Designing in the Dark: Eliciting Self-Tracking Dimensions for Understanding Enigmatic Disease

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ABSTRACT

The design of personal health informatics tools has traditionally been explored in self-monitoring and behavior change. There is an unmet opportunity to leverage self-tracking of individuals and study diseases and health conditions to learn patterns across groups. An open research question, however, is how to design engaging self-tracking tools that also facilitate learning at scale. Furthermore, for conditions that are not well understood, a critical question is how to design such tools when it is unclear which data types are relevant to the disease. We outline the process of identifying design requirements for self-tracking endometriosis, a highly enigmatic and prevalent disease, through interviews (N=3), focus groups (N=27), surveys (N=741), and content analysis of an online endometriosis community (1500 posts, N=153 posters) and show value in triangulating across these methods. Finally, we discuss tensions inherent in designing self-tracking tools for individual use and population analysis, making suggestions for overcoming these tensions.

Author Keywords

Personal informatics; self-tracking; patient-generated data; enigmatic disease; endometriosis; participatory design.

ACM Classification Keywords

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

INTRODUCTION

Today, self-tracking is widely practiced and common among health consumers. For instance, it is estimated that 69% of U.S. adults keep track of at least one health indicator [38]. Self-tracking is often performed passively through wearable sensors and fitness trackers, as well as proactively through self-report [7,60]. Individuals are often motivated to self-track to discover new insights about themselves or to achieve a particular health-related goal [8].

People with chronic conditions, who are often faced with a complex set of decisions and environments to navigate, have additional incentives to understand and manage their condition, and thus engage in self-tracking.

Self-tracking systems that *"help people collect personally relevant information for the purpose of self-reflection and gaining self-knowledge"* are part of personal informatics, as defined by Li and colleagues [59]. Within the health domain, personal informatics tools have traditionally focused on self-monitoring for individuals to gain health-related self-knowledge or achieve a health-related goal [26,54]. In fact, designs of such tools have been proposed and evaluated for many chronic diseases, including diabetes [5,41,69,80,91], COPD [12,102], cardiovascular diseases [4,96], and Parkinson's [11,72,77].

In the context of a chronic disease, there are a large number of data points that may be self-tracked. They fall into a set of well-known data types, or dimensions, which include signs and symptoms of the disease, biomarkers and behavioral markers like physical activity, treatments, self-management strategies, as well as potential environmental factors [15,98]. Designers traditionally rely on current scientific knowledge about the disease to identify which of these data types, and which specific variables among them, to incorporate in their self-tracking tools. For instance, current understanding of diabetes shows that diet is an important dimension, with macronutrients as specific variables of relevance; biomarkers and blood glucose measurements in particular are important for individuals to self-manage successfully. Similarly, environmental factors like irritants and allergens are potential triggers of asthma and as such represent important dimensions when building asthma self-management solutions.

However, there are many diseases for which it is not well understood which data types are pertinent to self-track, and for which specific relevant variables have not been fully enumerated. This lack of knowledge has been noted in the literature for rare diseases [106]. It is also significant when designing for enigmatic diseases. Across several diseases, enigmatic conditions seem to share heterogeneous symptoms, unexplained differences in treatment responses, and lack of symptom specificity [1,14,36,56,86,92]. Many enigmatic diseases are relatively prevalent; in fact, the heterogeneity in symptoms may be due to the large number of people affected. Examples of enigmatic diseases include

chronic diseases like interstitial cystitis, psoriasis, Crohn's disease, and chronic fatigue syndrome. Irritable bowel syndrome is another such chronic condition, where diet is an established data type to monitor, but specific diet triggers are unknown and in fact vary from one patient to another. Even relatively well understood diseases may have aspects that remain enigmatic: for example, why post-meal blood glucose spikes vary from one individual to another is an active area of research [103].

Previous HCI research has shown success in designing self-experimentation tools and n-of-1 studies to help individual users identify which specific variables are useful to monitor when managing their own health [50,51,105]. In such self-experimentation systems however, the emphasis on supporting each user individually might come at the expense of deriving insights across all users. By letting users track and experiment with what dimensions and variables they think are relevant to their own experience of their condition, these systems promote individual self-discovery, but might make it challenging to standardize and learn across individuals. There is an unmet opportunity to broaden the current conceptualization of personal health informatics to include not just self-tracking for the sake of self-knowledge and self-discovery but self-tracking for improving knowledge of disease across a group. This is particularly true for enigmatic conditions. Self-tracking data of enigmatic conditions, when taken in aggregate across a user group, can provide a novel view of the disease, can help enhance scientific knowledge about the disease, and can help bridge the gap that exists between the patient experience of these enigmatic conditions and their current medical understanding.

Here we explore the design of self-tracking tools to characterize enigmatic conditions and understand disease across individuals. Specifically, we aim to answer the following research questions: (1) what data to collect from individuals that align with their experience of disease, and as such makes their self-tracking relevant to them; and (2) what data to collect across individuals that may be used to further capture and characterize the disease through a standard set of variables. We focus on endometriosis, a prevalent yet enigmatic systemic chronic condition. Specifically, in this paper our goal is to identify and distill the dimensions of disease, along with specific variables relevant to self-tracking endometriosis. Such dimensions must represent the relevant variables of the disease, as experienced by individuals and help capture generalizable knowledge and discover patterns about the disease through learning at scale from the data generated by the individuals engaged in self-tracking.

