Needs, Challenges, and Opportunities in Long-Term Tracking to Support Migraine Management

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Abstract

People with migraine often track data related to their symptoms as part of managing the condition. However, people often struggle to make sense of their data, especially as their goals evolve. In this workshop paper, we discuss the particular needs and challenges people with migraine encounter when attempting to track, interpret, and collaborate with long-term migraine-related data. We focus on how migraine tracking goals evolve and on the resulting lapsing and resumption of tracking.

Introduction

People with chronic illnesses often turn to personal informatics as part of understanding and managing their conditions. Prior research has examined how personal informatics practices can support a range of chronic conditions (e.g., asthma [9], diabetes [4, 6, 13], hypertension [3, 7, 8], irritable bowel syndrome [10, 11, 16]). However, strategies used in these tracking domains are often insufficient for people with migraine, a condition characterized by unpredictable, intermittent, and poorly-understood symptoms [14]. Migraine symptoms often include pain, sensitivity to light, and impaired cognition. Due to the debilitating nature of these symptoms, migraine is a leading cause of lost workplace productivity [18] and is the seventh-highest cause of years lost to disability [19]. A wide range of factors, including diet (e.g., alcohol, caffeine), environment (e.g., glare, noise, weather), menstruation, sleep

patterns, and stress and mood, can trigger migraine symptoms. In addition, multiple factors often must accumulate before precipitating migraine symptoms [12, 20]. Health providers often encourage people with migraine to self-track as part of understanding and managing their symptoms, and both patients and providers believe self-tracked migraine data can help in communication and collaboration [2].

To characterize how people with migraine track and use data about their condition, we have begun a preliminary investigation into how people with migraine track and use migraine-related data. We surveyed 279 people with migraine, then conducted semi-structured interviews with 13 survey respondents and 6 health providers [15]. We identified 4 goals that people may bring to migraine-related tracking and data: (1) answering questions about migraines, (2) predicting and preventing migraines, (3) monitoring and managing migraines, and (4) enabling motivation and social recognition. We found that people with migraine and their health providers often have multiple goals, and these goals often evolve over time. These myriad and evolving goals present unique challenges in designing tools to support the collection and interpretation of long-term data. I am interested in attending this workshop to discuss three challenges our findings reveal in long-term migraine tracking: sensemaking of long-term migraine data; the use of tracking data by medical professionals; and additional needs, challenges, and opportunities for applications designed to support long-term migraine tracking.

Sensemaking of Long-Term Migraine Data
Because people with migraine have unique and evolving goals, "making sense" of data can be particularly challenging. The conclusions that data will be used to support will depend on a person's goal. For example, some people track migraine symptoms when they switch to a new migraine treatment, and often want to compare their symptoms before and after

the switch to determine whether the treatment is working. Others track to identify potential triggers, a process that requires comparing symptoms experienced after exposure to specific factors with symptoms absent those factors. Because people with migraine change their goals for tracking over time, they may experience particular difficulty with the lapsing and resumption that are typically part of tracking [5]. For example, different goals prompting resumption may require different data or analysis tools, and so previously collected data may not support those new or changed goals.

Use of Tracking Data by Medical Professionals
People and their health providers may need different visualizations and analyses of the tracked data to support their goals, creating additional challenges for the design and use of migraine tracking tools. For example, patients may be interested in more frequently reviewing shorter windows of data if doing so better supports their goals. However, providers may want to examine a patient's data since their previous appointment, instead of or in addition to the data interpretation needs of the patient. People therefore need support not only in interpreting data to support their own goals, but also in obtaining additional views on that data to facilitate communication and collaboration with providers.

Application Needs, Challenges, & Opportunities
In addition to supporting people with migraine and their health providers in the pursuit of the goals they know they have, applications may need to support identification of trends that people may have not thought to examine. For example, some people get more migraines during certain times of the year. Others are more likely to get them at specific times in their menstrual cycles. Gaining that understanding requires long-term tracking of migraine symptoms, as well as views of the data that can draw attention to that trend. Although health providers specializing in migraine may know to look for those

and similar trends, people with migraine and general practitioners may not be familiar with them. Applications to support migraine tracking therefore need to include enough knowledge about migraine to suggest tracking data people may not have otherwise thought to track, and to create visualizations and analyses of trends they may not have known to look for in large windows of migraine-related data.

People with migraine often associate self-tracking with negative emotions, making long-term tracking particularly challenging. One reason people might consider tracking negative is that it serves as a reminder of their conditions, which many people with chronic conditions find upsetting [1]. Similarly, as stress can be a contributing factor with migraines, people with migraine sometimes feel that the need to track and review migraine-related data can contribute to their stress, thus increasing the likelihood of a migraine. Despite the many benefits of having long-term migraine data, the burdens of tracking often cause people with migraine to lapse or abandon tracking. Applications therefore need to support these lapses and resumption. Helping people focus on the benefits of migraine tracking could also help people who want to track in concept but find the experience negative in practice (e.g., by emphasizing the progress people make).

Prior Work in Personal Informatics

My research focuses on designing, developing, and evaluating novel methods and tools to help people understand and manage chronic health conditions. I am particularly interested in supporting people in collecting, analyzing, and interpreting personal informatics data to address health goals, as well as examining and overcoming challenges in patient-provider collaboration with patient-generated data. My past research has focused on short-term tracking, both because people have trouble maintaining tracking and because interventions are often designed to support short-term engagements with

providers. Despite this, participants often expressed a desire for longer-term tracking. In addition to discussing supporting long-term tracking in migraine, I am excited to discuss how to support long-term tracking in the other domains I have studied with others. In this section, I briefly describe my prior research, highlighting areas where participants described a need for longer-term tracking to support their goals.

My prior research in personal informatics focused on helping people with irritable bowel syndrome (IBS) and their health providers examine food and symptom journal data to identify potential IBS triggers [16]. We created interactive, exploratory visualizations to help people identify the nutrients that correlate with their symptoms, as well as the foods in their diet that contained those nutrients. Because food tracking is highly burdensome, the journals had only 9 days of data, and the analyses and visualizations were designed for a single food and symptom journal dataset. However, both the patients and the providers expressed a desire for the visualizations to support longer-term, iterative use. People wanted to extend the system to aid the ongoing management of their IBS, so they could view dietary and symptom changes over time and review notes and progress between clinic appointments. This study therefore emphasized the need for tools designed to support chronic illnesses to consider long-term tracking and interpretation of data.

I have also examined how a mobile application providing holistic support for dialectical behavioral therapy can help mental health patients with high clinical complexity [17]. We found a similar need to help people monitor their progress over time as they engaged in therapy. In future work, we hope to examine how patients and providers can collaboratively review data to assess progress and develop treatment plans during the long-term management of the patient's mental health.

I look forward to participating in this workshop because my continuing research in examining how technology can help people with migraine will necessitate support for long-term tracking. I am excited to discuss the challenges I have already identified in long-term tracking with respect to migraine, as well as learning about challenges found by other researchers in their domains of study. I also look forward to meeting others in the personal informatics and health informatics fields to discuss current and future research and identify possible collaborations.

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