

Towards Personal Informatics Tools for Chronic Illness Management

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ABSTRACT

Many people with chronic illness suffer from debilitating symptoms that inhibit normal day-to-day function. It is unclear how to design tools to support this – many see self-tracking tools as a burden to use. We report here on an interview study with 12 individuals with chronic illnesses who collect data about their conditions. We reflect on ways to support the design of tools that will be more easily adopted by engaging curiosity, self-discovery and exploration rather than focusing on behavior change.

1. INTRODUCTION

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 [1,2]. Providing people with more control over their own care gives individuals more freedom and control over the management over their conditions [4]. One way we can support this shift towards empowering patients is through self-tracking tools for chronic illness management [9,15,16]. These tools allow individuals to collect data about themselves and their condition, and then reflect on that data with the goal of changing their behavior to improve their health and wellbeing. It is widely recognized that self-tracking can be very beneficial in a health care setting. Eastwood and colleagues [6] demonstrated that people who actively used a symptom diary had better adherence to protocols, better patient contact, 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 provided [3]. 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 [3].

In spite of these successes, many people are not motivated use these applications [16]. Researchers point to ways of maintaining motivation. However, these tools have been designed to address *clinical needs*, with clinical outcomes as metrics (e.g. weight loss metrics, or adherence to treatment protocols), rather than emphasizing *the interests of the people using the tools*. Specifically, one way to motivate users is to engage their curiosity, and interest in self-discovery.

While prior work sought to improve self-monitoring technologies for the purpose of behavior change, we explore the possibility that self-motivated curiosity and an interest in self-discovery might provide a lens through which we can improve the design of these tools. We conducted an interview study with 12 people who employ personal informatics practices in relation to a chronic

illness. We describe our study, present our findings, and discuss those findings in the context of related work. We propose that we can add value for users of self-tracking tools by improving the benefits the tool provides, and reducing the costs associated with using the tools. This can be done by reorienting ourselves towards curiosity and self-discovery (and away from behavior change), and by acknowledging the role of this self-tracking process in an individual's life.

2. INTERVIEW STUDY

How does curiosity and self-discovery manifest 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. We further recruited 12 participants with chronic illnesses who collected personal data to participate using a snowball sampling method.

Method. Participants took part in a semi-structured in-person interview (four were conducted over instant messaging). 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. We asked participants to bring the tools they; remote participants sent pictures of their tools by email. Our interview consisted of three topic areas; topic 1 focused on the participants' condition, topic 2 addressed the participants' motivation for collecting, and their collection practices, and topic 3 considered how participants used their data, and what they had learned from it.

Of the 12 participants, 10 were female and ages ranged from 18-55. These participants had a range of conditions including asthma, depression, diabetes, epilepsy, fibromyalgia, gastroesophageal reflux disease, hereditary angioedema, low blood pressure, migraines, and osteoarthritis. Participants had been collecting data for anywhere from 2 months to 28 years. Seven participants used forms, software or devices provided to them by their doctors as their collection tool. Three participants used more than one collection tool to obtain the data they desired.

3. FINDINGS

Our findings as a whole suggest that self-discovery is a powerful lens for understanding the management practices of some with chronic illness. In this section, we discuss some of the actual data collection practices—the tools, techniques, and usage.

3.1 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

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?
	Dealing with Triggers	How do I deal with triggers I can't eliminate? 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? Is my medication working?
	Side Effects & Elimination	Can I eliminate the need for medication by changing my lifestyle and eliminating triggers? What side effects am I noticing?
Status		Am I getting all the {sleep, nutrients, etc.} I should be? Are my indicators normal? Do I need to treat myself currently?
History		If I'm having problems now, have they happened before? Am I improving? How long have I gone without having an episode?

Table 1: Questions participants are asking of their data

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 participants decided on their own to collect data. 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."*

3.2 Questions

Participants used their data to seek answers to several different kinds of questions/concerns. Table 1 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. [10] in their work with data enthusiasts.

3.3 Collected Data

In order to answer those questions, participants collected a blend of qualitative and quantitative, objective and subjective data.

Episodes. *Episodes* were detectable incidents and participants were interested in their occurrence and frequency, as well as the feeling or severity of 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.

Triggers. *Triggers* were factors believed to cause an episode. P10 (Epilepsy) collected suspected seizure triggers like caffeine, meal times, stress, sugar, alcohol, and general excitement. *"Despite all the tests conducted on me, there is no definite known cause for my seizures. Therefore it is imperative that I understand the causes."*

Medication. Participants also tracked *medication* they consumed – 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.

Status. Some participants tracked *status indicators*, like blood glucose, which gave participants a sense of the current state of their condition. P7 (Diabetes) collects readings from a glucometer and responds accordingly with insulin treatments.

