Examining Self-Tracking by People with Migraine: Goals, Needs, and Opportunities in a Chronic Health Condition

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ABSTRACT

Self-tracked health data can help people and their health providers understand and manage chronic conditions. This paper examines personal informatics practices and challenges in migraine, a condition characterized by unpredictable, intermittent, and poorly-understood symptoms. To investigate how people with migraine track and use data related to their condition, we surveyed 279 people with migraine and conducted semi-structured interviews with 13 survey respondents and 6 health providers. We find four distinct goals people bring to tracking and data: 1) answering questions about migraines, 2) predicting and preventing migraines, 3) monitoring and managing migraines over time, and 4) enabling motivation and social recognition. Each goal suggests different needs for the design of tools to support migraine tracking. We also find needs resulting from an individual's goals evolving over time, their varied personal experiences, and their communication and collaboration with providers. We discuss these goals and needs in terms of opportunities for personal informatics tools to facilitate learning to: 1) avoid common pitfalls; 2) support customization and flexibility; 3) account for burden, negativity, and lapsing; and 4) support management with uncertainty.

ACM Classification Keywords

H.5.m. Information Interfaces and Presentation (e.g., HCI).

Author Keywords

Personal Informatics; Health; Chronic Condition; Migraine.

INTRODUCTION

As part of diagnosing and managing health conditions, people and their health providers often utilize data about a person's environment, behaviors, and symptoms. Such data can be especially helpful in the management of chronic conditions. Prior research has examined opportunities for technology to support personal informatics practices in managing a range of chronic conditions (e.g., asthma [35] , diabetes [16, 29, 53], hypertension [10,31,32], irritable bowel syndrome [38,39,62]). However, people with migraine present additional goals and needs that can be particularly difficult to support, due in part to the unpredictable, intermittent, and poorly-understood nature of migraine symptoms [57]. An estimated 14% of

the population experiences migraine, the third most prevalent disease in the world [65]. Symptoms can be debilitating, often including pain, sensitivity to light, and impaired cognition. Migraine is a leading cause of loss of workplace productivity [64] and is the seventh-highest cause of years lost due to disability [65]. People often turn to personal data to better understand and manage their migraines, but struggle to control symptoms [4], motivating additional research in the design of personal informatics tools for people with migraine.

Building upon Park and Chen's identification of migraine as an important condition largely unstudied by the human-computer interaction and design research community [57], this paper examines how people navigate their goals for using self-tracked data to understand and manage migraine, as well as the challenges and pitfalls they encounter. Our focus on self-tracked data builds upon and contributes to research in personal informatics that examines how people attempt to gather and interpret personal data (e.g., [12, 27, 38, 46]). Because people with migraine often turn to providers for help in managing migraine, we additionally build upon and contribute to research in patient-provider collaboration that examines how patient data can inform consultations and how current tools can better support associated needs (e.g., [15,62,69]). This paper therefore bridges an important gap between the challenges people with migraine face in managing their condition and the additional design challenges and opportunities for supporting people with migraine and their providers in their use of self-tracked data.

To characterize how people with migraine track and use data about their condition, we surveyed 279 people with migraine and then conducted semi-structured interviews with 13 survey respondents and 6 health providers. Our contributions include:

- Identifying four distinct goals that people bring to migraine-related tracking and data, each suggesting different needs for the design of tools to support migraine tracking: 1) answering questions about migraines, 2) predicting and preventing migraines, 3) monitoring and managing migraines over time, and 4) enabling motivation and social recognition.

- Characterizing additional design needs and challenges that result from an individual's goals evolving over time, from the variety of personal migraine experiences, and from a desire to communicate and collaborate with providers.

- Describing design opportunities in migraine self-tracking, including in facilitating learning to avoid common pitfalls; in customization and flexibility of tracking; in accounting for burden, negativity, and lapsing in tracking; and in tracking to support management with uncertainty.

BACKGROUND AND RELATED WORK

This section presents background in the domain of migraine and introduces additional challenges that migraine presents relative to other chronic conditions. We then review related research in personal informatics for health and in patient-provider collaboration with patient-generated health data.

Study Context: Migraine

Migraine is a prevalent and debilitating condition that can severely affect quality of life and productivity [64]. To help reduce the frequency and severity of symptoms, people often attempt to identify "triggers", or factors that cause or worsen their personal symptoms [52]. Because triggers vary across individuals [2,43], health providers often encourage self-tracking as part of attempts to identify personal triggers [63]. Both patients and providers believe self-tracked migraine data can help in communication and collaboration [8].

However, prior research examining a variety of conditions has found that people self-tracking to identify symptom triggers encounter multiple pitfalls: tracking too many factors, failing to track factors needed to answer their questions, and accepting dubious conclusions due to insufficient rigor [12]. Such pitfalls motivate examining how technology can support self-tracking to identify symptom triggers (e.g., helping people with irritable bowel syndrome identify foods that trigger their symptoms [38, 39, 62]). In contrast to previously-studied conditions, self-tracking in migraine can be especially difficult. A greater range of factors are relevant, including diet (e.g., alcohol, caffeine), environment (e.g., glare, noise, weather), menstruation, sleep patterns, and stress and mood. In addition, multiple factors often must accumulate before precipitating migraine symptoms [43,68]. This wide variety of factors, and interactions between them, further complicates and confounds identification of an individual's symptom triggers and increases the likelihood of inaccurate conclusions.

In their examination of challenges that people encounter in managing migraine [57], Park and Chen interviewed 12 people with migraine and 2 providers to characterize needs. These needs include: 1) determining whether a person's symptoms result from migraine, 2) determining what might trigger a person's symptoms, 3) developing strategies to manage symptoms, and 4) coordinating social recognition and assistance. We build upon and advance this work with a focused and in-depth examination of how people gather and use self-tracking data (e.g., in identifying triggers, in monitoring symptoms, in social recognition). To better understand the range of self-tracking needs and practices, we employed a mixture of methods that allowed examining a greater number of participants. To better understand provider perspectives on patient data as well as tensions between patient and provider expectations, we also recruited a larger and more diverse set of health provider participants, including both primary care physicians and headache clinic specialists. Our discussion further highlights additional design needs and challenges revealed in our focus on self-tracking data in migraine.

Personal Informatics for Health

Prior research has examined personal informatics practices and tools (e.g., [12, 27, 38, 46]), including in the management of chronic conditions such as asthma (e.g., [35]), diabetes (e.g., [16, 29, 53]), and hypertension (e.g., [10, 31, 32]). Compared to migraine, these conditions have relatively well-understood relationships between symptoms and contributing factors, and technology generally focuses on teaching people about those relationships or helping them learn how to manage them in the context of their lives.

Other research investigates chronic conditions with more acute, episodic symptoms. For example, symptoms of irritable bowel syndrome are often triggered by foods. Personal informatics tools can help determine what foods impact an individual's symptoms, such as through visualizations of self-tracked food and symptom data [62] or through a guided self-experimentation process [38, 39]. Research has also examined how to support people in maintaining control of their lives despite intermittent symptoms, as with intermittent fatigue in multiple sclerosis (e.g., [6, 71]). Our focus is on personal informatics in migraine, a condition characterized by unpredictable symptoms with individual and poorly-understood relationships to triggers. Successful management often requires learning about an individual's symptoms and collaborating with providers to identify appropriate combinations of behavior change, medication, and other treatments that fit the needs of that individual. Personal informatics challenges presented by migraine are therefore likely to draw upon and extend those in previously-studied conditions (e.g., conditions with well-understood symptoms, conditions better suited to self-experimentation).

Prior research in other contexts has studied many factors that can impact migraine (e.g., diet [9,19,38,53], menstruation [26], physical activity [18, 48], sleep [40, 60], stress [54]). However, current tools generally isolate data in domain-specific siloes [27,28]. Despite prior research emphasizing that intensive self-tracking is generally unsustainable (e.g., [12, 20, 25]), current tools also generally fail to support challenges presented by lapsing, resumption, or abandonment [17,25,27]. Migraine requires a more holistic and longer-term approach to facilitate understanding and addressing how multiple factors impact an individual's symptoms [43,68], suggesting new needs and opportunities for personal informatics research and tools.

Clinical Use of Patient-Generated Health Data

Many people turn to health providers for help making sense of collected data [12, 14, 15, 23, 30, 72], both because interpretation is often difficult [12, 46] and because tracking is sometimes initiated at the suggestion of providers [14, 30]. Reviewing patient-generated health data can help providers understand and contextualize patient health [67], which can lead to improved diagnoses, treatments, and health outcomes [14,55,66]. Sharing self-tracked data with providers can also foster motivation and accountability [14, 44, 46] and can ground and provide objectivity during consultations (e.g., [15, 26, 62]). Reviewing patient-generated data can also foster a sense of collaboration, with providers contributing their medical expertise while patients contribute detailed knowledge of their data and behaviors [7, 62].

