



Activity Theory Analysis of Heart Failure Self-Care

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ABSTRACT

The management of chronic health conditions such as heart failure is a complex process emerging from the activity of a network of individuals and artifacts. This article presents an activity theory–based secondary analysis of data from a geriatric heart failure management study. Twenty-one patients' interviews and clinic visit observations were analyzed to uncover eight configurations of roles and activities involving patients, clinicians, and others in the sociotechnical network. For each configuration or activity pattern, we identify points of tension and propose guidelines for developing interventions for future computer-supported healthcare systems.

Patients with chronic health conditions, such as heart failure, juggle a complex combination of everyday tasks in a bid to extend their life span, maintain an acceptable quality of life, and minimize—to the extent possible—the deterioration of their condition. Clinicians recommend that these patients follow a plan of care, which can be complex and often includes daily self-care activities such as adhering to a medication regimen, logging fluctuations in their vital signs, maintaining a low-sodium diet, exercising, and attending clinical visits with multiple care providers. The difficulties of constructing a plan of care (for clinicians), understanding and following it (for patients), and communicating changes to this plan highlight some of the collaborative and communicative complexities of chronic disease management.

Clinicians are responsible for monitoring the patient's self-care activities and adapting the plan of care depending on the patient's status and symptoms assessed during and between visits. Ideally, clinicians devise plans of care that match patients' expectations, promote patients' adherence to these plans, and scaffold patients in accurately assessing and reporting back on their performance in following the plan of care. However, clinicians and patients' views on accomplishing the plan of care differ. Granger and colleagues (2009) found that clinicians view patients' executing the plan of care as a matter of adherence, with nonadherence stemming from misunderstanding or inadequate knowledge about what to do. In contrast, patients described self-care as difficult work, the performance of which was hindered by a lack of effective strategies for implementing clinicians' self-care recommendations in everyday life. This disconnect highlights one potential opportunity for improving the delivery of care: by understanding the difficulties patients face, clinicians can develop and manage their patients' plans of care in a way that better promotes adherence to treatment.

Although patients can (and often do) lean on a support network of friends and family members to follow the plan of care and accomplish their daily self-care tasks, the burden is still significant. As patients' *workload* demands increase and their *capacity* to manage demands falters due to physical and mental symptoms, patients become overwhelmed and deviate from the plan, which can lead to a worsening of outcomes (Shippee, Shah, May, Mair, & Montori, 2012). One way that patients adapt to the workload of managing their chronic conditions is developing expertise about their condition, characterized by the development of new routines and decision-making processes (Riegel, Dickson,

Goldberg, & Deatrck, 2007). Some researchers have noted that such expertise development, often accompanied by mastery of health-related cognitive artifacts, empowers chronic disease patients to control their quality of life (e.g., Pols., 2012).

Once aware of the patients' care-related workload, clinicians have the opportunity to reduce it, for example, by better coordinating efforts among members of the clinical team or developing comprehensive treatment plans addressing multiple health conditions. Clinicians could also involve patients in decisions involving their treatment so that the priorities of treatment match patients' expectations (May, González, & Mair, 2009).

Collaboration around plans of care also requires that patients and clinicians maintain open and productive lines of communication. Accordingly, strong patient–clinician communication appears to benefit health outcomes (Stewart, 1995). However, studies have also identified factors undermining patient–clinician interaction, including lack of agreement or concordance between patients and clinicians about patient status, goals, treatment priorities, and beliefs (e.g., Street & Haidet, 2011). These patient–clinician communication barriers are notably present for patients living with a chronic illness (Rogers et al., 2000).

In this project, we sought to understand the interactions among patients, members of their close social circles, and their clinicians in the management of the chronic disease, heart failure, to better design effective interventions for this domain. As a research team of human–computer interaction (HCI) and health informatics scholars, we were particularly interested in the roles that technology currently plays in mediating these interactions and in finding new opportunities for technological interventions facilitating plan of care development and performance. We examined a corpus of clinical visit observations and research interviews of patients with heart failure using a combination of inductive open coding and model-based activity-theoretic analysis to reveal the diversity of patient goals, artifacts (computational and otherwise), and supporting community members at play in this complex activity space. As a result of our analysis, we identified eight recurrent interaction patterns centered on the patient, their clinicians, and their support network of family members and friends. We also uncovered design opportunities for interventions supporting heart failure management.

Activity theory as an analytic lens

Because our research questions involved understanding the role of existing practices and technologies in mediating patient–clinician interactions, our initial coding schemes centered on permutations of people, artifacts (computational and noncomputational), and patients' healthcare goals. This orientation directed us toward theories from the HCI and computer-supported cooperative work (CSCW) domains facilitating the exploration of the relationships among these entities. Traditional HCI techniques, like task analyses and the development of personas, did not sufficiently capture the multifaceted nature of the work that we uncovered in our interviews and observations. Activity theory appeared to be well suited to represent these relationships and helped resolve tensions identified during our preliminary analyses.

Activity theory is a descriptive theory that frames how people achieve goals through the mediation of artifacts, social context, social rules, and division of labor (Engeström, 1987; Kaptelinin, 2014; Leont'ev, 1978; Vygotsky, 1978). Activities can be observed at various levels of granularity, depending on who the people are and what goals they are trying to achieve. A common representation of an activity as defined in activity theory is Engeström's triangle (Figure 1, after Engeström, 1987), with the subject, object (or goal of the activity), and tools as part of the upper triangle. The base of the triangle is the social context of the activity and includes the community of practice (or other individuals involved), the social rules moderating the interactions between the subject and this community, and the division of labor used to determine how each represented person in the community contributes toward achieving the goal.

