“It’s not just technology, it’s people”: A Conceptual Model of Shared Health Informatics for chronic illness

ABSTRACT

Background: Chronic illness is a substantial public health burden and the day-to-day work of a person with chronic illness is central to illness management. However, although management programs are available to train people to manage their chronic illnesses, those programs rarely provide people with sufficient guidance on implementing fine-grained management strategies. This lack of guidance transfers much of the burden of day-to-day management practices to people with chronic illness.

Objective: To decrease the management burden many people have created technological solutions, but we claim that to be maximally effective and tailored to people’s needs, those solutions need to be informed by a model that integrate patient work and self-management frameworks with personal health informatics models. We see an opportunity to improve personal health informatics models to (1) incorporate the ongoing nature of management work, and (2) append a social dimension to more accurately depict the context of illness management.

Methods: We used qualitative methods to analyze the chronic illness management practices of 63 people through the lenses of self-management and informatics frameworks.

Results: Analysis results are distilled into a new Conceptual Model of Shared Health Informatics. We describe the people and work involved in chronic illness management and contribute a Conceptual Model of Shared Health Informatics depicting the process of chronic illness management in a social context.

Conclusions: Through insight into management work provided by our Conceptual Model of Shared Health Informatics, technology designers and implementers can improve the quality of chronic illness management tools to ensure confident and capable management of chronic illness.

Keywords: Personal health informatics; Quantified Self; patient work; self-tracking; self-monitoring; model; patient generated data; patient reported outcomes.

INTRODUCTION

Chronic illness is the leading cause of poor health, disability, and death, contributing to high healthcare costs—accounting for up to 86% of health care spending [1]. Over half of Americans have a chronic illness1, with 25% having more than one [2]. Management strategies are essential to living with chronic illness. People pursue management of chronic conditions within the constraints of their everyday lives [3,4], but healthcare providers are usually unable to tailor management programs to individuals, thus transferring the burden for implementing the fine-grained, day-to-day management practices to the person with the chronic illness. We need to support people in implementing effective management practices within the constraints of their lives to help them manage their chronic illnesses effectively [5]. (We refer to “people” rather than “patients” throughout this paper to acknowledge the whole person who manages a chronic illness, and not just their “patient” role, which may not resonate in settings outside of a clinic; management activities take place, overwhelmingly, in the course of normal day-to-day living [6,7]).

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1 The World Health Organization specifies that chronic illnesses ”tend to be of long duration and are the result of a combination of genetic, physiological, environmental and behaviours factors.”
Many new personal informatics tools—such as continuous glucose monitors, activity trackers (e.g., Fitbit), heart rate monitors, and smartphone apps (e.g., OnTrack)—promise to ease the work of management. However, individuals managing chronic illness who use these tools often experience barriers to effective use. These barriers include difficulties with: (1) deciding what data to collect and what tools to use, (2) using tools, (3) collating and formatting data, (4) understanding and reflecting on the data, and (5) formulating action plans based on the data [8]. Despite these barriers, many people routinely collect personally salient information to improve health and enhance quality of life [9,10]. Understanding the process of how people manage data and information for day-to-day chronic illness management is critical for developing personal health informatics tools that enhance management skills for confident, capable, and effective management of chronic illness.

In this study, we articulate the lived informatics process of chronic illness management. We know from the chronic illness self-management and patient work literature that self-management is not just about the “self”—many people are involved [5,7,11]. Other informatics models do not adequately represent these other people. To meet the need for an accurate informatics model including the social context of managing chronic illness, we construct and present the Conceptual Model of Shared Health Informatics (CoMSHI, pronounced com-she). We developed the CoMSHI by analyzing 29 video transcripts of Quantified Self (QS) speakers managing different chronic illnesses, 20 interviews with a community sample of adults managing Type 2 diabetes, and 20 interviews with a community sample of adults managing their children’s asthma. We evaluated these data sets in the context of self-management and personal informatics frameworks to inform the proposed CoMSHI.

The contribution of this paper is a Conceptual Model of Shared Health Informatics depicting the lived informatics process of chronic illness management in the person’s social context. This paper describes the components of the CoMSHI and relationships among those components toward the goal of supporting design of informatics tools that align with chronic illness management work [7].

**RELATED LITERATURE**

Our research builds on and extends literature in self-management of chronic illness and self-tracking, including personal and health informatics models.

