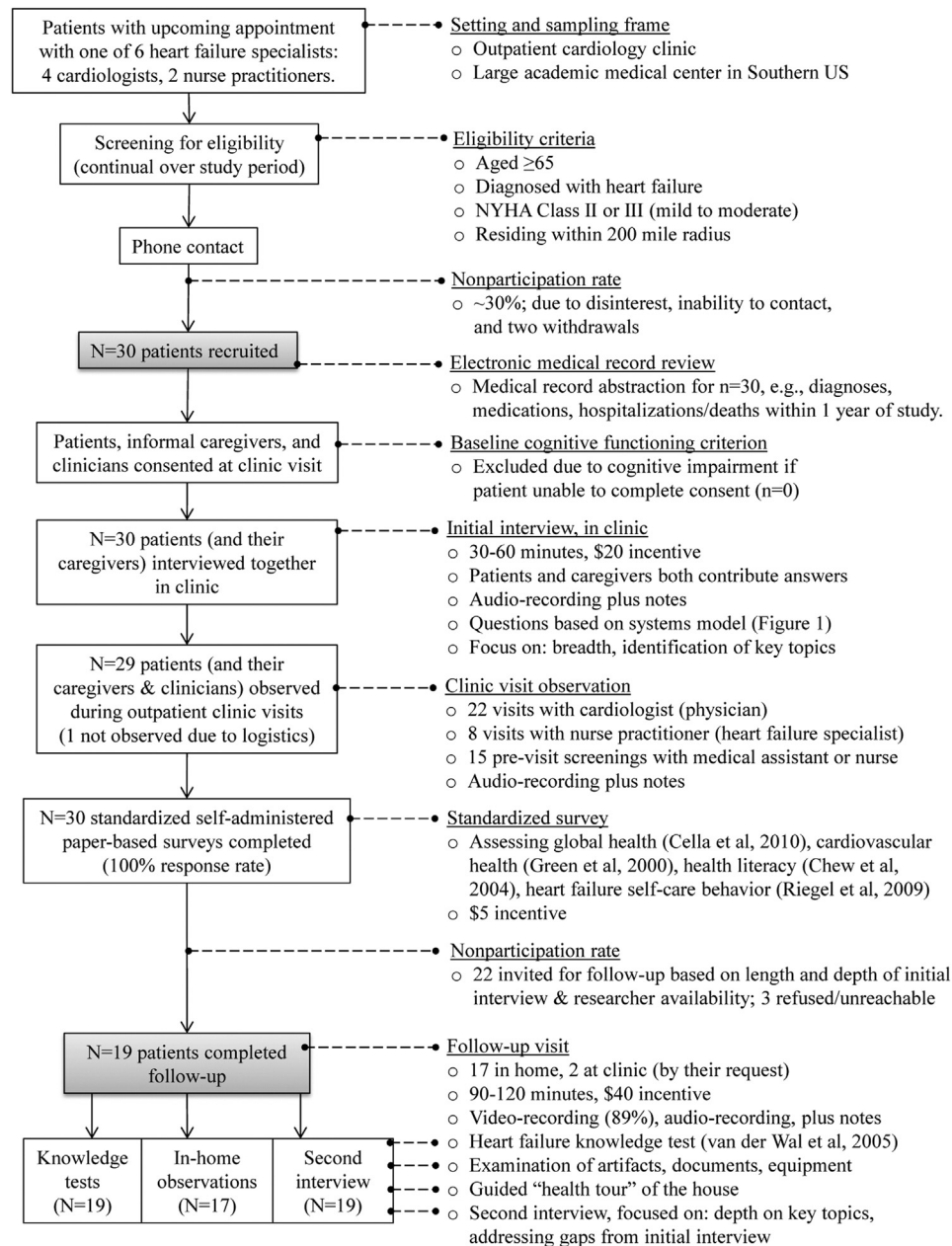


Fig. 2. Flow diagram and details for study recruitment and data collection.

during standard follow-up cardiology clinic visits; observation notes included information not captured in audio-recordings (e.g., physical descriptions) and notes on topics to address in subsequent interviews. One or two researchers stood in the corner of the clinic room and made unobtrusive recordings. Surveys were handed to participants in-person. Most completed these at home and them mailed back, although a small number of participants completed them during breaks in the first clinic visit. Patients could request help from others in completing the surveys, if they needed it. Knowledge tests were completed in front of the researcher during the follow-up interview.

Data collection for each participant spanned on average one month, permitting: findings about changes; concurrent analysis; and exploration of key themes across encounters (Creswell, 2013). In particular, while initial interviews were used to cover a large range of topics and to identify those that were particularly important, follow-up interviews were able to focus on changes since the

last interview, filling in any topics that were not yet covered, and probing deeper into topics of particular importance for that participant. Data collection spanned September 2012–March 2013. The Vanderbilt University Institutional Review Board (IRB) approved the study.

Professionally transcribed data files were entered into and analyzed in NVivo 10 (QSR International). Additional observation notes were added to the NVivo files, while surveys and medical record data were separately reviewed and integrated into the analysis. The goals of data analysis were to identify and describe barriers across the patient work system (Fig. 1). Barriers were defined as "any work system property or condition that makes it impossible, difficult, or unsatisfying to perform self-care work in a timely and effective way" (adapted from Holden et al. (2008, 2013a,b)). Barriers could be directly reported by participants or inferred from data. For each barrier category, we calculated the percent mentioning a barrier in that category as well as the number

Table 2
Stepwise, iterative, and model-based data analysis process.

Step 1. Orientation to data	
•	Analysts read transcripts, gain familiarity with data, note key cross-cutting themes.
Step 2. Preliminary analytic model development	
•	Lead author develops initial coding framework identical to that depicted in Fig. 1, creates coding book with taxonomy, definitions, examples, and instructions.
•	Other analysts trained on model and coding book over multiple sessions.
Step 3. Preliminary coding	
•	Lead author analyzes subset of data ($n = 15$ initial interviews), assigning one or more codes from broad systems model categories to each segment of data depicting a barrier. Lead author takes extensive notes on data content and coding challenges.
Step 4. Further analytic model refinement	
•	Lead author divides data coded in broad systems model categories into sub-categories based on observed patterns in the data, updates coding book accordingly. Minor refinement occurs on an ongoing basis including re-definitions, splitting, and merging of categories and subcategories.
Step 5. Final coding of full data set	
•	Data divided among lead author and other two analysts in 2:1:1 proportion; each analyst responsible for full orientation to and coding of own data set (see text regarding multiple analyst convergence).
•	Full data set ($N = 30$), including $n = 15$ initial interviews from preliminary coding, are (re)coded by analysts using refined analytic model, including subcategories developed for initial model (Fig. 1).
•	Rereading and re-coding occur iteratively to fix prior coding.
•	After final coding discussion, all coding is reviewed and finalized; analysts do final spot check.
Step 6. Barrier category description and quantification	
•	Broad categories and subcategories of barriers are divided among analysts, with each analyst reviewing all coded passages in their assigned (sub)categories to yield summary text.
•	Each analyst calculates barrier prevalence for assigned (sub)categories, using primarily interview and observation data.
•	Observation notes, medical record data, survey responses, and other collected data are reviewed and integrated into analysis of each related barrier (sub) category (e.g., knowledge test scores under person-knowledge, photograph of paper artifacts under tools). These are used in a secondary way, to support and add extra detail to interview data, not to identify new barriers.

of references to that barrier category, defined as nonduplicative mentions of a barriers within that category across all participants. Distinct barriers in the same category (e.g., trouble hearing, trouble seeing) described by a single participant were each counted as references. However, an attempt was made to avoid counting multiple references to the exact same barrier for a given participant. Any additional information provided about a given barrier was added to sub-codes created specifically to house additional content but not double-counted.¹ Patients and caregivers rarely openly disagreed about substantive content, though caregivers sometimes mentioned barriers that patients did not.

Table 2 further describes the analysis process. Analysts assigned and reassigned codes to segments of data judged as identifying a barrier (Miles et al., 2014). A stepwise analytic process was used, with earlier steps focused on identifying and broadly coding barriers, while later steps focused on further developing the conceptual model, identifying patterns, and then returning to the original data to revise the coding (Saldaña, 2013). Our data was the primary driver for decision making about how to define and group barrier subcategories, but existing work system models (Boehm-Davis, 2005; Fisk et al., 2009; Holden et al., 2013a; National Research

¹ Some participants did indeed mention the same barrier several times, judged in many cases to be a sign of the importance or severity of the barrier. A separate analysis could be conducted to identify those barriers mentioned several times by participants.

Table 3
Patient ($N = 30$) demographics and self-reported self-care adherence.

