Personal Informatics in Chronic Illness Management

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ABSTRACT

Many people with chronic illness suffer from debilitating symptoms or episodes that inhibit normal day-to-day function. Pervasive tools offer the possibility to help manage these conditions, particularly by helping people understand their conditions. But, it is unclear how to design these tools, as prior designs have focused on effortful tracking and many see those tools as a burden to use. We report here on an interview study with 12 individuals with chronic illnesses who collect personal data. We learn that these people are motivated through self-discovery and curiosity. We explore how these concepts may support the design of tools that engage curiosity and encourage self-discovery, rather than emphasize the behaviour change aspect of chronic illness management.

Keywords: Personal informatics, Healthcare, Chronic disease management, Qualitative studies.

Index Terms: H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous. J.3 Life and Medical Sciences: Health, Medical information systems.

1 INTRODUCTION

The continuing miniaturization and increasing affordability of sensors and electronic devices provide tantalizing opportunities for pervasive computing. One of these opportunities is in supporting self-monitoring, where tools have been designed to help people understand and change their behaviour in the context of wellness [9,17,27], eco-behaviour [14], and chronic illness management [4,29,39]. These kinds of tools apply principles of cognitive behaviour therapy [32] and goal setting theory [22], where a core tenet is that people may misinterpret their actual behaviour relative to their own desired behaviour. By visualizing one's actual behaviour relative to desired targets, these tools (e.g. [6,17,18,27]) aim to motivate behaviour change using elements of cognitive dissonance theory [12].

A prerequisite for this is effective data collection, and mobile devices (such as smartphones) offer the ability to collect data in a timely, in situ manner. This is especially important in the context of chronic illness management. People with chronic pain fill out paper-based "pain diaries" at the end of each day, trying to detail each incident of pain for the day, along with intensity and possible triggers. Consequently, by the time these patients are filling out the pain diary, they can no longer accurately remember the intensity, time of onset, or duration [11]. In contrast, a smartphone-based application can facilitate immediate data entry, when people are more apt to remember specific details (e.g.

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[2,17]). These can further be augmented with other digital sensors to collect information without explicit user intervention (e.g. [14], [18], [19]). Early trials of such tools for chronic illness management have been promising, with clients exhibiting better adherence to management protocols and better clinical outcomes (e.g. [11,27,39]).

In spite of these successes, an overwhelming problem is that many people are not motivated to start, or continue using these applications [27]. Some researchers point to more effective external support or additional features that engage users to maintain motivation. Yet, a more fundamental point is that these tools have, to this point, been designed to address *clinical needs*, with clinical outcomes as metrics (e.g. weight loss metrics, or adherence to treatment protocols), rather than emphasizing *personally motivating interests of the people using the tools*. Specifically, we see that one way to motivate users is to engage their curiosity and interest in self-discovery. We make use of Day's [10] definition of curiosity and exploration (or the process self-discovery), where curiosity is a state of tension induced by situations having high levels of uncertainty, and exploration is the resultant behaviour.

We are motivated by the recent popular interest in personal informatics, or the process and tools used to support collection of and reflection about personal data [19]. Li and colleagues report on studies of personal informatics enthusiasts, who build sensors to collect personal data about themselves, as well as visualization tools to explore and understand the resulting data [19]. These enthusiasts touch on domains such as personal finance, productivity, communication history, or mood. What seems to set these individuals apart is that they show a genuine curiosity and interest in a self-discovery process. We call this the "personal informatics lens": self-motivated curiosity and interest in self-discovery.

Within the context of designing tools for managing chronic illness, how can this "personal informatics lens" inform the design of self-monitoring tools? To address this question, we conducted an interview study with 12 people who employ personal informatics practices in relation to a chronic illness, and a pre-study with 4 general personal informatics enthusiasts. Findings from these interviews reveal curiosity and question-asking as a core practice in these individuals' self-management practices.

2 RELATED WORK

Self-Monitoring and Chronic Illness. While health management has traditionally been the domain of healthcare professionals, recent changes in demographics combined with advances in mobile technology have begun to change this dynamic [2,8]. Considerable efforts have been made to support "patient-centered care", where individuals are given more freedom and control over the management of their conditions [8]. Providing people with more control over their own care also has economic benefits, emphasizing prevention over reactionary techniques [28].

Delving into this literature at depth is beyond the scope of this work, but Eastwood and colleagues [11] provide an instructive example. Here, the authors construct a paper-based diary for self-monitoring in heart failure patients. In a small, randomized trial,

they show that people who were assigned to the diary condition and who *actively used the diary* had better adherence to protocols and better clinical outcomes. This is consistent with findings from other authors, who suggest that self-record keeping improves communication between patients and healthcare providers, and enhances the quality of care received [7], but that the challenge is encouraging active usage of the diary. To facilitate data entry, [11] suggest designing mobile applications for diaries, allowing for on-the-go data entry, so that patients do not forget. Both health professionals and patients see benefits and applications from this type of technology, including making patterns more evident, providing a record of events, and evaluating the success of interventions [7].

Recent advances in health monitoring attempt to bridge this gap, exploring the design of diaries for handheld devices such as smartphones (e.g. [3,11,23]). As a canonical example, the Wellness Diary [27] allowed for the same diary entry as a paper equivalent, and provided the ability to see past data (e.g. as charts), to enter other information (location, activity, etc.), and to integrate with wireless sensors that collect information continuously (e.g. pedometers). Similarly, some authors have focused on supporting management of specific illnesses. For example, Mamykina et al. [26] demonstrate that diabetes demands an active approach to management, and design a tool support the management process of those individuals [25]. While these tools have shown promise in small trials, Mattila et al. [27], described the core problem as still being motivation, both in terms of getting people to use the technology and asking them to continue with it.