**Self-Management of Chronic Illness**

Looking at the management of chronic illness from the person’s perspective, Holman and Lorig [5] describe self-management as consisting of three parts: (1) managing medical activities, (2) developing or maintaining new life roles or new meaningful behaviors, and (3) coping with the emotional impact of illness. Corbin and Strauss [11] define three ‘lines of work’ a person undertakes in self-management including illness work, everyday life work, and biographical work. The Chronic Illness Trajectory is composed of these lines of work. The patient work framework [7] incorporates these activities and relates them to the personal, social, and environmental contexts in which a person lives. This individual-level angle affirms the considerable effort required for managing chronic illness and the impact on other parts of the person’s life [6]. While acknowledging the many other types of work and contexts in which a person engages, this paper focuses on medical activities and illness work in the social context.

Wagner et al.’s Chronic Care Model (CCM) [12] is an interventional model designed to improve chronic illness care and consists of six components: (1) health care organization, (2) community resources, (3) self-management support, (4) delivery system design, (5) decision support, and (6) clinical information systems [13]. Redesigning care using the CCM appears to improve care and health outcomes including in people managing diabetes and asthma [14]. Wagner et al. [12] emphasize that a person’s self-efficacy is essential to self-managing her condition, and remind us that the person’s social circle and community resources play a vital role. Although Wagner et al. [12] mentioned only clinical information systems
affected by information technology [15], subsequent studies have examined the use of information technology as it relates to, or supports, other components of the CCM [16,17], for example by supporting patients in their daily decision-making [17]. Here we see an opportunity to build on the CCM evidence through informing better chronic illness management support.

**Self-Tracking**

To manage chronic illness, people often need to monitor their symptoms and their health by collecting data such as symptom and clinical parameters. Tracking can be an effective part of managing chronic illness, improving health outcomes [18] as well as communication with healthcare providers [19]. The Pew Internet & American Life Project [10] recently reported that 69% of Americans track health data for themselves or a loved one. As of 2013, 19% of adults with no chronic illness tracked a health factor, while 40% of those with one chronic condition engaged in tracking and 62% of adults with two or more chronic illnesses track one or more health factors [10].

As a larger proportion of people managing chronic illness participate in health tracking, healthcare providers and researchers need to understand the process they use as well as the ecosystem in which they are situated. Moreover, advances in information technology enable people to use various technological tools for tracking their condition, but limited evidence supports the efficacy of using these newer tools to accomplish successful management [20]. Barriers to successful self-tracking identified in prior research include: (1) insufficient support for patient- or tracker-provider collaboration [21], (2) lapses in use of tracking tools due to barriers in making sense of accumulated data [22], and (3) difficulty in remembering to track or deciding what to track [23].

MacLeod et al. [24] interviewed 12 people with a range of chronic illnesses who tracked some aspect of their health. The authors found that people wished to understand the unique ways their illnesses affected their lives, within the context of information obtained from healthcare providers. For people with diabetes, Mamykina et al. [25] developed MAHI—a mobile tracking and communication tool. Their work revealed that, even with coaching from a diabetes educator, people newly diagnosed with diabetes struggled with developing management self-efficacy and reflective thinking skills with respect to the data they captured. Our research seeks to complement this study through understanding the process by which other successful trackers meet this goal.

**Personal Informatics Models**

Three personal informatics models have articulated the process through which people track relevant health information: Li et al., [17]; Epstein et al., [22]; and Swan [26]. Li et al. [17] and Epstein et al. [22] focus on general informatics, while Swan [26] discusses informatics in the context of health. We describe this research in more detail below, and note that they informed the iterative qualitative coding process described in the Methods section.