Towards this goal, we experiment with a set of complementary approaches to iteratively identify the dimensions relevant to the experience of an enigmatic disease. Starting with preliminary interviews (N=3) and a series of five focus groups (N=27), we elicit basic data

types, or dimensions, from people with endometriosis. We further refine these relevant dimensions and identify a pool of specific self-tracking variables in a wider population through a series of online, anonymous surveys (N=741). These dimensions and variables are further triangulated with variables identified through the content analysis of an online public, anonymous endometriosis discussion board (N=1,900 registered members and 1,500 active members at the time of analysis).

Our work builds upon research in personal informatics to understand design of self-tracking tools. As such, this paper has the following contributions: (1) a series of complementary approaches to elicit the data types and the specific variables relevant to self-tracking an enigmatic disease; and (2) an exploration of the inherent tensions in characterizing a condition in a way that is both relevant to individuals' experience of the disease and meaningful for analysis at scale. It also contributes new knowledge about endometriosis, through the elucidation of novel dimensions and variables relevant to the patient experience.

BACKGROUND AND RELATED WORK
In this section, we review prior work in two fields primarily: personal informatics, specifically technology research for self-tracking, and informatics research on characterizing disease at scale. We also provide background on our condition of interest, endometriosis, in the context of characterizing enigmatic conditions.

Self-tracking
Previous work in personal informatics has focused on understanding motivations for the use of self-tracking tools and the implications on the tools' designs. In particular, research has focused on understanding progress towards achieving a particular personal goal through self-tracking, supporting users by providing data or knowledge that helps individuals self-monitor their progress [9,28,33,53,82]. Earlier models of personal informatics also helped to describe how people use self-tracking technologies to gain self-knowledge in the context of self-monitoring [59,66]. More recent human-computer interaction (HCI) research has focused on moving toward examining self-tracking in the context of self-discovery and self-experimentation [32,51,57,84], and personal informatics models have been expanded to include technology that is not necessarily associated with self-improvement [34,63]. For example, HCI researchers have begun exploring self-tracking out of curiosity as part of the quantified-self movement [20,34].

Within the context of chronic diseases, research has focused on how to support people with particular health conditions in self-managing their disease. Self-tracking applications are a particularly useful design for individuals with chronic disease, given these individuals dynamically experience symptoms over time, and self-tracking allows for capturing and documenting these changes as well as disease-related behaviors [26]. Because much of the self-management process can be specific to a given individual, prior research

has also examined the use of customization and personalization to tailor the design of self-tracking tools to users' specific needs [2,35,58,78]. These needs may also vary from disease to disease and may make technology development across diseases, such as rare diseases, challenging [60]. Yet there may be patient characteristics that are similar across users with even different conditions [61].

In contrast to prior work, our work seeks to inform the design of self-tracking tools when the purpose of the system is not exclusive to individual-level understanding of disease. This work follows the trend of broadening notions regarding the goals of self-tracking in personal health informatics systems. In particular, we are interested in examining the design of self-tracking tools for people with enigmatic conditions, in which it is not well understood how to self-manage symptoms nor is it clear which dimensions of the disease are relevant to the disease in the first place. Further, we seek to identify dimensions of endometriosis that characterize the disease across many patients. By expanding the scope of design in personal informatics in this way, tension emerges between the need to personalize interventions to support engagement and the data necessary for understanding the experience of disease at scale [73].

Within HCI research the design of self-tracking tools for purposes or needs other than a patient's personal understanding has been explored. For example, people with a particular condition may share self-tracking data with a clinical provider or with one's care team [47,85,100]. Moreover, data may be shared as part of a community [25], commonly as part of gamification-based features to incentivize engagement with the tool and with behaviors that support self-management [52]. Crowdsourcing to support individual self-management has also been examined [71], and social sense-making has been explored as a feature to help individuals make sense of their own health data [81]. Quantified selfers' collection and exploration of data is in an individual context, but these personal experiences may be shared with others [23].

Yet there remains an opportunity to better understand how self-tracking data may be leveraged to create new knowledge about disease beyond personal discovery, but rather for cohorts of people at scale. Such knowledge is essential for effective management and treatment of disease and to advance biomedical research.

The idea of leveraging the self-tracked health data of many individuals to discover new insights across a group is not new. Recent research showed value in examining a single variable (e.g., number of steps per day, collected passively) tracked across many individuals to learn about a behavior (e.g., physical activity) at the group level [6]. In this case, like in other recent examples, the data leveraged was collected via existing commercial apps, with their own set of engagement strategies. However, designing self-tracking tools that promote sustained engagement among each user and at the same time enable researchers to learn at scale and discover new disease insights is an open research question.

Recent clinical research, aided by the release of the Apple ResearchKit framework, has started leveraging self-tracking towards understanding diseases at scale. Studies deployed thus far rely on standard surveys, such as daily questionnaires. Results have shown promise in collecting large amounts of data from a diverse set of participants in a relatively short amount of time as compared to traditional biomedical research approaches [16,21,104]. Yet, the lack of engagement among participants of these studies eludes to the fact that the design of these self-tracking tools for population-level disease research is not clearly aligned with the experience of disease. Characterizing the experience of disease is essential to informing the design of tools that can facilitate learning about enigmatic conditions at scale.

Endometriosis: An Example of Enigmatic Disease

Endometriosis is a women's health disorder. It occurs when endometrial tissue commonly found lining the inside of the uterus grows outside the uterus and forms lesions. It is a prevalent condition, estimated to affect 10% of women, and is associated with many comorbidities [94].