Persuasion vs. Curiosity. Poor motivation is perhaps surprising, given that in general, these tools are deployed as a means for people to improve their own health. Many tools have been designed to guide behaviour change, appropriating theories from behavioural and social psychology [12,22,30,35]. These strategies generally rely on persuasive forms of feedback based on collected data [9,14,21,34].

Yet, while researchers have seen problems with fleeting motivation, the personal informatics community (embodied primarily by the Quantified Self group [31]) has seen considerable growth and interest. These enthusiasts go to great personal lengths to design their own tools to support their self-discovery process. In studying these enthusiasts, Li et al. describes the kinds of problems they encounter [19], emphasizing the role of personal reflection in this process [20]. It seems that reflecting on one's own data, and supporting the process of self-discovery (where people seek to understand relationships between different pieces of data) plays a central role in motivating these individuals.

If curiosity and self-discovery are motivating themes for personal informatics enthusiasts, might we also expect them to be motivating for those with chronic illness?

Summary. There is considerable opportunity for self-monitoring technologies, and several researchers have already begun to build such technologies for mobile devices (e.g. [3,5,23,25,39]). Much as with personal informatics enthusiasts, one possibility for encouraging people to use such applications is to engage their curiosity.

What does "curiosity" mean within the context of chronic illness? Chronic illnesses present themselves very differently: some illnesses have very overt symptoms while others do not; further, two people with the same chronic illness may exhibit wildly varying symptoms. To this end, our work explores this concept of curiosity and self-discovery by examining a wide breadth of chronic illnesses. Doing so allows us to explore the kinds of questions that are being asked, and compare and contrast—beyond specific case studies of particular tools or conditions—to understand how tools can be designed to support management practices for those with chronic illness.

3 INTERVIEW STUDY

What do curiosity and self-discovery look like in people with chronic illness? To understand these personal informatics needs and practices, we conducted an interview study, focusing on motivations for and methods of collecting data, and as well as use of the data for those with chronic illness. To help frame our understanding, we used a snowball sampling method to recruit four personal informatics enthusiasts (without chronic illness) for a pre-study. We then recruited twelve participants with chronic illnesses who collected personal data. We report mainly on the latter group, drawing comparisons to the pre-study as appropriate.

3.1 Method

Participants took part in a semi-structured in-person interview. Four of these interviews were conducted over instant messaging because the participants were remotely located. We used techniques described in [37] to ensure these IM interviews were effective [36]. The other eight interviews were conducted in person. We did not set concrete end times for our interviews, but instead took the time we felt was necessary to understand the participant's perspective on each of the three topics referred to below; on average this took an hour. We asked participants to bring the tools they use to collect and/or reflect on their data (e.g. notebooks, forms, smartphones, laptops); remote participants sent pictures of their tools or copies of their documents by email.

Our interview consisted of three topic areas and, while we ensured coverage of all relevant questions, we allowed the participants' responses to guide the flow of the interview. Topic 1 focused on the participants' condition, for example, the nature of the chronic illness, and how they were dealing with it. Topic 2 addressed data collection, in particular, the participants' motivation for collecting, and their collection practices. Finally, Topic 3 considered reflection: how participants used their data, and what they had learned from it.

Interviews were recorded, transcribed, and analyzed using inductive qualitative methods [15]. We did not determine a coding scheme in advance, but instead created codes from the data as they emerged. We then created affinity diagrams based on these codes, and allowed convergent themes to emerge.

3.2 Pre-Study

We recruited participants through word-of-mouth to understand first-hand the personal informatics enthusiasts addressed in prior work, focusing on people who collect data as a hobby. Table 1 summarizes these four participants. Participants collected data unrelated to a diagnosed health condition; thus, we focused mainly on topics 2 (collection) and 3 (reflection).

3.3 Primary Study

Table 2 summarizes participants of our primary study. Of the 12 primary study group participants, 10 were female. Ages of the participants ranged from 18-55. Participants had been collecting data for anywhere from 2 months to 28 years; Four participants had been collecting data for less than one year. Seven participants were following instructions from a doctor about what data to collect and how to collect it. Three participants used more than one collection tool to obtain the data they desired.

ID	Data Collected	Collection Duration (in years)	Tool	Age
P1	*Financial Data*: money spent on groceries	0.2	Notebook	19
P2	*Weight Loss Data*: food consumed, exercise	2	Mobile App	22
P3	*Fitness Data*: elevation, heart rate, distance, grade, cadence, weight, video footage	2	GPS, Computer Software, Scale, Sports Video Camera	35
P4	*Gas Mileage*: date of fill up, number of liters purchased, total cost, kilometers driven since last fill up	4	One notebook for each car	22

Table 1: Pilot study participant information.

4 FINDINGS

Our findings as a whole suggest that self-discovery is a powerful lens for understanding the management practices of individuals with chronic illness. In this section, we show that a motivating factor is the desire to take/re-take control of their lives given an illness. That process of regaining control varies depending on one's specific condition, so we articulate different types of questions people are attempting to address. We then discuss some of the actual data collection practices, specifically the tools, techniques, and data used.