Age	$M = 74.0$ (SD = 6.5) (range 65–86)
Gender	17 male/13 female (57%/43%)
Race ^a	18 White non-Hispanic (60%), 10 Black (33%), 2 Mixed-race (7%)
Education	10 (33%) completing 12 years, 11 (37%) >12 years, 9 (30%) <12 years
Household income ^b	7 (25%) ≤ \$15,000, 15 (53%) ≤ \$25,000, 21 (75%) ≤ \$50,000 (annual)
Marital status	16 (53%) married, 7 (23%) widowed, 5 (17%) separated or divorced, 2 (7%) single
Years diagnosed with heart failure ^b	$M = 6.84$ (SD = 5.5) (range 1 month–17 years)
Employment ^b	26 (87%) retired, 3 (10%) disabled/unable to work, 1 (3%) part-time
Insurance ^b	100% Medicare, 17% Medicaid, 10% military, 87% private supplement
Self-reported global health	Physical health: 33% “very good,” 50% “good,” 7% “fair,” 0% “poor” Mental health: 7% “very good,” 47% “good,” 27% “fair,” 20% “poor” Quality of life: 20% “very good,” 43% “good,” 20% “fair,” 10% “poor”
Heart failure type	9 (30%) systolic, 13 (43%) diastolic, 8 (27%) systolic/diastolic
Heart failure severity ^{b,c}	NYHA Class: 11 (37%) II or “mild,” 18 (60%) III or “mild/moderate” BNP: $M = 465.1$, SD = 552.8
Comorbidities	80% hyperlipidemia, 83% hypertension, 53% diabetes mellitus
Health literacy	47% get help reading hospital materials “all of the time” 57% with problems understanding written medical information “all the time”
Hospitalization/death ^b	23% hospitalized ≤30 days prior to enrollment (30% 60 days prior) 20% hospitalized ≤30 days after enrollment (30% 60 days after) 6 deaths (20%) and 54 total ED/hospital events within 1 year of enrollment
Informal caregivers	14 consented to participate: 6 spouses, 8 adult children
Patients' self-reported self-care adherence	31% sometimes forget to take medicine 17% do not weigh daily; 48% do not check ankles for swelling daily 30% report no/rare 30 min of exercise; 10% report no exercise 43% do not avoid dietary sodium on daily basis; 40% never/rarely ask for low-sodium items when eating out or with others

^a Compared to 81% White patients in hospital's volunteer registry.

^b If known.

^c NYHA Class = New York Heart Association functional classification (Class II is “mild,” with slight physical limitation and symptoms from ordinary exertion; Class III is “moderate” with marked physical limitation and symptoms from less than ordinary exertion); BNP = B-type Natriuretic Peptide, a biomarker for heart failure with higher values indicate progressing illness.

Council, 2011) were consulted when data were insufficient to guide those decisions.

Three researchers carried out data analysis: the lead author and two (Master's and PhD-level) co-authors. They represented diverse disciplines: human factors engineering and psychology (RJH), social science (CCS), and nursing (RSM). Several actions were taken to ensure convergence between analysts. First, the lead author trained the other analysts. Multiple pre-analysis readings and exercises were used to establish common theoretical grounding. Second, the lead researcher was present at most initial (60%) and follow-up (87%) interviews and observations and involved other researchers in 14 “tandem” interviews for convergence purposes. Third, during analysis, the lead author provided overall direction, took ultimate responsibility for analysis, possessed executive decision-making

authority, coded the largest subset of data, and conducted periodic and final spot checks of analyses.

Finally, all analysts participated in four Coding Discussions, involving the intermittent review of (a) coding categories and definitions, (b) examples of coded content for each category, (c) difficult-to-code cases, (d) coding discrepancies, and (e) coding strategies/techniques. Unlike post hoc inter-rater reliability measures, coding discussions are a proven technique for *facilitating*, as opposed to simply measuring, analytic convergence (Barbour, 2001; Berends and Johnston, 2005). Prior to the first coding discussion, each analyst independently coded data from three participants; the discussion then focused on comparing the lead's coding to that of the other two analysts, with correction of both and the updating of the coding scheme and definitions. For the second and third discussion, each analyst independently coded a new set of data and discussion focused on refining problematic definitions, coding anomalous or ambiguous passages, combining or splitting coding subcategories, and updating the coding book accordingly. The final discussion focused on review of coding categories used with relatively high or low frequency, fine-tuning of definitions, and other real-time minor adjustment. Finally, each analyst reviewed their coding to comply with analytic decisions made at the final coding discussion. Between discussion sessions, analysts consulted with one another on an ad hoc basis.

3. Results

Table 3 reports the demographic characteristics of patient participants and their self-reported self-care adherence.²

Data about barriers are presented in the text below. Percentages in parentheses refer to barrier prevalence among the 30 patients (caregiver-reported barriers are associated with their respective patient). Tables 4–7 list major barrier categories, their prevalence and definitions, and provide longer, illustrative quotes for each. When reporting quotes, we provide sub-scripted patient identifiers using an AGE/SEX/RACE format, with race designations of White (Wh), Black (Bl), and Mixed (Mix). Thus, a 66-year old black female is _{66/F/Bl}.

3.1. Person barriers – patient (Table 4)

Person-patient barriers arose from relatively stable characteristic of the patient. These were found for all patient participants, with an average 46.9 references per patient.

3.1.1. Demographic characteristics

Patients self-reported *age* (56%) and *genetics* (20%) as explanations for their conditions and limited self-care ability. Age was commonly given as a reason to discontinue exercise or indulge (“I'm 73 years old and I don't plan to deprive myself too much of anything”_{73/F/Bl}).

3.1.2. Biomedical characteristics

Many described *heart failure symptoms* that were barriers to self-care insofar as fatigue (67%) and shortness-of-breath (67%) impeded physical performance (exercise, shopping, cooking), sleeping difficulties (30%) impeded cognitive tasks (medication management), and nausea or lack of appetite (27%) impeded nutrition. In sixteen (54%), those symptoms had worsened over

time and many experienced *cardiovascular events* such as acute fluid overload (50%), coronary bypass surgery (40%), stent and angioplasty procedures (27%), and pacemaker insertions (40%). These, as well as *other medical events* (mentioned by 73%) such as infections (27%), resulted in disrupted routines and worsening self-care ability. Twenty-five (83%) mentioned *chronic comorbidities* such as diabetes (37%) or arthritis (27%) interfering with heart failure self-care (see also Table 3). For example, one patient described heart failure exacerbations from consuming extra liquids to treat a urinary tract infection: “I ended up having blood in the urine ... they say drink lots of water ... [as a result] I couldn't breathe and I mean I had a heck of a time. So you're damned if you do and you're damned if you don't.”_{74/M/Wh}

3.1.3. Mood and mental health

The majority of mood and mental health barriers involved *fear, anxiety, stress, and worry* about the future state of their disease and its effect on their lives (40%) (e.g., “having heart failure, it's real scary ... life seem like it's gonna shut down for you,”_{65/F/Bl}). *Feeling down and depressed* (23%) influenced motivation to engage in self-care activities (“I just don't feel like doing anything,”_{72/F/Bl}). Patients expressed *frustration* (27%) about limitations imposed by the disease, and the continuous demands of self-care. Medical record review revealed several participants were prescribed antidepressant or antianxiety medications (see also Table 3).

3.1.4. Personal limitations

The most commonly mentioned barrier-producing limitations were *functional* (93%), predominantly difficulty walking (63%), standing (37%), and getting up from a chair or out of bed (27%). Loss of functional abilities required dependence on caregivers (e.g., “[spouse] does everything for me, except breathe. I wished he could take over that,”_{74/F/Wh}). *Physical limitations* (67%) included lack of stamina and strength (37%) and limitations resulting from musculoskeletal injury or disease process (30%). *Cognitive-perceptual limitations* were commonly described (73%) and primarily involved memory problems (53%) and the inability to concentrate and comprehend information (17%). One patient described her difficulty remembering medications when going out, “I'll forget to bring 'em with me... I'll forget 'em when I get home. I just go to sleep and forgetting about the night pills.”_{74/F/Bl} Vision and hearing limitations (27%) were described as barriers to receiving and processing medical information.

3.1.5. Knowledge

Patients' *knowledge about heart failure self-care* was the most frequent knowledge barrier (87 references over 24 (80%) participants). Sixteen (53%) indicated a knowledge gap about how to comply with dietary restrictions. Several believed that not adding table salt to food would eliminate dietary sodium intake and one described drinking lots of water to “wash away”_{74/F/Bl} sodium after consuming fast food. In interviews, eight (27%) demonstrated limited understanding of fluid restriction. Of the 19 completing a standardized knowledge test, seven (37%) could not select from three choices the recommended daily fluid intake; four responded that one should drink “as much fluid as possible.” Further, 21% taking the knowledge test did not know that they should weigh daily and 21% did not correctly endorse the statement that a sudden increase in weight (>5 lbs over 2–3 days) warrants contacting a clinician.

Participants also lacked *disease and symptom knowledge* (78 references over 23 (77%) participants). Over a third (37%) who took the knowledge test could not select among three options the correct definition of heart failure. In interviews, a larger proportion (53%) indicated that they were not able to recognize heart failure symptoms or if they did, were unaware of the symptoms'

² We compared the age, sex, and race of the 30 participants to those of 15 screened and eligible nonparticipants who were not contacted due to a scheduling conflict ($n = 10$) or declined participation or could not be reached ($n = 5$). Age, sex, and race did not significantly differ between the two groups, as tested by *t*-test and chi-square test (p 's ≥ 0.05).

Table 4

Person barriers, their prevalence and definitions, and illustrative quotes.