Maybe because endometriosis' primary description is pathological in nature (presence of endometrial lesions outside the uterus), diagnosis is currently established through laparoscopic surgery and histological analysis of biopsied lesions [13]. There are no known biomarkers to help diagnose or monitor the progression of the disease [3]. Furthermore, its characterization is primarily driven by the nature of these lesions: disease stages fall into three stages – deeply infiltrated lesions, superficial lesions, and endometrial cysts [39]. Outside of these surgical stages, consensus description of signs and symptoms of the disease are limited to dysmenorrhea (painful periods) and infertility [17].

Despite its prevalence and its presence documented for centuries in patients, endometriosis is a widely enigmatic condition. Its causes and etiology are unknown. Further, individuals with the condition present with a wide range of symptoms beyond painful periods and infertility. But there is no consensus neither as to which of these symptoms are specifically related to endometriosis nor how they might be associated with each other and correlate with surgical stages [14,95]. For instance, individuals with severe stages of the disease might be asymptomatic, while those in a lower disease stage might experience debilitating pain during and outside their menses. Further, patients can present with all three types of lesions. Patients also show a wide diversity in their response to treatments, and it is not currently understood why and who will benefit from particular treatment [45].

Similar to the medical body, individuals with endometriosis have limited understanding of their own condition. People

with endometriosis experience systemic effects of the disease and consequently suffer a heavy disease burden [76,90]. However, most of the symptoms experienced by people with endometriosis are not recognized by the medical body as part of endometriosis, and people with endometriosis, do not always know which aspects of their health relate to the presence of the disease [99].

The large set of symptoms, their heterogeneity across individuals, and their non-specific nature results in a gap between how medical and research professionals conceptualize endometriosis and how it is experienced by patients. Such a disconnect is in fact often present in other enigmatic chronic conditions [36,74]. This disconnect has important implications for the design of personal informatics tools among enigmatic diseases and health conditions.

Characterizing Diseases Across Groups

Historically, the process of defining and characterizing a disease has been an ongoing activity in the biomedical discipline. First, as a few similar case reports emerge that do not fit with previously known phenomena, hypothesis for the existence of a new disease arises. When more physicians report more cases, scientific consensus starts to form as to the existence of the disease [18]. Once it has been accepted by the biomedical community that a new disease exists and warrants its own characterization, scientific consensus is achieved to describe the condition from a clinical standpoint [89].

Many diseases that were once considered enigmatic have become better understood and clinically defined by identifying the dimensions of the disease, primarily its signs and symptoms, as well as its boundaries, or the constellation of symptoms specific to a condition and not others [18]. For this to happen, collecting a wide range of signs and symptoms across a wide and diverse range of patients, as well as other disease dimensions is the first step towards identifying boundaries.

More recent work in biomedical informatics has helped to facilitate this process on a larger and faster scale through computational approaches to characterizing disease. Disease phenotyping helps answer questions about the characteristics that define a disease and the composition of these characteristics among patients [83]. A computable phenotype is a condition, characteristic, or set of clinical features that are derived exclusively from digital data [48,87]. Disease phenotyping has recently been primarily explored in the context of electronic health records, but other forms of data, such as patient self-reports, have been explored [64]. In the case of enigmatic conditions, precisely because there is no consensus in the clinical body as how to describe and define the disease, it is unclear that patient records are an appropriate data source for phenotyping and advancing knowledge of these diseases. It is unlikely clinicians take the time to document the constellation of non-specific symptoms patients experience and explicitly discuss it in the context of the disease, given how little time they have for patient interaction [88].

In our work, our ultimate goal is similar to the research in disease phenotyping, but our approach differs in the type of data we propose to leverage. Self-tracking data, which contains the direct patient experience, and circumvents clinical documentation, we argue, might provide a more comprehensive and more granular characterization of an enigmatic condition. As such, our work contributes to a largely unexplored new area of work, computational phenotyping of disease from self-tracking data. A first step towards this goal is to elucidate the essential dimensions or facets of the experience of the disease directly from people with the disease.

METHODS: DATA COLLECTION AND ANALYSIS

To understand the dimensions of endometriosis, data was gathered through four approaches: interviews, focus groups, online surveys, and content analysis of posts from an online endometriosis patient community. We selected these methods to triangulate the experience of the disease. Through interviews, surveys, and focus groups, we can learn directly from patients about endometriosis dimensions, each with varying number of individuals, varying degree of researcher input, and varying degree of discussions about experience of disease versus disease-tracking. One-on-one structured interviews have a smaller number of participants, but provide greater opportunities for the researchers to interact with participants. Focus groups enable for elicitation of information from a slightly larger number of participants all the while letting the researchers redirect the discussions. Online surveys reach a much larger number of participants, but researchers do not interact with them beyond the set of questions they ask. At the opposite end of the spectrum, content analysis of patient discourse represents a way to elicit dimensions "in the wild," without any researcher interaction or involvement. In these communities, there is also potential to capture experience of a much larger number of individuals. Our approach to elicitation was sequential and followed standard mixed-methods approaches starting with a qualitative-only analysis (interviews and focus groups), which helped design the schema for survey questions and the coding schema for content analysis [43,93]. Further, we varied the mental model of disease from researcher-based, generated through a review of the scientific literature of the disease, to patient-based, especially in regards to the content analysis, which was based on patients talking to each other without any researcher's input. This overall approach was used to bridge the gap between patient and researcher.

In this section, we describe each of these methods in turn. All study procedures were approved under protocol #AAAP9054 by our institution's Institutional Review Board for the Protection of Human Subjects. Work was conducted in the US for interviews and focus groups;

surveys and forum content analysis were English-speaking only and conducted internationally.