Li et al. [8] conducted an interview study of 11 self-trackers to derive a stage-based personal informatics model. Their model describes the process of general self-tracking for any purpose, and is composed of preparation, collection, integration, reflection, and action stages. This model focuses solely on the stages through which a single person progresses in self-tracking. The authors highlight the dependencies between each stage: a mistake in preparation can cause someone to collect the wrong data, and these problems then cascade to the integration, reflection, and action stages. Whooley et al. [27] expand on the integration stage of Li et al.’s personal informatics model with a discussion of why people track and how they integrate their data. More recently, Mamykina et al. [28] studied the process of “self-discovery” in a structured diabetes education program, showing how self-tracking can assist in scaffolding learning and reflection on cause-and-effect understanding of diabetes management.
The personal informatics model describes an ideal process for tracking, but that process can break down when it encounters the realities of everyday life [29]. To describe tracking in everyday life, Epstein et al. [22] propose the “lived informatics” model. The lived personal informatics model is based on 184 surveys and 22 interviews on self-tracking behaviors for physical activity, location, and finances. The authors refined Li et al.’s model by dividing its original preparation stage into two stages: deciding and selecting. Introducing a cycle named tracking and acting, they describe an iterative progression through collection, integration, and reflection. Finally, this model anticipates that people will lapse either temporarily or permanently.

Swan [26] proposes a model for personally-driven health and health care that includes self-tracking among the actions in which people might engage. Swan represents the social context and health outcomes, but they are secondary actors in the model and the evidence base for the model is unclear. Our research finds that, rather than being on the periphery, people other than the person with chronic illness are central to management.

**Social factors of self-management**

Using the models described above as reference points in addition to open coding, we define a model for personal health informatics informed by the experiences of people who are managing a chronic illness. Although much research has focused on tracking for general health and wellness (e.g., [30–32]), people who live with a chronic illness have further tracking requirements central to illness management that provide a rich opportunity for understanding through research. Furthermore, research examining the lived experiences of self-tracking find that this act of tracking is often coordinated or influenced by communication with health experts (e.g., [24,28,33]), with peers (e.g., [34]), with friends and acquaintances (e.g., [35]), among family members (e.g., [36]), and with workplace colleagues and by workplace programs (e.g., [37]).

To define and describe the ongoing, social processes that previous research has identified, our work makes three contributions. First, we examine the daily work of people who manage a wide variety of chronic illnesses. Second, we articulate how people employ problem-solving and collaboration to integrate self-management into their daily routines, particularly how social interactions inform the process. Finally, we enhance understanding of chronic illness self-management by creating a picture of the daily work involved in self-management that includes the social context.

**METHOD**

We obtained Institutional Review Board approval from the appropriate institutions for collection, analysis, and reporting of data used for this study.

**Data Sets**

We collected and analyzed the processes described by 63 people managing chronic illness from the following three datasets: Quantified Self (QS) speakers presenting to a peer audience about managing different chronic illnesses, interviews with adults managing Type 2 diabetes, and interviews with adults managing their children’s asthma.

**QS Cohort**

The Quantified Self community is an enthusiastic group of trackers. They describe themselves as an “international collaboration of users and makers of self-tracking tools.” QSers are active around the world with regional meetings and an annual conference. At meetings, self-trackers give “Show and Tell” presentations to describe their experiences. Participants track for many reasons [9], but a significant portion track to understand and solve health problems related to chronic illness.
For the QS data set, we selected videos posted on the QS blog [38] between January 2012 (blog inception) and April 2017 (study data collection) focused on managing a chronic illness, as defined in the Introduction. Twenty-nine videos (with a total running time of over 6 hours and 50 minutes) met the criteria for inclusion. In these videos, people described their work processes: information they tracked, how they analyzed and learned from that information, and when and how they shared information with others. Using the QS presentations gave us an overview of the cutting edge of how people built knowledge around self-tracking in their day-to-day lives. These presentations also allowed us to analyze their specific processes in a format that was meant to instruct other users, therefore giving us access to their expertise similar to an interview elicitation.

The 29 videos were presented by 23 people—four speakers made two presentations each and one speaker made three presentations. Sixteen speakers were male (70%). One speaker acted as a carer (4%) for a person with a chronic illness (i.e., someone who is designated to make healthcare decisions on behalf of that person; in this case, the mother of a child with a chronic illness). Table 1 describes the speakers’ employment and diagnosed illnesses. The mean tracking interval the speakers referenced was 2.84 years. Some of the speakers were involved in technology in their jobs, while most others were enthusiastic hobbyists. The average video length was 14 minutes, 6 seconds. Quantified Self speakers are denoted with Q# identifiers in the quotes highlighted in results.

