Individual and Social Recognition: Challenges and Opportunities in Migraine Management

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ABSTRACT

This study investigates how people manage chronic migraine – an illness characterized by unpredictable, intermittent breakouts in everyday life. Participants in our study must self-identify migraine symptoms, triggers, and effective coping mechanisms while also seeking social recognition and assistance from a social network during migraine attacks. We argue that the challenges in identifying and managing migraine as well as in communicating with clinicians and social networks arise in response to the patients' need to deal with the unpredictability and intermittency of the disease. We suggest technologies that, unlike current chronic care systems, enable patients with migraine and similar diseases to track a wide range of life events across intermittent time stamps and help make sense of subjective information. We argue that technologies should also help patients gain social recognition and assistance during breakouts. This work contributes to the growing body of knowledge in personal informatics and quantified-self research.

Author Keywords

Migraine management; migraine; chronic disease; self-care; self-management; health; personal informatics

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

In recent years, technologies for chronic diseases such as cancer [28], diabetes [11, 17, 24], and asthma [39], have attracted significant attention in the HCI and CSCW communities. Given the prolonged duration and significant health impact of chronic diseases, a majority of systems have been designed to engage patients in monitoring, reflecting, and learning about long-term disease management [24, 39, 35] and to minimize the potential negative impacts of the illness on people's everyday lives [11].

Despite the growing interest in chronic illness management practices, past research in the HCI and CSCW communities has focused mostly on the management of a few high-profile and well-known chronic diseases such as cancer and diabetes where the impacts and symptoms of the disease are constantly present [11, 17, 24, 28, 31]. In contrast, in this paper we aim to examine migraine – a distinctly different chronic illness characterized with unpredictable and intermittent breakouts. Such characteristics make the management of migraines and the consequent system requirements different from other diseases.

A migraine is a primary headache disorder. It involves an abnormal sensitivity of arteries in the brain to various triggers resulting in rapid changes in the artery size due to spasm (constriction) [3, 4, 38]. Although there is little consensus on whether to consider migraine a disease, recent medical research points out that migraine should be conceptualized as a chronic-episodic and sometimes chronic progressive disorder [22]. According to the WHO [38], while 15-18% of women and 6-8% of men suffer from migraine each year, nearly 90% migraine sufferers do not even know their specific condition, and more than a half have never consulted a clinician about migraine [15]. Additionally, migraine symptoms can cause lasting debilitation, forcing many patients to wait until symptoms disappear to resume their normal activities. For this reason, migraine is one of the leading causes of loss of productive time at work [32].

One unique challenge of migraine management lies in the difficulties of diagnosing and treating it. Unlike many other chronic diseases that have constant impacts on patients' everyday lives, migraine patients have to face intermittent, but extremely painful short-term breakouts caused by a wide variety of unknown triggers, either internal to patients themselves, or residing in their external environments. Thus, the goal of migraine care mostly consists of alleviating pain and reducing the duration of pain after breakouts. Migraine management therefore differs greatly from many other chronic diseases. Even though migraine has been studied in medical literature, it has not yet been reported in the field of HCI and CSCW, and it presents new challenges for designing chronic care management systems.

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As previous research shows [27], it is crucial to understand the behaviors in users' daily life in order to design health technologies; in this study we take a similar approach to obtain an in-depth understanding of migraine sufferers' daily practices. We intend to understand the challenges migraine sufferers face in the process of migraine management, and to explore opportunities for designing better technologies for assisting migraine patients. Our study identifies the critical need for both self-recognition and social recognition in migraine management: first, migraine sufferers have to perform a series of individual tasks to discover and identify their own triggers, and find effective coping mechanisms. At the same time, they also need to obtain social recognition and help during migraine attacks. These needs arise in response to the challenges of dealing with the unpredictable and intermittent nature of migraine attacks. Based on these findings, we suggest that future migraine management systems help patients perform extensive sense-making across a wide range of life events, occurring at different times. We also suggest that future migraine management systems should help patients to communicate and obtain support from social circles and to gain social recognition during migraine attacks. We believe this study provides new understandings of chronic disease management dealing with unpredictability and intermittency, and contributes to the growing field of personal informatics and quantified-self research.

RELATED WORK

A large body of HCI studies focuses on the use of technologies to mitigate the challenges of chronic care management [16, 19, 24, 29, 39]. Many studies focus on monitoring and collecting personal health information to support crucial aspects of chronic care management, such as tracking disease progress [24; 5] and sharing collected information with clinical providers [39]; others have also studied how technologies should be designed to fit the special needs of home healthcare activities [1]. Previous studies have investigated the role of online health communities and social networking sites in promoting social support for patients. In particular, online communities can empower patients, as they learn from each other [16], borrow individualized coping strategies from peer patients [17] and provide social-emotional support to patients who may not be able to obtain such support in real life [29]. As a result, patients with chronic illnesses such as cancer and diabetes were found to be more satisfied in their everyday lives after becoming connected to online communities [14,17].

Unlike many chronic diseases that have specific diagnostic criteria and measurements, migraine lacks an established physiological basis and a medical diagnostic measurement. Due to this unique challenge, the diagnosis and treatment processes for migraine are largely guided by patients' own descriptions of their symptoms. In addition, due to the invisibility of symptoms, a sufferer's life may appear to be normal in front of others, yet at the same time, a sufferer may be experiencing severe pain. During migraine attacks, patients must deal with their daily work, family and social responsibilities while also suffering from extreme pain.