Method 1: Preliminary Interviews

The primary goal of the interviews was to start elucidating the dimensions relevant to the experience of endometriosis according to patients to inform the design of later methods. Rather than specific self-tracking variables, at this stage we were interested with exploring the primary dimensions (e.g., signs and symptoms, treatments, etc.) in a small number of women to get an initial sense of the dimensions quickly. Consent form and interview guide are available in the auxiliary materials.

Interviews lasting approximately 45 minutes each were conducted with 3 women with endometriosis. Participants were recruited through flyers at a medical center and distributed through social media by endometriosis patient advocacy groups. Participants were incentivized to participate in the interviews with a $25 gift card. Eligibility criteria consisted of self-identifying as having endometriosis and being over the age of 18. In recruitment, diversity of participants by age and length of time with diagnosis were prioritized over representativeness. Participants were all White/non-Hispanic and in their 30s and 40s, with diagnosis of endometriosis obtained in their mid-20s, late 20s and 30s.

We adopted a semi-structured style for the interviews. Topics discussed comprised descriptions of signs and symptoms and the disease, diagnosis, and general experience with the disease. We also inquired about how much self-knowledge about the disease participants had and their attitude towards research in endometriosis. At the end of each interview, informal checking with participants was done verbally and data was collected until saturation was reached.

Audiotapes from the interviews were transcribed verbatim and transcripts were checked against the audiotapes for accuracy. Transcripts were then coded and analyzed. Codes assigned during the initial coding were organized into themes using thematic analysis during a second examination of the data. All analysis was performed using Excel for Mac 2011 version 14.5.5 software.

Method 2: Focus Groups

The results of the preliminary interviews informed the development of a structured guide to explore further disease dimensions in a larger group of people with endometriosis.

Overall five focus groups lasting approximately 90 minutes each were conducted with 27 adults over the course of three weeks. Focus group participants were recruited via flyers in gynecological offices and advertising in social media from patient advocacy groups. Eligibility criteria included self-reporting diagnosis of endometriosis through laparoscopic surgery and being over the age of 18. Individuals with endometriosis were incentivized to participate in the focus groups with $25 in gift cards but were ultimately paid $25 in cash. Those who participated had not interacted with the research team before. They only participated in one focus group each (i.e., no participants attended multiple focus groups). Age of participants ranged from 27-60 years of age with a mean of 37.5 years, and age at diagnosis ranged from 18-40 with a mean of 29.4 years. Participants were mostly White/non-Hispanic (77.8%), but there were also Asian women (7.4%), Hispanic (7.4%) and Black women (7.4%) represented. Consent form, focus group guide, and codebook are available in the auxiliary materials.

The focus group guide was used to direct the conversation toward eliciting the dimensions of the disease. Questions were distinguished between those that helped us understand how participants made sense of the disease, such as disease-relevant symptoms, and self-tracking of signs and symptoms. For questions related to self-tracking, participants were told of our explicit goal to build a self-tracking tool, with participants working towards self-tracking dimensions and prioritizing them. In particular, the group was prompted to discuss preferences for tracking particular disease dimensions and ranked them in how relevant they are to their experience of the disease as well as to phenotyping endometriosis. Current approaches to self-tracking their disease were also discussed, with participants also discussing what they track about endometriosis and how [70]. At the end of each focus group and informal checking with participants was done verbally and data was collected until saturation was reached.

Each focus group was audio recorded and transcribed verbatim; transcripts were checked against the audiotapes for accuracy. Transcripts were coded and analyzed by two independent coders using thematic analysis and Nvivo version 11. The two coders independently familiarized themselves with the data and identified initial codes that were iteratively refined, named, and defined in a codebook. The focus group data was then re-coded by each independent coder using the codebook codes and corresponding definitions. From the codes, major themes related to dimensions of the disease were identified. Inter-rater reliability was calculated for each dialogue turn and aggregated for each code, and the Cohen's Kappa scores for each theme was averaged over all codes [27]. Overall, there was strong inter-annotator agreement with Kappa ranging from 0.79 to 0.86 across each theme, and 0.85 across all identified themes.

Method 3: Online Surveys

Surveys were conducted to refine dimensions and elucidate tracking variables. Based on the dimensions identified and prioritized and the particular variables discussed by focus group participants, we developed questionnaires, with questions focusing on a dimension of disease. Participants were also informed of our explicit goal of designing a self-tracking tool. We split the questions across two anonymous online surveys, and advertised them through patient advocacy groups and their social media feeds.

Overall, the two anonymous surveys comprised N=741 and N=505 answers, although not every question was answered by all participants. Most respondents were 30-33 years old (Figure 1) and over 80% had been diagnosed officially through surgery while the rest were diagnosed unofficially or suspected diagnosis (see Table 1 of survey answers in the auxiliary materials).
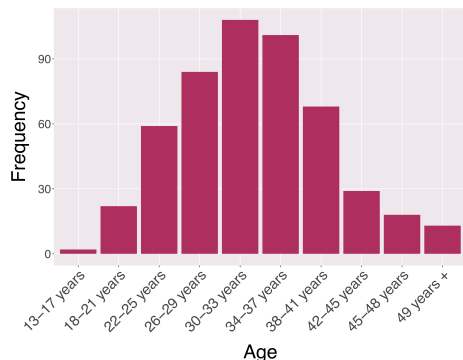
Figure 1. Age distribution of survey respondents (N=504).

