Designing self-care technologies for HF patients: A conceptual model

KNOWLEDGE   RESOURCES
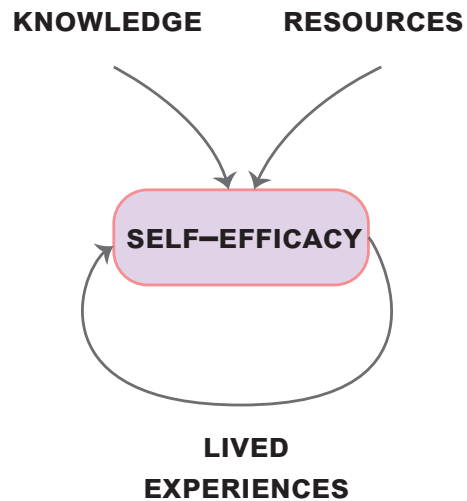
SELF—EFFICACY

LIVED

EXPERIENCES

Figure 1: Toward supporting heart failure (HF) patients after hospitalization, we identify three key elements affecting how patients engage in self-care. Knowledge and resources drive patients' self-efficacy, which is continually affected by their lived experiences, such as emotions, activities, and relationships.

KEYWORDS
Self-care; conceptual model; heart failure; post-hospitalization; self-management; chronic disease; HCI; qualitative inquiry.

Pantea Habibi
Department of Computer Science
University of Illinois, Chicago
phabib4@uic.edu

Barbara Di Eugenio
Department of Computer Science
University of Illinois, Chicago
bdieugen@uic.edu

Andrew D. Boyd
Biomedical and Health Information Science
University of Illinois, Chicago
boyda@uic.edu

Pamela Martyn-Nemeth
Department of Biobehavioral Health Science
University of Illinois, Chicago
pmartyn@uic.edu

Amer Ardati
Department of Medicine
University of Illinois, Chicago
aardati@uic.edu

Sabita Acharya
Department of Computer Science
University of Illinois, Chicago
sachar4@uic.edu

Richard Cameron
Department of Linguistics
University of Illinois, Chicago
rcameron@uic.edu

Karen Dunn Lopez
Biomedical and Health Information Science
University of Illinois, Chicago
kdunnl2@uic.edu

Carolyn Dickens
Department of Biobehavioral Health Science
University of Illinois, Chicago
cdickens@uic.edu

Debaleena Chattopadhyay
Department of Computer Science
University of Illinois, Chicago
debchatt@uic.edu

METHODS

This work is part of a larger study, which was approved by the UIC IRB, to explore ways to engage patients with HF after discharge. Hour-long semi-structured interviews were conducted with HF patients during hospitalization at the Cardiology division of the University of Illinois Hospital. RC conducted the interviews in collaboration with CD, AA, and ADB. 15 out of 20 patients completed the Patient Activation Measure (PAM) questionnaire, which is a uni-dimensional Guttman-like scale used to measure levels of patient engagement (1–4, higher score implies greater activation) [2]. Interviews were audio-recorded and transcribed.

Example Questions

(*Prognosis*) When was your heart problem first diagnosed? Can you recall how it unfolded?
(*Current hospitalization*) Why are you admitted to the hospital this time?
(*Etiology*) Do you know what causes it [sign or symptom]?
(*Coping strategies*) When you have that kind of pain, how do you deal with it?
(*Disease progression*) How have you changed your lifestyle since dealing with HF?
(*Care*) Do you have anyone to take care of you? Do you know how to take care of yourself?

Analysis was done using a grounded theory method (GTM) and focus on self-care of HF. Initial coding was developed iteratively, but not guided by a theory/framework. The research team met regularly to discuss emerging codes. Following open coding and memoing, axial codes were identified. Then core concepts were selectively coded and multiple iterations later, a framework was developed encompassing those themes.

ABSTRACT

People with chronic diseases undergo multiple hospitalizations. Outside the hospital, self-care technologies can help patients manage a chronic condition. Such self-care technologies are proliferating. But the current HCI knowledge about how to design self-care has largely been developed from only a few conditions. Chronic diseases may differ in many ways, which demands investigating domain-specific design requirements for self-care. Through in-depth interviews of 20 patients with heart failure (HF) during their hospitalization, we explore the challenges faced in managing HF, coping with the progression of the disease, and understanding the disease etiology. Using a grounded theory method, we identified how knowledge and resources drive patients' self-efficacy, which is continually affected by their lived experiences. Drawing on these factors, we then propose a conceptual model to inform the design of self-care technologies for people with HF after hospitalization.