Despite potential benefits of patient-generated health data, providers face barriers attempting to use such data. Providers

often lack time to review data or feel unequipped to interpret it, especially because data is often incomplete, disorganized, and unreliable [14, 69]. Current tools are generally not designed to support data sharing or collaboration in a manner compatible with provider workflows [14, 30]. When existing tools fail to allow patients to collect the data providers want, providers sometimes recommend paper-based tracking [14, 15]. Paper provides flexibility, but interpretation then generally requires manually sifting through pages attempting to identify patterns. No validated method exists for providers to interpret journal data, so the process is generally difficult and error-prone [34, 36]. Due in part to these challenges, many patients who share their data with health providers report disappointment in provider engagement with that data [30]. Patient-provider collaboration around self-tracking data can also break down when patients and providers have different goals or expectations [15]. In addition, some patients find self-tracking a negative experience that emphasizes health difficulties [1]. People with migraine face similar challenges when seeking help from providers, such that they often decide to discontinue clinical consultations [50, 51]. Our research aims to help address these barriers by engaging both patients and providers in characterizing needs and opportunities for self-tracking data and improved tools for understanding and managing migraine.

DATA COLLECTION AND ANALYSIS

To examine how people and providers work to manage migraine, with a focus on the role of patient-generated data, we conducted a survey examining experiences with migraine and then conducted follow-up interviews with a subset of survey participants. We also interviewed 6 providers for their perspective on working with patients with migraine. Summary information for all participants is in Table 1. Participants skew female, which matches migraine prevalence in the United States: women are three times as likely to experience migraines than men [59]. We refer to survey participants as SX, interview participants as IX, and provider participants as PX.

Survey of 279 People with Migraine

We surveyed 279 people about how they understand, track, and manage their migraines. The survey asked primarily open-ended questions about experiences with migraine, tracking related to migraine, and consulting with health providers about migraine. We focused on understanding what people found particularly helpful and unhelpful about tracking, health consultations, and sharing their data. Participants were recruited through university mailing lists, Facebook posts, and posts to two Reddit subreddits: one dedicated to migraine and another to surveys. Participants were entered into drawings for a single $100 and three $25 Amazon gift cards.

Three researchers conducted an affinity diagram analysis of open-ended survey responses. The first author then created a preliminary code book based on emergent themes. We coded three different categories of participant experiences: 1) using apps to understand, track, and manage migraines; 2) consulting with health providers about migraines; and 3) sharing data with providers during consultations. The three researchers discussed and iterated on codes to develop the final code book, which consisted of 40 codes. The first author then coded 100% of the data, while the other two

Survey Participants (279 People)

Gender	222 female, 51 male, 2 FtM transgender, 1 genderqueer, 1 genderqueer man, 2 no answer
Age	18–96, $\bar{x} = 33.8$ (7 no answer)
Years with Migraine	1–65, $\bar{x} = 17$
Apps Tried (106 people)	Migraine Buddy (71); 40 apps with <10 people each (14 could not remember)
Apps Used (56 People)	Migraine Buddy (30); 23 apps with <10 people each
Other Resources Tried (196 People)	paper journals (83), online articles about migraine (70), online forums such as reddit (44), custom spreadsheets (30), calendars (24), books about migraine (14); 17 methods with <10 people each

Migraine Interview Participants (13 People)

Gender	11 female, 1 male, 1 genderqueer man
Age	20–61, $\bar{x} = 32.15$
Years with Migraine	1–30, $\bar{x} = 15.8$
Apps Tried (8 people)	Migraine Buddy (5), Migraine Coach (2), Fitbit (1), Clue (1), Pacifica (1), Curelator (1), iHeadache (1), PTracker (1), Grid Diary (1) (1 could not remember)
Apps Used (3 People)	Migraine Buddy (1), Migraine Coach (1), Clue (1), Pacifica (1)
Other Resources Tried (13 People)	paper journals (7), custom spreadsheets (5), online articles about migraine (4), online forums such as Reddit (4), calendars (3), books about migraine (1), tracking help from family (1), discussions with other people with migraine (1)

Provider Interview Participants (6 People)

Participant	Area of Practice	Provider Type
P1	Family Medicine	Medical Doctor, Master of Public Health
P2	Family Medicine	Medical Doctor
P3	Headache Clinic	Nurse Practitioner
P4	Primary Care	Nurse Practitioner
P5	Headache Clinic	Nurse Practitioner
P6	Primary Care	Medical Doctor

Table 1: Summary information for all survey and interview participants.

researchers each coded 10% of the data. We then calculated inter-rater reliability, defining "agreement" as use of the same code within a given question response. As preliminary code agreement varied ($\kappa = 0.16 - 1$, $\bar{x} = 0.67$ for the 28 codes used more than 10 times, with 0.8 or higher for 11 codes), the researchers discussed and resolved any disagreements. Most disagreements resulted from misunderstandings about the code book and in infrequently-occurring codes. The first author then took a second pass through the data based on the discussion.

Interviews of 13 People with Migraine

After analyzing survey data, we identified themes to explore in more detail. We wanted to learn more about people who commented on successes or failures in tracking. For example, we reached out to individuals who said data had helped their health consultations, as well as those who had struggled to interpret and act upon data. We were particularly interested in people who had struggled with apps and turned to alternative methods. We emailed 23 people who had agreed to be contacted about follow-up interviews, and 13 responded to our request.

Semi-structured interviews were conducted by Skype or phone. Interviews covered: 1) the participant's general experience with migraine, 2) how the participant collected data, 3) what they liked and disliked about their method, and 4) how and with whom they shared data (e.g., family, friends, coworkers, providers). Questions encouraged participants to discuss their experiences, thoughts, and behaviors. Interviews were approximately 30 minutes, compensated with a $20 Amazon gift card.

A third-party service transcribed the audio recordings. Two researchers then open coded 2 transcripts. The first author open coded the remaining 11 transcripts, then affinity diagrammed the resulting codes and created a code book of 70 codes from emergent themes. Finally, two researchers coded the data using the code book. Inter-rater reliability is not often calculated on semi-structured interview data because different people can apply the same code to different parts of a conversation [3]. We therefore did not calculate reliability between researchers.

Interviews of 6 Health Providers
Finally, after learning about the expectations and experiences that people with migraine have when bringing their data to providers, we interviewed 6 health providers from a range of specialties about their experiences with patients with migraine (see Table 1). Interviews were semi-structured, 5 conducted in person and 1 by phone. Each interview covered: 1) general experiences working with patients with migraine; 2) experiences with patients who tracked information about their migraine, focusing on whether and how the provider interacted with patient data; and 3) provider reactions to specific examples of migraine tracking methods, collected from our interviews of people with migraine. Providers were recruited via email introductions from our medical collaborators and compensated with a $30 Amazon gift card. A third-party service transcribed audio recordings. Resulting transcripts were analyzed via a similar process of open-coding, affinity diagramming of codes to create a code book, and coding using the resulting code book.

Limitations
Many of the people with migraine we surveyed and interviewed were associated with professional and social networks of the researchers. Participants skew more highly-educated than the general population: 38% of survey participants have an advanced degree, and an additional 32% a bachelor's degree. Recruitment, particularly via a subreddit for migraine, may have biased our sample to people who seek an online community for migraine resources. Prior work suggests people who get migraines less frequently or less severely are less likely to dedicate as much time to tracking and management [57], so they may also not engage in such a community. Finally, 84% of survey participants were from the United States, as were all 6 provider participants. Tracking habits and care strategies may differ in other cultures or countries, so care must be taken when generalizing our findings.

RESULTS
Of 279 survey participants, 106 had used an app to try to understand, track, or manage their migraines, and 56 still used an app. Participants primarily reported using apps for tracking migraines (n=80), determining triggers (n=59), and tracking medication use (n=13). The majority of participants had used resources or tools other than apps to try to understand, track,

or manage their migraines (n=196), instead of or in addition to such apps. The most common use of other technological and paper resources was tracking, but participants also described online research and community support (see Table 1).

Many found technology useful for migraine-related tracking. Those who had used apps often felt their app was easy to use (53/106) and helped them identify trends and triggers (42/106). However, many found the tools they used failed to fully support their goals. This section discusses four challenges we found current technologies fail to fully support: 1) variety in personal tracking goals, 2) tracking goals that evolve over time, 3) variety in personal experiences with migraine, and 4) support for data sharing and collaboration with health providers.

Although we report counts of participants who expressed perspectives, the open-ended nature of survey and interview questions means not every participant was explicitly prompted about each perspective. As a result, additional participants beyond those in each count may have agreed with a perspective.

Tracking for a Variety of Goals
Informed by and building upon prior research on self-tracking goals (e.g., [12, 26, 42, 46, 46, 61]), we find four primary goals people bring to migraine-related self-tracking: 1) answering questions about migraines, 2) predicting and preventing migraines, 3) monitoring and managing migraines over time, and 4) enabling motivation and social recognition. Participants often had simultaneous and overlapping goals, but explicitly distinguishing them better facilitates consideration of the design implications of each goal for self-tracking data.

Goal 1: Answering Questions About Migraines
Many people who track information about their migraines do so with a goal of *diagnostic self-tracking*, or self-tracking to answer a specific question about a person's health [61]. Common questions include what behaviors or other factors contribute to an individual's symptoms and whether a new treatment or preventative medication seems to improve symptoms.