### Table 1: Quantified Self speaker demographics

<table>
<thead>
<tr>
<th>Employment</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Technology industry</td>
<td>8</td>
<td>35</td>
</tr>
<tr>
<td>Other industry</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>Academia</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>Healthcare (physician, nurse, etc.)</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Not reported</td>
<td>5</td>
<td>22</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Illness</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>8</td>
<td>35</td>
</tr>
<tr>
<td>Allergies (food or environmental)</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>Parkinson’s</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Crohn’s disease</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Chronic headaches</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Chronic neurological Lyme disease</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Chronic fatigue</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Heart valve disorder</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Panic disorder</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Arrhythmia</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Restless leg syndrome</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

**Interview Cohorts**

The interview participants were 40 people associated with Group Health Cooperative (now Kaiser Permanente Washington), a large integrated healthcare delivery system in Washington State. We recruited and enrolled a diverse sample representing the demographic makeup of Washington State (Error: Reference source not found). Twenty participants were adults managing Type 2 diabetes, and the other 20 were adults managing asthma for at least one child 12 years old or younger. All participants had a primary care provider in a Group Health owned and operated clinic. In the case of participants with
diabetes who have a carer, the carer participated in the research interviews where possible. These two cohorts were chosen because each is responsible for daily self-care related to the management of a chronic illness, each has frequent contact with health care providers and health care systems (e.g., scheduling appointments, filling prescriptions, scheduling lab tests), and all have regular opportunity and need to use communicate with their healthcare providers.

Most of the adults with Type 2 diabetes were over the age of 55, retired, and had at least one comorbid chronic illness diagnosis. We conducted one interview in the participant’s home, asking questions about tasks related to self-management, such as remembering to take medication or test blood sugar, learning about nutrition, and engaging in clinical care tasks, such as getting regular A1c blood tests ordered by their doctors. Diabetes cohort participants have D# identifiers in the quotes highlighted in results.

Like the interviews with the adults with diabetes, the interviews with the mothers of children with asthma were conducted one time, in participant homes, and the interview protocol asked participants to describe day-to-day management tasks. Asthma cohort participants are denoted with A# identifiers. Both sets of interviews elicited the experiences, priorities, and preferences from a non-expert standpoint, in contrast to the data set with quantified selfers, who often characterize their work as innovative.

Table 2: Interview cohort demographics

<table>
<thead>
<tr>
<th></th>
<th>Asthma cohort</th>
<th>Diabetes cohort</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>20</td>
<td>10</td>
</tr>
<tr>
<td>Male</td>
<td>-</td>
<td>10</td>
</tr>
<tr>
<td>Mean Age (years)</td>
<td>37.5</td>
<td>64.5</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School or less</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>At least some college</td>
<td>16</td>
<td>12</td>
</tr>
<tr>
<td>Race &amp; ethnicity</td>
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<td></td>
</tr>
<tr>
<td>Asian</td>
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<td>2</td>
</tr>
<tr>
<td>Black</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>White (Non-Hispanic)</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Other/No ethnicity given</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Hispanic*</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

*Hispanic ethnicity designation overlapped with other designations of race; total is > N

Analysis

We coded transcripts in ATLAS.ti using open coding; we drew on existing self-management, personal informatics, and health informatics literature. In examining social interactions described as part of daily self-management, we found our analysis required the creation of additional concepts that we used to form the CoMSHI. In the case of the QS videos, the qualitative coding helped us understand tracking process, decision reasoning, facilitators, and barriers. Using the second and third datasets—from individuals managing diabetes for themselves, or asthma for a child—we also analyzed the experience of novice people who manage chronic illness. We then reviewed the coded transcripts for themes, using an affinity diagramming method to iterate a final coding schema [39]. We used the final schema to organize data and inform the CoMSHI, presented after the results of the transcript analysis.
RESULTS

The primary themes emerging from our analysis consist of two parts—actors and work. The three types of actors are:

1. people with chronic illness—optionally including informal carers,
2. healthcare providers, and
3. other community members.

The types of work in which those actors engage include:

1. communication,
2. information,
3. collection,
4. integration,
5. reflection, and
6. action.

We will discuss each actor and type of work, supported with examples from our analysis.

Actors

Actors are the people with chronic illness, carers, healthcare providers, and community members. These actors interact with each other and can all perform aspects of work, as described in the next section. This designation of actors augments the models of personal informatics from Li et al. [8] and Swan [26] while confirming and extending the self-management frameworks with important people other than the person with chronic illness acting in the ecology.