INTRODUCTION

Nearly half of all Americans suffer from at least one chronic condition, and the number is growing. Chronic conditions, physical or mental, last for more than a year and require ongoing monitoring or treatment. They are likely to deeply affect patient's lives—challenging them to deal with symptoms, cope with long-term disability, understand medical advice from care providers, follow complex medication schemes, make radical lifestyle changes, and above all deal with the emotional impact of living with an illness. One of the most prevalent chronic conditions in the US is heart failure (HF).

HF is among the most expensive conditions treated in US hospitals, with the highest readmission rate for patients aged 65 and above [7]. Most HF readmissions are believed to be preventable through healthcare delivery improvements, such as intensifying post-discharge care. Outside the hospital, living with HF requires patients to manage their disease by themselves—to *self-care*. Self-care refers to managing symptoms, treatment, emotions, and lifestyle changes as part of living with a chronic condition—in collaboration with informal caregivers and formal care providers—to maintain a satisfactory quality of life or as long as possible [1].

Self-care technologies for managing chronic conditions, like diabetes, asthma, or heart failure, are proliferating. But traditionally, the design of these self-care technologies have been medically oriented, adopting a constructivist approach and prioritizing medical measurements—while ignoring patients' lived experience of their illness [4]. Prioritizing patients' experiences to uncover insights into the existential and social processes of illness as *lived* is epistemologically grounded in phenomenology—Merleau-Ponty's notion of embodiment as the basis of being-in-the-world [6]. To ensure that technologies are designed with a deep understanding of patients' perspectives and everyday practices, and thereby, have the potential for greater effectiveness and impact, we argue for bringing an HCI lens to self-care research. A few prior studies adopted an HCI lens to understand how to support self-care (e.g., [3, 5]), but none particularly looked into HF patients.

Participants

Interviewed participants had various reasons—related to HF–for being hospitalized. Their ages ranged from 28 to 83 (M = 56.05, SE = 3.02); 17 were African-Am., two Hispanic, and one Asian-Am. Patients were high school graduates (9) or had college degrees (7). Our sample was more ethnically diverse than the American population.

Table 1: Demographics of Patients Quoted

Patient	Age	Gender	Ethnicity
P03	60	F	Mexican-Am
P05	53	F	African-Am
P08	53	F	African-Am
P12	67	M	African-Am
P15	38	F	African-Am
P17	67	M	Hispanic
P21	46	M	Asian-Am
P22	39	M	African-Am
P24	62	F	African-Am

Table 2: Characteristics of Patients Quoted

Patient	Years of illness	PAM score	Education
P03	–	–	high school
P05	16 years	1	high school
P08	4 years	2	some college
P12	13 years	3	–
P15	14 years	1	some college
P17	8 months	3	–
P21	1 months	3	–
P22	2 months	2	high school
P24	7 years	4	high school

We bridge this gap by contributing a conceptual understanding of factors affecting HF patients' self-efficacy, i.e., confidence and ability to engage in self-care. Our work adopts a sociocultural perspective and develops the concepts bottom-up from data using a grounded theory method. In this paper, we describe three key elements that affect how patients engage with self-care: knowledge, resources, and lived experiences. Although similar themes have been reported before [3, 5], our primary HCI contributions are (1) a framework uncovering how the interrelationship between these themes mediate self-care strategies and decisions in HF patients, and (2) drawing on that, a conceptual model to design post-hospitalization self-care for HF patients.

RESULTS AND DISCUSSION

In our analysis, we focused on unearthing drivers that influence HF patients' self-efficacy in caring for their illness. We found that these factors relate to three areas: <u>knowledge</u>, <u>resources</u>, and <u>lived experiences</u>, such as emotions, faith, activities, and personal relationships. Prior work identified similar themes, for example, to support self-management after hospitalization for surgical services [5] or improve patient-provider communication for individuals living with multiple chronic conditions [3]. We expand self-care research in two ways: (1) focus on the concerns of patients with HF, and (2) identify how interrelations between knowledge, resources, and lived experiences affect self-efficacy. Below we describe our findings by each theme—focusing on its relation with other themes.