History. 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."

3.4 Tools

Participants with rigid and structured processes typically used tools provided by their doctors. While these participants felt their collection was reliable and accurate, they found the inflexibility frustrating. P13 (Hereditary Angioedema) uses a highly structured and specialized web form, but desired 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 immense flexibility, but little structure. These were used 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 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."*

P14 (Low Blood Pressure) did not always carry her notebook with her –she often makes notes on Post-It's and then adds them to the notebook later. She explains that 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. 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 tools used personalized templates they had created for themselves. These templates allowed for a certain level of flexibility because the participants were in control, but it also provided structure for 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, and had tried other tools before gaining enough of an understanding of their own needs to create personalized templates.

P10 (Epilepsy) used a spreadsheet with a column for each item he was tracking (medication, sleep, caffeine, meal times, stress level, sugar consumption, etc.). He preferred this method to others he had tried (paper spreadsheet, paper journal, electronic journal) because *"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 to add new types of data, while still providing support for reviewing the data.

3.5 Reflection

Many of our participant’s tools (in particular the non-digital ones) only allowed them to review raw data. P8 (Epilepsy) reflected on his data 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.”*

Even participants who used digital tools found the reflection tools to be insufficient. P6 (Depression) used a mobile app that provided visualizations of her data, 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.”*

P10 (Epilepsy) used the template he created in Excel to sort and filter 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...”*

DISCUSSION From Behavior Change to Self-Discovery. Many tools have been designed to guide behavior change, appropriating theories from behavioral and social psychology [7,13,17,19]. These strategies rely on persuasive forms of feedback based on collected data [5,8,12]. Yet, while researchers have seen problems with fleeting motivation, the personal informatics community has seen considerable growth and interest. These enthusiasts go to great lengths to design their own tools in efforts to support their self-discovery process. In studying these enthusiasts, Li et al. describes the kinds of activities/problems they encounter [10], emphasizing the role of the personal reflection on supporting this process [11]. 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 it to be motivating for those with chronic illness?

Although the personal informatics enthusiasts studied in [10] and in [11] 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 with their orientation to better understanding themselves, and in how the data collection addressed their curiosity about their own conditions. Although some of our participants began collecting data on the request of their provider while others took the initiative on their own, ultimately, 11 out of the 12 participants saw at least some value in the data they collected. They believed it would and did help them to understand their conditions and regain control over their own lives, which gave them a means to communicate more effectively with their provider and receive better treatment.

Li et al. [10] 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 current 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 way of analytic tools that allow them to explore possible relationships between different types of data, and these analytics 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 their medication.

Additionally, there is a movement 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. [10] 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 engaged in what could be described as a review-as-you-go technique, where they reviewed 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 make sense for specific applications will depend on whether there is insight to be gained in having a person collect data manually, and whether there is a mechanism to collect data automatically. There may be room to reduce the costs of data collection through automation, but a knee jerk decision to automate everything might be unwise.

A Cultural Shift. In Mattila et al.’s work [16], they saw that their Wellness Diary was more effective when part of a larger intervention program, and less successful as a stand alone application. They found that the users of their diary were not able to maintain a long-term interest without external motivation and support. Similarly, Maitland et al. [14] have suggested that self-monitoring technologies provide “a referential service rather than a continuous presence” and “support varying degrees of engagement and allow for gradual disengagement”.

It is important to recognize that these self-monitoring technologies make up only a portion of an individual’s illness management program. It is also important to maintain perspective on the role of that program in the individual’s life. These individuals are not just patients – they also have jobs and hobbies and families and friends. The costs of self-monitoring become increasingly high if we design technologies with a false assumption that they are a main focus for these individuals – instead, it may be possible to design self-monitoring technologies that recognize they are only a component of a much larger health intervention program, and recognize that users will not always prioritize their health tracking over their work or family or social life and hobbies.

Additionally, “health” is not just the absence of illness. People make trade-offs about “doing the right thing” that account for not only their condition, but also their context and situation. We’ve seen examples of this not only in the existing literature (e.g. [2,14,18]) but in our own work as well; 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.” So, the question is: who should define what “health” is? Ultimately, we believe that it should still be up to the individual. A tool should allow people to articulate their own perspective on what health is to *them*.

4. CONCLUSION

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 understand and manage their illness using data collection. We saw that their motivation for collecting this data was not unlike that of the personal informatics enthusiasts studied in prior work, but that they lacked the tools they needed to be able to engage in the deeper exploration of their data. By reorienting our thinking towards curiosity instead of behavior change, and maintaining perspective on the role of personal informatics tools in an individual’s life, we can design tools that can meaningfully change how we treat and manage chronic illness.

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