For example, of 106 survey participants who had tried an app, 65 had used it to attempt to identify factors that contributed to their migraines. Some apps provide graphs or analyses to help identify factors that correlate with symptoms, and 16 survey participants mentioned feeling that apps helped them interpret their data. However, another 16 survey participants explicitly discussed finding data hard to interpret. When asked in interviews, 10 of 13 participants described similar challenges (*I1*, *I4*, *I5*, *I6*, *I8*, *I9*, *I10*, *I11*, *I12*, *I13*). Because individual apps generally do not support tracking the wide range of factors potentially relevant to an individual's migraine, participants often track data across multiple apps. To identify trends, participants then needed to integrate data across apps themselves. *I10* explained she "*found it stressful ... there's no place in any of those apps for a whole health picture of, like, OK, I was nauseated today. I had a migraine today*". *S66* lamented that no single app helped him track and understand his data: "*I wish a program like a general health app (e.g, Lose-It) would track everything and do correlations.*" *S258* summarized that apps made it "*[t]oo difficult to put all the pieces together*". When people collect data in separate apps, the data typically remains siloed, creating additional barriers and burdens in interpretation.

Participants often used data to compare symptoms before and after a change. If people feel symptoms improve after a change, they may be more likely to commit to that change, especially if it requires behavior change or incurs side effects. If they do not feel symptoms improve, they may return to the prior behavior or ask their provider for another solution. Such "before and after" comparisons are therefore useful to get a sense for whether a treatment is helpful. 7 of 13 interview participants mentioned that tracking had helped them identify treatment-related trends (*I1*, *I2*, *I6*, *I9*, *I10*, *I11*, *I12*), with *I11* explaining "*you basically turn your life into a control of a experiment and try to change one thing at a time and see what works*". All 6 providers also wanted their patients to track as part of enabling comparisons to determine effectiveness and whether to continue a treatment.

Despite considering data useful for answering such questions, however, providers were wary of patients focusing too much on a single potential trigger. 4 of 6 providers (*P1*, *P3*, *P4*, *P5*) expressed concern people might see false patterns, leading them to make changes that could be unnecessary or inappropriate. When discussing participants who track foods to attempt to identify specific dietary triggers, *P1* explained that the practice was not only often futile, but also potentially dangerous:

> There can be a lot of overlap between dysfunctional eating and tracking, and so sometimes [tracking foods] reinforces dysfunctional eating like, "Oh, I got a headache after I ate bread, so now eliminate gluten from my diet", when it's just a way to kind of normalize dysfunctional eating.

Goal 2: Predicting and Preventing Migraines

Distinct from tracking to determine what factors increase an individual's likelihood of symptoms (i.e., Goal 1), many people track with a goal of predicting and preventing migraines. Of 106 survey participants who had tried an app, 15 had used it to try to predict their migraines. Because migraines often occur due to an accumulation of multiple factors [43, 68], people may not need to entirely eliminate factors that can contribute to a migraine. Other factors that may contribute are outside of a person's control. People therefore must not only identify their potential migraine contributors, but also be cognizant of exposure to factors that impact their likelihood of symptoms. 4 interview participants (*I1*, *I3*, *I6*, *I7*) described trying to predict likely migraines by paying attention to what they are exposed to, so they can take other actions to attempt to prevent a migraine. For example, *I6* described using the MigraineX app to get alerts whenever the barometric pressure was going to drop. When she gets those alerts, she explained:

> I do what I can to make sure that I'm really well hydrated ... that I get my best sleep ... that everything else in my body is as healthy as possible so that hopefully I can ride through that weather front without any other triggers.

Even when a migraine could not be prevented, participants benefited when a prediction provided an opportunity to prepare. For example, a person's menstrual cycle can be an important trigger of migraine symptoms, and *S257* described tracking to predict symptoms: "*The app can be validating: when I feel a migraine coming on I can see that it might be roughly the usual time in my [menstrual] cycle to get one. Instead of fighting it, I can just try to adjust my schedule and get through it.*"

I7 additionally explained how predicting a migraine allowed her to prepare: "*Even if it's just throwing extra rescue meds in my purse. It's an incredibly helpful thing instead of sitting there and floundering while you're on the train ride on the way home like 'oh my God, I wish had something to take right now'*".

Tracking for prediction and prevention is often complicated by people struggling to identify factors that impact their symptoms, especially because some important factors are surprising to many people with migraine. For example, 4 of 6 providers described overuse of acute medications as the top mistake among patients. Many people with migraine take acute medications (e.g., 224 of 279 survey respondents reported trying over-the-counter medication to stop a migraine, 201 of 279 reported trying a prescription acute medication). However, medication overuse can actually cause more frequent migraines, creating a cycle in which a person gets more migraines, which prompts them to take more medication, which leads to still more migraines [49]. Providers emphasized a need for education about trigger accumulation and medication overuse, as tracking other factors is likely futile absent this foundation. Many participants also wanted technology to be more prescriptive, including 5 interview participants (*I3*, *I4*, *I6*, *I11*, *I13*) saying they wanted apps to provide recommendations and make suggestions about what they might track or changes they might try.

Goal 3: Monitoring and Managing Migraines Over Time

Although many participants tracked to learn about their migraines (i.e., Goal 1) or predict migraines (i.e., Goal 2), others tracked to monitor and manage their condition. Tracking migraine symptoms was the most common reason survey participants reported using an app, with 80 of 106 people who had used an app reporting symptom tracking as among their goals. In contrast to prior goals, monitoring and managing migraines over time often focuses on symptom-related data, and therefore cannot help identify correlations with factors that might be related to symptoms. However, 10 interview participants discussed how such symptom tracking helped them remember and monitor their experiences (*I2*, *I3*, *I4*, *I5*, *I6*, *I7*, *I9*, *I10*, *I11*, *I13*). For example, *I2* talked about how tracking helped her monitor her symptoms, ensure she was not getting worse, and notice any need for changes:

> [my provider] saw the January and February and she's like, "Oh, that's a reasonable number of headaches", and then she saw March and April and was like, "That's too many headaches" ... And she was like, "Okay if you're still getting six or seven headaches a month in a couple months, we're gonna talk about doing something else".

Many providers encourage patients to track, and providers often use the resulting data to support diagnoses and treatment decisions. All 6 providers recommended patients track migraine symptoms under some circumstances. Of the 47 survey participants who had shared data with a provider, 10 felt that having the data directly influenced their diagnosis or treatment, and all 6 providers said the same. To support such migraine monitoring and management, patients and providers need data about migraine frequency and severity, as well as information about what treatments a person has been pursuing.

Goal 4: Enabling Motivation and Social Recognition
Although providers often recommend patients track to gain information, they also believe tracking can help motivate people to make changes to improve their symptoms. *P3* and *P5* work at a headache clinic, where they recommend behavior changes that can help reduce migraine frequency and severity (e.g., increasing exercise, modifying diet, relieving stress). Patient-tracked symptom data helps providers show patients that behavior changes actually impact their migraines. *P3* explained:

> [a patient] might think, "I'm doing so horrible, I'm doing so horrible", and then you look at it, and you're like "you actually cut back your severity by 50%" ... you kind of shift your perspective as you go on, and the new horrible becomes just the same horrible, even though it's improved. So, it's helpful to show that improvement more than anything.

The "before and after" comparison *P3* describes has similarities to interpreting what factors impact symptoms (i.e., Goal 1) and to monitoring migraines (i.e., Goal 3), but also differs in its purpose. For example, a person may make multiple small behavior changes, and then need to examine a larger, cumulative comparison to motivate themselves that all of these changes together are justified because they result in an overall improvement. Although data collection may be similar, a person seeking motivation to continue the overall process can therefore need different representations of data than when investigating a specific trigger or monitoring symptoms.

In addition to using data as motivation by demonstrating improvement, *P5* described using it to inspire accountability:

> We want to know whether they are really following the plan, the recommendations, because sometimes some patients say, "Oh, I'm not getting better, I'm doing everything." Well, what is everything? ... besides giving me information for diagnosis, treatment, and plan management, I think when they keep a diary, it also gives them accountability.

Outside of the patient-provider context, people also want to share data with others. Of 106 survey participants who had used apps, 23 mentioned that apps lacked support for social sharing. Similarly, 9 of 13 interview participants expressed a desire to be able to share data with friends or family (*I1*, *I3*, *I5*, *I6*, *I7*, *I9*, *I11*, *I12*, *I13*) and 5 of 13 with a boss (*I1*, *I2*, *I7*, *I11*, *I12*). Some already shared their data, despite the lack of explicit design support. For example, *I9* tracked her migraines on a Google calendar that she shared with her husband "*so he could see when I did have them and how I was feeling*".