Existing migraine management research is comprised mostly of clinical studies focusing on diagnosis and symptoms. For instance, it is often difficult to distinguish whether a symptom has resulted from migraine, another disease, or a side effect of a medication [9]. This lack of understanding migraine at the point of care often prevents clinicians from selecting the most effective medications, leading them to prescribe preventive medications only in most cases [13]. The challenges in diagnosing and treating migraine can lead to frustration and dissatisfaction among patients, often resulting in a choice to discontinue clinical consultations [21]. To effectively manage migraines, most clinicians recommend avoiding triggers – provoking factors that induce headache attacks alone or in combination [10]. Successful migraine management therefore relies primarily on the engagement of the patients themselves instead of healthcare providers. However, the wide range of triggers, from food intake to environmental factors, often keeps patients from recognizing them effectively. Blau and Thavapalan [10] noted, "*everything can produce a migraine*." This makes preventive self-care particularly challenging for patients.

It is noteworthy that although migraine management has been studied extensively in medical literature, very few studies have explored the use of technology for migraine. The existing technologies are mostly commercial mobile applications [1] designed for patients to track migraine characteristics, such as triggers, symptoms, attack durations and frequencies of the attacks. A medical study has evaluated web-based programs, reporting the usefulness of electronic diaries over traditional paper-and-pencil methods in monitoring the efficacy of over-the-counter analgesics [37]. Another study examined the impact on clinician-patient communication of online training programs before clinical visits [30]. Although these online systems are designed for tracking migraine-related events and improving the quality of clinical consultations, they often fail to consider the importance of interactions within a pool of patients or between patients and their social circles.

The challenges migraine patients face raises an important question as to how technologies can be designed to help patients better manage their migraine and to diminish migraine's possible impact in their lives. Thus, it is essential to first obtain a thorough understanding of the patient behaviors and needs exhibited within real-life migraine management processes. To do so, we conducted a qualitative study to understand migraine patients' daily disease

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[1] *iHeadache,* (http://www.iheadache.com), *iMangeMigraine* (http://itunes.apple.com/us/app/imanage-migraine/id340537912?mt=8), and *Headache Relief Diary* (http://itunes.apple.com/us/app/headache-relief-diary/id331098973?mt=8)

management practices as well as their attendant challenges, concerns and needs.

METHOD

To understand current migraine management practices, we conducted an exploratory study using contextual interviews with 12 participants suffering from migraine and interviewed two clinicians over the phone.

Contextual interviews [8] were conducted with 12 participants to understand how patients manage migraine in their everyday lives. To recruit participants, we disseminated the study announcement via fliers on campus or nearby coffee shops. We also recruited participants through the snowball sampling method – meaning people could refer friends and family members suffering migraine to us. Interviews were conducted at participants' homes, where most migraine management activities occur. Contextual interviews allowed us to gain a better understanding of how participants manage migraine attacks and to observe various artifacts that aided the migraine management process, e.g. migraine diaries. In general, interviews lasted about 1 hour and were audio-recorded. Photos were taken when participants showed their migraine-related activities or aid items. Study participants were adults ranging in age from 22 to 75, and all verbally consented following the university institute review board (IRB) requirements. All participants were clinically diagnosed and most believed that they could distinguish between a migraine and tension-type headache. Of the 12 participants, nine are female and the other three are males. This number is correspondent with the fact that females are more likely to have migraine than males.

We conducted semi-structured interviews using a brief interview protocol inquiring about possible triggers, medication/treatment, and tool use in managing migraines. The data collection and analysis followed a grounded theory approach, in which the first few interviews were discussed by a team of four researchers as soon as an interview was finished. The discussion helped us identify important questions and issues that were not explored initially, such as coping strategies, and allowed us to follow up on these critical issues in following data collection processes.

Since study participants' migraine symptoms differed in frequency, duration and severity, we divided them into three categories: patients with severe symptoms (five participants), intermediate symptoms (three participants), and mild symptoms (four participants). We grouped participants into these three types since the treatment strategies, needs and impact on a sufferer's everyday life were radically different depending on the severity of his or her migraines. For example, the frequency and duration of migraine attacks differed widely, with duration ranging from about 1-4 hours (mild), 1-3 days (intermediate) to 1-2 weeks (severe), and with frequency ranging from once or few times a year (mild-intermediate) to 5-6 times per week (severe). Participants were considered severe migraine patients when they met one of the severe categories of either duration or frequency.

In addition, to understand clinicians' attitudes about migraine management, we also performed brief phone interviews with two primary care physicians (one male, and one female). We studied primary care physicians because patients often visit them as their first step in treating migraine. Each phone interview took about 40 minutes. Clinicians were asked questions including how often they consult with migraine patients; how they diagnose migraines; common clinical treatments they use; difficulties they encounter when consulting with patients in migraine management; and what general advice they offer for managing migraine.

Besides the preliminary data analysis carried out during the data collection process, after all the interviews were finished, we further analyzed collected data using an affinity diagram [8]. The affinity diagram helped us to gain initial understanding of factors such as similarities in migraine management practice (i.e. treating symptoms, seeking information) across all the interviews. Then, we performed another round of data analysis by randomly selecting three interview transcripts from the 12 interviewees. Sample data were analyzed independently by three researchers using detailed line-by-line analysis techniques [34]. First, open coding [34] was used by each researcher to look for salient concepts and their properties (i.e. characteristics). Once these core categories were identified, axial coding was then conducted to systematically explore the properties and dimensions of the category. This led to the formation of subcategories, i.e. the three themes of coping strategies. The themes produced by each researcher were compared, discussed and revised through a series of iterations until agreement was reached among all researchers. Through this analysis, we were able to reveal how migraine patients manage their disease, cope with their symptoms, apply different treatments, communicate with clinicians, and deal with social issues.

FINDINGS

Numerous resources are available for people with migraine, such as a list of common symptoms and triggers in medical guidelines, as well as professional assistance from health providers. However, our study participants reveal that they face major challenges utilizing these resources in their everyday lives. In this section, we first describe why it is so difficult to utilize external resources in migraine management; then we report how our study participants were forced to undertake a process of self-discovery and self-trial in understanding their migraine and coping with the attacks. Lastly, we report on the implicit social recognition and assistance needed by individuals dealing with migraine attacks.