4.1 Motivation

Seven participants began collecting data because they were instructed to do so by their doctors. These participants generally believed that their data would help their physicians to recommend more effective treatment plans. P11 (Fibromyalgia) indicated, *"[My doctor and I] collect this data so we can track whether or not the medication is effective and whether or not the dose has to be increased or decreased. We're going to discuss if I have to increase the dosage based on the pain level in my notes."*

Five of the participants had decided to engage in data collection on their own, or on the advice of a friend. They saw it as a way of understanding their conditions and regaining control over their own lives. P6 (Depression) explains that for her it started *"when a friend sent me a book about diet and how it related to depression, specifically refined sugar. That got me interested in that and that's when I started logging a food journal to see what I was eating, and to see if I could find a correlation between what I was eating and how I was feeling."*

In either case, participants saw great value in this data collection practice. Five of the participants who had been instructed to collect data by their healthcare providers indicated that they would continue to collect the data even after their doctors no longer required it. P15 (Migraines) explains that her logs are *"very useful to me. If I felt I was getting bad again, I would have the data to take to my doctor and become an advocate for myself."*

Data collection empowers individuals to take the knowledge they are receiving from their care providers and translate it into something meaningful for them personally. P7 (Epilepsy) explains, *"My data is in my own words, not in medical terms, so I can actually understand what's going on. So if I just get told by all the doctors what's going on with me, it's kind of in a language that I don't really speak."* This collection process helps individuals augment their understanding of their conditions, and empowers them to take control of their own health. For P5 (Epilepsy), collecting data makes him feel *"much more in control, which is something that my condition takes away in the first place. I think it is empowering to take ones health into your own hands and not rely on doctors for all the answers."*

ID	Condition	Data Collected	Collection Duration (in years)	Years since diagnosis	Age
P5	Asthma, Diabetes	I,M,T	0.1, 28	9, 28	44
P6	Depression	I,T	2	15	42
P7	Diabetes	I,E,M	20	20	35
P8	Epilepsy	E,M	.3	18	18
P9	Epilepsy	E,M,T	0.2	0. 25	22
P10	Epilepsy	E,M,T	3	16	31
P11	Fibromyalgia	I,E,M	0.2	0.16	20
P12	Gastroesophageal reflux disease	E,M,T	3	3	21
P13	Hereditary Angioedema	E,M,T	14	14	30
P14	Low Blood Pressure	E,T	2	15	22
P15	Migraines	E,M,T	7	7	55
P16	Osteoarthritis	I,T	1.5	6	52

Table 2: Primary study participant information.
Data collected by participants include: (E)pisodes, (I)ndicators, (M)edication, (T)riggers.

While the initial impetus for collecting data varies, the key here is that our participants engage in this process because it gives them the subjective feeling that they are using the data to help control and manage their conditions. This means that they can use this data to understand or discover something about themselves, and potentially to use this as a means to communicate with health professionals to help them to better articulate their understanding of their condition and symptoms.

4.2 Illness

Participants in our study had been living with their conditions for 3 months to 28 years. These illnesses appear to manifest themselves very differently from person to person, and may also evolve over time. For instance, even though P8, P9, and P10 have all received the same diagnosis (epilepsy), each experiences a different kind of seizures, and the factors that bring on these seizures varies drastically.

For some, data collection provided a way of understanding their condition within the framework provided by their doctors, particularly those who had conditions considered to be *well-understood* by the medical community. For P7 (Diabetes) or P14 (Low Blood Pressure), data collection is a way of monitoring their conditions, and improving their lifestyles based on what they observed.

Other participants had conditions that they saw as being rare or *poorly understood*, such as P11 (Fibromyalgia) or P13 (Hereditary Angioedema). For these conditions, there was considerably less information available, and data collection became a core practice in informing their understanding of their illness and themselves.

For P13 (Hereditary Angioedema) and P15 (Migraines), the data collection allowed them to help others understand their conditions. P13 provides data that helps medical professionals to learn about her rare condition. *"It just provides really good, solid data when the literature for my disease is very poor, and so I've had some of my medical stuff published…[the data] gives a lot of leverage for other doctors to be connecting and saying 'I have a patient who is seeing these trends, are you seeing these trends as well?'"* P15 is hopeful the data will help her to communicate with family members. *"It would be helpful to share this with my sisters, who really have no idea just what I go through. Helping others around you understand the debilitating effect of these headaches is huge. For someone to react by saying 'oh, you have another headache today' when I am on the floor in the bathroom throwing up for 5-6 hours, I guess it just seems wrong. I would like them to understand what I go through."*

Episodes	Prevention	What can I do to reduce how many episodes I have? What techniques work to prevent an episode?
	Trends and Patterns	What time of day am I the most vulnerable to episodes? During what seasons are my episodes worst/most frequent?
	Dealing with Episodes	How should I respond to an episode? What can I do if an episode occurs?
	Consequences	What are the social costs of my episodes? What are the physical costs of my episodes?
Triggers	Identifying Triggers	What triggers apply to me? Am I correct in thinking that my episodes are caused by ____? Why did a particular episode happen?
	Trends and Patterns	Do I always have an episode when I do ___? Do my triggers work independently or when combined with other triggers? What combination of triggers is more likely to cause an episode?
	Dealing with Triggers	How can I alter my lifestyle to avoid triggers? How do I deal with triggers I can't eliminate? How can I still enjoy my life, and also eliminate triggers? What special arrangements do I need to make when travelling, eating out, etc.?
Medication	Dosage & Efficacy	How can I reduce the amount of medication I take? Do I need a different dose? Do I need this medication at all? Is my medication working? Am I taking the right medication?
	Side Effects & Elimination	Can I eliminate the need for medication by changing my lifestyle and eliminating triggers? What would my life be like without medication? What side effects of this medication am I noticing?
Status		Am I getting all the {sleep, nutrients, etc.} I should be? Are my indicators normal? Have I eliminated known triggers from my life? Do I need to treat myself currently?
History		How has my behaviour changed over a period of time? If I'm having problems with my condition now, have they happened before? Am I improving? How long have I gone without having an episode?