Sharing was motivated in part by a hope that people would better acknowledge their symptoms (e.g., family, friends, coworkers, providers). 3 participants shared data to prove their symptoms really existed and were as bad as they thought (*I1*, *I5*, *I12*). *I1* started getting migraines when she was a teenager, and felt that "*nobody believed me. They thought I was just being a melodramatic teenager with headaches who didn't want to go to class or something*". She therefore started tracking to "*[be] able to say, 'No, look, here's documentation of the last six months of my life that have been horrible. Please help me'*". Similarly, 3 interview participants mentioned they shared in order to prove to people that they were actually

Figure 1: *I02* initially used a Google Sheet to track migraine symptoms and potential triggers. She chose this method because it provided flexibility to track exactly what and how she wanted. Now that she understands her triggers, she just tracks bad migraine days on a calendar.

taking action to try to manage symptoms (*I1*, *I11*, *I12*). For example, *I12* shared his data with his boss, "*just to show them, 'Hey, I've been struggling with this ... and this is the work that we've been doing with my neurologist, we're working towards it. We're actively working on stuff'*". Overall, these goals illustrate myriad motivations and needs for sharing migraine data, each requiring different design considerations.

Tracking for Goals that Evolve Over Time
Whether, what, when, and how people want to track often depends on their current understanding of their migraine and whether they consider their situation stable. 10 of 13 migraine interview participants discussed how their tracking changed over time (*I1*, *I2*, *I3*, *I6*, *I7*, *I9*, *I10*, *I11*, *I12*, *I13*). We examine goal evolution in migraine to identify resulting design needs.

Participants often initially tracked intensively with a goal of better understanding migraines (i.e., Goal 1), then transitioned to more minimal tracking with goals focused on management (i.e., Goal 2, Goal 3). For example, *I2* originally had a goal of determining her symptom contributors. She therefore spent three months using a custom spreadsheet to track everything she thought might be relevant (e.g., activities, environmental factors, foods, mood, sleep). After identifying some high-likelihood contributors, she felt she had answered her questions. Her goal then evolved to management over time (see Figure 1). She now only tracks days on which her symptoms are severe enough that she takes her prescription medication, in a paper calendar she also uses for general everyday coordination.

Though the progression from intensive to minimal tracking was common, some found it insufficient. People often must return to goals they previously considered fulfilled, as *I7* explained:

> [I used to track] daily, but that was right back when I started on new meds, so I wanted to make sure that I was keeping track of absolutely anything in the worst case scenario sort of thing. Now I just keep track when something major changes. Like most recently I was supposed to up my dose to a 30 milligram day of my preventative, and that just wasn't working out. I feel like if I hadn't kept track of each day-by-day, I might have doubted myself, and been like, "no, no, no just keep doing what your doctor told you [to do]".

With each adjustment of her treatment, *I7* therefore returns to asking questions about her symptoms (i.e., Goal 1). Without this change in her tracking goal, she may not have realized her treatment modification had been detrimental.

As goals change, transitions in tracking strategies are often motivated by tracking burdens. To be prepared to answer questions that may arise, some initially wanted to track as much as possible about symptoms, treatments, and potential contributors. However, such intensive tracking is generally unsustainable, and 7 of 13 interview participants found their tracking experiences negative (*I1*, *I2*, *I5*, *I6*, *I11*, *I12*, *I13*), with all 6 providers additionally mentioning negative patient tracking experiences.

In addition to direct burdens, participants described frustration with negative emotions in tracking. *I11* explained, "*You're supposed to enter [information] everyday, which I totally get the validity of and rationalization behind, but it's just one more thing about the day that's dedicated to my disease and it isn't what I want to be doing with my time*". *P4*, *S107*, and *S140* further described a concern that tracking can worsen a person's overall experience with their condition, as with *S140*:

> when I track my pain closely, I pay more attention to it, and I'm less happy. I stopped my migraine diary after a couple of years and I honestly think ceasing to consciously observe my pain level every minute of the day made me feel better.

Some participants feared that migraine tracking could itself be a contributing factor. *I7* commented: "*The more I was focusing, tracking, journaling, the more migraines I was getting*". When participants suspected tracking was making their migraines worse, they often wanted to abandon tracking, despite potential benefits.

Given this combination of burden and negative experience, all 6 providers felt patients should track according to their goals, rather than indefinitely. *P3* explained "*we recommend they do ongoing tracking, as long as they're working with us. But once you're in a stable point, it's probably less important to keep tracking unless it's helpful for the patient, because it can become a burden*". *I6* similarly motivated a need to support lapsing, resumption, and abandonment in migraine tracking:

> Having it so you don't feel like when you have a gap in your data, you have just start from zero [is helpful]. Whatever [app designers] can do to kind of make it easy to fill in those gaps makes it less intimidating to get back in there.

Finally, despite concerns for minimizing tracking and its burdens, participants also described appropriate tracking as an important part of maintaining motivation (i.e., Goal 4). 4 interview participants (*I1*, *I2*, *I6*, *I7*) described tracking as empowering, especially over the long term, as *I1* explained:

> Just being able to look back at that however many years of journals and calendars stacked up and see that I'm not in the pain that I used to be and that I can live my life and understand the choices that I've made without being scared that I'm gonna be incapacitated the next day. That's a reward and I hope more people can get to that point.

From a provider perspective, *P3* also described modifying a patient's tracking according to motivational needs. She explained that if a patient was not seeing the benefit, she would have them "*flip their tracking, and have them track good moments*". Although such approaches do not remove concerns for burden, encouraging people to see positive aspects can help them in achieving tracking that supports their goals.

Tracking for Varying Personal Experience

Within and across tracking goals, varying personal differences require an ability customize tracking. 6 of 13 interview participants (*I1*, *I2*, *I3*, *I4*, *I10*, *I11*) and 5 of 6 providers (*P2*, *P3*, *P4*, *P5*, *P6*) mentioned the variety of experiences with migraine. 72 of 106 survey participants who had used apps and 11 of 13 interview participants expressed a desire for apps to better support customization (*I1*, *I2*, *I3*, *I4*, *I5*, *I6*, *I7*, *I9*, *I10*, *I11*, *I12*).

A key dimension of customization is *what* a person tracks. For example, *I1* explained she did not like using apps to record her migraines because she "*[doesn't] get all the symptoms that other people do*". *I11* explained a similar frustration with journaling data that she knew was not relevant for her:

> I have been doing this for 20 years now. There are some things I can just cross off my list ... say, whether I ate onions or something? ... I know this isn't a trigger. It's not a problem for me, can I just stop answering questions about onions?

Although customization can allow adding or removing factors to track, defaults and explicit support for particular factors will affect what people consider potentially relevant. *I3* explained how defaults influenced what she believed could be important:

> It makes sense that they would have a limited option of things to choose from, and then allow you to add more things. But it would be nice if that list was a little bit longer, because sometimes you're not sure if something you're feeling or something you did is relevant to the migraine. Or it may not occur to you, if you don't see it in a list, that it would be relevant.

A second key dimension is *when* a person tracks, specifically whether they prefer tracking *during* or *after* migraine symptoms. Of 13 interview participants, 7 reported tracking either during or after a migraine (*I1*, *I2*, *I4*, *I6*, *I7*, *I9*, *I19*), 4 reported only tracking after a migraine (*I3*, *I8*, *I11*, *I13*), and 2 reported only tracking during a migraine (*I5*, *I12*). Some people cannot track during a migraine: 36 survey participants mentioned having trouble using apps because interacting with a screen during a migraine was painful. *I4* described how her migraines impacted her cognitive ability to the point that data tracked during a migraine was often useless: "*The cloudy head makes it very difficult to put words into focus, I guess, and if I [tracked] during a migraine I'd look back and say, 'What the hell was I talking about?'*". In contrast, *I5* always wanted to record that she was taking medication during a migraine, before actually taking it. She explained that tracking during a migraine was necessary because it helped her remember to record the data:

> Usually ... when I'm starting to feel better, there are things [I had been unable to do] that I would want to do. It's often that I'd forget to write [the fact that I took the medication] down ... Record keeping wise, it was more accurate for me to write it down before I took the medication.

Because *I5* needs to track during migraines to ensure reliable data, she was wary of tracking with an app, as she feared doing so would worsen her migraines. She therefore needs to be able to record data without interacting with a screen, thus highlighting a third key dimension of flexibility in *how* people track.

Data in Communication and Collaboration with Providers

As mentioned above, people with migraine often wanted to share tracked data with their health providers. Of 47 survey participants who reported bringing data to a health consultation, 22 mentioned that concrete data was helpful. Similarly, 12 of 13 interview participants (all except *I8*) said tracking helped their consultations. 10 of 13 interview participants mentioned tracking, and the resulting data, helped them remember their experiences (*I2*, *I4*, *I6*, *I7*, *I8*, *I9*, *I10*, *I11*, *I12*), and 6 felt it helped them more effectively communicate experiences to a provider (*I1*, *I2*, *I6*, *I7*, *I9*, *I10*). *I6* explained:

> Really what I needed was a tool to talk to my doctor about, because it's really hard to just go in there and be like, "I have them a lot." When you speak in vague terms, you get vague treatment. That's essentially what I needed, was an empowerment tool to go in and say, "This is frequency. I need to know what treatment's doing. I need to know what's working, what's not".