People with Chronic Illness and Carers

People with chronic illness and carers are the actors most affected by the success or failure of self-monitoring, and are therefore central to chronic illness management. Carers are usually a spouse, partner, adult child, or parent. Although we saw no instances in our analysis, a close friend could take on a carer role as well. The carer often actively includes the person with chronic illness in the work and may act as advocates or facilitators in managing chronic conditions. Carer involvement—which is crucial in certain situations, such as a parent advocating and caring for a child with chronic illness—illustrates the fundamentally social nature of self-tracking and their work could not be adequately described without the social aspect of this model. One carer in our sample was the mother of a child with Type 1 diabetes, who told her son, “you’re a scientist along with us, and you’re making these discoveries.” (Q25)

Healthcare providers

Healthcare providers are skilled health professionals involved in a person’s care. Although most speakers referred to physicians when talking about healthcare providers, our analysis suggested the healthcare providers involved in managing chronic illness include many types of nurses (e.g., school nurses, clinic nurses, homecare nurses), physical therapists, pharmacists, nutritionists, and others. This finding is consistent with the self-management literature.

Community Members

Community members are non-health professionals with whom the person with chronic illness or carer interacts. This definition is more inclusive than Swan’s, which included only peers. This actor includes
the widest variety of people, such as intimate partners, friends, other people with chronic illness, colleagues, or schoolteachers.

**Work**

The types of work of self-management include *communication, information, collection, integration, reflection, and action*. These types of work are modified from the stage-based model [8] to add *communication* work, and redefine *preparation* to the more general term of *information*. Perhaps most important for the mechanics of the model, we eliminate the notion of discrete stages of work in favor of *unconstrained transitions between types of work*: this feature of our model reflects the continuous and social nature of work revealed in our data sets. As observed by Epstein et al. [22], our analysis showed that work can and does occur simultaneously. Furthermore, any actor can engage in any work, and actors often share work or hand off work to others during transitions.

**Communication**

*Communication* work involves actors sharing information or data and working together to make decisions about health management. Sharing might involve exchanging illness-related information, communicating tracked data, or posting visualizations on social media. Coordination includes such things as setting up follow-up appointments with healthcare providers, implementing an action plan with teachers, or confirming medication administration routines with the person with chronic illness and carers. This work is particularly important in management of chronic illness because of the number of actors and amount of work involved. Valdez et al. [7] refer to this as *articulation work*.

*People with chronic illness* and *carers* regularly manage these articulated care tasks with others. They might coordinate with healthcare providers to help with diagnosis and treatment decisions or record medication information to obtain help from others. A6 reported that she recorded the time her children took medication to coordinate with her husband:

> Usually we just keep [the medication log] right by the medicine … at least then we both know when the last time a certain medicine was taken. So it's worked so far. (A6)

*Community members* may detect abnormal symptoms or signs in the person with chronic illness and inform the *person* or *carer*. A4’s friend helped her notice her child’s allergy symptoms:

> What happened was we went to a friend's house and they had a dog, and my friend's a doctor and she was like "you know, she's having some kind of reaction to something, what's going on?" (A4)

*People with chronic illness* and *carers* also share information with *community members* to garner support. For example, a parent might share medication instructions with school personnel (A12).

Although we saw no instances of community members communicating with healthcare providers, it is possible that communication may take place in cases of emergency or carer absence.

**Information**

*Information* work describes an ongoing process of accumulating information to support the self-management cycle. This type of work is most analogous to Li et al.’s [8] *preparation* stage, which Epstein et al. [22] represent in two steps—*deciding* and *selecting*. We kept this type of work general, reflecting the many kinds of information work in which actors engage. People with chronic illness and carers perform much of the information work, as it is specific to the illness and their experiences. Participants described using third party information sources, such as Wikipedia or medical websites, to learn terminology to inform self-tracking and understand feedback (Q1).
Gathering information not only prepares people with chronic illness and carers for data collection, it also informs them throughout the process. One QS speaker describes information work with regard to patterns in her nutrition data. She engaged in this work while in the midst of reflection:

*I got suspicious of bell pepper, tomatoes, and eggplant… It turns out they’re in the same family. It’s called nightshade. It has neurotoxins in it. They inhibit cholinesterase. What does cholinesterase do? Oh, my word. This… looks like what’s been happening.* (Q11)