Table 3: Questions participants are asking of their data

4.3 Questions

To frame their data collection, participants articulated several different kinds of questions. Table 3 summarizes five kinds of questions participants asked about their personal data: *episodes*, *triggers, medication*, *status*, and *history*. Questions about episodes, triggers and medication are unique to participants with health concerns, while status and history questions are similar to those identified by Li et al. [19] in their work with data enthusiasts.

In general, individuals are interested in learning what should be *eliminated* from their life to reduce the impact of episodes. P10 (Migraines) explains, *"Recently I pretty much eliminated chocolate from my diet. I used to think it did not affect me, but eliminating it has proven me wrong. I now know that chocolate can affect [my] headaches."* Individuals are also interested in learning what they should be *adding* to their lives to prevent episodes. P6 (Fibromyalgia), for instance, tries *"to do something that relaxes you or…would take your thoughts away from the pain"*.

These kinds of questions are centered on self-discovery—understanding what the nature of particular episodes are, what brings on the episodes, what can mitigate it and so forth. For some participants it is an on-going, long-term process—perhaps owing, as suggested earlier, to the evolving nature of some of these conditions.

4.4 Collected Data

In order to answer the questions they had about their data, participants collected a blend of qualitative, quantitative, objective and subjective data.

Episodes. Some of the data collection was focused on tracking actual *episodes*. An *episode* had varied meanings for each condition: generally, they were noticeable, detectable incidents, and participants were interested in their occurrence and frequency, as well as feelings or sensations during the episode. For P8, P9 and P10 (Epilepsy), their episodes were seizures, and they tracked the frequency of seizures, as well as how they felt before, during and after, and any sensations they had. For P11 (Fibromyalgia), an episode was the twitching of her arms and legs. She tracked the frequency of her episodes.

Triggers. Participants collected information about exposure to potential *triggers*—aspects of one's environment that could cause an episode—and whether it actually did so. P6 (Depression) tracks factors she believes trigger a depressive episode (food, water, alcohol, sleep, exercise). While she originally started collecting food data, she saw value in expanding the range of data she collects, and continues this collection process because it *"…allows me to get really clear in my mind what the factors are that cause episodes, and how to handle them."*

P10 (Epilepsy) also collects triggers (caffeine, meal times, stress, sugar, alcohol, etc.). *"Despite all the tests conducted on me, there is no definite known cause for my seizures. Therefore it is imperative that I understand what causes them. I would definitely recommend this to other epileptics for the reason that only they can discover the particular causes."*

Medication. Participants also tracked *medication* they consumed. Participants were taking a combination of over-the-counter and prescription drugs, to prevent an episode or to eliminate one in progress. This allowed them to be more aware of how much medicine they were consuming, and to monitor the effectiveness of their medication regimen.

Participants who were interested in observing the success of their medication programs were often participating in drug trial programs, or were trying out a medication recommended by their physician. P9 (Epilepsy) is participating in a drug study program that requires her to collect data about the seizures she has and the medication she is taking so medical and pharmaceutical professionals can determine if the medication is working or if she needs a different dosage. She explains, *"If I didn't keep track, I wouldn't be able to see the decline in the amount of seizures."* Collecting this data allows her and her doctors to have an accurate understanding of her condition's progress.

Status. Some participants were also tracking *status indicators*. These were factors like blood glucose concentration, which gave participants a sense of the current state of their condition. P5 (Diabetes), for instance, collects the readings from her glucometer to determine her blood glucose level, so she can respond accordingly with insulin treatments.

History. Participants used data as a way of observing progression in their conditions. Several participants felt that, without the data, they might misjudge any improvement they were experiencing. P11 (Fibromyalgia) explains that, without the data, she *"… wouldn't know if the medication is having any sort of effect, because I wouldn't be able to track it. I would just try to pretend in my head that I'm doing better when really I might not be."* P11 had been recently diagnosed, where P5 (Migraines), has been dealing with her condition for five years. She explains, *"When I see that back in 2005, I had 8-10 headaches a month as compared to 3-5 a month now, I realize just how much better I am doing."* She feels she has been successful in observing the improvement that P11 seeks.
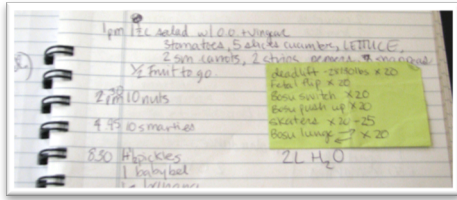
Figure 1: Notebook used by P14 (Low Blood Pressure)

4.5 Tools

Participants varied widely in the tools they used to collect this data. Some participants had extremely structured and rigid tools for collection, while others used systems that were extremely flexible, but highly unstructured. Only two participants used mobile apps for their self-tracking.