I7 similarly explained benefits of her tracking and data, even when data was not directly shared with her provider:

> I'll bring out the report that I printed out in with me, and even if [my health provider] doesn't ask to see it, I feel like it's good for me to have it there in case I forget anything. Mostly it's just helping me check on myself so that I don't forget something important, or exaggerate something wildly, when I'm like, actually it wasn't that bad. Yeah, it's just like having a set of checks and balances for me, by me.

Providers also appreciated their patients self-tracking. All 6 providers we interviewed reported they had recommended a patient track their migraines. 4 of the 6 providers said self-tracked data can help communication and collaboration (*P1*, *P3*, *P5*, *P6*). All 6 providers said they wanted to be able to see a patient's data in some circumstances. *P3* explained:

> It's a way to avoid misunderstanding, because a lot of time people will be talking about their headaches. Let's say they're talking about their migraines, but really they're just talking about their most severe migraines, and you're making this assumption that the five days a month are the only headaches they're having. When really they're having daily headache, it's just these five migraines that are really bothering them ... I feel like [having the data] takes those assumptions out of the way.

However, when patients and providers collaborate around data in a clinic appointment, they often struggle to interpret it. Of 47 survey participants that reported sharing data with their provider, 6 noted the volume of data made it difficult. *S136* explained: "*Because it was so dense and not in an easily digestible form like a chart, I don't think it was very helpful in our appointment*". All 6 providers reported they had struggled to interpret data in a clinic appointment, and 4 additionally said they did not want to see patient-generated data in some circumstances (*P1*, *P2*, *P5*, *P6*). These circumstances included patients bringing an overwhelming volume of data, as well as patients bringing data the provider is unprepared to or uncomfortable with interpreting (e.g., food-related data).

Although consistent with prior findings that patient-provider collaboration to interpret data can be difficult (e.g., [15, 62]), migraine data magnifies these difficulties due to: 1) the many factors that are potentially relevant to an individual's symptoms, and 2) the fact that those factors are generally siloed in their own app or other tracking method. *S198* explained that compensating for siloes is time-consuming and burdensome: "*I usually write things out ahead of time because the reports I want aren't quickly accessible or I have to wade through info and pick out what I need*". 6 of 13 interview participants similarly described integrating their data (*I1*, *I6*, *I7*, *I9*, *I10*, *I11*), with *I11* saying, "*Having to coordinate all the apps together and then when I'm at my headache appointment, I feel like I have to take 20 minutes before I go and ... copy all of the data out long-hand so that I have it all pieced together*". Some participants attempted to address integration challenges by using calendars or custom spreadsheets so they could track exactly what they wanted. However, 5 of 6 providers (*P1*, *P2*, *P3*, *P4*, *P5*) expressed that such custom spreadsheets were particularly difficult to interpret during a clinical consultation. Migraine tracking must account for the many factors that are potentially relevant to an individual's symptoms, but current approaches and tools for capturing and integrating the wide range of potentially-relevant factors can create challenges in effectively communicating and collaborating with providers around that data.

Of 47 survey participants who had shared data with their provider, 13 felt their provider did not engage as much as they hoped. A common breakdown is for patients to expect providers to directly review data. In part because of the challenges discussed in this section, providers often preferred patients interpret data themselves, on their own time. *P2* described trying to avoid misunderstanding by telling her patients, "*this is for you. This is you trying to do the detective work of figuring out what's going on here. You're going to be the best person to figure this out. I'm not going to be the best person to figure this out*".

In addition to aligning migraine tracking goals, successful collaboration around migraine requires agreeing about overall management goals. *I2* described a misalignment with her provider wherein both sought to use data for understanding (i.e., Goal 1), but within different overall management goals:

> [My doctor's] approach was much more like, "Let me figure out what drugs I can give you to have you stop having these headaches", rather than figuring out why I'm having them. I'm much more like, "I want to know why this is happening to me".

The complexity of migraine data and the variety of goals people bring to that data therefore present additional needs in self-tracking and patient-provider collaboration.

DISCUSSION

Our findings illustrate how people navigate their goals for using self-tracked data to understand and manage migraine, building upon prior research in migraine [57], personal informatics (e.g., [12, 27, 38, 46]), and patient-provider collaboration with patient-generated data (e.g., [15, 62, 69]). With our focus on the role of self-tracked data in migraine management, some of our results provide additional insights and detail within themes identified by Park and Chen. For

example, Park and Chen characterize trigger identification as an important challenge, within which we provide greater insight into specific barriers and design opportunities (e.g., emphasizing an accumulation of contributing factors rather than any single trigger, data integration challenges presented by using multiple apps to track different migraine-related data). We also surface data-centric insights that are distinct from the themes identified by Park and Chen (e.g., the importance of many different "before and after" questions in migraine management, roles for data in motivation and accountability in patient-provider collaborations, design challenges resulting from a person's migraine-related goals evolving over time).

Informed by our findings, this section discusses additional design requirements and opportunities for personal informatics tools to support people with migraine, organized into themes of: 1) facilitating learning to avoid common pitfalls; 2) supporting customization and flexibility; 3) accounting for burden, negativity, and lapsing; and 4) supporting management with uncertainty. Our findings, design requirements, and design opportunities also warrant exploration in other conditions with unpredictable, intermittent, and poorly-understood symptoms.

Facilitating Learning to Avoid Common Pitfalls

People often track to develop personalized understanding (i.e., Goal 1), but lack necessary background information to identify potentially relevant factors. Absent guidance on how to systematically answer questions, many people reach conclusions that are dubious, that lead them to needlessly avoid things they enjoy, or that are otherwise problematic (e.g., *P1*'s concern for dysfunctional eating facilitated by a spurious association resulting from an individual relating gluten to their symptoms after a single episode). Park and Chen emphasized a need for education regarding potential triggers of migraine symptoms, and integrating learning into health self-tracking tools is an important theme of prior research (e.g., in making healthy decisions throughout pregnancy [58], in making healthy interpretations and decisions around sleep tracking [60], in maintaining a healthy diet while identifying and avoiding foods that trigger symptoms in irritable bowel syndrome [62]). Our research extends these ideas by emphasizing key priorities for migraine learning in the context of self-tracking and resulting data.

Prior to using self-tracking data to robustly answer questions about their migraine, individuals must address two prerequisites: 1) controlling acute medication usage (i.e., over-the-counter and prescription pain relievers), and 2) understanding that migraine symptoms generally result from an accumulation of factors, rather than a single trigger. We have noted the first is important because overuse of acute medication often causes symptoms, leading to a cycle in which a person takes more medication, leading to still more migraines [49]. Tools should prioritize support for learning about medication overuse, and could support tracking an acute medication "budget", but should ensure this support does not create unnecessary burdens for people who already understand and have addressed this aspect of their migraine management. Designs should similarly emphasize accumulation of multiple factors, rather than overly emphasizing efforts to identify a single "trigger". An emphasis on accumulation also enables learning about health behavior change (e.g., healthier eating,

increased physical activity, better sleep), which our providers described encouraging as a means to improve an individual's overall resilience to factors that contribute to their symptoms.

Failing to address these prerequisites can easily lead to data being misinterpreted (e.g., attributing migraines that result from medication overuse to other spurious correlations, identification of spurious factors that happen to occur at a time when other factors accumulate). Growing interest in techniques for individualized understanding (e.g., [21, 22, 38, 39, 45]) fosters a desire to extend approaches from specific domains into general-purpose tools. Our results balance this desire by highlighting a need to ensure tools account for condition-specific challenges and pitfalls. A general-purpose tool that does not account for medication overuse, or which emphasizes individual factors instead of accounting for their accumulation, could easily confound or mislead in the context of migraine.

Supporting Customization and Flexibility

Within and across tracking goals, tools need to support customization and flexibility in what, when, and how people track. In deciding what to track, appropriate default options are important, in part because they influence what people consider potentially relevant. But the wide variety of relevant factors and personal experiences mean many people will not want to track all default options and may have other data they do want to track. Additional challenges are presented by data that is siloed in different tools or must be abandoned when a person changes tools due to a change in tracking goals. Similarly, people with migraine need flexibility in when they track, so tracking can be adapted to their needs and symptoms. Tracking designs often emphasize tracking "in the moment", but such a requirement is inappropriate for many people with migraine.

People with migraine often turn to paper-based tracking rather than tracking via an app. In addition to allowing greater flexibility, paper-based tracking does not require interacting with a screen during a migraine, which participants described as important. Unfortunately, resulting data is difficult to integrate, analyze, and interpret. Opportunities exist to explore hybrid solutions, such as tracking on paper and later digitizing data. Paper forms could be customized and printed according to an individual's current needs. Research in low-resource environments has examined using phones in digitization of paper forms (e.g., [11,24,56]), and technology-centric research has explored augmented paper (e.g., [5,33,47,70]), but potential needs and opportunities for hybrid paper-digital tracking are largely unexplored in personal informatics research.