Activity theory has been primarily used in the HCI and CSCW domains to understand and articulate the relationships among people and artifacts within complex sociotechnical systems. The theory has been used in healthcare research, though by and large to study interactions in hospitals such as diagnoses (Engeström, 2000) and surgical coordination (Bardram & Doryab, 2011). Here our focus on the

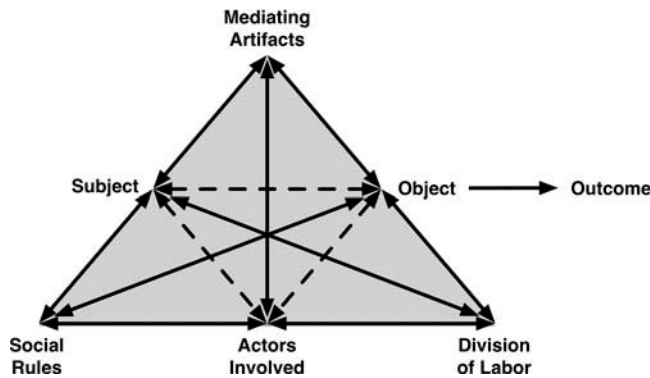


Figure 1. An adaptation of Engeström's (1987) analysis of activity and mediating relationships, reproduced from Voids et al. (2007).

development of patient-facing systems led us to examine chronic care scenarios with the patient as the “subject,” but we also examined the different roles that these subjects could take on as they interfaced with different aspects of the larger task and different aspects of a social and informational context.

Activity theory has also been used as a framework for supporting design (e.g., Gay & Hembrooke, 2003; Kaptelinin, Nardi, & Macaulay, 1999). Examples of activity theory-informed systems are numerous, including, for example, the SAIK project, in which activity theory informed the design of a computer-based patient scheduler for a Danish hospital (Bardram, 1997), and the Kimura system, which did away with the desktop metaphor for personal computers and instead organized data and applications related to specific activities as “working contexts” (Voids, Mynatt, & MacIntyre, 2007). In this research, we used each of our derived activity patterns as the basis for health informatics and mobile health (mHealth) design recommendations.

To facilitate our analysis, we used one of Mwanza's Activity-Oriented Design Method tools, the eight-step-model (Mwanza, 2001, 2013). This model consists of eight prompts that can be answered to identify the actors, goals, mediating artifacts, and social rules governing various activities at play. Because of our domain of study, the usefulness of this methodology stood out as the work to create and maintain a plan of care consists of numerous smaller activities, many of which demand that actors (and artifacts) take on different roles and relations relative to one another. Besides employing Mwanza's methodology, we also examined its suitability for guiding activity analysis in the healthcare space and reflected on ways that this methodology might be extended to more clearly suggest design opportunities in this domain.

Research design

This analysis was performed on data collected from a larger study of heart failure self-care with goals that included understanding patient–clinician interaction. The study was approved by the Vanderbilt University Institutional Review Board, and subsequent analysis of deidentified data was deemed nonhuman subjects research by the Indiana University Institutional Review Board.

Data collection

Participants were 61 English-speaking adults 65–86 years of age ($M = 73.3$, $SD = 6.7$; 52% male, 74% White) and received acute or ambulatory care at a large, academic medical center in the southeastern

United States (a 200-mile radius covering rural, urban, and suburban areas across two states). All had a diagnosis of chronic heart failure (25% systolic, 49% diastolic, 26% systolic/diastolic): 82% had high cholesterol, 90% had hypertension, and 61% had Type II diabetes mellitus. About half (51%) completed 12 or fewer grades of school. Of those reporting, 55% had an annual household income of \$25,000 or less (20% earned \leq \$15,000). Participants gave informed consent for the study and were paid up to \$65 for participation.

Participants were observed during scheduled outpatient specialty and primary care clinic visits; interviewed before or after these visits; observed and interviewed in the home; surveyed with a self-administered paper questionnaire; and (in half the sample) surveyed by telephone prior to and 2–3 days, 30 days, and 90 days after hospital discharge. Combined interviews lasted approximately 90–120 min per participant. Broad interview topics focused on patient characteristics; self-care task performance; artifacts used; and the social, physical, and organizational context of self-care. Clinic visit observations and interviews were audio-recorded and professionally transcribed. We selected a subset of 21 transcripts for analysis in this project, sampling broadly across patient sex, age, and whether patients were living alone. We attempted to have a balanced sample based on these criteria; as a result, our coded transcripts included a gender-balanced sample (57% male and 43% female patients) and covered the full age range of the interview participants (age = 65–86). Of our coded transcripts, 53% were from married patients and 38% were from persons living alone. A full description of data collection methods is available elsewhere (Holden, Schubert, & Mickelson, 2015).

Data analysis

Transcripts were coded using a primarily inductive thematic analysis (after Braun & Clarke, 2006). In the initial step, each member of the research team read and coded the same three transcripts, looking for the information-related activities and the artifacts used by patients to manage information. We reviewed the coded transcript segments together in a series of full-team meetings, developing a shared “code book” for the themes that we collectively saw emerging from our data. This scheme was then applied by three members of the research team to five additional interviews, followed by another meeting to assess the validity and coverage of our initial themes. At this point in the data analysis, we noted a strong orientation of various themes around accomplishing individual and shared goals. This led us to transition to a more top-down analysis of the data, using activity theory as a lens for unpacking the details of various actors’ goal-oriented activities.

For our second analysis pass, we applied Mwanza’s (2001, 2013) eight-step model for coding the remainder of the 21 transcripts. Each of these eight steps operationalizes one of the vertices of Engeström’s Activity triangle (cf. Figure 1) as well as the edges, which represent relationships between entities. We decided to use Mwanza’s model as opposed to a more traditional analysis, as it expedited the analysis process without compromising any of the edges and vertices of activity theory triangles. To mitigate the limitations of this approach, we frequently gathered our findings and reflected on the interaction of people and artifacts within a broader situational context. As part of this analysis, we focused not only on identifying and categorizing constituent parts of each activity pattern but also on understanding the unique role that mediating artifacts and computational technologies played in facilitating (or undermining) completion of each pattern’s “object,” or goal. We also annotated the resulting activity “triangles” with indications of critical edges—the relations that were most frequently under stress or implicated in challenges or contradictions during the interviews and clinical visits.