Participants who had the most rigid and structured processes typically used specialized tools provided to them by their medical teams. While these people collected data fairly regularly, and felt their collection was reliable and accurate, they found the lack of flexibility to be frustrating. P13 (Hereditary Angioedema) uses a highly structured and specialized web form where she enters data that is submitted directly to her doctor. This format facilitates communication between her and her doctor. She expressed a desire for more customizability. "*You have all these other categories that kind of just get lumped together. [T]here should just be a really user-friendly way of just saying, 'Okay I'm going to make temperature one of my new fields that I'm always going to fill out' So from that point forward, ... it was just always something that you tracked.*"

Seven participants used notebooks to collect data. This provided them with immense flexibility, but little structure. The used these notebooks to collect a variety of data, much of which was subjective. They appreciated the portability of the notebook, but were not able to find less cumbersome but equally portable solutions. P8 (Epilepsy) explains, "*There should definitely be easier ways to record the data. Mostly I just put the book in my backpack and take it to school with me. If I have a spare five minutes in class I'll pull it out and write it down.*"

This strategy of collecting data at school did not work as well for P14 (Low Blood Pressure). She uses her notebook to track what she ate, what she drank, the nutrients she consumed, how she slept, what exercise she did, and how she felt. This notebook is not something that she always carries with her—often, she will record her data on Post-It notes or scraps of paper, and then add them to the notebook later. She explains that this is because she is "*trying not to seem like I'm OCD when I'm writing it in the middle of class, because even I would think I'm crazy. I would look at me writing down all this different stuff and be like, 'you're insane'.*" The notebook provided her with a place to keep her data, while the Post-It notes provided her with a more discreet way of recording data (Figure 1). She feels that there is a social cost to recording her data, and uses her notebook for data storage, more than recording.

The participants that seemed the most satisfied with their collection tools were using personalized templates they had created for themselves in word processors or spreadsheet software. These templates typically allowed for a certain level of flexibility, because the participants were in control of the templates and what they were collecting, but it also provided them with some structure to their collection. These templates were most often created and used by individuals whose collection process was more mature: these people had been living with their conditions for longer than other participants, and had tried several other tools before gaining enough of an understanding of their own needs to create personalized templates.

P10 (Epilepsy) used an Excel spreadsheet with a column for each of the items he was tracking (medication, sleep, caffeine, meal times, stress level, sugar consumption, etc.). He preferred this method of collection to others he had tried (paper spreadsheet, paper journal, electronic journal) because it "*made it quick to compare triggers simply by sorting. Also, if I wanted to add a column (which I frequently would if I found another trigger), it would be much simpler on the computer.*" His spreadsheet allowed him the flexibility to add new types of data to his collection process, while providing him with support for reviewing the data in a manner different than it had been collected.

4.6 Collection Techniques

Three participants collected the data immediately following a specific action (meals, medication, episodes). Both diabetes patients (P5 and P7) developed a habit of making a data entry every time they ate a meal, did exercise, or drove a vehicle. This was facilitated by an automated data collection tool (in both cases, a glucometer with web-based reflection tools). P15 (Migraines) used time of day as the impetus for collection. She completes her pain diary immediately before going to bed, but occasionally skips an entry if she has a migraine at the time and does not feel up to it. In these cases, she fills in the gap the following night, but does not necessarily accurately remember what happened the day before.

Participants that entered their data either immediately after acquiring the data, or at a specific time every day were more likely to remember to make the entries overall and were more confident in the accuracy of their data. It became a problem when they were unable to make an entry at the time of the action for whatever reason (they did not have their tools with them, they were in a hurry, etc.), as they would often forget to come back to the data.

Other individuals collected data sometime later when they had free time. This meant saving up data and entering it all at once. This worked reasonably well for individuals who had physical artifacts to refer to when making an entry. P13 (Hereditary Angiodema) could retrieve the information she needed from empty medicine vials. She would pile these up and, when she could no longer tolerate the mess, enter the information from them. This strategy did not work as well when individuals had to rely on memory of the data. P11 (Fibromyalgia) would revisit her data when she had spare time, but the majority of it was subjective and difficult to remember, so she had numerous holes in her data, and she felt that the data she did have was largely inaccurate.

4.7 Reflection

Where participants in our pilot study seemed to take pleasure in exploring their data through tools, our main study participants reflected on their data far less. Many of their tools only allowed them to review the raw data. For P8 (Epilepsy), his reflection occurred whenever he made a new entry. "*When I write new stuff in, I'll look back and see what has changed and what hasn't, so I can get a sense of what the medication is doing.*"

P14 (Low Blood Pressure) also reviews her raw data, looking for changes and reminding herself of triggers. "*I notice, if I'm always eating six bananas a day, have I been doing that for a very long time? I don't eat six bananas a day, but if it's happened before it's written down somewhere, and I can access that information and know that's not a good idea, because I got sick from that before.*"

Figure 2: Reflection tools used by P6 (Depression)

Figure 3: Reflection tool used by P13 (Hereditary Angioedema)

P10 (Epilepsy) had developed what he believed to be an effective way of working with his data. Using the template he had created in Excel, he could compare triggers by sorting and filtering the data. The amount of control that Excel provided for him allowed him to reflect on his data in a way that was meaningful to him personally. *"This helped me to see that, while one trigger might not cause a seizure, a combination likely would… This spreadsheet allowed me to reduce my medication simply by avoiding triggers."*

Even for participants who used digital tools, the visualizations provided were insufficient for their needs. P5 (Diabetes) used a tool that was capable of showing graphs and trends, but she was not able to access them. *"I could download my readings to a website that would do graphing and trending for me, but I can't get to the site without having my MD also register on the site with me, which irritates me because I am the one who manages my diabetes, not my physician."*

P6 (Depression) used a mobile app that provided visualizations of her data (Figure 2), but she found them difficult to understand. *"I like the ones that are easily readable; I don't like esoteric graphs…where I need to have taken a statistics course to know how this graph works. I like anything that gives me a mental picture of where I'm at so I can see it quickly."*