People with chronic illness, carers, and community members may exchange information with each other about illness management and lifestyle adjustment. D3 shared health information management skills with other people:

*I don’t share that much with people, but…I have taught a class called Templates, where you go ahead and write out your medications, so I’ve been involved, certainly, in trying to tell people how to do things more than the other way around.* (D3)

Information can also come from social exchanges with other actors, such as facilitation from healthcare providers:

*I went and talked to my doctor about restless leg. We had a nice discussion about the genomic, the genetic aspects of this. He had some website stuff to go to.* (Q9)

Finally, actors may set reminders to initiate self-management work [40,41]. A person with chronic illness may set a reminder to have blood work done (D1) or a carer might set a reminder for a child’s physician appointment (R5). As also described by Valdez et al. [7] in their patient work framework, *Information* and *Communication* work support the rest of the work of self-management.

**Collection**

Collection work involves decisions about identification of tracking mechanisms and tracking activities. Although most speakers and participants recorded data in text or numeric form, some people used photo, video, and location data. Data types such as photo and video convey more information than does a simple number. People found richer data types especially helpful in tracking food intake, while both speakers with Parkinson’s Disease used video recordings to track changes in movement over time (Q20, Q24). Q14 even used the quality of her handwriting in her headache journal as an additional indicator of headache severity. Chung et al. [33] similarly discussed various types of collection, as well as boundary negotiating artifacts generated through tracking.

Collection work is usually performed by healthcare providers, people with chronic illness, and carers. It typically begins with a healthcare provider or community member recommendation or decision by the person with chronic illness or carer. In this collection work, actors collect data (numeric, text, or picture; objective or subjective) depending on the illness and purpose for collecting. Such data may include blood sugar levels, blood pressure, cholesterol levels, peak flow meter readings, and weight. Subjective data includes discomfort levels, degree of breathing difficulty, time of symptom duration, or location of pain.

Collection can involve collaboration among actors. This is particularly true in families [36]. For example, some parents of children with asthma share collection duties (ex. A6), especially if they share custody. Furthermore, spouses might track together (D6) and carers might track in collaboration with a person with chronic illness (Q25).
Integration

*Integration* work includes taking collected data and transforming it so that actors can analyze it. People detailed the various ways they collated and displayed data. Most people in the Quantified Self cohort and several participants in the interview cohort used a simple spreadsheet, customizing the type of visualization to meet their personal needs and preferences. Q10 describes how he visualizes his allergy symptoms:

> And this is a different way of looking at my sneezes. It's a cumulative graph…and the slope indicated how fast I produce sneezes. So if it's flat I don't produce as many sneezes and if it's very steep I produce a lot of sneezes in a short amount of time. (Q10)

Most integration work is performed to more deeply understand health status and illness progress or to determine the effect of medication or treatment regimens. D4 showed his integration work for his weight change and medication intake:

> This is my chart that I made. I went into Excel…. This is my weight. I weigh myself every day. See, I gained a couple pounds overnight and I can't remember if I took. I'm going to have to maybe make a little box to make sure I take three [medications] in the morning and three at night, I can't remember if I took my evening ones because I gained a couple pounds, see? (D4)

Many people found the type of visualizations they produced to be inspiring in continuing to manage their health, and Q17 described information visualizations she used as “incredibly motivating.”

Some people with chronic illness and carers use patient portals which provide the option to make a chart or table with their data. A17 explained that she used her patient portal to integrate data:

> I can chart my progress. I can see if my numbers are going up or going down, I can look and that and see like my blood pressure, it's not a test, but it's on there and I can see what my blood pressure was when I went in for the visit, so I actually like that. (A17)

Reflection

*Reflection* work represents time spent engaging with data, making meaning from data, and considering the collection experience itself. People with chronic illness or carers are usually the primary actors involved in reflection, with healthcare providers and community members providing additional insight. People with chronic illness and carers examine the effect of self-management behavior on the illness depending on their collected data. Based on results, actors might decide to make adjustments or do something new. D8 described reflecting on the effect food intake had on her blood sugar:

> I was writing down everything I ate during the…day and looking at the difference in my blood sugar, what caused it to be higher, and I had everything right there so that was more helpful. (D8)

We also saw that reflection work is social. D1 discussed reflection work done with her pharmacist:

> The pharmacist got involved in my cholesterol medication. She wanted me to go up a dose so we did a lot of communicating that way and that worked out. (D1)

For an in-depth discussion of coordinated reflection using one tool, in one disease context, see Schroeder et al. [21] for a description of person and healthcare provider collaboration in the context of Irritable Bowel Syndrome.