Results

Eight patterns emerged from our analysis, classified in three broad categories of self-reliance, patient–clinician cooperation, and patient–support group cooperation. Although we initially focused on patterns where patients interacted with one (or more) clinicians, we also discovered patterns in which patients exhibited (or wanted to exhibit) high levels of self-reliance, as well as patterns where

patients interacted extensively with companions, spouses, family members, friends, and other nonprofessionals as part of their self-care practice. In this section, we describe each of these eight patterns, characterized by the roles taken on by the patients, the clinicians, and/or the members of their social circle. We begin with the most straightforward (and, in some ways, desirable) category of patterns, *self-reliance*.¹

Self-reliance

Self-reliance is the pattern in which patients took on an independent role, interacting with their tools to achieve their goals (Figure 2). The instances in which we identified this pattern were characterized by a high involvement of patients in their own care with a low reliance on external help. From an activity theory perspective, this configuration is the closest to Leont'ev's (1978) original formulation: A subject (the patient) uses a series of mediating tools (typically, artifacts including medications and self-care plans) to perform self-care and accomplish a desired object(ive) (staying healthy). In our interviews and observations, this reflected a—more or less—stable set of daily practices and an empowered patient.

Self-reliance was one of the most common patterns in our analysis. We coded 86 passages in which participants talked about their own self-reliant practices or—more commonly—discussed self-reliance as an unrealized ideal. Overall, the pattern was present in data collected from 86% of our participants.

We saw instances of self-reliance that related to several facets of self-care, for example, diet:

It's the patient's—unfortunately—responsibility to be educated as to what they can eat and what they can't eat. ... It's not the end of the world if you have a piece of cake once at a party. It is if you do it daily, necessarily, but put it into—the social event into context—I mean you're not, anyway [laughs] unless, unless you want to wear a hospital gown to the party and just play patient big time and maybe walk around with an I.V. bottle and let everybody know that you know you're, you're a basket case. (V018)

In this case, the patient had a clear goal, understood the role that diet plays in achieving that goal, had the tools in place to evaluate the efficacy of the diet, and demonstrated independence in the reflection that occasional lapses will not affect the goal's realization.

Self-reliance does not necessarily imply that achieving or maintaining a goal is easy. The same participant, V018, mentioned the burden associated with taking care of himself: “I—I don't mean that sarcastically or facetiously, it's—being a heart patient is a full-time job” (V018).

Some patients in our sample adopted an increasingly *self-reliant* attitude toward their treatment after they or someone else that they know experienced a setback in health. For instance, one participant described packing 2 weeks of extra medications when traveling, after a deceased friend of his ran out of medications on an extended vacation.

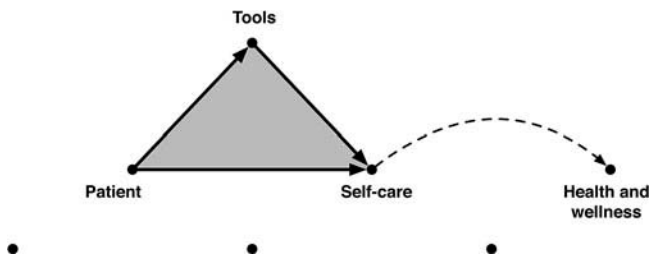


Figure 2. A schematic diagram of the self-reliance pattern, the pattern which hews most closely to the original, Leont'ev conception of activity theory. *Note.* In each of our activity theory representations (after Engeström, 1987), the subject represents the patient (based on our patient-centered analysis), and the outcome represents a high-level desire to be well or healthy. The other vertices are labelled as appropriate for each scenario. Shaded regions represent the critical relationships within the pattern, and heavily emphasized edges represent the critical relations—those that are most potentially prone to contradictions.

Some patients talked about self-reliance as an unattained “gold standard” in self-care. As patients were trying to meet this standard, they sometimes drifted from their goal by resorting to maladaptive practices (e.g., procrastination). We identified approximately 35 incidents of intentional nonadherence in the data, such as repeatedly postponing taking medications or self-administering additional doses.

Implications for mediating tools and supporting technologies

Successful instances of self-reliance reflected patient independence and implied the need to support continued self-care while minimizing the overhead. In the many instances in which self-reliance was not achieved, mHealth technologies could help build and maintain good habits; remind patients about the details of their plans of care; and facilitate connections to a support network of clinicians, family members, or friends (Baumer, 2015; Nunes et al., 2015).

Self-reliance: Patient as innovator

The *patient as innovator* pattern emerged during our second round of coding, as we examined a larger pool of transcripts and closely examined data on goal-oriented activities. In the end, we found instances of this pattern in over half of coded transcripts (59%).

The *innovator* pattern (Figure 3) is one in which the patient goes beyond simply carrying out an existing plan of care and begins improvising new approaches and solutions. The patients we qualified as “innovators” were individuals deeply involved in co-creating their treatment plans with their clinicians. They asked more questions of their clinicians and shared more information with them than did other patients.

In some instances, innovators made independent decisions about actions to take or not take. Although this could be considered noncompliance or nonadherence—a potential friction point we subsequently discuss—when this happened, some patients did discuss their decision with clinicians:

Nurse R.: . . . that steroid has probably gotten out of your system. So you’re starting to seeing [*sic*] the decline in your blood sugars.