P13 (Hereditary Angioedema) also used a digital tool, but found it did not support her reflection to her satisfaction (Figure 3). *"The reports I get online are how many attacks on what days, but if there were ways of creating reports I could individualize, to be able to compare days in the summertime where I have less than five hours of sleep with a head cold or something, would be a nice thing to do."*

5 DISCUSSION

5.1 Using the Personal Informatics Lens to Inform the Design of Tools for Chronic Illness Management

Although the personal informatics enthusiasts studied in [19] and [20] were not collecting data related to chronic illness, we observed similarities in the attitudes of our study participants with those studied in prior work—particularly in their orientation towards self-discovery, and how the data collection addressed their curiosity about their own conditions. While some of our participants began collecting data on the request of their healthcare provider and others took the initiative on their own,

ultimately, 15 out of the 16 participants saw value in the data they collected. They believed it would and did help them to answer questions to understand their conditions and regain control over their own lives, which potentially gave them a means to communicate more effectively with their healthcare provider and receive better treatment. Personal informatics enthusiasts in our pre-study and in prior work (e.g. [19,20,33,38]) also believe that data collection and reflection can help them to understand and improve their lives, and they demonstrated an interest in sharing that information with others.

Li et al. [19] outline a five stage model to describe the process of personal informatics practices. The reflection stage of this model is one area in which current tools for chronic illness management are unsatisfactory. Participants in our study expressed a strong interest in the understanding that a deep exploration of their data could provide, but they did not necessarily know where to begin, and lacked any meaningful way of reviewing their data. This was in part due to the nature of the data collection tools (i.e. on paper), but even those participants using digital tools found the visualizations overly technical and confusing, and generally irrelevant to their interests.

Reflection tools should serve to actively engage users by allowing them to explore possible relationships between different types of data, and these analytic tools should be informed by knowledge about the specific condition. This goes beyond merely visualizing history, or employing statistical techniques in a non-specific manner; instead, the system can suggest particular features or factors to explore based on an informed perspective of the user's specific chronic condition. For example, such a feature might identify triggers that are likely causing episodes, the likely effect of various factors on health indicators, and the effectiveness of a given medication. This approach addresses two kinds of problems: first, it can help overcome confirmation bias, and second, it can help direct one's inquiry into the data such that people are not overwhelmed.

Additionally, there is a movement in personal informatics and in chronic illness management to automate data collection as much as possible. Data collection is seen as a burden, and participants in our study expressed a desire for a magic tool that would provide them with all the data they desired with no or minimal effort on their part. Li et al. [19] discuss the possibility of reducing the users' burden by transferring "the responsibility completely to the system, i.e., making [the stages] system-driven." It might be argued however that manual collection itself can be a source of insight and understanding. Participants from our study who manually collected data using notebooks or paper engaged in what could be described as a review-as-you-go technique, where they would review data as they collected it, making note of new observations that stood out or revisiting old data to compare it to this new data. The determination of what modes of data collection are appropriate for specific applications will depend on a number of factors, including whether there is insight to be gained in having a person collect data manually, and whether there even exists a mechanism to collect the data automatically.

5.2 Designing to Support the Patient's Expertise

There is a growing movement to consider patients as "experts". Treatment plans should take into consideration that "some people might choose to make other priorities than those recommended by their healthcare professionals or may perhaps struggle with little success to integrate the prescribed actions into their everyday routines" [2]. Chronic illness management is not about simply reducing the symptoms of disease—instead, it involves a complex

negotiation of several competing values [24], one of which is the reduction of the occurrence and severity of symptoms. Some of our participants also reported flexibly negotiating their actions [26] to allow elements of their lifestyle to play out, even if it meant facing consequences. For instance, P10 (Epilepsy) sometimes intentionally consumes a beverage he knows to be a trigger for his seizures. "*Now I think – 'OK, I can have this [alcoholic] drink' but I know that I'm going to pay for it.*" It is because of his data collection that he knows how much he can consume, and what the severity of the consequences are for him personally. The knowledge he gained through data collection gives him the confidence to make these kinds of decisions.

Giving too much weight to this idea of patient expertise can be dangerous however. Mamykina et al. [26] argue that there is a concern that individuals may make false inferences based on the data they collect. They suggest that "…intelligent data analysis of true correlations and careful visualization techniques that highlight true patterns" [26] could help eliminate this concern, and enable individuals to draw more accurate conclusions based on their data. Yet there is a more subtle balance here: because participants' illnesses, data collection processes, and lifestyles are dynamic, temporary mistakes might ultimately lead to other valuable discoveries. We need to be careful here, of course: some inferences could be detrimental to one's health. For this reason, it is important that patients stay connected with their medical professionals, and do not use their data collection process as a substitute for expert medical care. While a patient could be considered an "expert" at being a patient (understanding daily routines or the social cost of certain actions), the expertise of the patient is generally not drawn from medical literature or medical experience. Health data collection can be a valuable tool, but should be done in close consultation with medical professionals to contextualize what is being found and understood.

We've also seen that a patient's expertise does not remain static over the course of their life: as patients live with their condition, their understanding of it develops. The same can be said for an individual's data collection process, particularly in chronic health management. As the individual better understands their data and their condition, they may adjust their collection process to better suit their needs. We saw that in many cases this required our participants to abandon their tools and pick up new ones, because their tools lacked the flexibility to meet their evolving needs.