Participants were not provided with any incentive for participating. Anyone could participate in the online surveys, but only the results for those who self-identified as having been diagnosed with endometriosis were included in the analysis of disease dimensions and tracking preferences. Duplicate responses were discarded (seven in the first survey and five in the second). Two surveys were conducted in order to decrease the length of one survey and increase the likelihood of respondents completing an entire survey.

The surveys comprised of both structured and unstructured questions. After basic demographics and diagnosis status questions, Survey 1 asked about the following dimension of endometriosis: emotions, moods, and affects; pain locations and descriptions; medication use; and self-management strategies. Survey 2 asked about other diagnosed conditions (or comorbidities); and types of diets experimented with. The survey also focused on the dimensions of endometriosis around menstruation and the menstrual cycle. In particular, we were interested in understanding to which extent the experience of endometriosis is linked to the different phases of the menstrual cycle. Thus, Survey 2 asked about the following variables: absence/presence of periods in the last three months and reasons for not having periods; period duration and cycle length when appropriate; hormone-induced versus natural cycle; period regularity; and type of feminine hygiene products used.

Survey data was aggregated and frequency counts were calculated for questions with structured survey responses. Free-text responses were mapped to particular variables of the disease, and medications and hormonal treatment responses were mapped to their medication classes. Analysis was carried out using RStudio Software Version 1.0.136 and Excel for Mac 2011 version 14.5.5

software. A full table of all frequency counts of variables across disease dimensions surveyed (pain; moods, emotions, effects; comorbidities; medications and hormones; self-management strategies and triggers; menstruation) are available in the auxiliary materials.

Method 4: Content Analysis

To identify dimensions of the disease without interference from the potential biases of the researchers, we analyzed the content of an online health community. The publicly available social platform Reddit was utilized, and the r/endo board in particular. Our goal for the content analysis was to enumerate and elucidate further the variables to track amongst the dimensions identified in the other approaches.

The r/endo board comprised 1,900 subscribed members and 1,500 posters at the time of analysis. Overall, the board contains 18,061 posts, among them 1,936 threads and 16,125 comments. As testament to its level of activity, the board has grown tremendously in the past year, and to date there are about 3,590 members. As such, it presents a good opportunity to observe and learn from patients directly about their experience of the disease. Furthermore, in order not to bias our results in any way, we made sure never to advertise our work in this particular forum.

A subset of 80 threads, corresponding to 859 posts, was selected for manual coding. The corpus comprised the first 50 threads in the discussion board and 30 random subsequent threads. Overall the subset represented posts from 153 unique posters and as a whole a corpus of 95,500 words.

The annotations were carried out in the Brat annotation tool (http://brat.nlplab.org/). Brat enables annotation of phrases (and disjoint phrases) according to customized categories (in our case disease dimensions), as well as coding additional customizable attribute information about each annotated phrase. Mentions of variables corresponding to specific dimensions of endometriosis were manually annotated, along with a range of attributes.

A detailed coding schema along with coding guidelines were developed. We aimed to annotate any explicit mention of a variable under the following dimensions: disorders (i.e., mentions of signs, symptoms, findings, and diseases); medications; supplements; medical procedures; biomarkers and diverse laboratory tests; emotions, moods, and affects; and activities of daily living. To facilitate subsequent analysis, each entity was mapped to standard ontologies whenever possible. For instance, the mention "BC" was manually mapped to the standard concept "birth control pill." We relied on the standard terminology from the UMLS (Unified Medical Language System) for these mappings.

Coders annotated a variety of attributes for each coded entity. For instance, for disorders, in addition to their mention they also had the following information coded: negation status, uncertainty status, who experienced it (the

patient, someone else, or no one, i.e., a generic mention of the disorder), who attributed it to the experiencer (the patient or someone else), and whenever relevant, which body location was affected. For medications, supplements, and medical procedures, we also kept track of mentions of efficacy whenever discussed explicitly by the post author. For instance, in the sentence *"my gynecologist thinks I have IBD,"* the term IBD was coded as a disorder, experienced by the patient, but attributed to the patient by someone else. In contrast in the sentence *"at night, my belly gets so bloated,"* the words "belly" and "bloated" get coded and mapped to the concept of "endo belly" (a known symptom of endometriosis amongst patients), experienced by the patient, and attributed by the patient as well.

Every post in the corpus was annotated by two independent coders, and adjudicated by a third coder. To analyze which specific variables within the dimensions of interest were discussed by patients on the board, we kept track of coding phrases, along with their attributes. For this study, because of our goal to elucidate variables about the patient experience of endometriosis, we only kept track of the variables that were experienced by patients specifically, and attributed to them by patients as well. We ignored other variables, like conditions attributed by others to patients, for instance.

RESULTS: IDENTIFYING DIMENSIONS OF DISEASE RELEVANT TO SELF-TRACKING
Overall, a set of specific self-tracking dimensions relevant to the experience of endometriosis were elicited.