Support for customization must also consider provider needs, including provider goals, limited time, expectations that patients lead the interpretation process, and the difficulty of interpreting data in formats that vary across individual patients. One possibility may be to define common or important questions (e.g., the various "before and after" questions in each of the tracking goals), then develop tools for quickly curating a person's data into a more standard format for answering these questions. Such tools might be used by a person prior to a clinic appointment, either because they intend to share the resulting data and visualizations with their provider or because they want to review the data themselves prior to the appointment.

Accounting for Burden, Negativity, and Lapsing

Tools also need to account for burden and negativity. Tracking can impose many burdens [20, 25], and participants described additional negativity (e.g., that tracking was a constant reminder of difficulties of their health condition, that stress associated with tracking could contribute to symptoms). Even when a person's information goals suggest "more data is better", tools must support people in balancing this desire for data against their lived experience with tracking [27, 61]. Current tools instead often assume continuous tracking and provide little or no explicit support for lapsing [17, 25, 27]. Research in other domains has noted tools often fail to support people as their goals evolve (e.g., healthy eating [13], financial tracking [42], menstrual tracking [26]), and we see a similar need to support lapsing and evolving goals in migraine. For example, a person with a stable understanding of their migraine may stop tracking, later resume symptom-only tracking as part of monitoring (i.e., Goal 3), and much later resume tracking behavioral data as part of asking a new question (i.e., Goal 1). Designs should support people in determining whether and what to track and should minimize any burdens or negative experiences in resumption. Designs will also need to account for such lapses in analyses and visualizations (e.g., in designing how to support "before and after" comparisons in data that includes lapsing and intermittent tracking, in historical visualizations that include many gaps and variation in what data is tracked over time). As tools explore how to support sharing migraine-related data with family, friends, and coworkers, any negative consequences of sharing will also need to be examined and addressed (e.g., embarrassment of the person with migraine, discomfort of the people with whom they share).

Supporting Management with Uncertainty

Diagnostic self-tracking often presents pitfalls to scientific rigor [12], a challenge that has motivated prior research in other domains to support self-experimentation and techniques for individualized understanding (e.g., [21,22,38,39,45]). The "before and after" comparisons found in migraine generally do not constitute rigorous experiments (e.g., they do not account for confounds), but more rigorous methods can often be impractical or unacceptable. First, designing an experiment to robustly test a single factor can be difficult, because of 1) the wide variety of potentially relevant factors, 2) a person's inability to control some factors (e.g., weather), and 3) symptoms generally resulting from an accumulation of factors rather than any single factor. Second, the debilitating nature of symptoms (i.e., being unable to do the things a person wants or needs to do) can mean a person is unwilling to risk inducing symptoms for the sake of a more rigorous experiment. Similarly, if a person makes a change (e.g., a new medication), and that change seems to improve symptoms, they may be unwilling to discontinue the change. When symptoms seem to be improved by changes with other benefits (e.g., increased physical activity), discontinuing for the sake of an experiment seems even more unreasonable. People with migraine will therefore generally have some inherent uncertainty regarding factors relevant to their personal migraine symptoms.

Personal informatics tools may be able to help people navigate this uncertainty by better differentiating the goals people bring to migraine tracking. For example, when tracking is intended to answer questions about a person's migraine (i.e., Goal 1), tools can maximize transparency in analyses, communicate underlying uncertainty, and explain potential confounds. Such tools might adopt existing representations of uncertainty for non-experts (e.g., [41]). Understanding that uncertainty, people may still want to implement a change if it has the potential to improve symptoms (e.g., a person may decide to entirely remove coffee from their diet, while understanding that correlational data behind the decision is limited). Similarly, representations of uncertainty could help people make better decisions in migraine prediction (i.e., Goal 2), analogous to results in other domains [37]. For example, tools could support a person in deciding about their accumulation of risk and what factors they can control (e.g., whether to have a coffee today). Similar to how *I6* used an app to monitor the weather and then acted upon other factors that she could control, tools might use a combination of self-report, modeling, and sensing across multiple factors (e.g., level of physical activity, menstrual patterns, sleep sensing, weather). Such tools would need to communicate their own uncertainty, but might reduce burdens and allow people to more effectively manage their symptoms. Data could also later be integrated across goals (e.g., data collected as part of symptom prevention could also later be used as part of answering questions about a person's migraine). Finally, in some cases, uncertainty may be best addressed by seeking additional expert support. Tools should therefore provide support for patient-provider collaboration throughout a person's tracking, including in determining goals, in interpreting the resulting data, and in deciding on next steps.

CONCLUSION

This paper bridges a gap between the challenges people with migraine face in managing their condition, underlying self-tracking challenges in personal informatics, and patient-provider collaboration with patient-generated data. We surveyed 279 people with migraine and then conducted semi-structured interviews with 13 survey respondents and 6 health providers. We find four distinct goals that people bring to tracking and data: 1) answering questions about migraines, 2) predicting and preventing migraines, 3) monitoring and managing migraines over time, and 4) enabling motivation and social recognition. We also find needs resulting from an individual's goals evolving over time, their varied personal experiences, and their communication and collaboration with providers. We further discuss these goals and needs in terms of opportunities for personal informatics tools to facilitate learning to avoid common pitfalls, to support customization and flexibility, to account for burden, negativity, and lapsing, and to support management with uncertainty. Our research motivates design and development of new personal informatics tools for people with migraine, as well as additional research examining how these results extend to other conditions with unpredictable, intermittent, and poorly-understood symptoms.

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REFERENCES

1. Jessica S Ancker, Holly O Witteman, Baria Hafeez, Thierry Provencher, Mary Van De Graaf, and Esther Wei. 2015. "You Get Reminded You're a Sick Person": Personal Data Tracking and Patients with Multiple Chronic Conditions. *Journal of Medical Internet Research* 17, 8 (2015).
   https://doi.org/10.2196/jmir.4209

2. Diane Andress-Rothrock, Wesley King, and John Rothrock. 2010. An Analysis of Migraine Triggers in a Clinic-Based Population. *Headache: The Journal of Head and Face Pain* 50, 8 (2010), 1366–1370.
   https://doi.org/10.1111/j.1526-4610.2010.01753.x

3. David Armstrong, Ann Gosling, John Weinman, and Theresa Marteau. 1997. The Place of Inter-Rater Reliability in Qualitative Research: An Empirical Study. *Sociology* 31, 3 (1997), 597–606.
   http://doi.org/10.1177/0038038597031003015

4. Glen Aukerman, Doug Knutson, and William F Miser. 2002. Management of the Acute Migraine Headache. *American Family Physician* 66, 11 (2002), 2123–2130.
   https://www.ncbi.nlm.nih.gov/pubmed/12484694

5. Daniel Avrahami, Scott E Hudson, Thomas P Moran, and Brian D Williams. 2001. Guided Gesture Support in the Paper PDA. In *Proceedings of the ACM Symposium on User Interface Software and Technology*. ACM, 197–198.
   https://doi.org/10.1145/502348.502385

6. Amid Ayobi, Paul Marshall, Anna L Cox, and Yunan Chen. 2017. Quantifying The Body and Caring for The Mind: Self-Tracking in Multiple Sclerosis. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 6889–6901.
   https://doi.org/10.1145/3025453.3025869

7. Stinne Aaløkke Ballegaard, Thomas Riisgaard Hansen, and Morten Kyng. 2008. Healthcare in Everyday Life: Designing Healthcare Services for Daily Life. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 1807–1816.
   http://doi.acm.org/10.1145/1357054.1357336

8. V Baos, F Ester, A Castellanos, G Nocea, MT Caloto, and WC Gerth. 2005. 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.
   https://doi.org/10.1111/j.1742-1241.2005.00469.x

9. Eric PS Baumer, Sherri Jean Katz, Jill E Freeman, Phil Adams, Amy L Gonzales, John Pollak, Daniela Retelny, Jeff Niederdeppe, Christine M Olson, and Geri K Gay. 2012. Prescriptive Persuasion and Open-Ended Social Awareness: Expanding The Design Space of Mobile Health. In *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work*. ACM, 475–484.
   https://doi.org/10.1145/2145204.2145279

10. JE Carnahan and Nugent CA. 1975. The Effects of Self-Monitoring By Patients on The Control of Hypertension. *The American Journal of the Medical Sciences* 269, 1 (1975), 69–73.
    https://www.ncbi.nlm.nih.gov/pubmed/1130437

11. Kuang Chen, Akshay Kannan, Yoriyasu Yano, Joseph M Hellerstein, and Tapan S Parikh. 2012. Shreddr: Pipelined Paper Digitization for Low-Resource Organizations. In *Proceedings of the ACM Symposium on Computing for Development*. ACM.
    https://doi.org/10.1145/2160601.2160605

12. Eun Kyoung Choe, Nicole B Lee, Bongshin Lee, Wanda Pratt, and Julie A Kientz. 2014. Understanding Quantified-Selfers' Practices in Collecting and Exploring Personal Data. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 1143–1152.
    http://doi.acm.org/10.1145/2556288.2557372

13. Chia-Fang Chung, Elena Agapie, Jessica Schroeder, Sonali Mishra, James Fogarty, and Sean A Munson. 2017. When Personal Tracking Becomes Social: Examining the Use of Instagram for Healthy Eating. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 1674–1687.
    https://doi.org/10.1145/3025453.3025747