Do I Have Migraine?

A unique behavior shared among our study participants was an uncertainty about the disease – do I have migraine, and what are my symptoms? Unlike many other diseases that have clear diagnostic criteria and identifiable symptoms, migraine has considerable diversity in terms of its onset, attack occurrence, duration, and symptom attributes. Although the most obvious symptom is headache, many other symptoms co-exist that are less known and differ from person to person. In addition, the intermittent and unpredictable nature of migraine also presents a great obstacle for people to recognize their disease. For instance, people may not associate occasional headaches with migraine, but instead interpret them as other medical problems. Recognizing the disease and understanding symptoms, therefore, is the first challenge involved in migraine management.

In our study, most interviewees began to experience symptoms in their teenage years; one participant had even suffered migraines since childhood. Similar to what has been reported in prior medical studies [13, 21], we found that migraine symptoms differ significantly among individuals. For instance, one participant described her symptoms starting with blurred vision, followed by vomiting within 2-3 hours with stomach pains; another participant described his pain as a belt tightened around his head. For the duration of symptoms, participants indicated periods ranging from 1 hour to 2 weeks. Moreover, symptoms may change over the course of a single migraine or resume after a long absence. In our study, one participant did not realize she had migraine for 40 years and never consulted a health professional until her daughter was diagnosed with the same conditions, indicating the challenges of recognizing symptoms among participants.

In the study, we found that the individualized and subjective nature of migraine symptoms not only made it difficult for participants to recognize their own symptoms, but also caused significant barriers in seeking professional help. In our study, even though participants had consulted clinicians previously, only 4 of them (1 with intermediate and 3 with severe symptoms) continued with clinical treatment after the initial visit.

Because of the intermittent and subjective nature of symptoms, the diagnosis of migraine depends on verbal communication between a patient and a clinician. However, our study showed that many participants believed it was not easy to communicate effectively with clinicians about what they experienced. As one study participant stated: *"It is difficult consulting with physicians about specifics because I don't know what details are relevant. A lot of the information, the clinician can't do much with…* [P1: Alicia[*], mild migraine]*."* For patients, the difficulty lies in the subjective nature of the disease and their insufficient understanding of different types of headache symptoms. They often struggle over what to report to their doctors and how much detail to supply. Eventually this communication barrier led many participants in our study to believe that their doctors did not have enough knowledge to treat them, leaving them to figure out the question of "what are my migraine symptoms" on their own.

The challenges in communicating with clinicians differed based on the severity of the disease. Participants with severe symptoms were often good at communicating with their doctors because they had frequent breakouts and spent more time finding triggers; accordingly, they were more satisfied with their clinical consultations in general. On the other hand, participants with mild and intermediate symptoms were often unable to describe their symptoms and triggers and often had lower satisfaction and expectations regarding professional assistance.

We also found that participants with severe symptoms tended to have a better understanding of their symptoms since, in addition to more frequent migraine attacks, they also had more severe, distinctive symptoms, such as vomiting, auras and pain in one side of the head, with prolonged periods of discomfort. In contrast, participants with mild and intermediate symptoms were often unable to distinguish migraine symptoms from ordinary headache (i.e. headaches with lesser frequency, duration, and intensity, without distinctive symptoms like aura or vomiting, and often relieved by over-the-counter medication). This lack of understanding of migraine among mild and intermediate symptoms participants influenced their decisions about obtaining clinical diagnosis and treatment, as seen in this quote from an interviewee with intermediate migraine symptoms:

"I think it may be something kind of serious but since it has only happened twice I don't want to go to the doctor and get no results… With my migraines with vertigo I never had the symptoms when I was at the doctor and it took them over a year to figure out that that was what it may be...after many tests that told them nothing."– P11: Gina (intermediate migraine)

Likewise, while all participants with severe symptoms found it relatively easier to quickly obtain clinical diagnoses, only half of the participants with mild and intermediate symptoms had visited a doctor for a migraine consultation in years or even decades after their first migraine breakout.

What Triggers My Migraine?

After identifying their illness as migraine, the next question for most participants is to determine what led to their migraine symptoms. For them, identifying triggers is critical in understanding and predicting the onset of migraine attacks. Triggers are 'provoking factors that, alone or in combination, induce headache attacks [10].' Migraine patients are advised to identify a causal relationship between triggers and symptoms, since avoiding or minimizing exposure to avoidable triggers can diminish the severity and frequency of their migraine attacks [10]. Not surprisingly, participants had a wide range of idiosyncratic triggers. For instance, coffee helps reduce migraine for one of our participants, whereas it often triggers migraine for many others. Even though many

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[*] All the participant names used in the paper have been changed, i.e. the patients are anonymous.

triggers are listed in various medical brochures, participants still had to rely on their own observation to discover their own triggers.

	Disease presentation
Triggers	fatigue, stress, allergies, menstruation, specific foods/ingredients, upset stomach, hunger, heat, air quality, alcohol, sleep pattern, weather, fluorescent lights, driving, and dehydration.
Symptoms	nausea, vomiting, photophobia (sensitivity to light), auras, sensitivity to sound, pulsing pain or sharp pain in distinct areas (in one side; behind eye; near ear; around head like a belt), tight neck muscles, blurry vision, numbness

Table 1: Diversity of migraine triggers and symptoms reported by our study participants

However, identifying triggers is a task that relies heavily on individuals' ability to make sense of numerous of daily activities occurring in their lives. As showed in table 1, our participants reported to us a diverse range of triggers that are all quite subjective and subtle to identify. For instance, not all weather changes will trigger migraines and have to do with the intensity of heat or cold (e.g. one participant's migraine started whenever the temperature was over 90 degree outside) or the kind of weather (another participant reported migraine on rainy days or very windy days) or sometime even simply a change in the weather (one participant reported his migraines appeared whenever the weather switched from hot to cold, or from dry to wet).