Demographic characteristics (41 references over 63% of participants)

Individual qualities representing membership to segments of the population (e.g., age, race, sex).

- “I’m putting it on old age since I’m seventy-four ... I’m forgetting to take my medicine. I’m running out of my medicine. My medicine one place and I’m another. And I’m forgetting to take my medicine ... I’m forgetting to drink the water ...”^{74/F/BI}

Biomedical characteristics (440 references over 100% of participants)

States and events related to health, disease, and medical condition.

- “She’s tired ... but it’s been kind of just gradually (progressing).”^{husband of 74/F/Wh}
- “Doctor also uh explained to me that what was wrong with me physically uh was actually fairly minor things and not unexpected at my age. Um it’s just your cumulative effect of all of them coming together.”^{81/M/Wh}

Mood and mental health (70 references over 68% of participants)

Problems of psychological or emotional well-being, including depression, anxiety, and negative emotion.

- “I used to play with my little dog, but he died on me. So now I just go to sleep and take me a nap and, and then I watch television.”^{80/M/Mix}
- “I get a little down sometimes and I have to get back, pull my, I have to pull myself back out of that because I know I’m only hurting myself.”^{67/F/Wh}

Limitations (87 references over 100% of participants)

Stable constraints on functional, physical, and cognitive-perceptual ability.

- “The doctors want me to walk around. I just can’t do it. And occasionally lately if I am sitting in the chair and I want to get up and do something I, I just don’t, just can’t get out of the chair.”^{85/F/Wh}

Knowledge (240 references over 100% of participants)

Gaps in awareness or familiarity with the precepts of heart failure disease and related self-care.

- “I know my feet would swell quite a bit and I just thought it was hot weather. You know, when hot weather comes feet swell.”^{80/F/BI} [did not recognize symptom of heart failure]
- “I don’t ever reach for the salt shaker, you know, so I don’t know where I’m getting all this salt at.”^{74/F/Wh} [did not understand sources of dietary sodium besides table salt]
- “Do you ever get off the medications for that or will I be taking this the rest of my life to keep me alive?”^{74/M/BI} [did not understand chronic, incurable, and progressive nature of disease]

Motivation (20 references over 47% of participants)

Lack of initial or sustained drive to accomplish general or specific goals.

- “So I can go anytime ... I mean, I don’t wanna fight it no longer, you know I’m just, I know a lot, a lot of people have put up with this problem for longer you know ... but I told [my cardiologist] if I’m in a bad shape and you see that I’m getting my last breath, I said let me go on.”^{74/F/Wh}
- “When I go to sleep at night, I think about tomorrow I’m going to walk around the block [for exercise]. But tomorrow comes and goes and I’m still saying the same thing. I just haven’t gotten the motivation to do it.”^{85/F/Wh}

Personal preferences and habits (142 references over 87% of participants)

Relatively stable and familiar personal preferences and tendencies developed and routinized over time.

- “I do not per se get up and put on the sneakers and go out for a walk. I have to have a destination and want a reason.”^{66/M/Wh}
- “I’m not supposed to have no pork, but I’ve been eating pork all my life. And sometimes it’s hard to just break habits, you know, like stuff like that.”^{74/M/B}
- “I do love Spam, Lord mercy, I could eat a whole can of Spam.”^{74/F/Wh}

Perceptions and attitudes (131 references over 93% of participants)

Specific beliefs and general evaluations of health, disease, self-care, treatment, others, and oneself.

- “I don’t like to talk about it [heart failure]. I don’t like hearing about it all day.”^{65/M/BI}
- “So, what I have to do, I have to, um, weigh myself every day, right? I have to write it down, but I don’t write it down. I know how much I weigh.”^{79/M/Mix}
- “What’s the sense of living if I can’t at least enjoy?”^{66/M/Wh}

Informal caregiver characteristics (41 references over 63% of participants)

Characteristics (e.g., availability, limitations, knowledge) or behaviors of informal caregivers.

- “I’m not with her every day and that’s probably one of the things we’re trying hard to get now a sitter because I work and most of us [in the family] do;”^{1st daughter of 82/F/BI}
“... everybody’s working together on this and, um, there don’t seem to be a problem. So, we’re, we’re getting there somehow, but, uh, it’s tiring, you know, we’re all doing our part, and my husband is working with me, he’s taking care of our home ... It’s hard, you know, uh, I never knew it would be this hard, but it’s hard. It’s hard.”^{2nd daughter of 82/F/BI}

Healthcare professional characteristics (48 references over 73% of participants)

Characteristics (e.g., availability, ability) or behaviors of informal caregivers.

- “You can’t reach a doctor when you call. I mean you reach an operator who may get you to a nurse.”^{81/M/Wh}

relationship to their illness. For instance, one participant readily described having heart failure symptoms of fatigue and shortness-of-breath that he attributed to problems with his back, stating “my heart is just fine.”^{79/M/Mix} Several references to knowledge barriers were medication-related, including 37% not understanding the purpose of their medications and 30% voicing uncertainty about medication colors and names, dosage, timing, and refills. Among a majority (53%) of participants, we discovered deficits in

sensemaking and problem solving, meaning that in novel situations such as experiencing new symptoms, participants struggled to make sense of what was happening and how to act.

3.1.6. Motivation

Some individuals expressed a *general lack of motivation*, including difficulty getting out of bed in the morning (17%), no interest in life (13%), and resignation to their illness (10%). Specific

Table 5
Task barriers, their prevalence and definitions, and illustrative quotes.

<p>Task difficulty (151 references over 93% of participants) Real or perceived excessive load demands or quantities of tasks or sub-tasks, relative to one's resources.</p> <ul style="list-style-type: none"> • “Quite honestly, just standing there getting the pills out of the bottle is hard.”^{85/F/Wh} • “Okay. In the morning I ... take Diovan 3 times a week, just Monday, Wednesday and Friday, so you see, that's kind of, okay, like Monday, Wednesdays and Fridays I take, I take my heart pill, I take my fluid pill, which is 3, I take bowel softeners, 4, uh, a half of a Spironolactone, uh, it's for my heart, it's good for your broken heart. Uh, I take, uh, um, (3 s pause) Allopurinol for my gout. And then I have a baby aspirin. How many's that? (4 s pause) (Interviewer: Six. Five.) Five? Then I take, see, see, I need a pencil.”^{67/F/Wh} • “[The] doctor's appointments has been a lot ... cause they got to take me back and forth to the doctor ... And you can't get organized like that.”^{74/F/BI} <p>Task timing (42 references over 60% of participants) Frequency, periodicity, ubiquity, duration, or presence of delays in a performed or recommended task.</p> <ul style="list-style-type: none"> • “Taking medications at the right time is something a lot of seniors have trouble with.”^{81/M/Wh} • “The druggist said I had three days I had to wait to get [my prescriptions] filled.”^{80/M/Mix} • “[Daughter] went to the store and it took about 6 hours [just reading nutrition labels].”^{70/F/Wh} <p>Task complexity (122 references over 90% of participants) Heterogeneity or variability, task turbulence (e.g., frequent changes), and need for precision in a task.</p> <ul style="list-style-type: none"> • Excerpt of patient's (P)^{65/M/BI} clinic visit with cardiologist (MD), about recent heart attack P: Okay. I have another question. They gave me some Nitro tablets, okay, now if, if this come up again do I take those Nitro tablets– MD: Yes. (P: –and go up to the emergency?) Yes. P: I don't take aspirin? MD: You can take aspirin too. Aspirin's good ... aspirin helps the blood clotting problem. So normally we would say, so are you taking an aspirin every day? (P: Yeah) Okay. So, but for the acute treatment of discomfort in your chest or your jaw the Nitroglycerin is the right way to go. P: How many do I take? MD: Well you can take up to 3 separated by 5 min and if your discomfort is not totally gone then you have, you know unfortunately you have to go the emergency room. P: (3 s pause) Oh, if the Nitroglycerin tablet takes care of discomfort– MD: If it takes care of, yeah, it takes care of it– P: –I don't have to come. MD: –it's gone, you don't have to come, but it has to be gone, not better, but gone. P: Okay. Now how many tablets do, how many of those low dose Aspirin do I take? MD: Normally we want you to take at least one a day. <p>Task ambiguity (85 references over 93% of participants) Degree of difficulty in accurately assessing some aspect of the task such as its state or performance.</p> <ul style="list-style-type: none"> • “I think your shortness of breath is coming from your oxygen being low, not your heart being weak” (nurse practitioner to patient^{74/M/BI}). • “I didn't recognize it as heart either when you swelled up. I thought it was gout”^{daughter of 74/F/BI} • “I didn't really associate [the sudden weight gain] with my heart because I had eaten a whole lot of stuff that weekend”^{73/F/BI} • “I just eat a piece of cheese. I don't know how much salt [is] in it, but I just eat, I cuts it off and eats a piece”^{74/F/BI} <p>Task conflict and inertia (82 references over 70% of participants) Conflicts or different levels of inertia associated with the goals and performance of different tasks.</p> <ul style="list-style-type: none"> • “They don't like for you to eat green leafy vegetables [when taking Coumadin].”^{84/M/Wh} • “I've been eating pork all my life. And sometimes it's hard to just break habits.”^{74/M/BI} <p>Task consequences (216 references over 100% of participants) Real or perceived undesirable or inadequate results of a task on a person's mind, body, health, or life.</p> <ul style="list-style-type: none"> • “The doctor, he's a great doctor, I love him to death, but all the medications that he's put me on, it makes me sick. The last one ... I took it for 3 days ... but I got sicker each day and do you know it took me 10 days to get over that? And I'm the same way with pain medication.”^{82/F/Wh} • “I told (my doctor) you know my getting up so many times at night and so she suggested (I take my diuretic in the morning), but I started taking it in the morning and it got to where I was afraid to leave the house ... I just stayed home, you know. There was no control at all.”^{81/M/Wh} • “Yes, it aggravates the fool out of me. I get up in the mornings, it takes me 30 min to put my clothes on, get all my scales, and get into the kitchen at my little table back there I've got, and take all this stuff ... blood pressures, uh, sugar count, and hell, I ought to get me a degree, you know, I, I'm almost a doctor.”^{80/M/Mix} 	
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motivational issues included *lack of self-discipline* and self-reported laziness with respect to exercise (27%) and splurging or *giving in to temptation* (53%) with respect to eating forbidden foods or drinking larger amounts of liquids (“So whenever I get an urge or something, I just really do it”^{73/F/BI}). Few clearly articulated what specifically motivated successful self-care.