14. Chia-Fang Chung, Jonathan Cook, Elizabeth Bales, Jasmine Zia, and Sean A Munson. 2015. More Than Telemonitoring: Health Provider Use and Nonuse of Life-Log Data in Irritable Bowel Syndrome and Weight Management. *Journal of Medical Internet Research* 17, 8 (2015), E203. http://doi.org/10.2196/jmir.4364

15. Chia-Fang Chung, Kristin Dew, Allison Cole, Jasmine K Zia, James Fogarty, Julie A Kientz, and Sean A Munson. 2016. Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. In *Proceedings of the ACM Conference on Computer-Supported Cooperative Work and Social Computing*.
    http://doi.acm.org/10.1145/2818048.2819926

16. C Clar, Katharine D Barnard, Ewen Cummins, Pamela Royle, and Norman Waugh. 2010. Self-Monitoring of Blood Glucose in Type 2 Diabetes: Systematic Review. *Health Technology Assessment* 14, 12 (2010), 1–140.
    http://www.doi.org/10.3310/hta14120

17. James Clawson, Jessica Pater, Andrew D. Miller, Elizabeth D. Mynatt, and Lena Mamykina. 2015. No Longer Wearing: Investigating The Abandonment of Personal Health-Tracking Technologies on Craigslist. In *Proceedings of the ACM Conference on Ubiquitous Computing*. ACM.
    https://doi.org/10.1145/2750858.2807554

18. Sunny Consolvo, David W McDonald, Tammy Toscos, Mike Y Chen, Jon Froehlich, Beverly Harrison, Predrag Klasnja, Anthony Lamarca, Louis Legrand, Ryan Libby, Ian Smith, and James A Landay. 2008. Activity Sensing in the Wild: A Field Trial of UbiFit Garden. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 1797–1806. `https://doi.org/10.1145/1357054.1357335`

19. Felicia Cordeiro, Elizabeth Bales, Erin Cherry, and James Fogarty. 2015a. Rethinking The Mobile Food Journal: Exploring Opportunities for Lightweight Photo-Based Capture. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 3207–3216. `https://doi.org/10.1145/2702123.2702154`

20. Felicia Cordeiro, Daniel A Epstein, Edison Thomaz, Elizabeth Bales, Arvind K Jagannathan, Gregory D Abowd, and James Fogarty. 2015b. Barriers and Negative Nudges: Exploring Challenges in Food Journaling. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 1159–1162. `http://doi.org/10.1145/2702123.2702155`

21. Nediyana Daskalova, Karthik Desingh, Jin Young Kim, Lixiang Zhang, Alexandra Papoutsaki, and Jeff Huang. 2017. Lessons Learned from Two Cohorts of Personal Informatics Self-Experiments. In *Proceedings of the ACM Conference on Ubiquitous Computing*, Vol. 1. ACM, 46. `https://doi.org/10.1145/3130911`

22. Nediyana Daskalova, Danaë Metaxa-Kakavouli, Adrienne Tran, Nicole Nugent, Julie Boergers, John McGeary, and Jeff Huang. 2016. SleepCoacher: A Personalized Automated Self-Experimentation System for Sleep Recommendations. In *Proceedings of the Symposium on User Interface Software and Technology*. ACM, 347–358. `http://doi.org/bwt4`

23. Mary Jo Deering, Erin Siminerio, and Scott Weinstein. 2013. Issue Brief: Patient-Generated Health Data and Health IT. *Office of the National Coordinator for Health Information Technology* (2013).

24. Nicola Dell, Jessica Crawford, Nathan Breit, Timóteo Chaluco, Aida Coelho, Joseph McCord, and Gaetano Borriello. 2013. Integrating ODK Scan into The Community Health Worker Supply Chain in Mozambique. In *Proceedings of the International Conference on Information and Communication Technologies and Development*. ACM, 228–237. `https://doi.org/10.1145/2516604.2516611`

25. Daniel A Epstein, Monica Caraway, Chuck Johnston, An Ping, James Fogarty, and Sean A Munson. 2016. Beyond Abandonment To Next Steps: Understanding and Designing for Life After Personal Informatics Tool Use. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 1109–1113. `https://doi.org/10.1145/2858036.2858045`

26. Daniel A Epstein, Nicole B Lee, Jennifer H Kang, Elena Agapie, Jessica Schroeder, Laura R Pina, James Fogarty, Julie A Kientz, and Sean Munson. 2017. Examining Menstrual Tracking To Inform The Design of Personal Informatics Tools. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 6876–6888. `https://doi.org/10.1145/3025453.3025635`

27. Daniel A Epstein, An Ping, James Fogarty, and Sean A Munson. 2015. A Lived Informatics Model of Personal Informatics. In *Proceedings of the ACM international Joint Conference on Pervasive and Ubiquitous Computing*. ACM, 731–742. `https://doi.org/10.1145/2750858.2804250`

28. Deborah Estrin and Ida Sim. 2010. Open mHealth Architecture: An Engine for Health Care Innovation. *Science* 330, 6005 (2010), 759–760. `http://doi.org/10.1126/science.1196187`

29. Aojg Farmer, Oj Gibson, L Tarassenko, and A Neil. 2005. A Systematic Review of Telemedicine Interventions To Support Blood Glucose Self-Monitoring in Diabetes. *Diabetic Medicine* 22, 10 (2005), 1372–1378. DOI: `http://dx.doi.org/10.1111/j.1464-5491.2005.01627.x`

30. The Robert Wood Johnson Foundation. 2014. Personal Data for The Public Good: New Opportunities To Enrich Understanding of Individual and Population Health. *Health Data Exploration Project* (2014). `http://www.rwjf.org/en/library/research/2014/03/personal-Data-For-The-Public-Good.html`

31. RH Friedman, LE Kazis, A Jette, MB Smith, J Stollerman, J Torgerson, and Carey K. 1996. A Telecommunications System for Monitoring and Counseling Patients with Hypertension: Impact on Medication Adherence and Blood Pressure Control. *American Journal of Hypertension* 9, 4 (1996), 285–92. `https://www.ncbi.nlm.nih.gov/pubmed/8722429`

32. Erik Grönvall and Nervo Verdezoto. 2013. Understanding Challenges and Opportunities of Preventive Blood Pressure Self-Monitoring At Home. In *Proceedings of the European Conference on Cognitive Ergonomics*. ACM, 31. `https://doi.org/10.1145/2501907.2501962`

33. François Guimbretière. 2003. Paper Augmented Digital Documents. In *Proceedings of the ACM Symposium on User Interface Software and Technology*. ACM, 51–60. `https://doi.org/10.1145/964696.964702`

34. Reetta Heinonen, Riitta Luoto, Pirjo Lindfors, and Clas-Håkan Nygård. 2012. Usability and Feasibility of Mobile Phone Diaries in an Experimental Physical Exercise Study. *Telemedicine and E-Health* 18, 2 (2012), 115–119. `http://www.doi.org/10.1089/tmj.2011.0087`

35. Susan L Janson, Kelly Wong McGrath, Jack K Covington, Su-Chun Cheng, and Homer A Boushey. 2009. Individualized Asthma Self-Management Improves Medication Adherence and Markers of Asthma Control. *Journal of Allergy and Clinical Immunology* 123, 4 (2009), 840–846. `https://doi.org/10.1016/j.jaci.2009.01.053`

36. Mehul Jhaveri and Elizabeth Lee. 2007. Performance of Electronic Diaries in Diabetes Clinical Trials Measured Through Overall Satisfaction of Site Coordinators. *Journal of Diabetes Science and Technology* 1, 4 (2007), 522–530.
http://www.doi.org/10.1177/193229680700100410

37. Susan L Joslyn and Jared E LeClerc. 2012. Uncertainty Forecasts Improve Weather-Related Decisions and Attenuate the Effects of Forecast Error. *Journal of Experimental Psychology: Applied* 18, 1 (2012), 126.
http://doi.org/10.1037/a0025185

38. Ravi Karkar, Jessica Schroeder, Daniel A Epstein, Laura R Pina, Jeffrey Scofield, James Fogarty, Julie A Kientz, Sean A Munson, Roger Vilardaga, and Jasmine Zia. 2017. Tummytrials: A Feasibility Study of Using Self-Experimentation To Detect Individualized Food Triggers. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 6850–6863.
https://doi.org/10.1145/3025453.3025480

39. Ravi Karkar, Jasmine Zia, Roger Vilardaga, Sonali R Mishra, James Fogarty, Sean A Munson, and Julie A Kientz. 2015. A Framework for Self-Experimentation in Personalized Health. *Journal of the American Medical Informatics Association* (2015).
http://doi.org/10.1093/jamia/ocv150

40. Matthew Kay, Eun Kyoung Choe, Jesse Shepherd, Benjamin Greenstein, Nathaniel Watson, Sunny Consolvo, and Julie A Kientz. 2012. Lullaby: A Capture & Access System for Understanding The Sleep Environment. In *Proceedings of the ACM Conference on Ubiquitous Computing*. ACM, 226–234.
https://doi.org/10.1145/2370216.2370253