Interviews
Several broad themes emerged from the preliminary interviews including pain and other symptoms, activities of daily life, treatments, self-management, and emotional burden of the disease. Menstruation was also a topic on its own. Each participant's experience of the disease was unique, but all participants experienced pain related to their endometriosis, and this pain was significant and debilitating. For example, I3 compares their pain to labor *"So, when I was in labor, my earliest stages of labor, it felt a lot like cramps I have during my period."*

Pain also had a significant impact on each participant's daily life. Examples of variables related to activities of daily life including missing work and social occasions because of endometriosis-related pain. I3 states that "*When I have periods, when it starts, I have a hard time getting out of bed and doing my normal routine."* Yet, the periodic nature of symptoms meant that participants who understood their patterns could plan for them. I2 says *"You would have to worry about what you're wearing because you're bleeding so much and so you kind of have to plan accordingly."*

When participants experienced disease flares, this impacted their daily life, avoiding intimate contact with their partners. I3 describes symptomatic episodes as feeling like

"Please do not touch me at all." Participants also isolated themselves from work and other responsibilities as I2 relates *"Okay, so, sometimes the pain was so intense that when you're in pain like that, you just can't do what you're supposed to do…I kind of know when those days or when you're expecting to have pain and so…I think to some extent I did plan my life a little bit around that."*

In treating their disease, a variety of medications were tried. Participant I2 states *"I was using a lot of over-the-counter pain medications, and I was taking like lots of Tylenol at some point, like [a] small jar, in a day or something."* However, the side effects of different treatments were also problematic and had a significant impact on quality of life. I3 relates this sentiment *"I can take normal birth control but I'm like a sexless zombie […] and then anything with Lupron sounds terrible."*

The existing lack of effective medical treatments led participants to experiment with self-management techniques: I3 says *"drinking very little alcohol, no caffeine, just eating hardly anything … and being very careful about what I was eating"*, as well as exercise, as described by I1 *"I try to run like two to three times a week and that helped"*. While these self-management strategies were not a cure-all for symptoms, they did provide psychological benefits. For example, I3 describes how *"I can deal with the pain if I can just know what I'm doing and it does not actively contribute to it."*

Focus Groups
From the focus groups, a set of nine dimensions emerged and were ranked by participants as critical to self-track. These included: pain; gastro-intestinal and genitourinary symptoms; other symptoms; menstruation; comorbidities; treatments; self-management strategies; life events; and moods, emotions, and affects.

Pain remained a major aspect of the disease, and participants vividly described their pain in terms of its location, severity, and specific qualities, *"I had this window of time where I got this same exact burning horrible can't-speak-to-me abdominal pain"*. This example also highlights the temporal aspect of the disease. *"I'm in excruciating pain for about five to six days", yet* symptoms also varied throughout the day*, "how I'm feeling at 8am is not necessarily how I'm feeling at 7pm."*. The effects of pain on activities of daily living were also an issue *"Like pain during sex is a big symptom for me and, umm, like I literally like avoid sex too because of this"*. A number of symptoms beyond pain were also identified. In particular, gastrointestinal and genitourinary symptoms were described in descriptive terms by quality and location *"It's like all of the bloating is putting pressure on my bladder too"*.

Other symptoms were discussed and were more systemic in nature, *"It's like fatigue and then also feeling like I'm getting a cold"*. The systemic nature of symptoms lead to a discussion of comorbid conditions that participants

experienced, *"I still have, I think, some allergy issues or autoimmune issues"*. These symptoms also occurred in a periodic fashion, similar to pain, as one participant describes, *"I get fever and a cold every month"*.

The cyclical nature of symptoms highlights the importance of the hormonal cycle as one of the dimensions of the disease. Menstruation is an important aspect not just because of its correlation with other symptoms but because excessive bleeding was a symptom on its own "*The last few years, bleeding was life threateningly excessive at times and [I had] anemia"*. Other menstrual symptoms were identified like breakthrough bleeding and spotting, *"Spotting is – yeah, I mean the whole gamut [bleeding] I think is very important"*. There was also consensus that infertility and its host of complications and treatments should be a dimension although for most there was no interest in tracking this.

Day-to-day activities were also discussed as an important self-tracking dimensions. Personal relationships were affected "*just casual sex is like annoying…*", along with work productivity and performance, "*I sweat and, you know, you're moving up the career ladder and you're like fearing that you can't go to work or like meetings*". Due to the severity and impact of symptoms on quality of life, participants experienced strong negative emotions, "*I was so depressed that I felt sick every day in some way, shape or form*".

Like the interviews, self-management techniques and medications were discussed at length in the context of a lack of effective options. Dietary triggers emerged as an important self-management strategy: *"I look at what and when I eat"*, as well as exercise, *"I take a walk with my dog"*.

Online Surveys
Survey responses identified similar dimensions of the disease as the focus groups, and a wider range of variables was elicited for each dimension. Pain was reported in more than 50 body locations along with over 150 descriptions of pain (Figure 2 for the top 15 and Table 2 and Table 3 of survey answers in the auxiliary materials). In comparison to established symptoms of endometriosis, the range of pains reported by patients is much wider and more granular.

Participants reported over 60 emotions, moods, and affects related to their experience of endometriosis. Most were negative and similar to those in the focus groups. The top emotions were frustrated, irritable, anxious, stressed, mentally foggy and overwhelmed (see Table 4 of survey answers in the auxiliary materials).