3.1.7. Personal preferences and habits

In several cases, current, sometimes longstanding, preferences and habits acted as barriers to optimal self-care. This included preferences for *consuming fluids* (47%) and *high-sodium foods* (50%), for example, “that's one of the hardest things ... I used to cover it in salt and no plain tomato is good.”^{67/F/Wh} Six (20%) participants displayed a *preference for independence* that conflicted with getting help with their self-care. A son described his father^{79/M/Mix} as “a

very independent man” whose desires for control manifested in “playing with” (i.e., skipping) daily medications or not attending appointments that required “begging people” for a ride.

3.1.8. Perceptions and attitudes

A common barrier (40% mentioning) was the *perceived unimportance of self-care* or the deprioritization of self-care activities, particularly low-sodium diet (23%) and daily exercise (20%). *Perceived lack of control* over health and disease was also common, with several stating that their health was up to a higher being (23%), their clinicians (13%), or no one (20%). Likewise, a third of participants described *avoidant attitudes* toward their disease, while three (10%) acknowledged the disease but preferred to focus on living life rather than extending it (“I'd rather live and do what I want to for three days than to live three months and not be able to

Table 6
Tool barriers, their prevalence and definitions, and illustrative quotes.

<p>Tool access and usability (70 references over 73% of participants) Availability, cost, accessibility, and ease versus difficulty of use of a potentially useful tool.</p> <ul style="list-style-type: none"> • “Never have [had a computer], don't even know how to, no siree, I want to so bad.”^{74/M/BI} • Excerpt of Patient (P)_{82/F/BI} and daughter (D) visit with nurse (N) and nurse practitioner (NP) <ul style="list-style-type: none"> N: Are you able to weigh at home? Do you get on a scale? P: No, I tell you what, I get up there and ... I'm too slow to make it (do) what it's supposed to do. NP: You probably get a little unsteady. D: She'll get one foot on and it's, you know ... maybe we need to get something you can hold on to ... she's too slow. It doesn't calibrate. So, you have to get off [the scale] and begin again.
<p>Tool design characteristics (61 references over 80% of participants) Aspects of the tool's design not strictly related to ease of use, e.g., accuracy, portability, and durability.</p> <ul style="list-style-type: none"> • (About out-of-date medication list) “Oh, yeah, we're about due for a new piece of paper.”^{85/F/Wh} • Interviewer: “I thought you had told me last time that you had a blood pressure sheet?” Patient_{68/M/Wh}: “I do and I didn't bring it with me.”
<p>Tool impact (33 references over 67% of participants) Undesirable effects on or response by the user caused by use of a tool.</p> <ul style="list-style-type: none"> • (About burden of pillbox use) “Somehow I don't like 'em, I like, uh, to see my meds in the cabinet and I take 'em one down at a time and take it, cause they [pills] all are just once a day, so I don't, uh, I don't know, I know that little pill, you know that little weekly [pillbox] thing is supposed to be more manageable for meds, but, I don't know, I, by the time I sit down and put one in Monday and one in Tuesday and one in ... you know what I'm saying?”^{73/F/BI} • “Since she know how to use that (motorized scooter), she will not use a shopping cart [to walk around a store for exercise].”^{daughter of 74/F/BI}

enjoy my life”^{68/M/Wh}). Nine (30%) expressed *negative attitudes toward medicine and clinicians* (“some doctors tell you anything, you have to be careful,”^{65/F/BI}) and twelve (40%) toward assistive *technology*, due to disinterest (23%), lack of skills (17%), or lack of perceived usefulness (17%).

3.2. Person barriers – other actors (Table 4)

Observations and interviews revealed an important but underappreciated fact: “self-care work” is distributed across multiple individuals besides the patient, most commonly the (lay) informal caregiver (National Research Council, 2011). In our study, fourteen (47%) patients had one or more caregivers to help with or directly complete tasks such as medication management, food purchasing and preparation, symptom monitoring, transportation, and communication with clinicians. Most caregivers were adult children living with or close to the patient (57%) but in some cases it was a spouse, grandchild, or multiple family caregivers. While typically helpful, informal caregivers were sometimes a source of self-care barriers. Furthermore, certain characteristics of healthcare professionals were identified as barriers to self-care.

3.2.1. Informal caregiver characteristics

Adult child caregivers were often busy, working people with families of their own and thus described as *unavailable* (75%). Adult children rarely described feeling overburdened by the caregiver role (13%), yet many cohabitating spouses mentioned the caregiver role as *stressful and tiring* (67%) (e.g., “I didn't have any (blood sugar issues) till he got sick. The doctor said it was stress,”^{wife of 79/M/Wh}). Caregivers themselves also had physical and cognitive *limitations* (54%) such as memory issues due to advanced age and medical conditions. Caregivers, like patients, sometimes lacked self-care

knowledge and skill (69%), especially involving dietary and fluid limitations (39%). Some caregivers had a negative effect on the patient's self-care by *modeling unhealthy behavior* (30%) and *putting the patient in bad circumstances* (46%), for example, by bringing unhealthy food into the house (e.g., [husband] likes fried chicken ... and that kind of throws us off cause I eat fried chicken with him”^{74/F/BI}). One patient's son described “sneaking” salt into his mother's food to make it taste better for her. We identified as a typical caregiver challenge balancing the desire to help with not imposing *too much control* (“[daughter]'s like the warden, I feel like I'm in prison”^{65/F/BI}) and the resultant risk of *fostering overdependence* (38%) (e.g., “I drug him out of bed every morning. He didn't want, 'oh I don't feel like getting up' so I made him,”^{wife of 79/M/Wh}).

3.2.2. Healthcare professional characteristics

There were relatively few mentions of clinicians acting as barriers to self-care and particularly few of current as opposed to past clinicians. Nevertheless, some participants described clinicians' *lack of access and availability* (27%), including appointment scheduling problems (10%), inability to access them between appointments (17%), and being unavailable during appointments (7%). Seven (23%) mentioned *problems receiving information* from clinicians, including the use of medical jargon and not being clearly informed about a condition.

3.3. Task barriers (Table 5)

Task barriers were those arising from characteristics of self-care activities. These were found for all participants, with an average 23.8 references per patient.

3.3.1. Task difficulty

Participants described the *general difficulty* of self-care tasks (70%): “caring for the heart is a hard job”^{65/F/BI} and “a struggle.”^{74/M/Wh} Eleven (37%) stated that adhering to a sodium-restricted diet was regarded as difficult and overly restrictive (“[2000 mg of daily sodium] ain't very much,”^{son of 85/F/Wh}), given that “everything has huge amounts of salt in it.”^{81/M/Wh} Four (13%) described the difficulty of physical tasks. Other difficult tasks were fluid restriction, getting health information, and monitoring for symptoms. Three (10%) stated that life itself sometimes seemed overwhelming (e.g., “I get nervous and tense and I just ... I just wonder if I'm just going to make it through ... this.”^{67/F/Wh}) Nine (30%) described how certain tasks such as organizing medications were *too difficult to do alone*.

Task quantity barriers involved multiple objects or subtasks, particularly the number of medications, which was mentioned by 21 (70%) patients (e.g., “I'm on a bunch and like, I'm a walking drug-store,”^{74/F/Wh}). Patients had between 3 and 28 active prescriptions ($M = 15.0$, $SD = 5.7$), taken at different times of the day or week, and often described as problematic: “it all adds up and it's very easy to get confused.”^{81/M/Wh} Two patients described intentional non-adherence due to the quantity of medications. Five (17%) described numerous clinical encounters, procedures, and professionals (“I got too many doctors,”^{65/F/BI}). Two patients mentioned the vast amount of health information, including on television and the Internet: “there's more information out there than you can possible read and there's more advice ... than you can possibly do.”^{74/M/Wh}

3.3.2. Task timing

Task frequency, periodicity, and ubiquity were barriers commonly associated with recurring tasks (50%). Five (17%) described “going to the bathroom every 5 minutes or so”^{84/M/Wh} and waking up multiple times at night to urinate, caused by diuretic medications. Periodic medication taking was commonly mentioned (23%), with most self-administering medications two to four times per day, and

more for those on insulin. Others mentioned the high frequency of daily symptom documentation, medical appointments, and trips to the grocery store (to buy fresh produce to accommodate a low-sodium diet). *Task duration* (13%) and *delays or lag* (20%) were also mentioned.