41. Matthew Kay, Tara Kola, Jessica R Hullman, and Sean A Munson. 2016. When (ish) Is My Bus?: User-Centered Visualizations of Uncertainty in Everyday, Mobile Predictive Systems. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 5092–5103.
https://doi.org/10.1145/2858036.2858558

42. Joseph (Jofish) Kaye, Mary Mccuistion, Rebecca Gulotta, and David A Shamma. 2014. Money Talks: Tracking Personal Finances. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 521–530.
https://doi.org/10.1145/2556288.2556975

43. L Kelman. 2007. The Triggers or Precipitants of the Acute Migraine Attack. *Cephalalgia* 27, 5 (2007), 394–402.
https://doi.org/10.1111/j.1468-2982.2007.01303.x

44. Yoojung Kim, Eunyoung Heo, Hyunjeong Lee, Sookyoung Ji, Jueun Choi, Jeong-Whun Kim, Joongseek Lee, and Sooyoung Yoo. 2017. Prescribing 10,000 Steps Like Aspirin: Designing a Novel Interface for Data-Driven Medical Consultations. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 5787–5799.
https://doi.org/10.1145/3025453.3025570

45. Jisoo Lee, Erin Walker, Winslow Burleson, Matthew Kay, Matthew Buman, and Eric B Hekler. 2017. Self-Experimentation for Behavior Change: Design and Formative Evaluation of Two Approaches. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 6837–6849.
https://doi.org/10.1145/3025453.3026038

46. Ian Li, Anind Dey, and Jodi Forlizzi. 2010. A Stage-Based Model of Personal Informatics Systems. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 557–566.
http://doi.acm.org/10.1145/1753326.1753409

47. Chunyuan Liao, François Guimbretière, Ken Hinckley, and Jim Hollan. 2008. Papiercraft: A Gesture-Based Command System for Interactive Paper. *ACM Transactions on Computer-Human Interaction (tochi)* 14, 4 (2008), 18. https://doi.org/10.1145/1314683.1314686

48. James J Lin, Lena Mamykina, Silvia Lindtner, Gregory Delajoux, and Henry B Strub. 2006. Fish'n'Steps: Encouraging Physical Activity with an Interactive Computer Game. In *Proceedings of the ACM Conference on Ubiquitous Computing*. ACM, 261–278.
https://doi.org/10.1007/11853565_16

49. Richard B Lipton. 2015. Risk Factors for and Management of Medication-Overuse Headache. *Continuum: Lifelong Learning in Neurology* 21, 4, Headache (2015), 1118–1131.
http://doi.org/10.1212/CON.0000000000000216

50. Richard B Lipton, Joan C Amatniek, Michel D Ferrari, and Michael Gross. 1994. Migraine. Identifying and Removing Barriers To Care. *Neurology* 44, 6 Suppl 4 (1994), S63–8.
https://www.ncbi.nlm.nih.gov/pubmed/8008228

51. Richard B Lipton, Walter F Stewart, and David Simon. 1998. Medical Consultation for Migraine: Results From The American Migraine Study. *Headache: The Journal of Head and Face Pain* 38, 2 (1998), 87–96.
https://www.ncbi.nlm.nih.gov/pubmed/9529763

52. Morris Maizels. 1998. The Clinician's Approach To The Management of Headache. *Western Journal of Medicine* 168, 3 (1998), 203.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1304871/

53. Lena Mamykina, Elizabeth Mynatt, Patricia Davidson, and Daniel Greenblatt. 2008. MAHI: Investigation of Social Scaffolding for Reflective Thinking in Diabetes Management. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 477–486.
http://doi.acm.org/10.1145/1357054.1357131

54. Margaret Morris and Farzin Guilak. 2009. Mobile Heart Health: Project Highlight. *IEEE Pervasive Computing* 8, 2 (2009). https://doi.org/10.1109/MPRV.2009.31

55. Lucille ML Ong, Johanna CJM De Haes, Alaysia M Hoos, and Frits B Lammes. 1995. Doctor-Patient Communication: A Review of the Literature. *Social Science & Medicine* 40, 7 (1995), 903–918. `https://www.ncbi.nlm.nih.gov/pubmed/7792630`

56. Tapan S Parikh, Paul Javid, Sasikumar K, Kaushik Ghosh, and Kentaro Toyama. 2006. Mobile Phones and Paper Documents: Evaluating a New Approach for Capturing Microfinance Data in Rural India. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 551–560. `https://doi.org/10.1145/1124772.1124857`

57. Sun Young Park and Yunan Chen. 2015. Individual and Social Recognition: Challenges and Opportunities in Migraine Management. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work & Social Computing*. ACM, 1540–1551. `https://doi.org/10.1145/2675133.2675248`

58. Tamara Peyton, Erika Poole, Madhu Reddy, Jennifer Kraschnewski, and Cynthia Chuang. 2014. Every Pregnancy Is Different: Designing mHealth for The Pregnancy Ecology. In *Proceedings of the Conference on Designing Interactive Systems*. ACM, 577–586. `https://doi.org/10.1145/2598510.2598572`

59. Birthe Krogh Rasmussen, Rigmor Jensen, Marianne Schroll, and Jes Olesen. 1991. Epidemiology of Headache in a General Population—A Prevalence Study. *Journal of Clinical Epidemiology* 44, 11 (1991), 1147–1157. `https://www.ncbi.nlm.nih.gov/pubmed/1941010`

60. Ruth Ravichandran, Sang-Wha Sien, Shwetak N Patel, Julie A Kientz, and Laura R Pina. 2017. Making Sense of Sleep Sensors: How Sleep Sensing Technologies Support and Undermine Sleep Health. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 6864–6875. `https://doi.org/10.1145/3025453.3025557`

61. John Rooksby, Mattias Rost, Alistair Morrison, and Matthew Chalmers Chalmers. 2014. Personal Tracking As Lived Informatics. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 1163–1172. `https://doi.org/10.1145/2556288.2557039`

62. Jessica Schroeder, Jane Hoffswell, Chia-Fang Chung, James Fogarty, Sean Munson, and Jasmine Zia. 2017. Supporting Patient-Provider Collaboration To Identify Individual Triggers Using Food and Symptom Journals. In *Proceedings of the ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, 1726–1739. `https://doi.org/10.1145/2998181.2998276`

63. Stephen D Silberstein and The US Headache Consortium. 2000. Practice Parameter: Evidence-Based Guidelines for Migraine Headache (An Evidence-Based Review) Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology* 55, 6 (2000), 754–762. `http://doi.org/10.1212/WNL.55.6.754`

64. GD Solomon and KL Price. 1997. Burden of Migraine. *Pharmacoeconomics* 11, 1 (1997), 1–10. `https://doi.org/10.2165/00019053-199700111-00003`

65. Timothy J Steiner, Lars Jacob Stovner, and Gretchen L Birbeck. 2013. Migraine: The Seventh Disabler. *Headache: The Journal of Head and Face Pain* 53, 2 (2013), 227–229. `http://doi.org/10.1186/1129-2377-14-1`

66. Moira A Stewart. 1995. Effective Physician-Patient Communication and Health Outcomes: A Review. *CMAJ: Canadian Medical Association Journal* 152, 9 (1995), 1423. `https://www.ncbi.nlm.nih.gov/pubmed/7728691`

67. Cristiano Storni. 2011. Complexity in an Uncertain and Cosmopolitan World. Rethinking Personal Health Technology in Diabetes with The Tag-It-Yourself. *Psychology Journal* 9, 2 (2011), 165–185.

68. Thomas N Ward. 2012. Migraine Diagnosis and Pathophysiology. *Continuum: Lifelong Learning in Neurology* 18, 4, Headache (2012), 753–763. `http://doi.org/10.1212/01.CON.0000418640.07405.31`

69. Peter West, Richard Giordano, Max Van Kleek, and Nigel Shadbolt. 2016. The Quantified Patient in the Doctor's office: Challenges & Opportunities. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 3066–3078. `http://doi.acm.org/10.1145/2858036.2858445`

70. Ron Yeh, Chunyuan Liao, Scott Klemmer, François Guimbretière, Brian Lee, Boyko Kakaradov, Jeannie Stamberger, and Andreas Paepcke. 2006. ButterflyNet: A Mobile Capture and Access System for Field Biology Research. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 571–580. `https://doi.org/10.1145/1124772.1124859`

71. Kathryn Yorkston, Kurt Johnson, Estelle Klasner, Dagmar Amtmann, Carrie Kuehn, and Brian Dudgeon. 2003. Getting the Work Done: A Qualitative Study of Individuals with Multiple Sclerosis. *Disability and Rehabilitation* 25, 8 (2003), 369–379. `http://www.doi.org/10.1080/0963828031000090506`

72. Haining Zhu, Joanna Colgan, Madhu Reddy, and Eun Kyoung Choe. 2016. Sharing Patient-Generated Data in Clinical Practice: An Interview Study. *Proceedings of the American Medical Informatics Association* (2016), 1303–1312. `https://www.ncbi.nlm.nih.gov/pubmed/28269928`