Over 25 comorbidities were reported, with prevalent conditions, such anxiety and depression, and reproductive and gastro-intestinal conditions ones like ovarian cysts and irritable bowel syndrome (see Table 5 of survey answers in the auxiliary materials). In addition a heavy disease burden

of four comorbidities on average per respondent was reported—more than in the general population [97].
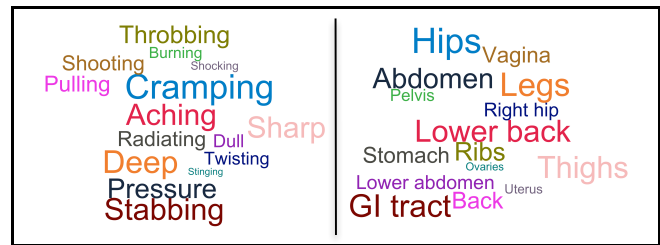

Figure 2. Top 15 pain locations and descriptions (N=737). Word size indicates frequency.
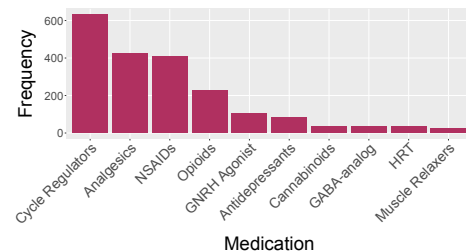

Figure 3. Combined top 10 medications (N=719) and hormones (N=204).
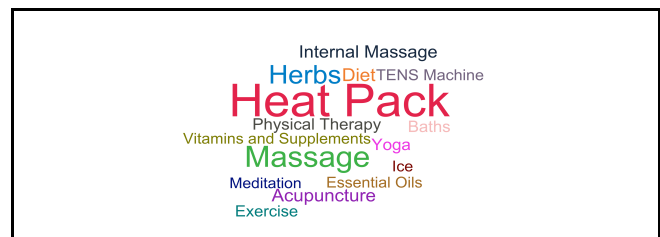

Figure 4. Top 15 self-management strategies (N=695).

Congruent with focus groups, participants also used a wide range of medications and hormones (Figure 3 and Table 6 of survey answers in the auxiliary materials; medications had N=719 respondents and hormones had N=204 respondents). There was heavy use of medications as compared to the general population with about three medication classes reported per participant—a typical finding for chronic disease patients [22,42]. The most prevalent treatments included hormonal cycle regulators and pain killers, including analgesics, anti-inflammatory, and opioids.

Participants experimented with a wide range of self-management approaches (Figure 4 and Table 7 of survey answers in the auxiliary materials). Similar to other chronic conditions, participants used an average of about three different approaches to manage symptoms [55] .

The surveys confirmed the findings of the focus groups, but also described a larger range and granularity of variables for tracking. A large set of respondents had not menstruated in the past three months (Table 8 of survey answers in the auxiliary materials), but still experienced many of the symptoms of endometriosis, indicating that even the most basic characterization of the disease according to the medical body (period cramps) might not be an accurate

representation of the patient experience (Figure 3 of survey answers in the auxiliary materials).

Content Analysis

The content analysis of the Reddit endometriosis board confirmed the aspects of the disease identified in the focus groups and online surveys. Of note, out of the 6,000 manually coded discussions of dimensions of endometriosis, most variables were about the patients (rather than generic mentions), but a high proportion of them were attributed to them by others and were discussed as examples of misdiagnoses or even stigma related to the disease. Frequent such disorders for instance included "absence of endometriosis," "drug seeker," and "hypochondria." While these disorders should not be incorporated into self-tracking variables, their sheer frequency in our corpus was surprising.

Analysis of the variables mentioned and experienced by the patient indicated that some dimensions contain a finite set of variables. For instance, we identified about 20 variables within the GI and urinary problems. Similarly, there were about 30 pain locations that were identified under the pain dimension. Some other dimensions, however, did not seem to converge across the corpus in prevalence. There were a very large set of self-management strategies discussed, and diet and exercises became their own dimensions, themselves with a wide range of variables that could be self-tracked by patients (e.g., dairy-free diet, soy-free diet, gluten-free diet, avoiding red meat, etc.). While it is expected to see a large pool of variables for dimensions like treatments, the fact that there is no evidence in the literature for what works makes the pool of variables larger. Patients are left to experiment on their own.

DISCUSSION

Our findings confirm that different data sources of patient experience provide complementary ways to elicit dimensions of endometriosis.

A Holistic, Patient-Aligned View of Endometriosis

Our process appears to be particularly useful in the context of an enigmatic disease like endometriosis. As compared to survey-based methods, we confirmed many of the known dimensions, such as pain and menstruation, but also identified a more holistic view of the disease with a wider range of dimensions, each with greater granularity of variables [37]. Qualitative studies of endometriosis put a heavy focus on pain as a primary symptom of endometriosis [31,101]. However, previous work reports intensity of pain, with little exploration of the types of pain, pain location, and how it is experienced [30]. Our methods identified specific body locations affected by endometriosis pain (e.g., sacrum, abdomen) and specific types of pains (e.g., twisting, burning). Similarly, for other dimensions of the disease, our methods enabled discovery of a larger range of relevant variables. For instance, Hungtington et al. identify rectal and anal pain, along with diarrhea and constipation as important gastro-intestinal symptoms [49].

Our analysis identified in addition nausea, heartburn, gas, fullness, and vomiting, as frequent symptoms reported by patients. Finally, we also identify the dynamic nature of the signs and symptoms experienced by patients, which vary throughout the menstrual cycle, day to day, and for some moment to moment—a phenomenon not described in the literature previously. The answers to our online surveys also indicated that the relationship between symptoms and phases of the menstrual cycle were not as clear as established in the literature [29].

From Patient Experience to Self-Tracking Variables

Beyond identifying the dimensions of the disease, the activities and discussions during the focus groups helped assess the attitude and motivations for using a self-tracking tool for the sake of endometriosis, as well as prioritizing which self-tracking dimensions and corresponding variables would be useful in a self-tracking app [70]. The online surveys and content analysis helped extend the range of variables under each dimension.