Knowledge

Knowledge, in our framework, entails an understanding of one's illness and care. In living with HF, individuals acquire knowledge about their illness and care in several ways, e.g., care providers' instructions (doctors and nurses), personal wisdom (i.e., insights into own lives, including personal problems), and collective wisdom (i.e., insights from others' experiences).

P05 was recently admitted for a follow-up checkup. She explains how she is trying to loose weight, as prescribed ("*he [doctor] says I gotta lose weight. I've been losing weight; I've been trying to lose weight.*"). But her actually taking an action is influenced by her lived experience, pleasure from activities ("*I don't eat three or four meals a day. If I could stick with two meals a day I'd do good, but I'm not gon' lie. I'm not no fantastic cook. My cousin does most of my cooking, and she brings it to me*"), which was brought about by a change in her physical resources ("*so they [at work] give me two vegetables, I take a spoon of each so, when I was working, I was guaranteed to do that every day but now ... now I'm not working. If she [cousin] don't send no greeneries, I don't eat no greenery.*")

P12 was admitted to the hospital with HF symptoms. He describes how his years of dealing with HF help him understand what actions to take ("*I'm having shortness of breath, uh, you know I was–you know I couldn't sleep, didn't have no appetite and the way it was going, well I didn't know better, so, uh, and my ... my appointment wasn't til' February 23rd and I couldn't try to put it off til' February 23rd the*
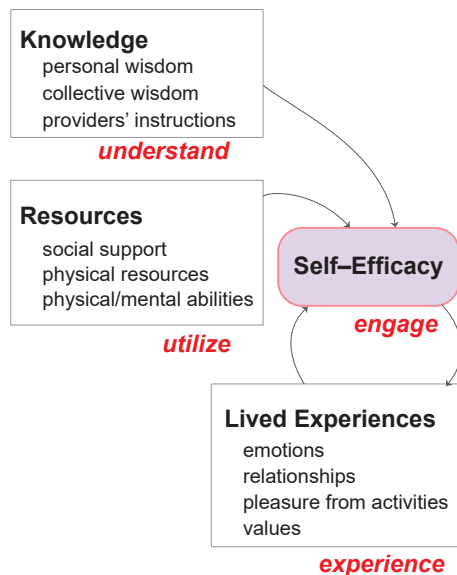
Figure 2: Our conceptual framework. Engaging patients with self-care requires building their self-efficacy, i.e., confidence in their own abilities to manage their chronic condition. We found how much patients *understand* about their illness and can *utilize* social and physical resources affect their self-efficacy, which is also impacted by day-to-day developments and their *lived experiences.*

way I was [feeling]—the things I was experiencing [...] for 11 years and alright you know, regarding the symptoms that I have experienced you know by having it, so you become educated about it"). However, tensions arise and confidence plummets when his understanding and lived experiences do not align with his care provider's assessment: "*but what I didn't understand 'bout myself, the way I was feeling, and they took my vital sign–my vital sign was stable, but I don't feel like I'm stable [...] I'm thinkin' she lied you know cause I was just in here...How can my vital sign be sta–stable under you know, my condition? You know, the machine's is malfunctionin' or somethin', but she said stable you know my...my blood pressure and ... the other... whatever blood pressure and my oxygen intakes level*".

P08, suffering from sarcoidosis, was admitted to the hospital for a routine procedure. She describes her efforts to learn about her illness from others: "*[...] when I first got it they said that the large percentage of people who had it was the African American. But I've learned, I've been to a convention. It is just as many white people [...]. in that room it was at least 300 people and at least 200 was white and young! Children! That's how I knew that this dis...this disease is more powerful than people – and you know, that they're not talking about it.*"

However, she doesn't want to join support groups—although aware that they can be a good source of knowledge—to avoid negative feelings: "*he [husband] tells – asks me why don't you go to the support groups? Lemme tell you about the support groups. They are so depressing [...] when they talk about it [disease], you just hear about the worst part. And it's kinda like am I going to end out like that? And you don't wanna hear this. It's just hearing people talk about how bad their condition is. I don't find support in that. I found it more depressing.*" An example of how emotions may influence knowledge gathering, and in turn, self-efficacy.