3.3.3. Task complexity

In half the participants, there was evidence of *general task complexity*, including complex medication schedules with multiple medications having multiple names, shapes, and colors (mentioned by 57%). *Changes in task* (57%) were especially common in medication management (43%), including new prescriptions, discontinuation of prescriptions, name and pill appearance changes (e.g., from brand name to generic), and changes to dosage or schedule. In several cases such changes resulted from a hospitalization. Other barriers included *conditional properties* (53%) such as taking medication in sequence or conditional on specific circumstances (e.g., “Right before I eat,”^{79/M/Wh}) and *precision requirements* or little tolerance for deviation (30%). Task complexity barriers were often related to—perhaps a function of—other task characteristics such as timing, ambiguity, and task conflict.

3.3.4. Task ambiguity

Ambiguity, or lack of clarity or transparency, was commonly present in *self-monitoring for symptoms* (77%). Eighteen (60%) described difficulty associating symptoms such as shortness of breath, dizziness, swelling, sudden weight gain, or chest pain with acute heart failure exacerbation versus other possible causes. This made it difficult to decide whether to be concerned, seek help, and take additional medications. Eleven (37%) also had difficulty self-assessing their health longitudinally because some signs of heart function were less “perceivable” (“I don’t have that much wrong that I can see that is wrong with me far as my heart. I can’t see what it’s doing inside,”^{74/F/BI}). Ambiguities sometimes resulted in patients “experimenting” with food and medication, including doubling or skipping doses.

Six (20%) referred to the ambiguity of *monitoring dietary sodium*. Participants spoke of “hidden” sodium and that “there’s more in that food than you really realize.”^{husband of 74/F/Wh} Ambiguity was especially pronounced when eating out. Several patients resorted to guessing and trial and error to determine sodium content (“I can’t know until I take the first bite you know?”^{74/F/Wh}).

3.3.5. Task conflict and inertia

Task conflict (60%) often involved needing to decide between or balance two or more self-care behaviors. Fourteen (47%) participants or their clinicians described balancing fluid restriction and diuretics, on the one hand, with avoiding dehydration, on the other. Among them, six (20%) described how fluid restriction conflicted with another medical condition, such as a urinary tract infection or diabetes, that caused thirst or required extra fluid intake (e.g., “I get thirsty, ‘cause I do have allergies and sinuses,”^{67/F/Wh}). Ten (33%) described balancing heart failure related dietary restrictions with personal dietary preferences, dietary restrictions for other conditions (e.g., gout, diabetes, high cholesterol), and medication-related restrictions. Six (20%) mentioned the conflict between the self-care regimen and life, in general, e.g., the difficulty of striking a balance between exercise, appointments, sleep, and a busy personal schedule.

Task inertia (40%) occurred when a self-care task opposed a strongly routinized behavior, particularly food preparation and consumption habits (27%). Three others described difficulty restricting fluid (“mom drinks a lot of water and enjoys it,”^{son of 85/F/Wh}), while others described the temptation of drugs and alcohol.

3.3.6. Task consequences

Consequences on the body, health, and mind (97%) produced by self-care tasks were commonly mentioned. Of the 118 such references, about half were related to medication side-effects, including effects on kidney function, bleeding, bruising, constant urination and resultant sleep disturbances, metabolic disturbances, appetite, dehydration, gastrointestinal problems, fatigue and weakness, hair loss, weight gain, headaches, pain, depression and violent thoughts, and risk of falling. Three individuals described severe allergic reactions and ten described general side effects, for instance, “for a day you feel blah,”^{81/M/Wh} or “all the medications that [doctor’s] put me on, it makes me sick.”^{82/F/Wh} One-third of respondents described undesired side-effects, particularly pain (20%) and fatigue or weakness (13%), resulting from daily physical exertion or exercise. Others (13%) mentioned problems due to dietary restrictions (e.g., “I just shut down if I don’t [eat regularly],”^{69/F/Wh}) or fluid restriction (20%) (e.g., “I stay thirsty,”^{80/M/Mix}).

Consequences on life and daily routine (70%) were primarily related to medications. Many (57%) described how diuretics, which caused frequent urination, controlled their lives and made it difficult to leave the house or get enough sleep (“I’m up all night. I mean, right now it’s killing me. I’m getting up four or five times a night,”^{74/M/Wh}). Enjoyment of life was compromised by both medications (“since I been taking some medicine again, I ain’t been right,”^{68/M/Wh}) and sodium restriction (“Bland, [food]’s too bland,”^{74/F/Wh}).

Other task consequences included perceived *personal costs or burden* imposed by self-care tasks, including daily tracking of vitals (“I feel like a secretary,”^{80/M/Mix}), appointments (“no matter what time you come, it’s an all day trip,”^{80/M/Mix}), and health-related activities of daily living (“It just tires me out to go to that store,”^{74/F/Wh}). Twelve (40%) patients raised *concerns about the general effectiveness* of following their self-care regimen. One patient who was not aware that the purpose of daily exercise was to strengthen cardiac muscle stated, “I don’t know whether that’s gonna benefit me or not because of the fact that I’m old,”^{74/F/BI} and several were skeptical about the effect of medications (e.g., “Well, can you tell me for sure that Coumadin [a blood-thinner] does more than aspirin does?”^{68/M/Wh}).

3.4. Tools and technologies (Table 6)

Tool and technology barriers were those related to the availability, design, or consequence of using some artifact in the course of self-care. These were found for 26 (87%) participants, with an average of 5.5 references per patient.

3.4.1. Tool access and usability

Participants described *unavailability* of computers (17%), appropriate mobility devices (10%), tools to measure and track vital signs (10%), a telephone or wireless connection for transmitting data (10%), or other self-care related equipment such as a pillbox or exercise bike. *Cost* (e.g., of broadband internet) was mentioned as a barrier to tool use by five (17%) participants. In nine (30%) cases, participants owned tools that they were *not accessible* when and where they were needed. For example, asked whether she weighs herself when visiting friends overnight, a patient replied, “If they have a scale. If they don’t, I don’t.”^{73/F/BI} Two participants were *not aware* of electronic tools available to them for medical information and communication with clinicians. *Usability* problems (50%) were also common. For example, three mentioned trouble weighing daily due to poor weight scale usability such as numbers that were too small.

3.4.2. Tool design characteristics

Problematic design characteristics included *inaccuracy* (40%), *size and portability issues* (33%), *problems with durability* (23%), *lack*

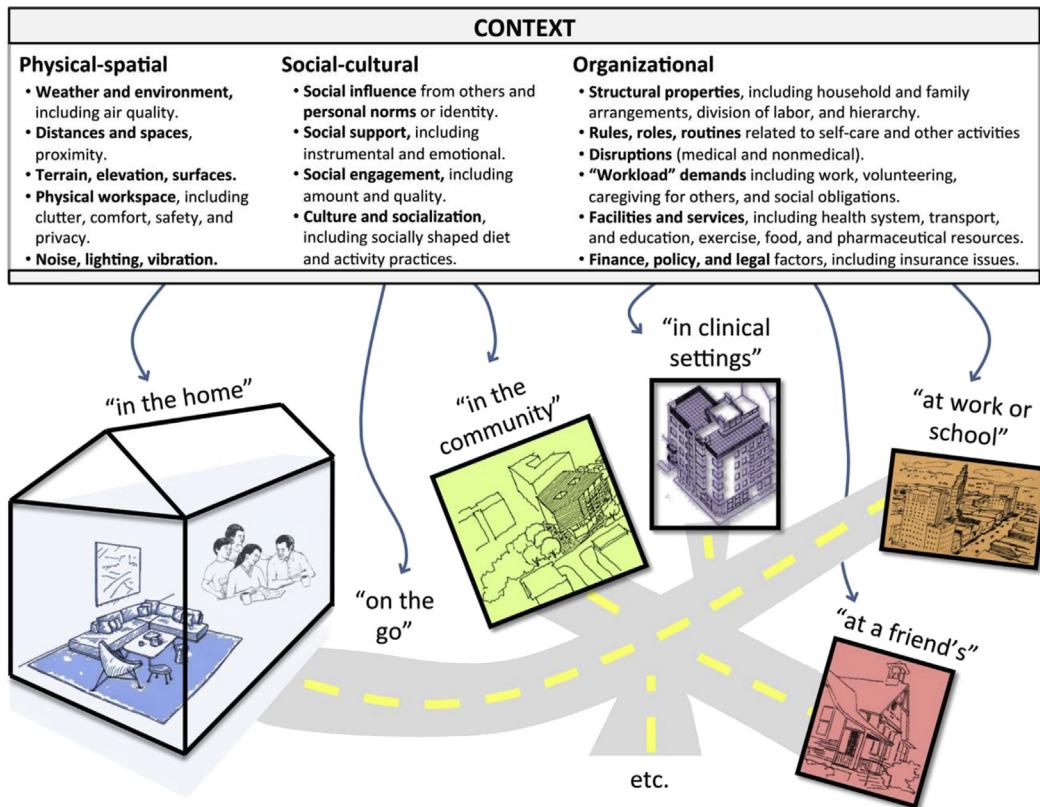


Fig. 3. Context barriers, organized into three context domains and multiple context spaces.

of transparency (23%), and inappropriate design for self-care tasks (23%). Ten (33%) participants were using paper artifacts with visible design problems, including paper lists that were not up to date, misplaced, or smudged. One participant, when asked about her heart failure dietary (i.e., sodium) restrictions brought out and read from an outdated list of post-stroke dietary (i.e., soft foods) recommendations. Another said he stopped writing down his daily weights because he ran out of paper diary sheets. In eight cases (27%), electronic information systems were problematic, including (1) difficulty of retrieving accurate and understandable information from the internet (“you find a lot of quack stuff,”^{81/M/W_h}) and (2) inaccurate or incomprehensible information in the clinic’s electronic health record (EHR) and patient portal systems. Another seven (23%) described design problems with tools used for assessing vitals, including poorly calibrated or unreliable blood pressure cuffs and weight scales.