In addition, triggers can be a combination of two or more factors, such as stress and hot weather. It is therefore difficult for people to know exactly what caused their migraine. In the study, only half the participants (6 out of 12) knew their possible migraine triggers; five of them had between two and 14 triggers, and one participant was not sure about what his triggers were. Possible triggers ranged from personal factors like diet, sleep patterns and stress, to environmental factors like weather changes and light. This wide range of potential triggers makes it particularly challenging for participants to distinguish genuine triggers from other uninvolved factors that co-exist in everyday life. One interviewee described his experience in finding triggers:

"I really don't know [my triggers]. It's hard to tell because they happen at such odd times. For instance, I had one – I was actually Skyping, doing an interview with a class and then all of the sudden I could feel, 'Oh, my vision is getting blurry,' and I started to get nauseous. I'm like, 'Oh, God,' you know? Another one I had was when I was asleep. I was completely fine going to sleep and then it woke me up and then I went to the bathroom and threw up. It was awful. So, there's no way for me to know, they are so unpredictable." – P6: Jason (mild migraine)

For Jason, the apparently random occurrence of migraines made it almost impossible for him to track down all possible life events that may constitute triggers. Also, the timing of his attacks, as described in the quotation, highlights other challenging aspects of trigger identification, since participants may not always remember to track relevant factors at a given time.

In our study, participants and clinicians demonstrated opposing viewpoints regarding identifying migraine triggers. The doctors participating in our study believed finding triggers was fairly easy for patients. One doctor stated, *"I usually tell [patients] to just write in their own notebook and then I tell them the main issue for them is to track, try to figure out the trigger…if they pay more attention to it (the triggers), then most likely they will figure it out [D01]."* In contrast, participants felt that finding migraine triggers was not as easy as simply writing things down. Instead, they perceived it as a labor-intensive process, in which they had to first determine all possible causes, then compare each different factor or different combinations of possible factors over and over again in order to make sense of a large amount of daily information. To identify triggers, participants had to recall events occurring immediately before or 1-2 days before migraine attacks, form hypotheses about which ones might be possible triggers, and experiment with them one by one. As described below, Rachael, a participant with severe migraine symptoms, used a headache diary to find out her triggers:

"For example, if I got a migraine today, I'm like, 'Did I eat chocolate today?' And I would write it in my calendar, 'milk chocolate.' And then if I got a migraine the next week, 'Did I eat pizza today?' And I would put 'pizza,' and then I'd get a migraine next week, I'm like, 'Okay, my boss yelled at me today.'… So it would be, 'pizza, boss.' Then, I was able to at least eliminate, 'Okay, so it wasn't pizza, it wasn't processed food, it wasn't this, it wasn't that.' So, then I would find a pattern eventually over six months, eight months. I just notice over time it was... 'Okay, it's definitely stress. I didn't keep it consistent, but I kept it over years enough to know that... I've kept them from the time I was 18 because it really affected my lifestyle."- P4: Rachael (severe migraine)

In Rachael's case, her migraine was not triggered by a factor such as food or exercise, but by her mental state, stress; her trigger identification process lasted years and required her to track a broad range of activities systematically over long period of time. By noting activities occurring near the time of each attack, Rachael was able to test hypotheses regarding what did or did not cause her migraine, using a trial and error process. After careful reviews, she was able to eliminate irrelevant factors. In her case, using a written diary was helpful in discovering her trigger; however, she also needed to constantly make sense of the diary by forming new hypotheses and eliminating unrelated factors. Especially for subjective triggers such as stress, mood and sleep quality, this hypothetical-deductive process had to be performed thoroughly and contextualized with other information – when, where, and what she was doing. In our study, we found that only participants with frequent and severe migraines were motivated to do such extensive trigger identification work.

Thus, even with a list of common migraine triggers, identifying one's own triggers is still a daunting task, and several participants with severe symptoms even consulted online forums in hopes of finding better and quicker methods to assist their trigger discovery process.

How Should I Cope With Migraine?

To cope with migraine symptoms, many participants developed a variety of strategies that worked for them. In this section, we describe these strategies according to their goals: *(i) alleviating symptoms, (ii) preventing symptoms from happening, and (iii) preparing for breakouts and migraine-related activities.*

The most common coping method among participants was using various medications and alternative solutions to alleviate the symptoms (See Table 2). Our findings in the study suggest that this coping mechanism was highly individualized for each person. Although all the participants had to take over-the-counter (OTC) drugs or prescribed medications, the effectiveness of these medications varied based on the severity of each person's condition, symptoms, or response to medications, such as side-effects. In addition to medications, participants also relied on alternative solutions to alleviate their symptoms, such as lying down in a dark room or listening to music. The efficacy of alternative treatments was also dependent on symptoms, triggers and personal preferences. For instance, one participant listened to soothing music to relieve her pain, while another interviewee mentioned he had to use earplugs to block out all sounds in order to alleviate the headaches.

Preventing symptoms from happening was another method many participants actively deployed, mostly through lifestyle changes, avoiding known triggers and the use of preventive drugs (See Table 2). Some participants adopted preventative strategies suggested by media sources or other patients. For example, Sean (P9) had tried *Bikram yoga* at a private studio, instead of typical exercise at the gym, based on a recommendation from a friend who also had migraine. Sean later developed his own body-stretching exercises at home that he believed to be most effective for his situation. Sean tried to perform these stretches daily or as soon as he sensed the onset of migraine [Figure 1]. Also, a few participants with severe symptoms took daily preventive medication prescribed by their doctors as a way to control migraine symptoms on a daily basis.