Resources

We define resources as an available means of supply or support. As expected, our analysis revealed three broad categories of resources driving self-efficacy, (1) physical, such as income, insurance, or food and shelter (e.g., P15: "*I'm on disability ... so, I have a caretaker come in– and do – and help me with... the activities of daily living.*"), (2) social, such as family, friends, or community (e.g., P03: "*usually my son or my daughter or one of them might come, every day.*"), and (3) abilities, such as physical, mental, or technological (e.g., P21: "*I mean, you–you could sit there and go online and check out WebMD and yeah, find out that you've got this rare case of [...]*").

Access to resources did not always imply an increase in knowledge. P22 was admitted due to shortness of breath. He mentions how tailored communication helped him understand his care: "*I noticed today – well, yesterday, the nurse, the doctor and the nurse were – she was explaining everything step-by-step. You know, they usually don't but she did. She explained stuff in a way that I could understand*".

Interestingly, we found that sometimes resources can act as a source of stress, in turn, dampening patients' confidence. P08 describes how her illness affects her relationship with her husband: "*with*

Figure 3: Design requirements for supporting HF patients during hospital-to-home transition.

my husband I started to feel like I wasn't attractive enough anymore. And even now with the weight gain and all the stuff he's seen me go through, you know it, he's a loving man, but you know everybody has a limitation. And I just pray that his limitation haven't hit yet but he's, he's been there for me and that's where I been lucky at – you know, and the depressions and the crying and things like that."

Lived Experiences

We explored the existential and social processes of illness as people *live* with HF, for a month or 49 years. Four sub-themes emerged: mood or *emotions*, *relationships*, *activities*, and *values*. As expected, emotions ran high in most patients. Often patients suggested stress as the disease etiology, e.g., P17: "*It [heart problem] started like when my nephew got murdered when I was noticing I had a lot of anxiety and I couldn't sleep [...] and then I was real nervous. I start smoking cigarettes and I got real sick. And I said to myself, something is wrong here. I don't feel right. [...] I noticed that – my ankle was swollen and I remember my ma had congestive heart failure and it's just, oh man.*"; or P20: "*Well, it [heart problem] happened a long time ago, up under stress. [...] I had ten kids, about ten to twelve kids to watch. And, they would put me up under stress ... but, I went to St. Luke Presbyterian for it. That's when the doctor found out I was under stress ... So that's how I found out I had congestion.*".

Different value systems emerged, such as, faith (P08: "*My faith is strong. I'm very involved in my church. And if it weren't for God I – I think I would've probably had taken my life long time ago.*"), independence (P24: "*Cause I'm independent. I like to do my own stuff. I don't like to just sit there and do nothing. I like to go out. I like to go places and do things. I like to cook.. everything.*"), or optimism (P04: "*I'm a type of person that never let nothin' bother me ... too much, you know? Cause as I was growing up our parents always told us don't worry about things, said because it's nothing you can do about it.*").

Personal relationships, although a resource (social support), sometimes evoked negative feelings, e.g., P03: "*And then ... I would make them [kids] take me to the store cause they never got what I wanted. So, they would take me to the store in the wheelchair. And uh, that was a...a...that was a lot. My daughter would help me take a shower and get dressed and undressed, and you lose a lot of dignity ... when you have people doing things like that for you. And I'm the kind that I get in my car and I go and I come and – I don't ask nobody nothing. I cried a lot. I got into a bad depression ..... I would try to do something but it just – all the time they were doing things for me – it's [wheelchair] taken away from me.*"