3.4.3. Tool impact

Ten (33%) mentioned negative consequence of tools or technology, including frustration and discomfort using computers and the internet. In another ten, we found evidence for potential over-dependence on tools, particularly the use of potentially out-of-date paper documents as an “official record” of one’s medications.

3.5. Context (Fig. 3, Table 7)

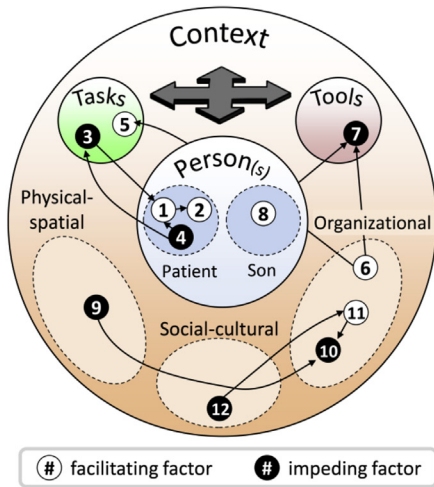
Contextual or environmental barriers were coded in three “context domains”—physical–spatial (105 references over 87% of participants), social–cultural (149 references over 93% of participants), and organizational (603 references over 100% of participants)—defined in Fig. 3.

We found that barriers in these categories separately and jointly influenced self-care in multiple “context spaces,” some of which are identified in Fig. 3. Table 7 gives examples of how factors in the

Table 7
Examples of barriers across context domains and spaces.

Context spaces	Context domains		
	Physical–spatial	Social–cultural	Organizational
“in the home”	“(stairs are) a little difficult. I’d rather have a house on the same level.” ^{73/F/BI}	“(husband) likes fried chicken. And that kind of throws us off, ‘cause I eat fried chicken with him.” ^{74/F/BI}	“I take care of my family ... I have two living with me, and uh by the time I get that done, my day’s gone.” ^{82/F/W_h}
“at a social event”	“my wife likes to go on cruises and unfortunately I’m a party pooper ... on the big ship cruise you have to walk quite a distance.” ^{81/M/W_h}	“Some of the things that were harder to change like ... going out and have a beer or something like that with the fellows.” ^{66/M/BI}	“being retired on a limited income it’s kind of stopped some of that (socializing).” ^{66/M/W_h}
“in the clinic”	“this place is too big for me to walk over” (referring to distances between two clinics). ^{80/F/BI}	“I had a couple of doctors I didn’t like much. Every time we went to them with something they’d say well this pill right here will take care of it.” ^{68/M/W_h}	“I got no money. I keep ... spending it on doctor bills.” ^{70/F/W_h}
“in the community”	“They want me to walk every day back and forth. That’s fine. But it’s cold.” ^{65/F/BI}	“I live in the government projects, and everybody’s always trying to play a little game with you.” ^{74/M/BI}	“the little drug store we use is (...) and it’s not open on weekends.” ^{68/F/W_h}

An 85 year old woman with heart failure
Self-care behavior: Exercise



- ① Although she knows importance of exercise
- ② and is motivated to exercise,
- ③ walking is difficult for the patient
- ④ due to physical impairment and fatigue.
- ⑤ However, she can swim
- ⑥ and has access to an outdoor community pool.
- ⑦ Although she has no car,
- ⑧ her son drives her there in the summer.
- ⑨ When the weather gets cold,
- ⑩ this outdoor pool is closed.
- ⑪ She does have access to a local gym with a pool.
- ⑫ However, she chooses not to go there because the gym's other patrons tend to be younger and she is self-conscious about what they will think when they see all her surgical scars.

Consequently, she exercises during the summer but not in the fall and winter

Fig. 4. An exemplar of a multi-factor interaction of facilitating and impeding conditions that ultimately result in difficulty performing self-care work. Arrows reflect interacting factors, while all the factors also interact to shape the ultimate behavioral outcome. Data, from an actual participant in this situation, are plotted on a “configural diagram,” adapted from Holden et al. (2013a).

three context domains served as barriers in four context spaces: in the home, at a social event, in the clinic, and in the community.

3.6. Interactions

Interactions are the *sine qua non* of human factors systems models and in our analysis, many of the barriers listed under individual components such as “person” or “task” could in fact also be described as barriers arising from the combination of two or more factors. For example, barriers related to tool usability often represented tool design (small font) interacting with person factors (low visual acuity). Certain task characteristics such as walking distance and medication complexity were only barriers to self-care because of the presence of other factors such as physical or cognitive impairment.

Sometimes many factors—hindering *and* facilitating—interacted to ultimately shape self-care performance, as seen in the case of one participant whose situation is depicted in Fig. 4.

4. Discussion

This paper demonstrated one application of patient-oriented or patient-engaged human factors, an area of great importance as patients and families are expected to play a more active role in their health and healthcare (Dentzer, 2013). Many prior studies have applied work systems models to understand barriers to clinician performance (e.g., Carayon et al., 2014; Gurses and Carayon, 2007; Gurses et al., 2012; Holden, 2011; Pennathur et al., 2013; Wiegmann et al., 2010). However, ours applies a work system model to study

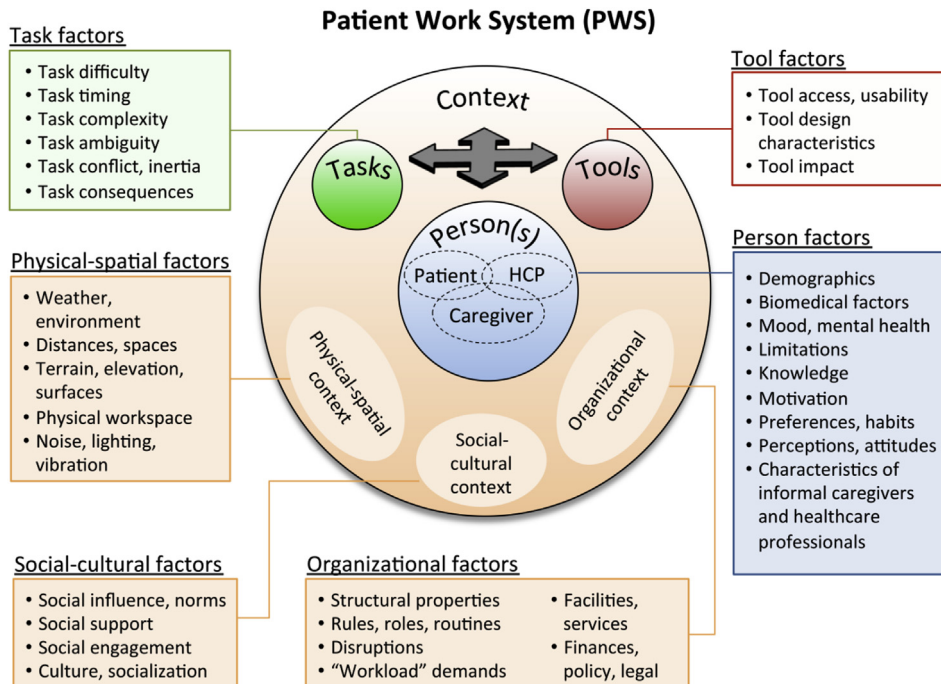


Fig. 5. The Patient Work System model (PWS), based on prior human factors systems models and adapted to depict the factors shaping patient work. HCP = healthcare professional.

person, task, tool, and context related barriers to the work performance of patients and informal caregivers. This is an important innovation as researchers increasingly acknowledge that what patients do resembles work activity (Granger et al., 2009) and can therefore be studied and supported using various ergonomic concepts, methods, and design strategies (Furniss et al., 2014). The patient work system (PWS) approach broaches the question, what kind of new design will be necessary, provided that patients and caregivers perform work? The approach also suggests consideration of the design implications of differences between patient versus professional work, including dissimilarity in supervision, accountability and legal responsibility, familial role distribution, reward and incentive structures, who suffers from performance breakdowns, control over design of the physical environment, the length of work “shifts” (e.g., 24 h for patients), and more (Logan et al., 2013). For further discussion of the research and design implications of adopting a patient work lens, see Valdez et al. (in press) and Schubert et al. (in press).