Participants often needed effective and timely strategies to prepare for potential breakouts. Based on their own disease management experiences, most participants had developed their own way of being prepared for with migraine attacks. Several participants carried aid items with them at all times, such as a Ziploc bag for vomiting or water for taking medication, in case they had an attack; others kept aid items ready at home for quick use, such as ice packs in the fridge or a certain tea available in the cupboard.

Figure 1. Individualized strategies – OTC medication in the bag for urgent triage for attacks (left) and body stretching method for preventive purposes (right)

Moreover, participants in our study used different reminder methods, including paper or online calendars or iPhone applications, to remember and coordinate migraine-related activities or to-do lists. These tools were used to keep track of medication intake (preventive drugs in particular) and activities participants had to reschedule due to migraine attacks, such as preparing others to pick up children or rearranging meetings and other daily responsibilities.

Treating migraine pain	OTC medications, Prescribed medication such as Topamax[2], Triptans, Imitrex, Caffergot, Vitamin B12, Botox injections, drinking water, wearing earplugs, using ice pack, lying down in dark room, listening to music
Preventing symptoms from happening	Preventive drugs such as Depakote, Botox injections, Diet (e.g. baking own bread, making fresh food, drinking coffee every morning), regular life schedule, exercise (e.g. developing daily stretching methods), and stress management.
Preparing for migraine breakouts and migraine activities	Carrying aid items such as a Ziploc bag for vomiting, OTC medication in a bag or traveling bag, and water for taking medication. Setting reminders for migraine related activities using a paper calendar and iPhone calendar.

Table 2: Participants' various individualized strategies for managing migraine

In the study, we noticed that although these methods were useful, only participants with severe symptoms had concrete management strategies. Since the impact of migraine was so intense and frequent, they found solutions proactively on their own. In contrast, participants with mild and intermediate symptoms were not motivated enough to

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[2] All strategies, including drug names, in table 2 were directly extracted from interview transcripts and reflect what the participants reported to us.

take similar proactive steps to develop their own individualized strategies. As a participant with intermediate migraine commented, *"I don't know if there really is a treatment since I can't really identify the trigger, it's hard to know how to prevent or how to treat. So, but, I mean, it is interesting. I have tried to figure out why they occur, but I don't get any sense of – there's no consensus presented in the information [available resources including information online], there's no regular story offered as to why these things occur. There's just a list of symptoms and some theories about why people get them."* Thus, the real challenge for inexperienced participants with mild and intermediate symptoms was *not* to find generalizable knowledge on migraine management/treatment, but to find meaningful self-knowledge that was relevant to their individual illness.

Beyond Individual Management

Despite the individual nature of migraine management described earlier, we found the management of migraine also comprises a social aspect that often involves and impacts other people in a patient's social circle, such as co-workers, family members, and friends. In our study, participants constantly reported their desire for more social recognition and social assistance for migraine, largely because of the unpredictable nature of migraine attacks.

Most participants in the study mentioned that some sort of physical help is needed during migraine attacks, either to cope with the pain, or to attend to responsibilities abandoned by them due to sudden migraine breakouts. When seeking assistance, participants relied on close networks such as family members, friends, or certain coworkers. An interviewee told us how she trained her family members as first line helpers for sudden attacks.

"It was difficult…I taught them [her children] all... a meal they could make by the time they were about four years old… if I was down in bed… they took turns and alternated and made their dinner for the family and I'd sleep it (the migraine) off in the bedroom..." – P5: Gwen (severe migraine)

In Gwen's case, even her 5 and 7 year old children have to be prepared for her sudden migraine breakouts, since the pain and other symptoms would prevent her from doing her daily chores. Having a list of helpers readily available who understand the difficulties a patient experiences during migraine attacks appears critical in managing the disease.

In addition to a close social circle, many participants also needed to obtain help from peripheral networks outside their close circle, such as coworkers or less intimate friends. Nevertheless, many participants in the study commented that, unless it is really necessary, they were often reluctant to share their migraine conditions with people in the peripheral network and often only shared their symptoms with close friends and family members. One interviewee with intermediate symptoms explained how he tried to deal with sudden migraine attacks at work:

"How do people really know that I'm having a migraine? I don't necessarily say, 'I'm canceling the meeting because I have a migraine.' I just said, 'I'm sick.'… I think that I don't tell people necessarily why. I just say I'm sick because I think that some people think that if, "Well, if you just have a headache, take some aspirin and get over it," whereas it's like, 'No, this is a special kind of headache.' ...So, I tend not to tell people I'm going home just because I have a headache." – P7: David (intermediate migraine)

During attacks, David did not reveal his disease to his colleagues, even though he was in a difficult situation where he had to call off meetings. Yet, since most his co-workers had never had migraine, David was afraid they might not understand the disease and associated symptoms. The lack of wide acknowledgement of migraine becomes a barrier for participants to communicate and share their situations with other non-patients, especially when the attacks happen periodically, and cannot be observed externally. Like David, many other participants chose to not share their migraine information, either coping with it alone, or claiming they were sick without revealing any details. For instance, Sarah, a participant with mild migraine symptoms, said: "*if you talk to somebody who hasn't had a bad, severe headache, then their attitude is more like, 'Why are you bothering me with this information?' But if you talk to somebody who has gone through it they're like, 'Oh, I know.'"* Clearly as these quotes indicate, although migraine participants suffer from extreme pain during attacks, there is not always sufficient social recognition from their social circles. Especially at times when many participants are unable to perform their daily activities, and had to rest immediately, others may not understand the urgency of such needs, and many employers even complain about patients for not completing their tasks on time. Patients' low expectations of others and difficulties in communicating their subjective, individualized pain led them to choose to simply say they were sick, rather than saying they were suffering from a migraine.

For this reason, although nearly all participants were good at sharing their migraine information within a close network of family and friends, many chose not to share it with people in their peripheral network. The severe-symptom participants tended to be more open in talking about their illness during attacks, because they experienced more frequent attacks, and expect higher-level social recognition from others.