V018: I thought, I—I thought I needed to just let you know that I had not been taking the medication, however not out of noncompliant, just that occasionally happens with the—uh, but I just thought it was fascinating that even without the medication—you know, 198’s not good—

The two patients (V018 and V005) with the most instances of innovator behavior also exhibited the most self-reliance, suggesting that having a grasp on effective self-care is a prerequisite to pushing the boundaries of self-care or appropriating artifacts or technologies. Patients exhibiting both innovator and self-reliance patterns demonstrated much greater empowerment than other patients.

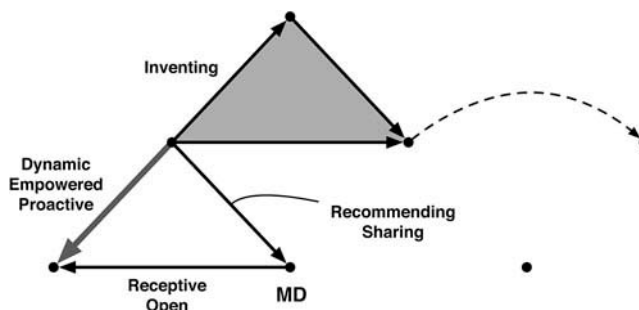


Figure 3. A schematic diagram of the patient as innovator pattern. *Note.* In this case, the patient is the primary actor, driving the innovations and propagating them to the rest of the care team.

Implications for mediating tools and supporting technologies

Technologies that assist patients in formulating questions to ask their clinicians might help to promote the innovator pattern. Because the innovator pattern also frequently describes patients who develop their own artifacts and tools, this is a population that might benefit from platforms that allow experimentation and prototyping using one's own medical record data and various mobile sensing devices and computing interfaces (see also Storni, 2010). Innovators seem likely to benefit from systems promoting self-reflection and could potentially play active roles in participatory design workshops to design new tools for others with similar medical conditions (e.g., Marcu, Bardram, & Gabrielli, 2011).

Patient–clinician cooperation: Physician as coach and coordinator

The *physician as coach/coordinator* pattern (Figure 4) appeared in 82% of coded transcripts. We observed it most frequently during observations of clinical visits, as clinicians asked patients for status updates since the last visit and used this information to adjust the patient's plan of care, including additional clinical appointments or referrals.

Dr. K: You could need medication if the symptoms persist for, say, another two more weeks—yes, I will be a little worried. Do you have a primary care doctor?

V013: Hmm-hmm [affirmative].

Dr. K: I would highly recommend giving them a call because it, you know—

V013's companion: Well, she goes to see him next month.

Dr. K: When you have a primary care doctor . . . you want to make sure that there are a couple of people seeing you when we're not seeing you back maybe as quickly. . . .

As part of their coaching, clinicians instructed the patients and often coordinated with patients' other clinicians:

Dr. O: I'll have to make a lot of phone calls to Dr. [M] and others. Um, I would like you to keep on doing what you're doing in terms of managing your—your pressure—

V003: Hmm-hmm.

Dr. O: —your, monitoring your—your—um, your weight, uh, and your sugars.

V003: Okay.

Dr. O: And then I'll get back in touch with you about any tinkering we're going to do with the blood pressure medications and, and other things. Okay?

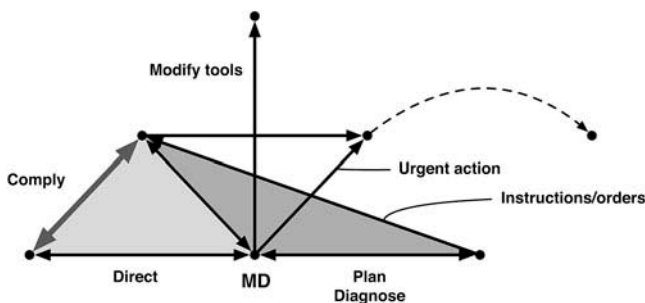


Figure 4. A schematic diagram of the physician as coach and coordinator pattern. *Note.* Here, the clinician(s) play a central role in diagnosing the patient's condition and establishing the plan of care, but it is up to the patient to carry out the actions implicated in that plan of care; the clinician(s) have no direct influence on the accomplishment of the goal.

A fundamental aspect of this pattern (illustrated with emphasis in the activity theory diagram; [Figure 4](#)) is that, in our observations, the clinicians were not normally in a position to directly affect the attainment of the object/goal; instead, they relied on patients to adhere to the recommended plan of care.

Contradictions within this pattern took a number of forms. Some were cases of intentional nonadherence on the patient's part. In other cases, contradictions resulted from conflicting instructions or plans of care for multiple conditions:

S011: No, but I should drink a lot of water because of the urinary, uh, —

I2: The urinary tract infection.

S011: — the urinary tract infections.

S011's companion: Even though there was once where they advised not to drink a lot of water . . .

S011: Yeah, that was funny.

Both types of contradictions were exacerbated when patients' and physicians' short-term goals differed. For example, patients described choosing between following a physician's advice and being hospitable to guests when constructing a menu. These cases were characterized by patients resorting to ephemeral reprioritization of other goals or activities and reinforce the highly socially situated nature of these chronic care activities and the importance of communication in negotiating rapidly changing goals and roles (see also [Mol, 2009](#)).

Implications for mediating tools and supporting technologies

Since the physician as coach/coordinator pattern relies on the alignment of patients' and clinicians' goals and commitment to a shared plan of care, technology should aim to facilitate shared decision making and care planning.

Technologies that help clinicians understand patients' goals, preferences, needs, and routines might enable clinicians to develop plans of care that more closely match the contour of patients' lives and improve adherence. Communication technologies, including secure patient–clinician e-mail ([Wade-Vuturo, Mayberry, & Osborn, 2013](#)) and pre-visit communication systems ([Kinnersley et al., 2008](#)), could facilitate coaching and information sharing.