People described how they had to give up activities due to HF (P03, who loves cooking and whose husband and daughter are "*okay*" cooks had to give up cooking after a surgery: "*That's [problem with walking] when...my daughter and my husband started cooking. I gained...oh my god, I gained like 70 pounds.*"). Some adjusted their lifestyle to align with their care goals (e.g., P05: "*I baked my fish...I like fish, but I like fried fish too [...] but I've been trying to do everything that would encourage losing weight.*"). Sometimes they discussed habits they *know* are exacerbating their condition, but cannot forego: P12: "*it's on me because I'm still smoking when I ain't got no business smoking*".
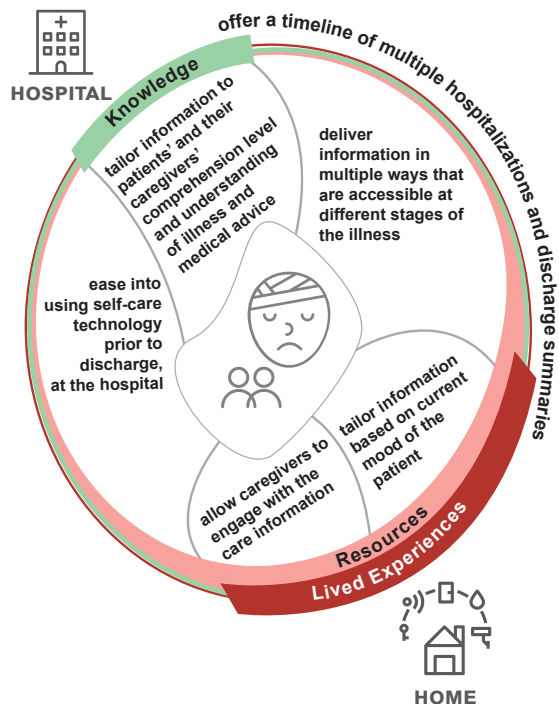
Figure 4: Our conceptual model, to inform the design of HF self-care technologies supporting hospital-to-home transition.

Note that lived experiences drive self-efficacy differently than how knowledge and resources do– they are often deeply interwoven and can be long-term (e.g., faith in God) or short-term (e.g., feeling helpless). Arguably, self-efficacy, i.e., confidence in one's abilities to self-care, can be considered a lived experience itself. We decoupled these two concepts to better inform technology design.

A Conceptual Model

Drawing on the conceptual framework described before (Figure 2), we developed a task-focused conceptual model to design for HF self-care after discharge from hospitalizations. Currently, most hospitals provide patients with general paper discharge pamphlets. We identify user types, core tasks, and useful metaphors, argue that the use of self-care technology should begin pre-discharge, and advocate offering information tailored to patients' comprehension abilities (Figures 3 and 4).

CONCLUSION AND FUTURE WORK

Reducing readmission rates of chronically ill patients has the potential to greatly reduce healthcare costs while simultaneously improving care delivery. To that end, we identified three key elements driving self-efficacy in self-care outside the hospital: knowledge, resources, and lived experiences. We described how HF patients' understanding of their illness and availability of social and physical resources mediate their self-efficacy, which is also continually affected by day-to-day developments and their experiences. We used our framework to develop a conceptual model that can inform the design of self-care technologies for HF patients after hospitalization. We do not claim that our results generalize to other chronic conditions, but we anticipate many elements would still apply.

REFERENCES

[1] J. Barlow, C. Wright, J. Sheasby, A. Turner, and J. Hainsworth. Self-management approaches for people with chronic conditions: a review. *Patient education and counseling*, 48(2):177–187, 2002.

[2] J. H. Hibbard, E. R. Mahoney, J. Stockard, and M. Tusler. Development and testing of a short form of the patient activation measure. *Health services research*, 40(6p1):1918–1930, 2005.

[3] C. Y. Lim, A. B. Berry, T. Hirsch, A. L. Hartzler, E. H. Wagner, E. J. Ludman, and J. D. Ralston. Understanding what is most important to individuals with multiple chronic conditions: a qualitative study of patients' perspectives. *Journal of general internal medicine*, 32(12):1278–1284, 2017.

[4] F. Nunes, N. Verdezoto, G. Fitzpatrick, M. Kyng, E. Grönvall, and C. Storni. Self-care technologies in hci: Trends, tensions, and opportunities. *ACM Transactions on Computer-Human Interaction (TOCHI)*, 22(6):33, 2015.

[5] A. H. Pollack, U. Backonja, A. D. Miller, S. R. Mishra, M. Khelifi, L. Kendall, and W. Pratt. Closing the gap: Supporting patients' transition to self-management after hospitalization. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, pages 5324–5336. ACM, 2016.

[6] S. K. Toombs. Illness and the paradigm of lived body. *Theoretical medicine*, 9(2):201–226, 1988.

[7] A. Zohrabian, J. M. Kapp, and E. J. Simoes. The economic case for us hospitals to revise their approach to heart failure readmission reduction. *Annals of translational medicine*, 6(15), 2018.