"[Migraine] makes me slow... If I am doing something – reading, designing application, I cannot... it affects my work... I say oh I need two hours off and they [his colleagues] say ok. I'm not that shy about these things. If you are shy, it's bad, you know. You cannot work, but people think that you are not working so that is bad... If I have headache or I need help, I will just give a call over there and somebody, a friend, or co-worker, just bring me home." – P12: Michael (severe migraine)

As shown in the quote, when migraine occurred, Michael actively sought two different types of help: requesting a ride home and asking coworkers to cover some work in his absence. His more frequent attacks made co-workers more aware of Michael's situation, and more apt to grant social acceptance his sudden absence from work due to the migraine breakouts.

In contrast, participants with mild and intermediate symptoms tended to stay passive and did not want to share their symptoms beyond their closest network because they were afraid of being misunderstood as invoking migraine as an excuse. As such, lesser frequency of attacks resulted in lack of social recognition and led mild migraine participants to be even more passive during attacks. Like David and Sarah, most participants with mild symptoms preferred to keep their illness private from external networks, despite often needing help from them, especially when their first line helpers were not available. Two participants in our study mentioned they never asked anyone for help and never expected proper understanding or emotional support from others. Therefore, it is worth considering how to help patients with mild and intermediate symptoms obtain social acknowledgment and assistance. We also wish to note that social recognition can go beyond simply providing help; it can involve showing understanding and acknowledging patients' difficult, stressful situations.

DISCUSSION AND DESIGN SUGGESTIONS

Our study uncovers the multi-faceted challenges, both from individual and social aspects, faced by people with migraine in the management of their everyday lives. In this section, we first discuss the need for sufferers to make sense of days, weeks and possibly years, of life events in order to understand their condition, as well as coping with unpredictable and intermittent migraine attacks. Then, we consider migraine's nature as an under-recognized disease, which makes it difficult to obtain appropriate recognition from others. We also discuss the need to engage patients with mild symptoms, who are currently underserved.

Making Sense of a Whole Spectrum of Life Events

As our study has shown, due the individual differences of migraine presentation, patients are often unable to easily identify their own triggers and symptoms using available medical resources. Instead, the management of migraine requires them to engage in a series of activities including recognizing migraine related symptoms, tracking down possible triggers from numerous of life events, and finding appropriate ways to cope with sudden breakouts.

Tracking and making sense of personal health data has been advocated broadly in recent personal informatics [18, 20, 24], and qualified-self initiatives [26]. As a result, many mobile apps and tracking systems have been developed to facilitate ways for individuals to understand their personal behaviors, such as apps that track exercises, diet and glucoses in diabetes management and sleep patterns [18, 20, 24]. Nevertheless, the current systems often emphasizes tracking and counting limited and often pre-determined measurements, instead of supporting the sense making of more subjective, and wide range, of possible life events. A recent study [12] has examined extreme users who have used existing self-tracking technologies and indicated that while most technologies focused on tracking symptoms and health outcomes, they often failed to capture and track *triggers* of the health problem, and the *context* in which the health symptoms occurred. This common pitfall makes it difficult for these systems to facilitate self-refection and self-recognition – a critical step identified in our study.

What we have found with migraine patients suggests that identifying triggers and effective treatments actually requires more extensive information tracking and sense-making efforts since what relates to migraine reaches far beyond diet, exercises and a few physiological factors. The triggers and coping mechanisms reported by our participants cover a wide variety of factors embedded in people's everyday lives. In particular, many of them are related to patients' subjective and situational feelings. For instance, whether a person feels hot or cold can depend on his/her physical condition at the time, and a person's stress level during the same task can be more or less depending on mood and the ability to perform the task. In addition, since many potential triggers are subjective factors that can hardly be defined using numerical scales, having a 1 to 5 scale may not be effective for patients to track them. Because of these challenges, we suggest a migraine management system should allow users to create their own tracking features from the spectrum of life events, and define the ways in which they want to track them. Doing so can provide people a chance to track life events beyond a few pre-defined triggers, and enable them to track these events in a way they prefer and feel comfortable with. For example, in such systems users can add stress as a tracker and define a tracking scale based on their own subjective perceptions. For instance, a weekly project meeting with the board can be categorized on a scale such as 'no stress, just regular stress, pretty bad, awful, and getting a headache right afterwards'. Migraine sufferers can also add temperature as a tracker based on their own experiences; 'hot weather' can be a serious trigger for some people, although it will not lead to any discomfort among others. This approach can allow users to personalize tracking features and to cover a broader range of activities. It also helps capture the contextual information that is relevant to the events being noted, similarly to what has been advocated recently [12]. Contextual information can be critical in understanding and making connections across several life events, especially when the trigger is a combination of multiple factors, e.g. hot weather and stress.

Having personalized trackers beyond conventional diet and exercise activities creates a more user-friendly way to engage patients and promote the use of personal informatics tools, as they will be more applicable to one's own preference and situation. Beyond migraine, this personal defined tracking mechanism may work for many other chronic conditions. For instance, mood has been suggested as an important, interesting factor in general chronic care management including physical performance [20, 26]. However, mood is also a subjective measure, and having a 1 to 5 scale may not be an appealing way to engage users and have them enter data in the system on a daily basis.

Coping with Unpredictability and Intermittency

Compared to other well-studied chronic diseases where the influences of the ailment are constantly present, migraine represents another range of health conditions that are characterized by unpredictable and intermittent breakouts, e.g. asthma, and chronic pain. Such characteristics make the management of these diseases and the consequent system requirements different from other chronic conditions.