Fig. 5 presents a summary of the final Patient Work System model. The specific factors in the boxes in Fig. 5 were derived based on empirical data but checked for consistency with existing definitions of professional and patient work systems and their sub-components (Boehm-Davis, 2005; Fisk et al., 2009; Holden et al., 2013a; National Research Council, 2011). Systems approaches have been called for in heart failure research (Retrum et al., 2013) and they promote systemic interventions in addition to educating, motivating, or reminding patients (Ditewig et al., 2010). Consequently, the model in Fig. 5 can serve as the basis for such research and interventions, both in the area of heart failure self-care and for other activities carried out by patients and caregivers.

4.1. Person factors – beyond the individual patient

By taking a systems approach, our findings about barriers not only confirm but extend prior research on barriers to heart failure self-care performance. For example, Riegel and Carlson's (2002) seminal interview-based study identified mostly person-level self-care barriers such as physical limitations, difficulty coping, knowledge deficits, distressed emotions, and multiple comorbidities, but fewer task, tool, or context barriers (e.g., difficulty affording medications). In particular, task complexity and related barriers (e.g., ambiguity, timing, conflict) identified here have not been well described in the past and the same is true of tool characteristics and organizational context barriers such as performance-compromising rules, roles, routines, and “workload” demands.

Like other prior studies, we found many person-level barriers. For example, the classic interview study by van der Wal et al. (2010) also found several patient-related barriers such as forgetting and lack of knowledge, but also emphasized many task-related barriers related to the complexity or disruptiveness of the self-care regimen. Our analysis also identified many task-related barriers, as well as barriers related to tool and context factors that were not found in the above two studies. The innovation of looking across the entire patient work system to identify barriers to heart failure self-care is clearly illustrated by looking at two recent systematic reviews of predictors of heart failure self-care. In Oosterom-Calo et al.'s (2012) review of 26 quantitative studies, 180 variables were tested, but among them 74% (133) were related to disease or individual characteristics such as age, gender, knowledge, or disease etiology, 13% (24) were related to household living arrangements, marital status, or caregiver characteristics, and only 7% (12) were related to the task or context conditions such as regimen complexity or family income. In a broader review by McEntee et al. (2009), including qualitative, quantitative, and mixed-methods studies of barriers to heart failure self-care, patient-level barriers were found in 75%

of reviewed studies (45/60), clinician barriers in 38% (23/60), and contextual (or “systems-level”) in only 22% (13/60). Few single studies have assessed barriers at multiple levels or explain how multiple barriers interact, as shown in the PWS framework and other systems models (Murray et al., 2004; Wu et al., 2008). Note that the PWS framework does not exclude person characteristics, but rather stresses how these might interact with other factors to shape self-care performance. Indeed, our findings suggest that there are many person-level factors shaping performance and that these may become progressively more important with age, cognitive decline, and disease progression: future work might even assess how changes to person-level characteristics over time might alter the nature or distribution of a person's work system and barriers therein. For example, with age and disease progression, certain tasks may become especially complex, tools may become more difficult to use, and the physical environment might become a greater impediment to self-care.

We also found that disease management was a collective effort (see also, Mickelson and Holden, 2013; Palen and Aaløkke, 2006), with informal caregiver and clinician team members' characteristics sometimes acting as barriers. Further research must examine what makes such collaborative chronic illness “co-management” problematic versus a source of resilience (Schubert et al., in press). For example, assuming the role of an informal caregiving can have detrimental effects on the caregiver's own physical and emotional health (Beach et al., 2000; Pinguat and Sørensen, 2003), which can negatively impact the patient. In a study by Beach et al. (2005), caregiver depression was associated with increased risk of patient mistreatment by the caregiver. Schulz et al. (2007) suggest caregiver well-being is related to the patient's suffering and the caregiver's ability to successfully reduce it. The intertwined interaction between the patient and informal caregiver requires further research.

4.2. Task factors – entanglements and trade-offs

Medication management tasks were particularly problematic due to factors such as difficulty and complexity; they are thus a good target for human factors research and interventions (Morrow et al., 2005). While we reported barriers related to attributes of discrete self-care tasks such as medication taking, our data suggested that self-care is entangled, i.e., intertwined with other life activities (Corbin and Strauss, 1985): for example, medication taking was inseparable from diet, activity, and sleep, as seen in the number of references to self-care task consequences (see also Simpson et al., 2000; van der Wal et al., 2010). Self-care tasks sometimes created conflicting goals, as when diuretic medication keeps patients homebound or awake at night. Another type of conflict was the workload imposed by multiple self-care tasks on top of other life activities (Shippee et al., 2012). Patients stated that goal and workload conflicts forced a choice between recommended self-care and other goals, with some choosing comfort or enjoyment over adherence. This raises an important question, framed by Greenhalgh (2009) and others (e.g., Forsythe, 1996; Reuben and Tinetti, 2012) as whose goals and views should dictate treatment decisions, judgments of treatment effectiveness, and design? While the present study assessed performance relative to the biomedical goal of managing chronic illness through self-care adherence, future research could take a more sociological view by assessing performance relative to how well patients cope with disease or how well they balance the multiple demands of life (Corbin and Strauss, 1985; Greenhalgh, 2009). Views that consider coping and managing trade-offs correspond with modern views of resilience and safety-critical performance (Hollnagel, 2009; Hollnagel et al., 2006).

Generally, the prevalence and importance of task barriers in this study indicate the need to adapt techniques such as workload

measurement and cognitive task analysis to the patient and caregiver domain so that task characteristics can be more systematically assessed.

4.3. Tool factors – usability (and beyond)

Consistent with human factors principles, tool barriers were not simply the lack of tools but also problems with their design and usability. This finding urges the application of human factors and aligned approaches such as user-centered design processes, usability testing, human–system integration, and implementation science (Fisk et al., 2009; Jacko, 2012; Karsh, 2004). These approaches have gained acceptance in the design of medical devices (Weinger et al., 2011), are gaining traction in health information technology design (Schumacher and Lowry, 2010), and are recommended for the design of patient-facing technology (Agarwal et al., 2011).

4.4. Key directions for the future and preliminary implications

Although here we did not provide thorough treatment of context and interaction barriers, these were numerous. Context and interactions are two of the most fundamental concepts in human factors (Wilson, 2014) and therefore bear further investigation in the patient (and caregiver) domain. Our study laid the groundwork for representing context and interactions (Figs. 3 and 4), but further work is needed.

Considering the findings of this study, an obvious practical consideration is to look more closely at existing self-care interventions. Relatively few interventions address contextual conditions such as the physical, social, or organizational characteristics of the patient's home or access to resources. Instead, most focus on education or providing additional support or contact from a healthcare professional or case manager (Ditewig et al., 2010; Molloy et al., 2012). Further, our findings suggest the need to better assess the value of multi-component interventions (Molloy et al., 2012). Such interventions might combine education on heart failure self-care (person), introduction of self-care strategies or changes to the drug regimen (task), novel tools and the provision of symptom-monitoring equipment (tools), and instrumental support and increased contact with the healthcare system (context) (see e.g., DeWalt et al. (2006)). Another implication is that if there are interactions between system factors, some interventions could be targeted, for example, introducing different medication management applications (tools) depending on levels of literacy (person), medication regimen complexity (task), and internet availability (context). Consider the complex case in Fig. 4; while some patients in this woman's situation would benefit from a free gym membership, her social context suggests an intervention that either allows her to exercise in her home or connects her to other gym members her age. Because a patient experiences multiple, especially interacting systems barriers, present findings have inspired us to conduct further research on and prototyping of rapid methods for assessing barriers and visualizing them for busy clinicians. Other findings imply practical considerations such as: developing interventions that target the patient–caregiver dyad not the patient alone, help patients integrate self-care tasks into their existing clinical and personal tasks, and introduce mobile applications that can be used in many diverse settings.

4.5. Methodological strengths and limitations

The study's main strengths included the use of a conceptual model to guide data collection and preliminary analysis; the iterative nature of analysis, permitting model and coding refinements; the use of multiple mixed methods; a team of investigators with

complementary disciplinary backgrounds; and a relatively large sample size for such in-depth research (which yielded over 1500 pages of transcripts). For comparison, in recent reviews of studies of heart failure self-care, 76–79% of studies that included interviews had a patient sample size smaller than ours and 39–47% had a sample size smaller than 20 (Harkness et al., in press; Siabani et al., 2013).

In presenting the data we endeavored to present a balance of prevalence across researcher-generated analytic categories and rich quotes and examples using the participants' own words and ideas. While using multiple analysts is challenging due to the need for common grounding and analytic convergence, we agree with others (Barry et al., 1999) that when done right, it can be a major strength. To this end we used multiple techniques including coding discussions to manage our multi-analyst approach. Furthermore, our study benefited from having both quantitative-prevalence and qualitative-descriptive components: while quantitative analyses revealed barriers (e.g., knowledge deficits, task difficulty and consequences) that warrant further research purely on the basis of their prevalence, qualitative analyses provide more insight into the complexities of barriers. For instance, knowledge deficits were most pronounced and problematic when patients encountered novel situations such as new foods or ambiguous symptoms and needed to apply learned knowledge or identify functional relationships under time constraints (Horowitz et al., 2004; Riegel et al., 2013).