Given the large number of self-tracking variables that can be tracked and the current means of tracking as described by participants in the focus groups, self-reports were considered by participants as a reliable way to track endometriosis for themselves and for learning about the disease at scale. Passive sensing was not considered an appropriate modality by participants, except potentially for simple physical activity monitoring like step count.

The online surveys and the content analysis helped determine which variables would easily be standardized in a self-tracking tool or rather left open for users to customize. For instance, the diet dimension, because of its very large range of variables identified in the content analysis, was determined to stay an "open" self-tracking dimension, while the pain dimension was standardized to 30 pain locations.

Characterizing Disease from Self-Tracking Data at Scale

Beyond the typical goal of self-monitoring and self-management, the identified dimensions can be used to inform the design of a self-tracking tool that allows for better understanding endometriosis across users. Specifically, self-tracking tools are appealing because they enable collection of a large and diverse set of people with endometriosis as compared to traditional research methods and allow for studying dynamic variation in disease symptoms over time. The disease dimensions identified through the approach presented in this study are well suited to the requirements of computational phenotyping.

Although identification of disease dimensions is useful for capturing the experience of endometriosis, additional factors need to be considered in characterizing disease at scale. Completeness and accuracy are important data characteristics for high-quality phenotyping [48]. In the context of enigmatic diseases this translates to a need to collect a standard set of data, namely variables of the disease, and do so in a longitudinal fashion in order to

capture the dynamic variations and accurately represent disease experience. Therefore, design of the self-tracking tool needs to support these information needs of researchers, and engage people with a particular condition in tracking a standard set of disease dimensions over time.

Implications for Design of Self-Tracking Apps for Enigmatic Diseases

First, because user engagement is critical to success, design of a self-tracking tool might include dimensions that are not a-priori important to the ultimate goal of the tool. When dealing with an enigmatic disease, it is not clear in advance which of these dimensions will in fact contribute to its phenotyping. For instance, emotions, affects, and moods might not end up part of an endometriosis phenotype, but there is still value to them, because they align with the way patients experience the disease. If tracking emotions is important to patients' self-management, then they will be more likely to engage with self-tracking in general.

Second, the choice of self-report in the design of the self-tracking app makes engagement even more critical. To engage individuals, previous research has demonstrated the important role of personalization [58,78]. For the dimensions with a too large set of variables, personalization in self-tracking presents a perfect opportunity. Orienting the design of self-tracking tools around a particular user's individual information needs and goals, such as making sense of one's disease, is useful in reducing the burden of self-tracking, can make self-tracking more meaningful, and thus engages the individual self-tracker further [65,67,68]. Negative experiences can also influence engagement, and tracking pain, for example, may remind patients they are sick and discourage use. In the case of endometriosis, it is also known the patients' symptoms have historically been stigmatized and ignored. For this reason, they may overcome any apprehensions they have about tracking in order for their symptoms to be recognized [10,46].

Third, some of our identified self-tracking dimensions are complex. For instance, pain may vary in time and location within an individual, as well as across individuals. Other symptoms vary at different time resolutions (e.g., menstruation at the day level, GI symptoms at the moment level). Thus, a self-tracking tool that aligns with patient experience of endometriosis needs to enable tracking at different time resolutions, a feature which is not traditionally accounted for in pain diaries [75]. Further, the analysis of the self-tracked data also needs to take these varying resolutions into account in a longitudinal manner.

Finally, some of our identified self-tracking dimensions may influence each other. Associations between pain and other variables, such as mood, have been investigated in the literature, and it is known that low mood may lead to less pain tracking [19,79]. This supports further the argument that a self-tracking tool for an enigmatic condition should have a wide range of variables, such that potential confounders and associated variables can then be identified.

Few of these associations are currently understood for endometriosis, and a self-tracking tool will help towards investigating these relationships.

Based on the findings of this study, we have developed a self-tracking application, called Phendo, and are experimenting with engagement strategies motivated by self-determination theory and citizen science. To date, Phendo is used by 3,000 participants from 65 countries.

Limitations

This study has several limitations. First, the endometriosis diagnoses of survey and online community participants were self-reported, without us contacting the participants for confirmation. However, we did not identify any trolling information in the Reddit posts, and only considered survey responses posted within 5 days of advertising in patient advocacy groups. Second, there might be a selection bias to the participants in our study. Social media users tend to be younger than the general population and those who are part of patient advocacy groups are probably more health literate than an average person with endometriosis [24,40,44]. Third, patients who are sicker may also be more likely to engage in research-related activities. In fact, there is evidence of this bias in the data collected through Phendo so far, where our participating population is young and with predominantly severe diagnosis of endometriosis. Finally, this study focuses on eliciting information from people with endometriosis, and as such lacks a comparison group that represents healthy women with a "normal" menstrual experience. The last two limitations affect in particular our goal of learning at scale from self-tracked data and discovering patterns that can help characterize endometriosis. In our current work, as part of the Phendo study, we are exploring recruitment that targets particular populations (women without endometriosis diagnosis, as well as women with less severe endometriosis). For these populations, we are exploring principles of citizen science to engage them in self-tracking for endometriosis research.

CONCLUSION

We contribute an understanding of the design of personal health informatics tools that leverage the self-tracking of individuals to better understand group-level characteristics of diseases. For diseases or health conditions where the relevant dimensions of the disease are not well understood, we outline a process for designing self-tracking tools in this context. We find there is value in examining different data sources to elicit the relevant dimensions of a disease. Triangulation across these sources informs what constitutes the experience of disease, indicating it is feasible to capture the disease experience directly from people with a particular health condition.

ACKNOWLEDGMENTS

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