Patient–clinician cooperation: Clinician as “scientist” and patient as data provider

Many patients generate data at home via self-measurement devices—scales, blood pressure cuffs, and so on—and log it for subsequent review by clinicians during clinical visits ([Mickelson, Willis, & Holden, 2015](#)). These data are usually manually logged on paper, or in a few instances electronically. Whatever method is used to capture the data, the *clinician as scientist and patient as data provider* pattern ([Figure 5](#)) relies on the patient to communicate data to the clinicians. Clinicians then interpret the data and act by, for example, making diagnoses, updating the patient's plan of care, or making changes to the data-collection instructions for subsequent visits. This pattern appeared fairly frequently in the transcripts, with 35 coded instances. The pattern was present in 64% of our coded transcripts.

Several potential friction points exist in this pattern. In some transcripts, patients were found to be logging data inconsistently or inaccurately—for example, forgetting to log, attempting to reconstruct data after the fact, or choosing not to log: “Well, really I'm supposed to weigh myself every day. They told me that once before, but I don't and I supposed to record it too, you know. I haven't done that in a long time” (V010).

Implications for mediating tools and supporting technologies

Computational interventions related to this pattern could include tools to facilitate or automate collection of health data at home, such as the whole-home or environmental sensing systems proposed by [Adib, Mao, Kabelac, Katabi, and Miller \(2015\)](#) and [Yun, Jeong, Lee, Arriaga, and](#)

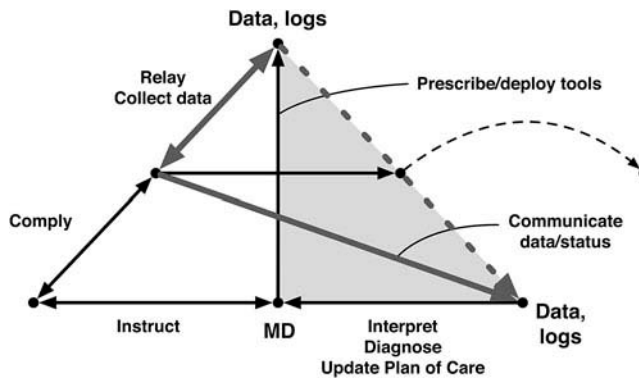


Figure 5. A schematic diagram of the clinician as “scientist” and patient as data provider pattern. *Note.* In this pattern, the physician configures the mediating artifacts to enable the patient to collect data about the evolution of his or her condition and facilitate diagnosis. However, it is up to the patient to realize those self-tracking activities, a key point of potential contradictions in the pattern.

Abowd (2010). Systems could also support self-reflection and discovery of health trends. However, the age, computer experience, and economic means of patients with heart failure may still pose practical challenges for data collection and visualization technologies.

The second area for potential technology design is communicating logged data to clinicians. In most cases today, patients are in charge of logging and hand-carrying the data to their clinicians. Devices automatically recording data and enabling clinicians to retrieve them as part of a visit (e.g., Andersen, Bjørn, Kensing, & Moll, 2011; Bardram et al., 2013) are still not widely used and often rely on patients physically bringing the device to their appointment. Automatic transmission of data to centralized health record systems could be one possible solution, with machine-learning technologies assisting clinicians in detecting divergences from normal routines or patterns in the large data sets.

Patient–clinician cooperation: Building trust and relationships

In this pattern, patients and clinicians share personal information that helps build *trust* (Figure 6). Although the information itself is not directly relevant to the patient’s medical outcome, the resulting trust may make patients more inclined to follow clinician’s directions (Heiden, Holden, Alder, Bodke, & Boustani, 2017; Lee & Lin, 2009). Among the patient–clinician patterns, we only found 13 instances of this construct (present in 32% of the coded transcripts), but these instances stood out as being particularly impactful, especially during difficult times: “My doctor would meet me in the hall and he’d say, ‘Well, if

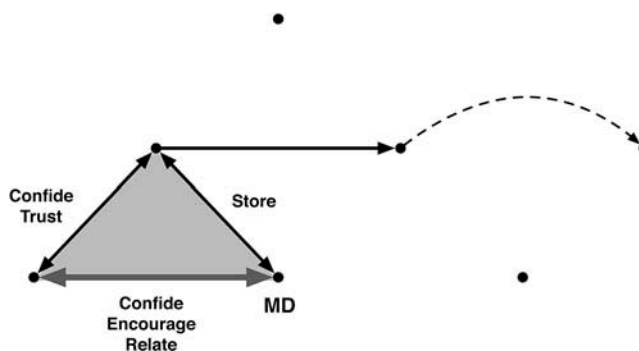


Figure 6. A schematic diagram of the building trust and relationships pattern. *Note.* This pattern focuses exclusively on the relationship (i.e., social rules) between the patient and the clinician and has little direct impact on attainment of the goal.

you're (still in the hospital on) Christmas Eve, I'll come back and have dinner with you” (V013). Personal conversations occurred throughout clinical visits, and in some cases long sequences of non-health-related conversation were quickly followed by patients sharing key health information or asking questions about their plans of care. In others, informal conversations about everyday life (e.g., upcoming holidays) served as common ground for clinical recommendations (e.g., following a dietary recommendation to avoid experiencing a hospitalization during those holidays).

Implications for mediating tools and supporting technologies

Existing technologies could better facilitate trust or *relationship building*. Existing patient–clinician communication technology (e.g., patient portals), exam room screen-sharing or tablet use, and simple visual aids could be more explicitly designed to facilitate trust, belonging, comfort, and communicative proximity rather than mere information exchange (e.g., Aarhus, Ballegaard, & Hansen, 2009; Jordan, Alexandra Silva, Nunes, & Oliveira, 2013).

Patient–support network cooperation: Distributed care

Despite an original orientation toward patient–clinician interaction patterns, our analyses revealed a broad spectrum of other relationships playing a key role in patients' disease management (Mickelson, Unertl, & Holden, 2016). Often, these relationships reinforced, augmented, or cut across direct patient–clinician relationships.