Study limitations included the only partially longitudinal design, with participant contact usually spread over only one month. Although this is better than most studies of self-care, which include only a single encounter, future research should extend the timeline to capture major changes and transitions. Not all barriers were immediately volunteered in response to general questions, with some barriers elicited through probes; thus, it cannot be said that all of the barriers coded for an individual were equally salient or would have been mentioned in a more open-ended interview format. This paper examined barriers but not facilitators, coping, resilience, or adaptive strategies. Data collection yielded numerous examples of these and further analysis is needed to demonstrate which work system factors and strategies result in successful performance. Participants were all volunteers receiving care at an outpatient cardiology clinic of an academic medical center, making them potentially different from the general population. We used targeted sampling to ensure representativeness on age, income, race, gender, education, and location but recognize that this did not eliminate the selection of individuals willing to engage in research and show up to at least one appointment. Furthermore, patients were relatively healthy compared to all symptomatic heart failure patients (note that we excluded both asymptomatic NYHA Class I and high-severity NYHA Class IV patients). While even these patients were sometimes quite ill and likely to experience hospitalization and death (see Table 3), we have conducted additional research with similar-sized cohorts of elderly patients who have been recently hospitalized ($n = 32$) and all-age (and thus sometimes uninsured) patients who presented to the emergency department with acute decompensated heart failure ($n = 31$). Future papers will compare barriers across these groups. The above restrictions of range as well as our sample size are particularly important to consider when interpreting prevalence data. Lastly, it is possible that some of the interview answers provided were influenced by the presence of a caregiver, social desirability effects, or cognitive–perceptual limitations of participants' verbal communication.

Lastly, this study was carried out with elderly heart failure patients. It remains to be seen to what extent the model is transferable to other patient and disease groups and what adaptations might be needed. For example, while one could begin an investigation of adolescent Type I diabetes patients using the model in Fig. 5, some of the subcategories may need to be changed, for example, to

distinguish between social influence from peers vs. authority figures (teachers, parents). Some categories such as functional limitations may also not be as relevant in some cases as they are with elderly heart failure patients.

5. Conclusion

There is now no shortage of advocates for patients to be involved in their health and healthcare. However, there is inadequate understanding of the actual “work” that patients and their informal caregivers do or the “work systems” that shape their work performance. The human factors discipline has the tools and expertise needed to better understand patient work systems and performance in a way that is comprehensive, theory-based, and methodologically rigorous. Importantly, human factors experts also have an opportunity to be involved in the design of work systems that better support patient work and engagement in health and healthcare.

This study demonstrates one application of patient-oriented or patient-engaged human factors—the conceptualization and data-driven refinement of the “Patient Work System.” For human factors to continue to make valued contributions to the fields of health and healthcare in a new era of “patient engagement,” we must build on this example by adapting other human factors approaches—including workload assessment, cognitive task analysis, user-centered design, usability testing, and participatory process redesign—to study and improve work done by patients.

(a) Scripted questions used for initial interviews

Topic	Example questions (edited for interviewer instructions)
Introduction and scoping	<ul style="list-style-type: none"> • (Patient), first, tell us a little about yourself ... • (Caregiver) how about you, (sir) (ma'am) ... ?
Medical condition(s) and knowledge (Person)	<ul style="list-style-type: none"> • Tell us a little bit about your heart condition called heart failure ... • And, very briefly, are there other health issues you've been dealing with?
Self-care activities and knowledge (Task, Person)	<ul style="list-style-type: none"> • What do the doctors or nurses say you should be doing for your heart condition called heart failure ... ? Anything they say to do specifically for heart failure?
Use of technology (Tools & Technologies)	<ul style="list-style-type: none"> • These days, you hear about people using the internet or computers to help with their health. Do you ever find yourself using the internet or computer for your health? • (Companion) do you all ever talk to each other by email or Facebook about (his) (her) health? • Are you on e-mail, Facebook, or anything like that? • What about computers in general? Do you use one?
Virtual health tour (Whole System)	<ul style="list-style-type: none"> • We want to spend some time now to talk through things you do for your heart failure. Take me through a typical day ... how do you take care of yourself ... ? • Is that a pretty typical day? What kinds of things do you find yourself doing when it's *not* a typical day? • (Companion), what kinds of things do *you* do on a typical day to help (Name) with (his) (her) health?
Physical, social, and organizational environments of self-care (Context)	<ul style="list-style-type: none"> • Where might you go on a typical day ... ? • Where might you go on a special occasion ... ? • Tell me more about where you live ... ? • Does anyone else live with you? • Where you live, what's it like to have a heart condition like heart failure ... ? • Do you typically talk to anyone about your heart condition?
Strategies (Whole System)	<ul style="list-style-type: none"> • (Well it sounds like you have a lot on your plate, taking care of your health) How do you actually manage it all? • Of all the things you do to take care of yourself, do you have any strategies to make any of these things easier to do? • When it comes to taking care of yourself, which things do you think you do a good job with?
Barriers (Whole System)	<ul style="list-style-type: none"> • What kinds of things make it harder to take care of yourself?
Wrap-up and general attitude (Person)	<ul style="list-style-type: none"> • We're coming to the end of our interview, so let me ask one more thing: how do you feel, overall, about having to manage your health ... ? • (Companion), how about you, any final thoughts? • ... anything else?

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Appendix A. Topics and scripted questions for (a) the typical initial interview and (b) a sample follow-up interview.

(b) Scripted questions for sample follow-up interview participant

Topic	Example questions (edited for interviewer instructions)
Updates	<ul style="list-style-type: none"> • Have you had any issues with your health since we met (on&hellip)? • Anything else new going on with you?
More on strategies (Whole System)	<ul style="list-style-type: none"> • What kind of advice would you give to someone who was newly diagnosed with heart failure? • You talked about adapting to what you're able to do ... ? • Thinking about all the things you do when you're managing your heart failure during the day, what kinds of things do you think you're doing a good job with? • What kind of tips and tricks do you have to make it easier to manage your heart failure?
More on social environment and caregivers (Context)	<ul style="list-style-type: none"> • Do you ever talk to other people who have heart failure? • You talked about (rehab class) and you would talk to some of the people there ... ? • You mentioned you have a son and a daughter and you talk to them sometimes about their health? • Do you find you're getting advice from friends, neighbors, family, or other people in your life about how to manage your heart failure? • Tell me more about how (husband) and others around you help with your care ... ?
More on self-care activities (Task)	<ul style="list-style-type: none"> • You said you'll walk at the mall. How's that been lately? You said you'll "take your time" when walking. Is that a strategy you find works for you? • Besides that, what kind of physical activity have you been able to do lately? • Tell me more about your successes and failures with eating healthy, low-salt foods? How tough do you find it to manage sodium or salt when eat eating out?
More on medications (Task, Whole System)	<ul style="list-style-type: none"> • (Ask to see medication list. Ask to see pillbox.) • How many pills do you take? How often do you take these pills? • Do they make you feel better? Are there side effects of the pills that you don't like? Do you ever not take a pill because of the side effects? • Do you get medications mixed up? How do you manage that? • Do you sometimes forget to take your pills? Tell me about that. What helps you remember? What do you do if you realize you forgot a pill? • How do you remember to get refills? Who picks the refills up?
More on barriers (Whole System)	<ul style="list-style-type: none"> • Thinking about (self-care), have any of those things been extra challenging lately? • What are some of the barriers you feel you have with taking care of your heart and your heart condition?
More on typical and atypical days (Whole System)	<ul style="list-style-type: none"> • What kind of things do you do nowadays during the day, now that you are retired? • Take me through a typical day, from when you wake up to when you go to bed. • (Probe: weighing, self-monitoring, writing things down, activities, driving, etc.) • So that's a typical day. Tell me about a day that maybe was very different from that. • Do you do anything special on those days with respect to managing the heart failure? Do you take any of your heart failure things with you when you go out? • Who drives when you go somewhere?
Health tour (Whole System)	<ul style="list-style-type: none"> • Would you be willing to take us on a walking tour of a typical day in your life? • (Probes and items/places to look for.)
More on technology use (Tools & Technology)	<ul style="list-style-type: none"> • Remember we talked about computers last time ... hypothetically speaking, what if someone said, "I have a computer program or Internet website and you can use it to help you with managing heart failure." What kinds of things would you want this computer program or website to help you do? • Besides computers, do you have any other technology you like to use, like a cell phone or anything automated?
Additional items (Whole System)	<ul style="list-style-type: none"> • How much control do you think you have over your health? • (Ask about living on a fixed income) • Do you think you have received sufficient information about taking care of yourself? • Broadly speaking, would you care to impart on us your philosophy on life?
Wrap-up and knowledge test (Person)	<ul style="list-style-type: none"> • On a scale of 1–10, how knowledgeable would you say you are about heart failure? (Why?) • Of the things you have to do for your heart failure, what doesn't really make sense or is too confusing? • (Administer knowledge test.)

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