Action

*Action* work describes concrete steps a person with chronic illness or carer implements, usually based on conclusions from reflection or on evidence from information work and often in collaboration with a
healthcare provider. Some people talked about making incremental adjustments to their daily routine (Q19), but other speakers were inspired to make more substantial lifestyle changes, such as avoiding certain medications for pain that did not work (Tylenol for Q19) or cutting out certain foods (swearing off caffeine for Q3 to reduce panic attacks). Some people also described weighing evidence from information and reflection work to cope with conflicting medical advice from healthcare providers (Q23).

Many people undertake action as a result of reflection on past problems. A14 explained her new strategy for storing her child’s medication to head off administration errors:

   I split them all up, and he was there [at his dad’s house] for two weeks so I bought several of these [pill organizers], pills for every morning because he takes one at night and three in the morning. So I put the three in here and the one at night and I just rubber banded these together, because he was there for two weeks. That’s how it’s like foolproof. You don’t have to pack three different bottles and remember what combination. (A14)

People also update their self-management program to sustain engagement. One person described his motivation for changing his methods:

   If you find a way to evolve the process frequently enough and meaningfully enough that you’re still excited about it as you go on, then I think that’s really powerful. (Q3).

Community members also participate in action work. They often provide support for health maintenance and illness management tasks—such as taking medication on time, going to the doctor, or eating. School personnel are often involved in maintaining a safe environment and providing emergency support. A12 explained how she worked with her child’s school:

   I have to do a separate inhaler for school, I have to have a current prescription, I have to have Dr. A specifically sign on the paper saying this is the plan, this is how much she gets it if she needs it, she can or cannot carry it with her. We don’t let her carry it with her, that’s too much responsibility and I think that’s pretty much it, but yeah, having a plan if an asthma attack occurs at school. (A12)

We applied what we learned about people with chronic illness and their management process to develop a conceptual model of social health informatics for chronic illness.

Conceptual Model of Shared Health Informatics

To bridge the gap between self-tracking and the social ecology of chronic illness management, we propose the Conceptual Model of Shared Health Informatics (CoMSHI) (pronounced com-she) (Figure 1). The CoMSHI is based on observed behavior, described information needs, and social interactions; therefore, the model is agnostic to specific tools used or data collected. We focus instead on elements and actors of the common ecology that speakers cited as drivers of successful chronic illness management. This model incorporates prior research (e.g., [8,24,26,35]) with further insights from our data analysis. By elaborating and refining based on the results from our transcript analysis, we formulate a new Conceptual Model of Social Health Informatics describing chronic illness management situated in the social context.

Figure 1: The Conceptual Model of Shared Health Informatics showing the social context of chronic illness management and the interplay between components. Actors are people with chronic illness, carers, community members, and healthcare providers. The work in which those actors engage includes information, communication, collection, integration, reflection, and action. All actors may engage in work and interact with each other around that work.
The CoMSHI is distinct from other models because we (1) prescribe no specific order to work activities, which allows for fluid task switching, (2) add actors as an outer layer that highlights social interactions in management practices, (3) add communication as a type of work, and (4) emphasize the importance of information and communication work in supporting the other components of the model.

In this model, we have modified Li et al.’s notion of stages of work to types of work because people with chronic illness do not simply progress through stages, but continuously perform work in support of their health [6]. We also moved from the static concept of a preparation stage to a broader, more dynamic notion of information work. This reflects the ongoing information gathering that supports the other types of work and actors. Finally, we propose that the process is more fluid than implied by Li’s paradigm of discrete stages of work. For example, a person might inform his physician about his symptoms after engaging with data during the tracking process. The notion of work in the CoMSHI is also different from that in Swan’s model of personal health informatics [26]. In that model, all work rests with the person with chronic illness, but we found that sharing work with community members, carers, and healthcare providers was key to successful self-management.