As a starting point, people can be provided with templates for data they could/should be collecting as a scaffold, relying on received wisdom about what factors may be important to collect. This builds on Li et al's argument [19] that tools should allow people the flexibility to abandon certain pieces of data, or to introduce new ones as their understanding of their condition and of collection process matures. Tools should enable users to make use of the greater understanding of the medical community while seeking the personalized knowledge their own data and observations provide. As they gain this maturity, tools may gain the capacity to provide recommendations to the user about potential modifications to the data they are collecting. Such a design augments knowledge about chronic conditions (which may be embodied in the design of a tool) and the personalized knowledge that people gain through the use of the tool.

5.3 Designing for a Range of Conditions

Prior work has studied health management practices and tool usage by individuals with a specific condition, such as diabetes [25,26,29], or asthma [1,4,39]. We have chosen to examine participants with a variety of conditions, including conditions that are rare, unusual, or poorly understood in order to understand commonalities in their needs and approaches to self-management.

We saw that although there were obvious differences in the actual data collected, the participants all had similar attitudes towards their conditions and data collection. Those who had lived with their condition for at least a few years seemed to have accepted that there would be no cure for their condition. Managing the conditions and their symptoms, or learning how to live with them, is something these individuals do continuously. Participants from our study sought to improve their conditions and their ability to manage them, but did not believe data collection would lead them to a cure. Instead, the end goal was to become successful enough at managing the condition that data collection was no longer required.

There were several differences between conditions as well. The following are terms that we adopted as a way of framing our own understanding of the different kinds of conditions that we saw:

Well-understood vs. poorly-understood conditions. Some conditions are reasonably well-understood by the medical community (e.g. diabetes), whereas others are less so (e.g. fibromyalgia) [4]. Across our sample, everyone sought personal knowledge, but people with poorly understood conditions had a lot less "received" knowledge to draw from (i.e. knowledge given to them by medical practitioners or online sources)—instead, they relied more heavily on their own data as a source of knowledge about their condition. This is understandable: without anything else to help answer questions or satisfy their curiosity about their conditions, they must rely on their own experiences to help inform their understanding. With this in mind, people with well-understood conditions have a different experience—the factors that influence their episodes are far better defined, and they can rely more on received wisdom to help answer their questions.

Actively-managed vs. managed-through-reaction conditions. Individuals whose conditions demanded ongoing attention (e.g. a diabetic who monitors blood glucose concentration frequently, and takes insulin accordingly) took a more active, but transactional approach to self-management. They were interested largely in status, and only sometimes history questions. Here, participants were far less engaged in terms of curiosity and more interested in immediate, specific needs.

In contrast, individuals whose conditions were only evident when they were having actual episodes (e.g. an epileptic) typically would deal with and then log these episodes (as a reaction). They were mainly curious about the commonalities of the triggers between episodes, rather than the specifics of each episode and how to respond to them. When they came to suspect relationships, they might test these out (e.g. P10 (Migraines) and her disappointing experience discovering that chocolate was a trigger). What was clear was that while their data was fine-grained, they were more interested in higher-level, coarse-grained trends and patterns. Discovering and revealing these types of patterns within one's collected data—particularly framed within the context of received wisdom rather than patient speculation—is something a tool should help in supporting the management of chronic illness.

6 CONCLUSIONS

Personal, pervasive tools hold great promise for the management of chronic illness. Through our interview study, we gained an understanding of how some people with chronic illness

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[4] Note that well-understood/poorly-understood conditions are distinct from common/rare conditions.

understand and manage their illness using data collection. Viewing this through the lens of personal informatics—and in particular, the desire to learn about oneself (self-discovery)—we see that there is a wealth of opportunities for the design of personal informatics tools to support chronic illness management. We drew several specific design implications from this work: that such systems should support scaffolded flexibility for data collection; that tools should ease data collection, though not necessarily through automation, and that tools should effectively support discovery of patterns and trends as informed through information from the medical community. These ideas provide a foundation for the design of tools that can meaningfully change how we treat and manage chronic illness.

REFERENCES

[1] J. Anhøj, and L. Nielsen, Quantitative and qualitative usage data of an internet-based asthma monitoring tool. *Journal of Medical Internet Research 6*, 3 (2004).

[2] S.A. Ballegaard, T.R. Hansen, and M. Kyng, Healthcare in everyday life: designing healthcare services for daily life. *Proc. CHI 2008*, ACM Press (2008), 1807–1816.

[3] V. Baos, F. Ester, A. Castellanos, G. Nocea, M.T. Caloto, and W.C. Gerth, Use of a structured migraine diary improves patient and physician communication about migraine disability and treatment outcomes. *International Journal of Clinical Practice 59*, 3 (2005), 281–286.

[4] L.K. Bartholomew, R.S. Gold, G.S. Parcel, et al. Watch, discover, think, and act: evaluation of computer-assisted instruction to improve asthma self-management in inner-city children. *Patient Education and Counseling 39*, 2 (2000), 269–280.

[5] J. Bauer, S. Consolvo, B. Greenstein, et al. ShutEye: encouraging awareness of healthy sleep recommendations with a mobile, peripheral display. *Proc. CHI 2012*, ACM Press (2012), 1401–1410.

[6] E.P.S. Baumer, S.J. Katz, J.E. Freeman, et al. Prescriptive persuasion and open-ended social awareness: expanding the design space of mobile health. *Proc. CSCW 2012*, (2012), 475–484.

[7] J.S. Beaudin, S.S. Intille, and M.E. Morris, To track or not to track: user reactions to concepts in longitudinal health monitoring. *Journal of Medical Internet Research*, (2006).

[8] T. Bodenheimer, K. Lorig, H. Holman, and K. Grumbach, Patient self-management of chronic disease in primary care. *Journal of the American Medical Association 288*, 19 (2002), 2469–2475.