For married patients, the spouse often played an important role in directly managing the patient's disease. The *distributed care* pattern (Figure 7) captures the sense of all the different roles that an informal caregiver or “care partner” may play, depending on the division of labor within the particular household:

S005: Boy, they changed the names of that, you know, medicine so often that I have trouble keeping up with any of 'em. [3-s pause]

Nurse practitioner: You know what? I think you do it—a very good job.

S005: Well, I've got my secretary [daughter]. She takes care of it for me.

Care partners in the distributed care pattern can sometimes feel overwhelmed by the work for which they are responsible. Care partners in our sample expressed the need to manage their own personal

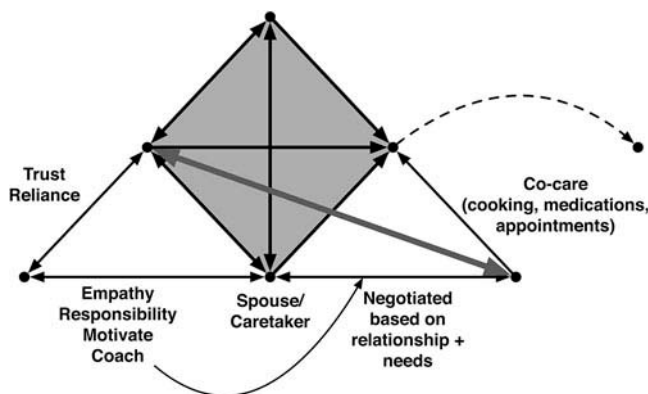


Figure 7. A schematic diagram of the distributed care pattern. Note. Here, the social context focuses on the patient's care partner (s) and the delicate balancing acts involved in establishing (or maintaining) social rules and division of labor in order to facilitate consistent, high-quality care when the patient cannot perform all of the plan of action tasks on his or her own.

lives while managing appointments, medications, logs, and nutritional cooking for the patients. One care partner described the difficulty of balancing care and her own needs:

V017's companion: It does keep me depressed some because it's constant. I got laid off from my job last March ... which is probably a blessing because since that time he's had three cancers and all this trouble and I've had to take him to chemo and radiation and just you know do all that, and that, it's not hard, but it's—it's time-consuming. It's hard when you're not used to it and I would like to be back working again. ... I miss people. ... But I can't—you know, I can't do that until I know that he's going to be okay.

Not surprisingly, the amount of caregiving workload a care partner experienced varied with the patient's level of self-reliance in managing their own disease. Furthermore, the patients who did not have a live-in spouse or care partner reported having higher workload and feeling more overwhelmed than patients who did. However, instances of distributed care appeared in interviews with patients in assisted living facilities or receiving professional home care, indicating that a variety of individuals can belong to a caregiving support network (Kemp, Ball, & Perkins, 2013).

The distributed care pattern appeared relatively frequently (57 instances, present in 77% of the coded transcripts). However, because only 52% of the patients in our sample were married, this indicates that a nontrivial number of our participants were seeking out and finding this kind of intensive distributed care assistance from other sources.

Implications for mediating tools and supporting technologies

Technology that supports the distributed care pattern should make explicit what patients expect from caregivers and what caregivers are actually doing, for example, shared to-do lists. Literature also indicates not all instances of distributed care are productive or even helpful (e.g., Corbin & Strauss, 1984). Goal misalignment between the patient, clinicians, and members of a patient's distributed care team or miscommunication can lead to undesirable outcomes. Therefore, technologies should strive for shared awareness, clear communication, and representation of multiple goals (Mickelson & Holden, 2015).

Patient-support network cooperation: Sensemaking

Some patients appeared to have somebody in their social network to help make sense of healthcare-related information. These individuals—generally patients' partners or children—served as interpreters or *sensemakers* of health information, relaying it to the patients using familiar terms and guiding patients' decisions (Figure 8). The main distinction between this pattern and the distributed care pattern is that sensemakers do not usually *act* on behalf of the patient but serve a more translational or advisory role.

In our dataset, patients relied on their sensemaking care partners during hospital visits, such as the following example in which a care partner interpreted a doctor's instructions for the patient:

V007's companion: Do you wanna hear what [the doctor] said?

V007: Yeah.

V007's companion: Yeah. [laughs] Your heart rate took off. When you have an infection—

V007: Oh.

V007's companion: —the medicine you're on normally doesn't regulate—can't regulate your heart rate, so that's why it—remember when we were in the hospital and it went up so high?

This was a significant, if infrequent, pattern (11 coded instances, pattern present in 32% of the transcripts). Because some patients were so reliant upon their sensemakers to keep up with new procedures, changing plans of care, and changing medications, those who exhibited this pattern typically did not demonstrate particularly high degrees of self-reliance.

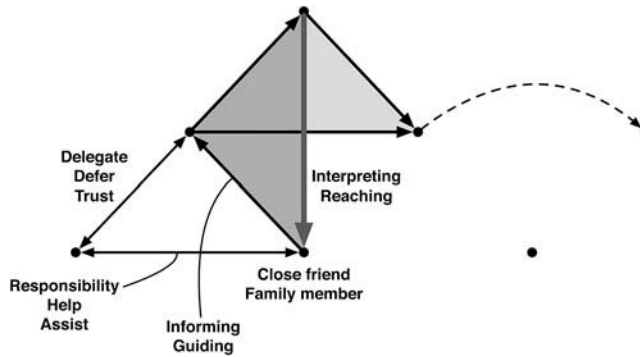


Figure 8. A schematic diagram of the sensemaking pattern. *Note.* Like the distributed care pattern, the focus here is on the relationships between the patient and the care partner(s); however, this pattern differs in that this assistance is focused more on tracking the plan of care and interpreting the mediating artifacts provided by the clinician and other members of the medical establishment.