A valuable addition to self-management models is the addition of carers to the ecosystem. Although the Pew Internet Research Project’s 2013 survey on health tracking found that 12% of trackers track for someone else [10], none of the other models include carers as actors. In our study, we included carers as main actors as well as people with chronic illness because carers assume an important role in managing chronic illness depending on the characteristics of the illness and person.
The CoMSHI extends prior work; Error: Reference source not found summarizes a comparison with that prior work. Our model situates people with chronic illness in their social context and recognizes that the work of chronic illness management is (1) distributed across actors and (2) ongoing, rather than linear and time-limited. The CoMSHI emphasizes collaboration and social sharing of health information while managing chronic illness through day-to-day work. We included carers as main actors because they can take on a critical role in managing chronic illness, often providing logistical and financial support and advocating for people with chronic illness.

Table 3: Characteristics of Conceptual Model of Shared Health Informatics compared to work from Li et al. [8], Epstein et al. [22], and Swan [26]

<table>
<thead>
<tr>
<th>Basis of model</th>
<th>Role of person with chronic illness in model</th>
<th>Social aspects of model</th>
<th>Outcome components of model</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Li et al. [8]</strong></td>
<td>Empirically-informed definition of personal informatics</td>
<td>One who collects information, reflects, and takes action</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Epstein et al. [22]</strong></td>
<td>Model of personal informatics incorporating empirically-informed construct of personal motivation</td>
<td>One who collects information, reflects, and takes action</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Swan [26]</strong></td>
<td>Descriptive model for “patient-driven” health care</td>
<td>One who collects information and takes action, with some interaction with others</td>
<td>Early, constructive model of patient-centered health care including some interaction with peers and professionals</td>
</tr>
<tr>
<td><strong>The Conceptual Model of Shared Health Informatics</strong></td>
<td>Empirically-informed conceptual model of health informatics use shared among actors</td>
<td>People with chronic illness are one of many actors, communicating, collecting information, reflecting, and taking action in social context</td>
<td>Expands on Swan to show a full social ecology around use of and interaction with personal health data</td>
</tr>
</tbody>
</table>

This model exposes the relationships among work and people during the process of chronic illness management that health informatics tools needs to support. New personal health informatics tools
designed to incorporate both ongoing work and the many actors involved would better align with the experience of people with chronic illness, thus supporting self-management activities and potentially improving health outcomes. Current research and tools often focus on personal informatics, self-management, or self-tracking—limiting how we think about health management and design to support it. Understanding how people with chronic illness share work to successfully manage chronic illness can inform the design of systems to support the ecosystem of work and actors outside of the clinic, where most management activities occur [6,7]. One QS speaker asserts: “in chronic diseases, health is not created in healthcare (Q16).” She creates health when implementing therapies in life outside the clinic, and her management practices are critical. Based on the CoMSHI, we recommend that, beginning with conceptualization, designers consider how their devices and software support sharing, ongoing work, and transitions between people and types of work when designing health informatics tools to support chronic illness management.

CONCLUSION

For people with chronic illness, effective management improves health outcomes, and new personal health informatics tools promise to help maintain those management activities, but they often fall short of supporting the true range of work and people involved. The health informatics community has an opportunity to understand how people share work to achieve successful chronic illness management and to use that knowledge to design more useful tools. This paper makes three contributions toward delineating the social context and work of chronic illness management. First, we analyze the daily work of people managing a diverse set of chronic illnesses. Second, we describe the problem-solving and collaboration people employ to integrate chronic illness management into their daily lives, focusing on the social interactions that underpin the process. Finally, we developed a model of this work and social context to advance understanding of how people accomplish chronic illness management. The Conceptual Model of Shared Health Informatics describes this management work, giving insights into the process and tools used by people who successfully manage a chronic illness, as well as the context in which they work. The CoMSHI expands its predecessors by including the social context around tracking work, recognizing that the person with chronic illness shares work with others, and characterizing work as ongoing and non-sequential. The CoMSHI demonstrates the fluidity of the management process and situates the person in their social environment. Most importantly, this work underscores the impossibility of extricating people from their social environment, even when describing their own health management work. We must consider the social aspects of health management when designing any health informatics tool. People employ technology to assist in managing their chronic illness, but that is only part of the puzzle. As one speaker said, “It’s not just technology, it’s people” (Q21).

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Conflicts of Interest

None declared

Abbreviations

CCM: Chronic Care Model
CoMSHI: Conceptual Model of Shared Health Informatics

QS: Quantified Self

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