[9] S. Consolvo, P. Klasnja, D.W. McDonald, et al. Flowers or a robot army?: encouraging awareness & activity with personal, mobile displays. *Proc. Ubicomp 2008*, ACM Press (2008), 54–63.

[10] H.I. Day, Curiosity and the interested explorer. *Performance & Instruction 21*, 4 (1982), 19–22.

[11] C.A. Eastwood, L. Travis, T.T. Morgenstern, and E.K. Donaho, Weight and symptom diary for self-monitoring in heart failure clinic patients. *Journal of Cardiovascular Nursing 22*, 5 (2007), 382–389.

[12] L. Festinger, *A Theory of Cognitive Dissonance*. Stanford University Press, 1957.

[13] Fitbit Inc. Fitbit. 2012. http://www.fitbit.com/.

[14] J. Froehlich, T. Dillahunt, P. Klasnja, et al. UbiGreen: investigating a mobile tool for tracking and supporting green transportation habits. *Proc. CHI 2009*, ACM Press (2009), 1043–1052.

[15] B.G. Glaser, and A.L. Strauss, *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine de Gruyter, 1967.

[16] L.T. Harris, J. Tufano, T. Le, et al. Designing mobile support for glycemic control in patients with diabetes. *Journal of biomedical informatics 43*, 5 (2010), S37–S40.

[17] A.C. King, D.K. Ahn, B.M. Oliveira, A.A. Atienza, C.M. Castro, and C.D. Gardner, Promoting physical activity through hand-held computer technology. *American journal of preventive medicine 34*, 2 (2008), 138.

[18] M.L. Lee, and A.K. Dey, Reflecting on pills and phone use: supporting awareness of functional abilities for older adults. *Proc. CHI 2011*, ACM Press (2011), 2095–2104.

[19] I. Li, A. Dey, and J. Forlizzi, A stage-based model of personal informatics systems. *Proc. CHI 2010*, ACM Press (2010), 557–566.

[20] I. Li, A.K. Dey, and J. Forlizzi, Understanding my data, myself: supporting self-reflection with ubicomp technologies. *Proc. CHI 2011*, ACM Press (2011), 405–414.

[21] J. Lin, L. Mamykina, S. Lindtner, G. Delajoux, and H. Strub, Fish'n'Steps: encouraging physical activity with an interactive computer game. *Proc. Ubicomp 2006*, ACM Press (2006), 261–278.

[22] E.A. Locke, Toward a theory of task motivation and incentives. *Organizational Behaviour and Human Performance 3*, 2 (1968), 157–189.

[23] R. Luckmann, and A. Vidal, Design of a handheld electronic pain, treatment and activity diary. *Journal of Biomedical Informatics 43*, 5 (2010), S32–S36.

[24] J. Maitland, and M. Chalmers, Self-monitoring, self-awareness, and self-determination in cardiac rehabilitation. *Proc. CHI 2010*, (2010), 1213–1222.

[25] L. Mamykina, E. Mynatt, P. Davidson, and D. Greenblatt, MAHI: investigation of social scaffolding for reflective thinking in diabetes management. *Proc. CHI 2008*, ACM Press (2008), 477–486.

[26] L. Mamykina, E.D. Mynatt, and D.R. Kaufman, Investigating health management practices of individuals with diabetes. *Proc. CHI 2006*, ACM Press (2006), 927–936.

[27] E. Mattila, I. Korhonen, J.H. Salminen, et al. Empowering citizens for well-being and chronic disease management with wellness diary. *Information Technology in Biomedicine, IEEE Transactions on 14*, 2 (2010), 456–463.

[28] M. Morris, S. Intille, and J. Beaudin, Embedded assessment: overcoming barriers to early detection with pervasive computing. *Pervasive Computing*, (2005), 333–346.

[29] D. Preuveneers, and Y. Berbers, Mobile phones assisting with health self-care: a diabetes case study. *Proc. MobileHCI 2008*, ACM Press (2008), 177–186.

[30] J.O. Prochaska, and W.F. Velicer, The transtheoretical model of health behaviour change. *American Journal of Health Promotion 12*, 1 (1997), 38–48.

[31] Quantified Self Labs. Quantified Self | Self Knowledge Through Numbers. http://quantifiedself.com/.

[32] S. Rachman, The evolution of cognitive behaviour therapy. In *Science and practice of cognitive behaviour therapy*. Oxford University Press, 1997, 1–26.

[33] S. Roberts, The unreasonable effectiveness of my self-experimentation. *Medical Hypotheses*, (2010), 482–489.

[34] V. Schwanda, S. Ibara, L. Reynolds, and D. Cosley, Side effects and gateway tools: advocating a broader look at evaluating persuasive systems. *Proc. CHI 2011*, (2011), 345–348.

[35] B.F. Skinner, *Walden Two*. Prentice-Hall, 1948.

[36] S. Stieger, and A.S. Göritz, Using instant messaging for Internet-based interviews. *CyberPsychology & Behaviour 9*, 5 (2006), 552–559.

[37] A. Voida, E.D. Mynatt, T. Erickson, and W.A. Kellogg, Interviewing over instant messaging. *CHI'04 extended abstracts on Human factors in computing systems*, (2004), 1344–1347.

[38] G. Wolf, The data-driven life. *The New York Times*, (2010).

[39] T.J. Yun, H.Y. Jeong, T.D. Hill, et al. Using SMS to provide continuous assessment and improve health outcomes for children with asthma. *Proc. IHI 2012*, ACM Press (2012), 621–630.