Implications for mediating tools and supporting technologies

There are two ways to approach the design of technologies for the sensemaking pattern: Either patients can be assisted in understanding the information that they possess but cannot comprehend—thus making them more self-reliant—or technology can support the current pattern of care partner sensemaking by making it easier for the care partner to access and translate information for patients.

Making information easier to comprehend for patients is a challenge that both the medical communities and the HCI/CSCW communities can address. Designing, developing, and promoting tools that assist patients making sense of their data through computer-generated insights or better visualizations can address the mostly unmet expectations for self-reflection tools for chronic illnesses (MacLeod, Tang, & Carpendale, 2013).

Technologies to improve sensemaker access to information could include secure, network-connected healthcare appliances and better third-party access to online health records and plan of care information.

Patient-support network cooperation: Advocacy

In a few cases, companions who accompanied patients to the clinical visit answered questions on the patients' behalf, ensured that patient reports were accurate, and made certain that the clinician was adequately attending to the patient's needs and concerns. The *advocacy* pattern (Figure 9) symbolizes the complex division of labor that occurs in these scenarios.

In the following example, a patient's wife asked about the anticoagulant that her husband was taking. Her question allowed the doctor to provide information that she thought was useful for the care of the patient.

V007's companion: I, I have a question about the Cou—

Dr. P: Yeah.

V007's companion: —he got his Coumadin. They told him, “Go—go—go get your Coumadin checked on Monday” ’cause they said something about the antibiotic could make the Warfarin, you know, worse—make it thinner.

Dr. P: Yeah. So did they?—

V007's companion: So, we took him in—

Dr. P: —did he have?—

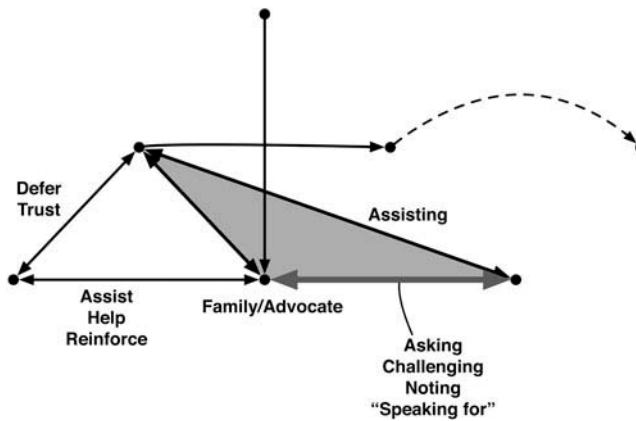


Figure 9. A schematic diagram of the advocacy pattern. *Note.* In this pattern, the patient delegates important communication and representation tasks to a trusted friend or family member.

V007's companion: —and they said that—well, they said, we'll—we'll call your doctor, we're—we're not gonna call you and tell you what it is. In the past, they just called them, and so—

Dr. P: It was 2–1/2.

V007's companion: Okay. That's good, okay.

The key to this pattern is defining the role the *advocate* will play in representing the patient. An effective advocate needs to have the patient's support and an appropriate level of assertiveness to represent the patient's interests. Advocacy is one of the rarest patterns connecting patients and members of their personal social networks, appearing in only 18% of transcripts (15 coded instances, overall).

Implications for mediating tools and supporting technologies

Our analysis of the advocacy pattern suggests two design paths. The first is helping advocates be more effective in their role. A variety of technologies could facilitate communication among the patient, the clinicians, and the patient's advocate. For example, technologies allowing remote communication during clinical visits could help advocates assist patients during clinical visits, when the advocate cannot physically attend.

The second design direction is empowering patients to take on their own advocacy duties, particularly when family members, friends, or others are not present or available. In these cases, technology might be used to prompt questions to be asked during clinical visits. In our interviews, patients sometimes mentioned the lack of an easy way to capture and recall questions to ask physicians at upcoming visits. Prospective memory technologies might help patients to remember the questions they want to ask or present computer-generated questions to help prompt questions related to their specific condition or plan of care.

Discussion

Above and beyond the eight fairly distinct patterns emerging during our analysis of patient interviews, our application of Mwanza's (2001, 2013) activity theory-based methodology highlighted the multiplicity of goals, artifacts, and social systems at play—and the various roles that individuals could take on under different circumstances.

We noted that individual patients' realization of a single healthcare object/goal can seldom be fully expressed with a single pattern. Instead, a more accurate representation would require the juxtaposition of several patterns, a common occurrence in activity theory analyses. This observation

helps to explain the frequent co-occurrence of several patterns across our dataset, validates the idea that activities (in the activity theory sense) often coexist and compete with one another, and suggests additional opportunities for the design of mediating tools and supporting technologies.

Juggling multiple roles

More than one third (41%) of our participants talked about their experiences juggling multiple roles simultaneously—over and above simply being a patient. Three patients were also responsible for managing the health of a close family member, which included setting up appointments on the family member’s behalf; going to the clinic(s) with them; refilling, preparing, and dispensing their medications; cooking and cleaning for them; and providing them emotional support. All of this work must happen without neglecting the work required for managing their own health. These patients often showed great self-reliance; they had evolved strategies to speed up their daily routine so that they had more time to help the person they were assisting. Often, the innovator pattern was also present, as these patients created shortcuts and optimizations to help streamline both sets of healthcare goals.