First of all, recognizing intermittent and diverse forms of symptoms makes the disease management more challenging to undertake. In this sense, patients have to learn to recognize the periodically occurrence of migraine symptoms, and to identify possible commonalties between different migraine attacks that may be separated by days, weeks, month or even years. Intermittency requires patients to engage more with the "diagnostic work" since it prevents others, even medical professionals, from easily being involved in the diagnosis process. Thus, in managing migraine, patients often take on a leading role and serve as "*diagnostic agents*" [25] to understand, and learn about the disease themselves. Oudshoorn [25] believes patients can take on this role since they "*have to perform all manner of articulation work required to make ... new healthcare services work.*" As a diagnostic agent, a patient with migraine has to track and link each migraine incident happened in the past in order discover the specific associations between contextual factors and their migraine symptoms. This explains why most of our study participants believed that seeing a doctor was not useful in helping them with migraine treatment.

The intermittency makes the daily activity tracking and information sense-making more critical for patients, especially when the sense-making may not be centered on information recorded continuously, but happen across different time periods when migraine attacks appeared. For instance, a severe migraine triggered by hot weather may have to be linked with past attacks in the previous summer or even earlier. This is certainly a difficult endeavor since these events are so temporally separated, and it may not occur to patients to consider them together. In this sense, a chronic care management system for diseases of an intermittent nature has to help patients connect these temporally disconnected episodes. To cope with unpredictability and intermittency in migraine management, we suggest that the system should not only track, but sustainably associate different types of migraine symptoms and life events in patients' past trajectories, and even enable suggestions for users. For example, the system might tell a user that past tracking information has shown severe migraine attack co-presented with high consumption of chocolate. Thus, chocolate might be a potential trigger. Or when a person cannot figure out why there was a severe migraine attack, the system can either retrieve information on past breakouts occurring in similar situations, e.g. in summer heat, or after a stressful project due date, to remind the user of possible triggers in these chronologically separate events. In addition, the system could even make suggestions to avoid certain triggers when possible or prepare coping materials – e.g., when the weather is going to be extremely hot the next day, the system can remind the user to stay inside, or bring more water and medication.

Second, the unpredictable nature of migraine attacks leads to difficulties among migraine patients, especially for patients with severe symptoms who have to rest and may even need immediate help in performing their current tasks. As our findings show, during attacks, migraine sufferers wished people in their social circles understood the nature of their migraine so that people could provide physical help. The study identifies two levels of help for patients: helping the patient cope with pain (e.g. taking them home, delivering medications), and taking care of various responsibilities patients were unable to perform, such as covering work, daily chores like cooking, etc. This collaborative aspect of migraine management is not sufficiently acknowledged in current systems, and most system designs assume coping with migraine as an individual task, neglecting the needs in obtaining physical help during migraine attacks. Nevertheless, since the breakouts are often unpredictable, it is difficult for patients to arrange social help in advance. In our study, we have seen participants who have prepared and trained people in their close social circles to be first line helpers who can take on tasks immediately.

However, the approach of obtaining and coordinating help may not always be effective when severe breakouts serve as a barrier to communicate these needs with others, and locate the available helpers in a timely manner. For instance, calling friends one by one may take some time, but a system to facilitate the sharing of a migraine status to all the first line helpers can be more effective. By communicating the migraine status to a sharable network, the patient can share his/her needs with all helpers at once, and to allow them sign up for tasks they are able to take on at the moment. Second, the system should also reach out to more peripheral people when first line helpers are not available. This can be seen as a similar suggestion made in a previous study [31] in terms of a connect platform that helps create help request, informing social networks, and coordinating helping activities. However, migraine patients cannot anticipate what kinds of help request they want and who to ask in advance, since it all depends on when an attacks occur, how severe it is, and how long it lasts. Thus, they have to perform this coordinating work of getting help the after migraine occurs. Additionally, since the degree of the disclosure of the migraine status and consequent needs may vary depending on the patient's situation, the system should allow patients to choose specific networks or to create predefined networks to share their migraine status information.

In particular, based on the study findings, we suggest that the system should consider people's preferences, as well as privacy issues pertaining to the sharing of migraine-related information. For instance, instead of sharing information with all co-workers, users can pre-select a small set of co-workers who they believe can understand the migraine situations and are likely to help. This subset of co-workers will be alerted as their front line helpers at work. When severe attacks occur, they can select the level of migraine, and the types of help they need to share with people they are comfortable with. The rest of their co-workers will only see an "unavailable" indicator or away from work message but will not receive other details. Similarly, when a person needs physical help, the request can be sent only to those who are physically nearby, so that relatives and friends who live remotely will not get such messages. Those on the receiving end can also define how they would like to receive such messages; for instance, a husband might want to know his wife's situation at once so he can arrange to help her or pick up children, but other friends may wish to limit disruptions to their own life or to be available only when they are not otherwise engaged. Allowing both migraine sufferers and their social network to define how the messages are delivered, the degree of detail desired, and the delivery method is critical in maintaining the balance between getting sufficient assistance and protecting privacy. Such "status delivery" systems could potentially benefit patients with similar health conditions, such as chronic pain, which is also intermittent and unpredictable in nature [7].

In addition, since the severity and duration of migraine attacks varies, the system design can also allow users to indicate the level of symptom severity as well as their specific needs. Based on the level of severity and duration, the system can provide the patient with a means of sending group notices to all those involved, and to tailor the message. The system can be integrated with the patient's daily schedule, so a migraine status sent at a given time could reach recipients involved in the patient's current activity for both work and home, and help can be sought from people who are located nearby at the time of the attack. Doing so could ease the stress and the coordination of workload for migraine patients during sudden breakouts.

Obtaining Social Recognition

Despite much of the emphasis in migraine management on the role of self-recognition, in the study we find that recognizing migraine socially is also critical in the management of migraine. The unpredictable and invisible nature of attacks makes it difficult for people in patients' social circles to understand and acknowledge it. First of all, unlike those managing other chronic illnesses, migraine patients experience sudden, unpredictable disease breakouts that disrupt their everyday lives, yet function like healthy people at most other times. Second, migraine is invisible to others since most symptoms are subjective feelings that cannot be measured, such as pain. Unless patients vomit or feel nausea, their migraine attacks can hardly be noticed by others. Just as a patient mentioned in the study – unless someone has experienced extreme pain previously, he/she may not understand how difficult it is during a migraine attack. Therefore, it is hard but critical for patients to obtain appropriate social recognition, as this may be the first step in seeking social support during migraine attacks.

When social recognition is lacking, we find that patients often strategize how they can communicate migraine information, and how much detail to share with others. Especially when dealing with pain and seeking help from peripheral networks, patients often experience a dilemma over whether to reveal their specific health status or to share only vague information to others (i.e. just being sick), because they are uncertain about how the disease will be perceived by others, and worry about whether misperception would occur. Because of this, many sufferers carefully conceal their symptoms from their external network to avoid being labeled as lazy or unwillingness in taking on some tasks, thus making the migraine attack at work or social events surprising to others who did not know the patient well.

Though social recognition for migraine patients is particularly lacking, it is also absent in many other diseases, and worth emphasizing in general. For instance, cancer patients may not share their chemotherapy appointments with co-workers but to ask for sick leave using general sick requests [28]. However, comparing cancer treatments that are often pre-scheduled in advance and can be hidden under regular sick leave, the sudden breakouts of migraine certainly present a greater level of challenges in obtaining social recognition, and proper understanding. In this research, we note the importance of obtaining social recognition, especially when the consequences of migraine breakouts influence and impact others, such as being suddenly absence from social events, canceling meetings or delaying task completions. We believe subtle ways of gradually building social recognition may help for both patients and their peripheral social members. With a simple micro-blogging feature, a patient could post and share brief text statuses through Twitter and Facebook updates, or he/she may display an icon or status indication of having migraine on their chat (mobile) messenger/window, which can also show education material by mouse-over or click. This would help increase an awareness in others about a patient's status at that point and their interest in learning more about migraine by exposing migraine related materials, and would eventually help gain social recognition from those who do not experience migraine. We note that this is still based on a patient's personal decision to disclose their real situation, but we have seen nearly all study participants express their wish to have others' understanding, acknowledgement, and empathy.

Engaging "Underwater" Patients

In studying migraine patients, we notice a clear dichotomy between patients with severe symptoms and those with mild symptoms. Just like 90% of an iceberg is underwater and invisible to the outside world, the practices of migraine patients, especially those with mild symptoms, have not been studied sufficiently. Medical study has shown that 90% of migraine sufferers do not know their specific condition and do not know the best approach to alleviate their pain; almost half of sufferers have never received a formal diagnosis [21], and even fewer have received consistent treatment [32]. It is therefore worth investigating how to engage and assist migraine patients with mild symptoms more effectively.

As our study has shown, the uncertainty of the disease has caused more difficulties and complexities for patients with mild symptom to manage migraine, both individually and socially. Patients often experience less frequent and irregular attacks, unclear triggers, and vague symptoms, which result in inefficient diagnostic work, and lead to the lack of social recognition from others. This group also faces more difficulties regarding clinical diagnosis, with the result that they are apt to ignore medical advice or to stop seeing doctors. However, the severity of migraine often increases over time [13], and it is important to consider this "under-the-water" group of patients and prevent their symptoms from deteriorating earlier. It is important for system design to take into account the need to engage and support this under-recognized migraine population.

In addition, our study shows that public recognition of migraine, unlike that of other chronic diseases [23], suffers from abundant misconceptions, and this makes migraine management even more challenging for patients with mild symptoms. The fact that most people experience ordinary and usually mild headaches creates a misperception of migraine, as non-sufferers may believe migraine is an ailment that can be resolved with a single dose of painkillers, or causes trivial discomfort that should not stop a person from working normally. Because of this, many migraine patients treat their symptoms privately and do not want to disclose them to others. There is an urgent need to create proper social understanding to support the under-recognized majority of migraine patients.

To better support this large group of "under-the-water" migraine patients, we believe that providing further motivation can help engaging patients with mild symptoms. Motivating patients to engage in health behavioral changes has been widely studied in HCI community recently [6, 24]; however, the key need with migraine patients lies in the self-identification process. As such, facilitating triggers, and coping mechanism discovery and the trial-and-error activities are needed in system design. For example, instead of starting from nowhere, a patient can receive a list of suggested triggers, e.g. banana, white chocolate, and wine, from a pool of known trigger list or peer patients' who have similar symptoms or types of attacks. In addition, by inviting patients to conduct data reflection sessions in the form of a game or quiz, the system could offer appealing ways to engage these underserved users and help them make sense of their migraine triggers. It would be useful to encourage patients to connect with other sufferers in a similar situation in order to help them gain a better understanding of migraine and benefit from the experiential knowledge of experienced patients, whose input could eventually help patients solve their own "puzzle" more easily.

CONCLUSION

Through our analysis of migraine sufferers' migraine management practices, we discover that patients face great challenges, both when they attempt to understand the individual manifestations of their illness and when they manage its social aspects by communicating about their condition and soliciting help. We argue that these challenges arise in response to the patients' needs to deal with the unpredictability and intermittency of the disease. We also argue that external resources and current systems are not appropriately suited for patients dealing with subjective symptoms, unknown triggers and treatments, as well as a lack of social recognition and help from others. Future systems should facilitate patients' extensive sense-making process of life events, help patients request support from social circles, and support the patients' gain of social recognition and acknowledgement. Finally, system design should also consider targeting patients with mild symptoms, the majority of the migraine population. We believe this work can contribute to prior chronic illness studies by offering insights into a previously under-studied disease, as well as its potential applicability to other similar illnesses.

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