One patient talked about taking care of her mentally-ill sister, which added a lot of work to her already-busy healthcare routine as a patient with chronic heart failure:

I make sure that [my sister] gets her nutritional requirements met, her doctor appointments, you know I take her to those ... to make sure that she’s being cared for appropriately. ... Tell her what she, you know, what she needs to do for the day and—and then most of the time it requires me to, several times to have to go back and remind her or back, I’m checking on you about this, not trying to drive you crazy, but you know it needs to get done. ... (V016)

Juggling the health-related work for two people implies that patients are unlikely to adopt any tool or technology that does not significantly reduce the already high demands on their cognitive resources, physical effort, time, and attention. Therefore, the bar for novel technology design may be quite high as patients will likely have little tolerance for poorly designed or badly executed technological interventions. Technologies must minimally be workload neutral, that is, adding only as many demands as they take away.

Multiple competing goals

Besides the complexity of juggling multiple activities, our analysis revealed evidence of patients, clinicians, and members of the patient’s broader support network engaged in similar activity but toward divergent objects or goals. It was not uncommon that patients and clinicians were motivated by different outcomes or used different measures of success. In our data, we saw examples of misaligned goals, for example, between the clinical goal of pharmacologically managing edema (fluid retention) and the personal goal of having an uninterrupted road trip:

V017: So I didn’t want to be, uh—be stopping on the road every fifteen minutes (to urinate).

I4: Yeah, a lot of people complain about that.

V017: So I didn’t take [the diuretic medication] then for several days in a week or two-week time.

V017’s companion: He’s on a large dosage of it and when he misses it, it just—he can miss like two days and tell it.

V017: I’d be in trouble. Went in and when [the doctor] says, “Have you been taking your medication?” No, yeah.

Self-modifying medication use to achieve a goal was frequent. Further, in other analyses we showed that these modifications are often not reported to clinicians and at times result in hospitalization or

harm (Mickelson & Holden, 2017; Mickelson et al., 2016). This is a serious issue warranting further investigation and experimentation with intervention strategies.

A disconnect between patient and clinician goals is also illustrated in narratives about unnecessary polypharmacy, or the taking of multiple prescription medications, particularly following medication changes during a hospital stay:

I said, “I just swallowed 15 tablets. . . . You need to call that hospital and find out what they were, because I don’t know.” [The physician] said, “Why would you do that? Why did you take 15 tablets?” . . . I said, “They told me that I needed ’em, so I took ’em.” But he said, “No, you didn’t need ’em. You could refuse them.” (V021)

This issue is caused both by a lack of clear communication among the activity participants and a lack of awareness about the amount of autonomy that the patient should have in the matter. Consequently, the presence of *multiple competing goals* suggests the important role of communication, information sharing, and accountability preserving technologies that explicitly encode objects/goals and desired outcomes and that are expressly designed to mediate conflicts among participants. In this particular case, it also resonates with the increased national attention given to overprescription, a problem that often occurs because various specialists do not coordinate in their prescription of medications. This illustrates an opportunity for technologies that give patients a voice in the development of the holistic plan of care and raise awareness about potential problems with how a plan of care is evolving as more health providers become involved.

Strengths and weaknesses of activity theory in this work

The operationalization of activity theory by Mwanza (2013) proved to be immensely useful for our study. Despite limited analytic resources among our small research team, her eight-step approach effectively catalyzed discussions about the shifting roles of and expectations and goals held by patients, clinicians, and other members of the patients’ care networks. It also enabled us to quickly understand how competing perspectives and goals could help to explain the conflicts and breakdowns that were so clearly described by our participants in their stories about their experiences.

Although many of our findings resonate closely with other research efforts spanning HCI, health informatics, and the medical community, we cite this as a particular strength of Mwanza’s activity theory approach. Even with a (relatively) limited set of qualitative interview data, we were able to independently triangulate issues that have been raised by others in the field—and uncover inspiration for applying interventions initially designed for multiple communication, collaboration, and coordination tasks to various facets of a specific healthcare issue: chronic cardiac care.

Limitations of the study

One of the major limitations of the study is that the analysis was conducted on interviews and observations that were not collected for that purpose but part of a broader study; we were thus limited in our ability to dig deeply into specific facets of patient–artifact–community relationships with the participants, as our analysis emerged from the data after the fact. In addition, the interviews were all conducted in the vicinity of a single, large city in the southeastern United States and may therefore not be representative of patients with other chronic conditions, who live in other regions, or who represent other cultures. Furthermore, not all transcripts included both the in-clinic and in-home interviews (more in-home interviews were represented than in-clinic interviews), causing a potential overrepresentation of the patterns connecting patients and members of their personal social networks, relative to the patient–clinician patterns.

Conclusions and future work

Activity theory proved to be a valuable lens to study the complex relationships among patients with chronic heart failure, their goals, the artifacts they are using, their clinicians, and the members of their support networks, including family and friends.

In this article we identified a number of distinct patterns from our analysis, including two patterns describing various levels of self-reliance (self-reliance, patient as innovator), three patient–clinician patterns (physician as coach/coordinator, clinician as “scientist” and patient as data provider, and building trust and relationships), and three patient–social network patterns (cooperative care, sense-making, and advocacy). We also examined some of the ways that these patterns overlapped and conflicted, even within individual patients and their surrounding communities of practice.

We also extracted a number of important design guidelines for the creation of more patient-empowering health systems from our analysis:

- Assisting patients in self-reflection around healthcare practices and data.
- Automatically collecting medical data at home.
- Sharing information between patients and clinicians prior to hospital visits.
- Reducing barriers between clinicians and patients during clinical visits; and improving the communication among patients, clinicians, and care partners.

This research demonstrates the value of applying an activity theory-based analytic methodology for making sense of nuanced relationships in the specific situations that patients with chronic heart failure commonly face. Our work also suggests a broad variety of future research in developing mHealth platforms, services, and systems for this—and other—chronic health conditions.

Notes

1. In our Results section, participants are identified based on their participant numbers (e.g., S005 or V008), interviewers are indicated with the letter I, and clinicians are referred to based on their title/position and the first letter of their pseudonym (e.g., Dr. P).

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